

## Living on the loop

– agency, skill and (re)enchantment in DIY Artificial Pancreas System use

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In this paper we explore a set of patient narratives from people engaged in developing and using automated systems to manage their diabetes treatment – so-called Do-It-Yourself Artificial Pancreas System (DIY APS). The data inspired us to reflect on the broader cultural narratives in association to artificial intelligence and machine learning in personal health technology, where AI and ML often seem to invoke fear of de-humanization, de-skilling and disenchantment. In contrast to this, we found that the DIY APS community generates and reanimates feelings of agency as well as invoking concepts of charisma and enchantment, forming collective engagement with health data and technology. In our analysis we draw on Haraway's well-known concept of the cyborg and more contemporary discussion of AI to point to both the embodied and the collective aspects of engaging with AI "in the wild". We suggest, that the optimistic experiences of "living on the loop" expressed in our data may provide inspiration for a wider discussion of how we may shape our engagement with AI in more human centered and collective ways.

**Keywords:** Automation, AI, Digital Health, Diabetes, DIY, Artificial Pancreas System, #wewillnotwait, Agency

### 1 INTRODUCTION

Cultural narratives associated with artificial intelligence (AI) and machine learning (ML) often evoke fears of de-humanization, de-skilling and disenchantment, or what, in its most catastrophic form, might be called the 'Terminator Syndrome' (Garvey, 2019; see also Frischmann & Selinger 2018). In this article we explore a set of patient narratives in which different associations are generated; where AI, automation and use of control algorithms serves to reanimate agency, where the work of achieving automation generates knowledge and skill, and where descriptions of the experience evoke concepts of charisma and enchantment.

The case we explore relates to user-driven innovations in technology used to treat type 1 diabetes (T1D), sometimes referred to as Do-it-yourself Artificial Pancreas Systems (DIYAPS). These innovations have made a significant impact in the landscape of diabetes treatment during the last decade (Gottlieb & Cluck 2019; Lewis 2019). Our specific focus here is on the ways in which those who use DIYAPS reflect upon and articulate their experience of setting up and using an automated system for insulin delivery and what automation and intimate

engagement with digital health technology means to users whose relationship is mediated through an online international, open-source community.

Using this case and through our analysis, we aim to contribute to an understanding of how people engage in and make sense of new “data-body-machine entanglements” where advanced health data analytics and automation is core. Recalling Haraway’s well-rehearsed notion of the cyborg (1991) as well as more recent discussions of implications of AI, we explore our informants’ engagement – not only with technology, but also with the broader community of fellow “loopers” and with the enchanted vision of living “on the loop”. Users’ experiences of agency, skill and (re)enchantment is thus not narrowly related to individual prosthetic agency, but also, in equal measure, to new collective engagements with health data and technology. Moreover, we propose to assess whether the optimistic experiences of “living on the loop” expressed in our data may provide inputs to broader discussions of how we may shape our engagement with AI “in the wild” in more human-centred ways.

## **2 BACKGROUND: BURDEN OF DIABETES AND DIYAPS**

T1D, an autoimmune disease in which cells in the pancreas responsible for producing the hormone insulin are permanently destroyed. Until a century ago diagnosis with T1D was a death sentence. This changed once pharmaceutically procured insulin could be used to treat people with diabetes. In this sense, (the) people (person) with diabetes (PWD) can be considered to live a prosthetic existence, both emulating and transcending Donna Haraway’s notion of the cyborg (1991; see also Kaziunas et al. 2018; Hess 2018). As Nikolas Rose writes, “The body of the diabetic has been prosthetic since the invention of insulin treatment: calculated chemical artificiality here has sought to replace the missing or damaged normativity of the body’s own vital processes” (in Matthewman 2018:38).

Subsequent developments have generally improved the lives of people with T1D from a biomedical perspective, yet the burden of managing the disease has not so much been eased as transformed by new drugs and new technology (Feudtner 2003). While the quality of insulins have evolved, as well as the technology for measuring Blood Glucose (BG), including Continuous Glucose Monitors (CGM), the burden of care relies on the actions and decisions of the patient. Life with T1D exists in the center of a continuous data feedback loop, where dosing of exogenous insulin must be calibrated with BG levels. The list of factors in this calibration is not infinite, but the complexity involved in the calculations, as seen from the perspective of the person making them, might seem to be. As discussed in much STS-literature on digital care technologies, self-management in chronic illness involves tinkering and trade-offs involving actors and resources well beyond “the self” (Mol 2008; Storni 2014; Danholt & Langstrup 2012).

Taking the human “out of the equation” as conscious and burdened center of calculation by using artificial intelligence and machine learning to close the artificial pancreas loop has long been considered the holy grail in diabetes research, but until recently progress has been slow, partly as a result of the proprietorial motivations of industry and partly due to lengthy clinical trials required by health regulators (Garfinkel 2020). Frustration and disenchantment were, thus, key drivers in the emergence of DIYAPS (Gottlieb & Cluck 2019). Initially this frustration was related to issues concerned with the ownership of personal data and a desire among parents of children with diabetes to access CGM data in real-time in order for them to be able to better monitor nighttime glucose levels of their child. The resulting Nightscout Project, paved the way for subsequent developments in Do-It-Yourself (DIY) diabetes (Lee et al., 2016; Kaziunas et al. 2018). In a model of diffusion that has characterized all subsequent developments within the DIY diabetes movement, the DIY code to allow access to real-time device data

was published as open-source software, freely available to anyone and linked by the social media hashtag #WeAreNotWaiting. Slowly but surely a large, global community has united under this banner (Litchman et al., 2018; Braune et al 2019).

Able to access real-time CGM data for the first time, other users sought to link CGM data to insulin pumps, which continuously secrete insulin subcutaneously according to settings prescribed by healthcare professionals and moderated daily by users. Developing control algorithms to link CGM data to insulin pump commands, the first DIYAPS was built in 2015 (Lewis & Leibrand 2016), well in advance of commercial, regulatory approved systems that are only now becoming slowly available. Common to all DIYAPS is that decision-making about insulin dosing is primarily undertaken by the algorithm rather than the user. There are currently three DIYAPS available and it is estimated that there are several thousand users worldwide. Estimates for prevalence are uncertain, in part because users find themselves in a legal grey zone. DIYAPS users must navigate and circumvent the proscriptions of health authorities, a feat made possible by the open-source model of diffusion in which each user is responsible for building their own system; a model which generates a community of DIY innovators who have started to live on their own modified medical device regimen in highly sophisticated and individualized ways (Demonaco et al. 2019).

### 3 METHODS

The data we draw upon here is based entirely on people's responses to open-ended questions at the end of an otherwise quantitative survey. The survey took place in 2019 as part of an EU-funded cross-disciplinary, international and patient-initiated research project (open-diabetes.eu). Due to the extra-institutional, non-regulated and online character of the DIYAPS phenomenon, respondents had to be reached in the online environments in which they engage, and inclusion had to rest on self-identification. Two versions of the survey were posted, one addressing adult users of DIYAPS and the other addressing caregivers of children (<18 years old) using DIYAPS. Here we report exclusively on the data obtained from adult users. 844 adults responded to the survey from a total of 35 countries, with 383 individuals responding to the open-ended questions

Respondents had been given the opportunity to answer the survey in English or in German and prior to our analysis the German responses were translated to English and the translation was checked for accuracy by a second reader with proficiency in both German and English. To analyze answers to the open-ended questions all three authors read through the responses using a thematic analysis-approach and initially did an open coding to identify themes. We then met and discussed our initial findings and settled on themes before doing another round of individual coding aimed at identifying more global and conceptually-informed themes. Discussing these at a second meeting we narrowed in our analytical and conceptual focus to explore agency, skill and (re)enchantment presented below.

### 4 FINDINGS

#### 4.1 Agency

Throughout the narratives there is a recurring motif of liberation from a burden and of agency being freed from the shackles of disease management: *"Much better results without thinking about diabetes every minute of my life"* (Male, 32, Poland); *"When on Loop, diabetes is much less of a burden than it used to be. I have more time for my own life and I have a chance to forget I have diabetes for a while"* (Female, 27, Czechia) *"So, I closed the Loop on September 23, 2018, which is the date I am now thinking is the day I was released from most of the chains that bind me"* (Male,

41, USA). Within these narratives of agency unchained, the informants often articulated their cyborg entanglements with technology in a very dualistic way, upholding a clear distinction between themselves and the devices they use. *"It was great having a second brain that would sit there and manage things for me in the background while my sometimes intense job took over and got in the way"* (Male 43, United Kingdom); *"It catches the balls I don't, it has a better brain, makes better decisions and is an awful lot quicker than me"* (Female, 59, United Kingdom).

As can be inferred from the previous quotes, even agency was ascribed to both human and machine. The distinction between the types of agency ascribed is telling: *"I was happy to hand over control to something which makes fewer irrational decisions and is less emotionally involved in the process"* (Female, 35, United Kingdom); *"I cannot compete with the ability of a computer to dispassionately make a rational insulin dosing decision every five minutes of the day"* (Male, 65, USA). Diabetes management is not just difficult because the calculations it requires are complex, it is also difficult because the decision-making process is imbued with personal values and emotionally driven actions.

Yet while the narratives suggest that PWD will willingly relinquish their agency to that of a machine, this is not a choice taken lightly. Delegation of agency to the algorithm constituted a leap of faith: *"It was very hard at first to trust the system. After doing things myself for so long, believing machines were doing it correctly was difficult. It took time for the trust to build."* (Female, 65, USA). This leap of faith is significantly bolstered through the community of DIY innovators: *"But the support of the looping community is a huge part of reason why looping is as straight forward as it is. From the detailed loop docs to the online support (real time and more informed than any commercial support I have ever had from a pump company) to the people I have met and the community I am so privileged to be part of."* (Female, 42, Australia). In this sense, it is the distributed agency of the DIYAPS community which generates trust, not least because this distributed agency is experienced as in harmony with, rather than opposed to, the agency of the individual.

## 4.2 Skill

As indicated above, building trust in DIYAPS was partly accomplished through the online community, but the actual building of the system was ultimately the responsibility of the individual user. This can be a daunting process and many of the informants expressed initial uncertainty, doubt in own "tech" abilities and fear of failure, when you *"[...] put your life in the hands of an app"* (Male, 33, Germany). However, in many of the narratives, the informants write about how the immersive process of acquiring and reading the instructions, following them, getting help and finally seeing the 'spectacle' of a working system and how this very process of immersion into the technology gives them new skills, knowledge and confidence in the system and in themselves: *"I saw it as a challenge to understand and build it. Understanding the algorithm and building it myself gave me a great understanding of the system and mitigated any fears I might have had about its functioning."* (Male, 31, New Zealand); *"Building my own closed loop system gave me a feeling of control, self-efficacy and power over my own well-being. It made me feel confident to live a better life with diabetes and a better life in general"* (Female, 29, Germany).

In the process of building these DIYAPS, PWD are not just challenged technically, but also in relation to their own understanding of how diabetes impacts on their bodies: *"Looping has provided me much detailed insight into the inter-workings of my endocrine system and diabetes management"* (Female, 24, France); *"I've gained a much better understanding of my diabetes and the way insulin actually works"* (Male, 47, Germany). *"Another advantage [...] compared to current commercial closed-loop systems for me is that I set my individual parameters to target values, corrections, temporary targets, etc., without preset limits. This requires that I am much more aware of my own diabetes and my own body than I was before closed loop"* (Female, 50, Germany). Closing the loop requires effort and automation does not come easy, but the effort involved is perceived differently to the quotidian requirements of diabetes management. A key to this is the transparency of DIYAPS and the individual customization required:

*"[DIYAPS] is a system that I trust a lot because I know how it works. That is not the case with a system from industry, of which I am a customer. Because these devices are black boxes, whose inner working is a corporate secret....However, DIYAPS is completely open, the calculation bases can (and sometimes even have to) be understood by the user and the setting is completely in the hand in which it belongs: the hand of the diabetic. Every diabetic is responsible for his life. He has always been. This does not change with DIYAPS. It only becomes clearer to many."* (Male, 53, Germany).

### 4.3 (re)Enchantment

Disenchantment with the device industry and the technologies that they had had at their disposal prior to DIYAPS/looping are highly prevalent throughout the narratives. Insulin pumps and blood glucose measuring devices were described as "dumb" and "black boxed" and the institutions as large, impersonal bureaucracies, be they regulators, device developers or healthcare systems, all apparently working in accordance with rules and agendas at odds with the desires of people living with T1D: *"The traditional medical technology companies progress on this ideal [closed loop, ed.] seemed unmotivated, uninspired, and unhurried."* (Male, 65 USA). Such sentiments are also forcefully voiced on social media under the hashtag #wearenotwaiting. In great contrast to these bleak depictions stood the evocative and emotional vocabulary our informants used to describe both the loop and the overall community experience of being a "looper". The narratives often referred to the system and its benefits with magical or semi-religious terms: Hearing about the system was experienced as "a revelation", seeing it work as "magic" or a "miracle" and the system was construed as 'superhuman' or a "guardian", as it intervenes, setting human miscalculations right: *"Since then I have felt better, healthier and safer, my 'guardian', the closed-loop, intervenes what I have miscalculated."* (Male, 48, Germany).

One informant wrote an extended allegory to explain her experience. She compared getting diabetes 12 years previously, to be given the responsibility for *"sensitive baby-like thing"* only with *"an umbrella, a flashlight and some firewood"*. Trying to manage in the dark and cold *"suddenly the whole field is flooded by the light of a UFO"* and she is invited on board and told, *"you can build a UFO yourself!"*. She further described getting help to build her "UFO" from pilots in the collective *"fleet"* and characterizing the *"colorful bunch"* as *"All cyborgs. Everyone with a homemade small spaceship"*. But the spaceships are not fancy and it is hard and dirty work building one: *"I have been up half of the night to craft my UFO"* and *"Neither can I solder nor read the 'white cryptic on black ground' language and my spaceship is not as beautiful, but it manages to fly. Automatically. With lighting."* (Female, 40, Germany)

On the face of it, the UFO story employs the spectacle of a sci-fi story to celebrate the capacity of technology to – literally – enlighten us and to tell us that DIYAPS is the technology of the future. However, the story also as another, less idealizing point about the "cyborgs" akin to Haraway's notion: they are dependent on one another, they are individually limited in their knowledge and skill; technology is not perfect and it takes hard work to tinker with both technology, body and life.

### DISCUSSION: Re-humanizing diabetes technology or enchanted determinism?

The insight that technologically supported chronic disease management should be seen as the continuous distribution and configuration of agency is a familiar one (Mol 2008; Oudshoorn 2016; Hess 2018) – PWD and other people with chronic conditions engaging with technologies for their self-care are everyday-cyborgs. However, when cyborg existence increasingly relies on automation, AI and machine learning, as in the case of DIYAPS, new questions surface: will this delegation entail dependency on black boxed computational processes? Will such powerful computational models leave PWD in "the machine zone" (Schüll 2012) where critical thinking is

suspended, and attention diminished – traded in for minimized friction with a burdensome reality (Frischmann & Selinger 2018)? Some contemporary scholarship on AI seem to breathe life back into technological determinism, suggesting that these systems, due to their predictive powers and opaque “reasoning” will have a powerful and negative impact on our societies and individual lives (ibid). Campolo & Crawford even suggest the concept of “enchanted determinism” for the combination of hyped discourses of AI’s “superhuman” powers and “the inability to fully explain how these results are produced” due to the opaqueness of the technology (Campolo & Crawford 2019, 1).

DIYAPS might be best considered as a case of intelligence augmentation more than artificial intelligence. In cultural terms, this is, perhaps, also more digestible, speaking of enhancement rather than encroachment in the entanglement of human and machine – a balm to Terminator Syndrome. Yet this is more than a question of finding more comforting terminology, as augmentation works for both parties closing the loop. The algorithm needs the support of the human to realize its full potential, this is especially so as people set up their DIYAPS, where establishing ground rules for insulin titration are inexorably bound up with the unique physiology of the individual and their life circumstances. At the same time, the algorithm makes decisions that, would be beyond the means of any individual, both quantitatively, in the sheer number of decisions that are being made, and qualitatively, in the sense that its decision making is impassive and not colored by human emotion. This is a digital cyborg assemblage in which, while the technology continues to stare into the biology, the biology is also staring back; birthing “a body that is configured and intimately understood by data and self-knowledge” (Lupton 2013).

In this paper we have analyzed experiences of engaging with emerging automated systems in diabetes management “in-the-wild” and identified narratives of re-humanized agency, of the acquisition of new skills and of a (re)enchanted relationship to technology. These largely positive and optimistic accounts of engaging with and relinquishing agency to technology do not debunk more concerned accounts of AI and machine learning technologies in our lives and societies, but they do suggest for more nuances in these accounts. What we find particularly interesting in our findings is the importance of getting “hands-on” experiences with the system and algorithms and its importance of building trust in both self and system. Likewise, the role of the collective agency and even activism invested in these new data-machine-body entanglements is something we consider worthy of more analysis and discussion. Indeed, it may even be said to be imperative as we continue our discussion of what might constitute more human-centered and socially beneficial AI and machine learning systems in healthcare and beyond.

## **ACKNOWLEDGMENTS**

We express our gratitude to the families of the DIYAPS community who supported and greatly contributed to this survey. The survey from which the data was obtained is part of the EU-H2020 funded “OPEN”-project (Outcomes of Patients’ Evidence with Novel, Do-it-yourself Artificial Pancreas Technology). OPEN is funded by the European Union Horizon 2020 Marie Skłodowska-Curie Actions Research and Innovation Staff Exchange (H2020-MSCA-RISE-2018) program.

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