

Diabetes:

my information, my support



DiABETES
SCOTLAND

KNOW DIABETES. FIGHT DIABETES.



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

Introduction

A refreshed Diabetes Improvement Plan¹ was published by the Scottish Government on 25 February 2021. To ensure the delivery of the Plan is influenced and informed by people living with and/or at risk of diabetes, the Health and Social Care Alliance Scotland (the ALLIANCE) and Diabetes Scotland have supported the development of a Diabetes Network to directly hear about people's individual experiences. Our aim is to ensure that people are at the centre and that their voices, expertise, and rights drive policy and sit at the heart of design, delivery and improvement of support and services. The network brings together people affected by diabetes to discuss and feed back to the Scottish Government as the Diabetes Improvement Plan is implemented.

One priority identified in the plan is to make improvements to the provision of information and support to people when they are diagnosed with diabetes. The following report summarises people's experiences of accessing diabetes information and support in Scotland. It includes:

The demographics of those who shared their views with us;

People's experiences of diagnosis and the initial support they received from their health care team;

The types of diabetes information and support that people said they would find helpful;

The importance of being able to access emotional and psychological support;

The flexibility required to make this support effective;

The barriers to accessing diabetes information and support;

And how to overcome these barriers.

¹ Diabetes Improvement Plan: <https://www.gov.scot/publications/diabetes-improvement-plan-diabetes-care-scotland-commitments-2021-2026/pages/3/>

Through an online survey, a series of focus groups and a workshop facilitated by Networking Key Services,² we were given a real insight into the views of people with lived experience of type 1, type 2, gestational and other types of diabetes.

Context

Conversations between the ALLIANCE and the Scottish Government started in early 2022. It was agreed the ALLIANCE's Diabetes Network would support engagement to ensure the planned redesign of group education services reflected the needs of individuals and their families. It was recognised that successful progress in improving care will require a collective effort and engagement from a wide range of stakeholders, including the third sector and, most importantly, people with lived experience.

The report from the engagement will contribute to the work to redesign Diabetes education and support self-management services and programmes across Scotland which is being undertaken collaboratively by the diabetes clinical community, the Scottish Diabetes Education Advisory Group and the Scottish Government.

Methodology

To ensure that as many people with lived experience of diabetes in Scotland had the opportunity to contribute to the redesign of group education services as possible, a multi-stranded approach was designed, consisting of:

An online survey, hosted on SmartSurvey and promoted widely via the Diabetes Network, the ALLIANCE's social media channels, e-bulletin, membership and website as well as through partners such as Diabetes Scotland and others.

A facilitation pack, which was produced for other organisations and community groups who wished to run focus groups. It was recognised that established trusted relationships can aid communities' involvement in such groups. Therefore, it was decided that by providing facilitation packs and guides, as well as being on hand to provide support and meeting accessible needs, better quality engagement could be achieved.

² Networking Key Services: <https://www.nkshealth.co.uk/>

Two focus groups with Network and ALLIANCE members ensuring that they were inclusive and accessible.

A news article on the ALLIANCE website outlining the opportunity to be involved in this engagement.

Promotion on the ALLIANCE social media accounts including Twitter, Facebook, Instagram and LinkedIn. It was also promoted via the ALLIANCE staff teams' individual Twitter accounts.

Promoted in the weekly ALLIANCE e-bulletin on three occasions which goes out to over 3,000 organisations and individuals, as well as the Self Management Network Scotland monthly newsletter.

A personalised email outlining the opportunity was sent to organisations working with key stakeholders to support in the promotion.

The following report was produced to detail the findings. These will be shared with those that participated, our delivery partners and the Scottish Government. They will also be promoted on the ALLIANCE website and through our social media channels.

Survey and focus group questions were designed with input from a representative of the Scottish Diabetes Group for both the survey and the facilitation pack. Opportunities to get involved were shared with the ALLIANCE's members, as outlined above, shared with Diabetes Scotland members, and clinical contacts of the Scottish Diabetes Education Advisory Group.

In terms of limitations, it is important to acknowledge that these findings represent the views of a self selected sample who chose to take part in the ALLIANCE's online survey or focus groups, as well as the workshop facilitated by Networking Key Services. As a result, these findings may reflect the views of the people who were already most likely to engage with diabetes information and support.

This survey was conducted during the COVID 19 pandemic where digital services were introduced as a necessary public safety measure replacing face to face appointments, therefore, participant responses need to be considered in this context.

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Demographics

Overall, 170 people responded to the online survey and 29 people took part in focus group discussions.

Of those who engaged through the online survey, 45.22% had personal experience of type 1 diabetes, 53.5% of type 2 diabetes, 0.64% of gestational diabetes, and 2.55% of other types of diabetes.

The majority of respondents were aged between 46 and 75, with 31.18% aged between 56 and 65, 18.24% aged between 66 and 75 and 17.08% aged between 46 and 55. However, those in younger age groups were also represented, with 4.12% aged 25 or under, 7.65% aged between 26 and 35 and 14.71% aged between 36 and 45. 6.47% were aged 76 or over and 0.59% preferred not to answer this question.

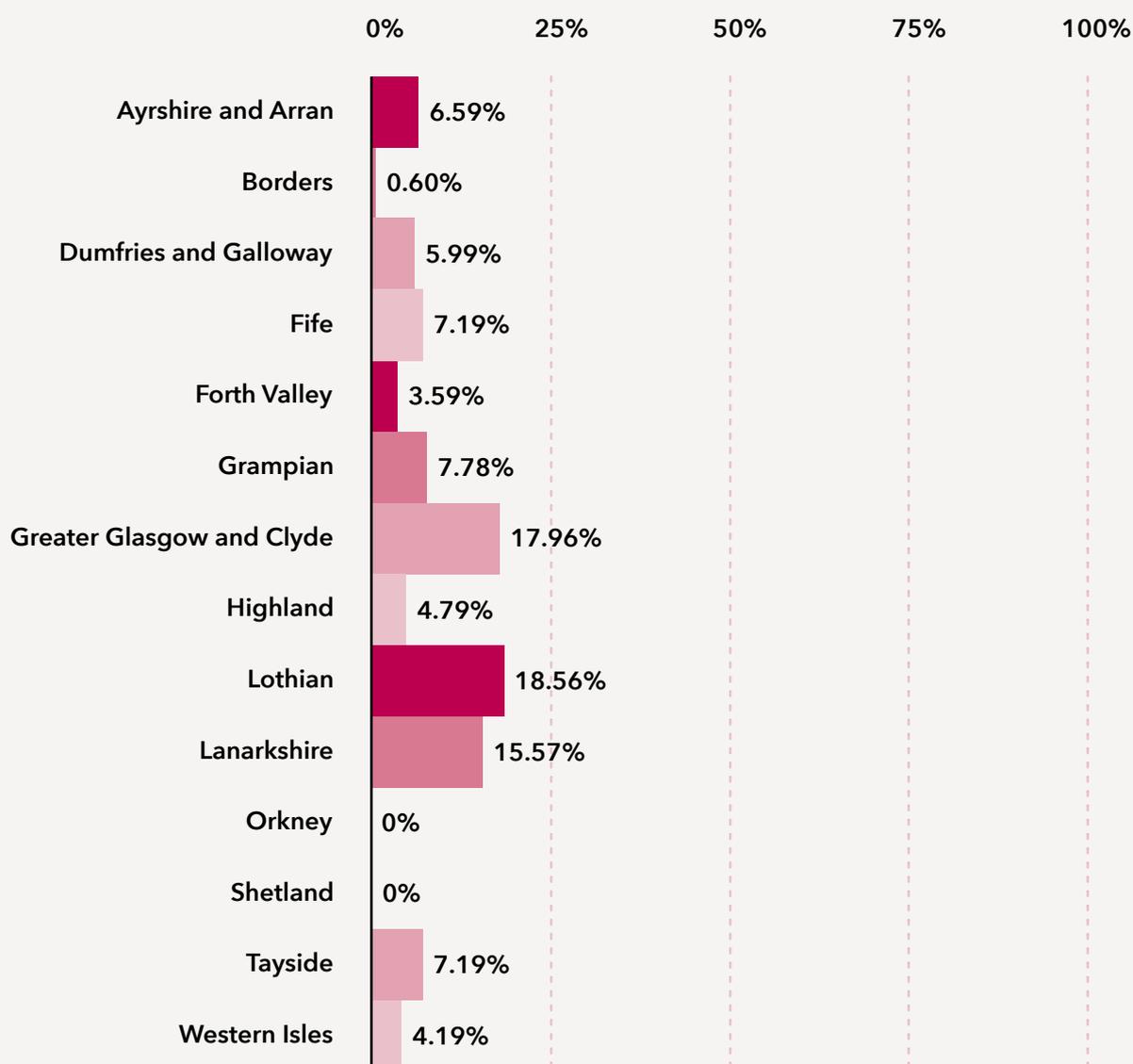


Most respondents (63.86%) were female, whilst 34.94% were male and 1.2% preferred not to answer.

In terms of sexual orientation, the vast majority of respondents (92.22%) identified as heterosexual or straight. 2.4% identified as bisexual and 1.8% as gay or lesbian, with 3.59% preferring not to answer this question.

The health board areas of those taking part in the online survey were evenly spread. However, the majority of respondents did report living in the central belt of Scotland, with 18.56% stating that they lived in Lothian, 17.96% in Greater Glasgow and Clyde and 15.57% in Lanarkshire. No respondents reported living in Orkney or Shetland.

Which Health Board Area do you live in?



When asked if they lived with any kind of disability, 59.52% of survey respondents said they did not, whilst 33.33% said that they did. 4.17% were unsure and 2.98% preferred not to answer this question. Notably, people with type 2 diabetes were more likely to report that they lived with any kind of disability (60.71%) than people with type 1 diabetes (52.86%). Those with gestational and other types of diabetes were even more likely to report that they lived with any kind of disability. However, the sample sizes for these two groups were very small.

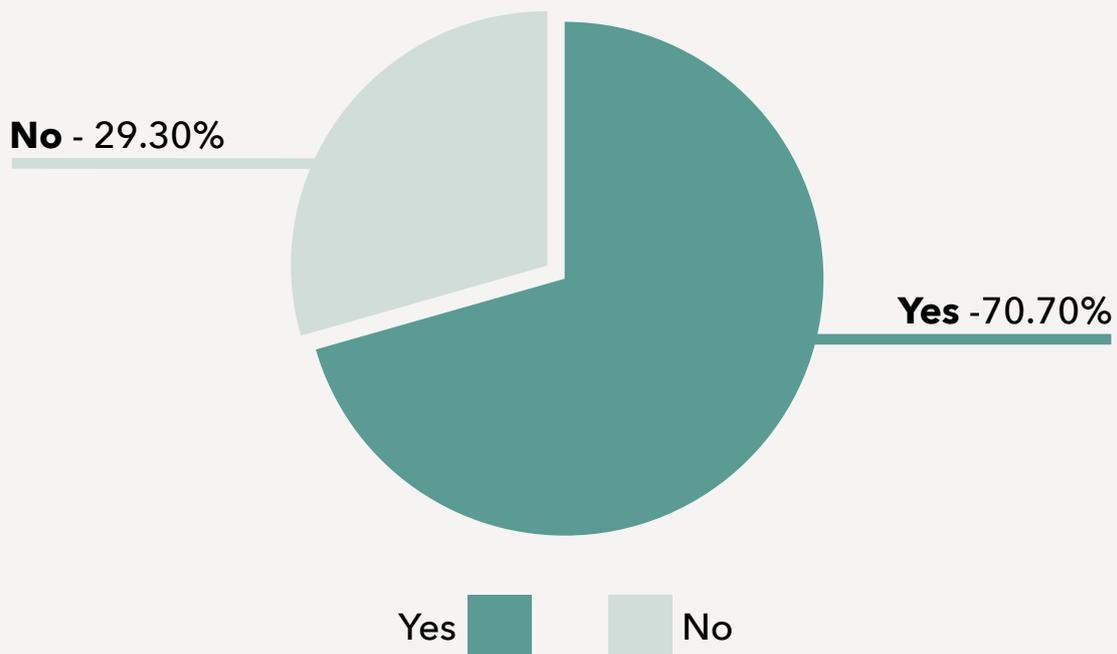
In terms of race and ethnicity, the vast majority (85.88%) of respondents were white. However, other groups were also represented, with 9.41% of online survey respondents sharing that they were Asian, Asian Scottish or Asian British and 1.18% sharing that they were African. 1.76% said that they were part of another ethnic group, 0.59% that they were part of mixed or multiple ethnic groups, and 1.18% preferred not to answer this question.

The online survey was supplemented by focus groups which were facilitated by the ALLIANCE and Networking Key Services. The ALLIANCE held two online sessions, one during the day and another in the evening, to allow for a range of working and caring responsibilities to not be a barrier to participation. One focus group was held specifically with South Asian women by ALLIANCE member Networking Key Services.

Diagnosis

Overall, people reported that their experience of diagnosis had been positive. When asked if they had been supported by their health care team to understand and manage their diabetes when diagnosed, 71% of survey respondents answered 'Yes'.

Were you supported by your health care team to understand and manage your diabetes when diagnosed?



There were slight variations, in terms of people's experience of diagnosis, based on people's reported health board area:

- Of the 11 people living in Ayrshire and Arran who responded to our survey, 62.5% shared that they had been supported by their health care team to understand and manage their diabetes when diagnosed.
- Only one person who responded to our survey lived in the Scottish Borders. They shared that they had been supported to understand and manage their diabetes when diagnosed.
- Of the ten people living in Dumfries and Galloway, 55.56% shared that they had been supported.
- Of the 12 people living in Fife, 75% shared that they had been supported.
- Of the six people living in Forth Valley, 83.33% shared that they had been supported.
- Of the 13 people living in Grampian, 53.85% shared that they had been supported.

- Of the 30 people living in Greater Glasgow and Clyde, 62.07% shared that they had been supported.
- Of the eight people living in Highland, only 42.86% shared that they had been supported with 57.14%, in contrast, sharing that they had not been supported.
- Of the 26 people living in Lanarkshire, 90.48% shared that they had been supported.
- Of the 31 people living in Lothian, 73.33% shared that they had been supported.
- Of the 12 people living in Tayside, 81.82% shared that they had been supported.
- Of the seven people living in Western Isles, 85.71% shared that they had been supported.

There were slight variations, in terms of people's experience of diagnosis, based on people's reported health board area:

- Of the seven people aged 25 or under, 100% shared that they had been supported.
- Of the 11 people aged 26 to 35, 72.73% shared that they had been supported.
- Of the 20 people aged 36 to 45, 75% shared that they had been supported.
- Of the 27 people aged 46 to 55, 66.67% shared that they had been supported.
- Of the 50 people aged 56 to 65, 72% shared that they had been supported.
- Of the 30 people aged 66 to 75, 56.67% shared that they had been supported.
- Of the 11 people aged 76 or over, 90.91% shared that they had been supported.

In terms of gender, 82.14% of people who identified as male and 65.31% of people who identified as female shared that they had been supported.

With regards to sexual orientation:

- Of the 154 people who identified as heterosexual or straight, 72.54% shared that they had been supported.
- Of the three people who identified as gay or lesbian, 100% shared that they had been supported.
- Of the four people who identified as bisexual, 66.67% shared that they had been supported.

In terms of race and ethnicity:

- Of the 146 people who said their race or ethnic group was white, 71.64% shared that they had been supported.
- Only one person who responded to our survey said that their race or ethnic group was mixed. They shared that they had not been supported to understand and manage their diabetes when diagnosed.
- Of the 16 people who said their race or ethnic group was Asian, Asian Scottish or Asian British, 75% shared that they had been supported.
- Of the two people who said their race or ethnic group was African, 100% shared that they had been supported.

And there were slight variations based on the type of diabetes reported, too, with 81% of those with type 1 diabetes and 63% of those with type 2 diabetes reporting that they had been supported when diagnosed. The sample sizes for those with experience of gestational and other types of diabetes were very small, with one person reporting the former type of diabetes and four people the latter. Of these, the person who reported experience of gestational diabetes said they had been well supported, whilst only two of the four people who reported experience of other types of diabetes shared that they had been well supported.

Type 1 diabetes

When asked to share more about their experience of diagnosis, those with type 1 diabetes discussed the helpful support they had received from health professionals, the importance of the manner of health professionals, the initial shock of diagnosis, the long term improvements that have been made in terms of diabetes information and support available, and current areas of diabetes information and support which could be improved.

Most people with type 1 diabetes were very happy with the support they had received following their diagnosis. As stated by some of the participants:



I have a fab team of diabetes nurses and a dietitian as well.



The diabetic nursing team and other care providers at the hospital were amazing and the aftercare provided by the diabetic nursing team was second to none. Me and my family were able to speak to the same nurse who had come into the hospital and this made a huge difference to all of us as she was amazing and so patient, reiterating information to help us get through.

People praised the support they had received with regards to guidance, exercise, medication, diet and 'carb control.' The manner in which health professionals offered this support was also very important, with people stating the difference 'friendly staff who were more than willing to help' made during their diagnosis.

This support was crucial given many people said they had struggled with the news of their diagnosis. There were a swathe of comments describing the experience of diagnosis as 'terrifying,' leaving many 'in shock,' as exemplified by some participants' accounts:



I was 9 years old. It was terrifying. I was in hospital for a week, without my parents.



(I was) scared at first but I'm gradually getting the hang of it.

Many of those who had been diagnosed with type 1 diabetes at a young age commented on the huge improvement in treatment they have experienced as they have gotten older: 'terrifying,' leaving many 'in shock,' as exemplified by some participants' accounts:



I have been type 1 since I was 6 years old. Now aged 60 the changes in medication and attitude are immense.



The advances in technology have been phenomenal and will only continue at pace.



(I was) diagnosed with type 1 in 1971. (It would be) unhelpful to comment on health care team response at that time when medical model only in use.



(I have had) diabetes for 11 years but I've learned more in the past two years through programs, webinars, focus groups. We learn from each other.

Those who had been diagnosed at a young age recalled that information and support had primarily been given to their parents:



My parents were given information but I had huge chunks of knowledge which I didn't know about until years later. As understanding of diabetes grew, so did my own knowledge, but there were times when I wondered why no one had pointed something out to me. I felt like I'd fallen through the gaps.

There is room for improvement, too, in some current areas of diabetes information and support. Some people spoke about feeling left to their own devices when they were first diagnosed, being left 'to find out a lot of information online.

Although there was praise for the practical support offered following diagnosis, people said more could have been offered in terms of emotional and psychological support:



I don't recall any counselling type support. It was simply practical and medical related advice.



Although I was supported everything was done virtually, so there was no one to one interaction. As I was newly diagnosed there was very little information or help on the mental wellbeing side of things. Diabetes has changed my life but although I knew the diabetic team were only a phone call away I felt so alone

Better access to formal emotional and psychological support will be further discussed in later parts of this report.

The COVID-19 pandemic also had an impact on the support people received following their diagnosis. As one participant said:



(COVID-19 has) reduced my access to services and freedom to get out and exercise. My health has deteriorated in these two years.

A number of people shared that they found it difficult initially to get a diagnosis of their condition, with many also stating that they had been initially misdiagnosed as having type 2 diabetes.

Type 2 diabetes

People with type 2 diabetes discussed the helpful support they had received from health professionals, the importance of the manner of health professionals, the impact of the COVID-19 pandemic on diabetes information and support and the importance of clarifying trustworthy online resources. In contrast to those with type 1 diabetes, too, people raised the stigma associated with type 2 diabetes.

As with type 1 diabetes, most people with type 2 diabetes were generally happy with the support they received following their diagnosis. As one participant said:



The GP was very thorough. I got much help and guidance from the Practice Nurse. I get regular checks and discussions and am invited to raise questions at any time. I use 'My Diabetes My Way'³ to check on results and to check progress... I feel that I am well supported – given the current pressures on the Health Service.

People with type 2 diabetes said that they had received helpful support with their diet, weight management and medication.

In contrast though, people with type 2 referred to the stigma associated with type 2 diabetes.

Furthermore, a large number of people with type 2 diabetes were noticeably frustrated with the support they had received following their diagnosis.

Many people with lived experience of type 2 diabetes reported examples of what they called unsupportive and sometimes 'rude' interactions with health professionals, as stated by one respondent:



The GP was very rude and said 'you have diabetes and it is all because of what you put in your mouth'... I left his surgery in tears and was comforted by the reception staff who were very kind... This was an awful way to be told you have any illness.

³ My Diabetes My Way: <https://mydiabetesmyway.scot.nhs.uk/>

The people we engaged with attributed this to the stigma associated with type 2 diabetes.

As with type 1 diabetes, people expressed feelings of 'shock' and 'worry' following their diagnosis, which were exacerbated by the stigma noted above:



I was overwhelmed, it completely undermined my sense of who I was – someone who was very healthy.

People said the support they had received following their diagnosis had been affected by the COVID-19 pandemic:



(I had received) very good support and follow-up examination and appointments initially. But once COVID-19 arrived and subsequently to that there has not been any contact or appointments with the team other than an eye test.

As also noted in the section above, many of the people with type 1 diabetes that we engaged with said that they had initially been misdiagnosed as having type 2 diabetes. Those who had been misdiagnosed said that they had noticed a difference in the support available to those with type 2 diabetes. As one participant said:



(I was not supported) at the start when first diagnosed. I had to find out a lot of information online. I was first diagnosed as type 2 incorrectly, and the difference in support between type 1 and 2 is staggering.

Many people echoed this sentiment, sharing that they had also been very dependent on online resources:

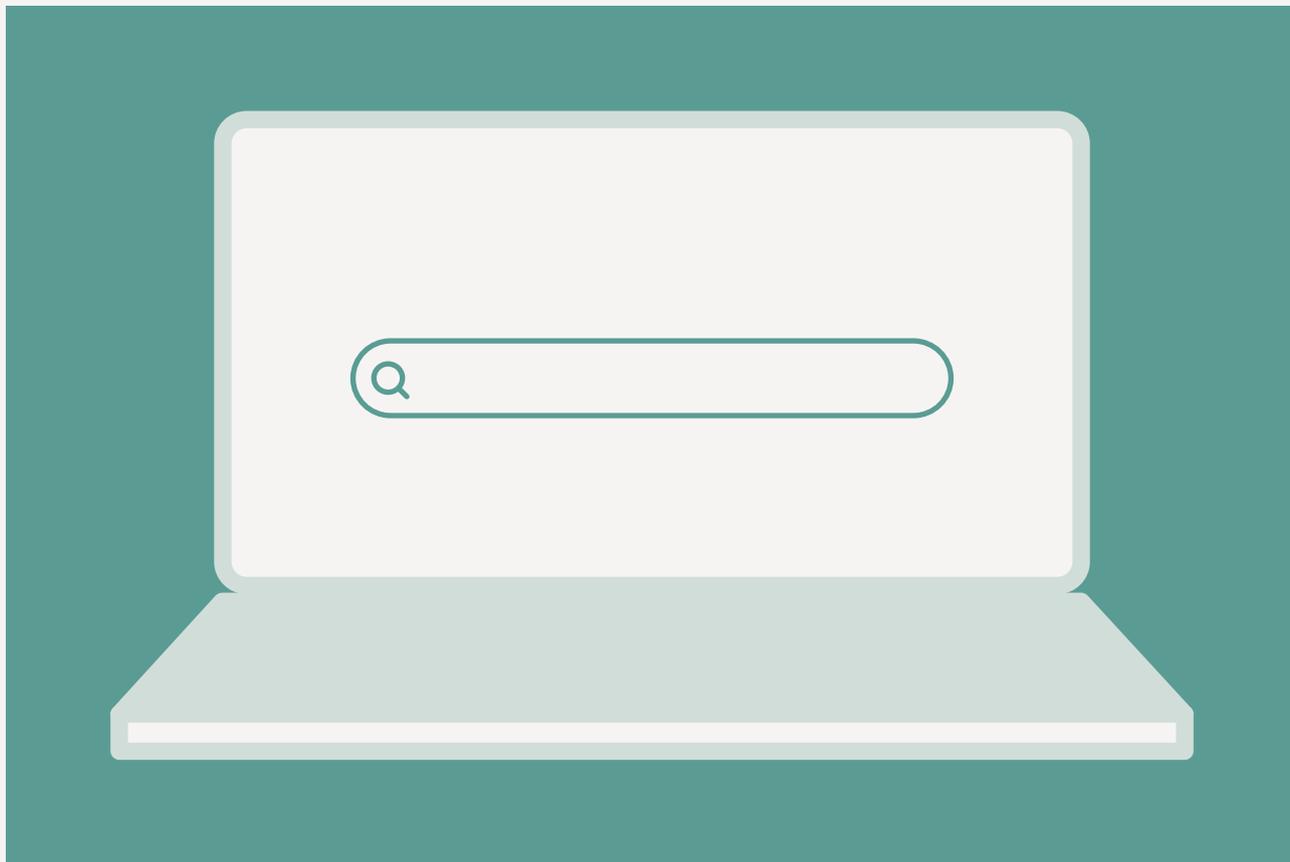


I had to rely on online resources. Even now, six months later, I still don't fully understand diabetes, and still have many unanswered questions.

However, people were unsure of what online resources could be trusted:



Googling diabetes sent me on a very wrong path and has led to other complications to my health. As a result, I am confused and upset and do not know where to turn.



Gestational and other types of diabetes

There were a low number of responses to the online survey from those with experience of gestational and other types of diabetes. One person in our sample reported having lived experience of gestational diabetes and two of other types of diabetes.

The person with experience of gestational diabetes said that they were well supported by their health care team following their diagnosis. However, they did not elaborate on their experiences.

People who reported experience of other types of diabetes reported more mixed experiences of support following their diagnosis. They shared that they had been diagnosed with glucokinase diabetes (GCK-MODY 2) and latent autoimmune in adults (LADA) diabetes.

As with other types of diabetes, people experienced difficulty obtaining a diagnosis, with one person sharing that they had initially been misdiagnosed as having type 2 diabetes. Another shared that they are still waiting to find out what type of diabetes they have.

The individual with lived experience of GCK-MODY 2 diabetes felt that 'there is almost no help or advice for this form of diabetes' as a result of its rarity. This view was shared by the individual with LADA diabetes, who shared that the lack of information about their type of diabetes caused a 'large delay' to them receiving their medication.



Common experiences of diagnosis

There were experiences which were common across all types of diabetes.

The most common of these was the initial shock and anxiety people experienced when they received their diagnosis, particularly for those with type 2 diabetes as a result of the associated stigma.

However, it should also be highlighted that some people shared that they had, instead, felt a sense of 'relief' following their diagnosis:

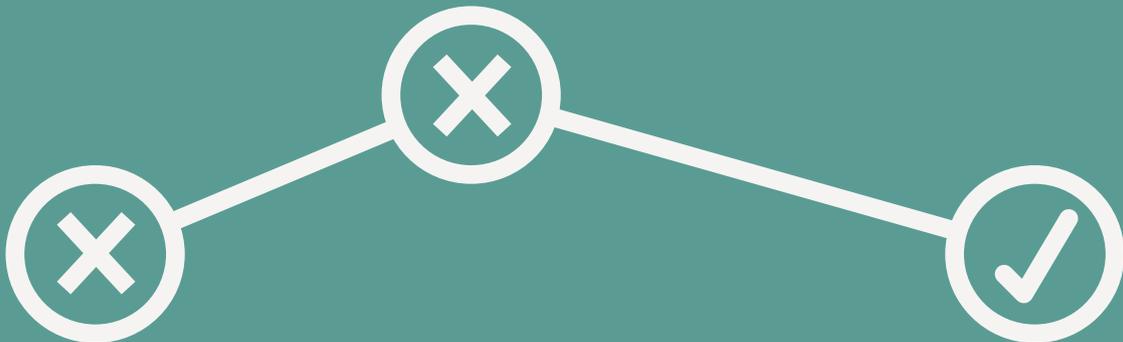


Relief! I knew something was wrong, and the other options were far worse. I had great medical support.

Responses indicate that the information and support given at this early stage greatly influenced people's perception of their diagnosis, as did the manner in which this information and support was provided.

Many people experienced difficulty obtaining this diagnosis. In our engagement, through focus groups and survey, many experienced a delay during their diagnosis or were initially misdiagnosed with another type of diabetes.

Further, the COVID-19 pandemic had an impact upon the information and support provided to people, regardless of the type of diabetes of which they had lived experience.



Types of diabetes information and support

Those taking part in the survey were asked to share how helpful they would find the following support:

- Group sessions in-person;
- Group sessions online (video call sessions);
- Online learning (work through at own pace online – for example written information with videos, quizzes);
- Online resources via recommended websites – for example digital information leaflets);
- Appointments with health professionals via telephone;
- Appointments with health professional via video call;
- Appointments with health professionals in person;
- Chat room discussions/message boards with health professionals;
- Chat room discussions/message boards with others with diabetes;
- Information online;
- Use of health trackers (such as monitoring glucose levels or weight);
- Nutritional trackers;
- Use of activity trackers (such as Fitbits);
- Meal planning support and advice;
- Information videos;
- Information podcasts;
- Leaflets;
- And other types of support (which people were asked to specify).

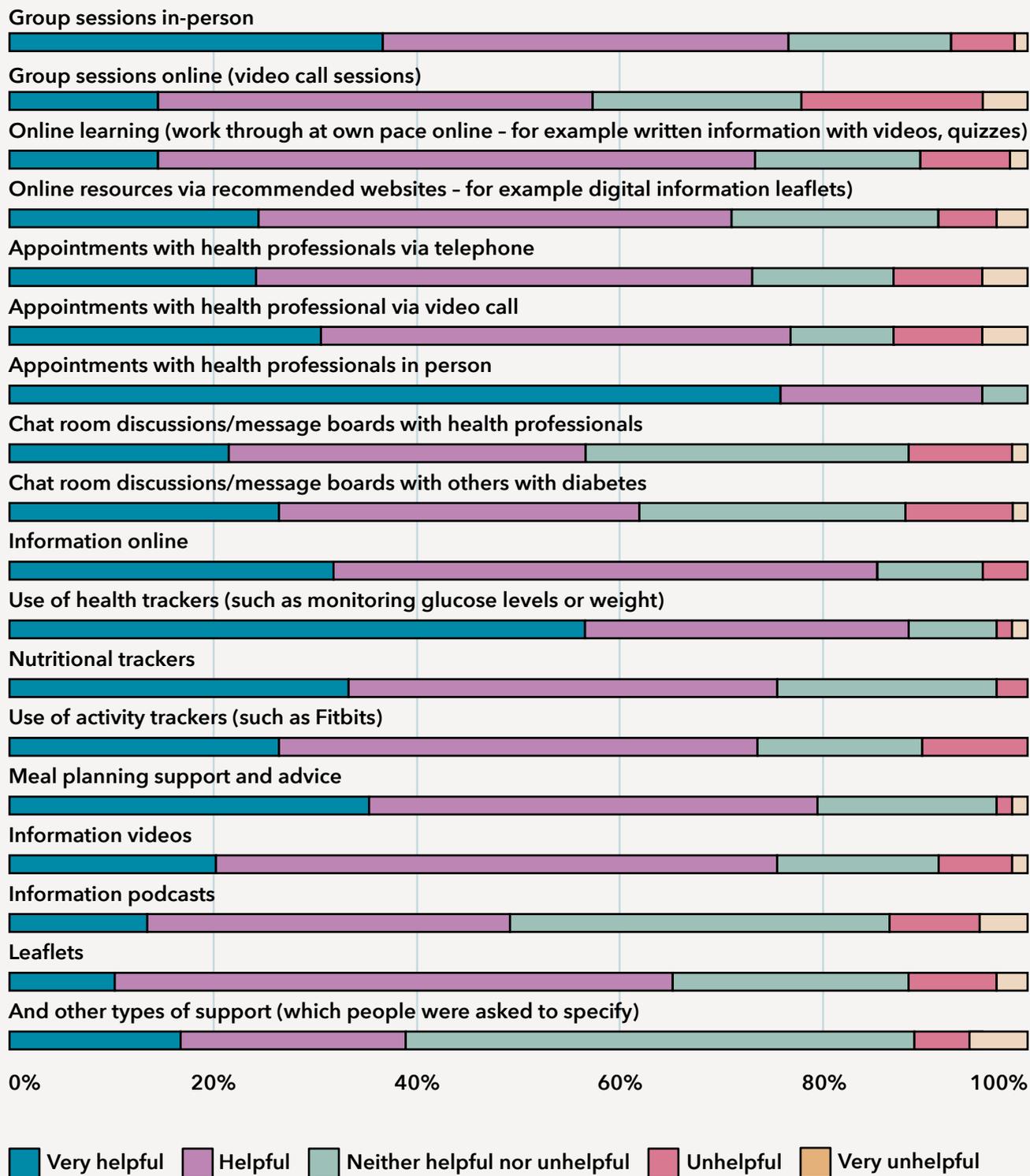
People's responses have been analysed below according to the type of diabetes they had lived experience of.

Type 1 diabetes

People with experience of type 1 diabetes rated most of the support suggested above as either helpful or very helpful. Of particular note, people rated the usefulness of appointments with health professionals in person (96%), health trackers (89%) and information online (86%) as either helpful or very helpful.

The only exception to this was information podcasts, in which the most common answer amongst people living with type 1 diabetes (37%) was that it would be neither helpful nor unhelpful.

Please consider which of the following options you think you might have found helpful after diagnosis?



When asked to provide more information on the options which were most appealing to them, the people with type 1 diabetes that chose to respond to our online survey expressed a preference for face to face support, whether that is with a professional or a peer:

“ I don't feel 100% comfortable with technology so face to face sessions are always better for me.

“ I much prefer face to face and specifically from someone who is already type 1 and not educated from a book.

There was also support for telephone and online support, although support for these options was not as strong. For the latter, some respondents showed a preference for Zoom as a platform for video calls:

“ The Zoom meeting once a week is great to catch up on what everyone is doing.

“ The Near Me video service my hospital uses is not the best. It can become hard to hear and even videos freeze. Any other video call service I use doesn't have this issue.

It was noted by some participants that accessibility requirements should also be taken into account during these online meetings and consultations:

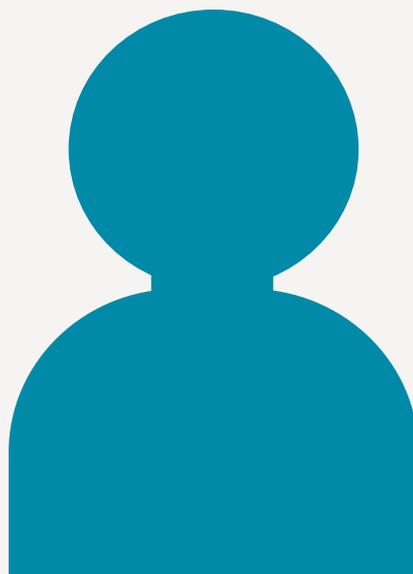
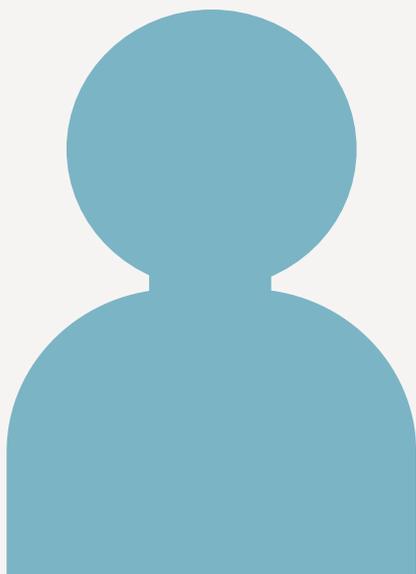
“ I'm hard of hearing which makes online discussions difficult due to the noise in the audio.

In terms of other online support, people spoke about the usefulness of WhatsApp, which one person said had been helpful for their peer support group:

“ It's great to have the WhatsApp group available 24/7 in case I feel I have a question to ask.

People with type 1 diabetes told us that peer support was crucial to support their wellbeing:

“ Peer support allows you to speak to others who understand and 'get it,' which helps you to feel less isolated.

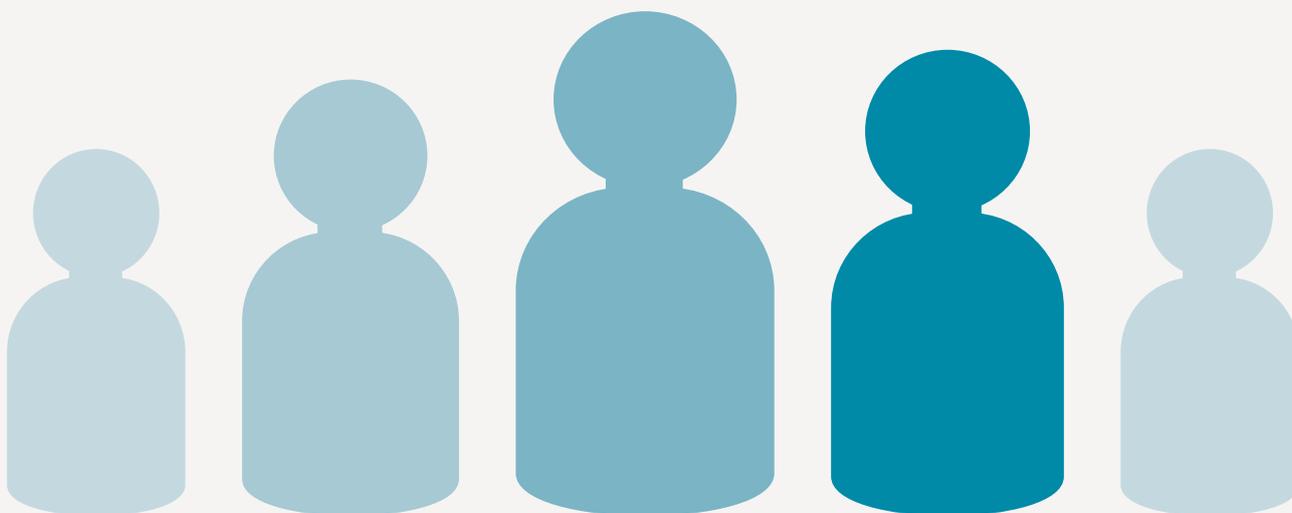


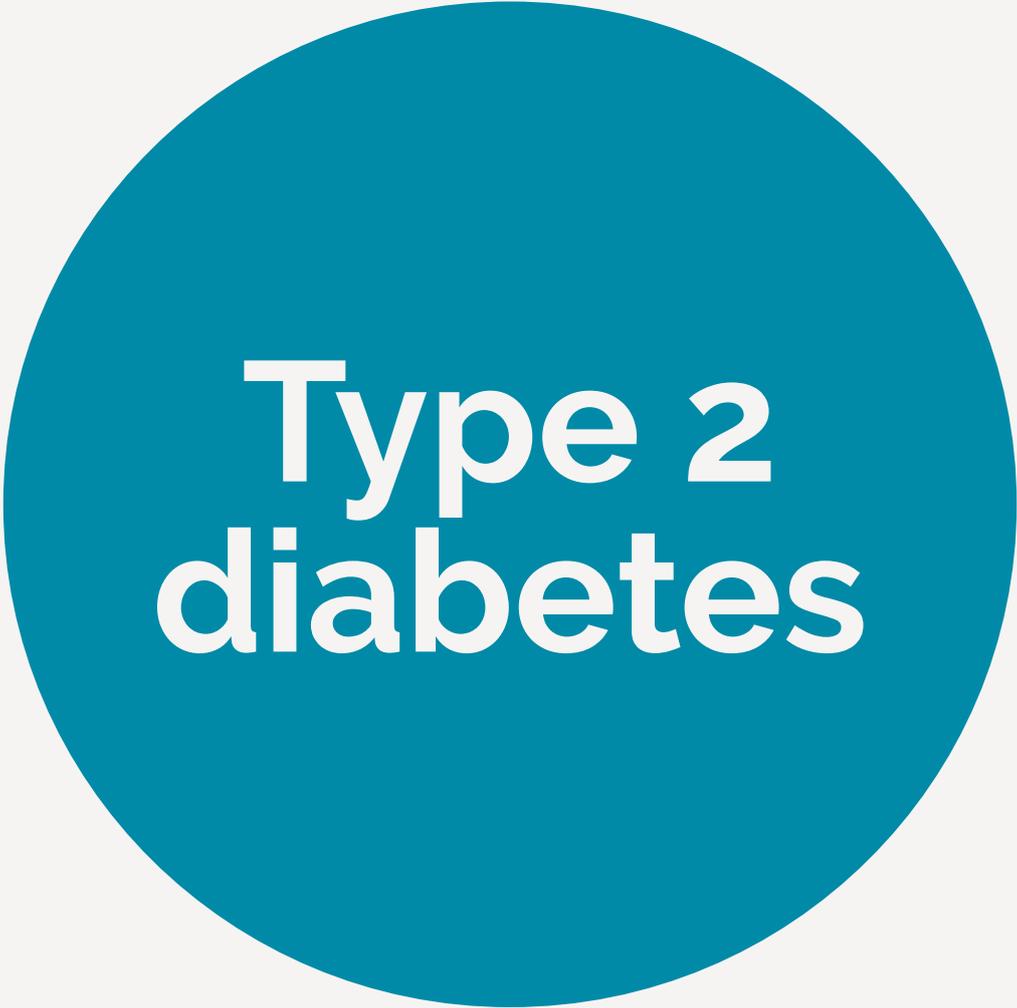
However, this support needs to come at the right time. One person shared that they thought peer support is sometimes offered too quickly following diagnosis:

“ Participating in a group session either online or in person soon after diagnosis is potentially problematic when the person is in the early stages of understanding and coming to terms with diagnosis. Some group members would need to be further on in diagnosis and treatment to assist the group.

Support and tools which promote independence and allows individuals to self manage their diabetes was also described as crucial. People with type 1 diabetes said that health trackers play an important role in this regard, supporting with diet and weight management, for example.

There was also a demand for support to be made available at evenings and weekends, as this is when ‘the majority of diabetes emergencies happen.’ This could take the form of online resources, which would allow people to access information and support at a time that suits them best.



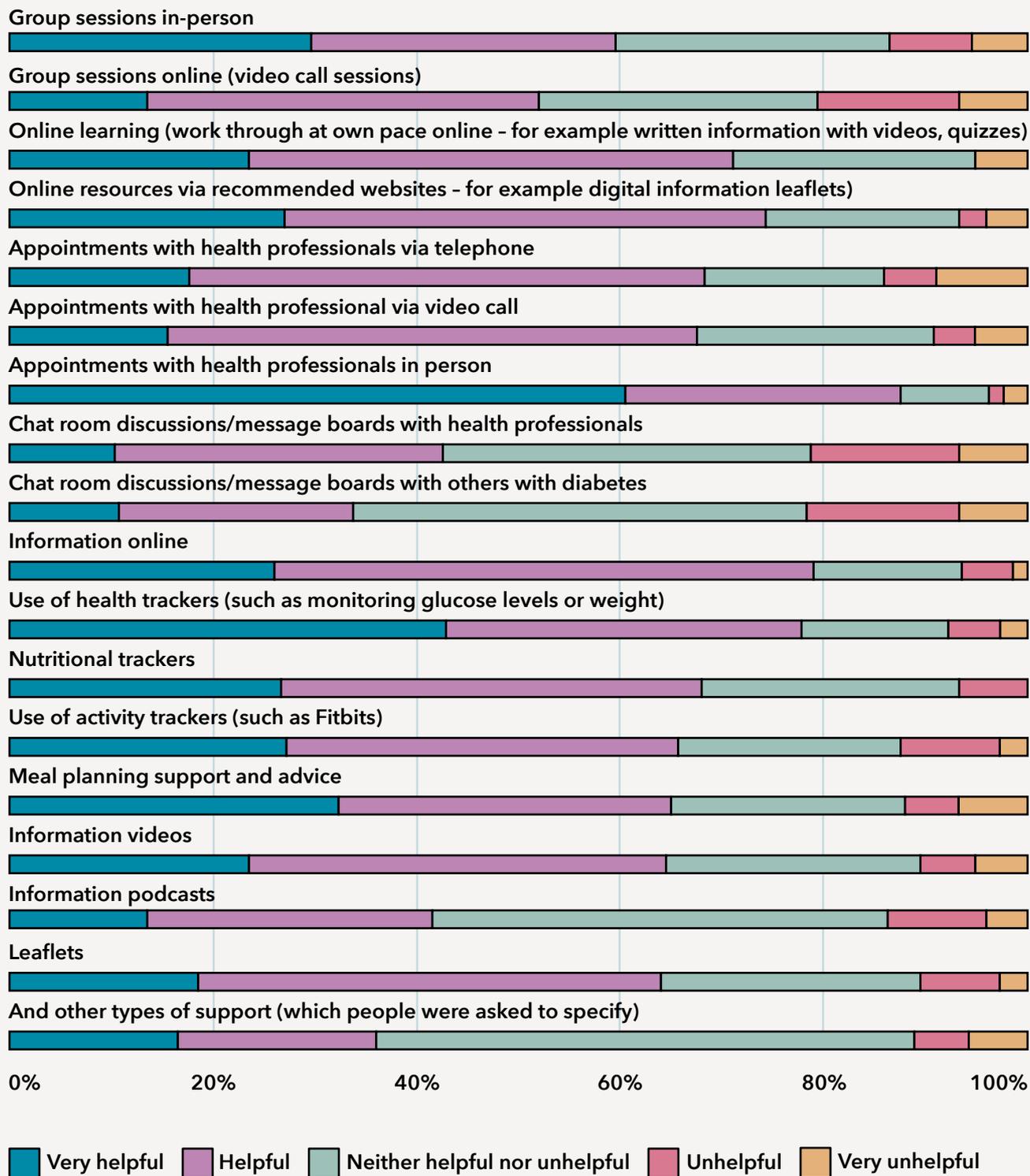


Type 2 diabetes

People with experience of type 2 diabetes rated most of the support suggested as either helpful or very helpful. Of particular note, 87% of respondents rated the usefulness of appointments with health professionals in person as either helpful or very helpful.

However, there were exceptions to this general support, in which people rated some options as neither helpful nor unhelpful. These included chat room discussions with others with diabetes (45%), information podcasts (44%) and chat room discussions with health care professionals (36%).

Please consider which of the following options you think you might have found helpful after diagnosis?



People with type 2 diabetes expressed a clear preference for face to face support.

Telephone support was also popular, however people with type 2 diabetes said that online support, and specifically video calls, were preferable as they are 'more like face to face':



I prefer face to face but if not possible then video calls. It's important to see the person with whom you are speaking.

People shared with us that there was 'a convenience of a video call' which allowed people with type 2 diabetes to 'work around a busy schedule.'

Any online meetings should take into account the accessibility requirements of those taking part, however. These should incorporate greater support for people with hearing loss. It was also suggested that language barriers may prevent people from being able to fully participate in both telephone and online appointments.

Forms of peer support were slightly less popular amongst people with lived experience of type 2 diabetes, who were less inclined to engage in group sessions and chat room discussions with others with diabetes:



I am not one for group meetings so wouldn't go to these.



I know what I should or shouldn't eat and don't need 'group sessions' of any kind to help me stick to a suitable diet.

However, there were still some people who said they would find peer support helpful:

“ I would like group sessions with fellow type 2 folks. (They are) good for ideas and to bounce subject matter, concerns, celebrations etc. We can learn from each other.

For many the greatest need is 'quick answers to questions, especially (from) diabetes nurses.' As was suggested by people with type 1 diabetes, those with type 2 diabetes suggested that this could be facilitated by signposting to online resources which are available when people need them:

“ Online is convenient, as I can consume those resources at any time that suits me.

“ Online resources appeal to me as I can access them when I want and how often I want without putting a strain on (my) GP practice.

People said that they would also like access to other resources which would support them to self manage their diabetes. It was suggested that this could include fitness tracking to manage their exercise, weight and sleep patterns, as well as support with diet, nutrition and meal planning.

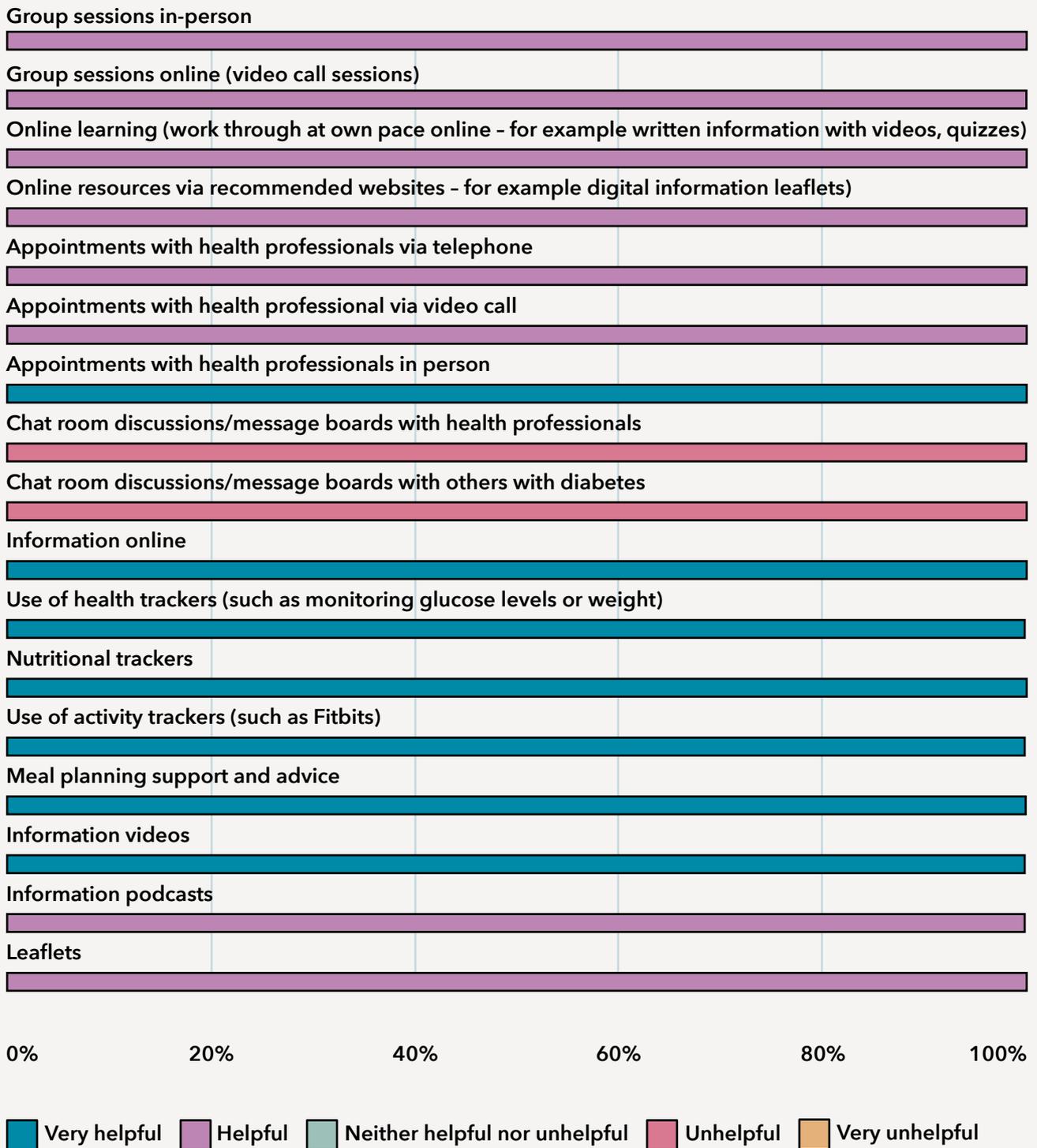


Gestational and other types of diabetes

The respondent who took part to share their experience of gestational diabetes rated most of the support suggested as either helpful or very helpful.

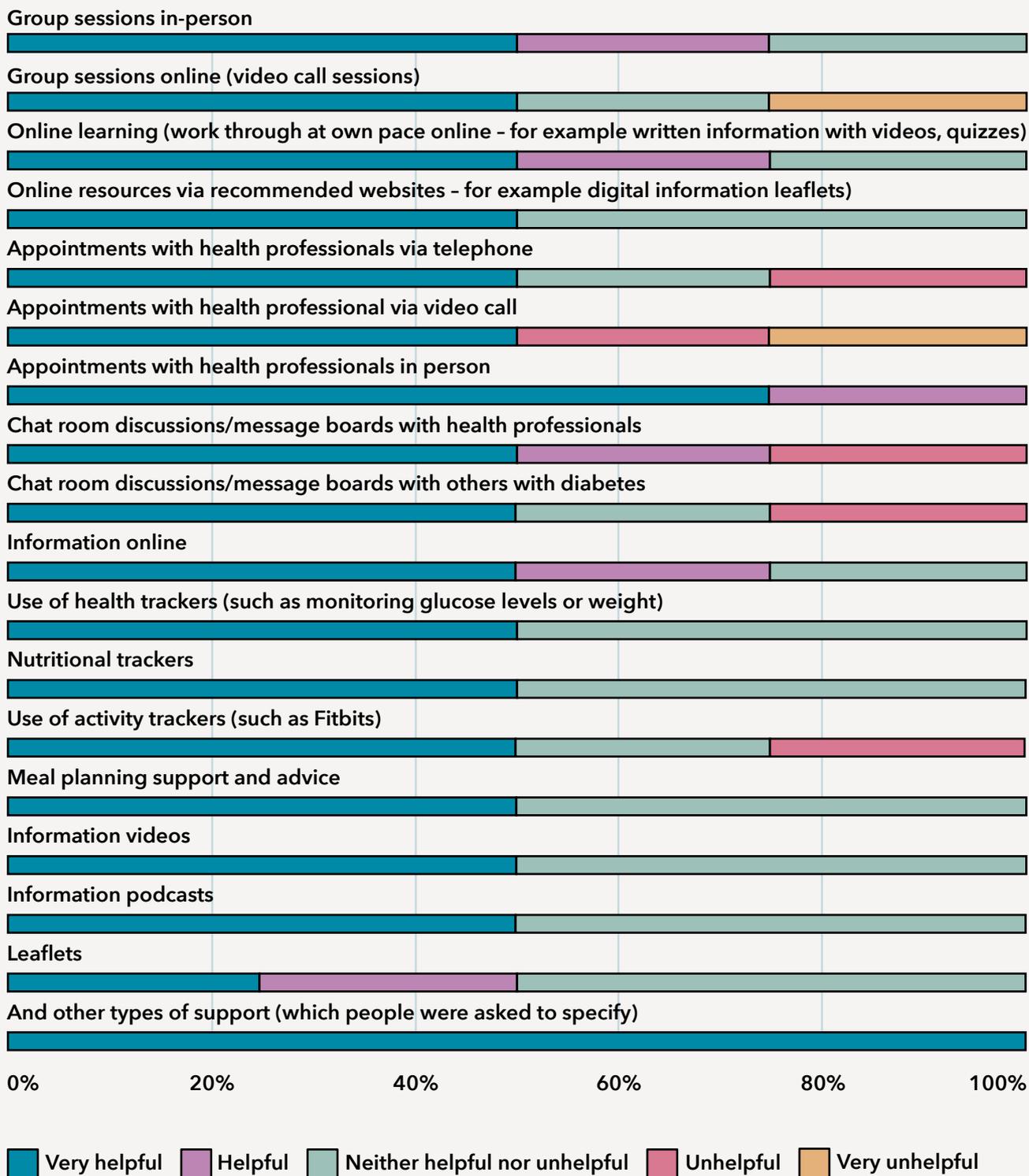
The only exceptions to this were chat room discussions with health professionals and others with diabetes, which they said would be unhelpful.

Please consider which of the following options you think you might have found helpful after diagnosis?



People with experience of other types of diabetes rated all of the support suggested as either helpful or very helpful.

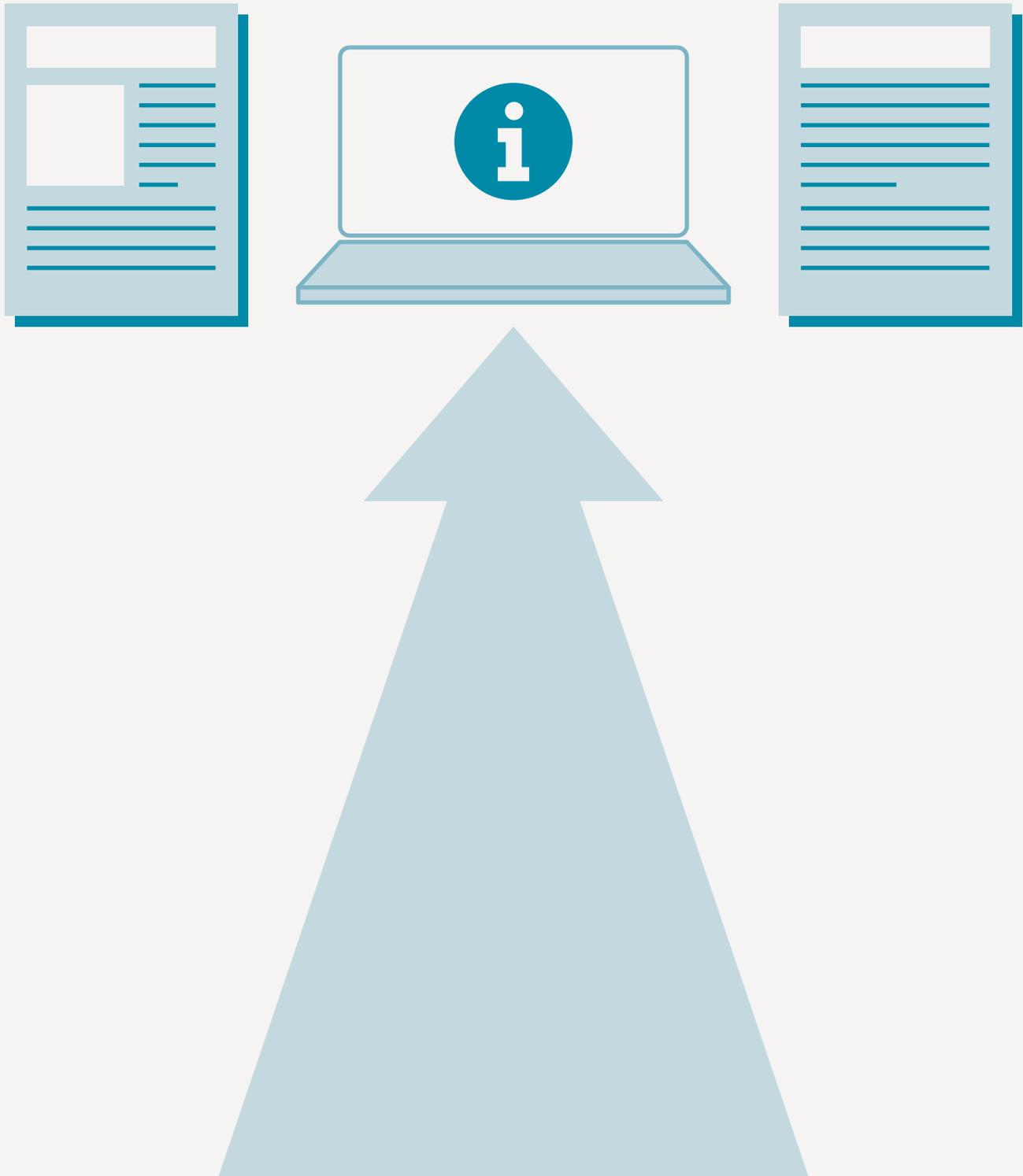
Please consider which of the following options you think you might have found helpful after diagnosis?



When asked to provide more information on the options which were most appealing to them, people with gestational and other types of diabetes discussed the importance of support being made available, 'when it is needed, not at a set time.'

Those with gestational and other types of diabetes also said that, for reassurance, they would like more guidance on where to find sources of information that are reliable.

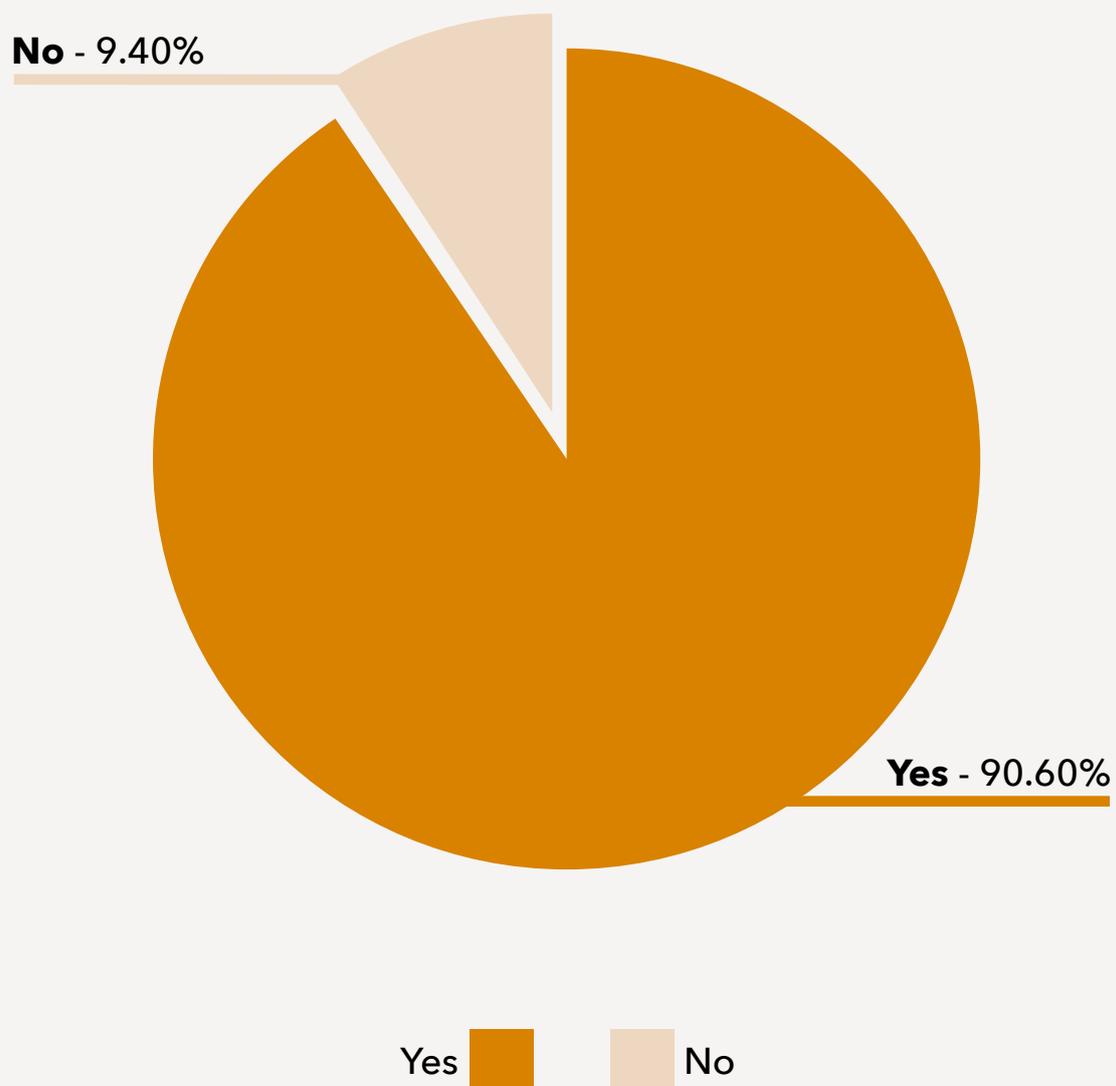
When asked for more information on the types of trackers that they found useful, too, people spoke highly of My Diabetes My Way, which they said encouraged them towards goals, 'motivating and helping when (they were) having a bad day.'



Emotional and psychological support

There was overwhelming agreement (91%) amongst our online survey respondents that people living with diabetes should have access to support for emotional wellbeing and mental health.

Do you think people living with diabetes should have access to support for emotional wellbeing and mental health?



This sentiment was consistent across all types of diabetes, with 96% of respondents living with type 1 diabetes, 86% of respondents living with type 2 diabetes, and 100% of respondents living with gestational and other types of diabetes agreeing with the above statement.

People said that there is a need to 'raise awareness that being diagnosed with any long term condition is life changing and will directly have an impact on your mental health.' However, people shared with us that diabetes, in particular, can have a significant impact on mental health as a result of the 'psychological effects of low blood sugar levels.' This can also have an impact on people's existing mental health:

“ I've had depression most of my life, so things affect that. But people don't realise the impact of other health conditions on depression.

Many suggestions were made, particularly in our focus groups, for ways in which the mental health of people living with diabetes can be supported.

Several people spoke highly about their experiences of speaking to trained professionals about their mental health:

“ I find sometimes talking it through can be hugely helpful. Having conversations about what I can and can't do with a therapist who is trained to talk these things through with you.

People also discussed self management and the importance of building people's resilience and ability 'to deal with the impact of a diagnosis' as well as how to 'live with it for the rest of your life.'

Most commonly, people spoke about the need for more peer support, learning from others who have gone through the same experiences:



We need some kind of direction to places to speak to other peers. It would be really helpful so you don't feel so alone. Forums and meet ups and things like that.

Third sector has a vital role to play in the delivery of emotional and psychological support. One person spoke very highly of the support they had received from Long Term Conditions Hebrides, who offer yoga, meditation, self care and self management strategies:



People have different long term conditions but (Long Term Conditions Hebrides) brings us together to connect. Face to face support is essential and reduces isolation, lets people connect.

Additionally, it was suggested that emotional and psychological support could also be provided in partnership with third sector organisations such as Networking Key Services, to overcome any language barriers that people may experience.

Flexibility

Survey respondents highlighted that having flexibility in the type of, and ways to access, support available to them was very important to help them manage their condition. Most respondents, whether they had lived experience of type 1, type 2, gestational or other types of diabetes, shared that fitting support around work and family commitments was often a barrier. Being offered flexible, person-centred support was also perceived as a way to better manage any changes in one's condition. One respondent with type 1 diabetes said:

“ With diabetes being a constant feature of my life, changes to my lifestyle or anything that may disrupt my management of the condition won't necessarily fall within the scheduled appointments of diabetes clinics. Having reliable sources of information that I can go to when needed is more suitable to a condition that can be ever changing.

Having a flexible approach was also seen as a way to be supported to better self manage their condition, and recognising that people are experts about their own condition:

“ It would make me feel more in control, rather than having my support options dictated to me. Less time travelling to in person appointments and spending time in waiting rooms. Helpful for people who are working, as they would have to take less time off to attend in person appointments.

(Respondent with type 1 diabetes)



It is my body and I'm the one with diabetes. Everyone should have the same opportunities to access support. Inequalities should not be present so support must be flexible.

(Respondent with type 1 diabetes)



Not everyone responds in the same way so if you have choices you are more likely to find the ones that suit you and help you understand better.

(Respondent with type 2 diabetes)

Being able to access services locally was highlighted as positive, helping to avoid unnecessary travel or long waiting times for short appointments.

When asked, "Would being able to access information and support when you feel you need it be important to you?", 95% of respondents with type 1 diabetes answered "Yes", as did 97% of respondents with type 2 diabetes. Open text answers highlighted the importance of there being good synergy between in-person and online services:



Digital information about the condition is helpful, and access to my records digitally, helps me track my goals for managing my condition. Access to the team at the hospital via email or video call would enhance the service.

(Respondent with type 1 diabetes)

“ Appointments with health professionals (in person or on the phone), and the online discussion/message boards with health professionals would allow me to ask questions when they arise, and I would be confident that I am getting a trustworthy response. Another option I would like is to be able to email my questions to a health professional.

(Respondent with type 2 diabetes)

“ Face to face support and other options should be available. Knowledge and experience is a powerful tool, so yes some options would be very helpful to enable me to better understand my illness as well as hearing of real life experience from others with the same goal as you, to better understand and have necessary support.

(Respondent with type 2 diabetes)

Peer support was also often quoted as important by respondents:

“ If something goes wrong it's not always 9-5 Monday to Friday. You don't want to call 111 as they are busy as it is. I have relied on other friends to check that I have done everything correctly. I had my first occlusion on my pump and I wasn't sure if I remembered everything I was told to do.

(Respondent with type 1 diabetes)

Barriers

The need for different types of support and flexibility in accessing services were suggested as ways to overcome some of the barriers that respondents faced to manage their condition, whether they had lived experience of type 1, type 2, gestational or other types of diabetes. Across groups, the most common reasons listed as barriers to accessing support were:

- Getting time off work to attend appointments;
- Childcare commitments;
- Lack of internet connectivity, lack of digital skills or no access to IT equipment;
- And transport difficulties which made it difficult to get to appointments.

Open text responses highlighted that a mix of face-to-face and digital options, with the ability to make choices about what kind of service people will access, is most useful:

“ Interruptions when at home makes online contact frustrating at times. Having face to face makes me feel more focused and listened to.

(Respondent with type 2 diabetes)

“ Variable access to the internet and weak telephone signal mean that I can have difficulty in getting online or using a video call. The question of alternatives to digital access have to be available for those in digital poverty.

(Respondent with type 2 diabetes)

Overcoming these barriers

In addition to promoting flexible, person-centred approaches to accessing services, survey respondents highlighted that having equitable access to information and support is key to overcoming some of the barriers listed above. This includes making information available in multiple and accessible formats, so that support, services, and resources can be fully available to those with additional support needs and/or with sensory loss. Intervening in the early stages of diagnosis was also mentioned as important. These points were best captured in some of the open text responses in the survey:

“ Diabetes comes in many forms and they are very different, and I feel should be viewed with clear distinction between the types. Remember people are living now who were diagnosed well over half a century ago – we are not all newly diagnosed and have a wide, varied and still evolving experience and understanding of the condition. We have knowledge but may not be informed on new practice – posters in waiting rooms and pamphlets are not likely to engage or easily motivate. The internet and online tools offer amazing routes to information and support, but the sheer volume and breadth of this can be repetitive, confusing and overwhelming. Clarity of trusted, reliable, up to date information, appropriate for personal needs (stage of the patient journey) is needed.

(Respondent with type 1 diabetes)

“ I think that the level of support should be equal to all. Many people are given misinformation based on a clinic's inability to fund support such as psychological support, technology or education. People who are newly diagnosed now have a very low level of support. I hear daily of people who are newly diagnosed who haven't had clinic appointments. Good support in the early days is vital.

(Respondent with type 1 diabetes)

Respondents also suggested making dedicated diabetes medical staff available to discuss treatment with.

Another theme that emerged as important in survey data, in terms of overcoming barriers, was to provide formal psychological support and addressing mental health concerns as part of managing one's condition. Being offered this kind of support was also considered a way to better understand the condition and to manage it:

“ I think more psychologists should be employed to work in the diabetes clinics to support people with diabetes from diagnosis through their life, and the challenges of puberty, pregnancy and menopause.

(Respondent with type 1 diabetes)

“ There is a serious lack of support, understanding and acknowledgement of just how hard living with life-long type 1 diabetes can be, and the effects it has on having a meaningful life. The fact that it is not considered a disability in many circumstances is shocking, and also the fact that if your diabetes is well managed it seems to be considered to almost not exist, is difficult to handle.

(Respondent with type 1 diabetes)

“ Lack of support and not truly understanding your illness has a negative impact on your mental health especially when other symptoms appear and you're told it's all from diabetes. How can one look after themselves if they haven't been given the tools to monitor or understand what diabetes entails.

(Respondent with type 2 diabetes)

Finally, across groups, My Diabetes My Way was mentioned as an important tool to help people address and overcome some of the barriers they experienced when managing their condition. One respondent with lived experience of gestational diabetes shared with us that My Diabetes My Way 'is the best tool going, and it needs to be maintained and kept current.'

Summary of findings

People's experience of diagnosis was mostly positive, with the majority of people sharing that they had been supported by their health care team to understand and manage their diabetes when diagnosed. However, there was variation between types of diabetes. 18% more respondents with type 1 diabetes reported that they had been well supported following their diagnosis, when compared with respondents with type 2 diabetes. This could be linked to the stigma associated with type 2 diabetes, with some people reporting experiences of more negative interactions with health professionals.

Accessible information and support provided at an early stage influenced people's perception of their diagnosis. Many people experienced difficulty obtaining a diagnosis. In this engagement many people experienced a delay during their diagnosis or were initially misdiagnosed with another type of diabetes. The COVID-19 pandemic had an impact upon the information and support provided to people, regardless of the type of diabetes of which they had lived experience.

Forms of peer support were slightly less popular amongst people with lived experience of type 2 diabetes, with less support for group sessions and chat room discussions with others with diabetes.

There was agreement amongst our online survey respondents that people living with diabetes should have access to support for emotional wellbeing and mental health. This sentiment was consistent across all types of diabetes with 96% of respondents living with type 1 diabetes, 86% of respondents living with type 2 diabetes and 100% of respondents living with gestational and other types of diabetes agreeing with the above statement.

People stressed the importance of a flexible approach which is tailored around their individual needs. It was highlighted that having flexibility in the type of support available, as well as ways in which people with diabetes are able to access this support, was very important to help people self manage their condition.

In terms of barriers to diabetes information and support, people highlighted:

- Getting time off work to attend appointments;
- Childcare commitments;
- Lack of internet connectivity, lack of digital skills or no access to IT equipment;
- And transport difficulties which made it difficult to get to appointments.

People suggested that these barriers could be overcome by equitable access to information and support, information available in multiple and accessible formats, early intervention, dedicated diabetes medical staff, formal psychological support and the maintenance of existing services such as My Diabetes My Way.

In terms of future steps, the ALLIANCE will circulate this report to the Scottish Diabetes Group for their consideration of the contents.

The report will, at the same time, be sent to members of the Diabetes Network, facilitated by the ALLIANCE and Diabetes Scotland, as well as to all those who contributed their views and experiences.

Members of the Scottish Diabetes Group will be invited to comment on the report and attend a future Diabetes Network meeting to feed back on the next steps.



About the ALLIANCE

The Health and Social Care Alliance Scotland (the ALLIANCE) is the national third sector intermediary for a range of health and social care organisations. We have a growing membership of over 3,000 national and local third sector organisations, associates in the statutory and private sectors, disabled people, people living with long term conditions and unpaid carers. Many NHS Boards, Health and Social Care Partnerships, Medical Practices, Third Sector Interfaces, Libraries and Access Panels are also members.

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

Our vision is for a Scotland where people of all ages who are disabled or living with long term conditions, and unpaid carers, have a strong voice and enjoy their right to live well, as equal and active citizens, free from discrimination, with support and services that put them at the centre.

The ALLIANCE has three core aims. we seek to:

- Ensure people are at the centre, that their voices, expertise and rights drive policy and sit at the heart of design, delivery and improvement of support and services.
- Support transformational change, towards approaches that work with individual and community assets, helping people to stay well, supporting human rights, self management, co-production and independent living.
- Champion and support the third sector as a vital strategic and delivery partner and foster better cross-sector understanding and partnership.

Take a look at an overview of our work in our online leaflet.⁴



ALLIANCE
HEALTH AND SOCIAL CARE
ALLIANCE SCOTLAND
people at the centre

⁴ Take a look at an overview of our work in our online leaflet: <https://www.alliance-scotland.org.uk/blog/resources/alliance-scotland-flyer/>

