Digital Mental Health: Co-Designing a Digital Platform to Support Work in Psychiatric Healthcare

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Abstract

Purpose

People with severe mental disorders need constant support and monitoring. With the reality of overworked healthcare professionals and long waiting lists, it can happen that patients do not get all the help they need. One of the ways that can contribute to solving that battle is digitalization in mental healthcare. We have designed and developed a digital platform that takes into consideration two perspectives: i) the patients and; ii) the healthcare professionals. In this paper, we focus on the co-design process of that digital platform.

Design/methodology/approach

This canonical action research paper describes a process of a co-design workshop conducted with 13 healthcare professionals at an Icelandic psychiatric healthcare unit. The source of the empirical data used during the workshop originates from their patients and is stored in the platform.

Findings

The main contribution of this paper can be summarized through three design principles: i) clarity and information accessibility regarding the patient's side; ii) flexibility when it comes to the healthcare professional's side, and; iii) a communication path between the two.

Originality/value

We had the rare opportunity to gather healthcare professionals for a workshop and aimed at giving insights into the research question: What design principles can be derived from a co-design process of a digital mental health platform with psychiatric healthcare professionals? The theoretical contribution is conceptualized through three design principles and a discussion on future aspects of digitalization in mental healthcare. The practical contribution is outlined in the changes made in the platform derived from the results from the workshop.

Keywords

Co-design, digitalization, platforms, mental healthcare

1. Introduction

Patients with severe mental illness need extensive support and care. The resources in mental healthcare are scarce, and support needs to be structured. Digital mental health (i.e., digital platforms or other technologies and interventions to support and improve the 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 [1]. Moreover, digital mental health has also been outlined as a way for healthcare professionals to attend to their patients at a distance, through data [2][3].

Across various healthcare domains, the design and development of digital platforms using co-design processes with the patients' needs in mind, has shown to be successful [4][5]. The literature on co-design often focuses on one specific type of end-user whereas in healthcare in general and in mental health in particular, there are two equally important partners to consider; the patients and the healthcare professionals [6]. In light of that, there is a gap in the literature regarding the co-design of digital platforms for digital mental health with the healthcare professionals and their needs in mind, especially

when aiming for integrating the digital platform seamlessly into the pre-existing work of the healthcare professionals over time [7].

We have designed and developed a digital platform called DataWell (herafter called "platform" or simply "DataWell") which takes into consideration the two perspectives: i) the patients and; ii) the healthcare professionals. The co-design process of that digital platform is a focus point in this paper, as well as in our collaboration with a psychiatric healthcare unit. The unit treats young people with early-stage schizophrenia spectrum disorders. The treatment, which classifies as early intervention, is individualized, but typically it is a combination of appropriate medication and other suitable interventions, like regular consultations and support from healthcare professionals, regular exercise with guidance, and occupational therapy. Before the beginning of this canonical action research (CAR), the treatment was delivered manually and on-site. We facilitated an intervention in the treatment by providing patients in the study with a smartwatch that gathered 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 visualized in the DataWell platform. The healthcare professionals at the healthcare unit wanted a better overview of their patients' conditions and enhanced decision-support. Therefore, the purpose of this CAR paper is to study the co-design process and principles derived from a co-design workshop. We explore the research question: What design principles can be derived from a co-design process of a digital mental health platform with psychiatric healthcare professionals? The main contributions are two folded. Firstly, the theoretical contribution consists of three design principles we suggest others consider when designing similar platforms. Secondly, the practical contribution is the platform in itself and the changes made with suggestions from this workshop. The platform is already supporting the work of the healthcare professionals and could become a bigger support when practical changes have been implemented.


2. Theoretical background

Mental disorders affect individuals and societies worldwide, and the impact is not easily measured to the full extent. The life expectancy of individuals with mental disorders is lower than for the general population, and living with a mental disorder can keep patients from being active in society. The estimated mental health-related burden accounts for 32.4% of years lived with disability (YLD) of all YLDs' in the world [8]. On average, one or more individuals with a mental disorder can be found in one-fourth of all families. The negative effects on family and friends can be difficult to estimate, and thus tend to be ignored [9]. Schizophrenia is a serious chronic mental disorder with a reported prevalence of around 0.7% [10]. The disorder can cause symptoms like delusions, hallucinations, thought disorders and negative symptoms which include 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 mostly due to poor physical health and a high suicide rate [11]. Due to the severity of symptoms serious life challenges like low employment rate (below 20%) and high homelessness (up to 20%) affects the group (mcniel2005incarceration). Another severe, chronic mental disorder is Bipolar Disorder (BD), which has a reported prevalence of 0.6% [12]. BD patients 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 [13]. Research suggests that increased physical activity can improve wellbeing for patients with schizophrenia as well as BD [14]. The COVID-19 pandemic unexpectedly accelerated the need for digital health services in general and digital mental health in particular. Due to this increased demand and urgency, the digital maturity and willingness for innovation within the healthcare systems increased all around the world [15]. Even though there have been some important voices raised regarding digitalizing the structured tasks and leaving the humanistic aspects of the care work un-digitalized [16], recent work has both shown that digital work within healthcare provides an important way to

reallocation of resources [17] and shown that the work within psychiatric care can benefit from increased innovation and moreover that digital mental health services can be delivered successfully online [18]. The need for online support to be complimentary but not intended to replace human interaction has been outlined [19]. Software is often developed with little or no 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 [20][21]. Co-design, which stands for cooperative design or collaborative design, is the act of including different stakeholders in an iterative process of designing and developing software [22]. Co-design is becoming more and more popular in the design process of software for healthcare purposes and findings support the use of co-design principles for person-centered solutions [23]. The authors of this paper acknowledge what the literature has underlined, namely the need for being mindful of the power differences between patients and healthcare professionals. This might especially be true when it comes to mental health [24]. The co-design process is concluded with guidelines for the development of our platform, and the guidelines are called design principles.

3. Methods

This paper reports on an action research (AR) project within mental health services, with healthcare professionals to complement the already existing service through digital mental health service via a digital platform. AR is an iterative research approach to conduct an empirical study, where the study plan can evolve during the process of the study. In its simplest form it begins with the collaborators of the study analyzing the subject, to come up with a theory which is then the foundation for change in how collaborators interpret the results [25]. This type of method fits well for interventions in practice. Collaborators in this context are the organization (here, the psychiatry at the hospital) and the researchers. AR has been widely used in studies in the discipline of information systems (IS), but also in other fields, such as to study digital work and digitalization of education [26]. Action research is the umbrella term for a variety of action-oriented, change-driven intervention methods where other, more specific methodological approach fit into. CAR has become a widespread approach to study the effects of digitalization, and the approach includes five principles: i) The principle of the researcher-client agreement: where the researcher may explain the process of AR and build trust for the continuance of the study ii) The principle of the cyclical process model: the process is an iterative one as described in Figure 1, iii) The principle of theory and theory development: Davidsson et al. (2014) argue that explicit theorizing is a vital part of the planning stage, as it ensures a framework that fits both client and researcher is designed, iv) The principle of change through action: outlines one of the main characteristics of AR, where changes can be made either on an individual level and/or on an organizational level, and, v) The principle of learning through reflection: where collaborators reflect on the outcome of the study and deliver a report [27]. Building on these principles we have adopted the model proposed by Davidsson et al (2014), to our own context, to describe the research process as a whole within our CAR project (see Figure 1 below). We use the same figure to illustrate the subset of data collected for this paper, that is the "Reflection" phase. We build this paper on CAR and adapt that to fit our co-design process. The intervention in this project is two folded: i) On an individual level, the intervention is carrying a smartwatch that collects health data, answering daily well-being questions and monitoring own health data. ii) On a project level, the intervention includes the changes made in the platform to better facilitate the needs of patients and healthcare professionals.
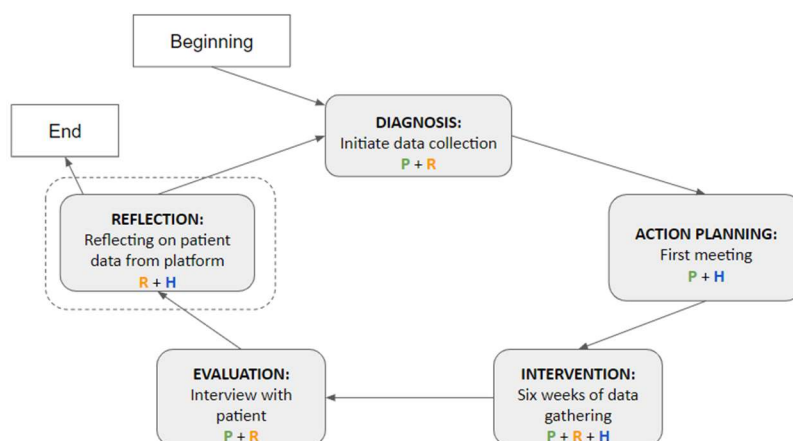
Figure 1: The iterative process of this research. This paper mainly focuses on the "Reflection" part.

3.1 Data gathering through a co-design process

The empirical data gathered for the purpose of this paper is derived from the reflection phase of the cyclic model presented in Figure 1 and the data consists of comments from a workshop with 13 healthcare professionals (H) at an Icelandic psychiatric healthcare unit that treat patients with schizophrenia spectrum disorders. The data used to conduct the workshop is stored in DataWell and originates from the patients treated at the healthcare unit. Researcher (R) is the first author of this paper and patient (P) is any patient included in the study (see Table 1).

Table 1

Phase, description and key characters, meeting the CAR principles.

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

The healthcare professionals had been presented with the digital platform before (which we have been designing in a cyclic process through our overall CAR), but the reflection phase which we draw data from to this paper was meant specifically to facilitate in-depth feedback from them. We split the healthcare professionals into three groups. Each group worked on three different, made-up scenarios (see below) that included logging in and using the platform (see Figure 2) and demanded interaction between group members. After 15 minutes, the next scenario was introduced, so in total, we have data

from 39 scenario engagements with the 13 healthcare professionals. The participants logged into the digital platform during each co-design workshop and were met with one scenario. The three scenarios were: 1) Joe, the patient who is going to meet his caseworker, 2) Otto, the healthcare professional who is engaged but overworked and wants an overview of his patients' statuses, and 3) 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 data used in this paper was voice recorded and transcribed verbatim and we have applied for and gotten ethical approval for the data gathering. The analytical approach for the transcripts was content analysis.
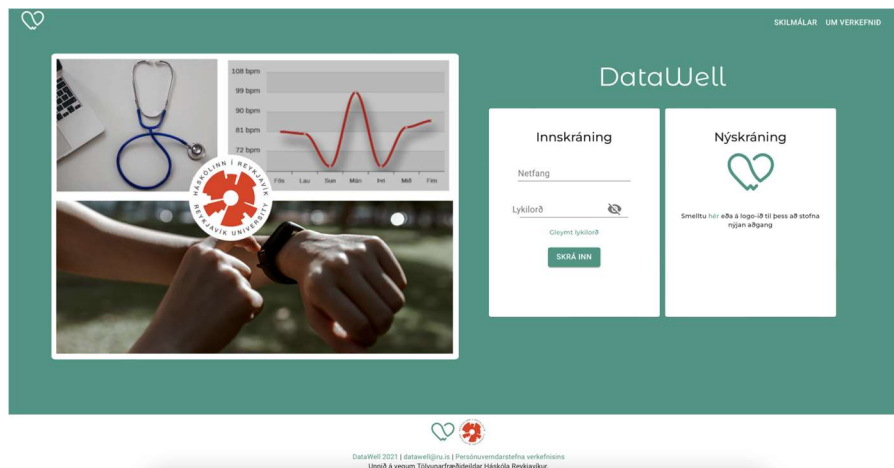
Figure 2: A snapshot of the login page of the DataWell platform.

As stated earlier, each healthcare professional worked with all three scenarios. The details of the scenarios were as follows:

Scenario 1. You are Joe the patient. You are going to meet a healthcare professional. You know that you will be asked a lot of questions when you meet. You decide to log on to DataWell to have information ready, so that you can give your healthcare professional insight into how you have been doing lately.

- Log in to 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?

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 in 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?

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?"

4. Empirical setting

As explained earlier, at Reykjavík University in Iceland, we have designed and developed the digital mental health platform DataWell. The platform has two perspectives: i) the patients (see Figure 3) and; ii) the healthcare professionals (see Figure 4). Patients can use their perspective of the platform to monitor their own health information and possibly use that information in their communication with healthcare professionals. The healthcare professionals' perspective displays an overview of their designated patients (see Figure 4), 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 DataWell to study the feasibility of platforms supporting psychiatric care. The platform is under further development through a co-design approach, both with patients and, as this paper focuses on, with the healthcare professionals that have been treating the patients.
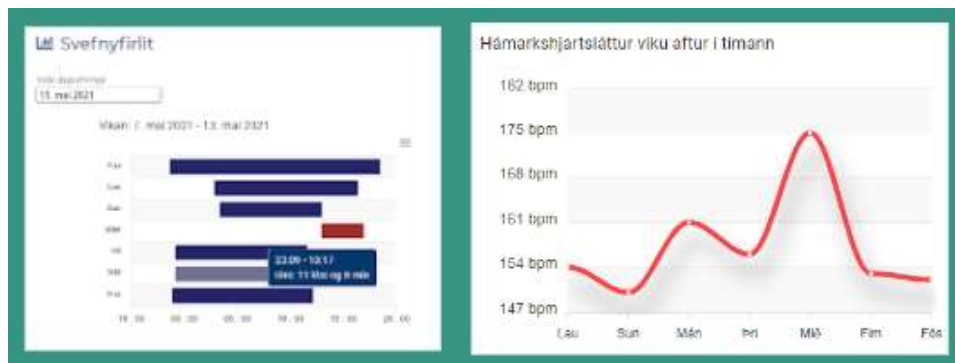
Figure 3: Snapshots from the platform, patients perspective. To the left, sleep data visualization. To the right, heartrate data visualization.

Nafn	Svefn (klst)							Skref (þúsund)							MindPoints (stig)						
	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
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

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Figure 4: A snapshot from the platform, an overview of five patient's data, from the healthcare professionals perspective.

To further elaborate on the overall project, we describe the project setting.

Landspítali University Hospital is Iceland's biggest hospital, located in Reykjavík, and responds directly to Iceland's Ministry of Welfare. One of eight clinical departments of Landspítali is the Psychiatric Services, that runs the Psychiatric Emergency Room along with twelve specialized teams that diagnose

and treat patients with different mental diseases. This paper's authors have an ethical approval from the hospital's ethics committee to do research with the patients and healthcare professionals of two of those teams, The Psychosis Team (that treat patients with schizophrenia) and The Bipolar Team. This ethical approval is valid for three years, from the 1st of May 2020 to the 1st of May 2023, with a possibility of extension. We started data gathering in May 2021, so at this point in time, we have been collecting data with patients for 15 months.

We first started this research project four years ago and at that point in time, our focus was on designing and developing the DataWell platform and DataWell mobile application. We wanted the platform to be able to receive, store and visualize both subjective and objective health data. The app was designed as a part of this project and its purpose is displaying questions on wellbeing, collecting answers, and sending data into the platform. When the platform and app were stable and ready to conduct data collection, we formed a board of experts with relevant people from the hospital and the university. This board met on a regular basis to discuss the steps of the project and the results of those meetings was the design of our CAR cycle and an ethical approval from the ethics committee at the hospital. When the ethical approval had been obtained, the board continued meeting to further cultiviate the project within the clinical setting.

In May 2020 we started including patients in the study. People that have either of these two severe disorders, i.e., schizophrenia or BD, can have a difficult time showing up for meetings, due to the difficult symptoms they are dealing with. Therefore, it was a challenge to include patients in the study, with the attendance to meetings being close to 50%. We included 21 patients in the study in total, three of those dropped out during data collection due to sickness or issues related to comfort. From that group of patients, nine patients are diagnosed and treated for BD (two dropped out) and twelve patients are diagnosed and treated for schizophrenia (one dropped out). data collection and feedback from patients. The patients that agreed to participate in the study carried a smartwatch from Withings for six weeks, collecting data on heart rate, sleep and motion, and feeding directly into the platform. During those six weeks they also answered five daily questions on general wellbeing in the DataWell mobile app. Throughout the six weeks, the healthcare professionals working with the patients could monitor their patients' data through the platform. The patients also answered a paper questionnaire three times (in week 1, 3 and 6). The questionnaire is a collection of validated questionnaires to measure level of anxiety, depression severity, view towards technology, self-efficacy, empowerment, and impact of self-monitoring. 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-designing approach. We ask questions on user experience and usability of the platform and address their view on data-driven mental health and on continuously collecting data.

After having obtained a lot of knowledge through communication with patients, it was time to reflect on the platform with the healthcare professionals working with the patients enrolled in the study. This consisted of a co-design workshop (see further details below) that we initiated to learn what guidelines could be used to i) further develop DataWell and ii) guide others in similar situations. The data gathered at this workshop is what this current paper reports on.

5. Results

The data that we gathered from the workshop included valuable feedback from the healthcare professionals, which we have summarized in three design principles: i) clarity and information accessibility regarding the patient's side; ii) efficiency when it comes to the healthcare professional's side, and; iii) a communication path between the two sides of the platform, that is, from healthcare professionals to the patients and vice versa. Moreover, we have learned that the healthcare professional's participation in co-design brings a sense of inclusion that we believe will be supportive of the practical use of the platform.

5.1 Clarity and information accessibility regarding the patients' side

Regarding i): The vision that the platform should be clean and accessible was evident when the healthcare professionals at the psychiatric unit got to talking, and one of the remarks that supported that idea was: "So, I believe this needs to be clean and very simple. Kind of user-friendly, so it's somehow obvious where to click." They agreed that the platform should be straightforward and accessible with the words: "You should be able to monitor all the data in one place." To support that thought, another one said: "It should be very clear that when you go to sleep on a Monday and wake up on a Tuesday, which day to choose on the chart." One measure in the platform is sleep points from 0 - 100, and on that topic, one of the partakers said: "I would like there to be a criterion to compare to." and she then concluded the subject with the words: "This interface is really convenient. Very simple and convenient."

5.2 Efficiency when it comes to the healthcare professionals' side

Regarding ii): When discussing how the platform should function from the healthcare professionals' side, one opinion was predominant, namely that the platform should be efficient when it comes to time and mouse clicks. This comment underlines that opinion: "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." Related to that same topic, one of the partakers said the encouraging words: "It is so simplifying that the interface for us [the healthcare professionals] is basically the same as for patients, only with the added option of statistics and seeing the group overview." Another healthcare professional added to the pool of efficiency-related comments: "we could use a search field for names." The researcher could sense that the healthcare professionals wanted the platform to be flexible in the sense that they could control their view as much as possible, like this practical comment underlines: "If you choose the 19th, the week of 19th-25th appears. I think you should be able to control the length of the interval you want to see." Another note on the efficiency was that "everything" should be one click away: "I would like to just choose exactly this week and get an overview of everything." Another partaker agreed: "Yes, I think it would be perfect if you could choose the time interval and overview. Then you could see how he slept and how he exercised this week." Discussing further, this remark that has to do with both flexibility and efficiency popped up: "Do we have a holistic view somewhere? Then we could see how much sleep there is and how steps are distributed during one day. Then we could see if he's awake during night time" and agreeing to that comment, another partaker stated the professional opinion that: "It could be convenient to see sleep and activity in the same place, especially if you're thinking if the person is in a mania, very active and sleeps less." Yet another one agreed: "So you could see the information pretty fast, like, 'yes okay, you've been very active or inactive. Or you have slept a lot this week.'" Lastly, an observation that harvested a large agreement in the group from other partakers was clearly stated: "The interface needs to be simple."

5.3 Communication path between the two sides of the platform

Regarding iii): Some healthcare professionals mentioned that it could support the treatment being able to use DataWell as an information platform. One of the observations in that regard was: "Maybe we should be able to add something there, questionnaires to submit, for example." On a similar note, one of the healthcare professionals speculated: "how about coping strategies, you know, if you are not sleeping well, we could throw in advice like 'okay, here is what you can do to help you sleep.'" Another partaker had ideas on supporting a healthy lifestyle: "It could even be nice to have a notification for drinking water or reminds you to exercise, maybe also a calendar to remind you when you have a doctor's appointment." Related to that comment, her coworker added: "I would like the platform to have notifications; our people (i.e., patients) tend to forget things."

Though not related to i), ii) or iii) one relevant observation is worth mentioning, namely: "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.'"

6. Discussion

In this paper we gathered data with 13 healthcare professionals through 39 scenario engagement in a canonical action research project via a co-design approach and aimed at answering the research question: What design principles can be derived from a co-design process of a digital mental health platform with psychiatric healthcare professionals? As stated at the beginning of this paper, resources in mental healthcare are limited and digitalization is one of the ways that have been pointed out to counteract that problem [1]. One of the ways the healthcare professionals that partook in our co-design approach pointed out as a potential supplement to the current treatment was to have a communication path via an end-to-end encrypted chat in the DataWell platform. They also raised the importance of enabling a function to share files with their patients through the digital platform, which might be helpful for some patients at particular points in time. If that function would be implemented, it has the potential to result in better time efficiency, enabling the healthcare professionals more time to attend to other more urgent matters. This speaks directly to two of the design principles that were derived from the co-design approach, namely: A communication path between the two sides of the platform, that is, from healthcare professionals to the patients and vice versa, and Efficiency when it comes to the healthcare professional's side.

What we can 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., (2022). This type of co-design approach with healthcare professionals can be beneficial to identify points of interest from expected users from both sides, that is patients and healthcare professionals. Through our analysis of the co-design approach, the researchers 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 [6][28].

Over time we presume that having access to the data in the digital platform could change the way healthcare professionals interpreted the status of their patients, and in light of that 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 [21][22][4] [6]. More specifically, from our case, the process of determining a dose of hypnotics becomes a significantly different process when relying on a patient's memory of her sleep quality, as opposed to when there is access to concrete, longitudinal reliable information on the length and depth of sleep, sleep stages, number of awakenings etc.

To sum up, from the co-design process described in this paper we derived practical and theoretical contributions. The practical contribution is the platform itself, with the improvements and ideas from the workshop. Also, triggering the sense of inclusion with the healthcare professionals that participated in the workshop, might encourage the use of the platform in practice. The theoretical contribution, namely the following three design principles: i) clarity and information accessibility in regards to the patient's side; ii) flexibility when it comes to the healthcare professional's side, and; iii) a communication path between the two. We suggest that others take these into account in their design co-design processes in healthcare in general and when designing and developing digital platforms for digital mental health in particular.

6.1 Limitations and future work

The results of this co-design approach are specific for Icelandic mental healthcare and can not necessarily be generalized for all other healthcare units. Also, the work was done in order to facilitate

the patients with serious mental illnesses, meaning that the needs might be different for patients with less severe mental illnesses. Moreover, the time we had with the group of healthcare professionals was limited to 2 hours and it was organized that way in order to gather a higher number of healthcare professionals to one location. We feared that it would have been improbable to do so if we asked them to attend a much longer workshop, or multiple workshops, because of their busy schedule. Furthermore, the pandemic restrictions did not allow for multiple in-person workshops. Future work will include testing the co-design method, and apply our design principles with a different set of patients and healthcare professionals to validate the results and extend them to other types of mental disorders such as bipolar or postpartum depression and their healthcare professionals.

7. Conclusion

In this paper we gathered data with 13 healthcare professionals in a canonical action research project via a co-design approach and aimed at answering the research question: What design principles can be derived from a co-design process of a digital mental health platform with psychiatric healthcare professionals? The main contribution of this paper can be summarized through three design principles: i) clarity and information accessibility in regards to the patient's side; ii) flexibility when it comes to the healthcare professional's side, and; iii) a communication path between the two. We suggest that others take these into account in their design co-design processes in healthcare in general and when designing and developing digital platforms for digital mental health in particular.

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