

## Designing Personal Health Records for Cognitive Rehabilitation

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**Abstract**—Personal Health Records (PHRs) are digital tools that give people the possibility to have access and control over their health data. They are usually used in situations when the patient is home or in casual encounters between the patient and the healthcare practitioner. Current related literature does not discuss much in terms of PHR usage in hospitals and possible implications for designing such PHRs. In this paper, we present the case of cognitive rehabilitation in a rehabilitation hospital. Patients in rehabilitation should take a leading role in their treatment as a prerequisite for more beneficial rehabilitation. We have analyzed the cognitive rehabilitation case and present a set of six design implications for designing a PHR for the patients in cognitive rehabilitation during their time at the hospital. We discuss these implications from a Computer Supported Cooperative Work (CSCW) perspective, where the PHR has been conceptualized as hybrid information spaces compounded by personal and Common Information Spaces (CIS). We found, that in cognitive rehabilitation, an important element for designing a PHR is its role not only in creating the possibility of sharing information between the patient and the healthcare practitioners, but, at the same time, offering some mechanisms for coordination between them as an incentive of recognizing patients work in the division of labor and helping the patient take more control over his/her rehabilitation.

**Keywords**-PHR; cognitive rehabilitation; coordination mechanisms; patients empowerment; CIS.

### I. INTRODUCTION

Personal Health Records (PHRs) are defined as “digital tools that allow people to access and coordinate their lifelong health information and make appropriate parts of it available to those who need it” [1]. PHRs emerged from the need of patients to take control of their health information and contribute to it [2]. Commonly, patient health information has been stored in Electronic Medical Records (EMR), which are used by healthcare practitioners to facilitate the management of patient’s treatment and also as a cooperative tool with other healthcare practitioners [3]. However, despite an increasing requirement in health policies in recognizing patients’ role as being active participants in their care, patients still do not have access to EMRs and their own health information. Often, the only way they get access is by obtaining a paper copy of their records. Thus, patients collect paper documents and create their own big paper folder that they usually bring over in consultations. This practice has limitations in terms of how the information is stored, retrieved, and shared. In response to these limitations, PHRs emerged around two decades ago to give patients the possibility to have access to their health data and also be able to generate more health information that they can share with whoever they want.

PHRs have been discussed in the literature under different lenses, and different types of PHRs have been developed. The CSCW field has contributed to increasing the understanding of the cooperative work in healthcare and introducing a set of digital artifacts that facilitate cooperation [4], offering in this way, better services to the persons in need. From a CSCW perspective, the PHR is a collaborative tool between patients and healthcare practitioners. The PHR has been conceptualized as an information space of a hybrid nature [5]-[7] representing a tool that integrates personal and interpersonal/common information spaces. In this paper, we follow this line of work and are interested in both the design of PHRs and their conceptualization as collaborative tools. Therefore, we address the following research question: “*How to design a PHR for cognitive rehabilitation?*” and “*How can this contribute to conceptualize PHRs?*”

Specifically, we analyze the collaborative use of a PHR in the hospital context, while patients are still hospitalized. PHRs are mostly designed to support the collaboration between the patient and health practitioners when the patient is home or when s/he has casual encounters with the healthcare practitioners. We argue that, in order to support collaborative work in the hospital context, the PHR needs to be designed differently. In addition, we also argue that PHRs need to accommodate the specific needs of the patient's clinical problem. Hence, in this paper, we identify and discuss implications for the design of a PHR in the case of patients in cognitive rehabilitation in a rehabilitation hospital. In this context, patients have to actively participate in care practices (not only receive care). Cognitive rehabilitation is a special rehabilitation program that is usually offered in rehabilitation hospitals to patients who suffer from some cognitive impairments after Acquired Brain Injury (ABI) caused mainly from stroke or accidents [8]. We have investigated the cognitive rehabilitation process in the Cognitive Unit (CU) of a rehabilitation hospital in Norway and defined a set of implications for the design of a PHR in such a setting. We discuss the PHR design implications in relation to the current conceptualization of PHRs within CSCW research and contribute to a better understanding of such tools.

In Section II, a description of our main concepts is presented. Section III gives an overview of how the data was collected and analyzed. Section IV is a detailed presentation of the practice of cognitive rehabilitation as a summary of our empirical study. Section V presents a set of implications for designing a PHR used in cognitive rehabilitation grounded in our empirical findings. In Section VI, we discuss the implications for design with a more conceptual perspective

drawn from the existing conceptual discussion of PHRs in CSCW.

## II. CONCEPTUAL GROUNDING

In this section, we present more in-depth the main concepts for this paper. Initially, we present PHRs and how they have been defined and described in the literature. Further, we present how PHRs have been conceptualized in CSCW as a hybrid information space. Moreover, we focus on the CIS as a concept and finally describe the concept of coordination mechanisms as a parameter of CIS and relevant for our discussion later in the paper.

### A. Personal Health Records

PHRs have been defined generally as Internet-based, lifelong health records that are controlled by the individual and are meant to promote the individual's engagement in his or her health and healthcare [1]. PHRs should be controlled by the patients who should as well enter at least part of the information. Davidson et al. [1] in a PHRs literature review found that there are different types of PHRs. One type of PHRs are those tethered to EMR. In that configuration, part of the PHR information is provided and maintained by healthcare providers. A patient can access the EMR and mostly read through the information, but it is usually not common to have the possibility to edit or change the data in the EMR, even when that is needed, required, and liable for the patient. This does not mean the patient will access the EMR and change the description of their diagnosis. However, the patient can contribute by describing more details about his/her situation, which will then help the doctor make a better diagnosis. Other type of PHRs are those fully controlled by patients, who enter and maintain their own health data [1]. This health data can be brought over to be discussed with the healthcare practitioners during consultations, and the collaboration and interaction happen outside of the PHR. Another type are PHR platforms/ecosystems. They are supposed to be a mix between standalone PHRs and tethered to EMR PHRs, but with a distinction to be untethered from a specific healthcare provider. PHR platforms are supposed to give the patient the freedom to use the PHR independent of where s/he is receiving the treatment. An example of PHR platforms from the Norwegian healthcare has been described by Vassilakopoulou et al. [7]. Helsenorge.no is a patient platform where the patient can find part of his/her health data arriving from different health settings. The aim of helsenorge.no is to give patients a space/platform where they can find health data such as diagnosis (epicrise), have the possibility to communicate electronically with their General Practitioner (GP), check their vaccine history, their medicine, etc. and possibly more services in the future.

PHRs are considered to have the potential to contribute to patients' empowerment by implying changes in the way healthcare is delivered and give patients the possibility of being more involved and getting more control over their care [2]. However, their usage is still low, and there is limited

research on how PHRs can empower the patients in having more control and being involved in their care.

Creating PHRs is associated with multifaced socio-technical problems attributed to their role of connecting multiple parties and social actors [9]. From a patient perspective, a PHR is valuable for accessing information and sharing health information with the ones s/he wants. From a healthcare practitioner perspective, the usage of a PHR could contribute to better coordination with the patient and the possibility to access information that surpasses organizational boundaries.

### B. PHR as Hybrid Informations Spaces

Researchers in CSCW have been discussing how to conceptualize PHRs. Cabitza et al. [6] argue that conceptualizing PHRs as tools that can just support the flow of information mitigates their full potential to be more collaboration and communication oriented. Thus, they suggest framing PHRs as hubs where patients and healthcare practitioners meet to enhance a collaborative relationship. Cabitza et al. [6] have defined the concept of InterPersonal Health Record (IPHR) as a hybrid electronic record that merges the typical EMR and PHR related features that aim at enhancing “relationships, communication, and collaboration between citizens/patients and their healthcare practitioners” [6]. The emphasis on the interpersonal aims to highlight the involvement in the management of care of both patients and healthcare providers. Cabitza and Gesso [5] describe MEDICONA as an example of an IPHR. MEDICONA implements the concept of a shared record among different user types, in addition to electronic messaging [5] and is described as an IPHR. Further, they discuss how the IPHR can be conceptualized as a CIS, where patients and healthcare practitioners can access the information that they need regarding health management in a common space. This conceptualization is compatible with Lahtiranta et al. [10] health spaces defined as collaborative information space for patients and health providers, which are not limited only to healthcare-related encounters.

Unruh and Pratt [11] identify a set of functional requirements for an information space designed explicitly for patients' cooperation with clinicians. They define explicit representations and increased interaction as a way that CIS can facilitate cooperation between patients and their clinicians.

Recently, Vassilakopoulou et al. [7] have conceptualized PHRs as information spaces of a hybrid character. They state that “PHR can be more than a private tool, serving as CIS that straddles work and non-work contexts, bringing together participants – patients and professionals – in a collaborative relation”. Thus, considering PHR as personal information space (serving sensitive health information management need) and CIS (stressing the cooperative dimension of the patient- healthcare practitioners' relations). They have analyzed and discussed two cases of a PHR: a) MyHealth, which gives the possibility to the patient to access and store

personal health information, and supports electronic exchanges between patients and healthcare providers. Moreover, it offers connections to several existing systems and the possibility for other applications to connect and extend the core functionality [7], and b) MyBook, which facilitates information sharing between the patient and his/her GP [7]. The cases described, such as MEDICONA, MyHealth, and MyBook, are examples of PHRs which facilitate communication, awareness through records, and collaboration based on the information shared in the common space. However, this literature considers mainly cases when the patient is outside of the hospital and has only occasional health encounters with the healthcare practitioner. The literature on PHRs has not yet addressed the use of PHRs in hospital/clinical context. In this context, it is assumed that patients do not need to have access to their health data as they are in close contact with clinicians. However, as patients are asked to cooperate/work together with clinicians (and not just receive care), they also need tools that enable them to take up this role. Thus, the case described in this paper contributes to the conceptualization of PHRs in a hospital setting in a context where the patient has to actively participate in the care practices (not only receive care).

### C. Common Information Spaces

In CSCW, PHRs have been defined as CIS or hybrid information spaces. While personal information spaces refer to patients' individual needs in managing health information that is personal to them, the concept of CI has been discussed in CSCW. In this subsection, we will present a deeper understanding of CIS as a concept.

CIS is a conceptual framework in CSCW which highlights the relationship between actors, artifacts, information, and cooperative work [12]. The aim is to provide an analytical tool that can inform developing systems that can support cooperative work [12].

CIS “encompasses artifacts that are accessible to a cooperative ensemble as well as the meaning attributed to these artifacts by the actors” [12]. In cooperative work settings, actors are interdependent. This requires that they coordinate who is doing what, when, and why [13]. Thus, what is called articulation work takes an important role. Articulation work as the supra type of work, which is necessary for the division of labor [12][14], can be facilitated by the usage of artifacts or mechanisms of interaction [15]. According to Schmidt and Bannon [12], CIS is necessary for distributed cooperative work to maintain some form of shared and locally and temporally created understanding about objects in the CIS.

An important characteristic of CIS is the openness and closure and the need for a balance between the malleability of information and the need for some closure to allow for translation among communities. In making this possible, a balance of interpretations among different webs of significance (as called by Bossen, representing people from different groups) is needed [13]. Hence, CIS requires a new

type of articulation work, which makes possible the coordination of interpretations.

In healthcare, there are some examples of CIS, such as [16] in which the influence of the physical position of artifacts used in a CIS in a hospital is investigated. In [17], CIS were investigated in emergency teams in hospitals.

Bossen [13] describes seven parameters of CIS such as the degree of distribution; the multiplicity of webs of significance; the multiplicity and intensity of means of communication; the level of required articulation work; the web of artifacts; the immaterial mechanisms of interaction and the need for precision and promptness of interpretation. Bossen [13] as well build his analysis of CIS in a hospital ward.

A relevant parameter for this paper is the “web of artifacts” described as material mechanisms of coordination to make possible cooperation among the distributed actors and having a better overview of the state of the work possible. Based on this definition, a PHR as a material artifact in the hand of the patient in which the patient can communicate, collaborate, cooperate with the healthcare practitioners, is a mechanism which materializes a CIS between the patient and healthcare practitioners.

In the literature, different types of artifacts that support a CIS are described. Bossen refers to the web of artifacts as material coordination mechanisms by referencing to coordination mechanisms as defined by Schmidt and Simonee [15]. However, Bannon and Bødker [18] have discussed that what is defined as boundary objects from Star and Strauss [19] can be as well used as a means for sharing items in the CIS. Thus, another type of web of artifact in CIS. The concept of boundary objects and coordination mechanisms have differences, as discussed in [20]. In this paper, we are particularly interested in coordination mechanisms and will get back to this concept in our discussion.

### D. Coordination Mechanisms

Coordination mechanisms have been defined [15] as “a specific organizational construct, consisting of a coordinative protocol imprinted upon a distinct artifact, which, in the context of a certain cooperative work arrangement, stipulates and mediates the articulation of cooperative work to reduce the complexity of articulation work of that arrangement.” Thus, coordination mechanisms are artifacts which aim to reduce the complexity of the division of labor in a cooperative work setting and make cooperation possible. The concept of the coordination mechanism, as defined, describes a material artifact. This approach has been considered narrow by Bossen [13], who emphasizes that organizational structures and division of labor also facilitate coordination of work since they explicate who does what and when. Hence, as another parameter of CIS, Bossen lists the immaterial mechanisms of interaction for these other constructs, which facilitate articulation of cooperative work. Coordination mechanisms aim to coordinate activities among semi-autonomous actors who should have a certain level of consensus in order to get the job done [20].

The PHRs that have been described in the literature as CIS [5][21]-[22] or hybrid information spaces [7] show mostly cases of artifacts that offer a space where the information is shared, and communication and collaboration are supported, thus resembling coordination mechanisms. However, they lack an aspect of a more cooperative relationship between the patient and the healthcare practitioners, where the patient has an active role in his/her care by taking over tasks and work in the division of labor. Moreover, cases of CIS discussed in healthcare [13][16]-[17] are mostly focusing on hospital wards and describing the need for sharing information among healthcare practitioners. The patient's voice and visibility in the process lacks. Hence, in this paper, we describe, in the next section, a case of a hospital ward where the CIS also involves the patient. Moreover, the requirements for a PHR are not only communication and sharing information but entering a cooperative relationship where the patient and the healthcare practitioners supporting him/her are interdependent on each other.

### III. DESCRIPTION OF THE COGNITIVE REHABILITATION EXISTING PRACTICES

We studied the process of cognitive rehabilitation in the CU of a rehabilitation hospital in Norway. The unit is specialized exclusively for offering cognitive rehabilitation. Cognitive rehabilitation is a special rehabilitation program that is offered to people that suffer from cognitive impairments after an Acquired Brain Injury (ABI). ABI is brain damage acquired after birth. The causes of ABI can be "from a traumatic brain injury (i.e., accidents, falls, assaults, etc.) and non-traumatic brain injury (i.e., stroke, brain tumors, infection, poisoning, hypoxia, ischemia, metabolic disorders or substance abuse)". The cognitive rehabilitation aims to support the patients in therapeutic manners, thus, either improving his/her functions in daily life or helping the patients to find alternative ways for compensating the lost functions through additional aids. Rehabilitation, as defined by the Norwegian Health Authorities [23], requires a multidisciplinary team that works together with the patient during rehabilitation. The multidisciplinary team involves different healthcare practitioners.

In our study in cognitive rehabilitation, the multidisciplinary team is usually compounded by the medical doctor, a nurse, an occupational therapist, a physiotherapist, a psychologist, a social worker, and a speech therapist. This team assists the patient throughout the 5 five weeks of rehabilitation at the hospital. Each offers specialized care to the patient based on their domain of knowledge.

Rehabilitation is based on the goal-setting theory. This theory is defined broadly as a process in which the patient and members of the multidisciplinary team agree on a set of rehabilitative goals to be achieved during the rehabilitation program [24]. Goal-setting is not only an administrative tool, but it is considered a clinical intervention. [24]. It has been shown that setting personal goals increases the possibilities of

behavior change by increasing motivation (the desire to act in a particular way) [25].

In the CU, the rehabilitation process is built based on the goal-setting theory. Thus, a patient, in collaboration with the multidisciplinary team, has to decide on a set of goals that s/he wants to work with during rehabilitation. Goals are mostly long term. As the time stay at the hospital is only for five weeks, the patient and the multidisciplinary team during the first week should agree on the things to prioritize for those five weeks and decide on a set of sub-goals for each main goal. The sub-goals should be SMART (Specific, Measurable, Achievable, Realistic, and Timely). As rehabilitation targets the increase in the patient's functional level in his/her daily life, the involvement of the patient in defining the rehabilitation goals is essential. The first week at the hospital, the patient meets with all the members of the multidisciplinary team one by one. In the ideal scenario, the patient comes already with a set of predefined goals, written by himself/herself. However, in many cases, the patient is not able to define his/her rehabilitation goals, and the multidisciplinary team members should help him/her. If the patient is not cooperating with the team, it is a risk that not relevant and specific goals would be set, and the result of the rehabilitation will be mitigated. The refining of goals comes together with the definition of a set of interventions that the patient would go through at the hospital to be able to achieve the goals. Interventions are defined as "an act performed for, with or on behalf of a person or population whose purpose is to assess, improve, maintain, promote or modify health, functioning or health conditions" [26]. It is absolutely relevant to the involvement of the patient in the process, so the patient later understands why s/he is doing different activities at the hospital.

The goals, respective sub-goals, and the interventions for each sub-goal are stipulated in a document called the goal plan document. This document is originated in the hospital EMR as part of the patient record. The goal plan is conceptualized to be shared with the patient as the main document of coordination between the team and the patient in rehabilitation. The document is designed to show the goals, sub-goals, and interventions, the team member that is responsible together with the patient for a specific intervention, and some more mechanisms that can help keep track of how the patient is advancing during rehabilitation. As the document is in the hospital EMR, the patient cannot access it. So, a printed version is given to the patient from the start. The electronic document is then shown during a meeting where all the multidisciplinary team, the patient, and if willing any of the patient's kin would go through the goals and agree on the final version. The final version will then be printed out and given to the patient.

During the time at the hospital, the patient receives a weekly plan every beginning of the week. The weekly plan involves all the activities that the patient should do during the week. The weekly plan is not part of the patient records in the EMR. It is maintained in a shared word document and printed

out for each of the patients. If changes are made, the team member that implements the change can print another version or, in some cases, the patients write over the paper. The activities in the weekly plans should relate to any of the interventions in the goal plan and consequently contribute to the patient's sub-goals. This connection is very important to be highlighted for the patient as part of his/her rehabilitation process. However, the restriction that the current procedure and materiality of the artifacts imposes is not exploring the whole potential.

When the five weeks of rehabilitation are finished, the patient returns home. S/he can continue rehabilitation by his/her own or receives additional help from local rehabilitation therapists. The plan on how the patient should continue rehabilitation home has been made since s/he was at the hospital. The therapists at the hospital have established some connections with local therapists. It is important that the patient continues training with rehabilitation goals and sub-goals and keeps us with respective interventions as taught at the hospital.

#### IV. METHODS

##### A. Data collection

The data that we have analyzed for this paper has been collected in two phases under the umbrella of the same project called "Patient Empowerment in Cognitive rehabilitation through the use of technology", which is a joint research initiative between a rehabilitation hospital and a university college in Norway.

Initially, as part of the initiative in boosting patients' involvement in their rehabilitation, the hospital decided to redesign the goal plan document and the procedures surrounding it. To redesign the document, a Participatory Design (PD) approach with workshops was taken in April-May 2018. First, the first author of this paper facilitated three workshops with a total of 10 patients, asking how to redesign the goal plan document (Figure 2) to make them want to engage more in their rehabilitation (more in detail this has been reported in another publication [27]). Second, the first author of this paper organized two PD workshops with the multidisciplinary team at the CU (20 participants). The healthcare practitioners were presented with a list of requirements from the patients' workshops and were invited to discuss these requirements and propose a new design of the document which would fulfill patients' requirements and, at the same time, fit within their routines and procedures. With the data collected, a redesigned document (as shown in Figure 2) was launched in June 2018 and has been in use ever since. Data collected were audio recordings of the workshops and designs of the new goal plan version from each of the participants. All participants signed a consent form before the workshops, and the data collected has been stored in safe locations at the hospital premises.

In the second phase, ethnographic observations of the rehabilitation process at the CU from an extended period of 6

months, August-December 2018, were conducted. Together with the CU management, we decided that for the ethnographic observations, the researcher (first author here) should shadow each of the health practitioners in the multidisciplinary team for a short period of time. This would minimize the stress of the patients and would give us the possibility to investigate the illness journey of more patients. The first author shadowed two occupational therapists respectively for 4 and 3 working days (8 hours shift during the day shift because in the afternoon most of the patients would go in their homes and no rehabilitation activities were planned at the unit) and participated in activities with 12 patients, one nurse for 6 days and met 5 patients, one physiotherapist for 4 days and met 8 patients, one speech therapist, one social worker for 4 days and met 8 patients and one psychologist for 1 day and met 1 patient. Handwritten notes were taken while observing. These notes were expanded with details at the end of each day when transcribed digitally. Digital notes were saved in a folder in the safe hospital network that the first author can access through an encrypted laptop given by the hospital. The staff member asked the patients for consent before the researcher would participate in any patient-staff meeting. This was documented by signing a consent form.

##### B. Analysis

Overall, a qualitative interpretative research approach [28] was adopted. First, the data collected were analyzed with the aim of defining a list of implications for designing a PHR for patients in cognitive rehabilitation. Second, reflections on these implications with the theoretical lenses of hybrid information spaces [7] were conducted. The principles defined by Klein and Myers [28] were used to do an interpretive analysis of the data collected in the two phases described in the previous section. We describe the process more in detail below.

Initially, the first author analyzed the audio-recorded data from the workshops and the designs of the patients and staff. Considering that the design requirements that emerged during the workshops were focused on the redesign of the goal plan document, which is a patient health record, the first author interpreted them with the perspective of possible design implications for a PHR. Moreover, the implications for design that emerged during the first iteration of interpretative analysis were supplemented and refined while analyzing notes from the observation period. The first author used a grounded theory approach to analyze the observation notes and defined a set implications for designing a PHR in cognitive rehabilitation in a hospital.



collaborate with a healthcare practitioner [1]. From the analysis of our data, we find that a PHR in cognitive rehabilitation should support not only common information and communication but also a cooperative work relationship between the patient and the multidisciplinary team. Hence, the PHR should facilitate the tasks that the patient should do and coordinate these patient's tasks with the tasks of the healthcare practitioners.

3) *Support different representations* – As stated above, rehabilitation goals can be divided into sub-goals, and for each sub-goal, there is a set of interventions. This tree structure is seen differently by the patient and the multidisciplinary team perspective. For the patients, the rehabilitation goals relate to the need for functioning in everyday life and should be articulated in that way. For the multidisciplinary team, the decision on rehabilitation goals and interventions is influenced by rehabilitation theories [29]-[31]. Thus, different representations of the same information are needed. During the PD workshops, we found that a classification of goals as defined by the International Classification of Functioning, Disability, and Health (ICF) [32] (as in Figure 1) was preferred more from the team. However, patients in workshops expressed that they did not relate to the classification of goals based on ICF and that “did not make sense” to them. One patient said, “is easier.. I want to have my goals, sub-goal and interventions... is that simple”. Hence, designing a PHR for cognitive rehabilitation while the patient is at the hospital requires that the health information shared with the patient should be explicitly represented in a way that the patient can understand.

The case of a representation of a health record in a format that relates more to healthcare practitioners is very common. PHRs should surpass this downside of the current way of delivering healthcare and support an explicit representation of the information for the patients – in a way that facilitates how they interpret the information. The label of this implication for design is adapted from Unruh and Pratt [11]. Such an implication for design is not unique to cognitive rehabilitation, but it is of extreme relevance in the case of cognitive rehabilitation due to the cognitive impairments that the patients in this patient group face.

4) *Integrate elements that can support enhanced interactions* – “We want to be asked how we feel in relation to our rehabilitation goals every week,” said one of the patients in the workshops. While at the hospital encounters between the patient and healthcare practitioners is quite intense, our participants in the workshops expressed that they would like to have more encounters with the multidisciplinary team where they can share their opinion on how rehabilitation is progressing. It is relevant to consider this when designing a PHR that supports cognitive rehabilitation. The PHR should integrate elements that can support the patient to have their say in rehabilitation and share their feedback with the multidisciplinary team.

However, in interactions, the two sides that should interact should agree. We found that the team agrees that

more interactions with the patient to ask about their perception of achieving goals would benefit the patient. This, however, would require changes in their routines, and they cannot be overwhelmed with data and consultation sessions (in analogy with Tang and Lansky [33]). For example instead of asking the patient every week on how they feel the PHR can support the patient to enter this information every week in his/her health data and be able to have maybe a meeting of discussing the information saved in the PHR every second week with one from the multidisciplinary team members. The interaction with the team will increase as the patient is giving feedback. Moreover, the encounter between the patient and the team member would be more meaningful as the discussion can be facilitated by the information kept track in the PHR on which both sides have agreed and share a common interpretation.

Thus, in cognitive rehabilitation, a PHR that can support and enhance interactions is needed. Moreover, the PHR should be flexible enough to support the negotiation of these interactions. This implication for design is more specific to the case of using PHRs in hospitals where the patient has more possibilities of encounters with the healthcare practitioners.

5) *Facilitating for personal spaces and having the possibility to negotiate boundaries for cooperation and coordination* – We found that patients' rehabilitation is individual. A PHR that aims to support the patient in cognitive rehabilitation should take into consideration the possibility of adapting to specific health information needs for the patient. During the workshops, patients expressed that they would like to have the possibility to keep notes and possibly share some of these notes later with the nurse or someone from the multidisciplinary team. During the observations, we saw patients writing and personalizing the goal plan and weekly plans, as well as other health information given at the hospital. The PHR should offer the patient this additional functionality to enable personalization that can fit the need for personal information spaces.

However, a patient's private space is challenged by the need for cooperation and coordination with the multidisciplinary team. For example, before setting the goals, patients are asked about their life. They receive a file that aims to find out more about their life before and after injury in the attempt to define better rehabilitation goals. Patient information, in this case, can be private, and the patient decides how much to put on the common space. However, not sharing part of this information would undermine the collaboration with the team and the definition of better rehabilitation goals. Thus, a PHR for cognitive rehabilitation in hospital should create the possibility for the patient to a) have personal spaces b) have the possibility to negotiate the boundaries of public and private spaces of information shared and decide where the boundaries stand and c) integrate elements that would motivate patients in expanding boundaries when the discloser of the information can improve rehabilitation.



6) *Support continuity after the hospitalization period* – This requirement surpasses the boundaries of the hospital, but it is necessary to bring up because continuing the rehabilitation therapies started at the hospital is determinative for rehabilitation success.

The rehabilitation is more related to what Wagner et al. [34] describe as the patient's Self-Management and Behavioral Change Support, which needs support for continuity. The patient should have the possibility to continue using a goal plan when moving from the hospital to home. Also, the patient should have the possibility to carry his/her own medical history from the time at the hospital and share that further with others that s/he considers relevant such as kin or local rehabilitation specialists. This is relevant since, in rehabilitation, the patient is not 'cured' once s/he leaves the hospital. Continuity of care is very important in the rehabilitation journey. The rehabilitation is considered finished when the patient achieves a desirable level of function [23].

Finally, the PHR design implications listed here are recommended for the case of cognitive rehabilitation in a rehabilitation hospital. The first two implications for design are special for cognitive rehabilitation. Instead, design implications 3-6 are not exclusive for a PHR in cognitive rehabilitation, but they have become specifically relevant for a PHR in cognitive rehabilitation.

## VI. DISCUSSION: A CONCEPTUAL UNDERSTANDING OF A PHR IN COGNITIVE REHABILITATION

PHRs are considered tools that facilitate patients' involvement and give them more control over their health information [2]. Moreover, a PHR shows the invisible work that the patient does in managing his/her personal health records [7]. Our case shows that this is especially important in rehabilitation, where the patient should have higher control over his/her health information, be actively involved, and become the one leading his/her own rehabilitation. This is not only a need but a necessity for the success of rehabilitation [29]. Thus, PHRs are tools that can make a difference in the outcome of the care for patients that have passed the acute phase and are in need of rehabilitation. This paper contributes to the design and construction of a PHR in cognitive rehabilitation specifically, but we also present insights that can be relevant in rehabilitation in general. While in the previous section, we described a set of implications for design that should be taken into consideration in designing a PHR for cognitive rehabilitation based on the analysis of our empirical case, in this section, we will take a more conceptual perspective and discuss the conceptual implications of our study.

### A. Hybrid Information Spaces

Vassilakopoulou et al. [7], in their paper, have argued for a conceptualization of PHRs as hybrid information spaces serving personal health information management needs (private information spaces) and facilitating information

sharing between patients and healthcare professionals (CIS). We argue that a PHR designed for patients in cognitive rehabilitation also works as a hybrid information space as it is partly personal and partly common. We discuss these two aspects in the following subsections.

1) *PHR in cognitive rehabilitation as a CIS* - Cognitive rehabilitation involves several actors from different disciplines working together with the patient in an interdependent cooperative relationship and using a series of artifacts to facilitate their collaboration and interpretations. While the multidisciplinary team members have a high level of awareness of the other webs of significance in the team (so a nurse is aware of what an occupational therapist does), the situation differs for the patients. Due to the patients' challenges in cognition, there is a higher need for interpretative articulation work despite physical closeness [18]. Thus, in this setting the CIS includes a) the information that is stipulated in the goal plan b) the information that the patient receives from each of the multidisciplinary team members as part of the rehabilitation therapies and c) the information the patient generates during rehabilitation such as notes or patient journey stories which are then shared with the team. The patient and the multidisciplinary team member have to interpret this information shared in the common space in order to do their part of the work.

Two coordination artifacts [13] are used to facilitate the sharing of the information in the common space between the patient and the multidisciplinary team: the goal plan document and the weekly plan. However, patients and the team have different needs for their interpretative work. The team has a higher understanding of the information. However, they as well are new in the CIS, which is created in the case of a new patient. Thus, they need to put more effort into interpreting the patient's individual and personal needs and goals. In rehabilitation, there are artifacts in place for sharing common information. Thus, enhancing the practice of these existing artifacts by moving from paper to digital should be considered when designing the PHR. Our findings show that a PHR needs to be a flexible tool in order to facilitate the interpretation of the common information. For instance, changes in CIS openness and closeness is important to adapt to each of the patients' requirements regarding the continuity of their rehabilitation and integration with information from other rehabilitation settings (outside of the hospital).

2) *PHR in cognitive rehabilitation as a Personal Information Space* - The rehabilitation process is individual and closely related to the specifics of the patients. A patient receives personalized information regarding his/her rehabilitation. One of the most important requirements is that patients are able to construct personal interpretations of this information that they can use on their own to continue rehabilitation. Providing the patients with a tool that facilitates the personal health information management based on their individual needs is of a strong relevance in rehabilitation where the increased awareness of patients



toward their rehabilitation treatment is the core part of the treatment itself.

Thus, our findings show that in addition to supporting and enabling a common space for information sharing, the PHR should also be designed for personalization.

### *B. PHR in cognitive rehabilitation as a coordination mechanism*

Coordination of activities, as described above, is relevant in rehabilitation. Having a CIS would give access to the same information, but it will not make sure that this will be used in a cooperative way between the patient and the multidisciplinary team. For example, when defining the rehabilitation goals, a PHR conceptualized as a CIS will give the possibility to have the goals shared. However, it will not guarantee that these goals would be written or initiated by the patient. To create a cooperative procedure that would support the process of rehabilitation and give patients a more explicit role in their rehabilitation, the PHR should integrate a requirement that the patients write the first version of the rehabilitation goals, and then the team looks at it and maybe approves the goals. Bossen [13] has described a set of parameters of CIS. Among the parameters are the web of artifacts, described as mechanisms that support the cooperation and facilitate interpretations in the CIS [18]. Bossen [13] further refers to this as coordination mechanisms described by Schmidt and Simonee [15]. Coordination mechanisms are not only means for sharing items in a CIS. They have the characteristics of supporting the coordination of activities in a cooperative setting where cooperative work between interdependent actors is happening. We have described coordination mechanisms in Section 2.D. In analogy to the characteristics of coordination mechanisms, the actors that are seeking cooperation - the patient and the multidisciplinary team - are interdependent in rehabilitation. They are as well interdependent in defining the goal plan and keeping track of activities during rehabilitation. Moreover, consensus is required between the patient and the team in order to do the interventions in rehabilitation. Thus, in cognitive rehabilitation, coordinating activities is needed in addition to accessing the CIS.

So, designing a PHR in cognitive rehabilitation accounts for a coordination mechanism between the patient and his/her multidisciplinary team. This will contribute to making explicit the patient contribution in his/her rehabilitation, increase the level of awareness regarding the activities that happen as part of his/her treatment, and as well influence patient's health literacy, involvement, participation in decision-making, and self-management.

Hence, we conclude that a PHR in cognitive rehabilitation can be conceptualized as a hybrid information space [7]. However, within the hybrid information space, our findings also show that the PHR should also work as a coordination mechanism [15] that recognizes the patient's position as part of the division of labor, supports the process of rehabilitation, and empowers the patient. The PHR as a coordination

mechanism would vary based on the diagnosis, patient's ability, the scale of willingness to be involved in his/her treatment, and the medical practitioners' commitment to supporting the patient. How much coordination and on what tasks the patient can take charge should be considered in individual cases. However, starting by discussing and recognizing the PHR as a coordination mechanism contributes to making the patient role in his/her care more active than just the receiver of care. A feeling of involvement, even in small tasks, will increase the perceived empowerment. The conceptualization of the PHR as a coordination mechanism also puts the burden on the staff as an important element in the coordination. Thus, the patient can feel safer and not left alone.

## VII. CONCLUSION AND FUTURE WORK

In this paper, we presented the case of cognitive rehabilitation. We defined a set of implications for design of a PHR for a patient in cognitive rehabilitation such as: Enhance the existing shared artifacts; Implement elements of coordination; Support different representations; Integrate elements that can support enhanced interactions; Facilitating for personal spaces and having the possibility to negotiate boundaries for cooperation and coordination; Support continuity after the hospitalization period.

Moreover, we discussed the design of a PHR for cognitive rehabilitation in hospitals under the current conceptualization of PHRs within CSCW as hybrid information spaces compounded by personal information space and CIS. We conclude that a PHR in cognitive rehabilitation can be conceptualized as a hybrid information space [7]. However, its development as a coordination mechanism that recognizes the patient's position as part of the division of labor will support the process of rehabilitation and empower the patient. The analysis of our case also contributes to the design of PHRs in the context of the hospital. Cognitive rehabilitation represents a very special case of hospitalization. Thus, as part of our future work, we want to investigate further if the implications for design for this specific case of hospitalization can be replicated in other cases or not. Moreover, the implications for design presented in this paper will be the bases for developing a PHR for cognitive rehabilitation as part of an inter-regional funded project by 2021.

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