Designing System Support for Sharing Everyday Data for Chronic Care

by

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Dedication

To my parents, Der-Ming Hung and Mei-Chou Wu
To my sister, Min-Wei Hung
To all the mentors and teachers whom I met along the way

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Abstract

The prevalence of chronic conditions has shifted care settings into private homes. In addition, the increasing availability of physical- and algorithmic-sensing solutions promises large quantities of data about one's everyday life that would be useful for such care. For a person significantly affected by a chronic condition, conducting chronic care at home is likely to involve a care team comprising family members, caregivers, and clinicians. The success of chronic care requires care team members to collaboratively assist people affected by chronic conditions by monitoring their lives and developing care routines for necessary self-care activities in response to different stages of their health trajectory. Sharing these everyday data for care (EDC) could provide awareness and support collaboration among care team members, which would assist the person with a condition requiring a care team (PCT). However, EDC details might have unintended consequences, such as negative impressions or the invasion of privacy.

A variety of solutions for user control have been developed and published in the existing literature on designing systems to support data sharing. However, very few user-facing solutions for user control have carefully considered the healthcare context, particularly the collaborative nature of self-care, the need to support fine-grained control to develop independence, and variance in the PCT's capacity to direct EDC sharing due to changes in their health and priorities. To address these considerations in the care context, this dissertation presents a threefold investigation into system designs that support PCT's sharing of EDC in the context of chronic care.

The first approach implemented a user-facing system, Data Checkers, to support fine-grained control and preview shared results. This would allow PCTs to explicitly regulate EDC data flow. The design of Data Checkers, including its grid-based interface, was grounded in a co-design process with a person with a severe condition, and it embeds the critical requirements for a PCT. A qualitative evaluation demonstrated the potential use of Data Checkers for long-term care.

The second approach investigated the applicability of user-created EDC groupings to simplify EDC sharing configurations. The goal of using these groupings is to reduce the user burden when managing many EDC sources. The results of a scenario-based study showed that self-generated EDC groupings can be reused as high-level units to efficiently create sharing settings for potential recipients when dealing with changes in health trajectories. These findings also suggested the possibility of developing a machine-assisted mechanism for suggesting policies that are consistent with the PCT's preferences, particularly as health changes.

The third approach considered using human and machine delegates to cover the responsibilities of sharing EDC to support PCTs whose capacity is greatly reduced due to health concerns and other life priorities. The results of a scenario-based interview study showed that obtaining assistance for sharing data requires nuanced considerations of both the delegate's characteristics and the implications of the delegation. Also, human and machine delegates possess possible complementary qualities for handling these nuances, which suggests the potential for a human-machine collaborative approach to EDC-sharing assistance.

This dissertation concludes with a discussion of the necessity to align user-facing system design with the nature and practices of care. Moreover, it provides a meta-analysis and identifies multiple capacity dimensions, including the capacity of a care team, which is critical to examining the development of a capacity-aware approach to EDC sharing for chronic healthcare.

Chapter 1

Introduction

1.1 Background

Improving the quality of life for people with health conditions is an important challenge to tackle (G. Anderson & Horvath, 2010). Health conditions could result in different levels of impact on people's lives. Some are temporary, some are long-lasting, even lifelong for chronic condition (Mamykina et al., 2008); some are minor, and some are severe (e.g., spinal cord injuries and disorders [John Hopkins Medicine, 2021; Meade, 2009]).

People whose lives are severely affected by their health conditions might require assistance from others during their everyday lives. For instance, for people with spinal cord injuries and disorders (SCI/D), neurological injuries often imply some degree of paralysis, sensory loss, and compromised organ function. As a result, people with SCI/D might have physical limitations and hence complex care needs that require assistance from others to perform different care-related activities, such as taking a bath, staying hydrated, keeping a diet, taking medication, and getting into bed. Such assistance would come from other people such as family caregivers, secondary caregivers, hired caregivers, and other medical professionals. In other words, there will be a team of people to provide support for different care activities.

This team of caregivers and clinicians consists of non-medical personnel such as family members and hired help, as well as medical professionals from traditional medical settings (e.g., a hospital). Those most immediately involved in daily or clinical care—the "care team" of a person with a health condition—are crucial to supporting self-care and the person's quality of life.

Depending on the complexity of the care that is necessary to maintain and improve someone's health, people with health conditions and others who assist with care, such as caregivers or clinicians, would need to monitor different external stimuli like medication or diet and various symptoms to understand and develop a better way of conducting self-care (Mamykina et al., 2008; Meade, 2009; Murnane et al., 2018; Raj et al., 2017; Rooksby et al., 2014).

With technological advancements, sensors are increasingly available to generate data about different aspects of a person's everyday life, including physiological factors like heart rate, behavioral factors like step count or sleep activity, psychological factors like emotions, or even contextual data like temperature or weather that could facilitate the understanding of how one's health is affected by these and other various factors (Ayobi et al., 2017; Karkar et al., 2017).

These everyday data, different from those data captured routinely in a traditional medical environment (e.g., a hospital), provide rich information to characterize a person's everyday life. Such characterization is useful for understanding the life of a person with a health condition and could be used to support monitoring, which is a critical part of self-care.

Recently, using data captured about one's everyday life for supporting care, or everyday data for care (EDC), including observations of daily livings (ODLs) (Piras, 2019) or patient-generated health data (PGHD) (Figueiredo & Chen, 2020), has received significant attention from the research community. EDC are defined as data captured about the everyday life of people with health conditions [1] that could be useful for care, including data such as heart rate, fluid intake, sleep quality, and loneliness.

I use the term EDC to include ODLs or PGHD, to emphasize diverse data sources generated about one's everyday life that could be useful for supporting different aspects of care, as opposed to data captured purposefully by people with health conditions or caregivers specifically about a health condition, which is commonly the case for PGHD. Additionally, I want to move away from "patient" to emphasize the identity of a person with a health condition as a human being who has other priorities in her everyday life

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[1] I use the term "person with a health condition" interchangeably with "patient" in this dissertation, to emphasize her identity as a human being. I recognize the unfortunate connotations of "patient" in that it privileges the medicalization of care and the clinical participants in care. However, I use "patient" in some parts of this dissertation, such as in the related work, to avoid confusion and to maintain consistency with some existing literature.

as well, instead of simply being a "patient," where the major focus will be solely on health.

These EDC could be generated automatically through sensors in a pervasive healthcare environment full of sensing devices and wearable devices or captured by the care team of people with health conditions. The use of EDC could provide benefits through bridging the hospital and home care environments by extending the monitoring of people's health outside of a traditional medical setting (Bodenheimer et al., 2002).

For people with severe chronic conditions who have functional limitations that make them in need of assistance from their care team members, these EDC would allow a sufficiently-sized care team, including a variety of family members, hired help, medical professionals, and people themselves, to collaboratively monitor their health conditions and coordinate within care teams (Büyüktür et al., 2017; Büyüktür et al., 2018). Sharing these data with care team members also allows the person with a health condition requiring a care team (PCT) to make use of the diverse expertise within the team to interpret data and make decisions (Amir et al., 2015; Consolvo et al., 2004).

However, as these EDC contain a great number of details about one's life, benefits for some might become concerns for others. Sharing these EDC provides others with a way to look closely into one's life, and people might want to present a certain kind of image (Goffman et al., 1978) and avoid undesirable inferences or impressions (Kumar & Schoenebeck, 2015; Thayer et al., 2012; Tolmie et al., 2016).

These benefits and concerns for sharing EDC make designing data-sharing systems a necessary and yet challenging task. To reiterate, data sharing for care involves not only the protective aspect (e.g., protecting one's image or privacy), but also the proactive aspect of sharing, supporting collaborative monitoring and coordination (Murnane et al., 2018; Raj et al., 2017), as sharing data could potentially facilitate the flow of information beneficial for care and medical decisions. Following Kariotis et al.'s call (2020), I use the term "data sharing" to highlight both the protective and pro-active aspects of dealing with data. Designing systems to support data sharing needs to properly consider both aspects to develop a meaningful solution.

Existing work on supporting data sharing has developed various approaches to enable control (Epstein et al., 2013; Rader & Wash, 2015) or understanding of the impact of sharing (Mazzia et al., 2012). However, the consideration of the health care context and its corresponding challenges is particularly lacking. This dissertation aims to tackle three gaps in existing research to further the understanding of designing data sharing for care.

First, sharing data within a care team is not as simple as sharing raw data with each individual. Moreover, proper considerations for care are needed, including the design for configuring data sharing for care. For one thing, the collaborative nature of care suggests that system design needs to properly consider the necessity to support group work within a care team (Birnholtz & Jones-Rounds, 2010; Consolvo et al., 2004; Nunes & Fitzpatrick, 2015). For another, supporting fine-grained control, namely the ability to fine-tune the details for sharing and how data are shared (Bahirat et al., 2018; Epstein et al., 2013; Könings, 2015), is important as it allows people to negotiate the right level of independence in the context of collaborative care (Büyüktür et al., 2018). The ability to perform fine-grained control will be the vehicle for people to configure the right combination of protection of privacy and the release of data. These aspects are largely missing from existing literature on system solutions for data sharing.

Second, data sharing should not be overwhelming. This is true in general, but it is particularly important for PCTs, as they have other priorities in life as well (Büyüktür et al., 2018). The increasingly available sensor data should be properly managed to facilitate sharing and tracking. Existing work on categorizing data sources to reduce the complexity of sharing configuration has taken a rather generalized view (e.g., one privacy taxonomy for all [Li et al., 2020]), where an individual-assisted simplification for sharing configuration is less explored.

Third, following the previous point, PCTs not only have other priorities in life, but they also might have a reduced capacity to manage data sharing as a result of their changing health conditions. A system design needs to not only be usable, but also allow different levels of user involvement, which is typically neglected by existing privacy and data-sharing designs, and support alternative approaches so that data can be shared in different care situations properly, even in a situation where the person with a health condition does not have the capacity to manage data-sharing.

1.2 Research Questions

In this dissertation, I present three projects that aim to address these challenges for PCTs to direct EDC sharing within care teams. The overarching question I am pursuing is:

> Q-Overall: How to effectively support people with health conditions requiring care teams (PCTs) to direct the sharing of their everyday data for care (EDC)?

The particular aspect I am investigating in this dissertation centered on designing system support for PCTs (or their proxies), whose capacity might change throughout their health journey, to direct EDC sharing with care teams, with particular considerations on managing a potentially larger number of EDC data sources, balancing the protective and proactive aspects of sharing for PCTs to maintain the desired level of independence in their health trajectories, and augmenting the collaborative nature of monitoring and care.

By "direct," I emphasize that PCTs could affect data sharing at different levels of granularity based on their priorities and capacities. In other words, I consider the possibility and necessity for system design to support a spectrum of user involvement, including both extremes.

On one end of the spectrum, PCTs could have total control over how each data flow is being regulated, namely how every single EDC data type will be accessible by each potential data recipient (i.e., care team members). In other words, PCTs should be able to exert fine-grained control over relationships between every single data-recipient pair as they see fit.

On the other end of the spectrum, PCTs could delegate the responsibilities and capabilities of managing EDC sharing to other actors to decide how different EDC data types will be shared with each potential data recipient. In other words, PCTs should be able to exert control through others so that PCTs can focus on other priorities in life and have limited involvement in making decisions about every single data flow if they find it appropriate.

To reiterate, here is the guiding question for my investigation:

> Q-Guide: How to support people with health conditions to direct data sharing in a way that respects their priorities and capacities and matches their desired level of involvement?

To systematically understand how to design systems to support a spectrum of user involvement in response to the dynamic nature of health care and personal priorities, I structure my investigation into three projects, each focusing on supporting PCTs to manage EDC sharing with complete involvement, some involvement, and limited involvement. The goal is to devise a more thorough understanding of supporting different PCTs on this spectrum to direct EDC sharing.

For PCTs who want a high degree of involvement, it is critical to provide a user interface design for PCTs to create sharing settings in order to interact with the underlying data sharing mechanisms. For PCTs who want control but only some degree of involvement, it is necessary to understand how the task of managing EDC sharing settings could be simplified using high-level concepts to constrain the amount of effort necessary to exert control. For PCTs who want only a limited degree of involvement, it is important to understand what sources of assistance are available and what kinds of assistance people would want to help with EDC sharing.

With these rationales in mind, I direct my investigation through three angles: user interface design, user-assisted semi-automatic sharing, and a team-based collaborative approach to EDC sharing management. These approaches exemplify different degrees of involvement of PCTs from high to low to accommodate PCTs' desired level of control throughout their health journeys.

Here are the three specific questions I seek to address:

> Q-1: How could we design a user interface for PCTs to exert fine-grained control over EDC sharing with care teams?
>
> Q-2: Could EDC data be grouped by PCTs for sharing to reduce the workload/complexity of sharing configuration?
>
> Q-3: How would people consider obtaining assistance from human and machine actors to assist with EDC sharing?

To answer Q-1, in the first project I present a web application, Data Checkers (DC), co-designed with a PCT. The application offers a grid-based interface to address the need for fine-grained control over EDC sharing with care teams, with the goal of helping PCTs to develop independence. An evaluation of DC suggests that it streamlines the process of configuring sharing settings that involve (1) multiple EDC types, (2) multiple care team members, and (3) the need for different fine-grained controls simultaneously. DC offers a person-centered and streamlined solution that features a user interface for PCTs to exert complete control over EDC sharing. It was designed for PCTs (or their proxies) who want to exert fine-grained control in a detailed manner. With the potential of having many EDC sources to be considered in the configuration process, additional mechanisms need to be established to support PCTs in other segments on the spectrum, namely those who prefer reduced involvement.

In answering Q-2, I investigate the possibility of using user-generated EDC groupings (i.e., grouping EDC types together as units to be shared) as a mechanism for PCTs to describe their sharing preferences. The investigation is documented in the second project, where I use scenario-based card-sorting to demonstrate the potential of using groupings as high-level units to further simplify the number of sources to be considered in sharing settings to mitigate the challenge created by increasingly available sensing sources. I show that participants were able to create groupings of EDC and, more importantly, these user-generated groupings could be reused as high-level units to specify EDC sharing settings involving different care team members under different care situations. The results suggest that individual-assisted grouping is possible and likely useful, with the potential of developing a semi-automatic approach to mitigate the impact of managing many EDC sources.

The first two projects attempt to address the challenges of sharing EDC through the lens of application design and technical mechanisms, where a user interface and findings with a direct technical implication are presented. While they share a similar theme to streamline and simplify the process of creating sharing settings, they did not consider a human factor adequately, namely the capacity of PCTs or their caregivers to exert control. In addition to their changing priorities in life, changes in their health or the care responsibilities for caregivers might also significantly affect their capacity to manage EDC sharing. A proper solution to tackle the challenges of directing EDC sharing will need to consider alternatives in response to the issue of reduced capacity, which is common in care.

The search for alternatives led me to consider whether the diverse care team members, who possess different expertise in the care and can utilize EDC, could provide such assistance with EDC sharing. Additionally, with machine intelligence gradually integrated into different aspects of our lives, it begs the question of whether and how machine intelligence could be introduced to provide assistance for EDC sharing, and in particular collaborating with care team members, who might also have changing capacity due to their commitment to care and other responsibilities. As the first step, I examine the potential of such an approach by answering Q-3. I seek to understand how people would consider human and machine assistance with EDC sharing. In the third project, I investigate the possibility of obtaining assistance from human and machine actors, or delegates, so that people with health conditions could direct EDC sharing through delegating control to these human and machine actors. Through an interview study, I show that, in the setting of sharing EDC with care teams, participants consider human and machine actors to possess different and possibly complementary characteristics. The recognition of these characteristics suggests the potential of a human-machine collaborative approach to EDC sharing, where PCTs could exert control through the collaboration of these delegates to proactively share EDC to facilitate collaborative monitoring while respecting their need for privacy and independence.

1.3 Project Overview

The following are overviews of these three projects.

In the first project, I investigated the challenge of supporting EDC sharing through user interface design. The main problem to be addressed was the lack of consideration of the care context in existing designs. This project highlighted the need to support data sharing to support within-team collaboration, and to provide PCTs with the tools to perform fine-grained control over EDC sharing in order to configure the appropriate amount and types of sharing that benefit the care team while respecting the PCTs' privacy. To gain a better understanding of the lived experience of PCTs and develop the necessary tools for them to exert fine-grained control, I employed a co-design approach through working with a person with a severe health condition. Through an eight-month weekly engagement with him, I (1) developed a set of requirements that are necessary to support care team collaboration, (2) identified four types of controls for users to tailor the details in data for sharing and to allow them dynamically adjust sharing in reaction to changes in their health journey, and (3) designed an application concept that embodied the requirements and controls, DC. DC features a grid-based user interface that allows users to configure sharing settings through visual composition and a preview panel that allows users to see data through a recipient's view. I implemented DC as a web application and demonstrated its potential through a comparison study with an existing standard design. Through studying DC with people with health conditions and caregivers, I showed that the design offered by DC indeed satisfies the design requirements and has the potential to support long-term EDC sharing to accommodate the changes in a PCT's health trajectory.

In the second project, I investigated the possibility of developing an individual-assisted approach to EDC sharing. The main goal was to reduce the complexity of configuration as a result of many sensing sources. The basis of my investigation was the examination of the possibility of using high-level units, or groupings, created by users to configure sharing settings. I designed a scenario-based card-sorting study to see whether people can group EDC using a simple criterion, comfort with sharing, and whether the groupings created could be used for specifying EDC sharing settings. As everyone could potentially face this challenge of sharing EDC to support care later in their life due to the prevalence of chronic conditions, I conducted this study with 25 participants with a variety of experiences with care. Through the use of think-aloud protocol and semi-structured interviews, I showed that while individual differences were prominent, participants were able to group data based on their own interpretation of the given criterion, and they were able to use these user-generated groupings as units for specifying sharing settings with the members of a care team. I also showed that such user-generated groupings, while not perfect, allowed participants to efficiently express their attitudes toward sharing in different care situations. The results demonstrated that user-generated groupings are possible and potentially useful, which might enable the development of an individual-assisted semi-automatic approach to EDC sharing.

In the third project, I investigated the possibility of using human and machine delegates to assist with EDC sharing. The major motivation was to ensure a viable approach for directing EDC sharing along the way of a PCT's health trajectory, and in particular when PCTs' capacity for configuring EDC sharing might be reduced. More broadly, I was aiming to develop an initial framework for understanding how assistance from human and machine actors could be properly introduced in managing EDC sharing. Given that people's capacity to direct EDC data sharing could be affected by other priorities in life and their health conditions, such an understanding is critical for further reducing the burden resulting from many data sources. I used a scenario-based interview study to obtain insights into how people consider different care team members to provide assistance in sharing. As these care team members possess valuable experience and expertise, their knowledge could be utilized to assist with EDC sharing to better facilitate data flow among care team members, which would be beneficial for supporting care collaboration. Using the scenario of spinal cord injuries and disorders (SCI/D), I examined how people think about using assistance from family caregivers, hired caregivers, and clinicians to help manage EDC sharing. As these care team members might also have varying capacities due to their responsibilities of care, I also included machine intelligence as a potential alternative to provide assistance. I conducted interviews with 25 participants; all except one had close family members with chronic conditions or had provided care as caregivers or nursing professionals. Through reviewing a list of EDC types selected based on existing work, I asked participants to describe how they would appreciate or show concerns for using a human or machine actor. I showed that people consider these human and machine actors to have different and complementary characteristics, which provide a framework for guiding how machine intelligence could be integrated into a human-machine collaborative approach for EDC sharing. These findings were subsequently verified with people with SCI/D and their care team members to confirm that this understanding matches the lived experience of people with severe health conditions and their care team members. I derived a set of design implications for systems designed to support a capacity-aware human-machine collaborative approach to assist PCTs to direct EDC in different care situations.

1.4 Contributions

In summary, this dissertation presents a three-fold investigation to improve the understanding of how to design systems to facilitate the sharing of Everyday Data for Care (EDC) through co-design, prototyping, evaluation, scenario-based card sorting, and interviews. The investigation was structured around PCTs' preferences on the degree of user involvement in the process of directing EDC sharing to support care, with the ultimate goal of developing a flexible system design to support EDC sharing that is adaptable to PCTs' capacity and different changes in their health journey.

The contributions of this dissertation include:

- A novel user interface design that supports fine-grained control over EDC sharing, with careful considerations of the care team context, for PCTs to negotiate privacy and independence.

- A demonstration of the potential of creating and using user-generated groupings of EDC to develop an individual-assisted approach for grouping EDC for simplifying sharing configuration to address the challenge posed by many EDC data sources.
- An understanding of people's considerations for using human and machine assistance that provides a framework for structuring a human-machine collaborative approach for PCTs to direct EDC sharing, to accommodate the changing capacity impacted by events in their health trajectories.

The overall contribution of this dissertation is a set of implications on how to design systems to support EDC sharing with care teams to improve care, with a particular focus on supporting a spectrum of PCTs who prefer different degrees of involvement in response to the dynamic nature of care. The three projects presented in this dissertation, each answering one of the three research questions, enable the development of approaches with different degrees of user involvement to configure proactive sharing while being aware of the needs for protection. These approaches will allow people with health conditions to negotiate their desired level of control over data to support care while respecting their changing capacity. The dissertation will conclude with implications and future research directions to realize the true potential of sharing EDC through a human-machine collaborative approach.

1.5 Dissertation Overview

This dissertation is divided into six chapters, which I describe briefly as follows.

Chapter 2 synthesizes existing literature that sets up the larger context for this dissertation. Three major areas of research are presented: chronic care and the collaborative nature of care for health conditions that require additional assistance from care teams; the increasing availability of data that could be used to support care and the associated challenges; and existing systems designed to support users' control over privacy and data sharing. Additional literature that is central to the core of each project will be presented in later chapters.

Chapter 3 follows the process of designing, developing, and evaluating a system for controlling EDC sharing. The system offers a grid-based user interface for PCTs to exert fine-grained control over data sharing among care team members. The chapter describes how I employed a series of human-centered design methods to develop this system and demonstrated the usefulness of such a system. The chapter concludes with a discussion on designing user-facing applications aimed at supporting PCTs in controlling data sharing for the long term. This chapter is adapted from a paper accepted for publication (Hung et al., 2022).

Chapter 4 describes the results of a card-sorting study on EDC types. The study used a scenario of SCI/D to contextualize the requirement of a care team, and hence the need to simplify the process of EDC sharing configuration. The main ideas examined are the possibility of creating high-level units and the utility of using these high-level units in configuring EDC sharing in different care situations. I present the design implications for a user-assisted semi-automatic approach. This chapter is adapted from a paper accepted for publication (Hung & Ackerman, 2022).

Chapter 5 centers on a formative study to understand EDC assistance. The study used semi-structured interviews to obtain insights into how people consider using different care team members and machine intelligence to cover different responsibilities required to share EDC properly. The findings from the study provide a general framework for assessing what a good delegate is and suggest a human-machine collaborative approach for sharing management. This chapter is adapted from a paper under preparation.

Chapter 6 summarizes the contributions of this dissertation work and reflects on how findings from the three research streams inform each other with regard to designing systems to support PCTs in directing EDC sharing. I highlight the necessity of supporting intermittent engagements with software systems that are essential to supporting data sharing for the long term in care, and argue for the importance of developing a capacity-aware human-machine collaborative approach to EDC sharing. I conclude with future areas of research.

Chapter 2

Literature Review

2.1 Overview

Chronic medical conditions vary widely. Some may cause minor discomfort to a patient (e.g., mild allergies); some may require only self-management of the condition, at least in some forms (e.g., mild depression). Other medical conditions, and some disabilities, may require a team of clinicians (e.g., congestive heart failure or one of the deadlier forms of cancer), and yet others may require an at-home care team to help with self-care and self-management along with a team of clinicians.

Sharing everyday data with stakeholders participating in care is an interesting setting to examine, as it involves additional factors that further increase the nuances in people's decisions to share data. For one, the intended recipients are not strangers or third-party organizations (e.g., a company in the case of usage log) where the usage of the data and the benefits for the person are not immediately clear. Instead, in the context of care, the recipients are the care team members who are likely to know the person and participate in care to some degree, which means these recipients could use these data in care and consequently benefit the person with a health condition requiring a care team (PCT).

For another, the data in consideration for sharing are not those captured in a medical environment (e.g., a hospital) where both patients and medical professionals are aware of the capturing and data are assumed to be shared with medical professionals directly. Instead, everyday data captured through sensors deployed through wearable devices or those in the environment are done outside of the traditional medical settings where both the PCT and care team members are less aware of the actual details and context as the capturing happens which means that the sharing decisions need to be well thought-out for these data to be useful while supporting the PCT's sense of control.

In this dissertation, I conduct a series of investigations centered on designing systems to allow a person with a health condition to direct data sharing for care. The term "data sharing" was chosen as it surfaces the proactive aspect of sharing data, acknowledging that sharing data proactively among care team members could support collaborative monitoring and allow care team members to respond more effectively. Moreover, "data sharing" suggests that a person with a health condition would weigh both the pros and cons of sharing to efficiently distribute these everyday data to her care team.

In contrast to privacy, which typically emphasizes the protective aspect of sharing, focusing on "data sharing" allows me to consider both the proactive and protective aspect of sharing and broadens my exploration of different approaches in the design space for different kinds of support (e.g., using the delegation approach).

In this chapter, I review the literature in the following three areas: self-care and care team; using everyday data for care, and existing systems and design to support data sharing control. The first two sections provide the context of the investigation, namely the collaborative care setting and the use of everyday data for care-related purposes. The last section provides a closer view of the existing approaches to facilitate control over data sharing. I end the chapter with a summary of the high-level gaps in the literature that this dissertations addresses.

2.2 Collaborative Self-Care for Chronic Conditions

With the increasing prevalence of chronic conditions (Centers for Disease Control and Prevention, 2020; World Health Organization, 2020), supporting chronic care becomes a critical challenge to tackle (G. Anderson & Horvath, 2010). Self-care has been identified as critical for managing all kinds of chronic conditions (G. Anderson & Horvath, 2010; R. M. Anderson, 1995; Bodenheimer et al., 2002). R. M. Anderson (1995) used the case of diabetes care to argue that, while "diabetes care plan," or simply "self-care plan" for a chronic condition such as diabetes, was typically first given by the clinicians (i.e., physicians) to people with diabetes, it should be applied with caution as that plan might not work universally for all individuals because some, if not all, may need specific changes for their unique situations. The individual should take the initiative and be empowered to work with physicians to collaboratively revise the self-care plan to suit her needs. In other words, people should be in charge of their own care, recognizing the importance of self-care. Self-care includes the everyday activities that people engage in to take care of themselves, manage their health, and continue to participate and be involved in life.

For people with severe chronic conditions, such as spinal cord injuries and disorders (SCI/D) [2], self-care becomes incrementally complex as it expands to consciously integrate the additional activities needed to maintain health. In the case of people with SCI/D, the neurological injuries often result in certain physical limitations such as paralysis, sensory loss for particular parts of their bodies, and compromised organ function. The implication is that people with SCI/D might need to use wheelchairs to commute and need to perform additional self-care activities to maintain their health and their quality of life. This could include taking medication, making conscious lifestyle choices (e.g., maintaining specific types of diet), cleaning one's environment and the medical equipment being used, bathing, keeping oneself hydrated due to sensory losses (i.e., not feeling thirsty), doing a bowel program to stimulate the bowels to cause a bowel movement and avoiding constipation, and even monitoring different aspects of one's health (e.g., pain or urination) (Ackerman et al., 2018; Glasgow & Anderson, 1999; Meade, 2009). In the Human-Computer Interaction (HCI) literature, self-care and self-management as terms are usually used interchangeably. Here I will use self-care to include self-management tasks performed by people with chronic conditions and disabilities (Nunes & Fitzpatrick, 2015).

Living with a chronic condition requires such people and their family members or loved ones to assist in the management of their health condition (Birnholtz & Jones-Rounds, 2010). When outside of the medical environment (e.g., a hospital), managing a chronic condition also involves various health professionals with different specialties working with the people and their families in response to different health changes (Büyüktür et al., 2017; Büyüktür et al., 2018; Felipe et al., 2015). The person with a health condition, caregivers, health professionals, and other stakeholders form an at-home care team who conduct different aspects of the required care (Amir et al., 2015; Büyüktür et al., 2017; Büyüktür et al., 2018; Suh et al., 2020). While some researchers use "care networks"

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[2] https://www.hopkinsmedicine.org/health/conditions-and-diseases/acute-spinal-cord-injury

(e.g., [Consolvo et al., 2004]) to denote a broader collectivity of involved others, Grönvall and Verdezoto (2013) use “intimate care network” to include only the family and the closest friends who participate in health management. In this dissertation, I use the term “care team” to denote an at-home care team that includes the person with a health condition, caregivers (primary, secondary, hired/paid, and volunteers), and clinicians–those most immediately bound up in the day-to-day care or in the necessary clinical care (Büyüktür et al., 2017; Büyüktür et al., 2018; Meade, 2009) and the term PCT to refer to a person with a health condition requiring a care team.

Recognizing the importance of the participation of these different care team members for self-care, designing technology to support individual care team members has received a persistent interest. One of the early–yet on-going–streams of research has been to empower people with health conditions by designing technological support for them to perform self-management, with the ultimate goal of achieving better health. For instance, Mamykina et al. (2006) used a combination of interviews, observations of support groups, and technology probe to understand how people with diabetes performed self-management and how reflection on actions resulted in changes in lifestyle. They found that people with diabetes needed to properly understand the correlation between their actions (e.g., nutrition intake) and blood sugar levels to successfully perform self-management (e.g., keeping their blood sugar levels low). To achieve that, people with diabetes needed to monitor actions and also sensor readings from glucose monitoring devices to develop a proper understanding. They suggested that health applications designed to support self-management through monitoring needed to carefully help users navigate through data to avoid the negative impact of confirmation bias. Research has found such design for self-monitoring to be beneficial, as it could trigger reflection, while also increasing a sense of control when managing a health condition (Mamykina et al., 2008).

In addition to self-monitoring, there is also technology designed to support the execution of different self-care activities (e.g., taking medication). For instance, Botella et al. (2013) presented a mobile app to help elderly patients adhere to their medication plan (e.g., medication, water, etc.). They found that providing photos for both the pills and the pillboxes helped patients recognize the right medication to take. In their 24 patients study, with the assistance of this app, patients never took more dosage than they should, and they never felt confused about the medication they needed to take, and most of them never ran out of medication at home (91.7% of users).

More broadly, existing design has chosen the direction of assisting individuals in following and executing the steps recommended by trusted professionals (M. L. Lee & Dey, 2015) to support person-clinician interaction. Lee and Dey (2015) presented their two case studies on how patients and physicians might react to and utilize the sensor observations of daily livings (ODLs). For patients, the ODLs data helped them either confirm their belief about how they adhere to the treatment plan or discover special occasions that they were not aware of. Patients who discovered special occasions that did not conform to their own impressions showed motivation to change the behavior accordingly, if reminded continuously. For physicians, the ODLs data helped them to focus on special occasions if the data aligned with their evaluation of the patients.

In addition to the benefits of supporting person-clinician interaction (e.g., adherence), as described above, recent work also started to pay attention to the importance of supporting caregivers or person-caregiver interactions (Birnholtz & Jones-Rounds, 2010; Yu et al., 2011). For instance, Yu et al. (2011) reported their study on a mobile game-based app, using experience sampling method (ESM), for depressed individuals and their caregivers. They found that, although with exceptions, the interaction between some pairs of the depressed individuals and caregivers did improve as the frequency of reassurance-seeking behavior decreased. Additionally, the perceived burden for some the caregivers also significantly decreased. As a result, multiple pairs of them were more satisfied with their relationships with each other, between the depressed individual and the caregiver.

As supporting such in-team collaboration between care team members had demonstrated benefits, the research community gradually recognized the importance of and pushed for design to support the care team as a whole. Consolvo et al. (2004) coined the term *computer-supported coordinated care* and used their work with elders and their caregivers to argue strongly the need to consider the care network, including family members, friends, neighbors, hired caregivers, and clinicians (e.g., doctors) and create a design with particular attention to diverse roles, the communication structure, and the importance of sharing information. Nunes and Fitzpatrick (2015) echoed such a view through their study of people living with Parkinson's disease to demonstrate the collaborative nature of self-care. They argued that, while self-care technology is traditionally designed for use solely by people with health conditions–possibly due to the move to emphasize the importance of empowering people with health conditions (R. M. Anderson, 1995)–designers of technology to support self-care should take into consideration the interaction between people with health conditions and others who participate in care, as they had observed various forms of collaboration (i.e., action and reaction) in the process of managing Parkinson's disease. The collaboration of people, carers, and others involved emerged naturally to act on symptoms, manage treatment, manage physical and psychological consequences, and perform lifestyle changes in response to the fluctuating disease trajectory, or their life in general.

The collaborative nature of self-care, as exemplified by the findings of Consolvo et al. (2004) and Nunes and Fitzpatrick (2015), suggests that designing systems to support the entire care team requires careful consideration of the various factors exhibited by such care teams: diverse expertise of team members (Consolvo et al., 2004), relationships among care team members (Büyüktür et al., 2018), how team members with different time commitments collaborate in a loosely coupled manner (e.g., with remote monitoring or in non-overlapping shifts) (Amir et al., 2015; Birnholtz & Jones-Rounds, 2010), and how the team membership changes constantly (Consolvo et al., 2004) through a long period (e.g., a lifetime).

For instance, Amir et al. (2015) presented their study on how a care team coordinated to provide care for children with complex conditions. The team included both health professionals and parents of the children. Through interviews, focus groups, and observations, they identified multiple characteristics that make such teamwork challenging. First, individual tasks and plans are loosely coupled for different health professionals and caregivers. Second, their plans will be revised continually. Lastly, different health providers engage with the patients at various different kinds of time scales. Having different moving parts executed by multiple care team members makes designing technology to support such teamwork a challenging task.

In addition to the diversity in a care team, as described above, it is also important to emphasize the role of people with health conditions, as their involvement greatly affects the outcomes of care. Similar to what has been found in the existing work on self-care for people with caregivers or care teams (Consolvo et al., 2004; Nunes & Fitzpatrick, 2015), Büyüktür et al. (2017) found that self-care activities are often performed collaboratively by the people with SCI/D and multiple caregivers or even clinicians who intermittently provide inputs. These teams of people work collaboratively to develop routines for performing different self-care activities, as people with SCI/D found that the routinization of self-care activities was important to maintain a sense of control of their lives. One key observation from Büyüktür et al. was that, as people with SCI/D had their own priorities and preferences, it often resulted in them selectively executing and adjusting the self-care activities. Moreover, people's priorities and preferences might also change with time, which meant self-care activities, which might already be very different from what was prescribed by the original self-care plan, would continuously need to be revised based on the priorities and preferences of people with health conditions to address the different changes in care.

These teams of family members, hired caregivers, medical professionals, and the PCTs need to collaboratively monitor changes in a person's health (Büyüktür et al., 2017) (e.g., sometimes life-threatening), care team dynamics (Consolvo et al., 2004), and adapt to the person's priorities in life (Pina et al., 2017), to address the health changes(Büyüktür et al., 2017; Büyüktür et al., 2018; Felipe et al., 2015) and develop care routines accordingly (Ackerman et al., 2018; Büyüktür et al., 2017).

While these studies demonstrated that self-care for people with health conditions requiring assistance from care teams (PCTs) is achieved collaboratively to improve the quality of life for them, it is important to recognize also that another critical goal for PCTs is to develop independence so that they can gain autonomy and a sense of control over life in their life-long health trajectories. The existing work in this area has shown that, such independence is collaboratively constructed, as well.

For instance, Birnholtz and Jones-Rounds (2010) used the context of senior care to examine the potential tension between privacy and awareness and how the elderly maintained their independence. They found that the elderly used different utilities, such as the physical attributes of their environments (e.g., porch), the temporal structure of their life and different routines (e.g., when to communicate with caregivers), and communication technology to mediate between the concerns for privacy and the need to support awareness to achieve independence. Based on their findings, they argued that independence and awareness are not necessarily the opposite of each other, as they see how facilitating a certain amount of awareness allows caregivers to have peace of mind so that caregivers will not try to monitor the life of seniors rigorously. This, in turn, allows seniors to maintain independence.

Büyüktür et al. (2018) studied self-care for people with SCI/D to examine how independence is developed and shaped under the care team context. They found that the care team collaboratively assisted the person with SCI/D to achieve both functional independence (i.e., doing self-care activities of a physical nature) and also effecting agency (e.g., making decisions on what and how to do self-care activities). During the process, different care team members, such as primary caregivers, secondary caregivers, and certain clinicians (e.g., occupational therapists and primary care physicians) shaped the development of the individual's independence in different ways with their own perspectives and preferences. On the one hand, they assisted the individual with SCI/D to attempt physical activity or followed the individual's request to conduct self-care activities in a particular way based on the individual's preferences. The goal set by the individual would be collaboratively achieved through the collaboration of care team members with different roles and responsibilities. On the other hand, they might push back on the individual's decision in situations where the decision collided with their own perspectives and goals. For instance, a primary caregiver might watch the nutrition intake of the individual with SCI/D closely as she might not otherwise be able to assist the individual if the individual is overweight. Such perspectives might be propagated through the structure of the care team to other care team members such as the hired caregivers, who usually follow the instructions of the primary caregiver. It is through the negotiation among care team members and the individual that independence is developed.

The studies presented above describe how self-care and the independence of a person with a health condition is achieved collaboratively for PCTs. Having care team members with different expertise, responsibilities, and time commitment means that a design to support chronic care needs to be attentive to these differences and assist the person with a health condition in coordinating with a diverse team. It is through collaboration among care team members that an individual can slowly develop her own independence (Birnholtz & Jones-Rounds, 2010; Büyüktür et al., 2018; Caldeira et al., 2017). To better support self-care and the PCT's independence, it is critical to carefully design the technology to support the collaboration within the care team. This dissertation builds on this previous literature about care teams and examines how users' control over data sharing within care teams can be facilitated.

I next review the literature on the use of data captured outside of medical environments to support collaboration for chronic care.

2.3 Everyday Data for Care (EDC)

Information needs vary widely among chronic medical conditions and disabilities. Significant research has examined the information needs and information sharing among people with chronic medical conditions and disabilities. For example, people want to share their status with their relatives, friends, and the larger social network. People readily seek both information (Civan et al., 2009; Klasnja, Hartzler, et al., 2011; Valdez et al., 2015) and emotional support (e.g., [Feng et al., 2004]) from these sources, including those who are not health care professionals. For instance, Skeels et al. (2010) reported that breast cancer patients seek and receive help from family members, other patients, community members, and professional connections. Valdez and Brennan (2015) and Valdez et al. (2017) highlighted the need for support and information within the patient's social network. In short, people with chronic medical conditions as well as people with disabilities engage in considerable information work (Hogan & Palmer, 2005; Kaziunas et al., 2013; Strauss et al., 2017), a type of patient work (Valdez et al., 2015).

Part of that information work and patient work, increasingly, is data work (Kaziunas et al., 2018), a term that extends the concept of patient work to involve raw data, including data from sensors, medical devices, and consumer electronics. Patients and caregivers must understand the uses of data, understand how to understand data, and know when to share data (and with whom) (Kaziunas et al., 2017). Sometimes patients and caregivers are left on their own to do data work.

In this dissertation, I focus on an important source of data for health care, namely everyday data for care (EDC).

Everyday data for care is defined as data captured about the everyday life of a person with a health condition, which could be useful for care. These data could be generated through different mechanisms, including sensors in a futuristic pervasive environment or those captured manually by care team members of people with health conditions (e.g., journal entries), or a combination of both (e.g., semi-automated tracking [Choe et al., 2017]). These data could include those that are commonly also collected during clinic visits (e.g., heart rate or blood pressure), data that characterize the person's behavior (e.g., sleep pattern) or emotional well-being (e.g., mood) and even contextual factors that could influence the person's life (e.g., weather).

In other words, EDC covers a wide range of data types that could be used to understand different aspects of a person's life.

The definition of EDC is very similar to that of patient-generated health data (PGHD), which has received significant attention from the research community in recent years. Figueiredo and Chen (2020) surveyed the literature in the areas of Health Informatics and Human–Computer Interaction to synthesize the findings from existing work surrounding the concept of PGHD. In this survey article, PGHD was defined as health-related data captured by patients or their care team members (i.e., caregivers) outside of medical environments. Figueiredo and Chen discussed different dimensions (e.g., what data to capture, who captures the data, whose data are collected) worth considering in designing the technology to support the use of PGHD, including sharing data with different care team members to support collaboration.

Another term that is closely related to EDC is observations of daily living (ODLs), for they contain patterns and observations about patients' lives that were not traditionally included in the medical record (Piras, 2019). In this dissertation, I use EDC to include PGHD and ODLs to focus on the potential data sources generated from a pervasive environment (e.g., a person's home), full of different physical or algorithmic sensors that could be used to support care. The definition is intentionally broad, as the relevance of data depends on the health conditions and interests of different individuals involved (Figueiredo & Chen, 2020). More importantly, I want to avoid centering the use of data on the "health conditions" of "patients." Instead, through the use of EDC, I emphasize their identity as human beings who have different priorities in life and how data could be used to support the different aspects of care to improve their overall wellbeing.

The definition of EDC also overlaps with Quantified Self (QS) (Quantified Self, 2020) and Personal Informatics (PI) (I. Li et al., 2010), as both QS and PI refer to the practice of using data captured about oneself to understand aspects of one's life. For instance, Li et al. (2010) introduced the term PI to refer to systems that facilitate the collection and use of data about themselves through understanding, reflection, and action. Li et al. developed a stage-based model of PI systems for understanding how people use PI data. Based on their survey and interviews with people who keep a record of and reflect on the information relevant to themselves, they identify five stages of people's PI practice: preparation, collection, integration, reflection, and action.

The model proposed by Li et al. can potentially be adapted to examine the practice of using EDC. The prominent difference is that EDC specifically focuses on using data for care, while QS and PI can include anything of personal interest. In this section, I will briefly review the literature on the benefits and concerns of using EDC. For a more comprehensive review (especially patient-generated health data), please refer to Figueiredo and Chen (2020).

Everyday data for care could be used to support many kinds of decision-making in health care. However, the range of data included in EDC and the context of data capture (e.g., at home) make EDC especially applicable to severe, long-term chronic conditions such as irritable bowel syndrome (IBS) (Chung et al., 2019), Parkinson's, dementia, and spinal cord injury/disorders (SCI/D) (Büyüktür et al., 2017). As chronic care requires consistent monitoring of how the lifestyle of a person with a health condition affects the person's health and life, collecting various details of possible triggers could be good for diagnostic tracking: care team members could use EDC to investigate how different factors (e.g., diet) trigger changes in a person's health (e.g., symptoms) and quality of life (e.g., sleep quality) (Karkar et al., 2017; Rooksby et al., 2014). Sharing these data within a care team could certainly be helpful as the person can work with caregivers and clinicians to collaboratively problem-solve (Raj et al., 2017). Moreover, a recent trend in the management of chronic conditions has shifted from a provider-controlled stance to a patient-centered one where people with health conditions take the lead in the care of their health (R. M. Anderson, 1995; Mamykina et al., 2006). Everyday data for care provides an excellent opportunity for people to become involved and take an active role in both understanding their health and decision-making.

With the proliferation of consumer sensing devices, a massive amount of EDC can be gathered that describe the physiological, behavioral, emotional, social, and other factors that could be relevant to care. As will be explained further below, these data hold great potential for supporting the collaboration of care teams to improve self-care at home, as they can be used to support individual care team members as well as between-member interactions.

For instance, Amir et al. (2015) used the case of engaging families of children with complex conditions to argue that engaging families was a complex and challenging task due to the lack of support for data sharing among different care team members. Families were often overwhelmed by the child's condition, and parents felt the lack of information during transitions as they would be taking more responsibility in care. Progress in health was often not monitored carefully, and different providers set up different goals, which further increased the difficulty of tracking progress. Additionally, health providers did not necessarily know how to engage with other providers. Having new providers join the team added to the challenge for coordination. To tackle these challenges, one of the suggestions made by Amir et al. was that sharing information among the team should be made easy to respond to different changes in health and support collaboration.

Indeed, the existing literature has shown multiple benefits of using EDC for people with health conditions.

At the individual level, research has shown that tracking and use of EDC allow people to understand their conditions (Ayobi et al., 2017; Mamykina et al., 2008), maintain a sense of control (Ayobi et al., 2017; Grönvall & Verdezoto, 2013; Mamykina et al., 2008), and make plans for self-management (Felipe et al., 2015; Mamykina et al., 2008).

For instance, Felipe et al. (2015) presented a study on how people with chronic pain (CP) could use Personal Informatics Systems (PIS) to improve their quality of life. They found that people appreciated several benefits provided by a PIS system. First, the data provided by PIS allowed them to understand their own condition, helped them plan for activities (to avoid more pain), and allowed them to personalize their self-care activities. Second, PIS could provide real-time feedback on different activities to help them avoid doing activities in a way that might stimulate pain. Such real-time feedback also gave them a sense of control, as opposed to worrying about how they might do things incorrectly. The ability to track data through technology allowed people to transfer the responsibility of tracking and monitoring to the technology so that people could focus on planning and other equally important aspects of their lives.

In addition to personal use, sharing these data could also create social benefits. Existing literature has shown that EDC can empower people with health conditions to have a voice in conversations with both both non-medical (Felipe et al., 2015) and medical personnel (Bagalkot & Sokoler, 2011; Murnane et al., 2018) and also support their interaction with clinicians (Chung et al., 2019; Schroeder et al., 2017), including allowing clinicians to gain a more holistic view of patients' self-care practices during clinic visits (Bagalkot & Sokoler, 2011; Chung et al., 2019).

For instance, Felipe et al. (2015) also found that, given the pain experience does not exhibit in physical form for other people, PIS systems could facilitate the sharing of pain data to help others surrounding them to recognize and understand the pain experience. Doing so had the potential of improving social acceptability of the pain experience and also how they handled the pain (e.g., the need to request a seat when pain increases). At the same time, sharing such data required additional considerations as people might want to release data in a nuanced way (e.g., data processing, representation, and different levels of access/transparency), depending on who was receiving the data. Their findings hinted at the need for fine-grained control over data sharing, which I will revisit again in this section.

The benefits of sharing EDC can also be extended to medical personnel: Bagalkot and Sokoler (2011) presented a sensor-based video recording app that allowed senior citizens who needed to perform rehabilitation exercises at home to document their performance and to use it as a medium to learn and discuss their progress. Bagalkot and Sokoler found that these recordings allowed senior citizens (users in their case) have a language (the video) to communicate with their health providers so that senior citizens and their health providers could collaboratively articulate what was going on. Therapists also found the data useful for helping them understand the aspects of senior citizens that were usually not accessible to them (e.g., how seniors performed their exercises at home).

While EDC provides a great number of benefits, existing research has also highlighted the challenges of utilizing EDC.

First, tracking EDC could be overwhelming, as EDC includes a wide range of data that are relevant to care, including the contexts that could facilitate the interpretation of other more directly relevant data types (e.g., heart rate) (Ayobi et al., 2017). Moreover, every person with a health condition experiences the condition differently and might have a unique perspective on what is important to track (Schroeder et al., 2018).

Second, people with health conditions might have difficulty making sense of EDC (Choe et al., 2014), as not everyone is proficient in reading data. As EDC includes a variety of data types about one's life, this issue could be faced not only by people without medical training, but also by medical professionals. For instance, Lee and Dey (2015) found that the use of observations of daily livings (ODLs) was useful in helping physicians to focus on special occasions and examine whether the data aligned with their own evaluation of people. Physicians, however, were concerned about how to integrate the ODLs data into their current practices. For one, they needed norms or standards for understanding and interpreting the ODLs data. For another, they needed mechanisms to help them correlate patterns with other data streams such as test results or other sensor readings.

Third, while care team members could help to make sense of EDC, they might have different expectations of what to track, the purpose of tracking, and, consequently, how to properly interpret the data (Bagalkot & Sokoler, 2011; Jacobs et al., 2015; Liu et al., 2011). For instance, Jacobs et al. (2015) presented their study on how health information (e.g., EDC) sharing preferences were different for cancer patients, doctors, and navigators, partly due to the misalignment of expectations. They found that some patients would hesitate to report or discuss emotional factors (i.e., loneliness) with their health professionals, because they think that "the doctors just won't care." Cancer navigators, however, actually considered loneliness an important factor to monitor. Doctors, as well, also expressed that it would be useful to report if there was a patient satisfaction issue, while the patients thought that "the doctors just won't change."

Lastly, revelations from the data could create undesirable impressions of the people with health conditions and affect their relationships with their care team members (Murnane et al., 2018). Privacy issues could be a major concern if these data are not handled properly (Chung et al., 2019; Murnane et al., 2018; Pina et al., 2017). People with health conditions need to find an appropriate balance between sharing EDC with different care team members (Prasad et al., 2012) to support collaborative monitoring and maintaining a sense of control (Murnane et al., 2018) and independence (Büyüktür et al., 2018) without the feeling of invasion of privacy (i.e., surveillance).

In addition to impression management and privacy concerns, prior research also suggests that maintaining fine-grained control over data is important for patients to negotiate a desired level of independence, namely the ability to fine-tune the details for sharing and how the data are shared. This is particularly true for patients with a physical disability, as they often want to acquire decisional independence and a sense of control over their lives. Büyüktür et al. (2018) used their findings on how independence was collaboratively achieved to argue that sensor-based systems designed to support the coordination and collaboration of care team members should allow the individuals to exert nuanced control over data for sharing (e.g., the granularity of data and the timing of sharing), as it was critical for the individual to maintain autonomy and direct her own care. Without such support, patients might be in a vulnerable position and lose control of their data to others or large institutions such as healthcare systems.

To summarize, the existing research has revealed the benefits of collecting, using, and sharing EDC to support both individual reflection and collaboration among care team members, while highlighting some challenges for care team members, including the person with a health condition. Our work follows this line of research to investigate how to support people in sharing a variety of EDC to support care collaboration while respecting their need for control and privacy. I next review the existing work on supporting sharing control and identify the gaps for further investigation.

2.4 Data Sharing Control and Privacy and Support

Sharing data can support different kinds of work, such as those of the government (Bowyer et al., 2018), research (Bowser et al., 2017), and coordination of professional and daily lives (Thayer et al., 2012).

Besides the benefits, the abundance of data poses a set of socially-oriented challenges. For instance, people have trouble understanding how their own data could be used by others (Gulotta et al., 2013; Vertesi et al., 2016). When data are shared with others, including friends, family, colleagues, and different organizations (e.g., a social media company or a government agency), people feel the need to carefully perform impression management (Choe et al., 2011; Vertesi et al., 2016; Voida et al., 2005) and negotiate relationships through data (Thayer et al., 2012). Additionally, people are worried about undesirable inferences or negative side effects as a result of others reading their data (Kumar & Schoenebeck, 2015; Thayer et al., 2012; Tolmie et al., 2016) and the consequences of data being leaked or abused (Langheinrich, 2001; Odom et al., 2012; Vertesi et al., 2016).

Concerns about the negative effects of sharing data have engendered research centered on privacy. Privacy has been generally defined in terms of two themes: as "the right to be left alone" (Warren & Brandeis, 1890) and as the ability to decide "when, how, and to what extent, information about them is communicated to others" (Westin, 1968). While the concept of privacy has continuously evolved in accordance with technical, social, and cultural changes (Nissenbaum, 2004), these two themes remain central to the research effort.

One approach to helping people with their privacy concerns consists of technical research that augments or facilitates user control.

Considerable research has been devoted to creating and revising privacy policies (and by extension data sharing policies). At first, researchers examined privacy policies, which state when specific data can be shared with specific recipients. Privacy policies consist of computational statements (Borders et al., 2005) in first-order predicate calculus or specialized computer languages. Access control is one of the areas that have developed various policies and languages for regulating data sharing and privacy. Access control refers to the technical and sometimes socio-technical mechanisms designed to regulate access to data. Originating in military use, access control is also prevalent in organizations as a means to structure how members of an organization access resources belonging to the organization. Several access control paradigms have been proposed, including role-based access control (RBAC) (Sandhu et al., 1996), relationship-based access control (Fong, 2011), and attribute-based access control (ABAC) (Servos & Osborn, 2017); I will selectively discuss RBAC and ABAC based on their relevance. More details on access control, including other existing access control mechanisms, can be found in the survey article by Kirrane et al. (2017).

In RBAC, users of a system are assigned to different roles that can subsequently give them the permission to access resources or execute actions. The concept of role facilitates the implementation of ideas such as inheritance between roles and separation of duties, which require multiple users to be involved to perform a critical operation. In ABAC, access is regulated by policies that utilize the attributes of the subject (requester), action (e.g., operations such as read and delete), resource/object (data), and environment (e.g., time, location and other factors of the situation). Compared to RBAC, ABAC provides a more flexible and robust way (e.g., through the object attributes) to accommodate other new resources that might not be known to the system and explicitly support the use of situation (e.g., contexts such as time and location using the environment attributes) to regulate access.

Despite this considerable research, end-users cannot or will not write and revise policy statements, finding them too complex and difficult (Kumaraguru et al., 2007; Luca & Zezschwitz, 2016; J. Zhao et al., 2016).

Instead, practice has swung to another approach to tackling privacy, which has been to allow users to create privacy settings through easier-to-use interfaces that use toggle buttons, elaborate tables, and other user interface widgets to manually manipulate privacy settings (e.g., Google's privacy settings).

The first category of user interfaces allows users to control the audience (i.e., data recipients). PViz (Mazzia et al., 2012) was an application that provided views with different granularity (e.g., group, sub-group, sub-group of sub-group) for users to understand how their profile information would be shared with their friends on social media based on their group memberships. It also proposed a mechanism to automatically generate labels for different groups that helped users understand the nature of the groups. Privacy Wedges (Raber et al., 2016) was an application that provided a user interface to allow users interactively select the audience with certain attributes (e.g., tie strength or friend group) to control social media sharing.

The second category allows users to tailor the data presentation before sharing with the target audience. My Data Store (Vescovi et al., 2014) allowed users to control the presentation of personal data by varying anonymity and using aggregation through mobile UI. PriCal (2014) allowed users to use mobile UI to specify privacy preferences over sharing calendar information on shared displays with three options, full, busy (no title), and hide. Epstein et al. (2013) proposed interactive techniques for users to manipulate visualizations of wearable data (e.g., from Fitbit) through gesture to prepare personal data for sharing. VeilMe (Wang et al., 2015) allowed users to 1) explore their own personality traits, 2) interactively manipulate the truthfulness of personality data being shared, and 3) automatically recommend default privacy settings based on personality traits and target audience.

The third category allows users to control both the data and the recipients through visual means. Reno (Iachello et al., 2005) supported computer-assisted location data sharing through two features: Instant Reply List (location data would be shared upon request by people on a pre-defined list) and Waypoints (automatically sharing data when visiting a pre-specified list of locations to selective recipients) to alleviate the burden of making a decision on every instance of sharing. Reeder et al. (2008) used a matrix representation with a tree structure display to enable access control through describing relationships between files and people's data access for the Windows operating system. Könings (2015) integrated a simplified matrix representation and the ability for users to define rules to control data sharing conditionally on a mobile platform. Bahirat et al. (2018) designed a layered mobile UI, powered by heuristics generated based on privacy settings data sets, for users to control Internet of Things (IoT) data sharing from coarse-grained (e.g., whose device and what data) to fine-grained (e.g., the purpose and frequency of sharing) control.

While these research efforts simplify and enhance the process of specifying sharing decisions, they do not properly address the challenges of sharing EDC to support care.

For one, with only a few exceptions (Bahirat et al., 2018; Epstein et al., 2013; Könings, 2015), most of the existing design lack support for fine-grained control that has been recommended by existing work to be an important tool for people with health conditions requiring care teams to negotiate their desired level of independence in their health trajectories. For another, these designs lack support for the collaborative nature of care for care teams, such as the need to perform collaborative monitoring or diagnostic tracking (Karkar et al., 2017; Raj et al., 2017; Rooksby et al., 2014).

Moreover, protecting a user against unintended information disclosures or unwanted solicitation is not the only important consideration; EDC needs to be *shared* dynamically to support care team members in addressing the changes in a person's health. Numerous studies have shown the efficacy of sharing health data, including in chronic care (Bagalkot & Sokoler, 2011; Chung et al., 2019; Murnane et al., 2018; Schroeder et al., 2017). To highlight this aspect of data, Kariotis et al. (2020) have suggested the need for the support of data sharing. In addition to data protection, in their view, data sharing systems should enable data owners who might have less capacity (e.g., knowledge or health/data literacy) to proactively share health data.

With the goal of supporting chronic care in the home environment, my work follows Kariotis et al.'s call to develop several means for supporting sharing, including using help from care team members, to tackle not only the privacy issues but also any challenges of proactive data sharing.

2.5 Summary

The existing literature has suggested that supporting care teams is important. Using data to support team-based care could enable collaborative monitoring and improve within-team interactions. Having a diverse range of care team members to participate in care means that data sharing, and thus systems design to facilitate data sharing, should carefully support the fine-grained control a person needs to direct data to different sub-groups within a team in a way that balances the information sharing needs while maintaining a sense of independence.

At the same time, there are some gaps in the literature that require further investigation to realize the full potential of using data to support care.

First, the existing literature on designing technology to support chronic care has demonstrated the collaborative nature of care, in which self-care activities for people with health conditions requiring care teams (PCTs) are achieved through the coordination and collaboration of care team members (Büyüktür et al., 2017; Consolvo et al., 2004; Nunes & Fitzpatrick, 2015). Such collaboration has also been shown to help PCTs construct the independence they need that is critical to improve the PCTs' sense of control (Birnholtz & Jones-Rounds, 2010; Büyüktür et al., 2018). While the ability to perform fine-grained control has been recognized to be a viable way for PCTs to effect agency (Büyüktür et al., 2018), existing designs lack support and do not properly consider the collaborative care team context.

Second, one of the open questions of EDC design raised by Figueiredo and Chen (2020) focused on the definition of health. The research community has recognized the importance of supporting people's other aspects of well-being, such as social and emotional wellness. Figueiredo and Chen argued that designing technology to support the use of EDC should avoid focusing solely on "fixing the health condition." This implies that future research for EDC should not limit itself to only data about a specific condition but also other data that could support care to improve one's overall wellbeing. Including all of EDC data sources means that system design should integrate mechanisms to reduce the complexity of configuring sharing settings, while still allowing people with health conditions to provide inputs to maintain a sense of control.

Third, Figueiredo and Chen (2020) cautioned that, while one of the main goals of EDC design is to support and empower people with health conditions to direct the use and sharing of EDC, designers should also stay conscious about how a design might shift the labor to people and generate additional burden. In other words, a system design to support EDC should take into consideration the balance between a sense of control and the level of involvement so that people with health conditions could truly benefit from the use of EDC. This is echoed by Kariotis et al. (2020) through their suggestion of design supporting data sharing for people with less capacity (e.g., health literacy).

In the section below, I state the gaps I identified from the existing literature, which I will address in this dissertation.

- The existing literature on design to support sharing control has limited support for fine-grained control and does not properly consider the care team context.

- The existing literature mostly focuses on sharing a small set of data types that are currently available, but fails to consider the increasingly available sensors that could generate an abundance of data, and how data sharing could be simplified with input from data owners (i.e., the people with health conditions) to avoid overwhelming the data owners.
- The need for a sense of control and the amount of data also highlight one aspect of data sharing for care that is critical but has not been properly addressed: supporting different levels of participation in accordance with the capacity of a person with a health condition to manage data sharing.

In the following chapters, I will present three studies that attempt to address each of these gaps in the literature. In Chapter 3, I present a user interface developed through co-design with a person with a health condition. This new design supports fine-grained control and more importantly, explicitly takes into consideration the use case of sharing data in a care team context. In Chap 4, I investigate the possibilities of employing user-generated groupings to simplify data sharing configuration to accommodate the increasing number of available data sources and keep the sharing configuration with care team members manageable. In Chapter 5, I explore the possibilities of using care team members and machine agents to serve as delegates and manage data sharing for care so that people with health conditions could direct data sharing through these delegates while focusing on other priorities in life. I will conclude with future directions for this stream of research to improve the support for sharing everyday data for care (EDC).

Chapter 3

Data Checkers: A Grid-based UI for Managing Everyday Data Sharing to Support Collaborative Self-care

3.1 Introduction

The Human-Computer Interaction (HCI) and Ubiquitous Computing (Ubicomp) communities have recognized the complexity and challenges of allowing users to manage the sharing of sensor data to support chronic care. While usable privacy and security research in these fields has proposed a number of designs for authoring privacy settings and sharing settings (or policies), these designs are not suitable for care: they do not support fine-grained control over data details or do not take into consideration the chronic care context (Lipford et al., 2010; Reeder et al., 2008). As an example, existing systems do not include support for dynamically changing care teams, the fine-grained control necessary to support personalized sub-groups within care teams, or the support necessary for the long term. As such, this chapter[3] reports my investigation into a user interface design, which addressed these concerns, to better support data sharing within care teams.

In this work, I have sought to find a middle ground technical solution that is com-

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[3] Adapted from a paper accepted for publication: Hung, Pei-Yao, Drew Canada, Michelle A. Meade and Mark S. Ackerman. "Data Checkers: A Grid-Based UI for Managing Patient-Generated Data Sharing to Support Collaborative Self-Care." *Frontiers in Computer Science* (Hung et al., 2022)

prehensive enough to allow fine-grained control of data sharing without overwhelming users with complex representations. I did so by co-designing with a person with a health condition to create an application with a grid-based visual interface. After developing my system, Data Checkers (DC), I performed a qualitative evaluation to understand its potential.

3.2 Related Work

In Chapter 2, I have reviewed literature that provides the background on the setting I examined: the potential of sharing everyday data for care (EDC) to support care coordination and collaboration. I also presented existing approaches for supporting data sharing, including technical mechanisms such as data access policies and user interface design to support the creation and management of data sharing settings. Below, I revisit the latter and state how this research is built on and extends existing work.

The main focus of this chapter is Data Checkers, a system I developed to support the management of sharing settings through a visual user interface with a preview utility to help users understand the impact of their sharing settings. I will describe the system design and implementation in more detail later. Here I briefly summarize the underlying mechanism to regulate data sharing.

In Data Checkers, I use concepts contained in attribute-based access control (ABAC) to model users' decisions over data sharing to define policies that regulate data flow based on attributes of data recipients. By doing so, I achieve a similar effect as role-based mechanisms while preserving the flexibility for extension. The conceptual difference from ABAC is that, instead of considering what action is allowed (i.e., read/write as in file operations), Data Checkers allows users to specify the type of fine-grained control (e.g., only sharing a weekly summary for a specific type of data) that will be applied to a data flow. In other words, Data Checkers uses a simplified version of ABAC that allows individuals to explicitly specify desirable control over data to tailor how data are received by others.

I propose a simplified model for the following reasons. First, users (i.e., people with a chronic condition or care-team members) can make simple decisions that focus on sharing and hide the technical details of data operation such as reading and writing. Second, different from a team of IT professionals hired by organizations to create a large set of policies in a comprehensive format, such as XACML (OASIS Open, 2013), to govern the access of organization resources, individuals without technical expertise should be able to develop their sharing policies starting from very basic cases and then incrementally refine their decisions. The simplified format used in Data Checkers is designed to capture the crucial aspects of data sharing and preserve some flexibility to cover a useful number of cases for supporting chronic care collaboration.

Next, I review existing designs that support control over data sharing.

Researchers investigating controlling data sharing have focused on two different research streams to mediate between users and the underlying access control mechanisms. The two research streams align with the major two factors that people consider in controlling data sharing (Bahirat et al., 2018): person (recipient) and data.

The first stream of effort focuses on the person dimension, with specific support for using meaningful groupings to help users categorize data-receivers. One prominent application area is to select who should receive data on social network platforms (e.g., Facebook) where users need to decide who or which social circles should receive a status update. For instance, PViz (Mazzia et al., 2012) provided views with different granularity (e.g., group, sub-group, sub-group of sub-group) for users to understand how their profile information would be shared with their friends based on group memberships. Privacy Wedges (Raber et al., 2016) proposed a user interface to allow users to interactively select audiences with certain attributes (e.g., tie strength or friend group) so as to control social media sharing.

The other stream of effort focuses on the data dimension. Since data need to be presented for human consumption, it is important that a user can exert control over how the data are presented. Existing work has explored the use of user interface (UI) designs and interactive data manipulations to prepare data for sharing. Epstein et al. (2013) applied a value-sensitive approach to developing a set of interaction techniques for people to interactively shape the presentation of their step data for sharing in order to preserve the benefits of sharing while minimizing harm (e.g., revealing information in an unexpected way). Similarly, Wang et al. (2015) proposed a system, VeilMe, that allowed users to interactively explore and understand their own personality trait data and to apply obfuscation to data at different levels (i.e., a trait or a sub-trait) to avoid sharing the exact details for different social groups in an organizational context.

Other studies proposed semi-automatic approaches for shaping data presentation.

Vescovi et al. (2014) proposed a system, My Data Store, that allowed users to select disclosure preferences of personal data streams such as location, social interactions, and mood using aggregation and anonymization. Schaub et al. (2014) proposed a context-aware system, PriCal, that allowed users to selectively share calendar entries for colleagues nearby a shared display with three levels of privacy: complete information, busy (with title hidden), and none.

There have also been designs that accommodate the need to control both factors. For instance, Reno (Iachello et al., 2005) supported computer-assisted semi-automatic location data sharing through location-based and recipient-based rules. Reeder et al. (2008) used a matrix representation to enable access control through describing relationships between files and people's data access. Könings (2015) employed a similar matrix representation with reduced complexity on a mobile platform through rule-based mechanisms. Bahirat et al. (2018) designed a data-driven layered mobile UI for users to control IoT data sharing (see Figure 6 in [Bahirat et al., 2018]), from coarse-grained (e.g., whose device and what data) to fine-grained (e.g., purpose and frequency of sharing) control.

The designs introduced above have different focuses on people and data in terms of the audience size and the types of control. The audience size ranges from a family, an office unit, contacts, an organization, social media, to the Internet. Most designs provide only coarse-grained control, and only a few support fine-grained control (Bahirat et al., 2018; Epstein et al., 2013; Könings, 2015). The scenarios considered include personal data control for sharing with digital devices/services, social media sharing within social circles, and office sharing with colleagues. Less is known about how to design UIs for people to exert fine-grained control over sharing, especially within healthcare. Existing consumer health apps also lack the capability of fine-grained control (e.g., Apple Health,[4] Fit[5] by Google, and HealthMate[6] by Withings). To the best of my knowledge, there were not any individual-facing applications (i.e., for people with health conditions) designed to support fine-grained control over EDC sharing with care teams for the long-term. There is a need for a design that allows PCTs and their caregivers to exert fine-grained control over EDC sharing while taking into consideration the needs of a care team and of the conduct of their chronic care. Data Checkers offers one such prototype.

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[4] https://www.apple.com/ios/health/

[5] https://www.google.com/intl/en_us/fit/

[6] https://www.withings.com/us/en/health-mate

I next turn to my design process, a representative scenario of care, and a set of design requirements.

3.3 Design Process and System Overview

3.3.1 Co-designing the System

In order to create a person-centered solution for managing EDC sharing, I adopted a co-design approach to work with a person (PCT) with similar care needs as people with SCI/D to explore the design space and develop an application concept.

I first describe the process of collaborating with this person in designing DC.

Co-design is an effective way for participants to organize and illustrate their experiences (Hieftje et al., 2014; Hong et al., 2018; McCarthy et al., 2017) and bring them into the design process. Co-design also allows participants to join the research in a way that can be dynamically adjusted to a participant's level of energy and comfort in taking the lead, both of which are particularly important for participants who are dealing with illness (Lindberg, 2013).

My research team formed a partnership, based on prior research interactions, with a person with congenital muscular dystrophy, a condition that in this case has resulted in severe physical disability and requires complex care management. Muscular dystrophy is a progressive and degenerative condition in which the person has diminished use of his limbs. In addition to muscle weakness, his respiratory system is also affected and requires additional care and monitoring. As a result, he uses a power wheelchair and requires assistance from caregivers to navigate different aspects of everyday life such as commuting, monitoring heart rate and fluid intake, assistance during the night, and using a ventilator when required. He has a team of people who assist him with self-care, including parents as his primary caregivers, a sibling as a secondary caregiver, 10-15 hired caregivers, and clinicians.

The partnership was beneficial as my co-design partner has the perspective of a person with a severe chronic condition working with a care team and is passionate about the potential of technology to improve the life of PCTs like himself. As a co-design partner, he was instrumental in shaping the design of DC and provided valuable insights on the life of a PCT.

During an eight-month engagement with weekly working sessions, my co-design partner and I worked to collaboratively explore the design space of EDC sharing applications, based on prior research and personal experience.

Our co-design process followed the Cooperative Inquiry method proposed by Druin (1999) and subsequently extended by Garzotto (2008). Druin argued that researchers should systematically involve users as design partners to participate in the entire research, design, and development process.

The first step of Druin's process is contextual inquiry, a form of user-centered design (UCD) (Cooper et al., 2012). We conducted observations and reflections on the chronic care process as well as stakeholders' involvement (e.g., caregivers and medical professionals). We iteratively discussed our findings and created representations such as personas and scenarios to document stakeholders' experiences of collaborating on care. These personas and scenarios also made explicit potential concerns and issues in sharing EDC. This step mapped out an understanding of the lived experience of a person with a severe chronic condition that could be used to ground the design and to examine what features were needed, in our case, for a system to facilitate data sharing with care team members in a way that respects a person's need for control.

Druin's second step is technology immersion, to allow design partners to get suitable exposure to technology, in our case, sensor data and sensing devices. We surveyed commercially available sensing devices and techniques so that our co-design partner understood what data could potentially be captured to characterize different aspects of people's health.

Druin's third step, participatory design, consists of collaboratively exploring potential designs through an iterative process. Based on the personas, scenarios, and understandings of sensor data (the previous two steps), my co-design partner and I investigated potential design requirements. We also created design artifacts such as sketches, lo-fidelity paper prototypes (Snyder, 2003), and hi-fidelity interactive mock-ups to iteratively design a software system that could be used to manage EDC sharing with care team members while being mindful of PCTs' concerns about independence and privacy.

Exploring different designs included the basic user interface. The co-design partner was passionate about games in general, and often brought up his observations about games as examples of visual interfaces that would allow him to exert control. Examples of games we examined ranged from poker cards, board games, to 3D computer games.

The design exploration therefore moved away from a typical smartphone app with a hierarchy of lists and toggles to a more visually-oriented user interface featuring elements that could be viewed at a glance. The design exploration also started examining designs where users could easily change states by rearranging different visual elements (as in games). My co-design partner and I brainstormed ideas, and I drew sketches that served as a medium for us to collaboratively iterate on designs.

Overall, the co-design process my co-design partner and I led to three outcomes. The first was scenarios of use. The second was a set of design requirements, based on standard usability concerns and in care requirements. The third outcome was an application concept, Data Checkers (DC). At the end, I implemented the agreed-upon design as DC, a web application which featured a grid-based interface, as shown in Figure 3.1.

At the end of the co-design process, I invited our co-design partner to be a co-author of a paper for this project to acknowledge his contributions to the research (Hung et al., 2022).

3.3.2 Care Scenario

Here I present one of the scenarios envisioned for our design. The scenario uses a person with SCI/D to ground the design requirements and the evaluation of our design.

The care scenario: Peter is a 19-year-old college student with spinal cord injuries due to a car accident that happened three years ago. With quadriplegia, Peter's upper limbs, trunk, and lower limbs are paralyzed, with only limited control over some parts of his upper body. As a result, Peter has a limited range of motion and physical activity without assistive devices. Peter, like others with quadriplegia (tetraplegia), also lost the ability to sense his body. For instance, he does not feel thirsty even if needing water, and so he cannot maintain proper hydration. Peter, therefore, needs assistance to perform various self-care activities to keep himself healthy. These activities include both doing and monitoring fluid intake, stretching, executing a bowel/bladder program, checking his heart rate, checking his body temperature, and moving his body during sleep to prevent pressure sores.

Such assistance comes from a dynamic team of family members, hired caregivers, and clinicians. Peter's mother is his primary caregiver who oversees his care. Peter and his

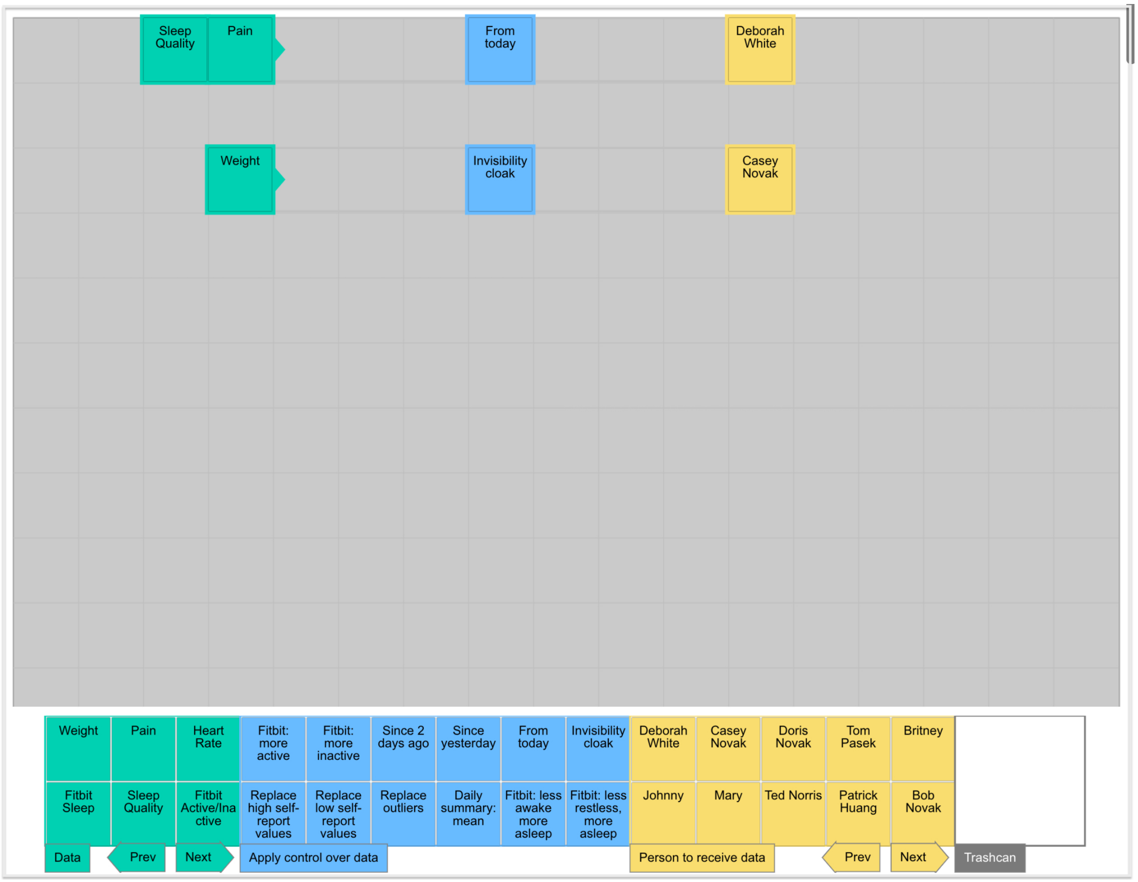


Figure 3.1: Data Checkers has a grid-based interface for specifying sharing settings.

mother hire 10-15 caregivers who are college students to take shifts and assist him day and night. Sometimes, a caregiver cannot make their shift or has to leave the position permanently for school or work. Peter's father and brother then have to substitute to assist until more caregivers can be found or hired. Similarly, adjustments need to be made when Peter's health changes. The primary and hired caregivers will then monitor more factors, including heart rate, fluid intake, sleep quality, and physical activity, in order to investigate potential causes and to develop care routines to manage any health contingencies. Clinicians from different clinics and health systems, including his primary care provider (family physician) and his Physical Medicine and Rehabilitation (PM&R) doctor, are involved when their medical expertise is needed, especially when Peter's health worsens. All these care team members would benefit from seeing data about Peter's health and care.

3.3.3 Design Requirements

Based on the prior literature, observations and interviews from my and others' prior work (Ackerman et al., 2018; Büyüktür et al., 2017; Büyüktür et al., 2018), and the co-design process we formulated five requirements necessary to adequately support the control of EDC data sharing for people (PCTs, such as Peter) to share with their care teams. While these requirements were developed within the context of SCI/D care, we believe they are true for other conditions that require similar care. This list of requirements is not exhaustive. Other requirements may be uncovered in the future, but we believe if these are not satisfied at a minimum, an application will not adequately address the data sharing needs of people in severe chronic care settings such as SCI/D.

These five requirements build on each of the previous ones. The requirements are:

Require1: Provide a user-friendly interface for specifying sharing settings. As a basic requirement, a system should provide a user-friendly interface that people without technical expertise can use (Demiris et al., 2008). Users should be able to navigate what Norman (2013) called the "gulf of execution," the alignment of system capabilities and what users perceive to be achievable through the system. Users (i.e., PCTs should be able to quickly learn how to use the system to efficiently accomplish what they intend to do (Rubin & Chisnell, 2008). With the goal of controlling their data sharing (e.g., including data from 20 sensors), users should be able to create and modify sharing settings easily, without having difficulty in using the interface to achieve their goal (Bevan et al., 2015; Cooper et al., 2012; Kuniavsky, 2003).

Require2: Support sending data to multiple members of a sufficiently-sized care team. Self-care is often a collaborative effort (Ackerman et al., 2018; Büyüktür et al., 2018; Nunes & Fitzpatrick, 2015). Care team members may need to have access to the same set of data to support day-to-day collaboration, including monitoring. Research has shown that such collaborative monitoring is beneficial or even critical (Birnholtz & Jones-Rounds, 2010; Caldeira et al., 2017). A system to support data-sharing within a care team must be able to support sharing specific types of data with multiple care team members. Our co-design process revealed that a size ranging from 10 to 20 is necessary for SCI/D (Büyüktür et al., 2018), which includes family caregivers (1-5), hired caregivers (5-10), and clinicians who closely work with the person with a health condition (around 5). Users (PCTs or their proxies) should be able to express how they want to share different data with each care team member, as opposed to a one-size-fits-all setting for everyone.

Require3: Support understanding of sharing settings. A system should present sharing settings for the care team in a way that is easy to comprehend. Users should be able to answer basic questions (Büyüktür et al., 2018) such as "Who has access to the heart rate data?", simply by looking at what is shown. PCTs and caregivers should be able to navigate Norman's (2013) "gulf of evaluation," letting users assess the state of the sharing. In the context of care, a system should also support users in answering questions such as "How do my data look like for my father?" so PCTs or their helpers can understand how sharing settings have affected the resultant data flows.

Require4: Support PCTs (or their primary caregivers) having fine-grained control over their data. In collaborative self-care, one should be able to control how much EDC could reveal about one's life by having fine-grained control over the sharing of EDC within the care team. In additions to users being able to choose recipients (Require2) and understand what the sharing settings are (Require3), they should be able to closely control how much detail is shared with each recipient (Büyüktür et al., 2018; Murnane et al., 2018; Prasad et al., 2012). This could include, but is not limited to, hiding or manipulating certain data (Epstein et al., 2013) and presenting summaries instead of raw data (Büyüktür et al., 2018). For example, through the co-design process, we identified four kinds of tools, which we termed "controls," that can help PCTs control the level of detail (e.g., daily summary), length of history (e.g., up to 7 days or 3 hours), the shape of data (e.g., remove outliers), and visibility of data (e.g., temporarily suspend sharing).

Require5: Support long-term sharing management by addressing health and care team changes. Chronic care is a long-term process (perhaps a lifetime), where the care team continuously creates and re-creates care routines to manage health contingencies (Ackerman et al., 2018; Büyüktür et al., 2017). This process requires monitoring different health indicators and care activities (Karkar et al., 2017; Rooksby et al., 2014). As well, members of a care team come and go for various reasons such as having multiple responsibilities and priorities (e.g., other jobs), relocating for job or school, and accommodating changes in a person's health (e.g., new symptoms or comorbidities) (Büyüktür et al., 2018; Consolvo et al., 2004). A system designed to support care should make it easy to manage data sharing to accommodate different occasions (i.e., health or team changes). This includes capabilities to tailor sharing settings for a particular set of data or people through understanding and repurposing existing sharing settings.

Data Checkers was designed to fit these requirements. We stress that while this list of requirements is by no means exhaustive, it includes a range of considerations that are critical for the care of PCTs (i.e., people with SCI/D). We believe these requirements will also be true for many people with severe care needs who are able to be involved with making care management decisions.

3.3.4 Data Checkers System Overview

Data Checkers (DC) was designed to manage EDC sharing, based on the design requirements outlined above. As shown in Figure 3.2, DC contains two features, the grid-based interface and a preview, that are particularly important to allow users (i.e., PCTs or their proxies) to implement fine-grained control and support the ongoing management of self-care.

The grid-based interface, similar to what is usually seen in checkers and chess, allows users to strategically express data sharing preferences for different stakeholders. Users can (a) place different blocks on the grid to specify how they prefer to share data with different care team members and (b) dynamically adjust the location of blocks to change sharing settings in reaction to changing health conditions and changing relationships among care team members. After specifying sharing preferences, users can (c) preview data according to stakeholders' perspectives to understand how data sharing is regulated by any given sharing setting.

3.3.5 Creating Sharing Settings

In DC, users configure sharing settings by laying out visual blocks on a board. As shown in Figure 3.3, there are three types of blocks: person (yellow), data (green), and control (blue) blocks. The lists of data, person, and control blocks can be extended if necessary.

- Person: DC currently supports sharing within a moderately-sized care team, in-

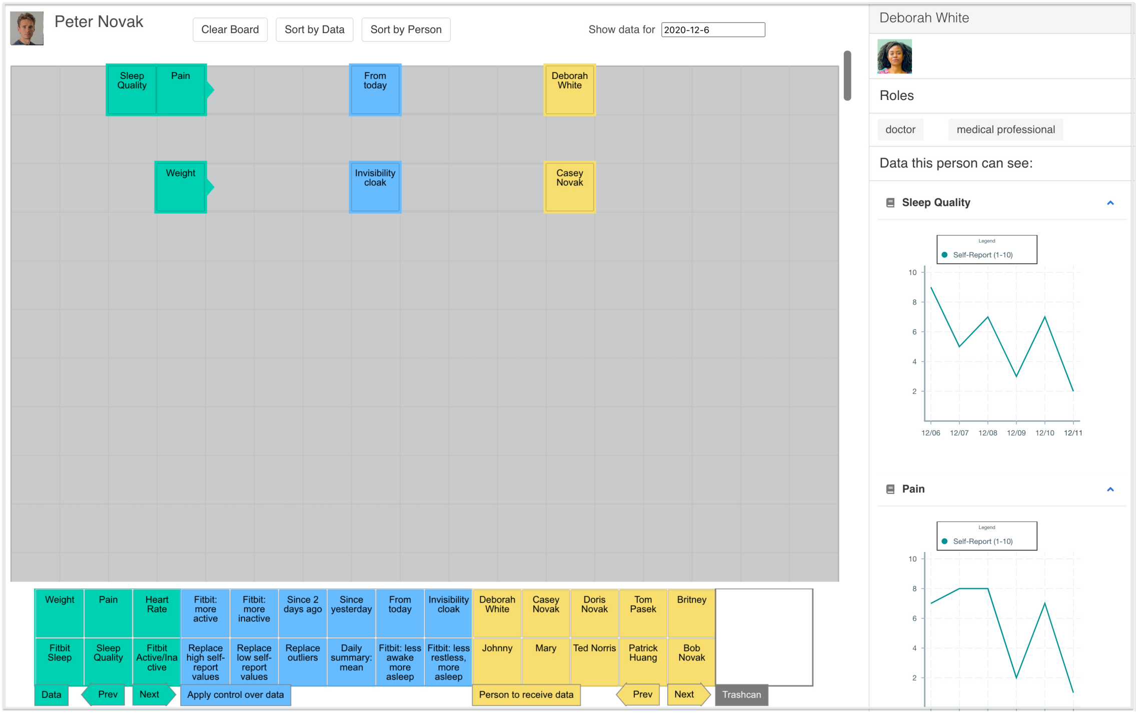


Figure 3.2: Data Checkers: On the left is (a) a grid-based interface for specifying sharing settings, and on the right (c) is a panel that shows the preview of data being shared in a recipient's view. Profile photos by Julian Wan and Leon Ell' on Unsplash.

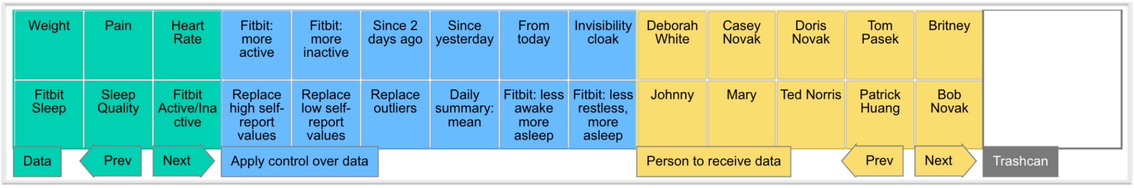


Figure 3.3: Essential elements in Data Checkers: On the left are blocks that represent different data sources (e.g., Heart Rate and Sleep Quality). On the right are yellow blocks that represent different people (e.g., Johnny and Doris Novak) with whom to share data. In the middle are blue blocks that represent different controls (e.g., Daily Summary) that can tailor the details being shared.

cluding family caregivers, hired caregivers, and clinicians (e.g., occupational therapist, doctor, nurse).

- Data: Data sources can include biomedical (e.g., heart rate), behavioral (e.g., activity status), and self-report data (e.g., pain).
- Control: There are four categories of controls (12 in total), tools that tailor the details of data being shared (e.g., share data only as an aggregated daily summary). These were the outcome of the co-design process described in Section 3.3.1.

There are two simple rules in Data Checkers that define how different blocks work together.

- Rule 1: A type of data (as a block) can be received by any person (as a block) on the right in the same horizontal row.
- Rule 2: Any control block being placed along that segment between a data block and a person block regulates how the person receives the data.

With these two simple rules, Data Checkers supports three basic operations that make it easy to create, modify, and extend sharing settings through visual composition of visual blocks. Figure 3.4 shows one example for each of these actions.

First, to create a sharing setting to give a person access to certain data, a user can simply put a person block (e.g., Dr. White) on the right of a data block (e.g., Heart Rate). Based on Rule 1, configuring these two blocks in such a layout indicates that data flow could be initiated to allow this person, Dr. White, to access raw data from this data source, Heart Rate. This data flow will not be restricted, as there is no control applied.

Second, to modify a sharing setting, such as adding a restriction (i.e., limiting access to data to the past week), a user can simply put a control block (e.g., Past Week) between the data and person blocks. Based on Rule 2, as the control block has been put in a location between the data and person blocks, it will be applied to the data flow (e.g., delivering heart rate to Dr. White). That is, the heart rate data will be processed by a specific control before the recipient can read. In this case, data generated prior to the past week will be filtered out, and data that are left will be delivered to Dr. White.

Lastly, to allow an additional person (e.g., the nurse Johnny) to have the same sharing settings as an existing person (e.g., Dr. White), a user can simply add the desired person (Johnny, in this case) to the right of people (Dr. White in this case) already included in the sharing setting. Based on Rule 1, this new person will receive the same data.

Moreover, based on Rule 2, this new person will receive the same data after the same controls had been applied. Essentially, data flow to this new person, Johnny, will be the same as that to the existing people (i.e., Dr. White).

Note that the above example only demonstrates how multiple care team members can be configured to receive specific data in the same way through the visual groupings of blocks that represent those care team members in a row. The same logic could also be applied to allow multiple data types and controls in the same sharing setting. The combination of Rules 1 and 2 allows users to visually define sharing settings that describe data flows consisting of multiple data types, multiple controls, and multiple recipients simultaneously, which is an advantage of this grid-based interface.

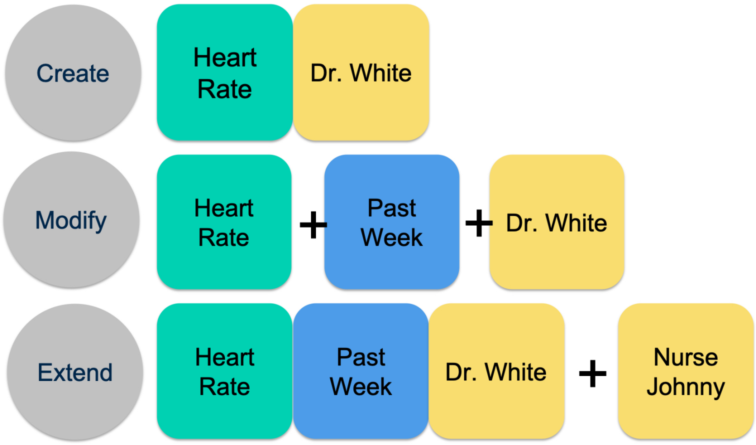


Figure 3.4: Data Checkers supports three basic operations that make it easy to specify and reuse sharing settings: create (top), modify (middle), and extend (bottom).

Following these two rules, users can strategically use the three basic operations to add and remove blocks on the board to allow or disallow people to receive different data sources. DC also allows users to enable and disable sharing settings within a selected row.

Note that laying out a set of blocks (e.g., Heart Rate, past week, Dr. White) in the first row has the same effect as laying out the same blocks in any other row. By doing this, DC offers users the flexibility to arrange sharing settings in a personalized manner.

To support managing data sharing with different care team members, Data Checkers also supports creating sharing settings using roles such as “primary care professional,” "nurse," or even "medical professional," similar to the use of roles in role-based access control (Ferraiolo & Kuhn, 1992; Sandhu et al., 1996). With both the individual and role blocks, it is possible for users to create sharing settings that are conflicting. Currently, Data Checkers defers to the most specific (e.g., for the individual) sharing decision when a conflict exists. This resolution mechanism also enables users to create exceptions for a specific individual (e.g., Patrick).

As the number of sharing settings increases, it is expected that users will need support to find sharing settings that involve a specific person or data type. DC allows users to re-layout sharing settings through "sort by data" and "sort by person" features. The sort-by-data feature allows users to reorder each row of sharing settings so that sharing settings that share a similar set of data types will be put into consecutive rows. Based on the same logic, the sort-by-person feature allows users to display sharing settings that share a similar set of recipients together. These two features make it easier to locate sharing settings about a specific data type or care team member.

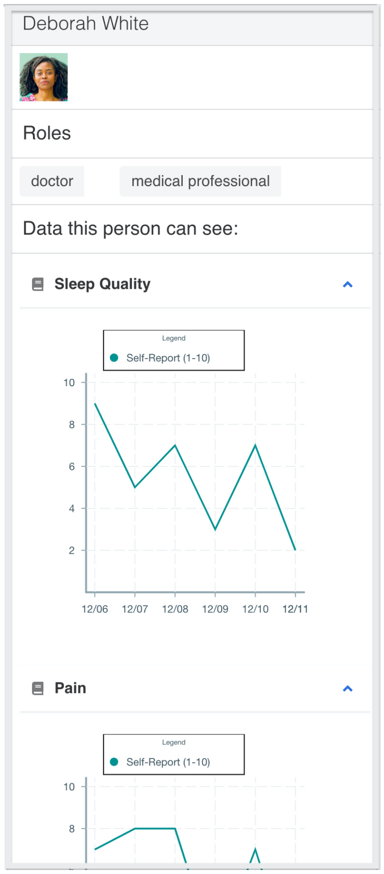
Additionally, there is a "clear board" feature that allows users to remove all blocks on the grid-based interface in case users need a clean start. The feature is expected to be useful to research participants. A future version that allows users to remove multiple rows of blocks simultaneously through selection could be implemented.

Note that in the remaining part of this chapter, I will use "sharing setting" to refer to a data-controls-recipients tuple that specifies "I want to share what data (data) to whom (recipients) after some data processing (controls)."

3.3.6 Previewing Data from the Stakeholders' Perspectives

The other major feature of Data Checkers is the ability to see a preview of data flows from the perspective of the data's recipients. As prior work (Büyüktür et al., 2018) suggests, allowing PCTs to see how data will be presented is important; users want to understand the effect of sharing settings. In DC, users can see the effects of sharing settings when viewing different care team members (Figure 3.5). This feature is designed to allow users to 1) experiment with different combinations of person, control, and data blocks while learning about the effects, and 2) verify whether data sharing settings have been configured as intended.

For instance, if a user indicates that she wants to share both sleep quality and pain



Deborah White

Roles

doctor

medical professional

Data this person can see:

Sleep Quality

Pain

Figure 3.5: Data Preview: showing data access (Sleep Quality and Pain) for Deborah White. Users can use the data preview to see the effect of the sharing settings. The profile photo used in this screenshot is by Leon Ell' on Unsplash.

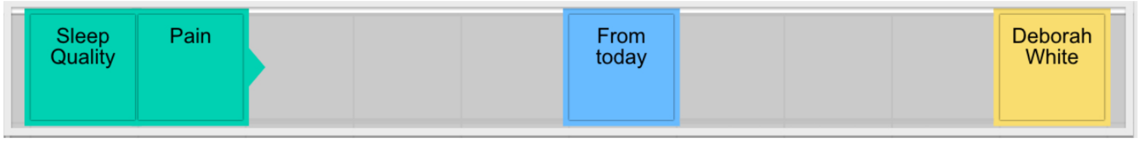


Figure 3.6: On this board, there are sharing settings that enable Sleep Quality access for Deborah White, in addition to Pain data.

with her physician, Deborah White, she can use the data preview capability to examine whether this physician will receive data as planned. As shown in Figure 3.6, this user can select Deborah White on the board, and the panel on the right (see Figure 3.5) will display information about Deborah White, including profile photo, name, and roles, as well as the different data, presented in visualizations, to which Deborah has access, given the current set of sharing settings.

In summary, Data Checkers has been designed to be easy to use and adapt. The interface uses a common metaphor and can be easily extended to new devices or personnel. Rules can be added by the users, caregivers, medical IT professionals, or by other users. Next, I turn to the architecture of DC and the server architecture that powers applications such as DC.

3.4 System Architecture and Implementation

DC was implemented as a web system. The architecture of DC consists of a frontend web user interface to support user interactions and a set of backend server-side application programming interfaces (APIs) (Mozilla & individual contributors, 2022a) that support the management of data sharing settings and the simulation of EDC data flow. In this section, I describe different system components that support DC in more detail and discuss how these components work together to provide an extensible architecture for managing EDC sharing.

3.4.1 DC Frontend User Interface

The frontend user interface of DC consists of four components: the grid-based user interface that supports the user-manipulation of data sharing settings, the data preview panel that displays data visualizations by simulating data sharing settings, a data sharing settings translator that translates the visual composition of different blocks that represent sharing settings based on the rules defined in the previous section into JavaScript Object Notation (JSON) format (Mozilla & individual contributors, 2022f) to be stored in a database, and a controller that detects important events, updates system state, performs queries, and directs data to different user interface components for display.

The frontend user interface was written as around 16000 lines of JavaScript (Mozilla & individual contributors, 2022e) and additional lines of HTML (Mozilla & individual contributors, 2022d) and CSS (Mozilla & individual contributors, 2022c) using the popular web user interface library React (Facebook & individual contributors, 2022). Additionally, the frontend uses libraries, such as Redux (Abramov & individual contributors, 2022) to perform state management and Axios (Zabriskie & individual contributors, 2022) to manage interactions with the backend APIs through HTTP requests.

Grid-based User Interface and Blocks

The main interface, including the grid-based board and three types of blocks (as seen in Figure 3.2) detects user interface events (e.g., mouse clicks) and associated events with different user interface elements (e.g., the color blocks or a grid on the board) to support interactive manipulation. For accessibility, DC supports only mouse clicks, instead of mouse dragging events. DC associates the events with user interface elements at different locations to determine (1) whether a color block (i.e., data sharing elements such as a data type, a recipient, or a control) has been selected (e.g., “pick up”) and (2) whether a block should be allocated to a particular grid.

There are three types of blocks–person, control, and data–that represent the three essential elements in sharing settings. These blocks are generated based on the corresponding registries in the database, which will be described in more detail in the backend architecture.

Blocks added to the grids by users (e.g., PCTs or their proxies) are stored as part of the system state, including the sharing setting element associated with each block (e.g., a primary caregiver named Mary) and the grid location (i.e., coordinates expressed in row and column). Each user interaction of adding or moving blocks will trigger an update to the system state, and hence the rendering of these blocks. By applying algorithms to the system state, functions such as “sort by data,” “sort by person,” and “clear board” were implemented to assist users with managing sharing settings, as shown in Figure 3.2.

Preview Panel

The preview panel displays basic profile information of a selected person block (e.g., Dr. White) and provides a simulated view of what this potential data recipient should see based on the current sharing settings. The simulation is done through the following process. DC will query the backend API to retrieve EDC data. As will be described later, the data retrieval will be regulated by a user’s data sharing settings, including applying data processing utilities indicated by "controls." The query retrieves the data that the recipient can see. The preview panel will pass the data to *data display containers* that serve as general interfaces for displaying different EDC data. These *data display containers* will check the data types and use the corresponding *data extractors* to extract data from the database into a format that can be properly displayed by the charts currently supported by DC, including a line chart, a dot chart, and a bar chart. While DC currently only supports three types of charts, more charts can be implemented through the mechanism of *data display containers* and *data extractors* to extend support to additional EDC data types.

Functional Components: Update Sharing Settings and Refresh Preview

The two above components mainly deal with the display of sharing settings, user interaction, and simulation of data preview. The other two components, the translator and the controller, serve to connect different user interactions and queries with the two user-facing components.

The first functional component is the *data sharing translator*, or translator. The translator subscribes to the changes in the user interface (i.e., the grid-based interface), and will translate the visual blocks' layout, when an appropriate change occurs, into the appropriate JSON-based settings for use in the database.

The second functional component is the *controller* that actively monitors changes in sharing settings, decides whether a new query is necessary to present the proper simulation of the data preview, and then queries and retrieves EDC for the preview panel. The controller will attempt to minimize the number of queries to ensure adequate performance while maintaining an acceptable user experience. For instance, if a user is rapidly changing sharing settings by moving and adding different visual blocks on the grid-based interface, the controller will queue the requests for the retrieval of simulated data until a certain amount of time has passed since the last change (e.g., 1.5 seconds). Doing so allows DC to carefully use computing resources to support rapid changes in the user interfaces without issuing a vast number of queries. The returned data will be delivered to the preview panel for display.

The above four components support the major features of the frontend user interface. Next, I describe the backend server-side utilities in the form of a database and a set of APIs to support the management of EDC sharing settings and the simulation of an EDC preview from a stakeholder's (i.e., a recipient's) perspective.

3.4.2 Backend Server Architecture

To support the frontend user interface for creating EDC sharing settings and data previews, DC heavily depends on the backend server-side system components to perform the non-user-facing functionalities. There are four major components in the backend architecture: a database (and a list of registries), a set of data sharing settings management APIs, a set of data generators, and a data sharing enforcement engine. In this section, I present an overview of the server architecture implementation and describe individual components.

The backend server architecture was written as around 14000 lines of JavaScript (Mozilla & individual contributors, 2022e) using the Hapi.js framework (Sideway Inc & project contributors, 2022) and the Node.js runtime (Node.js contributors, 2022). All components in the form of API services were developed based on Hapi.js. Additional components that do not handle HTTP requests from client applications were implemented using libraries provided by the Node.js runtime.

Note that while the description below will heavily rely on the use cases motivated by DC to explain the different functionalities, the backend architecture was implemented as a standalone backend server that can support other frontend applications designed to support EDC data sharing management and preview. The creation of another EDC sharing control application demonstrates the backend server's flexibility. This application, called Reference Design (RD), will be described in the next section.

Database and Registries

The backend server uses MongoDB (MongoDB, Inc., 2022), a document-based NoSQL database that allows data storage in the JSON format. The database stores the following:

- Raw data (i.e., EDC)
- Sharing settings
- System state (e.g., for frontend applications, such as DC)

- Person registry
- Data source registry
- Control registry
- Service registry

In addition to EDC data, sharing settings, and system state, there are four registries in the database that serve as the medium for different system components to communicate with each other. The person, data source, and control registries store possible values for sharing setting elements and additional information. The person registry contains information about each care team's personnel, including their names and care-related attributes, such as roles in a care team (e.g., primary caregiver). The data source registry contains information about each data source (e.g., heart rate), including the name and information of the device that generates the data (e.g., a specific Fitbit device and its unique identifier), which allows the backend APIs to identify data generated from the device. The control registry contains information on each "control," or data processing utility, including the name and necessary information (e.g., a URL) to invoke the underlying service that implements the control. The service registry contains information on different services that perform the actual functionalities. For instance, multiple time-based controls (e.g., limiting data access to this week or this month) could use the same underlying service (e.g., filter by time) to achieve the intended functions. The co-existence of control and service registries allows new controls to be composed using existing services.

As a frontend user interface such as the one in DC, can load and render items in these registries to create user interface elements (i.e., the person/control/data blocks in DC) for users to manage sharing settings, new elements (i.e., blocks) can be added by entering new entries into the registries. Currently, a PCT or a primary caregiver is limited to adding a new care team member (e.g., a hired caregiver) to the system by editing an existing template in JSON and uploading it to the database. Future work will add a frontend user interface to this process, or it can be included in DC. The frontend user interface will be able to render the new care team member as an option for users (e.g., a PCT). Similarly, a new data source or control can be created by adding entries to the data and control registries.

Data Sharing Settings Management APIs

The data sharing settings management APIs (DSS-APIs), provide the basic operations that are essential for keeping data sharing settings updated in the database. These create, read, update, and delete (CRUD) operations are typically supported by standard databases (Mozilla & individual contributors, 2022b). DDS-APIs provide interfaces for converting HTTP requests into MongoDB queries, performing the queries, and returning the responses (i.e., sharing settings in JSON).

EDC Data Generator

To focus the examination of DC on its user-facing features described in the previous section and also accommodate the future characteristic of the intended scenarios where many EDC data types are available to be considered for sharing, the server architecture implements a set of data generators that can be used to generate different types of EDC data (e.g., heart rate). These data generators accept a set of parameters, including the period of time a particular type of data needs to be generated (e.g., from 09/01/2021 to 04/30/2022). The generators can be configured to generate data at a specified speed (e.g., how many data records per day) depending on the requirement to simulate data generation while avoiding overwhelming the backend server. Using the same mechanism, the generators could also be configured to generate data at a pace exactly as what a particular device will (e.g., generating a data record every minute) to simulate continuous streams of EDC data. The data generated will be inserted into the database so that these data can be used by other system components to develop important functionalities, such as the component that will be introduced next: the Data Sharing Enforcement Engine.

Data Sharing Enforcement Engine

The Data Sharing Enforcement Engine (DS-EE) is the major component that enforces the data sharing settings created by users through DC. DS-EE ensures that every data flow to a client user interface (e.g., DC) will follow the data sharing settings (e.g., fine-grained control).

When a data request arrives, DS-EE invokes three sub-components–data enforcer, control enforcer, and person enforcer–to ensure the semantics of sharing settings is properly interpreted and executed. There are two major functions for each type of enforcers: (1) translate shorthand into a format understandable by other system components by retrieving information from registries and (2) execute the intended function based on the information retrieved. Here is the description with brief examples of what each enforcer does.

- Data enforcer: Supports short names, such as "heart rate," for specifying a data source and retrieves actual sensor data.
- Control enforcer: Supports short names, such as "invisibility cloak," for specifying a control and apply data processing required by a control (i.e., temporarily blocking the data flow).
- Person enforcer: Supports ID, name, and tag-based (e.g., for roles) specification of data recipients (e.g., A12345, Deborah White, and doctor) and retrieves an individual recipient's information.

For instance, the data enforcer will examine the data source registry to identify the information necessary for retrieving data. DS-EE allows data sharing settings and data requests to specify a data source through an abbreviated name, such as "heart rate." DS-EE will examine the data source registry (in the database) and extract necessary information, such as information about the actual data source (e.g., a sleep quality sensor from a user's smartwatch), to properly retrieve sensor data stored in the database.

The data, control, and person enforcers are implemented as web services that receive HTTP requests, perform necessary operations, and provide responses. A data flow is implemented through a series of services that transform a data request into an actual data flow. For instance, with a data sharing setting, "Doctors can access my sleep quality during weekdays and up to past week." As such, generating a data flow for Dr. Deborah White, who is a doctor on a user's care team, can be implemented as follows:

1. Receive a request to initiate a data flow that delivers sleep quality to Dr. Deborah White.
2. Person enforcer: Identify Deborah White as one of the doctors in the care team through a service.

3. Data enforcer: Identify a smart watch owned by the user as the data sources for sleep quality through a service.
4. Data enforcer: Retrieve sleep quality data from the smartwatch, from the database, within the requested range of time through a service.
5. Control enforcer: Identify a service, which can remove data based on timestamp, that implements the “past week” control.
6. Control enforcer: Execute the “past week” control through the service and output the filtered data.
7. Control enforcer: Identify a service, which can remove data based on timestamp, that implements the “weekdays” control.
8. Control enforcer: Execute the “weekdays” control through the service and output the filtered data.
9. Deliver the data to Dr. Deborah White.

Currently, a data flow is a set of JavaScript statements. Future implementations could wire these dataflows together through a scripting language.

As noted in the above example, and also in this chapter, DC supports a simplified version of the role-based access control (RBAC) through the person enforcer. The person enforcer can interpret sharing settings that use IDs, names, or tags to specify data recipients, effectively allowing sharing settings to be specified for a specific individual and roles, such as doctors or caregivers that could be useful for EDC sharing.

More generally, implementing these enforcers as services decouples the implementation (or interpretation) of the semantics of sharing settings from the actual syntax, ensuring the flexibility of updating the implementation and preserving the extensibility to incorporating new syntax in the future (e.g., supporting data categories or groupings, as shown in Chapter 4).

DS-EE allows for sharing settings that enable access to raw EDC data without any restriction (i.e., control). Sharing settings created by users will be enforced until they are disabled or removed. In other words, sharing settings regulate data generated both prior to and after the creation of these settings. If there is a need to have sharing settings that only regulate data generated prior to the settings' creation, a new control could be created that takes into consideration the timestamp and achieves the desired effect.

3.4.3 Integration and Extensibility

In summary, this web system consists of frontend and backend architectures that communicate through HTTP requests. Communication is mainly for three purposes: (1) load data/control/person registries to initialize necessary UI components for user control (e.g., visual blocks in DC), (2) manage data sharing settings, and (3) obtain EDC data to generate data previews to simulate the effects of sharing settings. As these requests are likely to be essential for any user interfaces that are designed to support EDC sharing management and simulation, the backend architecture could be effectively used to support additional frontend user interfaces through web APIs.

In addition to supporting additional user-facing designs, the system architecture consists of several components that are designed to be extensible to handle the need to support new EDC data types, new care team members, and new controls that PCTs might need for managing EDC sharing. Such extensibility is provided through the combination of backend components (i.e., database registries and data sharing enforcement engine) and frontend components (i.e., data display containers and data extractors). As part of the frontend architecture, *data display containers* and *data extractors* were designed to provide layers of abstractions to accommodate new EDC data types and the need for new types of visualizations. The backend architecture employs registries and services that allow the interpretation and enforcement of sharing settings to be updated (e.g., supporting new values and semantics) through reusing existing services or the implementation of new services.

Next, I turn to an evaluation study of DC's current design.

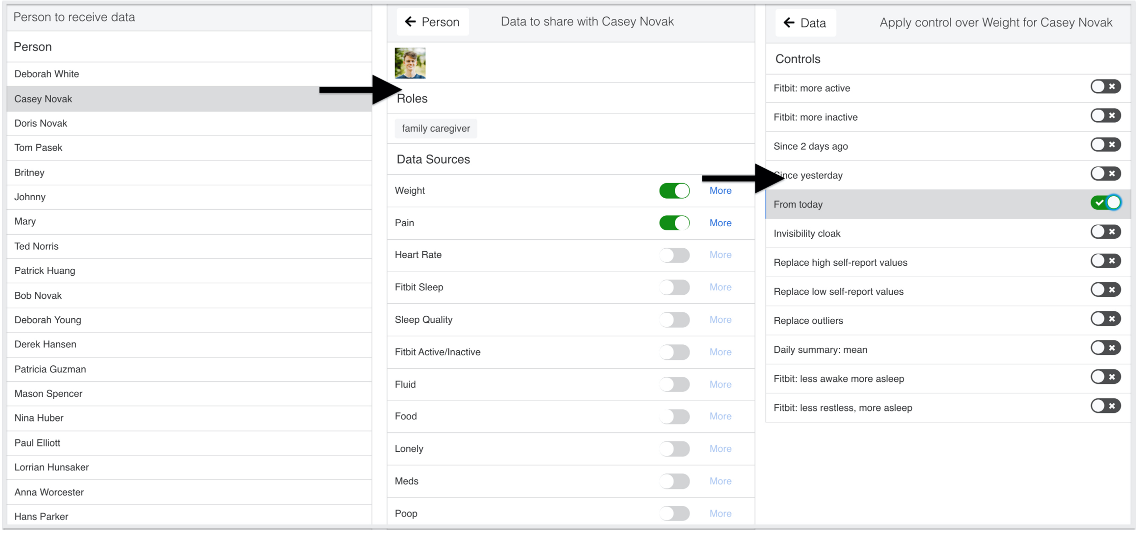
3.5 Methods

To examine whether DC allows users to better control data sharing within care teams, I invited people with chronic conditions or disabilities as well as caregivers to help evaluate Data Checkers. The goal of our evaluation study was to examine the design features of DC–including its grid-based interface and the capability to preview data–to determine whether they offered advantages over a conventional design in supporting data sharing for care.

To do this, I evaluated DC against a state-of-the-art design, which I will call Reference Design (RD). As a comparison, I chose a design that used a hierarchical design that is standard for organizing settings and options on all major desktop, web, and mobile platforms. This hierarchical design uses a list as the main layout for organizing different options. Such a conventional design allows users to progressively navigate through layers of options to execute a specific action through, for example, buttons or toggles as seen in settings within iOS or Android applications.

I chose to adopt the state-of-the-art application described in Bahirat et al. (2018) for the following reasons. First, their use case was for fine-grained control over Internet of Things data collection, including the use of sensing devices to generate data characterizing an individual's life at home, which is similar to what is needed for EDC. Second, the design uses a conventional design that features standard GUI widgets, such as lists and toggles, which provides familiarity to users and allowed us to examine the feasibility and advantages of using the grid-based interface offered by Data Checkers. Third, the design of Bahirat et al. can accommodate people, data, and controls, while giving different elements equal presence. Fourth, existing consumer health solutions lack considerations of fine-grained control and will not make a useful comparison. As a result, I chose the design used in Bahirat et al. as our Reference Design.

However, I found it necessary to modify the design of Bahirat et al. slightly. It was originally designed for mobile platforms with limited screen space, and I felt that comparing a web application on a browser with a mobile app on a handheld device would create confoundments from different device screen sizes and potentially different interaction techniques such as swiping. For a fair comparison, I implemented a web version of RD that provided more screen space and allowed users to see layers of options simultaneously, as commonly seen in Windows or Macintosh desktop software. I structured sharing settings in the order of person-data-control, as shown in Figure 3.7. This followed research findings where person and data had been found to be the dominant parameters people considered regarding privacy risks in sharing (Bahirat et al., 2018; Lederer et al., 2003). The order of different persons, data, and controls were randomized to reduce the effect of ordering on study results. The same order was used by both DC and RD. I followed the design by Bahirat et al. as faithfully as possible, including the use of toggle position and color scheme as indicators of further options.


Person to receive data

Person

- Deborah White
- Casey Novak
- Doris Novak
- Tom Pasek
- Britney
- Johnny
- Mary
- Ted Norris
- Patrick Huang
- Bob Novak
- Deborah Young
- Derek Hansen
- Patricia Guzman
- Mason Spencer
- Nina Huber
- Paul Elliott
- Lorrian Hunsaker
- Anna Worcester
- Hans Parker

← Person Data to share with Casey Novak

Roles

family caregiver

Data Sources

Weight	☑	More
Pain	☑	More
Heart Rate	☐	More
Fitbit Sleep	☐	More
Sleep Quality	☐	More
Fitbit Active/Inactive	☐	More
Fluid	☐	More
Food	☐	More
Lonely	☐	More
Meds	☐	More
Poop	☐	More

← Data Apply control over Weight for Casey Novak

Controls

Fitbit: more active	☒
Fitbit: more inactive	☒
Since 2 days ago	☒
Since yesterday	☒
From today	☑
Invisibility cloak	☒
Replace high self-report values	☒
Replace low self-report values	☒
Replace outliers	☒
Daily summary: mean	☒
Fitbit: less awake more asleep	☒
Fitbit: less restless, more asleep	☒

Figure 3.7: An adapted version of the layered design by Bahirat et al. (2018): each layer provides options to fine-tune data sharing, starting with person, data, and then control. Users who want to fine-tune the details being shared can find different options in subsequent layers. Profile photo by Carlos Lindner on Unsplash.

3.5.1 Evaluation Participants

The target users of Data Checkers are people with severe chronic conditions, such as people with SCI/D, and their caregivers. In addition to supporting people with health conditions requiring care teams (PCTs) to gain independence through sharing control, I recognize that caregivers might need to assist with data sharing when people's health fluctuates and thereby might mean limited capacity for self-managing their data. As a result, I recruited people with chronic conditions as well as people with caregiving experience who were 18 years and older. Participants were recruited through university mailing lists. This study included fifteen participants, with 13 females and 2 males. Participants' backgrounds were varied (see Table 3.1 for more details). At least 8 participants had direct experience with conditions that were likely to require care teams at some point in care, including caregivers or nursing professionals who had provided care for individuals with autism, stroke, neurological impairments, and SCI/D.

Table 3.1: Participant Description: The educational status of my participants was: high school degree or equivalent (3), bachelor or some college education (7) and masters (5). “Caregiver” (C) refers to a participant who has caregiving experience (including as a nursing professional), and “person” (P) refers to “a person with a chronic condition”.

	Age	Occupation	Background	Care-related experience
P01	26-30	Student	Nursing	C
P02	18-25	Student	Information	P
P03	18-25	Student	Medicine	P
P04	60-65	Higher Education	Information	C
P05	26-30	Student	Information	C
P06	26-30	Student	Health Informatics	C
P07	26-30	Behavioral Scientist	Health Informatics	C
P08	56-60	Unemployed	Latin American Studies	P
P09	18-25	Nurse Aide	Nursing	C
P10	18-25	Nurse Aide	Nursing	C
P11	18-25	Student	Neuroscience	P
P12	18-25	Student	Nursing	C
P13	18-25	Student	Nursing	C
P14	18-25	Student	Nursing	P and C
P15	18-25	Student	Nursing	P and C

3.5.2 Study Procedure

The study was conducted remotely through video-conferencing software (Zoom[7]) with screen-sharing enabled. Each study session took 60-90 minutes and was recorded. Consent was obtained through email prior to each study session. During each study session, participants first filled out a biographical questionnaire and watched two videos that explained the respective design and features of DC and RD to learn how to use both applications. The videos were created to provide consistent training across participants. I then provided participants with a tutorial task so that participants could ask questions to clarify their understanding of how to use the two applications.

After the tutorial tasks, each participant was then asked to complete four tasks (see the following section) that involved creating and modifying sharing settings using both DC and RD. The instructions for each task were displayed above the interface.

After participants finished tasks and acquired experience of using DC and RD, I conducted a semi-structured interview with each participant to probe how DC supports or hinders users' capabilities to control EDC sharing with care teams.

Participants who successfully completed the study were compensated for their time with a $20 gift card. The Institutional Review Board at the university reviewed this study. All data reported here have been anonymized; some light editing of quotes has been performed for readability.

3.5.3 Evaluation Tasks and Semi-structured Interviews

I designed four tasks that involved viewing, changing, and finding special cases among data sharing settings. These are three of the fundamental policy-authoring operations proposed by Reeder et al (2008). I retained this study's operation of viewing group membership (e.g., a person is a member of a hospital system) for future work.

During these tasks, a participant assumed the role of an individual with a severe chronic condition who received assistance from a care team (e.g., as a PCT like Peter in the scenario described in Section 3.3.2) and is actively considering how to share a set of data (see Table 3.2) with members of her care team (see Table 3.3).

These tasks were designed to verify whether a design could satisfy the five design requirements from Section 3.3.3. The tasks I asked participants to solve were:

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[7] https://zoom.us/

Table 3.2: Selection of EDC types

Exercise	Flatulence	Activeness	Sleep monitoring	Fluid input
Food	Hanging out	Heart Rate	Location	Loneliness
Medication	Mood	Pain	Skin condition	Sleep quality
Smoking	Bowel movements	Stress	Urine	Weight

Table 3.3: Selection of care team roles

Family caregiver	Paid caregiver	Primary care physician	Nurse
Psychologist	Respiratory therapist	Pulmonologist	Nutritionist
Social worker	PM&R doctor	Occupational therapist	Cardiologist

- T1–Create a set of sharing settings to share data with care team members.
- T2–Modify a set of sharing settings to accommodate changes in a care team.
- T3–Reuse a set of sharing settings recommended by health professionals in reaction to changes in health, and tailor the settings to one's care team.
- T4–Make maintenance changes to sharing settings after sharing data with a care team for a period of time to accommodate the varying time commitments of care team members.

Each participant was asked to complete T1 to T3 using both DC and RD, where the order of designs was counter-balanced to reduce any learning effects. Using RD allowed participants to have a basis for comparison to ground the discussion about why DC might or might not be a promising design. Participants were asked to complete T4 twice, first without and then with the preview feature, to facilitate the discussion on whether the preview feature is helpful for controlling EDC sharing.

These scenario-task combinations which exemplify the characteristics of data sharing in care and in care team collaboration, allowed us to examine whether DC's design sufficiently supports data sharing. Note that in the evaluation, I used ”the grid” to refer to Data Checkers and ”the list” to refer to Reference Design so that participants had an easy-to-understand and consistent vocabulary when discussing and comparing the two designs. This will be reflected in some of the quotations below.

After a participant completed *each* task, a follow-up question examined how useful a given design was for completing the task:

- Which of these designs (grid or list) is more useful for you to control data sharing for this task? Why?

If necessary, this was followed with the probe:

- How did the features or characteristics of each design help support the task? Hinder the task?

After all tasks were completed, a semi-structured interview was conducted to examine the overall experience of using both designs (DC and RD), as well as to investigate the potential of supporting data sharing over the long term to manage change. The questions were posed as comparing the two designs so as to tease out the dimensions that participants might use for evaluation and comparison. The semi-structured interview schedule consisted of the following questions:

- Which of these designs, grid or list, was more useful for you to control data sharing for care? Why?
- Which of these designs do you think would be more useful for controlling data sharing among multiple caregivers and clinicians? Why?
- Chronic care is a long-term process. Which of these user interfaces do you think would help people with health conditions or caregivers to control data sharing with care teams over a long period of time? Why?

Below I present only qualitative data from the evaluation study. While the study was non-probability-based, I believe the qualitative data are sufficient, to show the feasibility of DC's design for supporting care.

3.5.4 Data Analysis

I recorded both what the participants did and said through video and audio capture, and answers to interview questions were transcribed.

I used Situational Analysis (Clarke, 2005), an updated version of grounded theory, in my analysis. Situational Analysis recognizes the importance of Symbolic Interactionism (Strauss, 2008) in the interpretivist analysis of qualitative data; it also incorporates practice theory, among other additions. Situational Analysis can be seen, in Clarke's terms, as a theory/method package. This perspective was critical as background for my analysis. I see the problem and the application presented here as part of patients' and caregivers' data work (Kaziunas et al., 2017), which in turn is an increasingly important aspect of patient work (Valdez et al., 2015) and more broadly of interaction work (Strauss et al., 2017; Strauss, 2008). In my evaluation, I examined how my participants weighed potential changes in care practices in light of the data work.

In Situational Analysis, iterative cycles of data collection and analysis inform one another. Initial interviews were transcribed and analyzed using open coding to identify significant themes, utilizing Atlas.ti.[8] The coded interviews were then discussed by members of my research team and I in weekly data analysis sessions. New codes were generated collaboratively, as important concepts were identified, compared, and revised. These codes were later used as the basis for probes in future interviews. The process was repeated iteratively. Prior interviews were recoded to maintain consistency, and over time, new and recoded interviews led to important themes that emerged from the data. As part of the process, analytical memos were written and discussed as theoretical insights emerged from the ongoing data collection and analysis.

3.6 Results

In general, the participants were able to perform the evaluation tasks. DC was praised for enabling users to easily grasp how data were currently shared within care teams through the grid-based interface. Moreover, my participants found that DC enabled them to make changes to existing settings intuitively through visual composition. The data preview feature was well-received for allowing users to confirm their understanding of sharing settings and to learn about the effect of applying controls. In comparison, RD, with a design that participants could instantly recognize and were familiar with, was considered not as useful for performing data sharing within care teams. The evaluation results showed that RD's hierarchical design, while technically allowing users to achieve the same goals, was useful only in simple cases. RD's design made it challenging for users to consider multiple care team members simultaneously in the process of creating

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[8] https://atlasti.com/

and modifying sharing settings for care teams. I was surprised, but delighted, by how much better than RD my participants generally found DC to be for the requirements of complex care.

In the rest of this section, I elaborate how the design of DC satisfies each of the requirements from Section 3.3.3 in turn. Note that an interactive system such as DC provides an integrated experience through the combination of different features. The same feature, in combination with others, could offer utility that satisfies multiple requirements. I present how aspects of DC support each requirement for my participants. These results, I believe, show why DC is a promising design for sharing EDC in a care context, while also identifying room for improvement.

3.6.1 (Require1) DC is usable and useful for specifying sharing settings

Participants generally found DC to be usable in its grid-based interface and features supporting the expression and use of sharing settings. All participants (15 out of 15) reported that DC was easy to use.

However, DC's interface and capabilities were offered through a novel grid-based interface, and some participants needed time to learn it. All participants reported that DC was easy to use, but only five considered DC easy to use up-front. The other 10 stated they needed a period of learning how to use DC, after which creating or modifying sharing settings was easy. For example, P03 suggested that once he understood how to use DC, by "getting the hang of it," it was effective for controlling sharing:

> I think, yeah, once you get the hang of it, it's pretty intuitive to use. I don't think I've seen [the grid of DC] before. It's not something that people normally see. But I don't think it's something that's hard to learn. I think it's definitely a better alternative than the list [RD]. (P03, person with a chronic condition)

The novelty of DC's interface did not appear to be a huge obstacle. All participants were able to use DC to control the required data sharing in the evaluation tasks.

Acceptance, however, was not uniform. All participants thought DC would be useful for chronic care that dealt with complex care situations. One participant added that DC's unconventional design was effective but intimidating and overwhelming; this appeared to come from the novelty of DC's interface. However, some participants (6 of 15) stated they would prefer RD for simple cases that consisted of only one or two care team members or a small number of EDC data streams. I note that DC was not designed for these simple cases; it was an attempt to handle near-future scenarios with moderately-sized care teams and a number of data streams. I will return to this issue in the Discussion, because it suggests a relatively simple modification that can handle all cases.

There were several other usability issues mentioned by participants. These are relatively minor issues; none kept participants from finishing the evaluation tasks. DC uses a click-to-focus interface (for accessibility); a few participants wanted drag-and-drop as an additional user interface focus mechanism. One participant wanted a more recognizable format for the trash/delete area as can be found in Windows or Macintosh OS. There were several complaints about the use of screen real estate in DC; those participants wanted a tighter use of the screen.

Participants were also able to use the conventional design of RD to complete the tasks. However, since the tasks assumed moderate complexity in a care team, participants noted the difficulty of creating or modifying settings using RD's user interface. All participants mentioned the burden of too much clicking to navigate or how sharing settings are visually hidden, which made it difficult when creating sharing settings involving multiple care team members. I will discuss these issues further below.

In summary, my participants found DC even with its non-conventional design to be usable. Participants noted that a learning curve was required, but within the context of complex care tasks, as embodied by tasks T1 through T4, DC was sufficiently usable for specifying sharing settings. P13 stated:

> I would have thought the list [RD] would have been easier just from looking at it... [the list] looks a little more user friendly, but [it takes] many clicks to do things like changing the settings... With the grid [DC], you could just drag it [a data or a control block] and then it would be applied to like all three people. (P13, caregiver)

3.6.2 (Require2) DC is effective for EDC sharing involving multiple members of a sufficiently-sized care team

DC was designed to support a care team with up to 20 members, currently a reasonable size as suggested by prior work (Büyüktür et al., 2018) and our co-design process. All the tasks, from T1 to T4, were designed to involve different numbers of care team members ranging from 3 to 20, including family caregivers, hired caregivers, and different clinicians, so as to examine this requirement. I found that all participants who started T1 through T4 were able to complete the tasks (14 out of 15) (one participant was unable to start T4 because of Internet difficulties, but completed T1 through T3). More importantly, every participant stated that DC was capable of supporting sharing settings that could involve multiple care team members.

Participants expressed this capability in terms of either the utility resulting from being able to add or remove a care team member to/from a group (12 participants), or the utility resulting from being able to group relevant care team members together (13 participants). (Ten participants mentioned both benefits.) Five participants used their own experience to highlight the value of grouping care team members together. P08, one of the five, stated that DC would allow her to express sharing settings involving multiple doctors at the same time:

> I have [had] many, many situations where the grid [DC] would have helped immensely. ...This happens a lot with my care. [With DC,] I could put all of my doctors in one row and have them share the same data... assuming that all of the systems work together. If I could just have a system [like DC] where I go, boom, boom, boom, and that information gets shared, it would be lovely. (P08, person with a chronic condition)

While supporting a moderately-sized care team was also possible with the conventional interface of RD, all participants found it repetitious to create sharing settings involving multiple care team members. They had to individually specify settings for each care team member (and data type), as opposed to including multiple care team members simultaneously in the process of creating sharing settings. For them, DC's ability to have meaningful groupings of data and persons was valued when having sharing settings involving multiple care team members.

3.6.3 (Require3) DC's presentation of sharing settings facilitates the understanding of sharing within a care team

All participants (15 out of 15) expressed the belief that DC's grid-based interface would allow them to understand sets of sharing settings easily. They stated the ability to read sharing settings on one screen, as opposed to navigating through a hierarchy (as in RD), allowed them to quickly understand how the data were currently shared within the care team. There were three types of participant comments about their sense of understanding, all of which pointed to the advantages of the visual style of DC. Many comments were about visually taking in the team: being able to see everything at once or being able to form an overall picture (12 comments), not forgetting an individual (2), or seeing the entire team especially with changes and dynamics (6) (participants could make multiple comments about understanding). Other comments included not needing to rely on one's short-term memory but instead on visual perception, including not relying on short-term memory when creating or modifying settings (13), modifying one individual's settings by being able to see another's (3), and being able to visually double-check one's actions (4). A few made general statements about preferring visuals (2). All of these point to the efficacy in visually handling care situations where there are multiple recipients, each of which has multiple data types and perhaps multiple types of data flows (controls).

> I think if ...God forbid, my mom has a mobility-related accident and she needs a care team for 24-hour support and assistance, I really, really love the grid [DC] because, yeah, it gives you that blueprint outline of who has access to what. It gives you that zoom out view... like the full picture. (P05, caregiver)

In addition to the evaluation of the grid-based design, I asked participants to use and then discuss the data preview feature in DC. In T4, data preview was enabled to investigate whether it could assist participants in creating sharing settings and understanding their effects. Almost everyone (13 participants, with the other 2 participants missing data) stated the data preview was helpful for strengthening their understanding of the settings. However, two of the 13 positive participants commented that they could complete the task without using the preview but still thought it was useful. As to why the participants thought the preview was helpful, more than half (8) stated that the preview enabled them to view what a care team member would see, as P06 expressed.

> I like the fact that you're letting the user of the tool to see, like, oh, that's how granular that the information is like, that's what I'm really sharing. I think that's really important. (P06, caregiver)

Additionally, nine participants said that the preview helped them confirm the effects of the sharing setting, with two specifically stating that the preview helped them verify the effect of controls, as P07 stated (four participants mentioned both benefits).

> ...if I was a newer caregiver ...I could imagine it [DC with preview] being useful to trust that... when I toggle a setting, I can see it [the data preview] change right away and know that it worked. ...It [data preview] lets me trust myself and the system that I did the right thing to adjust the settings. (P07, caregiver)

The data preview feature solidified their understanding of sharing settings, and it also gave users enough feedback to make them confident that they were using fine-grained control correctly (which supported Require4 as well). This was in contrast to the state-of-the-art interface in RD, which hid an overview of settings behind a cascade of menus and toggles and which provided no feedback about whether data would be appropriately accessible.

3.6.4 (Require4) DC enables PCTs (or their primary caregivers) to perform fine-grained control effectively

In the evaluation, I examined whether DC would allow users to exert fine-grained control by applying types of controls: level of detail, length of history, shape of data, and visibility of data (see Section 3.3.3). I found that DC supports fine-grained control through the combination of directing data flows between groups of EDC and recipients, and the ability to simultaneously apply controls to each of these data flows. While doing Tasks T1 to T3, which required participants to apply controls to fine-tune how data were shared with members of a care team, nearly all of the participants (14 out of 15) explicitly acknowledged the usefulness of DC for efficiently fine-tuning these data flows between groups of EDC and care team members. Specifically, of the 14 participants, three valued

DC's ability to apply controls to groups of EDC and recipients, two reiterated the same point by stating that applying controls using RD is individual-based, and nine mentioned both characteristics. The ability to apply controls to affect multiple EDC and recipients was considered helpful, as P04 stated:

> I liked that you could group a set of categories and define relationships [using controls] in clusters, so that you could have this cluster of things [data and receivers], and you didn't have to handle them individually. You could treat them as a collective, so you could put weight and pain together and say, these [data] I am handling this way [control] and that you could group people, you can group symptoms [data], you could group actions [controls]. (P04, caregiver)

Five participants elaborated how DC would enable the efficient control of data flows. Their examples included how to modify standard settings for special occasions (e.g., going out or on a vacation) or for changes in the person's health condition.

Their examples also demonstrated that DC's controls, developed in the co-design process, are useful and practical for complex chronic care processes. For instance, P07 commented on how she would apply controls to share only summaries with specialists but could share more with people with whom she was close.

> A lot of people who were close [to me] might get a good amount of data, but then specialist might just ...need to get the summaries, and that might not need to get changed all the time. [For cases that need frequent changes,] being able to affect them quickly with just [a visual block representing a control] really was a nice idea. (P07, caregiver)

3.6.5 (Require5) DC supports health and team changes in the long-term through allowing reuse, reflection, and customization

As I argued in Section 3.3.3, a suitable design should support PCTs and caregivers in adapting to changes in health conditions and care teams over the long term. While the long-term benefits and tradeoffs of a design can only be validated through field deployments or randomized control trials, I adopt the approach recommended by Klasnja et al. (2011, 2017): to focus my investigation on how the design features of Data

Checkers support simple tasks (proximal goals) that could be essential for the long term.

When asked about which design (DC or RD) was preferred to control data sharing over a longer period of time after finishing all of the tasks, eleven participants (out of 15) thought DC would be suitable for long-term use, based on their experience of participating in chronic care. (I am missing explicit answers for the other four participants as the question was not asked due to lack of time.) However, six participants stated that RD would be useful when dealing with the simple case of having one recipient.

Participants noted that the ability to get a quick overview of settings (see Section 3.3.3) would be of significant help. This, I believe, led participants to state that Data Checkers' grid-based interface provided three unique advantages over a conventional design (as in RD) for adapting to changes in the care.

First, nearly all of the participants (10 of the 11 participants answering the question about the long-term) felt that the ability to visually compose sharing settings would enable PCTs to reference or reuse existing sharing settings, which is essential for long-term use. All of these participants commented that DC allowed them to add (or edit) elements in existing settings to create a new sharing setting. As I noted above, participants valued the ability to visually reference existing settings during the creation of new settings or the modification of prior settings when making adjustments, such as allowing additional data to be seen by care team members or adding controls to regulate data access. On the topic of reusing settings, P06 commented that DC allowed him to create settings confidently, knowing that he was accurately reusing what had been done before (and had previously worked):

> This task was a good example.... There are new people that I want to share data with. I have already thought about my data sharing preferences. I don't need to think about them again. [In this task] you were bringing on three paid caregivers and a doctor. I want them to be able to see the same stuff as my mom. ...it's as simple as just putting those blocks at the end and assigning them the same preferences as my mom. (P06, caregiver)

Second, some participants (4) noted that DC's way of displaying sharing settings in one screen created opportunities for reflection about their prior sharing decisions, which is important in the long term. As PCTs and caregivers will adjust sharing settings only when necessary, such stimulation for reflection is likely to be critical in making healthcare decisions (Mamykina et al., 2008; Mamykina et al., 2006; Owen et al., 2015). P06 made this point by saying that DC allowed him to rethink the big picture and prior decisions, which was not offered by the hierarchical design of RD, where details of sharing settings were buried inside the hierarchy:

> The grid [DC] is really good because it shows you what decisions you made in the past. Let's say a new relative, Tom, moves closer and has more caregiving responsibilities, you give him more data... When looking at the grid to remove or add privileges for Tom, you might say, oh, Crystal was my other caregiver that I forgot to take the permissions off for or, oh, why isn't Uncle Rob seeing that? (P06, caregiver)

Third, a person's health situation will vary over the long term. Some participants (4) specifically noted that DC's organization would allow them to create sharing settings for special cases (e.g., an event or healthcare crisis), which would be useful for adapting to changes in life. As P07 commented, DC, which does not have a strong restriction on how sharing settings are arranged and provides the capability to turn on/off sharing settings, would allow her to manage sharing settings for different use cases in a personalized way:

> ... For a person in maintenance mode for spinal cord injury ...[DC] empowers me to make the data on one side and all the recipients on the other. I can imagine ...three or four examples [of use cases] and a row for each use case. I could kind of turn it off right away and then add it again when I was ready. (P07, caregiver)

DC, then, offers three important capabilities that participants found likely to be beneficial for PCTs and caregivers throughout PCTs' health journeys: supporting the reuse of sharing settings, providing stimulation for reflection, and allowing personalized arrangements of sharing settings for different use cases. These capabilities were substantially more difficult to achieve in RD.

In summary, participants in my evaluation found Data Checkers, because of its design, able to fulfill the five requirements discussed in Section 3.3.3. These requirements, as I argued above, are necessary in supporting chronic care–especially in chronic care situations like SCI/D. It was gratifying but surprising to us how uniformly the participants noted the advantages of DC over RD in meeting these requirements. DC's ability to meet the requirements was in sharp contrast, for my participants, with RD, a current state-of-the-art conventional interface for managing data access.

3.7 Discussion

This chapter presented the design and evaluation of Data Checkers, a grid-based prototype application that allows people with health conditions requiring care teams (PCTs) and caregivers to share everyday data for care effectively with an at-home care team while still maintaining control and enhancing privacy. Results from my qualitative evaluation, based in a scenario of care for Spinal Cord Injuries and Disorders (SCI/D), indicate that Data Checkers meets the five design requirements outlined in Section 3.3.3, and therefore DC is likely to be usable and useful for SCI/D care or other conditions with similar care needs as SCI/D.

Results from this study highlight the importance of the identified design requirements and systems like Data Checkers that are built upon them. The results also reflect the need for additional work in this area to meet the expanding need for managing EDC and integrating it into the care management paradigm.

More work will be necessary to fully consider the promise of Data Checkers. There were a number of limitations of this study that have to be recognized. I developed the scenario and the initial designs around SCI/D. SCI/D often requires a medium sized care team (e.g., 5-20 care team members) and 20 data sources that include both sensor-generated and self-report data. While a focused setting allowed us to contextualize the design as well as ground the evaluation of Data Checkers with the participants, future work will be necessary to determine whether additional considerations are necessary for differently-sized care teams and different numbers of sensors.

Because of the prototype and evaluation's site, I also constrained the care network. I did not consider important information sources and recipients such as casual friends, church members, and social network acquaintances (Consolvo et al., 2004; Grönvall & Verdezoto, 2013; Skeels et al., 2010). Future work will be required to understand whether DC can be extended to include these groups and in what ways.

In addition, the evaluation study for my system was qualitative in nature. As with any interpretivist study, generalization is difficult. While the need for assistance can also be seen in care for conditions such as Alzheimer's disease, Parkinson's, dementia, bipolar disorders and a broad range of other complex health conditions, further studies will be needed to confirm my findings for other health conditions.

To demonstrate Data Checkers' effectiveness and cost-efficacy, with particular considerations of other health conditions, I will need to verify how my findings generalize. While the associated resources for conducting this type of analysis were beyond the scope of the current project, the data and findings will be important for pushing for the integration of programs such as Data Checkers into healthcare systems.

As well, my participants consisted mainly of people with chronic conditions or caregiving experience who were young and educated, whose experience might affect the feedback on the user experience of an unconventional design such as DC. Future studies would benefit from larger sample sizes and appropriate analyses.

There are also a number of potential avenues for future work, in addition to those suggested above. First, with more specialization in the healthcare system and increasingly available Internet of Things (IoT) and smart home solutions, supporting an increasingly complex care team structure and more diverse data sources will be required. One line of future work will be finding additional UI mechanisms to support increasing numbers of sharing settings, more complex teams, and a larger diversity of data sources.

Second, my participants wanted several usability additions. They wanted better use of screen real estate. More importantly, they felt that DC lacked an easy ability to find and change a single recipient's settings; this could be seen in the preference for RD in simple cases. DC currently has the ability to sort settings; adding the capability to filter for recipients would be an easy addition and would likely solve this issue for users.

Third, PCTs or caregivers will need to intermittently engage with sharing settings to accommodate changes throughout a person's health journey, a theme that emerged from my findings. While DC's grid-based presentation allows users to be more aware of other sharing settings and provides an opportunity for users to reflect on existing sharing settings, future work will be needed to facilitate such re-engagement over the long term.

Fourth, my study highlighted the visual benefits provided by the grid-based UI of DC, which relied on vision and mouse interaction (e.g., moving and clicking). Additional consideration will be needed to support individuals with different constraints, such as visual impairments or fine-motor issues. Conforming to Web Content Accessibility Guidelines (WCAG) (W3C Web Accessibility Initiative, 2021) would ensure that DC is perceivable and operable.

Finally, I plan to integrate machine assistance with DC as small intelligent agents that can work independently to identify and solve problems. Fischer et al. (1990)

proposed using critics (i.e., intelligent agents) to aid the architecture design process by providing feedback on a design problem (e.g., placement of appliances). In the context of sharing EDC to support chronic care, critics could be developed for DC to assist with re-engagement. A critic could also help caregivers and people with health conditions examine settings that might need adjustments to accommodate changes in health and care conditions. Such assistance could be particularly beneficial when PCTs have a reduced capacity for sharing management as a result of illness.

3.8 Concluding Remarks

This paper presents Data Checkers, an application for enabling users with chronic and complex health management needs, to have fine-grained control over their data sharing of everyday data for care (EDC) with a care team. Data Checkers offers a grid-based user interface that utilizes people's familiarity with other grid-based designs such as checkers. Data Checkers also visualizes the effects of sharing settings by presenting data from the perspective of the data's receivers, with the goal of helping caregivers and people with health conditions requiring care teams (PCTs) understand the implications of their sharing settings. My evaluation study showed that Data Checkers offers capacities that make it an encouraging option for managing sharing with care teams in the chronic care context over a standard, state-of-the-art design for data sharing. I also showed that the data preview capability supports users in managing data sharing by confirming users' understandings of how their sharing settings work. The combination of Data Checkers' fine-grained control over data sharing, as well as its ability to preview outcomes, suggests Data Checkers is a design with considerable potential to better support people with health conditions requiring care teams while they share everyday data for care (EDC) to support chronic care.

Chapter 4

Helping People to Control Their Everyday Data for Care: A Scenario-Based Study

4.1 Introduction

In this chapter,[9] I report a card sorting study to investigate whether EDC could be shared in groupings (i.e., grouping EDC types together as units to be shared) to simplify sharing configuration in a chronic care setting, such as for SCI/D, that requires the considerations of multiple factors. PCTs need to consider how to share many EDC types with care team members with different expertise and responsibilities so that they can collaboratively monitor PCTs' health and assist PCTs with different self-care activities in response to different care situations (e.g., new developments in PCTs' health) (Büyüktür et al., 2017; Nunes & Fitzpatrick, 2015). This study examines a user-assisted approach that could make EDC manageable through the creation and use of EDC groupings to reduce the effort needed to create sharing settings for every single EDC type. The study also investigates the applicability of using these groupings to create sharing settings for different care team members in different care situations. The goal is to develop an approach for EDC sharing that reduces user involvement to accommodate PCTs with

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[9] Adapted from a paper published at PervasiveHealth: Hung, Pei-Yao and Mark S. Ackerman (2022). "Helping People to Control Their Everyday Data for Care: A Scenario-Based Study." In *Proceedings of the 15th EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth)*, Tel Aviv, Israel, December 6-8. (Hung & Ackerman, 2022)

reduced capacity due to health reasons or other priorities in life while respecting the uniqueness of each individual (e.g., data sharing preferences or relationships with care team members).

In short, I found that my study participants could create groupings based on sorting EDC into five bins based on their levels of comfort about sharing the EDC. More importantly, these groupings demonstrate their utility as high-level units that allow participants to discuss how to share EDC with care team members conveniently, as opposed to describing sharing settings for each EDC type. The use of these user-generated groupings also seemed to reveal participants' inclination to share the same or more EDC when a person's health deteriorates.

These results are preliminary but provocative. The findings suggest possibilities for creating new technical mechanisms that can help people with health conditions and caregivers engaged in severe chronic care, and they may also resolve some of the difficulties of setting privacy policies overall.

This chapter will:

- Show that users can create groupings of EDC data that are meaningful to themselves and can be used to create EDC data sharing settings. Users can easily create these groupings.
- Demonstrate that participants could reuse these user-defined groupings as high-level units to specify sharing settings in study tasks, implying that it may be possible to create stable groupings for each user that simplify the process of creating and potentially maintaining data sharing and privacy settings.

In the following sections, I first review related work on support for data sharing and privacy. I then describe the study design, data collection, and analysis. I next present my findings. I conclude with implications for designing interactive systems to facilitate the creation and maintenance of sharing and privacy settings, as well as discuss the limitations of this study and future work.

4.2 Related Work

In Chapter 2, I introduced the background to this dissertation. Existing work has argued for the importance of supporting care teams to collaboratively assist with self-care for people with health conditions requiring care teams (PCTs). Moreover, with the increasing availability of sensing and wearable devices, supporting PCTs in directing data sharing to manage a lot of EDC is critical. Existing work has developed different approaches for supporting data sharing, such as access control mechanisms and user interface design. However, these studies lacked considerations of the collaborative nature of care and also did not consider the capacity of PCTs, which might be affected by changes in their health conditions and priorities in life. As a result, it is necessary to develop an approach to simplify sharing configuration while allowing PCTs to express their preferences and maintain a certain level of control.

In this section, I will review an additional approach to data sharing. This research stream consists of studies that seek to understand and model people's privacy and data sharing preferences, so as to inform interactive systems design to support data sharing or privacy configuration for different contexts, including social media or a ubiquitous computing environment (e.g., home).

For example, Choe et al. (2011) conducted a survey to understand habits and activities that people would like to avoid having recorded at home, an environment that is generally considered private. They found that self-appearance, intimacy, cooking and eating, media use, oral expression, personal hygiene, physical activity, and sleep are among the most frequently mentioned categories of data for which people would not want to be recorded. Li et al. (2020) used Mechanical Turk to create a taxonomy of "sensitive" photo features, including categories such as appearance, sleep, food, or medical condition, that classifiers could use to suggest photos that every user would not want to share. These categories could be used to develop further computer visions tools to support privacy-aware online photo sharing.

While both of these studies provide insights into aspects of one's life that people consider more sensitive or private, their investigation was situated in a regular context, without a specific purpose of sharing, such as supporting care. The existing work on data sharing and privacy has suggested that for purposes such as safety, security (Apthorpe et al., 2018; Barbosa et al., 2019; Emami-Naeini et al., 2017), or more specifically health (Bahirat et al., 2018; H. Lee & Kobsa, 2017), people generally would approve data collection and sharing. Moreover, some of these data categories, such as food, personal hygiene, physical activity, and sleep, could be important for understanding one's care. Therefore, it is reasonable to assume that the context of chronic care could affect people's preferences of sharing these everyday data, or EDC. As PCTs might have changing capacity due to health issues or their own priorities in life, it is necessary to investigate whether user input on different data could be utilized to simplify the process of creating sharing settings to manage many EDC data sources, while respecting their unique preferences.

A handful of studies have examined user-generated groupings for privacy, such as using groups of locations to understand privacy preferences for location sharing (Toch, Cranshaw, Drielsma, et al., 2010) and using data disclosure behaviors to develop privacy profiles for social media and marketing use (Knijnenburg, 2014), with the goal of developing privacy-aware features.

For instance, Toch et al. (2010) conducted a four-week field deployment study using a location sharing system, Locaccino, to understand how people share locations and how different locations were considered to be private. They defined the concept of "location entropy" to indicate the diversity of visits (i.e., using the proportion of visits from different unique individuals) and found that location entropy was useful for capturing the privacy value of a location. Essentially, they found that places with higher location entropy would likely be considered as less private, while places with lower location entropy (e.g., home) would likely be considered as more private. In addition to analyzing locations by the diversity of visits, they also studied how people's sharing preferences might differ based on the types of locations. Through asking participants to label locations they visited using a taxonomy: home, work, campus, transit, hangout, friend, shop, and unlabeled, they found that places that were considered to be more private were not home. Instead, participants considered shop, transit, and unlabeled places to be more private.

Knijnenburg (2014) adopted a similar approach to collect users' ratings of different personal information that represent their information disclosure preferences, but focused on developing sharing profiles to characterize the users, instead of data (e.g., in Toch et al.). Knijnenburg (2014) summarized three studies that develop sharing/privacy profiles of users in different usage scenarios, including mobile app recommender, online retailer, and social media sharing. Knijnenburg showed that through analyzing users' data sharing preferences, different "dimensions" (i.e., attitudes toward sharing different categories of data such as location or contact info) could be identified to differentiate users with different sharing behaviors. These profiles could be used to tailored privacy nudges or interactive system utilities that assist users with privacy control.

While both studies allowed users to create groupings of data (e.g., location data or disclosure preferences on different types of information), the groupings of data were used to develop a metric (e.g., location entropy, data categories, or sharing profiles) that work for all individuals. In other words, their outcomes presented a rather universal view, albeit useful, while the consideration of individual preferences was limited. These studies also did not examine the applicability of the outcomes in different situations, such as having a new development in health, which is common for chronic care.

Moreover, the goals of both studies were to classify data and users so as to provide further interactive systems utility (e.g., privacy nudges), instead of simplifying the process of creating sharing settings itself. While these approaches could arguably be applied to simplify the need to create additional sharing settings, more research is needed to investigate an approach that considers the reduced capacity of PCTs while also respecting their unique perspectives.

As far as I know, there have been no studies that examined whether having users group the types of data for themselves might help users, especially in healthcare settings. Such user-initiated groupings have the potential to be used to reduce the complexity of the sharing setting configuration while allowing PCTs to maintain some control to maintain their autonomy, which is critical for their independence in chronic care (Büyüktür et al., 2018).

In this chapter, I examine the possibility of using user-generated groupings of EDC to simplify sharing in a pervasive health care environment that could potentially generate data from a large number of data sources. I investigate whether the intermediate outcome of the user preferences collection process itself (e.g., data groupings) can be turned into a utility to simplify sharing settings creation further for PCTs, including creating sharing settings for care team members and for different care situations (e.g., developing a new symptom). My goal is to develop a mechanism to reduce the number of sharing settings being created and hence the user burden, which is critical for PCTs.

4.3 Methods

4.3.1 Participants and Recruitment

The goal of my study was to understand whether groupings of EDC could be created by users to simplify data sharing with care team members in a chronic care setting. To obtain an initial understanding of whether such groupings are possible and potentially useful, I invited participants with different backgrounds to participate in my study. Anyone can potentially have a severe chronic condition later in their lives. However, I specifically encouraged people with caregiving experience or people with a close family member who has a chronic condition to participate so that their understanding of receiving care and navigating health challenges for a range of chronic conditions could be properly brought into the discussion on EDC sharing.

Participants were recruited in the U.S. through university mailing lists and personal networks. I recruited 25 participants, all of whom had college degrees (or above) or were currently enrolled in a college program. There were 21 females and 4 males aged between 18 and 63 (22 as the median). Among the participants, 24 participants had either caregiving experience or at least one close family member with a chronic condition (see Table 4.1 for more details, including background). I excluded the data from P20 as P20 only provided partial data for this study. Participants with caregiving experience had provided care for people with a range of conditions, including epilepsy, autism, auto-immune disease, severe motor impairment, traumatic brain injury, and stroke.

4.3.2 Study Design

The study used card sorting followed by semi-structured interviews to investigate the possibility of using user-generated groupings to manage the sharing of EDC. As participants might not have had experience sharing a diverse list of EDC, using the card sorting allowed participants to engage in the process of comparing different EDC types and configure how these EDC would be shared with ones' care teams. The semi-structured interviews allowed the research investigator to follow up with participants to understand the process of grouping and sharing EDC. All the study activities were done remotely through video conferencing software (i.e., Zoom, 2020) and an online whiteboard platform (i.e., Miro, 2020).

Table 4.1: Participant description: "Caregiver" (C) refers to a participant who has caregiving experience (including as a nursing professional), and "person" (P) refers to a person with a chronic condition and/or a disability, and "PFC" refers to a person with a close family member with a chronic condition.

	Age	Gender	Background	Occupation	Experience
P01	26-30	F	Fashion	Student	PFC
P02	26-30	F	Counseling	Research assistant	C
P03	26-30	F	Linguistic	Student	PFC
P04	31-35	F	Education	Instructional designer	PFC
P05	26-30	M	Computer Science	Software engineer	PFC
P06	31-35	M	Computer Science	UX designer	PFC
P07	36-40	M	Social Work	Social worker	C
P08	31-35	F	Linguistic	Student	No
P09	31-35	M	Computer Science	Student	PFC
P10	18-25	F	Nursing	Student	C
P11	18-25	F	Nursing	Patient Care Technician	C
P12	18-25	F	Nursing	Student	C
P13	18-25	F	Nursing	Patient Care Technician	C
P14	18-25	F	Nursing	Student	C
P15	18-25	F	Nursing	Nurse aide	C
P16	18-25	F	Nursing	Nursing assistant	C
P17	18-25	F	Nursing	Student	C
P18	18-25	F	Nursing	Student	C
P19	18-25	F	Nursing	Student	C
P20	61-65	F	Nursing	Clinical nurse educator	C
P21	18-25	F	Nursing	Student	C
P22	26-30	F	Psychology	Care navigator	P & C
P23	18-25	F	Nursing	Student	C
P24	18-25	F	Nursing	Student	C
P25	18-25	F	Nursing	Student	C

To properly help participants consider sharing data in a specific chronic care context, I presented each participant with a scenario that described a person with spinal cord injury and disorder (SCI/D). The scenario was designed to introduce the setting of a particular kind of severe chronic care that requires a care team to assist the person. Many people with SCI/D utilize moderately sized care teams (8-25 people) whose members have different roles and expertise. Furthermore, monitoring ongoing health concerns would be beneficial for many people with SCI/D (Büyüktür et al., 2017; Meade, 2009). The scenario was realistic for my purposes: As sensors become more and more available in a pervasive health care environment, people and caregivers will have to make data sharing and privacy decisions.

In this scenario,[10] the person was injured severely as the result of a car accident. The person then required assistance from caregivers and health professionals to manage her health and everyday life throughout her lifetime (chronic care). The participants were asked to put themselves in the role of this person during the study to consider how they would group data about different aspects of their lives for sharing with a list of care team members. This list consists of a range of potential recipients of their data, including primary caregivers (e.g., family members such as a parent or a spouse), secondary caregivers (e.g., family members who occasionally help), hired caregivers, primary care physicians, psychotherapists, physical therapists, healthcare system/hospital IT workers, nurses (e.g., from a spinal cord clinic), and emergency room doctors.

A list of EDC was presented as everyday data for care that could be useful to share with care team members to support monitoring and diagnosis.[11] As participants might not be familiar with every EDC type, participants were first asked to review the list of EDC types and to understand the details captured in EDC. Inspired by prior work on people's attitudes toward sharing data (Bélanger et al., 2013; Choe et al., 2011; Nissen et al., 2019) and common care activities for people with SCI/D and their care teams (Ackerman et al., 2018; Büyüktür et al., 2017; Büyüktür et al., 2018; Meade, 2009), 32 types of data were selected, which covered a range of aspects of a person's life and her

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[10] This scenario was adapted from the scenario used in Chapter 3, with the same purpose of introducing SCI/D and different members of a care team for a person with SCI/D.

[11] The list of data types used in this study was developed based on the study described in Chapter 3. Additional data types were included to cover different aspects of one's wellbeing (e.g., emotional and social aspects) with the goal of supporting care in a more holistic manner (Figueiredo & Chen, 2020).

Table 4.2: Selection of Data Types

Computer game	Exercise	Fluid intake	Flatulence
Food/diet	Hanging out	Heart rate	Internet history
Intimate behavior	Location	Loneliness	Medication
Messages	Mobile app usage	Conversational dialogs	Mood
Pain	Phone calls	Recreational drug use	Stool
Relaxation	Religious behavior	Romantic dates	Skin condition
Sleep	Smoking	Social media status	Stress
Urine	Video use	Weight	Work activity

health condition (see Table 4.2).

It appeared that my participants understood the scenario, the data types, and care team roles. While I believed that participants with caregiving experience would be better grounded in their role-playing, everyone appeared to be able to discuss the rationale of their sharing decisions based on an understanding of the data types, care context, and the different care roles. Participants with caregiving experience were able to provide more detailed examples, but their data did not differ significantly from the others.

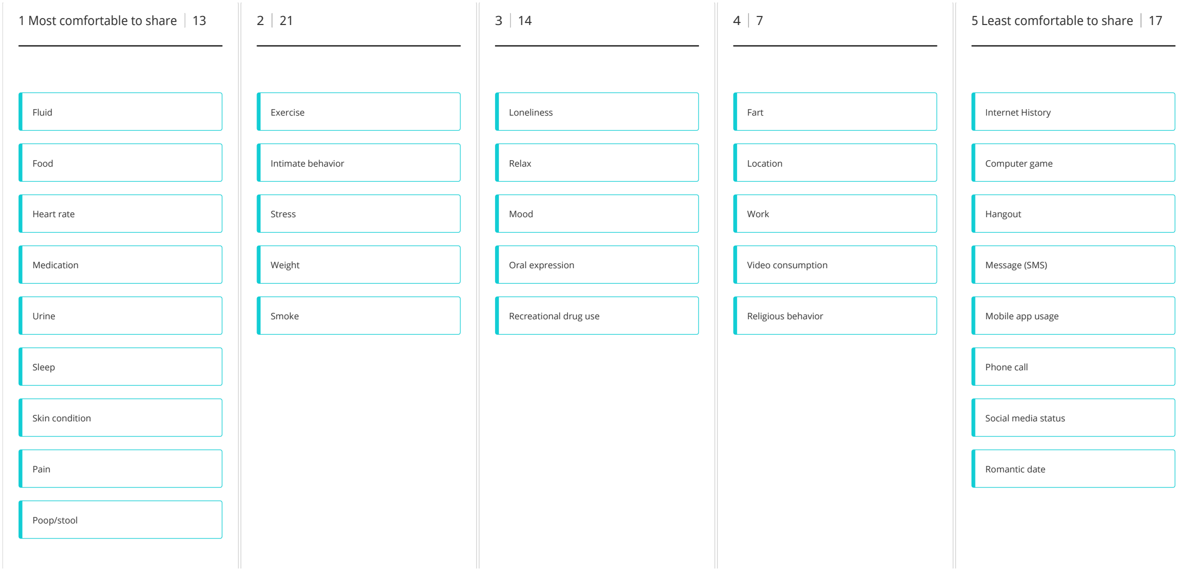
Participants were asked to sort the data types into 5 bins based on how comfortable they were in sharing data with their care teams, from bin 1 (most comfortable) to bin 5 (least comfortable). I did not define ”comfort,” but let participants supply their own definition. This ambiguity has been found to be useful in many card sorting studies (e.g., [Bernard, 2000, p. 269] and [Bernard, 2017, p. 249]).

The number of bins, 5, was chosen as it has been commonly used in existing data sharing and privacy research (Fogues et al., 2017; Gustarini et al., 2016) and also fits with general HCI findings about short-term memory constraints (Miller, 1956). I tested the number 5 in my pilot study (n=3), where participants preferred 5 clusters when given a choice. Five bins also allowed differences to be seen while not being an excessive number of bins. I will return to the selection of the number of bins in the Discussion.

This list of EDC types was entered into Miro (2020) as digital cards for sorting. In this chapter, I will use “bins” to denote the pre-determined number of containers given to every participant in the Miro-based card sort, and use “groupings” to denote the resulting collections of data types, which may be different for every participant, in the various bins.

Prior work on design for chronic care has suggested how changes in a person's health requires the care team to revise care routines (e.g., maintain proper fluid intake) and hence the use of data (e.g., monitoring) (Büyüktür et al., 2017; Hong et al., 2016). I used three situations (see below) in my study to examine whether EDC groupings could be used to support sharing when there were changes in health, and whether there were patterns that could be useful for simplifying EDC sharing.

- New normal: a regular day living with the chronic condition.
- Something going on: exhibiting new symptoms with the causes unknown.
- Emergency: feeling ill and being rushed to the emergency room.



1 Most comfortable to share | 13	2 | 21	3 | 14	4 | 7	5 Least comfortable to share | 17
Fluid	Exercise	Loneliness	Fart	Internet History
Food	Intimate behavior	Relax	Location	Computer game
Heart rate	Stress	Mood	Work	Hangout
Medication	Weight	Oral expression	Video consumption	Message (SMS)
Urine	Smoke	Recreational drug use	Religious behavior	Mobile app usage
Sleep				Phone call
Skin condition				Social media status
Pain				Romantic date
Poop/stool				

Figure 4.1: Participants created groupings of EDC by the level of comfort from the most comfortable (bin 1 on the left) to the least comfortable (bin 5 on the right).

Here, I report how my participants used those user-created groupings and how these could make EDC sharing more manageable. I observed their sorting the EDC data types using a think-aloud protocol. I then conducted semi-structured interviews to understand how easy or difficult it was to group the EDC and how these groupings could be useful for expressing sharing settings with different care team members under different care situations.

The guiding questions for the interviews for the presented scenario were as follows:

- How would you describe the data in this grouping?
- Were there data that were tricky to assign to a grouping? What were they (walking through each grouping)?
- When you stated how you would share data with this care team member (walking through each potential recipient), what went through your mind?
- When you stated how you would share data in this care situation (walking through each potential recipient), how was it different from the other situations?

4.3.3 Data Analysis

My findings in this chapter are based on the following information that was collected in the study: biographical information, data groupings (on Miro), and sharing preferences (on Miro), interview notes, and audio/video recordings. Transcripts were created for each recording. Furthermore, data groupings and sharing preferences were captured to allow further analysis.

I used Clarke's Situational Analysis (2005), an updated version of Grounded Theory, to analyze the interview transcripts and think-aloud data. Open coding was applied to interview notes and transcripts using Atlast.ti (Scientific Software Development GmbH, 2020) to generate initial themes. As is common with Situational Analysis, I discussed themes and categories with my research team through weekly meetings to identify emerging themes. Analytic memos were written summarizing the emerging themes, and themes that emerged were used to re-code all the transcripts to maintain consistency. This process was repeated iteratively.

Participants who successfully finished the study were compensated with a $20 e-gift card for their time and effort. This study was reviewed by my university's Institutional Review Board. Any data presented here have been anonymized; I have lightly edited some of the data presented here for presentation clarity.

4.4 Results

In this section, I describe my participants' sharing preferences for EDC generated in a pervasive healthcare environment. I provide a description of whether my participants were able to group the set of EDC types, as well as how any groupings were used to express sharing settings both with different care team members and in varying care situations. I start with a description of how my participants grouped data types and whether they found these groupings useful and usable.

4.4.1 Grouping EDC Is Usable and Useful

In my study, I asked my participants to perform a card sorting activity and create a list of EDC types into five bins, telling them to sort the types by their "comfort" of sharing that data with care team members (1: most comfortable, 5: least comfortable).

The participants were able to utilize the bins to group the EDC types. Figure 4.2 visualizes how participants grouped the data types. Three things leap out from the visualization in Figure 4.2. First, all 5 bins were used by nearly all participants. In fact, only P01 excluded bin 5, while all other participants distributed EDC to all five bins. Participants were at ease in doing so, as their think-aloud data indicated.

Second, there was some agreement among participants about the contents of each bin, but overall the contents could differ widely. Participants put largely physiological data in bin 1 (Figure 4.2), and all participants felt most comfortable sharing that data. (Remember this was in a scenario about health care.) Bin 5 tended to include deeply personal data, such data about sexual activity or drug use, and was not shared frequently:

> Um, religious behavior, I don't really see the health relationship with my health, but I guess I would worry about how people perceive me based on religious practice. (P19)

and

> These data [phone calls, social media messages, and recreational drug use] are the most personal. We don't share that with people that often. (P08)

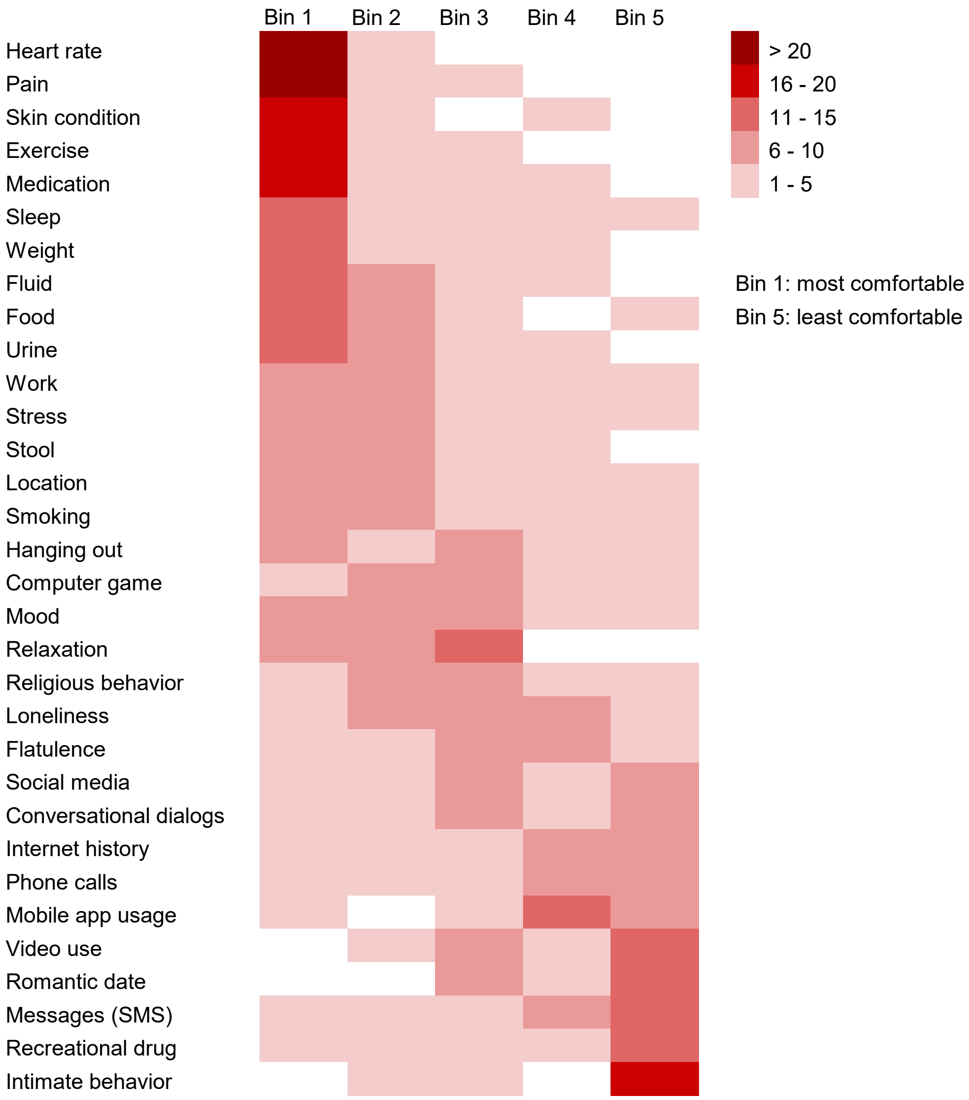


Figure 4.2: Heatmap showing how frequently participants assigned an EDC type to each bin. Very light pink=1-5, light pink=6-10, medium pink=5-10, dark pink=11-15, red=16-20, and dark red >20 (n=24). One participant omitted because of partial data.

However, the contents in bins 2-4 varied widely. There was some consistency. For example, phone calls were commonly assigned to bins 4 and 5, but also to other bins. If I look at how often participants used the same bin, one can see the variation: One data type (i.e., heart rate) was assigned to adjacent bins (i.e., within one bin of one another); four data types were assigned to one of three consecutive bins, but the rest of the 27 data types were assigned to more than three. For example, participants differed on their comfort level with sharing data such as smoking and location, where they could be placed by different participants in bins 1 through 5:

> Mostly like loneliness, relaxation, stress, work, and mood, I was mostly considering whether it was important for them [the care team members] to know that... and whether I would want to share that. (P24)

It follows that some EDC types were likely to be collocated within a grouping. For instance, heart rate and pain as well as stool and urine were pairs of data types that typically were put into the same grouping. However, heart rate and intimate behavior were less likely to be put into the same grouping, as people typically considered sharing data about intimate behavior to be uncomfortable.

Admittedly, some participants did signal that they found some EDC types to be challenging to assign to a specific grouping, resulting in ambivalence about the correct grouping. Note this ambivalence was not about what was uncomfortable to share per se–they could assign a data type that was uncomfortable to share to bin 5 (the most uncomfortable). Some participants who found themselves ambivalent about a grouping indicated that their ambivalence resulted when an EDC type's potential connection to health and the benefits of sharing were unclear to them:

> I think maybe weight and work, that are the ones I am debating,... because it's not like... the most embarrassing thing and it is for your health... but I am still hesitant. [P21]

This ambivalence, however, only adds to the difficulty of finding *one* set of groupings that will hold across all users. The differences in individuals' binning could be significant; my participants did not agree on what EDC data types should go in a specific bin (i.e., a comfort level). Figure 4.2 shows the variance in the groupings. Because of this variance, it is unlikely that any *one* taxonomy or classification scheme will suit all users.

Regardless, individuals could group the data types for themselves, suggesting that groupings could be potentially usable. While some participants needed to deliberate slightly more about a relatively small set of data, they were able to settle quickly. In other words, sorting EDC into groupings based on comfort level was a rather doable process for my participants.

Somewhat to my surprise, while my participants did not always agree on the types that went into each comfort grouping, these groupings seemed useful for themselves to allocate data to care team members. (To make it clear that I am talking about the individuals' set of groupings, I will call these "user-groupings.") *That is, once participants grouped the data types, they were able to use these user-groupings to describe their sharing preferences for different care-team members and care situations efficiently*, finding the grouping they made useful and usable for themselves. This strongly suggests that their own groupings could be used to reduce the number of data sharing or privacy policies that users might need to construct and maintain.

In summary, participants were able to put EDC into groupings based on how comfortable they were in sharing these EDC with care team members. These groupings were idiosyncratic enough to each individual that one classification scheme for all users is impossible or unlikely. While the exact data types in each grouping varied from individual to individual, the user-groupings appeared to be useful, since each individual participant was able to use his or her groupings consistently as units in expressing sharing settings.

Below, I will discuss how participants used the groupings to deal with the subtleties of who might receive the data, namely by varying the groupings specific recipients could see. I will then deal with how participants also used the user-groupings to share data when the person's health situation changed.

4.4.2 Utility of Groupings for Sharing Within a Care Team

Many people with SCI/D, as discussed above, rely on care teams. For a condition such as SCI/D, people might experience different degrees of neurological impairment, and for those with more severe conditions, they often require a care team to assist with different tasks in everyday life. Sharing EDC within the care team would allow team members to collaboratively monitor the person's health and handle changes that might arise.

The care team for a person with SCI/D is not homogeneous. Primary care givers, who are likely to be parents or spouses, are generally trusted more than paid or volunteer caregivers. Secondary care givers, such as siblings or other relatives, may lie between primary and paid caregivers. Care teams may also involve a range of clinicians including different kinds of doctors, nurses, physical and occupational therapists, etc. In this section, I describe how the user-groupings were useful for sharing data with different care team roles.

In the process of determining what EDC to share with different care team members, the user-groupings provided guidance for my participants to quickly identify what to share with a particular care team member. Instead of considering every single EDC type, the user-groupings served as units for my participants in their evaluations of what to share. Indeed, participants often considered multiple groupings at the same time for inclusion or exclusion. For instance, P02 commented on how she decided what to share with the primary caregiver and paid caregivers; she excluded three groupings at once and decided to share the other two groupings:

> I think [groupings] 3 to 5 is like more personal... The first group... everyone in my team should know. The second group ... I spend most of time with primary caregivers and hired caregivers, so I would like to share [data about] my life [in group 2 for this participant] with them. [P02]

Similarly, P03 explained how she would share EDC with her primary care doctor by including and excluding the groupings she created.

> For my primary care doctor, this one is more like... they [have to] kind of know my condition overall. That is why I share [up to] group 3, so that they would have a basic idea of how I feel and how my physical body works [groupings 1 and 2 for this participant], but they don't necessarily need to know my personal activities [groupings 4 and 5 for this participant]. (P03)

As shown in the comments above, my participants found their EDC user-groupings, created based on comfort level, to be useful units for determining sharing with specific care team members. In the study tasks, my participants went through each role and decided what groupings to share. (See Table 4.3 for the set of roles given to participants in the study tasks.) Only two participants deviated from using their initial user-created groupings, and they did so only once each.

That is, with the exception of P06 and P07, participants did not feel the need to restart the grouping process to specify sharing preferences for each role.

These user-generated groupings are by no means perfect for sharing with different care team members, but these groupings seem to be robust enough to be useful for creating EDC sharing settings. For instance, some groupings could contain data types that were relevant or even critical to share with a given care team personnel while also containing

	Primary	Second	Hired	PCP	Psych	PT	IT	Grouping changes
P01	3	4	2	2	3	2	0	no
P02	2	3	2	1	2	1	1	no
P03	5	5	3	3	3	1	2	no
P04	5	2	1	3	3	2	2	no
P05	5	3	2	4	5	2	1	no
P06	4	4	4	3	1	1	0	yes
P07	5	4	3	3	5	3	2	yes
P08	2	2	2	2	2	2	2	no
P09	4	4	1	5	4	3	3	no
P10	3	1	3	3	4	2	0	no
P11	5	5	5	5	5	5	5	no
P12	2	2	2	5	5	5	1	no
P13	3	4	4	4	5	2	1	no
P14	4	3	2	3	5	2	1	no
P15	2	2	2	5	5	5	0	no
P16	5	2	2	3	5	2	1	no
P17	3	3	3	5	4	3	2	no
P18	2	2	4	3	5	3	1	no
P19	3	0	0	2	2	1	1	no
P21	5	2	3	5	5	2	0	no
P22	3	3	3	4	5	2	2	no
P23	2	2	2	5	4	3	5	no
P24	5	5	1	4	4	1	0	no
P25	3	3	0	2	3	2	0	no

Table 4.3: EDC groupings shared with different care team roles: primary caregiver (primary), secondary caregiver (secondary), hired or paid caregiver (hired), primary care physician (PCP), psychotherapist (psych), physical therapist (PT), and healthcare system IT specialist (IT). The values represent the highest grouping shared. The last column shows whether a participant adjusted groupings in the process of creating sharing settings. (P20 was omitted since their data was partial.)

other data types that were not as relevant for this care team personnel simultaneously. Participants might decide to share these groupings, which contains those EDC types that are relevant or critical, when they do not feel strong discomfort about sharing those less relevant data within the same groupings.

> Data such as loneliness, religious behavior, social media [, some data types from those groupings I share]... I would be more comfortable sharing these data with psychotherapists because they are more socially and mentally oriented. They probably wouldn't need to know my skin conditions [a data type from those groupings I share], but I would be comfortable with them knowing more. [P10]

Again, I stress that the exact user-groupings for any given individual are not what is interesting here–it is, instead, that individual participants were able to reuse these user-groupings to create sharing settings without major challenges or re-grouping.

While my participants could use their groupings to assign EDC to care team roles, I acknowledge that a role is quite abstract. Sharing may differ from abstract roles (e.g., paid caregiver) to specific individuals (e.g., Sally, a specific person who has been with the PCT for a decade). Changes to the groupings might be required, for example, to allow different sharing settings for different individuals in the same role. Changes might also be required as PCT or caregivers better understand their sharing and privacy needs; this could be seen with P06 and P07, who changed their groupings in specific study tasks. However, I must note that the groupings would still be useful in jump-starting a process of customization. I will return to this point in the Discussion.

In summary, my participants found the user-created groupings of EDC useful for deciding how to share EDC with a specific care team role. One major benefit for participants was to use the groupings to quickly assess the sharing threshold for a given recipient. Participants were able to consider multiple EDC at the same time, without the need to examine every single EDC type for each recipient, which for this number or slightly more care team members or sensors would have been an overwhelming task.

4.4.3 Utility of Groupings for Sharing with Changes in Health Condition

Chronic care involves working with a care team to address any health changes over time. To design support for people to control EDC sharing for severe chronic care contexts, for example SCI/D, it is critical to understand how sharing preferences might change across care situations. I prompted participants to express their preferences about sharing EDC in three care situations: a regular day (the baseline condition), a situation where something may be starting to affect the person's health, and an emergency. I found that these user-groupings created based on comfort level with sharing, again, provides a good framework for participants to decide what EDC data to share in different care situations. I also found that the care situation did affect the threshold for sharing (i.e., sharing up to grouping X) generally in a positive direction as the person's health condition deteriorated. In other words, people are inclined to share either the same or additional groupings of EDC when their health situations escalate in severity.

Table 4.4 shows how sharing increased as the health needs were perceived to have become greater. In Table 4.4, I show the sharing threshold (i.e., the highest grouping that will be shared) for primary and paid caregivers, as well as two doctors, the primary care physician and an emergency room doctor.

For departures from a regular day (i.e., when there is a change in the person's health), the necessity of sharing increases. Such an increase is motivated by the need to have more people monitor a person and help with care and treatment, including both medical professionals and non-medical care team members. Sharing was differentiated by the recipient's role. Table 4.4 shows that sharing mostly stays the same or increases as the person's health situation deteriorates for selected care team members. Participants tended to keep or raise the threshold for care team members to share more with each of them so as to allow EDC to flow smoothly to care team members. Overall, fifteen participants changed their sharing settings, and four participants kept their settings. Among the 15 participants, thirteen participants shared more with at least one care team member, P25 shared less, and P16 shared more for some and less for some.

> The data is important for them [primary care doctors] to make medical decisions. Hopefully, they are working in my best interest. ...so a proper decision is made for my health. (P19)

Participant	Normal			Symptoms			Emergency		
	PC	HC	PCP	PC	HC	PCP	PC	HC	ERD
P06	4	4	3	4	4	4	4		4
P07	5	3	3	5	4	5	5		5
P08	2	2	2	2	2	3	2		3
P09	4	1	5	4	2	5	4		4
P10	3	3	3	3	3	3	4		4
P11	5	5	5	5	5	5	5		5
P12	2	2	5	2	2	5	5		5
P13	3	4	4	3	5	5	3		5
P14	4	2	3	5	3	5	5		5
P15	2	2	5	2	2	5	2		5
P16	5	2	3	3	2	5	3		5
P17	3	3	5	4	4	5	5		5
P18	2	4	3	2	4	3	2		3
P19	3	0	2	3	0	2	4		4
P21	5	3	5	5	3	5	5		5
P22	3	3	4	4	3	4	5		5
P23	2	2	5	3	3	5	4		5
P24	5	1	4	5	1	4	5		4
P25	3	0	2	2	0	2	2		2

Table 4.4: EDC groupings shared with care team roles increase when health situation deteriorates. Roles include: primary caregiver (PC), hired caregiver (HC), primary care physician (PCP), and emergency room doctor (ERD). The health situations included a regular day (Normal), when symptoms begin to emerge (Symptom), and an emergency requiring a trip to the ER (Emergency). I did not include the hired caregiver role in the emergency situation in my study; I omit participants for which I have only partial data.

> Even if they [hired caregivers] are college kids without medical training, they might be like the next best option [when there is a health change and other caregivers are not around]. (P13)

Participants wanted to share the most data in emergency situations. Overall, nine participants changed their sharing settings again, and ten participants kept their settings. Among the nine participants, eight participants shared more with at least one care team member, and one shared less.

There were only two exceptions to the general trend, sharing the same or more data when the situation worsened. P25 preferred sharing rather limited data with primary caregivers, secondary caregivers, and psychotherapists when her health deteriorated (in the something going on condition). P16 preferred to maintain a sense of control when there was a non-threatening change (i.e., something going on), but would let go of the control and entrust recipients with more data in an emergency when her life was at stake. Both P16 and P25 explained that a lack of medical expertise and the situation (e.g., health deterioration) were the main factors for such adjustments. For instance, primary caregivers, who were highly involved in care but were considered to have less medical expertise, were given even fewer EDC groupings in an emergency compared to a regular day.

Again, my results showed that the user-generated EDC groupings appear to be a useful way for people to express sharing preferences–this time across care situations. As people's health changed, the inclination to share more EDC was observed at the grouping level: participants either shared the same groupings or shared more groupings of EDC as people's health condition escalated.

4.5 Discussion

Repeatedly in my study, I saw evidence that participants binned EDC data types into groupings based on a criterion of "comfort." I also observed them reusing those user-generated groupings. The groupings differed from individual to individual, but one's groupings appeared to be valuable for the individual participant. These groupings were not perfect, but seemed to be robust enough to support EDC sharing configuration. Few participants changed their groupings when setting up privacy and data sharing, and more importantly, they constructed a number of nuanced settings using them in a number of study tasks. My participants were able to use these user-groupings to select what EDC to share with different care team members and in changing health conditions.

As far as I know, these findings have not been studied or observed before. These findings need to be confirmed, but they suggest that these user-groupings could be a valuable tool in easing the burden of dealing with the increasing number of sensors and EDC data in a pervasive healthcare environment. My study substantially extends the ideas of Toch et al. (2010), Knijnenburg (2014), and Li et al. (2020). Toch et al., Knijnenburg, and Li et al. merely examined user-generated taxonomies that were supposed to fit everyone; I found that such taxonomies are not likely to be as useful as individualizing groupings. I, on the other hand, showed that user-groupings (i.e., individualized groupings) could be useful for configuring data sharing (e.g., of EDC).

In the next subsections, I consider the possibilities I believe my study have uncovered–namely, the semi-automatic configuration of data sharing–as well as the potential limitations of this study and future work.

4.5.1 Creating Semi-Automatic Assistance

The findings above strongly suggest that allowing people with health conditions or their caregivers the ability to bin EDC data types creates valuable shortcuts and forms of assistance to people and caregivers in creating and potentially maintaining privacy and data sharing settings. A wizard-like mechanism would allow the simple binning of EDC data types and then the creation of straight-forward sharing rules.

In this study, I have analyzed data groupings that could be shared with roles such as primary caregivers. Although sharing decisions would involve considerations related to specific individuals (e.g., my primary caregiver, Mary), a similar mechanism could still be applied to bootstrap the creation of sharing settings that could be further tailored to individual needs.

Future work could also apply the methodologies proposed by Knijnenburg (2014) and Y. Li et al. (2020) to investigate more semi-automated approaches for EDC sharing configuration, where sharing profiles could be extracted from some user-generated groupings and applied to new types of data. Based on my observations on the individual differences in participants' groupings, I cannot foresee the completely automatic creation of sharing rules; some user involvement will be necessary. For users, allowing them to further customize automatically generated settings, either by changing groupings or making exceptions, would still be easier than creating settings from scratch.

In addition to the possibility of using user-generated groupings for data sharing configuration (Knijnenburg, 2014; Toch, Cranshaw, Hankes-Drielsma, et al., 2010), my findings further suggest that such groupings could be reused across different care situations (e.g., new symptoms emerge or an emergency), which is important in severe chronic care as care team members need to collaboratively monitor and adapt to changes in health and care (Büyüktür et al., 2017; Pina et al., 2017). Reusing groupings in different health situations would reduce the user burden of configuration, again reiterating the utility of such user-generated groupings for the chronic care context.

Finally, extending the findings of prior work that suggest safety and health could be reasons for people to share data (Apthorpe et al., 2018; Bahirat et al., 2018; Barbosa et al., 2019; Emami-Naeini et al., 2017; H. Lee & Kobsa, 2017), my findings further demonstrate that in the context of chronic care, people have the general tendency to share more at the grouping level when health problems escalate. Architectures or frameworks designed to support EDC data management should consider explicitly supporting the interaction between care situations and the threshold of comfort for sharing. For instance, having a system that made suggestions for sharing settings, potentially with customization, would ease the burden on people with health conditions or their caregivers. This would ease the burden that results from the need for separate settings for different health situations. Future work may uncover similar tendencies for roles. For example, sharing with a secondary caregiver (e.g., a family member) will likely be a superset of sharing with a hired caregiver. Such tendencies based on user-generated groupings of recipients (e.g., roles) could provide further simplification of EDC sharing to empower PCTs in directing their care (Bagalkot & Sokoler, 2011; Büyüktür et al., 2018; Chung et al., 2019; Felipe et al., 2015; Murnane et al., 2018; Schroeder et al., 2017).

4.5.2 Limitations and Future Work

There are several potential limitations to this work.

My exploratory study used non-probability sampling, but I believe my study has theoretical generalizability (Clarke, 2005). The use of user-generated groupings without requesting major changes was prevalent in this study. Yet, while I was careful when prompting participants to double-check that they were satisfied with their groupings, it is admittedly an unknown and surprising result. I do recognize that to gain widespread acceptance in health informatics or in medicine, additional studies, especially empiricist or positivist studies, will be required.

Additionally, I provide a pre-determined number of bins to guide the EDC grouping process. While the number seemed to provide a good scaffolding for participants in my study, future studies could consider examining other numbers to structure the grouping process. One direction worth exploring could be to identify whether there exists an ideal range where the resultant number of groupings is still manageable (under a certain threshold) while providing enough distinction (above a certain threshold) that supports the necessary differential treatment for different care team members and under different situations.

In this study, I asked participants who understood the care context (i.e., through caregiving or having a close family member with a chronic condition) but were not people with health conditions (except one), to role-play a person with a health condition. This allowed us to obtain initial results about whether EDC could be shared in groups to simplify sharing configurations and to understand considerations participants have when sharing EDC in groups. However, I acknowledge that people with health conditions might have additional perspectives on the utility of user-groupings. Future studies should examine using studies that involve people with health conditions as well to develop a more thorough understanding.

As I noted earlier in this chapter, I asked about sharing with abstract roles, but real sharing occurs with specific people in specific contexts. This issue remains for future studies to reaffirm the usefulness of user-groupings.

I examined only the ambiguously defined criterion of “comfort” in this study, and participants were clear that “comfort” included understanding how the data might be used in a care context. Future work should examine these and additional factors related to the care context to guide user-grouping creation. The factors participants used in evaluating “comfort” should be further analyzed. Furthermore, it is possible that other forms of grouping could exist in the context of chronic care, since chronic care is likely to involve tracking how different factors affect a person’s health (Karkar et al., 2017).

Similarly, while my data suggests that data sharing for care involves considerations of both benefits and risks, there could be multiple benefits and risks that need to be considered simultaneously. For instance, there are risks associated with sharing EDC with a care team member (e.g., generating a negative impression) and with EDC being leaked or accidentally stolen. The participants in my study identified the first type of risk by putting EDC types into the “least comfortable” bin. Further research is needed to investigate how considerations of different risks might affect data groupings for sharing.

Finally, my findings were generated through a one-time engagement with participants. In reality, supporting chronic care, by definition, will engender a different style of engagement across a longer period of time. Future studies should examine how stable these user-generated groupings are and the factors that necessitate changes in these groupings. It is also possible that the attitudes toward sharing these EDC data types might change for people with health conditions as they encounter different events in their health journeys and develop a better understanding of the benefits and risks of sharing. Future research could consider exploring machine-initiated intervention (e.g., using intelligent agents [Fischer et al., 1990]) that will periodically examine EDC groupings and call for users’ attention to determine whether adjustments are necessary (e.g., check-in after a new development in one’s health). This approach could be integrated with other methods that provide an estimate of a person’s understanding and expertise in EDC using data access logs (Hung & Ackerman, 2015). The integrated approach will allow adjustments based on people’s educational backgrounds or experiences to reassess whether and what aspects of the EDC groupings need to be modified to align with their preferences and expertise.

4.6 Concluding Remarks

My work aims to support people with health conditions requiring care teams (PCT) and their caregivers in a pervasive healthcare environment to control their sharing of Everyday Data for Care (EDC), specifically in the context of severe chronic conditions that require a care team and healthcare over time. This chapter presented findings that examine how to help users set sharing and privacy preferences for EDC. Through a scenario-based study with think-aloud card sorting and semi-structured interviews, I found that my participants were able to use self-generated groupings of EDC data, and more importantly, almost entirely kept those groupings when creating sharing settings for potential recipients and when dealing with changes in the health trajectory. The major contribution from this work is the surprising and speculative finding that users could garner assistance from their user-generated groupings of EDC data. This work offers hope that we can reduce the burden of authoring and maintaining data sharing and privacy policies through semi-automatic mechanisms, where the system suggests policies that are consistent with the users' preferences–especially as health changes and especially in difficult chronic care.

Chapter 5

Humans and Machines as Delegates to Assist with the Sharing of Everyday Data for Care: An Interview Study

5.1 Introduction

To unlock the full potential of supporting care with data while protecting the needs of people, I examine how to support people in their use and dissemination of data for improving their care. The setting I examine is a future scenario, where multiple types of EDC data are available through sensors (both physical and algorithmic) that could provide useful information about one's life and well-being on a continuous basis. These constant data streams, while potentially providing rich details that could be useful to provide care to a person, could be daunting to manage. This is especially problematic when a person is required to focus on health and other priorities in life (e.g., school, work, or family) (Pina et al., 2017). That is to say, a person might not have the capacity to handle the intricacies of data sharing.

A health condition might affect a person's capacity to exert control. An alternative is needed for a person to be in control while not being overwhelmed by data and thus giving in by choosing a share-all-or-nothing strategy. An approach that aims to help people control how their data are shared for care purposes should consider the differences in people's capacities. I believe that the provision of *delegates* in the form of people or automated solutions that can help with data sharing when necessary or desired can help people with health conditions from being overwhelmed. To this end, the question I ask in this research is how people might view different personnel (e.g., family, hired help, or medical professionals) involved in their care for managing data sharing. I additionally include machine intelligence as an option to investigate the possibility of a machine-assisted approach.

In this study, I explore the possibility of using delegates–human or machine-based–to support people with the process of data sharing. (Note that I use "sharing assistance" herein to refer to the tasks involved in sharing data, including understanding data and releasing data to a designated receiver. I use "delegates" to refer to human and machine-based agents that can provide such sharing assistance.). My aim is to augment care through the use of data without ignoring the constraints that arise from care, as well as the issues associated with data sharing.

Two recent studies have examined the possibilities of using human or machine-based assistance for data sharing, specifically delegates for sharing decisions. Yet, these studies have not examined care settings. Nissen et al. (2019) investigated how people might invoke different delegates (e.g., family, experts, AI/Bots) to evaluate their own consent to share data with third-party organizations. This study was limited in terms of details on what people considered as similarities and differences in the characteristics of delegates because the study data were collected through a questionnaire. However, the British study did find that people trust health experts with their medical records. Although, recent research had shown that trust in physicians (or health systems) in the U.S. was relatively low compared to other countries (e.g., the United Kingdom, the context of investigation for [Niessen et al. 2019]). Therefore, it would be interesting to examine the same topic in the U.S. context. Colnago et al. (2020) investigated how people might view machine-based agents in terms of providing the awareness of and control over data in the general Internet of Things (IoT) environments, a context with potentially low trust. In the present study, I build on the works of Nissen et al. and Colnago et al. by focusing on the involvement of both human and machine-based delegates in providing sharing assistance. However, I examine sharing assistance and delegates in the context of care, a setting with specific needs. In care settings, there is a need, as mentioned, for proactive data sharing due to changes in health conditions along one's health trajectory.

My investigation is designed to answer the following set of questions, with the long-term goal of designing an interactive system to provide sharing assistance to people with health conditions:

- Would obtaining sharing data assistance be considered beneficial?
- What kinds of help might be wanted?
- What issues might arise when using people from the care team as delegates or with using various forms of machine intelligence?
- What kinds of new arrangements might be made if we started to combine people and AIs?

To answer these questions, I design an interview study to understand the types of assistance that people would find beneficial for sharing data to support care. I conduct guided semi-structured interviews with 30 participants by using a scenario involving spinal cord injuries/disorders (SCI/D). I use SCI/D as the setting because I want participants to consider the multiple characteristics of self-care for a severe chronic condition in the future, for example, the impact of a health condition on a person is severe and warrants at-home assistance from family caregivers, hired caregivers, and clinicians with different specializations; maintaining health requires the assisted execution of various daily routines (e.g., nutrition, bowel program); and fluctuating health conditions (e.g., sometimes life-threatening) require collaborative monitoring and response in different care situations along one's health trajectory. By using a scenario based on SCI/D, my participants discussed the sharing of data within such a team of diverse expertise and relationships, which allowed me to uncover the issues and opportunities associated with sharing assistance in a context where the concerns for privacy and control are prominent.

The contributions of this study are as follows:

- I demonstrate that obtaining assistance for data sharing to support care is nuanced, situated, and extends beyond simply managing sharing settings.
- I discuss how people view the issues and potential of using care team members and machine intelligence as potential delegates to provide sharing assistance.
- I discuss the trade-offs and implications for systems to involve human and machine-intelligence delegates to share data in care.

In the following sections, I first review the related work on obtaining assistance with data sharing. Then, I describe the study design, data collection procedures, and analysis method. Thereafter, I present my findings. I conclude with several implications for the design of interactive systems based on machine intelligence to facilitate sharing assistance.

5.2 Related Work

In Chapter 2, I provided the background for this research, that is, the collaborative self-care context, where sharing everyday data for care (EDC) could facilitate care team collaboration to jointly assist PCTs with self-care. In this context, the ability to direct how everyday data for care (EDC) are shared with care team members is considered critical to ensure that PCTs can exert control and develop independence. Meanwhile, with the proliferation of various sensing devices, managing multiple EDC data sources becomes a daunting task. Given that the capacity of PCTs might be reduced owing to their health condition and other priorities in life, data sharing assistance is needed to properly facilitate data flows within a care team. In the remainder of this section, I review the literature on data sharing assistance and identify the gaps that are to be addressed in this chapter.

Approaches to receive data sharing assistance from various sources have been reported in the literature thus far. Family and friends are a common source from which people receive advice on sharing data with different digital services. Such advice might come in the form of an informal story shared proactively by family and friends (Rader & Wash, 2015) or in the form of others' sharing security behaviors (e.g., designing a password) (Das et al., 2014). While family and friends are often considered trustworthy, people are willing to seek assistance from people outside of their typical social circles when it is difficult to find the necessary expertise within their circles (Ackerman & Malone, 1990; Ackerman & McDonald, 1996). Moreover, recommendation systems that help people to obtain support indirectly from strangers have been developed (Chouhan et al., 2019; DiGioia & Dourish, 2005).

While these approaches have explored various sources of assistance, the types of assistance being sought, however, remain limited to suggestion and advice. The data owners continue to be required to review multiple recommendations and the sources thereof

(Y. Zhao et al., 2016). This is especially problematic in the case of chronic care because changes in heath could affect the capacity of a person with a health condition to make decisions.

To further alleviate the burden of data owners, other types of assistance should be considered. Recent studies have focused on higher-level assistance, such as assigning others (delegates) the power to make decisions for the data owners. Nissen et al. (2019) used a technology probe to understand how people might invoke diverse sources (e.g., family, friends, experts, crowds, AI/Bots) to evaluate their consent to share data with a third-party organization in different scenarios. They found that people have a higher level of trust in family, friends, and experts but a lower level of trust in crowds and AI/Bots. Additionally, people's delegation preferences varied by scenario (e.g., several sources are favored in certain scenarios but not in others). Colnago et al. (2020) conducted an interview-based study to understand how people consider permit privacy assistants (machine agents) to provide awareness and control data collection through the Internet of Things (IoT). Their findings indicated that people's positivity decreases when the level of automation increases, while people acknowledge the benefit of reduced cognitive burden because they could offload the decision-making process to machine-based agents.

The variations in attitude toward machine intelligence, which can be observed in a comparison between the results of Nissen et al. and those of Colnago et al., highlights the nuances of how people evaluate humans and machine intelligence in privacy-related scenarios. Such variation was reiterated by the findings of Hidalgo et al. (2021) on how people judge machine intelligence. Hidalgo et al. demonstrated that people judge machine-based actors differently from human actors in the execution of the same task in different scenarios (e.g., making a risky decision, producing creative work, or auditing candidates). However, in privacy-related scenarios (e.g., facial recognition in different settings or recommenders based on different data), people's evaluation of machine intelligence vis-à-vis that of humans shows greater variation, and there are no strong preferences for either machine-based or human actors. Such variation highlights the nuanced manner in which people evaluate the use of machine intelligence for privacy-related tasks. Therefore, the exploration of machine intelligence in other scenarios (e.g., chronic care) is crucial for furthering our understanding of how machine intelligence could be meticulously designed to provide sharing assistance (i.e., for EDC).

In this study, I extend the work of Nissen et al. and Colnago et al. to further the understanding of sharing assistance, especially in the context of chronic care. Although Nissen et al. and Colnago et al. investigated the delegation of sharing decisions, they examined only general data categories and third-party organizations. Because the literature suggests that supporting fine-grained control over data is crucial for people with chronic conditions to negotiate their independence, it is critical to further our understanding of the nuances in people's preferences and how the care context (e.g., being sick) and the specifics of EDC might affect people's delegation preferences. In addition, it is essential to understand how people consider machine-based delegates and human delegates differently. Nissen et al. did not collect the types of data necessary to understand the qualitative differences between machine-based and human delegates that might affect the types of assistance people desire and need for sharing EDC in their health trajectories (Strauss et al., 1997), nor did they explore how different types of delegates might complement each other in a multi-delegate approach. In this study, I examine both these aspects.

In what follows, I describe the method I used to examine these important questions. I then present my findings and discuss the implications for system design based on such a delegation approach.

5.3 Method

5.3.1 Participants and Recruitment

To understand how people view letting family members, hired help, medical professionals, and machine intelligence to assist with EDC sharing, I recruited interview participants based in the U.S. through university mailing lists and personal networks, as well as through caregivers with whom I had previously worked. [12]

Because my study was situated in a future scenario, where technological advances will enable us to capture diverse types of data, the population whose perspectives I was

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[12] This study follows the same setup as the study described in Chapter 4, including using the SCI/D scenario, the EDC types to consider, and the list of care team members. However, this study focuses on data sharing assistance and delegates. The data collection was done in conjunction with the study described in Chapter 4. For this study, I include five additional participants with substantial experience with SCI/D, which will be explained later in this section.

interested in studying were of those who could potentially be in this situation later in their life, namely, everyone. I recruited 25 participants. All of my interviewees had college degrees (or above) or were currently enrolled in a university program. Of the participants, 21 were females and four were males, and their ages were between 18 and 63 years (22 years was the median). Except for one participant, the other either had caregiving experience or had at least one close family member with a chronic health condition (see Table 5.1 for more details, including background). The participants who were caregivers or nursing professionals had provided care for individuals with a range of conditions, including epilepsy, autism, autoimmune disease, poor vision, severe motor impairment, traumatic brain injury, and stroke.

I confirmed my data by presenting them to an additional five participants (P26 to P30; three people with SCI/D, one primary caregiver for a person with SCI/D, and one clinician heavily involved in care for people with SCI/D). I wanted to supplement my interviews with a small additional set of participants to confirm that my other participants understood and could use the SCI/D scenario in this study. Moreover, I intended to examine whether my findings aligned with the lived experiences of people with SCI/D.

5.3.2 Study Design

In this study, I conducted semi-structured interviews to understand people's thoughts about sharing EDC and the idea of having human and machine-based delegates to assist with the sharing of EDC. Because the potential participants might not be familiar with EDC and the concept of delegation, the semi-structured interviews allowed me to progressively introduce topics for discussion based on the participants' responses. All of the study activities were conducted remotely by using video-conferencing software (Zoom, 2020).

The participants were asked to put themselves in the role of a person with a health condition during the interview. To properly prepare each participant to think about data and obtain assistance with data sharing in the care context, I presented to them a case describing a person with severe spinal cord injury due to a car accident. The person required long-term care with assistance from caregivers and health professionals to manage her health and everyday life. The story was designed to introduce the setting

Table 5.1: Participant description: "Medical professional" (M) refers to a clinician working professionally as a health care provider, "caregiver" (C) refers to a participant who has caregiving experience (including as a nursing professional), "person" (P) refers to "a person with a chronic condition and/or a disability, and "PFC" refers to a person with a close family member with a chronic condition.

	Age	Gender	Background	Occupation	Experience
P01	26-30	F	Fashion	Student	PFC
P02	26-30	F	Counseling	Research assistant	C
P03	26-30	F	Linguistic	Student	PFC
P04	31-35	F	Education	Instructional designer	PFC
P05	26-30	M	Computer Science	Software engineer	PFC
P06	31-35	M	Computer Science	UX designer	PFC
P07	36-40	M	Social Work	Social worker	C
P08	31-35	F	Linguistic	Student	No
P09	31-35	M	Computer Science	Student	PFC
P10	18-25	F	Nursing	Student	C
P11	18-25	F	Nursing	Patient Care Technician	C
P12	18-25	F	Nursing	Student	C
P13	18-25	F	Nursing	Patient Care Technician	C
P14	18-25	F	Nursing	Student	C
P15	18-25	F	Nursing	Nurse aide	C
P16	18-25	F	Nursing	Nursing assistant	C
P17	18-25	F	Nursing	Student	C
P18	18-25	F	Nursing	Student	C
P19	18-25	F	Nursing	Student	C
P20	61-65	F	Nursing	Clinical Nurse Educator	C
P21	18-25	F	Nursing	Student	C
P22	26-30	F	Psychology	Care navigator	P & C
P23	18-25	F	Nursing	Student	C
P24	18-25	F	Nursing	Student	C
P25	18-25	F	Nursing	Student	C
P26	51-55	F	Psychology	Clinical Psychologist	M
P27	56-60	F	Engineering	Care Manager	C
P28	66-70	F	Technology	Retired	P
P29	31-35	F	Design	Membership Liaison	P
P30	31-35	F	Social Work	Research Assistant	P

Table 5.2: Selection of Data Types

Computer game	Exercise	Fluid intake	Flatulence
Food/diet	Hanging out	Heart rate	Internet history
Intimate behavior	Location	Loneliness	Medication
Messages	Mobile app usage	Conversational dialogs	Mood
Pain	Phone calls	Recreational drug use	Stool
Relaxation	Religious behavior	Romantic dates	Skin condition
Sleep	Smoking	Social media status	Stress
Urine	Video use	Weight	Work activity

of chronic care provided by a care team. The various members of the care team were introduced, including the primary caregivers (e.g., family members such as a parent or a spouse), secondary caregivers (e.g., family members who provide help occasionally), hired caregivers, primary care providers, psychologists, physical therapists, healthcare system/hospital IT workers, a nurse (e.g., from a spinal cord clinic), and an emergency room doctor. In addition, machine intelligence as a potential delegate was introduced later in the interview. The severity of the SCI/D condition and the diversity of the care team members involved grounded the participants in a setting where topics such as data, self-presentation, relationships between individuals, and control emerged as important considerations and obtaining assistance or using delegates for health-related decisions became critical.

Because the participants may not have been familiar with the EDC concept, they were first asked to review a list of EDC types to understand the information contained in different types of data. In this manner, in later stages of the interview, the participants were grounded to comprehensively consider how they would let someone to assist with data sharing. Inspired by the literature on people's attitudes toward sharing data (Bélanger et al., 2013; Choe et al., 2011; Nissen et al., 2019) and common care activities for people with SCI/D and their care teams (Ackerman et al., 2018; Büyüktür et al., 2017; Büyüktür et al., 2018; Meade, 2009), 32 types of data were selected to serve as anchors for discussion. These data types covered a range of aspects of a person's life and their health condition (see Table 5.2).

As a part of the interview, the interviewer invited participants to review the data types and discuss their preferences for obtaining assistance from human and machine-based delegates in terms of the type of data, level of autonomy provided to the delegates, and effects of care situations. If a participant was unfamiliar with machine intelligence, I referred them to a smartwatch app with machine intelligence.

The guiding questions for the interview were as follows:

- What data would you let this delegate assist with sharing?
- What would you allow this delegate to do with these data?
- How would your preferences change in different care situations?

To understand the extents to which the participants were willing to delegate in the context of sharing EDC, I asked them to consider potential ways of working with delegates based on prior research related to software agents (Alan et al., 2016). These ways included offering suggestions on what to share and with whom, sharing data and notifying the data owners, and handling data sharing directly without involvement of the data owner.

In addition, I asked participants to go through delegation in the following three scenarios:

- New normal: A regular day living with the chronic condition.
- Something going on: Exhibiting new symptoms resulting from unknown causes.
- Emergency: Feeling ill and being rushed to the emergency room.

According to the literature on the design of chronic care, changes in health can induce a care team to apply or revise routines with the aim of managing a health condition, and this could require the team to use data (Büyüktür et al., 2017; Hong et al., 2016). The three scenarios listed above facilitated a discussion of how care situations might affect people's delegation preferences.

The participants who successfully completed the study were compensated with a $20 e-gift card for their time and effort. This study was reviewed by my university's Institutional Review Board. All of the data presented here were anonymized beforehand. I lightly edited some of the data presented here for clarity in presentation.

5.3.3 Data Analysis

Throughout the study, the following information was collected: biographical information, interview notes, and audio/video recordings. All of the interviews were recorded and transcribed. I used Clarke's Situational Analysis (Clarke, 2005), an updated version of Grounded Theory, for data analysis. I applied open coding to the interview notes and transcripts by using Atlas.ti (Scientific Software Development GmbH, 2020) to generate the initial themes. Then, I discussed the themes and categories in weekly project meetings to iteratively identify emerging themes.

In my analysis, I carefully examined whether the various participant groups (i.e., those without caregiving experience, with caregiving experience, with extensive experience in SCI/D) provided substantially different answers. As I expected, a greater number of stories about personal experiences were narrated by the third group, but the points they raised were substantially similar to those raised by the other participants. The participants from each group contributed the same common set of themes to the analysis. I will return to this point in the Discussion section. For discussing my findings, I treated all participants as being equally able to provide useful data.

The themes that emerged through these discussions were used to re-code all of the transcripts to maintain consistency. This process was repeated continually until research team members agreed upon the themes that were identified.

Next, I turn to the findings from my interviews.

5.4 Results

This study was designed to allow me to understand what can be useful and usable when people seek assistance for sharing EDC. As mentioned, the study was conducted in a scenario involving the provision of support to persons with spinal cord injuries/disorders (SCI/D), a condition which often warrants the use of a moderately-sized care team (8–25 people) (Büyüktür et al., 2018) and where the person with SCI/D can be overwhelmed on occasion. Although it might be possible for large healthcare institutions to provide closed-system solutions, I aimed to examine the feasibility of more person-centric, open-system solutions.

In what follows, I describe the possibilities and constraints associated with the provision of assistance in steps. First, I examined the participants' perceived needs in terms of assistance. Second, I looked at what the participants wanted from humans–family or other caregivers and health professionals–who might help. Third, I examined the types of support that my participants would be willing to consider from various forms of machine intelligence, as well as from a hybrid, coordinated combination of humans and machine intelligence. Along the way, I note the many nuances, constraints, and important situations highlighted by the participants, including a few that echo the considerations described as important in the literature. The findings mostly consistent with the experiences and expectations (e.g., in the case of machine intelligence) of the participants familiar with SCI/D (P26 to P30), which suggests that this set of findings could serve as an initial framework for understanding how to design systems to facilitate EDC sharing assistance for PCT.

I start with the basics: what were my participants perceptions about assistance.

5.4.1 Obtaining assistance

As expected, my participants thought about what delegation might involve and the implications of delegating EDC sharing to members of their care teams. By analyzing the problem from the vantage point of computer science, I assumed that people would separate the policies (or rules) controlling data streams (e.g., feeds from a sensor or self-reports) from the data (e.g., the actual heart rate data from 2 pm to 3 pm). This would mean that users would consider assistance as merely setting up rules for sharing, as opposed to viewing the data or monitoring the data continuously. This was not the case for most of my participants.

First, my participants thought that assistance would be valuable. As P04 stated, the life of a person with SCI/D can be difficult, and there will be times when they would be unable to attend to their data and data flows:

> I do not want to be the only person that can make the decision [to share data], given my life is not really stable. My doctor and my primary caregiver should make those decisions for me. For a primary caregiver and primary care doctor, they should know exactly everything that I do. (P04)

Moreover, I found that my participants were able to create informal rules or policies, such as “a primary caregiver should manage this type of data.” However, these configurations were not described as rules or policies by the participants. Many of the participants repeatedly created such informal rules over the course of the interviews. However, there was scant evidence of the participants' belief that these rules could be set up once and then ignored. The need to modify the rules was evident from a comparison between the rules created for one care situation (e.g., a regular day) and those created for other care situations (e.g., an emergency).

The majority of my participants assumed that a delegate would be able, and occasionally, needed to be able to view the data. Only a few participants mentioned the need for a delegate to manage certain data without viewing the underlying content. In other words, the participants often considered the ability to view the data as a prerequisite for providing any sharing assistance, instead of simply creating rules.

This finding can be ascribed to several reasons. Several participants never considered anything else. Others thought that the delegate would need to check, occasionally, for unusual values or patterns in the data to be of actual assistance. For example, P06 stated:

> If she [a family caregiver] does not know the data, then how could she decide? ... she might be questioned [i.e., have her decision questioned], she might not be able to argue why she approved or not. There will be a lot of guessing if she cannot see the data themselves... Otherwise, I think they [delegates] should see the data. (P06)

Another reason underlying the response that a delegate should view the data was the participants' belief that especially in critical situations, the delegate might need to examine the data so as to identify additional care team members, perhaps clinicians, to determine whether further action is necessary. According to these participants, the delegates should be able to view the data themselves.

Instead of considering only an individual delegate, a few participants explicitly considered having multiple delegates to manage EDC sharing collaboratively. For instance, P24 commented that she would delegate data sharing to three care team members to allow them to collaboratively access almost all of the data needed.

> [If the] primary caregivers and secondary caregivers are already given these data, then they know everything, almost. They can collaborate with a doctor who has the medical knowledge to create a care plan that is best for me. (P24)

In summary, the participants believed that obtaining assistance from an individual or a set of care team members could be important. Although they were able to formulate informal data policies, they did not think this meant that the delegates would be able to remain ignorant of details of the data. Moreover, the participants assumed that the delegates would view the data in the event that they sought assistance. Therefore, a decision related to delegating the capabilities and responsibilities of sharing EDC with care team members, most of whom work closely with the PCT, requires not only technical considerations (e.g., expertise) but also careful consideration of the social relationships within the care team, as I discuss in the following section.

Next, I turn to the personal considerations the participants found important for identifying a "good" delegate.

5.4.2 Human Delegates: Mutual Understanding, Objectiveness, and Data Compatibility

In this section, I describe the major characteristics that the participants considered important when deciding which individuals to delegate to. Nissen et al. (2019) found that their study participants trusted health experts to help them consent to the sharing of medical records. Their results point toward the trust people have in health experts concerning their health-related data. However, the results of Nissen et al. present only a part of the story about delegation. The participants of the present study, too, trusted health experts (i.e., medical professionals) and were willing to delegate, but they had important considerations that pushed them toward others as well. For these participants, a sense of mutual understanding and trust, as well as a belief in the person's ability to understand the EDC within the context of her situation and goals, was critical when selecting delegates and seeking assistance.

Medical Personnel

The care team for a person with SCI/D almost always includes medical professionals. The personal connection with a clinician is usually weaker than that with a family member, but the participants considered this a potential advantage in several cases: for example, the participants believed clinicians remain objective as a result. The participants opined that medical professionals would not let relationship bias affect how they shared the data. This meant that medical professionals would not become opinionated, form personal judgments about the person with SCI/D, or let such opinions affect how they manage the data, as exemplified by some participant's view of primary care providers.

> They [primary care doctors] are well educated. They also don't have personal connections … can have more objective opinions, based on facts, not like family members. (P12)

> They [primary care doctors] look at my data very objectively. They will look at the number, trends, and directions. They would not have their own personal input on it... Their role as professionals is to give suggestions, and is to put your data in a care plan ... not personally fueled things. (P14)

Medical professionals, who have medical training and widely believed to be objective, are good candidates for providing sharing assistance and using the data. These characteristics are especially important when people need more medical attention owing to changes in their health. On the other hand, important caveats emerged. The participants cast doubt on whether medical professionals could manage the EDC that might be relevant but not immediately clear. Medical personnel might not understand the context of the data, for example, the situational aspects surrounding creation of the data (Tolmie et al., 2016). Moreover, the participants questioned whether medical professionals would be capable of managing and using data of a more personal or subjective nature (e.g., cell phone usage or social network characteristics). Such data could be helpful for allowing medical professionals to devise a more personalized care plan, but they might not have the expertise or experience to analyze the said data. For caregivers, the reverse might be true, as I will discuss in what follows. P14's comment on the differences between medical professionals and caregivers illustrates the contrast:

> They [primary care doctors] do not know you as well... They might not know how to apply some more intimate data [social media]. I don't know how they would use .... [the data] in my care plan. While my caregivers might know and make accommodations, a primary care doctor does not know my personal preferences. (P14)

Because of the weaker relationship and the lack of context, the participants were concerned about sharing data or seeking assistance about the data they considered personal or private. While the type of data varied across participants, almost all of the participants were hesitant to share certain types of data. For example, Internet history, intimate behavior, phone calls, and romantic dates were typically considered more personal and private.

Even in case of the data that were obviously health-related (e.g., heart rate), the participants questioned whether clinicians would have the time or incentive to comprehensively examine the data, as a caregiver might.

> I think doctors are really busy... dealing with their own appointments every day. I do not think it would be good to have extra work for them [sharing data as delegates]. (P01)

In summary, as Nissen et al. (2019) reported, the participants of the present study trusted medical personnel to be objective and expert in handling and sharing their data. However, the participants were concerned that clinicians might miss critical aspects of their data and might not understand the data as well as someone closer to the PCT might because EDC data include a variety of relevant data captured outside of medical environments. In addition, the participants expressed concerns pertaining to whether clinicians would accept the workload required to consider the data and data sharing in detail.

Caregivers

Separately, the participants made a case for seeking assistance from people other than clinicians, especially for certain types of data. The participants opined that mutual understanding with the PCT could be critical for some delegation decisions. A shared understanding between the PCT and a prospective delegate about the PCT's health and preferences emerged as a key factor when asking an individual for sharing assistance. Family caregivers, for instance, were thought to belong to a unique category within the care team because they have an existing family relationship with the PCT. Family caregivers are close to PCTs and know them well. This closeness in relationship and deep understanding of the PCTs led the participants to feel that they could trust the family caregivers with making data-sharing decisions.

> Primary caregivers... they can access all the data. I need to have someone close to me to decide [about data]. It is like ... someone that can really help

> me decide. They are very close to me. That means they know me very well and what I went through. They must be the ones most knowledgeable about the situation. (P05)

A few participants further illustrated that such trust and understanding translate into the delegates "knowing what I want or do not want" or "respecting my will" from the PCTs' viewpoint. As P04 stated:

> I just try to give them [primary caregivers] more data ... This is based on trust; they are actually my family members. If they see something that needs to be shared ... I trust that they will not share it for other bad or evil purposes. (P04)

Mutual understanding becomes an advantage for family caregivers when the data shared with them could reveal personal or intimate details. The participants opined that the PCTs need to feel confident about a delegate's willingness to respect their preferences and maintain their secrets. However, as I will describe later, having family members managing data of a personal nature is not without concern. By contrast, hired caregivers and medical professionals (e.g., doctors) were thought to lack any considerable personal connection.

> I was sorting them [hired caregivers] by how close we are... How much they know me, or will respect my decisions... hired caregivers will not know me as much as my parents and secondary caregivers. (P02)

There were a few exceptions, for example, when a hired caregiver had been in service for many years. They, too, could be trusted to make data decisions.

In addition to valuing the closeness of the relationship and the belief in good intentions, which has been previously documented in the literature (Nissen et al., 2019), the participants valued the people who spent time with them and provided care to them on a regular (e.g., daily) basis. These people were thought to be more attentive toward the person's condition and to have developed a deeper and current understanding of the person's health and life. Being responsible for the data would allow a delegate to pick up bits and pieces of information here and there. The delegates could consider these pieces of information when providing care and monitoring health based on the shared data. The participants believed that care team members with this quality not only needed the data for doing their jobs but also to be able to provide better quality of care and make better sharing decisions. This was one of the major reasons that family caregivers might stand out as delegates. P16 and P17 emphasized the benefits of having someone who could notice additional information pertinent to the provision of care:

> They [primary caregivers] are the persons who spend most of their time with me. They almost know as much as I do... they might notice something that I have not specifically shared. (P17)

> While they [primary caregivers] are not medically trained, they would know me inside and out. They would see me through my entire physical journey... They are the most hands-on... they would be looking out for me... My parents will go above and beyond to send data to people who are best to have that information. (P16)

Nonetheless, as in case of the medical professionals, there were tradeoffs. The characteristics of family members that were considered as positives by some participants could be perceived as negatives by the other participants.

The participants were concerned about how delegating the responsibilities of EDC sharing might affect their family members. One concern pertained to overwhelming family members with data, especially those members who were highly involved and, possibly, have little medical training.

> For primary caregivers, I do not want them to have too much to worry about. They have to closely monitor me [already], so I do not want to overwhelm them. (P02)

Furthermore, as has been reported extensively in the literature (Vertesi et al., 2016; Voida et al., 2005), information sharing is a matter that involves presentation of the self (Goffman et al., 1978). One may wish to present a particular "face" to family members or others, and this is true even in situations involving illness or chronic care. Therefore, the participants strongly considered the implications of allowing someone within their care team to assist with information sharing. The participants asked themselves how a care team member, especially a family member, might view the person (i.e., themselves) after gaining access to their data. EDC could reveal details about one's mental state or lifestyle, and for this reason, EDC might expose or reinforce negative views. The participants were concerned that problematic data could be revealed to other care team members in an undesirable manner. Family members were of particular concern in this regard because data sharing might not always improve family understanding; in some cases, it could exacerbate disagreements and tensions between the PCT and a family member.

> Suppose I am using recreational drugs, and a family member thinks using drugs is not a good thing, he or she will decide by himself or herself to share the data with secondary caregivers, and they might look down on me or have different opinions about me... (P09)
>
> ... if [my data show] I am wasting a lot of time on social media, that kind of thing... I think a lot of it could [make me] feel like being judged ... (P11)

This concern could be exacerbated if the family member works with the PCT closely on a daily basis as a care team member. This was especially true for data that revealed details about behavior and social interaction, as can be inferred from the above two quotes.

By contrast, with adequate control over the data, a few participants indicated that they would feel comfortable sharing with additional caregivers. For instance, while primary caregivers were generally trusted, several participants felt a closer relationship with siblings, and they felt more comfortable letting siblings to disclose certain types of data. These participants stated that siblings are from the same generation and will understand certain issues better (i.e., than parents). For instance, P02 discussed how she would be more willing to let her brother manage a greater amount of data than their parents:

> For secondary caregivers, I can give them more [data]... if my brother [a secondary caregiver] knows how these things go, then he can share these things with my parents. I trust my secondary caregivers to filter the information [i.e., the data] to give the primary caregivers. They can also keep secrets for me. (P02)

P18 extended this assumption about shared views to hired caregivers. A hired caregiver, if trusted, would be able to understand what is going on with her life and integrate that understanding into caregiver–PCT interactions.

> I could see myself giving [hired caregivers, in this case, college students] a little extra data. College students are aware of like Tinder and stuff like that. In college, people engage in the social scene. I would feel more inclined to share that data because I figure many college students... if they don't use it, they know someone who does use it. I could see them being a friend and I can casually mention: Oh yeah, [I] used Tinder for 30 minutes or something like that. It would also mean that they can either relate to me or they would not judge me, so I just feel more comfortable.... They are not my parents, but I guess that is what made me more comfortable sharing that information. (P18)

In summary, the participants were clear that much could be delegated. By contrast, the participants highlighted the considerable nuance they felt necessary. People with health conditions are required to weigh the characteristics they find promising or detrimental in allowing individuals–whether family members, medical professionals, or even hired caregivers–to be of assistance with sharing data. For EDC sharing, my results indicate no optimal choice of delegate for assisting a person. More specifically, many of these characteristics are double-edged swords: family caregivers are close, but sometimes too close; medical personnel stay professional and objective, but they might ignore the data that require more context or time or those that are personal in nature. The way people weigh the nuance in evaluating different care team members' fit as delegates varied across participants. Because of this variance and nuance, aiding the selection and use of delegates might be helpful, that is, some level of machine intelligence might be able to simplify decisions pertaining to data sharing and data examination.

Next, I focus on the potential use of agents and software, or machine intelligence in general, for sharing data.

5.4.3 Potential of Machine Intelligence as a Delegate

As an independent delegate or alongside existing care team members, machine intelligence could serve as a promising alternative to assist with data sharing. The participants of this study found the idea of using machine intelligence to assist with data sharing as being plausible and potentially useful.

The participants were able to explain their views of the characteristics of machine intelligence and its uses. Although their technical understanding varied considerably and was often limited, the participants were able to conceptualize how machine intelligence could be used in delegation. Unsurprising, it was unlike using humans. As I will describe in the text that follows, the participants did not view machine intelligence as being adequately capable of replacing either caregivers or clinicians completely. However, they did consider machine intelligence to be promising in its own way. In what follows, I discuss how my participants viewed machine intelligence as a potential delegate for sharing assistance.

Data Proficient, Objective, and Consistent

The participants recognized machine intelligence as possessing several similar and other noticeably distinct characteristics compared to human delegates. The participants considered machines to be good in terms of data proficiency, ability to analyze data objectively, and consistency in behavior. The participants used these characteristics as a general framework to assess the idea of using machine intelligence as a delegate, especially in comparison to human candidates.

The first quality of machine intelligence identified by the participants was data proficiency, that is, the ability to analyze data and identify patterns, as well as to determine to whom the data should be sent. This quality was considered particularly useful in the presence of patterns worthy of medical attention. In fact, machines were, at times, considered better than family caregivers in carrying out such tasks because family caregivers were often criticized as having less experience with data.

> I feel like my mom [as primary caregiver] would not do a good job managing my data. The machine will like: oh... with the data you give me, you should do ...... I don't think my mom will be able to do that efficiently. (P15)

> Primary caregivers might not know whether the data look right or wrong... but the machine will know. The machine can share these data with primary caregivers and primary care doctors. It can also notify my care network, or a specific person. (P04)

Machine intelligence was considered objective, and the participants opined that it would not generate subjective opinions or judgments due to its task of data management. The difference between machine intelligence and human beings with similar characteristics (i.e., medical professionals) is that some participants explicitly suggested that it was less embarrassing to let machines manage and analyze personal and private data before sharing them eventually. Letting machine intelligence be the first responder eased the participants' feelings of potential embarrassment or of privacy invasion.

> It is just easier, that it [machine intelligence] is not a person that analyzes your data. They will not have judgment and... I think people trust computers to be accurate and will alert you. (P17)

Another characteristic of machine intelligence that the participants found valuable was consistency. According to the participants, machine intelligence will follow certain rules and be less likely to share data in an ad-hoc manner. Moreover, machine intelligence would be reliable, even under considerable stress (e.g., a medical emergency). This quality of being consistent provided my participants with peace of mind; by contrast, they believed that human delegates might act differently under pressure in ways that would contradict a person's interests, especially in the event of a medical emergency.

> Machine intelligence will follow my instructions ...... When faced with a conflict, people tend to argue.... Machines will not be involved in this and make any excuse. Others will not bargain with machines. There will not be extra argument or negotiation. I believe that human beings will make their own decisions. In an emergency, they are "expected to do something," then they might break the rules. (P06)

Limitations of Machine Intelligence

The participants recognized that machine intelligence might be constrained by the rules being followed. The participants doubted whether rule-following machine intelligence could adapt to changes or to humans in a nuanced situation. For example, P09 commented that machine intelligence could handle sharing with long-time care team members, but it might not know how to share with newly added care team members, which is commonplace in an SCI/D care team.

> I think a machine might just send information to someone who has been recently added to the team, someone that I do not know.... For existing members, direct sharing is fine... but, the machine should not make decisions for new people. They [machines] can keep running the analysis and offer suggestions. (P09)

Recognizing that the limitations of machine intelligence might prevent it from adjusting to nuanced situations, the participants questioned the capability of machine intelligence to deliver sharing assistance. While machine intelligence was valued for its ability to make decisions in a non-judgmental manner and handle stressful situations consistently, these benefits might come at the cost of it not being able to deliver the data or assistance in a socially appropriate manner. In other words, the participants perceived a socio-technical gap (Ackerman, 2000) in terms of the capacity of machine intelligence to manage the social aspects of data sharing. For example, P11 suggested that machine intelligence might deliver data to care team members in a manner less rooted in care than a human might do:

> I do not want people to hear my data from a machine... I would rather hear it from someone who takes care of me. I think it [the machine] is less humane, ... I would rather hear it from family members. Machine is impersonal. (P11)

In summary, the participants recognized the good qualities that make machine intelligence plausible as a delegate, including being proficient with data, avoiding personal judgments, and exhibiting consistent behaviors, even under stress. Meanwhile, they expressed doubts about whether machine intelligence would always be capable of handling the various aspects of data sharing that are central to care and care teams. This placed machine intelligence in a rather interesting position: the participants recognize certain good qualities of machine intelligence while expressing varying degrees of certainty (or uncertainty) about its behavior or its ability to behave well. In other words, participants believed machine intelligence to have the potential to facilitate EDC sharing but were uncertain about whether machine intelligence could live up to their expectation.

In the following section, I describe the different roles and responsibilities that participants suggested for machine intelligence in terms of sharing assistance so that it can manage such uncertainty.

Role of Machine Intelligence in Supporting Data Sharing for Care

The participants recognized the strengths and limitations of machine intelligence, and they acknowledged that the role of machine intelligence as a delegate for sharing EDC could be limited for now. The participants postulated that machine intelligence could play various roles that highlight its strengths in supporting other care team members, either as an independent delegate or as part of a multi-delegate collaboration (e.g., a recommender of human delegates). Here, I describe several roles of machine intelligence that stood out from the interviews. These roles shed light on the form of assistance that machine intelligence could provide to support human–machine collaboration in EDC sharing to support chronic care.

General-Purpose Delegate: The participants suggested that machine intelligence might function as a general-purpose delegate, similar to other care team members. Approximately half of the participants viewed machine intelligence as playing the same roles as other care team members, namely checking data and forwarding data to another care team member. A few participants even directly associated machine intelligence with a specific care team member (e.g., a doctor) based on their similarities.

> It [machine intelligence] is like a primary care doctor, because it can monitor my body condition, so it can send the data to someone who can help. (P05)

> Humans make errors, and machines make mistakes, too, but as long as … in this context, if it only decides which data should go to whom … I think it is comparable, because it is not a difficult task. (P08)

Consultant: Participants suggested that machine intelligence could function as a consultant to make suggestions to people with health conditions or care team members, instead of sharing the data directly. Nearly half of the participants thought that machine intelligence could offer suggestions to care team members and let the care team members decide the next step (e.g., sharing data with a suggested person). As described above, several participants were uncertain about the behavior of machine intelligence in terms of technical accuracy (i.e., sharing the right data with the right person) and social acceptability (e.g., delivering data in a socially appropriate manner). They preferred machines to assume a supportive role and leave the decision related to and delivery of data to human beings.

> I do not trust it [machine intelligence] to send information directly... it cannot make an intuitive call in an emergency situation like doctors and nurses can... the nurses and doctors should get the suggestions (from machine intelligence and make decisions accordingly). (P19)

> The machine will be able to determine [people's] heart rate and EKG. It [machine] can help doctors. It is okay for the machine to know all the data, but not handle it. The doctor should. (P15)

Dispatcher: Machine intelligence might also function as a dispatcher that can take over the responsibilities of monitoring and sharing data with the right care team members. A few participants viewed machine intelligence as taking charge of data sharing so that other care team members could focus on their responsibilities of providing care or treatment, especially in the event of any change in a person's health.

> If it [machine intelligence] can just manage it, then it can keep things more organized. I can focus on getting better, rather than being mindful of where my data is going. (P14)

> In a more emergent situation, the machine has a role, and by default, it knows everything ... The machine should just get whatever care team members need and share it with them. (P04)

Gatekeeper: The participants considered machine intelligence as a gatekeeper that could identify data segments worthy of sharing. A small number of participants saw machine intelligence as being able to analyze data and provide a preliminary evaluation of the need for further examination. This capability would complement other care team members, who might not have sufficient experience with data or the capacity to analyze data to make decisions. P05 commented on how care team members could send data to a machine intelligence to check whether a further escalation is needed or whether an event is a false alarm.

> If family caregivers have questions [about the data], they can send the data to a machine, and the machine will check and notify the doctor if necessary. (P05)

All of these roles reiterate how the participants viewed machine intelligence as having limitations, but they still identified potential uses. Machine intelligence could participate in different aspects of sharing assistance, and it can assume various ranging from weak (e.g., gatekeeper) to strong (e.g., dispatcher). While the participants wanted machine intelligence to assume a specific role in data sharing, this role was not static, and machine intelligence may need to transition to another role when a situation presents itself. For instance, while the dispatcher role might seem fully autonomous without constraints, the participants often assumed that the role would be useful mostly when there was a health deterioration.

In addition, in recognizing the limitations of machine intelligence, the participants noted they might share only a small set of data, namely those they are more comfortable sharing, with machine intelligence at first. Moreover, they might decide to share a variety of data but limit the level of autonomy of machine intelligence to only make suggestions at the outset. This is one of the prominent reasons to assign the consultant's role to machine intelligence. As P15 explained, doing so could allow her to observe how machine intelligence generated suggestions to share certain data. P15 would then evaluate these suggestions to develop an understanding of the behavior of machine intelligence over time.

> Machines are… I do not know... I would be okay with machines knowing the data... I would allow machines to only make suggestions because I kind of want to see what they are suggesting to understand how to deal with them [machines]. (P15)

As I described, another concern people have about machine intelligence is its capability to share data in a socially appropriate manner. In the context of care, this is especially important because failure to deliver data or suggestions appropriately might result in confusion and worries that could lead to additional emotional or physical burdens on top of the illness. This issue could potentially be alleviated by endowing machine intelligence with the ability to provide an explanation. P13 suggested that the ability of machine intelligence to explain the rationale behind a suggestion or action was critical for her to accept machine intelligence.

> I could not explain myself to a machine. They don't understand humans ... if a primary caregiver calls, they will say, "we will be doing this and that... here is why" The machine will just do cold turkey... I would want a little bit of explanation of why they send it [data]. (P13)

In summary, the participants were intrigued with machine intelligence as a potential source of help in data sharing. While the participants identified a number of limitations, they listed several benefits of using machine intelligence for data sharing, especially objectivity, consistency, and data proficiency. Above, I reviewed the suggested delegate roles of machine intelligence in sharing assistance that the participants identified. Moreover, the participants remarked how human delegates and machine intelligence could be combined to enhance the effectiveness of sharing assistance.

In the following section, I discuss the implications of my findings for interactive systems designed to support sharing assistance for EDC.

5.5 Discussion

I conducted an interview-based study to investigate the idea of obtaining assistance through the sharing of EDC to support chronic care. The results indicated that EDC sharing assistance was perceived as potentially useful and occasionally necessary to manage the changes in one's care. The participants considered EDC sharing assistance a multi-step process that not only required the creation of meaningful sharing settings but also engagement with and delivery of data.

Notably, the scenario that included care team members and data types was useful for grounding my participants, regardless of their experience, as they discussed the different factors that should be considered in the use of delegates. The participants were able to utilize their understanding and any experience of work with a family member, hired help, and medical professionals to evaluate their use as delegates. The participants identified the diverse and possibly complementary characteristics of human and machine-based delegates for providing sharing assistance. The potential of care team members as delegates was weighed based on characteristics such as mutual understanding, involvement in care, trust, as well as expertise in care, medicine, and data. A few of the participants preferred clinicians based on their expertise and objectivity, but they were concerned about the clinician not having sufficient time for data analysis. Other participants preferred their caregivers for the purpose because of the mutual understanding, trust, and involvement in care. Machine intelligence, as an alternative, was valued for its ability to analyze data consistently across different care situations and its capability to stay detached to avoid opinionated behaviors that might work against the interests of PCTs. Moreover, machine intelligence was assumed to be data-proficient in a way that caregivers might not be. However, machine intelligence was seen as being limited in its understanding of a person's context and in its ability to provide socially sensitive responses. The participants' recognition of its disadvantages, even with a limited understanding of its technical capabilities, engendered a range of roles for machine intelligence as an assistant to other delegates in providing care.

In this section, I discuss the implications of these findings for designing interactive systems to facilitate sharing assistance and suggest the possibility of a human–machine collaborative approach for EDC sharing assistance.

5.5.1 Providing Sharing Assistance Along the Health Trajectory

My findings expand on the work of Nissen et al. (2019) on obtaining assistance with consent to data requests. My results demonstrate that in the context of chronic care, where a delegate needs to share EDC proactively to support ongoing care, people's preferences about delegation might change based on their evaluations of the importance of various characteristics under changing conditions. For instance, the benefit of offloading work to machine intelligence, as reported by Colnago et al. (2020), emerged as an important consideration for incorporating assistance from machine-based delegates when a person's health changed. Such changes in delegate preferences suggest that a certain amount of coordination is needed for a person to arrive at a preferred form of delegation across situations. In other words, a PCT should be able to allocate EDC-sharing responsibilities to different combinations of delegates across care situations. Systems designed to facilitate sharing delegation should support such coordination across potential situations that people deem important so that they can maintain control. For instance, AI-based critics (Fischer et al., 1990) could be developed to help people clarify their preferred characteristics for delegation (e.g., characteristics of delegates, EDC to delegate, or a specific care situation) that are important to people to invoke appropriate sharing assistance along their health trajectories (Strauss et al., 1997).

5.5.2 Develop Understanding of Machine Intelligence as a Sharing Assistant (Delegate)

My findings pertaining to people's low level of trust in AI/Bots for sharing delegation echo those of Nissen et al. (2019), but they also reveal a more nuanced picture. People do appreciate certain qualities of machine intelligence (e.g., proficiency with data, objectivity, consistency) as a delegate, which suggests that existing work on machine-generated sharing suggestions (e.g., for privacy settings or profiles [Behirat et al., 2018; Smullen et al., 2020]) could be valuable. However, owing to a limited understanding and recognition of the constraints of machine intelligence (e.g., an inability to react to changes and socially ineptness), people might prefer not to permit machine intelligence to be fully autonomous on all EDC at the outset. Notably, this understanding is different from how machine intelligence was projected as biased and unfair by participants in the study of Nissen et al. One possible explanation is that access to specific data details (EDC), receivers (care team members), and context (chronic care) might alleviate some of the concerns compared to Nissen et al.'s sharing of an all-encompassing category (e.g., health data or medical records) with a third-party organization, the consequences of which were not completely understood by the users. My findings suggest that machine intelligence might be better-positioned to assist with chronic care than previously thought.

My findings on the contrast between human and machine-based delegates suggest a potential way to mitigate any user hesitation: people need time to develop an understanding of the characteristics and behaviors of human delegates. Interactive systems with machine intelligence designed for delegation should, therefore, support the development of users' understanding. Prior work has demonstrated that people are willing to develop an understanding of machine intelligence and adjust their approaches and expectations through piecemeal interactions with systems over time (Kim & Lim, 2019). Interactive systems equipped with machine intelligence could enable users to inquire about the machine intelligence's understanding of the care situation and its proposed behavior (e.g., how data will be shared in the case of a health emergency). In this manner, machine intelligence could provide a consistency of response, while its actions can be understood, which would provide people with a sense of control over their care.

5.5.3 A Human–Machine Collaborative Approach to Sharing EDC for Chronic Care

My results indicate that people recognize the tradeoffs between the characteristics of human and machine-based delegates and tailor their preferences for assistance in different care situations. This suggests the need for a user to flexibly select a delegate and the level of autonomy for the said delegate. My findings pertaining to how these characteristics might complement each other further suggest the potential of a multi-delegate approach to EDC sharing for chronic care.

As a start, instead of a human-only or machine-only approach examined in the literature (Colnago et al., 2020; Nissen et al., 2019), a machine-initiate-human-deliver approach could be employed to allow machine intelligence to identify opportunities or needs to share EDC, either proactively (as a consultant) or reactively (as a gatekeeper). Human delegates can then examine, assemble, and approve sharing recommendations based on their understanding of the PCT and deliver EDC. Such an approach could potentially reduce time commitments and avoid biases and judgments from human delegates because the initial data analysis is performed by machine intelligence. Moreover, this approach allows human delegates to integrate social and contextual considerations that might lie outside of the capabilities of machine intelligence. The responsibilities and capabilities of different delegates can be reconfigured for different tracking needs in reaction to changes in health (Büyüktür et al., 2017) once people with health conditions and human delegates have a better understanding of such human–machine collaboration.

My findings on people's limited understanding of machine intelligence suggest that such reconfiguration could best be supported by employing a training wheel approach (Carroll & Carrithers, 1984). For instance, machine intelligence could start with providing recommendations for only a small set of EDC before gradually revealing more advanced capabilities (e.g., pattern detection and automatic sharing). Interactive systems could limit the capabilities of machine intelligence to a few basic functions at first to help people develop a proper mental model of how machine intelligence behaves, before they are exposed to its more advanced capabilities.

Yang and Newman (2013) reported that an interactive system with machine intelligence that presents itself without acknowledging its limitations could cause users to spend an inordinate amount of time to understand those limitations, which would often cause frustration. By contrast, the adoption of a training wheel approach to progressively reveal the capabilities of machine intelligence would allow users to adopt and learn its behaviors. Because chronic care requires a care team to dynamically adapt to changes in health and care team structure, adoption of the training wheel approach would allow people with health conditions and surrogates such as caregivers to incrementally reconfigure the power and responsibility distribution among human and machine-based delegates to tailor EDC sharing assistance.

5.5.4 Limitations and Future Work

My study was situated in a US context, and it utilized a scenario based in a specific condition (i.e., spinal cord injuries and disorders). As with any interpretivist study, there are limits to generalization. For example, SCI/D represents a specific set of chronic conditions. Furthermore, attitudes toward data sharing could be different in other cultures, and care arrangements for chronic conditions will differ across countries. Additionally, the majority of the study participants were young adults (ages 18–35 years), who were generally comfortable with computers. However, my results are likely to be true in many contexts. The SCI/D characteristics of interest in my scenario may exist in the cases of numerous other severe chronic conditions, including degenerative diseases such as Parkinson's and dementia. Moreover, it is likely that the different and potentially complementary characteristics of human and machine-based delegates are likely to be true across diverse settings and conditions. Therefore, I believe that my findings offer useful insights for developing healthcare data systems that facilitate easy control over data for people with health conditions, especially when greater volumes and types of EDC will be available in the future. In this context, it seems useful to design interactive systems that allow delegates. Moreover, I believe that a multi-delegate approach for sharing EDC to support chronic care will ameliorate many of the challenges associated with the use of human delegates, as identified by the participants of this study. Further studies are needed to examine whether people's views on the use of human and machine-based delegates for EDC sharing assistance might shift for populations with different understandings of or relationships with data, care, and machines. In the future, I will investigate how to support people in configuring a multi-delegate approach for EDC sharing and develop software agents to assist with the configuration of delegation that includes human and machine-based delegates.

5.6 Concluding Remarks

In this study, I examined the idea of obtaining EDC sharing assistance from humans and machines in the context of collaborative self-care. My aim was to support PCTs with data sharing, especially with the provisioning of EDC data to care team members while protecting PCT's own privacy, which is important for care. In addition, I intended to consider how to realize data sharing in an open-system, non-institutionally controlled manner.

Through an interview-based study conducted with a chronic care scenario (spinal cord injuries and disorders), I revealed how people consider the idea of letting human and machine-based delegates provide data sharing assistance and how people view humans and machines as delegates. I found that obtaining assistance from delegates is nuanced and situated, and people want assistance not just to set sharing settings but also to analyze and monitor EDC. Making decisions to delegate the power and responsibility of managing EDC sharing to other members of a care team requires careful consideration of the mutual understanding between people and delegates, delegates' ability to understand the nature of data, and the effects of delegation on the relationships between PCTs and their care team members. While people recognize the potential of obtaining sharing assistance from machine intelligence, they have a limited understanding of machine intelligence and recognize limitations. Consequently, they are cautious when invoking assistance from machines. My findings on the contrast between human and machine-based delegates, however, signal the possibility of employing a multi-delegate approach. Such an approach would allow machine intelligence to complement the work of human delegates under the direction of a person with a health condition.

Chapter 6

Conclusion

In previous chapters, I introduced three studies that investigated how to design systems for supporting people with health conditions requiring care teams (PCTs), giving them the capability to direct the dissemination of everyday data for care (EDC) within care teams.

These three studies examined EDC sharing and particularly focused on supporting different configurations of sharing that respect PCTs' desired levels of involvement. The investigation was built on the premise that PCTs' priorities relate not only to health conditions, but also to other life situations such as school, work, and improving their health. PCTs' different priorities mean that they have varying degrees of capacity for directing EDC sharing, since changes in priorities mean that data sharing configurations may be either the center of their attention or a peripheral concern. A particular dimension I considered in these studies was the effect of health changes (e.g., deteriorations in health) on PCTs' EDC sharing capacity and PCTs' need for different types of support.

This dissertation aims to systematically examine system designs with three levels of user involvement (high, medium, and low) to support EDC sharing in ways that align with PCT members' capacity for control.

In the remaining sections of this chapter, I will briefly summarize the findings, reiterate the contributions and significance of the research, propose future research directions, discuss the limitations of the studies, and provide concluding remarks.

6.1 Summary of Findings

6.1.1 Systems designed to support PCTs in sharing EDC should align with the collaborative nature of self-care.

In Chapter 3, I employed a human-centered approach to create an EDC sharing system–Data Checkers (DC)–that enables PCTs to manually control EDC data flows. DC provides a grid-based user interface, together with the ability to preview sharing results in each care team member's view. The design of DC was produced through an eight-month co-design process with a person with a health condition requiring a care team (PCT). My design partner and I discussed the lived experience of a person with a severe health condition that necessitated assistance from different caregivers and clinicians to maintain self-care. Based on previous literature and findings from the co-design process, I identified a set of design requirements that are critical for the success of a user-facing system, such as DC, to control EDC sharing in a care team context. Besides standard usability requirements, I argued for the importance of supporting EDC sharing with multiple members of a sufficiently-sized care team (Require2); enabling fine-grained control through different tools to tailor the details, time span, shape, and visibility of data for sharing (Require4); and enabling adaptation to health and care team changes for long-term sharing management (Require5). The evaluation of DC, which compared DC with a standard graphical user interface (GUI) design, showed that DC, incorporating the design requirements, was more useful for handling EDC sharing with a care team. The results reaffirmed the importance of the proposed design requirements and demonstrated the advantages of aligning design with the collaborative nature of self-care for a person with a health condition requiring a care team.

6.1.2 User-generated high-level collections of EDC data types can potentially simplify EDC sharing configuration

In Chapter 4, I examined EDC sharing with the goal of developing an approach with light user involvement to enable PCTs to avoid the need for manual configuration of individual data flows: I investigated the possibility of employing user-generated high-level EDC units to simplify the specification of sharing settings and understand whether there could be usage patterns that could be used to semi-automatically simplify sharing configurations for when one's health deteriorated. I showed that participants were able to sort a set of 32 EDC data types into groups based on the concept of "sharing comfort." Some EDC types were commonly considered to be comfortable to share (e.g., heart rate) or less comfortable (e.g., intimate behavior), but other data types revealed the individual differences between participants in how comfortable they felt sharing different types of EDC. These individual differences, however, did not seem to undermine the usefulness of these data groupings for the people who created them. Participants could use their own groupings to specify how they would share EDC data with different care team members (e.g., caregivers and different clinicians), suggesting that an individual's groupings were useful for allowing that specific participant to more easily consider sharing, alleviating the need to examine each data type. Moreover, participants demonstrated a general tendency to share the same or more EDC data types at the group level when facing health deterioration situations. Such a tendency suggested that these user-generated EDC groupings not only had the potential to facilitate the specification of sharing settings at the group level, but also that some semi-automatic inference could be carried out to estimate what data to share when a person's health deteriorates. Such a semi-automatic approach could greatly simplify the configuration of EDC sharing, especially for different care situations.

6.1.3 Assistance for EDC sharing would benefit from a human–machine collaborative approach that carefully considers the complementary characteristics of human and machine delegates

In Chapter 5, I investigated the possibility of developing an EDC sharing approach that would require low levels of user involvement from PCTs, enabling decisions about sharing different EDC data types with care team members to be made by a set of human and machine delegates. Examining assistance from care team members and machine intelligence in sharing EDC for care, I showed that participants considered human and machine delegates to possess different and possibly complementary characteristics that are important when considering what types of assistance to ask of them. More specifically, when considering human delegates, participants valued the mutual understanding that could be used to gauge PCTs' preferences and delegates' participation in PCTs' care and lives, allowing them to better understand the context of EDC data capturing. However, participants worried that some human delegates might not have the necessary knowledge and skills to properly interpret EDC data, or that they might generate negative opinions toward PCTs. When considering machine delegates (e.g., machine intelligence), participants valued machine intelligence's capability to process and analyze data, generate insights, exhibit consistent and reliable behaviors even during health emergencies, and remain objective by not showing personal judgements. However, participants also worried that machine intelligence might not be able to properly interpret personal data and might not adapt well to changes (e.g., people joining or leaving a care team). Based on these considerations, participants suggested a set of roles for machine intelligence to assist with EDC sharing, in collaboration with human delegates (i.e., care team members): a general-purpose delegate assigned with different EDC sharing responsibilities, a consultant to actively provide recommendations for sharing, a dispatcher to alleviate the workload of care team members and enable them to focus on care, and a gatekeeper to provide analysis requested by human delegates. These findings provided a framework for understanding how a human–machine collaborative approach could be developed to facilitate EDC sharing.

6.2 Contributions Revisited

In this section, I revisit the research questions I aimed to answer and summarize the contributions of this dissertation.

The context of investigation for this dissertation was a chronic care setting, specifically involving a person whose condition affected her capability to conduct self-care activities. Consequently, she needed assistance from a care team to help with day-to-day care and collaboratively improve her quality of life.

As stated consistently throughout this dissertation, the goal was to investigate how we could design interactive systems to support data sharing, highlighting both the protective (i.e., privacy) and proactive aspects of sharing (e.g., supportive collaboration and improved care). I chose to examine these aspects in the aforementioned context because the person with the health condition had to consider issues such as privacy and self-presentation when sharing data with her care team members. Equally important was the need to support collaborative monitoring and coordination among care team members, which are crucial for the success of self-care in the home. The ability to direct EDC sharing among care team members is critical for the autonomy and independence of PCTs.

Supporting PCTs in directing EDC sharing requires special consideration of their capacity. A PCT has different life priorities, including, but not limited to, school and work, besides health. Moreover, changes—sometimes life-threatening changes—in a PCT's health can seriously affect how PCTs prioritize different issues (including data sharing) or simply the PCT's motivation to control data sharing. Consequently, interactive systems designed to support EDC sharing should support PCTs with varying sharing capacities in managing EDC sharing.

Considering PCTs' sharing capacity, the overarching questions this dissertation aims to answer are as follows:

> Q-Overall: How to effectively support people with health conditions requiring care teams (PCTs) to direct the sharing of their everyday data for care (EDC)?
>
> Q-Guide: How to support people with health conditions to direct data sharing in a way that respects their priorities and capacities and matches their desired level of involvement?

To systematically answer these questions, I formulated three further questions to guide my investigation. These three questions emphasized approaches that require different levels of user involvement (e.g., high/medium/low) to accommodate the capacity of PCTs to direct EDC sharing. In the remaining part of this section, I will present each research question and discuss the contribution made by the dissertation.

Q-1: How could we design a user interface for PCTs to exert fine-grained control over EDC sharing with care teams?

In Chapter 3, I presented a set of design requirements based on the literature review and the findings from the co-design process. This set of design requirements was incorporated into the interactive system I developed (DC), which provides a grid-based user interface and the ability to preview data sharing results from the perspective of recipients. This system was subsequently evaluated through a comparison study that suggested DC was useful for supporting fine-grained control over EDC sharing within a care team. I designed, developed, and evaluated the system and discussed the results demonstrating the benefits of aligning design to the requirements of collaborative self-care.

The outcome of this investigation was:

- A new interactive system, Data Checkers (DC), features a grid-based user interface and a preview function to permit fine-grained control over everyday data for care (EDC) to support collaborative self-care.
- DC satisfies the identified design requirements, according to the literature and my co-design with a person with a severe health condition. DC is likely to be useful for other chronic conditions that require a sufficiently-sized care team, such as spinal cord injuries and disorders (SCI/D).

Q-2: Could EDC data be grouped by PCTs for sharing to reduce the workload/complexity of sharing configuration?

In Chapter 4, I presented a study that investigated the possibility and applicability of employing user-generated EDC groupings to create EDC sharing settings with reduced user involvement, while still respecting the unique perspective of each PCT. Additionally, the investigation aimed to examine whether the need to create sharing settings for different care situations (e.g., when a person's health deteriorated) could be simplified through these user-generated EDC groupings. I presented evidence that these user-generated EDC groupings were useful for specifying sharing settings, which suggested the possibility of developing a semi-automatic approach for configuring EDC sharing.

I found:

- Participants could easily create groupings of EDC data types based on a simple criterion (comfort) that were meaningful to them and could be used to create EDC data sharing settings.
- Participants could reuse these user-defined groupings as high-level units to specify sharing settings for different care team members, implying that it may be possible to create stable groupings for each user that would simplify the creation and potentially the maintenance of data sharing and privacy settings.

- Participants tended to share the same or more EDC data at the group level when a person's health deteriorated. This implied the possibility of inferring sharing settings for different care situations, which could be used to reduce the amount of configuration necessary for different care situations in a person's health trajectory.

Q-3: How would people consider obtaining assistance from human and machine actors to assist with EDC sharing?

In Chapter 5, I investigated the idea of using assistance from human and machine delegates to help with EDC sharing configuration to accommodate changes in a person's health trajectory. The focus points of this project were to understand (1) what types of assistance people wanted, (2) what characteristics a good delegate should have, and (3) how assistance from machine intelligence could be integrated to facilitate EDC sharing. The results underpinned a framework for identifying a good EDC sharing delegate and deciding how sharing assistance from human and machine actors could be integrated.

This study determined:

- Obtaining assistance for sharing data in support of care is nuanced, situated, and goes beyond simply managing sharing settings.
- Participants considered the issues and potential of using care team members and machine intelligence as potential delegates for providing sharing assistance.
- The trade-offs and implications for systems aiming to involve human and machine delegates to share data in care provided indications for developing a human-collaborative approach to EDC sharing assistance.

Overall, this dissertation investigated system design to support the sharing of EDC among care team members. Through the lens of (1) user interface design, (2) user preferences, and (3) delegation capabilities and responsibilities, this dissertation demonstrates three approaches that require high, medium, and low user involvement for EDC sharing management. The results improve our understanding of the design of data sharing systems that consider the capacity of PCTs to properly direct data sharing.

6.3 Areas for Future Research

Besides the opportunities for further research presented in the previous three chapters, the three-fold exploration of system designs to support PCTs in directing EDC sharing was beneficial, since my investigation into user interface design, individual-assisted semi-automatic approaches, and delegation of EDC sharing management revealed insights with similar themes.

6.3.1 Designing a User Interface for Managing EDC Sharing and Support Collaborative Self-Care

In Chapter 3, I demonstrated that a key advantage of DC is enabling users to group key elements of sharing settings, data, individuals (recipients), and controls in ways that allow the creation of sharing settings to be aligned with collaborative monitoring and diagnostic tracking. My findings regarding how people create EDC groupings and use these groupings as high-level units for simplifying EDC sharing configuration, as shown in Chapter 4, further suggest that future research should consider strengthening support for the creation of user-generated groupings through user-interface design.

Although, in Chapter 4, I only examined the utility of user-generated groupings of EDC data types, similar considerations could be extended to individuals and controls to examine how PCTs could tailor the groupings of people (i.e., their roles) and controls to support sharing configuration.

Another finding from the grouping study was that users were inclined to share more EDC at the grouping level when their health conditions deteriorated. Such a use case aligns well with DC's ability to allow users to dynamically add (or remove) person, data, or control blocks (from a visual group) on its grid-based user interface to repurpose and modify existing sharing settings. Such built-in support for easy modification suggests that future research should investigate how to support users in creating sharing settings for different situations through visual composition, using DC's grid-based user interface as an example. Creating a visual user interface to allow users to understand how EDC sharing differs between situations by comparing and contrasting will enable users to critically examine sharing for different care situations and maintain a sense of control throughout people' health journeys.

The ability to use visual composition to create and modify settings using DC's grid-based user interface could potentially be extended to configure delegations (i.e., for creating delegation settings). In Chapter 5, I showed that people determined a set of roles for machine intelligence to provide types of assistance through EDC sharing that match their expectations and also deal with the uncertainty of how machine intelligence behaves in different care situations. While the DC "controls" were originally designed to represent different data processing utilities that enable fine-grained control, new control blocks could be introduced to add new semantics, such as roles to represent sets of capabilities (e.g., for checking data or making suggestions) or conditions to indicate different care situations (e.g., emergencies) and dynamically define delegation settings (e.g., delegate–control–data tuples). The preview feature could also be repurposed to help users understand the effect of delegation settings, such as what data are available to the team when using a particular delegate in a situation (e.g., an emergency). A more advanced version could support the creation of delegation settings to configure a multi-delegate approach for EDC (i.e., how multiple delegates could collaborate to provide sharing assistance). Given the success of the grid-based interface demonstrated in Chapter 3, DC has the potential to be useful for configuring EDC sharing assistance.

The overarching goal of this stream of research was to improve user interface design in ways that align with users' goals (e.g., priorities), the requirements of care, and existing self-care practices (e.g., collaborative monitoring and diagnostic tracking). The co-design effort and the evaluation of DC presented in Chapter 3 demonstrated that such alignment would result in a more useful user interface than the existing ones for PCTs to manage EDC sharing within care teams. Future research could consider developing a research agenda with a similar emphasis to create a suitable design.

6.3.2 Supporting Intermittent Engagement for the Long Term

This dissertation explores the design of systems to support EDC sharing for PCTs to direct care and facilitate their independence. The main issue concerns the capacity of PCTs to direct the sharing of multiple EDC data sources, since such capacity can vary based on PCTs' priorities and preferences and how their health evolves.

The need to support interaction with data in the long term should be a prominent consideration due to the nature of chronic (possibly life-long) care. The need to support interactions over time, originally included to contextualize the investigation, emerged during the three projects in relation to necessary changes.

In Chapter 3, the design requirements that inspired DC were based on previous research and the eight-month co-design process that allowed the development of DC to prioritize care. The evaluation of DC highlighted the critical necessity to support intermittent engagement throughout the lifetime of a PCT. Chronic care requires care team members to collaboratively adjust care routines in response to various changes, including new developments in a patient's health or care team members joining or leaving the team (Büyüktür et al., 2017; Büyüktür et al., 2018). A similar theme that emerged in the other two studies was that people are likely to adjust their sharing of sets of EDC data (in Chapter 4) and seek different kinds of assistance from delegates (in Chapter 5) when there is a new development in either health or care team membership. All these changes require adjustments to EDC sharing to properly support collaboration.

One approach to addressing these changes, as suggested by participants based on their experience of using DC, would be to design interactive systems to stimulate reflection and allow PCTs to intermittently interact with settings for managing EDC sharing. Supporting such reflection is critical because PCTs have different priorities in life besides health (and hence managing EDC sharing). Future research should consider designing such intermittent interactions to support reflection.

Two important dimensions to consider, as demonstrated in this dissertation, are the timing of reflection (when to reflect) and the target of reflection (what to reflect on). Since new developments in people's health or care team changes are likely to require re-examination of sharing, interactive systems could offer opportunities for reflection when a situation becomes manageable (e.g., a few days after a clinic visit). Regarding the target of reflection, the DC study revealed that guiding users' attention is important for enabling them to review only a limited set of preferences or settings, making such engagement less of a burden.

Another opportunity, as hinted by all three studies, would involve using intelligence agents (e.g., software critics [Fischer et al., 1990]) to examine sharing or delegation settings and identify elements that are worthy of PCTs' attention; for instance, a critic could highlight the settings involving data on a recent development in a person's health, or care team members who have reduced their participation in care, enabling PCTs to make necessary adjustments. Such intermittent engagement should allow PCTs to refresh their understanding of how EDC are shared in care teams (a DC benefit that participants identified) and decide what aspects of sharing need to be refined. Supporting such engagement is critical for the long-term success of EDC sharing.

6.3.3 Developing Capacity-Aware Human–Machine Collaboration for EDC Sharing

The dissertation set out to explore system designs for supporting PCTs to direct data sharing. The three studies presented in the previous chapters developed approaches with different levels of user involvement to support PCTs with different capacities for directing sharing. The results suggested the potential or applicability of these approaches and the importance of including a suitable user interface design, user-generated EDC groupings, and human and machine actors to provide sharing assistance.

While these approaches centered on supporting PCTs whose sharing capacity might be affected by their priorities, health concerns, and care team changes, reflecting further on the results prompted a more holistic view of what it means to develop a capacity-aware approach for EDC sharing.

First, the sharing capacity of a PCT requires a more nuanced, integrated view for system design. Besides new developments in health or bodily changes (e.g., health deterioration), PCTs' knowledge of and attitude toward sharing EDC can also change over time as they experience different life events and gain experience of sharing data. Consequently, PCTs may wish to adjust the forms of input or preferences they have previously used for interactive systems, such as user-generated EDC groupings. In Chapter 4, although it was not the focus of the study to investigate changes in people's preferences (i.e., groupings), the participants' inclination to share more data in health deterioration situations highlighted a need to provide supporting mechanisms for PCTs to communicate necessary adjustments to interactive systems. Capacity, in this sense, also includes the knowledge and experience PCTs acquire throughout their health trajectories, which they can use to configure EDC sharing. A successful approach to EDC sharing should not only consider the possibly reduced sharing capacity of PCTs, but also explore ways to support increases in capacity for managing EDC sharing.

Second, the capacity of care team members to develop a collaborative approach to supporting self-care should also be considered. In Chapter 5, I presented my findings on how people considered using different care team members to assist with EDC sharing. I showed that they considered several prominent characteristics, such as mutual understanding, data proficiency, and the objectivity to evaluate a delegate for providing sharing assistance. These characteristics shaped an initial framework for assessing how sharing assistance could be configured, which PCTs consider integral to facilitating EDC sharing. Capacity, in this case, did not depend solely on a PCT, but on the care team members who assist PCTs with self-care in their everyday lives (Birnholtz & Jones-Rounds, 2010; Büyüktür et al., 2018). Future research should consider examining the capacity of PCT members to facilitate a collaborative approach to EDC sharing, and increasing that capacity as individuals and as a team.

Third, capacity is not a static quality, and it takes time and interaction to develop a proper and accurate understanding. My results led to the recognition that capacity is not static, and equally importantly, that capacity, far from being instantly recognizable, can only be properly recognized through interactions over time (i.e., regarding a person's health trajectory). In the DC study, the participants mentioned that long-term management of EDC sharing should support the reflection that allows PCTs to evaluate how EDC is, or ought to be, shared. This would include recognizing care team members whose involvement in care has gradually faded over time. In the delegation study, participants stressed that some of the properties they valued as signaling the capacity of care team members to provide assistance, such as trust, relationships, and involvement in care, develop over time. Recognition of capacity is also important for machine intelligence because people may have unrealistic expectations of and uncertainty regarding machine intelligence's capacity as exhibited through its behavior. Ultimately, it takes time for people to interact effectively with machine intelligence and develop a better understanding of its capacity. Future research should consider how best to support PCTs in developing an ongoing understanding of the capacities of different actors (including care team members and PCTs) who can facilitate EDC sharing to develop a collaborative approach that respects everyone's capacity.

Lastly, the three approaches presented in this dissertation provided the initial building blocks for understanding the possibility and challenges of developing a capacity-aware solution for EDC sharing. This dissertation also highlights the need to support transitions between approaches with different levels of user involvement (e.g., high, medium, and low). The dissertation has shed light on how this could be achieved. All three studies pointed to a need to integrate machine intelligence to provide guidance or cover responsibilities when PCTs and care team members have limited capacity. The delegation study had already begun to explore the dynamics of and balance between the capacities of different human and machine actors to provide a multi-delegate human–machine collaborative approach. Future research should consider exploring interactive and automatic approaches to supporting the recognition of each actor's capacity (e.g., using discount expertise estimation [Hung and Ackerman, 2015]) based on interaction history, integrating machine intelligence to facilitate the transfer of responsibilities, and a truly capacity-aware human–machine collaborative approach to data sharing for care.

6.4 Limitations

This dissertation advances EDC sharing for PCTs; however, the described studies have several limitations that must be considered to further extend this line of research and continue investigation into the design of systems to support EDC sharing.

6.4.1 The scope of the research

First, all studies presented in this dissertation used non-probabilistic sampling for participant recruitment. Although the themes I identified were prominent and I believe hold true for PCTs with similar care needs, further studies should consider randomized sampling to strengthen the generalizability of the findings.

Second, to focus my investigation, all three projects used the scenario of spinal cord injuries and disorders (SCI/D). This scenario necessitated a sufficiently-sized care team (e.g., 8–20 members) to provide assistance (Büyüktür et al., 2018), and it also highlighted the dynamic nature of changes in health or care teams that might require the reconfiguration of EDC sharing (Büyüktür et al., 2017; Büyüktür et al., 2018). I found the scenario to be useful for properly orienting study participants during the study; however, experiences of living with other health conditions may not be the same as for people living with SCI/D. Moreover, the existing literature has repeatedly suggested that people with health conditions experience each health condition differently (R. M. Anderson, 1995; Schroeder et al., 2018). Future studies should consider examining EDC sharing for PCTs with other health conditions, with potentially different care team sizes or structures.

6.4.2 The participants and context of the research

Third, with some exceptions, I used participants who generally shared similar characteristics: young, educated, and generally comfortable with computers. I argue that (1) individuals of that age are the people who will face the challenges of managing the sharing of many EDC data sources in the future, and that (2) their education and comfort with computers allowed me to use their responses as a conservative measure for evaluating system concepts. Nevertheless, including participants with diverse characteristics could help future research to develop a more thorough understanding of the design of EDC sharing systems for PCTs. This would not necessarily invalidate the findings presented in this dissertation but would allow researchers to consider how factors such as comfort in trying a new user interface, the ability to evaluate utility and risk when grouping EDC data for sharing, and the recognition of ability and trust in a potential delegate might shift for a population with a different lived experience.

Fourth, the three studies presented in this dissertation were conducted in a US context, which has particular health systems, care team arrangements, approaches to health, attitudes toward data sharing, and social norms (e.g., for familial or professional interaction). Studying within a particular context allowed me to focus my investigation on the design space and propose a suitable system design; however, to design systems for supporting PCTs in EDC sharing, future research should consider investigating a different context and how these factors might suggest additional design requirements.

6.4.3 The scale of the research

Finally, as also noted in Chapter 3, I adopted the approach recommended by Klasnja et al. (2011) and Klasnja et al. (2017), focusing on investigating designs to support simple tasks (proximal goals) that could be essential in the long term. I used the same approach to study software user-interface design (in Chapter 3), create user-generated high-level EDC units (i.e., groupings) for sharing (in Chapter 4), and identify delegates to manage EDC sharing (in Chapter 5). Within the scope of each research study, I obtained meaningful outcomes that served as important building blocks for system design. It is worth noting that, as also discussed in all three chapters, PCTs' data sharing requires not a one-time decision, but continual refinement in response to changes in patients' health, care, and lives. This dissertation makes important observations regarding essential considerations for supporting piecemeal interactions and managing EDC sharing, while simultaneously hinting at a need for longitudinal research. To obtain additional insights into support for long-term EDC management, a long-term study is needed.

6.5 Concluding Remarks

The goal of this dissertation was to advance system design to support people with health conditions requiring care teams (PCTs) to share everyday data for care (EDC). The focus of the research was to identify different system solutions requiring varying levels of user involvement to enable a collection of systems to accommodate the changing capacity of users (i.e., PCTs) to properly facilitate EDC sharing. This dissertation demonstrates the potential of three different approaches with high, medium, and low levels of user involvement to support EDC sharing and provides an understanding of the advantages and open questions for each approach. The study context involved a particular kind of chronic care for people whose health conditions result in constraints (e.g., physical limitations) that require assistance from a care team to enhance self-care and improve health and quality of life.

This dissertation considers spinal cord injuries and disorders (SCI/D), which often cause severe injuries or result in paralysis, loss of senses, and organ function damage. People with SCI/D have complex care needs regarding taking medication, maintaining hydration, pressure relief, bowel/bladder programs, and condition monitoring (e.g., heart rate, weight, and pain measurement). Having assistance from teams of 5–20 caregivers and clinicians is thus critical for people with SCI/D to conduct self-care. There are, however, several factors that make designing systems to support people with such care needs challenging: people's health can change, as can care team structures (e.g., through high turnover rates for hired caregivers). People (i.e., PCTs) need to develop independence in this collaborative environment.

This dissertation used the scenario of a person with SCI/D working with a care team to motivate the need to facilitate data sharing, support care collaboration, and develop approaches that consider the capacity of PCTs to direct data sharing. Since increasingly available (physical and algorithmic) sensing solutions can capture details about a PCT's everyday life, EDC exacerbates the issue of large amounts of data being required for managing and developing capacity-aware solutions.

The series of studies presented in this dissertation enhanced understanding of the design of systems to support PCTs in directing EDC sharing. Throughout these studies, I invited various types of stakeholders to participate in the design, development, and evaluation phases of my investigation, and they helped generate valuable insights. They included:

- people with chronic conditions
- caregivers and other people with caregiving experience
- people with a close family member with a chronic condition
- a few clinicians

This allowed people involved in care to various degrees to have a voice and participate in the development of approaches that could potentially benefit them in the future. It also allowed me to investigate data sharing in an authentic context in the design space. Participants' understanding of care was evident in their comments during the different studies, such as those about the usefulness of Data Checkers to support care (in Chapter 3).

Finally, this dissertation recognizes the importance of developing capacity-aware approaches to support PCTs in EDC sharing and accommodate PCTs' many life priorities as well as the capacity of other actors (e.g., PCT members or machine intelligence) to provide care-related or data-specific assistance in need. The adaptability of interactive systems, designed with such awareness in mind, is critical for developing PCTs' sense of control and, hence, PCTs' quality of life.

Overall, this dissertation offers multiple tangible and intangible (equally important) outcomes, including:

- An eight-month engagement with a person (PCT) with a severe chronic condition to understand the lived experience of a PCT and co-design a solution. The co-design partner actively led the human-centered design process, applying his own experience and exploring solutions for himself and other PCTs like him. This also resulted in coauthoring of a manuscript that was accepted for publication.

- A set of design requirements, based on existing literature and the lived experience of the PCT, for interactive systems to support PCTs in managing EDC sharing, with a particular focus on the collaborative nature of self-care.
- Data Checkers–a web-based data sharing–incorporates the previously explained design requirements and provides a grid-based user interface and preview function to allow PCTs to exert fine-grained control over EDC sharing. This is an early attempt to provide an extensible user interface solution to support such control for the healthcare context, which has been recognized by existing studies as critical for patients to maintain their independence.
- An evaluation study that demonstrated the usefulness of DC in supporting chronic care in ways that align with the collaborative nature of self-care and highlighted important areas–reuse, reflection, and customization–that should be developed to support long-term EDC sharing management.
- A card-sorting study that examined a future scenario with a considerable number of EDC data sources provided surprising findings about the applicability of using and tendency to use user-generated EDC groupings for different care situations. These findings pave the way for the development of approaches that will simplify the specification of EDC sharing settings while allowing PCTs to maintain some level of control with reduced involvement.
- An interview study that examined sharing assistance from human and machine actors revealed valuable insights into (1) how the experience and expertise of PCT members could be utilized to provide sharing assistance and (2) how machine intelligence could be integrated into a human–machine collaborative approach to EDC sharing, including the use of roles to help users manage expectations and configure desirable behaviors.
- A discussion that synthesized the findings and provided insights into designing capability-aware interactive systems to support PCTs in sharing EDC in the long term.

In summary, this dissertation contributes to the human-computer interaction, data sharing/privacy, and health informatics fields by improving the design of interactive systems to facilitate data sharing and support care. The results of this dissertation provide insights into how EDC sharing–an increasingly available and useful source of data–could be managed to support chronic care in highly collaborative ways that respect PCTs' capacity for control.

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