

## Diabetes & its Complications

# Self-tracking As an Act of Self-Care and Its Implications for Patient-Agency: A Designer's Point of View

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### ABSTRACT

*The use of mobile applications (apps) to support self-management of diabetes in daily life has been widely adapted among Norwegian diabetics. Among other aspects, the increasing numbers of people with chronic health conditions, such as diabetes, an increased focus on self-care, and the proliferation of small and easy-to-use measuring devices, smartphone applications, and social networking platforms available to people have made self-tracking as in connection to self-management a focal point of diabetes research. Especially in the Norwegian context, where smartphones and internet access have become ubiquitous. It has become relatively easy today to produce and share personal health information, which only a few years ago seemed unimaginable.*

*Consumer health technologies have transformed the self-management of chronic conditions, such as diabetes. This paper explores self-tracking as an act of self-care and its implications on patient agency, considering the question of whether self-tracking leads to increased patient agency. The focus is also on the consequences of big tech and pharma companies collecting personal health data and if this might be counteractive to patient agency. The article is part of a larger research effort investigating the impact of design on the experience of diabetes in daily life.*

### Keywords

Diabetes, Mobile Application, Design, Self-tracking, Patient Agency, m-Health.

### Introduction

In the management of chronic illnesses such as diabetes, the concept of keeping a journal in order to capture routines and patterns of diabetes in daily life is not new. However, with the advent of sensor technology, the experience of tracking such routines and patterns has altered. In less than a decade, a number of new smartphone applications and wearable mobile sensors has made the wearer's ability to monitor sleep, food consumption, movement, blood sugar, mood, and a host of other physiological states and behaviors themselves a common reality. These apps and devices are conjuring a future in which diabetics and other chronically ill patients are more involved in the management of their own illnesses—one in which they can generate a wealth of health data that will benefit medical decision making and turn patients into equal partners in the decision-making process.

Recently, in response to the overwhelmingly positive attention that self-tracking has received in the medical and public health literature, critical discussions of self-tracking for health have begun to emerge in the social sciences literature. These critical analyses articulate a number of concerns regarding the social, cultural, political, and ethical implications of self-tracking.

This paper aims to analyze the debate around self-tracking apps for health as support tool for patient agency and the subsequent loss of patient agency through surveillance mechanisms inherent in the very same self-tracking apps. This is understood as backdrop to discuss how design can take an active role in shaping these practices and the affordances that they carry, believing that design can add a practical perspective on the context in which self-tracking practices occur.

### The Critical Review Methodology

In this article the critical review method as described by Grant and Booth [1] was conducted. With this methodology subtle connections

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are being drawn to the surface. This type of review strives beyond the mapping and description of articles and information, rather it aims to evaluate the existing body of literature and develop new hypotheses or models [1]. The varied and extensive literature touches upon the themes of self-care in diabetes or chronic illness in general; mHealth and the patient 2.0; patient agency and health surveillance. As such these topics have common themes, but originate from different fields of study. By applying the methodology of a critical review allows the researcher to analyze and synthesize these diverse materials [1]. This methodology often said to suffer from a lack of structure. Which might be argued is the case here too. However, the openness and flexibility offered by the critical review method allows me to culminate a lot of different reading materials and insights collected throughout the past three years of my PhD and consider it from the perspective of a designer working in the field of health care.

### **Diabetes, Apps and the Patient 2.0**

Medical rhetoric has long been characterized by a focus on disease and on the physician as healer. Now, in the era of managed health care, patients are increasingly being viewed as agents in the management of their own chronic diseases. This article examines the changes brought in by notions of agency, through the use of diabetes apps to manage diabetes in daily life. With the proliferation of smartphones and consequentially the rise of health and lifestyle apps available to people, a new type of “patient 2.0” [2] has emerged. In the case of the chronic illness diabetes, these technological tools redefine the culture of diabetes care and therapy.

Before the advent of self-administered blood glucose tests, the common treatment of diabetes involved a doctor prescribing a rigid daily schedule of diet, medication, and exercise. To maintain these rigid regimes alongside the routines of daily life was challenging [3]. Additionally, a number of individualized factors, for example stress or hormonal activity, can affect daily insulin requirements. A flexible approach in which patients take primary responsibility for managing their diabetes on a daily level by adjusting insulin dosages is a better way to confront these problems [4]. This also implies that the health care professionals are relegated to a supporting role in diabetes management [3].

With this more flexible approach, a daily management routine has been established along the logging or diary paradigm. The initial diabetes journal or diary, a paper-record book, has been translated into the world of digital smartphone apps. Based on a study by the Norsk Senter for e-Helse Forskning (Norwegian Center for e-Health Research), the diabetes app market is predicted to grow by 56% in the coming years [5,6].

Currently, these apps fulfill two primary functions in the daily management of routines of diabetes: firstly, to log daily activities, such as blood sugar levels, food consumption, and more. Secondly, current diabetes apps offer their users the possibility to turn single data entries into graphs and charts that enable the diabetic to reflect

on and draw conclusions from this collected data and, in some cases, even make predictions to inform future decisions.

### **Changing Dynamics**

Advancements in medical technology, such as blood glucose meters that fit into the pocket of a pair of jeans or sensor technology embedded into smartphones, have enabled the collection and measurement of data on our bodies. This has been vitally important in promoting the cause of self-tracking in general and in the case of self-tracking for self-management in chronic illness. Previously, people were able to record and monitor a certain amount of data on their own bodies simply by applying analogue technologies, such as scales and tape measures. However, these do not facilitate the same level of detail when recording data. One of the most poignant examples of the possibilities available to diabetics today is the Freestyle Libre flash glucose monitor [6], which requires the diabetic to wear a small sensor under the skin. This continuously monitors the interstitial fluids glucose levels. The information can be accessed by hovering the smartphone, with the appropriate app installed, over the sensor. The collected data will appear on the app within seconds, already turned into a graph that correlates this new measurement with previous measurements. This ability to instantly correlate and visualize information can, as the name of the product/service suggests, be liberating. It frees the diabetic from the need to prick fingers, collect blood drops onto test strips, and insert these into a glucose meter. However, all of these data collection technologies change the dynamic between the diabetic as a patient and the professional system that includes the doctor or health staff. It shifts the responsibility for good health or good self-management practice away from the professional healthcare system onto the individual. The premise for this thought paradigm is the assumption that the users are responsible diabetics, who are motivated and able to engage in self-management through these technologies. They imply that all people living with a chronic illness, such as diabetes are adhering to the standards set by a neoliberal utopian ideal of health, in which the quality of life lived depends on the responsibility taken for diabetic self-management routines [7]. This, of course, cannot be the reality these apps operate in. The more realistic scenario is that there are a number of people using these self-tracking apps in order to achieve a number of different outcomes. Discerning these acts of self-tracking and their implications for diabetics or other people with chronic illnesses must be understood in the context of data practices [7]. As such the tracking has situated meaning that is dependent on the perspective. From the healthcare providers perspective self-tracking, in some instances may be performed to delegate an active role to patients. In another instance, it might be to educate newly diagnosed patients or to monitor their compliance. It might also be employed to delegate most of the care to patients themselves [8]. From the patients perspective self-tracking can be used as a mechanism to gain control [9], as a means to reflect upon personal illness narratives [10] or to construct an identity in daily self-management practices [10].

### **Self-tracking as Self-Care**

The concept of self-tracking is one part of a larger paradigm of

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social practices in relation to the management of health information [11-13]. Generally, it can be divided into two categories: One in which personal health information management concerns itself with the management of health data by institutions, and another that considers self-tracking as an act of data collection and management by the patient him or herself. Rooksby and colleagues characterise these self-tracking practices as ‘lived’ - enmeshed in everyday life - and reveal five overlapping self-tracking styles [12]. Through directive tracking, people often pursue a specific goal such as losing weight. Documentary tracking highlights that people not only track to change behaviour, but also out of curiosity. Diagnostic tracking aims to uncover relationships between different phenomena such as diet and medication. Collecting rewards refers to people’s will to compete and receive rewards. In fetishized tracking people are primarily interested in the appeal and functionality of technologies per se.

In this paper the term the self-tracking falls into line of “enmeshed in everyday life”. That is because the treatment of diabetes in Norway, self-tracking is part of the daily management routine. Where healthcare workers are teaching diabetics to track their blood glucose levels in order to determine how much insulin the body needs. When considering self-management it is usually in relation to self-care. These two terms are too closely interrelated and it is not always clear how they relate. Self-management has at times been conceptualized to be a subset of self-care, which is focused on managing the impact of disease [14,15]. Contrary to this stands the notion described by Wilde and Gavin, who noted that the term self-care was often classified under the concept of self-management [16].

In order for the self-management to take place self-care technologies such as diabetes apps play a fundamental role today [9]. A cornerstone of self-tracking in relation to chronic illness is the ability of the tracking apps to visualize patterns in data; such as tracked food intake, exercise or insulin intake. By turning individual data points into graphs, charts and maps, the user has the ability to put an individual experience into a longer term context. According to Hansen, the act of displaying and giving feedback to users on their health in real-time and over time allows self-tracking to enable self-care [8]. However, the self-care technology is not necessarily limited to tracking apps. They include medical devices such as blood glucose meters [17] or web tools for collecting and analyzing health related data [10]. These technologies, can offer the user a better understanding of their habits and routines throughout their daily life, simply by collecting and visualizing data over time.

Current research often highlights the individual experience of self-tracking in chronic illness. Most studies it seems are qualitative studies exploring how people living with chronic illnesses, such as diabetes are focused on exploring the idiosyncrasies of chronic illness in daily life [18]. In his research Chen for example points out the need for individualized health technologies, in order to meet the individuals demands [19]. This finding underlines the subjective reality that self-care evokes. A person using self-tracking in order to monitor themselves and manage the impact

of their daily behaviour on their chronic disease is an inherently individual experience.

### **From the patient patient to patient agency to health surveillance**

Traditionally the relationship between healthcare staff and chronic patients, has been characterized by the healthcare staff or doctor being responsible for the health of the patient. In this scenario the chronic patient has limited agency. With the advent of the digital technologies that enable consistent self-tracking this notion is changing and replaced by the notion, that health is a matter of personal responsibility, which requires tools to manage this [20]. self-care technologies offer various solutions that enable this shift, among them illness specific management tools (for example Glucose meters), different self-tracking apps, diagnostic online tools, support communities for various chronic illnesses and more. With the dissemination of self-tracking apps it is not just the doctor or nurse that can collect data and analyse it. As Mauro and Setiffi observed: “as the sources of medical information shift from those controlled by doctors such as medical records and specialist journals to interactive websites and online communities, it is easier for individuals and patients to find information, get support and share their illness experiences with others with the same condition” [21]. This generally casts self-tracking for health in the light of a tool for agency. The notion of agency or patient empowerment in healthcare has been taking over a language of compliance with care, paternalistic and authoritarian models of the patient-doctor relationship [22] for a number of years now. From this perspective the word patient appears like a ghost from the past. On the one hand, as a noun, it sets the scene for a person suffering from an illness or a disease. On the other hand the adjective patient is synonymous with calm, quiet, and long-suffering. These two homographs are distinct in their meaning, however, unvaryingly connected in their appearance. Additionally, It is interesting to note that the five most downloaded diabetes apps in Norway used for self-tracking do not use the word patient. They set a discourse in which chronic conditions, such as diabetes are viewed as unruly things which need to be controlled. Diabetes apps are depicted as supportive tools that can “[help] you on your quest toward glucose control” [23]. In this framework, the data collected is viewed as knowledge that induces the user to take action. Often the language of self-tracking in the healthcare context speaks a language that only references the present. Disregarding that self-tracking evolves over time and brings about changes in the patient-provider relationship. Over time, patients may perform self-tracking differently (e.g. tracking new parameters, using different tracking tools) and gain an understanding of their condition which is more accurate than that of their providers. This may give rise to new forms of therapeutic alliance in which patients and providers are both considered ‘experts’ [13].

Given all of the optimism surrounding the potential of self-tracking in relation to chronic illnesses’ such as diabetes, it is not without criticism. It seems that the features that make self-tracking apps to be seen as a positive force giving the chronically ill agency, changing the relationship between healthcare staff and patients, and influencing the experience of chronic illness in

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a positive manner, are also the very same features, that give rise for concern. As previously discussed the ability of self-tracking apps to collect data anywhere and everywhere, by allowing the patient to record routines and emotions also foster a system of self-surveillance. Or as Lupton puts it, the “net of surveillance” is extended by encouraging users to turn the medical gaze upon themselves in the form of “self-surveillance” and to invite peers to participate in monitoring practices via the sharing of personal data on social media and other digital platforms. Usually surveillance is forced upon an individual by a system or others. Here she points out that the act of self-tracking does not invite the user to consider the data beyond the rational of control. There appears to be few instances in the apps designed to self-examine or reflect upon the data collected outside of the graphs and charts produced by the apps algorithm. This according to Sharon falls in line with the long history of medical surveillance and biopolitical governance as discussed by Foucault [24]. What Lupton further points towards is the open invitation to users to share their data with a network of like-minded people further blurring the boundaries of private and public life. While leading to a normalization of intrusive surveillance practices. Which are not limited to self-surveillance, but are extended to practices of surveillance and disciplining users by medical staff, healthcare providers, states or co-operations too. Viewed in this light critics such as Lupton or Olson position self-tracking tools in a culture of surveillance. From this perspective self-tracking for health does not build agency or empowers users, it rather does the opposite. As it creates a system in which the self-trackers open themselves up to the control of others.

This normalization of surveillance is linked to another point of criticism, in most cases digital self-tracked data are stored in cloud-based computing system, which allows the user to access the data he or she collected over time. Which is what has previously in this article has been identified as a means of building agency. The ability to be master of bodily data, that the patient chooses to share with the physician changes the relationship between these two entities. However, this view is not the whole picture. When people self-track using proprietary digital devices and software, when agreeing to the terms and conditions of the developers they often agree to provide their data, which may then be used for purposes by second and third parties that go well beyond the original intentions of the self-trackers [25].

To most reading this article it comes as no surprise that the data collected by the users, once stored on a cloud server becomes part of the digital knowledge economy. Where personal health data that was stored for private use, now becomes a commodity belonging to internet empires, big pharma companies or government organisations. The literature on surveillance often stresses this shift of data generation practices for personal use become ensnared in larger networks and economies without the express awareness of users [26,27]. According to Lupton these datasets are having an increasingly important role in shaping policy, commercial dealings, education, social welfare and healthcare, the management of groups and populations and in individuals’ personal and everyday lives [7].

### **From Self-tracking, body perception and role of design**

According to Lupton, self-tracking and the quantified self are measures for building identity [7]. Both by the act of tracking and interaction with the self and the data collected. But by re-reading the data as it is being collated by the apps algorithms into graphs. This supports the notion that using diabetes apps changes patient’s perception of self, by spending time quantifying their body and their illness. It also points to a need to consider the impact design has in this relationship between self-tracking as a practice and the designed visualizations depicting the data on the screen. The information that is reflected back at the user is a version of his or her own bodily experience. Using self-tracking technologies in general encourages people to consider their bodies and their selves through numbers [28]. The allure of these numbers is their supposed neutrality. They speak the language of the scientific, not the personal. By reducing the bodily experience of diabetes into an array of charts and graphs on the one hand and reduce the complexity of felt emotions into a set of emoticons on the other hand, the illness becomes quantifiable and hence appears manageable. This is the appearance the numeric has. Design in itself often concerns itself with the appearance of things, however, it also considers the meaning of these things. As Coughlin questions: “We can visualize the data we collect from countless gadgets, but will we understand what the data means?” [29]. This is indeed a challenge for designers as Smith and Vonthehoff found in their research on the experience of datafied health [30]. Where they describe an ongoing negotiation between self-trackers and their collected data. This invites designers to potentially question a proposed “aesthetic of the neutral” and ask if it is sensible to produce an image of the body or indeed of an experience that is based on statistic figures, which are displayed rather than an individual experience?

Designer’s and developer’s love affair with the quantifiable – meaning hard or objective data is presented as the best manner of assessing and representing the health state of one’s life. This has implications for designers too. Often the data is visualized in a neutral or scientific manner, speaking a similar visual language to graphs and charts seen of the stock exchange, or infographics on voter turnout. As opposed to a photographic image of the body, or an illustration of the body. Designers support these underlying messages by supporting this representation of bodily experience of diabetes. Often the tracked information is depicted in form of curves, or correlation diagrams, which imply a prediction for the future. Simply by having a line point up or down on a scale a prediction is implied in a graphic. In western culture today we carry in us the wish to have a positive prediction, meaning for the line graph to be seen as rising. In the case of blood glucose levels, that would be the opposite of a positive prediction for most diabetics. From this perspective, numbers alone do not tell us merely enough. It is the contexts in which numbers (or any other forms of data about the self) are created that are important. As two designers put it: context humanizes the numbers and places them back into our lives in meaningful ways. For example, a fitness tracker can tell us that our physical activity is down from the previous month. But it cannot tell us that the inactivity is due to a sprained ankle. Given

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that context, those declining numbers might tell a different story: that we are recovering steadily rather than slacking off. Even in that simple scenario, it is clear that a small bit of context can frame data in a much more insightful way [31].

In each case it is up to the designer to choose a form of representation, which leaves the user with an experience of data that is meaningful, and easy to grasp, with relatively little fear of misrepresentation. These issues might be not be of major concern for those simply seeking to self-track out of curiosity or a wish for self-improvement, it does, however, require notice in the context of self-care. Considering self-tracking as an act of self-care along the lines of Gantz, who describes self-care as situation specific and culturally influenced, that self-care involves the ability to make decisions and perform actions [32]. It is the ability to make decisions that design is implicit in. It is the design of the interaction, and the design of the graphics that influence the ability to make a decision. By making data input and comprehension effortless. But it is not just ease of use that design is implicit in. Even more so, it carries the responsibility of presenting data in a meaningful way. One that allows the user, the patient, the chronically ill to gain insight into their routines and actions in order to take steps toward self-care, instead of self-optimization. Acknowledging the ways in which the phenomena are collected, interpreted are always associated in social relationships, power dynamics and perspectives [33-35]. The notion to present in a bodily experience or an illness as abstracted events implies that self-knowledge can only be accomplished through datafing the body. As one's bodily states and functions become ever more recordable and visualized via data displays, it becomes easier to trust the 'numbers' over physical sensations [28]. In this designers would be complicit in creating a culture in which patient agency might grow in respect to the medical professionals acknowledging the patient as an expert in his own illness. But as an expert in what exactly? If the diabetic, simply becomes a statistician of his own life. A record keeper, ignoring data that is not recognized because it cannot be recorded adequately, the agency gained is still fundamentally lacking. In this scenario there is no space for an inkling, an unarticulated feeling, which cannot be quantified. But might well be of diagnostic and medical importance. Because the human mind might be able to correlate information, that the developers and designers did not factor into the algorithms of the app. And by not designing moments for self-reflection and free thinking users might miss the opportunity for this. What Lupton considers is the experience of tracking and re-visiting the data collected. Which considers self-tracking in the diabetic context as an active state of being. The diabetic is in active engagement with the chronic illness diabetes. For this designers and app developers can create space and moments in time. To allow the users of these self-tracking for health apps to reflect on their body experience in its quantified form vs. their body experience in its lived existence.

## Conclusion

In this article I have examined various sides of the debate on health self-tracking. Perspectives of patient agency have been weighed against a culture of surveillance, the role designers play

in producing a record of lived experience of diabetes and how this can shape body perception and the perception of chronic illness. Chronic disease situations are not cured, but are rather managed and "lived with." As a growing diabetic population adapts to this chronic condition over longer life spans, designers have a major role to play in creating self-care technology, interactions, frameworks for self-regulation and personal health agency. Most of the polarized debate on health self-tracking appears to fall along the lines of two irreconcilable positions. On the one side of the divide are the enthusiasts, Rivera-Pelayo, Zacharias, Müller, and Braun and Swan. They deem self-tracking technologies and practices to be a turning point in the management of health and chronic illness. The opposing side view these practices as carrying the potential for misuse which will lead to a medicalized society [36] and an increase of surveillance culture [28] which need to be resisted by employing subversive practices as suggested by Fox [37]. Currently I have found few designers who are taking an active stance in this discussion. In design research these phenomena are discussed through the lens of usability and the need for context as discussed by Boam and Webb [31]. The rich phenomenology of health self-tracking, requires a more differentiated discussion that the reduction to a nightmare scenario and a utopian concept full of promise [38]. I believe that the practicalities of designing self-tracking apps and the inherent interactions that grow out of that context can enrich this debate. I also believe a deeper reflection is necessary on the part of practicing designers, in their influence on body image and visualized experiences of chronic illness. In order to achieve this more research is necessary. This research needs to shed light on ways in which people incorporate and conceptualize personal health experiences and collected medical data. We still do not have enough insights into the nature of data practices. The manner in which people actively engage and interpret data that they collect about themselves. How they read the visualizations produced by these self-tracking apps, or how it actively or passively shapes their identity as chronically ill people. Lupton employs the term 'data sense' to encapsulate the complexity of the entanglements between human senses, digital sensors and sense-making in response to these lively data [7]. This is not just important and meaningful research in order to challenge the utopian scenarios presented to the public by academia and policymakers [7], but also for designers to understand how users make choices about which type of information to collect or how they reflect on what is collected. Questions such as how does data become meaningful? When does it lose meaning? Are considered, but in terms of interaction design, questions such How do people negotiate what their self-tracking devices tell them about their bodies and health, and what their bodily senses reveal to them? In order to ensure that users do not feel that their experience is discounted because it does not fit into a predefined set of parameters. In order to ensure that personal data has the potential provide comfort or reassurance. Or on the contrary to understand how do they frustrate or disappoint people?

Finally, the ways in which self-tracking technologies and practices are invented, brought onto the market, advocated and incorporated into organisations and institutions also require more attention.

What are the decision-making processes by which developers choose to work on self-tracking apps, other software and devices, and what are the tacit assumptions, expectations and norms about bodies and selves underpinning these processes needs to be better understood. This can then act as a foundation for future designers to potentially be mindful of these tacit assumptions or to challenge conventions on chronic illness and its experience in the future.

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