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Digitalization and Personal Health Data

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# Table of Contents

## Forword

*Polyxeni Vasilakopoulou, Miria Grisot, Hilda Tellioglu*

## Suppliers of Existing Systems in Municipal Healthcare Facing the Arrival of Large-Scale EHR Suites

*Ellingsen, Gunnar; Christensen, Bente; Hertzum, Morten*

## Addressing collective action dilemmas in the sharing of personal health data: Goldilocks and the installed base

*Wilson, Louise; Aanestad, Margunn; McDonald, Joe*

## CareFox: An Interactive Learning Application for Care-Students

*Unbehaun, David; Aal, Konstantin; Richert, Viktoria; Wulf, Volker*

## Back-Stage User Participation in Large-Scale IS Projects

*Mehmood, Hamid; Farshchian, Babak A.*

## Video consultations during Covid-19: repairing the lack of embodied encounters with patients in outpatient clinics

*Sloth Laursen, Cæcilie*

## Data Work in Healthcare: An Ethnography of a BI Unit

*Pedersen, Asbjørn Malte; Bossen, Claus*

## The Sensing and Numeration of Mental Health in a Refugee Camp

*Christensen, Lars Rune; Ahsan, Hasib*

## Structuring the Electronic Patient Record; an Easy Way to Improve Data Usability?

*Silsand, Line; Severinsen, Gro-Hilde; Pedersen, Rune*

## Urgent Digital Change – Learning from the COVID-19 Pandemic

*Malik, Aisha; Gyldenkærne, Christopher; Flagstad Bech, Christine; Mønsted, Troels Sune; Simonsen, Jesper*

## Opening-up digital platforms to accommodate patient-generated healthcare data

*Paparova, Dragana*

## On data discipline, citizen care records, and rehabilitation work

*Enslev, Lea; Finken, Sisse*

## Access and Use of Digital Rheumatology: Exploring “the social aspect”

*Muehlensiepen, Felix; Hochwarter, Stefan*

## Democracy and the politicization of personal health data: the Norwegian Smittestopp case

*Brown, Katherine S.M.*

Exploration of ethical issues in the implementation of digital monitoring technologies in municipal health care services

*Meum, Torbjørg Træland; Nilsen, Ety Ragnhild*

Support for Informal Caregivers: Use of Infrastructures

*Tellioğlu, Hilda*

User mobilization in bottom-up infrastructural transformation

*Dæhlen, Åsmund; Grisot, Miria*

Accountability, Transparency and Explainability in AI for Healthcare

*Moltubakk Kempton, Alexander; Vassilakopoulou, Polyxeni*



# Foreword

Infrastructures in healthcare play a key role in the ongoing transformative processes of digitalization. Emerging technologies such as artificial intelligence (AI) and the Internet of Things (IoT) accelerate transformation, while the growing availability of patient-oriented health applications contributes to a more active involvement of patients in their own care and well-being. The generation of personal health data is a key outcome and at the same time, a drive and a crucial building block of healthcare digitalization. More personal health data are collected in digital form than ever before. Through mobile phones, smart watches and other connected devices patients can self-report health data, monitor their chronic conditions, support their rehabilitation process, engage with personal wellness actively, by following training and activity data. This requires appropriate infrastructure capabilities, data sharing platforms and governance arrangements for data storage, curation and access as well as for having control of personal health data.

Digitalization is not about technology alone, it occurs at the intersection of people, healthcare systems and technology. New skills for both citizens and healthcare workers are required in data gathering and use. Digitalization generates changes in work organisation and task distribution, requires novel competences and opens up for learning opportunities. Advanced technology use requires broader and future-oriented, as well as more high-level skills and competencies from both patients and health professionals to secure the continuity of healthcare services.

Digitalization also calls for critical perspectives on the evolution and utilization of digital infrastructures for personal health data. Novel approaches are needed to manage consent and data guardianship, and to educate both citizens and health personnel to understand risks. With an increased availability of personal health data, the modes of healthcare provision can be reshaped, requiring new ways of organizing health services.

We wish to bring international researchers, healthcare professionals, IT professionals, administrators, and IT enterprises together to discuss these issues at the 8th International Conference on Infrastructures in Healthcare 2021. We particularly invite contributions that are methodologically based on ethnographic/case/field studies.

infraHEALTH started out as a biennial workshop, from 2019 a biannual conference. The events were held so far in different universities in Copenhagen, Denmark (2007, 2009, and 2011), the Arctic University of Norway (Tromsø), Norway (2013), Fondazione Bruno Kessler and University of Trento, Italy (2015), again in Denmark, Aarhus University (2017), and in Vienna, TU Wien (2019).

The 8th conference took place in Kristiansand, Norway. The conference is co-organized by the University of Agder, University of Oslo and Vienna University of Technology (TU Wien).

Polyxeni Vasilakopoulou, Miria Grisot, Hilda Tellioglu  
Conference Chairs

# Suppliers of Existing Systems in Municipal Healthcare Facing the Arrival of Large-Scale EHR Suites

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**Abstract.** With backing from national health authorities, large-scale electronic health record (EHR) suites have increasingly entered the European healthcare market. The overall goal for these systems is to fulfill the needs of healthcare workers in hospitals, nursing homes, home-care service, and general practitioner (GP) clinics. The EHR suites will replace existing EHRs in their targeted area. However, the national and regional authorities cannot mandate that municipalities and GPs implement these new EHR systems. Therefore, there will still be ways for the suppliers of existing systems to compete for market share and provide municipalities and GPs with viable alternatives. We explore these issues by focusing on how suppliers of the EHRs currently used by municipalities maneuver under the imminent threat from an EHR suite. Empirically, we focus on the three principal suppliers of EHR systems to the Norwegian municipal healthcare market. They are facing the introduction of a large-scale EHR suite in Central Norway in 2022 combined with the long-term national ambition of a common EHR system for the rest of the municipal health sector in Norway. Conceptually, we draw on information infrastructure literature.

## Introduction

With backing from national health authorities, large-scale electronic health record (EHR) suites have increasingly entered the European healthcare market. Some notable examples are the US-based companies Epic, Cerner, and Allscripts, the

largest players in the U.S. healthcare market with a market share of 28%, 26%, and 9%, respectively (Business Insider, 2020). Epic has also found its way into the Nordic countries, with installations in Finland and Denmark and a planned implementation in Norway in 2022.

The overall goal for EHR suites is to fulfill the needs of healthcare workers in hospitals, nursing homes, home-care service, and general practitioner (GP) clinics. EHR suites also enable patients to access their own healthcare data. Moreover, EHR suites are expected to ensure that clinical information is available in real time whenever requested, thus contributing to standardizing and streamlining workflows and patient pathways. EHRs also offer extensive structuration of the clinical content, which is a condition for decision support, integration, clinical research, and so on. However, such ambitions are often paired with centralized governance of the entire IT portfolio. EHR suites are supposed to offer centralized governance.

It goes without saying that EHR suites will replace existing, and more specialized, EHRs in their target area, which includes existing EHRs in hospitals, home-care services, nursing homes, and GP clinics. Consequently, the suppliers of the existing EHRs may be forced to withdraw from this market segment to explore opportunities elsewhere. However, although large-scale EHR suites may have backing from national authorities, there is no way national authorities can mandate that municipalities and GPs implement these EHR suites (at least not in Scandinavia). Municipalities are independent political entities, and GPs are autonomous entrepreneurs (Hertzum et al., 2021); thus, municipalities and GPs must be persuaded or incentivized to participate.

Accordingly, in the face of EHR suites, there might still be ways for suppliers of smaller existing systems to compete for market share and provide municipalities and GPs with viable alternatives. In this paper, we explore these issues by focusing on the suppliers of existing EHRs in municipalities and how the suppliers maneuver. Therefore, we pose the following research question: What countermeasures are possible for suppliers of existing EHRs to implement to withstand the arrival of a large-scale EHR suite?

Empirically, we focus on the three principal suppliers of EHR systems to the Norwegian municipal healthcare market. These suppliers face the arrival of Epic's large-scale EHR suite in Central Norway in 2022 through the Health Platform program, as well as the national ambition of a common EHR system for the rest of the municipal health sector in Norway.

Conceptually, we draw on information infrastructure literature to account for our wide empirical scope. We consider the information infrastructure as consisting of a heterogeneous ensemble of technologies and people with no centralized control (Edwards et al., 2007; Star & Ruhleder, 1996). This fits with our regional and national scope. There is no centralized governance structure for specialist care, municipalities, and GPs. Municipalities are self-governed political entities, GPs are individual entrepreneurs, and regional health authorities regulate hospitals. The

distributed governance of the information infrastructure may constitute a major challenge for large-scale EHR suites because it means that the various stakeholders must individually opt in to the system.

## Method

This study adheres to a qualitative and interpretive research approach (Klein & Myers, 1999; Walsham, 1995). Consistent with this approach, we aim to shed light on how the three suppliers of EHR systems in the Norwegian municipal healthcare market assess their future options when a large-scale EHR suite makes its way into Central Norway. The principal suppliers in the municipal segment in Central Norway are TietoEVERY and Visma, while DIPS Front has a smaller share of the market segment.

Data were collected in three one-hour interviews (conducted in autumn 2020 and spring 2021) with senior healthcare-segment managers from the three suppliers. In two of the interviews, two managers participated. In the text, the managers are referred to as Manager 1 to Manager 5. The first and second authors conducted and recorded the interviews via Zoom. In addition, we interviewed four key consultants from three different municipality consortia in Central Norway, each consisting of 6 to 12 municipalities. During late spring 2021, the first author also participated in a panel with the chairman of the board of the Health Platform where the prospects for the platform were discussed.

As background sources, we also include six interviews with Health Platform management in 2018, nine interviews with GPs in central Norway in 2019, and interviews with 10 healthcare professionals in Tromsø municipality during autumn 2020. All interviews were transcribed for analysis.

## The Health Platform program in Central Norway

The Health Platform is a regional program owned by the Central Norway Regional Health Authority and Trondheim municipality. In 2019, the program signed a contract with Epic Systems Corporation to acquire and implement the Epic EHR suite in the whole region, including all hospitals, GP clinics, nursing homes, and home-care services (Ellingsen & Hertzum, 2019, 2020; Hertzum & Ellingsen, 2019). The Health Platform is also a pilot for the national goal of ‘one citizen - one record’ (Direktoratet for e-helse, 2018).

As a suite system, Epic is largely self-contained. Most of the functionalities needed for health personnel are supposed to be provided by Epic, either as ready-for-use functionality or through configuration. Such a system does not encourage extensive collaboration with other system suppliers.

There are around 44,000 healthcare workers and 720,000 citizens in Central Norway. Of the three hospitals in the region, the university hospital in Trondheim, St Olav's Hospital, is the largest. The university hospital will replace its current EHR from Cerner with Epic. Nursing homes and home-care services are supposed to replace the systems Profil and Gerica, and GPs are supposed to replace their current EHR systems CGM (CompuGroup Medical) and System X.

The 64 municipalities in the region and the GP clinics have the option to participate in the Epic EHR implementation. As one of the owners of the program, Trondheim municipality is committed to implementing Epic by default, but many of the other municipalities have yet to commit fully to the program. Some municipalities feel that they are facing considerable pressure to opt in. However, there appears to be growing skepticism among the municipalities:

What really provokes me and makes me curse so that I get high blood pressure is when some of my colleagues in other municipalities say that the municipalities have no choice; we just have to do this and are stupid if we do not join because then we will be left behind (...). The thing is that we have a choice: We have the Health Platform, and we have three commercial suppliers. (Municipal Consultant 1)

Some of the concerns involve Epic's development of new functionality for the municipalities which users have not been able to see what they will get:

You don't replace an otherwise reliable EHR with something you haven't seen, you just don't do it. No municipality replaces an economy system or case management system without seeing what they get, but in health, it is apparently fine. (Municipal Consultant 1)

The municipalities are also concerned about to what degree they can influence future developments in stiff competition with other user groups. The resulting situation has created opportunities for the existing suppliers.

## The suppliers and their customers

There are three suppliers in the Norwegian municipal EHR market. In alphabetic order, the first supplier is DIPS Front, formerly known as ACOS Levekår. In 2019, DIPS ASA acquired ACOS Levekår to supplement their hospital-based EHR, which covers around 85% of this market. DIPS Front has 38 employees, but if the rest of the DIPS organization is included, then the total number of employees is around 300. DIPS Front's EHR system for the municipal market is Cosdoc. DIPS Front serves approximately 75 municipalities (about 21% of the municipalities). The largest customer groups are located in northern and western Norway.

The second supplier is TietoEVERY, an international company with 24,000 employees all over the world and around 4,600 in Norway. TietoEVERY's EHR for the municipal market is Gerica, which is implemented in approximately 107 municipalities. Currently, the mobile solution Life Care mobil pleie is undergoing much development. The supplier has many large municipalities among its customers in the southeastern region of Norway. Taking the population size in the

municipalities as a measure, TietoEVERY has around 50% of the municipal market in Norway.

The third supplier is Visma Enterprise AS, which has 11,000 employees in Europe and around 500 in Norway. Of these employees, 110–120 work in the healthcare segment with revenues of NOK 100 million related directly to the EHR. Visma’s EHR system is Profil, but a new version called Flyt Omsorg has been in development for some time and is almost ready to go live. The largest customer groups are in eastern, western, and northern Norway. Visma has the largest market share of the three suppliers when the number of municipalities is counted, which is around 200.

Table I. The 12 most populous municipalities in Norway (Statistics Norway, 2021) and their EHRs

1	Oslo	Gerica	7	Drammen	Gerica
2	Bergen	Profil	8	Asker	Gerica
3	Trondheim	Gerica	9	Lillestrøm	Gerica
4	Stavanger	Cosdoc	10	Fredrikstad	Gerica
5	Bærum	Profil	11	Sandnes	Profil
6	Kristiansand	Profil	12	Tromsø	Profil

In Norway, the municipalities are the lowest administrative and political elected level. As of January 1, 2020, there are 356 municipalities in Norway, a reduction from 422 municipalities in 2019. The largest municipality is Oslo with nearly 700,000 citizens, and the smallest is Utsira with nearly 200 citizens. According to the EHR suppliers, the collaboration between the supplier industry and the municipalities is good, and they expressed that they work closely together. This reflects that EHRs have been in use for a considerable time; the three systems have been in use for 20–25 years. The systems started out as archive and case management systems, which still are an important part of health-related municipal work. In addition, they include many areas (e.g., kitchen, storage, dry cleaning, and washing) that go far beyond the care process:

It is not a top score, but the users are relatively satisfied. And then the doctors are very dissatisfied because it is not the way they are used to working in their GP systems. But it is because you have to take care of very many different user groups around a patient. (Manager 2)

The suppliers recognize that over the years, their systems have come to lack up-to-date functionality. Especially, there has been complaints about clinical functionality and integrations within and across the healthcare sector. Thus, although the municipal healthcare sector has changed, the suppliers have not followed up with changes in their EHRs. A key problem according to the suppliers is that the municipalities have not allocated funds for evolving the EHRs. This opinion was shared by some of the personnel working in municipal healthcare:

The municipalities are not willing to pay anything for these systems. At the same time, they try to put everything into them. (Physician, municipality).

The reason is a combination of poor municipal finances and the fact that the budget is set by the political (and administrative) level, not by health personnel. As a result, the continued development of EHRs is not a high priority. However, the suppliers acknowledged that they are partly responsible for this state of affairs:

The municipalities have invested very little for many years. In other words, next to nothing. And we have not done that either, to be completely honest. We have been very careful with the investments because we have not made much money from it. (Manager 1)

This reflects a somewhat stable arrangement: The average municipality pays around NOK 150,000 per year for an EHR. Clusters of municipalities tend to use the same EHR system due to long-term regional cooperation, and because they seldom change suppliers.

Regarding the municipalities involved with Epic, the three suppliers were surprised that some municipalities apparently are willing to invest much more in Epic than in their current EHR systems. Manager 5 said:

I have read several case presentations to the municipal board from the councilors in the municipalities about whether they should join the Health Platform or not, and then the money is not exactly a problem, because then they are willing to spend many millions more than they do on today's solutions.

Manager 2 stated:

We are aware that for the Health Platform, the municipalities will pay almost NOK 300 per citizen per year, while with us it is probably between NOK 7 and 11 [...]. The Health Platform probably includes more functionality though, and if we add in something related to child health clinics and so on, we come close to NOK 20 per citizen. So, there are extreme differences here.

## Countermeasures

The suppliers have considered multiple options to maintain their market share in the municipal health sector in Norway. Five options (discussed in the following) stand out as countermeasures to the arrival of large-scale EHR suites such as Epic.

### Offer the municipalities appealing alternatives

The three suppliers emphasized that they need to be much more proactive in relation to the municipalities and present good alternatives to large-scale EHR suites. One supplier pointed out that they now have listened to their customers and started to invest more in making new solutions. The new initiatives have been well-received in the municipal sector:

What we now see in [the product] and what they have developed so far, looks very, very promising. (Municipal Consultant 2)

The managers explained that the new products (new EHRs and mobile and cloud-based solutions) in the pipeline focus on core care-related work tasks in nursing homes, care homes, and home-care services. This stands in contrast to the

Health Platform's plan to offer one solution for all 18 occupational groups in the municipality. This general-purpose approach may make things unnecessarily complicated. One manager said:

I have yet to see a project that succeeds in bringing together the physiotherapist, occupational therapist, wellness center, prison health service, child health clinic, nursing home, and GPs in a municipality into a common system. (Manager 1)

Another manager argued:

We always get the best results when we can develop a solution for a specific workgroup, and not for something else, for example, a mobile solution for home-care nursing and a physiotherapy solution for physiotherapists, etc. (Manager 5)

Although the suppliers adhere to a more narrowly focused strategy regarding the scope of the functionality of their EHRs, the suppliers acknowledged that users need to collaborate across the healthcare sector and among different professional groups. However, as they see it, this does not have to be accomplished in one all-encompassing system.

Interestingly, the suppliers have experienced that the municipalities increasingly are willing to pay more when they understand that they can get more modern and cloud-based solutions.

## Collaborate on supplying an ecosystem of integrated systems

The three suppliers recognized that municipal healthcare is heterogeneous and involves many domains and subdomains. Instead of using one system for all needs, an alternative is that the suppliers must collaborate, for instance, as part of an ecosystem to be able to deliver the best solution for a specific domain. Manager 4 stated:

Our goal is to be a driving force for a digital ecosystem on a market-leading platform. We will open up our products to realize data-driven opportunities, and we will focus appropriately over time together with leading customers to reduce risk.

Manager 3 said:

We are working on a kind of sandbox where we look at how we can make it easier for others to innovate in and around our product. The needs are so complex that we must make arrangements so that they can be covered by different suppliers, but simultaneously ensure that the user experience is seamless and good.

As an illustration of a collaborative effort between the suppliers, one manager referred to a demonstration at Ehin (the largest national e-health conference in Norway) where DIPS, TietoEVRY, Checkware, and a supplier of a GP system presented a seamless information flow across their systems.

Although the three suppliers expressed a positive attitude toward collaboration, none envisaged collaboration with Epic given its closed and self-contained character.



## Inspire local innovation

The municipality consultants and the three suppliers are concerned about the possibilities for locally initiated innovations. The suppliers apply user-centered agile approaches when they design systems and when they participate in optimization processes. One supplier emphasized that it had good experiences with ‘Design Thinking’ and had participated in several local innovation projects. Thus, as suppliers, they provided key technical competence and proactively suggested new solutions for future needs. Typically, users were too caught up in their hectic workday to foresee these needs.

The same supplier mentioned an innovation that the users had been very satisfied with, namely, the mobile solution. The supplier is focusing a lot of resources on developing this solution further. In this regard, they were quite surprised that Epic apparently could not provide a mobile solution and had told future Epic users that they could just use a personal computer instead. Users will likely experience this as a setback and may appreciate suppliers that are more attentive to locally expressed needs and wishes.

On the user side, there are worries that the current ownership of the Health Platform will make local innovation more difficult. The regional health authority owns 60%, while Trondheim municipality owns 40%.

## Build a strategic partnership with the largest municipalities

Among the three suppliers, interest in building a strategic partnership with the largest municipalities appears to be increasing. Several of these municipalities are quite resourceful and are moving forward with themselves in the driver’s seat. This is well recognized by the suppliers, who pointed out that a strategic partnership would make close, top-level collaboration with these municipalities necessary. Such collaboration could be very rewarding. One manager said:

Until now, we have mostly talked to system administrators in the municipalities, but we should talk much more with the councilor or the municipal director within the health service. (Manager 4).

As an illustration, the largest municipality, Oslo, has initiated an ambitious project named Metropolitan Emergency Room. TietoEVERY is working with Oslo on this project at the strategic level. In addition, Visma has expressed interest in delivering its EHR to nursing homes in Oslo and finds Oslo’s Metropolitan Emergency Room initiative interesting and innovative.

In Central Norway, TietoEVERY has been invited to visit several municipalities to discuss future market prospects before the municipalities decide whether to commit to participating in the Health Platform program.

## Adhere to national recommendations and directives

The three suppliers have a positive attitude toward national recommendations and directives, which they consider very important. The suppliers are willing to invest in developing the recommendations and are trying to adhere to them as best they can.

Some recommendations and directives focus on integration with national systems, including the national core record (Kjernejournal), citizens' access to their health information (Helsenorge), citizens' dialogue through Helsenorge (Digihelse), IPLOS reporting (Individbasert pleie- og omsorgsstatistikk), e-prescriptions, standards for e-messages, and the recent registration and reporting of COVID-19 tests and vaccinations. The suppliers also support the future shared medication list (Pasientens legemiddelliste), which will collect information about a patient's medication in one system.

Given the modest user-initiated development in the municipal sector, it appears that most of the development is driven by national recommendations and directives. Nonetheless, the suppliers underscored that providing integration with national systems involves a lot of work. Furthermore, the suppliers often have to deliver this work within short deadlines and therefore, may have to postpone their own development activities.

## Conclusion

The current EHR suppliers in Central Norway have been reinventing themselves in preparation for the increased competition for market share since the region decided to introduce Epic's large-scale EHR suite in 2022. At present, the health sector is served by an array of systems, each targeting specific areas and user groups. The current suppliers consider five strategies for countering the regional, and national, ambition of replacing this array of systems with one generic system:

- Offer the municipalities appealing alternatives.
- Collaborate on supplying an ecosystem of integrated systems.
- Inspire local innovation.
- Build a strategic partnership with the largest municipalities.
- Adhere to the national recommendations and directives.

The large municipalities, which want to run their own development processes, appear to be a particularly important partner in maintaining interest and competence in locally developed solutions for the municipal health sector.

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# Addressing collective action dilemmas in the sharing of personal health data: Goldilocks and the installed base

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**Abstract.** Shared information infrastructures are required for personal health data to be shared along patient trajectories. Building such data sharing infrastructures will involve multiple stakeholders, which can be expected to share some common goals, but also to have divergent interests and priorities. Thus, collective action dilemmas easily emerge and may prevent progress. In the paper we wish to investigate how social structures influence the emergence (or avoidance) of collective action dilemmas. We have conducted a retrospective, qualitative analysis of the establishment of the Great North Care Record in the UK, focusing on the approach to mobilize and organize the participants. We find that pre-existing, multi-organisational peer networks, forums and relationships were in place and were actively used as social modules for mobilization. These networks and forums allowed spaces and occasions for interactions, observations and negotiations that were necessary to avoid and resolve collective action dilemmas. Thus, these networks and forums provided a core “social installed base” on which to build. These networks had been ‘organically’ emerging along the patient flow patterns. They followed the “Goldilocks principle” (‘just right’) – small enough to allow the avoidance or resolution of collective action dilemmas, and large enough that benefits would accrue from the cooperation.

## Introduction

Sharing of personal health data between primary and specialist healthcare is required for safe care. However, many projects have experienced failures when organizing initiatives to establish shared care records, including the United Kingdom with its National Programme for IT (Currie, 2012; Justinia, 2017) and Denmark with its “Basic Structure of EPR” (BEPR) project (Aanestad and Jensen, 2011).

One of the explanations for the frequent failures is the size for such projects. Literature on large-scale projects finds that they are disproportionately prone to failures (Ansar et al, 2017, Flyvbjerg, 2017). A large project is more difficult to handle than a smaller one, and in particular it is challenging to ensure that the division of labour and coordination of work is optimal. In large projects it is exceedingly difficult to be able to detect and handle the interdependencies across several parts of the project, such as sub-projects that make decisions that impact other sub-projects (Bygstad and Hanseth, 2016, 2018). It is also more challenging to handle uncertainty and changes (Little, 2005). To reduce these kinds of risks, agile approaches are increasingly employed, also on large-scale projects. (Dingsøyr et al., 2019).

A second explanation of failures is the extraordinary socio-technical complexity of health and care work. Someone’s “constellation of care” (Wilson et al, 2017) means they may be using the services of a number of different care professionals working in separate departments in a range of organisations, each curating a separate part of the individual’s overall care record (Berg, 1999). Thus, challenges are also encountered when implementing information systems such as electronic patient record systems (Hertzum and Ellingsen, 2019). To reduce the risk for failures, participation of end-users is seen as a key factor for the successful procurement and implementation processes (Iivanainen et al., 2018; Wilson et al, 2017; Jenkins & Wilson, 2007)

Thirdly, healthcare organisations are not constants. The nature of public sector funding and the impact of changing policy is reflected in intermittent attempts to achieve improved patient outcomes via the vehicle of organizational change (Allcock et al, 2015). Mergers and splits occur and during the course of a project. However, although job titles and employers may change, often staff and roles in health IT remain the same. The “social installed base” can mitigate the risks of organisational churn.

There is also a fourth source of complexity stemming from the distributed and shared nature of integrated information infrastructures. Establishing such shared infrastructures require the mobilization and coordination of a set of actors (individuals, groups, and organizations), and while we may expect that they do share some common goals, there are also divergent interests and priorities among them. Therefore such initiatives are prone to so-called *collective action dilemmas*.

We have conducted an empirical study to answer the following research question: *How does the social installed base affect the scale at which a successful shared care record can be developed?* After presenting relevant theoretical perspectives on collective action dilemmas and collaboration, we will present a retrospective analysis of the successful establishment of the Great North Care Record in the UK, followed by an analysis of the approach to mobilize and organize the participants during the project, empirically illuminating the existence of a “social installed base”.

## Related research on collective action and collaboration

How can heterogeneous actors be convinced to provide the necessary resources for the common good? Actors may hesitate to participate, as it introduces a risk that the other parties may not reciprocate and provide their share of the resource. Such situations, where what is collectively rational diverge from what is individually rational, are called collective action dilemmas (Olson, 1965; Sandler, 2015).

Communities of practice, professional networks and forums are adaptable models for multi-organisational collaboration which can support knowledge exchange, collective learning and the adoption of shared identity (Wenger 1999, Kislov et al 2011, Wilson & Lowe, 2018). Networks are “...cooperative structures where an interconnected group, or system, coalesce around shared purpose, and where members act as peers on the basis of reciprocity and exchange, based on trust, respect and mutuality.” (Randall, 2013). Ferlie and Pettigrew (2005) describe networks as a form of organising which is an alternative to hierarchies and markets. Inter-organisational networks are a feature of professional life and exist across the spectrum of informal journal clubs through to strategic exchange forums to collective decision-making structures (Health Education England, 2020). The effectiveness of collaborative structures is dependent on a range of factors including the negotiation of purpose (Eden and Huxham, 2001), existence of trust (Six et al, 2006) and achieving a critical mass (The Health Foundation, 2014).

Integrated care requires collaboration and communication at a micro, meso and macro level - at the point of direct care (micro), between organisations (meso) as well as legal and policy frameworks (macro). On a regional footing, there are long-standing formal and informal networks in healthcare. Most recently, integrated care systems (ICSs) have been established by the UK government to promote collaborative working and ‘remove much of the transactional bureaucracy that has made sensible decision-making harder’ (DHSC, 2021): ICSs operate on a regional basis, clustering organisations in a geographical footprint.

## Research approach and case background

The Great North Care Record (GNCR) is an integrated care record project for the 11 NHS Hospital Trusts, 2 Mental Health Trusts, 370 General Practices, 1

Ambulance Trust, 70,000 staff and 3.6 million people living across the North East and North Cumbria (NENC) in England. We have conducted a retrospective qualitative analysis of the evolution of the GNCR programme from 2015 until 2020, the time period from the initiation of the Connected Health Cities (CHC) programme to the point of the GNCR shared care record go-live utilizing a common health information exchange for the region. The GNCR is a collaboration of NHS organizations, local authorities and universities and is now governed by the newly formed NENC Integrated Care System (ICS) Management Group, which is made up of Chief Executives of NHS hospitals, primary care and local authorities.

#### Data collection

Two of this paper's authors have been centrally involved in the establishment of the GNCR. Over a period of several years they worked with the GNCR programme: Professor Joe McDonald is an experienced clinical information: he was Chief Clinical Information Officer (CCIO) for a large Mental Health NHS Foundation Trust in the North of England when he joined the CHC and GNCR programmes as Director with overall strategic leadership responsibility. He was previously involved in the huge National Programme for IT (NPfIT). Louise Wilson was engagement lead at GNCR for three years: she has thirty years' informatics experience, convening national and regional networks.

Through this involvement they have access to wealth of information and insights about the evolution process and strategies employed, both documented and undocumented. To facilitate re-interpretation, as well as to control for insider bias the authors were interviewed by a third author, Professor Margunn Aanestad. In addition, three key written project documents were considered: Great North Care Record Vision (2016), Great North Care Record Technical Vision (2017) and Amy's Page (Wilson et al, 2020).

#### Data analysis

The analysis started by mapping the basic events of the evolution on a chronological timeline. Then we zoomed in on the challenges that related to the recruitment and onboarding of participants, where the collective action dilemmas would emerge, supported by deductive framework analysis of key published GNCR strategy documents. In the next section we present our analysis focussing on the strategy used in GNCR to co-develop infrastructure through active engagement with regional stakeholders.

## The GNCR initiative

### History and background of GNCR

This shared information infrastructure was a result of the North East and North Cumbria (NENC) component of the Northern England CHC three year pilot project (Shah et al, 2019, Steels et al, 2020) which began in 2015/6: the pilot operated on a geography dictated by the regional the Academic Health Science Network whence flowed the funding. CHC was intended to support multi-sector collaborations to test the idea of a Learning Health System (Friedman 2010, Foley & Fairmichael 2015) through partnerships across the NHS, academia, local authorities, patient organisations, suppliers and others. Four million UKP was allocated in 2015/16 by the UK government, to be spent over three years with no ongoing revenue to maintain the project.

The NENC response to the challenge of realising a Learning Health System was a three module approach to technology, informed by the work of Margunn Aanestad (2011, 2017). The three intended modules were:

1. Shared access to relevant health and care records
2. A platform to give the patients access to their information
3. A Trusted Research Environment (TRE)

The landscape of electronic patient record (EPR) systems in the North East and North Cumbria was described as a “perfect storm” in that all the hospital systems were from different providers and primary care systems evenly split between a *de facto* duopoly of suppliers. The GNCR approach was to connect existing health IT systems in the region, building on previous investments in technology. No partners were faced with a wholesale change of IT system with the cost and disruption that would create. The project would be built on the installed technical base.

With the relatively small and non-recurring funding and the commitment to a modular and cultivational approach, developing the regional shared record was prioritised. Although three modules were envisaged, there was only sufficient funding at that time to deliver one of the modules to the standards required for a safe, secure, trusted shared care record. The strategy was to “do one thing” and work on additional modules when possible. It was hoped that successful delivery of the first module would provide a foundation for future additions.

Delivering quick results and clear value early (Greenway et al, 2018) was critical so the shared care record development was prioritised, building on the achievements of implementing two existing and proven technologies that had begun deployment as part of a regional Urgent and Emergency care transformation programme (Maniatopoulos et al, 2017) - the Information Sharing Gateway (ISG) and the Medical Interoperability Gateway (MIG). These tools had allowed secondary care staff a one-way view of an attending patient’s primary care record with one button click from within in the context of the secondary care electronic patient record (EPR): hospital clinicians had a richer picture of the healthcare



record than they had previously had (GNCR, 2020), and the reputation for quality that the primary care record had was an important component in trusting the data they could see. The direct beneficiaries of this new way of working were those specialist healthcare practitioners as well as the patients and service users themselves. GPs also reportedly benefitted from fewer phone calls from other care delivery organisations seeking additional information.

Usage figures rose exponentially. By 2017, the technology and information governance (IG) arrangements were aligned and all 370 GP practices in the NENC region were sharing records with the 12 local hospital Trusts, 2 Mental Health Trusts and the regional Ambulance Trust. This first phase established the cultural foundations of trusted information sharing for direct care.

So having solved one collective action dilemma by all agreeing to deploy MIG in all organisations, the region faced a new collective action dilemma in evolving the full shared care record. By 2017, Health Information Exchanges (HIE) offered a natural evolution because they enabled two way viewing of health records for direct care by permitted practitioners. But within the NENC region, the leaders of three sub-localities proposed an HIE each but stakeholders were convinced by the logic to have only one. But which one? The dilemma was solved by engaging key partners in co-producing an evaluation criteria and selection process which then resulted in a shared selection and agreement on a single HIE. In doing so, strategic cooperation and a more formal governance structure was evolving.

A critical factor in driving that progress was a loose coalition of IT and health professionals that had formed, a kernel of like-minded people who had worked together on other projects as far back as the 1990s. Some had formed social friendships as a result, and found a new common goal in improved data sharing between organisations to improve direct patient care.

This coalition shared knowledge and found informal agreement on the best data sharing approach for the region which they then championed in other spaces, including more established networks, regional governance boards and within their own organisations. The coalition achieved a major leap forward in information sharing and in doing so became a team capable of coming together to deliver other modules of the increasingly shared vision, "...the only way to learn how to do this stuff - is to do this stuff".

With no formal authority to compel organisations to join the programme and with the continuous organisational churn in the NHS, progress was again made possible by the longstanding personal relationships of the participating actors. Trust was at the heart of the project: there are limits to the number of people actors can 'know *and* trust' and this limits the size of what is possible. Too small and the absence of economies of scale render the project too expensive, too big and the diameter of trust (Ainsworth & Buchan, 2015) is breached and information sharing with people you don't know overwhelms the confidence of the information governance community.

## The role of groups: the “Social Installed Base”

Central funding of regional NHS information technology (IT) projects tends to be *staccato* in nature. This financial instability, combined with the instability of continuous “churn” of NHS organisations is contrasted by the constancy of the people working in the NHS IT field: employers and job titles change but the “faces around the table” at regional NHS IT meetings don’t change as frequently.

From the start, the GNCR core team took a modular approach to building the social infrastructure for the project using existing groups across the region to build a “team of teams”. The GNCR *Vision* (2016) described a modular, cultivational engagement approach not just of starting with a defined but diverse coalition partnership then adding in sectors, organisations, professions - as implementation progressed. For example, teams of Chief Executives, Finance Directors, CIOs, IG leads, social care leads and local informatics boards that were already in place with terms of reference and decision-making mechanisms.

However, there were gaps so two new groups were set up: a GNCR membership network, offering an on-line discussion platform and in-person events, was launched in 2017, and the GNCR Professional Advisory Group made up of CCIOs was set up in 2018. The strong GNCR brand, dedicated benefits-led communications and focus on working with existing channels contributed to the rapid establishment of both groups. Taking this approach, different cohorts were able to advance at their own pace. A modular approach also invited a sustainable ‘growth road map’ that a ‘big bang’ approach did not - new professional groups or sectors would be added as needed by engaging with whatever regional peer network that cohort had established already.

## The Goldilocks myth? Not too big, not too small

The larger the number of partners involved, the more complicated the calculations become that participants make when faced with a collective action dilemma - calculations of trust, reciprocity, losses and gains and risk. Conversely, “...if the size of the group is reduced, the potential difficulties of organizing collective action are correspondingly decreased.” (Olson 1965 cited in Heckathorn 1996).

Unlike the churn associated with public sector restructuring, regional decision-making boards and networks are usually not set up and disbanded on a project-by-project basis but cover multiple topics of common interest.

Regional collaborative networks in Northern England have historically been influenced by ‘natural patient flows’ and administrative regions which in turn have been informed by other factors affecting human movement, specifically natural features like rivers and mountains and travel infrastructures - roads and railways. These leave a legacy influencing how regional collaborations operate.

An assumption underpinning the GNCR programme was that these established collaborations had already done the work of forming, storming, norming and

performing (Tuckman, 1965) and were familiar with making the calculations associated with collective action dilemmas for other initiatives encountered before GNCR. A meso-level ‘social installed base’ was in place. Thus, the GNCR engagement approach became to work out how to attach GNCR to their agenda rather than enrol them to the GNCR one - be adopted rather than adopt. This had the additional advantage of not placing further demands on busy people’s schedules for new, project-specific meetings.

For GNCR, this meant the size and scale of the shared care record project was driven by pre-existing relationships and the number of members belonging to existing networks rather than a calculation based on a notional “ideal” number of partners, organisations or patients: the social installed base defined the project size and scale.

### Acting collectively to overcome dilemmas

In the GNCR programme, voluntary cooperation – where actors choose freely whether to cooperate or not (Heckathorn, 1996) - was the only option available because at the time there was no regional strategic authority (possibly now remedied by the development of the ICS) and there was insufficient funding to incentivize organisations, beyond the benefits of time saved and safer care delivered. The ‘social norm’ of patient-centredness (NHS England, 2014) invited the voluntary cooperation of senior decision-makers. The articulation of the need for improved information sharing was not new, but GNCR offered the means to achieve it collectively and build incrementally to a grander regional scale.

In the North East and North Cumbria, the spaces and occasions for key members to observe each other, be informed about the others’ opinions, judgments, choices and undertake joint deliberations were well established in the form of regional collaborative forums. These forums became the place for GNCR-specific joint deliberations and negotiations - such as senior IT leaders agreeing criteria for technical specifications - which paved the way for common action.

In terms of monetary rewards, the CHC funding to the North East and North Cumbria provided a financial authority that legitimised the discussion followed. The CHC funding was secured by the established AHSN in NENC which in turn mapped broadly to a number of parallel forums and networks, the ‘team of teams’.

In the context of the GNCR, a consistent and compelling case relating to the benefits to patient care, improved outcomes and spending less on postage stamps was aligned with a well-communicated brand which also appealed to regional identity. Heckathorn noted Fireman and Gamson's (1979) argument “that potential social dilemmas in collective action are resolved through appeals to identity and building group solidarity.”

The principles of informed consent and public engagement which the GNCR operationalised also speak to the idea of seeking voluntary cooperation from the

public. A series of NENC Healthwatch-led public focus groups, participation in regional Citizens' Juries (Connected Health Cities, 2017), media communications, a patient-facing website and enquiry telephone line were all designed into the GNCR programme.

## Concluding remarks

The Great North Care Record is an initiative to improve health and care record sharing in the North East and North Cumbria with the express aim of improving care and outcomes: the shared care record is one element which saw the successful implementation of an interoperable health information exchange, connecting a technical installed base of disparate NHS and local authority IT computer systems operating within different health and care provider organisations.

From GNCR's inception, 'team of teams' - a social installed base of existing networks, forums and relationships - worked together to overcome a series of collective action dilemmas in order to realise the benefits would accrue from a shared care record. The footprint of the social installed base drove the size and scale of the project, and was arguably critical in informing the calculations that individuals made when facing dilemmas about if and how to proceed collectively.

Cultivating technical modularity (Aanestad et al., 2017) in the GNCR programme afforded advantages of incrementally building on digital infrastructure that was already in place. In parallel, working with the social installed base and cultivating social modularity afforded advantages of incrementally building on established human infrastructure. While much of the Information Infrastructure literature has prioritised attention to technology and architectural forms over the social aspects, the recognition that an information infrastructure involves a network of people has also always been central and is a domain for further exploration.

The commonality of language between the documented features of health and care networks and the features of collective action dilemmas - trust, reciprocity, shared purpose, gains, losses - invites further exploration to understand more about how working with established groups can enable collective approaches to digital transformation.

Whether this cultivational, modular approach to both professional engagement and technical implementation could be deployed in another region would depend on the maturity of its collaborations - how to connect the connected is also a question for further study.

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# CareFox: An Interactive Learning Application for Care-Students

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**Abstract.** Demographic transformation and medical-technical progress are generating new demands for standards and quality in professional caregiving. The job profile and especially the nature of care apprenticeships is changing significantly and use of digital media is becoming an increasingly ubiquitous and important aspect of the work. In this paper, we present a design case study that focuses on the development and evaluation of a multimedia learning application for and with care students. Adopting a user-centered design approach, we collected design requirements for the application in workshops and interviews with 23 care-students. The results show that it is important to create a structured approach to providing information and that social aspects such as chat allow for higher motivation and collaboration in learning. The findings also suggest that, by using game mechanisms such as a quizzes and difficulty levels, care-students can be further motivated to become more engaged with learning content.

## Introduction

Demographic change, medical-technical progress and increasing quality requirements are changing the nature of professional caregiving and care apprenticeships (Komendziński et al., 2016; ten Haken et al., 2018). While the need for professional and institutional care is increasing, the number of qualified professional caregivers is declining (Rothgang et al., 2012). In line with broader developments, digitalization in the healthcare sector is progressing exponentially (Bhavnani et al., 2016). This is having a growing impact upon the complexity of care, be it in the documentation of information, assistive systems, videogame-based interventions or robotics (Aloulou et al., 2013; Carros et al., 2020, 2020;



Fasola & Mataric, 2012; Müller et al., 2015; Unbehaun, Aal, et al., 2020; Unbehaun et al., 2018; Unbehaun, Taugerbeck, et al., 2020). Not only are mobile technologies evolving (Brown & Mbat, 2015; Ertl et al., 2019), but also forms of (digital) teaching and learning (Aal et al., 2018, 2014, 2015; Ertl et al., 2019, 2021; Fletcher, 1989; Weibert et al., 2017; Yerousis et al., 2015). There is increasing scope for digital applications to help care-students, in their apprenticeship to become a health-care professional, to acquire new knowledge and to verify the applicability of this knowledge in practice (Brown Wilson et al., 2020; Hofmeyer et al., 2018). Digital systems in care-education can create new opportunities for both formal and informal teaching and learning in care and health occupations. It can initiate and enable students to learn in the absence of teachers and learning groups and help them to acquire new knowledge and competences independently, without being bound to specific temporal and spatial constraints. With this comes a higher degree of autonomy and need for self-organization, not only with regard to the spatiotemporal aspects of learning, but also, with regard to goals, content, methods and evaluation (Dubs, 2000). Apart from potential changing how learning is organized, digital learning and interactive media can also have an impact upon the quality of learning (Kerres & Nattland, 2007). Several studies illustrate that substantial advancements have been made toward the development of novel technologies and identification of therapeutic areas as well as mobile devices and apps for health care professionals in medical practice (Aungst & Patel, 2020; Ventola, 2014). Inspection of the literature concerning digital applications to help care-students reveals that there is currently a lack of studies that design applications for and with care-students and examine the individual and collaborative effects of technology and provide recommendations regarding the design of appropriate functionalities and design related aspects for care-students. We therefore present here results from a design case study (Wulf et al., 2011) that describes how the process was pursued across the various steps of exploring, evaluating and designing a multimedia-based learning application for care-students. In this article, we present a prototype learning application that was designed for and evaluated with care-students. Workshops, semi-structured interviews, usability tests and observations in different care-schools provided the necessary information about the attitudes and practices of the target group. Care students played an active part in designing paper-based mock-ups and the development of the final interactive prototype. Individual interactions with the prototype, its impact on individual and social learning and the character of its appropriation was then investigated with care-students over the course of an 8-month user-centered design case study. The aim of this study was to address the research question: *"How should a learning application for care-students be designed in order to promote learning?"* Over the course of this work, we developed a learning application for the education of health care professionals, where individual and cooperative learning spaces can be

created. With the help of these learning spaces, training and work-related qualification needs were met while seeking to increase the quality of care and patient safety. The presented work therefore addressed central requirements arising from practical and theoretical needs from care-students and the mediation of complex nursing and medical learning content. We found in particular that the system supported individual and social learning, motivated users through a gamification approach and improved the learning experience in general. As a consequence, our study provides a new body of insights for the currently rather under-developed domain of learning applications for care-students. Researchers and developers may benefit from our results and reflections by drawing upon the proposed implications when addressing future improvements in the design of learning and teaching technologies across a variety of domains.

## Related Work: Mobile Learning, Gamification, and User Interface Design

It can provide personalized and contextual learning experiences and make a significant contribution to distance learning (Brown & Mbatl, 2015, p. 129). Research has focused on how learners' mobility, complemented by personal and public technologies, can contribute to the process of acquiring new knowledge, skills and experiences (Sharples et al., 2009, p. 3). A major advantage of mobile technologies is their ability to facilitate collaboration between an individual and a group, as well as across organizations. However, collaboration is also possible between those undertaking theoretical and practical training. Mobile technologies, especially in the field of distance learning, open up new possibilities for users to collaborate with others anywhere (Arrigo et al., 2005). The technology can thus become a constant companion and guide for learning (Sharples et al., 2009, p. 4). Mobile apps offer a large number of learning options and can feature in educational formats such as serious games, flashcards, etc. (De Waard, n.d., p. 119). For students, mobile technologies play a particularly important role, as they often prefer mobile devices to desktop computers. According to (Deterding et al., 2011), gamification can be defined as the use of game elements in non-playful contexts. Zichermann and Cunningham (Zichermann & Cunningham, 2011) describe it as incorporating a process of game thinking and mechanics. Both views see it as involving users in the process and being about solving specific problems. Kapp (Kapp, 2012) extends the definition by adding aesthetic components and sees it as a way to motivate people to act and to promote learning. The idea of using game mechanisms in non-playful contexts initially gained importance in digital marketing, where it was seen as a way of increasing motivation, user activity, and user loyalty. At heart it is about influencing behavior (Stieglitz, 2017) by motivating people to perform tasks for which they

would otherwise have little enthusiasm. This strategy brings people into a process that can help them master different aspects of life (Stampfl, 2012). Motivation is a broader concept and encompasses the totality of factors that determine the updating of targeted behavior or actions (Nitsch & Allmer, 1976). It can thus be understood as the justification of behavior in a person-environment relationship. This relationship is fundamental for the motivation process. Motivation also deals with the motives that drive people, move them and cause them to behave in a certain way. Research, here, is concerned with behavioral determinants such as age, culture, or situation that can change a person's behavior (Graumann, 1969). The demand for products with good usability has increased as users have become resistant to the frustrations caused by complicated and incomprehensible user interfaces. The user interface is the part of a computer with which people can directly interact. It consists of two components: the input, which captures the wishes and needs of the users; and the output, which represents how the computer is responding to those wishes and needs (Galitz, 2007). Therefore, the first impression when using an application is important and determines the success of the interface. It is important that users find that certain components meet their expectations, such as information selection, content quality, availability, timeliness and comprehensibility.

## Methods

Our study was framed around the concept of design case studies, as originally articulated by Wulf et al. (Wulf et al., 2015, 2011). This approach consists of three phases: (1) a pre-study consisting of empirical analysis of existing individual and social practices in the specific field; (2) design of innovative ICT-based artefacts related to the findings from the pre-study; and (3) investigation of interaction with and appropriation of the designed technical artefact over a longer period of time. In the **pre-study** we studied the existing practices, the organizational and social perspectives, and the individual and social needs and challenges confronting care-students. We initially conducted 10 semi-structured interviews in three different care-schools to gain meaningful insights into the everyday life of care-students. This approach enabled an open collaboration amongst a variety of actors, reflecting their different levels of knowledge, interests, and expectations with regard to a mobile learning application. In the **second iterative step**, concepts were developed on the basis of user journeys, which underpinned the creation of wireframes and click dummies. We designed and developed a paper prototype based on the findings from the pre-study. As part of the design case study process, we repeatedly re-designed and extended the paper-based prototype and developed an interactive prototype with Axure that was formally evaluated with care-students in the third stage. To facilitate a practical and needs-oriented solution, we applied a user-centered approach and involved

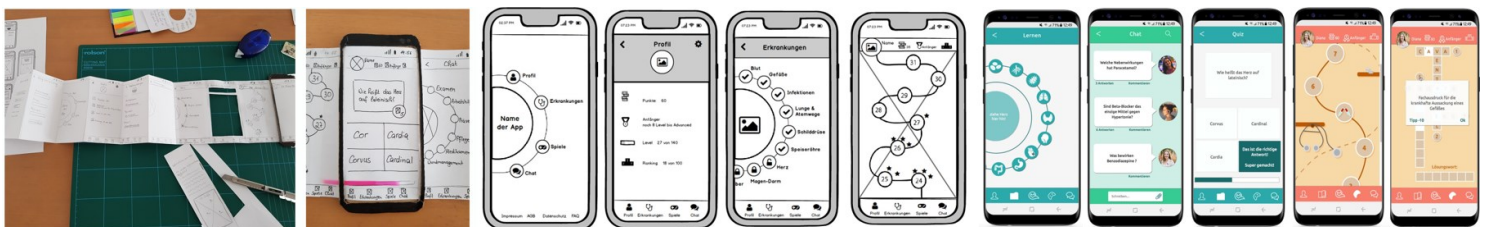
care-students as co-developers in different usability tests. This enabled us to draw upon their different bodies of knowledge, interests, and aspirations in the research and design process. Throughout the **third step**, the different designs, starting with the mock-ups, then the paper prototype, followed by the interactive prototype, were evaluated with the future users of the application. The participants in the interactive evaluation came from two different nursing schools and were in the first and second year of their apprenticeships. A total of 13 care-students participated in the tests. Usability tests were undertaken in the evaluation phase because we wanted to get a detailed understanding of how our participants experienced and understood the prototype. The participants were given specific tasks in order to obtain clear results. The tasks were embedded in scenarios that were realistic descriptions oriented towards the participant's goals. Overall, 23 people took part in the study, across the various phases. The target group consists of 16 to 23-year-old trainees in the health and nursing professions. A total of ten trainees were interviewed during the pre-study and the prototype was created with and evaluated by a total of 13 trainees. Over the course of the design case study, we conducted workshops with usability tests, observations and semi-structured interviews with the participants to understand their existing practices and to uncover the relevant technological, organizational and social perspectives that would need to be taken into consideration. The qualitative data consisted of audio recordings and field notes gathered over the course of the interviews and observations. This was analyzed using a thematic analysis approach. Based on the transcripts, coders performed an inductive analysis of the data and generated main categories. Coding discrepancies were discussed and eliminated by adding, editing or deleting codes, according to the outcome of the discussion.

## TECHNICAL OVERVIEW AND DEVELOPMENT OF THE PROTOTYPES

A low fidelity paper prototype was created after the first interviews. For the paper prototype, the central functionalities and interaction possibilities were incorporated according to the findings from the pre-study (interviews and workshops). At this point, only rough functionalities were proposed. To be able to simulate the interactions of the app, interactional elements such as the keyboard, input fields, warning messages, etc. were cut out individually. The final device was made of cardboard in order to be able to run through the individual paper screens. The wireframes show only the first drafts of the functions and the layout. The first image is the start page with different menu items: *Profile*, *Diseases*, *Games* and *Chat*. If the user selects the *Profile* menu item, he or she has the option of making profile settings via the *Settings* icon. In addition, the user is informed of previously obtained points, the status, the reached level and their

current ranking. In the profile settings, the user can change his or her image, username and password. The main disease topics can be found under the menu item *Diseases*. In the learning units, illnesses, anatomy, physiology and aspects of patient care are illustrated.

After preparing the paper-based prototype the participants were invited to navigate and execute typical user scenarios and the completion of possible tasks in usability tests. This served to identify problems during use and task completion or the paper-based prototype central screens, functionalities and interaction possibilities were constructed. The tests, here, only explored rough functionalities and individual paper screens were traversed by the cardboard device. The individual screens were displayed in a meaningful sequence, making it easier to draw them through the device. The usability tasks consisted of *logging in*, *viewing their own status*, *completing a learning unit* and *a level*, and *writing a chat message on the subject of medication*. Issues were identified and changes were then implemented in the interactive prototype before re-evaluation. This iterative process was pursued to encourage the users to be co-designers and to create, learn, make changes based on new knowledge, and re-design it together with us in a participatory fashion, so that a continuous improvement of the prototype was guaranteed (Barnum, 2011). The menu item *Learning* contains 16 further submenu items. These are the main individual learning topics. If one of the main topics is selected, the user will be taken to the next screen with specific menu items for the main topic. If one of these items is selected, the learning session begins. Information on each session is displayed both verbally and visually. The presentation of the learning units is based on the principles of Mayer's theory of cognitive multimedia learning (Mayer, 1997). Thus, they contain spoken or written texts combined with static or dynamic graphics, depending on which principle of multimedia learning makes sense. In the interviews, the participants were asked which multimedia presentation they would like to see on which topic. Anatomical and physiological aspects of the learning units are therefore represented with 3D models and animations. The topics of the learning units are not divided into anatomy, physiology, pathology and nursing, as is often the case in other applications (Richert, 2018). Instead, to ensure that these topics are linked, users will find, for example, that if diseases are the main topic and a disease is selected, there is not only a description of the disease, but also information about how a patient is to be cared for. In a similar fashion, physiological aspects can be found under anatomy. The texts of the learning units are written in simple language so that they are easily understood and the most



Figures 1,2 and 3 Paper-based Prototype (left); Wireframes (middle) and Figure Interactive Prototype (right)

important things are marked in bold. This requirement also arose during the interviews. As noted above, gamification involves the use of game elements in non-game contexts (Deterding et al., 2011). Learning is just such a context and it can be gamified by incorporating elements such as points, levels, progress bars, badges, and challenges. The goal is to become a top-ranked user by the end of the course. However, this can only be achieved if a user successfully completes all levels. Users are free to choose the order in which they tackle the 16 main topics. It emerged during the interviews that care-schools discuss the learning material in different apprenticeship years. If a subject area is selected, the players can complete a certain number of levels relating to that particular subject. By way of example, in the game world, if the *Heart* theme is selected, the player will be taken to the next screen showing the different levels. As it is not only factual knowledge tasks, but also transfer tasks that are set, each of the four specific topics in the heart area has two levels, which can be played in a random order. So, in total, there are eight levels that can be played. For each main theme, a competition level is also offered in which a match takes place against another random player. Challenges are provided by a mixture of time pressure and the nature of the tasks, so as to deliver cognitive stimulation (Blohm & Leimeister, 2013). In these ways, the game world can be seen to rely on a combination of intrinsic and extrinsic motivation, with competition, such as matches, leading to intrinsic motivation. The chat function is based on constructivist learning approaches, where learning is seen to depend on collaboration and cooperation (Colley & Stead, 2005). It draws inspiration from the concepts of situated learning and communities of practice. Communities of practice are self-organizing systems of informal learning (Gray, 2004). The app's chat function aims to enable such an online community of practice encompassing trainees, teachers, and experts. Here, the care students can solve problems partly through social exchange with each other.

## Findings from the evaluations

The registration process and logging in, as well as viewing the status achieved so far, posed no problems for the participants. The term *Diseases* led to the most frequent instances of incorrect use, because it was used in the prototype as a synonym for the individual learning units. However, this was the only point of confusion. The term was chosen because the menu navigation in the learning units depends on the diseases. Most participants were confused by the request to undertake the course unit regarding anatomy of the heart, because they did not understand whether the course unit was actually under the menu item 'disease' or under 'games'. As the participants knew from the earlier interviews that knowledge checks would take the form of mini-games, it seems likely that the confusion stemmed from this. Regarding the games in the game world, it was

noted that the levels should become progressively more difficult. Two participants also suggested that the points earned should only be visible on the start page at the end of the game and not after each question as was the case in the paper prototype. In addition, one participant asked if she could buy something with the points she had earned. So far, this option had not been considered, but we felt it might be useful if the user could buy tips with the points. With regard to the chat function, some of the participants felt that under posed questions, not only a speech bubble should be used to display the comment function and the number of comments, but also a button that could be clicked to reveal the answers. A further proposition was that it be possible to indicate the number of questions or answers in a circle or to create a sub-item for them in the *Chat* function, so that they could be sorted accordingly. Here, it was necessary to consider whether it would make sense to display new questions, as a user would probably not have the time to view every question. Hundreds of new questions can be asked within a short period of time. As with the paper prototype, the registration process and viewing one's status did not pose any problems when the interactive prototype was evaluated. However, one respondent commented on the possible need for a help field. Other suggestions were made to improve the game world. Three participants wanted the game to be explained in advance. This could be done by clicking on a question mark button. Alternatively, a small video or explanation could be displayed at the beginning of the game (this could then be skipped if not needed). During our observations, it was also noted that one respondent was not aware that the number in the crossword puzzle had to be clicked to get the puzzle. The same respondent also said that the solution to the puzzle should be displayed immediately after the puzzle had been completed. However, the other five participants enjoyed sorting the order of the letters and uncovering the solution, so it is not clear that this added functionality is necessary.

## Discussion, Implications and Conclusion

Early involvement of users in the design process has positive effects on user satisfaction, improves usability and ensures optimal adaptation to user needs (Sarodnick & Brau, 2011). As the goal of a user-centered design process is to design a product (or application) that has a high usability (Semler, 2016), the evaluations made it possible to determine how the multimedia learning application should be designed so that the users can achieve their goals effectively, efficiently and satisfactorily. Some of the advantages of a well-implemented mobile learning platforms are promotion of individual reflection processes (Yang, 2009) and the development of cognitive and emotional skills (Pimmer et al., 2014). A clear set of principles with regard to health and care practice learning is necessary for these advantages to be achieved in an effective pedagogical process (Lea & Callaghan, 2011). The principles of usable design

have a particular impact on an application's usability, as they ensure that user expectations are taken into account during the interaction with the product (Gralak & Stark, 2015). The need for training and support as well as one's own device preferences are also considered within this kind of design process (Taylor et al., 2010). The visual design of an interface plays a significant role in improving usability. There is a focus here upon creating order, increasing readability and making effective use of things like color contrasts. The user experience is also of critical importance (Mose, 2012). With the help of an appropriately aesthetic design, users can be addressed emotionally to generate positive feelings, such as joy and fun, when using an application (Jacobsen & Meyer, 2017). Beyond any personal or group motivational effects, we have also noted here that implementing design elements such as badge systems can help third parties such as moderators monitor a community and identify opportunities and problems. Improving the usability and acceptance of an application involves paying attention to one's choice of methods and the careful selection of design elements. The user-centered design process is particularly suitable for tailoring applications to the needs of users and active evaluation helps to identify problems before and during use. The evaluations provided by care-staff and students provided helpful feedback as the learning application developed. More than this, the participants offered up new ideas and potential improvements, actively playing a part in the design. Mobile learning refers to educational offers provided mainly on handheld computational devices. The advantages of mobile learning via a smartphone are spontaneity, portability and the provision of learning content in more easily digested bits and pieces (Traxler, 2005). We observed that, by incorporating aspects of gamification, chat functions to support collaboration and quiz games that initiate social interaction and collaboration, the app can serve as a gateway from individual and isolated learning towards mobile-based social learning and collaboration. Additionally, the level of difficulty and the possibility of adjusting the games and learning content to different interests, with access at different times and in different settings, was perceived to be both valuable and motivating. Our usability studies and evaluations confirmed that a well thought-out application, developed together with its future users can help to map the requirements of today's care apprentices to their needs and can enrich their daily apprenticeship. Over the course of our development of CareFox, a number of implications for the design of learning applications for care-students were uncovered. Our general recommendations would be that such applications should be available on smartphones because of the potential user-base it supports and, depending on the learning unit, that headphones be available when students watch a video with spoken text. This helps to avoid disturbing other people in their environment and aids comprehension. The aim is to use the app to repeat learning content and prepare for exams through playful exercises. As a smartphone is a private object, the student should use the app on their own and track their own successes. Apart



from this, we identified a number of specific design implications that would support better engagement: having an appropriate feedback mechanism; developing the competitive and collaborative aspects; providing a platform for exchange; offering rewards and making progress explicit; providing individual resources; ensuring the application is clear and well-structured; and delivering short rather than lengthy learning units. These implications may help to support designers working from a variety of perspectives, but most notably those seeking to design similar kinds of applications for care-students. **Feedback Mechanism:** There is an explicit desire on the part of users to get feedback on their own performance so as to be able to evaluate where there might be problems. This might include feedback on their results, their short-term and long-term progress, reminders, as well as motivational incentives. **Competitive and Collaborative Aspects:** Integrating competition-based and cooperative games should be considered in order to promote social interaction between the players around a topic. This helps to maintain long-term motivation. The implementation of a multi-player cooperative and/or competitive games may help students to become more involved and engaged. **Platform for Exchange:** A platform for exchange and problem solving should be available to the users, as problems often arise shortly before exams or in working life and interaction with others can help with finding a solution. This was a very important aspect and the users clearly wanted to solve their problems together with others, be they problems of understanding topics or problems in practice. Peer interaction is especially important here because students often do not dare to talk to their teachers about problems. **Rewards and Progression:** Rewards, or an achievement-based feedback system should be considered as we noticed there was both a sense of collaboration and competition between the participants. Building upon this, one possibility might be that care-students can obtain points that can be used more widely within their apprenticeship, i.e. for exam preparation, homework, etc.. In addition, the games should become more difficult as their knowledge increases and overtly foster competition. **Individual Resources:** As the app can serve as a way of repeating and reinforcing course content, the content should be limited to the essentials. Users want to have the most important information explained in a few sentences that draw upon their existing knowledge. They also want to be able to understand the texts right away, so that they do not have to search for explanations after a learning unit by trawling the Internet, etc. Having a **Clear and Well-structured Application:** A clear and well-structured presentation of the app's content and functionality is important, so that users can find their way around with ease. **Small Learning Units:** The learning content should be divided into small learning blocks, so that users can use the material during breaks or on the move and obtain rapid feedback. The work presented in this paper is based on a design case study for and with 23 care-students. It has illustrated that designing a learning-based application can practically enable care-students to access required

learning content in ways that are independent of place and time and that can be tailored to the individual needs of the apprentice. We observed that, by incorporating aspects of gamification, chat functions to support collaboration and quiz games that initiate social interaction and collaboration, the app can serve as a gateway from individual and isolated learning towards mobile-based social learning and collaboration. Additionally, the level of difficulty and the possibility of adjusting the games and learning content to different interests, with access at different times and in different settings, was perceived to be both valuable and motivating. Our usability studies and evaluations confirmed that a well thought-out application, developed together with its future users can help to map the requirements of today's care apprentices to their needs and can enrich their daily apprenticeship.

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# Back-Stage User Participation in Large-Scale IS Projects

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**Abstract.** In recent years, both the public and private sector organizations have started shifting to large-scale information systems (IS). Still, the results of these large-scale implementations are not very promising. Ensuring user participation is considered as a (partial) solution to overcome the issues associated with large-scale IS development. Given the complexities associated with the scale, the activities happening in large-scale projects are categorized as front-stage and back-stage, and it is essential to engage users in both of these activities. The literature around the component of user participation in back-stage of large-scale projects is not very mature. We contribute to this by studying a large-scale medical record system implementation in central Norway. Our findings highlight that the back-stage activities are very prevalent in large-scale projects whereas these activities lack adequate user participation.

## Introduction

HealthCare organizations have grown in size and contain a large number of users and vast volumes of data (Pilemalm & Timpka, 2008; Roland et al., 2017, Hertzum & Ellingsen, 2019). Such systems are usually introduced as large-scale suit systems with generic features and are configured according to the needs and requirements of a particular organization (Krabbel & Wetzell, 1998). Large-scale implementations are often problematic, and further research is required to better understand the associated challenges (Simonsen & Hertzum, 2008).

A challenge related to large-scale IS implementation is how to secure user participation. User participation is referred to as “*the fundamental transcendence of the user’s role from being merely informants to being legitimate and acknowledged participants in the design process*” (Simonsen & Robertson, 2012). Engaging users in the development and implementation of information

systems have shown promising results (Markus & Mao, 2004; Shapiro, 2005), but this success is often limited to small-scale projects (Oostveen & Van den Besselaar, 2004). Participation in large-scale projects is challenging because these projects have to deal with a multitude of stakeholders and their conflicting needs, organizational and political complexities and the issues related to long time spans (Pilemalm & Timpka, 2008; Simonsen & Hertzum, 2008).

In this paper we investigate participation in large-scale IS projects by building upon the concepts of front-stage and back-stage activities. Front-stage activities refer to cooperative activities such as group meetings, workshops, and co-design sessions. Back-stage activities refer to organizational activities that unfold in parallel to the front-stage activities, such as planning, preparations and negotiations (Bødker et al., 2017). The back-stage activities are considered to have a strong influence on the front-stage activities happening in the project, and can potentially shape the outcomes of the entire process. However, current research within participatory design and participation mainly focuses on front-stage activities (Dreessen & Schepers, 2018). In this paper we focus on back-stage activities in a specific large-scale project by addressing the following research questions:

- How are back-stage activities defined in large-scale projects, and how are they related to front-stage activities?
- How does participation take place in the back-stage of large-scale IS implementations?

Our research contributes to the emerging literature on what back-stage and front-stage activities consist of in large-scale IS implementation projects. Our findings suggest that it is challenging to create effective connections between front-stage and back-stage activities in large IS implementation project, in particular when these projects involve third-party vendors.

In the rest of this paper, we discuss some background literature, present our findings from a case study of a large-scale medical record system implementation in Norway, and discuss our findings related to the above-mentioned framework.

## Background

Scale in IS implementation is often defined in terms of the number and distribution of heterogeneous settings, users, and use of the system over time, and also depends on the organization's size (Roland et al., 2017). Some challenges related to large-scale participation are heterogeneous stakeholders, sustained participation, exchange of knowledge and information among stakeholders, and utilizing the insights from participation (Dalsgaard & Eriksson, 2013; Simonsen & Hertzum, 2008).

The goal of user participation is to let the users participate in the different processes through activities which are a collection of different methods, tools,

techniques, and decisions. Drawing on Goffman's (Goffman, 1978) concept of front and back stage, Bødker (Bødker et al., 2017) further classified these activities into the front and the back stage activities. They defined front-stage activities as the pretty images of success and back-stage as the hidden chaos of conflict and turmoil. Front stage activities include common participatory design activities such as requirements meetings, co-design workshops, prototyping sessions, etc., whereas the back-stage activities entail the processes that tie the activities together. Most of the research articles focusing on different user participation methods often describe the participation in the front-stage, whereas user participation in the back-stage is less documented (Dreessen & Schepers, 2018). Back-stage activities also seem to be overlapping with the boundary conditions of a project, as the boundary conditions are referred to as the factors that may prevent or constrain participatory activities in a project (Zahlsen et al., 2020). The critical difference between these two is that the boundary conditions always refer to the factors external to the participatory activities, whereas the back-stage activities include both the internal and external factors. A similar term "*context of design*" is used by Svanæs & Gulliksen, which refers to the factors that tend to influence and often aggravate the user-centered design process (Svanæs & Gulliksen, 2008).

## Case Description

Our case is about the implementation of a medical record system in Central Norway. The system is a pre-existing packaged software that was procured through a public procurement process, and is currently being customized. To prepare requirements specification for the procurement process more than 400 health and ICT employees from all over Central Norway have participated through more than 100 workshops. The implementation of the platform will affect around 40,000 employees in municipalities, hospitals, and the private sector, and 720,000 inhabitants.

The system will be implemented in several user organizations including a major hospital, a large municipality, and several smaller municipalities. This is a challenging process as the needs of the hospital –specialist healthcare --are different than those of the municipalities –responsible for primary healthcare. A dedicated company was established in March 2019 for contract follow-up with the selected supplier, and for implementation of the system at the user organizations. Project documentation reveals that user participation in different phases of the project is an area of key importance. Different user groups like application analysts, subject matter experts and super users have participated or are expected to participate in implementation activities. The vendor company continues to play a central role in the implementation processes.



The implementation process is coordinated among four implementation projects, one joint project, residing in the newly created company and three local projects residing in the user organizations. These projects are the places where most of the back-stage activities in our case are found. This paper will mainly look at the local implementation project in one big municipality. Table I presents the details of the subprojects under this local implementation project and the focus area for each. Our paper focuses on the *organizational development* subproject. This subproject is relevant for our research questions as it is responsible for making the users ready to use and utilize the new system, and focuses on users.

Table I: Subprojects for the local implementation project

Subproject	Focus
Organizational Development	Responsible for identifying the needs of users, training and teaching them how to use the new system and ensuring that the desired targets of benefit are met
Health and Care	Responsible for the academic content of health and care in the primary healthcare service
Information and Communication Technology (ICT)	Responsible for ensuring that the necessary activities in the technical area are conducted
Data	Responsible for ensuring the necessary needs for the analysis, management and reporting of data are met

## Methodology

We use case study because it allows us to understand the phenomenon in its natural setting (Yin, 2017). The phenomenon under study is user participation in back-stage/front-stage activities in large-scale IS implementation projects. Our case is the local implementation project. Currently we are in the framing cycle in our case study (Pan & Tan, 2011).

Our data includes semi-structured interviews, relevant documents, and field notes. We conducted five in-depth semi-structured interviews. Interviewee roles are provided in table II. The documents include project plans, project descriptions, stakeholder analysis reports, and benefit realization plans. Field observations were also carried out, but due to the Covid-19 pandemic, the observations lasted for only one and a half weeks. The data was collected during the spring of 2020. We obtained approval from our university ethical committee.

Table II: Interviewee Details

Interviewee	Name	Role in the Project
1	Carl	Subproject Manager (Organizational Development)
2	Martin	Researcher
3	Pete	Professional Coordinator (User Readiness)
4	Sofia	Professional Coordinator (Training)
5	Lisa	Professional Coordinator (Benefit Realization)

## Findings

We present our findings based on the different activities that are being carried out in the subproject for organizational development, and focus on participation is front and back-stage of these activities. These activities are shown in the table III.

### Readiness

Readiness is an area of activities concerned with identifying the needs of prospective users and making them ready to use the new system. There are five activities related to readiness presented in the project plan as described in table III. The activity present most in our data is maturity analysis. The project plan informs that this activity is about planning and conducting maturity analysis in form of digital surveys. These surveys are prepared under the guidance of the joint implementation project and are administered by the user organization.

Our findings show that the maturity analysis was focusing on two areas: the identification of user needs and future training and their Information and Communication Technology (ICT) competence. The former is completed by managers at all levels and the latter by both managers and all employees affected by the project. Carl, the sub-project manager for organization development, informs that one round of each of the maturity analyses has already been conducted: spring last year for the leaders and fall for the employees. When asked what happens to the results of the analyses, he answers:

“[The data] enters the project manager’s meeting. Processing and understanding of the result start with the two analysts looking at this from an academic standpoint. We then come up with our reasoning and present this to the organizational development team and the municipal council meeting.”

He shared an example from the first survey relating to ICT competence, where the feedback showed that the users did not know where to find information about the project. This feedback resulted in improved communication through the Google+ site developed by the local implementation project.

Table III: Activities under the organizational development project

Activity	Type of Activity
Readiness	Maturity analysis Organizational change measures Skills development for managers Review, change and update of current routines Program for preparation
Training	Learning culture Super user organization Super user training Organization and implementation of end-user training
Benefit Realization	User-friendly system for employees Medication management Citizen involvement Logistics Medical distance monitoring Information management Research (advanced use of data)

## Training

This activity focuses on training the future users of the new system. To facilitate the training process, a concept of "super users" is introduced. Super users are described as the go-to people in their department, and they are responsible for assisting other users. In the fall of 2019, a gathering was conducted to give the super users the information and knowledge they need to take the role of super user. The presentation on this gathering informed that the super users should cooperate with the leaders to develop a systematic and good learning culture, participate in contributing to good quality training in their unit, and transfer knowledge of use and utilization of the professional system to all employees with different needs. The concept of super user was originally defined by the vendor, as part of their standardized implementation process.

Looking at the learning culture and training plans, the project plan for training presents planned ways to give the municipality sufficient expertise to use the health platform. About the learning culture activity, the related documents show that it is mainly meetings with the units and, as commented on earlier in this section, the training of super users so they can share knowledge about the health platform with their coworkers. Leader meetings with the leaders of the local implementation project in the municipality are held to decide on the unit meetings. These meetings list the unit meetings' agenda and a list of who should participate from the project itself and the units. From the units, it says that the unit manager, department manager, and superusers should attend the meeting. When

asked which activity stands out within training, Sofia, answers that it's the systematic and continuous work with training. When asked about how the systematization of learning culture is done, she says:

“What we do, among other things, is that we go out on meetings on each unit with the leader teams and go through how they work with training. We have a dialogue about how the focus is on training, properly system usage, documentation requirements, and how to make this even better.”

She explained that these meetings are not discussing what the training should contain, but how to facilitate for it and work with it. For example, discussing when the training should be, having in mind that the training is for employees having their everyday workday running around between tasks.

## Benefit Realization

The goal of the benefit realization activity is to ensure that the result meets the goals of the implementation project. The project plan for benefit realization presents that the work done on benefit realization should secure documentation and realization of benefit. Benefit realization does not have clearly defined activities like readiness and training. The fundamental pillar of benefit realization is that the desired targets of impact must be met. To accomplish the targets of impact, there have been developed eight strategic targets of benefit for the implementation project. When asked about how these eight strategic targets were decided, Lisa, the champion for benefit realization, mentioned:

“To define these targets, we probably had half a year of workshops involving managers, subject matter experts, and user communities. We got 500 winnings and created a benefit model that categorized, analyzed, and picked the most important ones.”

She also mentioned having multidisciplinary meetings to define the sub-goals for eight of the main goals. These are the meetings where the vendor, health platform management, subject matter experts, and other with relevant knowledge participate in defining and understanding the target of focus and how to reach those targets.

## Other Activities

All activities discussed so far are formally defined by either the vendor or the implementation project management. During the interviews and observations, we also found some routines and activities that are ad hoc and not defined by anyone or in any plan but have a relevance with the research questions. One such activity is what was called a *work meeting* by our interviewees. Work meetings are meetings replacing or adding to already planned activities. They emerge when the ones responsible for conducting the meeting feel and think that there is a more efficient way of doing it. Pete, the champion for readiness, ends the interview with "readiness is so much more than what is described in the project plans; it is

all these little drips". An example of this is the activity related to role analysis. The process of going out on every unit and department to find and define all roles seemed tedious. The municipality decided to do this as a work meeting where they invited employees from each unit and department and thereby gathered more employees at the same time. Pete says there are two reasons for this: firstly, they don't have to facilitate, find contact information, and make appointments. Secondly, they would like to make the job least troublesome for the units/lines and of utmost utility for the health platform management.

Work meetings are a formal, albeit unplanned form of activity. Another form of activity –called *afterskiing* by our interviewees–is on the other hand both informal and ad hoc. *Afterskiing* are meetings happening after the actual formal meeting has taken place. Our interviewees described *afterskiing* as a place where even more decisions are taken, or you get more clarity in what the others think, what to go for, and how to relate. Pete, talking about the flow of information, says "we contribute where we can, and then there is probably a lot that happens in the formal meetings, but also in the informal." He emphasizes that informal meetings are a supplement for the formal ones. We also observed an *afterskiing* meeting during one of the leader meetings at a town hall that we observed. After the meeting and during the walk over to the workplace, it felt like the meeting was still going, but in a more personal way. There was a mix of personal conversations about weekend plans, personal meanings about the implementation project, and some continued discussions on the matters of the meeting itself. This phenomenon was also noticed during observations in an office environment. Over coffee machines, during breaks, and after the formal meeting were finished, the participants started to share their meanings and discussing possible solutions.

## Discussion

In this research, we aimed to explore how back-stage activities are conducted in large-scale IS projects, their relationship with front-stage activities, and how user participation takes place in the back-stage activities. Our findings highlight that the back-stage activities are very prevalent in the project that we studied. As the activities and tasks in the front-stage of the large-scale projects are extensive in number dealing with the heterogenous users and their complex routines, handling these activities and tasks is often facilitated by conducting the back-stage activities. For example, the maturity analysis activity aimed to identify the needs of the users for future training and gauge their ICT competence has a clear relevance with the definition of back-stage activities presented by (Bødker et al., 2017). Similarly, back-stage activities were also present in the form of unit, leader, and work meetings to discuss how a particular task needs to be executed and decide who will be participating in the execution of these tasks.

Large-scale projects also have some informal and undocumented activities overlapping with the back-stage, one of which is referred to as “afterskiing” in our findings. These activities can be a symptom of lack of formal channels for the users to reflect around different aspects of the project. Such activities should also be taken into consideration as they might have some influence on what is happening in the project. Our findings against the first research question are very much in line with what Bødker et al. (Bødker et al., 2017) have explored about the front and back-stage activities. However, our research investigated these phenomena in the context of large-scale projects.

Our second research question aimed to address how user participation takes place in the back-stage of large-scale projects. Our findings reveal that the component of scale limits the user participation in the back-stage activities, and instead, the users are restricted to what is happening in the front-stage. For example, most of the meetings were being attended only by the managers and some user representatives, whereas the decisions taken in these meetings had a strong influence on all the users. The participation of user representatives in the back-stage activities is interesting and overlapping with the concept of managed communities (Pollock et al., 2007), but it needs to be explored further, and we plan to do it as our future research. As discussed earlier in the paper, the actual goal of user participation is to shift the user’s role from being merely informants to being legitimate and acknowledged participants (Simonsen & Robertson, 2012). Some activities like the activity of maturity analysis were restricting users to only being the informants which is contradictory to the actual purpose of user participation. It was also observed that the growing size of a project demands more organizational work initiating a translation from participation to organizational work.

## Conclusion

This paper gives a glimpse of our investigation around how the back-stage activities are conducted in large-scale IS projects and how user participation works in these activities. We conclude that the back-stage activities are very prevalent in large-scale projects, but there is very little user participation in these activities. Our study only shows some preliminary results, and our current data were collected by studying only one sub-project. We plan to explore the case further and learn how the managed communities can facilitate back-stage user participation in large-scale projects.

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# Video consultations during Covid-19: repairing the lack of embodied encounters with patients in outpatient clinics

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**Abstract.** The Covid-19 pandemic has forced hospitals to adapt and rethink how they treat patients to limit the spread of the virus and avoid overloading during spikes of admission. Danish hospitals have implemented video consultations which enable patients and clinicians to see and talk to each other without the patients coming to the hospital. Based on observations of clinicians' video consultations with patients, as well as observations of online hospital meetings regarding virtual outpatient clinics, this paper explores clinicians' experiences with adopting video consultations. The paper unfolds what this new form of consultation repairs, leaves behind, and engenders. Finally, the paper speculates about how the digital transformation might anchor itself in the healthcare sector, also in a post-pandemic future.

## Introduction

The Covid-19 pandemic has dramatically changed the world as we know it. Restrictions on movement and gatherings are enforced to limit the spread of the virus. The world's hospitals are under severe pressure, and if the infection count increases uncontrollably, hospitals risk exceeding their capacity. To avoid overloading during spikes of admissions, and to limit the spread of the virus,



hospitals have been forced to adapt and rethink how they treat patients during the pandemic. In Danish hospitals, this entails that non-urgent treatments and surgeries have been postponed or moved to other hospitals (Region Hovedstaden 2021). Many consultations in outpatient clinics are also postponed or are held via telephone instead of physical meetings (Region Hovedstaden n.d.-a). The phone consultation challenges the format of the consultation because the clinicians are not able to see their patients and combine the visual input with the patients' statements in their assessment of the patients' health. As a new option initiated during the pandemic, the hospitals in two Danish regions have implemented video conferencing software that allows patients to have video consultations with the hospital. This enables the patient and clinician to see each other in real-time, which to some degree offers repair to the visual cues that are important during a regular consultation but are completely absent during a phone consultation.

Based on ethnographic fieldwork in a hospital, this paper seeks to unfold what this new form of consultation repairs, leaves behind, and engenders in a time of crisis. The findings suggest that while the video consultations lack some aspects of a bodily encounter, the video conferencing software elevates a phone consultation substantially by allowing clinicians to see the patients and by allowing other materialities to participate in the interaction. The paper ends on a speculative note, discussing how video consultations between hospital and patient might be embedded in the healthcare sector, also in a post-pandemic future.

## Digital transformations in the Danish healthcare sector

Danish digitalisation strategies have long promoted how telemedicine technologies have the potential to provide better care at a lower cost since patients can receive care in their own homes (Regeringen et al. 2012). Current strategies specifically outline how video consultations will be included in the array of healthcare services where they are imagined to be used not only as a telemedicine service for selected patient groups, but rather as an integrated part of the future healthcare services (Danske Regioner 2020; Sundheds- og Ældreministeriet et al. 2018).

In 2016 and 2017, two Danish regions, that combined cover almost half of the Danish population, implemented a new electronic patient record (EPR) system, The Health Platform (Sundhedsplatformen in Danish), with an integrated patient portal, MyChart (Min Sundhedsplatform in Danish). MyChart enables patients to, among other things, access their health information, write to the hospital where they receive treatment, answer questionnaires, and enter measurements (Region Hovedstaden n.d.-b). The integration of video conferencing software is one of the newer plugins integrated with the EPR-system, and patients access the video consultation via MyChart which exists both as an app and a website.

By March 2020, when the Covid-19 pandemic broke out in Denmark, video consultations were already being tested in a pilot project involving selected

departments across the two regions. In light of the pandemic, it was decided to release the video solution across all the hospitals in the two regions (Løve et al. 2020). This means that the shift to offering video consultations at the hospitals comprises a digital transformation which was already happening at the hospitals prior to Covid-19, but rather than a gradual implementation across the hospitals after an evaluation of the pilot project, the solution was instead released for broad implementation at all departments that deemed it relevant. The urgency of the pandemic sped up and expanded the implementation of video consultations in ways that were previously unimaginable, and thus jolted a digital transformation that would likely have otherwise taken years. In that sense, during the first wave of the pandemic, the future healthcare system collapsed into the present.

### Research on telemedicine and remote collaboration

For more than a decade, different telemedicine solutions have been developed, tested, and implemented to permit clinicians to provide ‘care at a distance’ (Pols 2012), delocalizing care and diagnosis from the hospital (Mort et al. 2003). STS and CSCW studies find that in such new care installations patients’ homes are reconfigured (Oudshoorn 2012) and patients are often required to develop diagnostic skills (Andersen 2010; Oudshoorn 2008). They also find that while work is delegated from hospital staff to patients (Oudshoorn 2008), specific tasks, such as monitoring, are delegated between human and nonhuman actors in distributed spaces and rely on collaboration (Langstrup et al. 2013). Studies also report on telemedicine projects being discontinued due to a lack of confidence in the diagnosis at a distance (Mort et al. 2003). Outside of healthcare, it has moreover been pointed out how distance matters for collaborating teams (Olson and Olson 2000), initially affecting cooperation and trust (Bradner and Mark 2002). However, studies also find that video conferencing improves remote collaboration compared to audio only and decreases misunderstandings (Karis et al. 2016; Olson and Olson 2000).

Consistently across the telemedicine studies, the solutions are used in the framework of a project. They are often tested on a specific group of patients, typically with chronic conditions, who receive equipment from the hospital/project (Andersen 2010; Langstrup et al. 2013; Oudshoorn 2008; Pols 2012). In the present case, two Danish Regions have rolled out video conferencing software as an emergency response during the current crisis, which is also seen in the context of social work (Pink et al. 2021). The intention is to offer video consultations with the hospital as an alternative to the in-person consultation - also once the situation returns to ‘normal’ (Løve et al. 2020). This video consultation solution differs from the aforementioned telemedical solutions because, first, the patient does not require any equipment from the hospital. If the patient has internet access and a smartphone, tablet, or computer with a camera and microphone, they can engage in the virtual encounter with the hospital.

Second, the solution is not limited to a small selection of patients with a certain condition. Instead, video consultations are intended to be available to any patient who finds the option relevant.

## A lens of care and repair

This article specifically attends to the *repairment* of the hospital consultation during Covid-19. By turning to video consultations, some of the visual elements lacking in a phone consultation are reinstated, which arguably offers repair of the consultation. In the investigation of the repairment, this article links the notion of repair with that of care (Buser and Boyer 2021; Jackson 2014; Tronto 1993). Fischer and Tronto define care as:

[A] species activity that includes everything that we do to maintain, continue and repair “our world” so that we can live in it as well as possible. That world includes our bodies, our selves, and our environment, all of which we seek to interweave in a complex, life sustaining web. (Tronto 1993, p. 103)

The definition points to how care is relational (de la Bellacasa 2012). Tronto also states that in this definition, care is not only between humans but can also be directed towards objects and the environment (Tronto 1993, p. 103). Others have furthermore argued how nonhumans partake in care work (Buser and Boyer 2021). Following this perspective, I look at the video consultations and the surrounding work as care and repair, making the consultation ‘as well as possible’ in a time of crisis. I attend to what is being repaired, as well as the directionality of care.

## Methods and empirical setting

The paper is based on ethnographic fieldwork (Crang and Cook 1995; Forsythe 1999) at a hospital in greater Copenhagen in the Capital Region. The hospital started using MyChart in early 2018 and selected departments have partaken in pilot projects testing new features. Access to the hospital was established in December 2017 during previous research (See Laursen and Finken 2020). During the first wave of the pandemic in spring 2020, the hospital initiated using video calls. Rather than being implemented broadly across all departments, it is voluntary for the individual departments and their personnel to use video consultations with patients. Due to the pandemic, the fieldwork has been fragmented and took place on selected days starting May 2020 and is still ongoing. The fieldwork includes in-person observations at outpatient clinics when clinicians held video consultations with patients, and online observations of online staff meetings where interested clinicians, technical staff, and quality workers meet at a bi-weekly online meeting to exchange experiences and to

provide technical support if needed. During both types of observations, I took extensive fieldnotes.

The findings section below is based on a preliminary analysis of the collected material on the hospital's use of video consultations with a focus on repairment during the pandemic. The section centres on two vignettes (Hammersley and Atkinson 2007) from observations with a clinical dietician from the gastroenterology department and a specialist clinical nurse from a neurology department. To protect their privacy, I use fictitious names.

## Hospital video consultations during Covid-19

The analysis of my material is guided by the questions of what the video consultation repairs compared to a phone consultation, as well as what is still left behind compared to an in-person consultation, which is presented in the first section. In the second section, I propose what the video consultation engenders.

### What is repaired and left behind

When the physical meetings are rescheduled to phone consultations it compromises the consultation in various ways because both visual and tactile elements are lacking. The video consultation repairs some of the visual deficits of the phone consultation; while it can be hard to observe body language through the video call, it allows the clinicians to see the facial expressions of patients. Visual elements of seeing each other; to look each other in the eyes, observe body language, etc. play a part in establishing rapport between patient and clinician. The clinical dietician Patricia explains that seeing the facial expression of her patients via video helps her evaluate whether they have understood the dietary guidelines she is educating them in. This can be tricky to evaluate simply by listening to their verbal responses and tone of voice in a phone call. Olson and Olson (2000) similarly report how video increases understanding between collaborators compared to audio only. Evaluating patients' understanding of the instructions given is a form of care that concerns making sure that patients can perform the necessary self-care until they have the next consultation.

Another benefit of the video consultation compared to the phone consultation is that the camera can be adjusted to show the patients' bodies. Patients can, for instance, show where they have pain and use their hands to gesture and visually demonstrate the symptoms they are explaining to the clinicians. This is highly relevant at the neurology department that attends to patients with conditions such as Parkinson's disease who have shakings, body stiffness, the experience of being unable to control their body properly, etc. The vignette below of a video call that Søren, the clinical nurse specialist in the neurology department, had with a patient with Parkinson illustrates an assessment of the patients' condition:

Søren has a video consultation with a patient living outside of Denmark. The patient has Parkinson's disease and two weeks ago he visited the hospital in Copenhagen to get the settings on his deep brain stimulation device adjusted. The consultation today concerns how his symptoms have been since last. Søren starts the video call on his laptop and the patient appears on the screen. They exchange greetings and talk about the cold winter weather. The patient stands up and walks to the window. He turns the camera and shows the snow-covered landscape with steep cliffs outside his house. (...) To assess the patient's balance, Søren asks the patient to walk back and forth in front of the camera. The wife picks up the phone and turns it towards her husband, so his walk is visible on the screen. He walks into the living room and back to the kitchen. Søren asks whether he can walk backwards and sideways. The patient does both without problems and he even dances a pirouette in the living room, before returning to the kitchen (Observation with clinical nurse specialist).

Søren observes the patient walk back and forth in front of the camera to see their walk and mobility which provides him with some visual cues to aid his assessment of the patient's condition. Søren also explains how he can guide the patients to use their camera to show him the scars from, for instance, operations so he can assess if there are swellings. These are assessments Søren normally does in an in-person consultation. In a phone consultation, patients can narrate such information to the clinician, but with the video call, clinicians can combine the patients' narrations with their own observation of the patients and, thus, it elevates a phone consultation substantially. These visual observations might be easier during a physical meeting, but the video is nonetheless an important repairment. According to the clinicians, generally, video consultations have limitations compared to physical meetings, but they are better than phone consultations. As one clinician expressed in one of the online meetings: "*Video consultations are way better than phone calls but worse than physical meetings*" (Fieldnote from online meeting).

Another repair offered by the video consultation is allowing relatives to join in the conversation. In the fieldnote above, the patient's wife participates in the consultation. The patients' relatives are often important for patients' treatment and for gaining insights into patients' health. Where a phone consultation makes it difficult for relatives to participate in the conversation, the video consultation allows them to participate similarly to accompanying the patient to an in-person consultation because both patient and relative can be visible on screen.

While touching, smelling, and listening to the patients' bodies are still absent in the video consultation, the visual deficits of a phone call are repaired by turning to video consultations. Furthermore, as will be explored below, the video consultation invites new materialities into the conversation between clinician and patient and opens up new possibilities.

## Beyond repair: What the video consultation invites

**Visual materialities.** During a video consultation, the focus of the conversation becomes centred on the screen where the clinician and patient can see each other.

As such, the video consultation is constituted through what is visible on the screen. During a video consultation both clinicians and patients may introduce other materialities than their own bodies into the consultation by including them in the view of the screen, as the vignette below exemplifies:

The clinical dietician Patricia has a follow-up conversation with a patient with lactose intolerance. She initiates the consultation by summarizing the advice she gave last time and then invites the patient to narrate how he has been doing. They talk about vitamin supplements and the patient stands up and collects a bottle of vitamin D that he shows to the camera, allowing Patricia to see the type and amount. (...) Patricia asks the patient what he drinks instead of milk and the patient walks to his fridge and pulls out a juice bottle which he holds up in front of the camera. (...) The patient explains about different types of foods that give him pain besides products with lactose. They discuss this for a while and Patricia also recommends him talking with his doctor about this issue. She suggests some modifications he can try, for instance, cutting down on the use of onions and garlic, and instead using the green part of spring onions. The patient is unsure what spring onions are. Patricia quickly turns to Google and finds an image that she shows him via the screen-sharing function (Observation with clinical dietician).

The inclusion of image sets the video consultation apart from a phone consultation, and several patients and clinicians take advantage of the possibility to show things on the screen. By being at home and having the hospital consultation via video, patients are enabled, or even compelled to show the clinician items in their home, such as vitamins and food, which they most likely would not have brought to a regular consultation. Patients also show things that are seemingly irrelevant to the medical aspect of the consultation, for instance, their view out the window. Previous research has argued that when care moves into the home it is necessary to consider the role of the space in this new encounter (Langstrup et al. 2013; Oudshoorn 2012) as the technologies may be considered intrusive (Pols 2012).

The video conferencing software also allows clinicians to show information to patients. Patricia uses screen share to show patients food and vitamins, so they know how they look. An important aspect of care in the consultations with the dietician seems to be ensuring that patients understand the information provided. In her video consultations, Patricia uses the option in the video conferencing software to combine verbal information with visual information; she has created PowerPoint presentations about the illnesses she provides dietary consultations for, which she shows patients in their initial meeting. She might also show them a video about digestion. The video consultation's emphasis on visuals engenders an invitation for new forms of materiality to participate in the consultation.

**Limited mobility and flexibility.** The distributed location of clinician and patient during a video consultation is another element that opens up new possibilities. The neurological department at the hospital sees patients from all of Denmark, as well as patients from Greenland and the Faroe Islands. The clinical nurse

specialist explains that for patients that live far away or have movement difficulties, video consultations make an obvious choice for the consultations that do not necessitate in-person meetings. In these cases, care is arguably directed towards aspects that surround a consultation, such as patients' transport. While the care 'situation' in outpatient clinics might be considered the consultation, offering flexibility can also be seen as an act of care. For patients, video consultations may provide more flexibility compared to regular consultations. In my observations, one patient reported that they accessed the video consultation from work, another that they used the waiting time to vacuum-clean.

The examples illustrate how video consultations can offer an alternative for patients who live far away or have difficulties coming to the hospital, or patients who seek greater flexibility in their contact with the hospital, for whom the video consultation can easier be fitted into their daily activities and save them the time and effort of coming to the hospital. Currently, during Covid-19, video consultations offer the benefit of conducting consultations without being in the same room and thus minimizing the risk of spreading the virus. However, the other benefits of non-co-located consultations may deem the video consultations desirable also in a post-pandemic future.

## Discussion and conclusion: Video consultations in a post-pandemic future

In contrast with previous literature on telemedicine which is typically delimited to studying the technology in the context of a project, this paper investigated video consultations when they were broadly rolled out to facilitate care at a distance between the hospital and remote patients in the light of the Covid-19 pandemic. Another key difference to other studies is that rather than receiving equipment from the hospital (e.g. Andersen 2010; Langstrup et al. 2013; Oudshoorn 2008), the patients use personal technologies they already own such as smartphones, tablets, and PCs. The findings elicited how video consultations repair some of the embodied aspects from a physical consultation, which lack in a phone consultation, by reintroducing visual elements that are important both for clinicians' assessment of the patients' health and for evaluating whether patients understand the information given during a consultation. While in a quite different context, research on remote collaboration has similarly pointed out how video enhances the understanding between parties compared to audio only (Karis et al. 2016; Olson and Olson 2000). The video consultation also makes it easier for patients' relatives to join in the conversation. In addition to the repairs, the video solution engenders new options such as sharing educational material and invites the visual materiality of sharing and showing things from the patients' home on camera during the consultation. Finally, the opportunity to have non-co-located consultations has the potential to ease accessibility to healthcare services for

people living far away, for instance, in Greenland and Faroe Islands, and for patients with mobility difficulties, or patients seeking more flexibility in their contact with the hospital.

The repairment offered by the video conferencing software has rendered the solution a good alternative to the in-person consultation for providing care during the pandemic. A prevalent question that remains is how the solution will be used once the majority of the population is vaccinated and it becomes less risky to meet in person again. The possibility of offering a non-co-located consultation in some cases seems relevant beyond pandemic times.

In the online staff meetings regarding virtual clinics, the participants discuss how patients should have the option to choose between physical, video, or phone consultations for the appointments that do not require that the patients come to the hospital, which is also proposed by Danish Regions (2020). Whether the video consultation will gain further traction thus seems dependent on patient choice. Based on my work so far, I identify three dependencies that need to be considered when offering virtual consultations. First, it requires a skilled evaluation of which consultations require in-person interaction. Second, the process of checking the patient's preference needs to be embedded into the current practices of booking hospital appointments, which could prove time-consuming. Finally, but very importantly, are the clinicians' preferences. Currently, several clinicians seem reluctant to use video consultations. This creates the task of training clinicians and getting them comfortable using the video solution. However, if they do not see the benefits of video consultations, deem that they have too many deficits compared to the physical meetings, or if the technical difficulties are too pronounced, then video consultations might not become embedded in treatment practices, despite a desire from management and patients.

One can only speculate how the use of video consultations might anchor itself in the healthcare sector in a post-pandemic future. However, it seems unlikely that the solution will disappear, and that the ongoing digital transformation will retract to a pre-pandemic stage. Thus, it will be interesting to follow the negotiations of when and how to use video consultations in the future. Further research might investigate what consequences this type of consultation has, for instance, on the patient-clinician relationship (Piras and Miele 2019) and the space of care (Langstrup et al. 2013; Oudshoorn 2012), particularly considering that patients use personal technologies. Embedding technologies in care infrastructures always requires practical work of continuously 'fitting' (Pols 2012) clinicians, patients, administrative tasks, devices, etc. to provide good care. When technologies are implemented on a large scale and connect with technologies uncontrolled by the hospital as in the present case, it seems particularly crucial. This paper has suggested some of the work that compels attention on the clinical side of the infrastructure. The multitude of sociotechnical dependencies on the patient side remains for future research.



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# Data Work in Healthcare: An Ethnography of a BI Unit

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**Abstract.** In this paper, we investigate a newly established Business Intelligence unit providing healthcare data and analyses for management and staff at five hospitals in the Region. Created in 2015, the Business Intelligence Unit repurposes data generated by digital healthcare systems and aims to “[...] support the Region [...] in delivering more welfare, better quality, higher impact, and greater sustainability for less money.” Within healthcare – and in other domains – there is a strong push towards becoming (more) data-driven and repurpose data to increase efficiency, quality, and cost-effectiveness. However, whereas there are numerous publications on ‘datafication’ in the abstract, there is a dearth of studies on how the data at the center of such processes is actually produced, and even fewer studies on the people and organizational units engaged in this work. Hence, we are engaged in an ethnographic study on data work at the Business Intelligence Unit in order to gain insights into the work and practices of generating healthcare data for secondary use. In this paper, we present the preliminary findings focusing on three themes: end-user engagement, creating meaningful data reports, and establishing trust. One overall contribution is that whereas Business Intelligence work does require technical competences to work with large-volume data, it also requires competences of engaging with healthcare staff and understanding their work practices.

## Introduction

A second wave of healthcare digitization has begun after the first ‘wave broke’ and electronic healthcare records (EHR) were implemented in the first two decades of this century in many countries in Europe and the Americas (Simborg et al. 2013). In the present ‘second wave’, the digital data produced by EHRs and other

healthcare IT systems are repurposed for secondary uses such as managerial overview, quality assessment, optimizing workflows, etc. This repurposing of healthcare data is at the center of numerous initiatives at local and government levels and within commercial companies.

However, whereas there is much attention upon the larger processes and the involved benefits and challenges of healthcare digitization (e.g., Hogle 2016, Hoeyer 2016, Ruckenstein & Dow 2017), there is a dearth of studies on the people working with that data. While the occupation of ‘data scientist’ has emerged and received attention and even led to new university programs, we know little about who is actually doing the work of collecting, filtering, formatting, analyzing and presenting healthcare data. Data work is often invisible, rendered to the background, or abstracted away as numbers and indicators (Star & Strauss 1999), and thus researchers, managers, and policy makers are provided an impoverished understanding of what it means and requires to become data-driven in healthcare and deliver on it. Furthermore, datafication entails shifts in occupations and professions that may change these or lead to the emergence of new ones. Hence, one overall research question to us is what do the actual work practices in healthcare around data look like?

In order to investigate this, we have commenced upon a long-term ethnographic investigation of a data work site in order to understand what ‘data work’ entails. The site is a Business Intelligence unit (BIU) providing data for hospital and ward management as well as regional politicians. In this paper, we present our first, preliminary findings.

## Datafication and Data Work in Healthcare

Our research into data work practices is situated in the larger context of datafication and the ambitions for public and private organizations to become data-driven. ‘Data’ has emerged as the new oil of the information economy (Van Es & Schäfer 2017), and as the central notion of Big Data (Mayer-Schönberger & Cukier 2013, Kitchin 2014). Premised on the spread in depth and scope of digital technologies, huge amounts of data are accumulated, algorithmically transformed, and repurposed to deliver purported benefits for citizens, organizations, and society. However, data is not ‘found’ and ‘collected’, but must be generated, shaped and presented – by people. As the emerging field of critical data studies argues, ‘raw data is an oxymoron’ (Gitelman 2013). Further, sharing data creates ‘friction’, since it has to be filtered, formatted and re-contextualized (Edwards 2010). Data requires work. Some of this work involves algorithms and high-level technical skills, but also hermeneutic judgement and situated knowledge is required, since data is entangled with the contexts of its production and use (boyd et al. 2012).

Ambitions for data-driven healthcare in many countries (Madsen 2014, Raghupathi et al. 2014, Mayer-Schönberger & Ingelsson 2018) has followed

digitization of the healthcare domain (Ruckenstein & Dow 2017). Those ambitions are also strong in Denmark, where the present study is conducted, and where ‘data-intensive resourcing’ is pursued in government strategies (Hoeyer 2016). Amongst healthcare staff, this has at times led to a feeling of being flooded with requirements to provide data to the extent that ‘meaningless data’ erodes professional judgement (Wadman & Hoeyer 2020). Whether data is actually ‘meaningless’ depends of course on perspective and on whether one understands and agrees with purpose of generating it (ibid).

Surprisingly few studies on data work have been published. ‘Data scientists’ have received attention as a new, emerging profession, but beyond that there are few studies upon who conducts data work. A couple of recent studies show how generating and making data useful is also conducted by professions such as electricians and energy advisors (Foster 2016, Fischer et al. 2017, Kristiansen et al. 2018). Also, within healthcare, an emerging attention to data work can be seen by studies that examine the actual work invested in producing, managing, analyzing, and deploying data (Bjørnstad & Ellingsen 2019, Bonde et al. 2019, Grisot et al. 2019, Islind et al. 2019, Pine 2019). Also, new emergent data work occupations such as ‘medical scribes’ and ‘clinical documentation integrity specialists’ and their role in producing healthcare data have been studied (Bossen et al. 2019, Pine & Bossen 2020). Most recently, Håland & Melby (2021) analyzed the work of coding cancer care pathways and identified five types of ‘accountability work’ which we see as an exciting analysis of what we call data work. Hence, gradually a better understanding of data work practices in healthcare is emerging.

However, we know relatively little about the work going on within BIUs in healthcare. Early frameworks for the links between Business Intelligence (BI) and healthcare were presented by Mettler & Vimarlund (2009) and Wixom & Watson (2010), and Madsen (2012) presents guidelines for healthcare organizations to become data-driven, including how to achieve overview of the availability of data, the need for standardization, how to get the data warehouse in order, the work of Chief Data Officer, etc., but there is little concrete information on the data work and workers themselves. Gaardboe et al. (2017) applied DeLone & Mclean’s model of IT system success to investigate the factors that contribute to BI success and found user satisfaction to be decisive. In a similar study, they identified two groups of users of BI information - system users and information users – and that BI was used for financial reporting, improving patient progress, and enhancing learning in hospitals (Gaardboe et al. 2018). Manchini et al. (2019) provide a review of 50 papers from 2010 to 2017 on BI in healthcare based on a framework of four BI capabilities: organizational memory, information integration, insight creation, and presentation capabilities. However, none of these studies provide a detailed analysis of BI work practices.

In summary, there is a need for ethnographic studies of data work as well as of BIUs in order to better understand what data work and datafication is.

## Methods

The present paper builds on participant observation by the first author, who participated in three online staff meetings (2 hours each), conducted four interviews (½ hour each - including three BIU staff members and a manager), one interview with two managers (1 hour), an introductory presentation by a BI representative (2 hours). Further, we have conducted analysis of a wide range of documents: Policy documents by the Region outlining the purpose of the BIU, and various internal BI documents describing work processes, the unit's strategies, etc. Additionally, a significant number of online videos for healthcare staff produced by the BIU explaining how to work with data have been watched.

Notes were taken during participant observation, interviews were transcribed and subsequently analyzed, and documents scrutinized for the purpose of this paper.

## Findings

The BIU was established in 2015 as a part of the Region's digitization strategy to make work procedures in healthcare more efficient and data-driven, as well as accommodate the demand for evidence-based decision-making. The BIU is also a part of the vision to proactively utilize data for forecasting with the help of artificial intelligence and machine learning. The BIU's own strategic vision is to better the "[...] organization, services, resource consumption, impact, and reputation by always delivering the best qualified data-information basis for decision-making and development." (internal BI strategy document). In addition, their mission is to support the Region's areas of business "[...] in delivering more welfare, better quality, higher impact, and greater sustainability for less money." (internal BI strategy document).

The BIU has developed rapidly. Whereas it had 16 employees and 290 users in 2015, the BIU has since grown to 45 employees and nearly 4000 users in the beginning of 2021. A central component in their strategy is to have an 'open BI-setup', which means that they actively pursue user participation by healthcare staff and management in their service delivery.

The BIU staff hold several job titles such as BI developer, BI architect, senior developer, and user experience designer. Most common – including our interviewees – the staff members hold the title of BI developer. In general, BI developers have broad profiles encompassing both technical skills (i.e., front- and back-end programming) and competencies such as working with large-scale datasets, identifying user needs as well as solving problems with data. Formally, their work covers data warehousing, data analysis, report development, support, advice, and education of other occupations in healthcare. Their main product is data

reports, which have a standardized format of presenting data as well as showing which data and which filters were applied.

## Open BI: User Participation, BI Portal Ninjas, and Data Heroes

The BIU's notion of an open BI-setup implies a user-centered approach, where they aim to be both inclusive and relevant to healthcare staff, administration, and management. It involves the following elements: User participation when developing new data products; BIU staff members and technology being easily accessible when needed; and training healthcare staff in data processing and use. Hence, the BIU seeks to transform healthcare workers into "smart data workers", as one BIU staff member phrased it. The purpose is three-fold: To ensure that data is valid and data reports meaningful; to ensure implementation of data products in healthcare practices; and, finally, to empower healthcare staff to work with and use data. Thus, the BIU staff does a lot of work to make themselves relevant for healthcare staff.

The open BI approach was applied from the beginning, when healthcare staff was included in the development of the 'BI-portal', the central portal through which healthcare staff and the BIU can access and work with data. Also, BI developers engage in iterative processes with healthcare staff when they develop new data reports in order to identify user needs, receive feedback, develop new ideas, and improve the data products. This enables BI developers to understand healthcare staff's context, and thereby ensure that the reports provide meaningful and valid data as well as being useful to them. In the BIU's own view, this is a crucial part of their work, as it is a way to gain healthcare members' trust in data and the BIU's work – an argument we will elaborate further in later sections. This practice is also a way to ensure the implementation of their data products in local healthcare practices. That data is put into actual use. One way to facilitate this is to design the data reports in the BI-Portal to be user-friendly. As much as possible, they should be self-explanatory and easy to navigate, thus reducing complexity and thereby reduce time spent on learning to read data reports and using the BI-Portal. This can potentially enable both busy as well as technically lower-skilled staff members to utilize the data reports.

The BIU also trains healthcare staff to become BI users and 'smart data workers', through workshops such as BI-Garages, SQL workshops as well as BI-Cafés. At BI-Garages, the BIU invites healthcare staff members into their office and introduces them to the BI-portal and the data reports. At the SQL workshops, healthcare staff learns how to use SQL to manage healthcare data. Furthermore, the BIU has developed two training programs, the 'BI-portal Ninja education' and the 'Data Hero education'. Through the BI-portal ninja education, administrative personnel and healthcare staff learn about the BI-portal and how to operate existing data reports. The participants at these training programs are typically medical secretaries and healthcare staff members who manage data from data reports such

as diagnostic reports or treatment time reports. The Data Hero training program is aimed at medical staff like clinicians and associated medical professions (e.g., biochemists, chief physicians, radiologists, etc.), administrative officers, and data workers at local wards. In this intensive three-week program, participants learn to create their own specifically focused data reports from existing data resources, and how to visualize data to support their own practices and needs. Further, they learn about Tableau, (a data-processing and visualization program), data sets, key figures, and the challenges involved in granularity.

The open and user-involving approach can be seen as an intervention where the BIU distributes data competencies to healthcare staff. This aims to empower healthcare staff to understand data reports, device their own when needed, make them trust data, and see how it can be applied to make their work procedures more efficient or improve quality. However, another point is that this intervention is also a way to consolidate the BIU's own work. When they work to make data valid and meaningful, make themselves visible through workshops as well as distribute data competencies, they work to get healthcare staff to accept data work as important healthcare work.

## Technical Skills: From Data to Meaningful Information

“To give data back to those who have fed in data in the first place”. That is how one of the BI developers explained the purpose of his work. Others offered us variations on the same theme: Providing meaningful information in the right place at the right time. More elaborately, their aim is to support healthcare staff - whether it is clinicians, administration personnel, or management - with data for decision-making and thus make it possible to improve work procedures as well as patient treatments and experiences. To accomplish this purpose, BI developers work to transform data into what they call “meaningful information” as well as to present it in a “meaningful way”. To make data meaningful is, we purport, a sociotechnical endeavor that requires technical skills, specific knowledge, and collaboration between different professions. In this section, we will illustrate how BI developers utilize technical skills and technologies to transform data into meaningful information and thus improve work procedures.

BI developers work closely with data in a technical sense and engage in data warehousing, data analysis, and data visualization. One central work process is to work with different, complex layers of the data structure that must be applied properly to enable data to function and be put to work. BI developers integrate data into the data warehouse from different internal sources (i.e., EHR, clinical quality databases, salary systems, etc.). They aggregate data into data sets and apply metadata; add different logics such as key figures and definitions; and apply visualizations on top of it and security beneath it, so the data is ready for presentation. A core task of their function is then to further process and visualize



these data in a meaningful way through data reports that are published on the BI-portal where healthcare staff can access them. These data reports are developed with Tableau software that has features enabling filtering and visualization of data through tables, statistics, charts, and graphs.

An example of this process is the ‘Turn-Around Time Report’ (TAT)’. This report was developed to support a biochemist’s practice of monitoring his unit’s turn-around time: How long does it take from the arrival of a sample to an answer is available in the laboratory system? Depending on the priority of a sample, this can be measured in minutes, hours, or perhaps even weeks. Previously, the biochemist would once a week manually enter the unit’s data into a spreadsheet to monitor its turn-around time. After consultation with a BI developer, this practice was transformed into the TAT, where the relevant data is automatically integrated on daily basis and presented in a way that is useful and meaningful to the biochemist. When needed, the report can effectively provide answers to questions that correlates with the unit’s objectives (e.g., how many samples are analyzed within 60 minutes?), and thus saves the biochemist time.

Of course, technical skills are imperative when automating redundant, time-consuming tasks, but this example also demonstrates how mutual collaboration between healthcare staff and BI developers in line with the open BI strategy results in relevant data that is put into use. Thus, the BIU does not only provide meaningful information and make healthcare staff’s tasks more efficient, but also give data back to them, so data work seems more meaningful in the first place.

## Collaboration and Domain Knowledge: Data Quality and Trust

As can be seen from the above, a crucial aspect of BI developers’ work is to collaborate closely with healthcare staff to ensure meaningful data of high quality. Data quality is important to both the BIU staff members and healthcare staff: If errors occur in data or data sets, they can result in healthcare staff distrusting data validity. Consequently, this can prompt them to not use the data products and instead solely rely on their professional judgement. To meet this challenge, BI developers strive to achieve specific domain knowledge in order to be able to correct errors in collaboration with healthcare staff, and hence ensuring that data is valid and meaningful.

Data quality and meaningful data often pose a challenge to the BIU, when end-users have not been involved in development from the outset. When “[...] the one who defines key figures is not necessarily the one who must use it in a given situation”, as one BI developer phrased it, the final data product can seem flawed to the end-user or not compatible with the actual work practice it should support. This is evident in situations where there is a difference between the registered data presented in a report and healthcare staff’s experienced reality. For example, a medical secretary was looking up how many of her patients were about to exceed

the limit of the warranted treatment time (In Denmark, per government regulation all patients must have a treatment plan within 30 days). In this case, the report displayed three patients that the medical secretary knew had been treated already. So, the question for her was, how many other errors could there be in the data report? According to the BI developer, who investigated the data, the answer was ‘none’, but it is more complex as such. As the BI developer explained, these kind of ‘errors’ occur because of differences in registration practice; differences in key figures, definitions, or codes; or different understandings of the usage situation. In this case, the three patients were registered with a wrong code at the local ward. The BI developer explained that someone had decided that they should use another code. The medical secretary objected to that code being ‘wrong’, because they had always used that code at her ward. The BI developer further elaborated on the situation: “[...] it is that kind of logic that is hard to communicate, that is, the complexity that is in this logic that we have in our data”.

If not resolved, situations like these can give rise to distrust in data validity and consequently cause specific data reports not to be used at all. So, in addition to having certain skills and knowledge of data analysis, BIU staff also need to have what one of the staff members characterizes as “domain knowledge”. Some of the BI developers have educational backgrounds in medicine and medical science, which provides for an initial understanding of the context and thus the data needed. However, to achieve the relevant knowledge for a specific work procedure, they must collaborate closely with healthcare staff and acquire experience within the domain. Thus, some BI developers shadow clinicians and take notes of their work procedures as well as sit next to them and go through all their tasks to identify the clinicians’ needs when they develop new data products:

“[We] go out and sit with the physician, when he has time, and talk about it and show him what is accessible. We ask him, do these numbers, these 27 patients we have found with bowel disease in your ward, do they sound right? Because we have no clue. We have no chance of knowing, if these 27 patients are 7 right ones and 20 wrong ones and if perhaps another 100 patients are missing” (Interview, BI developer 2)

As this example illustrates, the registered data might not be wrong, but the applied logics or visualization might differ from the medical staff’s experienced reality. To ensure data validity, and thus trust, BI developers move back and forth between their office and the wards and offices of healthcare staff to constantly test and validate the data quality. This shows how collaboration between BI developers and healthcare staff is crucial to ensure high data quality as it depends on the interdisciplinary knowledge of both data structuring and data context.

## Discussion

This paper presents the preliminary findings from an ethnographic study of data work in a healthcare BIU that provides data to five regional hospitals and decision makers. Based on interviews with BIU staff and management, observations at staff meetings, and document research, we identify and analyze what their work entails.

First, we have analyzed how the BIU employs a strategy of user participation, called the ‘open BI setup’ to transform healthcare workers into ‘smart data workers’. This approach implies involving healthcare staff when developing new data products, making data products easier to understand and use, and training healthcare staff into being BI users. We have found that the purposes of this strategy are to ensure data is valid and meaningful; to ensure implementation of data products in healthcare practices; and to distribute data competencies and thus empower healthcare staff to work with and use data. Further, we have argued that the BIU works to get data work accepted as important as well as meaningful and thus to make the BIU relevant to healthcare staff. This part of their practice can also be understood in relation to Håland & Melby’s (2021) notion of ‘legitimation work’ where work is done to legitimize a practice “[...] as being important and make their colleagues accept this as important [...]” (Ibid, p9). When doing this, they seek to consolidate their own work as well as ensure the implementation of data products.

Second, we have demonstrated how BI developers’ data work practices revolve around transforming data into meaningful information presented in an easily understandable way. This involves transforming tedious data tasks into automated and standardized data reports. Furthermore, we have argued that this is a work practice that requires technical skills, specific knowledge of the domain, and collaborative competencies by BIU staff.

Third, we have pointed out that high data quality and meaningful data is crucial to avoid mistrust towards data amongst healthcare workers. When errors occur, it can lead to mistrust of data when alleged errors are due to differences in registration practices; differences in key figures, definitions, or codes; or different understandings of the usage situation. We have found that BI developers counteract these challenges by acquiring domain knowledge and collaborating closely with healthcare staff to account for errors as well as to correct them. We found that this work is important to ensure implementation of data products in healthcare practices.

This article contributes to an empirical understanding and insight into the practices of data work in healthcare and is the first step at an ethnographic analysis of data work practices in a healthcare business intelligence unit, which aims at providing insight into the work of becoming data-driven.

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# The Sensing and Numeration of Mental Health in a Refugee Camp

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**Abstract.** In this paper we draw attention to the duality of mental health assessment in a refugee camp: its *sensing and numeration* by Medical Assistants providing door-step services to the refugees. Drawing on ethnographic fieldwork in Kutapalong, Bangladesh, we explore the moods that pervade the refugees and their dwellings as these moods are important to the Medical Assistants that service the refugees with health care and in turn assess their mental health. While we consider attuning to moods in Heidegger's sense as pervasive to the human existence, we consider the numeration of mental health by the medical assistants using a screening tool as equally significant. Comprehending how states of mental health are assessed in our case, we argue, requires that we pay attention to both the quantification of mental health by a screening tool as well as the ways that the experience of moods shape the assessments done by the health care professionals. Taking this analytical approach, we show how the assessment of the mental health of refugees by Medical Assistants in a camp setting were inseparably both a question of sensing as well as numeration. Where sensory experience may not be 'enough' on its own to warrant referral in the context of the health care infrastructure of the camp, and therefore the agency of numeration is a force that works well as an ally to the sensing of moods impressed on the medical assistants.

## Introduction

This paper explores the assessment of the mental health of refugees in Bangladesh by medical assistant providing door-step services. Recently, a digital screening tool has enabled Medical Assistants to quantify the mental health of refugees in the camp. Based on WHO SRQ-20, the screening tool enables quantification of the severity of mental health issues on a scale from one to twenty – where a score of seven or above is the cut-off point for referral to treatment. Yet the Medical Assistants do not rely on the screening tool alone to make their referrals. Ethnographic data show that in addition to relying on the screening scores they also rely on their intuition and bodily experience of meeting the refugees in their homes - seeing them, sensing them, picking up on their posture, frame of mind, and the atmosphere of the home. How is the mental health of the refugees 'experienced' by the Medical Assistants in part through numbers and in part through

bodily experience?

Poor mental health has long been known to have adverse effects and assessing it more readily and accurately in humanitarian crisis can arguably contribute to the well-being of for example refugees by providing those in need with referrals to treatment. However, what counts as poor mental health to those doing the referring is in practice located between ‘objective’ measures of mental health such as the WHO SRQ-20, and more ‘subjective’ valuation and bodily experience of moods, frames of mind, and atmospheres mediated through the senses. Neither numeration, nor bodily experience, thus stand alone in the assessment of the mental health of refugees in Kutapalong camp by the Medical Assistants. We refer to the above as the ‘dual quality’ of mental health assessment in Kutapalong Camp, which we engage with in this paper.

In most humanitarian crisis, mental health issues are tied to the life changing and sometimes catastrophic events leading up to the crisis. Worldwide, people are facing an increasing number of humanitarian crisis arising from conflict and disaster. In 2019, there were 70.80 million forcibly displaced people worldwide (UNHCR 2019b) of them 914 988 were Rohingya, our case in point, living in camps in Bangladesh (UNHCR 2019a). The Rohingya influx into Bangladesh followed their forceful displacement from Myanmar in 2017. Although estimated rates of mental health issues in the wake of humanitarian emergencies vary somewhat with circumstances and study methods, a meta-analysis indicate rates of 22.1 % for mental disorders (i.e. depression, anxiety, post-traumatic stress disorder, bipolar disorder, and schizophrenia) in conflict-affected populations (Charlson, et al. 2019). Existing studies offer vivid documentation of the ways in which displacement, trauma, and confinement affect Rohingya refugees in Bangladesh (Tay, et al. 2019). How idleness, the breakup of extended families, domestic disputes, and uncertain prospects for the future, depress the mood of the Rohingya refugees and drive some to mental illness (Christensen, et al. 2020). Arriving at a refugee camp can be lifesaving but living in a camp may be associated with stress and lead refugees to mental health issues (Christensen et al 2020). Despite this attention to mental health in humanitarian crisis, few studies have considered in ethnographic detail how mental health is understood and assessed by those working with the refugees taking responsibility for their well-being including their referral to treatment.

Our starting point is ethnographic field work conducted in Kutapalong refugee camp in Bangladesh. Numerous studies within human-centered computing and health care (Christensen 2015; Petersen, et al. 2021; Tellioglu and Wagner 2001) have employed ethnographic approaches (Blomberg and Karasti 2013; Christensen 2014), including in the Global South (Christensen, et al. 2019; Christensen, et al. 2018). Using an ethnographic approach, then, we explore the duality of the process by which medical assistants screen refugees for mental health issues and offer a theoretical exploration of how these assessments stem from numeration and bodily experience. Previous studies have long been occupied with what quantified data in the form of numbers mean and what they ‘do’ (Day, et al. 2014), and how they are mediated or themselves mediate phenomena (e.g. Hacking 1990; Porter 1995) (Desrosières 1998; Espeland and Stevens 2008). Studies have proposed that numbers are social entities (Lippert and Verran 2018; Verran 2012). In a tradition inspired by Michel Foucault, numbers are seen as a way to enable management through rational-scientific means (e.g. Rose 2004). Numeration may make a phenomenon visible and legible and be a source of agency (Scott 1998). Furthermore, studies of mental health have benefitted from a phenomenological perspective of lived sensory experience inspired by not least Heidegger (e.g., Gammeltoft 2018). Heidegger’s concept of *Beifindlichkeit* (attunement) and *Stimmung* (mood) are pertinent here. Attunement refer to how we humans are always already tuning into our

surroundings, open to our lifeworld and its atmospheres that we soak up as a matter of being-in-the-world. Attunement is a matter of existing in a world that we already always share with others, it is as such a matter of being or *Dasein* (lit. being-there), to use a central term from Heidegger, rather than an act of will or purpose. The point is that attunement is an inevitable part of being. “The world is always already the one I share with others. The world of *Dasein* is a *Mitwelt* (with-world). Being-in-the-world is being with others (*Mitsein*). Attunement as part of being in the world with others may make us sensitive to their moods (*Stimmung*) (Heidegger 1962).

In this paper, we will consider the moods that pervade the refuges and their dwellings as these moods are important to the Medical Assistants that service the refugees with health care and in turn assess their mental health. Considering attuning to moods in Heidegger’s sense as pervasive to the human existence, we use the concept together with the notion of numeration to designate the assemblage of *quantification* by virtue of the SRQ-20 screening tool and the *attunement* to the refugees by the Medical Assistants. Comprehending how Medical Assistants working in the camp with the refugees, come to understand the mental health of the refugees demands, we content, dual attention to numeration and attunement to moods within the camp.

## **The Study: Mental health among refugees at Kutapalong**

This paper derives from a collaborative research project conducted in Kutapalong refugee camp in Eastern Bangladesh by a Bangladeshi-Danish research team. Combining screening and ethnographic methods, the larger study investigated the mental health of refugees in the camp (Christensen et al 2020). The project included the screening of 2735 adults for mental health issues and interviews with selected refugees. The screenings were part of an outreach program staffed by mHealth teams comprised of one paramedic (female health care professional with a degree in health care) and one coordinator (male and often without formal education in the field of healthcare). Each mHealth team is dedicated to one area and goes door to door to provide primary health consultations and support to every household. Each mHealth team supports around 300 households, making 10 to 15 household visits every day. For every household, the mHealth team makes follow up visits within 14 days from the previous consultation session.

During the project, each of the paramedics visited the households in their area of the camp and in addition to providing primary health care as per routine (i.e., in relation to somatic issues), the paramedics also screened the adult members of the household for symptoms of mental health issues using a digital screening tool based on the WHO SRQ-20 standard (Beusenberg and Orley. 1994). The SRQ-20 is a 20-item screening tool which was developed by the World Health Organization (Beusenberg and Orley. 1994) and it has been widely used in low-income countries (Netsereab, et al. 2018; van der Westhuizen, et al. 2016). The SRQ-20 includes 20 questions, and on the basis of the refugees replies to these, a total score is calculated. The maximum score, indicating a high risk of mental health issues, is 20. Cut-off points differ between countries, but in most settings, people with scores of 7 or more are considered at risk of mental health issues. In South Asia, different cut-off points have been used (Christensen, et al. 2020). In our project we settled on a cut-off point of 7 meaning that those refugees that answered positively to seven or more of the questions, asked by the paramedics during the screening sessions, were referred to further diagnostics and treatment at camp clinics.

We base this paper on ethnographic interviews with the medical assistants that conducted the screenings with an interest in their experience. We interviewed them and



followed them on their rounds of house calls and screenings for mental health issues. In collaboration with our Bangladeshi partners, we interviewed 20 medical assistants, and visited with them as they provided services in the homes of the refugees. In eight cases, we met with the medical assistants and joined them on their house calls on more than one occasion. The medical assistants were aged 23-31 at the time and had been working in the camp between 1 year and 7 months and 2 years and 2 months. In addition, we carried out a series of ethnographic interviews with Rohingya refugees that is this paper mostly figure as background to the experience of the medical assistants that we foreground.

One of the first medical assistants we met was Sharmin (not her real name). She has been working as a medical assistant in the camp for 1 year and 11 months and had joined the humanitarian effort early when the camp was being established. In our initial conversations with her, Sharmin described the horrendous conditions in the camp in early 2018, when she came to work there, and her motivation to reduce the misery and suffering of the refugees.

### ***Sharmin: In the beginning***

Standing on a hill lets one appreciate the sprawl of shelters reaching into the horizon. Hosting close to 600,000 people in one-story shelters makes the Kutapalong extension site, as it is formally known, striking by its extent alone. According to the official Bangladesh policy, the "displaced Myanmar nationals" living in the camps are not refugees *per se* and are not to settle permanently. The shelters are built to be temporary to reflect the status of their inhabitants. That is, they are made with tarpaulin suspended over bamboo frames and have compacted stamped earth for floors. A dwelling will typically have a heavy cloth curtain, rather than a door, to separate the main entrance from the rough paths outside that serve as the street. Spread out empty sacks may serve as carpets. Each shelter leans on the next in long winding rows. The rows of shelters cluster and form blocks connected by gravel roads passable by trucks and lorries carrying people and supplies. Everything organised by the Bangladeshi military and international aid agencies. From conversation, it emerges that the camp has not always been this orderly "If I start from the beginning", Sharmin says, "there were no proper roads going into the camp. It was a wildlife reserve for elephants before the refugees came here. The roads were so bad that it was hard for us to walk and taking a car was out of the question, we had to follow footpaths and everything and everybody was scattered around. One problem was that the refugees used the roads and trails as toilets making the camp extremely dirty and we had to watch every step. We started 8 in the morning and worked until 4 in the afternoon, we had to leave the camp before dark for safety. During those days we had little water, food, or rest. They [the refugees] were worse off. Sleeping where they could and eating what they could find. The place was a filthy mess. Many had diarrhea and suffered exhaustion both physically and mentally." As we started to descent downhill, we can see how some things have changed. Roads have been built, shelters, and running water and sanitation has been introduced.

Sharmin, and the other women working as medical assistants [they are all women], move around the camp providing health care to the Rohingya. This was not readily appreciated or well understood at first. "In the beginning everyday was a challenge", Sharmin says, "it was difficult for them [the Rohingya] to accept that women can work like men, and what made it even more difficult was that I was with a male colleague of mine who was the program organiser. To them it is a sin for a woman to work like this with a man. They would not let us into their homes at first."

We move with Sharmin and her colleague between shelters doing house calls. The ground is muddy from the past days rain and it takes effort to walk without slipping. “we used to start our day going to the Majhi”, Sharmin says, “we had to register the refugees by household [...] we tried to convince him to allow us to do this registration. The work we do is totally app based and before we can provide treatment to people, we have to register the household using our tablet and take their names and pictures for their health records. Doing Khana [household registration], we repeatedly had to explain that we were a medical team and needed access but, in many cases, the Majhi<sup>1</sup> was not listening.” Only after repeated pleading over several days Sharmin and her colleague were allowed into the shelters. The refugees gave their names readily, but many refused to have their picture taken for the Khana registration. “We were under suspicion of being spies from Myanmar”, Sharmin says, “and it took a while to convince them that we are here to help them”. The female member of the households held out the longest and taking their picture was a hard struggle, Sharmin tells us. With every entry into a new block of the camp the story repeated itself. Only Sharmin was allowed to enter the house while her male colleague was told to stay outside in the street. “I was scared”, Sharmin recalls, “I entered every house alone with so many looking at me with suspicious. They could easily have harmed me and there was no one to protect me.” It was difficult to win over the refugees. “Especially the elderly questioned me - saying that it was not necessary for us to collect their personal information and take their pictures”, Sharmin says, “I continued to ignore my fear, and this is how we did Khana registration”. It was a struggle for Sharmin’s team to get accepted and especially the Khana registration brought up emotions among the refugees that had fled genocide and years of persecution at the hands of the Myanmar state. “It did take time to make a place in their hearts for us”, Sharmin says, “but now they are open and let us into their homes”.

We arrive at a shelter and Sharmin remove her sandals and prepared to enter. She pulls back the curtain separating the house from the street and talk to those inside. Sharmin gestures us to move inside with a flick of her wrists. The shelter is typical of the camp, around four times four meters comprised of tarpaulin over a baboo frame. We are let into the first of two rooms; there are no windows or ventilation. An adolescent girl greets Sharmin with affection. We have arrived today because the girl’s mother has been crying and neighbours have alerted Sharmin. The girls name is Samara, and she brings out her grandmother and mother. Their names are Jamila and Fatima. Samara and Jamila speaks in low voices and says that Fatima, Samara’s mother, has been possessed. She is reported to be crying through the nights and hardly ever to utter a word. Sharmin, the medical assistant, says that she thinks Fatima looks sad. Perhaps Fatima would consider a test to determine her mental state, she asks, and pulls the Samsung tablet from her bag. However, there is no test to be had. Fatima is not speaking nor willing to undergo the SRQ-20 questionnaire digitised and ready on the tablet in Sharmin’s hands. This is not uncommon. Rohingya usually do not seek medical or psychological treatment if they believe a person is possessed by a spirit but may approach traditional healers who perform rituals, religious practices, and pray. We sit there for a while – moved by Fatima’s dark sunken eyes visible just above the scarf she has drawn across her face to shelter from the men in the room. Sharmin hands out over-the-counter drugs - cough medicine to help the women breathe. Respiratory conditions are common among the Rohingya women in the

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<sup>1</sup> The Majhi is a local leader selected by the community to represent those that live within a camp block.

camp. Breathing the stale air of the home makes it easy to understand why. Outside a small gathering have assembled, mostly people from the block seeking Sharmin's attention. An adolescent boy asks for attention on his mother behalf, and Fatima withdraws further into the shelter as people peek into the room where we are sitting. We break up and Sharmin picks up her bag and hands it to her male colleague outside to continue their rounds. We follow.

A few days later we inquire about the wellbeing of Fatima. She is all-right in the sense that Sharmin, was finally able to persuade her to take the SRQ-20 test, and in the course of doing so secure a referral for her. Sharmin was able to persuade her a few days later after all the hustle and bustle of our visit had died down. They needed time to talk. Fatima's score was well above the cut-off point of 7. "Now, she can finally go and see a counsellor", Sharmin remarks.

### ***In lieu of a conclusion: The moods and the numbers***

The starting point of our ethnographic work was experiencing life in Kutapalong refugee camp through the perspective of the medical assistants on house calls.

In some cases, the medical assistants have been going to their clients' dwellings repeatedly for months, if not years, and in the process immersed themselves in the atmosphere of the homes they visit. The medical assistants may tune into the lifeworld of the refugees as they provide them services. Being sensitive to changes in mood and atmosphere. The own lifeworld is one that they in part share with the refugees. The refugees may draw the medical assistants into the way in which they are. Attunement to the refugees is part of being-in-the-world with them, to use an expression from Heidegger, and it makes the medical assistants sensitive to their moods. Their being with the refugees, alters them, although the medical assistants do not necessarily come to feel anxious, sullen, desperate, or sad themselves, or for that matter happy or excited, they do become attuned. At times, they may look to the SRQ-20 for confirmation, and ultimately referral, when changes in those moods and atmospheres are for the worse. The epistemics of being in the world is cooperated by the epistemics of a medical survey instrument. The mood or atmosphere of a refugee dwelling may set a tone, a mood is like a melody Heidegger notes, that may be picked up by the medical assistants, being there, and in turn lead them to use the SRQ-20.

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Arguably, numeration may provide a sense of certainty and legitimacy important for the act of referral. Numeration, we think, can in some cases be said to extend the sensory experience by imputing it with authority and connect it to a wider medical infrastructure. The medical assistants are counting their clients' symptoms when they screen them with SRQ-20. These symptoms come from a finite set of twenty symptom's

given in advance by the WHO. Arguably, the SRQ-20 on the tablet computers of the medical assistants represent the dominant model of ‘Western medicine’ and it gets its authority from there. The medical assistants are, in a word, leaning on the authority of the SRQ-20, and “Western medicine”, when they refer via the questionnaire. Sensory experience may not be ‘enough’ on its own to warrant referral in the context of the health care infrastructure of the camp, and therefore the agency of numeration is a force that works well as an ally to the sensory impressions of the medical assistants.

Arguably, then, what we have noticed above is a dance of agency between sensory experience and numeration in the screening for mental health issues by the medical assistants in the camp. Future studies may benefit from a heightened sense of how numeration and sensory experience may combine, re-enforce, and mangle in practice. To reiterate, previous studies have long been occupied with what quantified data in the form of numbers mean and what they ‘do’ (e.g., Day et al 2014), and studies of mental health has benefitted from a phenomenological perspective of lived sensory experience (e.g., Gammeltoft 2018). We have in this paper explored numeration and sensory experience in mental health services and find, numeration and sensory experience intersecting inseparably in practice.

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# Structuring the Electronic Patient Record; an Easy Way to Improve Data Usability?

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**Abstract.** In this paper, a qualitative trailing research approach is used, combined with information infrastructure theory to conduct a formative evaluation on an empirical project in North Norway. In this project parts of the clinical information in the electronic health record (EHR) were structured as openEHR archetypes to enable automatic reuse of data from the EHR system to a national medical quality registry. We explore the design-challenges when structuring clinical information for different purposes. Hence, we ask the following research question: What are the premises for reusing clinical information for both primary and secondary purposes? The paper aim to contribute with empirical results and discuss the importance of understanding the prerequisites and implications of reusing clinical information for a duality of purposes. As results we outline three important issues to address. 1) the demand for attaching context when reusing variables, 2) how to ensure reusing the right data, and 3) the challenges of granulating the variables. Lessons learned indicates that governance and competence are the most important prerequisites for improving data usability by structuring clinical information.

## Introduction

Over the last years, building global healthcare frameworks to improve clinical data usability have gained increased attention. In line with this, there are extensive

ambitions of reusing data from Electronic Health Records (EHRs), both for clinical use and for secondary purposes, like registries, research, and management (Greenhalgh et al., 2009; Häyrynen et al., 2008; Min et al., 2018). In Norway, gathering information from national medical quality registries is particularly important, since they are regarded as means to improve health systems and the quality of patients' treatment and care (HOD, 2020).

Today one of the main problems when it comes to exchange and reuse of health data is that most of the EHR content is registered as free-text information (Severinsen et al., 2020; Häyrynen et al., 2008). To comply with this, vendors, healthcare providers and even government programs have promoted and purchased solutions to solve interoperability between different health information systems (HIS). However, the flow of clinical data is not yet solved, and the outcome and expectations to improved data usability is still a "work in progress".

Previous research has investigated different approaches like HL7 FHIR (HL7, 2014), and openEHR (Beale, and Heard, 2008; OpenEHR, 2019) for designing standardized and structured information models (Bernstein, 2009), and how these approaches can solve the need for exchanging clinical information within and between systems. However, the primary purpose of clinical documentation is about collecting, assessing, and using clinical information in point of time, and recording information for colleagues taking over the patients on the next shift. A change in focus is needed for information to be used outside the context of patient's treatment and care, and reused for secondary purposes (Häyrynen et al., 2008). In another study, the duality of purposes was found to create tensions because the demand to generate data for secondary purposes led to more work of creating data for healthcare professionals (Greenhalgh et al., 2009). Still, there is limited knowledge about how exchange of clinical information within and between systems depends on the origin of the information, namely the primary purposes. How does the need for improving data usability play out in the existing clinical documentation practices?

One promising way to reuse free-text data from EHR systems is AI methods like Natural Language Processing (NLP). This has been tested, but so far been rather unsuccessful due to the variety and heterogeneity of the EHR content (Lee and Yoon, 2017; Malm-Nicolaisen et al., 2019). A different strategy for automatically exchanging healthcare data across different context is to standardize the clinical information in the EHR. We used a qualitative trailing research approach to follow and participated in one such standardization process in the North Norwegian health region between November 2018 and June 2020. In this project standardizing clinical information in the EHR to achieve semantic interoperability, was done using the rich information models of openEHR archetypes (Beale and Heard, 2008; OpenEHR, 2019). The goal of the project was to design an electronic registry form for the EHR system. The form was modelled by using clinical standards aimed to extract specific registry information from the EHR's database

and automatically exchange the information to the national spine and neck registry, NORspine (Silsand et al., 2019).

During this design process, several socio-technical challenges occurred. Hence, we connected the empirical findings with the theoretical framework of information infrastructures (Bowker and Star, 2000; Hanseth and Lundberg, 2001). This framework contributes with a specific perspective on understanding the complexity of design and an implementation process from both organisational, structural, technological, and human perspectives to be successful. In addition, the framework points out that designers should ‘build upon the existing installed base’, in this case the present clinical documentation process.

The empirical project was a collaboration between the regional program for implementing regional ICT systems (FRESK), and neurosurgeons working both at the hospital, and as leaders of NOR spine. We explore the design-challenges when structuring clinical information for different purposes and outlines three important issues to address. Hence, we ask the following research question: What are the premises for reusing clinical information for both primary and secondary purposes? The paper aim to contribute with empirical results and discuss the importance of understanding the prerequisites and implications of reusing clinical information for a duality of purposes.

## Background

Today, the documentation of treatment and care is mainly free-text descriptions, recorded retrospectively. Related to neurosurgery normally surgeons fill in a paper-based form after the surgery is conducted. Then, the surgeons need to go back and forth in the EHR system to gather all the relevant information. When the paper-based form is completed, a nurse logs in to the registry’s web-based portal and transfer the information into the portal (Silsand et al., 2019). The time and resource demanding double documentation, and lack of reuse and exchange within and between different systems reflects the limited maturity of the existing EHR systems in Norway (HOD, 2015).

In November 2018, a collaboration between FRESK (Norwegian abbreviation), and NORspine (Norwegian abbreviation), was established. The purpose was to design an openEHR-based form to implement in the new EHR system. The aim of the design was automatically reusing clinical data from the clinical documents in the EHR to fill out the registry form, and automatically exchanging the data in the form to NORspine. Reuse of data would limit the need for double documentation. An indirect goal of reusing clinical information into the registry was to raise the coverage rate of the registry from today’s about 70 % to the national goal of above 80%. The purpose of raising the coverage rate was to improve the quality of surgical treatment for spine surgery (Solberg et al., 2021), by raising the quality on information and knowledge of outcomes of different types of back surgeries. The



goal was to enable using registry data as a risk calculator for clinical decision support for spine surgery and minimize data errors by automating the process (Solberg et al., 2021).

The surgery form will be implemented in the new EHR system, DIPS Arena. This system is built in accordance with the openEHR specification, a promising framework to improve semantic interoperability for clinical data, including open specifications for designing clinical information models (archetypes) and software to designing them, in addition to an open clinical knowledge manager (CKM) for cooperation design and governance of the archetypes information (Beale and Heard, 2008; OpenEHR, 2019). An important principle of openEHR is that both clinical professionals and health informatics experts are involved in designing clinical standards (archetypes) to improve the usability of the clinical content. In Norway design and governance of archetypes are mainly done at a national level to ensure high quality and usability (Beale and Heard, 2008; OpenEHR, 2019). An archetype is a computable specification of the data points and groups of a specific clinical topic, e.g., 'problem/diagnosis'. Archetypes are defined as constraint structures based on the openEHR reference model, which holds the contextual meta-data in health records, and ensure that it do not need to be redefined in each archetype (Ulriksen et al., 2017; Chen et al., 2009). These archetypes can be used by national and local e-health programs, building as openEHR templates. Templates are a means of building clinical data sets to specific use cases, e.g., a registry form, composed of elements from one or more archetypes constrained for a particular setting e.g., National registry forms (Beale and Heard, 2008; OpenEHR, 2019). The template is uploaded in a software program, often developed by the EHR vendor, in where the final outline of the users' specifications and user interface is modelled.

## Method

This study was conducted as formative evaluation research in collaboration with FRESK (2017-2022). Formative evaluation research is a rigorous assessment process designed to identify potential and actual influences on the progress and effectiveness of implementation efforts (Stetler et al., 2006). In that perspective, the study was closely related to a trailing research approach because it required close collaboration between researchers, clinicians and stakeholders in the FRESK project as well as the vendor and the clinical ICT department. The data collection was an iterative process within the given context of the empirical project (Baskerville and Myers, 2004).

Creswell, (2003) has defined three elements of trailing research design, which has inspired the outline of this study. First, the science-theoretical perspective, in where we used II as a theoretical lens, to discuss, understand and give recommendations to the empirical process. Second, the research strategy, in where we describe

formative evaluation research as the main method of studying practice and organizational development, contributing to a ‘co-constructive’ learning process (Baskerville and Myers, 2004) for health personnel, developers, and researchers (Creswell, 2003). Working in close collaboration with the empirical program, the preliminary findings were discussed and presented to the project managers, vendors and users involved. In addition, preliminary findings were used as recommendations for the ongoing process (Hanseth et al., 1996). The two first authors had each a 50% position in the design team of the project related to developing archetypes, templates and forms in FRESK. Since the two first authors had a double role in the project and there was a risk of being too close to the empirical program it was important to discuss the data with both the third author, who has over 10 years of experience from research on both ICT in healthcare in general and openEHR in specific. Third, data analysis, we used II theory and particularly the design principles of standardization, bootstrapping and adoptability outlined by Hanseth and Lundberg (2001) to identify the socio-technical challenges.

## Data collection and analysis

Data was collected between November 2018 and June 2020, and included 420 hours of participatory observations, and 60 hours of meetings and workshops with different actors in the process (see table I).

Table I. Overview of the data collection

<b>Participatory observations in the design process</b>	
<i>Participated in:</i>	<i>Meetings/workshops with:</i>
<ul style="list-style-type: none"> <li>• Mapping variables to archetypes</li> <li>• Designing archetypes</li> <li>• Designing templates (OET/OPT) and forms</li> </ul>	<ul style="list-style-type: none"> <li>• The vendor</li> <li>• Clinicians</li> <li>• Project management</li> <li>• Members of NORspine registry</li> <li>• NRUA</li> </ul>
<b>In total 420 hours</b>	<b>In total 60 hours</b>

The data analysis followed a hermeneutic approach, characterized by simultaneous data collection and analysis (Baskerville and Myers, 2004). The objective of analysing collected data was to organize and structure the gathered material, to generate an understanding of how the socio-technical interdependencies influence the evolving empirical process (Klein and Myers, 1999). The data was analysed through the lenses of the II framework and its design principles.

The overall objective of conducting formative evaluation research is to bring knowledge back to the ongoing empirical processes in order to strengthen opportunities and understand any challenges so that adjustments can be made (Finne et al., 1995; Stetler et al., 2006). In this study, this was done by discussing and presenting the preliminary findings from the analyses repeatedly. We had

meetings with stakeholders; both the EHR vendor, the national archetype governance, the regional EHR governance, the spine surgeons, and members of the FRESK program.

## Results

Structuring the NORspine form was one of the first efforts where a health region in Norway participated actively in designing a standardized form by using the openEHR approach. In addition, the standardization implied reusing information for a secondary purpose. Following the design process from a paper-form to an electronic archetype-based one revealed necessary premises for improving usability of clinical data in a real-world context (Silsand et al., 2019). In this paper, three important issues for understanding the premises for reusing clinical information are presented: 1) the demand for attaching context to structured clinical variables; 2) the challenge of reusing correct clinical variables; 3) the challenges of balancing the variables to the correct granulation level.

1) Reuse of structured clinical information needs to include information about the context in which the information first occurred. For instance, if the value of a blood pressure (BP) is reused, it is not enough to reuse the systolic and diastolic values like 120/80. A clinician needs to have information of the patient's status when the reused BP was taken, e.g., was the patient treated for acute illness, or was the BP taken before or after haemodialysis? Was the patient sitting or lying, what instrument was used for measuring BP etc. It is the additional contextual information the clinicians receive that enables him to assess if the variable has clinical significance for a new clinical setting. Archetypes are examples of information models that includes relevant contextual meta information to ensure correct and valid reuse. Archetypes to reuse must be designed including skilled health information experts, in accordance with the openEHR specification, to ensure high quality information models.

2) Reusing the correct information is another important issue. For example, a patient may have conducted three surgeries in the same submission period, the main surgery of spinal fusion surgery a follow-up surgery cause by unforeseen postoperative complications and a knee surgery. Then it is of great importance that the information e.g., the variable "operation duration" is reused only from the main surgery into the registry form to represent the correct information addressed by the purpose of the registry. Consequently, reuse of information addresses governance of the queries that enable automatically utilization of data for several purposes (see figure 1).

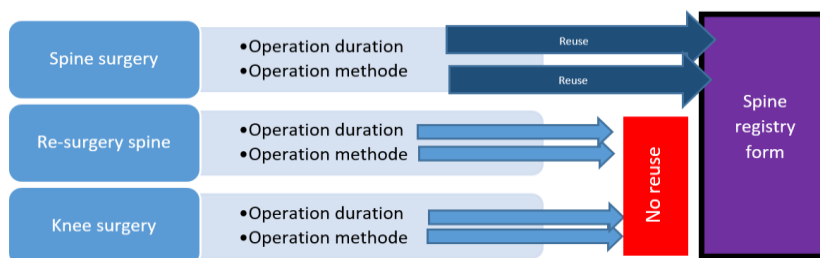


Figure 1. Reuse of the right information

3) Reuse of information from primary to secondary purpose includes dealing with transfer of archetype standards of different granulation levels. Within the EHR, clinical information about the patient’s present and past conditions is specified for primary purposes, but the NORspine’s form asks for information about diseases and illness on an aggregated level. For instance, the registry form asks for “endocrine diseases” as one aggregated variable. However, for a clinical purpose recorded in the EHR, “endocrine diseases” is too generic, and give very limited instructions and information for clinicians on how to follow up treatment and care for the patient. The clinicians need to know the specific disease since a patient is treated differently if she has Diabetes 1 or if she has Cushing disease. Hence for a primary purpose, it is necessary to specify which specific endocrine disease the patient have. Therefore, reuse of data demands for complex mappings between “endocrine diseases” and all the different endocrine diseases registered in the EHR system (see figure 2). There are several examples of different needs of granulation levels of structured clinical information related to utilizing data for primary and secondary purposes. As a result, an extensive web of mapped variables, that must be updated and governed, is necessary to comply with different goals of reused information (see figure 2).

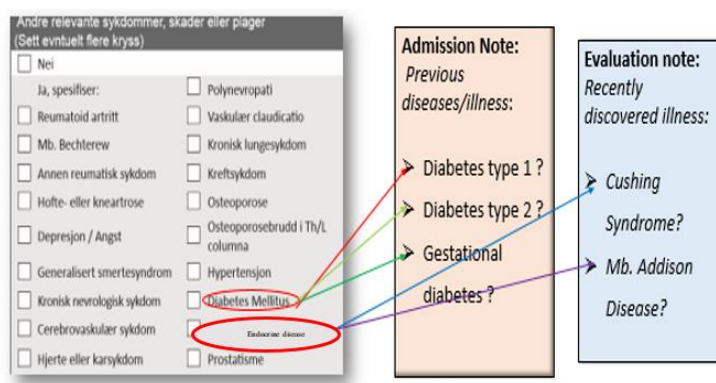


Figure 2. Different granulation levels of clinical information

To summarize the design of a standardized form to enable automatically reuse and exchange of clinical information; standardizing clinical information is the most important means to improve usability of clinical data, but also the main challenge.

## Concluding Discussion

There is an extensive amount of attention directed towards reuse of healthcare data within and between EHR systems, both for primary treatment purposes and secondary purposes like registries, research, quality improvement and clinical decision support. In this project we have followed the steps of the activities in the empirical project, in where structuring the clinical information within the EHR was the given approach for enabling automatically reuse of clinical data. In this paper, three important issues have been outlined for understanding the premises for reusing clinical information for primary and secondary purposes: 1) the demand for attaching context to structured clinical variables; 2) the challenge of reusing the correct clinical variables; 3) the challenges of connecting the variables to the correct granulation level.

The overall lesson learned from this study is that automatically reuse of clinical data is complex and challenging. The study has followed the empirical project from its early beginning in 2018 until it was put on hold in 2020<sup>1</sup>, and a broad range of socio-technical issues (which is not part of the scope for this paper) have influenced the design and implementation process. Designing standards based on the need from a registry form, represent a limited part of structuring an EHR system. Nevertheless, knowledge from previous work (Silsand et al., 2019, Severinsen et al., 2020) supported by II design theory (Hanset and Lundberg, 2001) underscores that a complex process as standardizing the EHR system needs to start with focusing on a limited part of the process. First, to gain instant profits early in the design processes, where users get access to working software can motivate them to continue contributing to the work. On the other hand, there is limited knowledge about the practical implications for all the stakeholders involved, when structuring clinical information for enabling automatically reuse for both primary and secondary purposes. Accordingly, for the stakeholders in the empirical project it was important to gain knowledge, highlight challenges, and to ensure that the step in the evolving design process was compliant with both short-term and long-term goals of structuring the EHR system (Hanseth and Lundberg, 2001). With this formative evaluation study, the research team has contributed to this process.

The three issues presented in the result section, is all about ensuring that the right clinical data is available for the right clinician or purpose at the right time. Because at any stage weather the data is recorded for a primary or reused for a secondary

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<sup>1</sup> The collaboration between the empirical project and NORspine was put on hold due to delays in the implementation of the new EHR system caused by the Covid-19 pandemic.

purpose, the data need to be characterized in terms of completeness, correctness, and precision relative to purpose. Accordingly, these the three issues are relevant when understanding the premises of reuse, and the understanding of each of the premises need to be compared with each other. Based on these issues we go on and summarize implications for design.

First, structuring clinical information for a duality of purposes demands for high design competence when designing information models (e.g., archetypes), as well as designing templates and forms. A duality of purposes demands for the correct use and granulation level of the clinical information models, through the step of templates and forms, and between different forms used for different purposes in different contexts. Accordingly, structuring an EHR is an extensive process which requires a team of competent resources to succeed.

Second, it is important to establish high quality governance of clinical information models, templates and forms in different organizational levels such as in this case the health region, the national archetype organization, NORspine, and the vendor. Governance includes an overview of the interconnections and queries between variables in the EHR, and where they are used for secondary purposes. Changing an archetype has consequences wherever this archetype is used both related to the forms that uses it, as well as the clinical process and exchange between healthcare levels. In addition, to understand the coherence between structured clinical information models, how they relate to the design levels of templates and forms, and consequences when upgrading on different design levels are needed.

Third, structuring the clinical information in EHR system is an important means to reach the goal of improved usability of clinical data for different purposes, but both the means and the goal rest heavily on competence and governance to carry out the structuration process. So far, there is a national governance for archetypes, however the necessary requirements for governance within the health regions and the hospitals has not yet been established by the empirical project.

Finally, our study has so far only stirred the surface, and the aspects in the introduction about collecting data, interoperability within and between systems, and using data for primary and secondary purposes need to be further explored.

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# Urgent Digital Change – Learning from the COVID-19 Pandemic

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**Abstract.** This paper investigates the digital transition that occurred during the COVID-19 pandemic. We elicit 3 cases of digital transition that took place as part of the contingency plan, that was executed in the Danish healthcare sector. It was a necessity in order to support the physical distancing between patient and healthcare staff and new treatment trajectories. We analyze the 3 digital transitions by looking at the constraining and enabling factors for implementation of the transitions and discuss how the transitions were related to the installed base (EPIC/HER system) and its governance model of IT-infrastructures in the Danish healthcare system.

## Introduction

The COVID-19 pandemic required swift and decisive digital initiatives from decision makers in all public sectors to meet a new reality, where the public sphere was a potent arena for the infection of citizens and public workers.

In the Danish healthcare sector, COVID-19 initiated a digital change force majeure that required both the rapid adaptation of new digital solutions and digital workflows in the interest of keeping citizens safe from infection during healthcare visits and keeping healthcare staff protected from infection exposure. In the Capital



Region of Denmark and Region Zealand (two of Denmark's five regions), the EPIC system<sup>1</sup>, an electronic health record (EHR) system, formed the backbone of the digital response. The urgency of the COVID-19 pandemic led to a rapid and unprecedented digital change, where the existing governance model, with its well-planned yearly releases, had to be abandoned. The rapid digital change was conducted by maintaining a top-down approach with swift region-wide rollouts with high levels of standardization across all clinical specialties and their clinical practices (Bansler, 2019; Bansler, 2021). This provided a fruitful opportunity to roll out digital solutions and innovations to fit the new clinical reality. However, the standardized region-wide rollouts were also met by an emerging need for local and clinical specialty-specific needs for handling the pandemic.

In the following section, we first outline our method and the case. Then we present an analysis of real-life experiences from the digital change, including new IT capabilities and changes to the EHR infrastructure. Finally, we discuss implications from the perspective of ensuring successful change in future scenarios where there is an urgent need for digital change.

## Methodology

This study comprises three cases that were followed during the first and second waves of the COVID-19 pandemic. The data collection was conducted by three co-authors and Ph.D. students involved in scholarships for three different projects while closely collaborating with two health care regions. The co-authors were all situated at their respective hospitals as the cases unfolded. This enabled them to closely observe the case and engage in open-minded discussions with fellow clinicians and technical staff. They had access to hospital IT infrastructure, regional documentation of initiatives, and various clinical department newsletters. In order to gain a better insight of the rapid digital initiative, semi-structured interviews were conducted with the Chief physician and Leading development and implementation manager from Capital region. Second interview was with a Project manager and her colleague, a Business relations manager from the IT department of the Capital Region. The third and last interview was with an experienced nurse now leading digital initiatives at the Hospital. All Interviews were virtually conducted using Microsoft Teams. Answers were recorded on Teams with consent.

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<sup>1</sup> [www.epic.com](http://www.epic.com)

## Case description

Patients infected with COVID-19 present an illness trajectory similar to other viral upper respiratory illnesses. There are three major trajectories for COVID-19: mild disease with upper respiratory symptoms, non-severe pneumonia, and severe pneumonia complicated by acute respiratory distress syndrome (ARDS). (Chavez et al., 2020). COVID-19 introduces an uncommon need for isolating patients during infection due to a potential incubation period of up to 14 days from initial exposure. COVID-19 is known to infect through both physical contact between people and exposure to airborne secretes from those infected. Infected individuals are required to self-isolate during the incubation period, and as a consequence, healthcare personnel treating patients in the last two categories of illness trajectories are at increased risk of becoming infected themselves.

In Denmark, the diagnosis and treatment of COVID-19 patients are organized through COVID-19 test centers, where citizens can order a test slot at any available test center through an online portal<sup>2</sup> and get an online reply within 24 hours after the test sample has been taken. Test-results are shared with healthcare personnel through the national data infrastructure and can be viewed by the personnel inside the individual patient journals in the regional EHR systems.

To be able to handle a potential rapid uptake in COVID-19 patients with respiratory complications, many clinical departments (i.e., outside respiratory illness) were forced to reorganize toward an uptake in both hospital beds and personnel capable of providing care and treatment of said patients. Consequently, many planned procedures were canceled or postponed through the EHR system to create both digital and hospital capacity in ward overview tools for the personnel to support planning and coordination.

Initiatives were taken in the EHR system to create new data categories for informing cancelations, including informing patients with appointments of new times for procedures, prescribing standardized medical treatment for patients across departments, and demanding a readiness for clinical and digital change for the involved clinical departments. The digital change included, among others, “Smart Texts” and electronic letters to patients postponing non-critical treatments, video-consulting facilities, workflow supporting (postponed) visitations, and ambulatory bookings. Furthermore, it incorporated registration of COVID-19 symptoms, diagnosis, and treatment; various reports supporting overview, planning, and

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<sup>2</sup> [www.coronaprover.dk](http://www.coronaprover.dk)

statistics of the COVID-19 cases; tools for contact tracing; as well as booking, registration, and workflow support for COVID-19 PCR<sup>3</sup> tests and vaccination.

## Analysis

In this section, three examples of the necessary digital changes that occurred during the pandemic are presented. The first example is video consultancy with clinicians. The second example is contact tracing, which represents the introduction of new IT capabilities to keep healthcare staff away from potential COVID-19 positive patients and to support contact tracing of infected patients. The third example is infrastructuring the COVID-19 illness trajectories. This represents changes to the EHR and the necessary organizational and clinical processes to ensure consistent and standardized treatment of COVID-19 patients.

### Video consultations with clinical staff

Exposing clinical staff to patients with COVID-19, thereby putting essential staff at risk of contracting the virus, poses one of the major risks of the national healthcare system as it reaches the brim of its capacity. A range of initiatives were introduced to minimize staff exposure to citizens, and an important digital tool for achieving this was an existing video consultation feature in the EHR system that was rolled out and activated to all clinical departments across the two regions.

Prior to the pandemic, the video-consultancy feature had been shown to be a controversial and political change (Stuart et al. 2020; Stommel et al. 2019; Kitamura and Wong 2010) toward the vision of Danish hospitals with more flexibility toward patient appointment types, treatments, and diagnostics. Video consultation was adopted relatively quickly. Therefore, it promoted physical distancing and enabled medical support without increasing the risk of transmission.

To ensure implementation during the first weeks of the first wave, department *champions* (i.e., secretaries, nurses, or doctors) were elected as partners for the region to (1) refer and communicate, (2) be responsible for adaption among staff, and (3) be responsible for department-level adaption of the video-consultancy tool.

The feature was activated in the regional EHR system, with the patients getting access via a dedicated patient portal, MyChart<sup>4</sup>. It was considered to have a positive effect on minimizing exposure and ensuring doctors had a new way of working remotely while keeping relatively good patient contact. Figure 1 illustrates the

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<sup>3</sup> Polymerase Chain Reaction

<sup>4</sup> [www.mychart.com](http://www.mychart.com)

uptake of video consultations during the first two pandemic waves in Denmark in the spring and winter of 2020.

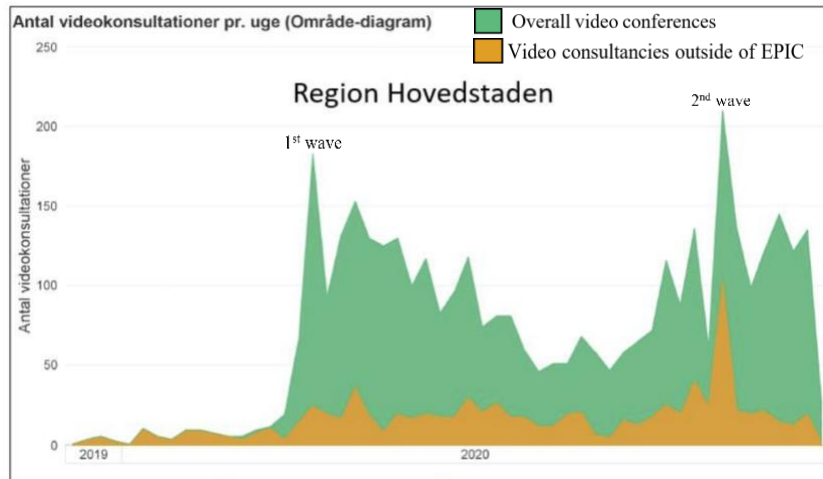


Figure 1 - Number of video consultations per week from 2019–2020 in the major Capital Regional hospital. Observe peaks during waves one and two.

The video consultation feature was announced by the region to be here to stay after the pandemic and was available for use by all clinical staff with patient contact after the first wave of the pandemic.

### Contact tracing of COVID-19 infected patients

During the first COVID-19 wave in 2020, the EPIC released a tool for contact tracing to prevent the potential spread of COVID-19 (see Figure 2).

First, this tool can trace which wards and/or ambulatories a patient has been to. Second, it can trace patients or staff with whom an infected patient has been in contact with. The contact tracing tool generates a report for clinicians to use, which eases contact tracing. This process of generating a report should be compared to manually looking up patient journals one by one. The manual process could pose a risk of overlooking important

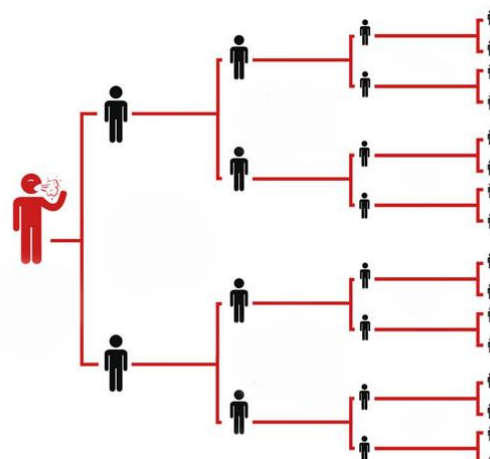


Figure 2: This figure shows the spread of COVID-19 from an infected person, if it is not prevented by contact tracing or other measures (illustrated with a contact number of two, i.e. an infected person spreads the disease to two others).

details, as well as taking up a significant amount of time for the clinicians. One nurse stated:

“It is easy to work with, and it saves a lot of time. Previously we had to look up each patient and would spend half a day on contact tracing for just one patient. Now it is done in half an hour.”

This automated contact tracing takes approximately one minute instead of the manual process taking approximately 2-3 hours. The tool received very positive feedback from healthcare workers using it. So far, the tool has been used primarily for COVID-19, but it can be used for other purposes when contact tracing is needed. The tool was made available for free during COVID-19 by EPIC, but with the positive feedback received from users, the hospitals will attempt to budget to make the tool permanent after the pandemic.

As a result of successful cooperation between the hospitals and the IT organization servicing the EHR, the tool was quickly implemented:

“It was great to see the way the clinicians and IT worked together for a quick implementation” (application coordinator working within the IT organization).”

## Infrastructuring COVID-19 illness trajectories

One of the main integrated and highly used features in the EHR system is order sets supporting clinical workflows for patient trajectories. Order sets are a structured collection of clinical guidelines, which physicians use for prescribing and ordering things, including blood samples, X-ray admissions, medications. These sets can be modified to meet the individual needs of the patient. Furthermore, it helps physicians to choose the right medicine and dosage along with other necessary information, such as instructions for the administration of the medicine and other decision support. Order sets are implemented to ensure standardized and consistent patient care across staff and similar departments across hospitals.

As an initiative to meet COVID-19, the cross-regional IT team initiated a taskforce (consisting of senior clinicians as IT product owners and members from the cross-regional IT team) to facilitate, support, develop, and optimize COVID-19-related work processes in both regions with new order sets. The project owner stated:

“Having our own people at the table with decision makers has been a success”

The new work processes were implemented after the taskforce had aligned and developed the new order sets. The implementation happened rapidly and top-down to all clinical specialties across all hospitals in both regions.

COVID-19 order sets from the first wave ensured correct medication and diagnosis registration, which met all clinical guidelines. The product owner along

with the cross-regional IT team frequently updated the order sets with the necessary items during the second wave caused disruption for clinicians.

While the implementation of the first COVID-19-related order sets went smoothly, feedback from clinical departments with COVID-19 patients started to reveal implications for the governing process of the digital initiative.

Initially, implications arose from the local physicians, who felt overwhelmed by many daily e-mails and newsletters accompanying the new order set rollouts for which the leading secretaries from each clinical specialty were appointed to be responsible for. The procedure for the centrally governed rollout prescribed that the responsible secretaries report any problems to the relevant project taskforce from the central IT service. Due to the amount of feedback that came from clinicians in response to the many newsletters and guidelines, the leading secretaries could not keep up with attaining feedback and sending it through the system to the project taskforce.

The physicians experienced that their feedback given to appointed clinical secretaries was not received at the taskforce level. It turned out that a lot of critical workflow feedback was never reported into the taskforce, which was expecting feedback to come as properly recorded complaint cases through the systems' standard reporting facilities. For example, the clinicians reported that there was not a well-understood practice for reporting patients cured after the 14-day incubation period. Therefore, patients that were no longer infected retained the status of being COVID-19 infected in the EHR system, causing a chain of problems regarding the continued patient trajectory. The problem escalated into a debate regarding the extent to which physicians had the autonomy to bypass the consequences of the EHR system workflow misunderstandings or whether situations where exceptions to the standard had to be taken to honor primary care purposes.

For a long period, the consequence of this was that physicians could not trust her system indicators of patients in their incubation periods, and this seriously compromised individual patient treatment as well as planning and coordinating patient care trajectories. A follow-up interview with the taskforce physician revealed that the feedback was never received at a high level.

## Discussion and conclusion

The digital changes following the COVID-19 pandemic can be seen as an example of the swift and exemplary introduction and implementation of new digital responses to acute and severe healthcare situations. This opens a valuable experience of alternative approaches to digital governance and change. However,

we also observe that there are fundamental differences in the premise of how well digital change affects the installed base of infrastructure supporting integrated patient trajectories.

Two new IT capabilities were identified, video consultation and contact tracing, which quickly found their relevance during the first wave of the pandemic. These loosely coupled technologies did not (at least at a surface level) have trouble being implemented and taken into widespread use. The two examples had a common characteristic of being relatively well received across clinical specialties, with little to no need for iteration or configuration.

The capability of video consultation capability has been identified as an example of a technology challenged by ongoing organizational resistance in a well-known conservative healthcare environment that was redeemed and reevaluated for emerging clinical needs during COVID-19. This digital solution had an immediate cross-specialty perspective and relevance that proved to be adapted across Danish hospitals, with no need for local technical configuration. While the technology had little need for technical configuration post-global implementation, it was noted that the technology had a foreseeable effect on the local clinical organization. For instance, physicians insisting on seeing their patients in real life had to either adapt to the technology or not see their patients during the first waves of the pandemic, thereby establishing itself as controversial.

Video consultancy had been introduced into the Danish healthcare sector prior to the pandemic with mixed results (Wentzer, 2013; Danmark, 2018), and there was resistance among healthcare staff that anecdotally preferred and insisted on seeing and examining their patients physically (Catapan et al., 2020). Thus, until the pandemic, most hospital staff insisted on the personal attendance of patients at the hospital as the dominating standard procedure of all diagnostics and treatments. A report conducted by the Capital Region of Denmark based on 22 patient interviews (RegionH, 2020) concluded that while the video constancy feature could help many patients, the ability of patients and doctors to choose for themselves was still recommended.

Similarly, we see the facility for contact tracing of COVID-19 infected patients as a stand-alone tool that in its premise and potential impact had immediate cross-specialty relevance. The tool quickly found clinical cooperation partners in hospitals that championed the technology toward good use to support safe clinical workflows.

These two technologies, while not unproblematic, had quick implementation success by not requiring complex integration with local clinical workflows, and the perspectives of both examples were cross-specialty relevant in nature. Such tools pose an example of a successful implementation driven by local needs, and the implementation shows that local and quick implementations can be carried out successfully when the stakeholders in question are collaborating with clinical staff. Furthermore, this implementation, which met an urgent local need, has shown potential for permanent and more extensive use, possibly after local adaptation, to meet the needs of other areas within the healthcare sector.

Our examples regarding infrastructuring COVID-19 illness trajectories demonstrate a greater level of implications and need for local adaption that was not allowed or met by the centrally governed digital change. As a heavily sociotechnical embedded change, this immediately led to the requirements of greater sensitivity to specialty needs, a need for an iterative approach to the implementation, and the possibility to make local configurations. We observe that this digital change received a rough start due to its high need for documentation, local adaption, technological re-education of staff, and strict guidelines that, locally, were poorly supported. Feedback from users was not properly responded to, and the command line of feedback from users was not clear to the clinical staff.

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# Opening-up digital platforms to accommodate patient-generated healthcare data

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**Abstract.** This paper investigates the process of opening-up digital platforms to accommodate patient-generated healthcare data (PGHD) and argues that in data platforms, barriers arise due to the entanglement of technology and policy. The empirical setting for the study is the opening up of a Norwegian eHealth platform for PGHD captured by external vendor technologies. The possibility to accommodate PGHD opens up new innovation arenas by recombining data from multiple sources and actors. However, such process is prone to a unique set of challenges when innovation is centered around data, instead of functionalities, such as: 1) open-up the data core using boundary resources; 2) control patient data across long chains of actors; 3) establish uniform rules to co-create data value. The findings show that the proves of opening up data platforms faces legislative barriers which should be overcome in a way that technology and policy enable each-other.

## Introduction

Novel sources of patient-generated healthcare data (PGHD) captured through medical devices, sensors and smartphone apps are entering the healthcare landscape, holding the potential to transform the way patient information is “generated, collected and analyzed in healthcare practices and used in clinical decision making” (Grisot et al., 2020). PGHD can support the needs for circular interaction between patients and healthcare professionals, changing the role of patients from passive recipients to active “prosumers” (Barrett et al., 2016), as

they consume and produce data using dispersed devices and under diverse circumstances. This opens up new arenas for data innovation by interconnecting patient data across a variety of actors and from dispersed sources, which can be recombined along multiple value-creation pathways.

One way of supporting innovation across multiple actors is by organizing their interactions around digital platforms. Digital platforms are underpinned by modular architectures, interconnecting core and peripheral modules using boundary resources as standardized interfaces. The boundary resources support the use and re-use of common components and can facilitate innovation on a larger scale by transferring design capabilities to external actors (Ghazawneh and Henfridsson, 2013). However, opening up the boundary resources can also lead to greater fragmentation and loss of control over the emerging innovation network in the platform periphery (Gawer and Cusumano, 2014). Therefore, the boundary resources need to be governed in a way that balances the trade-offs between expanding the platform with complementary components, but at the same time keeping control by setting up uniform rules, standards and shared institutional logics which govern the behavior of distributed actors (Autio and Thomas, 2020; Eaton et al., 2015)

In data platforms instead, the boundary resources connect the core and periphery, but those relations are established based on digital data, rather than functionalities, tools or applications (Tempini, 2017). The common core modules are full of data, and the external actors innovate with these data in the platform periphery (Bonina and Eaton, 2020). However, data are not components and do not embody functions in the same way as components do (Alaimo et al., 2020). Rather, data are captured as events, computed into tokens and then assigned meaning when they are used by actors, due to their semantic nature. Therefore, innovation in data platforms does not necessarily follow the same recombinant logic of modular architectures, as it happens at a more granular levels than assembling together a set of components. Although data innovation does not happen independently of the components, actors recontextualize these data across their value-creation processes and assign them meaning, rather than constructing a functionality (Aaltonen et al., 2021). Thus, data innovation distinguishes from recombinant innovation with modules, as it takes place in the way data is ported and used across actors' value-creation trajectories (Alaimo et al., 2020).

Research by Grisot et al. (2020) already shows that the re-combination of components can lead to multiple alternative value pathways around PGHD by aligning the underlying digital infrastructure and work practices to tailor the diverse needs for data exchange between patients and healthcare professionals. Besides this architectural perspective, research also reveals the complexity of data-based value-creation due to their use-agonistic character. For example, Tempini (2017) shows the multidimensionality of PGHD in the value-creation trajectories of actors organized around a social media platform. Similarly, Barrett et al. (2016) follows the evolution of an online community, and discloses the tensions stakeholders face as their goals and the meaning they assign to data change over time. However, while previous research has been focusing on the

generation of patient data using approved devices in an outpatient clinic (Grisot et al., 2020), and in peer-support communities (Barrett et al., 2016; Tempini, 2017), I hereby put my focus on the process of opening up the boundary resources to support larger scale innovation centered around PGHD from devices and technologies developed by external actors.

The research question I seek to address is: *what are the barriers in opening-up digital platforms to accommodate patient-generated healthcare data?* The empirical case follows the Norwegian national eHealth platform and reveals barriers in the process of opening up the data core for PGHD generated by external actors' components. The paper is organized as follows. In the methods section, I elaborate on the methodology used, introduce the case and explain the data analysis process. Next, I introduce the main findings of the study and elaborated on them in more details in the discussion section. At last, I present the main conclusions of the conducted study.

## Research Methodology

### Case description

The empirical setting for this study is the Norwegian healthcare context. The case is conducted by including: 1) a national eHealth platform in Norway "HelseNorge", which undergoes a process of opening up its boundary resources for external development and accommodate PGHD; as well as 2) three private vendors solutions for PGHD, which are part of the public digital ecosystem, but are not integrated with the national platform. HelseNorge provides citizens access to information stored about them in several health registries in the public sector. The platform was launched June 15<sup>th</sup> 2011, driven by the need to create a single point of entry portal for citizens, instead of letting them "search Google for health" across many websites. The platform has grown considerably throughout the years, integrating with several systems across the public infrastructure, including 11 approved digital health apps which are part of its tool catalogue. Currently, HelseNorge is undergoing a process of opening up its boundary resources for external development and incorporate PGHD as part of its ecosystem (Directorate for eHealth, 2019).

The case also incorporates three digital health tools for PGHD. 1) Mobile medical record system which is built jointly for patients and healthcare professionals and shares medical patient data using secure messaging, video consultation, photos, forms and other health information, stored in the cloud. 2) Shared patient diary, a solution for information exchange between healthcare professionals, service recipients and their relatives. The app shares information in the form of text, images, and video includes a common calendar for real-time updates and combines both medical and lifestyle data about a patient. 3) Outpatient clinic tool, used for specialist care which collects structured medical data about patients,

stored systematically in hospital systems, from where healthcare professionals can extract the data and monitor patient's health status.

## Data collection and analysis

The study was explorative and conducted using a qualitative method (Sarker et al., 2018a, 2018b). The data was gathered via 10 semi-structured interviews, using a snowball approach where participants recommended potential suitable candidates further. 7 interviews were conducted with representatives from the national HelseNorge platform, and 3 interviews with private vendors. To gain more insights into the context, online information, including websites, presentations, and strategy documents were also collected. The data gathering process lasted for 5 months, June-Nov 2020, although the case was followed in retrospect dating back to 2010, when the development of the national eHealth platform started to take place. Participants were technical and managerial staff, working with the national eHealth platform and private software vendors. The background of participants varies between: software architects, software developers/medical doctors, lawyers, consultants, data scientist, providing a wider perspective over the cross-disciplinary nature of the research problem. The interviews lasted for approximately one hour and were afterwards transcribed to analyze the data. The data gathering process was guided by the research interest on capturing and interpreting informants' meanings, and their understanding of the decisions that need to take place towards opening up the national platform to incorporate PGHD (Dubois and Gadde, 2002). The interview guides included questions on the challenges for extending HelseNorge's core functionalities with external solutions, the role of policy in making decisions about incorporating PGHD within the ecosystem and opinions on what is the way forward towards integrating PGHD as part of the ecosystem.

The data was analyzed in an abductive and iterative way (Alvesson and Sköldböck, 2009; Dubois and Gadde, 2002). The data collection and analysis were informed by existing theoretical concepts in the digital platforms literature (Aanestad et al., 2017; Ghazawneh and Henfridsson, 2013), which were used to initially define and re-articulate the research problem (Dubois and Gadde, 2002). The theoretical concepts informed the data gathering process, and were used to categorize the empirical data, coordinate the findings, as well as to direct and redirect the study as new insights emerged. The analysis moved iteratively between asking questions, generating the findings, making comparisons with existing knowledge and refining this again. The data was coded to establish categories for grouping the information gathered from the empirical work (Maxwell and Miller, 2008) and analyzed from the perspective of the platform owner. The findings were first organized around 6 key decisions of opening up the platform for PGHD and grouped around 3 barriers which need to be overcome throughout this process. Although the data collection was triangulated with information from official documentation and strategy documents by the Directorate of eHealth, these documents were only used as a first step to provide a contextual understanding over the case, and to inform the data collection process.

However, they were not systematically analyzed to generate the findings of the study, as the findings were based solely on the empirical data.

## Findings

The findings are organized around three main barriers for opening up the digital platform to accommodate PGHD captured through external components, defined as: 1) open up the data core using boundary resources; 2) control patient data across long chains of actors; 3) establish uniform rules to co-create data value. The findings are elaborated in more details as follows.

### Open-up the data core using boundary resources

HelseNorge.no was launched on 15<sup>th</sup> of June 2011, as a “Citizen Portal” working as a single point of entry for Norwegian citizens, which were previously “searching Google for health” across many websites. At the beginning some team members thought that platform-thinking could be beneficial in the long-run. However, this vision was abandoned due to the pressing deadline for delivering the first version and all functionalities were developed in-house. After the initial launch, discussions have been on-going on what functionalities should be supported next, what parts should the core connect with and which components should be developed externally. So far, decisions about expanding HelseNorge were supported when the team would identify a functionality they need and then 1) build it inside; 2) get a third-party vendor to build it; 3) or integrate with an existing vendor solution on the market providing these functionalities. Such an approach has resulted with many vendor-specific APIs adapted to the requirements and functionalities of the external solutions. What is currently set in place for vendors who want to connect with HelseNorge is a requirements list for certain areas, such as: video conferencing, appointments, journal patient health record, message exchanges between healthcare professionals and patients. Therefore, HelseNorge as of now has a very limited set of APIs exposed to third-parties, very few consumers that send data packages to it and even fewer which retrieve data and are creating solutions based on access to data from the core.

The lack of published APIs has resulted with some of the vendors having to “self-resource” boundary resources themselves in order to enter the ecosystem. Others decided to step back from the integration process, due to delays in API provision, followed by bureaucracy and large documentation. *“It would be much easier if the system was ready to share APIs with the private companies like us, if there was a system and rules that are there for that and APIs. We have a feeling that we have to fight for every access we get. (...) If there were more information and advice from the government on how to do things and more APIs ready from the beginning, then we would do things differently and we would save a lot of resources, money and time.”* (Informant, Vendor 1). Decisions about opening up HelseNorge are currently made around two options. 1) Contained environment, where smaller vendors who need a stable platform to support them can re-use a

lot of the core capabilities, with lower thresholds for innovation and fast innovation cycles. 2) Uncontained environment, in which external actors have a stable standalone platform, build all the functionalities themselves and connect to HelseNorge. However, the technical side of publishing APIs is considered “the easiest”, as challenges arise since APIs need to validate the party which gets access to patient data, verify the user and make sure that patient data is handled in accordance to policy and law. Therefore, these APIs need to work as digitalized contracts between multiple parties which do not only guide what functionalities to be developed, but also what data elements are processed, and how to regulate the behavior of multiple parties across the ecosystem.

### Control patient data across long chains of actors

Initially, data in HelseNorge was stored in a single storage solution called the Personal Health Archive (PHA). Although there were discussions about data being stored with responsible entities interacting with each-other, versus laying in a single storage, the sense for platform architecture which should do connections instead of storage was not there from the beginning. As HelseNorge started integrating with GP ERP and hospital EHR systems, patient data was getting exchanged outside of HelseNorge’s control. Therefore, decisions had to be made on how to govern patient data exchanged across multiple systems. It was decided that once citizens are handed over to another party, the respective systems are the owners of this data and take the responsibility as a data controller. Therefore, HelseNorge only provides access to view this data, and in some cases stores a copy in the PHA. *“Many people think ‘Helsenorge knows a lot about me’, but we are not allowed to read this data. (...) HelseNorge is saying ‘we know that you have some data at the health thrust, we cannot open it, but we can help you see it’, so we cannot snatch the information on the way to the user” (Informant, HelseNorge).* Currently, a lot of the data provided by HelseNorge is not owned by the platform. The platform is organized as consent-based and takes responsibility as a data processor only for the data processed inside its core components. Patient consent has to be registered in HelseNorge and the patient can stop sharing at any time. Although citizens can choose to use different digital health tools via HelseNorge, they have to accept the terms of use in the particular tool. This is due to the lack of control HelseNorge has over how patient data is handled throughout the entire chain of actors and whether this process is legal all the way.

One possible approach towards controlling the chain is the aspiration of the HelseNorge team for having a “dedicated HelseNorge law”, which states that the platform is the official national provider of healthcare services. In the absence of law which might provide an independent basis for data processing, they have to find complex solutions within the restrictions given by legal regulations. The lack of control has made it challenging to keep consent valid at all time and make sure that it is still within the scope of the time patients provided it. *“What I have experienced lately is that you should not completely rely on the definition of the terms in the GDPR, with regards to who is the controller, but you have to look at the whole chain to be able to see what is there, what is in factual circumstances that the working part has expressed. You have to see who is in the factual*



*situation the closest to take the control or responsibility in a complex chain.” (Informant, HelseNorge). Therefore, it is challenging to provide clarity of responsibilities when data is exchanged across many actors who often fail to understand what their legal responsibility is and what the terminology means.*

As data is re-written and re-copied across multiple systems, the data also gets stored in decomposed solutions across these long chains. Although the team is assertive that “the time has passed for single storage solutions”, all parties wish access to data, but they all avoid the responsibility to store it due to the strict legislation. Smaller vendors either keep data in the cloud to enhance scalability or store it on a third-party server and public actors do not want to use data kept in a storage they cannot trust. *“If the patients think that this is critical data and upload it in a storage, they think that someone will look into this. But that is not the case if you do not have an agreement in it, because no doctor will look into it before there is an appointment, or a reason for looking at it. So, it is a dangerous misconception if the patient thinks that ‘I gave this to the healthcare service in Norway, someone should react if something is wrong’ (Informant, HelseNorge).* Therefore, discussions are on-going on whether HelseNorge should provide a storage solution for vendors who do not want to store data themselves, and at the same time allow flexibility for larger vendors who want to store and keep data in their own storage solution.

## Establish uniform rules to co-create data value

Decisions about opening up HelseNorge also need to encompass establishing criteria on which PGHD captured by external vendors are allowed into the platform ecosystem. Such decisions need to be informed by setting universal rules and standards which reflect patient data privacy and security in the digital health tools developed by external vendors. At the time HelseNorge was launched, most of the standards which are in use today were either non-existing or premature. From 2016, the team started working with HL7 FHIR with the aim to standardize data exchange by not bringing in too much data, but keep it as small as possible, yet still within the clinical context. However, such standards are not mandatory for all vendors in the public infrastructure, leading to lack of understanding on what standards do different solutions for PGHD have to comply with. *“They {the municipality} said you need to have high security level, because it is sensitive data, and when we did and lost all of our users, I remember I called {the person} and I said: ‘you asked us to do this, and now you have to tell your workers that it is safe to log in with bankID, because we are losing everyone’.” (Informant, Vendor 2).*

One way of dealing with this fragmented portfolio is for the platform to establish universal criteria for evaluating digital health tools for PGHD. In 2015, the Directorate of eHealth started working on a framework for assessing digital health tools to make sure they bring benefit to the healthcare service and are safe to use in clinical practice, but such attempts have been dropped. What is currently set in place as a “screening procedure” to assess the external tools are testing and approval queries to verify that the tool is compliant with GDPR as well as

follows the Code of conduct for information security in the health sector in Norway. The tools also need to get a confirmation from the Directorate of eHealth that the content is clinically responsible. After that, they sign an agreement for third-party data processing. HelseNorge also has a publicly published tool catalogue as a library of digital health tools which can be prescribed to the citizens. However, the aim is for privacy and security to be embedded across all digital health tools in the ecosystem, instead of assessing individual cases. One-way forward is to provide self-declarations issued by an authenticated governmental body which approves the use of the PGHD tool and finds it to be trustworthy for patient treatment. However, as of yet, such process is still not set in motion.

## Discussion

Research already shows that innovation facilitated by digital platforms can result with “unpredictable innovative contributions by large, uncoordinated audiences” (Autio and Thomas, 2020), but this paper goes further by showing the added complexity of opening up when the re-combinative innovation is centered around data, instead of functionalities. Innovation in data platforms starts with boundary resources, but the way core patient data are used is more difficult to control due to their semantic nature. This shifts the focus of data innovation from the modular architectures in which they are generated, towards the ways actors use them across their value-creation trajectories. The findings show that the combined effects of innovating with functionalities and data (Tempini, 2017) challenge the process of opening up the boundary resources, as data also bring in the emergent role of policy and legislation. In data platforms, the opening up of boundary resources does not solely mean transferring design capabilities to external actors (Ghazawneh and Henfridsson, 2013), but they also need to manifest themselves as “invisible data rights” in the background. This creates difficulties in regulating access over data and controlling how data is used and re-used by external actors in the platform periphery.

Once data leave the core, they can be re-copied across multiple actors which assign them meaning. Due to data’s use agonistic nature, it is hard to track the data interactions across all actors, as the owners of the components are not necessarily the owners of data. In actors’ value trajectories, data decouple from the components that carry them and can be re-copied and assigned meaning on top of those components (Aaltonen et al., 2021; Alaimo et al., 2020). Thus, data can be re-used across long chains of actors where the partitioning of data rights is not always as straightforward once data leave their natural source. Instead, there is a need to look at the actual chains to determine who holds responsibility for what and how data rights are dispersed. Current laws such as GDPR do provide certain clarity on the roles of data controllers and processors, but when opening up for innovation on a large scale, data do not always flow from one actor to another, but across long chains of actors. This brings a new set of challenges on how to regulate the patient data use and keep the chains legal all the way.

The inability to control these long chains works as a barrier to support external data innovation. The lack of control rises as it is hard to determine a-priori how data will be used and track the interactions of data across actors' value creation trajectories. Data are not components and do not embody functions, but are recombinant resources which acquire meaning as they are collected, stored and used by actors (Alaimo et al., 2020). The way data are used, recombined and aggregated can trigger a new set of interactions which are not reflected in the existing law. Therefore, instead of thinking about complying with legislation when opening up the boundary resources in a linear way, the actors also need to make sure that the process of data use and re-use is legal across the chains in an on-going manner. Such a turbulent environment requires that new laws are created to provide more clarity, as well as old laws are constantly revised to reflect the changed circumstances. Therefore, the lack of clarity on how to reflect legislation in complex environments where data is exchanged across multiple actors, works as a constraint to data innovation.

Ensuring compliance with legislation and controlling the long chains can also be facilitated by setting up upfront criteria on which data bring value to the platform and its ecosystem. Such criteria can orchestrate actors by making sure that verified technologies, provided by legitimate actors catch relevant data which is of value to the healthcare service. However, the lack of universal criteria and legislative instruments to regulate the ecosystem actors in such an automated way, also suppresses the opportunities for patient data innovation on a larger scale. This paper contributes to the literatures on PGHD and digital platforms by showing that although platforms' modular architectures can facilitate the process of accommodating PGHD in digital platforms, innovations centered around data entangle technology and policy. Although the paper shows that accommodating PGHD in eHealth data platforms may be premature at the stage, the potential is promising towards that direction.

## Conclusion

This paper investigates the process of opening-up an eHealth platform to accommodate PGHD captured through external vendor technologies and shows that barriers arise due to the entanglement of technology and policy. The data-intensive environment brings in an increasing complexity in regulating data use and re-use across the long-chains of actors in the periphery, which suppress the innovation potential with patient data in the platform periphery. This research also has certain limitations, as the empirical study is based on a limited number of interviews and the case chosen is one where PGHD from external technologies is still not accommodated in the digital platform. Further research can go beyond by showing how to tackle the interplay of technology and policy and do that in a way that enables innovation with PGHD in data-intensive environments.

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# On data discipline, citizen care records, and rehabilitation work

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**Abstract** Reporting from an ethnographic study on municipal welfare provision, we focus on care workers' "data discipline" when engaging in result-documentation within rehabilitation work. We show how the care workers' own approach to result-documentation is a different kind of "data discipline" than the one called for by municipal management and supplemented by the digital care record. To unfold the analysis we draw on insights from Science and Technology Studies and Computer Supported Cooperative Work. We conclude the paper arguing that "data discipline" is practiced by care workers, they, however, engage in a different kind of data discipline.

## Introduction

*"How data are created, shaped and acquire legitimacy is often closely intertwined with normative statements of what should become visible and granted importance" (Bossen et al., 2016, p. 511).*

According to the Danish Social Services Law, the abilities, needs, and progression of citizens with cognitive and physical disabilities should continuously be accounted for by municipal authorities and service providers (Social- og Indenrigsministeriet, 2015; Socialstyrelsen, 2020). A tenet in the 2014 social supervisory reform is that result-documentation should be conducted by

case and care workers in an effort to render probable the “positive” effects of services on the rehabilitation of the citizen (Socialstyrelsen, 2016).<sup>1</sup>

Consistent with the national strategies (KL, 2017; Socialstyrelsen, 2016), the municipal management, within the present case, is concerned with obtaining data that makes visible and qualify how service providers (day care centers and residential homes) work with rehabilitation approaches and their effects on citizens’ functionalities and well-being. The documentation of rehabilitation takes place in electronic citizen care records where authorities and providers of services report on the individual citizen’s case<sup>2</sup>. However, in the municipal ambitions data is seen as crucial for rendering rehabilitation probable, and municipal managers voice concern that the documentation practices in the decentralized care units differ from one another and lack “data discipline” – i.e., as told during fieldwork, to systematically document the rehabilitation approaches used and their effects in electronic care records (field notes from observations and interviews).

The analysis presented here is situated on the centralized wish for “data discipline” by way of exploring documentation practices at a day care center. We shed light on care workers’ systematic approach, qualifying the work they are doing and their sharing of knowledge about it. By unfolding the care workers’ documentation of rehabilitation in and outside the care records, we show how they produce and interpret data by inventing categories, documents, and forms in order to learn from and optimize their methods and tailor the care of each individual user<sup>3</sup>. We argue that care workers create their own systematic approach for working in a data-informed way. However, as much of this work is invisible in the care record, their disciplined production and use of data differs from management’s wishes.

Previous research in the field of welfare provision and IT have looked into the changing nature of work and the role of professional discretion in standardizing and automatizing decision-making (Boulus-Rødje, 2018; Høybye and Ernst, 2018; Pedersen and Wilkinson, 2018; Petersen et al., 2021). Further, research has looked into the rationalization of public welfare professionals’ work, which has occurred from the evidence-culture of documenting, monitoring and measuring (Andersen, 2013; Jöhncke and Rod, 2015). Along similar lines, research in health care informatics has been concerned with new forms of “data work”, as situated practices of and cooperative efforts going into the making, re-purposing and

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<sup>1</sup> In an effort to obtain and share data about effects of social services, a national digitalization project called Fælles Faglige Begreber [Common Professional Terms in English] aims to make practices of result-documentation across Danish municipal actors more consistent and structured with new digital classifications (KL, 2017; Socialstyrelsen, 2020).

<sup>2</sup> This includes: services, which a citizen has been approved, details about e.g. medicine, health, background, and daily documentation of efforts related to the citizen’s rehabilitation according to goals, e.g. independence, structure, mental health, formulated by municipal authorities (field notes from observations and interviews in the citizen centre for disabilities).

<sup>3</sup> Care workers refer to the people at the units as ‘users’ (field notes from observations at a day care center).

sharing of data in order to enable and integrate information infrastructures (Bjørnstad and Ellingsen, 2019; Bossen et al., 2016).

While such research focuses on the changing roles and tasks of welfare professionals in information technologies and infrastructures, this paper is concerned with unfolding the term “data discipline”, which was encountered during fieldwork. With the paper, we show how care workers creatively relate to embedded political and normative categories in and outside the electronic care records. With this, we shed light on care workers’ “data discipline” and how a systematic approach, developed by care workers, does not fit the centralized demands for documentation in the care record. Our analysis, in this way, engages with how various approaches to documentation interfere with each other by looking at relations between formal (infra-)structures and situated practices of “recording” citizens (Berg, 1996, 1997; Chawani et al., 2014; Star, 2007; Suchman, 1994). This is to say that categories and classifications, embedded in information systems, are political and have disciplining effects (Bossen et al., 2016; Suchman, 1994). Similarly, in drawing on Ribes & Jackson (2012), we could say that data is infused with decisions, evaluations, and values, which designate what is taken into account and what is left out. In an effort to explore exclusions in categories, we turn to Star and Bowker’s (2007) concept ‘residual categories’, which refers to that which is left out in a classification system; the “none of the above” category, the dismissed or disbelieved lived experiences, something straining the technical capacities of the information system, or something falling between two stools (Star & Bowker, 2007).

We bring this theoretical orientation with us and situate our analysis on the local, decentralized data practices of care workers and their encounters with centralized and legal requirements, political goals, and structures in the technical set-up. Moreover, we look more carefully into the care workers’ documentation practices as they creatively use the embedded categories in the care record to make room for data that allows for their own systematic approach. That is, while the embedded categories in the care record have a structuring effect on how rehabilitation and documentation work is organized at the day care center, the decentralized practices are restructuring the structure of the care record.

Thus, in unfolding the empirical term “data discipline” in tandem with the theory presented, we argue that care workers are data disciplined as they use data to qualify their rehabilitation approaches in a structured way. However, the data discipline they engage in is different from the one called for by municipal management and the electronic care record. Although different, the data disciplines share in common that they put recordings of rehabilitation and progression on a specific meaning bearing path.



## Empirical setting and methods used

The paper is based on ethnographic fieldwork (Cook and Crang, 1995; Neyland, 2008) in a citizen centre for disabilities in a Danish municipality. The fieldwork was conducted during March to June 2019 by the first author who did observations and interviews at a day care center and at a residential facility for persons with cognitive and physical disabilities. The observations were conducted during care workers' staff meetings, their documentation practices in front of computers, when they filled out printed forms, and during various activities such as bike trips with users. Beyond observations, 6 professionals, including care workers, heads and coordinators of care units, and a volunteer coordinator, were interviewed. The interviews were semi-structured (Brinkmann and Kvale, 2015), conducted in Danish, and lasted on average around one hour. Transcripts and fieldnotes, presented in this paper, have been translated from Danish to English. Field material including national policy documents (KL, 2017; Socialstyrelsen, 2016, 2020), municipal policy papers, printed forms, and descriptions of the case management system have been analyzed using continuous situational mapping and memoing from situational analysis (Clarke, 2005; Clarke et al., 2018).

For this paper, we present data from one day of fieldwork at a day care center with focus on local care practices and documentation in the citizen's electronic care record. The record comes with standard tabs such as abilities assessments and action plans, which the authorities are required to fill out, and with pedagogical plans, which care workers are required to formulate and update; here, care workers report on the specific goals and initiatives that the authorities have formulated in the record.

For the project, a NDA was signed between the first author and the social services administration in the municipality. The involved participants were orally informed about the aim and scope of the study, guaranteed anonymization, and voluntarily participation.

## Analysis

Care units are required to report on a citizen's rehabilitation, but in the citizen centre for disabilities, several citizens lack verbal language; some have none at all, while others can utter single words. Due to the lack of verbal language, care workers emphasize that their daily reporting in the electronic care record is likely to represent their best assessment of a citizen's well-being *and* positive effects of the rehabilitation approaches. As a result, the care workers at the day care center which we follow here have come up with a way to make the pedagogical plans more structured by developing (what we refer to as) an indicator: the "coping signal". In the following, we will see how they fill out forms and categorize data in excel sheets, which helps them interpret what leads users to act aggressively.

However, we will also see how the electronic care record does not readily allow this type of data production.

## Inventing categories of coping signals

At the day of the fieldwork reported here, two care workers walk the first author through the documentation tasks they perform on a daily basis in the case management system. They access the care record of one of their users and navigate to the “pedagogical plan”, where they explain how they have to “add an effort” for each goal that has been agreed upon between the authorities, the citizen, and the providers of social services. Common goals are “structure”, “independence” and “mental well-being”. “An effort” is the activity or strategy that care workers put in motion to work towards a goal. Every day they make notes on “an effort”. In the record, they usually write notes in prose, answer multiple choice questions, or use drop down categories. The first author observes that there are 444 pages of documentation in the pedagogical plan for this user. One of the care workers explains that due to the difficulties extracting anything from the thread of notes, they have created their own indicator to qualify their work:

*“We had a long chat back and forth: What should we do with documentation? We thought it was difficult to extract anything from just writing notes. Because it was just a long thread of notes. It was difficult to see if what we do has an effect. So we decided to make these pedagogical plans more structured, so it was better for us”* (Interview with Maria, care worker at a day care center)

In the pedagogical plan in the electronic care record, the care workers are supposed to write daily notes in prose in a text field. However, as this care worker explains to the first author, the care workers and their manager decided at a staff meeting to supplement the notes with a personalized Word document, in which they explain the jotted down notes in the electronic care record. Further she explains that they decided to upload these documents, whilst knowingly straining the capacities of the case management system. The Word document contains categorized descriptions of behaviour and prescriptions of various rehabilitation initiatives designed for each user. They call this document “a coping signal”. Beyond making meaningful the notes jotted down, it also serves the purpose of indicating day to day well-being of a user through a traffic light signal:

*“Here we describe when John is in green, then how does he behave when he is doing well, and what we will do with him or towards him? What can we do to sustain that (green behaviour)? And then a more problematic behaviour can occur. That’s the yellow signal. There, we have also described how his behaviour is (in yellow) and what we can do to bring him back to green. Actions that will help him back to a good mood. And what we can do to avoid that it escalates to red. There (in red), we also have a description of how he is when he is in his most*

*horrible state. And what we can do to bring him back. We have one of these (coping signal) for each user. (...) John's behaviour is very labile and he can be really unwell. Other users aren't aggressive like that. Then instead, we use this as a comfort signal... They can be in red without kicking and hitting and all that. They can still be unwell mentally. So we use this as a way to look at their behaviour and interpret how they are doing physically and mentally".*  
(Interview with Susan, care worker at a day care center)

Each user's coping signal is modified regularly at staff meetings, where care workers categorize each user's states of *being* into colour codes that indicate what could be done to improve or what could be the cause of a user's particular state of being. The coping signal allows for them to do the daily required notes, but, in their own systematic way, which qualifies their work with all that it entails – their experiences, neuropedagogical knowledge, and skilled attentive knowing of marginal changes in behaviour and surroundings. By themselves, the categories and fields for reporting embedded in the electronic care record do not leave room for this type of qualification. Thus, without knowing the language of the coping signal and without accessing the document uploaded, the notes in the electronic care record make little sense. As it is, the care workers' data production method for sharing knowledge and learning about the effects of rehabilitation work is somewhat invisible for others who access the electronic care record.

### Counting and interpreting incidents of violence

In the development of these documentation practices, this day care center is inspired by neuropedagogical supervision and its use of risk assessments in order to prevent aggressive acts by users. Care units are legally required to report on violent incidents in standardized forms in the case management system, as the head of the day care center tells the first author. However, at this center care workers also attempt to count incidences and interpret the circumstances under which they surface. They combine the coping signal with forms and excel spread sheets to which they produce data about user-violence - which relates to anything from a slight push to more aggressive acts. In the day care center, they have designed a form with questions regarding the details of an incident. They have a pile of printed forms in their shared common rooms, so that a care worker quickly can grab one and fill it out, using a pen, right after the incident. The head of the day care facility gathers the filled-out forms and type the information in an excel sheet that can illustrate, over a period of a month, who was aggressive, towards whom, at what time, and so on. This allows the day care center to identify patterns, which they discuss at staff meetings. Alongside the coping signal, the excel sheet makes it possible for the care workers to interpret particular expressions of a user's behaviour. If John tends to be violent towards George three days a week, often between 12 and 13, the care workers can go back to their daily notes in the care record, check the colour code, and open the file to check

John's typical responses. With this reading of their data reporting, they attempt to see if any repetitive patterns were registered, such as e.g. poor sleep or changes in medication, or whether John only reacts in certain ways towards specific users or care workers.

This type of counting and interpretation of reported data helps the day care center coordinate their rehabilitating approach towards each user. We see how they reflect upon care workers' experiences with a user, numerical data from the excel sheet, behaviour coded in the coping signal, and daily notes in the care record. In this way, they mix different sources of data in a systematic and disciplined way. However, as we have shown, these systematically and disciplined ways of working and documenting rehabilitation are in part digitally unaccounted in the care record.

## Concluding discussion

We have focused on care workers' "data discipline" and shown how they intersect centralized formal and legal requirements with local requirements by using their own indicator, the "coping signal", as new categories for producing and documenting data to qualify their work and for sharing knowledge. While both municipal management and care workers share a concern for "data discipline", the care workers' use of data differs from the municipal (governmental) ambition. Even though care workers have invented a way of working meaningfully with documentation, their efforts are not acknowledged by the case management system and are thus to a large extent invisible.

In following Suchman (1994), categories act with a certain type of control and disciplining effect over social relations. Similarly, in the care record, we see how categories and fields value particular types of documentation and how categories are constitutive in organizing a particular type of care. The political focus on rehabilitation and progression is evident from the care record where calls to locate goals are made as prompts for notes and answers. In this way, categories assign value to and make visible notes expressed in a specific form, whilst other ways of noting and reporting on rehabilitation are invisible and excluded. Care workers translate these categories and political goals into their everyday work, but by restructuring available structures and changing the content, they make room for something differently valuable, which officially, might be residual.

In our case, residual categories (Star and Bowker, 2007) make us attentive towards that which is not part of the standard, but we also turn it around to see how care workers take advantage of the plasticity of the set-up by bringing in data that strains the technical capacities, inventing categories that might have been dismissed technically/politically, and initiating a data discipline that is fitable to local work requirements. The embedded categories in electronic care records and the care workers' own categories are equally political; they also carry with them

different valuations of what is worth knowing and worth counting. Data discipline, in this way, is acknowledged and practiced by care workers, however, they engage in a different kind of data discipline in order to qualify their rehabilitating work.

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# Access and Use of Digital Rheumatology: Exploring “the social aspect”

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**Abstract.** This paper reports on the results of a secondary analysis of qualitative and quantitative research data focused on the socio-demographic and -economic dimension of digital health service and telemedicine use in German rheumatology care. The qualitative data analysis revealed that particularly age, place of residence and economic wealth are attributed a high relevance for the use of digital health through patients. Among physicians, age in particular was highlighted to influence digital services. Access to technical equipment is unequally distributed in society, leading to a wealth gap, which, according to participants, should find greater consideration. The quantitative data suggested correlation between the location of medical practice and telemedicine use, which might indicate poorer infrastructure in rural areas in Germany. These results are transferred to Bourdieu's theory of social space (1979) and types of capital (1986). The individual positioning in social space is associated with health-enhancing privilege and opportunities to parts of society. This may also include digital health use, which according to our data depends in particular on the individual economic capital of each person. The influence of social, cultural and symbolic capital on digital health has yet to be explored, based on further primary data research.



# Introduction

Digital services and telemedicine have made their way into health care delivery. In fact, the COVID-19 pandemic has further accelerated the digital transformation of global health systems (Soto-Acosta, 2020). Studies suggest that digital services could improve care in several medical areas (Hewitt et al., 2020).

One of these areas is rheumatology care (McDougall et al., 2017). The potentials of digital health and telemedicine also face risks (Krusche et al., 2020). A hazard of particular relevance is the exclusive power and divisive potential of digital health regarding socio-economic status and further demographic characteristics. We understand socio-economic status as the combination of the characteristics of education, income and occupation (Baker, 2014). With demographic characteristics we refer to age, race (Stevens et al., 2021), gender, religion, home ownership, place of residence, health and disability status, and psychiatric diagnosis (Salkind, 2010). Those powers and potentials in turn might accord health-enhancing privilege and opportunities to sub-sections of society (Veenstra, 2007), including the access and effective use of digital health – which again is closely intertwined with the concept of digital divide:

“[T]he gap between demographics and regions that have access to modern information and communications technology and those that do not or have restricted access. This technology can include the telephone, television, personal computers and the Internet.” (WHO, 2021)

The influence of socio-demographic and -economic characteristics in relation to access to parts of society is also reflected in Pierre Bourdieu's theory of social space (Bourdieu, 1979; 1982). Each person's position within social space is determined by the dimensions of capital volume, capital structure and social career. Capitals are resources used by individuals and groups to maintain and enhance their positions in the social space (Bourdieu, 1986; Veenstra & Abel, 2019). According to Bourdieu, capital not only refers to economic capital, but also includes social, cultural and symbolic capital, which are interconnected and partially convertible into each other (Bourdieu, 1986). The notion of capital interplay refers to the intertwining of several forms of capital in the production of health (ibid.) and could also influence health care practitioners on whether digital services and telemedicine are used and offered to patients at all.

This work was inspired by previous research that related Bourdieu's theory to the distribution of health opportunities and equity (Paccoud et al., 2020; Veenstra & Abel, 2019; Veenstra, 2007; Xu & Jiang, 2020; Dragano, 2012), as well as previous CSCW research within this theoretical framework (Ludwig et al., 2017). We thrive to complement this knowledge with an empirical application of Bourdieu's capital approach to digital health use in rheumatology, thus exploring the possibilities and limitations of our recent empirical data (Muehlensiepen et al., 2021 a,b,c). For this purpose, we reassessed and conducted a secondary analysis of quantitative and qualitative data under the question: How do socio-demographic and economic aspects influence digital health and telemedicine access and use in rheumatology care?

## Methods

To gain an understanding of the association between socio-demographic and economic characteristics and digital rheumatology usage, we have re-assessed and analyzed quantitative and qualitative data that we gathered earlier in previous studies. These include 1) qualitative interview data with patients, physicians and stakeholders (Muehlensiepen et al., 2021a); 2) data from a fishbowl discussion at the annual German rheumatology meeting (Muehlensiepen et al., 2021b); 3) data of a survey with rheumatologists and general practitioners (Muehlensiepen et al., 2021c); and 4) data of a survey with rheumatology patients (Muehlensiepen et al., 2021a). Each of these investigations was methodologically distinct and included separate groups of participants:

1) In the time span between November 2017 and July 2019 we conducted expert interviews (n=28) with patients, providers, and stakeholders (digital health developers; representatives of the statutory health insurance system, and others) engaged in rheumatology care. The used interview guide was designed to explore perspectives on telemedicine, as well as barriers and potentials of telemedicine use. Although the link between socio-demographic and economic factors and digital health in rheumatology was not specifically asked about, some of the interviewees raised these aspects by themselves in accordance to the openly designed interview guide. The interviews were recorded and transcribed verbatim.

2) A virtual fishbowl discussion on the question “How does the internet affect the doctor–patient relationship?” was held at the first virtual annual conference of the German Society for Rheumatology 2020 (September 9–12, 2020). Participants were patients, health care providers, and stakeholders. Apart from the initial question, the content of the fishbowl discussion depended on the participants, who referred to the relevance of socio-demographic and -economic aspects on digital health use. The discussion was recorded and transcribed verbatim.

3) A cross-sectional, self-completed, paper-based survey of German outpatient rheumatologists and general practitioners has been conducted from September to November 2018; to investigate acceptance, opportunities, and obstacles to the implementation of telemedicine. In order to be able to characterize the sample surveyed, the questionnaire included questions on socio-demographic data as age, gender, and clinical location, among others.

4) In collaboration with the patient organisation Deutsche Rheuma-Liga LV Brandenburg, we designed a second a cross-sectional, self-completed, paper-based survey on the use of telemedicine, this time targeting rheumatology patients. The questionnaires were distributed between 1 September and 30 December 2019 in different settings, including working groups of the patient organization and rheumatology care practices. In addition to questions about the personal perspective on telemedicine use in rheumatology, we also obtained socio-demographic data: Gender, age, health status, place of residence, etc.

In these studies, we have not yet sufficiently elaborated and presented the connections between socio-demographic and -economic factors and digital health usage in rheumatology, which is why we considered a complementary secondary analysis to be of further value in preparing future research activities. The

secondary analysis followed a deductive approach which aimed to detect information on the influence of socio-demographic and -economic factors on the use of digital health in the data.

1&2) For this purpose, we examined the qualitative material with regard to text passages in which socio-demographic or -economic aspects were addressed. The transcript passages were imported into the software MAXQDA 2020 and analyzed based on qualitative content analysis by Philip Mayring (2000). Codes were assigned by FM according to a deductive category system centered on characteristics: gender, age, income / wealth, education level, place of residence. SH performed an additional consistency check and inconsistencies were resolved. For the presentation of the results, representative quotes of the discussion transcript were selected, translated and included in the text.

3&4) We screened the quantitative data sets based on the qualitative results and assessed which socio-demographic and -economic data were available to verify or support the qualitative findings. In this context, we found that reliable data on age and location (place of residence / location of the medical practice) were available for both the physician and the patient survey in order to correlate them with the use of telemedicine and willingness to use telemedicine. The data sets were uploaded to SPSS and subjected to correlation analysis according to Pearson.

## Findings

### Qualitative Data

We identified several passages in the qualitative data in which socio-demographic- and -economic aspects were attributed a significance for the use of digital services or telemedicine in rheumatology. The attributions or contextual factors differed depending on the potential user groups. Among the physicians, age in particular was raised as a relevant individual factor for the implementation of digital health, respectively, as one fishbowl participant put it, the investment in digital infrastructure:

“My rheumatologist is like that; she tells me that she won’t invest in any digital infrastructure here and I know five, six, seven rheumatologists who are of the same age.” (Fishbowl, Patient representative I)

Digital infrastructure is described here as a, probably, financial investment that older physicians in particular do not want to undertake. Among patients, also the age and complementarily the place of residence were discussed as relevant determinants of access to and use of digital health services.

“With Skype and the whole thing- Who of the old people up there in Mecklenburg or so has the technical equipment? – I always ask myself.” (Interview 4, Patient)

At this point, the interviewee mentions SKYPE as a paraphrase for medical video consultation, which “the old people”, e.g. in the sparsely populated region

of Mecklenburg, may not use due to missing technical equipment. In addition, location also plays a role in terms of adequate internet access, which according to one GP interviewed is not available in rural areas.

“It is a paradox, that patients who would be most affected by it [telemedicine], patients who live far away from the city, (...) still have white spots in their surroundings, for example areas, residential areas where ISDN is available. They don't even have DSL 2000, they don't have anything. And it doesn't matter whether they want to or not, they simply can't hold a video conference.” (Interview 22, General practitioner)

The interviewee described that, people residing far away from the city would be most affected by telemedicine. However, according to him, these are precisely the "white spots", i.e. areas lacking an adequate internet connection for telemedicine usage, which he describes as a paradox. But not only location, in the sense of place of residence, but also place in society determines access to technical equipment and sufficient internet connection:

“In many parts of society, that not only include special circumstances, but also students and the general population, from patients to doctors, who simply do not have the technical equipment. And I don't even want to mention the 5G network, which is also not available in Germany.” (Fishbowl, Rheumatologist IV)

According to one fishbowl participant, access to technical equipment is unequally distributed, which excludes certain parts of society from digital health services. Following this line of thought, another fishbowl participant links the use of digital health to the economic resources needed to purchase technical equipment in order to be able to use digital services at all. According to him, those are unequally distributed and might lead to a wealth gap in the access and use of telemedicine and digital health, which has been given too little consideration so far:

“We also have to consider that digitization creates a wealth gap: people who cannot afford large contracts, good mobile phones, good tablets, do not have good access. And this is also evident in telemedicine and applications. (...) Thus, I believe that we also have to consider the social aspect.” (Fishbowl, Rheumatologist I)

He describes the wealth gap in terms of access to digital health services as the "social aspect" that has been given too little consideration so far.

While age, income / wealth, place of residence age, income wealth, and location were attributed an important role in access to and effective use of digital health in the qualitative data sets, education level was only mentioned marginally (s. quotation ‘Fishbowl, Rheumatologist IV) in the qualitative data sets. Furthermore, gender was not referred to at all as a determinant of digital health use and access.

## Survey Data

A total of 485 physicians participated in the survey. Around 25% of the doctors surveyed reported that they used telemedicine. The majority of the surveyed

physicians (Table I) worked in provincial towns and towns. The correlation analysis indicated a minor negative correlation (-.12) between the location of the medical practice and telemedicine use. The smaller the population of the medical practice location, the fewer physicians indicated that they use telemedicine.

Circa half of the surveyed physicians were in the age between 51 and 60 years; 22% were older than 60 years; and 21% were between 41 and 50 years old. The correlation analysis indicated that the variables age and telemedicine do not correlate ( $r=-0.02$ ).

Table I. Physician Survey: Telemedicine use, location of medical practice and age

Location	Telemedicine Use		
	No	Yes	Total
City	57 (12.10%)	27 (5.73%)	84 (17.83%)
Town	109 (23.14%)	45 (9.55%)	154 (32.70%)
Provincial Town	124 (26.33%)	34 (7.22%)	158 (33.55%)
Rural Area	62 (13.16%)	13 (2.76%)	75 (15.92%)
Total	352 (74.73%)	119 (25.27%)	471 (100%)
<i>r = -.12 (Sig., 2-sided = .009)</i>			
Age	Telemedicine Use		
	No	Yes	Total
<30 Years	2 (.42%)	0	2 (.42%)
31- 40 Years	29 (6.16%)	9 (1.91%)	38 (8.07%)
41 - 50 Years	74 (15.71%)	26 (5.52%)	100 (21.23%)
51 - 60 Years	165 (35.03%)	62 (13.16%)	227 (48.20%)
> 60 Years	83 (17.62%)	21 (4.46%)	104 (22.08%)
Total	353 (74.95%)	118 (25.05%)	471 (100%)
<i>r=-.02 (Sig., 2-sided = .675)</i>			

A total of 708 RMD-patients participated in the survey. Circa 38% of the participants do not want to try telemedicine; 32% of the participants do not know

whether they would like to try telemedicine; and the minority of survey participants (31%) would try telemedicine. The majority of the surveyed patients (Table II) lived in rural areas (34%) and provincial towns (25%) The correlation analysis indicated that the variables willingness to try telemedicine and the place of residence do not correlate ( $r=0.02$ ).

Around 39% of the surveyed patients were in the age between 61 and 80 years; and 38% between 51 and 60 years. The correlation analysis indicated that the variables age and telemedicine do not correlate ( $r=-0.05$ ).

Table II. Willingness to try telemedicine, place of residence and age

Place of residence	Willingness to try telemedicine			
	No	Yes	Do not know	Total
City	56 (8.46%)	42 (6.34%)	43 (6.50%)	141 (21.30%)
Town	46 (6.95%)	44 (6.65%)	44 (6.65%)	134 (20.24%)
Provincial Town	64 (9.67%)	54 (8.16%)	46 (6.95%)	164 (24.77%)
Rural Area	85 (12.84%)	62 (9.37%)	76 (11.48%)	223 (33.69%)
Total	251 (37.92%)	202 (30.51%)	209 (31.57%)	662 (100%)
<i>r = .02 (Sig., 2-sided = .545)</i>				
Age	Willingness to try telemedicine			
	No	Yes	Do not know	Total
<20 years	16 (2.32%)	5 (0.72%)	6 (0.87%)	27 (3.91%)
21-40 years	23 (3.33%)	42 (6.09%)	37 (5.36%)	102 (14.78%)
51-60 years	69 (10.00%)	105 (15.22%)	91 (13.19%)	265 (38.41%)
61-80	137 (18.86%)	52 (7.54%)	79 (11.45%)	268 (38.84%)
>80 years	6 (0.87%)	19 (2.75%)	3 (0.43%)	28 (4.06%)
Total	264 (38.26%)	210 (30.43%)	216 (31.30%)	690 (100%)
<i>r = 0.05 (Sig. .221)</i>				

## Discussion

We conducted a secondary-analysis on qualitative and quantitative data following a data-related explorative and at the analysis level deductive approach which aimed to detect information on the influence of socio-demographic and -economic characteristics on the access and use of digital health and telemedicine in rheumatology care in Germany. The qualitative data revealed that age, wealth in terms of economic resources, and location - both place of residence as well as position in social space - determine access and use of digital health and telemedicine by patients in rheumatology care. Patients in peripheral locations have limited access to digital health services, leading to urban-rural and wealth disparities, which, according to study participants, should find greater consideration. With regard to physicians, age and location were primarily described as potential determinants of telemedicine use. The physician survey data revealed a slight correlation between the location of the practice and the use of telemedicine services. If practices are located peripherally, physicians use telemedicine less often. There appears to be no correlation between age and the use of telemedicine by physicians. The data of the patient survey revealed that there is no correlation between the place of residence or age of the patients and the willingness to use telemedicine.

Our empirical findings can be partly related to Bourdieu's types of capital (Bourdieu, 1986): Economic capital covers money, property and other financial assets. In the health sector, economic capital refers to the material resources required to access standard health services, pay in advance and acquire possibly better services (Paccoud et al., 2020), such as telemedicine or digital health apps. As economic capital is unequally distributed in social space, a wealth gap exists in relation to the use of digital health, as one fishbowl participant expressed. Cultural capital exists in three forms: the embodied state (through behaviors and dispositions learned over a lifetime), the objectified state (cultural goods possessed by the individual); and the institutionalized state (such as an educational qualification) (ibid.). For instance, digital (health) literacy could be attributed to the embodied and more rarely, as in school courses or even medical training, institutionalized state of cultural capital. Bourdieu defined social capital as the "aggregate of the actual or potential resources which are linked to the possession of a durable network of more or less institutionalized relationships of mutual acquaintance and recognition" (Bourdieu, 1986, p.248). The individual's social network might support, accompany and speed up access and use of digital health services and telemedicine, e.g. for the elderly. This may imply that health care tasks are transferred to the home care setting, leading to a displacement of work to informal caregivers (Bratteteig & Wagner, 2013).

Individuals are distributed in social space based on the composition of the capital they possess (Bourdieu, 1986). Capital is unequally distributed and so is the availability of adequate technical devices and resources, as well as the required digital or health literacy, which are prerequisites for effective use of digital health approaches (Cornejo Mueller et al., 2020). As reflected in the qualitative data, the unequal distribution of capital is associated with parts of

society not having access to digital health services and telemedicine and thus potentially receiving poorer health care. Complementing Bourdieu's types of capital, our analysis shows that age and place of residence are also important factors influencing effective use of digital services, which in turn could be related to social space and capital endowment. Consequently, recent COVID-19 induced digital health uptake could lead to an increase in the unequal social distribution of health opportunities.

## Limitations

This paper reports on an early approach to explore the socio-demographic and -economic impact on digital rheumatology access and usage in order to plan future research activities in this area. This approach has limitations, both methodological and theory-related. The data studied did not primarily target the influence of socio-demographic and especially education and economic factors on telemedicine use, which to this study is of particular relevance. For example, income or education level could have been assessed in the patient survey. Furthermore, the interview guides did not contain any specific questions on socio-demographic or -economic aspects. Plus, we did not perform statistical pooling due to the heterogeneous target groups in the surveys as well as partly different methodological approaches. Due to the limitations of the empirical material, we could only tentatively explore the relationships between cultural, social, and symbolic capital and digital health use.

Our paper contributed to existing knowledge by highlighting the socially exclusionary power and divisive potential of current digital health use, while providing another yet rare (Ludwig et al., 2017) application of Pierre Bourdieu's seminal theory, which we highly recommend to the community due its high declarative power with regard to social inequalities in (digital) health care use. As this is only the beginning of our research on determinants of digital rheumatology usage, we would like to expand our understanding and reach for further theoretical and empirical approaches at INFRAHEALTH 2021. We are especially interested in discussions and examples on how participatory design approaches as well as digital health in general can be used to overcome social barriers to access adequate healthcare. These aspects will be taken up in our follow-up projects to gain more insights into the socio-demographic and -economic determinants of digital health usage, specifically in rheumatology care.

## Conclusion

The results of our analysis indicate that individuals' location in social space and capital resources shape access to and use of digital services in rheumatology, with economic capital, age and location being of particular relevance. The results of our secondary analysis are still limited in their explanatory power, but emphasize the area, where more detailed primary data research is highly needed.



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# Democracy and the politicization of personal health data: the Norwegian Smittestopp case

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**Abstract.** In early 2020, at the onset of the coronavirus pandemic, many countries developed and introduced contact-tracing apps. These apps use one or more of several cell phone capabilities to notify citizens when they should enter self-quarantine because of close contact with an infected individual. Norway released a contact tracing app called Smittestopp in April 2020 which, though initially widely used, was also met with criticism for the way it handled personal health data. Shortly after Amnesty International issued a press release calling the app a surveillance technology, it was rescinded, and a different solution developed. This paper discusses Smittestopp as an example of the politicization of personal data in the context of a state of exception, in this case the covid-19 pandemic. The combination of the politicization of personal data and a miscalculation of how long the pandemic might last contributed to the app's negative reception both domestically and internationally. The paper argues that while the case did present a short-term challenge to Norway's democratic institutions, the context of the state of emergency coupled with other actions the Norwegian government has taken to curb infection rates indicates that these challenges were temporary and not a serious threat.

## Introduction

The COVID-19 pandemic threw a lot of things people had taken for granted into question. In the early months, much of this was related to how to keep the virus under control without overreacting to the point that individual freedoms were at a significant risk of being under attack. At the same time, however, the rate of viral

transmission, relative unpreparedness of the global community, and the number of people dying from the disease made it clear that the coronavirus pandemic deserved exceptional treatment.

While some countries imposed extremely strict lockdown measures, many democratic countries saw this move as both an unnecessary restriction on people's rights to movement and extremely difficult to do while maintaining citizens' trust in government. Similarly, in a rush to understand and track the virus spread, many governments turned their attention to developing contact tracing apps. While these apps do not limit a person's physical movements, their digital nature raises several privacy concerns. These concerns include questions around how to limit a government's right to collect and use health data in large quantities in exceptional circumstances, like the coronavirus pandemic. Unlike self-enforced stay-at-home orders or masking requirements, digital contact-tracing apps require the collection and storage of personal data, including health data. This opens digital contact-tracing apps up to a greater possibility for abuse on the part of the bodies administering them, usually governments, and thereby places them into a more dangerous category subject to more scrutiny than other pandemic-management tools.

This paper analyzes the case of the Norwegian contact tracing app called Smittestopp through this lens. The Norwegian case is particularly interesting because Norway has an extremely strong and developed democratic tradition, but the Smittestopp app was highly criticized and eventually rescinded due to concerns that data privacy rights were not sufficiently protected in relation to the severity of the COVID-19 outbreak in Norway. Ultimately, I argue that while concerns about government overreach and the breakdown of democratic institutions was legitimate, the way the case was handled may have strengthened Norwegian democracy.

## Background

After a 13-fold increase over the course of two weeks in coronavirus cases outside of China, where it was first discovered, the World Health Organization, (WHO) declared a pandemic on March 11<sup>th</sup>, 2020. (Cucinotta & Vanelli, 2020). By the 27<sup>th</sup> of March, the Norwegian Institute for Public Health (NIPH) announced it was “developing an app for contact tracing” in order to “reduce the time used for contact tracing”(Folkehelseinstituttet, n.d.). Contact tracing in itself is nothing new, with traditional or so-called manual contact tracing being carried out by health care workers identifying and contacting known close contacts of an infected person (Klar & Lanzerath, 2020; Williams et al., 2020). However, early in the pandemic, some saw this traditional version of contact tracing as insufficient due to its speed and the level of labor involved, suggesting digital contact tracing may be the only feasible solution to control the pandemic (Ferretti et al., 2020). More recent analyses also point to techno-optimism which assumes digital solutions to be more effective than manual methods as a contributing factor to their rapid development and uptake (Luciano, 2020; Sandvik, 2020a).

Discussions around the ethics of these apps were numerous in the scientific community as governments around the world moved quickly to develop and implement digital contact tracing apps (Dubov & Shoptawb, 2020; Ferretti et al., 2020; Klar & Lanzerath, 2020; Klenk & Duijf, 2020; Luciano, 2020; Morley et al., 2020; Ponce, 2020). In particular, a focus on ensuring contact tracing apps did not significantly infringe on individual rights to privacy was discussed, with some authors, like Parker et al. (2020) acknowledging a potential “conflict between liberty and privacy”.

Because the virus was initially discovered in China, by the time Western countries were discussing whether and how to implement contact tracing apps, China had already begun deploying its own digital contact tracing app through Alipay, a pre-existing and already popular wallet app (Mozur et al., 2020). This meant that as conversations around the ethics of contact tracing apps developed, they were often framed in terms of varying approaches in democratic versus non-democratic states. Hoffman (2020), in early April 2020, called tracing apps “an authoritarian regime’s instrument of choice” arguing that even though the WHO had praised the way China was handling tracking through extreme measures, “intact democracies have other resources at their disposal”, namely solidarity and cooperation from citizens. Western media generally agreed with this view, the New York Times publishing an article describing the Chinese contact tracing app, which dictates individuals’ movement and quarantines and sends personal data to police, as a “troubling precedent for automated social control” (Mozur et al., 2020).

The global nature of the virus, urgency with which governments were working to contain it, and a certain level of techno-optimism led to uncoordinated and varied approaches to the development and adoption of contact tracing apps. In early May 2020, MIT published information about various apps, including Norway’s, in a database which tracks whether each app is a) voluntary, b) limits how much data can be used, c) whether and when data will be destroyed, d) the amount of data collected, and e) whether data use is transparent (O’Neill et al., 2020). As of one year after the database was released, it contains information about apps for 49 countries and 29 U.S. states, each with different histories of use.

## The Smittestopp Case

The first version of the Norwegian app, Smittestopp, was developed locally by the Norwegian Institute for Public Health in collaboration with a government-sponsored lab called Simula. On March 27th 2020, NIPH published a post presenting the app as one of many technological solutions that may be able to help curb the infection rate in Norway (*Utvikler app for smitteoppsporing*). The app was to use Bluetooth and GPS-based location data from users’ mobile phones to identify whether users had been in the vicinity of other users who later tested positive for covid-19. It specifically called out the need for close attention to data privacy and security, stating that NIPH had already begun working with the Norwegian Data Protection Authority to ensure these concerns would be addressed (*Utvikler app for smitteoppsporing*).

Almost simultaneously, however, Norwegian news media, along with the Data Protection Authority and a number of politicians, began criticizing the app's approach to data collection and handling (Fremstad & Løset, 2020; Sandvik, 2020b; Skille, 2020a, 2020b). Complaints ranged from the amount of data collected and the app's ability to track movements to the amount of time that data would be stored (30 days) to a lack of transparency about the intention to use data for research in addition to the app's initial purpose of contact tracing (Sandvik, 2020b). In addition, the developers planned to store data centrally, users were not given an option for their data to be used only for contact tracing while opting out of other research-driven motives for the app's development, and the code was not open-source. These characteristics left the app vulnerable to privacy issues such as, in some cases being able to identify individuals and their movements.

Nevertheless, on April 16<sup>th</sup>, 2020, the first version of Smittestopp was released, with the prime minister, Erna Solberg, publicly expressing her support for it, stating that "if we want to get our lives back, as many people as possible must download the app" (Løkkevik et al., 2020). By May 3<sup>rd</sup>, around one-fifth of the population had downloaded and begun sharing data through the app (Grut & Zondag, 2020). Criticism around data privacy continued, even as NIPH and Simula continued to defend the app, citing extenuating circumstances and importance of deploying a contact tracing app quickly to slow the virus' spread.

By mid-June, concerns had grown enough that the Data Protection Authority issued a warning to NIPH stating that Smittestopp collected large amounts of data, some of which is sensitive and which allows for surveillance of individuals' movements (Datatilsynet, 2020a). That same week, Amnesty International published a press release describing Bahrain, Kuwait, and Norway's contact tracing apps as "among the most dangerous for privacy" (Amnesty International, 2020b). The document, like the warning issued from the Data Protection Authority, states that the Norwegian app is a "surveillance tool" that goes "far beyond what is justified in efforts to tackle COVID-19". It also cites that the amount of surveillance is "unlikely to be necessary and proportionate in the context of a public health response", implying that such extensive data collection would not have been appropriate even if infection levels had been higher. Shortly after the release of these two documents, on June 15<sup>th</sup>, NIPH announced it would delete data collected from the app and stop collection of further data (Folkehelseintittuttet, 2020). On July 6<sup>th</sup>, the data protection authority temporarily banned the app, and by the end of September it was announced Norway would move to the solution developed by Apple and Google (Datatilsynet, 2020b).

## A Threat to Privacy, a Threat to Democracy?

After the Smittestopp app was retracted, Amnesty International released a statement praising Norway for discontinuing it (Amnesty International, 2020a). In the weeks and months since then, questions have come up surrounding the ethics and effectiveness of contact tracing apps generally, and specifically the effect of the pandemic on the state of Norwegian democracy. In the case of Smittestopp,

this debate appears in the form of human-rights based language related to privacy. The positive correlation between democracy and privacy is often taken for granted, but as the pandemic has forced traditionally private personal health information into the public sphere, democracies have been forced to grapple with the extent to which individual privacy trumps matters of public health.

## Norwegian Democracy and Privacy

As the pandemic began and governments imposed restrictions on citizens' movements, the academic community raised concerns around the state of democratic rule and the extent to which governments could impose restrictions without sliding towards autocracy. This begs the question of what exactly a move toward autocracy might look like and when such a move might indicate a threat.

Norway regularly ranks highly on democracy indices (Alizada et al., 2021; The Economist Intelligence Unit, 2021). According to The Economist Democracy Index, Norway's democracy rating decreased from 2019 to 2020 because of "the swift imposition of restrictions on freedom from movement owing to the COVID-19 pandemic", however Norway remains number one on the list of 165 states worldwide (The Economist Intelligence Unit, 2021).

The Norwegian constitution, written in 1814, did not explicitly refer to democracy until 2004, when Article 100 was amended to include the "promotion of democracy" as part of freedom of expression (Gammelgaard & Holmøyvik, 2015). As such, the exact definition of Norwegian democracy is part of a national cultural mythology which also strongly emphasizes human rights, representation across geographic difference, and civic discourse.

These other aspects, especially human rights discourse, are emphasized more heavily in conversations around privacy than are the traditionally democratic norms of high levels of trust in government, strong government transparency, and healthy political discourse in society (Alizada et al., 2021; Christensen & Lægheid, 2020; Robinson, 2020). The Data Protection Authority, for example, must grant additional approval to any company that is planning to implement a project which has a "high risk for the data subjects' rights and freedoms", including "both the data subjects' rights under the Privacy Ordinance, and other fundamental rights such as the right to privacy, communication protection, freedom of expression, freedom of thought, freedom of movement, prohibition of discrimination, the right to freedom and freedom of conscience and religion" (*Datatilsynet*, 2018). The inclusion of the right to privacy with other human rights and democratic norms incorporates the privacy as part of Norwegian democracy, though the definition and limits of the right to privacy are not defined.

It is beyond the scope of this paper to thoroughly discuss the numerous ways privacy and democracy interact, but it is relevant to note that discussions around the right to privacy in democracies date far prior to the advent of information and communication technologies (ICT), and seen one way, fundamentally question

the importance of the individual right to “conceal” parts of themselves (Voice, 2016). Voice (2016) argues that to the extent that the right to privacy contributes to an individual’s autonomy in society, it is a key component of full, deliberative democracies such as Norway’s.

Following this logic, an extended breach of individuals’ rights, which include privacy, would indicate a slide away from democracy. As such, in normal times, Smittestopp’s privacy issues would have constituted a threat to the functioning of Norway’s democracy. However, as will be discussed below, the context of the global pandemic have changed what constitutes an acceptable breach on individual freedoms.

### An exceptional state

As government lockdowns around the world were put into place and a number of organizations raised the alarm about the state of democracy, another conversation about the exceptional nature of the pandemic was also happening. Giorgio Agamben (2005) used the term “state of exception” for periods during which a state legalizes lawlessness, or suspends the normal rule of law, to address a real or perceived threat. Agamben and others have warned that states of exception are dangerous for democracy, as they often give the sovereign more power without an end date, effectively making exceptional powers permanent and contributing to the deterioration of a balance of powers (Agamben, 2005; de Wilde, 2010; Patton, 2011). However, according to some scholars, while this link between autocratization and states of emergency is well established in political situations, such as when a leader “triggers a state of emergency” through a power grabbing act or exploiting a real political threat like 9/11 to make long-term changes, the link is not well established in the case of natural disasters like earthquakes and hurricanes (Graver, 2020; Scheppele, 2020). Scheppele (2005) calls these natural disasters “small emergencies” because they are more difficult to take advantage of and, historically, they are solved or managed quickly.

The coronavirus pandemic lies somewhere between the threatening political emergency and non-threatening small emergencies. Governments have taken extreme actions, which most agree are merited in the case of a naturally- caused pandemic. As such, to the extent that the Norwegian government treats emergency measures for coronavirus as it would other natural emergencies, it is unlikely that democracy will deteriorate. However, restrictions also have real political implications which, in the case of contact tracing apps, interact with politically charged issues like data privacy and security.

The Data Protection Authority is clearly aware of the challenges the pandemic presents: as of writing (July 2021), it has devoted a sub-theme on its FAQ page to the coronavirus. Of the nine topics listed under that theme, four relate directly to the Smittestopp app (*Datatilsynet*, n.d.). The response to the question “how the



Data Protection Authority can say yes to an app like Smittestopp” says that “we never would have accepted such an app in a normal situation. But now there is a state of emergency and thus it is important to use technology to fight the pandemic” (*Datatilsynet*, n.d.). Further, it states that because Smittestopp was not involved in a pre-approval process (*forhåndsdrøfting*), the Data Protection Authority did not have the possibility to reject the app, or the way it handles data. There are clear contradictions in this response, as the Authority simultaneously denies responsibility for the app and states the app would not have been allowed under normal circumstances. It is through calling on the state of emergency that the Data Protection Authority is able to do this, and yet as the pandemic continues over 16 months later, the line between emergency caused by natural disaster and emergency exploited through politics begins to blur.

## Politicization of Smittestopp

It follows that much of the concern surrounding the deterioration of democracy and contact tracing apps has to do with their potential use as political tools rather than as emergency management tools. The Smittestopp case is no exception to this; concerns around privacy and data handling related to digitized personal health data were the primary justifications for why the app should be retracted, while other emergency measures like stay-at-home orders and travel restrictions in Norway were not scrutinized in the same way.

The issue of data privacy is part of a larger conversation in Norway, where the national digital strategy states “it is a prerequisite that digital systems are secure and reliable, and that companies and individuals trust that systems and networks work properly” (Kommunal og-Moderniseringsdepartementet, 2016; Kommunal-og Moderniseringsdepartementet, 2019). At the same time, the Digitalization Strategy emphasizes the strategic importance of digitalization for Norway’s economic future. The development of Smittestopp through a government-funded research lab rather than through established big tech firms Google and Apple points toward a strategic political move. While part of the purpose of developing Smittestopp internally may have been to increase the population’s trust in the app and Norway’s digital competencies, Smittestopp’s failure to meet expectations meant that at best, this trust was not established and at worst, it diminished. This is not to say that other contact tracing apps like the Google/Apple solution are without issue, but rather that the approach to developing Smittestopp may have placed an over-reliance on political potential, thereby moving that particular aspect of Norway’s COVID-19 management strategy toward the category of a political state of emergency rather than a natural one.

This reliance on political goodwill was apparent in the way politicians talked about the app, with Bent Høie, the Norwegian Minister of Health, calling on the fact that Norway “is a society with high levels of trust and high digital

competency” as a reason for people to download it (Løkkevik et al., 2020; Regjeringen, 2020). This statement implies that Norwegian politicians expected residents to download the app *because* they trust their government to handle data responsibly, as it has in the past. This trust plays a key part in Norwegian conceptualizations of democracy. Thus, when it came out that Smittestopp did not sufficiently care for personal data, Norwegians’ trust the government competence could create a secure contact tracing app may have diminished more than it would have had Høie and others not emphasized the level of trust between citizens and government. Though public opinion surveys carried out by opinion.no indicated that overall trust in the government remained fairly constant from just before the release of the app (74% trusted the government) to just after it was rescinded (72% trusted the government), there was a 20% decrease in interest (from 60% of respondents to 40%) in the second version of the Smittestopp app from the first (“Fire av ti sier ja til ny smitteapp,” 2020; “Høy tillit til myndighetene tross åpne grenser,” 2020; “Stabil interesse for FHI-appen Smittestopp,” 2020; “Tillit til regjeringens første tre uker,” 2020). In other words, the politicization of the role trust played in people’s responsibility to download the app may have had the opposite effect the government was hoping to have: rather than increasing trust and confidence in Norway’s technical capabilities, Smittestopp may have increased skepticism and doubt.

## Conclusion

This essay began by posing the question of whether the Smittestopp controversy posed a threat to Norwegian democracy. The subsequent analysis of what democracy means in the Norwegian context and how rules of democracy change in times of crisis does not provide a simple answer. The pandemic remains a major global health and security threat. In the early days, when many believed the threat would be eliminated within a matter of weeks or months, the political implications of government actions seemed less important than eliminating the virus. Perhaps it was for this reason that the Norwegian authorities released an app with privacy issues despite protests from the technology and data protection communities (Sandvik, 2020a). Prime Minister Solberg implied as much when she stated that “the fewer people participating [in the app], the more intrusive will be the interventions in other areas” (Sandvik, 2020a). An optimistic view of the case assumes that, had the government known how long the pandemic would last and how difficult it would be to encourage enough people to download the app, it would have prioritized attention to security and privacy issues. The more pessimistic view sees the app’s development first as a politically strategic, opportunistic, and ultimately failed experiment in collecting and using citizens’ private health data and only secondarily as a pandemic management tool. The reality likely lies somewhere between these two, as the pandemic state of

emergency in many ways does resemble a natural disaster, or “small emergency” rather than a politically opportunistic one. As time passes, however, the restrictions and the ways they are communicated have become more obviously strategic. Governments may be realizing their actions in this exceptional time have real and long-lasting political consequences.

While authoritarian actions like those imposed through China's Alipay app or quarantine rules requiring travelers to stay alone in one room for weeks may be effective at curbing infection rates, they also have implications for human welfare and negatively influence democratic ideals like privacy and freedom of movement. The biggest mistake Norwegian authorities may have made with Smittestopp, then, was a miscalculation of the type of emergency the country was facing and the amount of time it would last.

There are strong indications that whatever damage Smittestopp did cause was not intentional. First, the government retracted the app swiftly after privacy issues came to light. This is a sign the government was not intending to use the app as a political power grab and that the responsiveness of government, another key component of Norwegian democracy, was still intact. The months following the Smittestopp controversy have shown no additional indications that the missteps were intentional; the new version of Smittestopp uses the Google/Apple solution, and public discourse around data use and privacy remains strong.

This analysis indicates that in a different situation, the development of an app such as Smittestopp with surveillance-like capabilities may have posed a threat to Norwegian democracy. However, the response to criticisms shows that government responsiveness and concern for individual privacy and autonomy remain intact, thereby neutralizing concerns citizens may have had around government trust. As the pandemic continues, it is impossible to know whether and how the case will affect the development of e-government and e-health software in Norway, but this is an area to monitor. There is also space for research on whether and how pandemics and other long-term non-political events fit into discussions on states of exception. As the coronavirus pandemic subsides, it will be relevant to monitor whether and to what extent emergency restrictions are lifted and whether data collection and use from apps initially intended for contact tracing subsides. These will be indicators of whether contact tracing apps are a new kind of tool that can be used to set up permanent states of increased surveillance or whether such fears were mostly unfounded, especially in a country with as strong a democratic tradition as Norway.

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# Exploration of ethical issues in the implementation of digital monitoring technologies in municipal health care services

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**Abstract.** The study is based on a research and innovation project on adoption and use of digital monitoring in municipal care services. The evolving use of technology is considered to meet future challenges in health and care services. However, the use of technological solutions in this context has also led to several challenges, and in this study, we focus on the ethical consequences of using welfare technology. Implementation projects are particularly relevant in this context because different stakeholders with different interest, values, assumptions need to collaborate closely and build integrated solutions to make such projects successful. Furthermore, it is a challenge to predict future consequences of using emerging technologies and we argue that ethical assessments must be part of the implementation process.

## Introduction

The demographic change in society has led to increased pressure on the organization and performance of health care services. In particular, there is a need for new models and technologies to support long-term care of the increasing population of elderly as well as people with chronic illnesses and disabilities. Accordingly, various research fields have focused on telecare and assistive

technologies that have led to increased knowledge and insight into currently available solutions and enabling technologies (Memon, Wagner, Pedersen, Beevi, & Hansen, 2014). The term welfare technology has been used in Scandinavia and national initiatives in Norway highlights technological solutions that promote safety and enabling people to better manage their own health (Helsedirektoratet, 2014). Innovation in care services has been on the political agenda in recent years as a strategy to meet future challenges in health and social sector. In particular, the Norwegian strategy for innovation in health care services highlights the use of new technology as a resource for value creation and emphasizes user influence, participation, and co-creation in the development of future care services (The Ministry Health and Care Services, 2011). Despite the promising impacts and opportunities with the use of technologies in elderly care, there is limited and inconsistent evidence about the effects of assistive technologies (Barlow, Singh, Bayer, & Curry, 2007) as well as limited use beyond the pilot-study level (Memon et al., 2014). In line with the increased use of computers as an embedded part of everyday practices, the scope of healthcare technologies has moved from singular tools to networks of systems, practices, and people, i.e., socio-technical networks (Bygstad, Hanseth, & Truong Le, 2015). Moreover, the various stakeholders involved in welfare technologies may have different values, assumptions, and worldviews, which may affect implementation and use of digital technologies (Greenhalgh, Procter, Wherton, Sugarhood, & Shaw, 2012). On the one hand, welfare technology is considered as the rationale and cost-effective solution to meet challenges in the health and care services. However, the professional value of clinical quality, patient safety and privacy may conflict with the business value of efficiency and return of investment (Greenhalgh et al., 2012, p.10).

Several studies have pointed out ethical issues by using welfare technologies, especially regarding use of monitoring technologies in the residential care of people with dementia (Niemeijer et al., 2010). Ethical issues such as privacy, confidentiality, security, autonomy, and informed consent have been discussed in several studies. Most of these studies have been based on established social and ethical norms but does not address ethical tensions caused by emerging technologies (Mittelstadt, Stahl, & Fairweather, 2015). Thus, participatory design methods have been recommended as a way to incorporate ethical principles into the design process of new technologies (Mittelstadt et al., 2015). Accordingly, there is a need to explore how ethical assessments may be part of the design and implementation of welfare technology and how ethical consequences can be translated into practical activities.

This study is based on a research and innovation project on adoption and use of welfare technology in municipal care services. The term welfare technology includes several technological solutions such as assistive devices, sensor technology, mobile technology and so on. In this study, we use the term digital



monitoring technology which refers to various sensors used in the municipal care service. The same technological solution was implemented in different municipal care services as part of a research and innovation project. In this study, we focus on how the implementation process affected ethical aspects and how ethical dilemmas were translated into practical activities. Furthermore, our study is inspired by user-oriented methods that emphasize design and development as iterative processes for mutual learning (Robertson & Simonsen, 2012) and thus enable co-creation with community members in the context of their daily practice.

## Related work

The terms ethics and morality are often used interchangeably and are closely related. Traditionally, ethics refers to the philosophical study of morality, where morality refers to special norms, principles, or beliefs (Mingers & Walsham, 2010). Ethical reflection has been an integrated part of healthcare for decades and “First do no harm” has been a predominant code of ethic among healthcare professionals. In nursing, there has been developed international code of ethics since 1953 which is based on four fundamental responsibilities: to promote health, to prevent illness, to restore health and alleviate suffering (International Council of Nurses, 2012). Furthermore, ethical assessments in the health service have been guided by fundamental human rights (privacy, dignity, security) and the principles of medical ethics (autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2001).

Several studies have focused on ethical aspects of welfare technology. A study by Hofmann (2012) has identified some potential benefits of welfare technologies such as better and more focused care, reduced risk and increased safety, and increased coping and self-determination, (Hofmann, 2012). The study also illustrates some moral dilemmas and that balancing between risk and benefits is challenging. On the one hand, tracking technology has been documented to increase safety and reduce fear and insecurity. However, it raises special issues with confidentiality, privacy, and dignity (Hofmann, 2012, p.395). Conflicting goals between stakeholders was also identified as a challenge, for examples when people with different competence enter the health care arena and become indispensable. Hofmann (2012) also argues that “technology may direct attention towards instrumental values, productivity and efficiency, and away from other phenomena important for human welfare such as hope, coping, vulnerability, dignity and meaningfulness” (p. 399). Similarly, a study by Mort et al (2015) pointed out that evaluation of telecare systems for older people has mainly concerned effectiveness and efficiency, while their social and ethical implication have received little attention (p. 439). They also argued that telecare cannot be meaningfully evaluated as an entity, but rather in the situated relation people and technology create together (p. 438). The study also showed how telecare practice

draws on a large sociotechnical system or network, how responsibilities in care networks are shifted and delegated in new ways, and how redistribution of tasks implies new meaning for privacy and confidentiality.

So far, studies have provided insight into the ethical debate and how welfare technology affects ethical values such as dignity, privacy, and autonomy. However, monitoring technologies are still in an experimental phase and there are few studies that demonstrate the outcome of such technologies (Hofmann, 2012; Niemeijer et al., 2010). The rapid development of digital technologies in the health service makes it difficult to predict the ethical dimension of emerging technologies. As stated by Mittelstadt et al. (2015), “it is a tension between the empirical and normative dimension of dealing with future and emerging technologies” (p. 2) Furthermore, they argue that potential consequences of emerging technologies are based on uncertain normative claims (how the future will and should be) and suggest ethical argumentation and discourse in order to clarify their epistemic and normative components (Mittelstadt et al., 2015). Based on Habermas’ approach to political discourse, they suggest a "methodology of translation" which involves “translation’ of uncertain claims to be comprehensible to other stakeholders in discourse” (p.1027). As indicated in the studies mentioned above, ethical aspects related to welfare technologies is not a static entity, but a dynamic process that is shaped in the socio-technical network.

## Research setting and method

The study is based on a research project in the municipal care services involving partners from different professional communities and organizational units. The project originates from a health innovation cluster that was formed in 2008 as a partnership between academia, public sector, and industry. This, in turn, resulted in a prolongation of the collaboration and a research project that lasted from 2014-2017. Eight municipalities, two vendors (companies) and researchers from two universities participated in this project. Participation was voluntary and ethical approval was granted by the Norwegian Social Science Data Service (NSD), no. 34831.

Digital monitoring technologies was selected based on identified needs related to the major challenge of maintaining safety for people affected by cognitive impairment and dementia. Behavior such as wandering, where people get up in the middle of the night, was associated with increased risk of falling and getting lost. Although healthcare workers carried out regular supervisions during the night, high-risk behavior was still a challenge in the time between the supervisions. Thus, digital monitoring was considered as a suitable option in this context. The technological solution was a web-based portal and sensors embedded in mattresses, bed-frames, and doors. The web-based portal played a key role, with an integration module that enabled the linkage to both existing

technologies and new technical devices. An alarm was triggered and sent to the night staff (mobile phone or tablets/pads) if the resident left the bed without returning within a specific duration of time according to alarm parameters in the portal. The alarm settings could be adapted to individual users by configuring alarm parameters in the portal. All municipalities adopted the same solution to a limited number of residents in nursing homes and residential care homes. The technology was known, but the figuration and context were new, and the technology had to be altered for the health care context. Furthermore, the process of the implementation was done in close cooperation between the vendor and the customer. This represented an innovative work method and included new service design and an iterative process of testing, altering, and retesting the technology in the clinical settings.

This study applies the interpretive approach to case study research and aims at producing an understanding of the implementation of digital monitoring technologies in municipal care service and the mutual influence between the system and its context over time (Walsham, 1995). Data collection has been a combination of participant observations, semi-structured interviews, and archival documents. A main source of data collection has been participant observation at workshops. In total, we have participated at six workshops that have gathered all the key people involved in the project, that is, nurses, nursing assistants, vendors, employees at the IT departments, and researchers. In addition, we have carried out 12 interviews with project members in the municipalities that included health providers and employees at the IT-department. Analysis of data was based on an interpretative approach to qualitative research (Walsham, 1995) and we have used NVivo to identify and categorize topics related to ethical aspects among stakeholders in our study.

## Findings

Presentation of the results is organized around three core themes: quality of care and effectiveness; privacy and safety; and responsibility and accountability. By focusing on condition, interaction/action, and consequences of the implementation process, provided an analytical lens to uncover ethical issues when using digital monitoring technologies in practice.

### Quality of care and effectiveness

The organization of the health and care service has undergone many changes in recent years and digital technologies have become part of everyday practice in the municipalities. Nevertheless, the use of digital monitoring technologies to support work processes during the night shift was a new intervention and was driven by policy strategies to ensure effective health services in the future. Health

professionals considered digital monitoring technology as an opportunity to provide more reliable care and act at the right time when the residents needed assistance during the night. Thus, they had a positive attitude towards the use of technology in this context as a means of promoting responsible nursing to the residents.

“Our employees actually have quite good attitudes towards the use of technology. I think a lot of employees find it quite exciting. Because if the technology is developed in a good way, then there are many of the people who live at home who will feel much safer (...)”

However, the implementation process also revealed some challenges such as the tension between the duty to provide responsible nursing and the efficiency of the service. At the start of the project, healthcare workers were concerned that digital technology would replace human resources. On the one hand, the management in the municipality has expectations that digital technology can replace human resources and thus lead to cost savings. National programs for the use of welfare technologies have highlighted benefits such as increased quality, time saving, and cost-efficiency. Thus, there was an assumption that the use of digital monitoring technology would increase the efficiency of the service. However, healthcare workers considered digital technology as a useful supplement in their work as stated in a quote from a project member:

“The technology helps the person to work at night alone, but the workload is not less, but it is somewhat more organized (..) a little more overview (...) someone have to receive the alerts, someone must act on the alert, someone has to deal with it and report if something is going wrong, so I do not look at this as a replacement of the staffing we have lost, the only thing is that it facilitates the work of the night nurse because they can be with the one who needs it most”.

The quote illustrates how digital monitoring supports the organization of work; however, it was not considered as a replacement of professional resources.

### Privacy and safety

The use of digital technology in nursing home/residential care homes affects ethical values such as privacy and some of the municipalities have included ethical reflection as part of the training program. Privacy issues have also been discussed at workshops and increased the awareness of individual assessments as illustrated by the statement from a healthcare worker:

“(...) it's fine for those who need it. For those who do not need it, we deactivate the bed alarms so that the patient can go to the toilet without us knowing about it. It is about using the technology where it is necessary - assessments are important”.

Privacy issues have also been discussed in relation to the “face-to-face” supervision traditionally performed during the night and some healthcare workers considered the use of digital monitoring systems to be less intrusive on privacy than regular “rounds”. Furthermore, patient safety is a major concern for healthcare workers and the use of digital monitoring technology provided increased safety and enabled more individualized care during the night. As

mentioned, restless behavior is a challenge for residents with dementia and cognitive impairment. A major concern for healthcare workers on night duty is when the residents get up in the middle of the night and the use of welfare technology provided an opportunity to act quickly and thus prevent the risk of falls and that the residents get lost. Although digital monitoring has led to increased safety of the residents, it has also led to challenges such as a lack of trust in the system due to technical issues. Lack of trust in the technology thus affected the safety of the digital service and led to delays in the implementation process.

### Responsibilities and accountabilities

The challenges of technological failure have raised the question of who is responsible for discovering and notify failure – healthcare workers or IT department or the vendor. Support from the vendor and IT department are mainly available during daytime, and thus entails a great responsibility for healthcare workers who have limited time and skills to detect system errors. Use of digital monitoring technologies has thus identified a need for extended IT support and risk and vulnerability analysis has been initiated to coordinate responsibilities and measures to ensure the safety and security of the service. However, a challenge has been coordination of activities and obtains commitment among participants. First and foremost, healthcare workers do not rely completely on the system and acts as a link between the vendor and the IT department. Project managers in municipalities have mostly cooperated with the vendor who has been responsible for the installation of technological devices, as well as user training. Still, collaboration with local IT department has been a challenge. The digital solution depends on the local wireless network, which is part of the technological infrastructure of the municipality, and thus the IT department is an important player in the project. They have been involved in workshops, but a challenge was a lack of resources to deal with issues that have been identified in the project. Moreover, the IT departments are organized in different ways and have various agreements on support. Several municipalities only have support during the day (08-16), while some also have support around the clock. In addition, several IT departments have recently merged the IT service in their municipality to regional networks and have become large organizational units. Thus, the technological solution of digital monitoring must be integrated into the local or regional infrastructure, and thus become part of a complex infrastructure arrangement. A quote from an IT consultant in municipalities illustrate this complexity:

“We have made a strategic decision to use a Windows-based platform (...) We have not allocated resources to maintain multiple platforms. Then when someone comes with a Linux Platform (which by the way is brilliant in itself) there will be a process that goes far beyond the project and beyond welfare technology as such, because we need to build up expertise on it”

Thus, the project required resources and expertise from the IT department as well as a common understanding of the complexity of the system. Although it has been a challenge, it has also been a useful experience as stated by an employee at the IT department:

“(…) But I have to say that the project has been very helpful to us, in terms of expertise, and if we had not made it, we would not have the understanding we have today in relation to infrastructure (…) the importance of involving IT (…) to see things in context, integrations and so on. I feel there has been a boost in competence for us, so it has been very useful”

A project manager in the municipality also suggested a slightly more pragmatic approach to the problem:

“(…) there is too much focus on not being able to rely on the systems rather than to make a plan for what you actually do when it (the system) goes down”

Some of these statements illustrate the ongoing negotiations on security and accountability in relation to the service. Healthcare workers are accountable for the outcome of the service and thus an important link between the different actors. However, the management have the responsibility for technological and organizational resources involved in the various tasks that affect the outcome of the services. Participation in the project created an increased awareness of the complexity of the new service as stated by a vendor; “it is both the technological and organizational - it is complex”. In addition, it formed the basis for a shared learning space that enabled the preparation of procedures to ensure the safety and quality of the service.

## Discussion and conclusion

This study has identified some challenges and “uncertain normative claims” related to the use of digital monitoring in municipal healthcare services. First and foremost, this study has illustrated the importance of balancing different moral values in the introduction of digital technologies in municipal healthcare settings. Stakeholders involved in the project had different expectations for the use of the digital service and illustrated a dilemma between the professional duty of nurses to promote quality care and the strategic goal of cost savings. This type of dilemma led to some reluctance to use the digital technology among health workers at the beginning of the project. However, practical use of the system in daily practice also showed that the technology enabled better care for the residents. Several studies have pointed out that the use of technology can direct attention to instrumental values (Hofmann, 2012) and may lead to a conflict between professional values and the business values of efficiency (Greenhalgh et al., 2012). A rational approach to the use of technology can be explained in terms of consequentialism that considers an action in terms of the consequences that it has (Mingers & Walsham, 2010). However, nurses have a duty to promote quality care (ICN) that focuses on the action itself (deontology) (Mingers & Walsham,

2010). Thus, the use of digital technology must be considered in relation to practice and Burton-Jones et al (2017) have conceptualized effective use of information systems as the effective actualization of affordances arising from the relation between the system and its user (p. 470). The findings from our case study illustrated various affordances (potentials for action) such as the ability to provide more individualized care and act at the right time when residents needed professional assistance. However, the use of digital technology did not lead to less use of human resources in this context, but it was used more effectively to provide responsible nursing to the residents. Furthermore, professional values such as respect, responsiveness, compassion, reliability, and integrity (International Council of Nurses, 2012) refer to character traits that nurses must demonstrate in order to make moral decisions. The ethical theory of virtue focuses on how people develop behaviors that lead to well-being for the individual and society. According to this approach to ethics, *phronesis* (practical wisdom, judgement) is emphasized as an overriding virtue that is developed in practice as part of a community (Mingers & Walsham, 2010). Practical wisdom can thus be included in ethical assessment as an ability to balance different and potential conflicting values. For example, balancing the need for privacy with the need for security to promote ethical decisions in practice.

The findings from this study also revealed ethical issues by integrating the new service into the infrastructure arrangement in the municipalities. The challenges illustrated in the case study were not just technical issues, but involved coordination of responsibilities, establishment of routines and negotiations to come to a shared agreement. Participants in our case belong to different professional communities with different interests, values, and knowledge. Several studies have illustrated the challenges and trade-offs when people with different competences enter the health care arena (Greenhalgh et al., 2012; Hofmann, 2012; Mort et al., 2015). The negotiations on socio-technological issues were more complex than anticipated and influences redistribution of task and responsibilities and implies new meaning for privacy, confidentiality, and safety (Mort et al., 2015). This illustrates the complexity of integrating new technologies into existing systems and implies that practice cannot be changed instantly, but co-evolves slowly over time (Hanseth & Lundberg, 2001). The ethical issues related to responsibility and accountability need to be translated into practical activities and made comprehensible to participant involved in the project (Mittelstadt et al., 2015).

Some of the ethical implications that have been identified in this study have been discussed during workshops to gain a mutual understanding of the use of technology in this context. This has led to the development of procedures and adjustments of the technological solution to increase safety when using the system. Thus, all participants in the project have participated in practical

discourses and show the importance of including ethical reflections as part of the design and development of welfare technologies.

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# Support for Informal Caregivers: Use of Infrastructures

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**Abstract.** Informal health caring became a substantial part of our society. In Europe, official health care institutions cannot really cover the required care activities without the involvement of family members in caring activities. This role was taken by informal caregivers for a long time already. This paper tries to bring up this crucial setting into attention of health care community by identifying caregivers' needs and requirements, mapping infrastructural elements to caregivers' needs to achieve a satisfactory product, technology and service provision in this area, by suggesting an interconnected health care infrastructure as a possible solution. This analysis ends up in a more complex interconnected care infrastructure consisting of people and technology components, in the tradition of research on socio technology.

## Introduction

Around 80% of all the care provided in European Union is carried out by family caregivers (Coon & Evans, 2009). Literature shows enough evidence that informal caregivers often express the need for help, not only in terms of financial assistance, as often proposed by social institutions, but also with respect to social and emotional support (Brownsell et al., 2012; Magnusson et al., 2004; Nies, 2004). Since a decade there have been a large number of European AAL (Ambient Assisted Living) research projects to obtain information and comfort for informal caregivers. Unfortunately, the results of these projects, like products, prototypes but also insights gained through the analysis of studies or user

evaluations, are still not enough disseminated. In our recent study<sup>1</sup> on the relevance and actual use of such results, we identified several products and services on the aspect of *staying healthy* (Hensely-Schinkinger et al., in preparation). In most cases, *sensor technologies* were used to capture data from homes of caregivers mainly to monitor the activities of care receivers or their situation in order to help them accordingly in case of need. Some other projects were addressing the *use of social network* to reach out and then connect the care receivers and in this course also partly the caregivers. The main target group of these projects are care receivers, so there is still room for research when it comes to offer support to informal caregivers (Levine et al., 2010).

In this paper we try to present systematically the needs and requirements of informal caregivers and to map them to infrastructural elements, based on our previous research (AAL project TOPIC<sup>2</sup>). Acknowledging the need for further investigation and technological development in this area, TOPIC, a European project by the AAL Joint Programme, aimed to advance the *understanding of informal caregivers' needs and design* information and communication technology (ICT) solutions to support them in their daily environments (Breskovic et al., 2013; Pinatti De Carvalho et al., 2013, 2014, 2016; Tellioglu et al., 2014, 2015, 2016, 2017; Hensely-Schinkinger et al., 2015, 2018; Hensely-Schinkinger & Tellioglu, 2017). The project addressed and solved the lack of an integrated social support platform and the lack of accessible ICT applications for elderly. The project congregated 10 partners located in Austria, Germany and France.

This paper introduces briefly the situation of informal caregivers before showing relevant elements of care infrastructures which are considered to be useful to support this target group. Afterwards needs and requirements of informal caregivers are described. It concludes with a suggestion how to map infrastructural elements to caregivers' needs to achieve caregivers' satisfaction in respect to products, technologies and services provided to them. We claim that an *interconnected health care infrastructure* based on the socio-technical approach can offer a possible solution to this not yet solved problem.

## Informal caregivers

Informal caregivers are diverse in many senses, in age, gender, relation to the care receiver, location of living, additional support provided by others, etc. The sociodemographic data in Europe (Birtha & Holm, 2017; Nagl-Cupal et al., 2018; Hoffmann & Rodrigues, 2010) shows that the age range of informal caregivers spans from 35 to 65. 35% of informal caregivers are children, 28% are parents,

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<sup>1</sup> [https://cts.wien/projects/aal\\_best\\_practice/](https://cts.wien/projects/aal_best_practice/)

<sup>2</sup> <http://www.aal-europe.eu/projects/topic/>

11% are spouses. Another fact is that 85% of informal caregivers are female. Higher the age of informal caregiver, the percentage of male informal caregivers increases. 72% of informal caregivers share their home with their care receiver. 62% of informal caregivers who live in another house are only in 15 min distance to their care receiver. 31% of informal caregivers are not supported in their health caring activities, without any support of their relatives or friends.

Health caring tasks defer based on the duration and type of the activities (Stokes, 2009). In Europe, around 30% of informal caregivers find their caring activities very intensive, with around 56 hours per week or more. More than 50% spend less than 10 caring hours per week. In Austria, there are 48% of informal caregivers who are in charge of health caring around the clock (Nagl-Cupal et al., 2018).

Being an informal caregiver is a temporary endeavor and while being the main proxy of the care receiver, the intensity of the care work depends on the health condition of the care receiver. The daily routine is mainly determined by the care receiver, all arrangements of caring (“need help and attention” or in case of professional help “late again”) and of course also by spontaneous interruptions which might occur unexpectedly. Informal caregivers do not have any time to do something else than caring, they are socially excluded, so they cannot meet friends or spend time with others. This burdensome period gets worse when informal caregivers still have a job, are old or have a health condition.

## Elements of care infrastructures

An “infrastructure is something that emerges for people in practice, connected to activities and structures” (Star & Ruhleder, 1996, p.114). It can be configured by adjusting different dimensions of it, like its embeddedness, transparency, reach or scope, links with conventions of practice, by considering the characteristics of the target group and their real environment. Seen from a health caring perspective, infrastructures become very central for informal caregivers. A combination of people and technologies can be the right infrastructural solution to help informal caregivers overcome the challenges they have.

Using the socio-technical approach (Mumford, 2001), we can say that *informal caregivers* are crucial actors addressing the social part of care infrastructures. Informal caregivers act and use several infrastructural elements to fulfill their goal of health caring. People around informal caregivers are usually their *relatives*, other *family members*, or their friends and neighbors. These people might have the most exchange with informal caregivers by visiting them or talking to them regularly, but they might be also locationally and relation-wise far away. Some of the relatives, especially the ones who are living in another city or having their own families and work, are usually in rare contact, only in particular cases, like taking care of legal issues, medical treatments, other organizational or financial activities. Some of them act only if they are asked for.

The most of the informal caregivers we were in contact with called at least one *friend* or *neighbor* who was on their side if they were in need of help. The case studies show that the geographic proximity of the people to the informal caregivers is a defining factor how much and how often their attention can be taken for aid. Sometimes it is only spending time with them by having a coffee or tea, sometimes just asking how they feel or whether they need help, but sometimes it is more than that, by taking even more responsibility of care processes to be carried out.

Certain care-related issues cannot be solved or answered by lay people. *Professionals* with different backgrounds are indispensable to help bear the burden of caring at home. Care professionals do not only provide their tangible services by coming home and providing health, physical therapy, housekeeping, cooking etc. services, but they are also available for ad-hoc questions or in unplanned occurrences. Furthermore, professionals are sometimes the only social contact that informal caregivers have from the outside world. So, it is important that professionals build a team with the informal caregivers and cooperate in respect to care activities that informal caregivers have to continue carrying out when professionals are gone and they are alone with the care receiver.

Besides single persons as professionals, some *organizations* are specialized in products and services for AAL and health care. Their offer is usually a trustful asset for informal caregivers, especially if these organizations are selected and recommended by professionals.

As all human beings, informal caregivers need a *social environment* in which they can exchange with others, usually with similar experiences. But also, they can get information about things directly from a care community they are interested in or want to be part of. The exchange with the peers does not need to be active always, some of the informal caregivers are good readers and commenters but not active posters.

Seen from *technology* perspective, two categories can be identified in the context of caring by informal caregivers: providing information and communication channels. *Information* provision can contain several data originated by professionals or the peers, by varying from being very specific to very general. This range can include medical, care or legal information, current services for particular care situations or changes in the society and official regulations. The information channel is normally one way, from several sources to the informal caregivers. But a search, filtering or configuration functionality of a platform can make the offers selectable and configurable and, this way, personalizable and interactive for consumers like informal caregivers.

On the other hand, the *communication channels* supported by the care infrastructures can be utilized in a larger flexibility in use, content and circle of people to reach out. Audio, video or textual communication have their strengths in specific situations and scenarios, and exactly there they should be applied. For

instance, combined with more innovative ways of stressing out oneself like storytelling or (video or audio) commenting, many to many communications can be a good countermeasure to fight against social isolation.

## Needs of informal caregivers

Based on the related and own research work in the area of AAL (mainly studied by applying qualitative methods), we summarize the needs of informal caregivers as knowhow, tangible, social and psychological support, which will be described briefly in the following subsections.

### Knowhow support

Health caring requires a certain degree of knowledge for day-to-day care arrangements in and outside the home, knowhow about care processes to ensure affordable care activities, especially by considering any possible health condition of the informal caregiver while providing domestic health care, including instructions of care or medical information covering diagnosis or treatment of the care receiver, etc. Informal caregivers need well-established trustful sources of information with an easy access that should offer a fast and useful reply even to an ad-hoc request.

### Tangible support

Due to the health condition, emotional or physical restrictions, not everything can be done by informal caregivers while caring at home. Tangible goods and services provided can be a supporting help to avoid a certain work load which informal caregivers have to carry. Some examples are: shopping support; household support like cleaning, cooking, taking care of the care receiver, e.g., bathing, medical health support like organization and arrangement of doctor's appointments, buying medicine at the pharmacies; food delivery; support for activities at official institutions like banks, state authorities; services to hand over caring for a while for having a break temporarily, spanning from couple of hours during a day to a longer period of time due to a rehabilitation or treatment process. Flexibility of the service providers is here the main success factor: the service should be provided both on a regular base and on demand.

Additionally, a marketplace on a customer-to-customer exchange could be very useful to inquire necessary equipment or furniture for caring and vice versa to offer things which are not needed any more for the specific health caring situation at home, like walker rollator or other type of exercising tools, often due to the change of the health condition of the care receiver. Secure, trustworthy and

easy to use platforms with a sustainable maintenance are most suitable infrastructures for such a tangible support.

## Social support

After having a hard change of the life situation, by becoming a caregiver and putting everything else behind this responsibility, social isolation and loneliness are the most common problems informal caregivers face. A well-accepted support to address these challenges is ideally characterized by offering services that are friendly, community-based, on- and off topic about health caring subjects, enabling active and passive participation or anonymized access.

There are several ways of providing a useful social support to informal caregivers: For a 24-7 ad-hoc support, a hotline could be established to reach out to professionals and their competent network to help informal caregivers in urgent situations. Health care related activities or other types of events, like gatherings to interesting subjects related, e.g., to active aging, health, culture, entertainment, making like cooking, hand crafted activities, etc., can be arranged and moderated by associations or by caregivers themselves within their peer community. Caregivers could be encouraged to initiate activities they think of.

Storytelling is one of the very useful approaches to express oneself. An easy-to-use interface of a care infrastructure can facilitate creating a common space in which caregivers find interesting stories of others, who they can connect to easily, and furthermore, they share their stories in a natural way by just telling and recording it in audio and video format and making it accessible to their peers. Commenting directly in the story could nudge the interaction between peers and through this help reduce or avoid loneliness of single individuals in a relatively natural way.

Due to their care situation, being positive can be sometimes very difficult for informal caregivers. Positive computing can be a helpful approach to address positivity in the designed platforms (Calvo & Peters, 2015). Photos, videos but also text of others expressing a pleasant or happy situation could be a positive impact to the mood and distract caregivers even from their rather depressed daily routines. In our studies in TOPIC, caregivers mentioned several times that they would like to have a (virtual) space in which they are not confronted with any care-related subject. They want to have a “care-off” time, individually but also together with others, and this on a regular base. They see this as a factor that helps normalize their burdensome life a little bit.

On the other hand, the already well-experienced support groups can be established also in virtual environments, by mimicking the elements of real settings to seem familiar to the caregivers. Furthermore, these support groups can be extended by a body system to offer an individual exchange with a trustworthy peer, no matter face-to-face or digitally.

## Psychological support

The hard and troublesome life of informal caregivers might end up with psychological breakdown or depression and hopelessness. In such and other cases informal caregivers need counseling and supervision on a regular base (through arranged appointments) or irregularly (via a hotline). In this type of support, confidentiality, one-to-one interaction, timeliness of the support are crucial requirements. Psychological support can be provided directly by according professionals depending on the mental condition of the informal caregiver. The communication and therapy if needed must be dealt confidentially, with a secure exchange with professionals, especially when it is digital. A hotline for ad-hoc emergency needs can complement this support and brings a more human approach to it.

## From needs to possible solutions

Table 1 summarizes the needs of informal caregivers described above by addressing some specific design-related requirements and by suggesting possible solutions and offers that are design inspirations for future work.

Table 1. Support needed for informal caregivers, requirements identified and suggested ideas for possible solutions

Needed support	Requirements	Ideas for solutions
Knowhow support	Usable, accessible, configurable, personalizable, simple language	<ul style="list-style-type: none"> <li>• Platform with small learning modules</li> <li>• Multimodal information provision, also combinations of audio, video and text</li> <li>• Up-to-date information dashboards with links to relevant institutions and sources</li> <li>• Not only pull access, but also a configurable push access to relevant and subscribed data</li> <li>• Possibility to pause and resume the consumption of the data available</li> <li>• Use of favorites, bookmarks for actions and instructions</li> </ul>
Tangible support	Regularly or on demand, flexible in delivery, secure, trustworthy, configurable, quality assured, well-selected and -adapted for caring	<ul style="list-style-type: none"> <li>• Bidirectional marketplace with relevant products and services</li> <li>• Configurable accounts for individual selection and subscription</li> <li>• Ad-hoc anonymized access to ongoing activities and events</li> <li>• A single point of access to rated and curated products and services</li> <li>• A single point of access to a comparison</li> </ul>

		of products and services
Social support	Friendly, community-based, on- and off topic about health caring subjects, enabling active and passive participation or anonymized access	<ul style="list-style-type: none"> <li>• 24-7 ad-hoc hotline support</li> <li>• Continuous offer on HC related activities, including arrangement and moderation</li> <li>• Continuous offer on off-HC-subjects related activities, including arrangement and moderation or only facilitation</li> <li>• Space for interactivity and support in initiating of organization of gatherings by caregivers</li> <li>• Virtual support groups</li> <li>• Body systems</li> <li>• Platforms for easy storytelling and multimedia commenting of others' stories</li> <li>• Platforms for sharing multimedia data (social network of caregivers)</li> <li>• Platforms implemented by applying positive computing<sup>3</sup></li> </ul>
Psychological support	Reliable professional help, regularly or on demand, confidential, one-to-one interaction	<ul style="list-style-type: none"> <li>• Hotline support for ad-hoc emergent help</li> <li>• Appointment based communication with professionals</li> <li>• Counseling and supervision</li> </ul>

Table 2 tries to map needs to infrastructural elements to build a coherent relation between the elements of care infrastructures and requirements of informal caregivers.

Table 2. Mapping the support needed by informal caregivers to infrastructural elements

Informal Caregiver		NEEDED SUPPORT			
		Knowhow	Tangible	Social	Psychological
INFRASTRUCTURAL ELEMENTS	ICT–Information	X	X		
	ICT–Communication	X	X	X	X
	Friends & Family Members		X	X	X
	Individual Professionals	X		X	X
	Professional Organizations	X	X		
	Peers	X	X	X	

Social and psychological challenges are dealt with by involving the right people through the most suitable communication channels. The right part of the Table 2

<sup>3</sup> <http://www.positivecomputing.org>



is rather actor oriented and individual. Knowledge and tangible support for informal caregivers are more general. They can be offered to a larger group of caregivers the same way. Organizations connected and information provided solely through ICT are possible on this general part. The access to the support on the left side of the table can be arranged by configuration, selection, filtering or bookmarking, while on the right side one-to-one or one-to-many connections can be initiated by the informal caregivers for which they can use selection and configuration possibilities of an infrastructure.

Following the thought of a care infrastructure, a further step can be taken to connect different infrastructural elements to a unified infrastructural system, what we would call *interconnected health care infrastructures*. Besides consisting of involved actors, these infrastructures, which also host non-human elements, are interconnected via interfaces based on standards and regulations, support coordination of care to improve self-management of care, support awareness among home inhabitants, intimate socials, extended socials, are usable and adaptable, open and secure with flexible access control. Further work is needed to detail such interconnected care infrastructures, preferably by using scenarios and use cases created around informal caregivers.

## Conclusions

In this paper, we identified needs and requirements of informal caregivers. The lessons learned presented are based on the related and own research work in the area of AAL. The main elements of a care infrastructure are systematically identified and put into relation with informal caregivers needs and requirements. This ended up in a more complex interconnected care infrastructure consisting of people and technology components, in the tradition of socio-technical approaches.

Additionally, ideas for possible solutions are presented by specifying concrete requirements of informal caregivers to address a possible solution space and possible implications for an infrastructural development in this direction. These should be seen as inspirations and initial ideas based on evidence-based case studies carried out so far in the area of informal health caring.

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# User mobilization in bottom-up infrastructural transformation

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**Abstract.** User mobilization plays a critical role in bottom-up processes of infrastructural transformation. In this study, we take a user perspective to how infrastructures transform, and investigate the work required to mobilize users. Our research is based on a case study of a project developing a novel solution for supporting data sharing in patient handovers in the context of primary care in the municipality of Oslo. We focus on the work of user representatives in the project activities, and specifically in their effort to engage their local organizations. In the analysis we identify three types of work for user mobilization: the work to identify benefits, anchor in the local leadership, and give a sense of ownership. We contribute to the literature on bottom-up user-driven change processes by showing the work required for user mobilization and conclude with implications for supporting users' learning.

## Introduction

This paper reports from an empirical study on the work to transform the socio-technical information infrastructure for patient handover in primary care in Oslo, Norway. Specifically, we investigate the activities to design and develop an application for patient handover that is expected to scale to serve all patients in the Oslo municipality. We focus on the work of user representatives (health workers) in these activities. While other ongoing IT implementations in Norwegian healthcare have taken a suite-system approach with large upfront investments and proprietary off-the-shelf software products, (e.g. the implementation of Epic in the middle health region (Ellingsen and Hertzum,

2019)), this project follows a bottom up approach, with limited upfront investment, iterative user-driven design and gradual scaling. This approach leaves more space to user participation. However, while user participation is recognized as a critical resource in transforming healthcare infrastructures, it remains understated and under researched (Garmann-Johnsen et al., 2020). User participation is not only the work to configure systems to local needs that is restricted to a design space defined by vendors (Ellingsen & Hertzum, 2019). It is also the work to engage users in a design process to transform organizations and data practices and procedures, while also contributing to technology design.

Recent studies argue for bottom-up processes of infrastructure development and emphasize strategies of ‘cultivation’, ‘growing’ and ‘coping with’ the existing infrastructure, conceptualized as installed base (Hanseth and Bygstad, 2017; Klein and Schellhammer, 2017; Modol, 2017; Mozaffar et al., 2017; Vassilakopoulou and Marmaras, 2017). In these approaches, user mobilization plays a critical role (Grisot et al., 2014). However, most research investigating strategies for infrastructure development and scaling take an organizational perspective (Vassilakopoulou et al., 2017) rather than foregrounding the work of individuals, such as user representatives, to mobilize users. As Hertzum and Simonsen point out the competences needed by health workers, such as to *prepare and make change*, are “thinly spread” (Hertzum & Simonsen 2019). In addition, Parmiggiani and Grisot show how when users engage in data practices, their involvement is emergent rather than only organized (Parmiggiani & Grisot, 2020). Thus, understanding the *work* of mobilizing users in bottom-up change processes is important in order to develop insights on how individuals can be supported in terms of competences and learning.

In this study, we address the following research question: *what is the work to mobilize users in user-driven health information infrastructure transformation?* By framing the research as transformation of an infrastructure rather than a system, we want to emphasize the open ended nature of the design-process of transforming an infrastructure, and also that the pre-existing socio-technical constellations play a critical role in shaping the transformation process (Aanestad et al., 2017)

To address this research question, we have conducted a longitudinal case study based on qualitative data. Our analysis focuses on the work of the user representatives in mobilizing users in their local organizations, and specifically on the work to identify benefits, anchor in the local leadership, and give a sense of ownership. Our findings contribute to foregrounding the many types of work required by users to transform a health infrastructure. We contribute to the literature on bottom-up user-driven change processes within the infrastructure literature by showing the work required for user mobilization and conclude with implications for supporting learning and with future research directions.

The paper is structured as follows. In the next section we describe the research design, data collection and our approach to data analysis. We then provide a description of the case. Then, we present our findings organized in three subsections about the different types of work: identifying benefits, anchoring in the local leadership, and giving a sense of ownership. Finally, we discuss our findings and contribution, and research implications.

## Method

The research presented in this paper is based on a longitudinal case study of the digital patient-handover project. The research is longitudinal as the authors have conducted intensive fieldwork in the project since February 2020 (fieldwork activities are still ongoing at the time of writing, May 2021). We have relied on four main sources of data in our research: observations, reflective sessions, interviews, and documents (see table 1). As we started fieldwork at the start of the pandemic in Norway, our data collection has been mainly digital (in Teams) except for few interviews and observation of work practices. Observations have been our primary source of data. We attended 2-3 project meetings per week where we have been able to conduct rich observations of the project team’s discussions about technology design, implementation plans, coordination of work. These meetings have been video recorded and the audio selectively transcribed for further analysis. Second, from October 2020 we have conducted two weekly reflective sessions with the project leader and with a user representative. These sessions were inspired by the reflection on action approach (Schön 1983) and dedicated to making our informants reflect on the activities of the past week, the status of the project as well as future plans. Third, we conducted semi-structured interviews with user representatives from the city districts about how they engaged their local organization, and we have conducted interviews with the head of the municipal Health Agency’s department for IT development to understand the larger context of the project. Fourth, we had access to the project documents, and we have analyzed policy documents about the digitalization of healthcare in Norway and in the municipality of Oslo.

<b>Method</b>	<b>Activity</b>	<b>Themes</b>
Observation	Observation (51) of meeting scenarios and stakeholder constellations. Two contextual observations (2) of healthworkers practices.	Information sharing and cooperation regarding technology design and service development; strategizing, sharing information, organizational development, etc. Insight into service practices “before” digitalization.
Reflective sessions	Weekly sessions with the project manager and one user representative. (From september 2020 – May 2021)	Reflections on the ongoing progression of the project, challenges, interdependencies, networking.

Interviews	Interviews with project manager (2), user representatives (2), and head of development (2).	Experiences about the local organizations, motivating and engaging users in project activities.
Documentation	Access to the project portfolio. Policy document.	Technical design, presentations, work descriptions, working documentation, etc.

*Table 1: Data collection*

To analyze our data, we followed three steps and an interpretive approach (Walsham, 1995). First, after each data collection session we discussed among us the highlight of the session. Second, we utilized Nvivo to systematically code our data by theme guided by core concepts from infrastructure theory (Braun and Clarke, 2006). Lastly, we have utilized a technique of ‘writing through codes’, inspired by (Crang and Cook, 2007), in which we articulate the themes by writing them out until they “work as arguments: individually and as a whole.” (p. 158).

## Case

We have conducted research on the design activities of the project team developing an IT application for patient handover and for making patient data available to healthcare workers across organizations as patients move along their care journey. The context of the study is primary care in the municipality of Oslo, where currently patient data is fragmented and stored in various Electronic Patient Record (EPR) systems and health registries. Information sharing practices across health organizations are based on electronic messages, phone calls and paper-based documents. In this study, we focus on the work of the core team which includes representatives from four city districts, two municipal agencies and a rehabilitation centre.

The patient handover process is a critical part of the care process. In their care trajectory patients move across care services with different locations, forms of care, and information and communication practices. As patients move, it is critical that their patient data and information are made available to healthcare professionals. The overall initial aim of the project is stated as “taking back control over data” and articulated in three parts: to develop an information hub with access to necessary information across organizations, to support reuse of data using structured data and standardized information models, and to create an interface with an overview of patients. The project started in 2019, ran a small pilot test, and was set up with a core team of developers, user representatives and a project leader. The project can be described as having a low budget and a bottom-up approach to stakeholders’ engagement. The stakeholders’ engagement into project sessions has varied over time depending on user representatives’ and project leaders’ efforts to motivate participation in the design process (Dæhlen &

Grisot, 2021) which has been especially challenging during the pandemic. Since the Covid-outbreak in March 2020 until September 2020 the project did not have dedicated developers, and have since September 2020 until May 2021 had one developer. The project has a core team, a steering group, and a reference group. In this paper we focus on the activities of the core team.

The core team conducts weekly meetings on technology design, and implementation planning. Overall, the team works with identifying requirements, designing functionality of applications, and creating novel procedures for data practices. Various experts are also collaborating with the team, for instance pharmacists, coordinators of the municipal EPR system, jurists, and participants from other ongoing relevant projects.

## Findings

In this paper, we describe and analyze the work of user representatives. They are professional health workers, often with experience in technology-related change management in their local organization. We focus on the work to engage their local organizations, and we identify three types of work: identifying benefits, anchoring in the local leadership, and giving a sense of ownership.

### User mobilization by identifying benefits

Since early 2020, one of the main topics in the design meetings has been to understand the benefits the novel solution would bring to the health workers. This was explored after newly appointed user representatives expressed some frustration. They expressed concerns about how to convince their local organization to join the project. They said: “we are going to get questions on what the benefits are, what is it that [the existing EPR] doesn’t already give, like, what are the differences?”. Thus, the core team worked on specifying concrete benefits that would make sense to health workers. For instance, they discussed how the data in the novel solution would enable richer and more structured information than previously in the transfer of patient across services. However, understanding the benefits, conveying them to users, motivating and enabling participation has been challenging. For instance, the novel solution would initially overlap in functionality with existing systems and a transition period from the existing practices to novel ones was envisioned. This would make the benefits less visible in the initial stages of implementation. One representative said: “it is a hard sell because right now we can’t just swap one system for the other, we have to do [register] in both for a period”. The identification of benefits was also instrumental in anchoring the project with the local leadership.



## User mobilization by anchoring in the local leadership

User representatives also worked to mobilize users by anchoring in the local leadership. This was a critical work as in the local organizations user representative faced the challenge of not having enough resources formally dedicated to the project. A user representative explained how they tried to set a local change process and did not succeed because of lack of formal mandates:

“it became completely unruly for the service and for themselves [health workers]. [...] So after having tested it out we just had to say: ‘that did not work, what now?’ [...] it became evident that if this is not embodied [nedfelt], read out loud and anchored all the way to the top and economically, so we can free up workers responsibilities—unless we can actually set aside money, it won’t become anything”

This became evident in June 2020 during the weekly design meetings, it was decided to free up (buy out) health workers in order to engage them in the project work. Another example is from the start of 2021, when a user representative talked about her experience of trying to free up two local health worker team-representatives to work on defining novel data practices:

“I hope that they can have a clean mandate every Thursday so they can work together. I think this is a critical criterion for success, so they can collaborate, which teams should start, how to we engage them, what functionalities do we start with. [...] that is, mandate to work 20 percent for [team representative 1] and [team representative 2]”

Afterwards, the user representative said that the process of freeing up health workers time “is a never-ending battle.” The representative expressed worry that the local administration still did not understand the scope of what was required, and that there was a general lack of knowledge of what such project entailed.

This was a general challenge for the representatives who themselves struggled to manage their own time and several roles and responsibilities within their local organizations. One representative said that his organization decided impromptu who would become user representative arguing “who can assign around with this here?”. The user representative later expressed that they felt inadequate in this role. Another representative described herself as a “multi-artist”, meaning that they had worked there for a long time, and experienced that the organization “pulls you in [to different projects] all the time”. Only one of the user representatives had been able to establish herself as working only with the project. Her local organization is the first implementing the application.

## User mobilization by giving a sense of ownership

Another challenge faced by the user representatives was about conveying the socio-technical complexity of the project to local participants. For instance, following a presentation about the novel functionality with fictional, neatly constructed data, a local section leader was positive. She proposed to roll out the novel solution to the entire organization of 271 employees by hiring extra health workers for a couple of weeks. This was in contrast with the user representative

concerns about how challenging it would be to start defining novel data procedures in a single team of health workers. The user representative said:

“the next step now is to reality-orient. But, I am more happy with having to lower expectations than having to all the time trying to keep it up. Which is a comfort. [...] What worries me is this quick-fix line-of-thinking, that the system will fix all the [health-]professional challenges of the organization. [...] we can’t just give people a new digital tool, they need to understand what lies behind”.

She then pointed out that some of this work would be to give a sense of ownerships to health workers:

“they need the time to become an ambassador, and find out why we have made the choices and why we are here, get a sense of ownership to the project. [...] because they [team representatives] are meeting the next node in the network, and again it takes them time to become good ambassadors”.

Later in the year the two team representatives attended the city districts weekly ‘news show’—set up by the head-of-district—to present the project for all employees. In a later weekly reflective sessions, the user representative explained that one of the team representatives wanted full responsibility of tutoring the use of the application to the caseworkers (health workers who currently are responsible for ensuring patient transfer across organizations). The user representative said, “[team representative 1] asked me to tie my hands behind my back, which is a good sign. She is leading the entire teaching session”. In the following months leading up to the official start of implementation in the two teams, the user representative of that district expressed a surprise towards the section leaders ‘forward leaning’ attitude towards the uncertainties that the change process necessitated.

## Discussion

In this study, we asked, *what is the work to mobilize users in user-driven health information infrastructure transformation?* We have approached this question by foregrounding the work of user representatives—professional health workers with a background in local, often technology related, change processes. We have presented their work to mobilize their local organization in order to engage local health workers, and analytically identified three types of work: identifying benefits, anchoring in the local leadership, and giving a sense of ownership.

User mobilization is a core issue in the literature on bottom-up information infrastructure evolution. In their seminal work, Hanseth and Lyytinen (2010) argue that to bootstrap a change process is important to motivate users so that they have “real motivation to use the IT capabilities.” Grisot et al (2014) also show that making a solution attractive for users triggers a self-reinforcing adoption dynamic. We expand on this stream of work by taking a user perspective into bottom-up infrastructure evolution and showing the work it takes to mobilize users. As our findings show, user mobilization requires different types of work, and the

individuals engaged in mobilizing users must face several challenges and tradeoffs. User mobilization is not simply the activity to enroll and motivate users, it also requires learning to work to mobilize users. Our findings show that three core aspects are critical. First, user representatives need to learn to navigate the organization. As our data shows, user representatives had to engage not only health workers, but also leaders at different levels and in different roles in the organization. Second, user representatives need to learn to enact persuasive tactics to engage their local organization. For instance, in our case this required user representatives to see themselves as ‘ambassadors’ of the new technology into their own organization, a new role they needed to learn how to perform. Third, user representatives need to learn which competences are required to act as ‘user representative’. This is however a very explorative and emerging role, and not well defined a priori. Our data show how this is not a role that can be assigned only based on availability, but a careful consideration of individual expertise is required.

When developing infrastructures, user mobilization is also distributed across different local contexts. Information infrastructures are sociotechnical arrangements that cross organizational boundaries and support open and heterogeneous user groups. This infrastructural dimension adds complexity to the task of mobilizing users. As our findings show, user representatives work to engage their local organization, but a strategy that works in one context does not necessarily work in another. Our findings therefore also show the importance of attending to users and involving users from different local contexts.

In conclusion, we have presented a study on user participation in infrastructure transformation and foregrounded the work of user representatives when engaging their local organizations. We think that our findings and contribution have two main implications. First, we show that user mobilization is a complex task that requires support from the local organization in addition to attention to the ongoing learning processes implicated in engaging users. Second, further research is needed to improve our understanding of the many, multifaceted roles implicated in acting as user representative in bottom-up user-driven processes.

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# Accountability, Transparency and Explainability in AI for Healthcare

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**Abstract.** The multiplicity of actors and the opacity of technologies involved in data management, algorithm crafting and systems' development for the deployment of Artificial Intelligence (AI) in healthcare create governance challenges. This study analyzes extant AI governance research in the context of healthcare focusing on accountability, transparency and explainability. We find that a significant part of this body of research lacks conceptual clarity and that the relationship between accountability, transparency and explainability is not fully explored. We also find that papers written back in the 1980s, identify and discuss many of the issues that are currently discussed. Up to today, most published research is only conceptual and brings contributions in the form of frameworks and guidelines that need to be further investigated empirically.

## Introduction

The increased availability of health data creates new knowledge-creation opportunities that can transform clinical practice. The rapid explosion in Artificial Intelligence (AI) allows leveraging health data for the development of powerful models that can automate diagnoses, enable a precision approach to medicine by tailoring treatments and increase the efficiency and effectiveness in the use of resources (Panch, Mattie, & Celi, 2019). A growing number of information systems supporting healthcare embed AI technologies. AI refers to machines performing the cognitive functions typically associated with humans, including perceiving, reasoning and learning (McCarthy, Minsky, Rochester, & Shannon, 2006; Rai, Constantinides, & Sarker, 2019). These technologies are used in

diverse healthcare application areas including processing medical imaging, supporting triage assessments, expediting disease diagnoses, automating patient monitoring and supporting biopharmaceutical development. As AI is infusing nearly every aspect of healthcare delivery, the governance of AI-enabled systems emerges as a growing concern.

A significant challenge in AI governance is the “black box” problem. This is the problem of putting in place an opaque process of transforming data inputs to insight outputs (e.g. related to diagnoses, or outcomes predictions). AI solutions that use machine learning are particularly susceptible to the black box problem. This opaqueness can pose limits on involving humans in operating and monitoring AI-enabled healthcare information systems. Transparency and explainability are directly related to addressing the black-box problem.

Furthermore, the multiplicity of actors and technologies involved in a) the registration, storage and management of the data required for the AI algorithms, b) the development, validation and maintenance of the algorithms and c) the development, deployment and handling of the applications that embed AI algorithms creates accountability challenges. The academic community can contribute sociotechnical approaches for accountability in AI systems (Vassilakopoulou, 2020). Ensuring accountability for decisions and actions within these complex infrastructural arrangements is key for introducing AI technologies in clinical practice (Habli, Lawton, & Porter, 2020).

The seminal work by Bovens and colleagues on accountability and governance (Bovens, 2007, 2010; Bovens, Schillemans, & Goodin, 2014) provides a comprehensive accountability definition that includes three complementary aspects: the obligation of actors to answer for and justify their actions, the interrogation ability of those affected and sanctions when systems work in unacceptable ways. This comprehensive definition indicates some interdependency between accountability and addressing the “black box” problem. One of the key aspects of accountability is the interrogation ability of those affected by systems and black-boxing may impair the ability to interrogate.

There is a strong interest on AI for healthcare in both academia and practice resulting to a growing volume of related research. We developed a synthesis of the extant body of research, by performing a structured literature review following the process proposed by Kitchenham (2004). The review was guided by the following research questions:

- RQ1: What are the key insights provided by extant research on AI accountability in healthcare?
- RQ2: How is accountability defined in extant research on AI accountability in healthcare?
- RQ3: How are the relations between accountability, explainability, transparency understood and conceptualized?

The remainder of the paper is organized as follows. First, we present the method used, then, we present our findings, finally, we conclude by discussing the implications for further research and end with overall concluding remarks.

## Method

The approach followed for the literature review is based on the three-step structured literature review process proposed by Kitchenham (2004). The steps include: a) planning the review, where a detailed protocol containing specific search terms and inclusion/exclusion criteria is developed, b) conducting the review, where the identification, selection, appraisal, examination and synthesis of published research is performed and c) reporting the review, where the write-up is prepared. We used these steps as our methodological framework.

To identify journal and conference articles to be reviewed, we combined two different sections of search terms with AND operators. The first section represents technologies associated with the objective of our research (AI OR “artificial intelligence”) AND (Healthcare OR Health). The second section reflects the concern for accountability in AI governance (accountability OR accountable). Combining these three sections we searched in the abstract, title or keywords within published research. We utilized Scopus as our search engine. This search yielded 73 articles. Furthermore, to ensure as wide coverage of related literature as possible, we searched for articles that are related to AI accountability in health but do not mention the words health or healthcare in their abstract, title or keywords. For this purpose, we searched for papers on (AI OR “artificial intelligence”) AND (accountability OR accountable) without (Healthcare OR Health) within outlets flagged by Scopus as medical, nursing or healthcare related. This search yielded 15 additional articles. The search was performed on April 5th, 2021.

For screening the papers, specific exclusion criteria were used. We excluded documents that are: a) not research articles (e.g. interviews, research proposals), b) not focusing on AI (but only causally mention AI), c) not engaging with AI governance (but only casually mention accountability), d) not focusing on healthcare (but only casually mentioning the word as one of many potential contexts for AI use), e) not written in English. We did not set any specific time period for our search. Interestingly, most papers identified are recent (published after 2018) but a couple of them are from the earlier AI spring of the 1980s. In total, 21 articles were included from the 88 that were initially identified. Within these 21 articles, 9 also include the terms explainability or Transparency in their abstract, title or keywords. We flagged these papers in order to explore the relations between accountability, explainability and transparency (RQ3) and we coded the papers’ content in a spreadsheet shared by the authors. Throughout the



process, we held meetings to ensure consensus in the coding. The distribution of papers over time is presented in Table I. The full list of articles reviewed is included in the Annex.

Table I. Articles distribution over publication years

<b>Publication Year</b>	<b>Selected Articles</b> (in parenthesis the papers that include accountability and also explainability/transparency)
1986	2 (0)
2018	2 (0)
2019	8 (2)
2020	5 (5)
2021	4 (2)

## Findings

The articles reviewed cover different AI healthcare application domains (see table II). AI for medical image analysis is the most frequent domain (2 articles discussing image analysis for breast tissues, 1 on the analysis of cancer tissues in general and 1 on image analysis for regulating radiation doses in CT scanners). AI applications for mental health (digital consultation services) are discussed in 3 articles. AI enabled surgery robotics are discussed in 2 articles and 1 article is on the use of AI for Electrocardiogram (ECG) interpretation. About half of the articles reviewed (11 of 21) do not engage with specific healthcare application domains but they discuss healthcare AI applications in general.

Table II. AI in healthcare application domains in articles reviewed

<b>Application Domain</b>	<b>Articles</b>
AI for medical image analysis	4
AI for mental health	3
AI for surgery robotics	2
AI for ECG interpretation	1
AI for healthcare in general	11

Around half of the articles reviewed are “solution-oriented” offering suggestions for what needs to be done in practice to ensure Accountability for AI in healthcare (12 out of 21 articles). The suggested solutions include design principles and requirements, technical artifacts (algorithms, software applications) and ethical guidelines. Furthermore, a significant number of the articles reviewed contribute to the literature at the conceptual level (9 articles) by discussing issues and identifying challenges and opportunities or suggesting frameworks and

conceptual maps. The remaining articles include legal essays and insights on users’ perceptions and behavior. It is interesting to note that three articles include both conceptual frameworks and solution-oriented contributions.

Table III. Articles’ Contribution Types (three papers had more than one type of contribution)

Type of Contribution		Articles
Solution-oriented	Design Principles and Requirements	4
	Ethical Guidelines	4
	Technical Artifacts (algorithms, software applications)	4
Conceptual	Discussion on Challenges and Opportunities	6
	Framework – Conceptual Mapping	3
Other	Legal Essays	2
	Perceptions and Behavioural Insights	1

By analyzing the articles, we found that a significant part of them lacks conceptual clarity. Around half of the articles reviewed (13 of 21) do not include a definition for the accountability concept. This is a significant issue as accountability is a malleable term and its liberal use easily leads to conceptual confusion. We classified the definitions provided in the articles that do define the concept using the work of Bovens on accountability and governance (Bovens, 2007, 2010; Bovens et al., 2014). Specifically, Bovens suggested a comprehensive definition which covers a) the obligation of actors involved in the development and deployment of AI systems to answer for and justify their actions, b) the interrogation ability of those affected by AI systems and c) the sanctioning potential that entails specifying what is acceptable in the use of AI and what happens when AI systems work in unacceptable ways. Within the articles reviewed we found one that defines the concept in a comprehensive way covering all three aspects (obligation, interrogation, sanctioning) and four that cover two of these aspects. The remaining three only cover one aspect (two only cover “obligation”, one covers “interrogation”). Overall, accountability is most frequently conceptualized as an obligation or responsibility of the actors involved (table IV). When accountability is defined as the ability to interrogate about AI-enabled systems, the focus is shifted from those involved in the development and deployment of AI-enabled systems to those affected by these systems and their own ability to pose questions and make sense of AI applications. Finally, the “sanctioning” type of definitions points to the need to have in place rules for what happens when AI is not within what is acceptable.

Table IV. Accountability Definitions in the papers reviewed

Definitions in the papers reviewed		Articles
Accountability Aspects	Obligation (also expressed as “responsibility for”)	6
	Interrogation ability	3

	Posthoc sanction potential (for blamable agents)	3
No Definition		13

The analysis helped us identify differences in the way the relationship between accountability and transparency/explainability is conceptualized. We were motivated to analyze this relationship by observing how these concepts are treated in non-scientific literature. We noticed that in popular press they are frequently used interchangeably. Interestingly, this issue appears in only one of the articles reviewed. Among the articles that include accountability and also explainability and/or accountability, most discuss them as discrete characteristics that can be assessed separately (four articles) or as discrete but enabling (four articles). In the latter category, explainability and transparency are conceptualized as being enabling for achieving accountability. Table V provides an overview.

Table V. Overview of the relationships between accountability and explainability/transparency

<b>Relationship between accountability and explainability/transparency</b>	<b>Articles</b>
Discrete	4
Discrete but enabling	4
Tightly related - conflated	1

Finally, an interesting observation, is that the majority of the articles reviewed are not empirical. Specifically, only 2 of the 21 articles reviewed include empirical data: one analyses trials with 14 pathologists on AI-enabled diagnoses for histopathological cancer tissues and one investigates women’s views on AI for the diagnostic interpretation of screening mammograms (922 participants). This suggests that more research efforts should be geared towards empirical studies.

## Discussion and Conclusion

AI opens up great opportunities for leveraging health data to generate insights that can improve healthcare delivery. In order to harness these opportunities, it is important to address AI governance challenges ensuring accountability in AI use. We performed a literature review to map and synthesize extant related research literature and we identified 21 articles published from 1986 to 2021. There is a gap in publishing activity from 1986 to 2018 which reflects the long “AI winter” that lasted from the late 1980’s till the early 2010’s (when the widespread use of machine learning rejuvenated the interest (and funding) on AI applications). Interestingly, the two papers that were written back in 1986, discuss the same issues that are discussed today. Specifically, Hartman suggests the adoption of

guidelines to increase programmer and provider accountability for clinical software, training clinicians to understand the limits of artificial intelligence, and determining the legal and ethical status of software (Hartman, 1986a). Furthermore, in a second paper published the same year, he points to the challenges created by black-box algorithms and to the need for delineating types of use (Hartman, 1986b). Enthusiasm for AI during the 1980s was followed by a severe cutback in interest which lasted for two decades resulting to limited advancement for the governance of AI. The same issues that were identified back in the 1980s were brought again in public debate and in academic discourse during the past few years (the first relevant papers were identified in our review in 2018). This time, national and international regulatory authorities are aiming to move swiftly. Recent activity at the policy level (European Commission, 2021) addresses AI use in high risk domains, setting rules and mechanisms to minimize unintended negative consequences of the rapid explosion in AI and introducing a risk based approach to categorize different applications of AI.

In our literature review we find that a significant part of the literature lacks conceptual clarity. This is problematic. When researchers do not define accountability or define it in different ways, they end up addressing different accountability issues, practices, and challenges. In other words, the discourse becomes fragmented. Future research should therefore be explicit in how key terms are used. We also found that the relationship between accountability and transparency/explainability is yet not fully explored. Some prior research, identifies transparency and explainability as significant accountability enablers (O'Sullivan et al., 2019; Rjoob et al., 2020; Sabol et al., 2020; Tosun et al., 2020). Nevertheless, this relationship may not be straightforward. Durán and Jongsma (2021) suggest that demanding explainability, including full technical transparency for AI may be overdemanding and not really needed for accountability. They use the example of physicians operating other technologies which they do not fully understand or cannot fully explain their inner working of (e.g. MRI scans), yet in these cases, physicians are sufficiently in control to be considered responsible. This review contributes to conceptual clarification by mapping the different accountability definitions and points to the need to further explore the relationship between transparency, explainability and accountability.

Another important finding of this review is the scarcity of empirical research identified. This is understandable when considering the novelty of the phenomenon. It is only recently that the availability of data and the use of AI techniques started to make an impact on organizations. Nevertheless, the high proportion of conceptual and literature-based papers suggests that research efforts should be geared towards empirical studies. The reviewed literature could provide a starting point for empirical investigations. For example, the guidelines and frameworks suggested could be empirically evaluated. There is also a possibility to utilize the literature in an abductive manner: mismatches between empirical

material and existing conceptually derived theories can be used as opportunities for theorizing (Markus & Rowe, 2021). This review can provide a basis for development helping researchers orient themselves and position their own work.

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## Annex: List of Articles included in the Review (in chronological order)

Authors	Title	Year & Outlet	Healthcare domain	Relation between Accountability & Transparency/ Explainability	Key contribution
Durán J.M., Jongsmá K.R.	Who is afraid of black box algorithms? On the epistemological and ethical basis of trust in medical AI	2021 Journal of Medical Ethics	generally about AI in healthcare	Discrete: physicians can be responsible, in terms of accountability without fully knowing or understanding inner workings.	Ethical Guidelines
Gómez Rivas J., ... Grossmann R.	Autonomous robots: a new reality in healthcare? A project by European Association of Urology-Young Academic Urologist group	2021 Current opinion in urology	robotics (autonomous robots)	N/A	Discussions on Pros and Cons
Ongena Y.P., Yakar D., Haan M., Kwee T.C.	Artificial Intelligence in Screening Mammography: A Population Survey of Women's Preferences	2021 Journal of the American College of Radiology	image analysis (mammograms)	N/A	Perceptions and Behavioural Insights
Rjooob K., Bond R., ...Peace A.	Towards Explainable Artificial Intelligence and Explanation User Interfaces to Open the 'Black Box' of Automated ECG Interpretation	2021 Lecture Notes in Computer Science	ECG interpretation	Enabling: lack of explainability and interpretability (which results to less transparency) increases difficulty of accountability.	Technical Artifacts (algorithms, software applications)
Abràmoff M.D., Tobey D., Char D.S.	Lessons Learned About Autonomous AI: Finding a Safe, Efficacious, and Ethical Path Through the Development Process	2020 American Journal of Ophthalmology	generally about AI in healthcare	Discrete	Frameworks and Mappings Ethical Guidelines
Basu T., Engel-Wolf S., Menzer O.	The ethics of machine learning in medical sciences: Where do we stand today?	2020 Indian Journal of Dermatology	generally about AI in healthcare	Discrete	Ethical Guidelines
Mattei P.	Digital governance in tax-funded European healthcare systems: From the Back office to patient empowerment	2020 Israel Journal of Health Policy Research	generally about AI in healthcare	Discrete	Discussions on Pros and Cons
Sabol P., Sinčák P., ... A., Jašková A.	Explainable classifier for improving the accountability in decision-making for colorectal cancer diagnosis from histopathological images	2020 Journal of Biomedical Informatics	image analysis (histopathological cancer tissues)	Enabling: "explainability improves the accountability of the proposed classifier"	Technical Artifacts (algorithms, software applications)
Tosun A.B., Pullara F., ... Fine J.L.	HistoMapr™: An Explainable AI (xAI) Platform for Computational Pathology Solutions	2020 Lecture Notes in Computer Science	image analysis (breasts)	Enabling: explainability enables accountability	Technical Artifacts (algorithms, software applications)
Forcier M.B., Gallois H., Mullan S., Joly Y.	Integrating artificial intelligence into health care through data access: Can the GDPR act as a beacon for policymakers?	2019 Journal of Law and the Biosciences	generally about AI in healthcare	N/A	Legal Essays

<b>Authors</b>	<b>Title</b>	<b>Year &amp; Outlet</b>	<b>Healthcare domain</b>	<b>Relation between Accountability &amp; Transparency/ Explainability</b>	<b>Key contribution</b>
Larson D.B., Boland G.W.	Imaging Quality Control in the Era of Artificial Intelligence	2019 Journal of the American College of Radiology	image analysis (control image quality, regulate CT scan radiation)	N/A	Design Principles and Requirements
Lysaght T., Lim H.Y., Ngiam K.Y.	AI-Assisted Decision-making in Healthcare: The Application of an Ethics Framework for Big Data in Health and Research	2019 Asian Bioethics Review	generally about AI in healthcare	Tightly related -conflated and coupled to the "black box" problem	Ethical Guidelines
Milosevic Z.	Ethics in digital health: A deontic accountability framework	2019 IEEE 23rd Enterprise Distributed Object Computing Conference	generally about AI in healthcare	N/A	Technical Artifacts (algorithms, software applications) & Frameworks and Mappings
O'Sullivan S., Nevejans N.,... Ashrafian H.	Legal, regulatory, and ethical frameworks for development of standards in artificial intelligence (AI) and autonomous robotic surgery	2019 International Journal of Medical Robotics and Computer Assisted Surgery	robotics (autonomous robots in surgery)	Enabling, although transparency and explainability are not much discussed in the paper	Discussions on Pros and Cons
Price W.N., II, Cohen I.G.	Privacy in the age of medical big data	2019 Nature Medicine	generally about AI in healthcare	N/A	Discussions on Pros and Cons
Schönberger D.	Artificial intelligence in healthcare: A critical analysis of the legal and ethical implications	2019 International Journal of Law and Information Technology	generally about AI in healthcare	N/A	Legal Essays
Vakkuri V., Kemell K.-K., Abrahamsson P.	Implementing Ethics in AI: Initial Results of an Industrial Multiple Case Study	2019 Lecture Notes in Computer Science	generally about AI in healthcare	N/A	Design Principles and Requirements & Frameworks and Mappings
Martinez-Martin N., Kreitmair K.	Ethical issues for direct-to-consumer digital psychotherapy apps: Addressing accountability, data protection, and consent	2018 Journal of Medical Internet Research	mental health (using AI and conversational agents)	N/A	Discussions on Pros and Cons
Pesapane F., Volonté C., Codari M., Sardanelli F.	Artificial intelligence as a medical device in radiology: ethical and regulatory issues in Europe and the United States	2018 Insights into Imaging	generally about AI in healthcare	N/A	Discussions on Pros and Cons
Hartman D.E.	Artificial Intelligence or Artificial Psychologist?. Conceptual Issues in Clinical Microcomputer Use	1986 Professional Psychology: Research & Practice	mental health	N/A	Design Principles and Requirements
Hartman D.E.	On the Use of Clinical Psychology Software. Practical, Legal, and Ethical Concerns	1986 Professional Psychology: Research & Practice	mental health	N/A	Design Principles and Requirements