

# Diabetes:

## my information, my support



### Summary of key findings

## Introduction

A refreshed Diabetes Improvement Plan<sup>1</sup> 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.

Through an online survey, a series of focus groups and a workshop facilitated by Networking Key Services,<sup>2</sup> 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.

The report from this engagement will contribute to the redesign of diabetes education and support self management services and programmes across Scotland.

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

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

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# Summary of findings

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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.



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# Diagnosis

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There were experiences which were common at the point of diagnosis 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.

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 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.

## 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.

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' and 'leaving many 'in shock'. misdiagnosed with another type of 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, people raised 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, which was attributed to the associated stigma.

Key findings about diagnosis of gestational and other types of diabetes can be found in the main report.

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# Information and support

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Those taking part in the survey were asked to share how helpful they would find different types of information and support, including group sessions, access to online resources, and appointments with health professionals via different methods (telephone, online, or in person). The full list of types of support can be found in the main report. People's responses were analysed according to different types of diabetes they have lived experience of.

## Type 1 diabetes

People with experience of type 1 diabetes rated most of the suggested support 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.

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.

## Type 2 diabetes

People with experience of type 2 diabetes rated most of the support suggested as either helpful or very helpful. 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%).

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'. 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.'

Preferred types and experiences of information and support available to people who have experience of gestational or other types of diabetes can be found in the main report.

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# Barriers

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Across groups of people experiencing type 1, type 2, gestational or other types of diabetes, the most common barriers to accessing diabetes information and 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;
- 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.

## 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.

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.

Finally, across groups, My Diabetes My Way<sup>3</sup> 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.'



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

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# What next?

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In terms of future steps, the ALLIANCE will circulate the full report to members of 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.

The Scottish Government will use this report to shape the development of Once for Scotland Diabetes Education and Supported Self Management Pathways for both type 1 and type 2 diabetes. These pathways will be drafted by two short life working groups that have been established by the Scottish Diabetes Group and the Scottish Government.



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.

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