



Pathway to Choice

**A joint partnership programme building awareness
of and access to type 1 diabetes technology choices**

JDRF IMPROVING
LIVES.
CURING
TYPE 1
DIABETES.

Report and recommendations
February 2020



Supporting people with type 1 diabetes to access life-changing treatments

400,000 people in the UK have type 1 diabetes - a life-changing condition that requires regular daily attention. Type 1 diabetes is caused when the immune system attacks insulin-producing cells in the pancreas. It's not yet fully understood what triggers the attack. The result is a lifetime reliance on injected insulin to be able to function and live. The condition is relentless. A child diagnosed with type 1 diabetes at the age of five faces up to 19,000 injections and 50,000 finger prick blood tests by the time they are 18.

A range of wearable medical devices already exists to help manage type 1 diabetes. However, only a small percentage of those living with the condition in the UK use these more technology-based treatments.

And currently, just 30% of people with type 1 diabetes stay within their recommended blood glucose target range¹, putting the majority at greater risk of complications such as kidney disease, nerve damage, heart disease and premature death.

People with type 1 diabetes who use these medical technologies may find it easier to manage their glucose levels and thereby reduce these risks. This is why JDRF has commissioned market research to understand the motivations and barriers people with type 1 diabetes face in making treatment choices.

The findings will enable us to explore the types of support and interventions we can develop to help people living

with type 1 diabetes choose the best possible treatments. The market research also highlights areas in which government, the Department of Health and Social Care and the NHS can improve support for people living with this life-changing condition.

Increased frequency and length of appointment times to discuss treatment options and better diabetes technology education for healthcare professionals are key recommendations.

Thank you to our partners, Abbott Diabetes Care, Dexcom, Insulet International Ltd and Roche Diabetes Care, who support JDRF's Pathway to Choice programme, which aims to build awareness and access to type 1 diabetes technologies.

This report is timely, providing an important insight into the experience of people living with type 1 diabetes. That experience informs our recommendations, contributing towards

developing understanding, policy, and practice, which we firmly believe will lead to increased adoption of type 1 technologies and improved health outcomes for people living with type 1 diabetes.



Karen

Karen Addington
JDRF Chief Executive

¹ National Diabetes Audit 2017/2018



Methodology

This report summarises qualitative and quantitative research exploring the experiences and barriers of people with type 1 diabetes with blood glucose monitoring technology and insulin pump therapy.

Quantitative research

The quantitative stage of research consisted of an online survey in September 2019 with 363 participants. This included 105 parents of children with type 1 diabetes and 270 individuals who live with type 1 diabetes. The research and full report this document is based on were completed by Dr Claire Bennett & Debbie Hazelton from nfpSynergy, a research agency appointed by JDRF to carry out this work.

Twelve of the participants were both parents of children with type 1 diabetes and had the condition themselves. As the demographic make-up of individuals with type 1 diabetes in the UK is not known, a natural fallout sampling method was used, which gave a broad demographic spread of individuals.

Qualitative research

This stage consisted of four focus groups carried out in August 2019, involving 24 people in London and Manchester. These groups included people with type 1 diabetes and six parents of children with type 1 diabetes, with a mix of men and women between the ages of 25 and 61 years. As these groups were exploring the barriers to adopting technology-based treatments, we aimed to recruit people who don't currently use wearable medical devices to manage their type 1 diabetes.

However, due to recruitment restrictions, there were a few individuals who currently used either continuous glucose (CGM) or flash glucose monitoring. These individuals were encouraged not to share their experiences of this technology until towards the end of the focus groups, to allow for an open discussion about all of the technology devices.

Definitions

Throughout this report, we use terms such as wearable medical devices and glucose management technology to refer to both how insulin is delivered and monitored via insulin pumps, continuous glucose monitors, and flash glucose monitors. For more information, see jdrf.org.uk/technology

There are many complex reasons why individuals do not engage with wearable glucose management devices. This report breaks down these into education and access to information, financial limitations and socio-economic factors, attitudinal barriers and physical attributes of the technology.

Read the full report:
jdrf.org.uk/pathwaytochoice

A close-up portrait of Maureen McGinn, a woman with long, wavy blonde hair, wearing glasses and a black turtleneck. She is smiling warmly at the camera. The background is a soft, out-of-focus blue and white.

Case study: Maureen McGinn

"I was diagnosed in 1990 and for the first 20 years, my diabetes care wasn't great. For years, I didn't get to see the consultant, nor saw the same doctor twice, so didn't really get anything out of these annual appointments and thought about having my GP manage my care.

"In 2010 the idea of insulin pumps was put to me in such a negative light that I didn't even consider one. Then in 2013, I met a number of people talking about them more positively, so much so that in April 2014 I went back to my consultant and asked for one – his reaction however was that my condition was not bad enough to warrant one on the NHS.

"Luckily someone I knew helped me get an appointment at a different clinic and I was told straight away I could have a pump because I lived alone, experienced significant blood glucose variability and had a fear of hypoglycaemia.

"The fact that these other, more holistic factors were considered made all the difference and the flexibility a pump has given me has changed my life.

"My new, proactive and forward-thinking team also gave me access to Facebook groups that I hadn't come across before, which meant I was in touch with online communities for the first time.

"There needs to be more awareness of the research and the improvements that technology can bring to type 1 care.

"There is an impression that tech is for certain types of people but I think the technology can be massively transformational for anyone. A year after receiving my pump, the nurse admitted to me that her first impression was that I wouldn't get on too well with one.

"If I hadn't been able to get the pump I would have continued to become more and more disengaged – that was the path that I was on. Now I feel part of a community, which is a massive support."

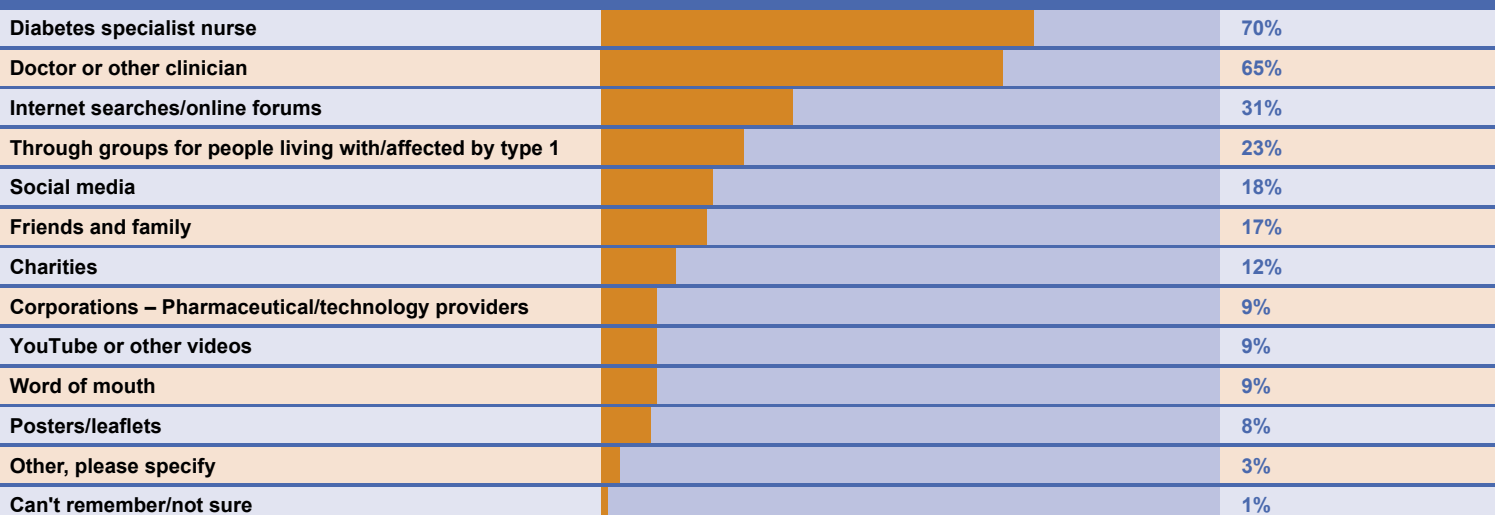


Findings

Barriers: Education and access to information

There are many complex reasons that individuals do not engage with wearable glucose management devices and this report breaks these down into education and access to information, financial limitations and socio-economic factors, attitudinal barriers and physical attributes of the technology.

Figure 1:
Places where individuals currently get information and support about their type 1 diabetes



"Where do you currently get information and support about your (or your child's) type 1 diabetes?"
Base: 363 adults 16+, Britain Source: JDRF, Barriers and drivers to technology, Sept 19, nfpSynergy

Barriers: Education and access to information

Awareness of available technology options is one of the most important steps to engaging with and possibly using it. When asked where they receive information and support about their type 1 diabetes, around two thirds of individuals engage with their diabetes specialist nurses or other clinicians to gain information. 31% of people are proactively looking on the internet or through online forums and 9% get advice on diabetes management through word of mouth.

This means healthcare professionals are a trusted source of information, and thus incredibly important in both providing and disseminating information, including advice on technology-based options.

"I would want to talk to somebody that probably has experience of different types of patients and sides of diabetes and they are able to see a bigger picture."

However, our research reveals that there is a perception that healthcare professionals are often resource and time-limited. In addition, some people have to take time off work or education for appointments, which can add to the perceived constraints of time and opportunities to engage with their healthcare professionals. Given that there are so many topics to cover and data to be reviewed during appointments about an individual's type 1 diabetes - such

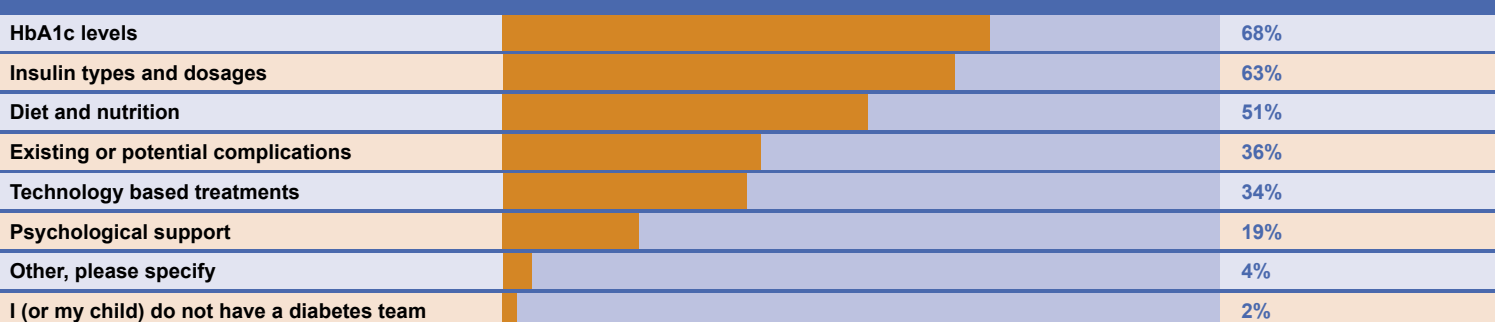
as HbA1c levels, insulin dosage, and diet and nutrition advice, there is often little chance for a wider conversation, including the potential role of devices.

"When I go to the hospital, I want to know that my blood pressure is ok, and that my kidneys are fine."

Given that there are limited opportunities to talk about technology-based options with healthcare professionals, it is not surprising that the desire for more information on this is a key priority for people with type 1 diabetes.

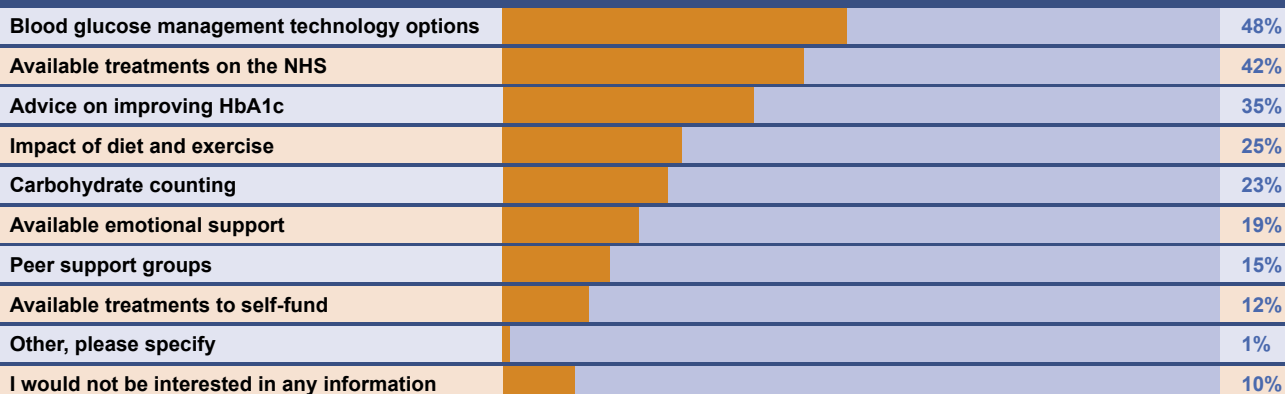
"Some [HCPs] know about technology and some don't."

Figure 2:
Areas that individuals speak to their diabetes team about



"What do you discuss with your (or your child's) diabetes team?"
Base: 363 adults 16+, Britain Source: JDRF, Barriers and drivers to technology, Sept 19, nfpSynergy

Figure 3:
Areas that individuals want more information about their type 1 diabetes



"Which of the areas below would you be most interested to gain more information about type 1 diabetes in?"
Base: 363 adults 16+, Britain | Source: JDRF, Barriers and drivers to technology, Sept 19, nfpSynergy

The importance of healthcare professionals in engaging people in technology use is also demonstrated by people who have, or currently use technology-based options.

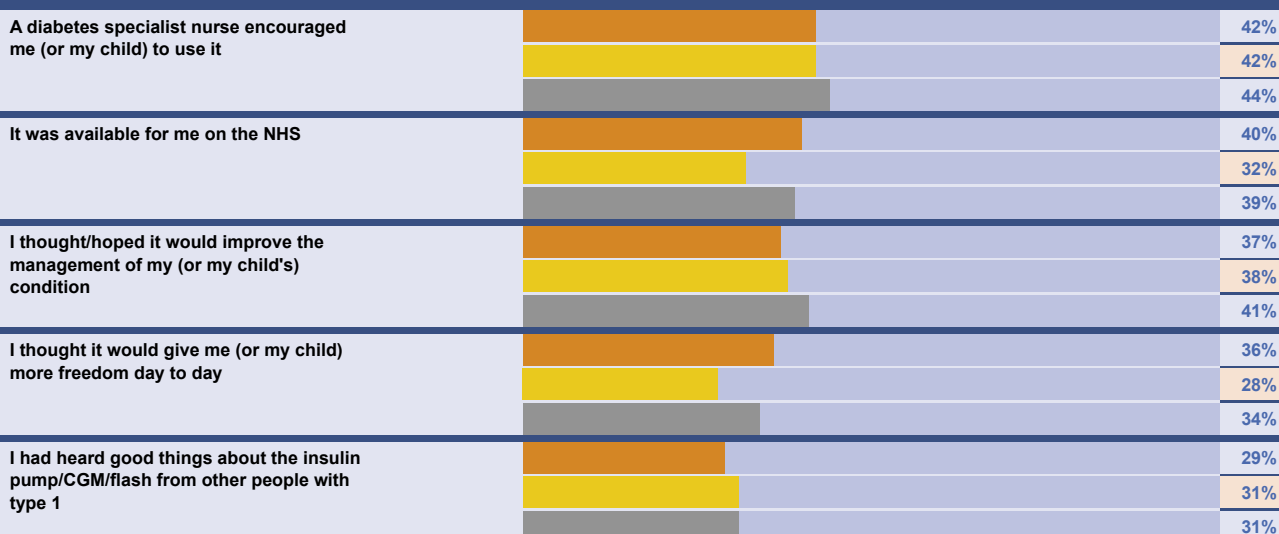
Our research reveals it is encouragement by diabetes specialist nurses that is the leading route to engagement with all technology options (insulin pump, CGM and flash devices). Conversely, a lack of recommendation from a healthcare professional is the main reason individuals have not engaged with technology.

Therefore, to increase awareness of technology-based options, a number of steps should be taken:

- Healthcare professionals need more time to discuss technology in appointments.
- Information given to people with type 1 diabetes about devices and their benefits needs to be consistent across the country. Our focus groups in particular raised concerns that there is still a 'postcode lottery' of information and engagement from healthcare professionals on this topic.

- Importantly, our research suggests that in order to empower people with type 1 diabetes to ask the right questions, they need to know where to look for information. Increasing access to trusted and clear information across all channels is important so that people are not just reliant on healthcare professionals. **"It's a postcode lottery, it depends how sympathetic your consultant is."**

Figure 4:
Top five reasons why individuals chose to use different technology options



"You said that you (or your child) have used, or currently use an insulin pump/CGM/flash. What encouraged you to use this technology?"
Base: 135/156/174 adults 16+, Britain | Source: JDRF, Barriers and drivers to technology, Sept 19, nfpSynergy

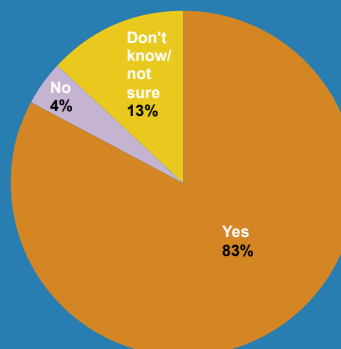
Insulin pump CGM Flash

Figure 5: Barriers to using continuous glucose monitoring

"Please select the reasons below that you (or your child) do not use continuous glucose monitoring (CGM)?"

My clinician has not recommended it to me (or my child)	29%
It is too much money to self-fund using it	23%
It is not available for me (or my child) on the NHS	22%
Don't know enough about it	15%
I have not heard of this technology	11%
Don't know how it would benefit me	9%
Want to stick with what I've always done	7%
Don't want a sensor attached to me (or my child)	6%
Feel that it may be too complicated to use	4%
Don't want to apply the sensor	4%
Don't trust the technology	4%
Don't think it will improve my blood glucose management	4%
Don't like the way it looks	3%
Think technology-based treatment might increase the burden	2%
Don't want (my child) to be constantly monitored	2%
Have heard bad things about it from other people	1%
Other, please specify	9%

If CGM was available on the NHS



"If continuous glucose monitoring (CGM) were available to you (or your child) on the NHS would you like to use this technology?"
Base: 207 / 53 adults (availability on NHS as barrier to CGM) 16+, Britain | Source: JDRF, Barriers and drivers to technology, Sept 19, nfpSynergy

Barriers: Socio-economic and financial

Two further barriers that impact engagement with technology-based options are people's socio-economic status and finances. The social level statistics measured tell us that the lower a person's income, educational attainment, social capital and access to peer support, the less likely they are to know about and use technology.

The social level classifications used in the research are based largely on people's professions². The research, based on these classifications, for example, found that 25% of people from social level DE have no awareness of flash glucose monitoring technology compared to only 12% at social level AB.

These findings are consistent when people were asked about all types of technology. Moreover, 32% of the higher social level (AB) are currently using an insulin pump, compared to only 18% of people with type 1 diabetes from social level DE.

"I don't work, I wouldn't have been able to afford it."

"It's just realising you've got to put in £4,000 - £5,000 in order to even get that ... at the end of the day. It such a big outlay."

An individual's finances were also often stated as a key barrier to engaging with the technology.

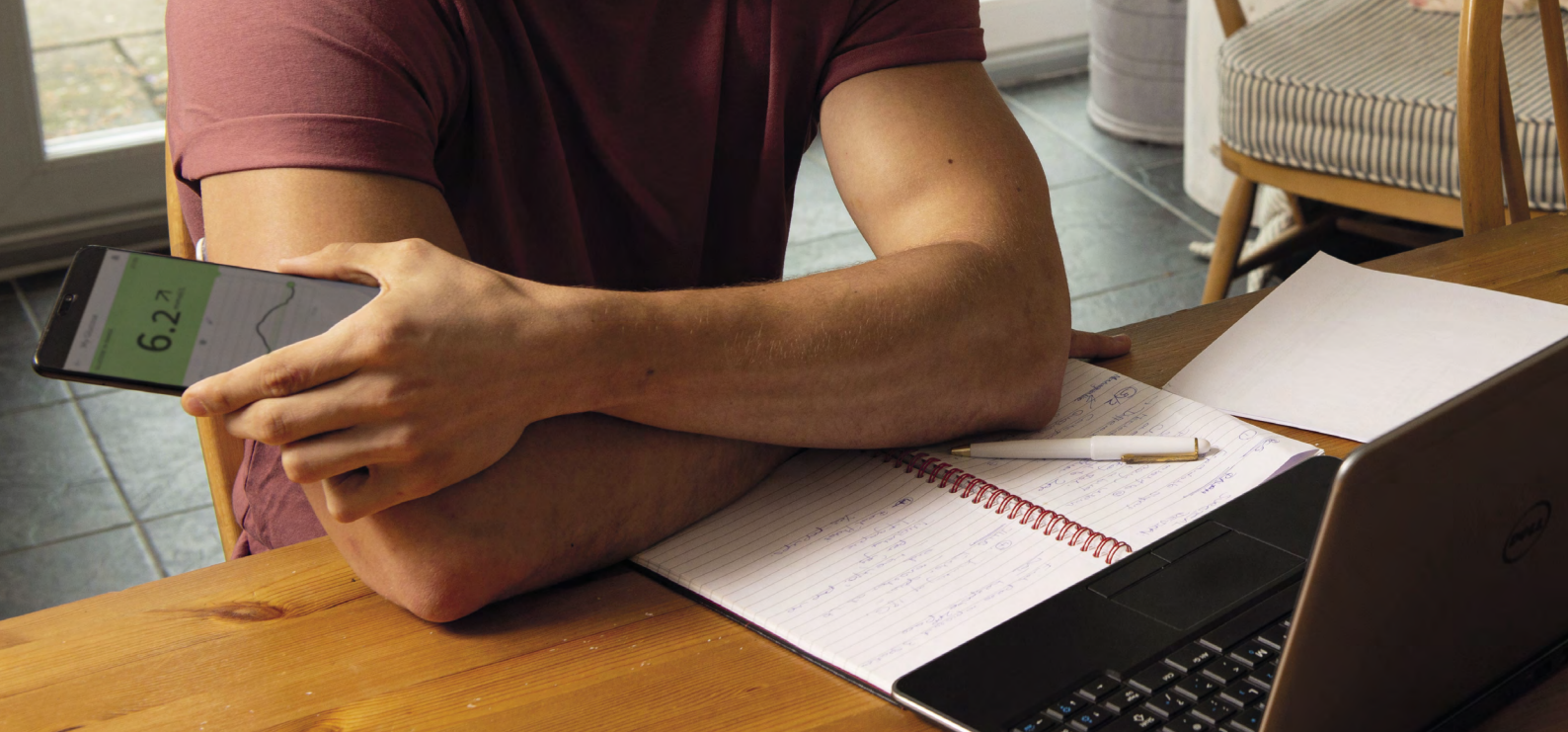
Considering the quotes above, it is understandable that for some, the combination of not having the personal finances available to self-fund and the technology not being available on the NHS (or individuals failing to meet the NHS criteria) is a non-negotiable restriction to their technology use.

This was further highlighted as an issue when we asked people about access to specific types of technology, in particular CGM, which has the added barrier of not having mandated funding within the NHS.

23% of respondents stated that CGM is too expensive to self-fund and 22% did not qualify for NHS funding. Of the 22% who do not qualify for NHS funding, 83% stated that they would want to use this technology if it were available on the NHS.

Therefore, acknowledging and trying to find the solutions to the financial and social barriers people face are a priority.

² Social level gradings: AB = Higher & intermediate managerial, administrative, professional occupations; C = supervisory and skilled manual and DE = Semi-skilled & unskilled manual occupations, unemployed and lowest grade occupations



Barriers: Attitudinal and physical

Our research reveals that there are also many attitudinal and physical barriers that prevent people accessing technology. On the whole, people who are happy or satisfied with their current diabetes management (whether or not they are achieving their treatment goals) are more reluctant to change and adapt to technology. For some, change symbolises risks that they are not willing to take. Physical appearance of the technology also has a strong influence for some when it comes to choosing whether or not to use it.

Overcoming this attitudinal barrier is reliant on getting good and independent information, but also by ensuring that the tangible benefits of different types of technology are understood by everyone. For example, people with type 1 diabetes need to know how different types of technology will enable them to improve their day-to-day management and HbA1c levels.

“I think for many people, if it’s not broken don’t fix it ... when something works I’m not interested in anything else.”

Our research demonstrates that the more information that technology can provide about blood glucose levels, management and patterns, the more people feel in control and, ultimately, the more interested people are in exploring the technological tools available to help them manage their condition.

Physical barriers

Physical barriers that prevent people accessing technology are inextricably linked to the attitudinal barriers. For instance, the more physical barriers that exist, the more attitudinal barriers there are and vice versa. Our research indicates that myths and misinformation about physical appearance can be key deterrents to the uptake of technology. These barriers can be overcome through education and exposure to updated technology as many people are making decisions to dismiss technology because of information they heard many years ago.

“I think if you manage fine with your injections, I don’t think you feel there’s any point [in using more advanced technology].”

Furthermore, how ‘discreet’ the technology looks can be an issue for some. Our focus groups explored how many individuals with type 1 diabetes do not want to be defined by their condition, and having visible technology can make people feel self-conscious and continuously aware of their condition.

“I would be quite happy to use it if I could go out and nobody would know I was doing it.”

Understanding more about how technology may benefit them and opportunities to see different types of technology is key to making informed choices. Physical barriers can be overcome, if the education and attitudinal issues are addressed.



Recommendations

JDRF believes everyone who wants and would benefit from type 1 diabetes technology should gain access to it. The insights from this report have informed our following recommendations:

1. People with type 1 diabetes should have more time with specialist healthcare professionals at appointments.

Our findings clearly show people with type 1 diabetes across all socio-economic groups need more time with their healthcare professionals at appointments.

- Allow sufficient time for a solutions-based conversation at each clinician appointment, following the type 1 diabetes technology pathway
- Ensure people with type 1 diabetes have access to trusted information to support their conversations with HCPs
- Provide all people with type 1 diabetes access to structured education on their condition from an accredited source, to support their ability to make informed tech choices with their HCPs. This education needs to be flexible, to fit within people's lifestyles

2. Healthcare professionals should receive mandatory training on type 1 diabetes technology.

Regarding insulin pumps for example, the most recent National Diabetes Insulin Pump Audit 2017/2018 recommends "considering whether there is adequate understanding, capacity and capability to explain and provide pump treatment to people with type 1 diabetes."

- We want the NHS to ensure all type 1 diabetes clinicians are trained and kept up to date on all type 1 diabetes technology with an emphasis on the empowerment of choice to best support a person with type 1 diabetes in deciding on treatment
- The NHS should provide protected time for training of HCPs on type 1 technology and its funding pathways, considering how agile ways of delivering training can help take account of shift patterns and other workforce needs
- Details of clinics with trained specialists should be made publicly available, so that people with type 1 diabetes can be confident in approaching their clinician about technology

3. Clinical commissioning groups should do more to reach people with type 1 diabetes from lower socio-economic groups.

Our research shows that people with type 1 diabetes from this group

are less likely to be aware of type 1 technology. Just 18% of respondents from this group discuss technology at their clinician appointments, compared to 46% of the least deprived. The National Diabetes Insulin Pump Audit 2017/2018 audit shows that pump use remains lower among people experiencing greater levels of deprivation.

- All CCGs to base their type 1 diabetes commissioning policies on NICE guidelines with regards to type 1 diabetes technology, thereby ensuring people who meet the criteria for diabetes technology are offered it and encouraging the adoption of best practice from around the country
- Create a national diabetes register, modelled on Scotland's SCI-Diabetes. This would have several functions including mapping type 1 diabetes technology uptake, recording spend breakdown per prescribed device, providing regional statistics regarding health outcomes, and empowering clinicians to see patient data in one system. Furthermore, ideally the register could also track which healthcare professionals are trained in which type 1 diabetes technologies

JDRF and partner organisations look forward to meeting key government and NHS policy makers to discuss our recommendations and explore ways of implementation.



About JDRF

JDRF is the type 1 diabetes charity. We are committed to eradicating type 1 diabetes and its effects for everyone in the UK. We:

- fund world-class research approved and administered by our international research programme to cure, treat and prevent type 1 diabetes
- make sure research moves forward and treatments are delivered as fast as possible
- give support and represent people with type 1 and their families

INPUT, the UK diabetes technology advocacy charity officially joined JDRF in October 2018. This merger unites our shared mission to accelerate the progress of type 1 research as well as improving people's access to new type 1 treatments and technologies, now and in the future.

jdrf.org.uk/about-us/

About Pathway to Choice

Pathway to Choice is a partnership programme led by JDRF and supported by industry partners Abbott Diabetes Care, Dexcom, Insulet International Ltd and Roche Diabetes Care.

The aim of the programme is to build awareness and access to type 1 technology choices for people with type 1 diabetes. It does this through building insight to influence policy and practice, increasing understanding of technologies among people with type 1 diabetes and raising public awareness of the condition.

jdrf.org.uk/pathwaytochoice

“There is an impression that medical technology is for certain types of people. But I think it can be massively transformational for anyone.”

—Maureen McGinn
lives with type 1 diabetes

Supported by:



Abbott

dexcom

Insulet



JDRF IMPROVING
LIVES.
CURING
TYPE 1
DIABETES.

JDRF is a registered charity in England and Wales (no. 295716) and in Scotland (no. SC040123).
A company limited by guarantee (England no. 2071638). Registered office: 17/18 Angel Gate, City Road, London EC1V 2PT.