



Photo by timJ on Unsplash

Becoming a Patient Researcher

Dr Emma Stendahl

www.misfires-erc.eu



This project has received funding from the European Research Council (ERC) under the European Union's Horizon 2020 research and innovation programme (grant agreement No 771217)



Life is changing

It was summer and I had just finished the first year of my master's studies at Stockholm University. I was tired, weak and had lost a lot of weight. Over a three-week period, I had lost about 12 kg, if not more. I remember one day looking at myself in the mirror and I started to cry. I was crying because I didn't know what was happening to my body. Crying because I no longer recognized the person I saw in the mirror. Around the same time, my vision started to become blurry. So blurry that I had to hold on to chairs and tables or whatever I could grab on to when moving around in the house. And I was extremely thirsty. An indescribable never-ending thirst. My mum forced me to go and see the doctor. At this point, I was so weak that I had to be carried to the examination room. My GP briefly examined me and sent me home with the message to rest; "Listen, you've been studying hard the last couple of months, you just need to relax for some time and give both mind and body a break". However, my GP's diagnosis could not have been more wrong. Later that evening I collapsed at home and was rushed to the emergency department at Karolinska Hospital. When I woke up, I was told that I had suffered from ketoacidosis, which is a severe life-threatening complication caused by extremely high blood sugar levels. On June 11, 2011 I was diagnosed with type-1 diabetes (T1D) at the age of 26.

T1D is an autoimmune disease in which a person's immune system attacks the insulin producing cells of the pancreas, and it can no longer produce insulin. Insulin is essential for life because it delivers glucose -blood sugar- which all cells in the body need to function. Too little insulin leads to many problems including increased blood sugar levels which can cause heart disease, nerve damage, kidney damage and pregnancy complications to mention a few. However, if the blood sugar gets too low it may lead to insulin shock, which is life-threatening if not attended to. Managing T1D is an exhausting job. No days off. No vacation. It requires attention all day, every day. Whether it is a meeting, eating at restaurants, travelling, partying, exercising, or going through a stressful moment, my diabetes is always ticking in the background. It forces me to constantly be prepared for interventions to respond to high or low blood sugar levels. It has been a lonely journey living with this disease and because I'm the only one with T1D amongst my family and friends, I had no one close to me that fully understood my struggles, frustrations and fears of living with T1D. However, things were about to change.

Joining MISFIRES

In October 2018, after finalizing my PhD in Business and Management studies at Stockholm University, Sweden, I moved to Ireland to be part of MISFIRES at University College Dublin. Funded by the EU Horizon 2020 Programme, the

research project examines failures in healthcare markets and studies how participants in these markets address and voice these failures to industry and government. As part of MISFIRES, I study T1D. Patients, caregivers, healthcare professionals and device manufactures are becoming ever more adept at understanding T1D and its cause and reactions, which means they are more technically able to fine-tune treatments. Despite this progress, patients are still not able to process and act upon their own data – for instance how your blood sugar reacts over the course of the day to certain foods you eat, or certain stress factors. This data is commonly locked into the devices, with no or limited ability to share across devices, and the analytics required to process such data are complicated. My research examines the interlinkages between digital activism, open data movement and user innovation for improved diabetes care. I focus on an open source community of T1D patients, caregivers, diabetes activists and entrepreneurs and I study how this community attempts to change the traditional diabetes healthcare market. They do this by reverse-engineering existing medical devices and collectively develop platforms and apps and cloud-based solutions to better suit personal medical needs and improve quality of life.

Becoming a patient researcher and diabetes advocate

I never used to tell people that I had T1D because I was embarrassed of my chronic disease and I didn't want to be labelled as a 'diabetic' or 'patient'. I kept quiet also because I was sick and tired of dealing with comments and questions such as: "How can you be a diabetic, you've always been eating so healthily" and "What?! So you have to take injections four times a day, I wouldn't be able to do that!" or "I have heard that women with T1D have difficulties getting pregnant, how are you dealing with that?" As I mentioned earlier, things were about to change. Researching and engaging with the open source diabetes community has encouraged me to stand up for my disease and take part in the collective fight for innovation in the T1D healthcare market to reduce both the physical and mental burden of living with the disease and to ultimately improve my own and millions of other T1D patients' quality of life. My role as a researcher, T1D patient and now turned diabetes advocate encourages me to focus not only on knowledge production (writing academic papers) but also invites me to make 'real' impact to the daily issues and demands among T1D patients. To be honest, it's not always been an easy journey, because there is no 'hiding' from the disease if you not only live it but also research it. But, on balance, it definitely brought me closer to it. I am very excited and proud to be part of MISFIRES aiming to make innovations in healthcare markets such as T1D more collaborative and participatory as well as pushing for innovation policy to better achieve patient interest.