Designing digital systems for rehabilitation practices

Gunnar Ellingsen
Professor, Department of Health and Care Sciences, UiT – The Arctic University of Norway
Norwegian Centre for E-health Research
gunnar.ellingsen@uit.no

Cathrine Arntzen
Professor, Centre for Care Research North, Department of Health and Care Sciences, UiT – The Arctic University of Norway
Division of Rehabilitation Services, University Hospital of North Norway
catrhine.arntzen@uit.no

Lina Forslund
PhD Candidate, Department of Health and Care Sciences, UiT – The Arctic University of Norway
lina.forslund@uit.no

Morten Nikolaisen
PhD Candidate, Department of Health and Care Sciences, UiT – The Arctic University of Norway
morten.nikolaisen@uit.no

Marianne Eliassen
Associate professor, Department of Health and Care Sciences, UiT – The Arctic University of Norway
marianne.eliassen@uit.no

Astrid Gramstad
Associate professor, Department of Health and Care Sciences, UiT – The Arctic University of Norway
astrid.gramstad@uit.no

Unn Manskow
Associate professor
Department of Health and Care Sciences, UiT – The Arctic University of Norway
Norwegian Centre for E-health Research
unn.e.manskow@uit.no

Abstract
The trajectories of patients in need of long-term rehabilitation services are extremely complex. Therefore, strengthening the rehabilitation field requires increasing organizational resilience to ensure robust processes and efficient collaboration and communication. In this study, we explored how digital systems can promote organizational resilience in rehabilitation practices. Methodologically, we applied an experience-based co-design approach in which we held three day-long creative workshops with approximately 40 participants each in 2021 and 2022. The goal was to design a digitally supported model for the care and rehabilitation of patients with acquired brain injuries. This paper presents the themes related to digitalization that emerged from the discussions in the workshops. The paper develops the argument that designing digital systems for resilient rehabilitation practices is far more than merely a technical issue. It requires broad sociopolitical engagement to put rehabilitation on the political agenda, and designers need to take a stance on both organizational and ethical issues. Analytically, we draw on the theoretical concept of information infrastructure and the theoretical concept of articulation work.

Keywords
Rehabilitation, acquired brain injury, digital systems, resilience, invisible work

What is already known about the topic:
- Current digital systems supporting the rehabilitation trajectory lack updated clinical functionality and mutual integration. Consequently, health professionals, patients and next of kin need to perform informal and invisible work to maintain the trajectory.

What this study adds to our knowledge:
- Two principles for designing digital systems can promote organizational resilience. First, designing digital systems for the rehabilitation field needs to take the situation on the ground as the starting point for a careful step-by-step design process in which the users are involved. Second, designing for the rehabilitation field requires sociopolitical engagement to promote rehabilitation at the strategic healthcare and political levels. In this process, designers cannot assume a neutral position; they need to take a stance on both organizational and ethical issues.

Introduction

Western healthcare is facing an ageing population, tighter budgets caused by decreasing public revenues, and new medical technology that allows patients with complex conditions to live longer (EHDIR, 2018). Consequently, current estimates suggest that by 2060, one-third of the working population will be employed in the healthcare sector (HelseOmsorg21, 2021). These prospects challenge both the sustainability and the responsiveness of the healthcare system: on one hand, it is necessary to secure resources and provide services in the long run; on the other hand, the healthcare system should be responsive and capable of managing unexpected events.

A possible strategy to address these challenges is to refocus health services on prevention and rehabilitation to reduce the impact of various health conditions, diseases, and injuries (WHO, 2022). Accordingly, the national health authorities in Norway aim to strengthen the user perspective and offer users and their families quality rehabilitation services in the areas of their residence (HOD, 2017). However, the trajectories of patients in need of long-term rehabilitation services (e.g., patients suffering acquired brain injuries (ABIs)) are extremely complex. Such patients often require highly personalized treatment and care indefinitely and the involvement of many different health professionals in a field that has thus far been a low priority (KPMG, 2020). Consequently, strengthening the rehabilitation field requires promoting organizational resilience to ensure robust and flexible processes (Tengblad and Oudhuis, 2019) and the ability to collaborate (Mark and Semaan, 2008) and communicate (Norris et al., 2008) efficiently.

Digital systems can contribute to organizational resilience because, among other things, they can support home-based follow-ups and support patient trajectories (HelseOmsorg21, 2021). However, the existing digital systems in Norwegian healthcare lack updated clinical functionality and mutual integration. Consequently, health professionals and next of kin need to perform informal and invisible work to maintain the rehabilitation trajectories (Star and Strauss, 1999). This situation poses major challenges for the development of digital solutions that can work well in the rehabilitation field. At the very least, we cannot expect rehabilitation data to flow seamlessly from one place to another without behind-the-scenes intervention (Denis, 2016).

Given the above, the following research question arises: *How can digital solutions contribute to organizational resilience in complex rehabilitation practices?*

To address this question, we held three day-long creative workshops. This paper develops the argument that designing digital systems for resilient rehabilitation practices is far more than merely a technical issue. It requires broad sociopolitical engagement to put rehabilitation on the political agenda, and designers need to take a stance on both organizational and ethical issues.

The rest of this paper is organized as follows: The next section describes the concepts used in this study. The Method section explains the methods employed. The subsequent section presents the results. The following sections discuss the results and present the conclusions.

Theory

In Norway, healthcare services are obligated to provide stroke patients with treatment, rehabilitation, and follow-ups according to national guidelines (HOD, 2022). All patients have the same rights to a standardized plan for diagnostics, examinations, and treatment at the right time, from the onset of symptoms to three months after an ABI. The goal is to provide equal treatment and follow-ups regardless of one's place of residence, avoid delays in the acute and rehabilitation trajectories, and keep patients well informed of the components of the various phases following an ABI.

When referring to human beings, the term *resilience* is defined as an individual's ability to adapt positively in the face of adversities, traumas, or threats (Fontes and Neri, 2015). Many people suffering an ABI become functionally dependent and socially isolated and experience depression and anxiety. This affects recovery, quality of life, and survival (Faria et al., 2017). However, some people manage to overcome these difficulties thanks to their resilience, although many need multi support to overcome their impairments/disabilities.

However, individual resilience does not take us very far when the focus is on digital support for the entire rehabilitation trajectory, in which many stakeholders (health personnel, patients, relatives, etc.) are involved. Therefore, we need to change the focus from individual to organizational resilience to ensure robust and flexible processes (Tengblad and Oudhuis, 2019) and the ability to collaborate (Mark and Semaan, 2008) and communicate (Norris et al., 2008) efficiently. Digital systems can play a role in all these areas.

To gain a better understanding of the digital dimension in the ABI patient trajectory, we need a theoretical concept that encompasses all the different systems in the trajectory. In this regard, it is particularly useful to apply the concept of *information infrastructure*, which has been used to study the design, implementation, and use of large-scale information systems (Aanestad et al., 2017; Ellingsen et al., 2022; Star and Ruhleder, 1996). Systems in an information infrastructure are never standalone entities; they are integrated or interdependent and deeply embedded in routines and practices. In a rehabilitation trajectory, an information infrastructure consists of many systems, healthcare personnel, institutions, and work routines. According to the information infrastructure concept, digital systems are never built from scratch; instead, they grow through the evolution of the installed base (Aanestad et al., 2017). This is an ongoing co-construction process involving technical and social elements (Ellingsen et al., 2022; Star and Ruhleder, 1996). During its evolution, the installed base grows and increasingly shapes its environment. For this reason, it is difficult to replace it. Therefore, new digital functionality must be carefully introduced to an installed base or adjusted in a stepwise manner. It is a process of constant negotiation and compromise among various stakeholders to achieve stability and alignment (Latour, 1987).

Atkinson (1995) points out the richness, complexity, and messy character of healthcare work. This is reflected in rehabilitation practices, with many different health service provid-

ers, patients, and next of kin needing to communicate and coordinate distributed work. The theoretical concept of *articulation work* has been used to describe the "activities required to manage the distributed nature of cooperative work" (Schmidt and Bannon, 1992: 7). Articulation work is "work that gets things back 'on track' in the face of the unexpected and modifies action to accommodate unanticipated contingencies" (Star and Strauss, 1999, p. 10).

An essential characteristic of articulation work is that it is often invisible to rationalized models of work (Star and Strauss 1999; Suchman, 1995). Star and Strauss (1999) note that invisible work is linked to where one stands in the professional hierarchy. Typically, physicians reside at the top, while therapists, patients, and next of kin find themselves further down the hierarchy, where they need to perform invisible work. Therefore, in design activities for the rehabilitation field, it is necessary to understand and engage in the dynamics between invisible and visible work (Denis, 2016; Star and Strauss, 1999; Suchman, 1995), both professionally and process-wise. Concrete design proposals can feed into and change these dynamics. However, this questions designers' traditionally neutral role – where they just develop systems in accordance with a requirement specification – as such design activities require that designers side with user groups in a weaker position at the expense of groups in a stronger position (Beck, 2002).

Method

This study is based on social constructivism where reality is socially constructed among the participants (Burr, 2015). Methodologically, we employed an experience-based co-design approach (Bate and Robert, 2006; Donetto et al., 2015) that draws on participatory design (see, for instance, Simonsen and Robertson, 2013) and user experience design, aiming to improve quality in the healthcare sector.

We held three day-long creative workshops with approximately 40 participants each from Northern Norway in 2021 and 2022. The participants included healthcare professionals, such as occupational therapists, physiotherapists, and nurses, personnel from the Norwegian Labour and Welfare Administration (NAV), ABI patients in the rehabilitation phase, and some relatives. General practitioners (GPs) were also invited, but none of them attended.

The workshops' overall goal was to lay the foundation for a digitally supported model for the care and rehabilitation of ABI patients. This paper presents the themes related to digitalization that emerged from the discussions in the workshops. In each workshop, we divided the participants into smaller groups to encourage discussion. In the first workshop, the participants engaged in discussions about experiences and problems related to the rehabilitation process. Some participants voiced concerns that personnel at the health policy level and GPs did not attend. To address these concerns, the research project established a top-level reference group to anchor the research activities into regional strategies for the rehabilitation domain. Moreover, a lack of robust digital support emerged as a key issue, albeit not explicitly. In the second workshop, we invited the participants to brainstorm ways to improve the rehabilitation process without dwelling too much on economic, organizational, and technical constraints. From a digital perspective, several participants suggested that everybody should use the same electronic health record (EHR) system, indicating considerable frustration with their current systems. In the third workshop, we held a session on digital design, in which we used the outcomes of the first two workshops as a backdrop and reintroduced some of the constraints that the stakeholders experienced in daily practice. To gain a more detailed insight into the entire rehabilitation pathway, we also conducted

two one-hour interviews after the workshops. The interviewees were a physiotherapist at the university hospital and an ABI patient's relative, both of whom had participated in the workshops.

We analysed the empirical data from several perspectives. We shifted our focus back and forth in an iterative manner between the viewpoints of the different stakeholders, as well as national ambitions related to digital systems in the healthcare sector. We thoroughly discussed the data among ourselves to obtain a balanced picture of the data. Theoretical tools are important for focusing and performing an analysis (Jarzabkowski et al., 2016). The themes that emerged from our data were informed by the information infrastructure framework and its focus on issues and challenges related to the implementation of large-scale information systems. Accordingly, our theoretical constructs illuminated and validated the themes on the installed base and articulation work emerging from the empirical data (ibid.).

The study has been approved by the Norwegian Centre for Research Data (ref. 659996). All participants in the project were given information about the study well in advance of the data collection, and all signed a written consent form. As researchers, we have adhered to research ethical guidelines in line with the Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects (HelsinkiDecl, 2023). The participants could see the data we collected about them, and they had the option to withdraw their consent during the study. The user representatives who participated in the study are a vulnerable group and the diagnosis they suffer from can cause them to struggle with fatigue and exhaustion. We therefore organized the workshops with frequent breaks and offered dedicated "rest rooms" for those who needed it. This patient group may also experience challenges relating to detailed information agreements and much information flow. Accordingly, we have endeavoured to follow up these participants extra carefully in such matters.

Case

This case consists of three vignettes representing different phases of the rehabilitation trajectory. Each vignette also represents a specific perspective: that of the hospital, of the municipalities, and of the patients and relatives.

The university hospital – closely connected health personnel

The Department of Rehabilitation at the University Hospital of North Norway offers interdisciplinary assessment, guidance, and treatment in physical medicine and rehabilitation, physiotherapy, occupational therapy, speech therapy, and social work services. The treatment aims to restore physical, cognitive, and/or social function that has been lost due to an illness or injury – for example, an ABI. The department offers medical rehabilitation from the patient's first day in hospital through various phases until discharge.

The EHR system DIPS Arena was implemented at the hospital in 2021, representing a considerable functionality upgrade compared with the old DIPS Classic. Before the introduction of DIPS Arena, the department prepared itself by organizing practical demonstrations and training courses and engaging its super users in the development process. The super users' participation was useful in explaining why the therapists in the department needed a specially designed set-up in DIPS Arena. For instance, since many therapists engage in activities in many departments, there were many discussions on how to organize and grant them access to DIPS Arena. According to a hospital physiotherapist, "It has worked quite well. I believe that most health personnel find DIPS Arena more useful and functional than the old DIPS Classic. It is easy to have an overview of the big picture."

The therapists use DIPS Arena actively throughout the day. When the Department of Rehabilitation receives a new ABI patient, the therapists first read the admittance report in DIPS Arena. Then, they examine the patient themselves and write an admittance report to the department. Each morning, the therapists meet and share the status of all patients in the department and any updates and plans. As a part of this, before they meet patients, they usually brief themselves by reading the daily notes produced by the nurses and the physicians' running notes. During the day, they also write their own daily notes.

Health personnel also frequently use the so-called yellow-note messaging system in DIPS Arena to communicate informally with other health professionals at the hospital. Senders may indicate urgent cases by ticking a box. All yellow-note communication is archived in DIPS Arena.

When a patient is discharged, a physician writes a discharge letter that is sent to the patient's GP. Additionally, a therapist writes an interdisciplinary report containing information on the patient's course and status at discharge. Depending on whether the patient is discharged to an institution, home, or other places, as well as the character of the report, the report is either sent to the necessary recipients or just archived in DIPS Arena. According to a physiotherapist informant, "This procedure is handled a bit individually." Outgoing reports are sent either by post or via an electronic data interchange system if the recipients have this possibility.

As patients are discharged to various municipalities, the therapists in the department frequently need to communicate with the health service apparatus in the municipalities. Due to a lack of digital communication tools, they spend a considerable amount of time on the telephone. Sometimes, they need to call municipal physiotherapists to inform them of patients returning home who need follow-ups. If a patient needs home care, they may also call home care nurses.

An alternative method of communication could be to use the electronic PLO[1] messaging system to communicate with therapists in the municipalities. However, only nurses are allowed to communicate through PLO. If the therapists on the ward have questions or need to send a message to a municipality, they must ask a nurse to write a PLO message to a municipality nurse. The therapists find this highly problematic because they have a different focus than the nurses and would therefore send different types of messages. This indicates that the rehabilitation field is low on the political agenda, as a physiotherapist confirms:

> I see that rehabilitation is given increasingly low priority. We must work to put rehabilitation on the political agenda to highlight the importance of enabling patients to continue living in society. We need to mobilize both politicians and GPs. (hospital physiotherapist)

The municipality – coordinating interdisciplinary follow-ups
Upon discharge from the Department of Rehabilitation, the municipalities take over the responsibility to follow up ABI patients. This may include offering a permanent or temporary stay at a nursing home or providing suitable home care services. In any case, interdisciplinary follow-ups are key to successful rehabilitation and recovery of function. These may include a physician, physiotherapist, occupational therapist, and nurse, as well as access to a speech therapist, social worker, psychologist, or others. These professionals are not necessa-

---

1. Norwegian: Samhandling-pasient med behov for kommunale tjenester – utskrivningsklar pasient. PLO=pleie og omsorgs melding, også kalt e-melding.

rily employed by the municipalities; they may be employed by private businesses that offer services to the municipalities.

The variety of healthcare personnel involved in a patient's rehabilitation is reflected in the various systems used. Nursing home and home care personnel use the EHR system Profil. Self-employed physiotherapists use Physica, Profil, or WinMed, depending on the type of service that they provide. Self-employed GPs use the EHR systems System X, CGM, and InfoDoc. If a patient needs a long-term follow-up, he or she has the right to an individual plan (IP), in which case assigned health workers can use the SAMPro system to collaborate. Many of these systems are in desperate need of modernization: "We use many different systems, but few of them are integrated. It is generally bad on all levels" (municipal physiotherapist).

A key point is that municipality therapists do not receive sufficient information from the hospital. While discharge letters are sent electronically through the GP systems and Profil, self-employed physiotherapists and private rehabilitation centres do not receive them automatically. If they are needed, they must ask for them, and the patients must provide consent. Alternatively, patients can bring printouts of their discharge letters, or if they have a summary care record, they can log on to a mobile app and invite, say, a physiotherapist to read it there. In other words, rehabilitation personnel, such as physiotherapists and occupational therapists, do not have access to summary care records. As a last resort, they must rely on what the patients tell them the problem is. However, for patients in the rehabilitation phase, it may be difficult to remember and express concerns.

Likewise, the interdisciplinary reports produced at the hospital are sent to GPs but not to the municipal healthcare services or self-employed physiotherapists. This is unfortunate because these reports are much more useful for therapists than for GPs. Therefore, therapists must often request these reports.

A lack of contact points at the hospital is another issue. When municipal and self-employed therapists have questions about how to continue a patient's rehabilitation process or about the degree of urgency, they must call the department and try to find a person who was involved in the patient's care. Another issue is the lack of access to the PLO messaging service that runs between the hospital's EHR system and Profil in the municipalities.

Private rehabilitation centres have similar problems when receiving patients from the municipalities. The centres need information on the measures implemented by occupational therapists and physiotherapists in the municipalities. Although this information can be found in Profil, Physica, or SAMPro, none of these systems exchange information with the rehabilitation centres' EHR systems – or with each other, for that matter.

Given the interdisciplinary nature of the rehabilitation process, another serious problem is the lack of shared calendars across the various institutions. Health personnel must therefore spend a considerable amount of time on the phone trying to schedule meetings: "If I could schedule meetings [in Outlook] without making phone calls, it would save me two or three hours per week. And I'm not alone. … We are talking about billions flushed down the toilet" (municipal occupational therapist).

The implementation of IPs and SAMPro was supposed to provide a more coordinated approach to the follow-ups of patients in need of rehabilitation. IPs contain information on the patients' goals and measures and the health personnel who provide them with services. Using the same platform, providers from different institutions, patients, and relatives can easily communicate with each other. In practice, however, IPs are rarely made, and at the national level, they account for only seven percent of those receiving home-based services according to one our informants. According to one informant, the reason for this is

that "everyone knows that someone has to start it, but no one knows who, so no one does" (municipal physiotherapist 2). Furthermore, having a plan does not necessarily mean that it is used. Some healthcare providers do not log on to SAMPro even though they receive email notifications that there is a message for them. Especially for home care personnel, it is not always natural to check email, so they do not know that there is a message. Furthermore, using SAMPro as a communication platform would require that all service providers involved in a patient's rehabilitation use it.

Involving a GP is another challenge: "I spend a lot of time calling the GP clinics, saying, 'It is not optional; you have to join. … Sorry, but I need an email address from one of you'" (municipal occupational therapist).

Patients and relatives – navigating the jungle

Along with service providers, both patients and relatives must be involved in the healthcare system to ensure the best possible rehabilitation outcomes. However, many of them find it challenging to engage with a fragmented health service apparatus and digital systems that do not exchange information. An occupational therapist described a typical meeting with a relative as follows:

> They don't understand why I don't know the content of the discharge letter or what the physiotherapist has written, and so on: "Can't you just read it?" "No, unfortunately, I cannot." Then, they must tell five or six different service providers the same story, which is immensely frustrating for them. (municipal occupational therapist)

Adding to the burden, healthcare personnel use Profil and ordinary mail to communicate with users – not electronically but through printouts. Municipalities also communicate with NAV with printouts from Profil using the traditional postal service, which makes communication slow and cumbersome.

Digipost can also be used for correspondence, but this is not an option for unfamiliar or cognitively impaired users. Moreover, if a user lacks the ability to consent, relatives cannot be granted access to the correspondence. Similarly, while citizens generally find it beneficial to communicate electronically with their GPs or read their patient journals on Helsenorge (i.e., their summary care records), many cognitively impaired users must rely on help from relatives or healthcare personnel to use this service.

The benefits of digital communication notwithstanding, physical meetings are often necessary. An ABI patient's husband described his experience of negotiating a service for his wife as follows:

> Meeting physically provided much more depth. For the GP to understand my wife's situation, we had to be there and explain it because I wanted the GP to spend five seconds considering what kind of measures would be best for her. (next of kin)

However, many patients and relatives find getting hold of health personnel challenging because many of them are extremely busy. This means that if a relative calls, he or she cannot expect an immediate response. This was acknowledged by one service provider informant, who emphasized that she always responded to missed calls, but she was sometimes unable to respond until three or four days later due to her busy work schedule.

This shows that for patients and relatives, navigating the healthcare system is immensely challenging and demanding on resources. Typical concerns include whom to contact and

who can be of any help. Many relatives feel that they are left to their own devices and must coordinate activities that are ultimately the responsibility of healthcare services:

> For many relatives, the greatest burden is that they have to call various service providers only to find that no one has spoken to another, and they do not trust that we have understood the core issues, which is actually justified. So, they keep calling, asking for a meeting, and this wears them out because, first, they don't have a complete overview themselves, and second, they don't feel competent and don't know what services are available. Then they realize that we don't communicate, so this is exhausting. (municipal occupational therapist)

Ultimately, many relatives find that the hospital and GPs let the patients go too early – that is, before they know sufficiently where they can get help. A next of kin informant suggested that a digital follow-up period might be beneficial – for instance, if relatives had any concerns, they could contact healthcare providers on a particular website. This might also help them not feel alone and serve as a counterweight to misinformation and unfounded hopes circulating on the internet:

> Many people search Google and find many strange things. There is something new, maybe research … something from the US that appears to be good. And then you talk about it and questions arise, like "Is it real?" "Is it replicable?" "Maybe in twenty years?" There is a lot of fake news. (next of kin)

Discussion

Our study demonstrates that the ABI patient rehabilitation trajectory is in desperate need of greater organizational resilience – that is, better coordination and communication. The identified problems tend to worsen along the rehabilitation trajectory, and health service providers, patients, and next of kin must engage in extensive articulation work to maintain it. It is therefore not surprising that service providers are calling for proper digital support.

In the first two workshops, many participants stressed the need for an all-encompassing EHR system that cuts across institutions. Such a strategy appeals strongly to many stakeholders. After all, it aligns with the recent grand policies in the healthcare sector: the large-scale Health Platform programme in central Norway (Ellingsen et al., 2002) and the national Common Municipal Health Record programme, both of which are derived from the government's "one citizen–one record" policy (Whitepaper, 2012). However, from an information infrastructure perspective, this strategy is highly risky because it represents a managerial perspective that imposes a large-scale system on local practices in a top-down manner (Ellingsen et al., 2022). This frequently results in systems that lack the highly valued flexibility associated with organizational resilience (Tengblad and Oudhuis, 2019). Such a strategy also implies that the influence of the installed base (i.e., the existing systems and practices) is generally overlooked. Although the installed base in this case includes insufficiently functional systems at the municipality level, there are also systems that work well – most notably, the hospital's new DIPS Arena system and the EHR systems at the GP clinics. This makes an all-encompassing EHR strategy for all healthcare workers illusory because different stakeholders will pull in different directions (Latour, 1987).

Therefore, a better alternative would be to make changes in the parts of the installed base that do not work well and to try to determine how the existing installed base may shape digitalization processes in both predictable and unpredictable ways. This became the focus of

the third workshop, in which the participants took their daily work situations as the starting point for suggesting technological functionality improvements. In line with the organizational resilience characteristics of collaboration (Mark and Semaan, 2008) and communication (Norris et al., 2008), the participants put forward the following design proposals:

a. Integration between systems that enable information exchange across organizational boundaries.
b. Information on who knows what about a case, who can then be contacted.
c. A communication platform on which health service providers may coordinate activities between them and with patients and relatives.
d. Clarification and communication of responsibilities.

Although some of these design proposals (i.e., integration and a communication platform) were technical in nature, the participants were well aware that their struggles were deeply embedded in organizational and political issues. One participant said, "It is insanely complex with all the groups involved." Another commented, "The coordination challenges are like a 'black hole,' and we don't have the resources that the university hospital has."

The ABI patient rehabilitation trajectory undeniably operates in a complex information infrastructural landscape that contains many entities (hospitals, municipalities, private rehabilitation centres, etc.), professionals, patients, and next of kin. Essentially, the trajectory is characterized by considerable articulation work, much of which is invisible to rationalized models of work (Star and Strauss, 1999). It is sufficient to consider that therapists lack access to summary care records and must rely on patients' mobile phones to read them. New digital systems will therefore inevitably challenge the existing socio-technical practices by making new assumptions about how work should be done and who should do it (Akrich, 1992).

When our informants call for a communication platform and clarification of responsibilities, they implicitly also call for digital systems that will make the current invisible work visible. This process is challenging because invisible work is often performed by people with a lower status than GPs and hospital physicians. This is particularly evident in this case, in which considerable invisible work is done by municipality rehabilitation personnel, patients, and relatives. Municipality personnel must request information from the hospital, find a person in charge, ask patients and relatives to repeat the patients' stories several times, and encourage GPs to commit themselves more fully to the collective activities around a patient. Thus, implementing new, "collective" digital support may require a change in the GPs' role to improve the overall collaboration between healthcare providers. In turn, this may challenge the current professional hierarchy. It is therefore reasonable to argue that digital systems must be implemented gradually and carefully so that the implementation teams can assess and manage their effects on local practices, including professional ranking, to move forward.

However, while digital systems can help make *work* visible, they also have the potential to make *people* invisible, not because of what they do but because of what they cannot do. After suffering an ABI, many individuals cannot use digital tools. This can make them invisible. This is a concern not only for organizational resilience but also for individual resilience if digital systems prevent patients from exercising it.

For designers, designing digital systems for the rehabilitation field raises ethical questions: for whom do they design digital support systems, and whose side do they take if controversies arise? This is a crucial (and perhaps unavoidable) issue due to the social and professional

hierarchies dominating the ABI patient trajectory. The fact that service providers lack access to interdisciplinary reports and the PLO service reflects this situation. Consequently, it is not difficult to agree with the physiotherapist who argued that we must put rehabilitation on the political agenda to highlight the importance of enabling patients to continue living in society. In this light, design in this field requires much broader sociopolitical engagement than we traditionally associate with the design of digital systems in healthcare (Beck, 2002).

Conclusion

Designing digital systems for the rehabilitation field presents considerable challenges. The rehabilitation trajectory is characterized by increasing complexity, with many individuals, groups, and institutions involved. In light of this complexity, we highlight two principles for designing digital systems that can promote organizational resilience. First, designing digital systems for the rehabilitation field needs to take the situation on the ground as the starting point and carefully implement systems step by step, with the users involved in the process. Second, designing for the rehabilitation field requires broad sociopolitical engagement to promote rehabilitation at the strategic healthcare and political levels. In this process, designers cannot assume a neutral position; they need to take a stance on both organizational and ethical issues.

References

Aanestad, M., Grisot, M., Hanseth, O. & Vassilakopoulou, P. (2017). Information infrastructures and the challenge of the installed base. In M. Aanestad, M. Grisot, O. Hanseth, and P. Vassilakopoulou (eds.), *Information Infrastructures within European Health Care: Working with the Installed Base* (pp. 25–33). Springer.

Akrich, M. (1992). The de-scription of technical objects. In Bijker, W. and Law, J. (eds.), *Shaping Technology/ Building Society: Studies in Sociotechnical Change* (pp. 205–224). MIT Press.

Atkinson, P. (1995). Work among the haematologists. In *Medical Talk and Medical Work*. SAGE Publications.

Bate, P. & Robert, G. (2006). Experience-based design: From redesigning the system around the patient to co-designing services with the patient. *Quality and Safety in Health Care*, *15*(5), 307–310. https://doi.org/10.1136/qshc.2005.016527

Beck, E. (2002). P for political: Participation is not enough. *Scandinavian Journal of Information Systems*, *14*(1), 77–92. https://aisel.aisnet.org/sjis/vol14/iss1/1

Burr, V. (2015). *Social Constructionism*. Routledge.

Denis, J. (2016). Data and its invisible work. In *Science + Technology by Other means – 4S/EASST Conference*.

Donetto, S., Pierri, P., Tsianakas, V. & Robert, G. (2015). Experience-based co-design and healthcare improvement: Realizing participatory design in the public sector. *Design Journal*, *18*(2), 227–248. https://doi.org/10.2752/175630615X14212498964312

EHDIR (2018). *Veikart for realiseringen av målbildet for Én innbygger-én journal*. Direktoratet for e-helse. https://www.ehelse.no/publikasjoner/veikart-for-realiseringen-av-malbildet-en-innbyggeren-journal

Ellingsen, G., Hertzum, M. & Melby, L. (2022). The tension between national and local concerns in preparing for large-scale generic systems in healthcare. *Computer Supported Cooperative Work (CSCW)*, *31*, 411–441. https://doi.org/10.1007/s10606-022-09424-9

Faria, A. et al. (2017). Care path of person with stroke: From onset to rehabilitation. *Rev. Bras. Enferm.* https://doi.org/10.1590/0034-7167-2016-0579

Fontes, A. P. & Neri, A. L. (2015). Resilience in aging: Literature review. *Ciênc Saúde Coletiva*, *20*(5), 1475–1495. https://doi.org/10.1590/1413-81232015205.00502014

HelseOmsorg21. (2021). *Bærekraftig helsetjeneste. Correspondence to the Ministry of Health and Care Services, 7 April 2021* (Ref. 21/4769). https://www.helseomsorg21.no/siteassets/brev-til-hod-om-barekraftig-helsetjeneste.pdf

HelsinkiDecl. (2023). *Declaration of Helsinki – Ethical Principles for Medical Research Involving Human Subjects.* https://www.forskningsetikk.no/ressurser/fbib/lover-retningslinjer/helsinkideklarasjonen

HOD. (2017). *Opptrappingsplan for habilitering og rehabilitering (2017-2019).* Helse- og omsorgsdepartementet. https://www.regjeringen.no/contentassets/d64fc8298e1e400fb7d33511b34cb382/no/sved/opptrappingsplanrehabilitering.pdf

HOD. (2022). *Skjematisk oversikt over pakkeforløp hjerneslag.* Helse- og omsorgsdepartementet. https://www.helsedirektoratet.no/nasjonale-forlop/hjerneslag/skjematisk-oversikt#skjematisk-oversikt-over-pakkeforlop-hjerneslag

Jarzabkowski, P., Lê, J. & Spee, P. (2016). Taking a strong process approach to analyzing qualitative process data. In A. Langley and H. Tsoukas (eds.), *The SAGE Handbook of Process Organization Studies* (pp. 237–253). SAGE.

KPMG. (2020). *Evaluering av opptrappingsplan for habilitering og rehabilitering.* Oppdrag fra Helsedirektoratet (2017–2019). Evaluering av opptrappingsplan for habilitering og rehabilitering (2017-2019).pdf

Latour, B. (1987). *Science in Action.* Harvard University Press.

Mark, G. & Semaan, B. (2008). Resilience in collaboration: Technology as a resource for new patterns of action. *CSCW 08 Proceedings of the 2008 ACM Conference on Computer Supported Cooperative Work*, 137–146. https://doi.org/10.1145/1460563.1460585

Whitepaper. (2012). Meld. St. 9 (2012–2013). *Report to the Storting (white paper) "One Citizen – One Record" – Digital services in the healthcare sector.* Ministry of Health and Social Affairs. 2012.

Norris, F. H., Stevens, S. P., Pfefferbaum, B., Wyche, K. F. & Pfefferbaum, R. L. (2008). Community resilience as a metaphor, theory, set of capacities, and strategy for disaster readiness. *American Journal of Community Psychology*, *41*, 127–150. https://doi.org/10.1007/s10464-007-9156-6

Schmidt, K. & Bannon, L. (1992). Taking CSCW Seriously. Supporting Articulation Work. *Computer Supported Cooperative Work (CSCW), vol. 1*, pp. 7–40. https://doi.org/10.1007/BF00752449

Simonsen, J. & Robertson, T. (Eds.) (2013). *Routledge International Handbook of Participatory Design.* Routledge.

Star, S. L. & Ruhleder, K. (1996). Steps toward an ecology of infrastructure: Design and access for large information spaces. *Information Systems Research*, *7*(1), 111–134. https://doi.org/10.1287/isre.7.1.111

Star, S. L. & Strauss, A. (1999). Layers of silence, arenas of voice: The ecology of visible and invisible work. *Computer Supported Cooperative Work (CSCW)*, *8*(1), 9–30. https://doi.org/10.1023/A:1008651105359

Suchman, L. (1995). Making work visible. *Communications of the ACM*, *38*, 56–68. https://doi.org/10.1145/223248.223263

Tengblad, S. & Oudhuis, M. (2019). A theoretical framework for organizational resilience. *EURAM Conference 2019*, Lisbon, 93–123.

WHO. (2022). *Rehabilitation.* https://www.who.int/news-room/fact-sheets/detail/rehabilitation