

Engaging people with diabetes in the Future of Diabetes project: Methodology and summary of findings

The future
of diabetes



To get a representative vision of what the future of diabetes care and support should look like, we wanted to ensure we spoke to as many people as possible. This included people with different types of diabetes, parents and carers, people of different ages and ethnicities, and those from different socio-economic groups.

We adopted a mixed methods approach, triangulating evidence from self-run Local Group conversations, facilitated 'Big Conversation' focus groups, social media 'chats' and data from an online survey. We also commissioned research to explore the experiences of people who we were less likely to hear from.

This briefing gives an overview of what we did, who was involved, and our findings. If you would like further information, please contact the Diabetes UK Policy team: policy@diabetes.org.uk

Local Group conversations

- We supported 41 Diabetes UK Local Groups across the UK to hold their own conversations between March and August 2017. The number of participants in each group ranged from 1–80. In total, more than 520 people took part¹.
- Two groups were specifically recruited to and facilitated to capture the views of people from minority ethnic groups.
- Local Groups received a standard pack containing a discussion guide, tips for facilitating the discussion, a feedback form and the following discussion questions:
 - 1 How did diabetes affect something you did in the last week?
 - 2 If you could change one thing about the healthcare you receive for your diabetes what would it be?

- 3 Does diabetes affect your life at work and how could this be made easier?
 - 4 What's the most frustrating thing for you about having diabetes? How could you be helped to overcome the challenges this poses you?
 - 5 What changes do you think are needed to help prevent Type 2 diabetes?
 - 6 How do you think it will be different to have diabetes in ten years' time?
- The feedback forms were returned to Diabetes UK, where responses were coded into categories by two members of staff and recorded in Microsoft Excel.

Big Conversation events

- We held seven Big Conversations across the UK in June and July 2017. These took place in Belfast, Bristol, Cardiff, Glasgow, Leeds, and twice in London. In total, there were 225 participants.
- A standard set of questions and topics were agreed to guide semi-structured group conversations. All facilitators received training and used standardised feedback forms to record themes and key quotes from the conversations. The data were then fed back to a coordinator and collated in Microsoft Excel for analysis.
- The following tables report demographics based on the information people gave us when they registered to attend the event. They therefore do not include people who withheld this information or attended without pre-registering.

¹ **Note:** Some groups did not include complete data about number of participants, therefore we have estimated from the information available to us for local group conversations and online conversation when reporting total participants by nation in the Future of Diabetes report.

Table 1: Experience of diabetes for participants at Big Conversation events

Experience of diabetes	Percentage
Type 1	48%
Type 2	43%
Other type of diabetes (eg, LADA)	2%
Carer, partner or relative	2%
Parent of a child with diabetes	4%

Table 2: Age of participants at Big Conversation events

Age	Percentage
18–24	7%
25–44	25%
45–64	38%
65+	30%

Table 3: Ethnicity of participants at Big Conversation events

Ethnicity	Percentage
White	86%
Mixed/ Multiple Ethnic Groups	3%
Asian/Asian British	8%
Black/ African/ Caribbean/ Black British	3%
Other Ethnic Group	<1%

Table 4: Number of participants at each Big Conversation event

Event	No. participants
Belfast	18
Bristol	30
Cardiff	27
Glasgow	31
Leeds	30
London 1	61
London 2	28

Online conversations

- Throughout June we hosted online conversations using Twitter ('Tweetchats') and the Diabetes UK Forum. Each session focused on one of the questions used in the Local Group discussions.
- The Forum discussion had 56 unique contributors. The Tweetchats had 40².

Experience of diabetes	Number of Forum contributors
Type 1	30
Type 2	21
Other type of diabetes (eg, LADA)	3
Carer, partner or relative	1
Pre-diabetes	1

² See Note 1 above.

The Future of Diabetes survey

- The online Future of Diabetes survey ran from June until August 2017. 7,164 people completed the survey in full. An additional 2,561 people submitted partial responses. The highest number of people to answer a question was 8,512.
- Survey questions were decided by the Future of Diabetes project group. The questions were designed to:
 - 1 Capture participants' current experience of diabetes using questions relating to the 15 healthcare essentials³ and priority areas identified through the preliminary Local Group conversations, and
 - 2 Give participants an opportunity to express how they would like to see diabetes care and support change in the future.
- The majority of questions invited closed responses. Top-line findings from these questions and participant demographics are included at Annex A.

Qualitative analysis

- Each part of the engagement exercise produced a large volume of qualitative data. A team of six Diabetes UK staff and a volunteer agreed an approach to analysis based on grounded theory⁴.
- Initially, two members of the team coded data from the first of the Local Group discussions and Big Conversation discussions into categories. These initial categories were circulated amongst the team.
- Each team member then used these categories to code an agreed section of the incoming data from the Local Group and Big Conversation discussions, the social media engagement and the survey. Emergent categories were compared to the categories from the initial coding. These were revised as appropriate until it was agreed that theoretical saturation had been reached. A tally of responses allocated to each category was recorded. Key quotes were recorded where it was felt that they helped to illuminate the nature of the category.
- The categories were then refined to produce six themes, with each containing a number of sub-themes. The tallies of responses within each theme allowed for the team to assess the prevalence of the topic within the responses. The remaining open response survey questions were allocated directly to the agreed sub-themes and themes. Responses which raised multiple issues received multiple allocations.
- The main themes informed the six sections of the Future of Diabetes report.

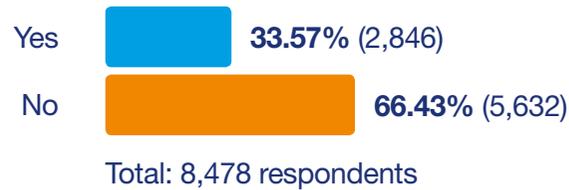
³ Diabetes UK. The 15 healthcare essentials: the care you should expect.

⁴ Bryman A (2012) Social Research Methods, 4th edn. Oxford University Press, p. 566.

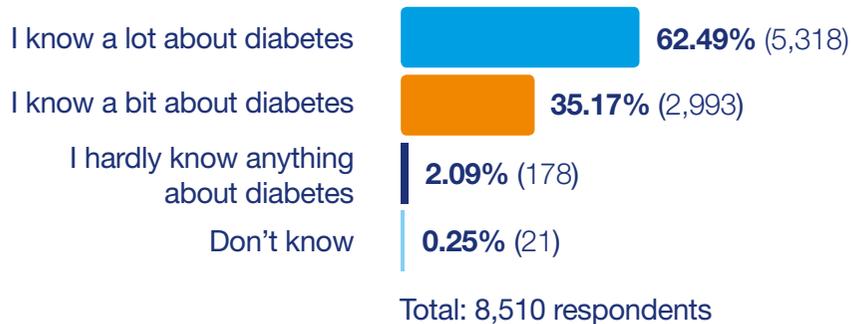
Annex A: Survey results

The following charts show the percentage and number of respondents answering each question. These results include all respondents who answered the question. Those who skipped the question are not included in question results.

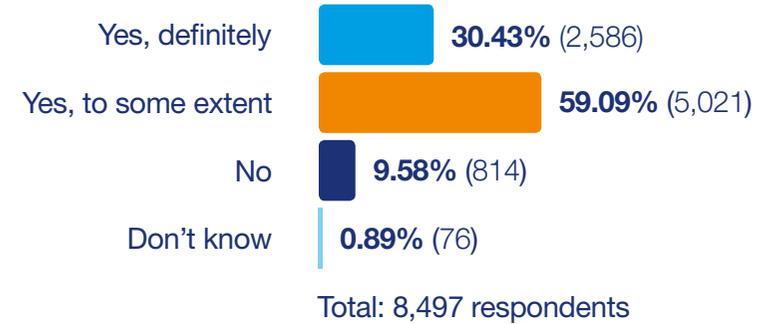
1 In the last week, do you feel that diabetes got in the way of you or your family member doing something that you wanted to do?



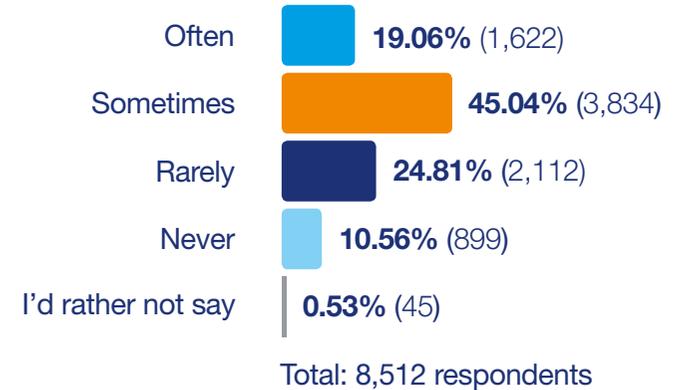
2 How would you rate your understanding of diabetes?



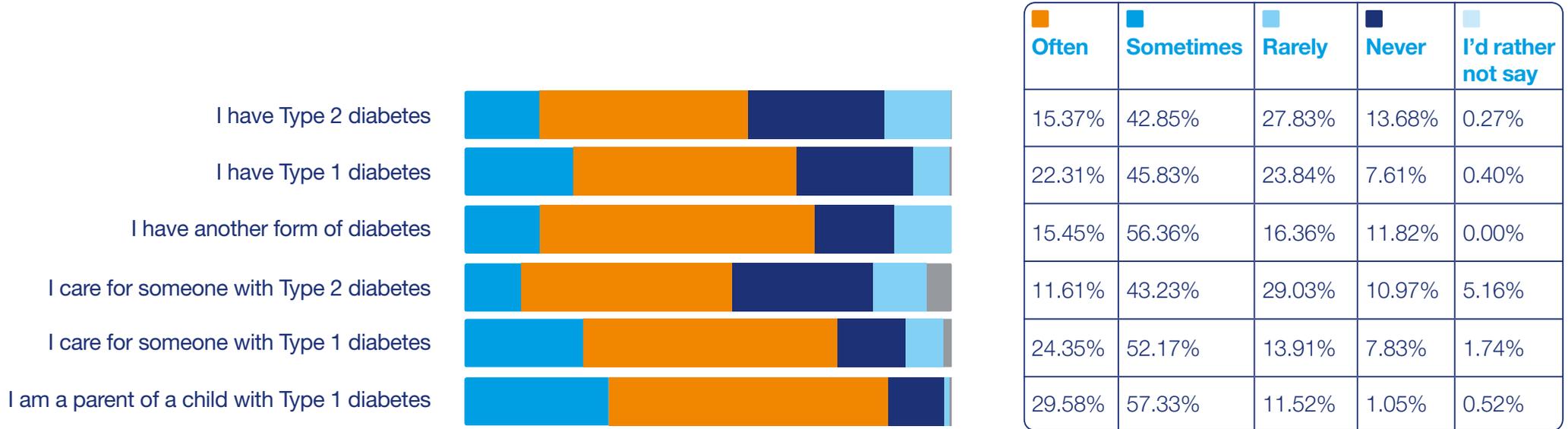
3 Would you say you feel in control of your or your family member's diabetes?



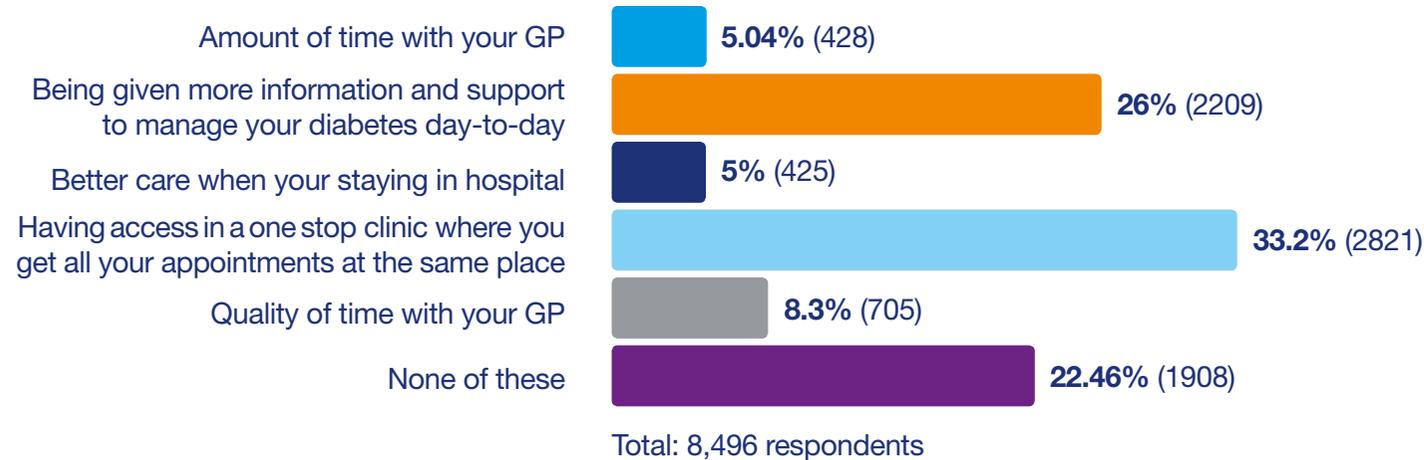
4 How often do you feel down because of diabetes?



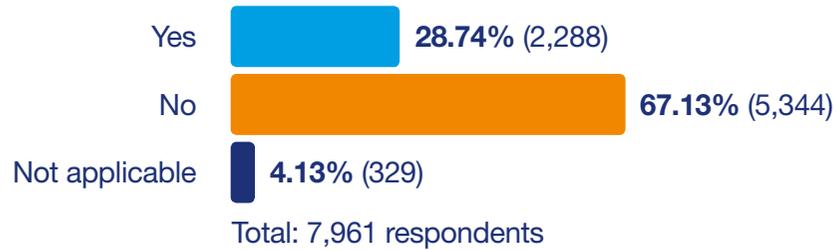
4 How often do you feel down because of diabetes? / What is your experience of diabetes? (Pivot)



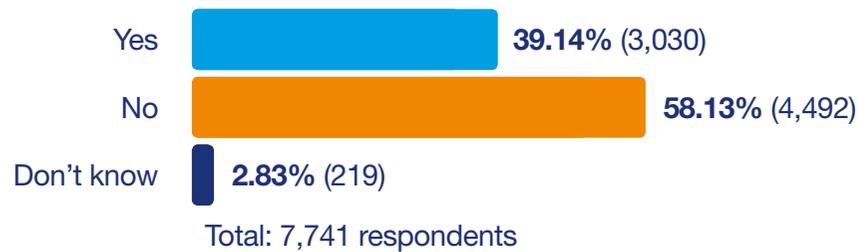
5 If you could change one thing about the healthcare you or your family member receives for your diabetes what would it be?



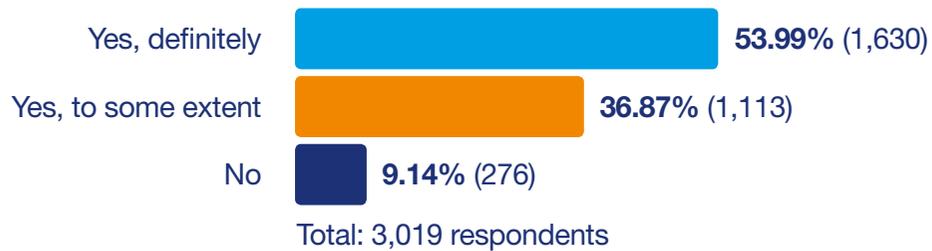
10 Have you or your family member ever had trouble getting the medication or equipment you need to manage your diabetes?



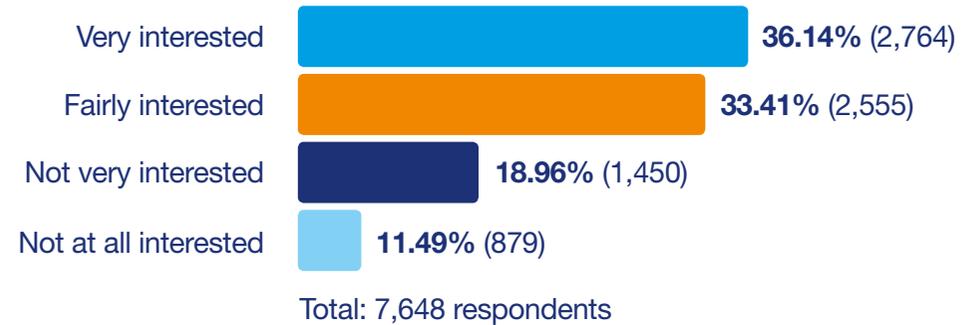
16 Have you or your family member ever attended a formal group education course, eg DAFNE, DESMOND, X-PERT, Bertie?



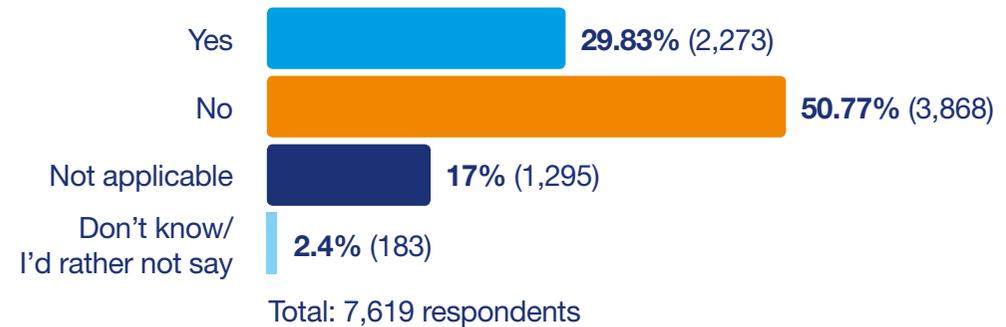
17 Do you or your family member feel more confident managing your diabetes because you attended this formal group education course?



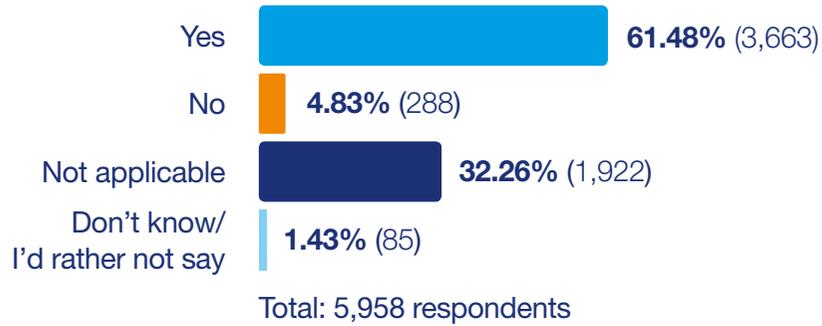
18 Would you or your family member be interested in going to a course or training about diabetes and how to manage the condition?



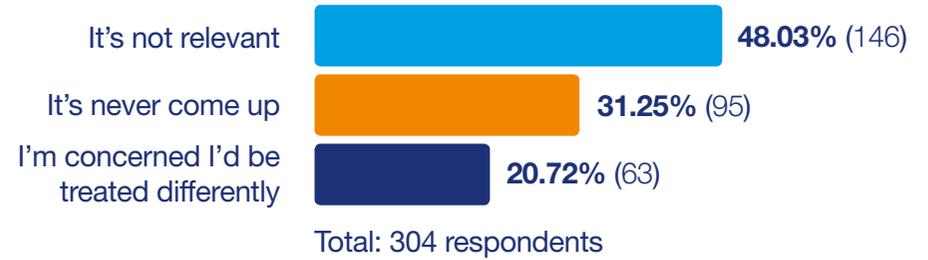
20 Has diabetes ever caused you or your family member difficulties at work?



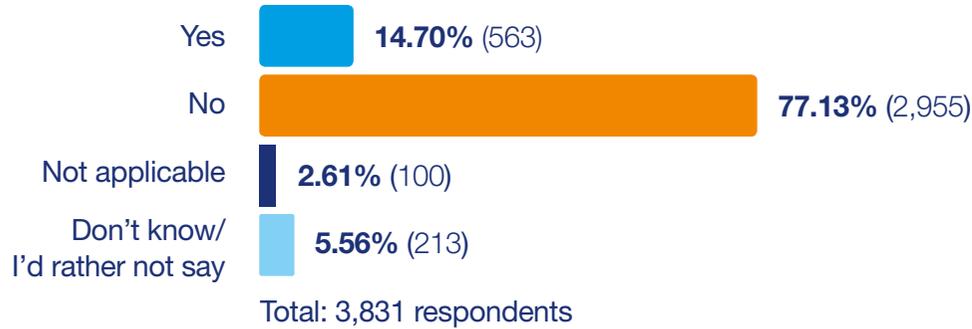
21 Does your or your family member's employer know you have diabetes?



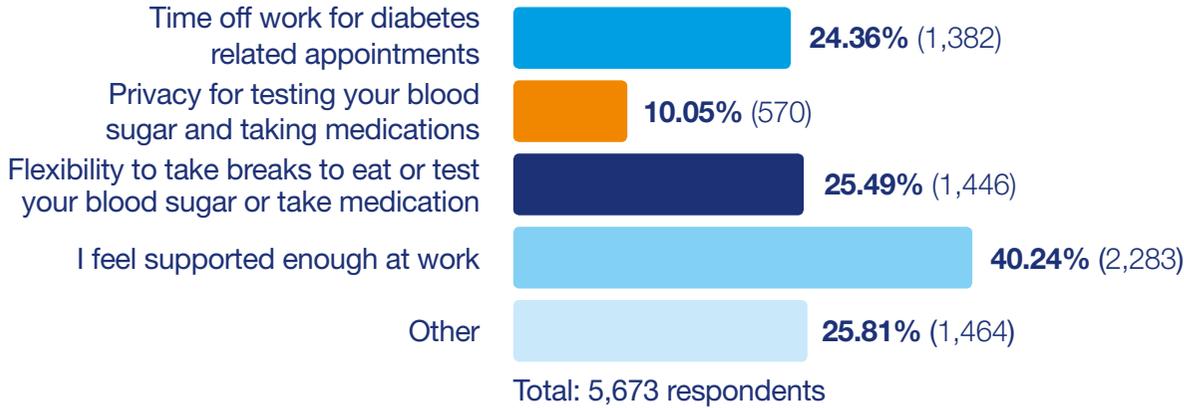
23 If you or your family member hasn't told your employer you have diabetes, why have you or your family member not told them?



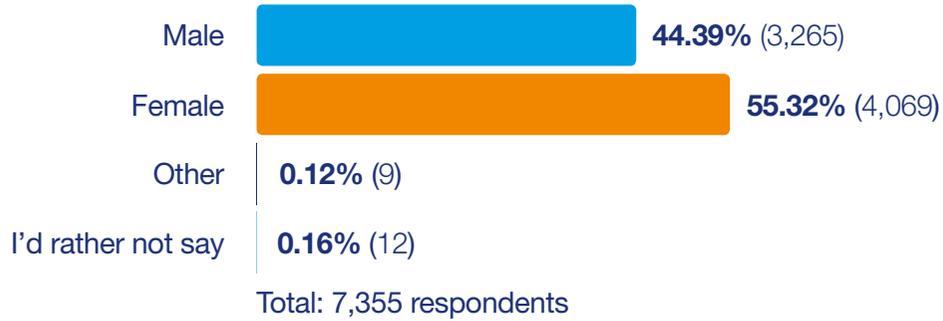
22 If your or your family member's employer knows you have diabetes, do you feel you've faced discrimination because of diabetes?



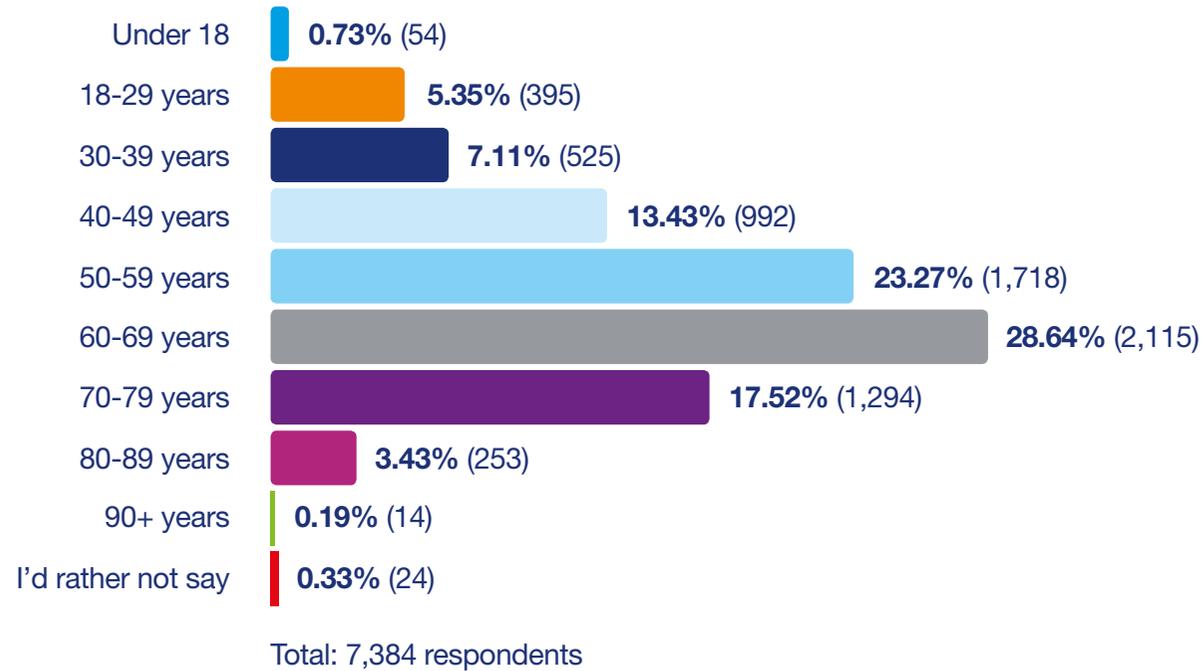
24 How could you or your family member be better supported to manage your diabetes at work? (Tick all those that apply)



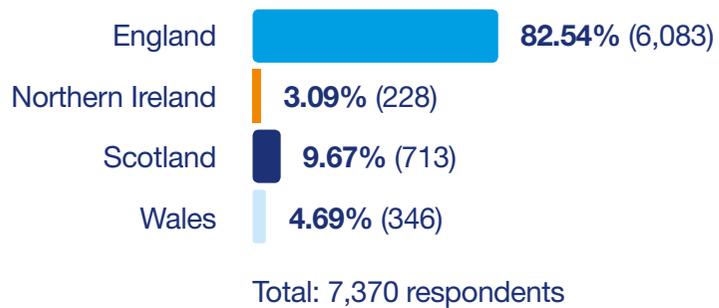
27 What's your gender?



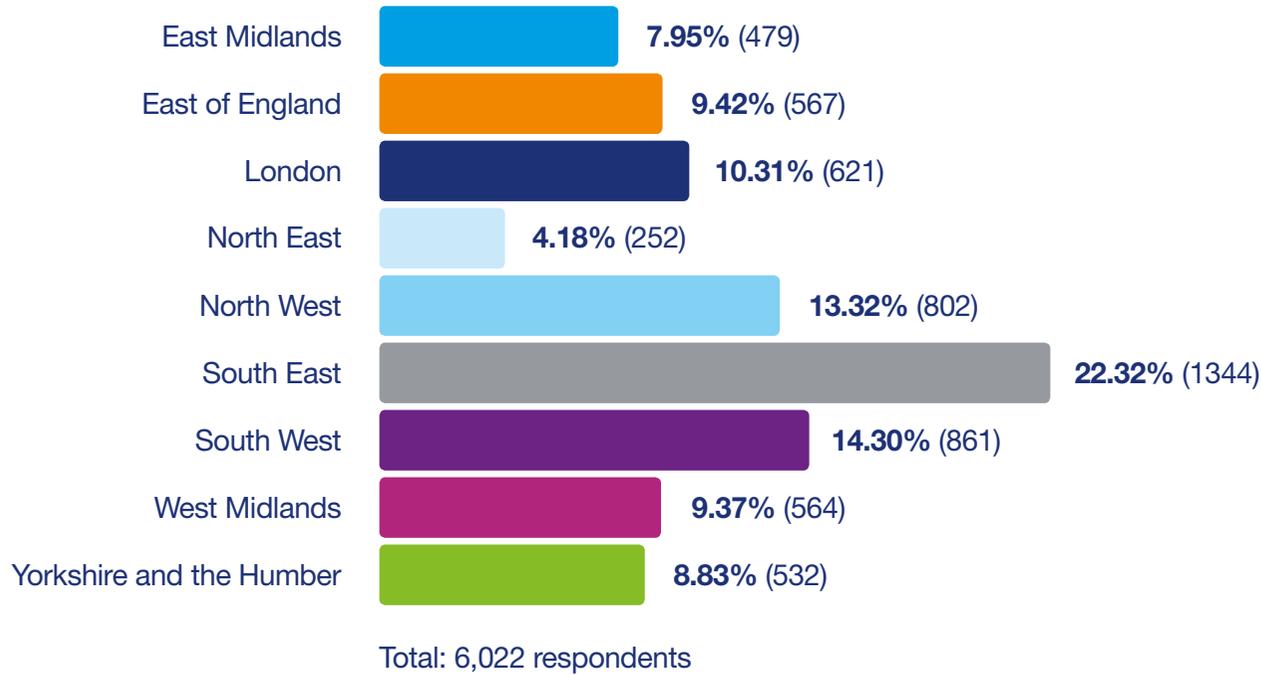
28 How old are you?



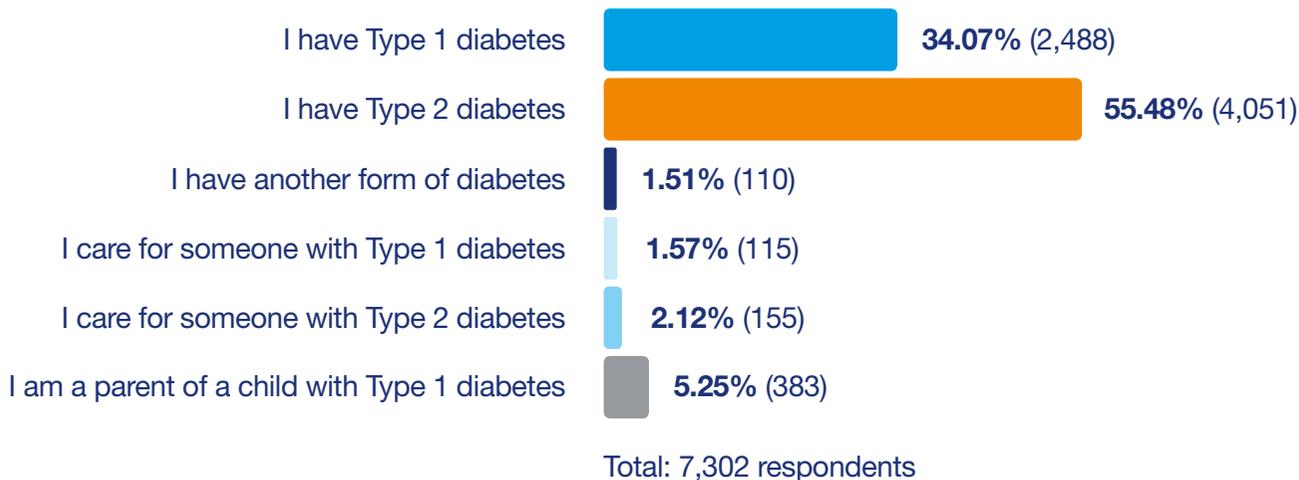
29 Where in the UK do you live?



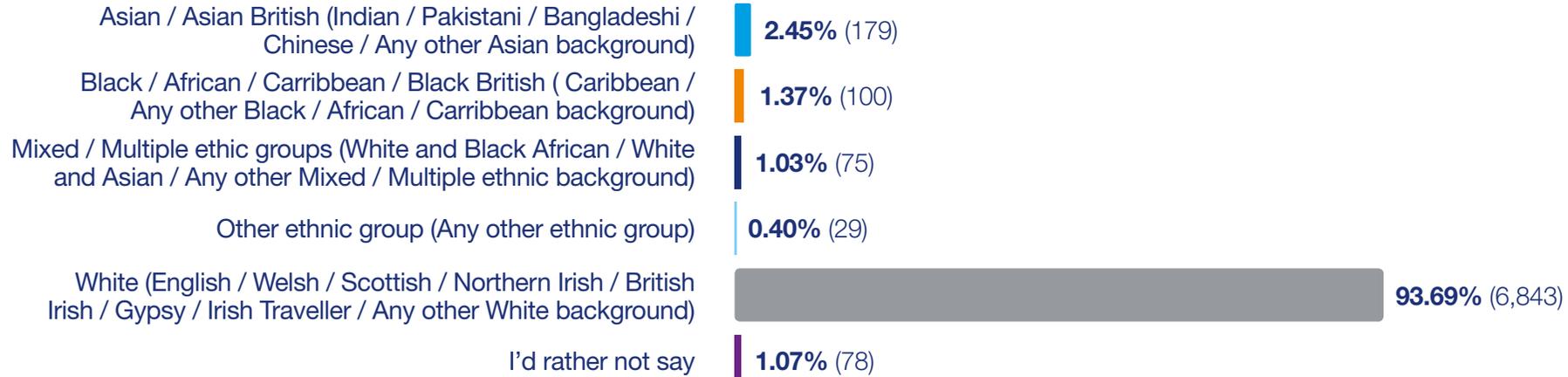
30 Please select the region you live in from the dropdown menu:



31 What is your experience of diabetes?



32 What's your ethnic group?



Total: 7,304 respondents