



# Covid and beyond:

confronting the  
unequal access to type  
1 diabetes healthcare



# Foreword and executive summary

400,000 people in the UK have type 1 diabetes, caused when the immune system attacks insulin-producing cells in the pancreas. The result is a relentless, challenging and lifelong reliance on injected insulin to stay alive.

This research and report have three aims. Firstly, to find out how people with type 1 in the UK had accessed diabetes healthcare, both prior to and during the pandemic. Secondly, to better understand some of the existing barriers to diabetes healthcare and the consequent impact on people's health and wellbeing. Finally, to be able to provide lived experience insight and create a set of recommendations to support policy makers, clinicians and people with type 1 in co-designing and developing diabetes healthcare as the NHS looks forward beyond the pandemic.

At JDRF we are committed to eradicating type 1 diabetes. Our research has led to new developments in diabetes technology and treatment and is laying the foundations for cures.

We support everyone living with type 1 diabetes, by working with policy makers

to increase availability of medicines and technologies, and by providing information and resources to help people manage their condition.

The scale of our quantitative research involving more than 1,000 people, combined with the scope of our qualitative research with 40 individuals representing groups hardest hit by Covid, has allowed us to contrast varying experiences of the pandemic. Adults living with type 1 diabetes faced a different impact on their healthcare to parents and children reliant on paediatric services.

The research also reveals variations in the experiences of people who have lived with the condition for different lengths of time, as well as contrasts between those affected by type 1 diabetes and those with other conditions.



## Findings

The experiences shared for this report depict an enormous withdrawal of NHS services during the pandemic, leading to starkly unequal access to type 1 diabetes care.

People affected by type 1 diabetes report that this has had a toll on their physical and mental health.

<b>The report reveals:</b>	<b>47%</b>	<b>63%</b>	<b>45%</b>
<b>BENEFIT FROM PRIOR TECH USE</b>	<b>LONG TERM IMPACT</b>	<b>ADULT CARE LACKED ACCESS</b>	<b>CHILD CARE LACKED ACCESS</b>
Those given type 1 diabetes technology choices before the pandemic felt better able to manage their condition during the crisis. But many who were diagnosed over 10 years ago are still using methods of treatment prescribed at diagnosis.	Almost half (47 per cent) of UK adults with type 1 diabetes believe the pandemic is likely to have a long-term impact on their life with the condition. Many report fears for their health due to missed appointments.	Some 63 per cent of adults with type 1 diabetes could not access their normal level of healthcare support relating to their condition. This is significantly higher than people who have other health conditions such as cancer or cardiovascular problems (45 per cent).	Among parents of children with type 1 diabetes, 45 per cent could not access their normal level of healthcare support during the pandemic.

### The report also reveals that:

- There is widespread support for the ongoing use of virtual appointments by telephone and video but the right to attend clinic in person remains of the utmost importance for people living with type 1 diabetes
- Impact upon routine appointments has been uneven. This variability in support includes the experiences of those from communities hardest hit by Covid: lower income households, ethnic minority groups and those living with other health conditions
- The personal experience and individual circumstances of people living with type 1 diabetes is often overlooked by healthcare professionals. Many feel the NHS should integrate and provide greater access to psychological support within standard type 1 diabetes treatment and clinic appointments
- Despite the major disruption to type 1 diabetes healthcare, a majority of adults (58%) felt the NHS had done its best to support them during the pandemic. This reflects an admiration of NHS staff and their efforts throughout the pandemic that we at JDRF share

*“This reflects an admiration of NHS staff and their efforts throughout the pandemic that we at JDRF share.”*



# Recommendations

This report sets out recommendations, rooted in our findings drawn from the lived experiences of our research participants. People with type 1 diabetes would benefit from:

- ✓ Greater provision of wearable type 1 diabetes technology
- ✓ A choice of virtual, telephone and face to face clinics offered to everyone with type 1 diabetes
- ✓ Improved communication from the NHS, which needs to be more proactive when care is disrupted
- ✓ Prioritisation of the long-term complications of diabetes when addressing the NHS backlog
- ✓ Mental health support to be embedded in all diabetes clinics
- ✓ The centring of people with type 1 diabetes at the heart of service design

## Moving forward together

These recommendations point the way for an NHS that can build back an integrated type 1 diabetes service, that optimises quality of care and support, as well as positive outcomes for those living with the condition.

People affected by type 1 diabetes hold expertise. It is forged by lived experience of a condition characterised by substantial self-management. For some this involves the use of technology, platforms and data to optimise treatment and health outcomes. Such expertise is valuable for clinical adaptation as we move beyond Covid.



JDRF is committed to working with its partners in the NHS, government and other stakeholders on the adoption of these recommendations, to help guide the rebuilding of NHS services and support.

*Karen.*

**Karen Addington**  
Chief Executive, JDRF UK





# Methodology

This report summarises qualitative and quantitative research exploring the experiences of people living with type 1 diabetes in the UK during the Covid pandemic.

## QUANTITATIVE RESEARCH

The quantitative stage consisted of an online survey undertaken in February and March 2021 by **1,152 participants**. This included **858 adults** who live with type 1 diabetes and **294 parents or carers** of young people with type 1.

As the exact demographic make-up of individuals with type 1 diabetes in the UK is not known, a natural fallout sampling method was used, which was determined by those who chose to take part in the survey.

A separate online survey with people living with other health conditions such as cancer or cardiovascular problems was conducted with 504 adults in April 2021. Their responses provided a useful comparison for the experiences of people with type 1 diabetes.

## QUALITATIVE RESEARCH

In-depth **telephone interviews** were carried out with **40 individuals** with type 1 diabetes who had taken part in the online survey. This included eight parents of young people with type 1 diabetes.

The focus was on those who were hardest hit by Covid and included (with some overlap) 12 people living in lower income households, 11 from an ethnic minority group, and 19 living with related health conditions such as rheumatoid arthritis or thyroid disorders.

Interviews were carried out in confidence and names have been changed in case studies that appear in this report.

**The research was carried out by nfpSynergy, in February and March 2021, a research consultancy appointed by JDRF.**

The report opens with a snapshot of the status of type 1 diabetes healthcare before the Covid crisis and goes on to look at access to technology, the role of telemedicine, and NHS provision and communication during the pandemic. It also examines why people with type 1 diabetes must be at the heart of service design and delivery going forward.



**Read the full report:**  
[www.jdrf.org.uk/covidandbeyond](http://www.jdrf.org.uk/covidandbeyond)

**1,152**  
participants

**858**  
adults

**294**  
parents  
or carers



# 1. Setting the scene:

## Type 1 diabetes healthcare before Covid

The UK has one of the highest rates of type 1 diabetes in the world, for reasons that are currently unknown. The number of new diagnoses is increasing by about four percent each year, an alarming rate given the devastating impact that it can have on the lives of individuals and their families.

The support that people receive can vary according to different healthcare professionals and teams, along with the ‘postcode lottery’ of different hospital trusts, clinical commissioning groups and local authorities.

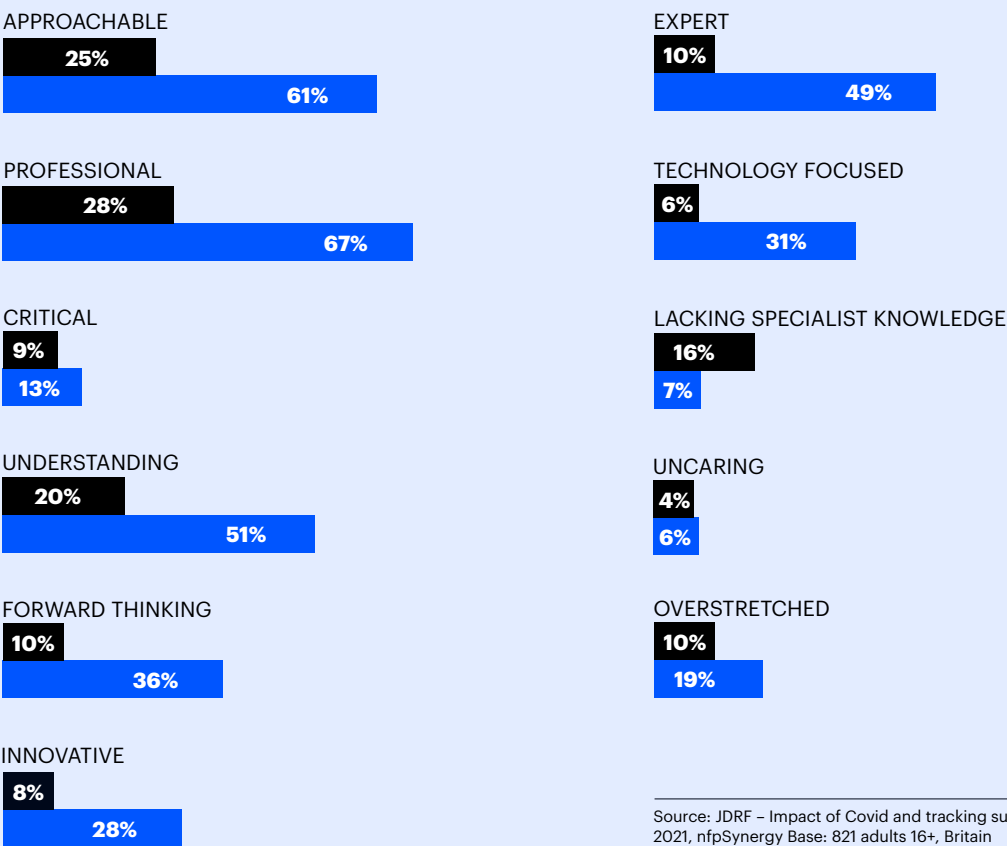
Although the phrase ‘postcode lottery’ is often used to describe the

uneven nature of NHS services, much seems to come down to individual healthcare professionals. During the course of this research, which looked at type 1 diabetes healthcare both before and during the Covid crisis, we heard glowing testimonies about some individuals, but there was clear frustration about others.

### Differences in how people with type 1 describe GPs and specialists

In normal times, how would you describe the GP or specialist when it comes to discussing your diabetes?

■ GP or nurse at surgery ■ Specialist diabetes team, doctor, or nurse



Source: JDRF – Impact of Covid and tracking survey Public and Adults survey 2021, nfpSynergy Base: 821 adults 16+, Britain



Survey respondents reported differing levels of joined-up support from their specialist teams pre-pandemic. For instance, some attend a ‘one stop’ check-up that includes retinal and podiatry tests, all reviewed by the consultant. Others need to go elsewhere for eyes and feet. For some, this is arranged by their specialist team, but others must pursue this support separately, via their GP. Several people expressed frustrations in seeking podiatry help, especially when GPs won’t make referrals. Others talked about the infrequency of eye checks and needing to push for appointments.

*Survey respondents reported differing levels of joined-up support from their specialist teams pre-pandemic.*

Some respondents mentioned how they find themselves needing to explain their type 1 again and again to their GP or practice nurses, or to correct mistaken assumptions: for instance, that type 1 diabetes is the same as type 2 or that it is only a children’s condition. We heard examples of GPs refusing funding for treatments or technology; prescription delays hampering supplies; or GPs who



don't understand the significance of foot pain to a person with type 1.

Parents of children with type 1 diabetes reported regular three-monthly appointments and, compared to adults, they described a more joined-up provision of services, a more supportive and patient-centred approach, and higher access to technology.

Personal satisfaction levels with the support received before Covid varied, but everyone agreed that significant improvements need to be made to overall provision so that more people benefit from best practice and fewer people face barriers.

Wishlist of improvements that people living with type 1 diabetes want to see when it comes to their healthcare, as set out by research participants:

- ★ Technologies being made more freely available with a wider range of up-to-date devices that are easier to access, and a more proactive provision (including reaching out to those who aren't pushing themselves forward)
- ★ Increased provision of structured education for people living with type 1 diabetes, both at diagnosis and then lifelong updates
- ★ Improving specialists' knowledge of technologies so they know what's available and can provide technical support
- ★ Improving specialists' understanding of lived experience so they can provide more responsive support
- ★ The provision of emotional and psychological support, both at diagnosis and for those who need it at later stages
- ★ Improving GP awareness, with type 1 flagged in medical records so that GPs (and other healthcare professionals) are alert to the issue
- ★ Ongoing consultation with people living with type 1 to identify needs and ways to improve support

Some respondents mentioned how they find themselves needing to explain their type 1 again and again to their GP or practice nurses, or to correct mistaken assumptions: for instance, that type 1 diabetes is the same as type 2 or that it is only a children's condition.





# 2. Increased access to type 1 diabetes technology is essential

## Background

Just 28.5 per cent of people living with type 1 diabetes in England and Wales meet their target haemoglobin A1c or HbA1c range (which measures average blood glucose levels over the past two to three months)<sup>1</sup>. In Scotland, this figure is even lower at 26.5 per cent<sup>2</sup>.

Having access to the right technology can be both lifesaving and life changing. Currently, whilst access to flash glucose monitoring is growing, only a small percentage of those living with type 1 diabetes in the UK have access to technologies such as continuous glucose monitoring or insulin pumps.

Levels of access to type 1 diabetes technology are often governed by irregular NHS services, depending on where individuals live. In recent years, National Paediatric Diabetes

Audits have also shown that children and young people from Black, Asian and minority ethnic groups in England and Wales are much less likely to use diabetes technologies<sup>3</sup>. Additionally, our [Pathway to Choice report](#) published in February 2020 found that for adults aged 16 and over, access to technology was lowest among those from the most deprived socio-economic groups.

Taken altogether, this presents a picture of widespread disparity in diabetes healthcare even before Covid hit.

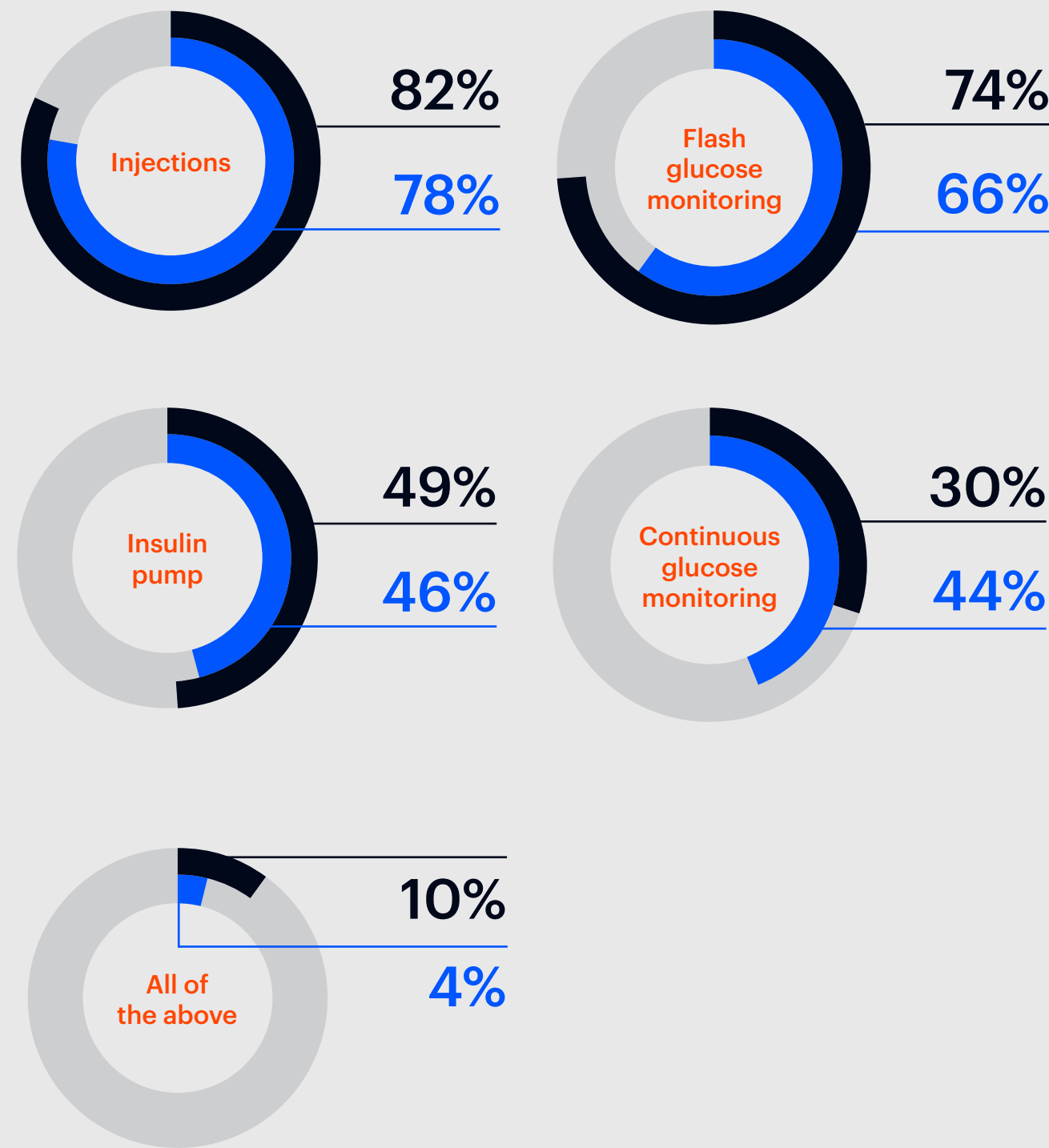


“There’s an element of postcode lottery. I can get this pump but someone an hour down the road can’t get it because their nurse isn’t trained for that pump.”

1 National Diabetes Audit 2019/20, Type 1 Diabetes  
2 Scottish Diabetes Survey 2019  
3 National Paediatric Diabetes Audit 2019/20

# Use of technologies amongst adults with type 1 diabetes

Which of the technologies below do you currently use, or have you used in the past?  
■ Were diagnosed 10 years ago or less ■ Were diagnosed more than 10 years ago



Source: JDRF – Impact of Covid and tracking survey Public and Adults survey 2021, nfpSynergy Base: 858 adults 16+, Britain



# Findings

Whilst insulin injections are still the most common way of managing blood glucose levels, our research showed that people are much happier using insulin pumps. However, these are much less commonly available. Usage remains at around 16 per cent in adults<sup>4</sup> and 38 per cent in children and young people in England and Wales<sup>5</sup>.

The research also found that many people who were diagnosed more than 10 years ago are still using the original method of treatment that was prescribed to them back then.

Diabetes UK, in its 2021 report “Diabetes Can’t Wait”, estimates that the percentage of people with type 1 being prescribed flash glucose monitoring, for example, varied from 16 per cent in some areas to 65 per cent in others, further demonstrating the regional disparity across the UK<sup>6</sup>.

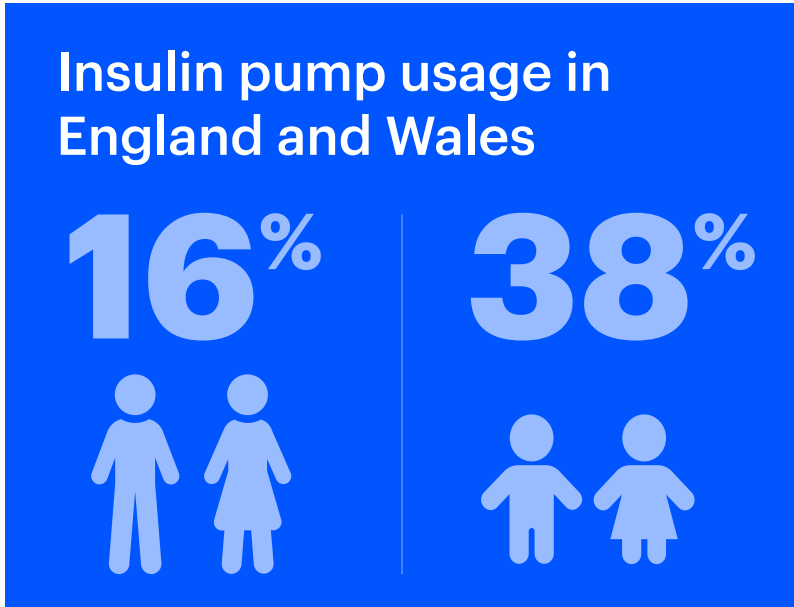
Our JDRF research demonstrates that during the Covid pandemic, there was a significant disruption in support from specialist type 1 diabetes teams – 46 per cent of people with type 1 did not visit their diabetes team and so went without the level of support and communication that they required to manage their condition. As a result, people faced delays in starting a new technology due

to lack of in-person training. The NHS will not usually release the technology until people have completed their training.

As a substitute, some people received technology training virtually often as part of a group rather than one-to-one training. They welcomed the opportunity because it enabled them to access the technology, but they reported that the training felt less clear, less hands-on and less personalised than in-person training.

In many cases, people who were already using monitoring technologies felt better placed to weather the absence of routine NHS blood testing that occurred because of Covid. They felt substantially more confident to manage their diabetes than people who continued to use traditional methods such as insulin injections and finger prick blood glucose checks. As well as being able to monitor their own glucose levels, some were also able to share their data remotely with their diabetes team, making appointments that did then take place more meaningful. Additionally, without so many distractions in their daily life, some found that they had more availability to educate themselves about the technology and improve their self-management. Diabetes UK similarly found that healthcare professionals could deliver higher quality of remote care to people with type 1 that had technology and provide more tailored support<sup>7</sup>.

4 NHS Digital, National Diabetes Audit -National Diabetes Insulin Pump Audit 2018-19  
5 National Paediatric Diabetes Audit 2019/20  
6 Diabetes UK, Diabetes Can’t Wait, (2021)  
7 Ibid



## CASE STUDY:

### Alison and Preetha

Alison is one of the lucky ones. When lockdown first occurred, she already had an insulin pump as well as the glucose monitoring system FreeStyle Libre and had completed an online course about self-management. **“Before I got this amazing FreeStyle Libre thing, I was testing myself between 12 and 20 times a day with finger pricks and now I can just scan my arm,”** she says.

During the Covid crisis, in the absence of NHS support, she felt better equipped to manage her type 1 diabetes. **“It’s not such a problem for me not to have done my blood tests. I have the data to know that there isn’t anything I should be worrying about. There is the technology out there... We’ve got the means to be self-standing and independent. And so when something like this [Covid] happens, we’re already doing it.”**

Contrast that however with Preetha from London who should have attended a DAFNE course for managing her type 1 diabetes last year. This would then have allowed her to access FreeStyle Libre. But the course was postponed due to Covid and she was told by her diabetes team that completing it online was not an option. A year on and she still doesn’t have a new date for the training. In that time, she feels that her health has deteriorated.

## Recommendations

Our findings clearly show that having access to the right technology can help people with type 1 diabetes to self-manage their condition. At a time of immensely increased strain on the NHS, this may have helped to prevent emergencies like severe hypoglycaemic or hyperglycaemic events from arising.

- ✓ All healthcare commissioners should base their type 1 diabetes commissioning policies on NICE guidelines with regards to specialist technology. This will ensure that people who meet the criteria for diabetes technology are offered it. This will also encourage the adoption of best practice around the country
- ✓ The NHS should ensure that all type 1 diabetes clinicians are trained and kept up to date on different type 1 technologies with an emphasis on the empowerment of choice to best support a person with type 1 in deciding on treatment
- ✓ The NHS should ensure that people with type 1 have information and support to make informed choices



### 3. Virtual appointments provide people with different ways to communicate with their healthcare professionals

#### Background

Before Covid, virtual clinics for type 1 diabetes in the UK were few and far between. The pandemic has forced the NHS to transform rapidly and to adopt innovation out of necessity. As a result, people with type 1 diabetes witnessed a considerable increase in remote appointments in 2020. Individual experiences have been very varied.

*“I’ve had a telephone appointment every four months. We’ve talked for half an hour. The consultant asked me about everything. And the DSN (Diabetes Specialist Nurse) has called in between to check ‘how are you?’”*

*“It [the appointment] was incredibly quick. I felt like I was being chucked off the phone, it was so rushed. It was 10 minutes when normally I have 30 minutes. She just asked some basic questions and that was it.”*

Some of the benefits of virtual appointments can include more time spent with clinicians and quicker routine follow-up appointments that don’t involve the expense and hassle of travel, parking or waiting rooms. However, a lack of formal evidence to date on the effectiveness of telemedicine means that we are yet to fully understand possible negative

consequences. These include further inequalities when it comes to access – for example, due to poor internet connectivity or low IT skills – or the risks of complications, eating disorders and mental health issues being harder to identify.

For further information, see our [position statement](#) on this subject.





# Findings

Before Covid, a little over one third of adult research participants had had experience of a telephone consultation. During the pandemic, this rose to nearly two thirds (63%). Similarly, the number of adults undergoing a video consultation more than doubled.

The figure for parents of children with type 1 diabetes having remote appointments is even higher. Almost three quarters had a phone appointment during Covid and more than half a video consultation. This inconsistency between adult and paediatric services for those with type 1 diabetes is a recurring theme across the research.

Interestingly, people with type 1 diabetes used remote ways of connecting with healthcare professionals considerably more than people with other conditions during the crisis and also expressed greater enthusiasm for using them.

The consensus was that video calls felt more personal compared to the more formal nature of telephone appointments and that, for people with access to type 1 diabetes technology, it was easier to share information on blood glucose levels on the screen.



Some people reported that remote appointments felt more business-like than in-person consultations. In part, this is due to specialist teams taking a more light-touch approach to consultations during the crisis, especially in the absence of data. But people also felt that remote interactions lose some of the social cues and informalities that make for more open, flowing conversation.

*“The consultation then just felt very fast, it was over in about 18 minutes. I had a number of issues that I wanted to raise and we seemed to get through those very fast and to be honest in a not terribly satisfactory way for me... I have had great relationships with consultants in the past, but relationships take time to build don’t they. How do you create one in 18 minutes?”*

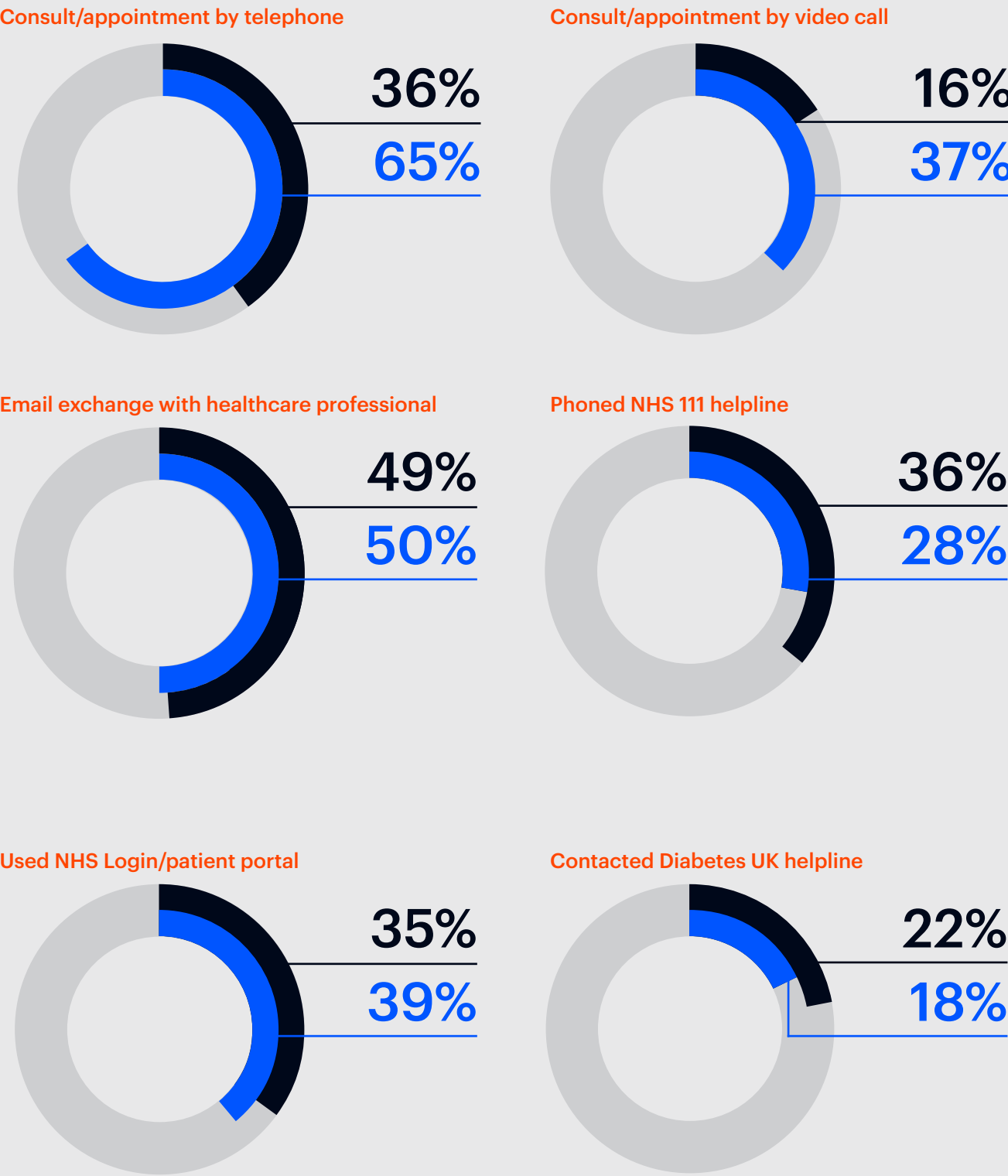
*“I haven’t felt fully confident talking to the specialist. I need to know people before opening up... It’s been less possible to build a relationship over the phone, rather than meeting them.”*

By contrast, in-person meetings allow both patients and healthcare professionals to raise and probe on issues in a more relaxed, exploratory manner. Therefore, at their best, remote appointments are seen to be efficient and suitable for routine catch-ups where there are no serious complications to discuss. At their worst, remote appointments can feel rushed, perfunctory and impersonal, especially when patients want to discuss issues in depth.

# Contact mechanisms used before and during Covid

Which of the following have you ever done during ‘normal times’, before the COVID-19 pandemic started? And which of these have you ever done during the COVID-19 pandemic?

■ Ever done before the COVID-19 pandemic ■ Ever done during the COVID-19 pandemic



Source: JDRF – Impact of Covid and tracking survey Public and Adults survey 2021, nfpSynergy Base: 858 adults 16+, Britain



A blended approach

For the most part, our research participants agreed that remote appointments were a realistic substitute for face-to-face meetings during the pandemic and should continue to be offered as an option in the future. However, the usefulness of the virtual appointments was often reduced by there being no accompanying lab tests, and therefore no data to base the meetings on.

Generally, there was widespread support for ongoing use of both telephone calls and video technology, in combination with in-person appointments. This was especially the case for those who have the hassle and expense of having to travel substantial distances, for example to larger teaching centres, either because of the closure of local services or because they have switched away from smaller trusts in order to access technology.

*“The hospital where I live is on the other side of town and parking is a nightmare... I was therefore really excited when I was told I had a virtual appointment.”*

Some people experiencing mental health problems and some with learning disabilities also reported finding it easier to keep remote appointments, since they feel less demanding and intimidating, with fewer barriers to participation.

In short, nobody wanted a wholesale or compulsory switch to remote appointments. But some envisage a blended approach where, for instance, they might alternate between in-person and remote check-ups, or they might choose which they prefer depending on whether their need is routine or acute.

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CASE STUDY:

Carla

“I had two experiences of telemedicine during the pandemic and I feel grateful for both as I know my diabetes team was pulled into clinical Covid work as well as their normal diabetes-focused work.

My first was my annual appointment which was a telephone call from my consultant. I went to the hospital a week before to have blood taken for my HbA1c. My consultation then happened in a scheduled telephone call, on time, and I probably had as much time as I would normally have had in a face-to-face hospital appointment.

The downside was the technology. A video appointment would have been preferable but my hospital did/does not have the technology available so it had to be a telephone call.

My second appointment was a group pump upgrade. This was done by Zoom video call because the company representative who was leading the meeting had the technology required, as did all the participants except for our diabetes specialist nurse from the hospital who had to join us by phone only. The meeting worked well and the peer interactions were particularly helpful when starting with a new piece of type 1 technology. I find I always learn a lot from the questions that others with type 1 think to ask.”

Recommendations

**Virtual clinics are becoming well-established, but research participants were firm that everyone living with type 1 diabetes should retain the right to attend in person if that is preferable. Further exploration of the viability of a blended approach to appointments is needed, together with more evidence on the effectiveness of telemedicine.**

- ✓ Everyone with type 1 diabetes should be offered a choice of how they attend appointments with their healthcare professional – whether virtually, by telephone, at a face-to-face clinic or a combination of all three. Best practice examples – drawing on the evidence of telemedicine’s benefits and limitations as it emerges – should be shared to encourage the use of virtual clinics among those who would benefit
- ✓ The visibility of shared data between patient and clinician is fundamental to the viability and sustainability of telemedicine. People with type 1 diabetes should be supported with uploading their data. Medical technology companies could help to facilitate this. The use of data registries such as Scotland’s SCI-Diabetes should be established across the UK to enable clinicians to see at a glance their high-risk patients and an overall picture of everyone’s data
- ✓ Data collection should in particular capture the impact of virtual clinics on lower socio-economic groups, ensuring the hardly reached are helped and finding ways to increase their access to clinics and technology



# 4. The NHS needs to get better at communicating during disruptive events

## Background

The physical and psychological toll that the Covid crisis has taken on many people with type 1 diabetes has been considerable. Many research participants reported a deterioration in their mental health, fuelled by increased anxiety and isolation. The heightened stress – together with reduced activity and/or exercise for some due to lockdown restrictions – generally made managing blood glucose levels harder. Some people felt that they didn’t have anywhere to turn when facing acute type 1 issues.

But there are others who feel that their diabetes control has benefited from a calmer lifestyle and, with fewer distractions in their daily life, have been able to give more attention to managing their condition. They have been home-based, not dashing around for work and leisure, and have been sticking to more predictable hours and mealtimes. With fewer demands on their time, some have done more physical exercise than normal.

*“Having lockdown, it gave you more time to concentrate on how you do things. So, a big change is how I manage blood sugars and hypos. Before, I’d just go and raid the kitchen cupboards. But now I stop my pump, take high-glucose tablets, do things in a more measured way. I measure my food more.”*

That said, life did not stand still for everyone. Some people (or their loved ones) continued to go to work; children went to school; people needed to visit the shops or walk the dog. As restrictions continue to ease, people with type 1 fear exposure to other

people’s lax behaviour, such as not wearing masks or social distancing. When interviewed in February 2021, many people expressed trepidation about the so-called return to normal in the coming months. They questioned to what extent they will feel safe in workplaces, shops, leisure venues or healthcare centres and hospitals.

**A rise in anxiety**  
In the early months of the pandemic, conflicting reports about the level of additional risk for people with type 1 diabetes sowed confusion. A lack of clarity about whether the risk was different for type 1 and type 2 diabetes, and the unknown impact of other health conditions all served to exacerbate people’s unease.

*“At first they said there was no greater risk. Then in summer we were hearing it was 25% of all deaths.”*

*“At the start, I was really stressed about the danger. They focused on diabetes in the warnings. I felt pretty vulnerable.”*

This uncertainty raised people’s anxiety levels and made it hard to judge risk. Some were unsure how much to isolate or whether to attend their workplace. Many felt that there was no consistent approach to advice from government or the NHS. Some received a letter telling them to isolate during the first lockdown, but many did not. Some then received a letter in February 2021, which felt late and redundant, but others did not.

*“I was petrified. It all seemed to be that it was diabetics dying... No letter arrived. Friends got one. I still haven’t had one.”*

Asked about their level of worry relating to their type 1 diabetes during the Covid crisis, 53 per cent of adults interviewed gave a score of 8 out of 10 or higher compared with 38 per cent in normal times.

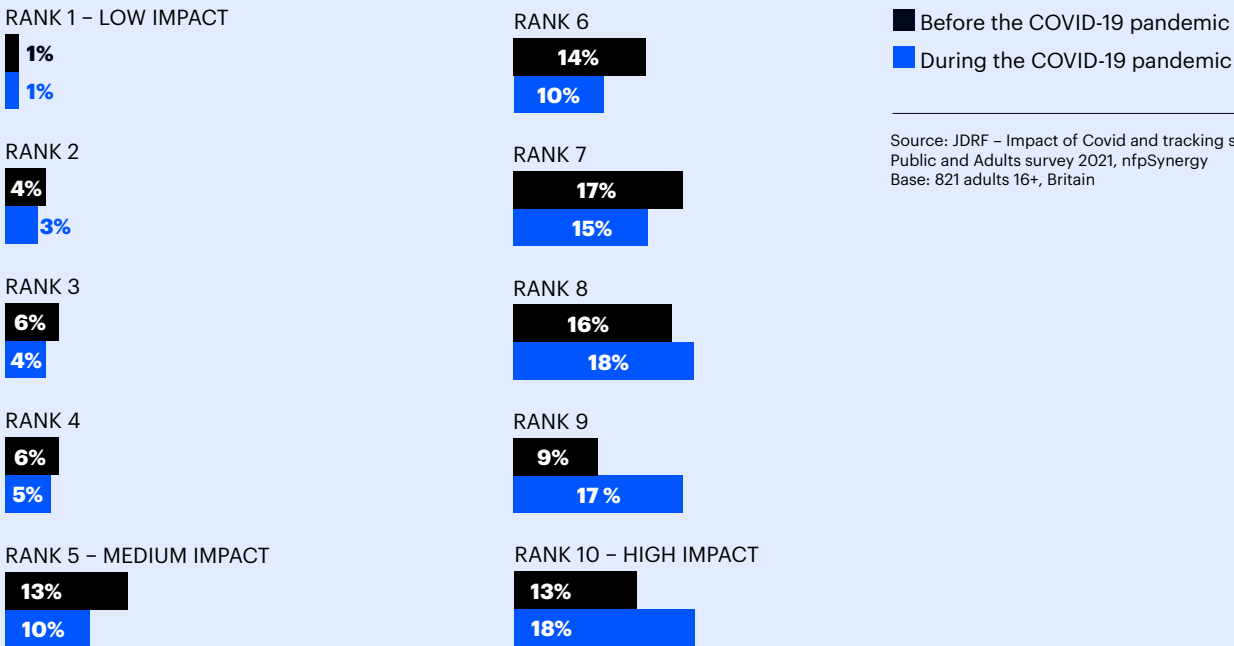
Asked to assess the impact of having type 1 on their mental health during the

Covid crisis, adults with type 1 gave an average score of 7.0 (on a scale of 1 to 10, where 1 was low impact and 10 was high impact). That is, they expressed a heightened sense of impact on their mental health. This compares to an average score of 5.9 for the impact of having type 1 on their mental health during normal times.



### Comparison of impact of type 1 during normal times and Covid

Please rank on a scale of 1 to 10 overall the impact that having type 1 diabetes has had on your life



Source: JDRF – Impact of Covid and tracking survey  
Public and Adults survey 2021, nfpSynergy  
Base: 821 adults 16+, Britain



Findings

All the research participants understood that this was an unprecedented crisis where anxiety and unknowns were inevitable. But they felt that clearer, proactive communication from authoritative sources (even just to acknowledge the unknowns) would have helped to provide context and reassurance in difficult circumstances.

As well as a marked increase in uncertainty, many of the research participants described feeling more exposure to risk. This was driven by the lack of clear information for people with type 1 diabetes, changes in lifestyle, and reduced NHS support, and all contributed to disrupting how they managed their condition during the pandemic.

Although people appreciated the pressures that the NHS was under last year, most adults living with type 1 diabetes reported not receiving the level of support and communication that they needed given the complexity of their condition. Some 63 per cent were unable to access their normal level of healthcare support such as routine check-ups, testing and acute support from their specialist teams. Some felt able to withstand the temporary disruptions because they didn't

experience any serious complications during Covid, but many are concerned that their health may have worsened as a result. For people who have other health conditions such as cancer who were interviewed by way of comparison, this figure was noticeably lower – 45 per cent.

Among young adults with type 1 diabetes, 71 per cent of 25- to 34-year-olds reported being unable to obtain their usual support.

Diabetes UK's 2021 report "Diabetes Can't Wait" similarly highlighted that across England 37.5 per cent fewer people with type 1 diabetes received the eight recommended care processes, including foot and blood pressure checks in 2020 compared to 2019. In North West England, it was 46.7 per cent fewer people compared to 2019<sup>8</sup>.

8 Diabetes UK, Diabetes Can't Wait, (2021)

Statements about NHS during Covid from adults with type 1 diabetes

Please tell us how much you agree or disagree with the following statements about how the COVID-19 (coronavirus) pandemic has had an impact on your life and type 1 treatment

THE NHS HAS DONE ITS BEST TO SUPPORT ME DURING THE COVID-19 (CORONAVIRUS) PANDEMIC



I HAVE NOT BEEN ABLE TO ACCESS THE NORMAL LEVEL OF HEALTHCARE SUPPORT FOR MY TYPE 1 DIABETES



THE PANDEMIC IS LIKELY TO HAVE A LONGER-TERM IMPACT ON MY LIFE WITH TYPE 1 DIABETES



THERE ARE TIMES WHEN I HAVE FELT UNSUPPORTED WITH MY TYPE 1 DIABETES



I'VE HELD BACK FROM CONTACTING THE NHS ABOUT MY TYPE 1 DIABETES EVEN THOUGH I NEEDED SUPPORT



Source: JDRF – Impact of Covid and tracking survey Public and Adults survey 2021, nfpSynergy Base: 821 adults 16+, Britain

Varying levels of contact

Whilst virtual clinics provided many positive experiences and opportunity for contact with healthcare teams, the quality of communication from the NHS was variable and resulted in many instances in emotional distress around, for example, advice on whether to shield or not.

Fewer people obtained information on type 1 diabetes from specialist healthcare professionals during Covid compared to normal times. For example, 53 per cent would look to a specialist diabetes nurse before Covid; during the pandemic this fell to 43 per cent. Instead, there was a modest rise in charities, support groups and social media being used as a key source of information.

It should be noted that 58 per cent of adults with type 1 diabetes felt that the NHS had done its best to support them during Covid and there were examples of good practice

where healthcare professionals had proactively checked on people's wellbeing. Some specialist teams also found alternative ways to provide testing, such as through using home test kits.

However, some respondents said that they did not receive any contact from the NHS regarding their diabetes throughout 2020. Some reported that their diabetes team made no proactive contact with them and did not respond to their emails or phone calls. As such, these people felt left behind by their healthcare teams, with no emotional support or information to help manage their condition.

"Before Covid, I felt I had support, they were really helpful... But now I feel like I'm dealing with it on my own. I've had no appointments. No one's checked up on me. Just to give you a call, to see how you are. But I've had no letter, nothing... I feel like I've been abandoned. I had one appointment booked, but it was cancelled. Then another one, and it was cancelled. I had one telephone call in September. But I don't feel that it helped me. It just felt like they were updating their records."

"I know we need to cut the NHS some slack. But what are the diabetics teams doing?... We just haven't heard anything. Why the silence, and why the delay... I felt alone, forgotten."

"There's been total radio silence for a year. I emailed, left a message, but nothing. I don't know if they even still exist."

Quotes taken in Feb/March 2021



Uneven support

The picture for routine appointments for type 1 diabetes is uneven across the UK but many people reported delays or cancellations on an unprecedented scale.

Some individuals had no appointments with their diabetes team for more than a year. Others managed to have at least one appointment, or else they had an appointment scheduled for the near future.

This variability in support experienced by people affected by type 1 diabetes includes those surveyed from communities hardest hit by Covid: lower income households, ethnic minority groups and those living with other health conditions.

The research found a similar situation for people needing acute support where some people were able to get in touch with their teams by email and phone to discuss issues that arose, while others tried to make contact but received no reply.

Compared to people with other health conditions, the research found that there were lower levels of in-person access to healthcare specialists among people with type 1 diabetes during Covid: 46 per cent of people with type 1 did not visit their specialist as opposed to 27 per cent of people with other conditions.

Half of adults with type 1 say that there have been times during the crisis when they have felt unsupported with their diabetes, but only one-third of adults with other health conditions felt unsupported.

Similarly, two-fifths of adults with type 1 held back from contacting the NHS even though they needed assistance, compared to one-third of people with other conditions.

Support also varied depending on where people lived. In Yorkshire, just 45 per cent of adults with type 1 diabetes surveyed felt that the NHS had done its best to support them during the Covid crisis compared to 71 per cent in London.

In the East Midlands, North West England and Scotland, a higher percentage of adults were unable to access their normal level of diabetes support compared with people living in London, South West England and South East England.

As already noted elsewhere, some significant differences between the provision of paediatric and adult services also became clear during the pandemic. Only 32 per cent of parents of children with type 1 diabetes felt unsupported at times compared with 50 per cent of adults. And 45 per cent felt unable to access the normal level of healthcare for their child compared with 63 per cent of adults.

“I’ve had all my appointments on schedule. One at the clinic, two by phone.”

“I’ve needed to chase them. I got the appointments because I’ve been on their case. I felt they were neglecting me.”

“It’s difficult to say what could have been done better. It was the first time for everyone. But there should have been some kind of communication going on. Re-disseminating information like numbers to ring. Provide some reassurance that the system is still running.”



Quotes taken in Feb/March 2021



Disruption to routine healthcare

Many people with type 1 did not receive routine tests during the past year. This has been a source of concern for some, especially as more time has passed. As highlighted in the section on virtual appointments, the value of the appointments that did take place was often undermined as the consultations were not rooted in lab test data.

When interviewed, people sounded increasingly anxious to resume tests. Some have detected a slow return to normal with appointments and tests being arranged, while others still haven't heard anything. Many expressed a 'fingers crossed' hope that a year without tests has not been harmful, but there is common agreement that further delay is unacceptable.

It is worth noting that a lot of people held back from chasing tests, partly because they didn't want to bother the NHS at a time of crisis, and partly because they were not keen to visit a hospital or healthcare centre during Covid. Just over a quarter shielded throughout the crisis, and 39% for part of it, so were being cautious about exposing themselves to potential risk. But for some, not attending hospital for routine checks had repercussions in terms of emergencies such as hypo- or hyperglycaemic events which GPs did not always have the specialist knowledge to deal with.

Although reluctant to criticise the NHS given the enormous pressure that it is under during Covid, many research participants questioned why the withdrawal of support was so absolute, why communication was poor and why so many services were still not up and running a year later. The stress of living with and managing type 1 diabetes can be considerable even in normal times; for many, the pandemic clearly served to exacerbate this and the lack of communication only added to their distress. In reality, it is likely that a lot of specialist diabetes staff were redeployed but this information was not passed on to patients.

*They did not expect a full service but had anticipated greater continuity of routine care.*

Many people spoke about the withdrawal of NHS services in terms of neglect, abandonment, anger, fear, uncertainty and anxiety. They feel that it was reasonable



to expect a better level of support, especially after the first Covid wave. They did not expect a full service but had anticipated greater continuity of routine care. Certainly, there should have been more communication about services, even if only to put the delays and disruptions into some context.

“There’s been a lack of communication when it comes to the routine tests. I’m really understanding of the pressures on the NHS, but I think that after 12 months we need some kind of plan. Consultants should say: ‘Go to this hospital if you want this.’ They should be more transparent in telling us.”

“I haven’t had my bloods done for a year. I think that things are probably fine, but who knows? My thyroid might be out of whack.”

“A letter just came out of the blue. My kidney test is now next month [March 2021]. I haven’t had anything since February 2019. God knows what’s going on.”



The long-term impact of cancelled services

Beyond the short-term impact of cancelled services and appointments, research participants expressed concern about the potential long-term impact. They fear that, in the absence of tests, their health may have worsened without them realising it, and opportunities might have been missed to identify and tackle these problems early. For instance, several people expressed fears about the possible harm to their feet or eyes.

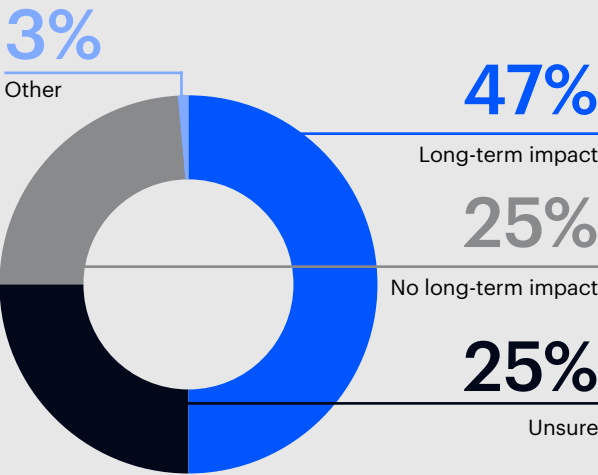
Several people spoke to their GP about foot pain since they were unable to contact a specialist. In each case, the GP was unaware why feet were a particular concern for people with type 1 and, from the patient’s perspective, did not take the issue seriously (for instance, did not refer the patient to a podiatrist).

The lack of in-person appointments during Covid – and in particular those focused on type 1 diabetes complications like kidney screenings, retinopathy and podiatry – is likely to have a long-term impact on the NHS in terms of resource allocation and service provision. Some research interviewees even opted to pay for retinal screening rather than wait any longer to be referred.

“It’s two years since my son’s last retinal test. There’s no reason it hasn’t started up again. It’s important, especially if you’ve been type 1 for many years.”



Pandemic’s likely impact on life with type 1



Almost half (47 per cent) of adults felt that the Covid pandemic is likely to have a long-term impact on their life with type 1 diabetes. Only 25 per cent disagreed that the pandemic is likely to have an impact. The other 25 per cent were unsure. In comparison, just 27 per cent of people with other health conditions felt that the Covid pandemic is likely to have a long-term impact on their condition.

Checklist of the things that people expected from the NHS during the Covid crisis:

- ☆ Provide timely, authoritative information on the risk to people with type 1 diabetes (including acknowledging the unknowns), and on the measures that people can take to stay safe and healthy
- ☆ Make proactive contact with patients to provide information and reassurance; and to identify needs and prioritise support. Crucially, communicate services are continuing, even if there are delays and adjustments
- ☆ Seek to maintain a routine programme of consultations and training. Offer a choice of telephone/video or, where possible, in-person appointments
- ☆ Maintain a programme of routine testing, either at people’s usual location or provide alternatives, for example GP surgeries, home visits/kits. Encourage channels for people with access to technology to share their data





## CASE STUDY:

### Grant

Grant has type 1 diabetes and suffers from a serious back problem so largely uses a wheelchair. Both he and his carer have been shielding in Yorkshire during the Covid crisis, meaning that he has not been able to exercise outside and had less help with personal care and around the house.

“This year has been the hardest. I haven’t done any walking so I’ve put on even more weight. I’ve spent the year in pyjamas, not going out, not doing anything,” he says.

“It’s 18 months since I last saw the [diabetes] specialist. I’d have liked a phone call to check in. It seems reasonable to expect that. I feel a bit like ‘why haven’t I been seen?’ But then there must be hundreds of thousands of people expecting the same thing.”

The past year has been made more difficult still because of pain in his feet. Early in the pandemic, he tried to get an appointment with his GP but was told that his symptoms did not sound serious enough.

“They should know that feet are a risk with diabetics. I’m so angry. Don’t get me started. I know I won’t get an appointment unless it’s something urgent. I’ve just lived with it for 12 months.”

## Recommendations

The long-term consequences of out-of-target blood glucose levels and the potential impact, with opportunities missed to identify and tackle problems early, give cause for concern. As do the disparities between the provision of regional NHS diabetes services and between paediatric and adult services.

- ✓ Screening for long-term complications of diabetes – such as complications related to foot, heart, eye and kidney health – must be prioritised when addressing the NHS backlog
- ✓ The NHS needs to improve communication with patients, being more proactive when care is disrupted and offering alternative solutions
- ✓ A clear system of oversight and accountability must be put in place, carrying out a regular audit of services across the country to ensure consistency of care across nations and regions of the UK. This will ensure that every person with type 1 diabetes is able to access equal services and support, along with addressing wider health inequalities. This should also empower adult diabetes services to be as strong as paediatric care. The use of data registries, as mentioned previously, could help with national, as well as regional, level audits

“It’s 18 months since I last saw the [diabetes] specialist. I’d have liked a phone call to check in. It seems reasonable to expect that. I feel a bit like ‘why haven’t I been seen?’ But then there must be hundreds of thousands of people expecting the same thing.”





# 5. People with type 1 diabetes must be at the heart of service design and delivery

## Background

The goal of any healthcare system should be to provide tailored, person-centred treatment so that people feel empowered to manage their health in ways that are most suitable to their lifestyle. Such an approach would also help to address health inequalities and the issue of depersonalised care. More personalised care is a key goal of the NHS Long Term Plan.

Whilst type 1 diabetes is a condition that is determined by self-management, lived experience is not always given the weight or value it deserves. In addition to being knowledgeable about the clinical nature of type 1 diabetes, healthcare professionals need to understand the emotional impact and realities that people living with it undergo.

People with type 1 diabetes should be considered as partners rather than as participants and have

greater influence in developing and evaluating treatments as well as in defining the value of such treatments and technologies. It is essential that healthcare professionals listen to their voice when it comes to translating lived experience of the condition into improved support and services.

**“The nurse has a diploma but no lived experience, no in-depth knowledge. She assumes that it’s all about sugar, that it’s simple equations.”**

*In addition to being knowledgeable about the clinical nature of type 1 diabetes, healthcare professionals need to understand the emotional impact and realities that people living with it undergo.*





# Findings

The research shows that 50 per cent of adults with type 1 diabetes surveyed have had experience of mental health problems; many talked about the psychological cost of living with the condition. Even before the pandemic, many felt the need for emotional support, but few had received formal support. The National Paediatric Diabetes Audit (2019/2020) found that 44 per cent of children and young people with type 1 diabetes require additional psychological support beyond their usual care team.<sup>9</sup>

Some feel that their diabetes specialists provide an element of empathy and pastoral care. Others would like more opportunity to discuss their feelings and to develop strategies to manage their mental health (which can impact on the ability to manage blood glucose levels).

**“I’d like some emotional support. There’s no chance to talk about this with the consultant or the nurse. It’s just a physical check.”**

**“Have more availability of mental health support. Living with a chronic illness takes a toll on you, there’s no doubt about it, and all the research shows that people living with type 1 are three times as likely to suffer from depression.”**

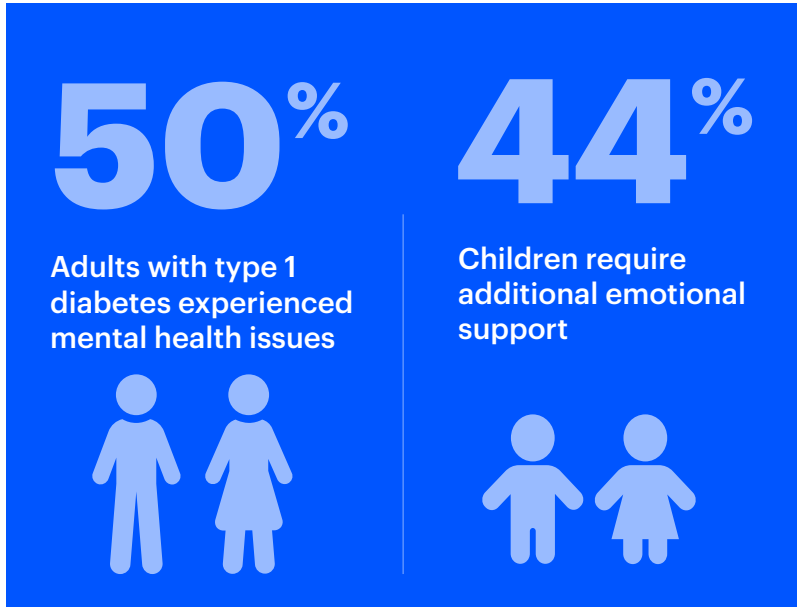
Improving specialists’ understanding of lived experience so that they can

prioritise emotional wellbeing and provide more responsive support is paramount.

During the pandemic, many of the research participants – whether newly diagnosed or people who have lived with type 1 diabetes for a while – looked to community networks and online forums for support. The rich pool of knowledge contained within such groups is a resource that the NHS could draw on in the future.

Some felt that their own practical knowledge of specialist technology surpassed that of their care teams. This reinforces the point made earlier about the need for a collaborative approach where patients are treated as partners and specialists can listen and learn from them.

*“Have more availability of mental health support. Living with a chronic illness takes a toll on you, there’s no doubt about it, and all the research shows that people living with type 1 are three times as likely to suffer from depression.”*



## CASE STUDY:

### Tom

Tom, who lives in Scotland, has experienced both sides of the coin when it comes to type 1 diabetes care.

Of his previous team, whom he felt empowered him, he says: **“We were invited twice a year to an update session. We would choose the topics; they would assemble some experts. Topics like exercise, changes in the curriculum. New ways of doing things, like pump trials. Updates on dosages, carb calculations... You had a say in the education you were getting.”**

However, he is extremely critical of his current team and dismisses his six-monthly review as a ‘tick-box exercise’ that doesn’t properly address his needs or the realities of his life. He is particularly frustrated that the team seem satisfied with his blood glucose levels even though he has recurrent hypoglycaemic episodes.

**“Not finding out what the patient needs. Just telling you what you are or aren’t entitled to. I feel that I’m being talked at. That’s the power dynamic – they must be right. But I come away without an answer. They haven’t helped me. What am I actually getting out of my review? Except getting threatened that my pump will be taken away.”**

## Recommendations

**The psychological impact of living with type 1 diabetes is often unmet by healthcare teams unable to focus more widely beyond blood glucose levels and other clinical examples of managing the condition. Putting people with type 1 diabetes front and centre of service design and delivery would start to redress the balance.**

- ✓ Support for emotional wellbeing for people with type 1 diabetes is needed - mental health support should be embedded in all diabetes clinics
- ✓ People affected by type 1 diabetes (including those hardly reached by traditional services) should be involved in the research and co-design of services to ensure that evidence-based medicine delivers on the health outcomes that are important to them
- ✓ The impact and evaluation of services should also focus on the priority health outcomes that people with type 1 define as most important

<sup>9</sup> National Paediatric Diabetes Audit 2019/20



## 6. Summary and next steps

“It’s [type 1 diabetes] always on your mind, it’s always part of you. You can never relax. There’s always a calculation, whatever you’re doing. Your day is full of numbers. Every couple of days there’ll be something different that gets thrown up. It might be the weather or stress.”

Living with type 1 diabetes can be stressful. Never more so than during a pandemic with the ensuing upheaval in NHS services, the swirl of conflicting information, the increased anxiety and the reduced opportunities to manage lifestyle choices.

What our research has clearly shown is that those people who already had the type 1 technology to help them to self-manage their diabetes were better equipped to cope with the disruption to healthcare services.

Making a wider range of devices easier to access throughout the UK would be of immense benefit not only in the short term but also in the event of a similar crisis in the future. Valuable NHS resources would be saved and the risk of long-term health complications mitigated.

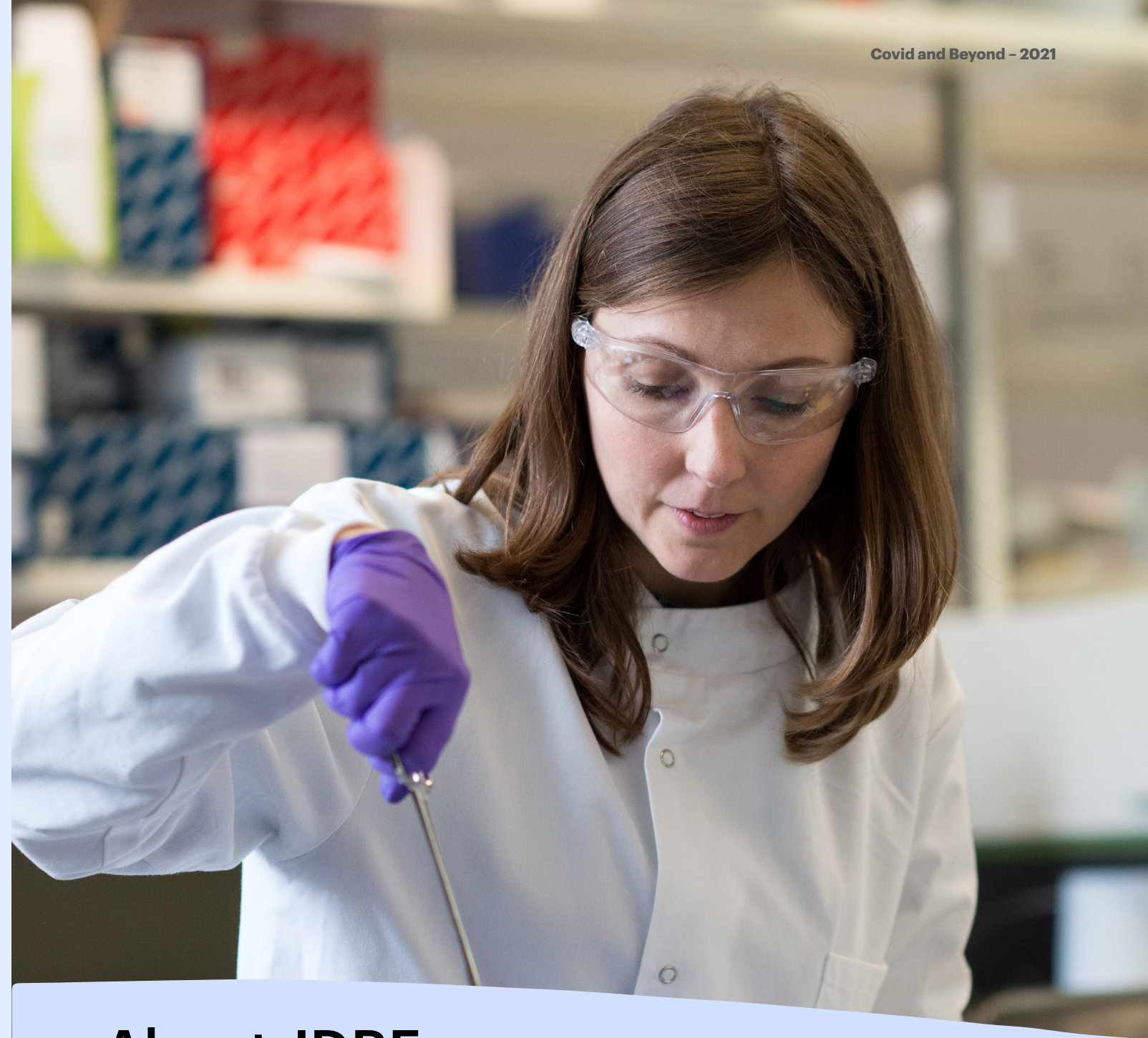
The research has also reinforced what we already knew regarding unequal access to healthcare support for people with type 1 diabetes, and highlighted a potential new divide in the event of virtual clinics being more widely adopted.

The level of treatment received by someone living with type 1 diabetes is affected by where they live, their socio-economic status, their ethnicity, and whether they are an adult or a child with type 1. To that list can be added anyone with poor internet connectivity or low IT skills, now at risk of being left behind by the recent transformation in telemedicine.

Listening to individuals’ accounts of living with the condition, and then working with them as active partners rather than as passive participants, is crucial to closing such gaps. Two-way communication between patients and healthcare professionals is key and should not stop altogether during a national health emergency. To do so only serves to fuel stress, fear and mistrust, which in turn makes managing type 1 diabetes all the harder.

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JDRF looks forward to meeting key government, parliamentarians, NHS policy makers, clinicians and other stakeholders, to discuss the recommendations contained in this report and to explore ways of implementation by involving the lived experience of people with type 1 diabetes.



## About JDRF

At JDRF we are committed to eradicating type 1 diabetes. JDRF research has led to new developments in diabetes technology and treatment and is laying the foundations for a cure.

We support everyone living with type 1 diabetes, by working with policy makers to increase availability of treatments and by providing information and resources to help people manage their condition. We:

- ✓ Drive research to cure, treat and prevent type 1
- ✓ Accelerate access to type 1 treatment technologies and medicines
- ✓ Provide information and support to people living with type 1

[jdrf.org.uk/about-us/](https://jdrf.org.uk/about-us/)



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