DBA Design Effectiveness Awards entry
November 2020
FOR PUBLICATION

Type 1 Diabetes Platform

HMA DigiBete

All statistics correct at time of publication

Executive Summary

In 2017, DigiBete approached us to co-design a digital platform to support children, young people and families living with Type 1 Diabetes (T1D) with training and self-management resources.

With lived experience of caring for a child with T1D, DigiBete's founders were keen to engage directly with the T1D community to help design an engaging resource that helps children and young people (CYP) living with T1D understand they are not limited by their condition, by providing access to clinically-approved information and advice that will help them self-manage their condition and live as normal a life as possible.

Existing digital diabetes resources are often adult, Type 2 focused, as this is by far the most common type of diabetes world-wide. So, prior to the design of the DigiBete platform, there was a significant gap in the market for a digitally enabled service that empowered CYP to better self-manage and families to better understand how to support them.

Despite there being a distinct lack of competing services, market access was not going to be easy – there were several NHS-led initiatives that had come before but had been decommissioned due to resource or funding issues. In addition to this, delivering a commissionable product into the NHS takes some start-ups 5-10 years before gaining local traction, let alone national attention with often 4-5 years to demonstrate significant impact[1].

The quality and design of the platform was going to be integral to the pace and scale of adoption and this needed to be led by the T1D community.

Through a co-design process, we worked with over 30 patient families of different ages and demographics, to inform the design and development process, validating the user experience, content, functionality, suitability for the audience and accessibility to ensure it met user needs. There is continued patient feedback from this group and the wider T1D community, continually informing the evolvement of the platform.

The result was an engaging web platform and an accompanying app with centralised content resources and personalised care plans. In recognition of the requirement for age-appropriate content, which was considerate of the patient's awareness and understanding of their illness and how involved they were in their own care, the patient groups were asked to design their own user interfaces – considering what graphics they'd like to see and how they might engage with the content. Our design team then took the graphics that had been created by the patient groups and brought them to life.

Ultimately, it was this unwavering focus on ease of use and intuitive design that was the key to success for the project.

Since launch, the multi-award-winning DigiBete platform has gained significant traction and recognition including:

- The web-platform signposted as the go-to paediatric diabetes resource on NHS.uk
- Reported NHS savings to date, as a direct result of using the app, totalling £442,370 with the potential for £1.6million+ of savings once rolled out to the entire patient cohort
- The app commissioned centrally by NHS England and NHS Improvement and rolled out to over 93.2% of paediatric diabetes clinics in England and Wales
- A 230% increase in funding received for the project since launch of the web platform
- Over 90,000 unique users that have engaged with over 3,200 hours of educational video content through the platform – information which, if delivered by a Specialist Diabetes Nurse, would have taken 2.8 years of clinic time to deliver
- A sustainable commercial model, which has directly led to other innovation projects with international giants such as *REDACTED CONFIDENTIAL DATA*

Background

In November 2015, after a prolonged period of unexplained illness, Maddie and Rob's 20-month-old son, Otis, was urgently admitted to hospital where it was confirmed he had entered Diabetic Ketoacidosis, a life-threatening condition caused as a result of prolonged high blood glucose.

Having been diagnosed with Type 1 Diabetes (T1D), this was just the start of an exhausting and emotional recovery period, and acceptance that part of Otis' pancreas had now failed and that he would need to inject a hormone called insulin for the rest of his life.

Maddie and Rob attended intensive training sessions to equip them for a lifetime of self-management. However, like many parents in this situation, the sheer amount of information they needed to learn and retain was overwhelming and they were frequently in contact with the clinic or admitted to hospital, at a great cost to the NHS.

NHS funding for online self-management support had run out and Otis' family and friends, who had not attended the hospital training, admitted they were now too scared to look after Otis without this vital information. Maddie and Rob lost their child support network overnight and unfortunately, this story is not uncommon for the families of the ~35,000[2] children and young people (CYP) in the UK living with T1D.

35,000
children and young people in the UK live with Type 1 Diabetes

T1D care has traditionally been via regular NHS appointments with diabetes teams, with additional face to face and verbal contacts from specialist staff between visits. Educational materials have been paper based and written in English. Group education sessions are offered to patients, but are often not well attended due to time away from school, or reluctance to meet unknown peers. Existing web resources are often adult, Type 2 focused, as this is by far the most common type of diabetes world-wide.

Motivated to make a difference

With first-hand experience of how difficult the T1D journey is, Maddie and Rob embarked on a collaborative project with the Leeds Children's Hospital diabetes team to create a sustainable social enterprise... and DigiBete was born, with the purpose of creating digitally enabled training and self-management resources to support families like theirs.

But how could DigiBete succeed where other NHS-approved resources had failed? They held the belief that by taking a design-led approach to digitalising what is typically provided as written or verbal information in a clinical setting, families will have 24/7 access to potentially life-saving information at the touch of a button.

Prior to our involvement, DigiBete had launched a basic, self-funded website in June 2016 housing 10 T1D videos to serve as a proof of concept – the idea was extremely well-received, but there was a stream of feedback around how the platform could be further developed to better emotionally support CYP and families living with T1D.

This prompted DigiBete to engage with us in 2017 to create an age-appropriate, scalable and easy-to-use digital training and self-management platform, with the purpose of providing families and carers access to both initial and refresher training, without needing to call the NHS.

Beyond providing continued, structured education for all children, young people and families to support both physical and mental health and wellbeing, the objectives of the platform were to:

1. Gain recognition as a clinically approved T1D resource that NHS healthcare professionals can signpost patients and their families to
2. Reduce the unnecessarily high and repeated level of NHS clinical contact that children and young people require on an annual basis
3. Create tangible financial savings for NHS diabetes teams
4. Empower children and their families to better self-manage T1D to improve health outcomes and quality of life, by extending the reach of clinical teams online
5. Create a sustainable operating model for DigiBete

Intended to appeal to audiences involved in diabetes care, DigiBete is used by:

- ✓ Children and young people (CYP)
- ✓ Parents, friends and family
- ✓ Schools and teachers
- ✓ Healthcare professionals

The scope of the work included:

- Co-production of the requirements and functionality for the digital platforms
- User experience and user interface design
- Production (see below for budget breakdown)

Taking a co-design approach

The need to engage with patients, families and clinicians in the development process was driven by the focus on developing engaging designs, and a desire to provide a seamless user experience for all audiences.

Whilst we knew this needed to be a digital platform, there was still scoping to be carried out at the start of the project, and a strategic approach was needed to discover the barriers patients face, in order to help solve some of their problems. We worked collaboratively with co-design facilitators 'mHabitat', who guided the team through mapping outpatients' current experience of living with T1D and visits to their diabetes clinic. In addition to input from the clinics to explore the service design of the current pathway, patients and families were instrumental in the design and user experience of the platform.

It was clear from the beginning that due to the complex nature of T1D, a 'one size fits all' approach to self-managing the condition was not going to work.

It was therefore important that the platform could be personalised and adapted to suit each family's needs. On the understanding that people like to consume digital content in a variety of ways, we devised a multi-platform approach to this project with the creation of both a web platform, which launched in February 2018, and accompanying iOS and Android apps, which launched in November 2019. A phased approach was applied to the creation of these platforms to accommodate funding streams, content application and clinical safety processes.

The total fee for the project (web and app) was *REDACTED CONFIDENTIAL DATA*, with 20% of this fee allocated to the design process *REDACTED CONFIDENTIAL DATA*

Designed by CYP for CYP

One of the outputs of the co-design process was the requirement for age-appropriate content, which was considerate of the patient's awareness and understanding of their illness and how involved they were in their own care.

As part of the co-design sessions, we asked CYP to conceptualise their own user interfaces – considering the type of graphics they would like to see for their age group, and how they might engage with the content.

Our design team combined these concepts with outputs of our research, and their user experience expertise, to bring the graphics to life within the user interfaces. By incorporating CYP-created graphics into the design, there was an increased opportunity to resonate with that target age group, as the user interface had been conceptualised by their peers. It also provided the co-design group with ownership of the platform, leading many co-design participants to become T1D community ambassadors – and even giving them the confidence to appear in some of the videos!

We then worked with the co-design participants to categorise the content, understanding how they viewed the support and advice they received, and classifying it into groups such as clinical, peer support and technology. This informed the taxonomy of the site and appropriate tagging of content, making sure content was easy to search and find for launch, but also in preparation for the scale-up of content and information as the platform grew.

Whilst video is the primary vehicle for the delivery of content, there are many other written and audio resources to support this. To validate that the content is well received, we designed an (optional) easy-to-use feedback mechanism into the user experience, along with age-appropriate quizzes throughout the site, to enable CYP to test their knowledge and understanding of T1D and signpost them to resources that can support them with any gaps in their knowledge. This made for a more interactive experience for the audience, rather than just the provision of information.

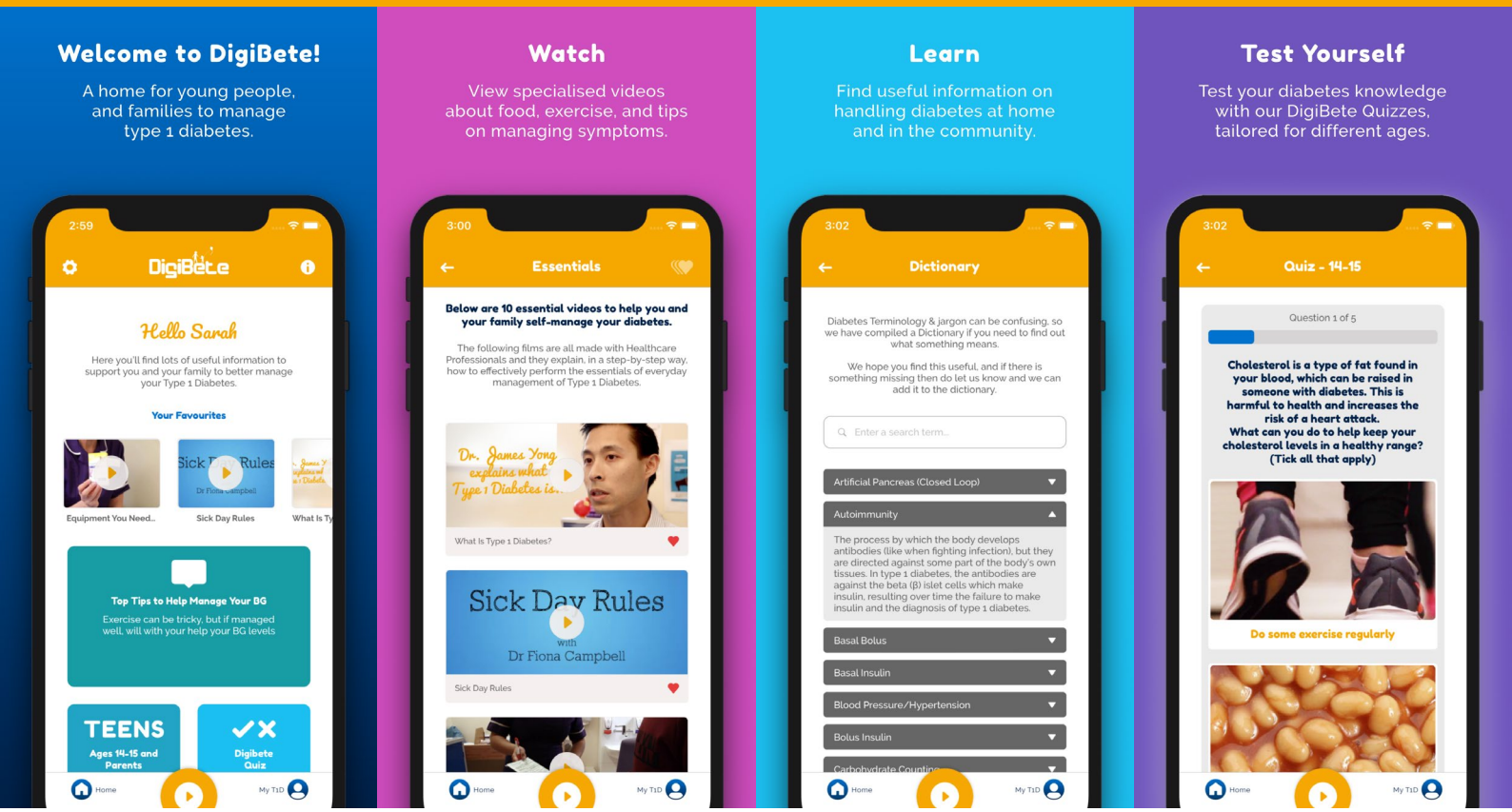
In a bid to combat health inequalities caused by language barriers, a translation service was designed into the platform. DigiBete is available in over 80 languages, providing CYP and their families with NHS approved clinical advice 24/7, irrespective of location and nationality.

Ultimately, it was this unwavering focus on ease of use and intuitive design that was the key to success for the project.

Before

After

Extending the platform to iOS and Android



After completion of the initial DigiBete web platform, the service was extended to an app format, delivering a bespoke tool to facilitate a more personalised approach, by addressing key barriers to good diabetes care.

The app provides easy access to all of the valuable training and self-management resources housed on the web platform. In addition, to align with the outputs of the service design research, functionality was designed to enhance the user experience including:

- **My T1D - A patient-held record of personalised information about their diabetes care, including the ability to record patient-specific insulin pump settings**
- **Appointment tracker to prevent missed appointments**
- **Clinic communication channels, with tailored support to groups of patients , either by age or by circumstance**

The design of the app incorporates a gamified reward model to encourage the consumption of content and information by patients, which has encouraged engagement from CYP in addition to their wider network.

It was essential that we used an iterative design process from the start of the project to build in capacity for user feedback and clinical safety considerations, with the app undergoing a 3-month period of clinical trials and evaluation across four sites.

Overview of market

The UK has one of the highest rates of T1D in the world, with approximately 35,000 children and young people in the UK living with T1D[2]. In children under five, the incidence of T1D is rising by five per cent each year[3].

The cost of diabetes to the NHS is therefore very high at an estimated £1.5m an hour, or 10% of the NHS budget for England and Wales[2]. This equates to over £25,000 being spent on diabetes every minute, with the requirement to treat complications representing the much higher cost[2].

Diabetes
costs the NHS £25,000 per minute

There is a good level of online information about T1D available from the NHS and diabetes charities, such as Diabetes UK and JDRF. However, resources are primarily focused around symptoms, diagnosis, product availability and research and very targeted towards an adult population living with T2D.

Prior to DigiBete, there had been some NHS-led initiatives that provided paediatric T1D resources online, but many of these have since been decommissioned due to either resource or funding issues.

There are over 1,000 apps on the App Store and Google Play designed to support people living with diabetes, but only 236 of these are evidence-based, clinically validated and recommended for patient use[4]. Excluding DigiBete, only three of these 236 apps have been specifically designed for children, but none of these have been specifically developed for a UK paediatric audience receiving NHS care[4].

Of the 1,000+ apps designed to support people living with diabetes, none had been specificaly developed for a UK paediatric audience before DigiBete

This might infer that DigiBete had an open market to walk into, but it is quite the opposite. The co-ordinated approach to offer nationwide, clinically approved information and advice outside of a clinical setting is not a challenge anyone else has successfully taken on, and so the risk was great.

The opportunity to support this niche but potentially expensive patient cohort is a complex challenge and requires a focus that only an organisation like DigiBete could provide.

Rather than competing with other resources, DigiBete has plugged a gap in what may seem like quite a crowded market on the face of it. This has not only enabled them to gain traction quickly, but by taking a community-based approach to design, they've moved away from an organisational approach to the provision of information, and put this in the hands of the T1D community; bringing together an ecosystem of partners and advocates, to compliment and support other T1D information-based resources and organisations.

DigiBete takes a T1D community-focused approach to digital service delivery

Results

DigiBete's reach and impact extends to benefit those families and communities who need it most, whilst providing significant potential efficiencies to the NHS. The app reduces the need for costly ad-hoc clinical contacts by improving education in real time, through both automated and customised support.

Objective 1:

Gaining recognition as a clinically approved T1D resource that NHS healthcare professionals can signpost patients and their families too

DigiBete has attracted recognition from NHS diabetes consultants, national charities including Diabetes UK and the Juvenile Diabetes Research Federation (JDRF) and the National Children Young Peoples Diabetes network (NCYPDN).

> **"We recognise DigiBete's growing importance as a high-quality peer support and educational platform. This is a vital adjunct to the clinical support delivered by healthcare teams."**
>
> National Children and Young People's Diabetes Network

And in 2018, NHS England began signposting to DigiBete as a go-to paediatric diabetes resource through the patient-facing NHS.uk website (see below).

With the onset of Covid-19 and the growing recognition within clinics that the DigiBete App offered an intuitive, practical, readily available and cost effective solution to allow clinics to support their patients remotely, especially useful during the current crisis, NHS England engaged with DigiBete in April 2020 with a view to offering this resource nationally. An agreement was reached for a support contract commencing 1st June 2020, to fund this service centrally and offer it to clinics free of charge, to encourage maximum uptake. DigiBete was one of only three digital diabetes platforms chosen by NHS England Diabetes Programme under the Covid-19 emergency response, and the only one supporting CYP and their families.

At the time of publication, 93.2% of the 155 clinics in England and Wales have been onboarded to offer the DigiBete app as part of their clinical services. 137 remote training sessions have been delivered to clinics, and patient onboarding has commenced with 28.4% of the 35,000 patient cohort now actively using the app. This represents a rapid level of onboarding for a new patient-facing technology within the NHS, and feedback has been that the ease of use and simplicity of the design has facilitated this.

In addition, a more comprehensive programme for healthcare provision across the North West region has been commissioned by NHS England and NHS Improvement to support transitioning to Adult (16-25). Further development of additional resources will take place during this 24 month contract to help clinics to fully integrate the App and resources into their services.

Industry recognition has been boosted by several significant award wins including:

- Sanofi Quality in Care (QiC) Award for Specialist Type 1 Services - 2018
- 'Best use of Technology and Social Media' at the Leeds Teaching Hospitals NHS Trust awards - 2018
- 'Best Third Sector Platform' at the Northern Dev Awards – January 2020

> **"DigiBete gained unanimous praise from patient representatives and healthcare professionals. It's a great resource – the videos are especially appealing to children. It succeeds in being 'aspirational' about what people with the condition can do, but also offering high quality practical advice in line with national guidance.**
>
> **"It provides quick answers to common questions, but also provides in-depth explanations for technical areas such as insulin pumps and brings lots of resources together in one place. There is real potential for this service to make a difference in helping to raise standards and produce more consistent guidance across the country."**
>
> Judges comments, QiC awards 2018

Objective 2:
Reducing the unnecessarily high and repeated level of NHS clinical contact that children and young people require throughout their T1D journey

DigiBete's ability to reduce unnecessary clinic contact during the pandemic has been recognised by NHS England through the national commissioning of the platform in order to provide patients with better remote support. Recent findings show that people with diabetes face a significantly higher risk of dying with Covid-19, but better management of the condition can help improve control and lead to better outcomes[5].

The NHS has invested in this technology to offer patients advice on treatment and care, as well as training to adopt healthy behaviours on diet and exercise.

"Living with Type 1 or Type 2 diabetes is a daily challenge for millions of people and knowing they are more at risk if they are infected with coronavirus will be worrying, but the NHS has taken action to help people and keep them safe, including the roll out of these helpful apps [DigiBete].

"Access to trusted information and support is key to helping people manage their diabetes and we are delighted to support these tools which will hopefully empower people to look after their own condition and reduce their risk."

Professor Partha Kar, national specialty advisor on diabetes for NHS England and Improvement

DigiBete users have watched over 3,200 hours of educational videos through the platform.

The information contained in most of these videos would traditionally be delivered via an in-clinic or remote demonstration or discussion, sometimes multiple times for those that struggled to grasp some of the concepts. It would take a Specialist Diabetes Nurse approximately 2.8 years to deliver the same level of information, based on holding clinics for five hours per day.

It could be argued that many of the videos contain 'softer' information that may not need to be delivered in a clinical context, but even if we just take the analytics for 15 'Essential Videos'* out of the 200+ videos on the platform, DigiBete users have watched over 1,400 hours of this 'essential' content, which would equate to 1.2 years of clinic time for a Specialist Diabetes Nurse that can now be freed up for critical clinic contact.

When consulting with 23 parents of children living with T1D, 91% of families surveyed said DigiBete would help reduce their need to contact their diabetes team in the future for non-emergencies.

* Essential videos cover very specific, clinically approved information that would always be delivered by a healthcare professional

Objective 3: Creating financial savings for NHS diabetes teams

The cost of diabetes to the NHS is estimated at £1.5m an hour, or 10% of the overall NHS budget for England and Wales. This equates to over £25,000 being spent on diabetes every minute, with the requirement to treat complications representing the much higher cost.

Good self-management of T1D can help patients achieve good blood glucose control, preventing associated complications, and reducing the need for ad hoc clinical contact. This in turn reduces the financial burden on the NHS from a cost of up to £4500 per patient per annum for inpatient care to treat short- and long-term complications of diabetes, to annual outpatient costs of £370 per patient[2].

Because the platform has been designed with ease of use in mind, not only from a patient perspective but also in terms of its management and capability for the clinic to personalise to their needs themselves, this has reduced operating costs. DigiBete is able to offer a cost-effective app subscription rate equating to <1% of clinic patient budgets. The return on investment is significant – reducing the physical preparation and distribution of sending out 4 letters to a patient each year covers the subscription cost alone.

NHS savings are currently reported at £47.50 per patient per annum which for the current patient cohort using DigiBete (9,330) totals £442,370 of savings per annum, with the potential for £1.6million+ of savings once rolled out to the entire paediatric diabetes patient population.

It has been estimated by NHS clinics that there is potential to increase this saving 10-fold once the platform becomes more embedded in the care pathway and the resulting impact is fully realised.

These additional cost savings, recognised and acknowledged by the clinic teams, will be derived from:

- **Process efficiencies within clinics**
- **Digitisation of communication with patients**
- **Reduction in unnecessary clinical contact**
- **Reduction in non-attendances, which cost approximately £120 per missed appointment**

Objective 4:
Empowering children and their families to better self-manage T1D, to improve health outcomes and quality of life, by extending the reach of clinical teams online

The DigiBete web platform has had over 80,500 unique users nationwide, with visitors staying for an average of 5 minutes, demonstrating that they are absorbing a wealth of content during their visit. If we assume that only 25% of this audience are patients and their families, we are actively engaging with over a 1/3 of the 35,000 patient cohort through this part of the platform.

The DigiBete app been downloaded 11,821 times with 79% of these downloads resulting in patient registrations following a clinic referral (9,330 patients).

When consulting with 23 parents of children living with T1D, 87% found the DigiBete platform helpful or very helpful with 91% feeling the content was high quality. 78% said they use the resource to train other members of their family, schools or their community about T1D.

Regularly received patient and parent reviews support the usefulness of the platform, positively commenting on the design and ease of use:

"It is great, there's so much on there but it's really easy to navigate!"

"It's really good, love how it's personal to individual child's needs. I've started to upload info – it will be great to have everything in one place."

Objective 5: Creating a sustainable operating model for DigiBete

Based on the success of the platform and the community it has created, DigiBete has successfully built an organisational structure which delivers a sustainable and robust commercial revenue, with a stream of funds invested straight back into supporting the T1D community.

The progress that DigiBete CIC (Community Interest Company) made since the launch of the web platform in February 2018 led to the creation of DigiBete Global Limited, a commercial arm created to provide better access to innovation funding for projects such as the DigiBete App design and development, which was subsequently gifted to the CIC to support ongoing sustainability. DigiBete Global mirrors the Tech4Good objective of the CIC and is licensed to further develop and expand the DigiBete 'model', which has been recognised by The Health Foundation as an exemplar for other long-term conditions.

Between November 2015 and the February 2018 launch, DigiBete raised a total of *REDACTED CONFIDENTIAL DATA* to support the initial stages of the platform design and content creation. In the period following the launch (February 2018 – November 2020), DigiBete received additional funding of *REDACTED CONFIDENTIAL DATA* representing a 230% increase in funding success post-launch within a similar period of time (27 months pre-launch and 33 months post launch). This includes winning The National Lottery's People's Project Award, awarded by public vote, which provided £50,000 of funding and has enabled the DigiBete team to carry out further work with children and young people, to create resources that will support them at home and in the community, and prepare them for adult care.

Since the launch of the app, clinic subscriptions have provided a further, sustainable revenue stream that will act as annual recurring revenue. Whilst the initial clinic subscriptions were set to provide a steady stream of revenue from launch, the vote of confidence that the national commissioning of the platform provided has been significant in expediting this commercial model with licensing app subscriptions revenue totalling *REDACTED CONFIDENTIAL DATA* in 2020.

As a result of this project, further innovation projects that DigiBete has embarked on include:

- **A collaboration with CYP MedTech, IBM and others to develop a Chatbot to benefit young people with T1D transitioning to adult services**
- **A development pathway project to enhance the DigiBete CIC web platform and app with important additional functionality**

Both of these projects will allow the CIC to further embed its services in the NHS Diabetes Care System and protect its sustainability and services in the long run.

REDACTED CONFIDENTIAL DATA

Influencing factors

The co-founders of DigiBete are the driving force behind this initiative.

Their passion and tenacity, combined with their lived experience of caring for a child with T1D, puts them in an ideal position to engage with the UK T1D community in a way that no-one else has been able to. That said, in order to bring their digital ambitions to life, they required a creative agency focused on user experience that could create engaging user interfaces and journeys that resonated with a diverse target audience. The platforms needed to live up to expectations, with a design that reflected the values of DigiBete and effectively represented the inputs of the CYP audience, which was achieved on both counts.

Alongside the digital platforms, DigiBete has built up a good social media following with high engagement levels which has provided visibility of the platforms however, most of this audience was built post-launch of the web platform:

2,477 Facebook followers

2,643 Twitter followers

The Covid-19 pandemic has undoubtedly expedited the national commissioning of several technology platforms, including DigiBete, but given that there was significant NHS engagement, both locally and nationally prior to March 2020, the effectiveness of the concept and design had been proven out prior to this point.

References

1. The Kings Fund
2. Diabetes UK
3. Juvenile Diabetes Research Foundation (JDRF)
4. ORCHA.co.uk
5. NHS.uk