

JUST IMPATIENT PATIENTS?

THE IMPACT OF HEALTHCARE PRIVATISATION AND COMMERCIALISATION ON THE ADOPTION OF DO-IT-YOURSELF ARTIFICIAL PANCREAS SYSTEMS BY PEOPLE WITH TYPE 1 DIABETES.

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ABSTRACT

The last decade has witnessed the development of a novel diabetes technology: the Do-It-Yourself Artificial Pancreas System (DIYAPS). The novelty of the DIYAPS lies in an algorithm that automates insulin delivery to people with type 1 diabetes (PWT1D), thereby improving the health outcomes usually obtained by standard diabetes technologies. DIYAPS are freely available and developed by PWT1D as a response to the slow development of life-enhancing technology by commercial parties, under the motto #WeAreNotWaiting. In this paper, I explore how the DIYAPS movement can be seen as a reaction to the marketisation of health technology and, linked to that, privatisation in healthcare. I argue that members of the DIYAPS movement can be characterised as health-optimisers. They take responsibility for enhancing their own and their fellow PWT1D's wellbeing, and demonstrate a desire for greater independence from medical professionals. At the same time, they actively resist participating in the commodification of health. They do not pay for the newest, most innovative health technology. Instead, they create it themselves. As such, the DIYAPS case draws attention to how, in response to marketisation and privatisation in healthcare, the self-reliant, responsible expert-patient may come to shape their patienthood by taking matters into their own hands.

I. INTRODUCTION

The last decade marked the development of a novel diabetes technology: The Do-It-Yourself Artificial Pancreas System (DIYAPS). The novelty of the DIYAPS lies in an algorithm that automates insulin delivery to people with type 1 diabetes (PWT1D), thereby improving the health outcomes usually obtained by standard diabetes technologies: glucose monitors and insulin pumps. DIYAPS are freely available and developed by PWT1D as a response to the slow development of life-enhancing technology by commercial parties, under the motto #WeAreNotWaiting.

Medical doctors and medical anthropologists commonly cite PWT1D's impatience and frustration with a commercial market that has failed them as the reason for the emergence of the DIYAPS movement (Dowling *et al.*, 2020: 1978; Jennings & Hussain, 2020: 869; Kesavadev *et al.*, 2020: 1219). In this paper I explore further the ways in which the DIYAPS movement can be seen as a reaction to the marketisation of health technology and, linked to that, privatisation in healthcare. In doing so, I draw attention to modern-day dynamics in the UK, US and several West-European healthcare systems that may explain a wider trend of patient-led, non-proprietary innovation (Kempner & Bailey, 2019; Wicks, 2018). Specifically, I focus on trends such as privatisation and marketisation in healthcare which, sociologist Nikolas Rose argues, have led people to become 'self-governing patients,' that is, patients who: take responsibility for looking after themselves and the communities they are part of; have a desire to educate themselves about their health condition and gain independence from professional medical experts; and act as health consumers, making financial investments in their own wellbeing (Rose, 1992, 1996a, 1996b, 2001).

I conclude that, similar to the self-governing patient, members of the DIYAPS movement can be characterised as self-reliant health-optimisers. Yet, unlike the self-governing patient, members of the DIYAPS movement actively resist participating in the commodification of health. They do not pay for the newest, most innovative health technology. Instead, they create it themselves. As such, the DIYAPS case draws attention to how, in response to marketisation and privatisation in healthcare, the self-reliant, responsible expert-patient may come to shape their patienthood by taking matters into their own hands. And, as will become clear, they do so with remarkably positive health outcomes.

II. WHAT ARE DIYAPS?

The DIYAPS is an automated, open-source insulin delivery system designed by and for PWT1D. It connects existing diabetes devices, namely a continuous glucose monitor (CGM) and insulin pump, to a freely accessible algorithm designed to calculate insulin doses, which is hosted by an app on a communication device (usually a smartphone). When a person first starts using a DIYAPS, they need to manually enter their personal settings, such as target blood glucose levels and standard basal rates¹, in the app. The system then provides recommendations on how to readjust the settings to make calculations more accurate. The process of entering and tweaking personal settings can take several weeks (Lewis, 2016).

Once the settings are calibrated and the CGM measures falling or rising blood glucose levels, the algorithm automatically calculates how much insulin is needed to bring levels back 'within range'. The pump then automatically provides the correct amount of insulin, meaning that there is no need for interference by PWT1D; the 'loop' between CGM, algorithm and insulin pump is closed (Crabtree *et al.*, 2019: 64; Dowling *et al.*, 2020: 1978; Lewis, 2018: 790-791). Hence, many refer to DIYAPS as 'closed-loop systems' and to DIYAPS users as 'loopers'. Closing the loop does not mean that the system requires no further user involvement. All DIYAPS applications emphasise the need for users to keep monitoring and testing the system to make sure it keeps working as desired.

DIYAPS were developed by PWT1D and their caretakers under the motto #WeAreNotWaiting. The #WeAreNotWaiting movement is a response to the slow development of quality-of-life-enhancing devices by the health technology industry. In 2013, PWT1D Dana Lewis together with her partner Scott Leibrand decided to take matters into their own hands. They built and iterated an algorithm, closing the loop for Dana in 2014, and alongside Ben West shared the code for this system open source under the name OpenAPS (Lewis, 2018: 790). The movement grew from there, and two more DIYAPS applications were developed by PWT1D and those close to them: AndroidAPS, which uses the OpenAPS algorithm and an Android phone, and Loop, which uses a different algorithm on an iOS device (Kesavadev *et al.*, 2020: 1221-1222). Together, the systems have several thousand users (O'Donnell *et al.*, 2019: 4; OpenAPS, 2021b).

DIYAPS consistently outperform standard diabetes technologies, such as glucose monitors, glycaemic readers and insulin delivery pumps or injections (Kesavadev *et al.*, 2020: 1218). This is because, firstly, DIYAPS calculate more accurately than people how much insulin should be provided and, secondly, the

¹ Basal insulin is provided on an ongoing basis throughout the day (Railton, 2019).

system checks blood glucose levels every five minutes – much more often than the average person with diabetes does (Crabtree *et al.*, 2019: 66). As a result, DIYAPS users’ blood sugar levels are more constant and lower on average compared to non-users: DIYAPS users report a 15 to 20% increase of time within the safe range of blood sugar levels (Jennings & Hussain, 2020; Lewis, 2018; Toffanin *et al.*, 2020). To illustrate the significance of this number, a 10% increase of ‘time in range’ reduces the risk of retinopathy by 64% and the risk of developing microalbuminuria² by 40% (Wilmot *et al.*, 2020: 6). It must be noted that DIYAPS users are a self-selected sample of PWT1D who have dedicated time and effort to better manage their illness. However, the abovementioned improvements are so significant that even less dedicated users are still expected to benefit – albeit to a lesser extent (Jennings & Hussain, 2020: 870).

The impact of DIYAPS reaches beyond blood sugar levels. Without DIYAPS, living with diabetes requires much time and attention. Monitoring blood sugar levels and dispensing insulin throughout the day means interrupted conversations and disrupted nights of sleep. AndroidAPS user James, sharing his experiences with a UK-based team of medical experts, describes the continuous thought processes involved in managing his illness before AndroidAPS as follows: “Should I give a correction bolus?³ Should I change my basal rate? How can I reverse that trend? I used to invest lots of energy in answering questions like these. Now, the app handles them on my behalf. It’s not perfect, but it does a much better job than me” (Marshall *et al.*, 2019: 1555). In short, diabetes presents a significant cognitive load and time constraint (Dowling *et al.*, 2020: 1977; Gottlieb & Cluck, 2018). DIYAPS lifts much of this cognitive load from PWT1D by making calculations and doing the monitoring for them. It has been estimated that DIYAPS save PWT1D up to one day a month in time (Crabtree *et al.*, 2019: 66).

III. REGULATION AND COMMERCIALISATION: DIYAPS AND OTHER DIABETES TECHNOLOGIES IN COMPARISON

A key characteristic of DIYAPS is that the technology is not medically approved nor regulated, because they have not been tested in clinical settings (Kesavadev *et al.*, 2020: 1217). However, they are “tried, tested and tweaked” on a daily basis by thousands of users who give feedback to the developers, report glitches in the system and suggest improvements (Crabtree *et al.*, 2019: 66). In other words, it is technology built by the

#WeAreNotWaiting community for the community. Since DIYAPS are open-source and thus not a commercial product, it is unlikely that medical regulatory agencies will come to regulate the systems.

The US Food and Drug Administration does not regulate non-commercial products, and has explicitly stated that DIYAPS therefore do not fall within their authorisation (Best, 2020: 1; OpenAPS, n.d.-a). This is both surprising and arguably undesirable given that thousands of people have come to rely on DIYAPS. Similar to the FDA, the European Medicines Agency (EMA) states that its focus is on “market authorisation” and makes no mention of the regulation of non-commercial products (EMA, n.d.). Since regulating non-commercial medical supplies does not fall within the mandates of the FDA and EMA, the non-profit organisation Tidepool is hoping to bring their artificial pancreas application called Loop to the market with FDA approval (Snider, 2020). This case suggests that it may only be possible to regulate DIYAPS by commercialising the technology, which is a slow process and potentially exclusionary to those with limited financial resources.

In the absence of regulation and approval, health insurance often fails to provide coverage for adverse incidents (e.g. hypo-/hyperglycaemic incidents, or, the occurrence of extremely low or high blood sugar levels) suffered by DIYAPS users, and these systems are poorly integrated into mainstream healthcare (Dowling *et al.*, 2020: 1978-1979; Kesavadev *et al.*, 2020: 1217). As a consequence, the DIYAPS movement and scholars of diabetes technology alike stress that DIYAPS place a great deal of responsibility onto the user (Leelarathna, 2020: 657; OpenAPS, 2017a; Toffanin *et al.*, 2020: 113). For the purposes of this paper, I adopt Rose’s definition of ‘responsibility’ as having to bear the consequences for one’s actions and, by implication, having to make an effort to avoid negative and obtain positive outcomes (Rose & Lentzos, 2017: 27-28). Responsible persons know they have to pay – be it in monetary terms, in time and effort, or in the form of guilt, shame or social stigma – for any adverse events they may cause. As a consequence, they behave in ways that benefit them in the long run; they scrutinise and control themselves, thus “governing their own conduct” (Rose & Lentzos, 2017: 27-28). In order to enjoy the health benefits of DIYAPS whilst avoiding the physical, emotional and financial costs of, for instance, hospital admission in case of a hypoglycaemic incident, users must invest time and effort to use the technology diligently. That is, they must set up the system properly and monitor its workings, as the following excerpt from the OpenAPS online user guide emphasises:

Remember as you consider this project that this is not a “set and forget” system; an OpenAPS

² Retinopathy and microalbuminuria are both common complications of diabetes. The former affects eyesight, the latter affects the workings of the kidneys (National Health Service, 2018; Koroshi, 2007).

³ Bolus insulin has a strong, short-lived effect on blood glucose levels and is usually taken at meal times (Railton, 2019).

implementation requires diligent and consistent testing and monitoring to ensure each piece of the system is monitoring, predicting, and controlling as desired. The performance and quality of your system lies solely with you. (OpenAPS, 2017a)

DIYAPS users express a willingness to assume responsibility, both for familiarising themselves with the system, and for accepting the costs of possible adverse events (Gottlieb & Cluck, 2018: 147; Marshall *et al.*, 2019: 1555). If they do not, they must resort to commercially available technologies which come with two main limitations. A first disadvantage is that these technologies are expensive, especially insulin pumps and CGMs (the latter being considered the ‘gold standard’ amongst medically approved diabetes technologies). Because of the high price, healthcare providers are sometimes hesitant to recommend the most advanced applications and leave PWT1D with glycaemic glucose readers instead of CGMs and injections instead of insulin pumps (Kesavadev *et al.*, 2020: 1218). In the United Kingdom, for instance, CGMs are only recommended to PWT1D who “can demonstrate a motivation and ability to make full use of the technology” (Lawton *et al.*, 2015: 249; National Institute for Health and Care Excellence, 2008), which in the UK has been shown to favour patients with a higher socioeconomic status (Farrington, 2018). The high price similarly explains why medical regulatory authorities are careful in recommending reimbursement for these technologies (Sumnik *et al.*, 2019: 442), thereby limiting access to people with low incomes or without private insurance (Onisie *et al.*, 2019: 823). DIYAPS, by contrast, are affordable. The software is free and the hardware to build a DIYAPS costs approximately 150 USD (excluding the pump, for which users will remain dependent on healthcare professionals, but which most PWT1D do now have) (OpenAPS, n.d-a).

A second disadvantage of commercially available diabetes technology is that innovation is slow, as the #WeAreNotWaiting motto clearly articulates. Commercial APS are emerging but, compared to DIYAPS, these offer few individualisation options and interoperability between commercial systems and devices like CMGs and insulin pumps is limited (Dowling *et al.*, 2020: 1978). In sum, commercially available diabetes technologies fail to meet PWT1D’s needs, and access to these technologies is sensitive to inequities.

IV. THE SELF-GOVERNING PATIENT

Nikolas Rose posits a theory of how people have come to regulate their health in reaction to the increasing privatisation of healthcare and marketisation of health products and services. Rose’s theory finds its roots in Michel Foucault’s work on ‘governmentality’, which proposes that citizens’ modes of thought or ‘mentalities’

are shaped through norms and dominant frameworks of knowledge that align with the government’s objectives (Foucault, 1991: 95; 101-102). As citizens come to internalise these norms and bits of knowledge – or ‘modes of subjectivation’, in Foucault’s terms (Foucault, 1988: 18) – the state no longer needs to control citizen conduct through force (Foucault, 1991: 99). Instead, citizens discipline themselves, thus playing an active and integral part in their own ruling and becoming “allies” in governance (Rose *et al.*, 2006: 89). Rose applies the principles of governmentality to explain people’s health conduct in the last five decades, the era of neoliberalism – which he prefers to call ‘advanced liberal rule’ – that followed the decline of the welfare state (Rose & Miller, 1992: 198; Rose, 1996a: 40). Neoliberal rule relies on governmentality to govern citizens “at a distance” (Rose, 1996a: 43). The norms on which neoliberalism primarily relies are responsibility, autonomy and free choice. By instilling people with these norms, they come to govern themselves so that direct governmental control is no longer necessary (Rose, 1996a: 53-54).

Responsibility, autonomy and choice came to dominate citizens’ mentalities in the last quarter of the twentieth century, thanks to institutional rearrangements. As social insurance systems got watered down and health insurance in part became a private affair, citizens came to bear a greater share of the costs of adverse health incidents individually. In other words, they were gently compelled to take on greater responsibility for their wellbeing and a more active role in safeguarding their own health. This ‘imperative of health’ (Lupton, 1995) was reinforced by the rise of market-like rhetoric that replaced centralised planning and control with logics of entrepreneurship, self-optimisation and self-dependence (Rose & Miller, 1992: 200-201; Rose, 2001: 18). Self-optimisation, then, is presented as both a duty and a right. On the one hand, social standards of productivity and efficiency as well as widening gaps in social safety nets impose the ‘imperative’ of health (Rose, 1996a: 56-58). On the other hand, health and wellbeing are talked about in the language of freedom, autonomy and personal development. The choice to adopt healthier lifestyles, for instance, is a means towards the happiness and fulfilment that everyone is entitled to (Rose, 1996a: 58-59).

The disintegration of social insurance caused a shift from passive, collective responsibility to active responsibility for oneself and one’s own small community. Instead of relying on state-provided healthcare, underpinned by passive solidarity with the entire collective, people now have to actively pursue new strategies to improve their quality of life (Rose & Miller, 1992: 197-198). In doing so, people join in communities, movements and patient organisations based on, for instance, a shared disease history or genetic predisposition, to voice their demands more loudly. Rose notes:

While many critics see the new biomedicine as individualizing, we can already see new forms of collectivization emerging ... 'at risk' individuals are joining into groups and organizations, not merely demanding public provision and rights, but making their own claims on the deployment of biomedical technologies and the direction of biomedical research.
(Rose, 2001: 19)

These communities take on traditional state tasks, as care and support are now in part provided from below by them rather than by a top-down government. People become what Rose terms 'self-governing patients': Health-optimisers who play an active role in the ruling and improvement of their own wellbeing. He moreover argues that people feel a sense of social responsibility and concern towards their fellow community members, which shows in efforts to support one another and to advance the wellbeing of the group (Rose, 1996a: 56; Rose 1996b: 332-334).

People's active engagement in the optimisation of their wellbeing leads to a greater need and desire to inform themselves about their health condition. Patients are to become 'experts of themselves' - knowledgeable subjects with sufficient expertise to address their health needs without extensive support or assistance from healthcare professionals. In this sense, the expert-patient is more self-reliant and independent from professional care (Rose, 1996a: 59). Furthermore, unlike the passive patient who accepts professional medical advice without question, the expert-patient voices their needs, demands and possible dissent, thereby challenging and reversing traditional authority relations. The rise of the patient-expert is paralleled by the growth of self-help manuals and patient organisations that set up forums and directories to share knowledge (Rose & Miller, 1992: 195; Rose 1996a: 58-59).

A final characteristic of the self-governing subject is that they support a neoliberal, private health market by participating in the quantification, commodification and marketisation of life. The rising popularity of 'wearables' – portable devices that monitor one's fitness and activity – is a clear example of such participation, Rose notes. More generally, Rose presents self-governing patients as people who act as 'enterprising selves' in what he terms 'enterprise culture', which is characterised by a continuous striving for more happiness, more productivity and more success. Consumption, then, is a key means for the enterprising self to achieve better quality of life, presenting a direct route to greater wellbeing (Rose, 1992: 150, 156). Investments in health are particularly popular, making health goods and services prone to commodification and marketisation (Rose, 1992: 157). Thus, the self-governing patient acts as a health consumer who, in the pursuit of self-enhancement, financially invests in private healthcare, healthy lifestyles and health-optimising tools and technologies (Rose, 2001: 18). The imperative of health

drives the self-governing patient to the market, which promises to provide the most innovative services and products thanks to efficiency and competition (Rose, 1992: 155, 157). Captured by both the promise of innovation and rhetoric of free consumer choice, self-governing patients uphold a neoliberal system in which health is a commodity to be paid for on the private market (Rose, 1996a: 54; Rose & Miller, 1992: 198-201). On the whole, Rose paints a picture of a patient who in recent decades gained autonomy and ownership over their own wellbeing and health behaviours, paired with a greater need to inform themselves about and invest in their health.

V. THE DIYAPS USER: A SELF-GOVERNING PATIENT?

Much like the self-governing patient detailed by Rose, members of the DIYAPS movement show themselves to be active, inventive and autonomous in their creation of APS technology. Clearly, DIYAPS developers demonstrated immense resourcefulness and engagement when they first created the system, dedicating their free time to develop and finetune the system over years (Lewis, 2019: 11; Rao & Cunnane, 2016). The average DIYAPS user also shows agency and commitment to improving their health. Browsing the web and joining online DIYAPS communities (usually on forums and on Facebook) is the first step that, though small, reflects a desire to look beyond traditional diabetes technologies.

Familiarising themselves with the workings of a DIYAPS is the second, more demanding move. DIYAPS user guides are expressly written in an accessible style (Kesavadev *et al.*, 2020: 1228), but are still lengthy and require a basic understanding of medical concepts such as basal rates and the insulin to carbohydrate ratio (OpenAPS, 2020a). Setting up the system is time-consuming and requires dedication. For instance, personalising the algorithm requires the user to read and understand coding instructions (Kesavadev *et al.*, 2020: 1229-1230). Additionally, PWT1D intending to use DIYAPS often face scepticism and resistance from their healthcare providers (Gottlieb & Cluck, 2018: 143). It takes courage, perseverance and commitment to go against the advice of mainstream healthcare providers and adopt a novel technology.

Regardless of professional backing, many DIYAPS users find support in various online DIYAPS communities. Users share experiences, tips, glitches and solutions on online forums, in Facebook groups, Slack channels and on Twitter (OpenAPS, 2017b). Support is not merely technical or practical but also emotional, and online help is complemented with real-life sessions in which users learn how to 'close their loop' (Kesavadev *et al.*, 2020:

1227-1228). The online community is very active and DIYAPS users can usually count on instant help when they run into a problem. The experience of Melissa, user of the app Loop, illustrates the high level of mutual support:

I found the trickiest step was setting up Nightscout, because I misread a line of the instructions. After 20 min of frustration, I posted a request for advice in the Looped UK group and got help to resolve the issue within 15 min. (Marshall et al., 2019: 1559)

This shows that, whilst DIYAPS users are ultimately individually responsible for the proper use of DIYAPS technology, they are embedded in community networks characterised by social concern and mutual care.

The above observations show that members of the DIYAPS movement conform to the image of the self-governing patient who wishes to optimise their quality of life and is driven by responsibility for their own and their community's wellbeing. But how are these characteristics linked to privatisation and marketisation in the domain of health? The answer is that members of the DIYAPS movement have assumed responsibility for the development and spread of quality-of-life-enhancing support that, in their view, neither publicly funded healthcare nor the private health market provides (Gottlieb & Cluck, 2018). This responsibility is demonstrated not just in the creation of the APS itself, but also in the high level of care and support of the community as a whole – care and support that commercial parties and mainstream healthcare providers working with tight budgets may not deem profitable. As such, the #WeAreNotWaiting movement is not just a reaction to slow innovation by health technology companies. Rather, members of the movement also seek to comply with the imperative of health in full recognition that the responsibility to enhance their quality of life is their own.

A further commonality between member of the DIYAPS movement and Rose's self-governing patient is their level of expertise and their desire for independence from expert authority. The mere fact that DIYAPS are more advanced and effective than the traditional diabetes technologies provided by healthcare providers, shows how deep an understanding DIYAPS developers have of their illness. Although users generally lack such an understanding of the algorithms DIYAPS rely on, they at least need basic knowledge on, for example, the previously mentioned basal rates and insulin to carbohydrate ratio to be able to run the system.

Furthermore, DIYAPS enable PWT1D to directly access their own health data. Usually, healthcare professionals present PWT1D with data reports during the clinical encounter, along with their interpretation of what these data mean. By contrast, DIYAPS users can read out and analyse their data themselves, to subsequently interpret and annotate it with their lived experiences. This feature enables them to (re)direct their own treatment

– something users say they missed before the DIYAPS (Gottlieb & Cluck, 2018: 149).

More important in regard to privatisation and marketisation is the fact that DIYAPS allow users to gain greater independence from healthcare professionals and health insurance. Normally, PWT1D are dependent on their healthcare providers to access diabetes technologies and, as mentioned in Section III, healthcare providers do not recommend the most advanced technologies to all patients due to their high price. To obtain an insulin pump, for instance, patients often first have to prove that they can regulate their blood glucose levels with only injections. PWT1D therefore fear that they will not be able to access commercial APS when these enter the market (Gottlieb & Cluck, 2018: 146-148). DIYAPS, by contrast, are affordable and available without prescription. The software is free, and if a PWT1D already owns a CGM and an insulin pump – which most do – the additional hardware to build the DIYAPS costs around USD 150 (OpenAPS, n.d.-a). By opening up access to the most advanced diabetes technology without medical advice, DIYAPS thus bring about a shift in PWT1D's independence.

The above discussion shows that members of the DIYAPS movement and Rose's self-governing patient share significant similarities. The two differ, however, in one important respect. Whereas Rose's patient perpetuates the marketisation of health by consuming health products and services, the DIYAPS user does not partake to the same extent in the commodification of life and wellbeing. The often-cited reason for the creation of DIYAPS is impatience and frustration with a slowly innovating commercial health technology industry. Members of the movement thus refuse to act as waiting consumers. But the motivation of DIYAPS users and developers goes beyond that. As articulated on a #WeAreNotWaiting gathering in 2013, they insist they can “bring together the best and brightest minds from around the world to help make things better for PWDs” and to show that non-proprietary innovation is possible. DIYAPS developer Lane Desborough voiced his vision for the future of APS technology in rather stark terms by saying: “Closed, proprietary systems will die. Open, standards-based, interoperable devices will thrive” (DiabetesMine Team, 2019). Thus, the DIYAPS movement is built on the notion that non-commercial efforts can produce high-standard technology – and proves it.

In doing so, the DIYAPS movement urges us to rethink the idea that privatisation and marketisation are the quickest routes to innovation – an idea upon which our healthcare systems are partly built, as Rose reminds us. The movement, for instance, highlights that the mandate of the FDA and EMA is based on the assumption that innovation only occurs if it is commercially exploitable. The DIYAPS encourages us to consider expanding the mandate of regulatory agencies like the FDA and EMA

to include regulating non-commercial products and services.

VI. CONCLUSION AND IMPLICATIONS

To conclude, the DIYAPS movement is made up of people who feel a strong responsibility for enhancing their own quality of life, as well as that of fellow PWT1D. They must take this responsibility because the mainstream healthcare apparatus – consisting of professional medical care, health insurances and the commercial health technology industry – does not offer treatment that significantly reduces both the physical and cognitive burden of living with diabetes. The onus to obtain positive health outcomes is thus on PWT1D themselves. A further reason for PWT1D to use DIYAPS is a desire for greater independence from professional healthcare and health insurances. Without DIYAPS, PWT1D would rely on these parties to grant them access to expectedly pricey commercial APS. Finally, the DIYAPS movement wants to show that non-commercial innovation is possible. The movement is motivated by the belief that good alternatives to the commercial health technology industry are feasible, and proves that non-proprietary efforts indeed can be successful.

Is it desirable that patients need to take matters into their own hands because the market fails them and public healthcare does not meet their needs due to slow innovation and limited budgets? That question I leave for others to answer. The reality is that patient-led, non-commercial research and development is growing. Besides DIYAPS, examples include lithium carbonate studies conducted by people living with amyotrophic lateral sclerosis (ALS) (Wicks, 2018), OpenBCI, open-source guidance that helps cardiac patients build a DIY heart rhythm tracking device (Silva, 2015) and Jitterbug, a machine-learning system that predicts future blood glucose levels of people with diabetes (Ming, 2016). What the patients behind these initiatives have in common is that they cannot obtain the quality-of-life-enhancing treatment and technology they desire through regular healthcare channels. In taking responsibility for developing these themselves and by sharing their innovations with fellow patients, they resemble Rose's self-governing patient. These patient-innovators draw attention to the limitations of commercial health market and mainstream healthcare, and make non-commercial innovation a reality. As such, they urge us to either address the inequities and market failures currently present in our healthcare systems, or to consider regulating non-commercial drugs, devices and technologies.

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BIOGRAPHY

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