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Living with Technology

Data work and smartwatch data trends for patients with serious mental illnesses

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Abstract. As healthcare is being reshaped by technology, researchers are increasingly relying on patients to generate data. However, the efforts patients dedicate to data collection for research and treatment purposes are seldom scrutinised. We examine the data work of 21 patients diagnosed with schizophrenia or bipolar disorder who participated in our digital mental health intervention, equipped with a smartwatch and a mobile application. We offer in-depth insights into their somatic experiences while living with technology over time by analysing the impact of data work when living with technology. Our paper offers insights into the data work of patients, highlighting its importance as a valuable resource for future digital mental health interventions. We outline what living with technology for individuals with serious mental illnesses entails by unravelling their data work into five themes. Moreover, we provide a model that others can use when incorporating somatic IS artifacts into practice.

Key words: Data Work, Somatic Experiences, Digital Mental Health Interventions, Bipolar, Schizophrenia, Smartwatches.

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1 Introduction

Mental health is becoming increasingly important in modern society; yet, resources remain limited, and in many countries, they are insufficient to meet the urgent needs of patients. Digital mental health interventions have surfaced recently and refer to the use of digital interventions as a treatment option for people seeking mental healthcare. Digital mental health interventions have the potential to increase access to evidence-based support and to continuously collect data over an extended period, which, in turn, can enhance decision-making (Safavi et al., 2019; Torous et al., 2019). A systematic review of digital mental health interventions for young people with depression and anxiety finds that the interventions only show clinical significance when use is thoroughly supervised (Garrido et al., 2019). Additionally, the uptake of digital mental health alone, for instance, through mobile applications, remains low for both patients (Fleming et al., 2018) and healthcare professionals (Sawyer et al., 2024; Schueller et al., 2016). To counteract the low uptake, the literature is shifting towards a combined data-driven approach that better suits the realm of digital mental health than a single solution (Seif-erth et al., 2023; Torous et al., 2019). A combinatory data-driven approach can, for instance, involve digital platforms that collect both subjective and objective data from mobile applications, alongside objective data from wearables and sensor feeds (Islind & Vallo Hult, 2022). Figuring out a balance between subjective and objective data, and understanding the notion of living with technologies for those with serious mental illnesses, is an emerging research agenda that information systems (IS) research should contribute to (Lorenz & Recker, 2023; Werntz et al., 2023). The term serious mental illness includes the diseases schizophrenia, bipolar disorder, schizoaffective disorder, and major depression, and refers to individuals with severe psychological conditions that significantly impair their ability to function and participate in daily and occupational activities (De Hert et al., 2011).

In order for combinatory data-driven approaches to data collection to succeed, the people living with serious mental illnesses (hereinafter called patients) need to be included in the design of their own care (de Azevedo Cardoso et al., 2024). Data-driven approaches require effort, which is typically associated with the work of data scientists or other specialists who process and interpret data. However, there is a less-discussed type of effort, namely the foundational contribution to all data collection, and that is the invisible work conducted by patients or their healthcare professionals. All this effort has been termed ‘data work’ (Bates et al., 2016; Fiske et al., 2019; Parmiggiani et al., 2020; Rothschild et al., 2022). Although the work on which data collection rests is important, the work that patients do in connection with data-driven approaches is often

not examined equally closely within the literature as the work conducted by healthcare professionals is (McVey et al., 2021).

With wearable and ‘bringable’ sensors such as smartwatches and smartphones, the work of producing personal data can be conducted alongside every other activity that takes place during a person’s daily life, such as exercising, traveling, and working (Waardenburg et al., 2022), thereby transcending boundaries such as those between work and spare time (Mettler, 2024). As wearable devices become an integral part of IS research, interesting questions about data work arise. When focusing on the cognitive load that patients contribute to their own treatment, i.e., the often-invisible effort that they put into their data work, there is another important aspect to consider, namely, the physical impact of wearing IS artifacts such as wearables. The impact of living with technology has been discussed as a somatic experience, and we rely on that notion in this paper. Somatic IS artifacts are defined as devices that sense bodily information, such as movement or heart rate, and respond to those (Lorenz & Recker, 2023). Somatic IS artifacts are, therefore, connected to the human body and interact with users by utilizing their physiological data, such as displaying step counts or providing information on sleep quality, all features of wearables. In this paper, we bring the data work required by patients, along with the somatic experiences, centre stage and provide insightful findings from research where patients wore a smartwatch for six weeks and reported their well-being daily through a mobile application. This approach enables combinatory data-driven care and self-care through a digital platform, enhancing the decision-making process for patients and healthcare professionals. The patients in the study were diagnosed with schizophrenia or bipolar disorder, and they were part of an outpatient clinic entering into digital mental health as one of their treatment options. We gathered data from 21 patients, twelve of whom are being treated for schizophrenia and nine for bipolar disorder, type 1. We analysed the smartwatch data feeding into the digital platform and conducted semi-structured interviews. Of the 21 patients in the study, three opted out of the interview after the data collection was completed. In this paper, we focus on examining the data work and somatic experiences of patients living with the technology over an extended period.

Against this backdrop, we pose the research question: What is the impact of data work when living with technology for patients dealing with schizophrenia or bipolar disorder? Our paper yields a three-fold contribution. *First*, we offer insights into the data work of patients, highlighting its importance as a valuable resource for future digital mental health interventions. *Second*, we outline what living with technology for individuals with serious mental illnesses entails through unraveling their data work.

Finally, we provide a model that others can use when incorporating somatic IS artifacts into practice.

The impact of data work is complex and varies among individuals. Some patients find it convenient and beneficial, while others experience mixed or predominantly a negative impact. Assessing these responses is essential—not only to refine data collection for future research—but also to help patients validate and understand their experiences. Normalizing diverse somatic experiences as part of data work and IS artifacts is important, and we propose a model to help others understand the impact, emphasizing that emotions exist on a spectrum rather than as binary outcomes. Our findings clearly illustrate that they do curate physical responses, and the data work involved is tangible and real. Our paper, through in-depth insights into ways in which patients dealing with schizophrenia or bipolar disorders experience somatic IS artifacts, shows that data work and somatic experiences are intertwined, offering a novel contribution to the field of IS.

2 Related work

Bipolar disorder is a chronic mental disorder that is most often discovered between the ages of 15 and 24 (Müller-Oerlinghausen, Berghöfer & Bauer, 2002). Bipolar patients typically experience extreme mood swings and activity fluctuations, from being hyperactive to total inactivity. Patients often experience sleep difficulties and may struggle with day-to-day tasks (Rahman et al., 2020). Schizophrenia is another chronic mental disorder that is most often diagnosed early in late adolescence or early adulthood. Schizophrenia typically causes extensive delusions that are often paranoid and voices that converse with or about the patient. It also includes negative symptoms, such as flattened affect, loss of pleasure, social withdrawal, and loss of drive, which negatively impact the quality of life (Schultz et al., 2007). Schizophrenia patients also face a number of life challenges, such as a low employment rate (below 20%) and high homelessness (up to 20%), and are three times more likely to be in prisons than in psychiatric institutions (ibid). Patients with serious mental illness have a lower life expectancy of 13-30 years. About 60% of the excess mortality is due to physical illness, including type 2 diabetes, cardiovascular disease, respiratory illness, and obesity (De Hert et al., 2011). Recently published studies have reported the benefits of using digital health interventions in addition to traditional treatment for patients with schizophrenia (Gillis et al., 2024) and bipolar disorder (Nielssen et al., 2023).

The shifting landscape of healthcare occupations is marked by an escalation in data-related tasks. Healthcare institutions are establishing or expanding information management and intelligence units and increasingly calling for digital platforms to har-

ness data for enhancing efficiency and quality (McVey et al., 2021), driving a broader transformation within the healthcare sector to integrate and leverage this newfound wealth of information (Hoeyer, 2023; Hogle, 2016). Moreover, these transformations extend beyond the technical nature or simplicity of bringing data in. Instead, it marks a revolution that we need to critically examine to comprehend the somatic IS artifacts and their impact on patients. The patients' effort is vast, and that effort often entails unpaid labor or invisible data work, which traditionally takes place outside the borders of healthcare (Islind & Vallo Hult, 2022). In existing literature, the work that takes place in the background or behind the scenes is often overlooked. More specifically, work involved in gathering the data in the first place, such that the data becomes available for others (Bertelsen et al., 2024; Parmiggiani et al., 2022; Sambasivan et al., 2021) used for enhanced decision-making in healthcare, is often disregarded. The data work and the somatic experiences of patients are closely intertwined aspects. Data work is necessary to gather information, and to fully comprehend the impact that data work has on patients, the experiences of somatic IS artifacts need to be examined. Due to the duality of data work and somatic experiences, we examine those in parallel. Up until now, "the technological, analytical and emotional work undertaken by all actors within the healthcare system that is necessary to make data clinically and personally meaningful" (Fiske et al., 2019, p.2) has been the focal point of the data work literature, while physical strain has yet to be explored; a gap which we explore in this paper.

In recent years, there has been a surge in research on the concept of living with technology and its impact on individuals. Within that realm, somatic experiences of somatic IS artifacts both receive and transmit signals to and from the human body. These artifacts operate by assimilating bodily data, encompassing physiological signals and movement patterns, as input to individuals. Within that realm, somatic IS artifacts both receive and transmit signals to and from the human body. These artifacts operate by assimilating bodily data, encompassing physiological signals and movement patterns, as input while aligning their functionality toward fulfilling physiological objectives rather than cognitive ones (Lorenz & Recker, 2023). Illustratively, examples of such artifacts encompass wearables, nearables (sensors placed near the body), intelligent implants, and prosthetic apparatuses that transmit and receive data, all designed to address objectives such as optimizing and monitoring vital physiological parameters (Óskarsdóttir et al., 2022; Prasopoulou, 2017). These somatic IS artifacts not only encompass sensors that can receive and transmit signals, but they also cater to a specific somatic experience through the material properties and their ergonomic fit and design, meant to trigger physical responses (Lorenz & Recker, 2023; Recker et al., 2021). Somatic IS artifacts, for instance, wearables, have therefore been shown to have bodily

attributes and not only a mental impact on their users. The way patients such as those dealing with schizophrenia or bipolar disorders experience somatic IS artifacts has not been researched to date. With somatic experiences, we target the interconnection between body and mind, focusing on the experience of sensor data on the one hand and the deciphering of subjective and objective well-being on the other.

That brings us to data work and the invisible work often carried out by patients within healthcare when collecting such data. The evolution of data-intensive resourcing, involving the production, processing, and utilization of data, has significantly impacted healthcare work and its practitioners across multiple dimensions (Bossen et al., 2019; Parmiggiani et al., 2022; Pedersen & Bossen, 2024). Data work that is specifically carried out by patients has been examined in the literature in some ways, although its exploration is not vast. The papers to date examining data work carried out by patients, outside the borders of healthcare, are, for instance, on stroke patients (Caldeira et al., 2021), cancer patients (Cerna et al., 2020), physiotherapy patients (Blixt et al., 2022), and fertility tracking (Costa Figueiredo & Chen, 2021). The research to date has been more focused on healthcare professionals, and individual healthcare personnel are increasingly engaged in data-related tasks as part of their professional responsibilities, necessitating the acquisition of new skills (Cruz, 2023; Møller et al., 2020). Physicians, while benefiting from an expanded pool of data for patient assessment and enhanced decision-making power, encounter challenges associated with the influx of ‘meaningless data’ (Budd, 2023; Tajirian et al., 2020). Moreover, an increasing amount of work within healthcare involves data management, as administrative staff, such as clerks, are required to develop proficiency in data processing (Pine et al., 2022). However, for all of this to become effective in practice, the data needs to be gathered in an efficient and human-centered manner. It is, therefore, vital to investigate what happens in the background and what data are needed by patients for data-driven decision-making to take place.

3 Research approach

This paper is based on data from 21 patients, combining quantitative data from smartwatches with qualitative data derived from semi-structured interviews. This study outlines a part of a larger research project that aims to holistically view the potential of using a smartwatch and a mobile application as support in the treatment of patients who are diagnosed with bipolar or schizophrenia (Sigurðardóttir et al., 2022, 2024, 2025) in collaboration between Reykjavik University and Landspítali hospital in Iceland and

bound by an ethical approval from the Bioethics Committee for Health Research at Landspítali hospital (nr. 55/2020). The focal point of this paper is two-fold: (i) the patients' data work, specifically related to the collection of their own health data through smartwatches, and (ii) the somatic experiences of the patients while engaging in data work.

The patient sample consists of two groups: (i) patients aged 18-50 with bipolar type 1 receiving outpatient care from a specialized bipolar team focused on evidence-based treatment and early intervention, with treatment lasting up to three years (approximately 70 patients at a time), and (ii) patients aged 18-35 with early-stage psychotic disorders, including schizophrenia, treated at specialized psychiatric facilities for up to two years (around 100 patients at a time). Patients are selected through convenience sampling by healthcare professionals. The healthcare professionals suggested, based on clinical experience, the exclusion of those without a smartphone, experiencing homelessness, or being assessed too seriously ill by healthcare professionals.

The study process involved four main steps: (i) healthcare professionals introduced the study to potential patients and sought their permission for researchers to contact them, (ii) due to ethical restrictions on patient data, the first author (hereinafter researcher) used the hospital's landline to call patients and schedule meetings for further explanation, (iii) during these meetings at the hospital, the researcher explained the study's aims and process. Patients who agreed to participate provided informed consent and received a smartwatch and a mobile application with daily well-being questions, and (iv) data collection occurred over six weeks, involving continuous smartwatch data, daily well-being diaries via the app, three questionnaires on paper and discussions, and access to medical records two weeks before and after the study. All data was integrated into a digital platform, and semi-structured interviews were conducted with patients after the six-week period (see Table 1).

The semi-structured interviews focused on two aspects: (i) the data work patients performed and (ii) their somatic experiences of living with technology. Of the 21 patients in the study, three opted out of the interview after the data collection was completed. The interview guide consisted of 42 questions, beginning with inquiries about daily routines and experiences with technology. It also examined patients' awareness of health-related behaviors, such as sleep and physical activity, and whether their perspectives on these behaviors changed over the course of the study. Additionally, patients were asked about their feelings toward data collection and sharing, as well as their discussions with healthcare professionals about the collected data, and whether access to the data influenced their treatment. Questions also addressed whether data collection impacted stress levels, aiming to capture any psychological impact of the digital

<i>Patient id.</i>	<i>Diagnosis</i>	<i>Interview length (in minutes)</i>	<i>Days of data collection completed</i>	<i>Comments</i>
1	Schizophrenia	46:03	41	
2	Schizophrenia	39:23	14	
3	Schizophrenia	31:06	42	
4	Schizophrenia	26:28	41	
5	Schizophrenia	44:29	22	
6	Schizophrenia	42:10	12	
7	Schizophrenia	25:52	24	
8	Schizophrenia	31:35	35	
9	Schizophrenia	31:23	42	
10	Schizophrenia	19:18	3	
11	Schizophrenia	No interview	10	Quit during the data collection interval
12	Schizophrenia	36:07	42	
13	Bipolar	32:45	38	No steps recorded in data (only used smartwatch during the nights)
14	Bipolar	30:05	20	
15	Bipolar	50:08	42	
16	Bipolar	25:39	27	
17	Bipolar	No interview	7	Quit during the data collection interval
18	Bipolar	31:38	0	No sleep recorded in data (only used smartwatch during the days)
19	Bipolar	18:59	36	
20	Bipolar	20:32	42	
21	Bipolar	No interview	36	Did not attend interview

Table 1. The data collection effort, the length of interviews, and the smartwatch data.

tools. Practical topics, such as reminders, data privacy, and customization preferences for digital health interventions, were also discussed. This paper includes visualizations of smartwatch data and patient-specific trends, along with an analysis of interview responses to understand the impact of the smartwatch and app on patients' data work and somatic experiences (see the analysis section for details). All interviews were transcribed verbatim and translated from Icelandic to English for this paper.

3.1 Mobile application

As part of this study, we designed and developed a mobile application to support treatment for individuals with serious mental illness, together with the patients. While the interviews primarily analyzed data work and somatic experiences, they also informed further development of mobile applications. The patients and healthcare professionals provided iterative feedback on the questions and the statements ended up being: (i) I was successful in achieving my goals, (ii) My mental state was positive, (iii) My physical condition was good, (iv) I experienced little stress, (v) Today's movement was good, and (vi) I slept well last night. The patients answered these questions daily on a five-point Likert scale, ranging from "strongly disagree" (left) to "strongly agree" (right). The responses generated a single score, the 'MindPoint,' ranging from 10 to 30, reflecting the positivity of their answers and providing insight into their daily well-being. The purpose of the mobile application was to support self-care and help the patients keep track of their own data. Moreover, the data from the mobile application is fed into a digital platform, which healthcare professionals use to monitor patient data.

3.2 Data analysis

For the data visualizations from the smartwatch data, we display two time-series variables: (i) sleep in hours and (ii) the number of steps taken each day derived from the smartwatch, manufactured by Withings, fetched through their Application Programming Interface (API) into our digital platform. The raw data includes descriptive variables, and we present the sum of the deep sleep and light sleep variables, step count, and heart rate in our results, illustrating the outcome of the data work.

Our data analysis was a thematic approach, focusing on understanding the efforts involved in data work and the somatic experiences of living with technology. The first round was exploratory and inductive in nature, involving open coding of all the interviews by analyzing the empirical findings through thematic analysis (Braun and Clarke, 2006). The first round was rooted in physical and emotional responses, insightfully

described by the patients, and we closely adhered to the patients' own formulations and descriptions of their data work (Gioia et al., 2013). The codes that emerged in the first round were of many sorts, and some sentences had more than one code; some examples of codes being 'sweat', 'tired', 'forgetting', 'surveillance', 'interesting', 'mobile connection', 'sports', 'feeling sorry', 'dry spots', etc. The second round of thematic analysis included categorizing the data using the codes, creating a broader grouping of the quotes from the patients. One category could have more than one code, and we were careful to make distinctions between different types of experiences when analyzing. Examples of codes were 'skin problems', 'sleep', 'treatment', 'goals', etc. The third round involved clustering the quotes into themes outlined in the findings, inspired by the literature. The abductive approach in this round entailed shifting between inductive and deductive reasoning to continuously revise, sharpen, and re-formulate both the research design, the analysis, and the conceptual contribution (Gregory and Muntermann, 2011; Van de Ven, 2007). We selected the literature based on data work and somatic experiences as a combinatory lens, meaning that we viewed "reality from the theoretical viewpoint or perspective" (Van de Ven, 2007, p. 104) of data work and somatic experiences. The first analysis round was conducted by the first author, while the last two phases were supported by the last author. At last, we arrived at five themes that shed light on the multifaceted experiences connected to the data work of patients; all five themes are elaborated on in the next chapter.

4 Results

Our findings are outlined through five themes: (i) unraveling patterns yielded through data work with smartwatch over time, (ii) the body and the wearable can become entangled curating somatic experiences that are unique, (iii) data work with smartwatches can cause bodily discomfort and harm, (iv) living with technology can have overt and covert impact on decision-making, and (v) data work can trigger a feeling of surveillance and increase paranoia.

4.1 Unravelling patterns yielded through data work with smartwatches over time

The patients wore the smartwatch over time, and to dive into the data that the data work yielded, we analyzed the data over time. The patients' data patterns were diverse, and some patients walked and slept both dangerously little and truly much, which could be influenced by personal characteristics or preferences but could also be con-

nected to their disease situation or process. In Figure 1, we present time-series plots for the sleep and step data for six randomly selected patients. Patients 1, 5, and 9 have schizophrenia, and patients 14, 15, and 20 have bipolar disorder. With these results, we want to highlight that wearables are truly powerful for shedding light on the ebb and flow in the patterns of behavior of patients with serious mental illnesses, as the data fluctuation is much more severe compared to people not living with serious mental illnesses. Ergo, the figure serves as an illustration of the results of the patients' extensive data work over six weeks, showing the power of wearables for patients.

The most insightful data from the smartwatches was the step count and sleep patterns, according to both patients and healthcare professionals. First, we dig into the three patients selected who have schizophrenia. When examining the data from patient 1, the pattern fluctuates mildly at the beginning of the interval. However, on day 23, the shifts start to amplify, and the patient's sleep fluctuates up and down, from 10 hours per night on day 23 to 5 hours on night 24, and to 12 hours again the day after, and so on. These are staggering changes. Interestingly, when the patients' sleep pattern changes on night 24, the step count decreases and remains steadily low, while the sleep fluctuations persist (standard deviation for sleep is 2.37 hours, and for steps it is 2.745 steps). If we examine the sleep data for patient 5, the patterns form waves, where each night does not deviate significantly from the next. The number of hours spent sleeping per night still varies, ranging from around 8 hours to 16 hours. The fluctuations in the patients' movements are even more noticeable, ranging from 616 to 19,693 steps per

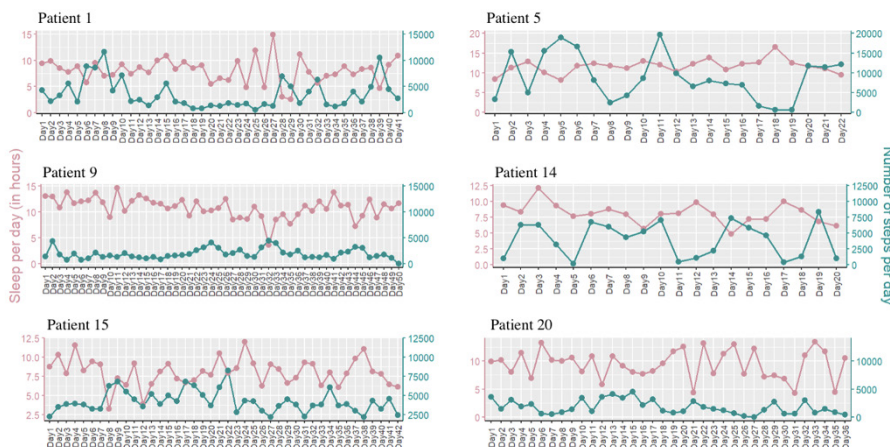


Figure 1. A grid of line plots displaying smartwatch data from six patients. The pink line represents sleep duration, while the green line represents the number of steps taken.

day (with a standard deviation of 1.8 hours for sleep and 5,780 steps per day). When examining the sleep patterns of patient 9, the data show a nightly average of 10.8 hours, with a range of 3.6 to 14.6 hours, indicating significant fluctuation. The step data is consistently low, and the average value is 1,890 steps, with a maximum of 4,429 and a minimum of 9 steps during the day, which is truly staggering (standard deviation for sleep is 2 hours, and for steps, it is 977).

When we examine the three patients who have bipolar disorder, there are also truly insightful patterns that the wearables yield. If we first examine the data from patient 14, the sleep data fluctuates rapidly between nights, ranging from a minimum of 4.9 hours to a maximum of 12.1 hours. The average step count is 3,946, while the minimum is 191 and the maximum is 8,352, indicating that this patient's step counts vary on different days. What we find interesting is that on the days when the patient sleeps for a long time, the step count is relatively low (standard deviation for sleep is 1.6 hours, and for steps, it is 2,746). If we examine patient 15 next, we observe a similar pattern to patient 14, where the number of steps is low when the sleep peaks. Moreover, when little sleep is recorded, the number of steps increases (the standard deviation for sleep is 1.8 hours, and for steps, it is 1,392). Lastly, if we examine patient 20, the data are truly interesting, as they show stark contrasts in recorded sleep between days 20, 21, and 22, with sleep durations of 12.6, 4.4, and 13.2 hours, respectively. The step count is consistently below 5,000, ranging from 215 to 4,555 daily steps (standard deviation for sleep is 2.6 and 1,236 for steps).

4.2 The body and the wearable can become entangled, curating somatic experiences that are unique

Although it is clear from the analysis of the data patterns that wearables can yield important insights into patients' fluctuating behavior, there are nuanced experiences to be reported regarding the deep experiences of patients over time. The patients wore the smartwatch and collected data in the app over time. They explained that the smartwatch had become a part of them in a way that they had become entangled. The data work that the patients were engaging in was not as taxing with the smartwatch, compared to the data work of filling in the app. The filling in of the app was a more explicit task that they needed to remember, while the smartwatch simply collected data without requiring any actions from the patient's side; ergo, the smartwatch outlined a somatic experience where the patient and the smartwatch became one. The patients shared detailed accounts of their experiences and when discussing whether there was discomfort or any kind of excitement coupled with the smartwatch, some patients explained a

nuanced somatic experience, where the smartwatch became a part of their everyday life and an extension of their body: “Yes. It was very informative, for example, regarding sleep [...]. And yes, this is just an added convenience in day-to-day life. Little things like that that just save time or are just so convenient.” (P8) Similarly, another patient explained: “Just really interesting and so informative. Like especially with the sleep and stuff, I could feel that.” (P9) Another patient outlined that at first, the smartwatch felt like a bit strange but became a part of them over time: “At first it was a little strange to have something on my hand, but then it ended up just being comfortable.” (P19)

When the patients were reflecting over the somatic experience of being one with the smartwatch, albeit during the six weeks intervention, one patient outlined: “I just thought this was a positive period, and you know, I didn’t think it was uncomfortable even though it was for a long time. I am, in fact, considering buying a smartwatch myself.” (P5)

Many patients felt that wearing the smartwatch, using the app, and overall engaging in data work was liberating. Some wanted to buy their own smartwatch after the period: “I’m thinking of buying such a watch” (P19). The patients were interested in knowing more about their data and saw the smartwatch as an entangled part of their being after the data collection period. Their subtle engagements had trickled down to their everyday lives, and the smartwatch and the data were becoming an important part of them.

4.3 Data work with smartwatches can cause bodily discomfort and harm

Our empirical data shows that collecting and following one’s health through a data-driven approach can be informative and supportive. The patients were enthusiastic about finding ways to ease their situation and wanted to engage in the data work. However, some patients found the smartwatch disruptive to wear, and they had to invest some time and work into effectively wearing the smartwatch, as one patient described: “Sometimes, like now, it can be a bit loose, especially when I’m coming out of the shower [...]. But if I tighten it more, it can be uncomfortable, so I adjust it a lot. Sometimes, I have it a little tighter and sometimes looser. It can hurt to wear it all the time.” (P2) Other patients felt that they needed to live with some discomfort, brought on by the data work, for instance tightening or loosening the smartwatch from time to time: “I didn’t need to take it off much; maybe it was just that I had to adjust it because I have such a weak pulse that I had to tighten it up if I was going to exercise.” (P5) The patient also describes moments when she needed to take the smartwatch completely off: “I’m

taking a ceramics class, and I kind of had to take it [i.e., the smartwatch] off because it was difficult to clean it like that.” (P5)

The patients described that they had to invest in data work, to get quality data and their experiences when doing so, were both specific and sometimes even included bodily discomfort which interfered with their daily life: “The disadvantage of it [i.e., the smartwatch] is that you never take it off, and you sweat under it, and maybe after swimming, you were wet.” (P6) Another patient had a similar somatic experience: “Just interesting and informative, really. Sometimes I find it uncomfortable to wear it the whole day, you see, but that’s okay - I take it off for a while and put it back on, you know, just rub the area and put it back on, and it’s just fine.” (P7) Another patient elaborated: “What was maybe most irritating is that when you sweat, it gets stuck [on the wrist]” (P20). Yet another patient kept the smartwatch on even though it was causing skin irritations, which goes to show that sometimes data work with wearables can be truly taxing: “Look, it started rubbing me a bit, and I have [...]. It’s starting to get better now, but I had some really dry spots.” (P8) The researcher replied by asking what he did then, and if he moved it to the other hand or kept it off for some time. “No, I just continued to wear it. Because it wasn’t that uncomfortable, I just saw them [i.e., the dry spots].” (P8) The excerpts from the interviews and the experiences of the patients when engaging in the data work needed to collect the quality data illustrate that it is not always comfortable to collect data and engage in data work; sometimes, it can even include some bodily harm.

4.4 Living with technology can have an overt and covert impact on decision-making

The smartwatches impacted some patients’ everyday lives, both by providing data to guide their decision-making, e.g., whether to try to sleep more or move more, and altering some of the patients’ routines. Some patients also explained that they felt good about living with technology (both the smartwatch and the app), but still elaborated on the notion that it impacted their decision-making to some extent, and the somatic experience of a cohesive, genuine cohabitation led to the smartwatch impacting their decisions: “I didn’t find it uncomfortable at all. I found it quite comfortable to wear, which helps you be mindful of your sleep. I always come back to [talking about] sleep; it was convenient to be able to just go to the app and see how long you slept. So, I sometimes said to myself: okay that’s enough sleep for now, gotta get up.” (P11) Another patient elaborated on the smartwatch helping to yield better sleep patterns: “It was great

to have the watch. I started to be more mindful about my sleep; it's sad to get yellow [i.e., color in the data] when I've gotten a lot of green." (P13)

The patients explained that the data work had both overt and covert impacts on their decision-making. Some explicitly stated how they had engaged in activities to yield data and be perceived as good data workers, while others elaborated on the impact on decision-making in more subtle ways. When discussing how the days with the smartwatch were compared to the days without them [i.e., before the study began], one patient elaborated: "They got more focused, and I could see how I was feeling. And then I just tried to work on it, to maybe go for a walk or something like that instead of hanging out and watching TV or something like that. Or on the computer." (P6) The somatic experience is noticeable, and the patients' lives are influenced by the data work that they are engaged in.

When discussing if the smartwatches sometimes impacted the stress level of the patient, one of the patients explained: "Well, if I had walked 4.500 steps, it was a bit tempting to walk the last 500 steps and so on." (P4) The patient is pointing towards the notion that the data work and insights into own data, can turn manic. However, the same patient also described positive reactions when things go well: "When you have achieved your goals, that's awesome. It creates a little boost, you know." (P9) The findings show that there are mixed feelings in this particular group of vulnerable patients when it comes to scrutinizing data, thinking about data and doing data work for research purposes. Moreover, there are noticeable complexities that are illustrated through the empirical data regarding the production of data on the one hand and the patients' enhanced role within their own care on the other hand. By engaging in the data work, the patients are slowly taking steps towards better understanding themselves through data and the dynamics of the relationship between the patient and the health-care professional, which has the potential to evolve over time.

4.5 Data work can trigger a feeling of surveillance and increase paranoia

Some patients had a nuanced view of the way data work can impact the mind deeply: "There was a period, because I wasn't feeling well [mentally], that I knew the device would monitor it [...], I didn't feel too good about it, but I was still able to turn around the thought that the universe would come to an end because of that, but then this thought came to me that I should be doing better." (P6) The patient points toward an important note that the data work of seriously mentally ill patients may lead to uncomfortable thoughts. When other patients reflected on if there were any negative feelings

regarding healthcare professionals having access to the smartwatch data, a patient responds: “No, I just see this as a tool for me to feel better.” (P20) The patients embraced the somatic experience and the smartwatch, which was indeed impacting their lives but that patient did not experience deep surveillance feeling although that is quite common in this patient population. Asking if they would want to continue to wear a smartwatch, and how that would look for them: “Yes, I would probably do it in a very similar way, I would wear a similar smartwatch, which I could then maybe take off sometimes, you know, but I would definitely sleep with it.” (P5)

Some of the patients also illustrated feeling self-deprecated: “It worked kind of like pressure on me, you know, when I had been lazy, the thought came to me that I just have to go do something. When I could see that I had only taken a few steps that day, when there were days like that, I tended to put myself down a little for that.” (P9) Another patient expressed a similar sense of self-deprecation: “Just fine. I have to admit that I had trouble remembering to answer the survey on the mobile phone ... I’m just so sorry.” (P5) When discussing if the healthcare professionals having access to the data collected made the patients feel discomfort: “It made me feel uneasy when I thought about how inactive I had been, you see. It was like, I was like: Okay, wouldn’t it be smart to go exercise or do something.” (P11) Other patients also reported a feeling of surveillance, both through the sharing of data with healthcare professionals and the notion of someone else observing them through their data. When reflecting on their days during the data work period, compared to days without wearing the smartwatch or engaging in data work, one patient described experiencing what could be considered a feeling of someone watching them through the data yielded through the data work: “Look, in the beginning, like this in the first half, maybe, the first three weeks. Then I was extremely aware, it took me a long time to reach the goals and, you know, to be actively moving. Since I was being watched.” (P9) Another patient reflected on the process as a whole: “I started getting this rash on my wrist, so I started not using it because it bothered me a lot. But when I did use it, it was very uncomfortable, not that I didn’t trust it, but I felt a little uncomfortable that someone was watching me. Then I always took it off before I went to sleep because I was sweating so much.” (P18) It is clear that the data work has been challenging for this patient. As the results show, the patients needed to carry out a considerable amount of data work when participating in this combinatory data-driven approach to data collection. Alas, our findings also highlight the dark aspects of data work when it is carried out either as an embedded part of healthcare or for research purposes.

5 Discussion

The recent debate surrounding the exploitation and data mining of human data for others' gain has given rise to the discourse on surveillance capitalism (Zuboff, 2019). Surveillance capitalism further highlights that the design of our information systems and data practices can systematically polarize views (Zuboff, 2019), underscoring the importance of an ethical compass in the data work of patients. In addition, our findings show that some patients involved in this study themselves feel as if they are under surveillance. As information systems become an increasingly powerful part of our lives, and as we streamline data collection efforts and, to a greater extent, engage in datafying our lives, we cannot forget the importance of ethically evaluating our impact on the people with whom we engage in our data collection efforts. Although we clearly had ethical approval for this study, we wanted to carefully examine the impact of data work and somatic experiences on the patients that we were working with. Although the patients raved about the interesting insights they gained by participating in the digital mental health intervention, exemplifying the positive impact of living with the smartwatch, they also highlighted the darker aspects of data work through their insightful thoughts on the impact it had on them. More specifically, while many pointed to the dark aspects of living with the technology, most still wanted to continue the data work and would have chosen to keep the smartwatch. All patients, except two, reported finding this approach to digital mental health intervention interesting, which is promising. However, it is essential to note that these patients are in a vulnerable position regarding authority and tend to want to 'fit in'. They may not have reflected deeply on the harm that they still discussed during the interviews. As outlined by Hatton (2017), there are specific mechanisms that contribute to and give rise to the invisibility and visibility of certain work. Data work is a work type that tends to be forgotten, with its impact and importance often slipping through the cracks. Data work is ever so important and needs to be evaluated for its worth on all levels; also, in the small effort that wearing a smartwatch may be seen as it clearly has an impact on the patients, as shown in this paper.

Additionally, the efforts of the patients in healthcare cannot be forgotten, as their efforts to improve and enhance the quality of care and to move healthcare professionals from narratives to numbers in terms of quality data for enhanced decision-making purposes (Lindroth et al., 2018). The data work of patients has, up until now, not been discussed in length in the literature. In this paper, we build on and extend the already proclaimed definition of data work: "By data work, we are referring broadly to the forms of technological, analytical, and emotional work undertaken by all actors within the healthcare system that are necessary to make data clinically and personally meaningful" (Fiske et al, 2019, p.2). The work of patients goes beyond just collection, and their data

work includes a sense-making process where they attempt, both individually and in collaboration with their healthcare professionals, to make sense of the data and actively use it to better engage in their ongoing treatment. Furthermore, our study revealed that the effort patients invest in enhancing data-driven decision-making within healthcare is significant and important for the future of healthcare. Although data-driven monitoring has been shown to have a positive impact (Dogan et al., 2017; Smith et al., 2023), there are also reasons to be careful, as illustrated in this paper. Furthermore, the future of mental health must incorporate digital mental health to a significant extent in order to effectively cope with the limited resources of mental healthcare (Nghiem et al., 2023). Nevertheless, we must tread lightly and carefully consider the impact of data work on patients. Interestingly, the patients included herein are under extensive control and meet their healthcare professionals regularly, yet still do not bring themselves to discuss their own data during these conversations. Perhaps that is an area that could be a topic for future research to tailor a conversation around data between patients and healthcare professionals, making the work of both patients and healthcare professionals more visible to each other through curated conversations about data and data work.

In recent years, engagement with one's own data has been shown to be truly impactful and, frankly, revolutionary for people with schizophrenia (Simões de Almeida & Marques, 2023), and similarly, engagement with their own data has been proven pivotal for patients with bipolar disorder (de Azevedo Cardozo et al., 2024). Likewise, the flow and ebbs of subjective data in combination with objective data have been shown to impact and improve people's perception of their own sleep quality (Biedebach et al., 2023). However, although wearing smartwatches has been shown to have little impact on most people (Karlgrén & McMillan, 2022), our study shows both the intricacies of having a serious mental illness, as well as generic thoughts that any person, with or without mental illnesses, could experience. Song et al. (2024) have illustrated that there are causal dynamics of sleep, circadian rhythm, and mood symptoms for patients who have serious mental illnesses. Regarding the sleep and step data outlined herein, it is interesting to observe the large fluctuations in hours of sleep per night and reflect on the fact that the fluctuations are visible for most patients. Additionally, the standard deviation seems to be larger than in a group of healthy individuals when compared to relatively healthy cohorts (cf., Biedebach et al., 2023; Karlgrén & McMillan, 2022). On the other hand, some patterns in the data differ between individuals, where some patients tend to walk less on the days when they sleep more, whereas this trend cannot be observed in others. It is essential to be aware that smartwatch data can reveal certain characteristics that may indicate a mental disorder or personal traits; various factors can influence individuals and, consequently, lead to different behaviors. Conclusively, our

digital mental health intervention revealed significant fluctuations in the data, highlighting interesting insights that can be gleaned from the data generated through the analysis.

The analysis of our empirical data focused on conceptualizing the somatic experiences of data work associated with smartwatch use among patients with serious mental illness. Rather than categorizing our findings into discrete options, we observed that patients' feelings and experiences aligned along certain spectrums; physical and emotional. This dual-spectrum approach enabled a more nuanced analysis. Our two-by-two somatic experience model, presented in Figure 2, places these spectrums on a single plane, allowing for the mapping of patients' somatic experiences to specific points. This approach acknowledges the complexity of feelings and experiences while providing clarity. In the lower-left area, little to no discomfort was reported, indicating high adherence to smartwatch usage. The light grey area to the right represents those with some emotional discomfort but minimal physical effort, suggesting neutral adherence. The grey area on the top left encompasses individuals who experience emotional effort but minimal physical strain. Finally, the top-right quadrant represents both physical and emotional strain, where patients may be less likely to adhere to smartwatch use or participate in research. This model underscores the importance of involving patients—or others if applied beyond healthcare—in designing their care practices, aligning with de Azevedo Cardoso et al (2024).

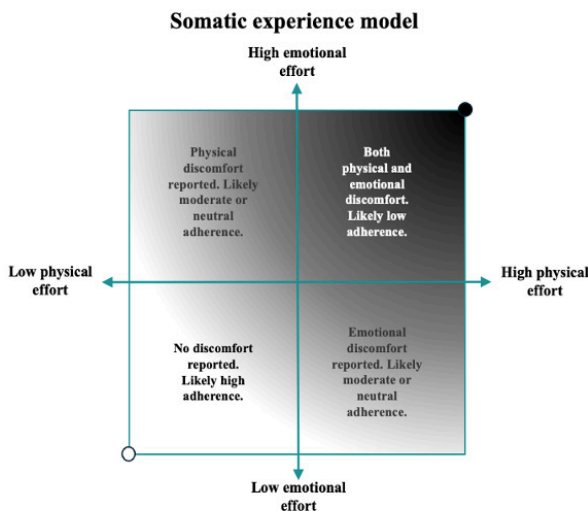


Figure 2: The somatic experience model.

A growing body of literature highlights the importance of providing human support during the use of any digital mental health intervention (Werntz et al., 2023), and our paper corroborates this finding. We argue that incorporating data work for patients with serious mental disorders requires constant monitoring of the data collection process, and vulnerable patients need ongoing explanations and discussions, which in turn enrich their participation in their own care, as supported by our findings. Hence, one of the important insights from this study, where patients lived with technology for six weeks, illustrates the importance of discussing somatic experiences. In fact, the interview proved to be liberating for discussing the somatic experiences, and meeting the patients' multiple times was fruitful. We met with the patients every three weeks, and in addition, they had the phone number of the first author of this paper so they could always contact her with inquiries regarding the study. Moreover, they also had effortless access to their healthcare professionals as part of their outpatient treatment, which is a crucial success factor. Nevertheless, we remained passive to avoid influencing the patients' participation in data collection. Therefore, we recommend that others who embark on embedded data work for patients, especially those dealing with serious mental illnesses, carefully cater to the need for continued support during data collection.

Our paper shows that somatic experiences of somatic IS artifacts, which operate by assimilating bodily data—encompassing physiological signals and movement patterns—as input, while aligning their functionality towards fulfilling physiological objectives rather than cognitive ones (Lorenz & Recker, 2023), have an impact on their users. These somatic IS artifacts not only encompass sensors that can receive and transmit signals, but they also cater to a specific somatic experience through the material properties and their ergonomic fit and design, which is meant to trigger physical responses (Lorenz & Recker, 2023; Recker et al., 2021). Our findings clearly illustrate that they do curate physical responses, and the data work involved is tangible and real.

6 Conclusion

In this paper, we analyzed the somatic experiences embedded in the data work of patients diagnosed with serious mental illnesses. Our findings show that the data work of patients is inherently complex. We illustrate our findings through five themes: (i) unraveling patterns yielded through data work with smartwatch over time, (ii) the body and the wearable can become entangled curating somatic experiences that are unique, (iii) data work with smartwatches can cause bodily discomfort and harm, (iv) living with technology can have an overt and covert impact on decision-making, and (v) data work can trigger a feeling of surveillance and increase paranoia. Our paper provides

in-depth insights into living with technology, which can be both mentally unsettling and physically demanding, yet also rewarding at times. Interestingly, most patients expressed a desire for continued data work using smartwatches and mobile applications. Our paper makes a three-fold contribution. *First*, we offer insights into the data work of patients, highlighting its importance as a valuable resource for future digital mental health interventions. *Second*, we outline what living with technology for individuals with serious mental illnesses entails through unraveling their data work. *Finally*, we provide a model that others can use when incorporating somatic IS artifacts into practice. Our paper, through in-depth insights into ways in which patients dealing with schizophrenia or bipolar disorders experience somatic IS artifacts, shows that data work and somatic experiences are intertwined, offering a novel contribution to the field of IS.

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