Breakthrough T1D™
Formerly JDRF

Access For All

The impact of technology on the lives of people with type 1 diabetes

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breakthrought1d.org.uk

Contents

"I have not heard of hybrid closed loop. I think artificial pancreas rings a bell. I think it is something I should have heard [of]."

Female, 54, South East

Foreword

Karen Addington, Breakthrough T1D Chief Executive

The use of technology can transform the lives of people with type 1 diabetes. Whether its devices that assist with precise insulin dosing or technology that continuously monitors glucose levels, these advancements can ease the daily pressures of managing type 1. However, we know that many people face barriers accessing the technologies they need to help improve their lives.

We're at a pivotal moment of change in type 1 treatment. Hybrid closed loop technology is now approved for use on the NHS in England, Wales and Scotland, with Northern Ireland now considering it.

This represents the most significant treatment advancement since the discovery of insulin. This is why we commissioned this new market research to gain deeper insight into people's experiences and attitudes towards type 1 technology.

We at Breakthrough T1D have a proud history of driving forward the research breakthroughs in every major field of treatment, including continuous glucose monitors, insulin pumps and hybrid closed loop, making life-changing treatments available through the NHS to people living with type 1 diabetes.

We first surveyed people living with type 1 about their use of technology in 2019 for our Pathway to Choice[1] report. Five years on, our latest research shows there has been progress in people's access and use of these technologies. However, people living with type 1 continue to face challenges, such as limited availability of devices on the NHS and technology not being recommended to them. We also know that huge discrepancies exist across the four nations.

Exciting developments in cellular therapies offer promising potential for curative treatments. By understanding where people get information around diabetes technology, we can shape services and support that are fit for the future. This report is a valuable resource for researchers, industry and policy makers, enabling them to better understand and address the diverse needs within the type 1 diabetes community.

The NHS, charities and industry stakeholders now need to work together to address systemic issues across the UK for fair and equitable access to technology for every person with type 1 diabetes.

As JDRF changes its name to Breakthrough T1D, our focus and commitment holds fast in working to ensure fair and equitable access to existing and new emerging treatments for everyone with type 1 diabetes. We're working with the NHS, Parliamentarians, other charities and industry to redefine the future of type 1 diabetes treatments and health outcomes.

About type 1 diabetes

Type 1 diabetes is a serious autoimmune condition. It affects both children and adults, regardless of their diet or lifestyle. Over 400,000 people in the UK are living with type 1. There is currently no way to prevent it, it can be fatal and at present, there is no cure.

With type 1, the pancreas stops producing insulin, the hormone the body needs to get energy from food. This means a process the body should do naturally and automatically becomes something a person with type 1 diabetes must look after themselves every day. Without insulin, a person with type 1 would die within a few short days.

People with type 1 must constantly monitor blood-glucose levels and self-dose themselves with insulin. If blood glucose levels are too high or low and left untreated, it can be fatal or lead to long-term complications like sight loss, kidney failure, and in some instances, limb amputation.

To treat type 1, people must inject or deliver insulin through a pump, carefully balancing these insulin doses with eating and activity throughout the day and night. Technology can make everyday life with type 1 much easier, supporting people to keep their glucose levels in their target range and avoiding complications.

[2] Breakthrough T1D, Pathway to Choice, February 2020

Introduction

Type 1 diabetes technology has undergone significant advancements in recent years. Devices are becoming easier to use, wearable and integrated with mobile phones. Technology can help ease the daily demands of managing type 1, such as finger-pricks and insulin injections. It can also help reduce the risk of hypoglycaemia and hyperglycaemia, and long-term serious complications.

Pioneering technology can dramatically reduce the number of daily decisions people with type 1 have to make.

Through our market research, we explored the experiences of people using type 1 technologies and the impact it has on their lives.

As well as technology that supports people every day, advances in cellular therapies herald a new future of curative treatments. With such promising developments on the horizon, our market research helps us to understand people's attitudes towards current and future treatments so that we can improve care and support.

Following our first report in 2019, *Pathway to Choice*, we wanted to update our understanding of people's experiences and see how access to technology is progressing.

In autumn 2023, we commissioned market research to gauge people's awareness, use and motivations for using technology. We also looked at how this might be affecting access and uptake.

Through qualitative and quantitative market research with people with type 1 and parents of children with the condition, we set out the following objectives:

Understand awareness, use and satisfaction with existing diabetes technologies

Identify motivations and barriers to adopting technologies

Evaluate attitudes towards future cellular treatments, therapies and screening

Look at trends and differences from our 2019 research

This report sets out our findings and our recommendations on the action needed so that every person with type 1 diabetes gets access to the technology that's right for them.

Methodology

This report summarises quantitative and qualitative market research that we undertook to explore the experiences of people living with type 1 diabetes.

Quantitative research

In total, 557 people took part in our online survey in October 2023. This included 143 parents of children with type 1. This gave us a snapshot of experiences with further insight gathered from in-depth qualitative interviews.

Qualitative research

We carried out 20 one-hour interviews in October and November 2023. Of these, 18 were with people living with type 1 and two were parents of children with the condition. Interviewees were a broad range of ages, from different geographical areas and from a variety of socio-economic backgrounds. Eight people were from minority ethnic backgrounds to make sure we accurately represented the diabetes community.

"Nowadays, social media is such a big thing where people like to share their conditions. They will give you updates, they will give you advice. You know what is good, what is not good."

Female, 40, Yorkshire and Humberside

Findings

Awareness and use of technologies

Understanding what devices are available is a crucial first step in encouraging people to adopt new technology. Our research looked at the evolving awareness and use of devices to manage type 1 and how people find out information about them.

People were asked about five devices:

- insulin pumps – deliver insulin automatically throughout the day and night
- continuous glucose monitoring (CGM) – a wearable device that measures glucose levels in real-time
- flash glucose monitoring – a wearable device that you can scan to check your glucose levels
- hybrid closed loop (HCL) – also known as the artificial pancreas, takes readings from a CGM to tell a pump how much insulin to automatically deliver
- smart insulin pens - inject insulin and records data on a mobile phone app

Respondents had almost universal awareness of both insulin injections and insulin pumps. There was also growing awareness of CGM and flash glucose monitoring technology since the last report. These are both now as well-known as the insulin pump.

The technology that people were least aware of was HCL. Only a quarter (25%) said they were aware of it and knew a lot about it. Socio-economic background was the greatest predictor of whether people had heard of HCL. Respondents from lower socio-economic groups and those over the age of 65 were least likely to have heard about HCL. The interviews revealed people were confused about what the technology did and felt insecure about using it.

The findings of our market research survey showed that younger people, more affluent respondents and people from ethnic minority backgrounds were the most likely to have heard about the technology. While health inequalities around access are prevalent and cited across statutory data sources, our market research shows that ethnicity is no inhibitor to people knowing and being informed about new technologies.

While 88% of respondents said they were aware of the smart pen, the interviews revealed that there was some misunderstanding over what a smart pen was. Some people confused it with other insulin pens and injections.

Sources of information

Diabetes specialist nurses and doctors continue to be the main trusted sources of information for people with type 1. They play a crucial role in informing people about what technology is available and encouraging them to explore these options. Trust in healthcare professionals was highest for people over the age of 65. While the majority of people felt that health care professionals gave them a comprehensive overview of what technology is available, others said they also carried out their own research. Social media and groups for type 1 diabetes are increasingly important ways for people to share information.

Some people said that after hearing about technology from friends or social media, they then asked their healthcare professional to see if they could try it. Our research revealed that for younger people and women in particular, they used social media to access first-hand experiences and honest reviews from others using diabetes technology. This trend shows the growing significance of communities for peer-to-peer support.

Managing type 1

Injecting insulin remains the most common way to manage blood glucose levels. While 91% of people use injections, this has decreased by 5% since our last report. The use of insulin pumps, CGM and flash glucose monitoring have all increased. This is particularly seen in younger age groups and people living in urban areas. Fewer people used insulin pumps or smart pens to manage their blood glucose levels. HCL was currently being used by 16% of people.

Drivers and benefits to technology

Managing type 1 diabetes is personal and people need support to help them explore the technologies that work for them. When people find the right technology that suits their needs, they report having better management of their type 1 and lower levels of anxiety.

Motivations

Recommendations from healthcare professionals, particularly diabetes specialist nurses, strongly influenced people to try insulin pumps, CGM and flash glucose monitoring. Alongside the availability of these technologies through the NHS, a key motivation was the hope that the technology would improve diabetes management for themselves or their children.

Influence of peer support

Our research showed that first-hand experiences shared by others who have used technology are significant motivators for trying new devices. Peer support helps to expand people's knowledge, provide reassurance and helps to develop deeper understanding in those considering new technologies. One parent we interviewed said hearing how other parents with young children had introduced HCL had helped his family switch to the technology:

"I managed to get in touch with a couple of other families who had younger children, and they gave me quite a bit of advice. We got quite good control and then once we got to that point, we saw the benefits quite quickly." Parent of child living with type 1, male, 39, South East

The benefits

People who answered our survey highlighted several key benefits to diabetes technology. Those using insulin pumps and HCL said they liked the precision offered by these devices. They also recognised significant lifestyle improvements, such as increased flexibility and reduced anxiety about diabetes management. CGM and flash glucose monitoring were valued for their ability to reduce the frequency of finger-prick tests, providing real-time data on glucose levels and offering alarms. CGM was seen as more effective overall due to its ability to display trends in glucose levels and potentially improve sleep quality.

Smart pen technology had lower awareness among respondents, with nearly a third (29%) unsure of its benefits. However, a quarter (25%) recognised that smart pens could deliver insulin more precisely, reducing concerns about diabetes management. Opinions on smart pens varied; some viewed them as a gradual step towards more advanced technology, while others considered them useful but not revolutionary.

Barriers to using technology

There are different reasons why people living with type 1 diabetes decide against using certain technologies. These range from availability and appearance to the pressures of navigating new devices.

Factors such as the physical burden of wearing devices and disparities in access and cost, all contribute to the decision-making process, while many have simply not been made aware of new technology by their clinicians. Understanding these barriers is crucial in addressing the diverse needs and preferences of people with type 1.

> "I tried another [insulin pump] a few months ago, but I completely freaked out about it. I did not like it because it had wires, whereas this one is small so hopefully that will be ok. I felt a bit like an ill person."
>
> **Female, 22, North West**

Insulin pump

More than a quarter (26%) said insulin pumps not being available on the NHS or not meeting the criteria for access was a significant barrier to their use. A similar number (27%) reported that their clinician or nurse hadn't recommended an insulin pump. Concerns about its appearance deterred some people. Around one in five expressed reservations about tubing or using an insertion device. During the interviews, people mentioned not wanting to wear a device that reminded them of their condition. This was particularly seen in men, where more than a quarter (26%) indicated that tubing was a deterrent, leading them to favour their existing diabetes management over switching to an insulin pump.

However, participants expressed an interest in smaller, less bulky devices, similar to technology they are already used to wearing.

Smart pens

Lack of knowledge about the technology was the main barrier for the uptake of smart pens (35%). More than a quarter (27%) hadn't had the technology recommended to them by their clinician or nurse.

CGM and flash glucose monitoring

For CGM and flash glucose monitoring, appearance was much less of a barrier.

Resistance to adopting these technologies often stemmed from either a lack of recommendation by a healthcare professional or people were satisfied with their current method of management.

While more people had been recommended CGM or flash glucose monitoring since our previous report, there was an increase in the number of people who expressed dislike for the appearance of the devices. There was also discomfort with the idea of continuous monitoring.

Availability on the NHS

Limited availability of devices on the NHS posed a significant barrier to trying different technologies. More than three quarters (76%) of people said they'd like to use CGM if it was available to them, with a similar level of interest (70%) in smart pens.

Fewer people said they were interested in HCL (39%), with variability depending on ethnicity and socio-economic background.

Impact of technology

When people used technology, they reported positive impacts on their day-to-day lives like greater management over blood glucose levels. Nearly half of respondents (47%) said using technology made them happier, and 46% reported feeling less anxious about their blood glucose levels.

> “I've heard of it [HCL] in passing, but I wouldn’t be able to tell you anything about it.”
>
> **Female, 28, Yorkshire and the Humberside**

Using CGM helped boost people’s confidence and they felt less anxious about their diabetes, an improvement from our last report.

There was also an increase in the perception of CGM contributing to better management over glucose levels. Users of HCL emphasised feelings of freedom and happiness because of the technology.

When asked about what the impact would be if they could no longer access their current technology, most thought it would see the management of their diabetes deteriorate. This was particularly seen in people using CGM.

Overall, people expressed high levels of satisfaction with the technology they use to manage their diabetes. This is a trend that has remained stable since our last market research. HCL received the highest satisfaction rating, with 92% of people reporting being satisfied or very satisfied with the technology. Levels were slightly lower (81%) among those using injections.

> “The technology can be life-changing. Having the CGM is really important. Matched up with closed loop and insulin pumps, it makes the world a better place for us to be in."
>
> **Male, 22, South East**

> "Within a few weeks of her going on the pump, she looked so much better... definitely back to her old self."
>
> **Parent of child living with type 1, female, 40, London**

"I remember when I was diagnosed vaguely. I was sitting there, crying and screaming and my dad would be trying to give me my insulin. I think having more time trying to explain what is going on, why you need to do things would help."

Female, Age 27, West Midlands

Future treatments

Many promising research projects are aiming to find life-changing breakthroughs and potential cures for type 1. We asked people about the possible future treatment options on the horizon to gauge their interest and identify areas where additional information and support is needed. These options ranged from cutting-edge beta cell transplantation to more responsive forms of insulin.

1. High interest in future treatments

Interest in future treatment options for type 1 was high, but people emphasised the need to make informed decisions on new medical advancements. They often said they wouldn't want to be the first to try treatments like beta cell transplantation.

2. Interest in delaying onset

One in four children (25%) in the UK are diagnosed with type 1 diabetes so late that they are hospitalised with a life-threatening complication called diabetic ketoacidosis (DKA)[2].

DKA is an illness that occurs when blood glucose levels are dangerously high. It can cause nausea, vomiting, stomach pain and rapid breathing. It can also potentially lead to a coma. It's vital that healthcare professionals, and parents, have the knowledge to be able to detect the signs of undiagnosed type 1 diabetes. When diagnosed, vital insulin treatment can begin quickly and DKA can be prevented.

Three quarters of people (75%) in our survey said they would want to know if their child was going to develop type 1. There was also high interest in treatments that could delay the onset of type 1 in children until they are older. Some people shared positive experiences of participating in the ELSA study and using a finger stick blood test to screen for the risk of developing type 1 in their children or siblings. Through screening and early identification, children and their families can be educated about type 1 diabetes and how to spot early symptoms, lowering the risk of developing DKA. In one study, this approach was seen to reduce the likelihood of DKA to less than 5%[3].

3. Desire for information

Stem cell-derived beta cell transplantation is an emerging treatment currently in early phase clinical trials that may be suitable for some people with type 1. It involves growing new insulin making cells from established stem cells in the laboratory and then implanting these cells into a person with type 1. Early phase trials are focusing on treating people who have very unstable blood glucose levels, and are unaware they have severe hypoglycaemia.

Stem cell-derived beta cell therapy is based on knowledge gained through islet transplantation, a treatment the NHS has used since 2008 to help people who can't sense severe low glucose levels. Islet transplantation involves extracting insulin-producing cells from the pancreases of organ donors and infusing them in the liver of someone with type 1 diabetes.

This can help improve blood glucose levels, restore awareness of hypoglycaemia and avoid severe hypos. Some people may not need insulin therapy at all for several years after the procedure. Knowledge around islet transplantation in our survey was low. Although few people currently have access to this treatment, 65% wanted to learn more about it.

In our research, more than three quarters (78%) of people wanted to hear more about research on forms of insulin that respond to blood glucose levels and release the right dose.

[2] National Paediatric Diabetes Audit Report on care and outcomes 2021/2022, published 2023
[3] Ziegler A, Kick K, Bonifacio E, et al. Yield of a Public Health Screening of Children for Islet Autoantibodies in Bavaria, Germany. JAMA, published 2020

Recommendations

The insights from this report have informed our following recommendations:

Recommendations for Hybrid Closed Loop

1

Increase awareness of hybrid closed loop

Our report shows that many people, especially those from lower socio-economic backgrounds, have low awareness of HCL. It's important to promote this technology and inform people with type 1 about their eligibility for the device.

2

Ensure that everyone who needs and could benefit from HCL is part of the national rollout

Limited availability of devices on the NHS is a significant barrier for people living with type 1 diabetes. Interest in new technologies is high, especially among those currently not eligible. Addressing these gaps is essential to providing equitable access for all.

3

Comprehensive training for all healthcare professionals involved in the rollout of HCL

Trust in healthcare professionals is high, so leveraging training and education from medical technology providers is essential. This will ensure both healthcare professionals and people with type 1 diabetes are well-informed and supported.

Recommendations for early detection

1

Establish a national diabetes registry

Modelled on Scotland's SCI-Diabetes database, a national diabetes registry would track the adoption of type 1 diabetes technology, record spending for prescribed devices, and provide regional health outcome statistics. This would enable clinicians to access patient data within a single system. Additionally, the registry could track which healthcare professionals are trained in specific type 1 diabetes technologies.

2

Establish a national early detection programme for type 1 diabetes

The UK is already lagging behind other countries when it comes to screening for type 1 diabetes. With treatments to delay the onset of type 1 on the horizon, a comprehensive early detection programme is essential to identify and support people at risk and in the early stages of type 1 diabetes.

3

Embed post-screening monitoring and ongoing support for those who test positive for biological markers of type 1 diabetes

This approach will help reduce the risk of DKA at diagnosis and minimise short and long-term complications.

Recommendations for future treatments

1

Drugs that delay the onset of type 1 diabetes must be approved by NICE and rolled out for use on the NHS

Every moment a person can delay dependence on insulin represents a critical opportunity to avoid complications and the burdens of life with type 1. This can also play a key role in preventing complications such as eye, kidney and heart diseases.

For children at risk of type 1 who are approaching adolescence, delaying the onset of type 1 would allow their pancreas to grow to adult size, giving better disease outcomes.

2

Improve patient education and involvement in emerging therapies for type 1 diabetes

People living with type 1 are eager for information about new therapies, but awareness of the full range of current treatments remains relatively low. As new options emerge, navigating different treatments may become even more complex for both people with type 1 diabetes and their healthcare teams.

Research efforts must prioritise involving people with type 1 diabetes to understand their information needs and perceptions of risks and benefits of emerging therapies. Clinical pathways should be developed to support informed choice and decision-making.

3

Raise awareness of clinical trials to help the development of future treatments for type 1

We must increase participation in clinical trials to significantly accelerate the discovery and validation of new therapies, ultimately improving the quality of life for people living with the condition.

Efforts should focus on educating people about the importance of clinical trials, the potential benefits of participation, and addressing common concerns and misconceptions.

Healthcare providers, advocacy groups and research institutions must collaborate to create accessible resources and communication strategies that emphasise ongoing trials and their potential impact on advancing treatments.

Summary

Our report shows how vital technology is in supporting people with type 1 to live their lives. People told us how technology like CGM and insulin pumps made type 1 more manageable, alleviated the daily stress, and gave them freedom and confidence. One standout technology highlighted in our research is HCL.

The automation offered by this technology has the potential to transform the experience of people with type 1 as it's made more widely available on the NHS.

Our findings illustrate the pivotal role of healthcare professionals in shaping perceptions and decisions when it comes to people adopting technology. The internet, social media and groups for people with type 1 also provide much needed support and information.

However, there are barriers to people getting access to the technologies they need. Limited availability of devices through the NHS and technology not being recommended by healthcare professionals are among the key hurdles. With discrepancies across the different nations, there's a clear need for equitable access to transformational technologies.

Furthermore, some people with type 1 are reluctant to try new technologies, despite their benefits, because they can be bulky, physical reminders of their condition. Social attitudes to type 1 play an important part here, and more health care professionals should be aware of these experiences. Choice in devices available is key.

Looking forward, research projects are finding life-changing new treatments and ultimately working towards potential cures for type 1. From growing insulin producing beta cells in labs to stem cell therapy and creating improved types of insulin, we're funding research that transforms the lives of people with type 1 diabetes.

We're also funding a study screening large numbers of children, laying the groundwork for a potential UK-wide early detection programme.

The ELSA study has already screened 20,000 children aged 3-13 to find those at risk of developing type 1 before they become unwell. The research will provide crucial insights to ensure an earlier and safer diagnosis for thousands of people.

Breakthroughs in treatment and technology hold the key to avoiding life-threatening hypos and hypers, and the risk of long-term complications associated with type 1 diabetes. Equally important is lifting the mental health burden that comes with managing this relentless condition day in, day out.

Now is the time to advance the adoption of technology, establish a national registry and early detection screening programme, and champion emerging treatments and trials. As partners and advocates, we have the power to drive change and transform lives. By uniting our efforts, we can accelerate progress for a future where everyone has access to life-changing technologies and treatments.

Only then will we improve the physical and mental wellbeing of people living with type 1 diabetes in the UK today. Together, we can create a brighter tomorrow for all those affected by type 1 diabetes.

About Breakthrough T1D

We are Breakthrough T1D the leading global type 1 diabetes (T1D) research and advocacy charity, we help make everyday life better while driving toward cures. Today, we are opening doors that were once closed by T1D diagnosis. We do this by connecting the brightest minds and investing in the most promising research, campaigning for access to treatments and technologies, and supporting the T1D community. Tomorrow, we will make this condition a thing of the past.

Find out more: **https://www.breakthrought1d.org.uk**

Recruitment of participants
As well as recruiting through our own channels, we also spoke to people who weren't already part of our network. This made sure we had a diverse range of respondents using different technologies to manage type 1.

With thanks
The research and full report this document is based on were completed by nfpResearch, a market research agency commissioned by Breakthrough T1D (formerly JDRF) to carry out the work.

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For information, support, and more on how to get involved, visit: **breakthrought1d.org.uk**

For further information, please contact:
Breakthrough T1D, 17/18 Angel Gate, City Road, London, EC1V 2PT

Telephone: **020 7713 2030**

Email: **info@breakthrought1d.org.uk**

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