

FRUSTRATED

to

FUTURISTS:

Diabetics Transform Self-Management

Diabetes technology continues to enhance the management of the condition - but **not without patient input.**

Graphics: Dhruva Al-Zaidi

John was only a teenager in 1965, enjoying his usual summer routine of delivering newspapers after school when he was told that he would need a lifetime of injections and wouldn't live past the age of 30. No, this is not a scene from a twisted Stephen King novel, but the harsh reality of type 1 diabetes before the emergence of diabetes technology that would soon change the trajectory of the treatment for the chronic disease.

With no disposable syringes at the time, just 44 years after the discovery of insulin by Dr Frederick G. Banting, John, who has asked not to be named for privacy reasons, had the tedious job of boiling his glass syringe every morning with the hope of sterilising it well enough for another week's use. Sometimes, he even had to sharpen the needle with a stone to repair its blunt tip.

Today, approximately 422 million people are living with diabetes worldwide, according to the World Health Organisation. In the UK, over 5 million people are affected. Insulin is a hormone produced by the pancreas and is required for people with type 1 diabetes, as well as some with type 2, to enable the transportation of glucose to vital muscle cells that emit energy. Without insulin, diabetics face complications that impact their long-term quality of life, such as eye problems, nerve damage, and kidney failure.

But following the emergence of diabetes technology in the 1950s, the condition has become much more manageable and the burden on diabetics like John has lessened. These technologies include devices such as continuous glucose monitors (CGMs), insulin pumps and digital insulin pens. This month, the NHS



will launch a world-first access scheme to the 'artificial pancreas', an automated insulin-delivering device that automatically adjusts insulin doses depending on blood glucose needs.

It's also announced this will be part of a 5-year strategy to equip tens of thousands of people with type 1 diabetes, including children and pregnant women, with a hybrid closed-loop pump. This pairs an insulin administering pump with a CGM, which 'communicates' when insulin is needed depending on the glucose results in real time.

The latest diabetes devices, like CGMs and now, wireless pumps, have helped relieve the pressure that people living with the disease face, including at work,

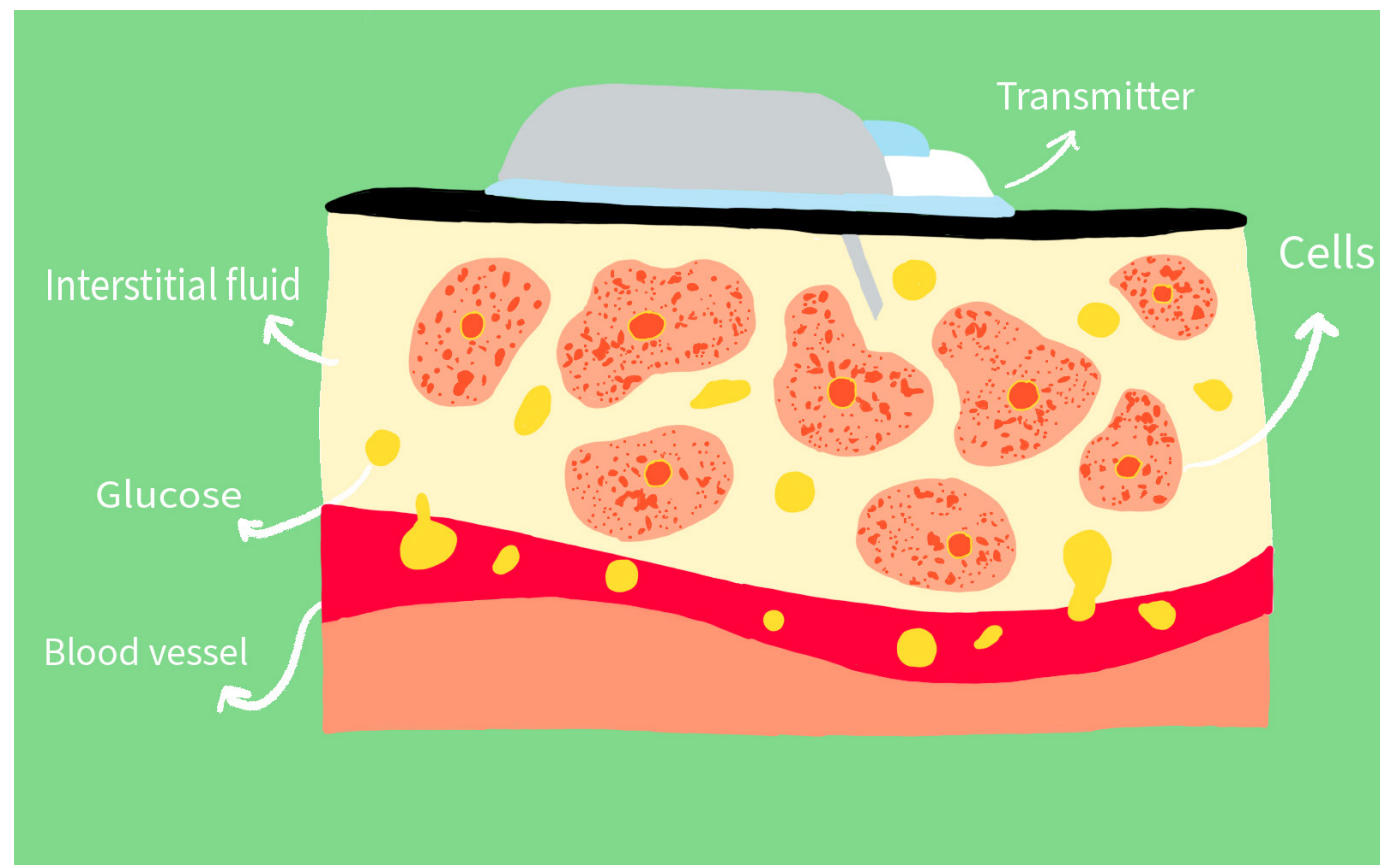
their social life and for some, their relationships. For one, it alleviates the tiring process of delivering multiple daily injections (MDI) across body sites, like behind the arms, the abdomen or buttocks, with extra care to avoid lipohypertrophy – fatty tissue that forms as lumps under the skin if insulin is repeatedly injected in the same place.

Or the agonising procedure of pricking the finger several times daily with a lancet needle to squeeze enough blood for a glucose testing strip, leaving fingers sore and numb to the touch.

Admirably, these individuals have persisted in living with the complexities of diabetes and have come to terms with what the condition means to them. In

John (above), enjoys riding his bike as part of his diabetes management. Photo rights to John.

A CGM (below) is inserted 0.5 millimetres into the skin, reading the interstitial glucose, rather than the capillary blood cells, through a transmitter. Illustration: Dhuha Al-Zaidi



some cases, many even feel more knowledgeable than their doctors, who can misunderstand their patients' needs given their limited time to see them during appointments. This undeniable sense of frustration has been empowering, leading to more patient collaborations with healthcare practitioners and the medical device industry, eventually changing how diabetes is self-managed.

But where groundbreaking technology may be practical, there's an extent to which one can rely on it. Issues with disruptive CGM alarms, which are more jarring than the default ones on the phone, overwhelming blood glucose data on demand, and inaccessibility due to high costs and NHS waiting lists, remain.

As a result, the formation of the DIY closed-loop community, which started the movement as a response to their frustration, suggests diabetes technology still has a long way to go.

A diabetes clinical researcher, patients and innovative diabetes technologists and designers living with type 1, share how the journey from manual insulin therapy to automatic, pain-less sensory devices have emerged and transformed millions of lives - thanks to the devoted members behind them.

John recalls when he first received a tethered, also called tubed, Animas insulin pump in 2004. "It was complete and total freedom," he says. "I remember it was like being a kid again - the first time I went to bed with that pump on, I couldn't bring myself to believe that I could go to sleep without fear of going into hypoglycaemia at night because I didn't eat enough before."

Hypoglycaemia is the process when blood glucose levels dip, which requires people with diabetes to treat it by eating enough carbohydrates and sugar. Continuous glucose monitors are devices worn on the arms that measure blood glucose and

were created with the hopes of replacing painful finger-pricking tests that diabetics must endure multiple times a day. Measured by a small sensor, a thin filament material pierces the skin by 0.5 millimetres and only requires a mobile phone or device reader to read the interstitial glucose levels in real time. The device is to be replaced every 14 days.

Research looking at the use of diabetes technology in patient self-care found that consistent use of CGMs and pumps had improved HbA1c levels. This measures the blood glucose attached to haemoglobin to identify diabetes control, by 0.3 to 0.6 percent.

Sure, AI machine learning has significantly aided diabetes management, but the recent progressive diabetes tech has not prevailed without fed-up diabetic patients, whose input has been paramount in attesting to its success.

CGMs Redefine Confidence

Diabetes is a "very personal disease that affects you in different ways," says Aidan Khan, an aspiring medical university student based in Ontario, Canada. Diagnosed as young as five years old, Khan describes his upbringing as "chaotic", but commends diabetes technology, which he is granted under the governmental Assistive Devices Program, for alleviating his struggles.

The COVID-19 pandemic shook the world and caused turmoil for years after its announcement in 2020. For some diabetics, the inability to access face-to-face hospital consultations; the uncertainty of when the next visit with the endocrinologist would come, impacted their time in range (TIR). This refers to the data that measures the time the blood glucose is within a 'target goal' and differs between each individual.

This affected Khan's mental health, where the fluctuations in his emotions: stressed, crabby, and irritable, disrupted his blood glucose levels and caused him to alternate from hypos to hypers - high blood glucose, which ultimately triggered a seizure.

Khan was eventually given the Tandem t:slim insulin pump with control IQ technology, and the Dexcom G7 CGM. "The ability to predict and adjust the basal rates smoothed out a lot of issues with the spiking and adjustments with multiple daily injections," Khan says. "That helped me gain better control of my diabetes and gave me the break I needed to recover."

Basal rates are also known as

'background insulin' and is a slow-acting insulin often taken at night to operate up to 24 hours. Thanks to the unique functions of the Tandem t:slim, Khan now enjoys integrated 'modes' that enhance his quality of life. For example, the sleep mode stops supplying insulin during sleep to prevent hypos, as does the exercise mode during intense activity.

The increasing use of Abbott's FreeStyle Libre CGM, which is now accessed by more than 5 million people in 62 countries according to its data, reportedly reduced diabetes-related burdens, improved hypoglycaemia unawareness, and even cut paramedic callouts and hospitalisations.

John, who like Khan suffered from a critical hypoglycaemic seizure which left him unconscious for hours, was provided with a CGM that helped him remain on top of his self-management. "The CGM allows me to drive my car, ride my bike and I can see whatever is going on in the world and not worry about it," he says.

This is something he never could have imagined as a teen when he could only measure



his blood glucose levels by dipping a test strip into his urine and comparing the result to a corresponding colour chart. "The most important thing I can see [from the CGM] is a graph that shows trends, and I can proactively make decisions instead of worrying about what has occurred in the past."

The FreestyleLibre was first introduced to the UK by the NHS Drug Tariff in 2017, with a mission to expand access to at least 20 percent of people in diverse regions with 'hard-to-reach' groups. But issues with getting this life-changing tech, expensive external funding outside of health insurance, and for those in the UK, tiresome NHS waitlists, have forced some to resort to their own methods of coping with the demands of diabetes that patients must comply with.

People living with diabetes often experience overwhelming thoughts about managing their condition.

Photography: Yogendra Singh. Illustration: Dhuha Al-Zaidi



DIY systems are here for good... at least for now

Of course, the evolution of these medical devices doesn't come from luck or bedtime wishes and requires a substantial amount of research, funding, and licensing to ensure it is safe. The first commercially available hybrid closed-loop system - a model that synthetically adopts the function of the pancreas by dispensing insulin in small intervals whenever the body needs it, was introduced to the UK in 2016. Yet asking a person with diabetes to wait to receive such transformative treatment is about as reasonable as poking someone incessantly and asking them not to react.

Hence, technological-minded diabetics found themselves forming an online community called #WeAreNotWaiting to provide a solution for those fed up with costly, time-consuming, and inaccessible healthcare.

The movement was first founded by Dana Lewis and Scott Leibrand in 2013, who initially wanted to increase the volume of CGM alarms that alert its users of fluctuating blood glucose at a level which requires them to take immediate action. Now, this empowering hub paved the way for 'open-source licensing' for thousands of community members, enabling free use of software available on GitHub, that merges pumps with CGMs to manage diabetes better.

A deep dive into the impact of DIY systems on glycaemic control conducted by the Diabetes, Obesity, and Metabolism organisation found that the 80 participants who implement-

ed the system into their daily routine had an overall increase of TIR, by just over 9 percent.

As of March this year, Lewis reports more than 3000 world-wide individuals are implementing DIY closed-loop systems - just from self-reports alone. One UK Facebook group, dedicated to sharing looping resources and advice to fellow committee members, has over 3,000 participants, indicating a growing commitment to the movement.

Other DIY systems include AndroidAPS and Loop, which rely on apps and websites like xDrip+ that conveniently read CGM results from a phone and upload it to a cloud software to adjust insulin based on the glucose result from 30 minutes prior, and the current reading. Another notable mention is Nightscout, which was created by parents and caregivers as a reliable way to remotely access CGM readings of children with type 1 whilst they were at school.

When offered the FreestyleLibre 2 by the NHS after experiencing a life-threatening hypoglycaemic episode overnight, Tom, who has asked not to be identified for personal reasons, says he no longer feels worried about losing control of his blood glucose levels

"Just having the ability to read my sugars built into my phone is awesome," he says. "When they updated the Libre, so you didn't have to scan the sensor and uses Bluetooth to send the reading to my phone, it reduced the effort I had to put in to keep on top of things."

Tom channelled his "annoyance at doing insulin calculations" during every meal into a practical app that integrated his carbohydrate-to-insulin ratios - a flexible calculation that determines how much insulin is needed to make up for the carbohydrates consumed, depending on individual needs. Though this won't be accessible to anyone else yet, this customisable function helps Tom gain better control of his condition.

Through the xDrip app, Tom connected his CGM to his Bangle

Js.2, the world's first open-source smart-watch, to permanently display his blood glucose readings on screen, without having to scan it with an external device or mobile phone. The results have been rewarding: "Xdrip itself is better as it's easier to input information, is very customisable and it can predict your blood sugar given the information you put into it - what you've eaten, how

without being unaware.

A POV of Tom's watch screen, displaying his blood sugar reading on the top left.

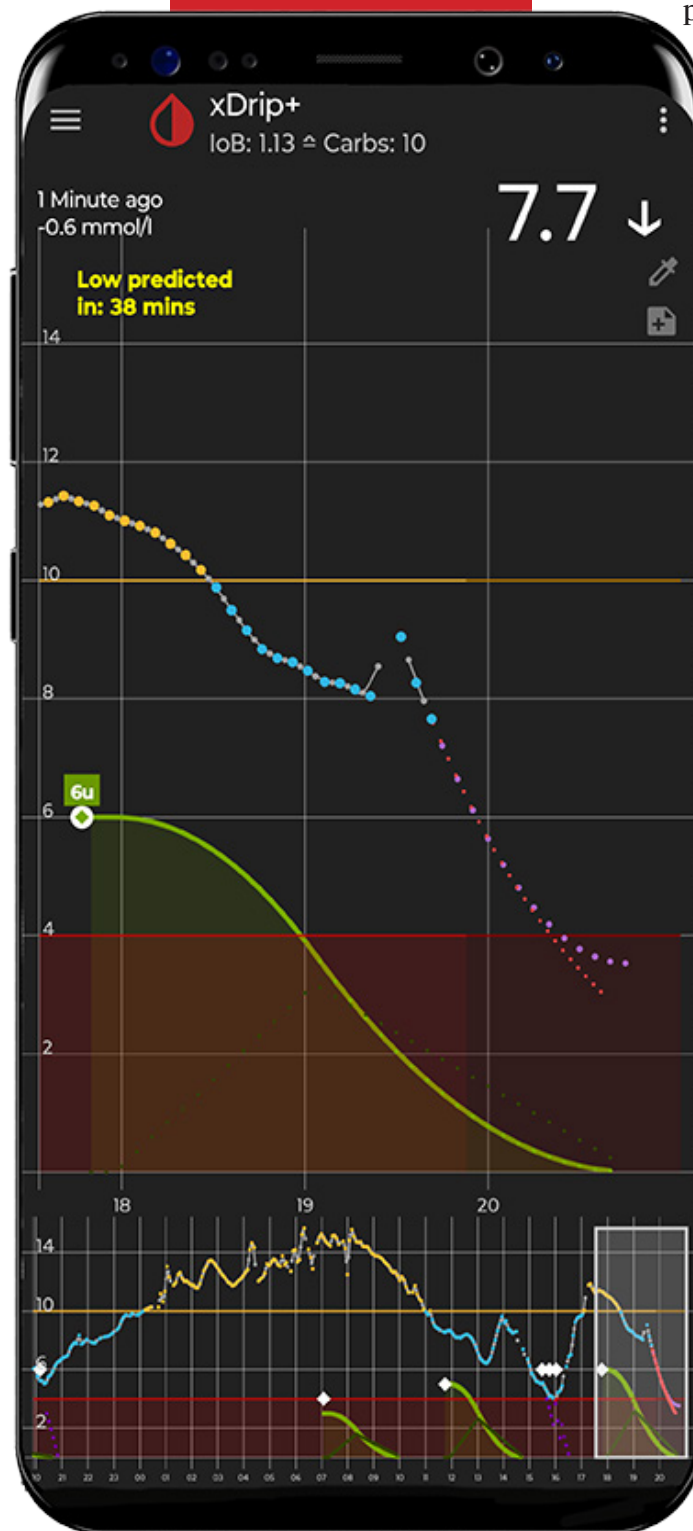
much insulin you've injected, and what your blood sugar is doing, from the Libre sensor data," he says.

Too good to be approved?

Some reports suggest that DIY APS systems can save a day's worth of time per month. But whilst this promising fact may appeal to like-minded diabetic tech fanatics, there are concerns about the extent of its use. The leading charity Diabetes UK notes that only users who are well-versed in machine learning and can refine algorithms to their own needs can operate the system adequately.

The Juvenile Diabetes Research Foundation (JDRF) has also warned against any use of unregulated DIY systems and claims that they may carry risks. Since the software only relies on community members who share their expertise through online forums, DIY systems remain unregulated in the UK so users cannot report any incidents.

Still, only one in five clinical commissioning groups fund commercial closed-loop devices, and it is dependent on those who meet the criteria as set by the National Institute for Health and Care Excellence. The price of obtaining these devices out of pocket can cost up to £3000 just for set-ups. Alas, DIY systems are here to stay, as reports expect an 18 percent growth in the APS market from 2020 to 2025.



A POV of Tom's data on xDrip, displaying his IOB, or 'insulin on board', predicting hypos and analysing the insulin absorption rate.

Photography: Tom/ Adobe Stock.
Graphics: Dhuha Al-Zaidi

Unveiling the Players Behind Diabetes Care

Edward Chao, a clinical professor at the University of California San Diego, began specialising in diabetes due to the "patients with diabetes that show tremendous resilience", he says.

A mission to "understand the unmet needs and frustrations" that people with diabetes face, as a non-diabetic, may be delusional or far-reaching to some people. However, Chao was determined to apply human-centred design (HCD), a system that adopts patient input and applies it to clinical research to refine something based on the feedback, in his research.

"The thing about medicine is it keeps you humble, no matter how long you've been working, or no matter how expert you are, in any field or subfield there's always so much more to learn," he says. "Patients are the ultimate teachers."

He, along with a dedicated team of researchers, designed an app that offers "real talk" to people

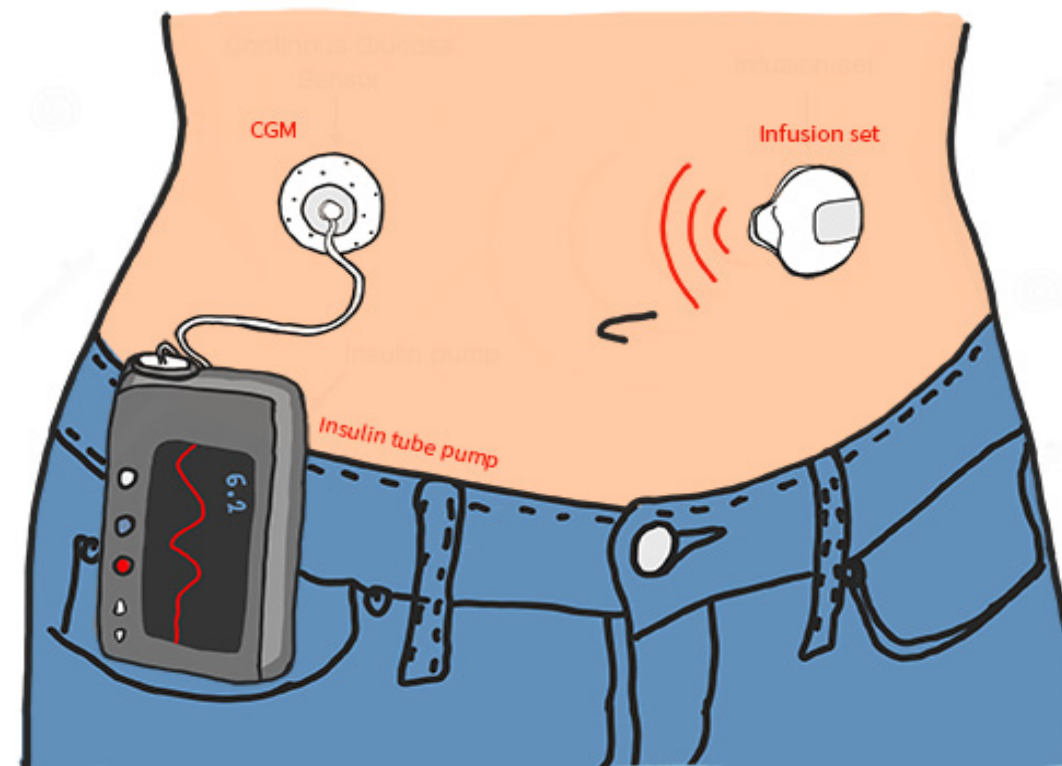


Illustration: Dhuha Al-Zaidi

with diabetes. In assessing the necessary improvements that diabetes technology needs, Chao found that patients thought the instant and easily accessible blood glucose data from CGMs to mobile phones was overwhelming. He also found that patients required personal face-to-face interaction with their healthcare practitioners for effective communication.

Chao's research reports that patients with diabetes typically saw their healthcare team for 2 hours each year. His attempt at finding a solution was Glucose - a personalised app that acts as a facilitator for patients new to the CGM phenomena and in need of support. The app offered three valuable services: the ability to log individual blood glucose targets, a daily tracker to fulfil these goals, and an online hub with fellow diabetics that proposed questions and answers.

The positive responses from its users, similar to the DIY APS systems, found that patients felt more comfortable exchanging advice with each other, and said their initial concerns about CGMs were understood and remedied.

nosed with type 1 diabetes. This shifted his perspective on the struggles that people with diabetes face, as he came to terms with his own. Eventually, the invention of the first Food and Drug Administration (FDA)-approved InPen was born.

"The concept that has underscored everything I've worked on in the industry is ultimately providing things that people want to live with," he says. "You can't describe to somebody what it's like to be walking

down the aisle in a supermarket with your kids and realise that your blood sugar is low, and you don't know what to do about it.

"You're starting to get confused, and your kids are there and you know you have responsibility for them. If you can make somebody understand that, then you've started to help them understand what it's like to have type 1 diabetes."

The InPen is a smart insulin pen that combines the same functions of an insulin pump for diabetics who enjoy the benefits of MDI. This multifaceted invention tracks insulin intake, records the dose of insulin in your system, and even embeds a dose calculator for carbohydrate consumption.

"The thing about medicine is it keeps you humble...."

Patients are the ultimate teachers."

A former advocate for the DIY community, who even built several of them, Saint says “Its existence is almost too bad”. “They exist because people are irritated that they don’t have access to the technologies that they want.”

He emphasises the need for safeguarding in the industry, and that despite many attesting to the safety of DIY systems, there’s a reason why medical device companies are held to higher standards that are emphatically put in place.

Now as the CEO of Beta Bionics, which launched the iLet Bionic Pancreas, Saint hopes to assist struggling diabetics to gain access to closed-loop pumps and ultimately tackle healthcare inequality.

The National Institute of Diabetes and Digestive and Kidney Disease (NIDDK), found that people with type 1 with access to the Bionic Pancreas were more significant in maintaining TIR by 11 percent, than their counterparts who had the standard-of-care management like MDI. Yet whilst his own experiences as a type 1 diabetic may influence the devices he creates, Saint understands that every

diabetic struggle is different. He hopes to expand access to as many technologies as he can, very soon. “We always did a good job of designing a great product for one highly engaged person, and that’s wonderful, but I would rather design a product that can help many people get a lot better, rather than one that can get very better,” he says.

Connecting Diabetics Beyond Bluetooth

The development of revolutionary diabetes technology is just one small step towards managing the complex disease. Santiago Paulos, a visual designer for diabetes technology says, “Technology has cleared up some headspace, but it also creates new problems.”

A study looking into the progression of flash glucose monitoring found that consideration for people with diabetes who are not familiar with nuanced digital platforms, which CGMs rely on to share data, must be a priority for healthcare professionals.

Online diabetes blogs, forums or even social media communities enable connectivity among people living with diabetes and add value to self-care. There, tech-savvy DIY experts also take to online chat forums to extend a helping hand to less expert users through established ‘build’ sessions. These are marketed on social media and attract several attendees who rely on effective algorithms built by the diabetes community, for them.

Paulos spends a regular day navigating the intricacies of branding and user interface interaction for the diabetes platform MyWay Digital Health. But his ‘side hustle’ involves sitting behind a persona called The Diabetic Survivor, a company that offers diabetes merch with a side of humour. Think stickers, hoodies, or mugs labelled ‘dead pancreas gang’. “It is about touching certain elements of life with diabetes and trying to make it a little bit easier,” he says.

Paulos has been living with diabetes for 26 years and says technology has improved lives and contributed to “challenging many misconceptions of diabetes management”. He has been an advocate for DEDOC - an online committee of diabetes campaigners at scientific conferences, for the past three years. Their goal is straightforward: to clarify misunderstandings involving the disease.

These invested members, who unite from diverse countries, get together to challenge researchers and medical industry professionals in exchange for collaboration and awareness. Important issues like healthcare equality remain key issues that

need addressing. “The reality is that in the world there is still a lack of insulin or supplies, rather than sensors. Because of this conference, I have seen some harsh realities, where even if you have the last sensor, you cannot charge it. So, technology is not only the cutting edge, sometimes pricking your finger, that’s technology too,” he says.

Our Diabetes Tech Can’t Wait is a campaign undertaken by Diabetes UK and is urging fair and equal access to technology that people with diabetes are eligible for.

Enlightening Future Developments

The NHS 5-year strategy falls under the NHS Long Term Plan, which will supply tens of thousands of people living with type 1 diabetes with hybrid closed-loop pumps, and aims to ease the distress they may face.

An additional £2.5 million budget has been granted, on top of the yearly £10 billion a year funding that is allocated to diag-

nose and treat diabetes.

In the United States, a new insulin delivery device designed by the DEKA Research and Development will be offered to patients as young as 13, with the ability to automatically adjust insulin based on CGM readings and a control algorithm. Only what differentiates this device is that it’s powered by Tidepool Loop - a now FDA-approved platform begun by patients who wanted to assemble their own APS.

In a statement addressing its collaboration, the founder of DEKA and the American entrepreneur behind the commercialisation of the twist pump, Dean Kamen, says “Sequel chose to partner with Tidepool, a diabetes-focused non-profit organisation, because the underlying technology is community-driven, designed for and by people living with diabetes, provides individuals with a high degree of customisation and most importantly - delivers the clinical results patients are looking for.”

Saint also looks forward to launching his company Luna Diabetes, an automated closed-loop insulin device that administers insulin overnight. This “innovative” product attempts to represent the needs of those who enjoy the functions of an insulin pen but may feel more enticed to use a pump at night.

Sean can’t share any exciting details yet but says “Luna Diabetes is making great progress. They’re in the clinical trial at this point, and the data looks good.”

“There never will be a good time to be diagnosed with type 1 diabetes, but there’s never been a better one. We’re finally getting some real choices available to people like smart pens, better closed-loop pumping technologies, better CGMs, faster insulins, and other therapies that may not be approved in type 1 yet, but may will be in the future.”

“It’s been cool to watch that over the last 20 years,” he says.

People with type 2 diabetes may also be able to look forward to a world-first trial that could offer closed-loop devices to type 2 diabetics in the UK, according to scientists at the University of Cambridge.

Emerging
twist pump.
Photography:
SequelMed.

Graphics:
Dhuha Al-Zaidi



Illustration: Dhuha Al-Zaidi

Hybrid Closed-Loop



A standard form of checking blood glucose is by finger-pricking. Photography: Dhuha Al-Zaidi



The trial saw 26 insulin-dependent participants living with type 2 compare blood glucose results between standard treatments and closed-loop technology. The results from the device showed improvements in TIR, as well as reductions in HbA1c levels. The study group also claimed to have more confidence in self-managing their condition, after halting excessive injections and finger-prick tests.

Technology has provided hope for millions of people worldwide living with a demanding condition like diabetes. We're far from an era where patients, like John, were once asked by doctors to

eat a block of cheese on their birthday, for fear of triggering hyperglycaemia after indulging in a troublesome slice of chocolate cake.

People with diabetes, alongside understanding researchers, engineers, and healthcare practitioners, are behind the remarkable strive to improve quality of life. They have undoubtedly channelled their frustration and persisted, which undeniably led to the emergence of revolutionary devices that transformed how the disease is managed.

There is still hope that the exhausting and painful process of finger-prick testing will one day become a distant memory.

The first insulin pump created by Dr. Arnold Kadish in 1963. It administered both insulin and glucagon, and was about the same size as an army backpack.

Photography: The Human Trial, Facebook.
Graphics: Dhuha Al-Zaidi

Dhuha Al-Zaidi is a staff writer covering science at WIRED.

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