



## Empowering Patients with Chronic Disease Self-Management



By Kyle J. Rose (INSEAD)

**Managing chronic diseases can be an exhausting and, at times, demoralising experience. Combining personalised software and connected devices can ease the burden and provide motivation.**

I was diagnosed with Type 1 diabetes as a teenager. A blood glucose measurement of 800 mg/dl (8 times normal) landed me in urgent care. I soon learned about my new daily requirements involving syringes and lancets...and then did my best to return to “routine” life. It was frightening and difficult to accept that diabetes would be with me forever, 24/7. It required checking blood glucose levels and matching my insulin doses, injected subcutaneously, to my food intake. I adjusted reasonably well to the round-the-clock management. However, there were good days and bad days, with my blood sugar levels and my mental health.

At university, I had my first major loss of motivation. I didn't want to have to "manage" my diabetes and actually stopped taking care of myself. My endocrinologist at the time, Dr. Adam Law, helped me realise that I needed to change my habits and together we worked through it. I never would have guessed that fifteen years later, it's now me doing the advising, to health care professionals about my experiences managing diabetes in some of the most challenging conditions of extreme sport, adventure and travel all around the world.

Patients with diabetes often feel they are facing a string of scare tactics from healthcare professionals. "Do this or else!" This together with the stigmas and stereotypes such as laziness and that we brought this condition upon ourselves, explain why so many patients become depressed.

I initially resisted my parents' suggestion to attend a diabetes camp, but fortunately, I finally went, and met other people going through the same experience as me. They spoke of the normal life, one could have, despite having diabetes. I still recall how good that made me feel. Surrounded by a sea of negative notions, this positive experience brought in a much needed **breath of fresh air**. I quickly learned that many others had the same experience at these events and began understanding the importance of community for diabetes sufferers. Little did I realise that my entrepreneurial journey to help fellow diabetics had just begun.

## **Rallying communities**

Not everyone can attend a camp, and though online sharing cannot replace being there, it represents a virtual camp to some degree. Social media sharing/campaigns, sometimes considered the new frontier in the treatment of chronic disease, can be as overwhelming as the traditional hospital approach with its overabundance of printed matter.

Campaigns and projects that have been most successful often focus on specific areas and subjects. These patient-driven initiatives are able to do this while remaining open/inclusive to all. However, this is not as easy as it sounds as we learned at a prior entrepreneurial initiative, Team Type 1 (TT1). Founded in 2005, TT1 is an all-diabetes sports team of cyclists, triathletes and runners, spearheaded by the world's first all-diabetes professional cycling team.

*Editor's note: Kyle explains TT1 in this Knowledge interview from 2010*

The goal was to show that people with diabetes could live extraordinary lives and even compete in professional races. This positive side of diabetes was rare at the time and parents of newly diagnosed children in particular latched on to our feel-good mission. We didn't realise at the time, however, how intimidating exercise can be and I learned later that some people actually felt more alienated because what our extreme athletes were doing seemed so unrealisable for them. This was compounded because restrictions imposed on T1D athlete spokespersons ultimately hurt our organisation's credibility with the diabetes community.

Nevertheless, by sharing our stories and inviting others in the community into our fold, we built connections with many others who became our advocates, not just our fans. We realised that grassroots social communities (online and otherwise) could potentially be the biggest educators and supporters of those living with diabetes and aspiring to live a full life.

## **mySugr**

My next projects drew from these lessons and I soon became involved in an exciting venture called [mySugr](#), founded in 2012 by people with diabetes. mySugr, creates digital health solutions for people with all forms of diabetes. Our products are characterized by the intelligent combination of design, technology, and medical expertise.

Particularly well-known is the mySugr Logbook with more than 300,000 registered users across the United States and Europe. Through our health platform, we have connected hundreds of thousands of diabetics to a patient community that brings self-management of diabetes to a more fulfilling level. Using gamification, mySugr provides motivation and positive feedback as users track their vital statistics.

It also allows users to build up a data set to better understand how their bodies react to specific foods, moods and activities. Sharing of achievements, struggles, and pictures of food are possible via social channels such as Facebook and Twitter, letting users tap into an existing self-sustained, self motivating community, without the risk of exclusion.

## **The road ahead**

mySugr Logbook is FDA-registered and CE-marked as a medical device in the U.S. and Europe respectively. The work required to have achieved this has

continued to prove helpful as we begin to integrate an increasing number of third party devices with the mySugr platform. These ‘connected’ devices are already being used frequently by people with diabetes for glucose monitoring, medication infusion, and tracking weight and activity.

However, connected devices, with Bluetooth capability are not accessible to everyone. Much still needs to be done in emerging markets. A significant percentage of people with diabetes live in low and middle income countries. We’re also faced with growing instances of diabetes among the low income groups of developed countries. The trend of obesity is one driver and in [this recent study](#) it’s clear that it is hitting the poorer, harder.

I am convinced that through a simple user interface and gamification, we can continue to help people self-manage. In low and middle income countries, picture-based intuitive logic gives us an edge against illiteracy, and as smartphone-penetration increases, we will be able to drive medical education in the future. We have also developed a product (mySugr Importer) which uses an optical character recognition (OCR) algorithm to import data from older and less expensive, blood glucose meters which may not have capabilities to ‘connect’ otherwise. Once we get this data into the cloud, we can help make it actionable for patients.

It has been amazing to observe the online community and watch how those coping with diabetes typically welcome the opportunity to help others around them. By motivating them to help themselves, they in turn share their successes and motivate others and a domino affect is created. Big organisations in the health care industry are realising the power of such peer-to-peer interactions to influence new modes of disease management. We are excited to have both Roche ventures and iSeed on board as strategic investors in mySugr. Companies outside of the pharmaceuticals/medical device sectors have also taken note such as telcom operator Etisalat which has partnered with mySugr in the Middle East. These are exciting signs for the future. While many organisations involved in health care claim to be patient-centred, surprisingly, the patient is still often left behind. In our case, patients are in the driver’s seat and at 300,000 strong, their unified voice is disrupting health care to create much-needed change.

**Find article at**

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### Healthcare Management

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