



Healthcare  
Improvement  
Scotland

**SHTG**  
Advice on health  
technologies

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# Patient Organisation Submission Form

## Subject of SHTG Assessment

Closed loop systems and the artificial pancreas for type 1 diabetes mellitus (T1DM)

## Name of patient organisation

JDRF, the type 1 diabetes research charity

## Health/medical conditions represented

Type 1 diabetes

## Contact name for this submission

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## Role of contact person

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Date of submission

September 2021

**Please complete the SHTG Declaration of Interest form.**

**Please complete this form using the accompanying guide and do not include patient identifiable information.**

**Accessible Language:** Where not specifically required for scientific/technical explanation, please use plain language, explaining acronyms and other non-lay terms.

Please note that the information submitted on this form will be held by the SHTG in accordance with Healthcare Improvement Scotland's [policies](#). This information may be published on the SHTG website or disclosed to third parties in accordance with the Freedom of Information (Scotland) Act 2002 (FOISA).

1. Tell us about the sources you used to gather information for this submission. (See page 6 of guidance.)

500 words maximum

This information comes from ongoing conversations with people living with type 1 diabetes. Through JDRF's community engagement team, we provide information and advice to people living with type 1, including advice specifically regarding how they may be able to access technology. Many people reach out to us with questions about how they might be able to access technology, as well as any issues they may be facing with their current healthcare team or method of treatment. Many of these people who our community engagement team speak to express a desire for emerging technologies. As such JDRF works to increase the availability of treatments and technologies for type 1 diabetes, and ensure that all those who would benefit from existing treatment methods are able to access it. These people come from across the UK.

We also have regional teams based across the UK, including in Scotland, who engage with local communities, carry out events and fundraise for JDRF. This enables us to gain an "on the ground" perspective across the UK and identify commonalities and disparities between access to technology and provision. We are also carrying out a body of work to target communities that have been under served by the healthcare system, including those from socially deprived areas, from ethnic minority backgrounds or people who may not have English as a first language.

JDRF also takes views and works with researchers and academics within the field of type 1 diabetes. For example JDRF has contributed to funding Professor Roman Hovorka's artificial pancreas research at the University of Cambridge since 2006. Researchers such as Professor Hovorka are committed to making automated insulin delivery technology available to the wider community.

This submission is also formed by experience working with manufacturers of diabetes technology. We are partners with a number of organisations who make technology such as flash and continuous glucose monitoring and insulin pumps. Their expertise and knowledge of technologies support the view that a closed loop system would be beneficial for a wide number of people with type 1 diabetes.

## 2. What is the health condition and how does it affect the day-to-day lives of patients and their carers? (See page 7 of guidance.)

500 words maximum

In Scotland in 2019, there were 33,452 people recorded as having type 1 diabetes. This is 10.7% of the total number of people living with diabetes in Scotland, of any kind. The prevalence of type 1 diabetes in Scotland has risen since 2010.<sup>1</sup>

Type 1 diabetes affects people of all ages, however it is normally diagnosed before the age of 30. Many people experience a diagnosis as a result of diabetic ketoacidosis - a serious event where the blood glucose levels are high, resulting in hospitalisation, or in some circumstances it can lead to comas or fatalities. As such this can be highly traumatic for people who are newly diagnosed and their families.

Type 1 diabetes does not impact every person in the same way, and much is reliant upon the individual's lifestyle, for instance how active they are, their diet, BMI, smoking status, as well as issues such as access to technology and frequency of access to healthcare and appointments. However, most people with type 1 tell of their experiences of the difficulties of living with it constantly, where one has to constantly think about their condition and act to manage their glucose levels more effectively. This includes adjusting insulin levels depending on the amount of carbohydrates in a meal, as well as adjusting for activity levels, for different weather conditions and more.

As such the psychological toll that type 1 has on people cannot be understated. It is a condition that results in "diabetic fatigue" of the toll of making consistent decisions, as well as living with the burden of the physical symptoms. Many people with type 1 and their carers also face issues with their glucose levels at night, meaning they face a restless night where parents may need to check their child's levels several times. This results in further loss of productivity and also missed school for young people, with frequent appointments and fatigue.

Physical symptoms result from hypoglycaemic or hyperglycaemic episodes, where a person's blood glucose reaches unnaturally high or low levels. This can result in fatigue, dizziness, nausea, sweating, mood swings, blurred vision, headaches and more. The long term impact of unstable blood glucose control is also significant - complications can arise with a person's eyes, leading to a condition called diabetic retinopathy which can lead to loss of eyesight. Similarly in Scotland in 2019, 270 people with type 1 diabetes in 2019 had a record of a lower limb amputation, which occurs as another complication from diabetes.<sup>2</sup> It can also impact a person's cardiovascular system, with 1,218 people with type 1 in Scotland in 2019 having a record of myocardial infarction.<sup>3</sup> Type 1 can also impact a person's renal system, thereby the condition can impact a person's whole body over a long period of time, which

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<sup>1</sup> [Scottish Diabetes Survey](#), 2019

<sup>2</sup> [Scottish Diabetes Survey](#), 2019

<sup>3</sup> [Scottish Diabetes Survey](#), 2019

can be exacerbated through a number of factors relating to sub-optimal glycaemic management (the complexity of managing the condition makes judgements about the individual's "good or "poor" glycaemic management inappropriate).

### 3. What do patients and carers want from the health technology? (See page 8 of guidance.)

400 words maximum

Closed loop technology could have a tremendous impact on the lives of people with type 1 diabetes and their families or carers. Closed loop technology would enable the person with type 1 diabetes to not have to think about their condition as often, as they have the reassurance of their technology automatically testing their glucose levels, and adjusting their insulin accordingly. This would reduce the need for carbohydrate counting, adjusting for exercise levels and activity, for the weather and other factors that can destabilize a person's glucose levels and result in potential hypers or hypos.

As this technology is much easier to use and live with than other traditional methods of type 1 diabetes self-management, such as finger prick tests or injections, it is particularly suited to a number of groups of people - however it must be acknowledged that almost everyone with type 1 could benefit from this technology being widely available to them. The reduction in daily decision making could particularly support people with mental health issues or learning disabilities, as well as children and young adults beginning to manage their diabetes independently.

Quality of life would be vastly improved by closed loop or artificial pancreas technology. There is evidence that access to technology to help manage one's type 1 diabetes can have a substantial impact on improving HbA1c control, thereby reducing the risk of long term consequences, and removing some of the burden of the condition.<sup>4</sup>

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<sup>4</sup> Majeed, W, Thabit, H. Closed-loop insulin delivery: current status of diabetes technologies and future prospects. Expert Rev Med Devices 2018; 15: 579–590. <https://pubmed.ncbi.nlm.nih.gov/30027775/>

4. What difference did the health technology make to the lives of patients that have used it? (Leave blank if you didn't make contact with anyone who had experience of the health technology.) (See page 9 of guidance.)

500 words maximum

One of our supporters shared their story with us: "Two and a half years after DIY looping my closed loop system I met the criteria to change sensors and soon after this my clinic became an early adopter of CamAPS FX and I was offered access to the system under the NHS. Within days of starting the CamAPS FX system I began to notice improvements in my diabetes. Although it wasn't perfect it was much better than my DIY system, even in the initial three weeks where I was still learning to use the technology. I also began to notice my mood improving too.

After my first week with CamAPS FX my time in range was already better than I had managed to achieve (with a lot of effort) with my DIY version. Things have continued to improve and I'm now spending much less time worrying about my diabetes and just getting on with my life again.

The regular lows have disappeared as have the deep hypos and spikes. The CGM is very accurate (when I use a blood glucose meter to calibrate it) and so my confidence in the system grows daily. I spend hardly any time interacting with the system other than at mealtimes or telling it I'm heading out to exercise... There is not much I miss about my DIY system other than being able to see my blood glucose readings on my watch, However, this might be something the CamAPS can do in the future, as well as running on Apple's iPhone."

We also heard from parents of a child with type 1, aged 5. "Since his diagnosis, we've been on a number of different pumps and sensors which didn't really work out at all. Then we were able to join the study [clinical trial for the artificial pancreas system] which was amazing. Using the app has meant that multiple people can access their child's data at any time, meaning that his care is not in the hands of just one person". This aspect of the app gives the parents reassurance and support, as well as a greater sense of freedom. Being able to involve people remotely in their son's care is an "absolute game changer."

The app has also reduced the impact of monitoring the child's blood glucose levels at night, and they can now check by looking at the phone app rather than going up and doing a blood test.

His HbA1c has been "fantastic" since starting on the system. They also feel that using the CamAPS FX has helped identify problems before they arise. They expressed that they "knew that it wasn't going to fix everything, but it was going to help us manage the condition better. I would say that that goal - of better management - is being achieved".

"With the amount of tech that's needed for the closed loop system, the more things there are that can go wrong." But despite occasional issues, the parents are clear they wouldn't go back. "I feel very very very grateful for the opportunity to be on the app and I definitely would not want to go back."

Most importantly, the app has meant that type 1 diabetes doesn't stop their son getting the most from school and home life. "He's a very happy, healthy boy and that's the main thing."

5. **Additional information you believe would be helpful for SHTG to consider. (See page 9 of guidance.)**

In March 2020 Professor Roman Hovorka from the University of Cambridge launched the first licensed, downloadable artificial pancreas app: CamApps FX. The CamAPS FX app is backed by 13 years of clinical research carried out by Professor Hovorka and his research group. Publications related to the use of the control algorithm behind the app can be found in [the Lancet](#) and [The New England Journal of Medicine](#).

[JDRF Position statement for Access to Technology to manage type 1 diabetes](#)

6. **Please summarise the key points of your submission in up to 5 statements. (See page 9 of guidance.)**

Closed loop systems would have a substantial improvement on the quality of life of people living with type 1 diabetes, allowing them more freedom and flexibility in their daily lives, without the need to constantly think about their type 1 diabetes.

This improvement would manifest in both improved psychological wellbeing through a reduction in diabetic fatigue, along with reduction in physical symptoms that are caused by high or low HbA1c levels, given the evidence that technology can assist in stabilising these.

The long term benefit of closed loop is significant also, both in the value for patients and also in reduced cost to the NHS, from complications relating to type 1 diabetes and hospitalisations from DKA.

All people with type 1 diabetes could benefit from closed loop technology, and it is important that all patients are offered an informed discussion with their clinicians to make sure it is a viable option for them, ensuring that people who have not accessed technology in the past are not left behind.

In England, closed loop technology is currently being piloted among 1000 people with type 1 diabetes - the results of this will be instrumental in demonstrating the value of such technology given it is not currently widely accessible and many people are DIY-ing their own technology - which is unregulated and therefore not as rigorous as official assessment.

7. Please give us details of anyone outside your organisation that had a role in preparing your submission. (See page 10 of guidance.)

300 words maximum

The case studies shared about the closed loop system have been taken from conversations with our supporters, then compiled into public content on our website for media output purposes. They did not have a direct role in submitting this consultation but their insight has been a vital role in shaping the argument in favour of widespread introduction of closed loop systems.

8. Do you consent for your submission to be posted on the SHTG website? (See page 10 of guidance.)

Yes

No

Thank you for completing this form. It will be given to SHTG members to inform their development of an Advice Statement for this technology.