

Written evidence submitted by JDRF

Summary

JDRF is the world's leading type 1 diabetes research charity. It funds research to cure, treat and prevent type 1 diabetes.

This evidence submission is based upon market research of over 800 adults and parents or guardians of people with type 1 diabetes, including 40 in-depth qualitative testimonials. JDRF sought to understand the impact of the Covid pandemic on people affected by type 1 diabetes and assess the level of reduction in routine diabetes care. This research was compiled into a report, 'Covid and Beyond: Confronting the unequal access to type 1 diabetes healthcare', published in October 2021.¹

The report sets out several findings relating to the differences between those who were able to 'weather the storm' of Covid more easily and those who could not, thereby demonstrating significant health inequity from the pandemic that must be remedied. For example there were disparities in access to routine care and forms of virtual appointments; paediatric services were typically less disrupted than adult care; and those with access to wearable type 1 diabetes technology felt more able to independently manage their condition than those without, highlighting the vast benefit that technology can provide for future NHS sustainability.

This research has led us to a number of recommendations for the government in supporting the NHS to build back stronger in its ability to support people with type 1 diabetes throughout periods of disruption and centre the voice of lived experience within NHS structures. The recommendations are:

1. Increased access to type 1 diabetes technology is essential
2. A choice of virtual, telephone and face to face appointments to provide people with type 1 diabetes different ways to communicate with their healthcare professionals
3. Improved communication from the NHS, which needs to be more proactive when care is disrupted
4. People with type 1 diabetes must be at the heart of service design and delivery

¹ JDRF, [Covid and Beyond: Confronting the unequal access to type 1 diabetes healthcare](#), 2021

Key issues to consider

Invest in technology to support NHS sustainability

Type 1 diabetes is defined by self-management, with the person with the condition responsible for around 99% of its treatment. This means that wearable medical technology can be a lifeline, as it relieves much of the burden of daily-decision making and complex management of carbohydrate counting, insulin delivery and blood glucose measuring. In England and Wales currently only approximately 10% of adults with type 1 use an insulin pump, despite the use of one making someone more likely to achieve their recommended blood glucose levels.²

It is key that people with type 1 achieve their recommended blood glucose levels, as high or low levels can result in both short and long term health consequences. Immediate symptoms can include nausea and drowsiness, light-headedness and blurred vision. But if severe high or low blood glucose levels are not remedied, this can lead to coma or even death. As such this can necessitate ambulance or emergency hospital issues, creating further burden on already strained NHS services.

In the longer term, frequent high or low blood glucose levels can lead to complications for a person's eyesight, kidneys, heart and feet. This can lead to eventual blindness, kidney problems, cardiovascular issues and even amputations. These long term health problems further place pressure on the NHS, with the person affected by these health issues requiring lifelong support to assist them, creating more financial pressure on the NHS that could have been averted.

As such, JDRF recommends that the government empowers the NHS to invest in technology based solutions for type 1 diabetes management. Immediate upfront cost of technology when assessed through NICE is often more expensive than the existing forms of treatment such as insulin pens and blood glucose test sticks. In the future to support the longer-term sustainability of the NHS, more weight must be given to treatments that accrue long-term savings and demonstrate cost effectiveness through reduction in complications.

The future of virtual appointments

Telemedicine was essential throughout the pandemic in providing people a safer means to communicate with their healthcare teams, through phone or video calls. In addition to supporting shielding and social distancing measures, there were a number of benefits that could be applied for people in 'normal' times also. For example, a video call allowed the person with type 1 and their clinician to share data recorded by medical technology such as flash or continuous glucose monitors on the screen for discussion, therefore making appointments more valuable and integrated. These virtual health appointments also reduced time taken in travelling to GPs or specialists, making them more suited to, for example, single parents and those who have other commitments such as work or school. They also removed the cost of travel and parking, making them more accessible to people from a lower socioeconomic background.

² NHS Digital, [National Diabetes Audit, 2019/20, Type 1 Diabetes](#), 2021

However it must be recognised that a wholesale adoption of virtual appointments as default would not be suitable. Many people with type 1 in the pandemic could not access the same number or format of virtual appointments, with some only receiving a phone call as opposed to a video call. Many expressed that this style of appointment felt less personal and inhibited the social relationships that enrich appointments, especially with those newly diagnosed who require more support. Additionally, people who do not have English as their first language may have found difficulty navigating phone calls given the removal of body language and cues. The use of virtual appointments also could further widen the digital divide, as they necessitate access to smart technology and the internet.

JDRF recommends that post-Covid virtual appointments can be continued in providing support and advice from healthcare professionals to their patients with type 1 diabetes and their families. However the choice of face-to-face or virtual must be decided by the patient and reviewed before each new appointment, in order to promote a patient-centred approach.

Communication and support from the NHS

JDRF understands and appreciates that the NHS was under immense pressure during the pandemic, and that one could not expect a consistency of routine care. However, unfortunately many people with type 1 diabetes felt completely unsupported at times throughout the pandemic. JDRF's Covid and Beyond report highlighted that services for people with type 1 diabetes experienced greater disruption than for other comparable health conditions. According to our survey, 63% of adults with type 1 were unable to access their normal level of healthcare support, compared to 45% of people with other health conditions. Half of adults with type 1 say that there have been times during the Covid crisis when they have felt unsupported with their type 1 diabetes, compared to only a third of people with other health conditions. We also found lower levels of in-person access to healthcare specialists for type 1 diabetes during Covid, compared to people with other health conditions.³

The report highlighted that access to support depended on location, with people in London and the South of England typically experiencing greater continuity of care than in Scotland and the Midlands.⁴ Furthermore children generally received more support than adults with type 1 diabetes, potentially given the repurposing of adult clinical staff to Covid wards where paediatric teams were not. This health inequality must be remedied going forwards.

The research found that many people with type 1 diabetes decided against contacting their healthcare teams in order to protect the NHS. Furthermore many heard differing advice about their level of risk, and if they were required to shield or not. Differing advice created unnecessary distress and confusion, and this must be remedied going forwards.

This withdrawal of support is concerning for a number of reasons. As stated above, high or low blood glucose levels can result in severe complications for people with type 1 diabetes. These complications can be treated more effectively if they are diagnosed early, yet missed

³ JDRF, [Covid and Beyond: Confronting the unequal access to type 1 diabetes healthcare](#), 2021

⁴ JDRF, [Covid and Beyond: Confronting the unequal access to type 1 diabetes healthcare](#), 2021

appointments means that potentially hundreds of people will be facing worsened outcomes from later diagnosis. Consequently it is essential that diabetes appointments are prioritised within the NHS backlog to address this.

Centring the voice of lived experience

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. Our Covid and Beyond report suggests that many GPs are unaware of the specifics regarding type 1 diabetes, for example why a person with type 1 may be concerned about their feet. There is also a prioritisation of clinical and physical health outcomes experienced by many people with type 1 when speaking to their clinicians, as opposed to an understanding of the mental health burden that type 1 can create. Covid and Beyond found that over 50% of people with type 1 diabetes had experience of mental health problems, compared to 19% of the general population.⁵

Lived experience and mental health outcomes must be given fair weight within the rebuilding of the NHS and its services, for example through embedding mental health support for people with type 1 diabetes and other such conditions within Integrated Care Systems. 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.

Conclusion

Living with type 1 diabetes can be stressful. Never more so than during a pandemic with the disruption in NHS services, conflicting information and advice, the increased anxiety and the often rapid changes to lifestyle, for example through lockdowns and exercise restrictions, that can create newfound difficulties managing type 1. What our research has clearly shown is that those people who already had the technology to help them to self-manage their diabetes were better equipped to cope with this disruption to healthcare services. Making a wider range of devices easier to access on the NHS 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.

Telemedicine provided a lifeline in the pandemic for people with type 1 diabetes to communicate with their healthcare teams, and can carry forward many benefits as the NHS recovers. Yet it must not be offered as standard to all patients given issues regarding accessibility and its impersonal nature. The choice of face-to-face or virtual appointments should be decided by the patient and their family as far as possible.

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 centring the voice of lived

⁵ JDRF, [Covid and Beyond: Confronting the unequal access to type 1 diabetes healthcare](#), 2021

experience as the NHS builds back stronger services for type 1 diabetes, preventing future disruption on such a scale.

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