

The Impact of Ageing on

**Type 1 Diabetes** 

**Breakthrough T1D** 

**Long Report** 

January 2025





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# Project details and acknowledgements

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This project has been delivered to ISO 9001:2015, 20252:2019 and 27001:2013 standards.





































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## **Executive Summary**

### The Impact of Ageing on Type 1 Diabetes

Breakthrough T1D commissioned M.E.L Research to explore the experiences of over-45s in the UK who are living with Type 1 Diabetes. Type 1 Diabetes is a chronic, life limiting autoimmune condition in which the pancreas is unable to produce insulin. This presents many acute medical conditions such as 'hypos,' or diabetic ketoacidosis (DKA), which can result in medical emergencies, as well as long term health complications such as heart disease, stroke, sight loss, nerve damage and kidney failure.

The key aims of this research were to discover:

- Understand current access and attitudes to Type 1 technology and treatments amongst those over the age of 45 as well as attitudes to ageing with Type 1 Diabetes;
- To provide an evidence base to engage and influence NHS and other services for people with
   Type 1 Diabetes; and
- To provide an evidence base for Breakthrough T1D to develop information resources to resolve unmet needs among people over the age of 45 with Type 1 Diabetes.

This qualitative and quantitative research project is grounded in people's lived experience. Specific approaches were adopted in order to hear the voices of people with Type 1 Diabetes and to listen to their views on their experiences and recommendations.

During the course of fieldwork, participants shared how Type 1 Diabetes has affected their life. They spoke openly about the physical and emotional impact, but also their search for information, barriers faced, a lack of awareness by medical professionals and in hospitals, and fears for the future. Moreover, they spoke of fears of losing cognitive ability and the reliance on others for care, especially given the lack of understanding surrounding the condition. The picture they painted was of a condition that can feel relentless, due to the need for constant monitoring and its unpredictability. For example, some spoke of how it's a condition that they can never feel fully in control of. They spoke of how you do the same things for two days in a row and yet your blood sugars can behave in very different ways.



The participants in this research were diagnosed from childhood right through to their 50s and beyond. Some were diagnosed as recently as within the last couple of years, and some had lived with the condition over 50 + years. The participants had mixed outlooks on life, from feeling positive and optimistic for the future to experiencing loneliness and everyday struggles.

Ageing was largely seen as a period which created great apprehension and concern. This can be contextualised within the current crisis in NHS and social care. Participants were extremely concerned that there was not the capacity, training, understanding or relatively basic knowledge of type 1 diabetes to offer care for them. There were also fears around potentially worsening physical side effects, or the impacts of type 1 Diabetes becoming more and more complex alongside other health conditions.

Participants shared their fears about hospital visits, often based on personal experience or stories they'd heard from others. Experiences on hospital wards were relayed of patients having their insulin taken away, having dosages denied and having to find the strength to self-advocate to manage their own insulin requirements. There was evidence of some of this fear being extended to care homes, too. There was wariness around whether or not care home staff would have to understanding and training required to deal with a complex condition, to understand carb counting and insulin ratios etc. For families who were caring for an elderly type 1 parent, this fear meant that care homes were simply not an option for their family.

This is the first generation of people with Type 1 Diabetes who are living healthily into older age, as life expectancy continues to increase. This presents the healthcare system and care sector with a potential crisis: the population is ageing, and from this generation onwards that will include much higher numbers of people living with Type 1 Diabetes. This makes the timing of this research more important than ever. If we are unable to identify and address this growing area of concern soon, a generation of type one diabetics will fail to get the support and care they need as they age.

#### This report examines:

- Experiences of diagnosis
- Where people turn for information and support
- The role and impact of technology in diabetes management
- Hospital visits
- Menopause and women's health



- Getting older and the need for care
- Care homes



## Introduction

### **Background**

In the UK, the prevalence of diabetes (Type 1 and Type 2) continues to increase in the UK with an estimated 5.6 million people living with diabetes. Of this, approximately 8% are Type 1 Diabetics. In England between 2017-18 and 2021-22 prevalence of Type 1 Diabetes went up from 248,240 to 270,935¹ cases. Unlike Type 2 Diabetes, Type 1 Diabetes cannot be reversed and there is currently no prevention or cure. Type 1 Diabetes is a chronic, life limiting autoimmune condition in which the pancreas is unable to produce insulin. This presents many acute medical conditions such as 'hypos,' or diabetic ketoacidosis (DKA), which can result in medical emergencies, as well as chronic health complications. In the long term, people with Type 1 Diabetes are more likely to experience associated medical complications such as heart disease, kidney, cardiovascular problems, retinopathy and sight loss and nerve damage.

In order to minimise the above risks, people with Type 1 Diabetes need to monitor and manage their blood glucose carefully, 24 hours a day. This includes the following strategies:

Management Strategy	Description
Insulin pump therapy	Continuous insulin delivery.
Multiple daily injections	Regular injections of insulin to mimic natural insulin secretion patterns.
Glucose monitoring	This can be continuous glucose monitoring through technology, which can give real-time monitoring of glucose levels, and/or 'finger pricking' to check blood glucose at regular intervals.
Personalised carb counting	Counting carbohydrates consumed and calculating insulin ratios to deliver appropriate insulin dosage.

For these reasons, living with Type 1 Diabetes can be an overwhelming experience and there are high instances of emotional burnout and psychological distress amongst those living with the

<sup>&</sup>lt;sup>1</sup> NHS Digital - National Diabetes Audit 2021-2022



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condition. Recent research cites that people living with Type 1 Diabetes are twice as likely to experience depression than those who don't<sup>2</sup>. In addition, ageing as a Type 1 Diabetic also presents unique challenges as the body changes, as the ability to manage your own Type 1 Diabetes may decline and as other diabetic complications may develop. For example:

- Menopause symptoms, driven by changes in hormones other than insulin, including mood swings and fatigue can impact emotional health, affecting diabetes management.
- Ageing individuals with Type 1 Diabetes may face physical limitations that hinder their ability to manage the condition effectively.
- Cognitive decline is a significant challenge for elderly individuals with Type 1 Diabetes, affecting their ability to adhere to treatment plans, monitor blood sugar levels, and make informed decisions about their health.
- Polypharmacy the use of multiple medications is common among elderly Type 1
   Diabetes patients. Managing multiple medications can lead to medication interactions,
   side effects, and difficulties in adherence to diabetes treatment plans.

There is limited research into Type 1 Diabetes and ageing, despite globally an estimated 70% of people living with Type 1 Diabetes being over the age of 30<sup>3</sup>. Moreover, given advances in information and technology on diabetic management, we now have the first generation of individuals with Type 1 Diabetes in old age. Whilst this is welcomed progress, this poses several issues and challenges regarding the provision of care and support. The crisis in NHS and social care in the UK is well-documented, but within this context, are people with Type 1 Diabetes getting the care they need as they navigate different life stages and are their voices getting heard?

As a leading global charity which strives to find a cure and prevent Type 1 Diabetes, Breakthrough T1D commissioned M.E.L Research to:

 Understand current access and attitudes to Type 1 technology and treatments amongst those over the age of 45 as well as attitudes to ageing with Type 1 Diabetes;

<sup>&</sup>lt;sup>3</sup> Burahmah J, Zheng D, Leslie R. <u>Adult-onset type 1 diabetes: A changing perspective</u>. *European Journal of Internal Medicine*. 2022;104:7-12. doi:10.1016/j.ejim.2022.06.003



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<sup>&</sup>lt;sup>2</sup> Ng SM, Corbett T, Doble E, Brooks A, Kar P. <u>Managing the psychosocial impact of type 1 diabetes in young people</u>. bmj. 2022 Apr 4;377.

- To provide an evidence base to engage and influence NHS and other services for people with Type 1 Diabetes; and
- To provide an evidence base for Breakthrough T1D to develop information resources to resolve unmet needs among people over the age of 45 with Type 1 Diabetes

In order to do this, we spoke directly to people aged over 45 living with Type 1 Diabetes and their carers. This research and report is led by their voices.



## **Results/findings**

## Methodology and participants

This was a quantitative and qualitative, multi-stage research project, comprising of an online survey, online community, focus groups (both remote and in person) and in-depth interviews. We spoke to participants who were over the age of 45 with Type 1 Diabetes (T1D), and to people caring for those within that bracket.

The online survey was distributed via a panel provider, achieving 150 responses, and was also shared within the T1D community, on social media, which led to a combined total number of 364 completed surveys, 16 of which were completed by carers, on behalf of the person they care for. The focus of the survey was on setting the scene: what is life like currently for over 45s with T1D, how do they feel about the management of their T1D and what concerns (if any) do they have about getting older.

When it comes to current management of Type 1 Diabetes, the breakdown for methods of administering insulin was as follows:

Figure 1: How do you currently administer insulin?

Method of administering insulin	% of
	respondents
Division	00.40/
Pump	20.4%
Injections	45%
Smart pen	17%
Hybrid closed loop (HCL)	18%

Base: all survey respondents (364)



Survey respondents were asked to give a general assessment of how they'd rate their diabetes management and confidence in managing it moving forwards, to ensure that voices were heard of people with a range of experiences. Almost 60% would describe themselves as being 'very confident' or 'fairly confident', with 25% registering a level of anxiousness around their diabetes management.

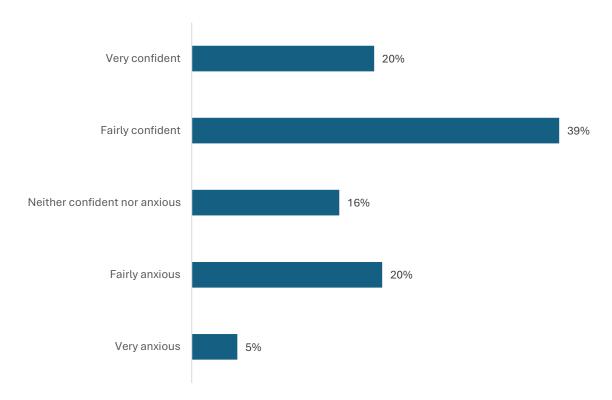


Figure 2: How confident do you feel about managing your diabetes, as you get older?

Base: survey respondents with a diagnosis of T1D (348)

The second stage was conducted as an online community, hosted on the qualitative platform, Recollective. 24 participants, all of whom had put their names forward at the end of the survey as being open to taking part in further research, completed the tasks in this segment. The tasks were released over three consecutive days, with the project set up to take about 15-20 minutes of time per day. Some chose to spend longer than this – up to an hour or more - as they reflected on their answers. Tasks took a range of formats, from creating diagrams of people's support networks, writing in answers to journal-like prompts, and ranking and sorting provided lists to determine priorities and impacts. There were also open discussion threads taking place, and moderators were able to prompt for further explanation on interesting answers in real-time.



The gender split was 5 men and 19 women. Best efforts were made to recruit on a proportionate basis, but these were the respondents who signed up and completed all tasks within the timescales required. Within this group there were participants aged 47 to 71, who shared a wide range of experiences with Type 1 Diabetes. The focus of the online community was to expand on the questions of the survey in a more qualitative way. It allowed time for more reflection and consideration, and for exploration of the 'why' behind some of the quantitative answers of the survey.

In November 2024, seven focus groups took place. Two were face-to-face – one in London and one in Stockport, near Manchester – and five took place remotely. The in-person groups were recruited by an external recruiter, with participants who had not engaged in the earlier stages of the research. Four of the online groups comprised of participants from the online community, who were separated into groups based on shared characteristics or experiences, to allow more focused discussion. These groups included:

- 1. Experiences of menopause and women's health
- 2. Experiences of living with multiple health conditions and hospital visits
- 3. Experiences over the age of 65
- 4. Expressed high anxiety regarding ageing with T1D

The final online group was also recruited from via an external recruitment provider and was made up of adults who were caring for older parents with a diagnosis of Type 1 Diabetes. Individual interviews were arranged for people who could not attend the focus groups or preferred to speak one to one with a researcher. The primary focus of the groups was to ask 'what happens next?' questions. There was some discussion of topics from earlier stages, but the majority of the time centred on the question: 'What needs to change, to improve the lives of over-45s with T1D, and to give them greater confidence in what lies ahead as they get older?'

Participants in the qualitative stages (online community, focus groups and depth interviews) were thanked for their time with a gift voucher.



All of the fieldwork has been analysed to produce a presentation to Breakthrough T1D and their partners, and findings and recommendations have been collated into this report.

#### **Report structure**

The structure of this report follows the journey of the participants who took part. The experiences shared were analysed and split into two journeys that run concurrently. Firstly, is the Type 1 Diabetes Journey itself. Starting at the point of diagnosis and progressing through the appointments, technology and years living with the condition. This will then be overlaid onto the typical Life Journey and the stages of ageing. Exploration of women's health and menopause and then the ageing process, in the context of a diagnosis of Type 1 Diabetes, were discussed at length by participants. Type 1 Diabetes impacts and interlinks with so many elements of a person's overall physical and mental health that it's important to explore how these life stages could be improved for a population who are living longer than ever with Type 1 Diabetes.



## **Diabetes Journey**

The participants across all stages of the research process talked openly about their life with diabetes. The relentlessness of the condition, which requires 24 hour a day monitoring, as well as everyday risks and challenges, take its toll. A frequent point of discussion was 'diabetic burnout'. For participants, this emotional toll is a side to Type 1 Diabetes which is rarely



discussed. For example, during our online community, participants were asked to select any image which illustrates their diabetic journey (see image). The main theme of selected visuals indicates high levels of stress, anxiety and burden. Participants explained the inability to switch off, tiredness of constant monitoring, symptoms of high and blood sugars and the low unpredictability of the control.

Whilst this research explores key touch points in diabetic and life journeys, it is important to note that diabetic burnout is a constant strand of life with type one diabetes. All touch points covered in this report

are complicated and exacerbated by the emotional toll of diabetic burnout.

### **Diagnosis**

The journey with diabetes, for all the participants, begins at diagnosis, or on the immediate lead up to diagnosis. This is a defining period for Type 1 diabetics and can hugely impact their trust and relationship with health providers and their ability to manage their condition. The participants taking part in this research had been diagnosed at ages ranging from young child, through to their fifties and beyond. For the purposes of analysis, they have been sorted into two categories: those diagnosed at the age of 29 and younger, and those diagnosed aged 30 plus.



As a general trend, the impact for these groups was slightly different. Those diagnosed at a younger age – often took the news more factually. This was internalised as a condition they would have for life and they had learned how to administer insulin and monitor it. This diagnosis was also framed through the eyes of childhood and understanding of T1D of the time (in the 60s, 70s, 80s). There were few avenues to talk about this experience and consequently a social attitude of 'just get on with it'. For those diagnosed into adulthood and beyond, who were more settled into their lifestyles and managing lives that involved managing households, partners, children, grandchildren and work, the impact was felt more acutely. Whilst there were some who felt immense relief at having answers to their symptoms and having a clear route forward, many were fearful, shocked, and faced with having to learn an entirely new approach to their life. Of the 364 survey participants, 221 had been diagnosed before they turned 30, and 143 after turning 30. The average age of diagnosis for survey respondents who had a diagnosis themselves was 25, and the average diagnosis age for those whose carers had completed the survey was 44.

For those who were diagnosed as children, their recollections of diagnosis were fairly straightforward and pragmatic. For example, one woman, now in her 60s, was excited at her diagnosis as it meant she matched her brother, who had been diagnosed five years earlier. She also shared that at the point of her brother's diagnosis "We always knew there was going to be a cure in 5 to 10 years. So, when I was diagnosed five years later, well, we were nearly there, surely." She also felt the impact on her daily life was less than for those diagnosed now, "Because we didn't have all the measures or we didn't have anything, so it didn't really matter so much." She described having one injection a day then running off to continue playing.

"It was devastating actually. At first when I was in hospital and they went through everything, I thought, yes, I can do this, this is easy, then the reality kicked in." (diagnosed in early 50s)

For those participants diagnosed post-30, the impact of diagnosis was often shared as being negative, overwhelming and shocking. They described the impact of trying to adjust to huge lifestyle changes and the pressure of understanding insulin ratios, carb counting, blood glucose monitoring, hypo symptoms and treatments, and technology. Moreover, many participants spoke of how the route to diagnosis itself was stressful and had included illnesses, lots of



investigative work, acute Diabetic Ketoacidosis (DKA), hospitalisation and sometimes misdiagnosis. Participants described a physically and emotionally exhausting and confusing time.



## Case Study 1: 'Josephine'

Josephine is diagnosed with celiac disease and had adjusted to a lifestyle and way of eating that supports this.

In her forties, she went on a holiday with a group of friends and new symptoms developed quickly. She ended up in intensive care, with medical staff trying to find out what was wrong.

She left hospital at the end of her holiday with a new diagnosis of Type 1 Diabetes, some insulin, and and the news her life had changed again. She had been aware that having one autoimmune condition can increase likelihood of developing another, but had hoped that it wouldn't happen to her.



One focus group participant, diagnosed two years ago, shared that she had endured a seemingly relentless process of searching to try and find out what was happening to her body:

"After going through loads of different tests and being told all different things and then you finally get told what it is. And I'm still waiting to have the gallbladder out. That's another thing that's come up, so it's like you feel like it's one thing after another."

For another mother, a holiday turned into a hospital stay, as she ended up in a coma four years ago:

"I felt really s\*\*\*, just really unwell. During that night, I became really poorly. [...] Ended up waking up in intensive care in Bangor Hospital Intensive Care where I stayed in intensive care for three nights, then three nights on the normal ward before they discharged me."

She was sent home with a whole new lifestyle and insulin, needing to adapt and understand the diagnosis she'd been given, as well as processing the impact of the hospitalisation itself.

Some participants described processes that in hindsight had shown the signs and symptoms of Type 1 diabetes much earlier than their diagnosis. Concerns were expressed that there remained strong assumptions that only children are diagnosed and that their symptoms as an adult (including DKA), were sometimes overlooked.

"First of all, they thought I had a blood clot on my lung... I felt like I kept going back to the hospital because I felt ill. My eyes kept feeling blurred. I'd sit down and be tired.... [it wasn't until] I had the highest ever measured blood sugar reading at the hospital then I was admitted in... they were triple checking because they couldn't believe it." (diagnosed mid-40s)

For this participant, this experience was the beginning of a difficult relationship with doctors as she questioned their understanding of the condition.



A recurring sentiment that surfaced amongst the group who were diagnosed in their adulthood was one of 'why me?' Each had little prior exposure to and knowledge of Type 1 Diabetes, no family history, and it had not been something they felt was a risk. Consequently, their symptoms and diagnosis had blindsided them.

"Just over the space of a week I lost a huge amount of weight. They called me Mrs. Sticky Mouth because I couldn't talk properly and my mouth was constantly dry. I was constantly drinking coke, constantly peeing and I knew something was really seriously wrong [...] It was a bit difficult at age 38 going through the diagnosis. I got a bit of depression, took me a long while to shake that." (diagnosed in late-30s)

They found comfort in speaking to a group who shared similar experiences, and of a group where most had been diagnosed since COVID, one of the more settled participants shared some hope:

"I've just turned the four years. And you're quite right, it does get easier. I've just engaged with so many people that I found out in type 1 that you don't know. You want to be a sponge in my eyes, absorb everything, because we've all lived different lives, and we all experienced different things. But I still see myself as new. But I can relate to you both, in the last two years, it's mindblowing. And that big question is why, isn't it? Why me?"

Conversely, there were also stories of participants who had had a smoother process to diagnosis in their thirties and beyond. For one, the news he had Type 1 Diabetes was a relief: "Why? Because I thought I had another serious, serious complaint. I could have hugged the specialist." He explained that once he had that news, he could then learn what he needed to and find ways to accommodate his diabetes management into the lifestyle he already enjoyed. Another participant had spent one night consistently visiting the bathroom, and was advised by his wife to get straight to the doctor the next day, where he was lucky to have a GP who himself had Type 1 Diabetes. He found the conversations and support from said doctor to be supportive and insightful, and this had allowed him to embrace the next chapter and learn how to adjust to his new needs.



#### **Information**

Access to information regarding managing T1D and minimising long-term risks is crucial. There were three main avenues through which participants gathered information on Type 1 Diabetes: via medical professionals, via the internet or via peers who also have Type 1 Diabetes. For many, it was a case of using a variety of methods, according to what they need and when. For example,

"I would contact the healthcare team if it was daytime, or if I had the time to actually get on the phone to them. But if not, I would be online looking at the various, sometimes Diabetes UK or NHS."

People also described the difference between needing medical advice versus wanting some emotional support.

The advice of medical professionals was viewed with varying levels of trust or wariness. Some participants sought medical advice throughout their Type 1 Diabetes journey, sharing reports of trusted advisors. Some GPs and diabetic teams were praised for paying so much time and attention to people's care, whilst other participants reported feeling like a number, or as though their appointments were rushed. Experiences with medical professionals are explored further later in this report, but it's important to remark on the differing levels of reliance people put upon this advice. Those who would not automatically seek medical advice cited a number of factors in this decision; some felt medical information was too formal or a step removed, and prefer to hear from people dealing with the same thing; some had had bad or traumatic experiences with medical staff and were reluctant to rebuild trust; and some simply felt their local GP or diabetic teams did not have the time to spend with them to lead to conversations that really matter. Those who had high praise for their experience with medical staff referred to GPs who spent longer than their ten minute appointment speaking to the patient, or to the medical staff who also had Type 1 Diabetes and hence seemed more invested in patient care. One carer spoke of a fantastic ongoing relationship with the community nursing team in her local area, whose guidance and support had enabled her to care for her husband at home, at times where hospital may have been considered the only option.

The internet, or 'Dr Google', as it was referred to by some participants, is the source of a wealth of knowledge. It's available at all hours, has limitless information and is easily searchable. Participants searched for information on management post-diagnosis, technology, day-to-day tips and how to respond to certain symptoms or reactions. Some spoke to the benefits of being



able to search for information when they were up worrying in the middle of the night, and others liked being able to sift through information at times that suited them and in the moment they needed it, instead of making and waiting for appointments.

As with any discussion on the internet, it would be remiss to not discuss the dangers of Dr Google, and searching the web for health advice. There is no regulation on what's being shared, and it relies on people having the knowledge and awareness to be able to filter which sources are reliable and which are not. Some reported turning to specific sites like JDRF (now Breakthrough T1D), Diabetes UK and the NHS, but others were following social media influencers and sites with more holistic, lifestyle intervention advice and medicines. As one person warned, - "You get some maniacs on Twitter, so you'd have to be careful. Some absolute lunatics. They've got insulin pills and stop eating carbohydrates and you'll be fine. Just take the cinnamon. Don't listen to any of them." Someone also pointed out that even if there's some wariness around approaching doctors, it's hard to filter who you're getting advice from on the internet, and doctors are the ones with the medical training: "I think it's like Dr Google. You don't know what information you are getting. So it's all very well saying the doctor's not good enough, or the practice is not good enough, but is going on to Google any better? Are you really going to get sound information?"

The third route, peer support, was accessed by people both in person and online, and the value of speaking to those with shared lived experiences was unmatched. One participant group respondent shared that, "The diabetic nurse specialist I've got now, she's amazing. I'm with a community team. It's completely different. She's amazing, but she doesn't have diabetes. So, she can give me the science, the background behind it. But the way of living an experience of these things, I've always found that peer support is more helpful than healthcare support." Whilst acknowledging the place of factual, medical support, she felt that true understanding was the value in communicating with other people with Type 1 Diabetes.



Some participants attend in person meetings, which allow them both the chance to connect with others with Type 1 Diabetes but also to access some 'pre-filtered' information sources as people are invited in to speak.

"I go to regular monthly diabetic network support meetings and we have a specialist coming in every month to do a talk. So we heard a few months ago these new things that are coming out. So whenever there's new research coming out [...] there's a kidney specialist, there's a foot specialist and then a consultant who says, 'This thing's coming out in the next six months. You can't get it now, but you might be able to get it in six months' time on the NHS'"

There was some acknowledgement in focus groups that the existence of groups like this in the local area are not available to everyone and that this can lead to people feeling isolated or like there's few places to turn. In a face-to-face focus group in Stockport, one woman shared that she'd searched on Diabetes UK and similar websites to try and find in-person groups, and been left feeling flat when there was nothing accessible to her. There were conversations about the fact these groups need to be physically accessible, in the local area, but also that they have to be at a time that works for people's work and family lives. There was also comment that service provision is catered more towards the needs of Type 2 Diabetics.

It is also important to note the importance of the internet as an advice tool for carers. There is little support available to carers for those with Type 1 Diabetes, or carers as a section of the population as a whole, so people spoke of relying on Google searches to top up their knowledge. The focus group of carers was made up of adults caring for their ageing parents, so they had not necessarily been involved at the point of diagnosis or in the learning journey of the individual's diabetes management. Many had found themselves learning on the job at the point their parent could no longer take full control of their own diabetes management, so it was a case of learning as quickly as possible and being able to support and advocate for their care. What they then learn



through these channels is influencing their care of a vulnerable adult, so it's vitally important they are being given the correct skills and resources.

### **Technology**

For those with CGM sensors, this was a vital step in the management of their Type 1 Diabetes. It had given them confidence in staying on top of their numbers, and participants with a hybrid closed loop shared repeated sentiments of 'relief', or of a 'weight being lifted'. Some stated positively that 'everything changed' with tech upgrades in their T1D journey.

"I'm very grateful that we've got the CGM now because years ago it was so difficult. It was all guesswork."



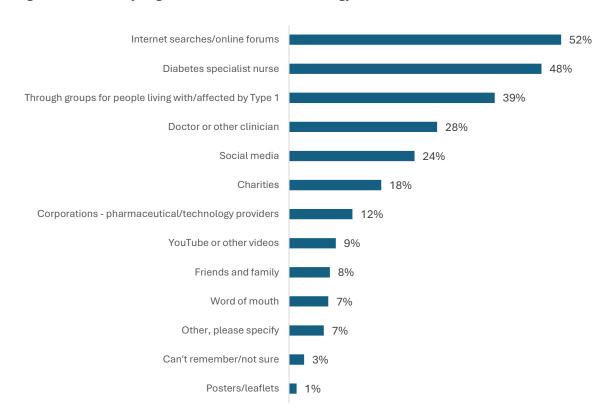


Figure 3: Where do you go for information on technology?

Base: survey respondents with a diagnosis of T1D (348)

When it came to conversations about where people learned about technology options, the internet and online forums (52%) were closely followed by diabetes specialist nurses (48%) and support groups specifically for those with Type 1 Diabetes (39%). When directly asked if technology was a topic in their routine medical appointments related to their diabetes, 52% reported receiving helpful advice, and just under 10% that the information given was not very helpful. Of the 39% who were not having this discussion in said appointments, just under half wished that this was something that time was dedicated to and they felt could be of benefit.



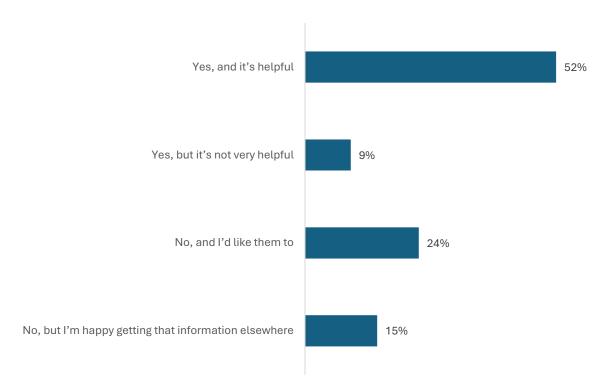


Figure 4: Does your HCP/DSN discuss technology options with you?

Base: survey respondents with a diagnosis of T1D (348)

Some diabetes specialist nurses (DSN) connected to participants in this research were seen as crucial, particularly when it came to practical, tailored advice. They were "brilliant" for these patients. One shared that their DSN keeps them up to date on the new technology, so they know what may be to come in the future, "...but then it'll be, oh, it's years away. So you just kind of tick along with your life as it is." Another had access to a DSN who also has Type 1 Diabetes:

"She told me about the Libre. And then I'm now on the Dexcom. [...] She's been the best influence for me. And also she keeps me up to date. I actually just got an appointment through today. And the clinic just feels it's there. Instead of going to waste of my time with the doctor who hasn't got a clue seriously. It's a waste of time. They're just guessing. So seeing her, I feel I get a personal service and I've also got a phone number. I can ring her. So that's been a game changer for me."

Access to technology came up in many focus group discussions, with participants asking one another for advice, sharing the benefits of their own tech, or advocating for the rights of others having open access to technology to manage their diabetes well. The assumed direct benefit of this for an ageing population will be covered in more detail in a later chapter of this report.



In one focus group, there were some tentative reservations about ongoing monitoring, with some sharing they felt more pressure to constantly monitor their blood glucose numbers. Some described waking and checking over and over in the night and an element of increased anxiety knowing your blood glucose the whole time (especially when out of range). For some, whilst constant access to their blood glucose was useful, it did add to the sense of overwhelm. This was particularly pertinent to people in the early stages of their diagnosis who felt extremely stressed during time out of range.

"You get information overload. And at one point I was constantly checking, even if I felt all right, my alarms hadn't gone off, I was constantly checking. And if I went over 10, I'd be like, oh my God, I'm going high. And it's only through peer support that I've realized that you haven't got to be under 10 all the time. That's impossible."

The dominant theme regarding technology however was positive. Participants were excited to share the impact advances in technology had had on their diabetes management, their day-to-day life and their hopes for the future. This was true regardless of when they were diagnosed and their current life stage.

"It's changed our lives having a CGM, it really has. And the pain has been a big game changer because I thought nothing was happening for years and having diabetes for so long, I just thought it's never going to change nothing. And then all of a sudden they've brought out a lot and there is a lot of change going on."

There were multiple references across the research to people commenting on the improvement in their sleep and sleep quality, as a result of tech management of their diabetes.

"My sleep quality since I've been on Control-IQ has been amazing. I can sleep through the night now, which is a bit of a miracle."



This is just one example of a vitally important area of people's overall health, and an indicator as to overall stress levels. Technology allowing better nights of sleep is a clear indicator of the sense of relief they bring to those who have access. This was often grouped with discussion on making life more like it was before they had Type 1 Diabetes:

"I've gone from being about 65% time in range and now average about 85%, and that is insane for me. I've never had that before. I actually feel as close as you can actually probably feel to being non-type. But it has given me my life back in terms of quality."

The hope of new and improved technology was a source of comfort for many, who had hopes of more stability in their levels and their diabetes management taking over less of their time and attention. One man shared that, "I'm looking forward to the closed loop system. That's an opportunity, I think. I've been on a pump for eight years, which was a real-life changer. [...] I would hate to be without it. And I just wish I had done it many years ago." This sentiment was echoed by others, who similarly wished they'd opened themselves up to new options in technology much sooner than they had, once they'd realised the impact.

"I think I'm more optimistic than when I was first diagnosed. When I was first diagnosed, I thought I wouldn't live past 30, or I would be blind or I'd be missing limbs or I would have severe complications. [...] I think the technology has enabled me to understand and look after myself and be more involved. [...] I'm fairly optimistic, which is weird for me."

The impact of technology for carers was discussed at length, particularly in the focus group of adults who care for their parents. It allows them more control and clearer oversight of their parent's condition, and allows monitoring remotely at times they can't be physically present. One daughter of a parent with Type 1 Diabetes shared that,

"I love the apps. It tells me if I could go in now, what is he on, what will it tell me he's on. So, I get alerts if they're on highs or lows, and if I'm concerned about it, then I could call someone to check in."



Most of those we spoke to were not full time carers, and juggled this role with work and care for other family members and children, so anything that helps with organisation and support was embraced. The hybrid closed loop system has been a source of relief for the carers whose parents have access, and has allowed them to feel things are more under control.

#### **Hospital visits**

"We've all heard a story of someone that wasn't allowed any breakfast because the nurse wasn't there, so she couldn't give him any insulin. So, he couldn't have his breakfast this morning. We've all had so many times and we don't want to be there."

Participants were given multiple opportunities throughout the study to share any thoughts about hospital stays as someone with Type 1 Diabetes, and many shared both personal experiences and anecdotal stories they'd heard of others. Participants expressed their fears and concerns around the potential need for future hospital inpatient stays.

Of 38 survey responses who have recently had an inpatient hospital stay, 26 reported that they did not have access to a Diabetes Specialist Nurse or member of the diabetes team during their stay.



68%

■ Yes ■ No

Figure 5: Did you have access to a DSN or a member of the diabetes team whilst in hospital?

Base: survey respondents who have recently had an inpatient hospital stay (38)

For those without access to diabetes teams, they are left in a stressful environment with incredibly busy staff carrying a lot of weight on their shoulders, and need to try to self-advocate. This is alongside dealing with whatever the reason may be for their actual hospital admittance.

Overall, hospital inpatient stays are regarded as a source of anxiety for many with Type 1 Diabetes. Reasons for this revolved around the potential loss of control of their own diabetes management, fears around lack of understanding of their condition and how it interacts with other illnesses and injuries, and poor past experiences. One topic that was a source of worry for many participants was their ability be able to keep control of their own insulin whilst on a ward.

Participants pointed out that Type 1 Diabetes is a complex condition that requires constant monitoring, and those with a diagnosis have learned to self-manage their condition. As a result of this independence, any situation where the ability to have this control taken away was a source of worry. This was exacerbated when this had happened to them previously or they knew people with this experience. People with Type 1 Diabetes are aware of the importance of their insulin and being able to access it when needed, so the thought of not having access or having to try and justify their need to staff caused concern.



Personal stories of challenges accessing insulin whilst on hospital wards were common amongst the participants. For example, some relayed experiences of having their insulin restricted to a certain number of units of insulin whilst on their ward, of people having their insulin locked away out of their reach, or of staff being unavailable or unwilling to assist with hypos when required. One participant relayed witnessing a patient in another bed on her ward arguing with nurses about the need for more insulin which was locked in a cupboard. She explained:

"And then just before she was eating, she'd go, 'No, I need X amount of units,' and they'd go, 'No, you can only have this unit while you are on this ward.' She wasn't getting the correct insulin, the bloods were going high, and they're going, 'No, you're not having any more insulin."

The person sharing this story ended up stepping in on behalf of this patient, and advised the staff that they'd need to get her insulin before she fell into DKA. One participant shared that he needed to hide his spare insulin pens as staff had asked to lock his insulin in a medical cupboard and restrict his usage.

The lack of understanding from staff was a source of anxiety, not just in terms of access but in different insulin types.

"They wouldn't let me have my pens. They wanted to give me my insulin with the food. I'm on NovoRapid. And they wanted to give me Actrapid. Yeah, they took it all away from me... Didn't have a clue. It was like I was talking to people from another planet."

It was also acknowledged that, whilst the range and accessibility of technology options may be improving, that can add complications when in an inpatient medical setting. In order to properly run care for patients with Type 1 Diabetes, hospital staff are facing a landscape not only of a complex condition, but one where there is a myriad of technology and management options. This presents a large spectrum of information that staff would need to have a level of understanding of to properly support patients that have Type 1 Diabetes, or to plan for situations like general anaesthesia where a patient can't control their own condition. As one participant said, "it's one thing giving an injection of insulin, it's another thing being in charge of someone's pump and knowing how that works as well."



## **Life Journey**

This next section of this reports delves deeper into specific life stages and the interplay with T1D.

The word cloud below was generated based on journal-style responses from participants in the online community, when asked if there were any concerns they had about getting older. The size of the words is proportionate to the amount of times they were used in people's answers. There were physical references, such as hypos, menopause, hormones and insulin, but also words hinting at the mental load participants are experiencing. 'Struggling', 'burden', 'difficult', 'concern' and 'coping' are some examples of this, along with concerns about being able to maintain the level of control they have over their Type 1 Diabetes management.

Figure 4: Concerns around ageing with T1D



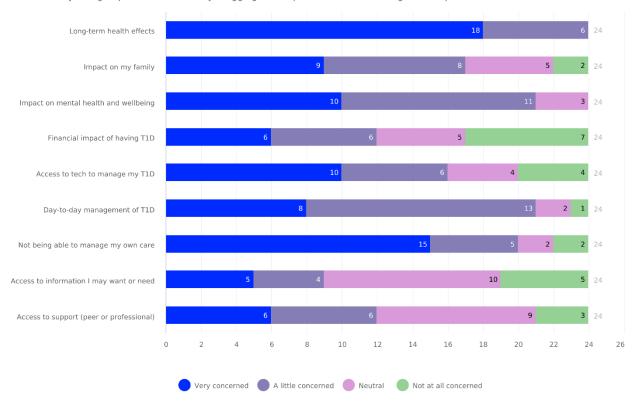
Members of the online community were also offered the opportunity to 'sort' certain aspects of their life with Type 1 Diabetes into brackets defining whether they were things they were concerned about or not. Of the group of 24, 18 labelled 'long-term health effects' as something they were 'very concerned' about. 15 also assigned this label to the potential issue of 'not being able to manage my own care'. 'Impact on mental health and wellbeing' was labelled by 21 as 'very concerning' or 'a little concerning', with the same number ranking some level of concern about 'day-to-day management of their T1D.



Figure 5: Confidence in managing T1D as you get older



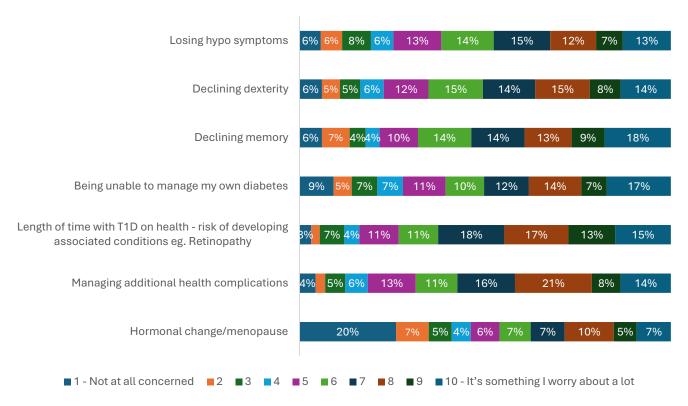
When it comes to your Type 1 Diabetes, please sort the following cards into categories according to the level of concern you feel for these potential impacts. Move a card into a group by clicking the card and selecting the desired group from a list. You can also drag cards directly into groups. Reorder cards by dragging them up and down or selecting "Move Up" / "Move Down" from card's menu.



Participants were then shown a list of options of potential related issues and side effects, and asked to rank on a scale from 1-10 which were causing worry for them, and to what extent. The spread of answers gives an indication of the range of implications on people's emotional and physical state when living with Type 1 Diabetes.



Figure 6: Specific worries about ageing with Type 1 Diabetes



Please note, the 'not applicable' option was removed for clear reading of the chart, but was selected by the 5 male participants regarding the 'hormonal change / menopause' option.



#### Women's health and menopause

Perimenopause and menopause were dominant themes across this research project. This complex life stage impacts upon women's physical and emotional health. In addition, the hormonal changes experienced are further exacerbated and complicated by Type 1 Diabetes which makes the condition more challenging to live with. This led many women to express how they felt completely unprepared and uncertain what to expect and where to turn for help. Participants spoke of the difficulties understanding the perimenopause and menopause and the challenges getting medical diagnosis or support to manage the symptoms. Having T1D complicates this process, and women felt alone in navigating the impact of this life stage on their T1D.



## Case Study 2: 'Anna'

Anna has always found balancing her Type 1 Diabetes and her periods difficult. Periods had always made it more difficult to balance her blood sugars, and she was more prone to hypos at that time.

When she started to notice signs of the onset of menopause, there was some apprehension, as she'd heard from friends that menopause itself could be a difficult period... She hadn't realised her T1D would exacerbate this even more.

Anna found herself having to do her own research online and speak to fellow women to be able to find solutions to manage her Type 1 Diabetes during menopause. She struggled to get proper support from her GP, who told her HRT was too risky.



"There is very little at all out there. It is a desert in terms of information. I'm part of the Menopause mothers WhatsApp group, and we share a lot of information between each other. That's been really helpful, because everyone seems to get batted backwards and forwards between the diabetes team and the GP. And nobody again will take ownership of treating the menopause."

Participants on treatments such as HRT felt this was beneficial in stabilising their blood sugars and diabetic control. However, they experienced difficulties in accessing these. Participants relayed stories of being told by medical professionals that certain medications including HRT were not available for people with Type 1 Diabetes. When a barrier like this was put in place, it was unclear where the open door would be that they could turn to as an alternative treatment, or if there was any treatment available at all.

"And one of the GPs was like 'Look, you can't get HRT.' And I went 'Why?' 'Oh, you can't get this because you're a higher risk of heart disease [because of T1D]"

As a result, women often had to seek out their own information and had joined and shared support groups of others going through the same thing. Many expressed concerns they were not being listened to by medical staff, and felt they'd had to be quite forceful to get their voice heard. They'd had to equip themselves with information before medical appointments, so they had absolute clarity on what they were asking and fighting for. For some, this epitomised their whole journey with Type 1 Diabetes. They had had to self-advocate so many times, that this stage of their life felt like the next battle.



"Nobody's doing the research. [...] I keep saying to them, there's lots on pregnancy, but pregnancy lasts nine months, but a menopause can last 30, maybe 40 years. It's a much bigger chunk of our lives. So, I think there's a really valid point to get loads more information out there."

It is notable that some women compared the views and support received by medical professionals during pregnancy in direct contrast to their experiences of menopause. For example, women felt that there was much greater awareness and understanding of diabetes and gestational diabetes which made them feel supported during pregnancy. Participants shared that they had medical staff on hand who they could direct questions to, they were given more information to help manage their expectations and anxieties and there was knowledge of associated complications and risk during pregnancy. The experience of the menopause was however the complete opposite and thus, left women feeling alone, stressed and unaware of options to manage symptoms and their diabetes. The effects of this were profound in terms of trust in medical professionals as well as exacerbating day to day struggles.

"I am also struggling with perimenopause which is also well known to have an impact on cognitive functionality. Therefore I find it more difficult to manage my diabetes."



#### Older age and retirement

The experience of retired participants was mixed. For many, retirement consisted of active lifestyles and enjoyment of hobbies and travel. For those who had been diagnosed at a young age, there was a feeling of being surprised to have reached this age given what they have been told of the life limiting nature of Type 1 Diabetes over the year. Some participants struggled living alone, which caused concerns around where they could access support in the case of emergency. Many participants shared that they had co-existing health conditions, such as neuropathy, arthritis, deafness, underactive thyroid and hip problems, which were often complicated by their Type 1 Diabetes.

"I don't feel confident managing my T1D now, never mind as I get older. One of my main issues is living on my own and maybe not having the regular care, somebody looking out for me and making sure that I'm doing it properly."

For those retirees who were diagnosed much earlier in life, there was both a joy at life, but also an impending nervousness based on life expectations. One retiree shared:

"When I was diagnosed, I wasn't expected to be alive now [...] And here we are, and strong and fit, I think. So, all good. But then you think, well, where are the complications? They've got to come at some point."

The prospect of 'getting older' was a source of apprehension and nervousness for many participants especially regarding the ability to effectively manage their diabetes as cognitive and physical abilities decline. A key theme was the importance of maintaining autonomy in managing their diabetes for as long as possible. There was a strong sense that no one else could manage their diabetes like they themselves do, which was also compounded by a lack of trust in medical staff or care staff to do this on their behalf. The only hope was technology and the potential of HCL. There was a view that HCL would offer some comfort if people were unable to manage their condition, but that their life would deteriorate if their diabetic care was passed to other individuals.



There were also fears around the physical symptoms themselves, some of which were inevitable fears many people have about ageing; however some were directly linked to living with Type 1 Diabetes for many years. For example, one participant shared that:

"I worry about my feet. Even though I've not got anything wrong with my feet, but then I do worry about it because you hear people have had toes amputated and you hear things."

Some participants had witnessed other type one diabetics experiencing a lot of extra health concerns:

"I've seen some horrendous things, from ulcers to amputations, so that does worry me. It frightens the Jesus out of me, to be honest. Pins and needles, if I get there, I'm thinking, "Is this a progression? Is it this? Is it that?" and your mind races."

Furthermore, participants were concerned about the risks of developing other autoimmune disorders: "What does bother me is that it's quite a high chance of getting another autoimmune disorder. And I know people in our support group have got Parkinson's and things like that."

Together these fears compounded high levels of anxiety relating to ageing amongst this age group. This was then compounded by a lack of assurance that they would be properly cared for if their health deteriorated.

"I feel very concerned about ageing and my diabetes care. I'm constantly checking the lifespan of diabetics. It's not helping my mental health."



#### Care homes and care for the elderly

Needing care and being in a care home is a big source of anxiety. There is a general perception that care home staff lack the necessary training and understanding of Type 1 Diabetes, including the flexibility required for insulin dosing, carb counting and the use of diabetes technology. Participants felt "a lot of the staff in care homes are used to Type 2 but not Type 1." There was a view that insulin was administered in a 'one size fits all' way and lacked any nuance or understanding regarding ratios and variables. Some participants had either worked in care homes or had visited people in care homes and their fears were based on witnessing residents being given incorrect dosages, staff not being available to administer insulin and a lack of support, guidance and sufficient training of staff.

"So yeah, I think there's a lot of learning that would need to be done in social care ... We've all heard a story of someone that wasn't allowed any breakfast because the nurse wasn't there, so she couldn't give him any insulin....We don't want to be there. We don't want to be there."

There was also a lack of confidence that any links with hospital diabetic and endocrine departments, regular external checks regarding time in range or advocates (especially if they had dementia) were facilitated. Consequently, for many, a care home was not an option for them as they believed being admitted would lead to a rapid deterioration in their health.





## Case Study 3: 'Chris and Angela'

Chris was diagnosed with Type 1 Diabetes at the age of 12, and it's therefore been something his wife, Angela, has had insight on since they met in their early twenties. They've lived a full and busy life, raising children, welcoming grandchildren and travelling together.

Now aged 71, Chris is beginning to need more and more support with the day-to-day management of his condition. He prefers to use injection pens, but is finding them harder to hold with precision and sometimes forgets to administer his insulin.

Whilst Angela hopes to support him at home for as long as she can, she is also getting older and aware that in-house carers and potentially a care home may be an option for the future. They're anxious about what this may look like in practice and nervous about the thought of someone else managing Chris' care.

This anxiety was also expressed by adults who care for their parents who wanted to keep care in the family for as long as possible. Their reasons and fears revolved around lack of confidence that care staff would understand the intricacies of their parent's condition and whether they'd have the skill to take care of them properly.



"I just think you hear too many horror stories about people not being cared for well enough. And yeah, I just don't trust it."

The growing crisis in social care in the UK fuels the lack of confidence that things will change in the future. Views that care homes do not have the resources, staff expertise and knowledge to cope now, let alone in with increasing numbers of individuals with T1D was notable. The scale of the work involved to increase confidence and capacity of staff was doubtful. This cemented the perception that maintaining autonomy in managing their own diabetes for as long as possible was imperative. To give up the control would be damaging to their health.



## **Conclusions and recommendations**

This research project had the purpose of delivering some clear recommendations in terms of policy and potential improvements to the care being received by over-45s with Type 1 Diabetes. This report has guided readers through a clear journey of emerging themes, all of which offer opportunity for change.

Participants were given a chance to share what they felt the most important changes and areas of focus were to be, and these thoughts are summarised below.

#### Further education for medical staff

A recurring comment across all stages of the project was the need for more in-depth training for medical staff about Type 1 Diabetes. Whilst there was recognition of the huge pressure already on people in these roles, it can't be denied more knowledge is essential, when it comes to the complexities of Type 1 Diabetes. It requires constant monitoring and the management of the condition has huge consequences, including death, when not done correctly or in a timely fashion.

There were suggestions of mandatory regular updates to training regarding Type 1 Diabetes, with some noting that they feel, "many still follow very old fashioned rules & targets." There were also comments that there seems to be far more understanding of Type 2 Diabetes than Type 1. As a minimum, it was suggested that,

"All should understand about blood glucose ranges & treatment needed if low or high." The desire for this updated training fed into the fact that patients, "want to trust HCPs looking after you in any medical setting."

Within this understanding should come recognition of the importance of those with Type 1 Diabetes being able to continue self-management as far as possible. With hospitalisation, a fear for lots of participants in this research project, confirmation that the staff taking care of them would understand their Type 1 Diabetes would make a huge difference in alleviating some of this fear.



Alongside this, there were many comments about the tone and language used with patients in a medical setting. Participants said that:

"Care needs to be positive and encouraging [with] less ambiguity and more proactive action."

There were comments in the online community urging GPs to "be more approachable, listen to concerns [and] take the patient seriously," and to, "make access to information a part of your treatment / routine."

It all circles back around to feeling informed and confident in the options being provided by medical staff.

#### Access to diabetes champions / specialists in hospitals

To further improve the experience of hospital patients with Type 1 Diabetes, and to help allay some of their fears about the potential need for hospitalisation, a suggestion was the potential instatement of diabetes specialists or champions in all hospitals.

Diabetes specialists would be a member of staff, a healthcare professional, available at all times for when patients are admitted who have Type 1 Diabetes. There could then be immediate consultation with the patient and the team managing their care to make sure there is thorough understanding of their diabetes management in the context of their care. This could help speed up the process of better education in hospitals, as having an available, appointed expert would mean that all medical staff could access this person and information when working with a patient with Type 1 Diabetes.

Diabetes champions differed slightly, in that the vision of participants was that this could be more of a voluntary role, likely taken up by someone who has Type 1 Diabetes themselves. One participant took it upon herself to enact this role at a care home where she worked, and saw the position as an advocacy role. It was about providing support to someone in a vulnerable position, and helping them to communicate and speak up for what they need when under the care of others in a medical setting.

#### Improved access to technology



Access to technology was a key point of progress across all stages of the research, with many sharing the benefits they already receive as a result, and other looking forward to getting or upgrading their own. There were calls for, "full and free choice and access to diabetes management technologies," for all. It was seen as a high priority to equip people with Type 1 Diabetes with the technology that would help their diabetes management and alleviate some of the burden of decision-making about their care.

Whilst there is currently a focus on tech for children and young people, there were calls for this priority to be extended to the elderly. In the words of one participant, "access to technology should be a priority for those living with T1D as they get older to enable continued self-management." It would alleviate the amount of pressure on people assisting with their care, and would provide some peace of mind to people who are concerned about their own memory or skills of dexterity declining. It seems to be viewed as a vitally important step in enabling people to maintain independence for much longer.

# Further research on the interplay between Type 1 Diabetes and other conditions

A regular point of discussion was how complex Type 1 Diabetes can make the management and treatment of other health conditions, as well as the recognition that it can cause or exacerbate symptoms of others. Despite this, there is little research and understanding of these relationships and the interplay between other conditions.

One example was the relationship between different autoimmune conditions, with multiple participants having more than just their diabetes. In the online community, one participant shared there's a need to,

"Examine the way that diabetes over the long term tends to invoke other auto immune diseases with their own problems. I developed coeliac condition after 35 years as diabetic."

Another vital period for research is the impact of perimenopause and menopause, as for those who have experienced it, it has been a time of stress and uncertainty and difficulty managing their diabetes. As discussed in this report, "menopause and menstruation information matters to every female living with diabetes." Further research and, as a result, more thorough support and information, could make a huge change to navigating this stage of women's lives.



Along with this, there were calls for more joined up thinking regarding treatment, both for Type 1 Diabetes and for any related / co-existing conditions.

"We seem to be geared up more for someone to be ill, have an intervention and recover, long term conditions don't seem to fit anywhere. Perhaps we could start with mapping the patient journey as I expect different things started at different times, adding to the overall complexity we have now reached. It can't be easy for anyone at any stage of the process."

There was a running narrative of people having to seek out and fight for information, which all adds to the mental load of living with Type 1 Diabetes. With a clearer process and check-in points, updated to reflect the lifestyles those with Type 1 Diabetes are living now, and reliable information sources, there would be an easier path through the period of diagnosis and beyond.

#### A clear strategy for care homes

The care system for the elderly is one that is facing the need for overhaul, as a result of an ageing population. In addition to these changes, there needs to be consideration of the increased number of people with Type 1 Diabetes who are reaching an older age and a period of life where they may need full time care.

The need for consistent monitoring for those with Type 1 Diabetes means their care is complex and there needs to be a high level of trust and understanding from anyone taking over or assisting in that care. There are calls for thorough training of staff, the potential for some sort of accreditation for T1D expert care homes, and the importance of strong communication.

People with Type 1 Diabetes can be very fearful of the potential of their care being out of their own hands, and the topic can produce emotive responses. One participant shared that,

"We have spent many years relentlessly trying to deal with this cruel condition and deserve help if we need it. [...] these staff need to be available 24 hours a day, 7 days a week, as there are no breaks or holidays away from Type 1."



The focus needs to be on "safe, effective care," and on facilitating patients and residents being able to have a say in their own care for as long as they are able, as, "more often than not the patient with diabetes knows more than the nurse or doctor about their own diabetes and should be listened to."

Along with practical steps being put into place, it is about considering the messages being put out to reassure people getting older with Type 1 Diabetes of changes that are being made. Participants shared strong opinions of fear, and horror stories they'd picked up along the way, and narratives like this can take time to change and help rebuild peoples' trust in the system.

# 'Action plans' for those with Type 1 Diabetes, to help others understand care needs

This suggestion is related to those about hospital and care home settings, but could have a wide impact overall. There was suggestion of those with Type 1 Diabetes creating some kind of action plan for their care. There could be a template, in which important details like medical information, the technology they're using and information on any related conditions could be held. This could be kept updated and be on hand if a situation arose where somebody else needed to take control of their care for any period of time.

There was encouragement that care, whatever the capacity of the patient, be, "led by their wishes and needs", as far as possible. Some emphasised the importance of, at appointments, "people are asked routinely 'what do you want / need?" Some participants had already put their own plans in place in case they were needed, and one of the adults caring for her mother had designed an action plan for her and their support network for if anything happened where more care was needed. Feeling prepared can help to alleviate some fears, as well as meaning things could be put into place faster should the need to hand over care come up unexpectedly.



