Living With Technology: Digital Mental Health & Patient Flourishing

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Abstract

Healthcare systems everywhere are under pressure, and one of the ways to counteract long waiting lists and low resources is through digitalisation and data. Mental healthcare, in particular, has been fighting an uphill battle, bearing more than 30% of the overall disease burden while getting less than 10% of the total healthcare budget. One possibility to battle that skewness is to move towards care where patients are empowered to take greater responsibility for their own wellbeing. A way to do that is by relying on data collected by the patients and brought into healthcare. The term ‘wearable devices’ functions as an umbrella term for devices that collect physiological data and are used to track information that people can use for their own health monitoring. While there are different types of wearables, including smartwatches, smart jewellery, smart glasses, and smart shoes, smartwatches have gained the most traction by being easily available. Smartwatches are an attractive option to support patients needing to monitor their health metrics, with no exception for patients with serious mental illness. In mental health, monitoring objective data like sleep and movement can be useful, and adding subjective information like feelings can be determining. Subjective data can be derived from mobile applications (app), where patients can log their lived experiences. Changing healthcare systems to incorporate a more patient empowerment-friendly approach introduces new digital health technologies that the often-overworked healthcare professionals will then need to monitor. Therefore, adopting a co-design approach is essential in healthcare platform design, as it enhances the likelihood of the platform being successfully integrated and effectively used by both patients and healthcare professionals. Human flourishing—the development of individuals reaching their highest potential—is an integrated lens throughout this thesis, to truly try to understand the humans involved in this research.

This thesis focuses on how digital mental health platforms can foster human flourishing by integrating the continuous collection of data into the daily lives of patients with bipolar disorder and schizophrenia. This research focuses on the ways in which patients engage with wearables and apps to support their mental health trajectory and enhance their overall wellbeing. The research is interdisciplinary in nature, but the main target of the contribution is the field of Information Systems (IS). I discuss patient empowerment and introduce a shift to patient flourishing, as well as detailing the somatic experiences and data work patients go through when they contribute to science. Furthermore, this research outlines a co-design process with patients and healthcare professionals seeking to understand how to effectively co-design platforms that can be used in practice. Finally, I explore data trends from wearables on a group-level basis and an individual-level basis.

This research entailed exploring the feasibility of smartwatches, mobile apps and platforms supporting psychiatric care is studied with 21 patients and 13 healthcare professionals. It included using a co-design approach to design and develop an app and a digital health platform to support patients with serious mental illness with their treatment. The digital platform and app go by the name DataWell, the name reflecting on 'Data for Wellbeing'. The patients in the study are all receiving care in Landspitali, hearing to two different diagnoses and thereby two units, the bipolar team and schizophrenia unit. Patients carried a smartwatch for six weeks, continuously collecting data into DataWell. Additionally, they answer six daily wellbeing questions in a mobile app. To supplement that data, they also answer a questionnaire three times over the interval, and at the end of the period, they attend a semi-structured interview. The overall method employed in this research is canonical action research (CAR), which adheres to principles emphasizing both practical implications and research implications.

This research presents several key findings related to the design, development and use of a digital mental health platform and app. First, a co-design process with healthcare professionals led to the identification of two design principles: (i) clarity and accessibility of information from the patient's perspective, and (ii) efficiency and flexibility for healthcare professionals. Second, the majority of patients felt encouraged by monitoring their data continuously and expressed interest in continuing the data collection. Third, a two-dimensional framework to capture patients' experiences involving data work and somatic experiences, with the horizontal axis reflecting the physical impact of data work and the vertical axis reflecting its emotional effects. Additionally, emphasis is put on that self-efficacy is an important factor in patient empowerment and that a focus on individual behavioural patterns is more effective than group-based approaches for patients with serious mental illnesses. Lastly, the DataWell platform, which incorporates perspectives for patients, healthcare professionals, and researchers, was developed as a digital tool to support mental health management. The accompanying app prompts users to answer daily wellbeing questions, calculates a subjective wellness score (MindPoints), and provides a weekly summary of their mental health status.

This thesis makes a three-fold theoretical contribution. First, it blends in with the growing IS literature on data work in healthcare. When patients participate more in their own care, their engagement in invisible data work grows. Second, it discusses a connected concern, namely somatic experiences, by examining how wearables and apps affect patients' bodily experiences. Further – it demonstrates how individual-based data analysis can bring meaningful insights into healthcare. Third, it advances the literature on human flourishing and connects it to co-design, as well as conceptualising 'patient flourishing' and 'living with technology'.

This research offers a three-fold practical contribution to digital mental health through the development of two innovative technologies, the DataWell app and platform, and a novel approach aimed at improving treatment and wellbeing for individuals with serious mental health conditions. The DataWell app prompts daily wellness questions, promoting reflection and self-awareness, helping patients track mental health fluctuations. The platform integrates data from a smartwatch and an app, providing patients with clear visualizations of their data and offering healthcare professionals an efficient way to get a quick and comprehensive overview of their patients' status that day. The data-driven approach constitutes another practical contribution by combining subjective and objective data, as well as qualitative methods with data-driven approaches; this approach provides a comprehensive understanding of the nuanced experiences of patients with mental

health conditions. The data-driven approach emphasises individualization through personalised analysis, is mindful of data-work and actively fosters patient flourishing.
Keywords: Schizophrenia, Bipolar Disorder, Digital Platform, mHealth, Smartwatch, Wearable, Mobile Application, Mental Health, Serious Mental Illness, Co-design, Wellbeing, Digitalization, Platforms.

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Þá finnst mér eftirfarandi tilvitnun viðeigandi í þessu samhengi:

> "Það verður að vera gaman, annars er svo leiðinlegt."

Þetta gildir almennt, og ekki síst þegar skrifa á doktorsritgerð. Það verður að hafa gaman af rannsóknarefninu, því annars verður mjög, mjög leiðinlegt. Ég var heppin með það, að rannsóknin vakti hjá mér svo mikinn áhuga að ég átti á köflum erfitt með að hugsa um annað.

Annars gerðist það í árdaga þessa verkefnis að við hófum samstarf með geðsviði Landspítala. Mér líður eins og verkefnið sjálft hafi átt sitt eigið líf frá byrjun – og að frá því hafi stafað einhver orka sem hjálpaði til við að keyra rannsóknina, ásamt því að búa til hvata til að deila niðurstöðum áfram. Verkefnið heldur áfram eftir skil, enda af nógu að taka þegar kemur að því að bæta líf og meðferð á sviði geðheilbrigðis. Það er líka eitthvað við það að láta gott af sér leiða, og það mun alltaf vera aðal markmiðið mitt með rannsóknum. Það að fá að bæta heiminn (þótt það sé bara smá) er dásamlega góður hvati. Takk fyrir samstarfið öll saman, bæði þjónustuþegar og starfsfólk Laugaráss og Geðhvarfateymis.

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Publications List

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Other Selected Publications by the Author

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Contents

Chapter 1

Introduction

1.1 Motivation

In 1986, the Ottawa Charter for Health Promotion was organised by the World Health Organization (WHO) in collaboration with Welfare Canada and the Canadian Public Health Association. The charter brought together politicians, healthcare professionals, academics, and other representatives to exchange knowledge and establish future healthcare priorities. A key outcome of the charter was the commitment to ‘enable people to increase control over and improve their health’ (WHO, 1986). While the term ‘patient empowerment’ had not yet been coined at the time, this commitment closely aligns with its core principles.

The surge of wearable technology has brought about the revolution of personal data, capturing our movements and daily activities as digital data. As wearable technology has been entering healthcare, it has driven a significant shift in healthcare delivery, placing greater emphasis on data-driven insights. The integration of wearable technology has significant potential for monitoring purposes, particularly for people who receive limited care in the current healthcare system (Sheng et al., 2022). Wearable technology refers to body-worn electronic devices embedded with wireless communication abilities designed to collect and transmit user data (Goel et al., 2024). Wearable technology, also called wearables, enables real-time data monitoring, allowing healthcare providers to make timely, informed decisions without requiring patients to be physically present, supporting early interventions and a more personalized approach to healthcare delivery (Hicks, 2019). However, to maximise the impact of how wearables can be utilised for healthcare purposes, further research is needed (Köhler et al., 2024). Wearables can yield valuable data, which could become particularly useful to better outline informed decisions. Incorporating data, such as wearable data, into decision-making processes, instead of basing decisions solely on intuition or experience, is called data-driven decision-making (Provost & Fawcett, 2013). In a healthcare setting, this can entail both institutional-level and patient-level decisions (Provost & Fawcett, 2013). Furthermore, data-driven decision-making has the potential to empower patients by enabling active participation in their own care trajectory, but in order for that to happen, the opinions of the individuals also need to be heard (Weiner et al., 2015). That brings in subjective data based on the experiences of people, an area of concern that has also been on the rise in recent years. Subjective data can also be captured through digital traces of data via mobile applications, for instance. Wearables for objective data and mobile applications for subjective data, in general, and data-driven decision-making, in particular, all fall under the umbrella of novel ways of utilising data for understanding and informing healthcare trajectories.

As the stream of literature on wearables grows, there is a simultaneous focus on preserving what makes us human. While the literature deviates between a fascination with an immense volume of data and the preservation of the self, there has been a growing interest in the field of Information Systems (IS) on human flourishing. Human flourishing refers to how the design of IS can enhance a person's wellbeing by supporting a balanced integration of physical, emotional, social, and psychological dimensions simultaneously (Hylving et al., 2024). Data increasingly influences our everyday lives, transforming how people perceive and engage in their wellbeing while also creating newfound tensions between self-optimisation and genuine human flourishing (Marabelli & Newell, 2023). However, individuals with severe mental disorders are not primarily driven by self-optimisation but are instead more focused on quality of life. As a result, they may more easily fall into the category of those genuinely wanting to flourish, engage in self-care, and become active participants in their own lives. Personal data can promote self-awareness, and especially for people who may not have been active participants in their own lives due to illnesses for some time, it can prove valuable to learn to listen to their own body through a data-driven approach (Islind & Vallo Hult, 2022). However, the literature has also shown that tunnel vision on data-driven measures can intensify health-related issues (Baron et al., 2017). Furthermore, the literature has demonstrated the potential to increase participation in one's own life, especially for those undergoing treatment and gradually engaging in self-care and active participation following severe mental health episodes (Cella et al., 2018). However, to reach that sweet spot of focusing on human flourishing, increased participation in self-care, and embracing a more data-driven life, it is crucial to tailor such a process alongside the participants. The use of wearable devices and mobile applications can either hinder progress or outline an immense revolution.

Sociotechnical research examines the interplay between social systems and technical systems, emphasising the importance of addressing both dimensions in the development of new systems (Sandberg, 1985). 'Digital mental health' is sociotechnical in nature, encompassing the personal practices undertaken by individuals with mental disorders for assessment, support, prevention, and treatment (Adams, 2024), with the aim of using technology to improve or better understand their mental health. This includes, but is not limited to, the collection and observation of subjective and objective health data. In this thesis, I elaborate on a co-design process in a mental healthcare setting, through my case of digital mental health, where the included patients are receiving treatment and a smartwatch, a mobile app and a digital platform complement and support their ongoing care. Additionally, I initiate a discussion on 'patient flourishing' and contend that individualised data analysis is the most effective approach for individuals with serious mental illnesses.

1.2 Relevance

Mental illness is estimated to account for 32.4% of the overall disease burden globally, making it the number one cause of years of healthy life lost due to disability (Vigo et al., 2016). People who have mental disorders often need extensive support and care; however, these conditions are frequently undertreated and, in some cases, remain entirely untreated due to limited access to mental healthcare. Other reasons for not seeking care include the stigma of mental illness or a lack of general knowledge of mental disorders (WHO, 2022). Also, government budget intended for mental health purposes does not nearly reflect its scope (Vigo et al., 2016). As a result, mental healthcare units worldwide are experiencing a crisis in terms of long waiting lists, and an overall shortage of services for individuals dealing with mental illness, urging them and healthcare professionals to look for digital solutions. However, unguided self-help apps for mental health have seen low adoption rates (Fleming et al., 2018), a trend that has also been observed among healthcare professionals (Sawyer et al., 2024; Schueller et al., 2016). To corroborate this, a systematic review of the use of digital mental health solutions for young adults indicated that digital interventions only demonstrate clinical significance when they are closely monitored (Garrido et al., 2019).

In this thesis, I conceptualise ‘living with technology’ to describe how patients incorporate digital tools into their daily lives. This concept reflects not only how patients experience these tools but also how they actively use them to manage their conditions to enhance their lives. ‘Somatic IS artifacts’ take in physiological signals and movement patterns and align functionality toward fulfilling physiological objectives (Lorenz & Recker, 2023). While the term can encompass a range of technologies, in the context of this thesis, it specifically refers to smartwatches. This terminology is used to emphasise the connection to somatic experiences—the bodily and sensory dimensions of interacting with such artifacts. These experiences include practices such as wearing the device, perceiving its outputs, and responding to its feedback as part of everyday life. For individuals living with severe mental illness, including conditions such as schizophrenia and bipolar disorder, such technologies might play a crucial role in supporting the monitoring of sleep, physical activity, heart rate, and other key indicators of mental and physical state (Vigo et al., 2016; Schultz et al., 2007). However, the ways in which people with these conditions engage with somatic IS artifacts—their practices, interpretations, and embodied experiences—remain underexplored in current research. This thesis contributes to the discussion by examining how people in this situation experience these technologies.

The role of data in healthcare has become increasingly central, drawing attention to the practices involved in collecting and managing various types of health data—work that is frequently invisible and distributed across both healthcare professionals and patients. This has been conceptualised as ‘data work’. While existing research has primarily focused on the growing burden of data work on healthcare professionals—who are often required to develop new competencies to manage data-intensive tasks (Cruz, 2023; Møller et al., 2020; Sun et al., 2023)—a smaller body of work has explored how patients themselves engage in data work (Pols, 2012; Pine et al., 2018). To ensure that data-driven practices contribute to human flourishing, it is crucial to understand how data is gathered in ways that are not only efficient but also human-centred. Therefore, it is essential to investigate the background processes and the data work required by patients to facilitate data-driven decision-making in practice.

1.3 Case Description

Data work takes place in a certain context, and in this thesis, that context is linked to a digital platform (hereinafter simply called ‘platform’), which is software that connects users’ needs with the services offered by providers. In a healthcare setting, platforms can facilitate a connection between healthcare and patients, such as a platform that collects and visualises health data. The supply and use of platforms are becoming increasingly established in healthcare (Islind, 2018). This thesis outlines a standalone PhD research project that includes the design and development of a digital platform called ‘DataWell’, for which I served as the lead architect and designer. Rather than starting from scratch, the platform was developed as a clone of an existing system that had been implemented for a previous research project. Over my 4.5-year PhD process, several groups of skilled computer science students contributed to the design and development through regular meetings. I supervised the groups in the development to ensure both technical and conceptual coherence, integrated user feedback, and monitored the platform use. The name DataWell reflects two key aspects: first, that the data collected is intended for wellness purposes, and second, that it serves as a rich resource or ‘well’ of data. The design process was conducted in a co-design process with the psychiatric unit at Landspitali Hospital (see Figure 1.1), specifically for people facing serious mental health challenges. Patients contributed to the design of the mobile app and platform through informal dialogues, sharing their perspectives and experiences. Healthcare professionals participated in co-design activities from both their own viewpoint and in consideration of patient needs, contributing insights in both informal settings and during a structured co-design workshop. Additionally, input on the mobile app design was gathered from academics in the university's psychology department. The platform collects and visualises health data to be used alongside treatment. The platform takes into consideration three perspectives: (i) the individual, (ii) the healthcare professionals, and (iii) the researchers. The collaboration with Landspitali is ongoing and fruitful, with the possibility of growth and becoming an increasingly bigger part of their treatment support. The data collection was such that I provided the participants in the study with a smartwatch that gathers objective data (e.g., heart rate, steps, and sleep) and a mobile app to answer daily questions on their mental and physical status for complementary subjective data. The data is collected and visualised in the DataWell platform. Additionally, I have collected three instances of questionnaire data with the participants, where the focus is on health-related habits, views towards technology and self-efficacy, but also measures anxiety and depression.

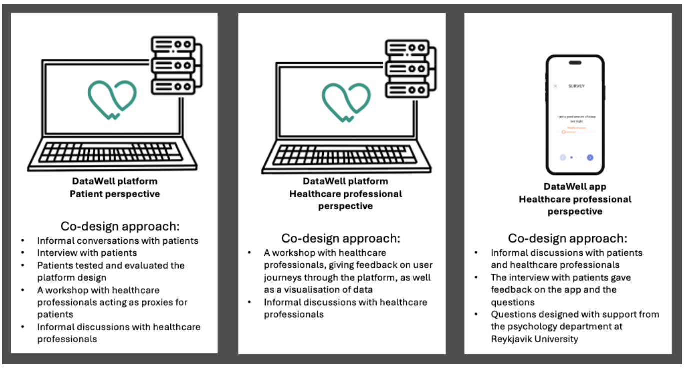


Figure 1.1: Overview of involvement in the co-design process. Patients contributed through informal dialogue and interviews, healthcare professionals contributed through a co-design workshop and informal conversations, and psychology faculty provided additional guidance on the mobile app.

1.4 Aim and Research Questions

Data-driven decision-making is, as stated above, the act of relying on data as a source when decisions are made instead of basing them on pure intuition or experience (Provost & Fawcett, 2013) and in a healthcare setting, this can include decisions on an institutional level or on an individual level. In this research, I focus on data-driven decision-making on an individual level when I investigate the design, development and use of a platform to collect data to supplement treatment for people with mental disorders. The data that I have collected in the research is both objective and subjective, creating a meaningful data triangulation (see Figure 1.2). The collection includes 4,5 years of data collection with 21 patients and 13 healthcare professionals. The data is both quantitative and qualitative and has yielded four publications that are appended to this thesis. The thesis explores the following main research question:

How can a digital mental health platform foster patient flourishing through data derived from patients' experiences of living with technology?

Figure 1.2: Overview of the DataWell platform and its data collection. The platform integrates two primary data sources: (i) objective data collected from a smartwatch, and (ii) subjective data that comes from six daily questions regarding their mental and physical wellbeing.

This thesis is comprised of four research papers, each addressing a specific research question. The research questions are explored individually in each paper (see Table 1), with the corresponding answers to research questions in Chapter 5, all contributing to the cumulative answer to the overall research question laid out above in their own way. Ergo, the cover text alongside the papers combined address the overall research question and in Table 1. The table also provides a link between research questions and the stream of literature each question primarily contributes to, and the discussion topics that are most relevant. The discussion topics illustrated in the table serve as overarching themes of the thesis.

The thesis integrates both design-driven and data-driven approaches (see Figure 1.3) and incorporates insights from both healthcare professionals and patients.

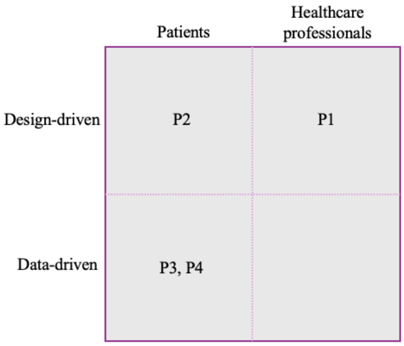


Figure 1.3: The figure provides a conceptual overview of the focus areas of the papers included in this PhD thesis. Paper 1 is labelled as P1, Paper 2 as P2, etc. The two dimensions in this 2-by-2 matrix represent, on the horizontal axis, the primary stakeholders addressed in the research, distinguishing between papers that focus on patients and those that focus on healthcare professionals, and on the vertical axis, distinguishing between papers that focus on design and those that focus more on data

The thesis has four appended papers (see Figures 3 and 4). The first paper, titled “A Novel Approach in Psychiatric Healthcare: Co-Designing a Digital Platform”, was published in the Journal of Workplace Learning in 2024 and relied on data that was collected through the co-design of DataWell with 13 healthcare professionals of the schizophrenia team at Landspitali. The paper presents a design approach that guides the development of our platform and app, while offering design principles for other developers creating similar platforms. The data presented in this paper were collected during a co-design workshop I hosted with healthcare professionals. In the workshop, the participants were given different scenarios that served as boundary objects for our discussions. This paper led to two design principles for digital mental health platforms: (i) clarity and information accessibility from the patient's side, (ii) efficiency and flexibility when it comes to the healthcare professional's side. One conclusion from this paper was the necessity for a notification option in the mobile application, which has since been implemented in the DataWell app. The involvement of healthcare professionals in co-design fosters inclusion, which was recognised as a key factor supporting the practical use of the platform.

The second paper, titled "Collecting Data from a Mobile App and a Smartwatch Supports Treatment of Schizophrenia and Bipolar Disorder," was published as a book chapter of Challenges of Trustable AI and Added Value on Health in 2022. The paper's focus is on the design of the DataWell platform and app. The results were based on a content analysis of interviews conducted with patients and highlighted key factors to consider when designing similar platforms. These valuable insights helped guide the software design in the continuation of this research. The paper highlights that the majority of patients felt encouraged by monitoring their own smartwatch data. The results from this paper were used to further guide the design and development of the DataWell platform and mobile application. The paper contributed to the literature and to other designers with four main aspects to consider for patient generated health data in mental health: (i) sharing data easily with healthcare professionals, (ii) being able to engage with your own data, (iii) the smartwatch use can help the people regulate routine in their daily life, (iv) tonality and phrasing matters.

The third paper is titled "Living with Technology: Data Work and Smartwatch Data Trends for Patients with Serious Mental Illnesses" and has a data-driven approach. It has been accepted with minor revisions to the Scandinavian Journal of Information Systems. This paper's primary focus was on two things when analysing the interviews with patients: (i) the 'data work'—the effort participants in similar studies put into collecting their own health data, and (ii) 'somatic experiences'—the bodily experiences participants have while using wearable devices. Parallel to that, we presented two time-series variables, i.e. total nightly sleep duration and daily step count. The paper yielded interesting results in the form of quotes from patients. The content analysis of the quotes was conducted in four distinct rounds. Through iterative content analysis, engaging with participants during the study period, transcribing discussions, and systematically coding and categorising the interviews, profound and meaningful insights were gained from the participants, warranting careful reflection in the results. Through our analysis we explore the somatic experiences of patients as they engage in data work using smartwatches and a mobile app. Findings reveal a duality between somatic experience and data work of experiences, from taxing to rewarding. We contribute insights into patient data work as a resource for future digital mental health tools, and a model for understanding somatic experiences with IS artifacts in mental health contexts.

The fourth paper, titled "Wearables for Good: A Data-Driven Approach with and for Patients Dealing with Schizophrenia and Bipolar Disorder," has been accepted to the European Conference on Information Systems 2025 (ECIS). This paper explores the insights that smartwatch data can provide for individuals living with schizophrenia and bipolar disorder. It also examines questionnaires with a particular focus on self-efficacy, discussing how self-efficacy is crucial for patient empowerment and linking these findings to insights gathered from interviews with participants. Additionally, the paper involves machine learning analysis using smartwatch data at both the group and individual levels. Specifically, the paper contributes in three key ways: (i) it demonstrates that self-efficacy—the belief in one's ability to succeed—can be an important stepping stone toward empowerment; (ii) it highlights the need to focus on individual patterns when engaging with individuals with schizophrenia and bipolar disorder, advising against generalizations or solely relying on group-based methods that define broader behavioral patterns; and (iii) it emphasises the necessity for IS researchers to study personal datafication through case-based, data-driven approaches to promote human flourishing in IS.

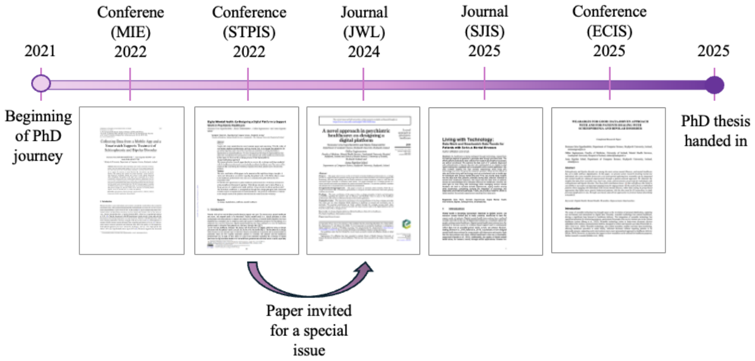


Figure 1.4: Timeline of key milestones in this PhD journey, highlighting accepted conference papers and journal publications. The figure showcases three conference acceptances, including one paper selected for a special issue, as well as two journal publications.

1.5 Contribution

The overall impact of this PhD research lies in easing people's access to their health data and fostering human flourishing in mental health, by supporting and enhancing treatment. By exploring the potential of digital mental health interventions for individuals with serious mental illnesses, this research examines how co-design can be utilised in the development of mental health platforms and investigates the impact of data work on individuals with schizophrenia and bipolar disorder. By shifting the focus to the individual and designing care with those who receive mental healthcare, this research contributes to a more human-centred approach to mental healthcare, promoting collaboration, destigmatization, and overall human flourishing in mental health.

This thesis is interdisciplinary in nature, with a primary focus on contributions to IS research. *Firstly*, I contribute to the growing literature on data work within healthcare by conceptually engaging with the data work of patients through their detailed accounts and experiences of living with technology. *Secondly*, I contribute to the ongoing discourse on somatic experiences by discussing ways in which data from patients can be brought into healthcare in meaningful ways through individual-based analysis instead of attempting to extrapolate group-based knowledge from the continuously collected subjective and objective data. *Thirdly*, I contribute to the body of literature on human flourishing and co-design. Over several years, I engaged with 13 healthcare professionals and 21 patients with serious mental illnesses. This collaboration resulted in a practical mental health platform and a data-driven approach to digital mental health that benefits both patients and healthcare professionals.

Table 1.1: The research questions addressed in the included papers and their corresponding themes and streams of literatures

RQ	Paper	RQs in paper	Stream of literature	Discussion topic
i	1	What design principles can be derived from a co-design process of a digital platform to enable digital mental health with psychiatric healthcare professionals?	Human flourishing and co-design	The move from patient empowerment to patient flourishing
ii	2	How should a smartwatch and a mobile app be used to support treatment of schizophrenia and bipolar disorder?	Data-driven mental health	Data work and living with technology
iii	2	How can a digital platform function as a bridge between patients and healthcare professionals.	Patient empowerment	The move from patient empowerment to patient flourishing
iv	3	What are the effects of data work when living with technology such as a smartwatch and a mobile app for individuals with serious mental illnesses?	Data work and somatic experiences	Somatic experiences and data for good
v	4	How can wearables integrate into mental healthcare, and what potential insights does wearable data provide for individuals with schizophrenia and bipolar disorder?	Human flourishing and co-design	The move from patient empowerment to patient flourishing

Chapter 2

Background

2.1 Mental Health

Mental disorders cause individuals and societies difficulties in terms of measuring the long-term impact on the people living with mental disorders, their families and the healthcare system. This effect is not easily measured and is therefore often ignored (WHO, 2003). Living with a mental disorder can cause communication difficulties, which sometimes keeps patients from working, studying, taking care of relatives and so forth. In addition, the life expectancy of individuals with mental disorders is lower than that of the general population (Viron & Stern, 2010). The prevalence is also high, with at least one individual with a mental disorder found in 25% of all families, and that can seriously harm the quality of life of everyone affected (WHO, 2003).

Bipolar disorder is a recurrent, chronic mental disorder affecting cognition and the ability to function in daily life. The disorder is most often discovered between the ages of 15 and 24 (Müller-Oerlinghausen, Berghöfer & Bauer, 2002). Bipolar disorder is characterised by recurrent fluctuations in mood and energy levels. Patients experience alternating between different levels of depression, going from subthreshold depression to major depression and different levels of mania, including hypomania and mania (Aref-Adib et al., 2019). During a manic episode, patients experience elevated mood, increased energy, sleeping difficulties, and, in some cases, delusions (Vigo et al., 2016). In contrast, in a depression episode, individuals experience low energy levels, and in the most severe episodes of depression, there is an increased risk of suicide, contributing to the elevated mortality rate within this population (ibid). The progression of bipolar disorder varies from patient to patient, but the reported prevalence rates indicate that the broader bipolar disorder spectrum has a prevalence of 2.4%, including bipolar I disorder which is observed in 0.6% of individuals, and bipolar II disorder in 0.4% and subthreshold bipolar disorder (i.e., patients who experience symptoms characterized by depression and mania but do not meet the criteria for bipolar disorder I or II) affects approximately 1.4% (Grande et al., 2016).

Schizophrenia is also a chronic mental disorder. The disorder includes psychotic episodes where patients can experience delusions, hallucinations and disorganised speech. Negative symptoms like loss of will and social withdrawal can also be present (Schultz et al., 2007). Schizophrenia patients, similar to bipolar disorder, are known to be at a higher risk of being affected by physical health issues, such as diabetes and cardiovascular disease (Eisner et al., 2023). Additionally, these patients are often marginalised and faced with violations of their human rights, including abuse, homelessness and neglect (WHO, 2003). Bipolar disorder and schizophrenia are commonly classified as psychotic disorders and are two of the most severe mental illnesses. Consequently, individuals diagnosed with either condition are often studied in tandem (Kalisperakis et al., 2023), which is why both disorders are included in this thesis. The symptoms associated with schizophrenia and bipolar disorder can be fundamentally different, but they may also overlap in certain areas (Pearlson, 2015). Individuals with bipolar disorder often face challenging symptoms that can disrupt their daily lives, affect their relationships, and hinder their ability to thrive (Grande et al., 2016). People who have schizophrenia experience even more severe symptoms and are more likely to be unemployed or homeless, as well as socially isolated (Schultz et al., 2007). Both groups face negative effects on their quality of life, and they also have to live through and face the stigma associated with their disorders (Singh, 2021). However, many individuals with schizophrenia and bipolar disorder are able to lead fulfilling and successful lives through understanding and managing their condition (Gillis et al., 2024), and some also experience forms of recovery (Slade & Longden, 2015). Related to that, there are many different studies that support that serious mental illness can be diagnosed as well as conditions monitored with smart devices (smartphones, wearables, nearables), through speech recognition, GPS data, etc. (Saccaro et al., 2021), although it has been pointed out that data-driven approaches in treatment require ongoing monitoring, especially for patients with serious mental illness (Kang & Exworthy, 2022).

2.2 Digital Health

Wearable devices, such as smartwatches, smart jewellery, and smart glasses, have become increasingly common in recent years. They track health data and promote healthier lifestyles, contributing to a growing interest in personal health metrics, including sleep patterns, movement and heart rate data. As the popularity of wearable devices has risen, their accessibility has improved, which has fuelled interest in their practical and theoretical applications in healthcare. Recent research reflects this trend, demonstrating promising potential for their use in clinical and self-management contexts. For example, one study demonstrated sleep apnea can be detected using wearables (Chen et al., 2021), and another shows precise results with cardiac arrhythmia (Nazarian et al., 2021). Additionally, a recent systematic review of smartwatch interventions in healthcare suggests that smartwatches may lead to positive health-related outcomes, but it emphasises the need for further research to validate this potential (Triantafyllidis et al., 2024). In terms of treatment for mental illness, digital health shows promise. A recent study reported that digital health interventions, which included online surveys, interviews, and stakeholder workshops, can enhance traditional treatments for patients with schizophrenia (Gillis et al., 2024). Additionally, internet-delivered cognitive behaviour therapy has shown promise for treating bipolar disorder (Nielssen et al., 2023).

Chapter 3

Related Work

This chapter examines previous studies in mental health to establish the foundation for this thesis and highlights the need for innovation in this area of concern. It also contextualizes the thesis within the broader scope of the IS literature and elaborates on the related work upon which this thesis rests. To lay the groundwork of examining how a platform, wearables and mobile application should be designed, developed and used to support the treatment of individuals with bipolar disorder or schizophrenia, and what the overall effects of living with a smartwatch are, for people with serious mental illnesses, there are four areas of concern that will now be examined: (i) patient empowerment, (ii) human flourishing and co-design, (iii) data-driven mental health and (iv) data work and somatic experiences. All these areas of concern within the IS literature, also serve as the streams of literature, to which this thesis contributes.

3.1 Patient Empowerment

Over time, patient empowerment has expanded to include more dimensions, particularly adding access to information, ensuring that individuals have the necessary resources, knowledge, and tools to understand health-related information and make informed decisions about their care (Fumagalli et al., 2015). Despite continuing discussions on its precise definition, patient empowerment can be viewed either as a process or a goal at both individual and societal levels (Roberts, 1999; Akeel & Mundy, 2019; Johansson et al., 2021). Fumagalli et al. (2015) characterise patient empowerment at the individual level as follows:

> “Patient empowerment is the acquisition of motivation (self-awareness and attitude through engagement) and ability (skills and knowledge through enablement) that patients might use to be involved or participate in decision-making, thus creating an opportunity for higher levels of power in their relationship with professionals.”

Patient empowerment is a process through which individuals develop a deeper understanding of their condition and treatment, enabling them to take greater control over their health and make informed decisions about their care (Bravo et al., 2015). The process consists of four stages: (i) individuals reach an understanding in their role in treatment; (ii) their knowledge expands to the point where they can actively engage with their healthcare professionals; (iii) there is an enhancement of the patient’s skills; and (iv) the environment provides support for patient participation (WHO, 2009). In this thesis, I take an individual perspective, viewing empowerment as an ongoing process rather than a fixed outcome. The concept has three critical conceptual components: shifting power from healthcare professionals to patients, fostering active participation, and acknowledging patients’ expertise in managing their own health (Halvorsen et al., 2020). Self-efficacy refers to a persons’ belief in their ability to complete a task or achieve a goal, encompassing their confidence in themselves to control their behaviour, exert an influence over their environment, and stay motivated in the pursuit of their goal (Rieder et al., 2021) and has been closely linked to patient empowerment. Reaching a higher level of self-efficacy and thereby fostering patient flourishing is an achievement, especially with individuals who have serious mental illness. These elements are fundamental to fully grasping the broader concept and its implications. However, achieving genuine empowerment requires addressing the inherent power imbalances in healthcare, where professionals have traditionally held greater authority over patients (Halvorsen et al., 2020). Using apps for self-care is one aspect of modern patient empowerment and can have a positive effect on an individual’s life, helping them monitor their condition more closely. A recent study on individuals with diabetes shows a positive correlation between cumulative self-care behaviour and the use of a self-care app (Kebede & Pischke, 2019). Another study found that older patients with chronic obstructive pulmonary disease reported positive experiences with a mobile application for disease management, with one of the emergent themes being: *'gradually becoming independent by continuous online learning'*, directly aligning with the core of patient empowerment (Zou et al., 2024).

3.2 Human Flourishing and Co-Design

Human flourishing refers to a process in which individuals achieve their fullest potential. This concept has been of human interest for centuries, but was brought into the discourse of IS just recently (Koutsikouri et al., 2024), and is closely related to wellbeing, quality of life, and happiness. Within the field of positive psychology, human flourishing entails three fundamental dimensions: connection, that is feeling loved, valued, and cared for; positivity, which reflects the tendency to focus on the positive aspects of a situation; and resilience, which denotes the capacity to manage or recover quickly from difficulties (Lomas et al., 2023; Ekman & Simon-Thomas, 2021). Within IS, human flourishing highlights the influence of digitalisation on wellbeing, emphasising the role of technology in fostering human potential and addressing user needs (Koutsikouri et al., 2024). Moreover, when considering human flourishing in IS, it is important to proactively integrate human thriving and wellbeing into the design and development of emerging technologies to ensure they are intentionally designed to positively shape individuals' lives (ibid). IS researchers must also recognise that human flourishing is shaped by unique circumstances, values, and needs, which vary from person to person and should be considered in all aspects of IS.

As Ellingsen et al. (2022) pointed out, a 'big-bang implementation strategy,' where one electronic health record system is entirely replaced by another in a single transition, is not recommended for large-scale healthcare software implementations. Instead, introducing new software into healthcare requires careful planning due to the complexity and sensitivity of the domain. In the IS literature, many examples can be found of failed software implementations in healthcare, often due to usability challenges or a limited understanding of the practices involved, particularly when end-users were not involved in the development process (Islind, 2018; Ellingsen et al., 2022). One way to mitigate the risk of software implementation failure is to involve users in the design process. This idea dates back to the 1970s with the introduction of 'design participation' (Cross, 1972), which later evolved into 'participatory design'—a labour-driven initiative aimed at increasing workers' influence in work-related technological change (Spinuzzi, 2005). Participatory design is ideological in nature, but the movement was followed by the term 'collaborative design', which later became 'co-design'. Co-design provided guidelines on how to use situated expertise when designing software (Sanders & Stappers, 2008), and there is considerable interest in co-design research (Noorbergen et al., 2021). Interestingly, research on co-design has emphasised earlier parts of the design phase (ibid). Participation in co-design can foster a sense of ownership over the developed software, which may, in turn, enhance motivation for its adoption in practice (van Rijn & Stappers, 2008). Given the complexity of digital technologies, the end-user groups involved in co-design can also be diverse and have different levels of skills (Papoutsi et al., 2021). Within a single group, users may have varying needs (e.g., patients with different healthcare requirements), while multiple groups—such as patients, caregivers, and healthcare professionals—may be engaged simultaneously (Islind et al., 2019). This diversity further adds to the complexity of co-design processes and end-user engagement (ibid). One study reported on using co-design as a method of designing the content of a virtual collaboration platform (Vallo Hult et al., 2020). Co-design is increasingly adopted in healthcare software development, with growing evidence supporting its effectiveness in creating person-centred solutions (Rowe et al., 2020). Certain positive outcomes of co-design, for example, empowerment and social connection, are closely aligned with dimensions of human flourishing. However, the relationship between the two remains underexplored in the existing literature. In the context of IS, this gap highlights the need to examine how digitalisation facilitates the interconnection between co-design and human flourishing.

3.3 Digital Mental Health

Digital mental health is a concept used for a broad scope of digital health technologies supporting mental health, such as platforms, mobile apps, wearables and other digital intervention tools, to support and improve reach and access to healthcare resources (Adams, 2024; Garrido, 2019; Sigurðardóttir et al. 2022a).

There is considerable interest in utilising smartwatches for mental health applications, and there are interesting studies that have explored the use of smart devices, such as wearables, in mental health treatment. In 2021, Saccaro et al. demonstrated that various data sources collected from wearables show meaningful associations with bipolar symptoms and diagnosis. These include movement patterns, sleep metrics, heart rate variability, electrodermal activity, voice characteristics, and keyboard metadata. Digital phenotyping refers to the use of digital data (e.g., smartphone usage, social media activity) to create a comprehensive view of behavioral patterns (Torous et al., 2016). In the context of mental health, digital phenotyping holds particular promise for identifying conditions such as stress, anxiety, and mild depression (Choi et al., 2024). Additionally, a study on bipolar disorder demonstrated that smartwatch data can be effectively used to detect periods of depression and mania with a high degree of accuracy (Lipschitz et al., 2025). There are also studies that underline the usefulness of wearables for patients with schizophrenia, including a study on heart rate and motor activity monitoring that showed successful detection of autonomic dysregulation during episodes of paranoia, hallucinations, and delusions (Fonseka & Woo, 2022), and another one on sleep tracking, which may facilitate early detection of disease onset and the exacerbation of acute symptoms (Kalisperakis et al., 2023). In a recent paper focused on improving engagement in study designs for patients with bipolar disorder, a randomised trial revealed that an effective approach should incorporate a combination of wearable and mobile monitoring strategies (Van Til et. al., 2020).

The use of smartwatches alongside traditional treatments has the potential to enhance the treatment of chronic diseases like mental disorders, and mental healthcare has been identified to be one of the key areas where smartwatches can significantly improve treatment outcomes (Köhler et al., 2024). Smartwatches can be a factor in empowering patients, and they can help increase the weight of data-driven decision-making to significantly improve mental health (Köhler et al., 2024; Sigurðardóttir et. al, 2022). Some researchers have raised concerns about the role of smartwatches in patient empowerment, emphasising that the support of healthcare professionals is crucial in facilitating patient empowerment (Kang & Exworthy, 2022). Also, researchers have emphasised the need for studies that explore and contribute to related topics such as stigma, health literacy, and help-seeking behaviours (Masri et al., 2024). While this thesis does not directly address stigma, it contributes to the health literacy of the patients by providing patients with access to visualisations of their own health data.

The existing literature has yet to reach a consensus on the role of wearables data-driven decision-making for improving mental healthcare. Further research is required to establish how wearables and wearable data contribute to enhancing the treatment possibilities of individuals with bipolar disorder and schizophrenia. Addressing this critical gap, this PhD thesis advances knowledge on the integration of wearable technology into mental healthcare.

3.4 Data Work and Somatic Experiences

Data work refers 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). On that note, in her book, Pols (2012) pointed towards the issue that patients need to put in effort when they receive remote healthcare, e.g. there can be an effort to learn how to use the software used in healthcare. Although she did not call it data work at the time, she addressed the core of what is now often called data work. As has been shown, wearable data can effectively support individualised trajectories in mental healthcare; however, the work required by individuals in gathering that data remains a lesser-known trajectory. The digital maturity and willingness for innovation within the healthcare systems increased worldwide when the COVID-19 pandemic unexpectedly accelerated the need for digital health services in general and digital mental health in particular (Lee & Lee, 2021). As healthcare continues to evolve, a growing portion of work is now focused on data-related tasks. As a result, hospitals and healthcare institutions are expanding their capacity to manage these tasks by establishing platforms that can effectively utilize increasing datasets to improve efficiency and the quality of care (McVey et al., 2021). This shift is driving a broader transformation within the healthcare sector, highlighting the importance of integrating and strategically using data to optimise both clinical and operational processes (Hoeyer, 2023; Hogle, 2016). Moreover, these changes extend beyond just the collection and integration of data; the present moment represents a critical opportunity for IS researchers to examine the somatic IS artifacts currently in use and, importantly, to critically assess their impact on people. Much of the data work conducted by patients often takes place outside hospital settings, goes unnoticed, and remains unpaid (Islind & Vallo Hult, 2022); in existing research, typically, no credit is given to the efforts that happen behind the scenes.

The labor involved in initially collecting data, e.g. ensuring its availability (Parmigiani et al., 2022; Sambasivan et al., 2021; Bertelsen et al., 2024) for use in healthcare decision-making is often overlooked. The process of data work and people's somatic experiences are inherently interconnected. Data work is essential for gathering information, yet fully understanding its implications requires examining how people experience and interact with somatic IS artifacts. Given this duality, these aspects are analysed in tandem. To date, research on data work has primarily focused on "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). However, the physical strain associated with these processes remains underexplored, representing a research area in need of further investigation. Additionally, companies have started data mining for personal information, which has evoked discussions on surveillance capitalism (Zuboff, 2019), reminding researchers to critically evaluate ways of working with patient data.

Research has increasingly focused on the experience of living with technology and its impact on individuals. Within this domain, somatic experiences associated with somatic IS artifacts have garnered particular attention. These artifacts interact bidirectionally with the human body, receiving and transmitting signals while assimilating physiological data, such as movement patterns and biometric signals, as input (Lorenz & Recker, 2023). Unlike traditional cognitive computing systems, somatic IS artifacts are designed primarily to fulfil physiological functions rather than cognitive ones. Examples include wearables, nearables (proximity-based sensors), intelligent implants, and prosthetic devices that collect and transmit data to optimise and monitor vital physiological parameters (Prasopoulou, 2017; Óskarsdóttir et al., 2022). Beyond their technical function, these artifacts also shape somatic experiences through their material properties, ergonomic design, and intended physical interaction, influencing the body's response to digital health interventions (Lorenz & Recker, 2023; Recker et al., 2021). While wearables and similar devices have been recognised for their physiological and psychological effects, the specific experiences of people with conditions such as schizophrenia and bipolar disorder in relation to somatic IS artifacts remain underexplored. In this context, somatic experiences refer to the interplay between body and mind, encompassing both the perception of sensor data and the interpretation of subjective and objective wellbeing. How wearables and other devices introduce labour for patients highlights the discussion on 'data work'—the often invisible labour undertaken by patients within healthcare systems to facilitate data collection. The increasing reliance on data-intensive healthcare practices, including the production, processing, and utilization of patient-generated data, has reshaped both healthcare workflows and professional roles (Bossen et al., 2019; Parmiggiani et al., 2022; Pedersen & Bossen, 2024). Although some studies have explored data work performed by patients, research in this area remains limited. Existing studies have examined patient-led data collection in contexts such as stroke rehabilitation (Caldeira et al., 2021), cancer treatment (Cerna et al., 2020), physiotherapy (Blixt et al., 2022), and fertility tracking (Costa Figueiredo & Chen, 2021). However, the literature has predominantly focused on data work carried out by healthcare professionals. As healthcare personnel assume increasingly data-intensive roles, they must acquire new competencies in data management and interpretation (Cruz, 2023; Møller et al., 2020; Sun et al., 2023). Physicians, for example, benefit from expanded access to patient data, which enhances clinical decision-making but also introduces challenges related to data overload and the presence of non-actionable information (Hoeyer & Wadman, 2020; Budd et al., 2023; Tajirian et al., 2020). Similarly, administrative staff are now required to develop expertise in data processing to support healthcare operations (Pine & Bossen, 2020). For data-driven decision-making to be effectively implemented in practice, data collection must be both efficient and human-centred. Consequently, it is essential to examine the often-overlooked data work performed by patients and their role in enabling meaningful, evidence-based clinical decisions. In this related work section, I have made deliberate choices about scope, and naturally, not every adjacent area within IS could be covered. For instance, the vast body of literature on shared decision-making could, in some respects, be considered relevant, particularly as this research focuses on the patient as the center of healthcare (Légaré & Thompson-Leduc, 2014). However, the thesis has prioritised the lens of living with technology, with its emphasis on continuous data collection and the associated advantages and drawbacks. Therefore, shared decision-making was excluded to maintain a focused narrative and to avoid interrupting the conceptual contributions of this work.

Chapter 4

Research Approach

This chapter outlines the research methodology, describes the empirical context, and details the various phases of the research presented in the thesis, concluding with ethical concerns. The research has followed a CAR approach, which is an iterative research methodology, one that emphasises collaboration, change through action, and rigor, based on a cyclical outline with five stages: diagnosis, planning, intervention, evaluation and reflection, which have been adjusted to the details of this thesis (see Figure 4.1). The CAR process outlines the sequence of participant interactions throughout the intervention. The process began with the initiation of data collection and proceeded through an initial meeting, followed by a six-week data gathering period. During this time, patients engaged with the technology while I monitored the process with support from healthcare professionals. Following the six-week period of data collection and sustained engagement with the smartwatches and app, interviews were conducted with patients to explore their experiences. This led into a final reflection phase, during which researchers and healthcare professionals jointly reviewed the collected data. This phase served a dual purpose: to design for practical implications and to contribute insights back to the scientific community. The design activities were thus primarily concentrated in the final two stages, namely the patient interviews and the subsequent reflection on patient data. Although I made an effort to include patients in the design, their effort can be viewed as informal co-design in the sense that patients did not participate in structured co-design sessions, but rather contributed design ideas and concerns through conversations with me. These contributions emerged both in informal conversations throughout the study period and in the interview at the end of the data collection interval. As a more formal co-design effort, I held a co-design workshop independently of the CAR process to explore more design ideas (cf. Chapter 4.5.1). Occasionally, I would also have informal conversations with healthcare professionals that also contributed to the design and development of the app and platform.

CAR enables researchers to actively engage in all stages of the study, allowing for adjustments between iterations, and CAR, among other types of action research (AR), are commonly utilised in IS (Baskerville, 1998; Davison et al., 2004). I obtained ethical approval (ethical approval nr. 55/2020, cf. chapter 4.6 and appendix E) for the research, with six-week data collection per participant. In this overall CAR, the feasibility of smartwatches, mobile apps and platforms supporting psychiatric care is studied with 21 patients and 13 healthcare professionals. The platform and app were developed as a part of this PhD through a co-design approach, both with patients and with their healthcare professionals, working with computer science students as developers. While the students did not take part in co-design sessions with patients or healthcare professionals, their technical expertise influenced the design and user flow through ongoing development meetings at the university. As such, they played a supporting role in the co-design process, contributing to the refinement and feasibility of proposed design ideas.

In addition to using the cyclical CAR outline, the intervention followed the five key principles of CAR, including (i) a researcher–client agreement, ensuring mutual understanding between researchers and patients as well as healthcare professionals; (ii) the cyclical process model that emphasises a research process that is iterative in nature, circling planning, action, and evaluation; (iii) the principle of theory, integrating theoretical insights into the research process; (iv) the principle of change through action, allowing for interventions that are practical - to drive improvement; (v) the principle of learning through reflection, fostering critical reflection to refine both practice and theory (Davison et al., 2004). In terms of iteration, the research process involved ongoing refinements primarily aimed at optimising procedural aspects rather than implementing major changes to the technology itself. Adjustments were made in response to emerging challenges and practical insights, for instance, streamlining the initiation of data collection by scheduling interviews at times convenient for patients, often aligning them with existing appointments with healthcare professionals to reduce the likelihood of missed meetings. Early 'first meetings' also revealed that patients tended to experience tiredness when starting with the questionnaire, leading us to place it at the end of the session instead. Additionally, scheduling follow-up meetings during the initial meeting proved effective in maintaining engagement. Although no changes were made to the app or platform during the data collection period, several suggestions emerged, such as adding a notification feature, which has since been implemented and may enhance future iterations of the intervention.

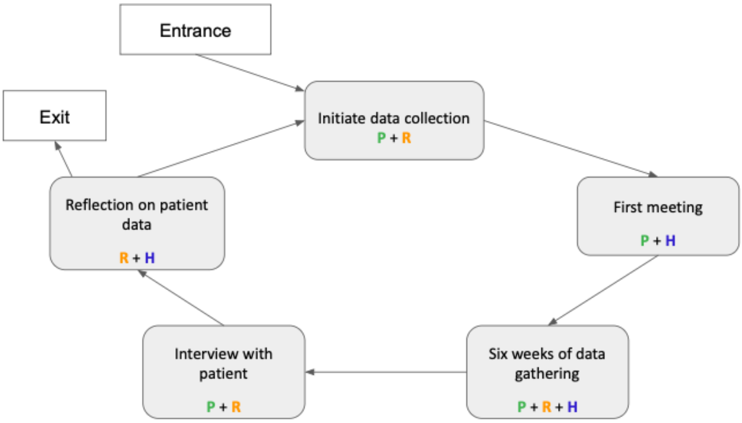


Figure 4.1: The process of this CAR project. This figure illustrates the cyclical process of the project, where the researcher (R) is me, the patient (P) is any patient included in the study and the healthcare professional (H) is any healthcare professional involved.

Adding a layer of complexity to the research setting, this study was conducted across two distinct units at Landspítali Hospital (see further Chapter 4.1). CAR is a type of AR, and the control structures used in AR projects are considered one of the main challenges of this approach. (Avison et al., 2001). The control structures pertain to issues such as initiation and authority warrant (ibid), which were carefully considered at the beginning of this research initiative. The initiation of this research was genuinely collaborative, involving both Reykjavik University and Landspitali hospital. This collaboration stemmed from a mutual recognition of the need for digital innovation and interest in data-driven support as a complement to treatment. As for authority warrant, the need for intervention was collaboratively assessed during the ethical approval process (i.e. in the very beginning) in close dialogue within the research team, which had healthcare professionals who already possessed the professional standing needed to take actions within their units. The action planning proceeded smoothly, facilitated by the healthcare professionals from our research group as project ambassadors, a doctor for one unit and a psychologist for the other. Thereafter, I worked closely in finalising the action planning and executing the intervention with the healthcare professionals at the units, while evaluation of the results was mainly done by me. As previously noted, the researcher–client relationship played a key role in establishing a shared understanding among stakeholders (Davison et al., 2004). It is also important to remain mindful of the power dynamics inherent in conducting research within hospital settings, namely, the patient-healthcare professional relationship and the patient-researcher relationship. These dynamics can influence the research outcomes, as patients may express overly positive responses to interventions proposed by individuals they perceive as holding positions of authority or expertise (Simeonova et al., 2020; Beerepoot, et al., 2020). Throughout the project, all research activities remained anchored in the dual goals of achieving practical change through action and generating knowledge through reflective practice (Davison et al., 2004). The decision to adopt CAR over other forms of AR was primarily motivated by its methodological rigour and formal structure, offering greater clarity for the research group, especially in the early stages of the project. Additionally, CAR's strong emphasis on generating theoretical insight was considered a significant strength in the context of this study.

I have, with the support of diligent computer science students, designed and developed a digital health platform to be used in psychiatric care, called DataWell, which facilitates the use of data for wellbeing. The platform has been designed and developed during this PhD, through a co-design approach. Co-design refers to a collaborative creative process in which end-users actively contribute alongside designers to shape the final product (Sanders & Stappers, 2008). A core principle of co-design is that end-users should have a voice in the design process, as it directly influences their daily lives and work environments (Joshi & Bratteteig, 2016; Kensing & Greenbaum, 2013). DataWell combines the following patient-generated health data types. Subjective data from a mobile app on daily wellbeing; and objective data from a Withings Steel HR smartwatch, which supplies heart rate monitoring (beats per minute), sleep monitoring (sleep duration, sleep depth, interruptions), activity monitoring (estimation of ten activity types), and step count (based on distance). One reason for choosing this particular smartwatch is its unusually low power consumption. The battery lasts for up to 25 days, which is convenient for research purposes, especially when working with participants who have severe mental illness. This extended battery life eliminates the need for frequent charging, helping to reduce the cognitive load of having to remember to recharge the watch. Additionally, Withings provides accessible, structured research data through an Application Programming Interface (API).

4.1 Empirical setting

Landspitali Hospital is Iceland's biggest hospital and has been my collaborator through this project. One of the eight clinical departments of Landspitali is the Psychiatric Services, which runs the Psychiatric Emergency Room along with twelve specialised teams that diagnose and treat patients with different mental diseases, sometimes on an inpatient basis and at other times as outpatients, depending on the type and severity of symptoms. Patients from two of those specialised teams were included in this project, Laugarás and the bipolar team.

The bipolar team is based at Kleppur, a historic building located just outside the centre of Reykjavík, near the harbour. This building has a significant history, having served as Iceland's primary psychiatric institution for decades. The location holds a certain fearful perception, stemming from times when outdated methods were used in psychiatry both in Iceland and elsewhere. Furthermore, the name Kleppur has been, in the Icelandic language, connected with negative meanings such as crazy, stupid or dangerously unstable. Even though Kleppur to date carries this

Figure 4.2: Kleppur is located on the harbour, slightly outside of Reykjavík busiest areas.

historical stigma, the facilities remain in use and function as the primary outpatient mental health facilities (see Figure 6).

The schizophrenia team operates across two distinct locations in Reykjavík. The first clinical practice is called Laugarás (see Figure 7), where the inpatient facilities are based. Laugarás is located in Laugardalur, which is a centrally situated family neighbourhood within the city. The second clinical practice is Víðihlíð, positioned slightly outside of the city in the Kleppur area, where the primary focus is on providing outpatient services (see Figure 7).

I had access to Víðihlíð during the data collection interval, where there are meeting rooms (see Figure 8) that I could use to have meetings with patients. The patients included in this project have either schizophrenia, bipolar disorder or related disorders, and can, due to symptoms, have a difficult time committing to meetings. Including patients in the study proved to be a challenge, with attendance at meetings around 50%. A total of 21 patients were included in the research. However, three of them dropped out during the data collection phase due to health issues or discomfort. This group consisted of nine patients treated for bipolar disorder, of whom two dropped out, and twelve patients treated for schizophrenia, of whom one dropped out.

Figure 4.3: The schizophrenia team operates out of two different locations in Reykjavík. To the left: Laugarás, where the inpatient facilities are located, and to the right: Víðihlíð, which focuses more on outpatient services.

Figure 4.4: Inside a meeting room in Víðihlíð is where most of the meetings with patients in the Schizophrenia team were performed.

4.2 The Role of the Researcher

The initial motivation for this PhD research was the empowerment of individuals with serious mental health disorders. Beyond merely analysing data from individuals with severe mental illnesses, the aim was to identify and develop practical solutions that could directly support and benefit this population. This objective led me to choose a co-design approach, which facilitates collaborative engagement, and the adoption of a CAR methodology, which prioritises both practical outcomes and theoretical contributions. This research design approach also allows for flexibility, enabling researchers and healthcare professionals to collaborate in understanding what is effective and what needs to be changed. They can then implement those changes and try again.

An initial step in the research process involved developing a detailed research plan and securing ethical approval (see Chapter 4.6). Following this, the research plan was formally presented to both participating hospital units during two-hour online meetings. In these sessions, I—acting in my dual role as a PhD student and lead architect and designer of the DataWell system—outlined the objectives, methodology, and envisioned outcomes of the study. These presentations concluded with open discussions, during which healthcare professionals posed questions and provided feedback. This initial engagement proved valuable in establishing mutual familiarity and rapport, facilitating subsequent interactions between myself and the healthcare staff. Participation in the research initiative was entirely voluntary for healthcare professionals, who could choose whether to assist in identifying patients for collaboration or to engage in research-related discussions with patients.

Carrying out the study in a controlled setting fostered an environment where patients felt encouraged to seek support and technical guidance, offering valuable insights, not just for the patients but also for me as a PhD student. I was also responsible for presenting the research approach to healthcare professionals to encourage inclusion and co-design. Additionally, hosting a successful co-design workshop focused on the design of the platform. Furthermore, I took the lead in recruiting patients and providing them with smartwatches, meeting with patients three times during the data collection period and addressing occasional technical inquiries that arose. I also played a key role in collecting and analysing questionnaires, as well as conducting and analysing interviews. Throughout this process, these insights were reflected while writing scientific papers together with other researchers in the project to report the findings. Altogether, these experiences have given me a unique opportunity to understand the patients and how this approach affects them, and especially the in-depth interview at the end was mind-opening.

In the literature, self-efficacy has been linked to empowerment, highlighting the importance of that thematic stream in my work (Arvidsson et al., 2023; Rawlett, 2014). Co-design is another important aspect of this work. I developed a research plan, and from the beginning, I wanted to promote collaboration with both patients and their healthcare professionals to make a meaningful change within healthcare. As the concept of human flourishing recently arose within the IS literature, I felt like that concept was also deeply connected to the core of this research. Human flourishing refers to humans developing to their highest potential and in alignment with their best interests for a fulfilling life. In the context of IS, human flourishing emphasises how digitalisation can affect wellbeing by exploring how IS can support human flourishing, further highlighting the importance of putting people first in design and development (Hylving et al., 2024). I find human flourishing to be highly relevant in the context of health, particularly if we narrow it down to 'patient flourishing.' Shifting the focus to patient flourishing opens up a discussion for researchers and healthcare professionals to focus on information systems that support patients in reaching their full potential within the scope of their disease boundaries. This perspective on patient flourishing emphasises their abilities rather than their disabilities, highlighting what individuals can achieve when they are given the opportunity to thrive.

Like many people, I have had loved ones who have faced serious mental health challenges. My grandfather was diagnosed with bipolar disorder at a time when the stigma surrounding mental illness was still truly strong. This experience influenced me in two significant ways: (i) from an early age, I felt I understood the patients' side of the disorder and its symptoms and felt that since this had happened to my dear grandfather, it could happen to anyone, and (ii) my grandmother's response to his illness was both unusual for the time and inspiring. Rather than hiding the diagnosis, she addressed it with openness and compassion, speaking openly about symptoms, medication, and their situation with respect and in a way that was simply amazing, especially for that time. The combination of personal insight into the patient experience and witnessing my grandmother's open approach to mental illness sparked a sustained interest in exploring the lives of individuals with serious mental health conditions. This personal connection has made the research presented in this PhD thesis so close to my heart. Lastly, as per Reykjavik University guidelines, a declaration of authorship should be outlined as a part of the cover text for any PhD thesis that is submitted to and defended at the Computer Science Department, outlining my contributions to each stage of the research and publication process for the papers in this thesis. Specific contributions are outlined in Table 4.1, where ME = Main effort, includes the main effort in the indicated column. EE = Equal efforts, includes that there was a shared equal effort between at least one other author of the paper. CE = Contributing effort, entails important effort, but there is someone else in the author list that delivered the main effort. LE = Learning effort, includes an effort of a learning character, for instance, by assisting with the data collection or the analysis.

Table 4.1: Declaration of authorship contribution.

Paper name	**Idea**	**Related work & literature**	**Data gathering**	**Research design**	**Artifact design**	**Analysis & synthesis**	**Draft**	**Administration**
Paper 1	EE	EE	ME	EE	EE	ME	ME	CE
Paper 2	EE	EE	ME	EE	EE	ME	ME	ME
Paper 3	ME	EE	ME	EE	EE	ME	ME	ME
Paper 4	ME	EE	ME	EE	EE	ME	ME	ME

4.3 Including Participants

Including patients in the study involved a considerable amount of effort. First, I met the healthcare professionals at the units to discuss possible participants among their patients. There were three exclusion criteria for the study: (i) individuals who do not own a smartphone, as the approach involves a mobile app that operates exclusively on smartphones; (ii) individuals who are currently homeless, as recommended by the healthcare professionals in the research group. This patient group is considered at higher risk of losing the smartwatch provided for the study; (iii) individuals who healthcare professionals consider to be too severely ill to manage the demands of participating in a study of this nature.

The potential participants were asked by their healthcare professionals (e.g. when they came to the unit for treatment) if a PhD student from Reykjavík University could call them with information about a research effort that was ongoing. Following this, I received a list of individuals who had expressed interest, and proceeded to contact each of them by phone. During these calls, I briefly introduced the study and invited them to attend an informational meeting for a more detailed explanation. When introducing myself, I stated that I was a PhD student calling from the hospital and that they had been identified as individuals who might be interested in contributing to research of this nature. Some of the partakers were quite difficult to get hold of, which slowed down the process. After that phase, I had meetings with patients lined up, but as the attendance was less than 50%, it introduced a new task: rescheduling meetings. When participants did show up, we met for an hour-long meeting where I gave a more detailed description of the study and offered participation. If they wanted to participate, they signed an informed consent and then got a Steel HR smartwatch from Withings (see Figure 4.7) that was connected to their smartphone, access to the mobile application and the platform, and a booking for another meeting in three weeks. At the end of the meeting, they filled out the first instance of a questionnaire.

I included 21 patients in total to the study. Three of those dropped out during data collection due to sickness or issues related to comfort. From that, nine patients are diagnosed and treated for bipolar disorder (two dropped out), and twelve patients are diagnosed and treated for schizophrenia (one dropped out). Thus, seven patients with bipolar disorder and eleven with schizophrenia have completed all data collection steps.

I also included 13 healthcare professionals who are working with the group of patients diagnosed with schizophrenia. In general, the treatment approach used at the unit consists of structured consultations where various questionnaires are used to monitor the physical and mental health of the patients. They also use interventions such as increased physical activity and occupational therapy, which have proven effective in treating the two disorders. The healthcare professionals need to manually read and interpret all clinical data and all instances of answered questionnaires. The healthcare professionals showed a collaborative spirit throughout the process and general openness toward innovation in mental healthcare, perhaps driven by the aforementioned high volume of manual work and the scarcity of available resources.

4.4 Data Gathering

The patients in the study carried a smartwatch from Withings for six weeks (see Figure 4.5), collecting data on heart rate, sleep, and motion, feeding directly into the platform. During those six weeks, they also answered six daily questions on general wellbeing in the DataWell mobile app. Throughout the six weeks, patients' healthcare professionals could monitor the data on the platform. The patients also answered a paper questionnaire three times (in week 1, 3 and 6). The reason this questionnaire was paper-based is that we had not yet programmed it into the mobile app by the time the patients participated in data collection. However, during discussions with healthcare professionals and patients, the idea of adding the questionnaire to the app emerged, as some patients expressed a preference for completing it digitally.

Patients attended a semi-structured interview at the end of the six-week period, where the focus was on reflecting on the platform with a co-design approach. I asked questions on user experience and usability of the platform and addressed their view on data-driven mental health and on continuously collecting data (Sigurðardóttir et al., 2022).

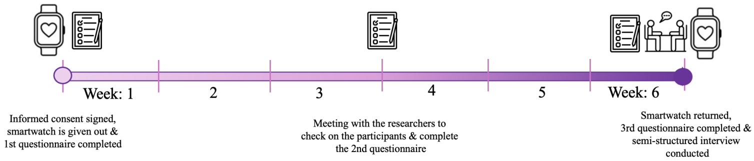
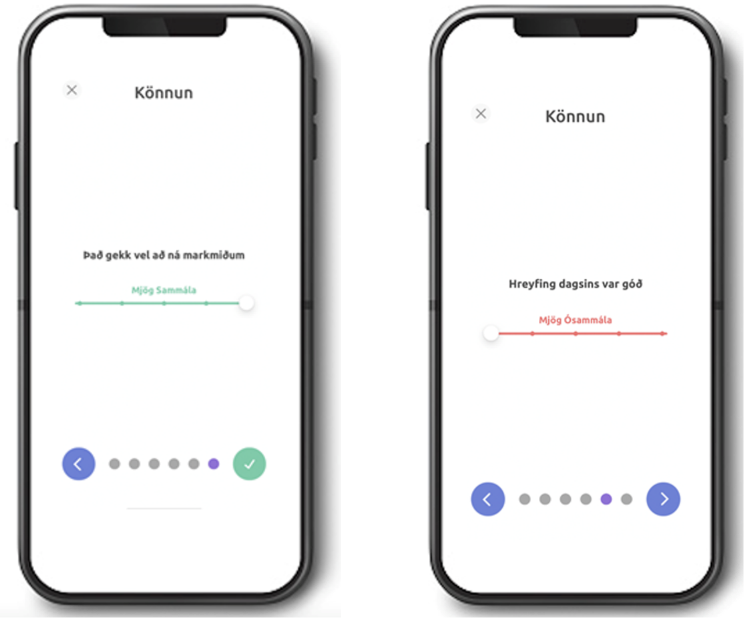


Figure 4.5: Study period from the beginning of week one to the end of week six. The research study timeline details patient interactions and data collection stages over a six-week period.

The process of the empirical data gathering with patients was outlined as follows. The patients who agreed to partake in this six-week study carried a smartwatch for these six weeks in total, collecting data into DataWell. They also answered six daily questions on general wellbeing in the app, which feeds data directly into the platform. The questions in the mobile app (see Figure

4.6) were phrased as statements that participants were to answer on a scale of 1-5 about how their day went, opening with the sentence, ‘How well do the following statements apply to your day?’, and then displaying five statements describing successful feelings ‘I was successful in achieving my goals’, ‘My mental wellbeing was positive’, ‘My physical wellbeing was good’, ‘I experienced little stress’, ‘My exercise today was good’, ‘I slept well last night’. Each answer from the daily survey results in a score, and all together, the six questions result in an overall score, which I have conceptualised as MindPoints (further elaborated on in the results chapter).



Það gekk vel að ná markmiðum

Hreyfing dagsins var góð

Figure 4.6: The DataWell app presents six daily wellbeing questions, with responses measured on a 5-point Likert scale that feeds data directly into the DataWell platform.

The patients answered a questionnaire three times (in weeks one, three, and six). The questionnaire consisted of 63 questions covering various topics: 8 demographic questions, 6 on self-efficacy, 9 on depression (PHQ-9), 7 on anxiety (GAD-7), 8 on digital health technology and social media use, and 25 questions on health and lifestyle habits, as well as views on tracking and managing personal health data. During the research period, healthcare professionals are able to monitor their patients' data through the platform. Patients attend a semi-structured interview at the end of the six-week period, where the focus is on user experience and usability of the platform and their view on data-driven mental health and on continuously collecting health data.

Figure 4.7: Withings HR Steel was chosen as the smartwatch. It collects movement data, sleep patterns, and heart rate. The band of the smartwatch is made from flexible rubber and features a simple design.

The interviews with patients were conducted at the end of the data collection period. The average duration of each interview record was 32.43 minutes, with a range from 18:59 to 50:08 minutes (see Table 4.2). The interview guide was developed with input from our research group, which includes psychologists, psychiatrists, sports scientists, and computer scientists. My aim with the interview guide was to explore the experiences of patients during the six-week data collection period, specifically focusing on their perceptions of using a smartwatch and an app for support in their treatment. I recognise that patients are experts in their own lives and disease patterns, and perhaps this is why the interview data was insightful.

The interview began with gathering contextual information about each participant's daily routine prior to the study, including their previous use of technology. Participants were then asked to reflect on their experiences throughout the study period, comparing their daily lives before and after incorporating smart devices. I paid particular attention to whether and how the wearables had influenced their awareness of health-related behaviours, such as sleep patterns, physical activity, and overall wellbeing. Additionally, the guide examined the usability and impact of the provided mobile application and platform, including how frequently participants used the interventions. Patients were asked to reflect on the questions presented in the mobile app and their phrasing and how they interpreted and responded to them, partly for me to further develop this intervention, but also to reflect on what kind of phrasing was sought after. Additionally, the interview investigated the use of smartwatches, focusing on which features were most frequently utilised, whether the device was worn consistently, and whether prolonged use resulted in any discomfort or new insights. I asked about patients' views on data sharing, particularly in relation to their diagnosis. One question addressed whether patients had discussed the collected data with their healthcare professionals, and who initiated that conversation. I also wanted to understand if patients had any concerns regarding their healthcare professionals having access to their data and discuss whether they would prefer the option to temporarily restrict data sharing. Moreover, the interview explored the psychological effects of using smart devices and apps, particularly concerning stress, by asking if patients believed that their stress levels increased or decreased as a result of using smartwatches, or if the devices had been supportive in managing their daily lives. The potential benefits of automated reminders—such as prompts for exercise, medication adherence, or sleep—were also discussed, with an interest in whether patients would find features of that sort helpful or intrusive.

At the end of the interview, participants were asked whether they would consider continuing to use smart devices for health monitoring beyond the study. If so, I asked them to share which features they believe would be most useful for their personal needs.

On a related note, I could not allow the patients to continue using the smartwatches after the six-week data collection period had passed, as the smartwatches were needed for other research purposes. However, many patients expressed a desire to keep

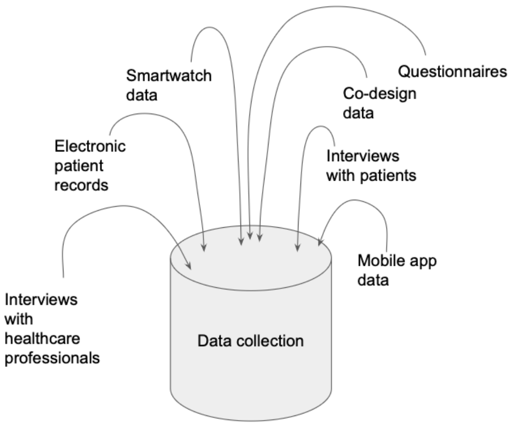


Figure 4.8: The ethical approval allows for data collection from interviews with both healthcare professionals and patients, electronic health records, questionnaires, smartwatches, a mobile app and a co-design workshop.

them, and occasionally, it was even challenging for the patient to let go of the smartwatch, which in turn made it hard for me to enforce the condition to take the smartwatch back. This raises an ethical dilemma: Is it acceptable to provide patients with a device that helps them regulate their condition, only to later withdraw its availability? Although this dilemma is certainly present, the data from this thesis shows that patients were most often positive about having engaged in the study, even though they had already returned the smartwatch when the interview was conducted. In the case of this research, there was no other way than to return the smartwatch, but this situation with the smartwatches also raises an important consideration for the hospital regarding access to wearables for patients. Should patients have access to wearables for self-care? Another consideration is patient acceptance with this particular group of patients, whereas this thesis gives indications of good adherence to a smartwatch approach.

The interview concluded with an opportunity for patients to add any additional comments that may be relevant to the study and its approach, and then they handed in the smartwatch. The interviews were transcribed verbatim.

The ethical approval allows the collection of data from the pa-

Table 4.2: The data collection effort and length of interviews and smartwatch data.

Patient id.	**Diagnosis**	**Interview length (minutes)**	**Days of data collection completed**	**Comments**
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

tients electronic health record, to complement the aforementioned data collection. Combining these different data sources creates an interesting data triangulation (see Figure 4.8).

The data in this thesis not only includes data from the patients, but also data from healthcare professionals derived through a co-design workshop. Before the workshop, healthcare professionals were introduced to the platform, where I, as a PhD student, explained the research idea and the software we wanted to demonstrate and collaboratively design further. At the workshop, I split the healthcare professionals into three groups. Each group worked on three different, made-up scenarios (see further Chapter 5.2) that included logging in and using the platform and demanded interaction between group members. After 15 minutes, the next scenario was introduced, so in total, I have data from 39 scenario engagements with the 13 healthcare professionals. The participants logged into the digital platform during each co-design scenario and discussed an assignment in groups. The data was voice recorded and transcribed verbatim, and the analytical approach for the transcripts was content analysis.

4.5 Data Analysis

The final step in the CAR outline (see Figure 4.1), prior to the next iteration, is ‘reflection on patient data,’ which encompasses both quantitative and qualitative forms of analysis. The analysis for the cover text was abductive, meaning that it was a delicate dance between the literature engagement and the papers appended to this thesis. Each paper served as an input into that process, while each paper also had its individual analysis process, outlined below.

4.5.1 Paper 1

The healthcare professionals working in the aforementioned healthcare units had been presented with the DataWell platform before. The platform is being designed in a cyclic process through our overall CAR (Figure 4.1), the workshop being the reflection phase of the model, meant to facilitate in-depth feedback from healthcare professionals. We divided the healthcare professionals into three groups. Each group worked on three different scenarios: (i) Joe, the patient who is going to meet his caseworker, (ii) Otto, the healthcare professional who is engaged but overworked and wants an overview of his patients' statuses, and (iii) The blank paper where we ask: "How should the look and feel of a platform like this be to best support your type of work with patients?" The three scenarios all included logging in and using the DataWell platform and called for interaction between the healthcare professionals. After 15 minutes, the next scenario was introduced. In total, we have 39 scenario engagements from the 13 healthcare professionals at the unit (psychiatrists, sport scientists and case managers). The data used in this paper was voice recorded and transcribed verbatim (46 pages). The analysis of the empirical data was done through qualitative content analysis in order to interpret the empirical data using an inductive approach (Bryman, 2012; Kohlbacher, 2006). We used the qualitative data analysis software NVivo (release 1.7) for coding the scenarios during the content analysis (Vallo Hult & Islind, nvivo compendium).

4.5.2 Paper 2

The interview guide for a semi-structured interview at the end of our data collection period was developed with input from our research group, which includes psychologists, psychiatrists, sports scientists, and computer scientists. Our aim with the interview was to explore the experiences of patients during the six-week data collection period, specifically focusing on their perceptions of using a smartwatch and an app for support in their treatment.

We recognize that patients are the experts in their own lives and disease patterns, which is why the interview data is so insightful.

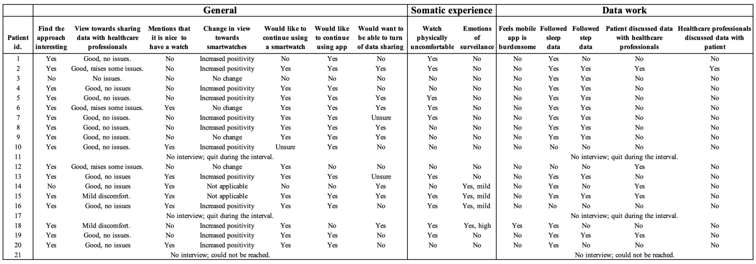
The interviews were transcribed verbatim and then analysed with the NVivo software, which is a software analysis tool primarily addressed at qualitative data, through the following content analysis approach. In the first step of the analysis of the interviews, open coding was applied to categorize patients' experiences, i.e., going through all the interviews and applying a code with the first thing that came to mind. The second step involved going through the interview transcriptions again and assigning text labels to data snippets based on the patients' own descriptions (Gioia et al., 2013). In the third step, an abductive approach was employed to organize the insightful comments from the patients into categories that were influenced by existing literature on wearable data in health IS (Gregory & Muntermann, 2011; Van de Ven, 2007). In the end, the data was grouped into overarching themes capturing different aspects of the patient's experiences. Engaging with patients at three points throughout the data collection period, particularly during the in-depth interview at the end, provided valuable insights into their experiences and the impact of this approach on them. Most patients shared that they found continuous data monitoring encouraging and some expressed an interest to continue the data collection.

4.5.3 Paper 3

This paper primarily focuses on two key aspects: first, the efforts of patients as they collect their own health data, which has been called 'data work'. Second, it examines the bodily experiences patients may encounter while using wearable devices, which have been called 'somatic experiences'. This paper analyses the transcriptions of the aforementioned patient interviews through the lens of these two concepts. The results are presented in context with an overview of the data visualizations derived from the wearables in the study to offer valuable depth to the data analysis. Specifically, we present two time-series variables: (i) total sleep duration in hours and (ii) daily step count. The total sleep data was collected using the Withings smartwatch and retrieved through the Withings API into our platform. The raw data encompasses various sleep-related variables; however, we will focus on presenting the sum of deep sleep and light sleep as the total sleep. Additionally, we include heart rate and step count for context and to demonstrate the patient's results from the data work.

The qualitative content analysis of the interviews focused on understanding the physical experience of interacting with the wearable technology, as well as capturing the effort involved in generating personal data, which can both be emotional and require a time investment from the patient side. We used a combination of perspectives from research on data work and somatic experiences, meaning we viewed "reality from the theoretical viewpoint or perspective" (Van de Ven, 2007, p. 104). This approach helped us uncover aspects of data work that happen when using digital health technologies, which might otherwise go unnoticed or be taken for granted. The analysis was conducted in four distinct rounds. In the first round, we adopted an inductive approach to coding the interviews. This initial coding process involved reviewing each interview one sentence at a time, generating codes based on the content of each sentence, and labelling the sentences with the codes simultaneously. The resulting codes were of various types, with some sentences assigned multiple codes. Examples of the codes included 'sweat,' 'tired,' 'forgetting,' 'surveillance,' 'interesting,' 'mobile connection,' 'sports,' 'feeling sorry,' and 'dry spots.' The codes, having emerged from our interviews with the patients, represented the physical and emotional responses, closely aligning with their descriptions and actions in generating personal data (Gioia et al., 2013). We then organized these comments into a table using these codes, which helped us gain a clearer overview of the dataset. The third round of analysis was abductive in nature and involved clustering the quotes into themes inspired by existing literature, specifically dividing them into somatic experiences on one side and data work on the other. The abductive approach in this round required shifting between inductive and deductive reasoning, allowing us to continuously revise, refine, and re-formulate the research design, analysis, and conceptual contributions (Gregory and Muntermann, 2011; Van de Ven, 2007). In Figure 4.9, is a table that was used to further guide the analysis.

After engaging with patients during the interviews, transcribing the discussions we had, and iteratively going through coding and categorisation of the interviews, we felt that the insights we had gained from the patients were profound and meaningful. We felt strongly that our analysis and results needed to reflect those



	General							Somatic experience		Data work				
Patient id.	**Find the approach interesting**	**View towards sharing data with healthcare professionals**	**Mentions that it is nice to have a watch**	**Change in view towards smartwatches**	**Would like to continue using a smartwatch**	**Would like to continue using app**	**Would want to be able to turn of data sharing**	**Watch physically uncomfortable**	**Emotions of surveilance**	**Feels mobile app is burdensome**	**Followed sleep data**	**Followed step data**	**Patient discussed data with healthcare professionals**	**Healthcare professionals discussed data with patient**
1	Yes	Good, no issues.	No	Increased positivity	No	Yes	No	Yes	No	No	Yes	No	No	No
2	Yes	Good, raises some issues.	No	Increased positivity	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	Yes
3	No	No issues.	No	No change	No	No	No	No	No	No	Yes	Yes	No	No
4	Yes	Good, no issues	No	Increased positivity	Yes	Yes	No	No	No	No	Yes	Yes	No	No
5	Yes	Good, no issues.	No	Increased positivity	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	No
6	Yes	Good, raises some issues.	Yes	No change	Yes	Yes	Yes	Yes	No	No	Yes	Yes	No	No
7	Yes	Good, no issues.	No	Increased positivity	Yes	Yes	Unsure	Yes	No	No	Yes	Yes	No	No
8	Yes	Good, no issues.	No	Increased positivity	Yes	Yes	Yes	No	No	No	Yes	Yes	No	No
9	Yes	Good, no issues.	No	No change	Yes	Yes	Yes	No	No	No	Yes	Yes	No	No
10	Yes	Good, no issues.	Yes	Increased positivity	Unsure	Yes	No	No	No	No	No	No	No	No
11	No interview; quit during the interval.									No interview; quit during the interval.				
12	Yes	Good, raises some issues.	No	No change	Yes	No	No	No	No	No	No	No	Yes	No
13	Yes	Good, no issues	Yes	Increased positivity	Yes	Yes	Unsure	Yes	No	No	Yes	Yes	No	No
14	No	Good, no issues	Yes	Not applicable	No	No	Yes	No	Yes, mild	No	Yes	No	Yes	No
15	Yes	Mild discomfort.	Yes	Not applicable	Yes	Yes	Yes	Yes	Yes, mild	No	Yes	Yes	Yes	No
16	Yes	Good, no issues	Yes	Increased positivity	Yes	Yes	No	Yes	Yes, mild	No	No	No	No	No
17	No interview; quit during the interval.									No interview; quit during the interval.				
18	Yes	Mild discomfort.	No	Increased positivity	Yes	No	Yes	Yes	Yes, high	Yes	Yes	No	No	No
19	Yes	Good, no issues.	No	Increased positivity	Yes	Yes	No	Yes	No	No	Yes	Yes	Yes	No
20	Yes	Good, no issues	Yes	Increased positivity	Yes	Yes	No	No	No	No	Yes	No	No	No
21	No interview; could not be reached.									No interview; could not be reached.				

Figure 4.9: Topics that came up during the interviews. Some comments were spontaneous, such as participants mentioning how nice it is to have a watch. Other topics were more directly related to the interview questions, such as whether participants would like the option to turn off data sharing.

insights with depth. Consequently, the fourth and final step of our analysis involved positioning the quotes along a spectrum and developing a model to generalize our findings to other patient groups.

4.5.4 Paper 4

The analysis in this paper was exploratory in nature and had three parts (see Figure 4.10). Our analysis's first phase entailed examining the self-efficacy results from the questionnaire, focusing on changes across three instances based on the average outcome of the six self-efficacy questions. To explore self-efficacy and empowerment further, this data was analysed alongside interview responses. The quantitative questionnaire data were analysed using RStudio, as detailed in the results section. In phase two, an exploratory analysis was conducted on the smartwatch data to investigate the potential for clustering individuals based on shared characteristics. However, the approach was adjusted since the data revealed individualised patterns, as reported in the results chapter. Rather than clustering individuals, we now focused on identifying and illustrating different types of 24-hour patterns in the overall data collection, with data from all 21 patients. To identify these patterns, we employed the unsupervised machine learning algorithm k-means clustering to identify clusters, aiming to explore factors that define distinct 24-hour periods across

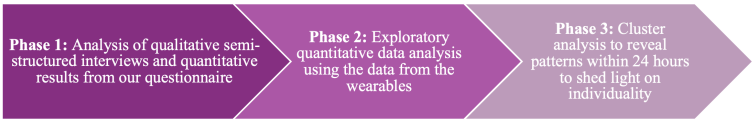


Figure 4.10: The approach of data analysis entailed three phases, as outlined in the diagram above.

the patient cohort. The k-means algorithm is widely used and is effective with small datasets and bigger datasets. It is iterative and forms clusters of data by assigning each observation to the cluster with the closest mean, updating the cluster centroids after each iteration. (MacQueen, 1967). Clustering of data allows for a fine-grained, individual-level analysis by grouping 24-hour periods such that those daily observations within the same cluster exhibit more similarities than between different clusters. This method has been effectively used in applications such as characterising digital phenotypes (An et al., 2020). In the third phase, we decided to move away from group analysis and focus on each individual. Cluster analysis with k-means was done for all patients, then viewed, explored and analysed the different data types in context with others and with the clustering. The results chapter presents findings by exploring a subset of patient data and drawing conclusions from the analysis.

4.5.5 Ethical Considerations

Writing an application for ethical approval from the hospital's ethics committee was an important matter that needed to be managed at the beginning of the research. I organised a series of meetings with a group of healthcare professionals who were part of the research team established for the project. This group consisted of experienced researchers and healthcare professionals who, after attending several meetings, developed a shared understanding of what the research should entail. The group collaboratively wrote an ethical approval document that includes detailed descriptions of the project's intentions. The ethical application addressed various aspects such as data collection and processing, data access and storage, deletion of data, data security, and different scientific and ethical viewpoints. We also addressed the questionnaires in the study, the DataWell platform and app, as well as patient support during the data collection interval. The research group was successful in getting ethical approval from the Health Research Ethics Committee at Landspitali (Siðanefnd Heilbrigðisrannsókna á Landspítala), on the 15th of March 2021, reference number 55/2020 (see appendix E). Formal written consent was obtained from each participant, this written consent was also approved by the Landspitali Ethics Committee (see appendix F).

As a research group, we were working under a strict plan connected to the ethical approval we obtained. This plan specified that we could only contact patients using a phone at the hospital, as the names and phone numbers of study participants were confidential. The healthcare professionals involved in the study were truly professional and helpful; they identified patients who might be interested in participating and included them on a contact sheet stored in the hospital system, known as Heilsugátt. Access to this list was restricted to hospital personnel, although it could be printed out. The group of patients involved in the study were often substantially ill and, in some cases, heavily medicated, which made it challenging to reach them. Additionally, they did not always attend scheduled meetings. When they missed meetings, they had to be called again to reschedule, making it challenging and time-consuming to include all the patients in the study. Therefore, I spent a considerable amount of time at the hospital working on the inclusion of patients. Being in the environment, among patients and healthcare professionals, getting to know them and their treatment and habits has been valuable. When patients did attend, most of the meetings were both pleasant and productive. Most patients spoke positively about their healthcare professionals and the care that showed enthusiasm for learning about innovations in the field, which contributed to their willingness to engage in the study.

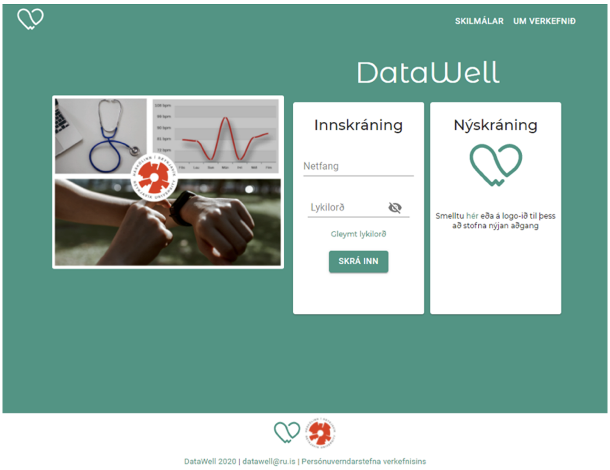
In this effort, I played a key role in obtaining the necessary ethical approval, which involved extensive reading, careful attention to detail, and communication with stakeholders and the lead of the ethics board.

Chapter 5

Results

5.1 Digital Platform And Mobile Application

DataWell is a digital platform designed and developed through a co-design approach during this PhD research. It integrates various types of data, primarily from (i) Withings smartwatches and (ii) the DataWell mobile application. The platform has the purpose of enhancing treatment for individuals with serious mental illnesses, specifically those seeking care for schizophrenia or bipolar disorder. Throughout this research, the design focus has been on the patients, their symptoms, and the capabilities they share, to try to achieve the best results for them. Furthermore, the focus was on improving the treatment they are already receiving. The navigation, phrasing, and visualisations of DataWell have been shaped through a co-design process that involved individuals with lived experience and healthcare professionals. Additionally, I got occasional input and assistance from our colleagues at the psychology department at Reykjavík University. The platform offers three distinct perspectives: one for patients, another for healthcare professionals, and a third for researchers. Patients can, through a secure login, access their perspective of DataWell (see Figure 5.1), where they can monitor health data collected from both the smartwatch and the mobile application. The data visualisations are designed to be user-friendly, serving as tools to facilitate constructive conversations with healthcare professionals.



Smelltu hér eða á logo-ið til þess að stofna nýjan aðgang

DataWell 2020 | datawell@ru.is | Persónuverndarstefna verkefnisins

Figure 5.1: The homepage of the DataWell platform includes sign-in with a password and an option for sign-up with an email, along with project information.

From the healthcare professionals' perspective, they can access an overview of individuals who have permitted them to view their data. This view provides a simple yet comprehensive overview of the patients they will attend to that day. Healthcare professionals can also review detailed information, such as historical heart rate charts and step counts, on an individual level. Researchers, on the other hand, can download structured data and access the perspectives of both patients and healthcare professionals within DataWell.

At the beginning of my PhD journey, the DataWell platform and its associated mobile application had already been initiated by my supervisor, Anna Sigríður Islind, in a collaboration project between the Department of Computer Science and the Department of Sport Science. Originally, the platform was designed and developed for high-achieving athletes in sports, with three perspectives; (i) a player perspective, (ii) a coach perspective and (iii) a researcher perspective. It was designed to collect and visualize data from smartwatches and measurements uploaded by coaches. My effort involved taking the existing conceptualization of the platform, and adopting it as well as growing it to fit the context of mental health.

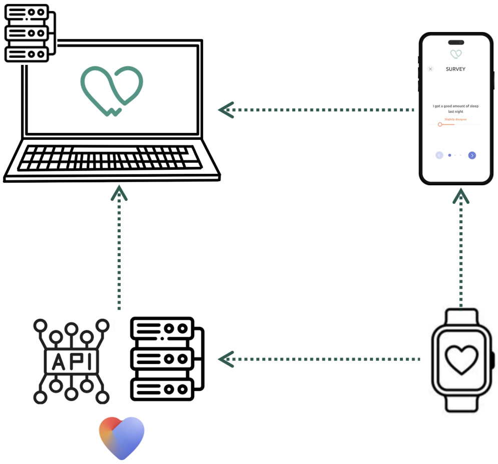


Figure 5.2: An overview of the relational architecture within this research. Arrows indicate data flow, with outgoing arrows representing data transferring and incoming arrows indicating data reception. The smartwatch sends data to the smartphone, allowing participants to access their wearable data there, while also storing it in the Withings database. DataWell fetches this data to put it up for visualization on the platform. Survey responses are sent from the smartphone to DataWell to be displayed as MindPoints.

For the past four and half years, I have led the design and development of the DataWell platform and its mobile application. As the lead architect and designer, I have overseen the iterative development process, ensuring technical and conceptual coherence while integrating user feedback. Throughout this period, me and Anna Sigríður have supervised close to 20 bachelor's students and one master's student across seven development teams, each contributing to the platform's continuous evolution.

The app connects to DataWell (as seen in Figure 5.2). The questions in the mobile app were phrased as statements that participants were to answer on a scale of 1-5 about how their day went, opening with the sentence, ‘How well do the following statements apply to your day?’, and then displaying five statements describing successful feelings ‘I was successful in achieving my goals’, ‘My mental wellbeing was positive’, ‘My physical wellbe-

Figure 5.3: The DataWell logo on the green signature color, representing health, growth, and life.

ing was good', 'I experienced little stress', 'My exercise today was good', 'I slept well last night'. When my collaboration with the psychiatric unit at Landspitali was initiated, I recognised a parallel between the player-coach relationship in sports and the patient-healthcare professional dynamic in a healthcare context. This insight led me, along with the first development team, to adapt the platform's terminology and functionality from a sports science framework to a healthcare-oriented one. Consequently, DataWell evolved into a platform tailored for individuals with mental disorders, incorporating perspectives for three key stakeholder groups: (i) patients, (ii) healthcare professionals, and (iii) researchers. Students participating in the research have gained hands-on experience in both frontend and backend development. The backend is responsible for receiving and collecting data from two primary sources: (i) the DataWell mobile application, which prompts users with daily wellbeing questions, calculates a subjective wellness score (MindPoints), and provides a weekly summary, and (ii) data from the Withings API, including smartwatches and sleeping mats, which contribute objective health metrics. The platform's relational database is hosted on Heroku and the frontend, developed in React JavaScript (ReactJS). The mobile application was initially developed in Xamarin but has since been migrated to React Native as part of the work of one of the student groups. The platform and app feature a white logo on a clean green background, which is the chosen theme color for the platform. The logo and theme were selected through a co-design approach to symbolize health, growth, and life (see Figure 5.3). The platform presents information in a user-friendly format tailored to each stakeholder group, based on insights gathered from previous user testing and workshops with healthcare professionals (see Figure 5.4).

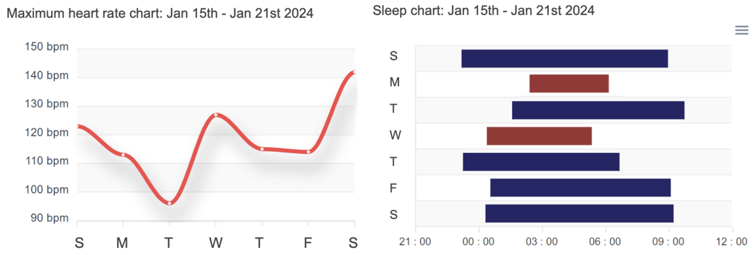
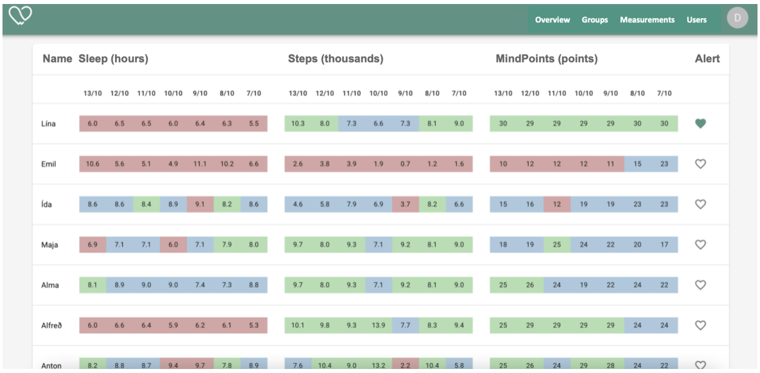


Figure 5.4: From the patient's view on their smartwatch data from the DataWell platform. To the left is a line chart of the maximum heart rate, and to the right is a sleep chart for one week.

Students working on DataWell are exposed to the complexities of managing an existing digital infrastructure, contributing new functionalities, and ensuring system maintenance. They also gain experience in handling highly sensitive research data within an active research endeavor, learning best practices for security and ethical data management. Additionally, students were required to work collaboratively following established team programming methodologies (e.g., Scrum, Agile), with precise and transparent time logging, fostering teamwork and problem-solving skills. By structuring the development process around iterative refinements, user feedback, and interdisciplinary collaboration, DataWell serves as both an evolving research tool and a valuable learning experience for students engaged in its development, furthering the notion of human flourishing not only for patients and healthcare but also for the future generation of developers.

The DataWell platform features a focused table (see Figure 5.5) specifically designed for healthcare professionals to get an overview of the patients and those assigned to them in the system. This table was developed in collaboration with healthcare professionals to offer a quick and comprehensive overview of the status of their people while minimising excessive navigation and clicking. It presents a prioritised list of data from patients—here using pseudonyms—gathered from smartwatches and the DataWell app. People who require special attention, such as those with inadequate sleep detected by their smartwatch, are placed at the top of the list. Additionally, healthcare professionals can elevate specific individuals to the top of the list by clicking the heart icon



Name	Sleep (hours)							Steps (thousands)							MindPoints (points)							Alert
	13/10	12/10	11/10	10/10	9/10	8/10	7/10	13/10	12/10	11/10	10/10	9/10	8/10	7/10	13/10	12/10	11/10	10/10	9/10	8/10	7/10	
Lína	6.0	6.5	6.5	6.0	6.4	6.3	5.5	10.3	8.0	7.3	6.6	7.3	8.1	9.0	30	29	29	29	29	30	30	♥
Emil	10.6	5.6	5.1	4.9	11.1	10.2	6.6	2.6	3.8	3.9	1.9	0.7	1.2	1.6	10	12	12	12	11	15	23	♡
Ída	8.6	8.6	8.4	8.9	9.1	8.2	8.6	4.6	5.8	7.9	6.9	3.7	8.2	6.6	15	16	12	19	19	23	23	♡
Maja	6.9	7.1	7.1	6.0	7.1	7.9	8.0	9.7	8.0	9.3	7.1	9.2	8.1	9.0	18	19	25	24	22	20	17	♡
Alma	8.1	8.9	9.0	9.0	7.4	7.3	8.8	9.7	8.0	9.3	7.1	9.2	8.1	9.0	25	26	24	19	22	24	22	♡
Alfreð	6.0	6.6	6.4	5.9	6.2	6.1	5.3	10.1	9.8	9.3	13.9	7.7	8.3	9.4	25	29	29	29	29	24	24	♡
Anton	8.2	8.8	8.7	9.4	9.7	7.8	8.9	7.6	10.4	9.0	13.2	2.2	10.4	5.8	25	26	24	29	28	24	22	♡

Figure 5.5: A focused table in the healthcare professionals' side of the DataWell platform was created with a co-design approach. Patients are prioritised further up the list based on smartwatch and app data, such as those with insufficient sleep. Healthcare professionals can also manually highlight individuals requiring closer monitoring.

on the right. This feature is helpful for identifying those who might require closer monitoring for reasons that may not be captured by objective data sources. Reasons for concern may arise during interviews, including changes in medication, challenging life circumstances, suicidal thoughts, etc.

During this PhD research I was able to have informal conversations with the healthcare at the hospital about the impact of the DataWell platform and app, but also on their general digital environment. Overall, healthcare professionals expressed frustration with the overwhelming number of computer systems, many of which were not user-friendly or tailored to their specific needs. Some preferred more flexible platforms, while others emphasised the importance of reducing the number of clicks required. Ultimately, healthcare professionals seek to maximise their time spent supporting patients, rather than navigating inefficient or poorly designed systems. The findings outlined in this thesis show that involving healthcare professionals in the design of digital platforms and apps is crucial. This conclusion comes from informal discussions and the differing attitudes I observed among healthcare professionals in two units within the institution. One unit was significantly more positive about the intervention than the other. I attribute these differences to the sense of ownership over the platform, app, and overall approach, which was stronger in one of the units.

5.2 Aggregated Results

The results from paper 1 revealed outcomes from different scenarios at a co-design workshop. First, the healthcare professionals acted out a situation where this individual was preparing for a meeting with their healthcare professional, and the most mentioned topics that came up were visualisation, calendar and graph criteria. Second, they acted out a busy healthcare professional seeking to map what to expect during his workday ahead, finding that visualisation, calendar, watch, and organisation were the most mentioned topics. Visualisation, wellbeing and interpretation came up the most for scenario 3, which was more open and asked what the look and feel of such a platform they thought should be. The results from paper 2 showed that patients were generally comfortable sharing their data with healthcare professionals, viewing it as a beneficial aspect of their care. Many expressed a sense of empowerment from engaging with their health data, feeling more in control of their health journey. Interactions with the smartwatches varied. Paper 3 results revealed a range of patient perspectives on data work and somatic experiences, spanning from wholly positive experiences to concerns about surveillance. The primary contribution of the paper lies in identifying a duality between somatic experience and data work. Additionally, the paper offers conceptual insights into patient data work as a consideration for the design of future digital mental health platforms, along with a proposed model for understanding somatic experiences with IS artifacts in mental health contexts. Results from paper 4 show that self-efficacy is a foundational element of empowerment. This paper suggests that individualised analysis is preferable for groups with schizophrenia and bipolar disorder, and also that wearable data should be integrated into a broader patient narrative, incorporating qualitative interviews and questionnaires to offer a more comprehensive understanding of the patient's experience, ultimately promoting patient flourishing.

These aggregated findings across the papers contribute to the overall thesis by emphasising the importance of personalised data analysis, the move from patient empowerment to patient flourishing, and the need for a holistic, integrated approach to digital mental health. The individual papers collectively reinforce the argument that wearable data should be considered within the broader context of individual patient narratives and experiences and suggest pathways for future research and design in digital mental health.

5.3 Paper 1: Co-design

Title: *A Novel Approach in Psychiatric Healthcare: Co-Designing a Digital Platform*

Status: Published

Outlet: Journal of Workplace Learning

Type of outlet: Journal

Full reference: Sigurðardóttir, S. G., Óskarsdóttir, M., Ingimarsson, O., Islind, AS (2024). A novel approach in psychiatric healthcare: co-designing a digital platform. *Journal of Workplace Learning*, Vol. 36 No. 3 pp. 209–222,
doi: https://doi.org/10.1108/JWL-11-2022-0149

This study involved a co-design process with healthcare professionals at a psychiatric unit and aimed at two objectives: (i) exploring practical implications for the ongoing design and development of the platform and app, and (ii) gathering insights to identify best practices for designing similar platforms. We received valuable feedback from the healthcare professionals, which we summarised into three design principles that other researchers and developers can consider when creating similar platforms. The first design principle emphasises the importance of clarity and information accessibility from the patient's side. The second principle focuses on efficiency and flexibility when it comes to the healthcare professional's side. Finally, we illuminate the need for having a notification option in the mobile application. An additional conclusion was that the healthcare professional's participation in co-design brings a sense of inclusion that we recognize as a supportive factor for the practical use of the platform.

In Scenario 1, a group of healthcare professionals at this workstation took on the role of an individual receiving care at their institution. They acted out a situation where this individual was preparing for a meeting with their healthcare professional. To do so, they imagined having decided to log in to DataWell to gather relevant data to bring to the meeting. They were assigned tasks that were meant to unite them in the assignment, for example, to look for activity (i.e. sleep, steps, etc.) on days that they were to choose from a calendar in the platform. With the unique connections that healthcare professionals have with their patients, knowing their diagnosis and often personalities and history, they are well-positioned to empathise with them and envision how they would respond to the platform design. During the workstation activity, participants acted as patients and engaged in discussions with their colleagues about how the platform could be optimized for patient use. They exchanged ideas on how patients would navigate the platform and what design improvements could enhance usability.

For our data analysis, we employed content analysis using NVivo software. Our findings revealed that the most frequently mentioned codes were 'visualisation' and 'calendar.' The code 'graph criteria' also appeared often, followed by the code 'sleep.' The phrasing of the tasks may have influenced the results to some extent, but I accounted for this potential influence by attempting to add more nuance to the analysis. For example, healthcare professionals placed strong emphasis on 'visualisations' in their insightful discussions, underlining that clarity and accessibility of visualisations and graphs were important, and ensuring that each criterion was well-defined. However, the 'calendar' code can be seen as more directly related to the task itself. Figure 5.6 is a chart illustrating the coding for this scenario. A more detailed description of the analysis can be found in the paper in appendix A.

In Scenario 2, healthcare professionals were invited to assume the role of 'Otto the psychiatrist,' a busy psychiatrist seeking to map what to expect during his workday ahead. In order to achieve this goal, he turns to the DataWell platform for an overview of his patients' statuses. The participants of the workshop thereby employed the DataWell platform as a boundary object, unifying their discussions within this specific scenario. In all three groups, insightful conversations emerged regarding how the platform could best cater to Otto, who represented relatable healthcare professionals like themselves. Mentions of 'Visualization' and 'Calendar' were the most prevalent, likely influenced by the wording of the assignment. Nonetheless, participants generally stressed the importance of having visualizations that are both descriptive and informative. One participant encapsulated this need with the observation, *"Do we have a holistic overview somewhere? You know, where you can see sleep and steps during the same day?"*

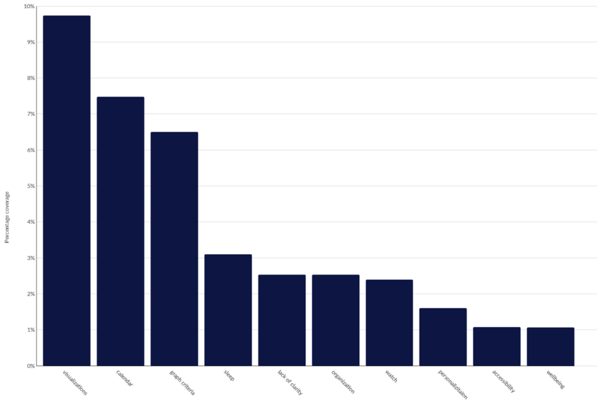


Figure 5.6: Codes that emerged when in the analysis of scenario 1 of the workshop.

and another by saying *"I just want to select one week and get an overview of everything."* From this scenario, we identified the second design principle: 'efficiency from the healthcare professional's perspective'. Figure 5.7 illustrates the most frequently mentioned codes from the transcripts of this scenario. Scenario 3 was designed to be simple and open-ended. Here the healthcare professionals were asked to reflect on the question: *"How do you think that the look and feel of a platform like this should be to best support your type of support to patients?"* The responses were more varied, likely due to the phrasing allowing for personal interpretations. During the analysis process, it became evident how

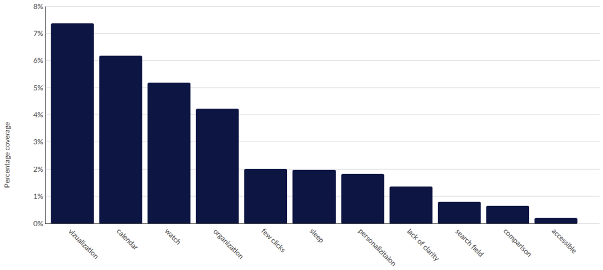


Figure 5.7: Codes that emerged when in the analysis of scenario 2 of the workshop.

thoughtfully the healthcare professionals considered the patients' experiences, as this comment captures: *"I wonder precisely in this context whether if it would be possible to highlight somehow when things are going well. You know, you went for a walk here last week, how did you feel then?"*. Another healthcare professional liked the idea of having data as a conversation starter, stating: *"At least they have some data. You know, I see here that you did not sleep much. What was bothering you? Was it anxiety or what was it? That's kind of the starting point in a lot of conversations."* Figure 5.8 presents the most frequently mentioned codes from the transcripts of this scenario.

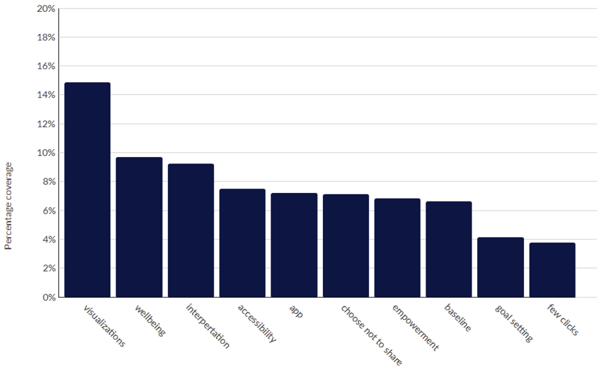


Figure 5.8: Codes that emerged when in the analysis of scenario 3 of the workshop.

5.4 Paper 2: Experience as Expertise

Title: *Collecting Data from a Mobile App and a Smartwatch Supports Treatment of Schizophrenia and Bipolar Disorder*

Status: Published

Outlet: Challenges of Trustable AI and Added-Value on Health

Type of outlet: Book chapter

Full reference: Sigurðardóttir, S. G., Islind, A. S., & Óskarsdóttir, M. (2022). Collecting Data from a Mobile App and a Smartwatch Supports Treatment of Schizophrenia and Bipolar Disorder. In *Challenges of Trustable AI and Added-Value on Health* (pp. 239-243). IOS Press.

In a healthcare context, platforms have the potential to facilitate communication between patients and healthcare professionals by enabling the monitoring of patient-generated health data (PGHD). In this paper, we took a platform perspective, along with the view of the patient through PGHD. Within the platform literature, PGHD refers to data collected and generated by individuals, which is then integrated into a healthcare system to improve the quality of care. This paper focuses on the design of DataWell, a platform that visualizes and provides access to health data and thereby fosters greater patient involvement in their own treatment. The aim was to explore both the clinical significance of PGHD and its growing relevance in mental healthcare and, that way, address the following questions: (i) how should a smartwatch and a mobile app be used to support the treatment of schizophrenia and bipolar disorder? and (ii) how can a digital platform function as a bridge between patients and healthcare professionals?

Participants who agreed to take part in this six-week study had completed a questionnaire at three points during the study: the first, third, and sixth weeks. The questionnaire included a set of validated constructs to assess anxiety levels, depression severity, attitudes toward technology, self-efficacy, empowerment, and the perceived impact of self-monitoring. The purpose of this data in this paper's context was to establish a connection between questionnaire responses and how participants engaged with the platform, smartwatch, and mobile app. Throughout the study, participants wore a smartwatch that continuously collected data and integrated it into the platform, which was a new experience for most. Additionally, participants responded to six daily wellbeing questions within the mobile app, which was discussed in the interview in relation to the real-time data being fed into the platform. During the study period, healthcare professionals had access to the PGHD through DataWell, which allowed for gathering insights from patients about their perspectives. The analysis of the interviews focused on user experience, platform usability, perspectives on data-driven mental healthcare, and the continuous collection of PGHD. A content analysis approach was applied to the interview data, and the findings were used to inform future refinements in the design and development of DataWell.

This paper primarily highlights findings from the patient's perspective. Most participants found continuous data monitoring to be motivating and expressed interest in continuing the data collection beyond the study. Engaging with patients at three different points throughout the data collection period—particularly during the in-depth interview at the conclusion—offered valuable insights into their experiences and the impact of this approach. One participant encapsulated her perspective by stating, "This really matters", underscoring the significance of the study and its potential for continued research. Our analysis revealed four key findings: *Firstly*, patients were generally comfortable sharing their data with healthcare professionals. Many were already accustomed to disclosing personal information in medical settings and viewed data sharing in this context not as an intrusion but as a beneficial aspect of their care. One participant explained, *"It's good that healthcare professionals have access to the data because they're just trying to help you." Secondly*, many participants described a sense of empowerment gained from engaging with their own health data. One patient noted, *"Seeing your own health data is a good feeling,"* while another added, *"It encourages you to see an overview of the steps."* These reflections suggest that self-monitoring fosters a sense of control and engagement in one's health journey. *Thirdly*, the way participants interacted with the smartwatches varied significantly. Some individuals actively tracked their data throughout the day, analyzing their step counts and reflecting on their overall wellbeing. Others preferred to disengage for a few days and then review their data in larger segments, using it to contextualize their emotions and the progression of their condition. One participant, initially unfamiliar with wearable health devices, shared, *"I'm not quite sure, but it was really new to me because I have not worn anything like this before that measures heart rate, steps, and sleep."* Over time, he noticed some behavioral changes, remarking, *"Yeah, a little bit at least, I'm going to bed at the right time now."* Lastly, the way questions were framed in the mobile app proved to be crucial. Ensuring inclusive and considerate communication emerged as a key factor in user experience. One participant observed, *"Maybe what I got out of this was that you just reflect a little bit—you get these questions, then you wonder how was the stress today. You tune a little bit into yourself with this too."* Another patient expressed appreciation for the phrasing of the questions, stating that they felt acknowledged as an intelligent and capable individual rather than being addressed in an overly simplistic manner.

When examining health platforms and patient-generated health data (PGHD), it is essential to consider not only the data itself but also how it is presented and utilized. Data sets can vary significantly in size, ranging from just a few values to extensive arrays of data points, making granularity a crucial factor in data interpretation (Perin et al., 2018). Additionally, trends in data visualization may be structured relationally, hierarchically, or through a combination of both, which influences the selection of graph types that best support patients in understanding their own health information. Rather than existing in isolation, individual data points accumulate over time to form a broader dataset, which can be visualized for dual purposes: (i) serving as a decision-support tool for healthcare professionals, and (ii) fostering self-monitoring and self-care for patients (Islind et al., 2019). Self-monitoring, in this context, refers to the systematic tracking of health-related information, enabling individuals to assess their wellbeing over time. Prior research suggests that wearable technology can encourage increased activity levels in users (Brickwood et al., 2019), and our findings reinforce this, as most participants in our study reported feeling empowered by their use of wearables. Given this engagement, the design of health platforms that handle extensive data should be conducted through a participatory process involving all relevant stakeholders, with particular emphasis on ensuring that patients have a voice in shaping the platform. Cognitive impairment is common among individuals diagnosed with schizophrenia (Bowie & Harvey, 2006) and bipolar disorder (Lima et al., 2018), often making it challenging for them to process written information. Because of these cognitive challenges, how PGHD is integrated into discussions, as well as the methods used for its collection, interpretation, and application, are central concerns in this research. As a result, our focus has been on supporting patients in gathering, comprehending, and reflecting on their own PGHD. Our findings suggest that incorporating PGHD into mental healthcare can contribute to improved wellbeing for patients by fostering a patient-centered approach and strengthening their partnership with healthcare professionals, aligning with previous research (Burns et al., 2019).

Our findings reveal essential insights into the role of patient-generated health data (PGHD) in mental health services, particularly in supporting individuals with schizophrenia and bipolar disorder. Engaging with their own health data through DataWell has shown to be an empowering experience for patients, giving them a greater sense of control over their wellbeing. Additionally, the ability to seamlessly share PGHD with healthcare professionals emerges as a key factor in successfully integrating platforms into clinical workflows. Another critical takeaway is that wearable technology, such as smartwatches, can aid in structuring daily routines, offering patients a tool to monitor and regulate their habits more effectively. The way information is communicated—both in written form and in direct interaction—also plays a significant role. Thoughtful phrasing and a respectful tone in communication foster a more inclusive experience for individuals with schizophrenia or bipolar disorder, reinforcing their active role in the treatment process. In light of these insights, we emphasize that incorporating PGHD into digital health platforms is not only beneficial but essential in shaping future approaches to mental healthcare. A more in-depth discussion and analysis of these findings are available in Appendix B.

5.5 Paper 3: Data Work

Title: *Living with Technology: Data Work and Smartwatch Data Trends for Patients with Serious Mental Illnesses*

Status: Published

Outlet: Scandinavian Journal of Information Systems

Type of outlet: Journal

Full reference: Sigurdardóttir, Steinunn Gróa; Ingimarsson, Oddur; and Islind, Anna Sigridur (2025) Living with Technology: Data work and smartwatch data trends for patients with serious mental illnesses, *Scandinavian Journal of Information Systems*: Vol. 37: Iss. 2, Article 17. DOI: 10.17705/3SJIS/037.26

This paper's main focus was the data work and effort that the patients in the study put into data collection and featured two types of results: (i) quantitative insights derived from the smartwatch data gathered with patients during the data collection period, and (ii) qualitative analyses, validating the data work and the somatic experiences that patients are exposed to when participating in data collection efforts. Figure 21 presents the quantitative part of the results, i.e. time-series plots of sleep and step data from smartwatches for three randomly selected patients diagnosed with schizophrenia: patients 1, 5, and 9 and three diagnosed with bipolar disorder; patients 14, 15, and 20. The goal is not to establish statistical differences between patients or different diagnoses but to offer insights into the outcomes of patients' data collection over a period of up to six weeks. Additionally, variations in sleep patterns and step counts suggest potential influences from personal characteristics, preferences, or the progression of their condition. The data for patient 1 showed significant fluctuations in sleep patterns, similar to those observed in patient 20. In contrast, patients 5 and 9 exhibited more stable sleep patterns. Patients 14 and 15 demonstrated rapid shifts in their sleep, which were often inversely correlated with their step counts. Step activity varied widely among the patients; patient 5 had the highest fluctuations, while patient 9 and 20 maintained consistently low activity levels, and the other patients displayed moderate variation (see Figure

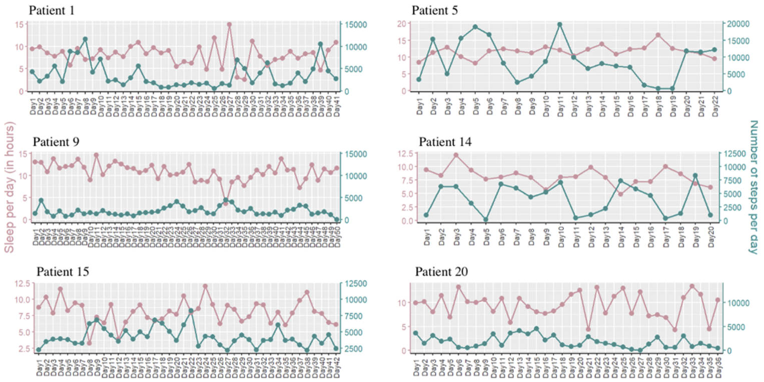
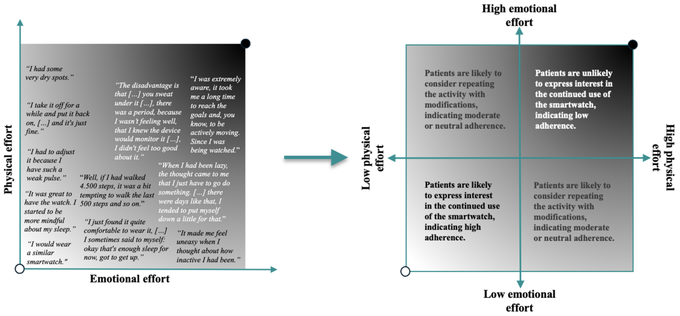


Figure 5.9: Smartwatch data: the pink line represents daily sleep, while the green line indicates daily step count for selected patients with bipolar disorder (patients 1, 5, and 9) and schizophrenia (patients 14, 15, and 20).

5.9, and more detail can be found in Appendix C).

This paper had more emphasis on the qualitative part of the results, where we analysed interviews with the patients that were conducted after our 6-week data collection. To clarify our interpretation of the interviews, we categorised the comments into three categories: (i) bright, (ii) neutral, and (iii) dark aspects of data work. Some insightful comments were categorised as 'bright.' For example, one patient discussed their experience of wearing a smartwatch for an extended period: "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." This comment indicates that the collection period resulted in a largely positive experience for this patient. Other comments classified as bright had a slightly less positive tone. For instance, one participant noted, "It was great to have the watch. I started to be more mindful about my sleep; it's sad to get yellow [i.e., colour in the data] when I've gotten a lot of green." Many comments were classified as neutral, including one from a patient who shared their experience with the smartwatch "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." One interview question explored whether patients perceived smartwatches as a source or an inducer of stress. One participant acknowledged occasional stress induced by the device when they said; "Well, if I had walked 4.500 steps, it was a bit tempting to walk the last 500 steps and so on." However, this response was classified as 'neutral.' The classification reflects a perspective that being prompted by a smartwatch to engage in additional physical activity, such as completing a step goal, is neither entirely positive nor entirely negative. Most of the patient experiences were either positive or neutral; however, there were also some comments that were classified as 'dark.' One such comment reflected the feelings provoked by the fact that healthcare professionals had access to the information collected: "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." One individual did not have an easy time wearing the watch, describing feelings of surveillance: "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.". This insight reminded the researchers to always maintain good contact with patients, be accessible, and include healthcare professionals as part of our team (see quotes and classifications in more detail in Appendix C).

Classifying experiences and emotions is both intriguing and challenging, yet it risks oversimplification. Hence, it is a rewarding endeavour to explore the nuances of what patients shared and convey that depth to readers. In an attempt to do so, we introduced a framework (see Figure 5.10, left) to classify patients' experiences of wearing a smartwatch. Patients' feelings and experiences are complex and should not be viewed as discrete; instead, they can be understood as existing along physical and emotional spectrums. The framework, therefore, aims to capture the complex and nuanced information gathered from the interviews, recognising that patients' experiences can elicit a range of both negative and positive emotions and that they exist on a spectrum. The framework includes quotes from patients in this research, positioned within this spectrum to provide a clearer understanding of their meanings. Positioning the patient quotes within the spec-



"I had some very dry spots."

"I take it off for a while and put it back on, […] and it's just fine."

"I had to adjust it because I have such a weak pulse."

"It was great to have the watch. I started to be more mindful about my sleep."

"I would wear a similar smartwatch."

"The disadvantage is that […] you sweat under it […], there was a period, because I wasn't feeling well, that I knew the device would monitor it […], I didn't feel too good about it."

"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."

"Well, if I had walked 4.500 steps, it was a bit tempting to walk the last 500 steps and so on."

"When I had been lazy, the thought came to me that I just have to go do something. […] there were days like that, I tended to put myself down a little for that."

"I just found it quite comfortable to wear it, […] I sometimes said to myself: okay that's enough sleep for now, got to get up."

"It made me feel uneasy when I thought about how inactive I had been."

Patients are likely to consider repeating the activity with modifications, indicating moderate or neutral adherence.

Patients are unlikely to express interest in the continued use of the smartwatch, indicating low adherence.

Patients are likely to express interest in the continued use of the smartwatch, indicating high adherence.

Patients are likely to consider repeating the activity with modifications, indicating moderate or neutral adherence.

Figure 5.10: To the left: A framework demonstrating the physical and emotional effects of data work in a two-dimensional space. The figure shows real comments from real patients and evaluates them on the spectrum. To the right: A two-by-two matrix illustrating the relationship between emotional and physical strain in data work. This model provides a more generalised perspective, complementing the more specific one on the left.

trum led to a more generalised framework, a two-by-two matrix that demonstrates four different fields, depending on the level of physical and emotional effort. Different fields indicate different levels of likely adherence (see Figure 5.10, right).

This paper examines the physical effort of data work on patients with serious mental illnesses and highlights the duality between somatic experience and data work. Our findings reveal a spectrum of somatic experiences—from mentally and physically demanding to rewarding—embedded in daily data work. We contribute: (i) detailed insights into patient data work as a resource for future digital mental health tools, and (ii) a model for understanding somatic experiences with IS artifacts in mental health contexts.

5.6 Paper 4: Data Exploration

Title: *Wearables for Good: Data-Driven Approach with and for Patients Dealing with Schizophrenia and Bipolar Disorder*

Status: Published

Outlet: European Conference on Information Systems (ECIS)

Type of outlet: Conference paper

Full reference: Sigurðardóttir, S. G., Ingimarsson, O., & Islind, A. S. (2025). Wearables for Good: Data-Driven Approach with and for Patients Dealing with Schizophrenia and Bipolar Disorder. In *Proceedings of the 33th European Conference on Information Systems (ECIS)*, Amman, Jordan, June 16-18, 2025.

The main focus of the paper, is on the use of wearables for good, based on the data from the 21 included patients. The findings from this paper can be summarised in three key points. First, it highlights self-efficacy as a crucial foundation for empowerment. Second, the analysis of wearable data at the group level did not reveal significant patterns. This lack of group-level patterns leads to the third point: each individual's data displays unique characteristics, and we recommend that these patterns be considered and utilised holistically.

Figure 5.11 shows self-efficacy measures from the questionnaires that were executed in week 1, 3 and 6 of the data collection interval. Viewing the data from the questionnaires, there were noticeable fluctuations in terms of self-efficacy that caught the eye, especially for those who were diagnosed with schizophrenia. More specifically, it shows the self-efficacy values in the three measuring points (the questionnaires) for the patients in the study who had a schizophrenia diagnosis. What is visible in the figure is that most patients show a slight heightening in self-efficacy throughout the interval, but some answer in a different way; see patient 2 (N3) and patient 7 (N7), for instance, who both score significantly lower on the self-efficacy scale in the second questionnaire. Note that patient 7 reported signs of instability in their illness and did not want to answer some questions in the questionnaire, including parts of the self-efficacy scale.

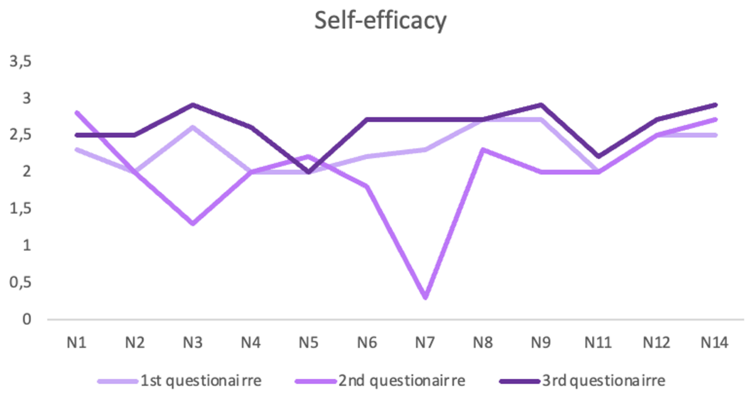


Figure 5.11: Self-efficacy over time for the patients diagnosed with schizophrenia. The horizontal axis represents patients, while the vertical axis shows the values obtained by patients on the self-efficacy scale. Each patient has three measuring points, assessed through three questionnaires executed in weeks 1, 3, and 6.

The findings from the interviews with patients are not the primary focus of this paper but some quotes were included to underline the need for innovation in mental health. One question was about the experience of wearing a smartwatch for an extended period of time, that is the six-week period. It was during this discussion that one of the patients commented: “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.” Another patient expressed a positive sentiment about the intervention but noted that wearing the smartwatch had influenced their daily decision-making. “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.” The descriptions of the patients highlight the role of wearables in fostering empowerment and self-efficacy, as represented by patients’ overall active engagement with the data. These insights also suggest a clearer understanding of patients’ goals, such as aiming to reach the “green zone” in their data collection.

The wearable data consists of daily observations from the patients in the study, and it was of interest to identify patterns in

Figure 5.12: The figure presents a cluster plot featuring four clusters of data points that illustrate daily observations from the smartwatches for all patients in the study. The most important variable on the horizontal axis is the heart rate average, while the most important variables on the vertical axis are step count and wake-up duration.

the data within this information. To explore these patterns, k-means clustering was employed. The results of this analysis are presented in Figure 5.12.

The optimal number of clusters in this study was determined using the elbow method. This technique involves running k-means clustering for k values ranging from 1 to 10, then plotting the average distance between data points and their centroids for each k. The 'elbow' point is the point in which adding another cluster no longer significantly reduces the distance. This point was observed at k $=$ 4; therefore, the k-means clustering was performed with 4 clusters.

The clusters in Figure 5.12 visibly overlap, perhaps indicating that this type of clustering is not as meaningful as it would be if the clusters were more distinct. This finding led us to adopt an individual-based approach, where we analyse the specific traits of each person by examining their unique daily observation, i.e. 24-hour windows of wearable data. This approach results in 42 daily observations of 24-hour windows per individual, as their participation spans a total of six weeks. The patients in this study are dealing with a severe condition. Their behaviour is, therefore, not

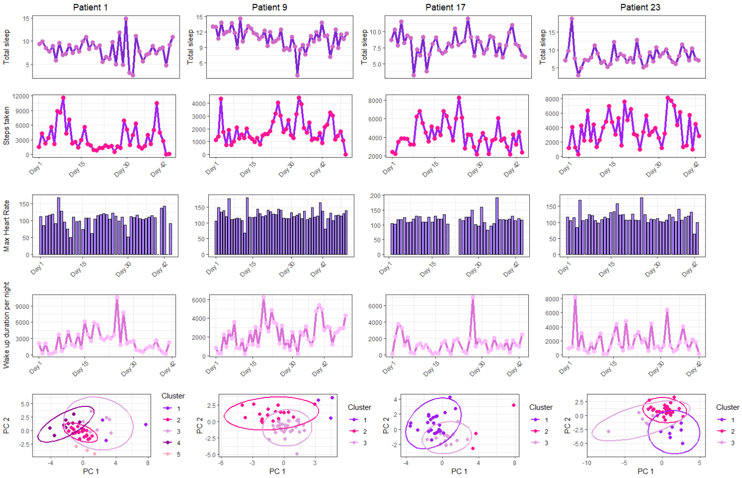


Figure 5.13: Daily analysis of total sleep in hours, steps taken, max heart rate, wake-up duration and an individual cluster analysis that includes these metrics.

typical in the sense of wearable data, and therefore, every data point can be considered an anomaly, as our data indicates. This atypicality underscores the importance of adopting an individual-level approach to data analysis, rather than relying on generalised profiling. Our analysis highlights the unique patterns of each individual (see Figure 5.13).

It is important to note that there is overlap within each patient's cluster plot, indicating that the 24-hour windows do not reveal distinct clustering patterns, but it is also noteworthy that the clusters vary significantly in size and shape between patients. These variations further supports the notion that each patient's data is unique, reinforcing the need for individualised analysis rather than a generalised approach for a group of patients. Such individual-specific patterns suggests that, in practice, each patient's smartwatch data could be used to support their specific treatment and process, since there are known indicators in both sleep patterns and heart rate data that have been significantly linked with bipolar disorder and schizophrenia. Furthermore, rather than being analysed in isolation, the data should be integrated into a patient narrative, incorporating qualitative interviews and questionnaires to provide a more holistic understanding of the patient as a person, ultimately fostering patient flourishing.

Chapter 6

Discussion

The following discussion will be divided into three main discussion topics, all focusing on contributing to the literature of IS in general, and to each of the streams of literature laid out in the previous chapters of this thesis in particular. The three main discussion topics are: (i) the move from patient empowerment to patient flourishing, (ii) somatic experiences and data for good, and (iii) data work and living with technology.

6.1 The Move from Patient Empowerment to Patient Flourishing

Human flourishing describes the ongoing development of individuals, fulfilling their highest potential and desire to live well; this includes a holistic view of wellbeing that integrates physical, emotional, social, and psychological aspects (Hylving et al., 2024; Koutsikouri, 2024). Nowadays, there is significant interest in how individuals interact with and respond to emerging technologies in general, and how individuals interact with wearables and apps in particular. These new forms of interaction between human bodies and technology provide valuable insights into the impact of personal data collection on human flourishing, particularly for those with serious mental illnesses such as schizophrenia or bipolar disorder. As data increasingly influences our lives, it also transforms how individuals relate to and understand their own wellbeing. This shift creates new tensions between self-care and flourishing

(Marabelli & Newell, 2023). While collecting health data can enhance various aspects of life, the pursuit of an optimised self may also have unintended negative consequences, potentially exacerbating clinical disorders and neuroses (Aupetit et al., 2019). When engaging with individuals experiencing chronic mental illnesses, it is essential to proceed with caution and care. Additionally, there is increasing interest within the field of IS in the design, development, and implementation of technologies aimed at supporting individuals with mental illnesses (Langrial & Lappalainen, 2016). From this perspective, the integration of wearable devices aligns well within the scope of IS research concern. Human flourishing is highly relevant in the context of health, particularly if we narrow it down to 'patient flourishing.' This shift opens up a discussion for researchers and practitioners to focus on IS that support individuals receiving and partaking in care in reaching their full potential within the scope of their disease boundaries. This approach emphasises their abilities rather than their disabilities, highlighting what individuals can achieve when they are given the opportunity to thrive. Self-efficacy, defined as an individual's belief in their own abilities, has long been associated with empowerment (Ozer & Bandura, 1990). However, the precise relationship between self-efficacy and empowerment at the individual level remains ambiguous (Arvidsson et al., 2023; Rawlett, 2014). While self-efficacy is a personal attribute that can fluctuate over time, empowerment is normally defined either as a process or goal. Other psychological attributes, such as self-esteem and self-confidence, have also been linked to empowerment (Tengland, 2008), and this thesis does not suggest that patient empowerment is solely dependent on self-efficacy but rather acknowledges it as one of several contributing factors. In particular, 'patient empowerment' comprises four hierarchical levels: the motivated patient (who is willing to seek information and adhere to treatment), the self-caring patient (who actively looks for information about their condition and takes more control over their health), the producing patient (who begins to help others by sharing their experiences), and the patient activist (who aims to change policies and raise awareness in healthcare by assisting others) (Johansson et al., 2021). Looking into these levels in context with this research, I argue that self-efficacy can affect each of the four levels, but also that self-efficacy can affect the ability to climb up the empowerment stairs. A recent systematic review found that online communities play a significant role in supporting patient empowerment, emphasising the importance of support in the empowerment process (Johansson et al., 2021). This finding aligns with insights gathered from interviews conducted during this research. As discussed above, one key takeaway is that self-efficacy serves as a foundation for empowerment and additionally, in data-driven mental health, providing support is determining for success.

As the findings in this thesis show, empowerment and human flourishing are closely related, as empowerment encompasses people gaining control of their lives and making informed decisions, which are essential for patient flourishing. I argue that human flourishing is also closely related to co-design, where relevant stakeholders are given the power to affect the design of software that will, in some cases, become essential for them to flourish. In healthcare settings, co-design contributes to patient empowering by involving patients in the development of software, advancing their knowledge and skills, in addition to ensuring that the resulting solutions are more user-friendly and better integrated. Recognising lived experience in the way that successful co-design does, promotes social engagement and validation, and thereby patient flourishing. Recent literature highlights concerns that some individuals may develop an excessive dependence on wearable devices, fixating on idealised metrics or attempting to eliminate every recorded irregularity. This preoccupation can itself become a source of anxiety, contributing to dissatisfaction, distress, or exacerbating health conditions that may require medical intervention (Baron et al., 2017). Personal datafication intersects with various psychological, medical, and behavioural conditions, including orthosomnia—an obsessive focus on achieving optimal sleep; productivity paranoia—compulsive time optimisation; and body dysmorphia—distorted perceptions of physical appearance (Greene et al., 2023). How self-optimisation reshapes concerns for wellbeing within personal datafication—if people become overly fixated on optimising their health metrics—remains an important agenda for IS research. The cumulative effects of such behaviours may pose substantial risks for human flourishing at both systemic and societal levels (Kaplan et al., 2023). Given these concerns, examining the impact of wearables, particularly on individuals already vulnerable due to the ways wearable data can be utilised, represents a pressing issue for IS research, especially within health IS. These concerns underscore the urgent need for IS scholars to investigate personal datafication in situ, using case-specific analyses that demonstrate how data-driven approaches can be leveraged to promote human flourishing. This research illustrates that wearables can be beneficial even for individuals with severe mental illnesses; however, careful implementation is key. An important finding is that data analysis should prioritise individual patterns rather than relying on group-level extrapolations to ensure meaningful and effective interventions. As addressed in Chapter 2, the definition of patient empowerment opted for in this thesis is a process through which individuals develop a better understanding of their condition and treatment, enabling them to take greater control over their health and make more informed decisions on their care (WHO, 2009). One key factor in promoting individual patient empowerment is the accessibility of information, and wearables can significantly contribute to this effort. However, the ways to cultivate empowerment, particularly patient empowerment through the use of data, have not been extensively studied (Náfrádi et al., 2019). Although some impactful research indicates that adherence to treatment is highly dependent on patient empowerment (ibid), there is limited exploration into practical approaches for achieving empowerment and identifying the necessary steps in that process (Johansson et al., 2021). Even though there is rising interest in the IS literature for digital empowerment (Sharma et al., 2022), there remains a gap in both this domain and empowerment literature in general—the need for detailed, contextualised descriptions of how empowerment can be achieved. Ergo, digital empowerment is still rather unclear and ubiquitous as a concept. This thesis contributes to this ongoing discourse by highlighting the role of wearable technology in engaging individuals with psychotic disorders, demonstrating how interactions with data can foster empowerment. Importantly, my findings emphasise self-efficacy as a fundamental step toward both general and digital empowerment. Rooted in long-standing IS research dating back to Compeau and Higgins (1995), self-efficacy serves as a critical prerequisite for empowerment, with our findings indicating that strengthening self-efficacy enhances the overall process of empowerment. Self-efficacy refers to a person's belief in their ability to accomplish tasks or achieve goals, encompassing their confidence in regulating their own behavior, influencing their environment, and maintaining motivation in pursuit of their objectives (Rieder et al., 2021). Attaining self-efficacy is a significant milestone, particularly when working with individuals with serious mental illnesses. The findings reported herein demonstrate that self-efficacy serves as an important stepping stone toward empowerment. Moreover, the use of wearables, particularly smartwatches, can play a meaningful role in fostering self-efficacy, ultimately contributing to the empowerment of individuals with schizophrenia or bipolar disorder.

This research highlights that improving self-efficacy—defined as the belief in one's ability to successfully accomplish specific tasks or goals—is a crucial step toward achieving empowerment for individuals with severe mental disorders. This is particularly relevant as we move toward more digitalisation in psychiatric care, with the potential for wearable technology and apps to become an integral part of future treatments.

Providing our patient cohort with access to data about their own health has potentially enhanced their health literacy, which can counteract self-destigmatization and potentially reduce stigma from the loved ones of patients (Choudhary et al., 2024). Additionally, the dissemination of the overall research and research papers, both through international conferences, as well as local events such as the local psychiatric assembly and a technical conference hosted by Advania, along with several smaller presentation venues, has contributed to fostering awareness and discussion on the subject.

The concepts underpinning this thesis are therefore brought together in the Patient Flourishing Model (see Figure 6.1), which centres the idea of patient flourishing as a multidimensional concept. Patient flourishing is here conceptualised as the growth in wellbeing of patients within their disease limits, grounded in four interconnected aspects: self-efficacy, patient empowerment, co-design, and living with technology, each of which contributes to the patient's flourishing. These core factors are not isolated; rather, they are iterative and mutually influential, meaning that growth in one aspect may encourage growth in another. The outer circle of the model elaborates on some of the key attributes of each aspect, but they are not merely descriptors of an aspect; they can collectively affect patient flourishing through one or more aspects, for instance, using data to support treatment may strengthen a patient's belief in their own abilities, just as participating in co-design can encourage feelings of empowerment and control. By situating these interrelated dimensions within the broader goal of

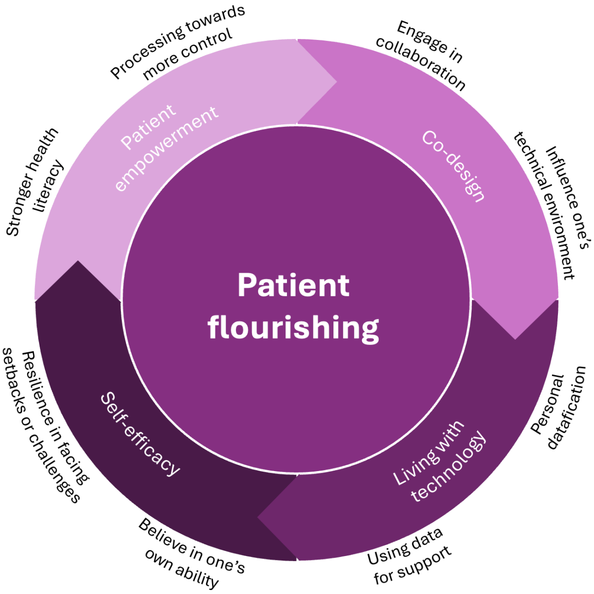


Figure 6.1: The Patient Flourishing Model conceptualises how self-efficacy, patient empowerment, co-design, and living with technology can all contribute to the flourishing of patients. The model is iterative in nature, meaning that each factor dynamically influences and is influenced by the others, supporting patients in enhancing their wellbeing. Surrounding the core factors, the outer circle takes into consideration attributes associated with each contributing factor, illustrating how these dimensions collectively shape and support 'patient flourishing'.

patient flourishing, the model provides both a conceptual framework and a practical lens through which to view digital mental health interventions.

6.2 Somatic Experiences and Data for Good

Individuals with schizophrenia or bipolar disorder experience varying phases of their condition, which can affect their ability to engage with external factors, including digital health tools. Their interaction with a smartwatch and its data may differ depending on their current state. Additionally, both the condition itself and the effects of medication can influence cognitive abilities, which may make it difficult for individuals to monitor their own data effectively. This observation aligns with findings from a recent systematic review on the perception of wearables, which suggests that the benefits of wearable technology, particularly smartwatches, are strongly influenced by a user's fundamental psychological needs—autonomy, competence, and relatedness (Soltani et al., 2024). Given that schizophrenia and bipolar disorder are often chronic conditions (Grande et al., 2016; Schultz et al., 2007), it is essential for individuals to have a positive attitude towards long-term interventions, which is supported by the interviews with patients. While interventions aimed at enhancing self-efficacy in symptom detection are valuable, research suggests that individuals with bipolar disorder often struggle to accurately assess their mood, particularly during hypomanic episodes (Grande et al., 2016), and that those with schizophrenia frequently often insight into their symptoms. Notably, some participants reported that wearables helped them recognize changes in sleep patterns, which can serve as an early indicator of an impending episode. Smartwatches, therefore, hold potential for empowering individuals to identify symptoms—such as disruptions in sleep and movement—before their condition worsens, enabling them to take a more active role in their treatment rather than relying solely on healthcare professionals. However, further research is needed to confirm this clinically. As interest in the relationship between technology and personal wellbeing increases, the findings in this research highlight the multifaceted impact of smartwatch use on patients, both in terms of the physiological experience of wearing a somatic IS artifact, and the impact of continuously collecting data through smartwatches. I have found that these devices encouraged healthier behaviors, such as increasing step counts and improving sleep patterns. However, the wearables and the knowledge from the data also had some negative effects, including skin sores from the watch and feelings of guilt associated with usage. This research highlights 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. Somatic IS artifacts not only consist of sensors that receive and transmit signals, but they also provide specific physical experiences through their material properties, ergonomic fit, and design intended to evoke physical responses (Lorenz & Recker, 2023; Recker et al., 2021), as also elaborated on in this thesis. This thesis offers a novel contribution to the field of IS by demonstrating the interconnection between data work and somatic experience. The findings from this thesis illustrate that somatic IS artifacts indeed stimulate physical responses, as elaborated on in Paper 3, and the data involved is tangible and real. Patients' experiences ranged from describing the data collection period as 'a positive period,' to expressing that they sometimes had to put in effort to produce desirable data, 'go exercise or something,' to feelings of surveillance, captured in remarks like 'somebody is watching me' (see section 5.2 and 5.5 for more details). They also noted that sometimes they had to 'take it [the smartwatch] off for a while' and that it sometimes caused discomfort, 'rash on my wrist' (see Paper 3 for more details). The findings from this thesis illustrate that these devices indeed stimulate physical responses, and the data involved is tangible and real. Given the nuanced and deep nature of the responses, Paper 3 introduced the framework presented in Figure 5.10, demonstrating that somatic experiences are directly tied to the data collected. This thesis thus provides in-depth insights into how patients with schizophrenia or bipolar disorder interact with somatic IS artifacts, revealing that the act of monitoring and interpreting data is not separate from bodily experience, but in fact intertwined.

Individual differences in physiological structures and personal style, including variations in bodily sensitivity and other physical factors, can influence the comfort and usability of smartwatches (Xu et al., 2025). These findings align with an ancillary insight from the interviews, which highlighted the diversity in personal style preferences among participants. While some found the watch to complement their style perfectly, others felt it was either too large or too small, leading to differing attitudes toward the data collection with the smartwatch. These divergent opinions on the smartwatches suggest a practical concern for others to consider while designing an intervention of this sort, namely that offering multiple design options could better accommodate individual preferences and enhance user acceptance. Smartwatch design options vary widely in both technical and aesthetic aspects, and different types could be offered either within or across brands. Additionally, the Withings smartwatch band, made of fluoroelastomers rubber (see figure 4.7), presented both advantages and drawbacks. While its durability and water resistance made it convenient for continuous wear, some participants experienced skin irritation (see Section 5.5) due to the lack of breathability, while others had to frequently adjust the band to alleviate discomfort. However, some participants reported no issues at all, highlighting the variability in individual experiences. These insights emphasise the importance of material considerations to ensure comfort and long-term usability, as well as discussion on how seamlessly a wearable device integrates into daily life without causing disruption, catering to the notion of somatic experiences as an important part of research relying on tangible devices (e.g., Lorenz & Recker, 2023). Factors such as the material's flexibility and the device's structure play a significant role in determining its 'comfort-to-wear' level, and how different materials in wearables affect the human body (Qiao et al., 2022; Shimura et al., 2023). Given these variations, offering smartwatch bands made from different materials could enhance comfort and increase the likelihood of sustained device usage.

The use of smartwatches alongside traditional treatments has the potential to enhance the treatment of chronic diseases like mental disorders, and mental healthcare has been identified to be one of the key areas where smartwatches can significantly improve treatment outcomes (Köhler et al., 2024). As this thesis has demonstrated, smartwatches can be a contributing factor in patient flourishing, and they can help increase the weight of data-driven treatments to improve access to mental healthcare. Some researchers have raised concerns about the role of smartwatches in patient empowerment, emphasising that the support of healthcare professionals is crucial in this process (Kang & Exworthy, 2022). Also, researchers have emphasised the need for studies that explore and contribute to related topics such as stigma, health literacy, and help-seeking behaviours (Masri et al., 2024). While this thesis does not directly address stigma, it contributes to health literacy of the patients by providing patients with access to visualisations of their own health data. The existing literature has yet to reach a consensus on the role of wearables in data-driven decision-making for improving mental healthcare. Further research is required to establish how wearables and wearable data contribute to enhancing the treatment possibilities of individuals with bipolar disorder and schizophrenia. Addressing this critical gap, this PhD thesis advances knowledge on the integration of wearable technology into mental healthcare. As society becomes increasingly data-driven, it is essential to critically assess the appropriateness of profiling individuals to derive generalised human traits. While it is well established that each person possesses unique characteristics, categorising individuals into predefined groups can seem counterintuitive. The findings outlined herein indicate that this approach is particularly counterproductive when dealing with individuals who exhibit drastically different digital footprints, especially as illustrated by their wearable data. Research on digital phenotyping has become increasingly impactful (Torous et al., 2016). For instance, it has been employed to identify groups at risk for specific conditions based on data obtained from wearables (e.g. Kalisperakis, 2023; Choi, 2024). While there are attempts to establish profiles or patterns to better illustrate types of patients with psychotic disorders (e.g., Kalisperakis, 2023), the findings suggest that it is more productive to focus on the daily experiences of individuals and to prioritise individual-level analysis over generic clustering or profiling. This thesis contributes insights into the digital phenotypes of individuals with schizophrenia and bipolar disorder, highlighting the ebb and flow of their conditions. Centring on an individual-level approach is far more meaningful than attempting to create generic profiles. By employing machine learning methods to classify individual patterns, the results demonstrate that individuals retain their uniqueness. The cluster analysis (see Chapter 4.5) highlights the impact of digital phenotyping at an individual level, as each person is examined separately. In this regard, this thesis contributes to the IS literature by highlighting that, in certain cases, generalizing behavioral patterns to categorize patients into profiles is not meaningful. Instead, the findings of this thesis underscore the importance of recognizing individuals and focusing on their unique 24-hour patterns. The IS field has traditionally excelled in generating in-depth insights and prioritizing individual perspectives, and this thesis advances that agenda. Specifically, when working with individuals whose wearable data exhibit significant fluctuations, the results demonstrate the value of digital phenotyping at the individual level rather than attempting to identify overarching patterns. Thus, this thesis emphasises the significance of analyzing individual patterns, introducing the concept of the meaningfulness of the 24-hour cycle as a novel contribution.

6.3 Data Work and Living with Technology

There has been growing research interest in the exploitation and data mining of personal information for others' gain, sparking discussions on surveillance capitalism (Zuboff, 2019). Maintaining a strong ethical framework regarding patient data work is more crucial than ever, especially as surveillance capitalism shapes the design of our information systems and data practices, often polarising opinions (Zuboff, 2019). As information systems increasingly integrate into our lives, it is vital to ethically evaluate our impact on those from whom we collect data. The findings from this thesis show there is value for patients in the digital mental health intervention approach. However, it is important to consider that these patients might feel vulnerable in regard to authority and, therefore, may have a tendency to conform. Although the patients appreciated the valuable insights gained from participating in the digital mental health intervention and highlighted the benefits of using the smartwatch, they also pointed out the negative aspects of data work through their reflections on its impacts, aspects they may have overlooked because of their tendency to conform. The interviews revealed that some patients experienced a sense of surveillance, a concern that warrants careful consideration. This recognition of surveillance feelings motivated a deeper exploration of data work and somatic experiences, which is crucial to evaluating the effort put into data work at all levels. For instance, the seemingly small effort of wearing a smartwatch has a notable impact on the patients, as shown in this study. While I had ethical approval for this research, I still wanted to carefully assess the impact of data work and somatic experiences on the patients involved. Certain mechanisms contribute to the invisibility or visibility of various types of work, with data work often being neglected or underestimated in its significance (Hatton, 2017; Pols, 2012). Notably, while many acknowledged the drawbacks of living with the technology, most expressed a desire to continue the data work and would choose to keep the smartwatch. One way to address these concerns would be to incorporate a feature that allows users to flag feelings of surveillance, or other difficult emotions within the platform or app. WHO has guidelines discouraging the use of language that may trigger difficult emotions, such as thoughts of suicide (WHO, 2023). Following those guidelines may be particularly important when designing for individuals in vulnerable positions. However, research has also shown that exposure to 'dangerous words' does not increase the likelihood of suicidal behavior (Anestis et al., 2015). Through the co-design process, the language used and the tonality were carefully considered from the perspective of the patients on the one hand and the perspective of the healthcare professionals on the other hand. Additionally, patients' efforts in healthcare should not be forgotten, as they contribute to the work of healthcare by improving the quality of care and providing valuable data. Also, by transforming personal experiences into measurable information, they help shift healthcare from subjective narratives to objective data, supporting better decision-making (Lindroth et al., 2018). Data work performed by patients has not been explored extensively in the literature. Addressing this topic, I build on the previously established definition of data work (i.e. Section 3.4). Patients' contributions extend beyond mere data collection; patients' data work encompasses a sense-making process in which they strive—both independently and in collaboration with their healthcare professionals—to understand the data and actively utilise it to engage more effectively in their ongoing treatment. This thesis highlights the significant role that patients play in enhancing data-driven decision-making within healthcare, which is highly important for the future of healthcare. While data-driven monitoring has demonstrated positive outcomes (Dogan et al., 2017; Smith et al., 2023), it is important to proceed with caution, as discussed in this thesis. However, the future of mental health care must integrate digital mental health solutions to address the limited resources and waiting lists (Nghiem et al., 2023). It is still vital to carefully consider how data work impacts patients. Interestingly, the patients in our study, despite being under considerable supervision and having regular meetings with their healthcare professionals, did not engage in discussions about their own data during these appointments. This observation suggests a potential area for future research: developing structured conversations about data between patients and healthcare professionals to enhance mutual understanding and visibility of each other's contributions in the realm of data and data work.

Both patient groups in the study are under regular medical care from the psychiatric department at Landspitali. Healthcare professionals closely monitor patients through various metrics, such as repeated inquiries about their mental health status, questionnaires and longer interviews. Additionally, physical health indicators, such as fluctuations in BMI, are, in some cases, indicators of change in disease progression and are therefore monitored in certain cases. Currently, the interpretation of collected data relies on manual analysis by medical staff. Through the literature, it is apparent that there is a need for technological understanding alongside clinical value (Fitzpatrick & Ellingsen, 2013). This observation is also visible in practice, as digital tools used in healthcare settings are often underused, perhaps because the design is often not done with users and, therefore, not user-friendly. Research on data generated for administrative purposes has been dominating the literature with a focus on electronic patient records (EPR) and data collected and 'owned' by healthcare. However, the focus has been shifting towards patient-generated health data (PGHD), and data that is produced and 'owned' by the patients, and brought into healthcare with the dual aim of supporting healthcare professionals in their work and the patients in self-care. Each data entry is a part of an array in which data over time builds up a larger data set that can then be visualised for the dual purpose of triggering self-care for patients and functioning as a decision-support for healthcare professionals (Islind et al., 2019).

Engaging with one's own personal data in general and health data in particular has proven to be impactful and even revolutionary for individuals with schizophrenia (Simões de Almeida & Marques, 2023) and similarly showed good results for patients with bipolar disorder (de Azevedo Cardozo et al., 2024). Moreover, the interplay between subjective and objective data has been shown to enhance people's perception of their sleep quality (Biedebach et al., 2023). However, while wearing smartwatches has demonstrated little impact on most individuals (Karlgren & McMillan, 2022), this thesis highlights the complexities faced by those with serious mental illnesses and the common experiences that anyone, regardless of mental health status, might encounter. Causal relationships between sleep, circadian rhythm, and mood symptoms in patients with serious mental illnesses have been highlighted (Song et al.,2024). In examining sleep and activity data with the cohort in this research, there are noteworthy fluctuations in the number of hours slept each night, and these high fluctuations are visible for most patients. Looking at the standard deviation of sleep duration, they do appear larger in our cohort compared to healthy cohorts (cf. Biedebach et al., 2023; Karlgren & McMillan, 2022). However, distinct patterns emerge among individuals; some patients tend to walk less on days when they sleep more, while others do not exhibit this trend. It is important to recognise that smartwatch data can indicate traits associated with mental disorders and personal characteristics, as various factors can influence an individual's behaviour. What this thesis has shown is that wearables are promising as a supplement to the traditional monitoring of and for patients dealing with mental illnesses.

In the analysis process of interviews when exploring somatic experiences associated with smartwatch use among our cohort of patients, I identified two primary dimensions: (i) the physical and (ii) the emotional load. Rather than categorising the findings into rigid, predefined categories, I observed that participants' experiences existed along a spectrum between these two poles. Adopting this dual-spectrum perspective enabled a more nuanced and comprehensive understanding of the interplay between physical and emotional aspects of smartwatch use. I developed a two-by-two somatic experience model, illustrated in Figure 24, which places these spectrums on a plane. This model enables a mapping of patients' somatic experiences to specific points, acknowledging the complexity of their feelings while also providing a clear framework. This model highlights the importance of involving patients—or others, if applied beyond healthcare—in the design of their care practices, aligning with the findings of de Azevedo Cardoso et al. (2024). There is a growing body of literature emphasising the need for human support in digital mental health interventions (Werntz et al., 2023), and my findings align with this perspective. I argue that data collection for individuals with serious mental disorders requires continuous monitoring and engagement. Vulnerable participants benefit from ongoing explanations and discussions, which not only enhance their involvement in their own care but also provide reassurance throughout the process. A key insight from this PhD research, in which participants engaged with technology for six weeks, is the importance of discussing somatic experiences. Interviews provided a valuable platform for these discussions, and meeting with participants multiple times throughout the data collection period proved beneficial. I conducted check-ins every three weeks, and participants had direct access to me via phone for technology-related inquiries. Additionally, they maintained easy access to their healthcare professionals as part of their outpatient treatment, all of which were crucial for ensuring a supportive research environment. However, while support was critical, we in the research group intentionally maintained a passive role to avoid influencing participants' engagement with the data collection. Based on this PhD research, I recommend that researchers undertaking embedded data work for individuals with serious mental illnesses balance ethical considerations with the need for continued support, ensuring that participants feel guided without undue influence.

6.4 Contributions to Information Systems Research

Firstly, this thesis has demonstrated how wearables can capture meaningful fluctuations in smartwatch data, emphasising the importance of individualised analysis rather than profiling groups based on trends in the data. *Secondly*, the thesis has illustrated that the effects of wearing a smartwatch can not only be positive or negative, but rather that there is a whole spectrum of effects it can have on individuals, a spectrum that captures both emotional and physical attributes. *Thirdly*, the thesis shows the impact of appreciating the somatic experiences of carrying a smartwatch which in turn has ripple effects through the data work of the patients, which needs to be seen and discussed in times when it is a necessity to start relying on data-driven mental health to a larger extent in the healthcare system that is exploding from pressure. *Fourth*, reflecting on the experiences of a person through their lived day mediated by a smartwatch app with daily wellbeing questions can be useful for individuals caring for their mental health. *Fifth*, despite challenges such as inconsistent patient engagement and a high dropout rate, our findings show that many patients valued the opportunity to track their health data and actively participate in their treatment and care. *Sixth*, the co-design process with healthcare professionals identifies three key design principles

Table 6.1: The contributions made to IS research and their specific focus within theory.

No.	Contribution to IS research	Main focus
1	How wearables can capture meaningful fluctuations in smartwatch data.	Individual data analytics
2	The effects of wearing a smartwatch can not only be positive or negative.	Data work
3	Appreciating the somatic experiences of carrying a smartwatch.	Somatic experiences
4	Reflecting on the experiences of a person through their lived day mediated by a smartwatch app with daily wellbeing questions can be useful for individuals caring for their mental health.	Patient flourishing
5	Patients valued the opportunity to track their health data and actively participate in their treatment and care.	Patient flourishing
6	The co-design process with healthcare professionals identifies three key design principles for digital mental health platforms.	Co-design

for digital mental health platforms: (i) clarity and accessibility for patients, (ii) efficiency and flexibility for healthcare professionals, and (iii) the integration of notification functions to enhance engagement.

The main theoretical contribution outlined above, can be summarised as a three-fold contribution. *Firstly*, this thesis contributes to the growing literature on data work within healthcare by conceptually engaging with the data work of patients through their detailed accounts and experiences of living with technology. The patients are engaging in invisible work and partaking in their own care to a larger extent through their engagement with data. *Secondly*, this thesis contributes to the discourse on somatic experiences, by outlining the ways in which wearables and apps can impact the bodily experiences of patients. Moreover, the thesis shows that data from patients, can be brought into healthcare in meaningful ways through individual-based analysis, instead of attempting to extrapolate group-based knowledge from the continuously collected subjective and objective data. *Thirdly*, this thesis contributes to the novel literature on human flourishing through a thoughtful co-design approach, spanning multiple years, engaging 13 healthcare professionals and 21 patients with serious mental illnesses, ultimately leading to a platform that is used and a data-driven approach to digital mental health that is fruitful for both patients and healthcare professionals. Moreover, the thesis contributes the conceptualisation of patient flourishing on the one hand and living with technology on the other hand.

6.5 Limitations and Future Work

This research has several limitations, some of which also present valuable opportunities for future research. First, the completeness of the wearable data varied due to participant dropout and inconsistent device usage, particularly during certain times of the day. This variability may be attributed to the voluntary nature of participation. Additionally, participants were at different stages of their illness, and the research team deliberately chose not to impose incentives or pressure to ensure continuous engagement. Despite these challenges, the findings suggest that wearable data offer promising insights into mental healthcare, particularly given the pronounced rhythmic fluctuations observed in individuals with severe mental illnesses. Second, the sample size was limited to 21 participants, and no separate control group was included. As a result, further research with larger, more diverse samples is necessary to enhance the generalizability of the findings. Third, regarding the platform designed, developed and used as a part of this PhD thesis, it was co-designed for supporting healthcare professionals in their clinical decision-making and as a self-care tool for patients with severe mental illnesses. Since all participants in this research had a diagnosis of severe mental illness, their specific needs, as well as those of the healthcare professionals involved, may not be representative of individuals with less severe conditions. Future research could explore the applicability of human flourishing through co-design in other contexts. This would help assess the validity and transferability of the co-design approach to other mental health conditions or broader digital health platforms. Moreover, the platform could also serve as a stepping stone for other conditions through a more global approach to data-driven healthcare. Fourth, the 13 healthcare professionals who participated in the co-design process were specialists in mental health. Therefore, their insights may not be generalizable to other areas of healthcare delivery. Expanding the scope of future research to include healthcare professionals from diverse healthcare domains could provide a broader understanding of how digital health interventions in general can be adapted across different healthcare contexts. Fifth, future research should prioritise health literacy, particularly in light of the increasing complexity introduced by artificial intelligence (AI) in healthcare. While AI can often successfully explain health outcomes, discuss treatment options, identify symptom patterns, etc., it can also go off track and offer misleading information. Given the varying levels of patients' ability to critically interpret health information, these developments underscore the urgent need to strengthen health literacy and promote equitable understanding of mental health conditions. Sixth, it is possible that collecting own health data in collaboration with healthcare professionals, researchers and potentially loved ones, introduced an increased sense of engagement or attention into patients' lives, which may have affected the overall outcomes of the study. Seventh, the 'human flourishing of healthcare professionals' would be an interesting avenue for future research. Eighth, this thesis did not explore stigma related to mental health, but it would be an interesting avenue to pursue, particularly with a focus on digital health. Ninth, while the DataWell platform was designed, developed and used for the purpose of this research, future research will focus on the sustainability of the platform by continuing research in collaboration between the university and Landspítali while also exploring the possibility of utilising DataWell in other countries and contexts. Finally, although this research did not unravel loneliness to a large extent, some of the participants felt a disconnect; one area of future research, could be to try and dig into human flourishing much more, and focus on reducing loneliness—through self-care and co-care—perhaps by sharing experiences and data with loved ones to a much larger extent. The different perspectives of the overall research have various empirical data sources, which result in different publications (see figure 6.2). This holds hand in hand with the fact that the DataWell platform has different perspectives, namely the patient's perspective, the healthcare professional's perspective and the researcher's perspective. It also has a researcher's perspective, the third perspective. A potential way of expanding the research (and thereby expanding the data collection) is to add yet another perspective to the platform, with the perspective of the loved ones of a patient, that is, the next-of-kin perspective.

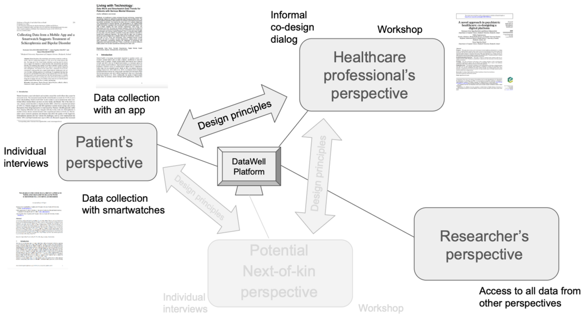


Figure 6.2: The image shows how the three different perspectives of the research have various empirical data sources, and that they result in different publications. It also shows a potential way of adding another perspective, where the focus would be the loved ones of a patient, i.e. the 'next-of-kin'. The platform is situated in the middle, indicating that it currently has three perspectives and the potential to add a fourth perspective for the next of kin.

6.6 Epilogue

In this section, I reflect on the process of writing the thesis, focusing primarily on word usage and further conceptualising patient flourishing. The word 'patient' is not one of my favourites. Drawing on my experience, particularly when my mother was diagnosed with breast cancer, I recall that she was not attached to that term. Throughout her treatment journey, which thankfully had a positive outcome, she consistently said that she did not want to be labelled as a 'patient'. She wanted to remain herself; a woman with her own career and opinions, personality traits, hobbies, and family, rather than being defined by the word patient, which seemed to overshadow everything else. This perspective has stuck with me, and as I worked on this research, I found myself hesitant about what word to use. In one of my early papers, I tried using the term 'participants' instead of 'patients', but one of the reviewers strongly opposed that approach and insisted on the conventional language. Consequently, I have ended up using the word albeit somewhat reluctantly in my published papers.

In this cover text, however, I have taken the liberty to use alternative terms when appropriate, referring to individuals as people, persons, humans, or individuals seeking care. Sometimes I may call them people with lived experience, and at least once, I used the term ‘experts’. Ultimately, they are simply people. Moving away from the word patient acknowledges that individuals are not solely defined by their medical conditions or interactions with healthcare professionals. It is not about distinguishing between ‘all the patients’ and ‘everyone else’, but simply about ‘all the people’. Language plays a critical role in shaping perspectives and power dynamics in discussions about healthcare and digital health technologies. Using the term ‘patient’ creates a subtle divide between that person and ‘us’. As healthcare increasingly incorporates digital health technologies and person-centred approaches, we must shift toward more inclusive terminology that reflects individuals’ agency, lived experiences, and diverse interactions with healthcare systems. That said, I have also recognised that the term ‘patient’ can sometimes be necessary to avoid overcomplicating discussions. I am particularly interested in the concept of human flourishing, especially within healthcare. I argue that it can be beneficial to think about ‘patient-flourishing’, which then refers to how individuals who are patients, hopefully temporarily, can thrive within the context of their illnesses, allowing for growth within the disease boundaries. Conceptualising patient flourishing herein has also liberated the notion of patient in a sense, as it has the notion of empowerment embedded into the concept itself. This shift in perspective aligns with co-design principles, where individuals engage actively in shaping their own care, contributing insights, and co-creating digital solutions (Sanders & Stappers, 2008; Rowe et al., 2020). Such a linguistic and conceptual shift is particularly relevant in IS research, where people’s interactions with wearable devices, apps, platforms, and other technologies extend beyond traditional design and increasingly focus on people.

Patient empowerment has been conceptualised in various ways: as both a process and a goal, and at both the individual and societal levels. In this thesis, I adopt an individual perspective on patient empowerment, emphasising it as an ongoing process rather than a fixed outcome. This choice of definition is rooted in two key considerations: (i) one of the main findings of the thesis, particularly in the fourth paper, where it was found to be more meaningful to conduct individual data analysis for people with serious mental illness. Given this result, it is more appropriate to view empowerment as an individual phenomenon. Exploring patient empowerment from a broader societal perspective remains a valuable avenue for future research; (ii) the understanding of empowerment as a continuum rather than a final state. Since individuals progress at different rates, framing empowerment as a process rather than a binary categorisation is a more equitable approach, and better aligns with the broader aim of supporting patient flourishing.

As a researcher, one of the most significant revelations for me has been the depth and richness of qualitative data. Engaging with the patients in our research cohort through interviews was an incredibly rewarding experience, allowing for the opportunity to have conversations in which patients openly shared their treatment journeys, their lives before and after the intervention, and their personal reflections, which was invaluable. Iteratively analysing these interviews further highlighted the richness of the data, deepening my understanding of the participants' experiences in ways that other methods cannot capture.

Chapter 7

Conclusion

This thesis outlines the integration of digital health technologies in mental healthcare, focusing on human flourishing through four appended papers and this cover text. In general, this research contributes to the field of IS and, in particular, to the growing discourse on digital mental health by emphasising the role of personal datafication, co-design, and the potential of digital health technologies to support patient empowerment through self-efficacy, as well as patient flourishing.

This thesis demonstrates that when patients are granted access to their health data and are able to engage with it on their own terms, they often experience a sense of empowerment that can support their capacity to flourish within the constraints of their condition. The patients I worked with during the course of this research generally presented a positive attitude toward reflecting on their mental health through a mobile app, although they commonly forgot to do the daily survey, indicating that reminders or notifications may play a supportive role in sustaining engagement. Moreover, involving patients in co-design processes can further contribute to patient flourishing by promoting agency and relevance. For researchers, engaging healthcare professionals as co-design partners is equally critical. Such collaboration fosters a sense of shared ownership, which is essential for the continuity and long-term integration of developed tools. At the same time, attention must be paid to both the data work and the somatic experiences required of patients, as these factors may also present difficult burdens. During data collection, maintaining strong communication and offering appropriate support to patients is essential. Recognising patients as experts in their own lives means not only valuing their contributions, but also being mindful of the tone and language used when working with individuals with lived experience. In addition, this thesis demonstrates that personalised analysis of wearable health data is essential, as individual fluctuations offer more insight than group trends.

This research delivers three practical contributions to the field of digital mental health through the development of two innovative digital health technologies (the app and the platform) and a novel approach that collectively aims to enhance the treatment and human flourishing of individuals with serious mental health conditions. The outcome of enhancing the treatment and overall wellbeing of individuals with serious mental health conditions by combining the use of an app, smartwatches, and our platform, along with regular meetings for support. The practical contributions can be summarised as follows: (i) app: The app prompts patients to answer daily wellness questions. It serves not only as a tool for tracking mental health status but also promotes reflection and self-awareness, allowing individuals to better understand their mental health fluctuations, potentially enhancing human flourishing. (ii) platform: The platform integrates data from smartwatches and a mobile app, in the patient perspective of the platform by visualizing the collected data in a clear way; and also providing healthcare professionals their perspective with a comprehensive yet direct way to monitor this data, offering valuable insights that can inform treatment decisions and provide support. (iii) data-driven approach: The data-driven approach constitutes another practical contribution by combining subjective and objective data, as well as qualitative methods with data-driven approaches; this approach provides a comprehensive understanding of the nuanced experiences of patients with mental health conditions. The data-driven approach emphasises individualisation through personalised analysis and actively fosters patient flourishing.

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Appendix A

Publication I: A novel approach in psychiatric healthcare: co-designing a digital platform

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A novel approach in psychiatric healthcare: co-designing a digital platform

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Abstract

Purpose – This paper aims to focus on the involvement of mental healthcare professionals in a co-design process of a digital healthcare platform. Many people with severe mental disorders need constant support and monitoring, and with long waiting lists and scarce resources in mental healthcare, there is a dire need for innovative digital solutions to counteract those issues. This paper elaborates on a co-design process of a digital platform and mobile app designed for people with mental disorders. The platform primarily considers two perspectives: i) the patients and ii) the healthcare professionals.

Design/methodology/approach – This paper is based on canonical action research, where the co-design involvement with 13 healthcare professionals is analyzed and their interactions with three primary scenarios are focused.

Findings – The main contribution of this paper is three co-design principles: i) clarity and information accessibility regarding the patient's side, ii) efficiency and flexibility when it comes to the healthcare professional's side and iii) a notification function in the mobile application.

Originality/value – The theoretical contribution is the conceptualization of the three co-design principles that others can use when designing digital platforms in healthcare in general and psychiatric care in particular. The practical contributions are firstly outlined through the co-design process itself, where scenarios to guide the work are used, and secondly, the improvements made in the digital platform derived from the results of the co-design process.

Keywords Co-design, Digital platforms, Mental healthcare, Data-driven healthcare, Psychiatric healthcare, Information systems

Paper type Research paper

Corrigendum: It has come to the attention of the publisher that the article Sigurðardóttir, S.G., Óskarsdóttir, M., Ingimarsson, O. and Islind, A.S. (2023), "A novel approach in psychiatric healthcare: co-designing a digital platform", *Journal of Workplace Learning*, Vol. ahead-of-print No. ahead-of-print. https://doi.org/10.1108/JWL-11-2022-0149 did not include full details of all affiliation details at initial submission.

Our guidelines state that the ScholarOne record must accurately include all affiliation details at initial submission.

Ingimarsson, O.'s affiliation has been amended to include School of Health Sciences, University of Iceland, Reykjavík, Iceland as a second affiliation. This has now been amended in the online version of the paper.

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Introduction

A large portion of patients with severe mental illness need extensive support and care. However, the resources in mental healthcare are scarce, and support needs to be structured and delivered more innovatively. Digital mental health (i.e. digital platforms or similar digital tools and interventions to support and improve the care delivery of mental health digitally) has been identified as a potential way to improve reach and access to healthcare resources for the patient, at a relatively low cost (Bevan Jones *et al.*, 2020). Moreover, digital mental health has been outlined as a way for healthcare professionals to attend to their patients at a distance through a data-driven approach (Sigurðardóttir *et al.*, 2022b; Davenport *et al.*, 2019). A recent survey of healthcare professionals who work with individuals in early course psychosis showed that most professionals felt they would benefit from and showed interest in receiving digital skills training (Camacho and Torous, 2021). One of the issues with implementing digital health interventions for people with psychosis or bipolar disorder (BD) is negative attitudes and skepticism of the health care professionals, resulting in lack of motivation to engage with the digital interventions. One possible way to address that problem is to involve healthcare professionals in the design process (Aref-Adib *et al.*, 2019). Across various healthcare domains, the design and development of digital platforms using co-design processes with the patients' needs in mind has proven to be successful (O'Brien *et al.* (2021). However, most of the literature focuses on the needs of the patients (Schueller *et al.*, 2019). More specifically, the literature on co-design often focuses on one specific type of end-user, whereas within healthcare in general and in mental health in particular, there are two equally important partners to consider: the patients and the healthcare professionals (Islind *et al.*, 2019). In light of the scarce literature on the healthcare professionals' side, this paper contributes to the gap in the literature regarding co-designing digital platforms for supporting digital mental health with the healthcare professionals and their needs in focus. We aim for an integration of the digital platform to function seamlessly within the pre-existing work of healthcare professionals (Islind and Lundh Snis, 2018).

Canonical action research (CAR) is a method that allows for interventions as a part of the research. The study plan can also evolve throughout the research period, allowing researchers to elevate the collaboration with the stakeholders in the project during the research interval. Changes are allowed both on an individual level and on an organizational level. The collaborators are then able to reflect on the outcome of the research together and use what they learned to evoke changes inside the organization, but one of the focal points in CAR is to share the findings in the academic literature (Davison *et al.*, 2004).

In this paper, we report on a CAR study focusing on the design and development of a digital platform called DataWell (hereafter "platform" or "DataWell"), which takes into consideration the aforementioned two key perspectives: on the one hand, the patients [reported elsewhere (Sigurðardóttir *et al.*, 2022a)] and on the other hand the healthcare professionals. We have primarily worked with one unit that treats young adults with early-stage schizophrenia spectrum disorders. The main focus of this paper is the co-design process of that platform and how it supports the work of the healthcare professionals. The treatment, which classifies as early intervention, is personalized but typically combined with appropriate medication and other suitable interventions, i.e. consultations and support from healthcare professionals, regular exercise with guidance or occupational therapy. Before entering into this CAR study, which has now been ongoing for two years, the treatment was delivered in a manual, analogue, on-site format. In this project, we facilitate intervention in the treatment by providing patients in the study with a smartwatch and a mobile app that we have designed and developed. The smartwatch gathers objective data (e.g. heart rate, step count, elevation and sleep), and the mobile app asks daily mental and physical status questions for complementary subjective data. The data flows into the DataWell platform and is visualized there to aid the healthcare professionals at the unit in getting a more comprehensive overview of their patients' conditions.

Therefore, this paper aims to study the co-design process, focusing on the needs of healthcare professionals. To do so, we explore the research question:

> *RQ1.* What design principles can be derived from a co-design process of a digital platform to enable digital mental health with psychiatric healthcare professionals?

The main contributions are twofold. Firstly, the theoretical contribution consists of three design principles we suggest others consider when designing similar platforms to support digital mental health. Secondly, the practical contributions are both the co-design process, where we used scenarios to guide the work, and the improvements they led to in the platform.

Theoretical background

Mental disorders

Mental disorders affect individuals and societies worldwide, and the full extent of the impact is not easily measured (Dattani *et al.*, 2021). The life expectancy of individuals with mental disorders is lower than that of the general population, and living with a mental disorder can hinder patients from being active members of society. The estimated mental health-related burden accounts for 32.4% of years lived with disability (YLD), out of all YLDs' in the world (Vigo *et al.*, 2016). Schizophrenia and BD are two serious mental illnesses that are often difficult to manage and tend to require long-term care (Camacho and Torous, 2021; Schueller *et al.*, 2019). Schizophrenia is a serious chronic mental disorder with a reported prevalence of around 0.3% (Dattani *et al.*, 2021). The disorder can cause symptoms like delusions, hallucinations, thought disorders and negative symptoms, including lack of interest and motivation, social withdrawal and loss of personal hygiene. The life expectancy of patients with schizophrenia has been estimated to be 22.5–25 years shorter than in the general population, primarily due to poor physical health and a high suicide rate (Tiihonen *et al.*, 2009). Due to the severity of symptoms, serious life challenges like low employment rate (<20%) and high homelessness (≤20%) affect the group (McNiel *et al.*, 2005). Another severe, chronic mental disorder is BD, which has an estimated prevalence of 0.6% (Dattani *et al.*, 2021). Patients with BD often experience extreme mood and activity fluctuations. They may also have trouble sleeping and performing daily tasks. (Mansell *et al.*, 2007). Research suggests that increased physical activity can improve well-being for patients with schizophrenia and BD (Callaghan, 2004).

Digital mental health

Healthcare increasingly relies on digital technologies, and research interest reflects that. A systematic literature review found that in 2017, 37 papers were published on the topic of digital technologies and healthcare. However, the number of publications increased significantly over the next few years, with 147 articles published in 2021 (Sikandar *et al.*, 2022). Despite important voices raised regarding digitalizing the structured tasks and leaving the humanistic aspects of the care work un-digitalized (Susskind and Susskind, 2015), recent work has both shown that digital work within healthcare provides an important way for reallocation of resources (Vallo Hult, 2021) and shown that the work within psychiatric care can benefit from increased innovation, that digital mental health services can be delivered successfully online (Titov *et al.*, 2019) and that they can be complimentary but not intended to replace human interaction.

Software is often developed with little contribution from the expected software users, leading to time and resources being spent on less feasible features at the cost of attributes that mean more to the actual users (Lárusdóttir, 2009; Slattery *et al.*, 2020). Co-design, which stands for collaborative design, is the act of including different stakeholders in an iterative process of designing and developing software (Eyles *et al.*, 2016).

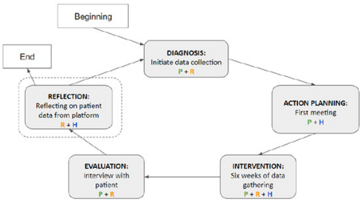
Digital platforms facilitate a connection between different stakeholders, such as communication on social media platforms or conducting business transactions on platforms like Airbnb. Moreover, they enable the sharing of health data to support healthcare. One general piece of advice from a research agenda on digital platforms is to define what digital platform means explicitly. In this paper, we rely on a sociotechnical definition: technical elements (of software and hardware) and associated organizational processes and standards (De Reuver *et al.*, 2018). Additionally, digital platforms have been studied as an integrated part of healthcare, as Islind and Lundh Snis (2018) and Vallo Hult *et al.* (2020) show.

Aledavood *et al.* (2019) described the prototype platform Niima intended for psychiatry. They recommended that researchers interested in platforms for mental health keep in mind flexibility of access control and data sources, which are helpful observations because research on platforms in the field is limited and the flexibility allows for incorporation of new angles (e.g. data sources, stakeholders). They also highlighted the importance of privacy protection.

Co-design is becoming increasingly popular in healthcare platform design, with evidence indicating that it improves person-centeredness (Rowe *et al.*, 2020). Boundary objects are tools, ideas or other things that can create a bridge between people with different backgrounds or professions. Boundary objects are often used systematically to connect people who have computer knowledge (i.e. developers) to people who do not (i.e. potential users). Boundary objects have been used successfully to co-design healthcare platforms (Islind *et al.*, 2019). We acknowledge what the literature underlines: the need to be mindful of the power differences between patients and healthcare professionals.

Research approach

CAR is an iterative research approach to conducting an empirical study. CAR entails that the collaborators of the study analyze the problem area to arrive at a theory which outlines the foundation for change in how collaborators interpret the results (Davison *et al.*, 2004), and this paper, which is an extension of a previous paper (Sigurðardóttir *et al.*, 2022b), is based on findings derived from a CAR study. Collaborators in this context are the organization (here, the psychiatric unit at the hospital) and the researchers. The aim of the co-design process reported herein is to elevate and complement the already existing service and to enhance the design features of the platform, alongside healthcare professionals.



When?	What?	Who?
Diagnosis	Watch and app to patient, initiate data collection	Patient and researcher
Action planning	First meeting	Patient and healthcare professionals
Intervention	Six weeks of data gathering with data streaming to platform to be looked at by healthcare professional	Patient, researcher and healthcare professionals
Evaluation	Interview with patient	Patient and researcher
Reflection	Meeting and chat between healthcare professionals and researchers, using patient data from platform	Healthcare professionals and researcher

Figure 1.
Left: The iterative CAR process; right: phase, description and key characters, meeting the CAR principles

Notes: This paper focuses on the "reflection" phase. After the first reflection stage, either the CAR study ends, or continues through another cycle

Source: The figures in the article were created by the authors for the purpose of this publication, and they are not based on any previously published image

CAR builds on change-driven interventions, which has become a widespread approach to study the effects of digitalization. The approach includes five principles that we relied on to design our research approach (Davison *et al.*, 2004; Sigurðardóttir *et al.*, 2022b). Building on these principles, we have adopted the model proposed by Davison *et al.* (2004) in our context to describe the research process as a whole within our CAR study (see Figure 1 below, the subset of data collected for this paper is labelled "reflection").

The intervention in this study is twofold:

1. for patients, it includes carrying a smartwatch that collects health data, answering daily well-being questions and monitoring their own health data; and
2. for healthcare professional, it includes the changes made in the platform to better facilitate the needs of healthcare professionals.

The latter part outlines the focus of this paper. The patient data used for illustrative purposes at the workshop originates from DataWell, gathered by the patients treated at the unit. Researcher (R) is the first author of this paper, and patient (P) is any patient included in the study (see Figure 1).

Data gathering through a co-design process

The empirical data is derived from the reflection phase of the iterative, cyclic process presented in Figure 1. The data consists of transcripts from a workshop with 13 healthcare professionals (H) at an Icelandic hospital, the psychiatric unit that treats patients with first-episode psychosis. The CAR study is ongoing, and the platform has been in design and development for four years, and active participation by the healthcare unit dates back two years (ethical approval number 55/2020). We wanted the platform to receive, store and visualize both subjective and objective health data. The app was designed to display questions on well-being, collect answers and send data into the platform. Iceland was the natural study site of choice based on two main reasons:

1. due to its closeness to researchers; and
2. due to a dire need for innovative solutions like digital mental health in psychiatric care based on low current number of psychiatrists and low prospect of newcomers to the profession.

The healthcare professionals had been presented with the platform before, but the reflection phase, from which we draw data for this paper, was meant specifically to facilitate in-depth feedback from them. We divided the healthcare professionals into three groups. The three scenarios included logging in and using DataWell (see Figure 2) and required interaction among partakers. They logged into the platform during each scenario engagement (15 min) and engaged with one scenario at a time, resulting in 39 scenario engagements from the 13 healthcare professionals at the unit (psychiatrists, sport scientists and case managers). The

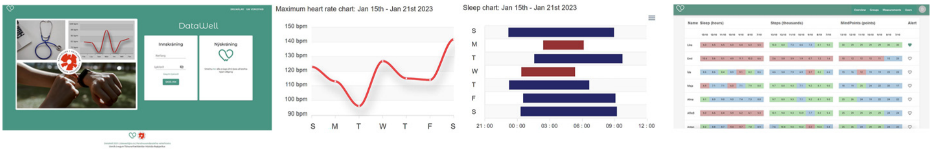


Figure 2.
Left: Snapshot of the login page of DataWell; middle: heart rate visualization and sleep data visualization from the platform; right: snapshot from the healthcare professionals' perspective of DataWell, an overview of five patient's data (their names are pseudonyms)

Source: The figures in the article were created by the authors, for the purpose of this publication, and they are not based on any previously published image

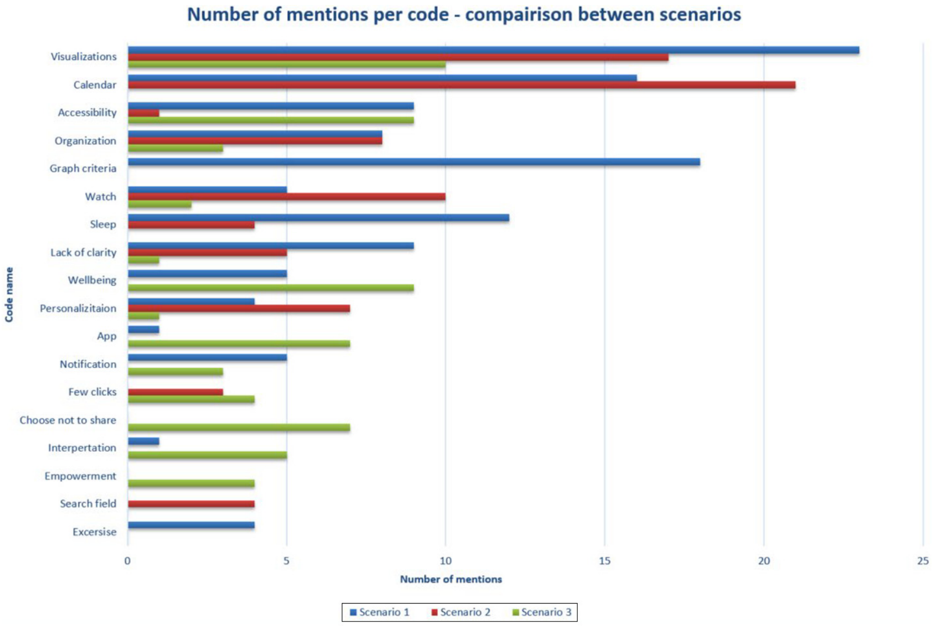


Figure 3. The bar charts describe the qualitative content analysis

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workshop was voice recorded and transcribed verbatim (46 pages). The analysis of the empirical data was done through content analysis to interpret the empirical data using an inductive approach (Bryman and Cramer, 2012). We used the qualitative data analysis software NVivo (release 1.7) to categorize the comments by content, assigning each comment a descriptive code. Subsequently, we reviewed the comments and codes to merge similar codes. Finally, we created a visualization of the number of comments marked with each code (see Figure 3).

The details of the scenarios were as follows:

(1) Scenario 1. You are Joe, the patient. You are going to meet a healthcare professional. You know that you will be asked some questions when you meet. You decide to log into DataWell to have information ready to give your healthcare professional insight into how you have been doing lately.
    - Log into DataWell with Joe's username and password.
    - Find out how many steps Joe took yesterday.
    - Find out how many steps Joe took Monday 4th of October.
    - Find out when Joe went to sleep last Thursday.
    - Find out how Joe slept last night?
    - Change Joe's name in the platform.
    - Explore the platform.
    - How could the look and design of the platform be more accessible for patients?
    - What sort of addition to the platform could be useful for patients?

(2) Scenario 2. You are Otto, the psychiatrist. You have shown up at work. You do not have a lot of time, but you want a little overview of your patients' statuses so you know what to expect today. Your patients are on Team 2.
    - Find Team 2 and pull heart rate data for Tim, Antonia and Alex for the period July 19-25. Take a look at Tim's sleep data for the same period. What was his step count for those days?
    - How could the look and design of the platform be more accessible for a healthcare professional?
    - What sort of addition to the platform could be useful for healthcare professionals?

(3) Scenario 3. The empty paper. Here we ask: "How do you feel that the look and feel of a platform like this should be to best support your type of support to patients?"

Empirical setting

Landspítali University Hospital is Iceland's largest hospital, with a Psychiatric Services department that runs a Psychiatric Emergency Room and treats patients with mental illnesses such as schizophrenia and BD. The patients herein either have schizophrenia or BD. The study has included 21 patients, so far, who wore a smartwatch for six weeks, answered daily questions in a mobile app and completed a paper questionnaire three times (more details in Sigurðardóttir *et al.*, 2022a, 2022b). Healthcare professionals monitored the data on the platform, and patients reflected on their experience in a semi-structured interview.

We designed and developed the platform DataWell to enable digital mental health at Landspítali. The platform has two perspectives: i) the patients and ii) the healthcare professionals (see Figure 2). Patients can use their side of the platform to monitor their own health data, both from the smartwatch and the app, and are able to use the visualizations to facilitate their communication with healthcare professionals. The healthcare professionals' perspective displays an overview of their designated patients, with the possibility of getting a more detailed overview of individual patients. In this overall research project, we, in collaboration with Landspítali University Hospital, are using the DataWell platform and app to study the feasibility of platforms supporting psychiatric care. The platform and app are under further development through a co-design approach, both with patients and, as this paper focuses on, with the healthcare professionals treating the patients.

After obtaining a vast body of knowledge through the intervention with patients, it was time to reflect on the platform with the healthcare professionals working with the patients, as elaborated on below.

Results

The data that we gathered from the workshop included valuable feedback from the healthcare professionals, which we have summarized in the three design principles mentioned above. Moreover, from our data, we conclude that the healthcare professional's participation in co-design brings a sense of inclusion that we recognize as a supportive factor for the practical use of the platform. Below is a bar chart from the final set of NVivo codes, excluding codes mentioned three times or less.

Scenario 1

From the first scenario, we understood that when designing platforms to fulfil a similar function, it is important to keep in mind: *clarity and information accessibility regarding the* *patient's side*. The partakers had enthusiastic conversations about how they believed the platform would best function for their patients while acting as patients. The healthcare professionals are in a unique position to act as proxies for their patients since they know them well and have insights into their history as well as their medical condition. Even though we (the authors) also recognize the importance of patients themselves having a say in the design and development of the platform, this paper takes the aforementioned view of the healthcare professional's involvement.

The most frequent code was "visualization" and thereafter "calendar" (see Figure 3). This might be rooted in the phrasing of the assignment, since healthcare professionals were instructed to look for the "patient" activity (sleep, steps, etc.) during days chosen from a calendar. Nevertheless, the healthcare professionals expressed that when it came to patient visualizations, the focus should be on the criteria, in the sense that it should be made clear to the user what the graphs represent. On a similar note, sentences marked with the code "graph criteria" were quite frequent, as the chart below shows. Following are a few quotes in that regard, mostly concerning sleep stages: "I need some criteria here to know if this is good" as well as: "Can you see a scale somewhere, that shows what getting 88 [in sleep score] means?" Here, the healthcare professionals were discussing the information needed to grasp the visualizations of the data. A similar quote was: "What happens if you hover over the sleep stages?" where the healthcare professionals are trying to understand the functions of the platform. Another quote, also related to visualization of sleep data, was: "I need to know what the criterion is. You know, how much we want [to define as] deep, how much is REM, how much you know?" afterwards, a healthcare professional asked: "Did anyone find a rating on the quality of sleep?" The code "sleep" also appeared frequently, followed by sentences marked "lack of clarity", underlining the partakers' opinion that clarity is an important advantage for this particular patient group.

Some interesting comments on clarity in the visualizations were highlighted: "I think this is not descriptive enough, at least to someone who doesn't know what this [i.e., average heartrate] means". The healthcare professional herein is trying to understand the underlying meaning and use the visualizations better. Sentences that were coded as "Organization" referred to arrangements of functions, data and interface elements in the platform, such as where components should be located, how they should look, their operations, etc. One healthcare professional for instance said: "You should be able to keep track of this just in one place" and a similar quote was uttered regarding how the weeks in the calendar should be structured: "No, you know that the week always starts on Monday. So [it should be the case that] if you choose maybe the fifteenth, then that whole week always appears, you know". The analysis also showed significant interest in the topic of "watch", reflecting their interest towards smartwatches in practice: "So you never know exactly how accurate these watches are". and in regard to sleep and watches "Because you know, with my watch, not that I listen to it 100%, but with that I know that light sleep means I was not laying still". Furthermore, "Personalization" was a visible topic, stressing the need for personalization of some parts of the platform to tailor it to own interests or needs. Furthermore, there was an interest in the topic of "Accessibility", highlighting the need for clarity regarding location of information on the platform. Overall, they seemed satisfied with the DataWell platform: "This is a very convenient interface. This is very simple and convenient". Lastly, the code "wellbeing" was an important one, which is illustrative of the high level of care and concern they have for their patients (see Figure 3 for clarification).

Scenario 2

From Scenario 2, we encountered the design principle of efficiency and *flexibility when it comes to the healthcare professional's side*. The partakers of all three groups had a fruitful conversation about how the platform could best work for healthcare professionals like Otto. Sentences we coded with “Visualization” and “Calendar” were the most common. Moreover, the partakers did emphasize that the visualizations on the healthcare professionals’ side of the platform needed to be descriptive and comprehensive: “Do we have a holistic overview somewhere? You know, where you can see sleep and steps during the same day?”. Highlighting the need for healthcare professionals to access information quickly: “I just want to select one week and get an overview of everything”. They had good conversations on the calendar structure, as they wanted to choose how many days to visualize at a time and not a fixed week-long period, like it is currently on the platform. Navigating the platform, they started to realize that this is something they find important: “Look, I couldn’t choose an end date”. They discussed this further and another healthcare professional agreed with the words “Maybe you want to see ten days and not nine”. Yet another agreed, saying: “Yes. You should decide the date interval yourself”. Sentences coded with the keyword “Watch” also appeared frequently, establishing partakers’ interest in the objective data coming from the smartwatches in the study. One of the comments was about the data sent from the watches to the platform, on exercises: “There is some understanding in the watch of how you are using your body”. Brainstorming on how they could get the most information out of the platform, one of the partakers said: “If it were possible, to show in this column that he didn’t have the watch”. and agreeing that removing the watch could be information that healthcare professionals would want access to: “Would it be possible to see how much [i.e., how many hours during the day] the person was wearing the watch?”. The code “Organization” also came up frequently, meaning that they had opinions on the structure of the platform, where certain key elements (like a patient list or step overview) should be, and how tasks should be executed, speaking directly to the efficiency and flexibility design principle. Consequently, one of the observations was: “But is it somehow possible to change what people you see here?” Discussing how this combined would benefit them best, a participant explained: “it simplifies things to know that the interface we [i.e., healthcare professionals] get is actually exactly the same interface they [i.e., patients] get”. The code “Few clicks” was apparent (this was a subject that was revisited in Scenario 3), i.e.: “I, as a healthcare professional, feel that this should be simple and that you should be able to find information fast. I would not feel like clicking too much and working with the data because then I could just as easily ask the patient: ‘How did you sleep?’” and on a similar note, one of her coworkers simply added: “Also maybe, since we are thinking about healthcare professionals, make sure that there are not too many mouse clicks, so you don’t spend too much time on it”. “Sleep” also had several hits, for example concerning a patient irregular sleeping patterns: “But do you think this interval of the day that he is sleeping on, should this be flagged?” The code “Personalization” comes next, where partakers underlined the need for flexibility in the platform, that they as healthcare professionals could adapt the platform to their needs, i.e. regarding the calendar feature: “I really think that this could be fixed [. . .] Change it so that you can insert a date interval, from one date to another”. “Lack of clarity” came up a few times and has a practical value, things that could become more coherent within the platform. Moreover, sentences including a “search field” came up, directly connected to the efficiency principle: “So, as I was saying, it would be nice to be able to search by name”. (See Figure 3 for details.)

Scenario 3

In Scenario 3, we encountered the third design principle: *a notification function in the mobile application.* This scenario was more open, and the results were interesting but more scattered (see Figure 3 for density). Again, “visualizations” was popular. One of the healthcare professionals stated:

> I wonder precisely in this context whether it would be possible to highlight somehow when things are going well. You know, you went for a walk here last week, how did you feel then?

Many observations related to general well-being of patients but also to the code “interpretation”. One reflection from a healthcare professional was:

> At least they have some data. You know, I see here that you did not sleep much. What was bothering you? Was it anxiety or what was it? That’s kind of the starting point in a lot of conversations.

Some healthcare professionals mentioned that it could support the treatment if it was possible to use DataWell as an information platform: “How about being able to add coping strategies, you know, if you are not sleeping well, we could put in advice on what you can do to help you sleep”. Another partaker added: “I would like the platform to have notifications; our people (i.e., patients) tend to forget things”. and this observation got a lot of support, like this one: “I think it needs to be simple and airtight, kind of. And preferably with a notification because our people repeatedly forget”.

Although not directly related to our main contributions, there is one relevant observation that we believe outlines a strong practical contribution and is therefore worth mentioning. It is the idea of including a communication path between the two sides of the platform: “Maybe healthcare professionals should be able to add something in there, e.g., if a patient needs to submit a questionnaire”. In addition, the healthcare professionals highlighted the need to choose not to share data:

> I think it is important, since we want to empower patients, that they can turn off data sharing. That is: “now X is not allowed to see how I slept” or: “I do not want to share data for this particular day”.

This is relevant particularly as it relates to general well-being and personal privacy of the patients.

Discussion

This paper describes a co-design process of a digital mental health platform. We reflect on a co-design process with 13 healthcare professionals in a CAR project, where we used scenarios as boundary objects in a co-design process.

As stated early in this paper, resources in mental healthcare are limited, and digitalization is one of the ways that have been pointed out to counteract that problem (Bevan Jones *et al.*, 2020). The healthcare professionals that partook in our co-design and scenario engagement pointed out the platform as a potential supplement to the current treatment and suggested that having a communication path via an end-to-end encrypted chat in DataWell would be feasible. Furthermore, they raised the importance of enabling a function to share files with their patients through the platform, which might be helpful for some patients at particular points in time. If that function was implemented, it would enhance the potential for better time efficiency, enabling the healthcare professionals to have more time to attend to other, more urgent matters (Sigurðardóttir *et al.*, 2022b). This speaks directly to one of the design principles derived from the co-design approach: *efficiency and flexibility when it comes to the healthcare professional’s side.*

What we derive from this paper is that co-design is good practice when it comes to the development of software for healthcare purposes, in line with Sigurðardóttir *et al.* (2022a). This type of co-design approach with healthcare professionals can be beneficial to identify points of interest from expected users on both sides, that is, patients and healthcare professionals. Through our analysis of the co-design approach, we derived a strong feeling of ownership in the way that the healthcare professionals engaged with this digital platform because they have been an integrated part of the development, also prior to the co-design workshop. As we see it, this type of approach has the potential to increase the usability, user experience and overall usage time of the platform within the organization while also securing interest for further development (Idowu and Elbanna, 2020; Islind *et al.*, 2019). Moreover, we encourage others to use scenarios as an integrated part of co-design, as they can trigger discussions on the topic and beyond. Scenarios can in that sense be boundary objects as they connect partakers through a common project for discussion, and we found that to be useful in practice, which is in agreement with what the literature has stated before (Islind *et al.*, 2019). Scenarios can, in that context, be intraprofessional boundary objects when they create that bridge between members of the same profession, but they can also be interprofessional when scenarios provide a common ground between healthcare professionals and researchers.

Over time, we presume that having access to the data on the digital platform could change the way healthcare professionals interpret the status of their patients and, thereby, affect the way clinical decisions are made, towards a data-driven decision-making process. That assumption is in line with previous literature on the topic (Eyles *et al.*, 2016; Islind *et al.*, 2019; Larkin *et al.*, 2015; Slattery *et al.*, 2020). More specifically, this novel approach has the potential to help healthcare professionals determine the appropriate dosage of hypnotics by relying on longitudinal sleep data, in contrast to relying only on a patient's recollection of their sleep quality.

To sum up, from the co-design process outlined in this paper, we derive both practical and theoretical contributions. The practical contributions are both the platform itself, with the improvements and ideas from the co-design process, as well as the co-design approach (using scenarios as boundary objects). As discussed at the beginning of the paper, patients with mental disorders have been overlooked, and there is a need for a new approach to their treatment. We see this work as a contribution in that regard. Also, triggering the sense of inclusion between the healthcare professionals that participated in the workshop encouraged the use of the platform in practice and increased acceptance. The novel theoretical contribution is the conceptualization of the following three design principles:

1. clarity and information accessibility regarding the patient's side;
2. efficiency and flexibility when it comes to the healthcare professional's side; and
3. a notification function in the mobile application. We suggest that others consider these in their co-design processes in healthcare in general and when designing and developing digital platforms for digital mental health in particular.

Limitations and future work

On the practical side, the platform was co-designed for the dual purpose of aiding the work and decision-making process of the healthcare professionals when caring for patients with serious mental illnesses while also functioning as a self-care platform for these patients. The patients that were included in the study have all been diagnosed with severe mental illnesses, and hence their needs and the healthcare professionals needs derived from this case may differ from the needs of others dealing with less severe mental illnesses. Here, future work could include testing the co-design method and applying our design principles and scenarios with different patients and healthcare professionals to validate the results and extend them to other types of mental disorders or other types of platforms.

On the research side, the results of this co-design approach are specific to digital mental health and cannot necessarily be generalized to other healthcare delivery. Future work will include further development of the co-design method and design principles, together with an analysis of the data collected by the patients, to shed light on the mix between subjective and objective data for augmenting the future digital mental health.

Conclusion

Healthcare is increasingly working towards modernizing approaches to patient care. As part of that discourse, we designed and developed a platform and app to support digital mental health for individuals with serious, chronic mental disorders, with the potential to alleviate the strain on healthcare professionals in the psychiatric healthcare sector. We present findings from a co-design process with 13 healthcare professionals in a CAR project where we analyze 39 scenario engagements to derive knowledge on co-design using scenarios as boundary objects. The theoretical contribution is the conceptualization of the three co-design principles that others can use when designing digital platforms in healthcare in general and psychiatric care in particular. The practical contributions are firstly outlined through the co-design process itself, where we used scenarios to guide the work, and secondly, the improvements made in the digital platform, derived from the results of the co-design process. More specifically, in scenario number one, healthcare professionals placed themselves in the patients' shoes. The most common topics that emerged related to the comprehensibility of the platform, indicating that the healthcare professionals wanted to ensure effortless navigation for the patients. That concern was summarized in the first design principle: i) *clarity and information accessibility in regard to the patient's side*. In scenario number two, healthcare professionals reflected on their own use of the platform while busy at work to gain a quick overview of their patients' status for the day. The themes that arose revolved around time efficiency and adaptability, suggesting certain visualization types and streamlining the platform to avoid excessive clicking. Hence, the following design principle emerged: ii) *efficiency and flexibility when it comes to the healthcare professional's side*. In scenario three, the participants got no formal instructions except contemplating how a platform like this one should look and function. As a result, the discussion varied more than in the other scenarios. Nevertheless, topics related to the well-being of the patient were prominent, with an emphasis on ensuring that patients use the app to reflect on their feelings each day, preferably with a notification function within the app. As a result, the third design principle materialised: iii) *a notification function in the mobile application*. We suggest that others consider these in healthcare co-design processes, especially when developing platforms for mental health.

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Appendix B

Publication II: Collecting Data from a Mobile App and a Smartwatch Supports Treatment of Schizophrenia and Bipolar Disorder

Challenges of Trustable AI and Added-Value on Health
B. Séroussi et al. (Eds.)

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Collecting Data from a Mobile App and a Smartwatch Supports Treatment of Schizophrenia and Bipolar Disorder

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Abstract. Mental disorders affect individuals and societies around the world negatively, with the health-related burden of 32,4% out of the overall disease burden. This large part of the overall burden underlines a growing need for innovation to support the treatment of mental disorders like schizophrenia and bipolar disorder. This empirical study features two groups of patients; a group of nine patients diagnosed with bipolar disorder and a group of twelve patients diagnosed with schizophrenia. The patients in the study carry a smartwatch for six weeks, continuously collecting data into a digital health platform. Additionally, they answer five daily wellbeing questions in a mobile app. To supplement that data, they also answer a questionnaire three times over the interval and at the end of the period they attend a semi-structured interview. We offer four main aspects to consider for PGHD in mental health: i) sharing data easily with healthcare professionals, ii) being able to engage with your own PGHD, iii) the watch use can help the patients regulate routine in their daily life, iv) tonality and phrasing.

Keywords. Schizophrenia, Bipolar Disorder, Digital Platform, mHealth, eHealth, Smartwatch, Mobile Application, Mental Health

1. Introduction

Mental disorders cause individuals and societies around the world effects that cannot be measured easily. The estimated mental health-related burden accounts for 32.4% of years lived with disability (YLD) of all YLDs' in the world [1], not to mention the often overlooked effects mental illness can have on close family and friends. One of the more severe, chronic mental disorders is bipolar disorder (BD), which has a reported prevalence of 0.6% [2]. Patients diagnosed with BD experience extreme mood swings and activity fluctuations from being hyperactive to total inactivity. Patients with BD generally suffer from sleeping difficulties and may struggle with day-to-day tasks [3]. Schizophrenia is another serious chronic mental disorder with a reported prevalence of 0.3% [2]. The disorder causes extensive paranoia and delusions that affect the quality of life negatively. Schizophrenia patients also face various life challenges, such as a low employment rate (below 20%) and high homelessness (up to 20%) [4]. Research suggests that increased

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physical activity can improve wellbeing for patients with schizophrenia as well as BD [5]. In fact, these two disorders are often researched together due to similarities in symptoms [6].

Digital platform (hereafter "platform") is essentially software that facilitates a connection between user’s needs and what a service provider has to offer. The supply and use of platforms is becoming increasingly established, for example in healthcare [7]. In a healthcare setting, a platform can potentially create a bridge between a patient and healthcare professionals through monitoring of patient-generated health data (PGHD). PGHD in a platform setting encompasses data produced and collected by patients, which is brought into a healthcare platform to enhance the quality of care. PGHD is any clinically relevant data collected and used by patients and either shared or not shared with healthcare professionals, and PGHD can in some sense contribute to increased wellbeing or health outcome. A study on PGHD from wearables for self-monitoring reports that patients believed that using wearables to regulate their symptoms has the potential of improving the overview of their condition [8]. In this project we collect PGHD with smart devices; both automatically (with a smartwatch) and manually via a mobile app. All data is collected and visualized in a platform.

This paper is based on an empirical study that features two groups of care recipients (hereinafter patients) who are under medical care; one group diagnosed with BD and the other group with schizophrenia. The interventions with the patients include increased physical activity, which has proven effective for treatment of the two disorders. Patients also attend structured consultations with a healthcare professional where they are asked, among other things, to assess their quality of sleep. Our project entails the design of a platform that enables health data to be visualized and accessed, to involve the patients to a larger extent in their own care. Through the empirical, multidisciplinary research project reported on herein, our goal is to provide insights into both the clinical value as well as the increasingly important value of PGHD in mental healthcare. From that, we seek to answer the research questions: i) How should a smartwatch and a mobile app be used to support treatment of schizophrenia and BD? and, ii) how can a digital a platform function as a bridge between patients and healthcare professionals?

2. Methods

We have designed and developed a digital health platform to be used in psychiatric care, called DataWell; which reflects the use of data for wellbeing. The platform is under further development through a co-design approach in this project. Our platform combines the following PGHD types. From the a Withings Steel HR smartwatch we gather heart rate monitoring (beats per minute), sleep monitoring (sleep duration, sleep depth, interruptions), activity monitoring (estimation of ten activity types), and step count (based on distance). The sensors in question are: heart rate infrared sensor, day and night motion sensor and high precision MEMS 3-axis accelerometer [2]. A reason for choosing this particular smartwatch is their unusually low power consumption. The battery charge lasts up to 25 days, which we consider an important factor when it comes to patients with severe mental illnesses. Additionally, Withings provide accessible, structured data through an API, which is convenient when building a new platform. Although outside the scope

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[2] https://www.withings.com/eu/en/steel-hr

of this paper, it is important to mention that we have data from the electronic patients records (EPR/EHR) for two years.

The process of the data gathering is as follows. The patients who accept to partake in this six weeks study answer a questionnaire three times (week one, three and six). The questionnaire includes a collection of validated constructs to measure level of anxiety, depression severity, view towards technology, self-efficacy, empowerment, and impact of self-monitoring. The idea behind that data collection is to create a link between the outcome of the questionnaire and the way patients choose to use the platform, watch and mobile app. They carry a smartwatch for these six weeks, collecting data into our platform. They also answer five daily questions on general wellbeing in our mobile app, which we designed as a part of this project and the mobile app feeds data into the platform. During the research period, the healthcare professionals are able to monitor their patients, through the platform. Both patients and healthcare professionals attend semi-structured interviews separately at the end of the six-week period, where the focus is on user experience and usability of the platform and their view on data-driven mental health and on continuously collecting PGHD. The analytical approach for the interviews is content analysis and the results will be used to further guide the design and development of the platform. In this paper, we focus on findings from the patients. We have included 21 patients in total. Three of those dropped out during data collection due to sickness or issues related to comfort. From that, nine patients are diagnosed and treated for BD (two dropped out) and twelve patients are diagnosed and treated for schizophrenia (one dropped out). Thus, seven patients with BD and eleven with schizophrenia have completed all data collections steps.

3. Results

The majority of patients felt encouraged by monitoring their data continuously and expressed interest in continuing the data collection. Meeting the patients three times over the data gathering interval, and especially the in-depth interview at the end has enabled a unique opportunity to understand the patients and how this approach affects them. One patient summarized her view with the words: “This really matters.” which is encouraging for the continuation of the study.

Overall, we identify four main findings. *Firstly,* sharing data with healthcare professionals seems to come quite easily to them. Most of the patients are used to sharing all sorts of things with healthcare professionals and feel that the data sharing in this experiment is no invasion, but rather supportive. On that note, another patient shared: “It’s good that healthcare professionals have access to the data, because they’re just trying to help you.”

Secondly, an important finding has to do with the empowerment of the patient, a feeling that many of them describe. One patient said: “Seeing your own health data is a good feeling.”, while another shared: “It encourages you to see an overview of the steps.” What can be learned from that is that observing and monitoring one’s own data helps in the empowerment process.

Thirdly, is that the usage of the watches is different between individuals. One patient described his opinion on how the experience with the watch has been like: “I’m not quite sure, but it was really new to me because I have not worn anything like this before that measures heart rate, steps and sleep." Continuing, now on his view on if there have been some changes since the start of data gathering: "Yeah, a little bit at least, I'm going to bed at the right time now." In general, some patients like to monitor their data closely, see the steps "coming in" over the course of the day and reflect on them in terms of how they feel and how they're doing that day. Others want to let it rest for a few days and then see a chunk of data in the platform. This gives them context and understanding on they're feelings and the development of the disease for the days in question.

Lastly, regarding the mobile app and the way that the questions in there are formulated, we found that inclusiveness in all communication with patients and putting ourselves in the patients' shoes is truly important. One patient said: "Maybe what I got out of this was that you just reflect a little bit about how, you know you get these questions, then you wonder how was the stress today. You tune a little bit into yourself with this too." Another patient expressed gratitude and satisfaction in the phrasing of the questions in the mobile app stating that the questions were inclusive and that they addressed them as a "thinking human being" and not a "7 year old" or "someone stupid."

4. Discussion

When discussing health platforms and PGHD, it is vital to reflect on the data collected, the way the data is presented and used. To begin with, data can consist of either a few values of data points or multiple ones and the granularity of data is thereby important to consider [9]. Also, when showing trends, they can be relational, hierarchical, or a combination of the two, which is an important aspect to consider when choosing types of graphs that can help the patient understand their data. Each data entry is not an autonomous entity; rather, it is a part of an array in which data over time builds up a larger data set that can then be visualized, for the dual purpose of i) functioning as decision-support for the healthcare professionals and ii) triggering self-care and self-monitoring for patients [10]. We consider self-monitoring to be the tracking of health-related information for patients and using that information to monitor wellbeing or health systematically. Prior research has shown that using wearables for self-monitoring can introduce an increase in the activity of the consumer [11], and in this paper, we corroborate those findings by showing that wearables are by most in our patient group, considered empowering. With that in mind, when designing a health platform that takes in extensive amounts of data, we recommend that it is done in a participatory work with all stakeholders involved and especially highlight the importance of giving the patients a voice in that process. Cognitive impairment is a common observation for individuals with schizophrenia [6] and BD [12], it can result in difficulties with written information. Because of that, the way PGHD enters the conversation, and the way the data is collected, discussed and used are key aspects of this research project. Consequently, we focused on helping the patients collect the PGHD, to understand their data and to reflect on their data. From our findings we conclude that in mental healthcare, PGHD can improve the wellbeing of patients. PGHD points towards a patient perspective through patient centricity and PGHD can improve partnership with the healthcare professionals, in line with [13].

In conclusion we have derived knowledge about the kind of data that is useful in mental health services and when it proves to be an effective addition to existing clinical treatment. Our findings can be summarized and forwarded through four major aspects: i) sharing data easily with healthcare professionals is an important factor for a platform to be implemented in clinical practice, ii) being able to engage with own PGHD, empowers patients that are diagnosed with BD or schizophrenia, iii) the watch use can help the patients regulate routine in their daily life, iv) tonality and the way patients that are diagnosed with BD or schizophrenia are addressed in conversations, is vital. From our findings, we conclude that collecting PGHD into a platform outlines a key feature of future support in treatment of schizophrenia and BD.

4.1. Limitations

In this project the patients observe their own physiological health data, combined with their daily mental status, to observe trends in how their psychological health fluctuates in context with the physiological data signs. However, some patients forgot to fill out the daily survey in the mobile app, which might have caused them overlook those trends. Future work will include notifications in the mobile app, to compensate for that. Another direction in future work is to analyze if some patients show signs of dis-empowerment through an approach like this, possibly with a higher level of anxiety, stress, dropout rate, etc. Another aspect worth mentioning, is the inclusion of patients which was a considerable challenge due to their preexisting diagnosis, which renders them unable to predict what kind of day it will be; if they will be able to show up or not. There was about a 50% dropout rate during the appointments, but with perseverance of the first author when re-booking sessions multiple times, we managed to get all patients to meet with us.

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Appendix C

Publication III: Living with Technology. Data work and smartwatch data trends for patients with serious mental illnesses

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

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Living with Technology

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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 (Seiferth 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 harness 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

Patient id.	*Diagnosis*	*Interview length (in minutes)*	*Days of data collection completed*	*Comments*
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 connected 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

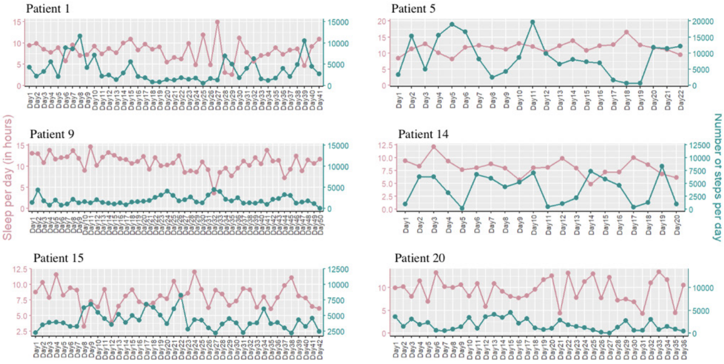

Figure 1. A grid of line plots displaying smartwatch data from six patients. The pink line represents sleep duration, while the green line represents the number of steps taken.

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 healthcare 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 (Karlgren & 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; Karlgren & 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).

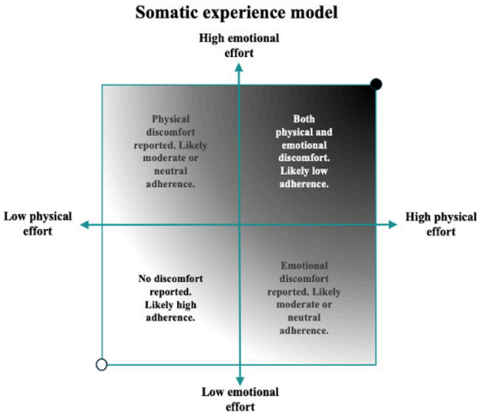

Figure 2: The somatic experience model.

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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Appendix D

Publication IV: Wearables for Good: Data-Driven Approach with and for Patients Dealing with Schizophrenia and Bipolar Disorder

ECIS 2025 Proceedings

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WEARABLES FOR GOOD: DATA-DRIVEN APPROACH WITH AND FOR PATIENTS DEALING WITH SCHIZOPHRENIA AND BIPOLAR DISORDER

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WEARABLES FOR GOOD: DATA-DRIVEN APPROACH WITH AND FOR PATIENTS DEALING WITH SCHIZOPHRENIA AND BIPOLAR DISORDER

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Abstract

Schizophrenia and bipolar disorder are among the most serious mental illnesses, and mental healthcare has yet to fully embrace digitalization. In this paper, we present action research involving twenty-one individuals who wore wearable devices for a six-week period exploring how wearables can be integrated into mental health for enhanced empowerment through a patient-centered approach. We illustrate the insights that data from wearables (e.g. heart rate, sleep, and movement) can provide for individuals with schizophrenia and bipolar disorder. Our three-fold contribution shows: (i) that self-efficacy (the belief in own ability to succeed) is an important stepping stone for empowerment, (ii) the need to focus on individual patterns when engaging with individuals with serious mental illnesses, rather than relying on group-based approaches that define more generic behavioral patterns, (iii) the dire need for IS researchers to study personal datafication in situ, through case-based, data-driven approaches to promote human flourishing in health IS.

Keywords: Digital Health, Mental Health, Wearables, Empowerment, Smartwatches.

1 Introduction

The surge of wearable technology has brought about the revolution of personal datafication, capturing our movements and interactions as digital data. Recently, wearable technology has entered healthcare, driving a significant leap forward in healthcare delivery. The integration of wearable technology has significant potential for monitoring purposes, particularly for people who receive limited care in the current healthcare system (Sheng et al., 2022). Wearable technology refers to body-worn electronic devices embedded with wireless communication abilities designed to collect and transmit user data (Goel et al., 2024). Wearable technology, also called wearables, enables real-time data monitoring, allowing healthcare providers to make timely, informed decisions without requiring patients to be physically present, supporting early interventions and a more personalized approach to healthcare delivery (Hicks, 2019). However, to maximize the impact on how wearables can be utilized for healthcare purposes, further research is needed (Köhler et al., 2024).

Wearables can yield valuable data, which could become particularly useful to better outline informed decisions. Incorporating data–such as wearable data– into decision-making processes, instead of basing decisions solely on intuition or experience, is called data-driven decision-making (Provost & Fawcett, 2013). In a healthcare setting, this can entail both institutional-level or patient-level decisions (Provost & Fawcett, 2013). Furthermore, data-driven decision-making has the potential to empower patients by enabling active participation in their own care trajectory, but in order for that to be well executed, more research is needed (Weiner et al., 2015). Wearables, in general, and data-driven decision-making, in particular, both fall under the umbrella term of personal datafication. Personal datafication refers to the movement towards responsible use of personal data for enhanced decision-making and in our paper, we contribute to that stream of literature. As the stream of literature on wearables grows, there is a simultaneous focus on preserving what makes us human. The literature deviates between a fascination with an immense volume of data and the preservation of the self. In our paper, we outline the intersection of these two streams of literature and contribute to both.

In recent years, there has been a growing interest in the field of information systems (IS) on human flourishing. Human flourishing refers to how the design of information systems can enhance a person's well-being by supporting a balanced integration of physical, emotional, social, and psychological dimensions simultaneously (Hylving et al., 2024). Data increasingly influences our everyday lives, transforming how people perceive and engage in their well-being while also creating newfound tensions between self-optimization and genuine human flourishing (Marabelli & Newell, 2023). However, individuals with severe mental disorders are not primarily driven by self-optimization but are instead more focused on quality of life. As a result, they may more easily fall into the category of those genuinely wanting to flourish, engage in self-care, and become active participants in their own lives. Personal data can promote self-awareness, and especially for people who may not have been active participants in their own lives due to illnesses for some time, it can prove valuable to learn to listen to their own body through a data-driven approach (Islind & Vallo Hult, 2022). However, the literature has also shown that tunnel vision on data-driven measures can intensify health-related issues (Baron et al., 2017). Furthermore, the literature has demonstrated the potential to increase participation in one's own life, especially for those undergoing treatment and gradually engaging in self-care and active participation following severe mental health episodes (Cella et al., 2018). However, to reach that sweet spot of focusing on human flourishing, increased participation in self-care, and embracing a more data-driven life, it is crucial to tailor such a process alongside the participants. The use of wearable devices can either hinder progress or outline an immense revolution.

In recent years, digital phenotyping has gained traction, referring to the use of digital data to curate a holistic digital view of behavioural patterns (Torous et al., 2016). The term digital phenotyping was coined by Torous et al. (2016) and has since gained influence in outlining profiles of behaviour through "moment-by-moment quantification of the individual-level human phenotype in situ using data from personal digital devices." (p. 2). Digital phenotyping has, for instance, been used to identify groups of individuals who may be at risk for specific conditions versus those who are not, with insights derived from data such as that obtained from wearables. While there are attempts to create profiles or patterns through digital phenotyping to better illustrate types of patients with psychotic disorders (e.g., Kalisperakis, 2023), there are minimal attempts to highlight the individual trades and specifics of the person. In recent years, clustering has proven impactful within IS research, demonstrating general behavioural trends using data from wearables (Biedebach et al., 2023), and while that approach is meaningful when the digital traces of data are similar, it can be less meaningful to find generic patterns, when the individuals prove as ill as those with serious mental disorders. In light of this, we aim to identify individual patterns through our analysis to highlight the meaningfulness of thinking about the individual, especially when dealing with digital traces of data that could all be seen as anomalies or outliers. This is especially relevant given that each patient's trajectory when dealing with serious mental illness is indeed unique.

The notion of human flourishing is intertwined with patient empowerment herein. Patient empowerment is commonly understood as a process in which individuals progressively take greater control over their treatment decisions, in part through gaining knowledge about their health conditions. The concept can be examined both through an individual lens, focusing on the capabilities a patient has gained in managing their own treatment, and also through a societal lens, assessing the extent to which patient empowerment has been achieved within a healthcare system or population (WHO, 2009). Studies in IS have reported a link between patient empowerment and self-management behaviors, placing patients who are more engaged in self-management higher on a patient empowerment scale (Johansson et al., 2021). Furthermore, an empirical study found that self-efficacy—i.e., the belief in owns ability to accomplish specific tasks or goals successfully—acts as a mediating factor in the relationship between patient empowerment and self-management behaviours (Wang et al., 2022).

Mental health patients and other individuals facing mental health challenges often encounter limited access to psychological support, highlighting the urgent need for innovation in the field of mental health. In response to that challenge, digital mental health interventions can provide effective solutions in terms of cost, convenience, and accessibility (Masri et al., 2024). This is especially valuable as mental health disorders are becoming more prevalent globally (WHO, 2022). Recent studies on smartwatch interventions in mental health indicate promising benefits, for instance, when it comes to sleep tracking (Kalisperakis et al., 2023) and engagement with smartwatch solutions (Meyer et al., 2018).

This research is driven by the interest of furthering the understanding of how self-care can be cultivated and human flourishing mediated through wearable devices for patients with severe mental illnesses. In addition to that, we are interested in shedding light on how self-efficacy can become a stepping stone for increased empowerment. Furthermore, we seek to further deepen the knowledge of how data-driven mental health should look like and to explore in what ways smartwatch data can be supportive in treatment. The paper draws on an action research project spanning four years with twenty-one individuals who have been actively engaged over time. The patients all had schizophrenia or bipolar disorder, and empowering them as well as engaging them as more active participants in their everyday lives has been the focal point. They wore wearables for an extended period of time, and in this paper, we analyze the data while also analyzing how the wearables impacted their well-being. We do so through the research question of: *How can wearables integrate into mental healthcare, and what potential insights does wearable data provide for individuals with schizophrenia and bipolar disorder?* We contribute an in-depth understanding of how wearables can become an integrated part of mental healthcare in the future while advancing the growing body of research on personal datafication through an exploratory approach. More specifically, our paper has a three-fold contribution. Firstly, we demonstrate that self-efficacy is an important stepping stone for reaching empowerment. Secondly, we argue that it is more meaningful to focus on individual patterns when engaging with individuals who have schizophrenia or bipolar disorder, as opposed to attempting to create clusters or profiles that define broader groups or generic patterns of behaviour. Thirdly, we highlight the dire need for IS researchers to engage in research on personal datafication in situ through specific cases that show how data-driven approaches can be used to harness the good and to further cultivate the notion of human flourishing within IS research and practice. To sum up, the overall impact of this study lies in easing patients' access to their health data, fostering patient empowerment, and supporting and enhancing their treatment. By moving the focus to the patient and designing the care with patients for patients, this research contributes to a more human approach to mental healthcare, promoting collaboration, destigmatization, and overall human flourishing.

2 Related Research

Bipolar is a chronic mental disorder that affects cognition and generic functioning. The disorder is characterized by fluctuations in mood and energy, alternating between different levels of depression (major depression, subthreshold depression) and different levels of mania (hypomania and mania) (Aref-Adib et al., 2019). In a manic state, patients experience elevated mood and energy and sometimes even delusions. In contrast, in a state of depression, energy levels are low, and in the most severe episodes of depression, patients can be in suicide danger; therefore, the mortality rate is higher in the community. The progress of the disease is different from patient to patient, but most patients have bipolar I or bipolar II (Grande et al, 2016). Schizophrenia is another complex mental disorder that includes psychotic episodes and is characterized by delusions, hallucinations, disorganized speech, and negative symptoms like loss of will and social withdrawal (Schultz et al., 2007). This group of individuals is more likely to have physical problems like cardiovascular disease, resulting in a higher mortality rate than the general public (Eisner et al., 2023). Additionally, patients stand a higher chance than others to be faced with injustice like abuse, neglect, homelessness, and human rights violations (Singh, 2021). The World Health Organization aims for less stigma towards mental health issues and easier access to treatment (Singh, 2021). Schizophrenia and bipolar disorder are often considered to be the two most severe mental illnesses and are often categorized together as psychotic disorders. As a result, individuals battling either condition are often researched in tandem (Kalisperakis et al., 2023), which is why both disorders are included in this paper. In our research, we wish to lessen the stigma of mental illnesses as well as find ways to ease access to mental healthcare.

In recent years, wearables, such as smartwatches, have become increasingly integrated into people's lives, offering a modern way of tracking one's own health data and promoting a healthier lifestyle. As smartwatches have become more affordable, both adoption and usage have increased, fuelling the interest in using smartwatches and other wearables within healthcare. As a result, research interest in the use of smartwatches in healthcare has increased. A recent systematic review of smartwatch interventions in healthcare in general indicates that smartwatches may bring positive health-related outcomes but stresses the need for further research to validate this potential (Triantafyllidis et al., 2024). Furthermore, recent research has indicated promising accuracy, demonstrating that smartwatch data can detect various health challenges, such as sleep apnea (Chen et al., 2021) as well as cardiac arrhythmia (Nazarian et al., 2021). However, there are also initiatives that show that the placement of smartwatches on the wrist is suboptimal (Pires et al., 2023), but in general, there is a consensus to be found in the literature about the impact of smartwatches if the same sensor is used, over an extended period of time and worn by the same individual (Sigurðardóttir et al., 2022, 2024). In addition to that, the research on what patterns using data from smartwatches can yield is in its infancy.

There are numerous studies on bipolar disorder that have collected a diverse range of digital data, including movement, sleep patterns, heart rate, electrodermal activity, voice characteristics, and keyboard metadata that have been significantly linked to bipolar symptoms and diagnosis (Saccaro et al., 2021). A study from 2024 showed that a smartwatch can spot periods of depression (80.1% accuracy) and mania (89.1% accuracy) in patients with bipolar disorder (Lipschitz et al., 2025). Studies have also shown the usefulness of wearable technologies in schizophrenia, including sleep tracking, which may help predict disease onset or acute symptom exacerbation (Kalisperakis et al., 2023). Additionally, heart rate and motor activity monitoring can detect autonomic dysregulation during episodes of paranoia, hallucinations, or delusions (Fonseka & Woo, 2022). Further research is needed to assess how smartwatches can be effectively utilized and integrated into routine clinical care for bipolar disorder and schizophrenia. Smartwatch use parallel to traditional treatment has the potential to aid in the treatment of chronic diseases like mental disorders, and mental healthcare has been identified to be one of the key areas where smartwatches can make a meaningful difference in treatment (Köhler et al., 2024). Smartwatches can contribute to patient empowerment and be used to enhance the power of data-driven decision-making and essentially further mental health significantly (Köhler et al., 2024; Sigurðardóttir et al., 2022). Some have, however, raised critical voices towards smartwatches as a driver for patient empowerment, emphasizing that the support of healthcare professionals is highly important in this context (Kang & Exworthy, 2022). Overall, the existing literature has yet to reach a consensus on the role of wearables, in general, and smartwatches, in particular, in data-driven decision-making for enhancing mental healthcare. Further research is needed to determine how wearable data can illustrate trends in behavioural patterns among individuals with serious mental illnesses.

3 Research Approach

The research approach utilized in this project is action research (Baskerville & Myers, 2004), which is a structured and widely adopted approach in IS research conducted within specific organizational settings. In this action research project, we are collaborating with Landspitali Hospital in Iceland to examine the feasibility of using wearables to support psychiatric treatment. We have obtained ethical approval for a study that involves six-week data collection for each patient (ethical approval nr.

55/2020). Moreover, each patient was asked to sign an informed consent prior to participation. This particular action research project focuses on the utilization of wearables as an integrated component of treatment for individuals with serious mental illnesses.

3.1 Empirical Setting

Our project spans four years in total. The patients who are invited to participate in the study come from two different units of Landspitali Hospital. *Firstly*, patients with type 1 bipolar disorder who are currently getting treatment in the bipolar team at the hospital. The team provides specialized, evidence-based treatment for bipolar, emphasizing early intervention, and the service functions as an outpatient resource. The patients are between the ages of 18 and 50 when they begin their treatment with the team and are offered treatment for up to three years. At each point in time, roughly 70 patients receive treatment via the bipolar team. *Secondly*, patients with early-stage psychotic disorders (schizophrenia) in treatment. The unit at the hospital that treats them provides a specialized, evidence-based, early-intervention psychiatric treatment for young people with developing psychotic disorders. Patients begin their treatment in the service between the ages of 18 and 35 and can be in that treatment for up to five years. The unit delivers both outpatient and inpatient treatment to patients depending on the severity of their condition and has around 100 patients. Both patient groups show similar symptoms, which is why we engaged both patient groups. The mental health services in Iceland are rather analog, which is why the action research project was crafted to digitalize and modernize the care for the patients, to better cater to their extended needs and use a data-driven approach to help the individuals reach self-care potential while also enabling the healthcare professionals' access to more reliable data.

3.2 Data Gathering

The sample approach was a convenience sample, where all interested individuals (also called patients herein) were welcome to participate. The exclusion criteria were not owning a smartphone, being homeless (recommendation from the healthcare professionals, as they would be more likely to lose the smartwatch that we provided for research purposes), or being evaluated by a healthcare professional as being currently too ill (e.g., suffering from psychosis). The data collection period was six weeks for each patient. To draw meaningful conclusions, the data collected in the project is objective and subjective. For objective data, we supplied the patients with wearables to measure heart rate, sleep, and movement. The choice of wearable technology was a Withings Steel HR smartwatch that is equipped with a heart rate infrared sensor, motion sensor, and accelerometer. The smartwatch collects beats per minute, steps taken, distance moved, the time it takes to fall asleep, sleep duration, sleep cycles, and sleep interruptions. It also provides activity monitoring and calorie expenditure. For subjective data, a questionnaire was administered three times over the study interval; first in the beginning, then at the end of week three, and lastly at the end of the six-week study period (see Figure 1). The questionnaire consisted of 63 questions covering various topics: eight demographic questions, six on self-efficacy, nine on depression (PHQ-9), seven on anxiety (GAD-7), eight on digital technology and social media use, and 25 on health and lifestyle habits, as well as views on tracking and managing personal health data. At the end of the period, the patients partook in a semi-structured interview focusing on their experience with data-driven decision-making in their everyday life and their experiences from continuously collecting data. In this paper, we report on twenty-one patients who successfully completed the six weeks of data collection (see Figure 1).

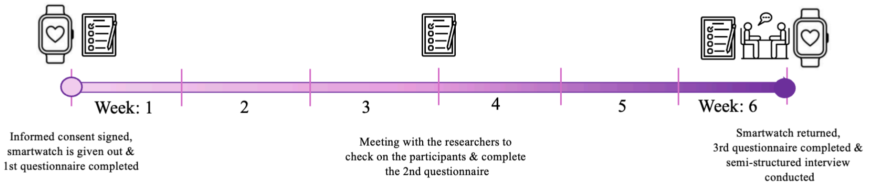

Figure 1. Study period and data collection stages over a six-week period.

The data completeness varied between the patients, as participation was voluntary. Table 1 below shows the data completeness for each patient during their six-week period of participation. The patients partook during a varied period, as the inclusion of each of them was done through a convenience sample; ergo, it could sometimes be weeks between the starting date of a new patient in the study since many were excluded based on the exclusion criteria elaborated on above.

Patient	**Nights recorded in dataset**	**Days recorded in dataset**	**Diagnosis**	**Comment**
Patient 1	41	42	Schizophrenia	Full participation
Patient 2	14	15	Schizophrenia	Wore the watch merely for two weeks
Patient 3	42	42	Schizophrenia	Full participation
Patient 4	42	41	Schizophrenia	Full participation
Patient 5	22	34	Schizophrenia	Wore the watch sparsely
Patient 6	12	15	Schizophrenia	Wore the watch only for the first part
Patient 7	25	25	Schizophrenia	Wore the watch for 25 days and nights
Patient 8	35	42	Schizophrenia	Wore the watch more during daytime
Patient 9	42	42	Schizophrenia	Full participation
Patient 11	3	4	Schizophrenia	Low participation
Patient 12	10	11	Schizophrenia	Only wore the watch for 11 days and 10 nights
Patient 14	42	42	Schizophrenia	Full participation
Patient 15	38	0	Bipolar disorder	Only recorded nights, therefore no activity data, four nights missing
Patient 16	20	20	Bipolar disorder	Wore the watch merely for 20 days and nights
Patient 17	42	42	Bipolar disorder	Full participation
Patient 18	22	22	Bipolar disorder	Wore the watch merely for 22 days and nights
Patient 19	7	8	Bipolar disorder	Only 7 nights recorded
Patient 20	0	42	Bipolar disorder	No nights recorded. Patient reported feelings of paranoia during the interval
Patient 21	36	42	Bipolar disorder	36 nights recorded but full participation during days
Patient 22	36	42	Bipolar disorder	36 nights recorded but full participation during days
Patient 23	42	42	Bipolar disorder	Full participation

Table 1. *The vastness of the data for each patient, alongside clinical diagnosis and additional information. Note: Patients 10 and 13 dropped out (ergo, the table holds 21 patients as the paper reports on, while their names in our dataset differ due to two dropouts).*

3.3 Data analysis

For our analysis, we have a three-pronged approach. *Firstly,* our analysis focused on the self-efficacy results from the questionnaire, visualizing changes in the self-efficacy values across three instances based on the average outcome of the six self-efficacy questions. This data was analyzed alongside the interview responses to explore the self-efficacy and empowerment of the patients. The semi-structured interviews, each lasting about an hour, were analyzed through a four-step content analysis by the first author of this paper. The first step involved open coding to categorize the experiences of the patients when it comes to somatic experiences and multiple types of data work. In the second step, text labels were assigned to snippets of data based on the patients' own descriptions (Gioia et al., 2013). The third step employed an abductive approach, organizing quotes into categories based on existing literature on wearable data in health IS (Gregory & Muntermann, 2011; Van de Ven, 2007). The final step involved grouping the data into themes reflecting both positive and negative aspects of the patient's experiences. Quantitative data from the questionnaire were analyzed using RStudio, as detailed in the results. *Secondly*, we also conducted an exploratory analysis of the smartwatch data, where we attempted to use clustering to group individuals based on similar characteristics. However, the data illustrates such individual trades (as elaborated on in the second part of the results here below), so we decided to shift our approach. Instead of clustering individuals, we focused on illustrating types of 24-hour patterns. To do so, we utilized unsupervised machine learning to identify clusters, aiming to explore factors that would identify types of 24-hours. Clustering enables a granular, individual-level analysis by grouping 24-hours such that 24-hour periods within the same cluster exhibit greater similarity to one another than to those in different clusters. This method has proven effective for applications such as characterizing digital phenotypes (An et al., 2020). *Thirdly*, in our individual-level analysis, we employed the partitional clustering algorithm K-Means, as presented in the third part of the findings below. This algorithm was chosen due to its effectiveness with datasets that have balanced cluster sizes and a limited number of clusters. Additionally, K-Means is computationally efficient and provides interpretable results. The algorithm iteratively assigns each observation to the cluster with the nearest mean, refining the cluster centers with each iteration (MacQueen, 1967). A key parameter in K-Means is the number of clusters, K, which is determined by identifying the 'elbow point' in an elbow plot– where the rate of decrease in cluster impurity begins to plateau. K-Means was applied to the wearable data to uncover meaningful patterns representative of 24-hour periods (see Figure 2).

Figure 2. The three-pronged approach to our data analysis (here, outlined in phases).

4 Findings

Our findings will be structured as follows: (i) we outline self-efficacy as an important stepping stone for empowerment, (ii) we conduct data exploration from wearables on a group-level basis, which shows that the patterns of each individual have unique characteristics, which is why we (iii) illustrate the meaningfulness of individual-level clustering of 24-hour windows that can be found in the data.

4.1 Self-efficacy as an important stepping stone to empowerment

When analyzing self-efficacy from the questionnaires, there are fluctuations in terms of self-efficacy that are note-worthy, especially when it comes to those who were diagnosed with schizophrenia. To better lay out the fluctuations, Figure 3 shows patients 1-14 (who all have the same diagnosis, namely schizophrenia), and that particular group of patients is more ill compared to the remainder of the patients, who have been diagnosed with bipolar disorder. What can be seen from the figure is that most patients experience a heightening in terms of self-efficacy over time, while some have a more varied experience; see N3 and N7, for instance, who both show signs of significantly lower self-efficacy in the second measuring point (the 2nd questionnaire). It is noteworthy that the N7 reported signs of instability in their condition during the data collection period in the interview and opted out of answering some of the questions in the questionnaire, including parts of the self-efficacy scale.

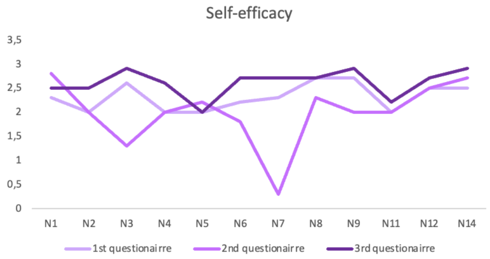

Figure 3. The self-efficacy over time for the patients diagnosed with schizophrenia.

Those who experience higher self-efficacy over time are also those who remain stable in terms of their illness scores gathered through the questionnaires (GAD-7, which measures general anxiety disorder, and PHQ-9, which measures the degree of depression). As already outlined in the method, we conducted semi-structured interviews with the patients. The findings from those are not the main focal point of this paper (and are reported on elsewhere in more detail), but to illuminate the need for innovative approaches with those suffering from serious mental illnesses, we still wanted to include some of the insightful comments of the patients. The patients generally found it interesting to engage with the wearables and to be a part of the action research. Overall, the smartwatches helped me reach my goals in everyday life: *“Yes. It was very informative, for example, regarding sleep […]. And yes, this is just an added convenience in day-to-day life.”* Another patient explained, *“It's just really interesting and so informative. Like especially with the sleep and stuff, I could feel that.”* When discussing how the feeling of having a smartwatch for a longer period, albeit during the six-week intervention, was affecting them, one patient responded: *“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.”* Another patient said they felt good about it but still explained that the wearable impacted their decision-making to some extent: *“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.”* All of this points towards the wearables being an important feature in their pathway towards empowerment, even represented through the notion that the patients wanted to buy a smartwatch or engage with the data, illustrating clarity on their goals (wanting to reach the ‘green’ (i.e., good) zone in their data collection).

4.2 Data exploration from wearables to yield insights on a group-level

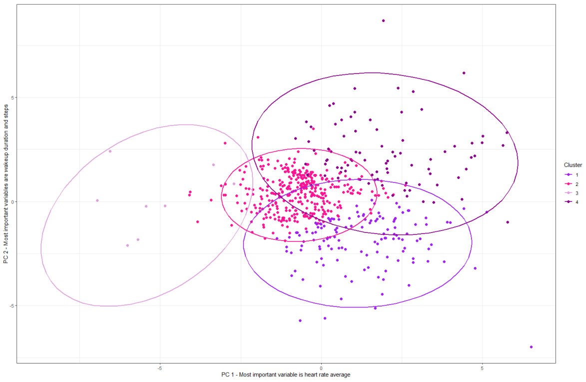

Figure 4. Cluster plot illustrating 24-hour data points for all patients in the study. The x-axis has the heart rate average as the most important variable, while the most important variable on the y-axis is the wake-up duration and step count.

The number of clusters was chosen through the elbow method. The elbow method is used to outline if adding an additional cluster increases the information gained or not. Specifically, we recorded the ratio of within-cluster distances of all clusters to distances between cluster centers and determined when it ceases to change (much). This created an *elbow* at $K=4$, after which not much change occurred, which is why there are precisely four clusters shown in the figure above. As can be seen, the clusters in Figure 4 are somewhat overlapping, pointing towards the notion that this type of clustering may not be as meaningful as it often is when the clusters are distinct. This realization is what led us onwards in our analysis towards an individual-based approach, where we examine the specific trades of each individual separately by examining their own 24-hour window (which ultimately leads to 42 24-hour windows per individual, as their participation outlines six weeks in total).

4.3 Meaningful individual-level clustering to show types of 24-hours

Since the patients all are dealing with severe mental illnesses, their data can perhaps all be seen as outliers or anomalies as their behaviour is not particular in any way. Those who are healthy (in the general population) have more similar patterns, while those seriously ill have more distinct and unique patterns (such as shown in our data). This calls for an individual-level approach instead of profiling on a more generic level.

Our analysis shows that each individual is indeed specific (see Figure 5). The visualizations for patient 1 show a period where there is a high variance in total sleep but another period with fewer fluctuations between days. The step data is more stable, either gradually going up or down. Conversely, maximum heart rate is notably steady, while wake-up duration shows peaks, especially on days when the patient experiences longer sleep durations. The cluster analysis shows a grouping between three major types of nights: bright pink nights, characterized by moderate heart rate, wake-up duration, and step counts; purple nights, with lower heart rate values but more variability in steps and wake-up count; and light pink nights, distinguished by a higher heart rate profile. The total sleep visualizations for patient 9 show slight fluctuations between days, apart from one night where no sleep is recorded. What is interesting is the consistently high duration of their sleep. We see in the step data that they have quite consistently few steps and that the heart rate is rather high with notable spikes. Wake-up duration fluctuates, with the highest value reaching more than 1.7 hours and going down to 3 minutes. The cluster plot primarily reveals two clusters, with the exception of three outlier data points (marked in purple). The bright pink cluster has data points that are mostly positioned below 0 on the x-axis, indicating frequent nightly wake-ups and elevated maximum heart rate values during sleep. Additionally, this cluster is located higher on the y-axis, suggesting an association with increased waking heart rate values and a relatively high step count. The light pink cluster is associated with lower waking heart rate levels, lower sleeping heart rate levels, and fewer nighttime awakenings. For patient 17, the total night sleep duration and step count exhibit significant variance, while the maximum heart rate remains stable, except for one notable spike. The wake-up duration remains low, except for one night, which exceeds 1.9 hours.

The cluster plot for patient 17 shows two primary clusters. The first, represented in purple, is characterized by lower heart rate values during sleep. The second, shown in a light pink color, is defined by relatively few wake-up incidents, a higher step count, and a balanced heart rate during sleep. The plot also shows three bright pink outliers that seem to primarily represent nights of higher heart rates but are more spread in terms of other variables. For patient 23, the total night sleep typically fluctuates significantly, ranging between 5 and 12 hours, except for one anomaly at 18.6 hours. Similarly, the variance in steps taken is considerable, while the maximum heart rate remains more stable. The wake-up duration fluctuates between 0.3 hours and 2.3 hours, although most nights, it does not exceed 1.1 hours. Regarding the cluster plot for patient 23, there are three visible clusters, the bright pink representing a cluster of 24-hour windows, which are associated with higher wake-up counts and a lower number of steps taken. The purple cluster represents lower wake-up counts and a relatively high number of steps. The light pink cluster extends across the plot to the left, but the most significant indicator is that the wake-up count for these data points is rather low. The bright pink cluster represents high wake-up counts.

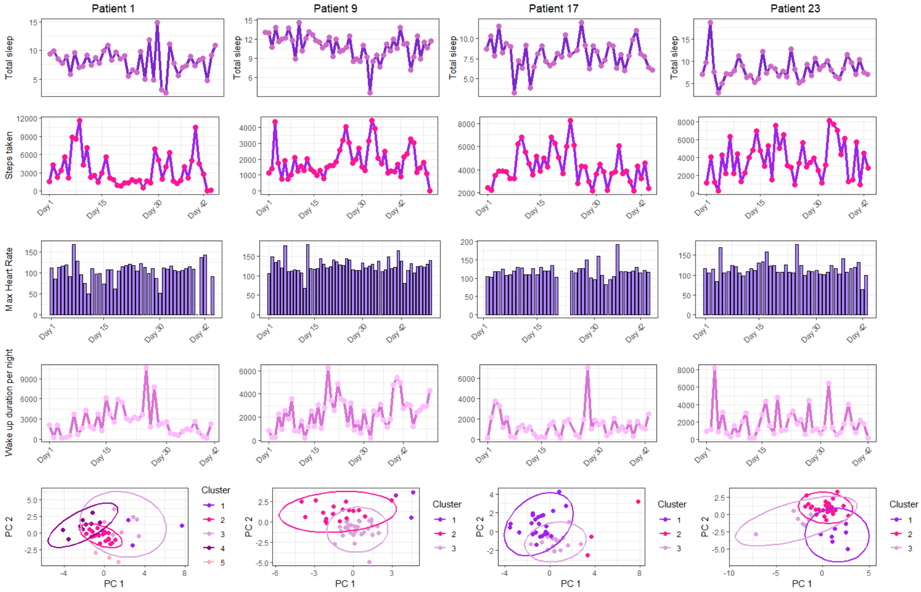

Figure 5. *Daily analysis of total sleep in hours, steps taken, max heart rate, wake-up duration, and an individual cluster analysis that includes these metrics.*

It is important to note that there is overlap within each patient's cluster plot, indicating that the 24-hour windows do not reveal distinct clustering patterns, but it is also noteworthy that the clusters vary significantly in size and shape between patients. This further supports the notion that each patient's data is unique, reinforcing the need for individualized analysis rather than extrapolating knowledge based on and for a group of patients. This suggests that each patient's smartwatch data could be used to support their specific treatment process since there are known indicators in both sleep patterns and heart rate data that have been significantly linked with bipolar and schizophrenia, but their individual pathway is not a representation of a certain population or a group of patients. Furthermore, rather than quantitively analyzing the wearable data in isolation, the wearable data should be coupled with patient narratives, incorporating qualitative interviews and questionnaires to provide a more holistic understanding of the patient as a person, ultimately fostering patient flourishing.

5 Discussion

New interactions between bodies and technology open an important avenue into how personal datafication conditions human flourishing, especially when it comes to those dealing with significant mental illnesses such as schizophrenia or bipolar disorder. Human flourishing refers to the optimal continuing development of human beings, including their potential and desire to live well, and encompasses a holistic view of well-being that includes not only physical but also emotional, social, and psychological aspects (Hylving et al., 2024). When data increasingly conditions existence, it also reshapes how individuals engage with and understand their own well-being, manifesting new tensions between self-care and flourishing (Marabelli & Newell, 2023). Although data can augment aspects of life in productive ways, the pursuit of the optimized self can also take a problematic turn, exacerbating a variety of clinical disorders and neuroses (Aupetit et al., 2019). When working with people suffering from chronic mental illnesses, there is a need to be specifically careful and tread lightly. Moreover, there is a growing interest within the field of IS, designing, developing, and using information systems for people with mental illnesses (Langrial & Lappalainen, 2016), and as we see it, the use of wearables falls well into the realm of IS research.

Individuals with schizophrenia or bipolar disorder experience different phases of their condition, which influences how capable they are of engaging with external factors. Depending on their condition, they may interact differently with the smartwatch and the data. Further, both the medication and the disease itself can impact cognitive abilities, which may, at times, make it challenging for individuals to monitor their own data. This speaks directly to the results from a recent systematic review on the perception of using wearables that revealed that the outcomes of using wearables, in general, and smartwatches in particular, are highly dependent on the user’s basic psychological needs (autonomy, competence, and relatedness) (Soltani et al., 2024). Schizophrenia and bipolar disorder are often chronic conditions (Grande et al., 2016; Schultz et al., 2007). Therefore, it is important for patients to have a positive attitude toward interventions that may be used long-term, as reported in the study in the interviews with patients. Interventions that increase patient's self-efficacy in detecting disease symptoms are important, but patients with bipolar disorder commonly do not read their mood accurately, especially with hypomanic symptoms (Grande et al., 2016), and patients with schizophrenia often do not have insight into their illness symptoms. As reported in the study, some patients felt the benefit of wearables in detecting changes in sleep, which can be an early sign of a disease episode. A smartwatch has the potential to help patients recognize symptoms such as changes in sleep and movement before their condition worsens, empowering them to take action for their own treatment rather than relying entirely on healthcare providers, but further research is needed to confirm this clinically.

5.1 Unravelling the importance of self-efficacy as an important stepping stone for empowerment

Patient empowerment is a process that includes four stages: (i) individuals’ reach an understanding of their role in the treatment; (ii) the knowledge has grown to the level of the patient being able to engage with their healthcare professional; (iii) an enhancement of the patient’s skills and; (iv) the environment fosters support with patient participation (WHO, 2009). One important factor when it comes to encouraging the process of individual patient empowerment is, therefore, linked to information accessibility, and wearables can unquestionably contribute to that effort. However, ways to cultivate empowerment in general and patient empowerment in particular through the use of data have not been studied extensively (Náfrádi et al., 2019). While there are impactful papers that have shown that adherence is highly dependent on patient empowerment (Náfrádi et al., 2019), there is little research on how to reach empowerment practically and identifying which stepping stones are involved in that process (Johansson et al., 2021). In recent years, the IS literature has become increasingly concerned with digital empowerment (Sharma et al., 2022). Yet, the same gap persists in that stream of literature, as within empowerment literature, in general, there is an inherent need to provide thick descriptions of how reaching empowerment can be done. Ergo, digital empowerment is still rather ubiquitous and unclear. Our paper contributes to that discursive commitment by outlining the importance of engaging with individuals with psychotic disorders through wearables, as the engagement with data can impact empowerment in a positive manner, but importantly, we also outline self-efficacy as a stepping stone on the way towards empowerment in general and digital empowerment in particular. We rely on the notion of self-efficacy, which is a long-withstanding concept within IS research, dating back to Compeau and Higgins (1995). More broadly, our paper shows that self-efficacy is an impactful prerequisite for empowerment and that empowerment is elevated by boosting self-efficacy. As already stated, self-efficacy refers to a person’s belief in their ability to complete a task or achieve a goal, encompassing their confidence in themselves to control the behaviour of themselves, exert an influence over their environment, and stay motivated in the pursuit of their goal (Rieder et al., 2021) and reaching that, is an achievement in itself, especially when working with individuals with serious mental illnesses. Through our results, we have shown that self-efficacy is an impactful stepping stone towards empowerment, and it can be meaningful to use wearables in general and smartwatches in particular to increase self-efficacy and, in turn, enhance the empowerment of individuals with schizophrenia or bipolar disorders. Conclusively, our findings point towards the notion that it is meaningful to cater to improved self-efficacy (i.e., the notion of the belief in one's own ability to successfully accomplish specific tasks or goals) as a vital stepping stone for reaching empowerment when dealing with individuals that have severe mental disorders, especially when slowly going towards increased digitalization, such as the one that we have elaborated on through wearable technology use as an embedded part of psychiatric care.

5.2 Revealing the type of 24 hours that patients with schizophrenia and bipolar have through a novel approach to individual-level analysis

As the world becomes increasingly data-driven, it is time to critically examine when it is meaningful to make profiles of individuals to extrapolate more generic human trades. What we know, is that we all have individual trades, and it can seem counterintuitive to cluster humans into types. At least our findings show that it is counterproductive to do so when dealing with individuals who have such drastically different digital traces illustrated through their wearable data. As already argued, digital phenotyping has gained an impact in recent years, referring to the use of digital data to curate a holistic digital view of behavioral patterns (Torous et al., 2016). Digital phenotyping has, for instance, been used to identify groups of individuals who might be at risk for attracting specific conditions versus those who are not, derived through data, for instance, data from wearables. While there are attempts to create profiles or patterns through digital phenotyping to better illustrate types of patients with psychotic disorders (e.g., Kalisperakis, 2023), we show that it is much more meaningful to cluster on the types of 24-hours and rely on individual-level analysis than to engage in finding generic clusters or profiles. Our paper thereby contributes insights into the digital phenotypes of individuals with schizophrenia and bipolar disorder by illustrating the ebb and flow of their conditions. Furthermore, we clearly show the meaning behind focusing on an individual-level approach, and instead of attempting to curate generic profiles, we show the meaningfulness of understanding the type of 24 hours that the patients may experience instead. We do so by relying on the machine learning method clustering to outline digital phenotypes of individual trades as a broader framework on which we base our insight that profiling or clustering generic trades together is not meaningful. Instead, each individual has their uniqueness. Through our use of clustering, we thereby show that the individuals are, indeed, individuals. They have individual trades and impact in engaging in digital phenotyping on an individual basis, analyzing each individual separately. To the IS literature, we therefore contribute with insights on the notion that, in some cases, it is not meaningful to engage in generalizing behavioral patterns to find profiles of types of patients. Instead, our findings show the meaning behind and importance of seeing the individual, focusing on the type of 24-hours. The field of IS has predominantly been successful in just that, engaging with in-depth insights and seeing the individual, and our paper furthers that agenda and shows that when engaging with people who have true fluctuations in their wearable data, it is impactful to engage in digital phenotyping on an individual-level basis, instead of trying to attempt to find generic patterns in the data. Ergo, we show that it is meaningful to focus on individual patterns, and the meaningfulness of the 24 hours is thereby a novelty herein.

5.3 Outlining the importance of human flourishing within the IS literature through personal datafication in situ

Recent literature suggests some people may become excessively reliant on wearable devices, obsessing about idealized metrics or eliminating every disturbance recorded by their devices, which, in itself, becomes a source of anxiety, leading to dissatisfaction, grief, unhappiness, or furthering health issues requiring medical treatment (Baron et al., 2017). Personal datafication is seen to intersect with a variety of underlying or preexisting psychological, medical, or behavioral conditions, such as orthosomnia—obsessive fixation on optimal sleep—, productivity paranoia—pressure to optimize time—, and body dysmorphia—delusions about flaws in one's physical appearance (Greene et al., 2023). How self-optimization reshapes concerns for well-being within personal datafication remains an important agenda for information systems research, with cumulative effects expected to pose substantial risks for human flourishing at systemic and societal levels (Kaplan et al., 2023). All this combined, makes the notion of studying the impact of wearables, especially on those already vulnerable through the way wearable data can be utilized, a pressing issue for the IS literature in general and for the health IS literature in particular. We thereby outline that there is a dire need for IS researchers to engage in research on personal datafication in situ through specific cases that show how data-driven approaches can be used to harness the good to further cultivate the notion of human flourishing within IS research and practice. Our paper illustrates that it is possible to do good through wearables, also when dealing with individuals suffering from severe mental illnesses, but it has to be executed carefully, and the data analysis, focusing on individual trades rather than on group-level extrapolations, is key. The study primarily has two limitations that should be noted, and that also can serve as areas for future research. *Firstly*, the data completeness varied due to the voluntary nature of participation, but still, our results show that wearable data reveals robust pathways for the future of mental healthcare due to the excessive ebb and flow that patients with serious mental illnesses show through the data. *Second*, the data is limited in terms of sample size (21) and lack of a separate control group; thus, further studies would be interesting to determine results that would allow generalizable assumptions to be drawn.

6 Conclusion

In our paper, we show how wearables can be integrated into mental health. Moreover, we also illustrate what data from wearables can illustrate in terms of insights on individuals with schizophrenia or bipolar disorders by illustrating the ebb and flow in changes through data in our action research study with twenty-one individuals diagnosed either with schizophrenia or bipolar disorder. We contribute with an in-depth understanding of how wearables can become an integrated part of mental healthcare in the future and further the growing research on personal datafication and, more generally, to the vast literature on health information systems within information systems. More specifically, our paper has a three-fold contribution. *Firstly*, we show that self-efficacy (i.e., the notion of the belief in one’s own ability to accomplish specific tasks or goals successfully) is an important stepping stone for reaching empowerment. *Secondly*, we show that it is meaningful to focus on individual patterns when engaging with individuals that have schizophrenia or bipolar disorder instead of trying to create clusters or profiles that would define broader groups or more generic patterns of behaviour. *Thirdly*, we show that there is a dire need for IS researchers to engage in research on personal datafication in situ through specific cases that show how data-driven approaches can be used to harness the good and to further cultivate the notion of human flourishing within IS research and practice.

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Appendix E

Ethical Approval number 55/2020

LANDSPÍTALI
HÁSKÓLASJÚKRAHÚS

Reykjavík, 15.mars 2021
ós/te

Oddur Ingimarsson geðlæknir og aðjúnkt
Geðþjónusta
Lv-71

Varðar erindi 55/2020 „Gagnadrifin heilbrigðisþjónusta: Færum máttinn til þeirra sem glíma við andlega heilsufarskvilla”.

Ágæti Oddur

Höfum móttekið svör ykkar dagsett 26.febrúar 2021 ásamt fylgigögnum og svarar þetta athugasemdum nefndarinnar með fullnægjandi hætti.

Samkvæmt umsókn er fyrirhugað að safna eftirfarandi upplýsingum úr sjúkraskrá vegna vísindarannsóknarinnar:

Kennitala
Kyn
Sjúkdómsgreiningar
Dagsetningar sjúkdómstengdra atvika (fjöldi innlagnardaga, fjöldi innlagna, komur á spítala, tíðni símtala, tíðni rafrænna samskipta, lyfjagjöf, stigun á geðhag, breytingar á stigun, ástæða breytingar).
Hæð, þyngd, BMI, blóðþrýstingur, hjartsláttartíðni.
Stigun á heilsufari. Notaðir eru þrír litir til að lýsa heilsufari þjónustuþega á Laugarásnum og í geðhvarateyminu. Grænn þýðir stabíl heilsa, gulur þýðir að fylgjast þar vel með heilsu viðkomandi og rauður eru þjónustuþegar sem þurfa aukna þjónustu vegna bráðra veikinda eða vegna erfiðs tímabils. Óskað er eftir aðgangi að upplýsingum um litakóðann og einnig færslum í

sjúkraskrá 2 vikur fyrir og eftir breytingar til að meta betur ástæðu breytinga á heilsufari.

Rannsóknarúrtakið verður tvískipt, annars vegar einstaklingar með geðhvörf af týpu I sem sækja meðferð í geðhverfateymi Landspítala, meðalfjöldi þjónustuþega á hverjum tímapunkti er 70 einstaklingar, hins vegar einstaklingar sem sækja þjónustu á Laugarásinn meðferðargeðdeild, þar eru rúmlega 100 manns á hverjum tímapunkti. Útilokaðir verða þeir sem ekki eiga snjallsíma, eru í erfiðri félagslegri stöðu (heimilislausir eða í mikilli neyslu) eða eru í yfirstandandi alvarlegum veikindum að mati meðferðaraðila.
Að auki verður meðferðaraðilum þátttakenda boðin þátttaka, áætlaður fjöldi u.þ.b. 30 einstaklingar.
Óskað er eftir því að skoða breytur ár aftur í tímann og ár fram í tímann og safna því mælingum frá tímabilinu 1.maí 2020-1.maí 2023. Gert er ráð fyrir að íhlutunin sjálf standi frá vori 2021 til loka árs 2021.

Rannsóknarlok eru áætluð 1.desember 2025.

Endanlegt samþykki Siðanefndar heilbrigðisrannsókna á Landspítala fyrir ofangreinda rannsókn er hér með veitt.

Siðanefnd bendir rannsakendum á að birta siðanefndarnúmer rannsóknar þar sem vitnað er í leyfi nefndarinnar í birtum greinum um rannsóknina. Jafnframt fer nefndin fram á að fá senda tilkynningu um lok rannsóknar þegar þar að kemur, auk afrita af birtum greinum um rannsóknina.

Gangi ykkur vel við rannsóknarstörfin

Virðingarfyllst fyrir hönd Siðanefndar heilbrigðisrannsókna á Landspítala,

Tinna Eysteinsdóttir
____
Tinna Eysteinsdóttir, forstöðumaður.