Ph.D. DISSERTATION

Design for Data-Driven Communication in Healthcare Services

헬스케어 서비스에서 데이터 기반 커뮤니케이션을 위한 디자인 연구

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Abstract

The prevalence of smartphones and wearable devices has led to a dramatic increase in patient-generated health data (PGHD). The growing interest in PGHD has offered new opportunities to improve doctor-patient communication to become more data-driven. Data-driven communication using PGHD enables patients and physicians to fill in gaps between understandings by supplementing existing clinical data, as well as providing a more comprehensive picture of ongoing patient health. However, challenges in integrating such new types of data and technologies into existing healthcare communications remain. Patients often lose their engagement and motivation in data collection, resulting in incomplete data. Even if PGHD is wholly collected, physicians and patients encounter challenges in utilizing such data–representation and interpretation–in healthcare practices. Furthermore, it is challenging for both patients and physicians to collaborate through PGHD in the current workflow due to the lack of time and information overload. From the HCI research perspective, designing a system supporting data-driven communication utilizing PGHD has the potential to address such challenges, which calls for further exploration in four design spaces: data collection, representation, interpretation, and collaboration. Therefore, in this dissertation work, I aim to explore unsolved questions in each design space by conducting a series of design and deployment studies and provide empirical findings and design guidelines.

In the design space of data collection, I investigated how the semi-automated tracking tool can support patients to track various types of PGHD, especially

food journaling. With the design of mFood Logger, a semi-automated data tracking tool, I conducted an empirical study with 20 patients and 6 clinicians. I identified desired data types for data-driven communication from the patients' and clinicians' sides and uncovered the challenges and opportunities in collecting data within clinical contexts. I was able to understand the feasibility and acceptability of PGHD in clinical practices, as well as clinicians' presence–either remotely or in-person–as an enabler that encourages patients to keep tracking PGHD in the longer-term. Incorporating critical topics regarding data collection from the literature and findings from my work, I discuss the applicability of PGHD and data tracking modes.

To support data representation for clinicians, I designed and implemented DataMD that displays PGHD, considering situational constraints through a participatory design process with 18 various stakeholders (e.g., clinicians, EMR developers). Through the participatory design workshop, I found that the ways of data representation that clinicians desired converged to efficiency and familiarity due to the situational constraints. Clinicians wanted to see a large amount of data at once, avoiding using novel visualization methods due to the issue of learnability. Considering those requirements, I designed and implemented DataMD, in which various types of PGHD are represented with considerations of clinical contexts. I discussed the role of data representation in data-driven communication.

As the critical aspect of data-driven communication, I present different data-interpretation strategies from patients, providing design guidelines to help effective data-interpretation. By conducting interviews with 20 chronic disease patients, I found that they shaped their interests and assumptions by incorporating prior experiences rather than logical evidence. I also identified four data-interpretation strategies: finding evidence to confirm assumptions, discrediting data to preserve initial assumptions, discovering new insights, and deferring drawing hasty conclusions from data. These understandings help designers and researchers advance the design of systems to support data-interpretation.

Lastly, to support collaboration via data, I demonstrate how clinicians and patients collaborate by sharing and utilizing PGHD based on the system I designed. I deployed the integrated system consisting of a patient app, MyHealthKeeper, and a clinician interface, DataMD. I investigated how the system could support collaboration via data. Clinical outcomes revealed that collaboration via PGHD led patients to succeed in behavior change. App usage log also showed that patients could even remotely collaborate with clinicians without direct interactions. Findings from these studies indicate that the key opportunities to facilitate collaboration between clinicians and patients are the integration of data prescriptions into the clinician's workflow and intervention based on natural language feedback generated within clinical contexts.

Across these studies, I found that the design for data-driven communication can support patients and physicians to collaborate through PGHD. By conceptualizing how PGHD could improve the existing doctor-patient communication to data-driven communication within four design spaces, I expect that this work will shed new light on how the design should be derived for data-driven communication between patients and physicians in the

real world. Taken together, I believe this work contributes to empirical understandings, design guidelines, theoretical extensions, and artifacts in human-computer interaction, computer-supported cooperative work, and health informatics communities. This work also provides a foundation for future researchers to study how the design of the system supporting data-driven communication can empower various users situated in different contexts to communicate through data in other domains, such as learning, beyond the context of healthcare services.

keywords: Data-Driven Communication, Doctor–Patient Communication, Patient-Generated Health Data (PGHD), Healthcare services, User Experience (UX), Human-Computer Interaction (HCI)
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Chapter 1

Introduction

1.1 Background

Data is everywhere. It is no exaggeration to say that the spirit of our times is in data. We live in an era where data is utilized in all kinds of fields. With the rapid advances and prevalence of ubiquitous and computing technologies, we have reached ’4V’ by which data can be characterized—Volume, Variety, Velocity, and Veracity [1]. We have long recognized the power of numbers–quantified data, which leads us to see the rhetorical expression of “data-driven” in various domains [2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12]. In almost all areas of our lives, including marketing [5], education [6, 3], business management [4], sport business [11], security [12], healthcare [10, 13], journalism [8, 9], and finance [7], the ‘data-driven approach’ has become more popular than ever. It is because of the belief that the data-driven approach can be much more efficient and accurate than the past approaches that rely on empirical knowledge and gut feel.

What does the data-driven approach aim for in various domains? The data-driven approach is believed to help the communication process among different stakeholders be more accurate and efficient by delivering messages based on data, mostly numbers [2]. In this sense, from the perspective of the SMCR communication model [14], data-driven communication means that the message is based on data. In other words, the message can be formed, converted, and delivered via data. For example, a sender who encodes the message can use data to form the content of the message (sender). While seeing the graphs or stats or hearing the numbers in the results (channel), the receiver decodes the message (Receiver). Since there is a specific way to interpret data (e.g., stats), the sender can convey the precise meaning intended to the receiver. I suggest that this type of communication can be defined as data-driven communication, in that the process of forming and delivering a message is mediated by data.

In the healthcare domain, data-driven communication is fundamental since clinical activities are mostly based on data and communication. For example, a healthcare service begins with data collection. Healthcare providers collect various types of data to determine the patient's current status. The data can be anything from specific indicators (vitals), lab test results, symptoms, to even emotional responses [15]. Although more granular or detailed data might be needed in some cases, the ultimate goal is to make medical decisions (e.g., diagnosis, treatment plans, prescription) to improve the patient's health among various stakeholders [16, 17, 18, 19]. This process seems simple at first glance but obstacles that complicate the process still remain. Various stakeholders, such as patients, caregivers, doctors, nurses, and practitioners are intertwined with each other, as well as the types and amounts of information that they need or understand are different.

One of the critical issues of data-driven communication in the healthcare domain is the storage and use of data [20]. A huge amount of health data is generated and accumulated every second. The problem is that the amount of data is too huge to be effectively managed in a secure way. At the same time, healthcare services require accurate and effective communication among various stakeholders by using such data. There have been numerous research and industrial attempts to solve this over the last 30 years [21]. Eventually, some have been solved by the introduction of the Electronic Medical Record (EMR) in the mid-1990, replacing paper charts [21]. Unlike paper charts that could be lost and could not be tracked, EMR has many advantages in security issues. Healthcare providers can access their patients' information faster and easier than ever before, enabling time-efficient processes [21].

Although the introduction of EMR has clearly contributed to improving data-driven communication, it is still limited in its focus on provider-centered communication [22, 23]. EMR allows healthcare providers to have control over health data while patients cannot [22, 23]. In general, the data required for communication is determined by the healthcare providers. Furthermore, the data is closely related to clinically meaningful data, which is not accessible and understandable in many cases. This leads patients to retain a passive role in communication between their providers [16, 24, 25].

There is another limitation of EMR with regard to data-driven communication. There still are some types of data that cannot be easily captured, such as patients' symptoms, everyday behaviors that might affect their prognosis, medication routine at home [26]. These data were naturally less considered in most EMR systems [13] due to its capture feasibility [27]. As such, personal experiences and daily activities—such as eating and exercising—are often excluded from data-driven communication. It has been believed that capturing and considering such data is burdensome and even inaccurate despite its benefits [13]. This data has been used in a few contexts where those data are considered essential (e.g., rehabilitation, diabetes). Even within those contexts, such data was used mainly in limited some ways, such as diaries and questionnaires [28, 29, 30]. Still, patients remained on the edge of the communication process.

1.2 Motivation

The rapid advances of ubiquitous technologies and changes in the care paradigm have brought new opportunities to solve these challenges. Started in the late 2000s with the spread of mobile technology, the *Quantified-Self Movement* [31, 32] has fostered a culture in which individuals actively track, utilize, share, and analyze their personal data everyday to obtain self-knowledge [33, 34, 35]. It was then when a variety of new types of personal data, such as step count, appeared with the help of digital devices. In particular, the healthcare domain has paid attention to these data in that most of the newly generated data are related to everyday health. As the healthcare paradigm shifted from disease-oriented and provider-centered to care-oriented and patient-centered [36, 37], some patients and physicians began to share such data including step counts, sleep time, calorie information within clinical contexts [38]. The Office of the National Coordinator for Health Information Technology (ONC) in the United States defined such data as "Patient-Generated Health Data," which refers to health-related data created, recorded, gathered or inferred by or from patients and their caregivers including family members [39].

In the HCI community, a number of researchers have paid attention to support data-driven communication in healthcare contexts by sharing and utilizing PGHD. Studies has covered current practices and system designs of using PGHD in various types of clinical contexts, ranging from weight loss management [40, 41], mental health [42, 43] to itching [44], breast cancer [45, 46], Parkinson's disease [47, 48], and irritable bowel syndrome [38, 49, 50]. Although many studies have been separately carried out, according to West et al.'s literature review of clinical use of PGHD from the HCI perspective, primary interests in this community converge to three topics: (1) The design of data collection tools and practices; (2) the design of data use and interpretation; and (3) clinical practices and training [51]. By incorporating the systematic review of literature [13, 51] and related works after their publication [52, 43, 53, 54, 55, 56, 57, 58, 48, 59, 49], I identify four design spaces for data-driven communication: data collection, data representation, data interpretation, and collaboration (See Chapter 2).

1.3 Topics of Interest

1.3.1 Design Spaces

The HCI community has delved into various topics surrounding data-driven doctor-patient communication from the perspective of design. Despite the broad range of relevant studies, unsolved questions still remain over four design spaces in **(Figure 1.1)**: data collection, data representation, data interpretation, and collaboration via data.

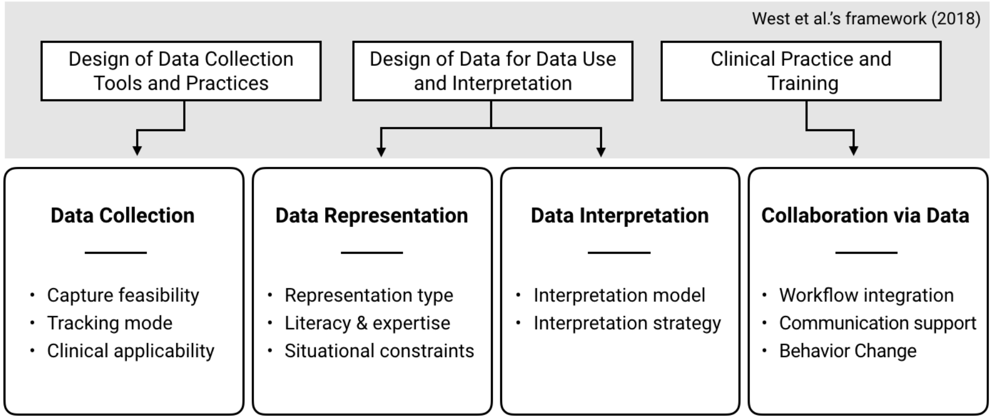

Figure 1.1: Four design spaces for data-driven communication.

Data Collection

As data collection is the very first step for data-driven communication, many studies have examined which types of PGHD are required for constructive communication and how those PGHD can be effectively captured/gathered. With intensive drives from both academia and industry, novel sensors and algorithms that enable the easy tracking of new types of PGHD emerged []. Although users–patients and healthcare providers–can track their data by utilizing various tools, it leads them to encounter another problem: how to access data scattered in silos and manage heterogeneous(multiple) types of data at once. This issue goes back to the dimension of tracking mode, in that tracking methods determine the characteristics of data [60]. Automatically tracked data is relatively structured and easy to store but it often leads users to overlook self-awareness [60]. On the contrary, manually tracked data such as food intake is usually unstructured and hard to process [60]. However, studies have identified that users can benefit from manual tracking that increases self-awareness and mindfulness [60, 61, 41, 62].

Maximizing benefits from both tracking modes, the most recent trend leans towards semi-automated tracking, in which data is collected by both a person (manual) and a system (automated) [60]. There are several studies on designing tools to support semi-automated tracking [63, 64], which focuses on encouraging long-term tracking and users' engagement. According to Bentley et al.'s research [65], using an accessible tracking tool and reminders can involve users in longer-term tracking of various types of personal health data (e.g., step count, food intake, weight, mood, pain). This reveals that research of tracking modes highlights the accessibility of the tool.

Along with this sustainability of data tracking, clinical applicability–accuracy and relevance–is the other critical issue of data collection. Even though the data is consistently and accurately collected, it cannot be utilized unless it is clinically relevant [41, 13, 51]. This is often the case when patients initiate data tracking without any intervention, whereas clinician-initiated tracking is more likely to be relevant for clinical decisions [66]. There are separate studies related to clinician-initiated tracking (relevance) [66, 41, 47] and tracking modes (accessibility) [60, 63, 64, 67, 68] but no studies on integrating them. Thus, taken together, the part of this dissertation work focuses on how an accessible tool helps patients tracking data for a longer-term within the clinical contexts.

Data Representation

The HCI community has long been interested in data representation, focusing on designing understandable feedback that helps users obtain insights from the raw data [69, 70]. In the healthcare domain, data representation becomes a more critical design space. Laypeople are not familiar with the new types of personal health data so that they cannot easily understand what data conveys without appropriate representations. Some studies have paid attention to develop visualization techniques suitable for health data, emphasizing its accuracy [71]. Others have attempted to design and evaluate ambient and metaphorical representations [72, 73]. In addition to these representations, recent studies have focused on textual feedback due to the advances in natural language processing. These different types of representations argue for their benefits and drawbacks in a specific context. For example, some visualization methods such as graphs are not accessible for certain users with low literacy [74], whereas people with high literacy prefer graphs due to its accuracy and saliency. This implies that good or bad data representations mostly rely on users' contexts.

In this sense, literacy is considered the most important dimension in data representation. Researchers have examined which data representation can be useful for people with low eHealth literacy (e.g., older adults) [75, 76, 77, 78, 79, 80]. Some of the related work above (i.e., ambient/metaphorical feedback, natural language feedback) have argued its benefits for low literate people. In a similar vein, there are many prior works related to how to convey insights from the data in an accurate but easy way, which forms an independent discourse and risk communication [81, 82, 83].

Comparing the growth and enthusiasm of data representation for people with low literacy, usually patients, little is known for how to represent PGHD for healthcare experts. Healthcare providers usually have a high level of literacy and expertise but that does not necessarily mean they are well aware of PGHD. A few studies have discovered that even clinicians lack data literacy because they also are not familiar with PGHD, which calls for further studies. To investigate appropriate data representation for healthcare providers, situational constraints should be considered, according to the prior work [13, 51]. Lack of time [13, 41, 40, 84] and information overload [40, 85, 86] are well-known challenges in clinical settings, which can directly impact the design of data representation. Since little is known about which types of data representation clinicians prefer and want to see regarding PGHD, further investigations are warranted. Therefore, this dissertation work covers specific design requirements for PGHD representation from clinicians.

Data Interpretation

Data interpretation becomes more significant, as heterogeneous data streams are rapidly increasing. To understand how users interpret data, the concept of personal informatics has suggested a five-stage model in which individuals are rational and predictable [87]. More recently, as a critical perspective on prior discussion, the discourse of lived informatics has emerged [88, 89, 90]. This perspective highlights that individuals are dynamic and unpredictable, which makes them uniquely interpret data depending on their different personal contexts (e.g., preference, situation) [91, 92, 93]

Based on those models, studies have delved into data-interpretation strategies in two ways: N-of-1 trial and self-reflection. The strategy of N-of-1 trial originated from clinical practices to overcome a small N problem. Despite a single case, individuals can obtain measurable insights in a credible way. With the rise of Bayesian methods, it became a more popular and promising approach for interpreting PGHD [94, 56, 95]. On the contrary, self-reflection focuses on subjective insights that cannot be easily converted into testable questions [96]. Although this approach can shape how individuals perceive data and insights–even from N-of-1 trials, there is little knowledge about data-interpretation strategies from this perspective. This does not necessarily mean that these two strategies are not competing with each other. Rather, they can be integrated or interchangeable strategies that complement their drawbacks. In this sense, I examine what strategies individuals adopt to interpret PGHD from the perspective of self-reflection and how to integrate them into the other.

Collaboration via Data

Collaboration via data is the ultimate goal of data-driven communication. In this design space, some previous studies have investigated workflow integration as an enabler for collaboration [13, 40, 51, 49]. There are many empirical works to examine challenges and opportunities to integrate the use of PGHD into the current workflow through surveys, interviews, and observations [13, 51, 38, 50, 49]. Based on the systematic review, West et al. suggested a new workflow model where clinicians and patients collaboratively review PGHD during the medical consultation [51]. Yet, designing or deploying the system to modify the current workflow has not been investigated despite the ample understanding of workflows.

In addition to workflow integration, some studies have focused more on the communication scenes, such as conversations or interactions during the medical consultations. Chung et al. emphasized that PGHD can be a role of boundary negotiating artifacts, which can facilitate collaborative decision-making between patients and clinicians [50]. Furthermore, a few studies have highlighted non-verbal interactions such as eye contact when reviewing data during the medical consultation.

While close workflow integration and communication support are the catalysts for collaboration, behavior change is about the outcome of the partnership. Many of those studies have aimed to promote behavior change [94, 47, 58, 97], but few studies have demonstrated empirical evidence, such as clinical outcomes. In general, designing and deploying an actual system to support collaboration–data tracking tool and clinician interface–has not been explored. As such, in dissertation work, I aim to design and empirically evaluate an integrated system that can support collaboration between patients and clinicians based on PGHD in-situ.

1.3.2 Research Scope

Supporting to use of PGHD in healthcare services is not simple. As mentioned above, in healthcare services, since the relationships among various stakeholders are intertwined and communication goals are different, the use of PGHD might not contribute the same to all types of communication. **(Figure 1.2)** shows three types relationships possibly related to data-driven communication based on the literature [98, 99, 100, 17]. First, data-driven communication can occur in a patient-patient relationship, mainly from the peer-support perspective [101, 100]. Some studies have investigated online behaviors of sharing their PGHD [101]. Even in these studies, the main focus was on how to promote mutual positive emotional support or exchange. In other words, rather than focusing on sharing and utilizing PGHD in the communication process, such studies suggest that the use of PGHD is one way to promote peer-support. This means that the use of PGHD can be used as a supplementary rather than a key role in improving DC among patients.

Second, data-driven communication can occur among healthcare providers, which is the most common data-driven communication in the healthcare domain. However, as mentioned above, the primary problem in this relationship is not the lack of data but the effective access and management of a number of data. Therefore, to support data-driven communication among healthcare providers, several issues should be addressed first, such as how to manage access to the data at the right time [102, 103] and how to reduce information overload [104]. In this sense, the use of PGHD for communication among healthcare providers is not an appropriate approach, as it might increase cognitive overload and confusion.

Considering previous studies [105, 13, 51], data-driven communication between patients and healthcare providers can be varied in two ways depending on whether the patients are hospitalized or not. Data-driven communication between inpatients and healthcare providers needs different types of data than PGHD [105]. Inpatients want to obtain transparent data on the discharge or medication, which can be obtained only from their physicians or nurses [105]. On the other hand, data-driven communication between the physician and outpatient is most likely to be greatly improved through PGHD. Because

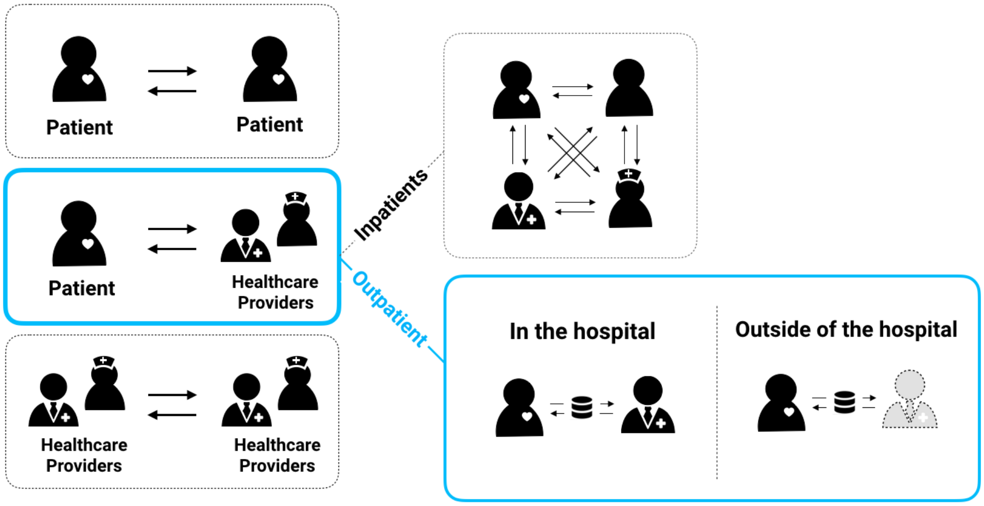

Figure 1.2: Research scope of this dissertation work.

PGHD is inherently data that shows the patient's behaviors outside of the hospital, it is easy for healthcare providers to estimate and comprehend the overall condition of patients [13, 51]. Patients can take initiatives in talking with healthcare providers through their own data, having the opportunity to become more involved in their care processes [106]. Accordingly, in this dissertation research, I seek to explore how to support data-driven communication between the outpatient and clinician.

1.4 Thesis Statements and Research Questions

In this dissertation work, I propose a model of data-driven communication between the patient and clinician mediated by a digital system consisting of a clinician interface and patient app **(Figure 1.3)**. This model describes how PGHD can support doctor-patient communication. In this model, the patient collects various types of data by using the patient app, and the data is transferred to the platform. Then, the clinician can see the data on the clinician interface, and have a medical consultation session with the patient.

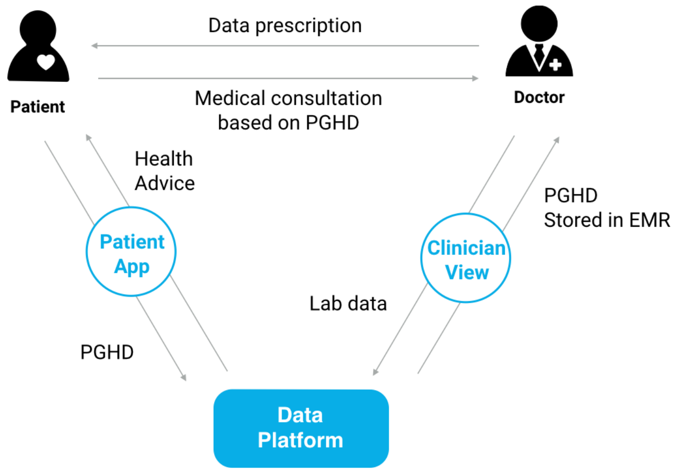

Figure 1.3: Model of Data-Driven Communication. This model presents how the communication process between a patient and a doctor can be shaped by PGHD. The patient uses an app to collect PGHD and brings them to their doctor. In a doctor's office, the doctor review PGHD transmitted from the patient's app to the EMR. After reviewing PGH, the doctor has a conversation with their patient and prescribes specific activities (e.g., healthy eating, walking) based on PGHD during the medical consultation.

Although many studies of PGHD in the Human-Computer Interaction (HCI) community have investigated each design space of doctor-patient communication via PGHD, there are still unexplored topics over four main design spaces. Therefore, based on the model, I propose the following thesis statements and set out to examine the following claims. Understanding the doctor-patient interaction process based on PGHD should be conceptualized in the perspective of data-driven communication to systematically identify design opportunities and potential challenges in each communication stage. Examining what design support is needed to help data-driven communication in each design space is important to identify design opportunities and support for each user group. Thus, I propose that evaluating the designed system for data-driven communication in the real-world setting is necessary to discover practical benefits and drawbacks.

To verify the thesis statements, I examined the following research questions (RQs) through a mixed-method approach:

> *RQ 1.* How can an accessible tracking tool support collecting various types of PGHD, considering clinical applicability?
>
> *RQ 2.* How should PGHD be represented for clinicians, considering situational constraints?
>
> *RQ 3.* What strategies do patients adopt to interpret PGHD?
>
> *RQ 4.* How can the system support collaboration between the patient and doctor?

1.5 Thesis Overview

This dissertation is divided into eight chapters **(Figure 1.4)**.

In Chapter 2, Conceptual Background and Related Work, I conceptualize the data-driven communication based on the literature and demonstrate previous works regarding four design spaces, respectively. Beginning with the concept and a brief history of doctor-patient communication, I present how data could be integrated into the existing communication. I also summarize

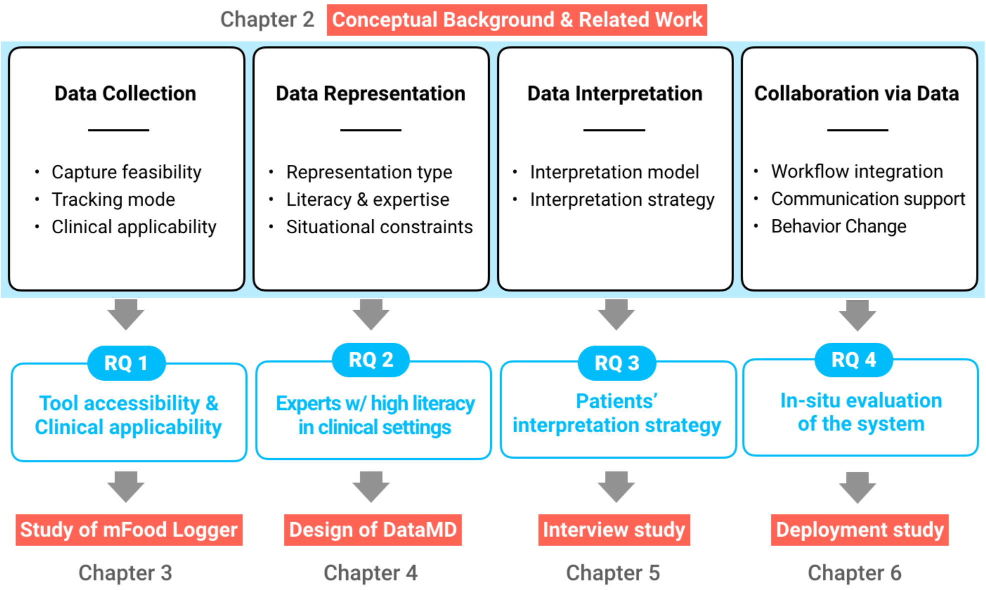

Figure 1.4: Thesis overview.

the prior work of the use of PGHD within clinical contexts. Then, I briefly introduce a design framework around the use of PGHD based on HCI literature. Following the framework, I present the related works for each design space, data collection, data representation, data interpretation, and collaboration via data, in order.

In Chapter 3, Data Collection: Study of mFood Logger, I present how an accessible semi-automated mobile logger could support the tracking of various types of PGHD including food intake within the clinical setting. Briefly introducing the motivation of this study, I describe the preliminary work that outlines clinical requirements for data collection. Based on the results of the preliminary work, I present the design of mFood Logger, suggesting three design goals. I then demonstrate the methods for the field study in which 20 participants were asked to use the mFood Logger for six weeks. Findings include both patients' and clinicians' sides. The last part of this chapter includes the lessons learned and the future direction of the work.

In Chapter 4, Data Representation: Design of DataMD, I begin with the main issue–situational constraints–surrounding data representation for clinicians. I present the results from the preliminary work, analyzing the current and new workflows to help effectively represent PGHD. In addition, I provide three design goals to achieve successful data representation for clinicians. Then I describe the details of the methods (i.e., participatory design workshop). I present ways of data representation for clinicians based on the results of the participatory design workshop. Based on the findings, I demonstrate the design and implementation details on DataMD. At last, I summarize the lessons learned and design guidelines obtained from the design process.

In Chapter 5, Data Interpretation: Data-Interpretation Strategies, I investigate patients' perceptions and interpretation strategies for relationships among various types of data. Through the semi-structured interviews and card sorting activities, I present assumptions that patients generated based on their lived experiences and report four types of data-interpretation strategies. Put together, I summarize lessons learned and provide design guidelines to support data interpretation.

In Chapter 6, Collaboration via data: Deployment Study, I describe how the designed system–clinician interface and patient app–could help collaboration between clinicians and patients in terms of workflow integration, in-depth conversation, and behavior change. Based on the results of the deployment study, I present the clinical evidence on behavior change as an outcome of the collaboration. I also suggest an analysis of the app usage log to examine remote collaboration. Along with those results, I report how workflow integration can help doctor-patient collaboration through the results of observations. At last, I discuss how collaboration should be supported based on the findings.

Finally, I provide design guidelines and discuss opportunities for future work in Chapter 7, and summarize contributions of this dissertation work in Chapter 8.

1.6 Contribution

This dissertation presents three types of research contributions in the field of HCI: empirical research, artifacts, and theoretical contributions [107]. Specifically, my work has generated the following contributions.

1.6.1 Empirical research contributions

In each study in this dissertation, I used empirical methods to address research questions. I used deployed the designed tools that support the whole process of data-driven communication. I also used interviews and observations to generate a deeper understanding of patients and clinicians interpret data representation and collaborate with each other through data. From the results of studies, I derived design guidelines for data-driven communication.

1.6.2 Artifacts contributions

I iteratively designed, developed, and evaluated the system that consists of the patient's data-tracking application and clinician interface. The designed clinician interface makes a novel contribution because the actual clinician interface for the PGHD use had not been fully implemented prior to this despite the growth and enthusiasm on this topic. Designs of data-tracking applications for patients also make a unique contribution as findings from this research were reflected in the actual Personal Health Record (PHR) system in the Seoul National University Bundang Hospital and actually used by patients and doctors in the clinic.

1.6.3 Theoretical contributions

I have identified the concept and constructs of data-driven communication to lay the groundwork for building new theory in this space. Also, this dissertation research includes theoretical implications based on empirical findings to extend existing theory. By conceptualizing data-driven communication from the perspective of HCI, this research extends the use of PGHD to a part of the communication process.

Chapter 2

Conceptual Background & Related Work

In Chapter 2, I conceptualize the data-driven communication based on the literature and demonstrate previous works regarding four design spaces, respectively. I begin with the concept and a brief history of doctor-patient communication, and explain how data could be integrated into the existing communication. As the main body of my work is on the use of PGHD, I also summarize the prior work of the use of PGHD within clinical contexts. I then describe the theoretical framework around the use of PGHD based on HCI literature. Following the framework, I present the related works for each design space, data collection, data representation, data interpretation, and collaboration via data, in order.

2.1 Data-driven Communication in Healthcare Services

In this section, before discussing how to improve doctor-patient communication through data, I explain doctor-communication by answering four main questions and introduce a focus of this dissertation research. Next, I present a brief history of a patient-centered care perspective and a vision of data-driven healthcare. Lastly, I introduce a definition of data-driven communication in healthcare in the context of this dissertation research.

2.1.1 Concept of Doctor-Patient Communication

In this dissertation work, data-driven communication is about doctor-patient communication, as described in the above section. It is not surprising doctor-patient communication has been considered as a central clinical function in the therapeutic process in that it enables to deliver high-quality healthcare [17]. Fong Ha and Lognecker called doctor-patient communication as even "the heart and art of medicine" [17]. A number of the literature identified that goals of doctor-patient communication are to (1) facilitate information exchange, (2) build an effective relationship, and (3) make shared decision-making [108, 17, 24, 18]. In this vein, most literature ascertains the ultimate objective of any doctor-patient communication is to improve the patient's health and medical care [16, 17, 18, 19]. Unfortunately, these explanations seem to sound broad and abstract because doctor-patient communication is a complex one. The range and types of doctor-communication are too broad and dynamic to be summarized in a few sentences.

I start with a simple question: what is doctor-patient communication? The easiest answer is "conversation between a doctor and patient," which is half correct. It is related to the reason why it is called 'communication' not 'conversation.' Communication encompasses verbal conversation and nonverbal expressions or behaviors [109]. In a broad sense, communication is the whole process in which the sender sends a message containing intention or information and the receiver decodes it [109]. In this process, even unconscious and implicit biases also can be a part of the communication [110]. Indeed, researchers have considered these implicit biases as a research topic in doctor-patient communication. Studying doctor-patient communication is about not only the conversation but also behaviors and tools. The communication process does not necessarily face-to-face. Remote communication such as telehealth session [111] can be another type of doctor-patient communication.

The second question is about when and how doctor-patient communication occurs. Doctor-patient communication can be explained by the transactional model [112], as many conversations around us everyday. In this model, communication is the process of continuous change and transformation. The role of senders and receivers reverses each time in the communication process as both sending and receiving occur at the same time [112, 113]. Applying the model to doctor-patient communication, the physicians can be senders if they ask questions for history-taking. Patients are receivers who should decode (understand) the message. After then, patients can be senders who send their answers (messages) to physicians as receivers. Here, the channel of communication can be varied. The most typical scene is office visits where patients and physicians are sitting on chairs and having a conversation. In this case, the communication process is synchronous and constrained to a certain space. Telemonitoring is also possible in several countries including the United States. This type of communication which is called Computer-Mediated Communication [114] can be asynchronous and not limited to the specific places [115].

The third question is the difference between typical communication and doctor-patient communication. One of the distinctive difference is whether there is a very specific and obvious collaborative purpose. As described above, the ultimate goal of doctor-patient communication is patient health [108, 17, 24, 18]. To this end, patients and physicians exchange a large amount of information during the communication process. Exchangeable information can include clinical aspects–current physical status, medical treatment, lab test results, or care plans. It also contains non-clinical aspects such as patients' emotions and pain [15].

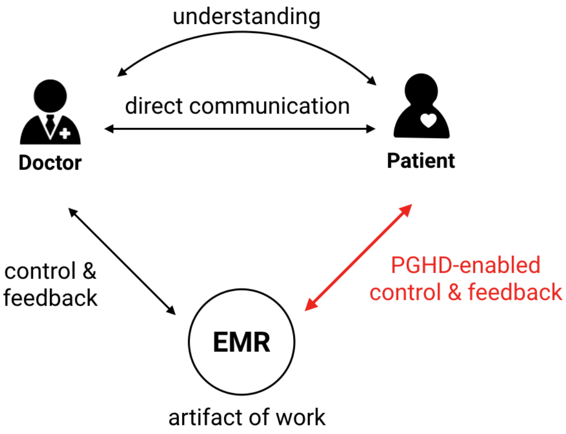

Figure 2.1: Model of doctor-patient collaboration through the artifact. Revised by using the cooperative work framework suggested in [115].

To exchange this large amount of information, physicians and patients need artifacts that enable them to effectively generate and share information, which is called a 'medical chart'. In modern doctor-patient communication, this chart has developed from the format of paper to an electronic system [21]. **Figure 2.1** illustrates how the artifact (the chart in this case) helps improve understanding of both sides of users–patients and physicians–from the perspective of computer-supported cooperative work [115]. As such, artifacts like the medical chart can contribute to converting physician's medical decision-making to the collaborative process where patients can participate [50]. However, there are conflicting study results regarding how those artifacts influence doctor-patient communication [116]. Some have identified positive effects, whereas others argued no impacts or even negative effects [116]. This will be presented in detail in the next section.

In addition, there is a difference between physicians and patients in terms of values, knowledge, and situated contexts, which makes doctor-patient communication distinct from other types of communications. According to Barlund's transactional communication model [112], communication is a conduit and each individual has its own filter to receive and interpret transferred information. The issue is that individuals form their own filters depending on their conditions and environments. This suggests that there is a possibility of changes in intentions of messages sent. What if physicians give information about medication and patients understand in an incorrect way? What if patients give inaccurate information about them and physicians make wrong decisions? Here, the unique problem of doctor-patient communication occurs. Medical communication seeks to accuracy and completeness because it is related to safety. Data-driven communication can address this issue by bridging the gap among different understandings.

The last question is about the focus of this dissertation research. What aspect do I focus on in doctor-patient communication? I examine the artifact to support doctor-patient communication in this dissertation research. More specifically, I focus on discovering and designing the artifacts by which patients and physicians communicate in a more data-driven way. Due to the rise of a patient-centered care perspective, doctor-patient communication is considered as the collaborative decision-making process than just one-directed information exchange. In this vein, I consider that PGHD and the system for use of PGHD are artifacts that help collaboration between patients and physicians. As such, from the HCI research perspective, I examine how such artifacts should be designed and how those designed artifacts can help doctor-patient communication.

2.1.2 Brief History of Patient-Centered Approach

The principles of patient-centered medicine date back to the ancient Greek school of Cos where there is a significant focus on the beliefs and mindset of the patient in the diagnosis and treatment theories [117].

However, it was not always the case. Before and after World War II, physician-centered medicine had been more common practice [118, 119]. The physician-centered approach includes a disease-oriented perspective [118, 119]. The disease was an object to be removed but there were few effective treatments and accessible information for patients. Patients had to rely on the physician's knowledge, so physicians mostly were highly regarded and paternalistic [120, 121]. After the war, physicians became even more overtly distant from patients as diagnostic and therapeutic technology were more specialized. Medical training reflected advances in biomedical knowledge, focusing on disease and the increasingly complex technology of medical practices [118]. Physicians had a much larger store of knowledge and treatments, but ironically, it resulted in further separation of the physician and patient [118]. Patients felt they neither heard nor understood the selected treatment and reasons why it was chosen. Despite the increase of dissatisfaction with visits to physicians, it was largely ignored as being irrelevant to patient care. The patient-centered approach was unnoticed until the mid-1980s [122, 123]. After the mid-1980s, as a part of the consumer movement, the call for change in medical practices arose, which highlights the patient's autonomy as a goal of care [122, 123]. Doctor-patient communication began to be considered as a more critical aspect of care [118, 119].

Patient-centered care does not necessarily deny the physician-centered approach but means the only physician-centered approach is not sufficient in clinical care. Being patient-centered does not mean complying and giving a patient everything they request [122]. This approach means being respectful of the patient's point of view and arriving at a management plan that is acceptable to both the patient and physician, which is called quality care [124]. To this end, good doctor-patient communication should be required. Research has shown that patients appreciated and valued good communication and well-coordinated care [17, 125]. Many other studies also have revealed that patients who reported good communication with their care teams are more likely to be satisfied with their care, and especially to share pertinent information for accurate diagnosis of their problems, follow advice, and adhere to the prescribed treatment [17]. In addition to patients, physicians also benefit from good doctor-patient communication. The known benefits are greater job satisfaction, less work-related stress, and reduced burnout [126, 127]. This seems obvious but it has taken a long time to identify these benefits.

There have been many studies to measure the quality of doctor-patient communication and how to improve it [17, 128, 129, 130]. The conventional approach leaned to mostly communication education and practices [129, 130, 131]. The prevalence of Electronic Medical Records (EMR) has completely transformed doctor-patient communication. Many studies have attempted to identify whether and how EMR use influences doctor-patient communication [116]. Several studies have suggested objective evidence that EMR use may negatively impact doctor-patient communication [116]. The lack of skill and unfamiliarity to use EMR was the early theme of these studies. More recent studies, commonly reported issues were less face time and a reduced number of eye contact due to increased screen time [25]. However, according to Alkureishi et al.'s recent review study, 22 studies have shown different results on EMR use and the overall patient satisfaction or doctor-patient relationship: no impact (16), a positive impact (5), and mixed results (1) [116]. Based on these findings, Alkureishi et al. encouraged healthcare providers to adopt EMR as a communication tool [116] in that it has the potential to improve doctor-patient communication.

2.1.3 Emergence of Patient-Generated Health Data

The vision for personalized care becomes more popular and thereby medicine requires new types of data. The paradigm of precision medicine has developed over the last couple of years, which has been defined as a medical model to provide an accurate diagnosis, prognosis, and tailored therapeutic strategy for each individual [132]. Bittencourt argues that it is necessary that embracing new types of data that can show a large amounts of continuous monitoring data from each individual [132]. According to Bittencourt, in order to provide truly personalized precision health, each healthcare provider also needs to factor in individual patients' preferences. This argument is in line with the vision of patient-centered care [133].

The emergence of patient-generated data (PGHD) by mobile devices provides an opportunity to achieve both precision medicine and patient-centered care. Patients can take the initiative in their care by sharing their data, not staying a passive role in the background of the care process [50, 106, 66]. Physicians can obtain new insights and understand their patients by reviewing the new types of data that they have not seen before. As such, integrating patient-generated data into doctor-patient communication empowers patients to take an initiative in their care and doctors to achieve the vision for precision medicine.

The rapid growth of consumer technologies including smartphones and wearable devices has led to the design and use of tools that allow individuals to track their own health-related data. Quantified-self Movement proposed by Wired magazine editors Gary Wolf and Kevin Kelly in 2007 has spread out quickly. Lupton suggested that converting everything into data and numbers became a culture and called it a self-tracking culture [33, **?**]. The goal of self-tracking is to get self-knowledge from the data. The benefits of self-tracking are usually exemplified in a health-related way, such as helping a sleep disorder by knowing sleep patterns or improving diet by journaling food intake.

It is an undeniable fact that the key enabler of this movement is technological advancements. As personal devices have grown more portable and powerful, consumer-directed applications have proliferated and have exponentially increased the breadth and depth of personal data streams. According to the Pew Research in 2012, 70% of Americans—especially those suffering from chronic diseases—log at least one of their or their family members' health-related behaviors [134]. In 2016, 46% of consumers in the United States actively adopted digital health, having used three or more categories of digital health tools [135]. Nearly a third of people who downloaded a health app did so because the app was recommended by their doctor and nearly a quarter of Americans owned a wearable device such as an activity tracker in 2016, up from 12% in 2015 [135]. With varying amounts of active or passive consumer data entry, these devices can provide day to day or even second to second information about a person's location, diet, movement, symptoms, blood pressure, and heart rate [15, 136].

As healthcare services call for collecting and utilizing such data to achieve the vision for precision and data-driven medicine, those data are called patient-generated health data within healthcare contexts. The Office of the National Coordinator for Health Information Technology (ONC) defines PGHD as "health-related data created, recorded, or gathered by or from patients (or family members or other caregivers) to help address a health concern [39]." According to the ONC definition, PGHD includes, but is not limited to health history, treatment history, biometric data, symptoms, and lifestyle choices [39]. There are two characteristics distinct from data generated in clinical settings and through encounters with healthcare providers: (1) patients are primarily responsible for capturing these data; and (2) patients decide how to share or distribute these data to healthcare providers and others [39].

There are various types of PGHD collected, shared, and used in clinical settings. Demiris et al. have systematically reviewed 21 studies published up to May 2018 and identified 19 different data types [15]. According to them, almost all the PGHD systems examined in the article collected three data types: (1) physiological measurements including blood pressure, weight, body temperature, heart rate; (2) behaviors such as activity level, calorie-burning, sleep quality; and (3) symptoms including frequency, intensity, side effects. However, this article [15] pointed out that the PGHD systems mostly rely on manual tracking of such data rather than the active use of available sensors despite the rapid growth in pervasive technologies. They explained that this slow start and gradual growth align with the PGHD adoption curve expected by the ONC, which suggested that we are currently in an early adopter stage for PGHD in clinical care and research. This implies that there many uncovered opportunities to improve the use of PGHD within healthcare contexts still remain to investigate.

2.2 Four Design Spaces for Data-Driven Communication

In order to lead clinician-patient communication to data-driven communication using PGHD, a system is needed to support it. To simplify, patients need a mobile device to help collect data and facilitate sharing, and doctors need an interface to access and interpret patient data. Most importantly, the devices should be able to support data-based communication as a collaborative process. Here are three unique design challenges: (1) Confronting the needs of different user groups. Patients and physicians are in different situations and have different values, so requirements can be different, and sometimes even conflict [51, 106, 38, 50]. (2) Medical practices may have unique processes that are strongly established, and there may be unique problems that result from them [13, 51]. (3) Medical services are regulated culturally and institutionally. Depending on region or environment, requirements may vary significantly [137].

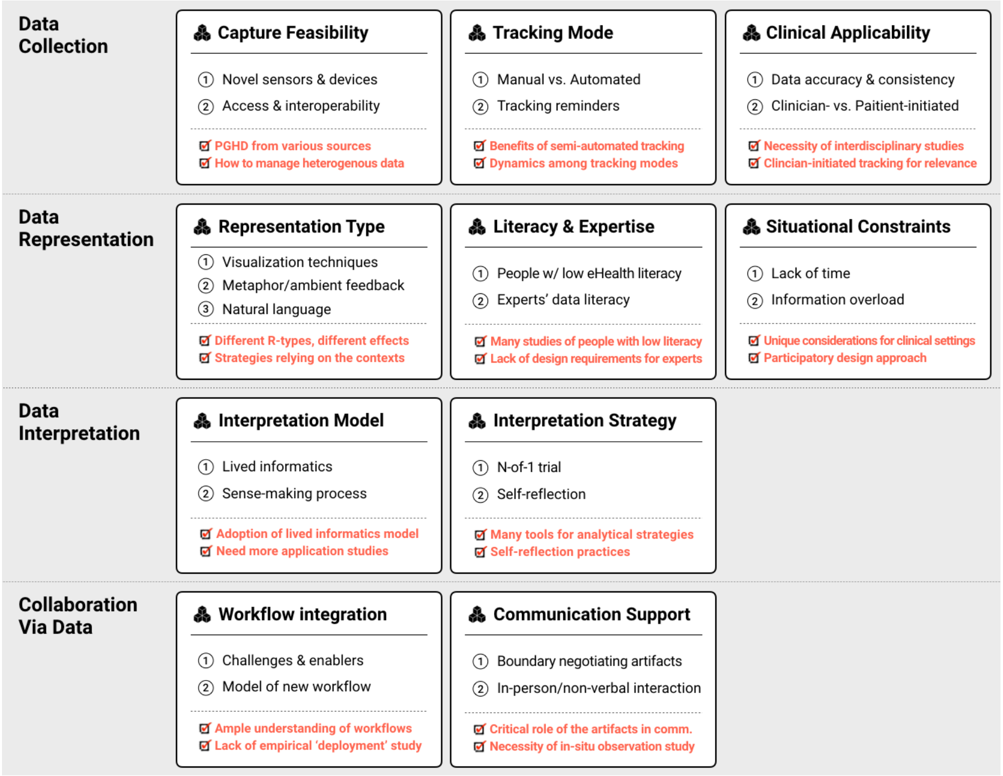

Figure 2.2: Summary of the related work.

The HCI community has been working in various directions to overcome these challenges in the use of PGHD. Some studies have explored patients' perception of self-tracking and the challenges and opportunities of sharing tracked data with healthcare providers. There are also studies that looked at clinicians' perceptions and willingness to use PGHD to integrate it into medical practice. One of the common findings of early studies is that PGHD should be studied in a narrow range, and more solid evidence should be found. As a result, many studies explore design to utilize PGHD in a variety of clinical contexts, for example, chronic diseases, weight loss, mental health, itching, Parkinson's disease, etc [51].

In a recent review study, West et al [51]. reviewed these studies comprehensively and identified design spaces to support data-based communication using PGHD from the HCI perspective. According to West et al., there are three design spaces. The first is the design of data collection tools and practices. This is also aligned with Demiris et al.'s study as suggested in the above section. PGHD is often incomplete and lacks contexts [15]. Many studies have paid attention to data collection, in that data collection is the very first step of data-driven communication.

Secondly, the design of tools for data use and interpretation is proposed as another design space. I modify 'data use' to 'data representation' because such term means more than what they intended [13, 51]. In recent work, West et al. recommended drawing on clinical standards for displaying information and showing relevant information by filtering data to address issues of 'data use' [13, 51]. In the previous work, West et al. [13] described that data representation is closely related to data standardization, which is consistent with the latest work. As such, I consider the concept of 'data use' in [51] as data representation to clarify its meaning.

Data interpretation is related to representation but this issue is significant enough to be dealt with from the HCI research perspective. Data interpretation encompasses the concept of reflection known to offer new values of PGHD

[60, 88]. Studies have revealed that individuals sought to look back not only based on PGHD but self-tracking practice itself so that they could reach to new insights and achieve behavior changes [138, 96]. Recent HCI studies have attempted to promote one's reflection through good designs [60, 96]. In this sense, data interpretation can be an independent design space for data-driven communication.

West et al. presented clinical practice and training as another problem space [51]. Considering the other work [50], the collaboration between the patient and doctor can be the most critical aspect of this design space from the HCI perspective. As the EMR affected a lot in doctor-patient communication, the design of the system displaying PGHD (also embedded in the EMR) has a great potential to impact on doctor-patient collaboration. Many previous works have identified what system is needed for collaboration for doctor-patient communication in the exam room [38, 50, 13]. However, these studies are mostly formative studies where empirically investigate perceptions or current practices [66, 50, 47] or scenario-based situation [13, 106] rather than integrating the interface into the existing EMR system in the hospital. As such, we still need further research that examines doctor-patient collaboration mediated by the system in the real world.

Incorporating West et al.'s design spaces [51] and the perspective of data-driven communication together, I suggest that four design spaces towards a design for data-driven communication be investigated: data collection, data representation, data interpretation, and collaboration via data **(Figure 2.2)**.

2.2.1 Data collection

The HCI community has delved into three main topics in this design space: data capture feasibility and data accessibility; data tracking mode; and clinical applicability. In this section, I summarize relevant literature and suggest the direction of the study.

Data Capture Feasibility and Data Accessibility

In the HCI field, related work has dealt with a broad range of disease and clinical settings (refer to Chapter 1.2), which reveals that specific types of PGHD are required for certain diseases or clinical contexts. Many of those types of data can be captured by using commercial technologies (e.g., step count, heart rate), but some (e.g., continuous glucose) might be difficult to track in accessible ways. Even if a certain PGHD can be captured, a granularity of that data might not fine-grained as much as individuals want [136]. In this sense, Choe et al. define how much a certain type of data can be tracked as data capture feasibility [27]. According to them, there are two aspects of data capture feasibility: data types and capture frequency [27]. Data types often determine data capture feasibility. The capture frequency represents data granularity, which is related to what extent fine-grained or coarse the data can be tracked. Depending on the data type, the available and required frequencies might be varied [136].

Highly capturable data such as step count is popular and commonly considered for PGHD use scenarios [47], in that it allows researchers and participants to obtain finer-grained data with accessible technology including smartphones. However, the subtle difference between what clinicians and patients want to see. This causes the issue of data relevance [13]. Without intervention or guidance from clinicians, some types of PGHD suggested by patients might not correspond to what the clinician sees as useful and actionable [13].

To avoid that challenge, researchers have explored data requirements and developed data collection methods for a very specific context. In addition to popular data such as step count and sleep, researchers also collected specifically defined data only applicable to a certain context. For example, Karkar et al.'s study targeted IBS patients, asking them to track the type of food that triggers the symptom, types of symptoms, and the time of ingestion [94]. Recently, my colleagues and I have developed a sensor to measure the limb usage of stroke survivors and proved its clinical validity [139]. It allows stroke survivors to monitor behaviors that they have never tracked [139]. Likewise, the development of these new technologies can be a way to increase capture feasibility and address data completeness or relevance issues.

However, as these different kinds of data are tracked and stored in silos, the issue of data accessibility arose [136]. My colleagues and I reviewed 240 personal health apps from the App Store and selected 45 apps that support semi-automated tracking. We characterized the data accessibility of these apps using two dimensions—data access methods and data types. More than 90% of our sample apps (n = 41) provide some types of data access support, which include synchronizing data with a health platform (i.e., Apple Health), file download, and application program interfaces. However, the two approachable data access methods for laypeople—health platform and file download—typically put a significant limit on data format, granularity, and amount, which constrains people from easily repurposing the data.

This issue of data accessibility is connected to data interoperability, which is one of the critical issues of using PGHD. West et al. pointed out that a lack of standardization hinders the integration of PGHD into existing health-provider tools [13]. In particular, there are challenges regarding the integration of web-based services (which many self-logged devices and apps are) into legacy systems [13, 136]. Many self-logging apps do not provide a means of exporting data, or they only do so in proprietary APIs which are not intuitive for patients or clinicians to use.

Taken together, previous studies reveal that capture feasibility becomes more improved for various types of PGHD. In response, the recent research on data tracking tools emphasizes tool flexibility that allows users to synchronize various commercial tracking tools, while providing a set of loggers by which users can customize their inputs [63, 140, 64]. In addition, health data platforms such as Apple Health also provide APIs for integrating a wide range of existing health apps [136]. These series of research and industrial drives suggest that there is a growing possibility of considering and leveraging data that is measurable with traditional sensors and data through customization tools [136].

Data Tracking Mode

Data tracking modes have been recognized as one of the most relevant problems in the HCI community since types of tracking mode can impact individuals' self-awareness and engagement in tracking [138]. Any of the tracking modes are situated between the spectrum ranging from fully manual tracking to fully automatic tracking [60].

As both of those tracking modes have clear strengths and weaknesses, in many cases, many researchers and tool designers have attempted to combine them. Choe et al. defined this integrated mode as semi-automated tracking in which data is collected by both a person and a system along a spectrum ranging from mostly manual tracking to mostly automated [60]. According to Choe et al., semi-automated tracking addresses challenges in both manual and automated tracking by: supporting awareness and engagement; offering better accuracy than fully automated tracking or fully manual tracking; and helping mitigate privacy concerns over automatically collected data by engaging a person.

Since food journaling is one of the biggest challenges still unsolved, many researchers in the HCI community have attempted to examine how to effectively collect food intake data by adopting different tracking modes. Much research has been carried out to achieve two goals in the food journaling: (1) to record in detail for expert analysis or assessment and (2) to self-monitor one's behavior [67, 140]. The former is focused on the healthcare providers 'side, while the latter is focused on building patients' awareness during the process of recording.

In terms of lowering the capture burden and enabling more easier analysis, studies have suggested alternative input methods, such as employing photo-based food journaling [67, 141], using chewing sounds [142, 143], or scanning receipts [144]. These methods are either fully automated or mostly automated, which can reduce awareness by dramatically lowering the burden. Previous studies have shown that people who are aware of their current behavior are more likely to lose weight [145, 146]. In this sense, the automation of food journaling may not be the answer, since it may eliminate the positive effects of self-monitoring [67]. In addition, these methods encounter technical challenges as described above. The use of chewing sounds has been validated in the study context, but there might be many practical difficulties left before applying to the free-living environment. Using photos also has unsolved drawbacks: analyzing each type of food from different cultures is still challenging, and accurate intake cannot be estimated from photos alone.

Manually journaling food intake is flexible and simple method, which has the advantage of self-awareness. Despite these positive effects, adherence remains a recognized challenge. Food journaling, especially by paper, is an arduous task that leads to fatigue [29, 147], and therefore, continuous recording is highly unlikely. Research has shown that adherence to self-monitoring is less than ideal [146], and others have reported that adherence deteriorates over time [148]. Therefore, self-logging studies try to minimize the burden of users to encourage long-term usage. Technological support, from electronic diaries [149] to smartphone applications, has somewhat lowered the burden of the traditional paper-based method. Carter et al. [149] found that the recording rate via smartphones is significantly higher than that via websites or paper. The general input methods of various smartphone health applications (e.g., MyFitnessPal, Noom Coach, Lose It) aims to lower users 'burden, by modularizing menus and portions.

Some studies have attempted to support semi-automated tracking for food journaling [67, 140]. Cordeiro et al. have developed a photo-based light-weight food journaling tool that supports photo-taking and text input to supplement the context [67]. In a more recent study, Luo et al. have explored how semi-automated tracking tools should be designed for dietitians through a participatory design approach, aiming to achieve two goals: accessible tracking and easy analysis [140]. As such, recent research is moving towards supporting semi-automated tracking, acknowledging its benefits.

Clinical Applicability

Even if the issues of capture feasibility and tracking mode could be addressed, there is still the critical and practical obstacle left. Accuracy and relevance are required to be used in a clinical setting. Unfortunately, most consumer devices for self-logging are not approved for medical use [150]. Clinicians often perceive the data quality and sampling from such devices to be poor and perceive the devices to be unreliable [13]. Even if some studies have demonstrated that some devices have good reliability for particular purposes, clinicians are unwilling to use them for various reasons. A systematic review study that evaluated measurement accuracy for Fitbit activity trackers in controlled and free-living settings has reported that consistent evidence indicated that Fitbit devices were likely to meet acceptable accuracy for step count approximately half the time, with a tendency to underestimate steps in controlled testing and overestimate steps in free-living settings [151]. This also means that clinicians should take risk of inaccuracy if they decide to use that technology, which leads them not to adopt that technology. Likewise, most new metrics and sensors encounter this clinical applicability regarding the accuracy, even though they are clinically validated in controlled settings. In the recent study that I and my colleague conducted [139], data tracked by finger-worn sensors were proven that they are clinically valid, showing higher correspondence, 80%.

Like the issue above, it still needs to be validated in a free-living environment.

However, even if the accuracy is verified, the data collection technique may be unacceptable for healthcare providers unless there is evidence that PGHD tracked by a certain technology is connected to actual clinical outcomes [13]. In this vein, the issue of data accuracy is mostly relying on advances in the engineering domain and active research in clinical disciplines. The development of new sensors or metrics should be coupled with the clinical evidence and shared in the medical domain.

On the one hand, data relevance is another critical issue of data collection. From the perspective that using PGHD plays a supplement role, collected data does not necessarily perfectly accurate but should be relevant enough to support the collaborative decisions. However, expectations towards data collection from patients and clinicians are often misaligned [66]. Zhu et al. categorized two ways of data collection depending on who initiates data collection: clinician-initiated and patient-initiated tracking [66]. When clinician requests to collect PGHD, data is more likely to support diagnoses [66, 38], whereas patient-initiated tracking focuses more on self-knowledge [138].

Many studies pointed out that the integration of PGHD into the clinical systems and workflows is necessary to effectively utilize PGHD during the clinical process [13, 51, 38]. In this sense, we first need to further investigate data collection initiated by clinicians, in that data they want to track is more likely to be used. Also, how clinician-initiated tracking impacts on data collection has not been empirically examined despite its importance.

As a summary of this design space, the sustainability of data tracking and clinical applicability are the critical issues of data collection. Even though the data is consistently and accurately collected, it cannot be utilized unless it is clinically relevant [41, 13, 51]. This is often the case when patients initiate data tracking without any intervention, whereas clinician-initiated tracking is more likely to be relevant for clinical decisions [66]. There are separate studies related to clinician-initiated tracking (relevance) [66, 41, 47] and tracking modes (accessibility) [152, 63, 64, 67, 68] but no studies on integrating them. Thus, taken together, the part of this dissertation work focuses on how an accessible tool helps patients tracking data for a longer-term within the clinical contexts.

2.2.2 Data Representation

The HCI community has long been interested in data representation, focusing on designing understandable feedback that helps users obtain insights from the raw data. In the healthcare domain, data representation becomes a more critical design space. In this section, I summarize the literature according to three dimensions: types of data representation, literacy and expertise, and situational constraints.

Types of Data Representation

There are several taxonomies to categorize types of data representation. It is a common way to categorize graphical and textual representation regardless of domains. Data visualization is a well-known example of graphical representation. Iliinsky and Steele characterized data visualization as to be algorithmically drawn; easy to regenerate with different data; often aesthetically barren; and relatively data-rich [153]. Representative examples are traditional graphs such as bar, line, and pie charts. On the other hand, textual representation is based on readability and helps people to get information from data in a more natural way. Recently, with the growth of technologies for Natural Language Processing (NLP), textual representation such as a conversational description of data becomes more popular, especially for people with low literacy [154, 65, 155].

As data representation is intertwined with many contexts–health literacy, technology literacy, clinical environment, data types, it becomes a more important issue. Categorizing the representations of health data into four types, counts, graphs, stylized representations, and textual feedback, Consolvo et al. [154] identified the advantages and disadvantages of each of them as follows:

- **Counts** are simple but the basic building blocks of other types of representations. Most data can be represented in the form of counts, which is the least abstract type of information and straightforward. Counts usually require to support automatic recordings, but they can also be useful for manual logging because counts represent a very important dimension of the behavior (i.e., amount). However, there are also some drawbacks. As counts are aggregated, it is difficult to extend or interpret meaning when there is no other information. Without valid criteria, users can get the only limited meaning. For example, when the user walked 9,000 steps, it is hard to explain what this is. If counts are displayed with the goal of 10,000 steps, then the user can extend the meaning by comparing steps walked to the goal. There is another disadvantage of counts. Counts can be connected with a false sense of knowledge and comfort.

- **Graphs** are the most common feedback. It is known for helping users understand patterns (e.g., relationships, trends over time) in their data.

On digital devices, graphs can be more powerful with additional functions (e.g, scalable navigation, interactive annotation). However, graphs often amplify the effect of missing data and make users mislead the meanings of data, especially users with lower levels of scientific training [72, 81, 82].

- **Stylized representations**, also known as ambient or metaphorical feedback, are one popular way of data representations in healthcare services. It expands the range of locations of feedback, in that these types of representations usually are on the very surface of the device, such as lock screen. Prior works have identified that users prefer this type of representation due to its attractiveness and personalization [72, 73]. Yet, there are several disadvantages such as learnability issues and low accuracy.
- **Textual representation** serves a similar function as graphs but avoids the risk of graphs (e.g., misunderstanding of the data). According to the studies, textual representations are accessible to users with low numeracy by providing feedback in everyday language [65, 155]. Also, it can be more salient either by acknowledging achievements or by drawing the user's attention. There are still a lot of avenues to further investigate this type of representation: the effect of framing, frequency, or length of the textual feedback [65]. Due to the advances in NLP technology, many researchers pay more attention to a textual representation.

The previous works suggested that combining different types of representations should be considered rather than just adopting only one type. Data representation types need to be used differently depending on who the users are and what their requirements are. Even if the users are suffering from the same disease, their specific situations can be different [156]. Raj et al. suggested that contextual frames in which self-management varied depending on certain factors-physical activity, food, emotional state, insulin, people, and attitudes [156] should be considered when designing data representation.

Health Literacy and Expertise

As mentioned earlier, one of the important considerations in data representation is literacy that allows users to recognize and understand the meanings of representations. The healthcare community has long been interested in the ability to perceive and process health information, also known as health literacy [157]. With the introduction of digital technology, the concept of health literacy is expanded in the area of eHealth Literacy [157]. The best-known eHealth literacy model is Lilly developed by Norman and Skinner [157]. They define eHealth literacy as the ability to seek, explore, understand, and evaluate health information online, and to apply the knowledge gained to deal with and solve health problems [157]. According to the Lilly model, eHealth literacy consists of analytical skills (i.e., traditional, information, and media literacy) and context-specific skills (i.e., health literacy, computer literacy, and science literacy) [157]. Norman and Skinner suggested that some information should be converted into an easy representation because individual's literacy can be shaped differently depending on knowledge, information, and media forms [157].

In the field of HCI, studies have been conducted on how to effectively deliver health information and personal health data to people with low literacy through digital tools. In particular, some studies have been investigated older adults with low eHealth literacy but high health data needs [76, 75, 80, 79]. Arcia et al. conducted a participatory design with low literate people to examine desired data representation [78, 77]. According to the study, people wanted to represent the data based on these guidelines: be information-rich; support data comparison; provide context; and employ familiar color and symbolic analogies [78, 77].

However, the issue of literacy and knowledge related to representation is not just a matter of the laypeople. Even for healthcare professionals, data literacy is a critical issue. West et al. described that healthcare experts often encounter the issue of data literacy because they are also not familiar with PGHD [13]. According to the study, clinicians are concerned that they do not have appropriate expertise or training to effectively use or validate PGHD [13]. In addition to the lack of training, they suggested other issues: the lack of standards for data representations, the lack of access to appropriate electronic tools for analysis, not being familiar with new tools for PGHD, and the wide variety of data [13].

The body of previous work implies that the issues of data representation should be determined not only by its type, but also by the user context in which the representation is to be used. Indeed, research on how to present PGHD to people with low literacy in the HCI field has been conducted in various ways, including design, development, and field study. On the other hand, when it comes to how to convey data to healthcare professionals such as clinicians, it has been at the early stage. Some studies have covered challenges and opportunities surrounding experiences of healthcare providers, but little has been empirically studied on what representations healthcare experts prefer.

Situational Constraints

Many studies have suggested that situational constraints should be considered when designing PGHD representation for clinical settings [13]. Even the same information can be differently represented depending on situational constraints such as the lack of time. PGHD is often shared and utilized in a clinical context. This means that the use of PGHD is intertwined with the issues of clinical practice. Therefore, the representation of PGHD needs to be designed, considering the uniqueness of this clinical environment.

The common issue related to clinical practices is a lack of time. As clinicians usually work under time constraints, it is reported they are skeptical about using PGHD within existing clinical practices [13]. Furthermore, as current systems or interfaces do not support clinicians to find relevant information, clinicians feel more inconvenient when they review PGHD than conventional clinical data [13].

Another typical issue is cognitive load during medical consultation [85, 86]. The way in which information is represented might determine the extent to which overload affects a user. In particular, in clinical treatment, there is already a lot of information that clinicians should review, in addition to PGHD. Studies have suggested that too much information lowers a liability, productivity, and morale but increases levels of stress [85, 86, 13]. In this sense, West et al. suggested simplifying complex information is a good way to unload cognitive burden [13].

2.2.3 Data Interpretation

Data interpretation becomes more significant, as heterogeneous data streams are rapidly increasing. I review two topics in this design space: interpretation model and data-interpretation strategies.

Interpretation Model

Starting from the concept of personal informatics proposed by Li et al. [158], the HCI community has investigated a wide range of topics related to self-tracking and quantified-self [35, 159, 160, 161, 162, **?**, 13, 163, 164, 165, 166, 167]. Much of this work has considered individuals rational and predictable, investigating behavior change or goal achievement strategies [160, 95, 164, 168, 165, 166]. As a critical perspective on prior discussion portraying rational and predictable self-tracking, the discourse of lived informatics has emerged [88]. Rooksby et al., who coined the term of *lived experience*, highlighted the diverse ways in which people use informatics tools [88]. They suggested that we concentrate on unique individual stories and contexts [88]. Inspired by this perspective, Epstein et al. proposed a new model for the use of personal informatics tools to explain various personal tracking practices, including tool abandonment [169]. Some other studies also have carried out from the perspective of lived informatics, such as past memories [170, 171], personal informatics data on social media [172], metadating by using personal data [89], and the documentary informatics [173].

The perspective of lived experience has been expanded with related discussion on topics such as technology as experience [93] and self-tracking as a social practice [33, **?**, 174, 175]. Such discussions focus on how people interact with data in their everyday lives. Wright and McCarthy emphasized the way people recursively and flexibly construct or make sense of their experiences with data (as technological artifacts) [93]. They explained that non-linear sense-making processes consist of six stages, including anticipating, connecting, interpreting, reflecting, appropriating, and recounting [93]. This corresponds to Dervin's *Sense making* process [91, 92, 176]. She explained that people attempt to utilize their ideas, attitudes, feelings, and memories as a bridging strategy when facing a gap, such as having a question [91]. Because these strategies are inherently based on personal experiences and diverse temporal-spatial contexts, Dervin suggested that we change our focus from *nouns* (e.g., goal, criteria) to *verbs* (e.g., think, feel, imagine) when we design information systems to help people [92].

Taken together, such discussions lead me to pay attention to how people interpret–think and feel–data when they face a gap between their data and their personal contexts. The way in which people interpret could vary depending on their interests and assumptions derived from their personal contexts [91, 92, 93]. Therefore, identifying data-interpretation strategies can provide design implications to make sense of data by helping us respond to such questions: What do people want from their data? How do personal experiences affect the way they think about their data? What attitude do people take when facing a gap between their assumptions and data representations?

Interpretation Strategies

In the HCI community, many researchers have studied personal informatics to help people make sense of their self-tracking data based on the analytical approach (e.g., N-of-1 trials). The analytical approach, bridging a gap by using explicit evidence (e.g., statistical analysis), is aligned with the initial vision of the quantified-self movement, providing numerical and precise insights [31, 177]. Many studies have attempted to provide data feedback to help self-trackers gain clear insights by using statistical analysis (e.g., correlation, n-of-1 trials) [178, 179, 180, 181]. Jones et al. proposed a system that automatically filters significant correlations between data types [180]. This work [180] revealed how people form new interests based on the provided analyses but did not identify how people react to and feel about their data based on past interests and assumptions.

Addressing individuals' different interests, recent studies have focused on support in conducting N-of-1 trials, a process in which people make hypotheses based on personal interests, collect data with scientific rigor, and test hypotheses through statistical frameworks [182, 94, 71, 183, 184, 185]. They have shown that supporting self-experimentation was helpful for patients with irritable bowel syndrome [94] who had clear questions (e.g., Does X trigger symptom Y?). Despite the obvious advantage, studies have reported that there are challenges to clearly identifying what people want from their data [180, 182, 94, 183]. Because everyday lives do not exactly correspond to the scientific world where everything is manipulatable and predictable, people cannot easily elicit what they want to review from their data when asked with the format of hypothesis [182, 94]. Daskalova et al. discussed that even college students with the relevant statistical knowledge could optimize their hypotheses for self-experimentation through an iterative process [184].

Adopting an explorative approach, Choe et al.'s recent work has examined the reflection patterns and types of qualitative insights found by self-trackers [96, 60]. Their findings have revealed that self-trackers recalled their past experiences to explain the data they captured [96]. They also found that self-trackers came up with questions from their data that made them visually explore their data more [96]. Based on this study, I further identify interpretation strategies, focusing on people's interests and assumptions about data ahead of exploration of data. Also, I aim to unveil how people construct their attitudes about data through their prior interests and assumptions rather than focusing on exploration patterns and insights derived from data.

2.2.4 Collaboration via Data

In this section, I outline the design space of collaboration via data with three dimensions: workflow integration, communication support, and behavior change. Collaboration via data is the ultimate goal of data-driven communication. The topics of workflow integration and communication support are two key enablers for collaboration via data.

Workflow Integration

Workflow integration is the prerequisite of inserting PGHD into clinical practices. Clearly, the adoption of data-driven consultation is challenging, as the existing workflow is already tight and dense. The challenges that hinder the integration of data-driven consultation mostly relate to situational constraints within the clinician's office, such as information overload and lack of time. Clinicians are responsible for multiple tasks, both behavioral and cognitive, and therefore need a high mental capacity [86]. Internally, numerous types of reference data are needed to support clinicians' decision making [85, 186]. Externally, some resources are displayed on the EMR, while others are presented in the paper form [187, 25, 85]. Several studies report that clinicians encounter difficulty in appreciating the value of data-driven consultation due to such information overload [188, 86]. Furthermore, the lack of time has come to the fore [189, 84, 190].

A well-designed interface could be helpful for integrating data-driven consultation into the existing workflow [191, 192]. According to Kim et al. [41], showing patient-generated data on a standardized interface can help clinicians better understand their patients. When interpreted using the six activities suggested by West et al. [13], Kim et al.'s study implied that an interface can help clinicians overcome information overload by supporting the stages of discovery, evaluation, and initial hypothesis formation. The study also showed that the clinician interface's summary data allows clinicians to assess patients' status, and the detailed information enables them to discover abnormal points very quickly [41]. It implies that the role of the interface is important in overcoming the problem of insufficient time.

Communication Support

It is known that better communication leads to a better medical outcome–higher adherence and health promotion [193, 194]. Previous studies have shown a possibility of improving the communication quality between patients and doctors by using PGHD (e.g., symptom-tracking data) [50, 66]. According to Chung et al.'s work [50], patients and healthcare providers create boundary negotiating artifacts to support collaboration based on PGHD. As boundary negotiating artifacts, PGHD can mitigate conflicts and coordinate consensus between different stakeholders surrounding patient health.

To support patients and doctors to use PGHD as a boundary artifact, it is necessary to design an interface displaying PGHD. According to previous studies [84, 195], clinicians have difficulties counseling patients in the exam room due to a lack of confidence, information, and time. Taft et al. [196] found that an EHR helped physicians' communication skills in the exam room by assisting them with the reading and writing of medical information. The problem is, according to many studies [187, 25], that clinicians' focus on devices while reviewing medical data could cause exclusive viewing [25]. The same problem could arise during a data-driven consultation [187]. However, the characteristics of patient-generated data distinctively differ from those of medical data, since patients play a significant role in the acquisition of the data [197, 191]. Therefore, patient- generated data is more likely to lead to collaborative viewing [50, 198, 199]. According to Kim et al., patients showed great interest in self-logged data and were highly engaged with their medical treatment when reviewing their data on the interface with clinicians [41]. The studies mentioned above suggest that a well-designed interface might help to both improve clinicians' counseling skills and increase patient interest.

While close workflow integration and communication support are the catalysts for collaboration, behavior change is about the outcome of the partnership. Many of those studies have aimed to promote behavior change, but few studies have demonstrated empirical evidence, such as clinical outcomes. In general, designing and deploying an actual system to support collaboration–data tracking tool and clinician interface–has not been explored. As such, in dissertation work, I aim to design and empirically evaluate an integrated system that can support collaboration between patients and clinicians based on PGHD in-situ.

Chapter 3

Data Collection: Study of mFood Logger

This chapter[1] reports an empirical study conducted to investigate how a semi-automated data tracking tool, mFood Logger can support tracking various types PGHD including food intake data, in addressing RQ1 (How can an accessible tracking tool support collecting various types of PGHD, considering clinical applicability?). Beginning with the preliminary work that presents findings on the clinical feasibility of PGHD through clinician interviews, I demonstrate the design rationale and interface of an accessible data tracking tool, mFood Logger. Based on the findings from a six-week field study with 20 patients and six clinicians, this chapter draws an understanding of how the accessible semi-automated data logger helps patients track various types of data including food logs, in-situ.

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[1] The preliminary version of Chapter 3 was published as a conference proceeding [41] in the 2016 CHI Conference on Human Factors in Computing Systems.

3.1 Motivation

The rapid spread of mobile techology–smartphones and wearable devices–has enabled people to quantify every aspect of their daily lives, including their walking, sleeping, eating, and smoking. These are crucial to preventing and managing diseases [141, 200]. However, the medical world has not made good use of PGHD, even though, anyone who has visited their doctor's clinic has heard the following advice: "Exercise more, watch what you eat, and do not smoke or drink." Moreover, lifestyle diseases are increasing globally [141], and lifestyle management and modification are becoming as important as medication treatment and surgery. Thus, collecting data on activity level, sleeping, and diet, etc. is also extremely important.

Despite its importance [141], it is far more difficult to record food intake compared to other lifestyle factors. Thus, the development of food-intake recording techniques has long been an interest. The HCI field and industry have both made many attempts to overcome the challenges of food journaling. Popular applications such as Noom Coach, MyFitnessPal, etc. somewhat overcame the limitations of the traditional method of food-intake recording through the semi-automation of journaling and database updating. Attempts to reduce users' recording efforts and minimize content loss have led to fully automated food-journaling solutions [142, 143]. On the other hand, Cordeiro et al. argued that full automation might undermine the mindfulness benefit of food journaling and proposed a photo-based lightweight food-journaling application for the self-reporting of food intake [67, 201].

Although previous works have made many contributions, there are still several problems related to food journaling. First, until the recent studies such as Bentley et al.'s work [65], most of the preceding works have dealt with food journaling only and have not thought of food data as a part of PGHD. This could be considered a limited approach, because eating is not an isolated habit but is interrelated with other habits, and considering other habits offers a more valuable and extended point of view. For example, people often eat too much given their amount of daily activity or eat high-calorie food at night, and it is hard to understand these aspects if only food journaling is considered. Second, the applicability of food intake data collected by food loggers as a lifestyle factor is rarely considered in the clinical context. Despite technological advances and a plethora of studies on food journaling in the HCI field, in the actual medical field, the paper based diary is still a popular method, as it is not only cost-efficient but also accessible. However, there has been relatively less interest in exploring the clinical applicability of mobile food loggers.

A new strategy must be developed that utilizes food logs interrelated with other data, such as steps and sleeping time, in the clinical context. Thus, we[2] aim to (1) understand the clinical applicability of food-journaling practices and (2) explore clinicians' requirements when utilizing PGHD. To do so, we conducted interviews with clinicians and field deployment study to examine this topic.

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[2] All uses of "we," "our," and "us" in this chapter refer to contributors of this research project.

3.2 Preliminary Work & Tool Design

3.2.1 Clinical Requirements for Data Collection

The preliminary interviews were conducted to understand the way in which PGHD is currently used during medical examinations. We recruited five medical specialists from Seoul National University Bundang Hospital who showed interest in the topic: C1 (otorhinolaryngology), C2 (family medicine), C3 (obstetrics & gynecology), C4 (rehabilitation medicine), and C5 (urology). We met doctors one on one for 40 to 60 minutes on average, and each doctor was rewarded with $100. We asked them how they would use/are using PGHD, and what types of data they would consider useful for actual diagnosis and prescription.

Current Usage of and Need for PGHD

All clinicians recognized PGHD as *'good data if provided but not necessary'*. Clinicians mainly expected that if PGHDs were used, they would be able to identify patients' conditions more accurately and faster compared to history taking. The current history taking process is necessary to identify patients' condition, but it takes a long time and lacks credibility. C2 likened the history-taking process to *"being a detective and making an inference about the patient's current condition."* He said, *"The history of fat matters [...] I need to know everything about my patient's lifestyle. For now, I usually use a simple questionnaire, which is time-consuming and not accurate."* The clinicians expected that PGHD could solve this kind of problem. C3 said, *"History taking is a conventional way but I think we (clinicians) can replace it with the data like step count or something like that.*

It'd be useful 'cause we can practically see the changes followed by the intervention." C4, a rehabilitation medicine clinician, expected PGHD to help address these difficulties, noting the difficulty in identifying whether certain exercises were carried out, and what the intensity of the exercise was, through the current history taking.

Clinicians thought that PGHD would be helpful for a variety of patients receiving treatment in different departments. C1 said, *"Data such as activity, sleep, meals, and weight are the most basic and will be very useful in many departments."* Similar but more specifically, the C5 said that patients who need to continue to manage their living habits will benefit the most, and recommended a group of patients who need regular hospital visits, such as elderly people, patients with chronic diseases (e.g. arthritis), and cancer survivors. C2 also said it would be particularly useful for patients who regularly visit hospitals and who need to modify their usual lifestyle, such as those with metabolic syndrome. In addition, C3 expected this data to be useful when taking care of cancer patients who are highly motivated and require high levels of intervention.

Several clinicians said weight information would be of great value to be PGHD because it is one of the most basic data that always measured in hospitals. C1 said, *"Weight control is a crucial part of treating obstructive sleep apnea syndrome. If patients do not lose weight, they rarely improve. On the contrary, by just losing weight, many patients actually show improvement. However, for now, the majority of doctors do not conduct interventions for patients' weight loss because of their difficulty."* C4 similarly said weight is important, explaining that it would be more useful if there were more information, including muscle mass and fat volume.

However, clinicians have taken a different view of the types and importance of data needed other than weight, depending on their major or diseases that they are interested in. For departments that treat lifestyle diseases, such as obesity, food diaries are important references. In departments that treat diseases for which lifestyle is considered a risk factor, dietary information can also be required. When treating lifestyle diseases, medical specialists need to derive patterns in (1) nutritional content, (2) total calorie intake, and (3) daily distributions (time and frequency) from food-intake records collected. On the other hand, when weight and food management are additionally recommended for disease improvement, rather than such detailed information, medical specialists want to identify whether patients maintain regular diets. They expect to provide more helpful weight-control advice based on this data.

Potential Benefits and Challenges

Medical practitioners claimed that PGHD can be used for self-monitoring and as a communication tool between the medical staff and patient. That is, clinicians believe that PGHD will contribute to patients' awareness of their lifestyle and increase the effects of doctors' medical advice.

While such benefits were identified, the following issues were reported as barriers: (1) Patients often fail to continue tracking data (issue of continuity) and (2) the data might not accurately represent their behaviors (reliability). Even if the patients diligently track every detail, medical practitioners encounter practical barriers during the process of analyzing and reviewing the data. First, clinicians are not able to examine every record due to a lack of time (in the case of university hospitals in Korea, examination time is extremely restricted due to the high numbers of outpatient clinics). Therefore, the raw data collected from patients should be summarized/patternized prior to medical checkups. Second, at present, the analysis process is not automated and it significantly depends on human efforts to manually analyze data (e.g., nutritionists), and consequently, a high amount of time and money is consumed. Third, the collected PGHD is not integrated into the hospital information system (i.e., EHR). Such restricted accessibility discourages clinicians from cross-referencing the PGHD with other patient data. Even though food intake data is recognized as meaningful, clinicians often encounter such practical difficulties. These issues were considered during our field study.

3.2.2 Design of Data Collection Tool: mFood Logger

The data-logging tool was designed as simple as possible to address the difficulties regarding data acquisition. We also focused on resolving the issue of data consistency that medical staff members doubted based on their prior experience with paper-based diaries. Therefore, accessibility was the top priority of the application design [**?**]. We developed an app with three buttons for indicating users' feelings of fullness after a meal along with a free text box for selective input about the context of the food intake **(Figure 3.1)**. There are two buttons to track smoking and drinking data. We could obtain (1) the timestamps of meal intake and subjective fullness, (2) smoking data (frequency, timestamps), (3) drinking data (frequency, timestamps) when the user pressed each button. Meal context, such as menus or nutritional information, was inserted as free text. Referring to previous studies [178, **?**] on the importance of reminders, we attached a small (1x1cm) physical sticker as an ambient reminder on the patients' smartphones.

Figure 3.1: The interface of mFood Logger. Mobile application for button-based logging. <Left> The logging page. Button (a), (b), (c) refers to portion size: "little", "just right", and "too much". Rectangular buttons below refer to "smoking" and "drinking" (Right) The weekly summary view.

Maximize Accessibility

Consistency was our top priority. During the interviews, doctors doubted that the patients would consistently record food intake based on prior experience. Clinicians emphasized that data should be collected for at least a certain period to identify patterns and trends. Therefore, we minimized the page depth of our application and the amount of information collected to lower the burden of users and support consistency. We divided the features into two simple parts, (1) record and (2) view, maintaining a single depth for each part. We also developed a widget so patients could record right from their home screen.

Enrich the Context

To enrich the context, we provided free text input for patients who desired to log additional information. We did not predetermine the structure of the input so that patients could freely log whatever they thought was important (e.g., what they ate, how they felt about the food, where they ate, or with whom they ate). We did not suggest items beforehand, because patients might have felt pressured. Timestamps from the button input were also automatically recorded; however, a previous study [**?**] showed that timestamp data is inaccurate due to frequent backfilling. Therefore, the free text input could help compensate for inaccurate data from missed logging. Moreover, free-text entries could also help identify what patients considered important regarding their nutritional intake.

Simplify Feedback

Another aim was to simplify feedback. We were originally interested in how the doctors used the collected data and how the patients reacted to the intervention. However, feedback from applications has been found to be an important factor to affect users' motivation [201]. Therefore, we kept feedback neutral and eliminated judgments or evaluations. We visualized the weekly input **(Figure 3.1)**. Each bar represents a day, and the vertical axis represents time. Green represents food, orange alcohol, and black smoking. Through this visualization, patients obtained basic information about their eating habits, such as regularity and frequency.

3.3 Study Design

We conducted a field study to investigate how the mFood Logger can support patients to collect PGHD. Twenty participants were asked six types of PGHD for six months by using that tool. For each patient participant, two medical checkups were scheduled, where a patient and clinician share and discuss collected PGHD. During the study period, we conducted focus group interview sessions with clinician participants to examine their experiences. This study was approved by the Institutional Review Board of Seoul National University Bundang Hospital (IRB #B-1504-296-302).

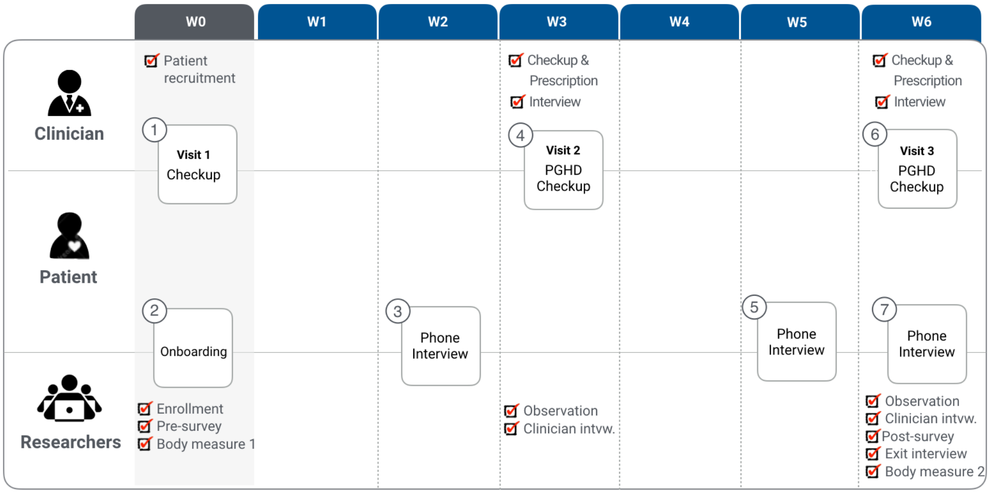


Figure 3.2: Overview of the study procedure

3.3.1 Participants

We recruited six medical experts from Seoul National University Bundang Hospital. We assumed that interest in food intake data would differ according to specialty. Therefore, doctors from diverse specialties were recruited including those who already participated in the preliminary interviews: otorhinolaryngology (C1), family medicine (C2, C6), obstetrics & gynecology (C3), rehabilitation medicine (C4), and internal medicine (C7, C8). The doctors recruited patients who were suffering from lifestyle diseases **(Table 3.1)**. The patients were screened based on two criteria: whether they possessed a smartphone and whether they were capable of using their smartphone at a basic level. The patients' employment statuses were as follows: employed (9), self-employed (6), full-time homemaker (3), etc. (4). The patients were highly educated overall: Most were high school graduates (8) or university graduates or above (14).

We asked patients to log their food intake, drinking, and smoking data with our mobile app. Patients were also provided with wearable devices (Misfit/Fitbit), which we asked them to use to track activity and sleep data. They had control over the data via the web (individual ID/PW) so that they could delete the data they did not desire to share. The field study lasted for six weeks, and excluding the two dropouts, we obtained data from a total of 20 patients **(Table 3.1)**. The two patients could not visit the hospital for the required checkups due to the sudden Middle East Respiratory Syndrome situation in South Korea and an unexpected business trip.

3.3.2 Study Procedure

This section reports the study procedure in detail **(Figure 3.2)**.

PID	**Gender**	**Age**	**Disease**	**CID**
P01	M	60	Hypertension, Heart disease	C01
P02	M	55	Heart disease	
P03	F	65	Hypertension, Hyperlipidemia	
P04	F	64	Diabetes mellitus,heart disease	
P05	F	51	Hypertension, Hyperlipidemia, Diabetes mellitus	
P06	M	42	Hyperlipidemia, Obesity, Sleep Apnea	C02
P07	M	47	Diabetes mellitus, Sleep Apnea	
P08	F	25	Sleep Apnea, Chronic rhinosinusitis	
P09	M	50	Hypertension, Sleep Apnea	
P10	F	53	Sleep Apnea, Chronic rhinosinusitis	
P11	M	54	Hypertension	C03
P12	M	58	Obesity	
P13	M	47	Hypertension, Hyperlipidemia, Diabetes mellitus	C04
P14	M	67	Hypertension, Obesity, Sleep Apnea, heart disease	
P15	M	45	Hyperlipidemia	
P16	F	48	Diabetes mellitus, Myoma uteri	C05
P17	F	59	Hypertension, Breast cancer	
P18	F	53	Diabetes mellitus, Breast cancer	C06
P19	F	43	Breast cancer	
P20	F	71	Hypertension, Diabetes mellitus, Breast cancer	

Table 3.1: Demographic information of the patients.

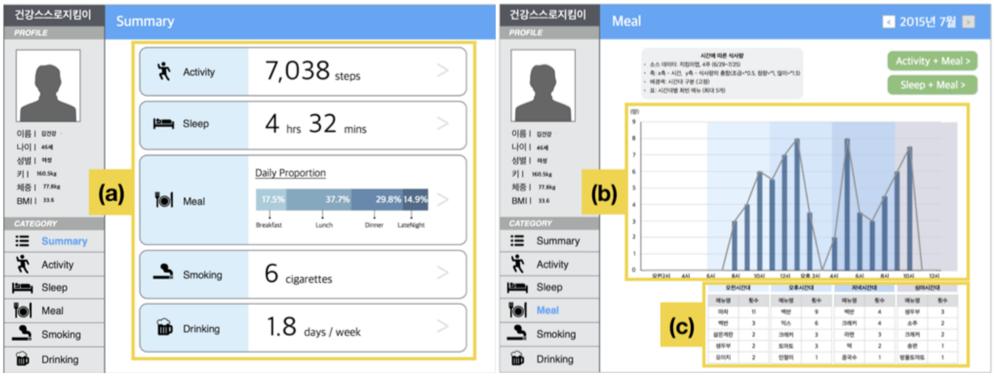
Patient Interview

We first conducted 30–60-minute semi-structured interviews with patients to examine their lifestyle. We asked the patients about their perceptions of health and health management strategies. After the interviews, we explained the procedure and installed the application we designed on their smartphones. During the field study, patients had to complete two phone interviews. We asked patients if they had noticed anything new about their eating patterns, if anything about the process was inconvenient, and how they felt about the medical intervention. Lastly, we inquired about the changes in their health behavior, the experience of app use and data-integrated checkups. The checkup sessions and interviews were recorded under permission. Rewards of $300 were given to the patients who went through two checkups and four interviews. Patients who dropped out were rewarded $50 per checkup or interview. No reward was promised based on the activity, sleep, and food-intake data.

Medical Checkups based on PGHD

To explore the difficulties and possibilities of using PGHD including food-intake data in the medical context, we arranged two checkups during the eight-week field study. Researchers attended the checkups and observed how doctors used the data (Figure 4). After each checkup, we opened workshops which all the participating clinicians were asked to attend. The clinicians exchanged their experience about the checkup and opinion about the clinician view.

The two checkup sessions at a three-week interval were designed to promote data sharing in the natural workflow. To do so, as mentioned in the pre-



Activity 7,038 steps

Sleep 4 hrs 32 mins

Smoking 6 cigarettes

Drinking 1.8 days / week

Figure 3.3: Examples of the clinician web interface. (a) The summary view that shows the average of the patient-logged data. More detailed information of each data was provided as individual views. (b) Portion size (calculated by button input) per time (c) Top ranked menus per time.

liminary clinician interviews, data summarization, automated analysis, and system integration were considered. We (1) analyzed and summarized the data before the scheduled checkups, (2) visualized diverse charts for the clinician web interface separate from mFood Logger, and (3) provided this data on the EMR. Direct integration to the hospital system was attempted but was unattainable due to hospital network security. Instead, the visualized data was made accessible through a link on the EMR screen (Figure 2). In consideration of the clinicians' lack of experience in impromptu life-log data interpretation, data was sent to the clinicians at least 12 hours prior to the checkup so they could review it in advance.

The clinician web interface was iteratively designed while reflecting the requirements identified during the clinician interviews. A summary view and individual views for each type of data were given **(Figure 3.3)**. The summary view was designed considering the fact that clinicians cannot examine every record. During the first checkup, summaries of the frequency, time, and menu of meals were provided. We modified the data presented in the second checkup after conducting a workshop with the doctors. During the second checkup, we provided data about mealtime, subjective fullness, and menu. After the second checkup, we conducted another workshop with medical experts to obtain further requirements.

Data Analysis

Three types of data—(1) data logs, (2) patient interview transcripts, and (3) checkup observations—were analyzed.

First, we collected activity and sleep logs automatically by the Fitbit and Misfit APIs and manual food intake logs from the food journaling app (mFood Logger). We analyzed the adherence rate of each lifestyle log. In the case of automatically collected logs, we calculated their "collection rate" by counting the days that had data input during the experiment. In the case of manual logs by mFood Logger, we calculated the "food journaling rate" by counting the days patients logged at least three or more times. The results will be mainly discussed in the Patient Side section of our findings.

Secondly, in order to analyze the patient interview transcripts, we went through three ideation sessions in which we analyzed the transcripts. We theorized the main issues using thematic analysis [202], which consists of the stages of coding, noting, and integrating. In the first stage, researchers open coded the transcripts independently. After reading each line of the interviews, researchers wrote down the key phrases or sentences on post-it notes to break down the transcripts and identify key points. In the second stage, researchers added notes on each code by checking similar concepts, considering what they had discussed in the previous session. During the last stage, by using an affinity diagram repetitively, we grouped the notes by their main topics and finally established seven issues. Each stage was followed by active discussion. The results will be mainly discussed in the Patient Side section of our findings.

Thirdly, we observed how the collected food intake data was used during actual medical examinations. A total of 40 examinations were observed (2 examinations x 20 patients) and recorded. Researchers transcribed the 40 recordings and used utterance-by-utterance analysis. The results will be mainly discussed in the Clinician Side section.

3.4 Results

The findings of the field study were derived by analyzing both the patient side and the clinician side.

3.4.1 Patient Side

The first notable characteristic was that the presence of the doctor significantly affected food journaling behavior, as it contributed in forming a sense of duty toward food journaling among patients. That is, it ensured patients did not forget to journal and led to more precise descriptions of what they had eaten. The second notable point was that the patients improved their perceptions of the data and their health behavior. Lastly, patients had difficulty in consistently recording their food intake, because they often forgot. Our findings support previous studies that have revealed the difficulties of food journaling [67, 201].

Clinicians' Encouragement of Journaling

Many patients performed their food journaling diligently, which might have been caused by the influence of the doctors. The average food journaling, sleep data-collection, and activity data-collection rates were 81%, 88.2%, and 94.9%, respectively. The food journaling rate was lower than the activity and sleep data-collection rates. However, considering that food journaling data was collected manually and that an average of three meals per day was assumed, 81% is a relatively high rate.

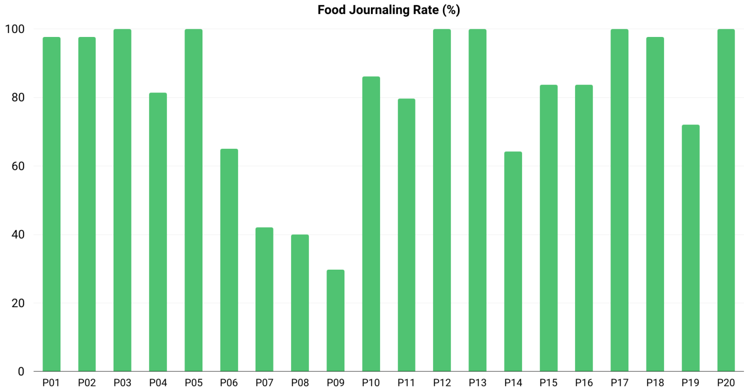


Figure 3.4: Food journaling rate of each patient. A relatively high journaling rates was identified (Avg.=81.0, SD=22.3).

When the food journaling rate of each patient was examined individually, a majority of the patients scored relatively high journaling rates (Figure 3). There were six patients who had journaling rates of 100%, which means they logged three times or more every day. On the other hand, the first quartile consisting of five patients (P06, P07, P08, P09, P14) had journaling rates under 76%. However, through the interviews, we identified that most of these patients stated that they originally ate less than three times a day. P06 said he ate once a day and had been trying intermittent fasting. Similarly, P08 reported that he regularly skipped breakfast, and P07 was under a strict meal plan after surgery.

The number of data entries from patients was also high. A total of 5,500 records were submitted, containing 2,877 memos and 2,326 button-clicking entries. The memos required more effort from users, but the higher number of memos versus button-clicking entries may have been due to the characteristics of the free-text-type memo. The patients freely wrote diverse memos, and some patients even separated their memos into multiple entries.

Importantly, patients regarded the doctors as supervisors, and their presence naturally led to a sense of obligation among patients. *"Since I knew that the doctors were going to view my records, I put more effort into it."* (P17) Some patients were influenced even more strongly, reporting that they felt pressure or that they considered food journaling their obligation. Interestingly, although patients did not consider themselves self-motivated and showed relatively passive attitudes, their journaling rates remained high. *"It was because the doctor told me to do it. If not, why would I? There's no inner motivation..."* (P01).

However, the passive and negative attitudes patients showed in the early stages slowly changed. In the early stages, they considered food journaling a chore to get finished, whereas as time passed, they started to interpret the entries by themselves and discover patterns from the data they had collected. Patients started to see food journaling more positively after they saw that the collected data could help them to better understand their eating habits. *"I found out that my eating habits were not as good as I thought they would be. I started to think* *that I should be more careful about what I eat"* (P17).

Some patients went beyond examining their habits and showed a desire to change their diets or reduce portion sizes. Signs of improvement showed the mindfulness effect of food journaling. *"There are times when I eat meat several times a day, like chicken at lunch and pork for dinner. Before, I would just vaguely think that I ate too much meat. But now, if I see that kind of record, I start reflecting upon my diet and try to improve my next meal."* (P16) In some cases, patients not only avoided high-calorie foods and reduced portion sizes but also searched for additional information and managed their nutritional intake. *"I was aware that I had to write down everything I ate. So sometimes, I would be like 'Is it okay to eat this much?' I also tried to eat carbohydrates, fat... and especially protein. Even when I went to buffets, I tried to eat more protein."* (P14) This implies that clinicians' encouragement of journaling could lead patients to modify their behavior.

Detailed Journaling and Caregiving Feedback

Another interesting aspect was that patients started to record in enhanced detail. Patients expected that medical staff would check and evaluate their record data, and, therefore, started to write what they ate in detail, once they got used to recording. P05 started out with brief menu names. However, after experiencing the first data checkup session with the doctor, she started recording in detail, such as moving information from the nutrition label, or describing her portion size in diverse measures. As for the patients who put in additional effort into journaling, they started expecting detailed feedback from their doctors. They considered a detailed checkup the reward of their extra effort and desired the other to acknowledge their effort. *"I thought that doctors couldn't* *thoroughly know what I ate from the original amount of information I was journaling. So if I were eating a snack, I would input the calories on the label, and so. Doctors may understand my eating behavior better."* (P05)

Some patients claimed that they would not mind if they had to invest more time and effort, if guaranteed for a detailed feedback from the doctor. This implies that a presence of a doctor or medical staff and their feedback can positively affect the quality of data collected. *"It doesn't take like 10- 20 minutes. If I have to do it anyway, taking 1-2 more minutes is not a problem if I could get a better checkup."* (P19) Patients who were suffering from diseases that were relatively more closely affected by dietary intake said that they expected disease-aware feedback, such as a customized menu or dietary guideline. *"I have diabetes, so while I'm journaling, I wonder if I'm keeping my diet on the right track. It would be nice if I could receive feedback of what sort of side menus I should eat etc...."* (P18)

Patients showed positive reactions toward friendly feedback from doctors, rather than requesting concrete and objective information such as calories. Simple words of encouragement or affirmation affected patients. *"The doctor said it's okay to eat pizza, once in a while. After looking at my intake records, he assumed that I was undergoing too much stress. After the checkup, I went home and ordered some Chinese food. It tasted so good. I loosened up a bit and felt okay to eat like that once in a while."* (P17) This implies that mechanic feedback may not be the answer to satisfactory feedback. Chronic disease is a state patients have to live with, and this may lead to an elongated sense of stress [203]. This point may be easily overlooked, when entirely relying on systematic feedback, both content-wise and communication- wise. Patients traditionally experience moderation and regulation. As inferred in P17's quote, emotional interaction may also be an important factor of feedback.

Enhancing Perceptions of Data via Communication

Patients enhanced their perception of the data through the data integration checkups. The communication with doctors enriched how patients interpret data, and this led to an increased sense of awareness. Each patient (total of 20) went through two checkups. During the 40 checkups, the doctors utilized the food-intake data by showing it to patients, explaining notable points, and planning possible future modifications. Patients identified their eating habits and tried to improve their behaviors in line with the doctors' recommendations. *"After the checkup, I realized that my lifestyle patterns were likely to make me gain weight."* (P14)

Patients were strongly motivated to modify their behaviors based upon what the doctors said rather than the effect of the self-awareness formed through the act of recording their eating behavior. A majority of the patients showed excessive trust and dependence on medical experts. *"If my husband told me, I probably wouldn't really listen. But if it's from a doctor, then I really think that I should pay attention."* (P04) Patients showed that they immediately trusted and accommodated the doctors' suggestions. *"I'm trying to follow what the doctor said. I'm not the type who really listens to others. But now I eat salads more than three days a week."* (P11)

Discussion about patients' willingness to accommodate doctors' suggestions is necessary. It is critically important that patients follow the directions of medical experts. Through that process, patients' self-awareness is enhanced, and this encourages healthy behaviors and the modification of original eating behaviors. However, this may lead to a passive attitude and cause patients to wait for instructions from an external presence. During the user study, we observed patients who showed heteronomous attitudes. *"[I do this] because the doctor told me to. How could I keep doing this on my own?"* (P01) Doctor–patient communication consisted of orders that were obeyed, and patients stayed passive and heteronomous. However, such communication traits did not affect the journaling rate, and surprisingly, those who showed passive attitudes tended to have even higher journaling rates.

Ambient Reminder for Self-Logging

Previous studies have identified that the most cited reason for not journaling is forgetting. This was also found in the field study. Even though the overall level of adherence was high, patients still cited that they often forgot to journal. Patients reported that there were situations in which they were more prone to forgetting and that they still forgot from time to time even after they got used to journaling. *"I would often forget to log my dinner meal if I was at an outing or meeting likely to involve drinking."* (P11) If journaling did not happen during or right after consumption, the sticker triggered the behavior. The sticker helped patients think back and identify when their last meal was and whether they had recorded it. *"When I saw the sticker, I remembered and looked at the recordings on my app to see if I'd left anything out."* (P12) The usefulness of the sticker was also cited by a majority of patients. Some said that they recorded less and left things out when there was no sticker (during the eight- week experiment, the sticker had worn off toward the end, and some patients had to remove it from their smartphones). *"When I'm busy, everything is hurried. I still remembered when*

I had the sticker on, but now I forget more often." (P13) This result shows how ambient reminders can also support consistent journaling [65, 72, 204].

Another interesting point was that some patients considered the wearable device itself an ambient reminder. *"After I stopped wearing the wearable device, I also started to skip journaling what I had eaten."* (P19) Another notable finding was that the device was used to track activity and sleep, but it also served as an ambient reminder of food journaling. Patients perceived activity, sleep, and food intake together as a whole symbol, representing lifestyle improvement. Many patients, therefore, perceived the wearable device and mFood Logger as a reminder of "health." *"After wearing the device (Fitbit), when I was eating something, let's say an apple, I would think of whether it was okay to eat it or not. It made me think about stuff. I just kind of fiddled with it when I was bored, sometimes unintentionally. But in some way, it was... like a symbol of health."* (P09) This implies that consistent food journaling may increase when understood within a more comprehensive context, such as a healthy lifestyle.

3.4.2 Clinician Side

We conducted our field study while considering the difficulties pointed out from previous studies, such as workflow integration [38], and by doing so, we derived rich findings, including specific challenges and benefits. Lack of time [38] was not reported as a challenge, while clinicians said that they were able to promote communication. Clinicians also reported their lack of confidence in interpretation of PGHD, and their level of interest varied. However, the detailed requests from clinicians who have actually used such data during medical checkups suggest the potential of overcoming such challenges.

Lack of Confidence in Planning

The level of usage of PGHD, including food data during medical checkups, differed with specialty. The general case was showing, when the clinicians read the collected PGHD along with the patient, and explaining, when the clinicians descriptively explained the data to their patients. Only a few cases of planning, when clinicians suggested a specific plan based on the PGHD, were witnessed. During the 40 examinations, clinicians (1) showed the food data 21 times, (2) explained the food data 17 times, such as identifying eating behavior patterns, and (3) only provided specific plans 13 times.

C01, C04, and C06 focused on showing data and by doing so triggered communication with the patients. They commented that *"explaining the PGHD"* increased *"communication with patients"* (C01) and enabled a more thorough *"history taking"* (C06). In other words, the data summary provided on the EMR helped clinicians understand the patients' lifestyle in a relatively shorter amount of time. C01 reported as follows: *"If I ask the patient how he has been and what he has eaten, this already amounts to a few sentences. It was more effective to read right from the data summary and quickly grasp the big picture rather than asking."* (C01) This shows that data summarization and workflow integration (in our case, being able to view PGHD on the EMR) help overcome time limitation and support time-efficient communication.

However, it was difficult to overcome clinicians' lack of confidence with just the data summary. C01 and C04 rarely suggested plans for their patients. On the other hand, C02, C03, and C05, who were relatively more interested and confident in interpreting PGHD, actively explained the data to their patients and used it to suggest plans. They also made the most use of the food-intake data. *"[Explain] Your mealtimes are quite delayed, and since you rarely exercise, too many calories are stored during the nighttime. This may be the reason you find it hard to lose weight. (...) [Plan] I recommend you eat your meals and your nighttime snacks a bit earlier."* (C02, Medical Examination of P08). As observed in the utterance, clinicians had to identify the relationship between food intake data and other PGHD in order to give specific plans. To support this process, there is a need to thoroughly examine how clinicians practically use PGHD.

Learning from Experience

We were able to identify the relative importance within the food data components and the specific needs regarding data visualization during the field study. Interestingly, although we collected and visualized PGHD based upon clinicians' needs by referring to the initial interviews, their comments and requirements changed or became more detailed after their first actual practice.

First, we identified the relative importance of the food data components. Before the field study, clinicians said that the time, frequency, and portion size were equally important data. However, during the field study, clinicians claimed that the most important food data was *"portion size."* During the first examination, we provided doctors with summaries of objective data, such as mealtime and frequency. However, all six doctors who participated in the experiment claimed that despite being relatively subjective, *"portion size is must-have information"* (C01, C02, C03). Doctors said that without knowing how much the patient ate, it is difficult to interpret a meaningful pattern, even though the information about what they ate (menus) is provided. In other words, portion size is necessary data to determine whether the patient needs behavior modification. Reflecting such feedback, during the second examination, we provided data summaries focused on portion size.

Secondly, clinicians started to give specific requirements regarding data visualization and raised the necessity of additional data mapping. Doctors required data that represented the regularity of patients' mealtimes, such as *"at what time of the day they eat"* so that they could interpret the average *"daily pattern at a glance"* (C03). The third distinctive point was *"unusual moments"* (C01), such as eating out, skipping meals, or eating late at night. This is because the irregular context of meals described above is correlated to overeating, gorging, and unbalanced nutritional intake. In addition, since doctors considered skipping meals important information, they brought up the necessity of distinguishing if a user forgot to record or if they actually skipped a meal by adding a *"skip"* button. Likewise, distinguishing a late meal and a midnight snack was also an issue.

Understanding Patients Further by Overlapping Data

As mentioned above, it is important to understand the food intake data within the context of other PGHD in order to provide specific plans. Clinicians saw potential in cross- referencing food intake data with other PGHD. However, since doctors cannot concretely relate a certain outcome to a certain lifestyle factor, they lacked enough evidence to determine cause and effect.

Even so, clinicians still said it was meaningful to understand the tendencies within an individual patient. During the workshop, C02 and C03 suggested overlapping *"activity"* (C02, C03) data with food intake so that *"the input–output of energy balance"* can be considered. Energy balance has been implemented in some healthcare applications, and medical experts confirm its medical value. Moreover, C03 proposed overlapping food intake with sleep data based on the evidence that irregular sleeping may evoke irregular eating. This request was reflected, and during the second checkup, we added the (1) *"food+activity data"* and (2) *"food+sleep data"* views. As for the (1) *"food+activity data"* view, the area graph of the meal portions (food) and the line graph of the steps (activity), were overlapped by synchronizing the time axes (2) and as for the *"food+sleep data"* view, the last meal hour of the day was overlapped with the sleeping hours.

There remain requirements that were notable but not reflected due to practical issues. *"Alcohol"* (C02) was also mentioned as a possible correlative variable with food intake, since drinking mostly accompanies high-calorie side dishes and late-night eating. Moreover, all of the doctors requested the food intake data be overlapped with clinical outcome data, such as weight or blood pressure.

3.5 Limitations & Conclusion

There are several limitations to this work. This study did not fully control all the conditions. We also could not investigate the interrelationship between lifestyle data quantitatively. Despite these limitations, this paper provides qualitative insights for designing applicable strategies utilizing lifestyle data in the clinical context.

Despite these limitations, this study contributes to providing an empirical understanding of how to collect and use PGHD in clinical settings from both perspectives of patients and clinicians. Although researchers have attempted to solve this problem, most have not considered its applicability in the clinical context. In this study, we provided an understanding of food-journaling practices and the applicability of lifestyle data in the clinical context. By observing 20 patients who recorded data including food logs, steps, and sleeping time, we found that patients recorded their food logs diligently, as they were conscious of clinicians. Clinicians were surprised by the high adherence rate of journaling and tried to overlap food data with other data, such as steps, sleeping time, etc. This study contributes by providing qualitative insights for designing applicable strategies utilizing lifestyle data in the clinical context.

3.6 Chapter 3 Summary

In this chapter, I provided an understanding of how the accessible semi-automated data logger helps patients track various types of data including food logs, in-situ. Through a field study with 20 patients and 6 clinicians, I described insights into designing future healthcare technologies using PGHD, discovering that food journaling is more valuable when it is combined with other PGHD.

The key findings in this chapter are as follows: (1) Patients were significantly conscious of the clinicians, even during the period when they did not come for a checkup. The patients considered the doctors as supervisors, which led them to record their food logs diligently. Most patients desired detailed feedback about their logs and personalized diagnoses based on their PGHD; (2) The clinicians wanted to cross-reference the food intake data with other PGHD. However, clinicians lack concrete medical evidence about the relationship between PGHD and outcomes; therefore, further studies need to focus on investigating the medical value of PGHD.

Chapter 4

Data Representation: Design of DataMD

In this chapter[1], I explore the design space of data representation. In particular, I examine how PGHD should be represented in an interface for clinicians, which is a relatively less explored topic. This chapter answers the research question 2 (How should PGHD be represented for clinicians, considering situational constraints?). I first present the preliminary work to identify situational constraints that influence data representation: analysis of current workflows and design goal definition. Then, I describe the participatory design process where 18 stakeholders including clinicians, EMR developers, HCI researchers actively participated to find effective data representations. As a result, I report three design requirements for a clinician interface displaying PGHD. Then, finally, I introduce the details of the implementation of the clinician interface, DataMD.

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[1] The preliminary version of Chapter 4 was published as a conference proceeding [40] in the 2017 CHI Conference on Human Factors in Computing Systems.

4.1 Motivation

It is difficult for clinicians to acquire a thorough understanding of their patients in the medical office. To understand patients, clinicians collect evidence by reviewing various kinds of lab data, such as vital signs and specific test results [205, 206]. In order to determine the correlation between the lab results and the symptoms patients report, clinicians often ask their patients additional questions. Based on these fragmented pieces of evidence and their prior knowledge, clinicians make medical decisions, such as which medicines to prescribe [186]. They also have to explain the type of medication and any side effects of the treatments to their patients. All these tasks should be done in as little as five to at most 20 minutes [38, 41]. This is a common problem in the hospital, and it is obvious that the doctor′s office is a site where clinicians encounter information overload [188, 205, 207], which inhibits clinicians′ ability to understand their patients completely.

It is extremely challenging to insert another process into this already dense workflow. It is even more difficult when the new process involves patient-generated data consultations. Previous studies and reports have already pointed out the obstacles of utilizing such patient-generated data within the medical setting [208, 38, 13]. Many issues relate to data capture/access and further situational constraints in medical practices [13]. As mentioned above, situational constraints, such as lack of time [84] and information overload [85, 86], have been pointed out as some of the most challenging and endemic obstacles.

Despite these challenges, major hospitals and healthcare providers are attempting to adopt data-driven consultation [209]. Quickly obtaining information on patients′ everyday lives is more critical in specific clinical settings where overweight patients suffering from chronic diseases need regular visits to check their overall health conditions and receive advice from clinicians. It is crucial for clinicians to have a thorough understanding of their patients for precise diagnosis and proper treatment [210, 211, 212], especially in the case of chronic disease patients [191]. In the past, patients mostly provided their daily habits through verbal recall, which was time-consuming and forced doctors to make estimations. On the contrary, data-driven consultation helps clinicians gain a deeper understanding of their patients' behaviors and feelings [38] in a relatively short amount of time. In other words, if the data-driven consultation process is well integrated into the current workflow [192], the doctor–patient relationship can be improved despite the situational constraints [191, 38, 198].

However, it was not until recently that the integration of data-driven consultation, inwhich clinicians utilize self- logged data in the hospital, began to be researched. Chung et al. identified the feasibility, benefits, and challenges of data-driven consultation from the perspective of both healthcare providers [38] and patients [50]. West et al. [13] reviewed prior studies and examined clinicians using vignette-based roleplaying. These studies derived empirical findings by investigating how data-driven consultation aligns with current workflows and work practices. However, little research has been done on the role of actual clinician interfaces and the way in which such interfaces should be designed [191, 192].

Therefore, we[2] aim to design an interface that provides a set of clues for checkup conversations, by which clinicians quickly understand their patients. To do so, we examine the current clinical workflow and explore how the data-

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[2] All uses of "we," "our," and "us" in this chapter refer to contributors of this research project.

driven consultation interface should be designed. Given these objectives, the research questions is as follows:

- What are the barriers and enablers to align using PGHD with the clinical workflows?
- How should a clinician interface for data-driven consultation be designed?

In order to answer the questions, we conducted a 15- month-long user-centered design process with 18 stakeholders. Focusing on the first question, we set design goals based on the preliminary study. We found two issues clinicians encountered: (1) difficulty catching any distinctive events that caused dramatic changes in patients' behaviors when clinicians were not monitoring them and (2) difficulty discovering those events quickly and discussing them further with patients. To reflect on these issues and address the second research question, we conducted a design workshop and designed a dashboard interface for supporting conversations in the exam room. Then, we implemented the interface, DataMD, which can be integrated with the current electronic medical records (EMR) system.

4.2 Preliminary Work

Before starting how to design data representation, we examined workflows and set the design goals to identify situational constraints that influence data representation.

4.2.1 Workflow Journey Maps

We identified the current workflow and discovered opportunities to insert data-driven consultation. We conducted in-depth interviews with four clinicians with different specialties from Seoul National University Bundang Hospital: otorhinolaryngology (C1), family medicine (C2), rehabilitation medicine (C3), and urology (C4). The interviews consisted of two parts and took a total of 40 minutes. During the first part, we asked clinicians about their behavioral procedures in the examination room and their interaction points with the EMR system, paper reports, and nurses. During the second part, we investigated clinicians' opinions on how they would integrate data-driven consultation into the existing workflow based on the scenarios they wrote. After the interviews, we combined the journey maps of the existing workflow from each clinician into a unified journey map. Finally, we concluded with the final two journey maps that represented the current (as-is) and desired (to-be) workflows (Figure fig:workflow).

As a result of the preliminary study, four behavioral tasks were identified: skimming lab data on the EMR system, asking patients follow-up questions, typing in comments on the EMR system, and orally prescribing and explaining medications **(Figure 4.1)**. Clinicians emphasized that data-driven consultations can aid in the betterment of the first two tasks, which involve iterative learning about patients through conversations. This provides the clinicians with the prerequisite information and allows them to approach critical questions without wasting time. This provides the clinicians an opportunity to plan behavioral changes with the patient.

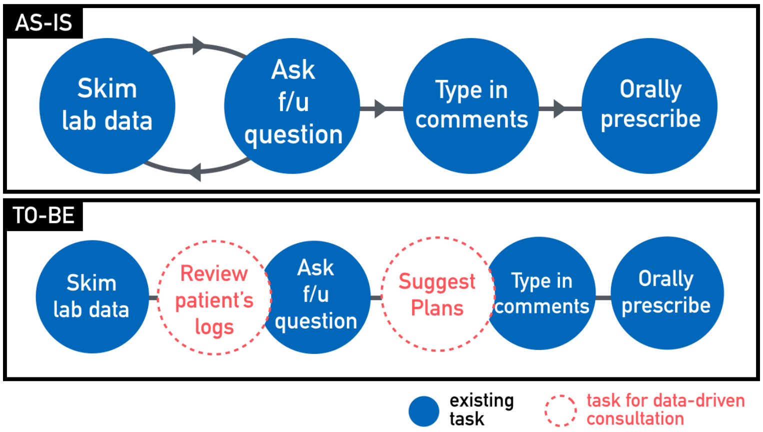

Figure 4.1: The two boxes are the current and desired workflows. Each circle represents a task and is ordered by time. The to-be workflow is what the clinicians want/expect in terms of change.

Clinicians addressed the necessity of a uniform clinician interface that integrates patient-generated data from various individual tools, supporting the findings in previous studies [81, 191, 198]. Interestingly, clinicians emphasized that the new interface should be designed as a separate window from the existing EMR system. They pointed out that EMR data and patient-generated data differ in terms of reliability, validity, and medical value, as revealed in previous studies [213, 192]. They clarified that patient-generated data has not yet been proven to have a clinical correlation with any diseases and that a separate window would help distinguish patient- generated data from medically verified data. Therefore, we decided to design it such that the patient-generated data was separate from the EMR system.

4.2.2 Design Goals

We refined the requirements by observing actual data-driven consultations and conducting discussion sessions with clinicians. We derived three themes from the requirements, which were gathered from three types of data. The main data were transcripts containing 40 cases of six clinicians using patient-generated data in Chapter 3, which were re-analyzed considering the scope of this study. Other data were collected from clinician interviews and survey results. We asked clinicians about their thoughts on data- driven consultation and investigated their perceptions of the usefulness of each type of data through a survey. After extracting and listing several requirements from the data, we conducted a thematic analysis and elicited three themes.

Helping clinicians skim data quickly

We found that the clinician interface should help clinicians skim trends from various types of data quickly so that they can discover distinctive points. Clinicians want to be able to review summarized data to understand patients effectively. C2 commented, *"To put it simply, I want to see my patients' status at a glance; that is, in as little time as it takes them to leave the exam room and enter my office."* Simultaneously, clinicians need to review data in detail to determine abnormalities. For example, clinicians often read the trends of the activity data (steps) and discover an unusual point when the number of steps taken suddenly decreases. They then need to scrutinize the data collected that day. These conflicting requirements imply that both summarized and detailed data are needed.

Supporting collaboration of clinicians and patients

It is important for clinicians to read the data collaboratively and discuss them with their patients. Clinicians think they can answer critical questions quickly using patient- generated data and that discussing cases with patients can increase the quality of care. While patient-generated data is produced by the patients, lab data is generated at hospitals. Patients are interested in and knowledgeable of their data [197, 50]. Thus, an interface should be designed to facilitate doctor–patient collaboration and discussion [81, 25, 38].

Creating procedures to enable clinicians to have an impact on their patients

Clinicians highlighted that data-driven consultation was useful only when it included specific plans that could affect patients in the real world. This implies that not just reviewing data but actually setting goals creates therapeutic value [214], especially by motivating patients to modify their behaviors [50, 41]. Despite such importance, little research has been conducted on setting goals with patient-generated data. We observed that clinicians easily forget patients' unrecorded data. Since clinicians orally set goals, patients and clinicians cannot remember them with exactitude. To prevent goals from being lost, a clinician interface should be designed to record them and influence patients' lives.

4.3 Study Design

To design the clinician interface, we employed a user-centered approach.

4.3.1 Participants

A total of 18 participants—clinicians (4), healthcare informatics experts (3), healthcare service providers (3), a healthcare service developer (1), an EMR developer (1), a college student (1), and HCI researchers (5)—were involved in the design process. The long-term design process allowed us to explore various issues and more thoroughly develop the design.

4.3.2 Participatory Design workshop

We conducted a design workshop with 18 participants to make sketches of a concrete interface. The objectives of the co-creative design workshop were to (1) make sketches of a concrete interface with clinicians who were aware of the current workflow and (2) consider unexplored issues through the participation of various stakeholders. The participants were divided into four groups with various backgrounds. Every group contained a clinician or healthcare informatics expert.

The design workshop consisted of three sessions (structure, visualization, and paper prototyping), which took a total of five hours. Before the group activities, we explained the current workflow and essential requirements, and printed guides were distributed to each team to serve as reminders for participants. Most of the time was spent on teamwork, but there were presentations after each session. During the first session, we asked everyone to spend 30 minutes selecting an interface structure. The participants were provided with examples (e.g., dashboard, grid view). Afterward, they were asked to make a new structure for a clinician interface. In the second session, participants spent 80 minutes sketching ideas about data visualization. We handed out data samples in Excel-sheet format. In the last session, each group spent 70 minutes making a paper prototype. Finally, each participant had three votes to cast on the paper prototype components. A week after the workshop, we documented the results with a decision- making list. After all the participants attended charrettes, we shared the voting results and reached the final guidelines. After finishing the design workshop stage, we implemented the interface, Data MD, on the actual EMR system.

4.4 Results

In this section, I present two types of results: design requirements from the participatory design workshop and implementation of DataMD.

4.4.1 Design Requirements

We explored how the three design goals can be reflected in the clinician interface through a design workshop.

All-in-one interface with a hierarchical structure

The first design guideline was related to a desirable structure. The results showed that the information should be organized hierarchically on a single-page screen.

All-in-one interface is more efficient. Interestingly, all the groups proposed new types of structures in which all data were displayed on a single page. We expected that navigating separate pages would allow clinicians to read data faster, but the results indicated the opposite. Clinicians and health informatics experts argued that a single page is better for a holistic review. *"Clicking wastes time, so one screen is better for speed"* (C2). A single view was also beneficial for cross-referencing various types of data. One team's developer and designer preferred to distribute information across a few pages, but they changed their minds after hearing the clinician's opinion. Another group reported similar processes.

The legacy system, the existing EMR system, influenced clinicians' preferences for combining all the data in a single page. Clinicians were accustomed to the current EMR system, which runs on a 21-inch monitor. As they were used to reviewing heterogeneous data on a single-page view, it was natural for them to design the new interface in a similar way. *"I'd rather not design it too differently from the (current) EMR"* (C1). Two other clinicians (C2, C3) and an EMR developer made similar points.

Hierarchical structure for skimming data quickly. Most groups discussed the issue of information overload caused by listing the data on a single page, and two groups proposed a hierarchical information structure to solve this issue. During this process, there was a discussion on the importance and characteristics of each data type. Clinicians suggested that each type should be distinguished, as they categorize weight, blood pressure, and stress as outcome data in their practices. The activity, food, and sleep data were considered primary data that affect the outcome data.

They suggested a three-level data summarization process involving a holistic summary, individual data summary, and detailed individual data. This could be connected to interpretation levels. For example, if a holistic summary were to represent the average quantity of activity, meals, and sleep, a clinician could think, *"This patient did not exercise but ate a lot. No problem with sleeping."* After that, the clinician might decide to review the individual data summary of activities and get a new interpretation: *"S/he is usually active but only has inactive days on particular weekends."* If needed, the clinician could look into the detailed individual data. This step-by-step sequence might improve effectiveness, because some information might not be necessary but could be selectively interpreted.

All the groups mainly dealt with a holistic summary, since it is essential to deciding the level of interpretation required. The two highest ranked components were a different type of representation of a holistic summary. One was a table with numeric values (e.g., averages) to help clinicians quickly comprehend each value. The other was a multi-line graph where the multiple lines overlapped to enable clinicians to compare various data trends. Clinicians supported its usefulness, stating that the current vital signs are visualized in the same way. For this reason, we agreed to adopt the overlay graph and test it in the field despite several issues with axis synchronization and its complexity of interpretation.

Line graphs for trends and heat maps for distinctive points

In this section, I mainly describe the result of the drawing session where participants discussed data visualization.

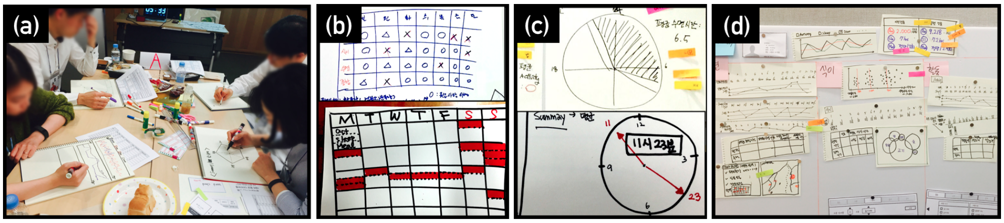

Figure 4.2: (a) is a scene of sketching ideas in the second stage of the workshop. (b) shows sketches of a calendar-style grid with O/X marks. (c) presents ideas that borrowed a schedule pie chart to represent wakeup time, bedtime, and sleep duration. (d) is an example of a paper prototype.

Easiest visualization for representing trends. Participants agreed that an individual data summary could help clinicians scan trends effortlessly. That is, an individual data summary shows a span of data, while a holistic summary provides a snapshot of data. As for the voting results, the most popular individual summary visualization was the time-series line graph. There are two merits to using a line graph. Because line graphs are common, clinicians can quickly catch trends from them, and some values are displayed on line graphs. In addition, it is possible to visualize any time-series data with ease, whereas other new visualizations depend on the data type.

One of the groups argued the necessity of customized visualization techniques based on the different traits of each data type. Activity data could be represented on a calendar- style grid view with O/X marks, because whether patients achieve their goals is important **(Figure 4.2-b)**. It would allow clinicians to check at a glance if their patients are exercising continuously. In the case of sleep, some borrowed a schedule pie chart to represent wakeup time, bedtime, and sleep duration **(Figure 4.2-c)**. However, many participants were concerned that those visualizations required additional interpretation and did not show trends well.

After discussion, all participants agreed on the common formats, such as the line and bar graph formats, due to their familiarity. It reflects the conflicts between the needs and costs of using patient-generated data in the exam room. Clinicians were confident that using the data would be useful, but they had trouble anticipating the difficulties associated with the data. The cost, including misinterpretation of the data and learning system, influenced their preference for familiarity. Since clinicians did not want to take risks or have uncertainties, they were inclined toward common visualizations and various options (e.g., summary & details, reference values).

Heat maps for looking into distinctive points in depth. Heat maps were chosen to express detailed individual data for the primary data (i.e., activity, food, and sleep). When clinicians discover a distinctive point, such as a sudden decrease in a line graph, they form initial hypotheses and want to verify them [53]. They want to know exactly what happened at that point. Many participants tried to represent the details of each data type by dividing a day into three sections: morning, afternoon, and evening. It reflected the requirements that clinicians wanted to examine in-depth dimensions beyond daily quantities. It was also expected to promote communication between clinicians and patients. As the visualization was similar to the mental model of a daily routine—morning, afternoon, and evening—patients could talk about their status and feelings without difficulty.

During the charrette, the heat map was considered an appropriate format to visualize amounts in each time section. Adding an additional time section, night, was suggested to review problematic points. For example, many patients take a late-night meal impulsively, which would be dealt with separately from supper. In addition, a stacked bar graph was selected for sleep data due to the different structure of sleep quality data.

Multiple numeric input fields for prescribing measurable goals

The requirement of creating preset procedures to prescribe goals and therefore impact patients was emphasized. Clinicians desired to set goals as they would prescribe medication on the EMR system. One group suggested the idea of setting goals by entering exact numbers. The idea was popular with participants, especially clinicians. This simple interaction was expected to help clinicians compress a discussion with patients and integrate it into the workflow. An additional opinion that the history of the prescribed goals should be shown was also reflected.

To adjust and set specific goals, appropriate criteria were required. Clinicians noted that reference values are needed to make immediate decisions. Among many candidates, two values were selected: the average of an individual patient's data during the total logging period and the average during the interval between the last visit and the current visit.

During the workshop, some participants commented that a similar group's average could be helpful. However, it was not reflected in the interface, because there would not be enough data to calculate in the early stage. The discussion of reference values changed frequently. Participants could not decide which reference values would assist clinicians' decision making. This implied that a field study should be conducted to identify the final reference value choices.

4.4.2 Implementation: DataMD

We implemented the clinician interface, named DataMD, enabling clinicians to utilize patient-generated data based on the design guidelines. After developing the first prototype, we modified it five times based on the feedback from the workshop participants. we revised the graph scale, certain kinds of reference values, and the color of the graph and background. Considering the legacy system, we made a small button on the bottom right of the original EMR page to access the interface for patient-generated data. In response to the clinicians' request, we also chose a dark theme to maintain consistency with the existing system.

We confirmed the six types of data, which can be classified into two categories (primary and outcome data), as discussed in the section above. The primary data area includes activity, food, and sleep data, and the outcome data area includes stress, weight, and blood pressure data. Every data type has a unique color to prevent confusion **(Figure 4.3)**. There had been save buttons placed on each goal, but we reduced it to just one button, reflecting clinicians' comments that it was too confusing.

Holistic summary

The holistic summary area is located at the top left, which is expected to help clinicians skim data quickly and choose the level of interpretation.

Figure 4.3: The view of the clinician interface is named *DataMD*. A clinician, the intended user, can: (1) skim patient-generated data via the numerical summary and graph with multiple trend lines (2) review a trend line for each data component, and discover abnormal points (3) if needed, look at the heat map to check for details (4) adjust the goal with his/her patient.

- **The profile** is provided as a bar at the top. It contains patients' basic information, such as name, sex, age, disease, and body mass index (BMI).

- **The numerical summary** consists of six boxes, which represent the average or the latest value of each data type. For the primary data, average values are displayed to catch a snapshot of a patient: average number of steps, food portion size and eating frequency, and sleeping duration. All the data boxes include the last goal number in a small font.

- **The graph with multiple trend lines** represents the relative trends of each data type. Due to the axis synchronization issue, the axes are not displayed. Instead, we define the lowest data point as zero and the highest as 100. This component helps clinicians cross-reference and compare the six types of data so that they can discover correlations between them.

Primary data area

The primary data area contains three data components. Each data component has four elements, including an individual data summary, detailed individual graph, reference values, and numeric input fields for goal setting.

- In **the activity data** component, there is a trend line graph for grasping the total daily number of steps. The heat map in the activity data component represents the intensity of exercise during four predefined time sections: morning, afternoon, evening, and night. Two input fields are provided to insert a goal number for the daily step count and a required duration of a high-level exercise per day.

- In **the food data** component, there is a bar graph representing the average portion size per day. The heat map represents the portion size for each time section. Additionally, the frequency of snack intake is provided with another tab for the trend line graph. There are four input fields to input frequency of meals, portion size per meal, time of eating, and frequency of snack intake.
- **The sleep data** component is different from the other primary data. The total sleep duration and wakeup/bedtime are represented with a unique type of trend graph with a bar element. A stacked bar graph is used to visualize the quality of sleep based on the duration of light sleep, deep sleep, and awakening. There are three input fields to set the bedtime, wakeup time, and total sleep duration.

Outcome data

The outcome data are different from the primary data. There is only a summary of each data type, because these data do not have qualitative dimensions. They are usually cross-referenced with the primary data, so we chose different graph forms.

- **Stress data** is represented in the heat map to emphasize a remarkable change. Since individuals cannot control stress levels, there is no input field to set a goal.
- **Weight data** is visualized as a line graph with a reference line of the previous goal weight. There is a numeric input field to set a goal weight.
- **Blood pressure data** is visualized in a line graph, similar to weight data. There are two lines, the highest and lowest values, with dotted reference

lines.

4.5 Limitations & Conclusion

There are some limitations to this study. Because the study site was a university hospital in South Korea, findings might not be representative of a larger sample or more diverse environments. As the same design might work differently depending on the situation or culture, ages, gender, or geographical conditions, we need to further investigate a broader range of cases. Despite these limitations, this study makes a contribution to identifying specific design requirements for a clinician interface, reflecting various stakeholders' perspectives.

4.6 Summary of Chapter 4

In this chapter, I described a design of DataMD that supports data-driven consultation. Beginning with the analysis of as-is and to-be workflows that can impact on data representation, I reported design goals to effectively represent PGHD. Then, through the participatory design workshop with 18 stakeholders, I found three design guidelines: (1) All-in-one interface with a hierarchical structure; (2) line graphs for trends and heat maps for distinctive points; and (3) multiple numeric input fields for prescribing measurable goals. I demonstrated the design and implementation of DataMD, in which various types of PGHD are represented with considerations of clinical contexts.

Chapter 5

Data Interpretation: Data-Interpretation Strategies

This chapter[1] presents how patients interpret various types of PGHD based on their lived experiences, focusing on the data they are interested in reviewing, the assumptions they have about their data, as well as the way in which they explore their data. By conducting interviews with 20 chronic disease patients, I report four main data-interpretation strategies. This chapter provides foundational knowledge to integrate two different approached towards data-interpretation: analytical and explorative approach.

5.1 Motivation

The virtue of self-tracking is considered the ability to gain accurate and objective self-knowledge through numbers, beyond the "vagaries of intuition" [31], yet laypeople often face pitfalls in self-tracking, such as insufficient scientific rigor [35]. To overcome these pitfalls, many researchers have focused

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[1] The part of Chapter 5 was published as an extended abstract [215] in the Asian CHI Symposium in the 2019 CHI Conference on Human Factors in Computing Systems.

on designing systems that help self-trackers gain insights through statistical methods, such as n-of-1 trials and Bayesian methods [94, 182, 184]. These analytical approaches, including self-experimentation, provide clear answers for specific types of tracking that help people look for links between data points, such as “diagnostic tracking” [88].

The tendency to overemphasize such analytical approaches, however, might limit the way people question, present, and imagine their data that are “enmeshed with everyday life” [88]. Although such approaches can lead people to focus on an overly simplistic answer [89], researchers and system designers often idealize purely statistical approaches to interpreting data, widening the gap between the lives people lead and their interpretation of their data. Prior studies have shown that converting individual interests about data into testable hypotheses is challenging [94, 182]. People usually neither think about data in the form of hypotheses [94], nor consider it as prosaic numbers [89]. Rather, people attempt to interweave data with personal experiences and interpret data, as a part of sense-making process [93].

The discourse of lived informatics [88, 89, 33, 90, 216] leads us to pay attention to how people live with and alongside their self-tracked data. When facing a dissonance between lived experience and data, people can utilize data-interpretation strategies to bridge the gap, which corresponds to the sense-making process [91, 93]. *Sense making* is a unique process by which people find answers to their questions by utilizing their ideas, emotions, attitudes, and memories [91]. Here, a data-interpretation strategy is considered an attitude toward interpreting data, incorporating an individual’s interests and assumptions. A data-interpretation strategy can make people either engage with or disengage from data. For example, self-trackers who have strong assumptions about the relationship between specific data types might observe data that contradict these assumptions. If the self-trackers decide to reject the data in favor of maintaining their initial assumptions (a rejection strategy), the value of their self-tracking data is limited by confirmation bias. In this sense, we need to understand and investigate various data-interpretation strategies when people review and explore their self-tracking data.

Unfortunately, despite the emphasis on lived informatics [88, 89, 90], we still have a limited understanding of how people interpret their self-tracking data based on their personal experiences. Since Rooksby et al. proposed the concept of lived informatics, some studies have adopted the concept to investigate various aspects of self-tracking [169, 90] and data experience [89, 170]. In the sociology context, Lupton has addressed the concept of a data double that an individual continuously reconfigures and reinterprets through self-tracking data [33, **?**]. However, little is studied about the use and interpretation of different types of self-tracking from the perspective of lived informatics. Many studies of self-tracking data in the healthcare field have focused on analytical approaches [178, 180, 94, 182, 184]. In recent work, Choe et al. identified the process of gaining insights from long-term tracking data [96], but we have a limited understanding of the way in which people think about and interpret different types of data based on their individual interests and assumptions.

Thus, we[2] aimed to understand how people interpret various types of self-tracking data based on their personal experiences by examining 1) the data they are interested in reviewing, 2) the assumptions they have about their

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[2] All uses of "we," "our," and "us" in this chapter refer to contributors of this research project.

data, and 3) the way in which they explore their data. By conducting semi-structured interviews with 20 chronic disease patients who tracked their personal health data for one month. Based on the findings, we discuss the role of a design to resolve the tension between lived experience and data interpretation as well as design implications to integrate data-interpretation strategies with analytical approaches.

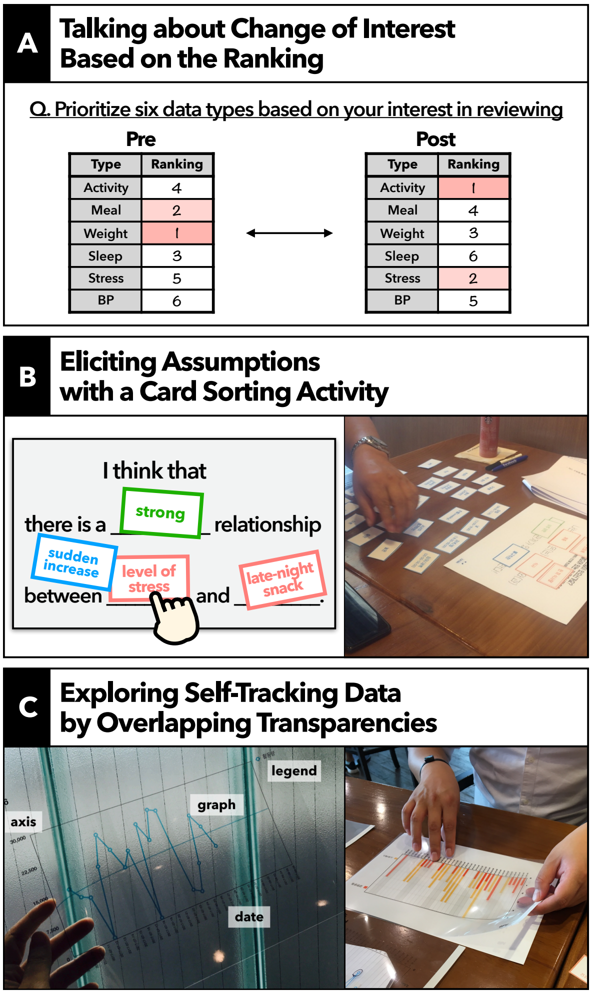
5.2 Study Design

We recruited a total of 20 participants and conducted semi-structured interviews including a card-sorting activity and a think-aloud session. This study proceeded under the context of a larger project about proving clinical effects of self-tracking as an intervention, and it was conducted in a general hospital in South Korea under the approval of the study site's IRB.

5.2.1 Participants

In the parent project of this study, a total of 60 patients were recruited at the clinician's office after a screening process covering their ability to use digital devices and disease type. All participants were suffering from sleep apnea and specific chronic diseases (e.g., hypertension, hyperlipidemia) that meant they had to visit the doctors at least once a month.

Forty of the participants were asked to track daily six types of data–some with sub-items–for one month: activity (step count), weight, meals (subjective satiety of each meal and snack intake frequency), sleep (total duration and subjective sleep quality), stress (subjective stress level), and blood pres-



Pre

Type	Ranking
Activity	4
Meal	2
Weight	1
Sleep	3
Stress	5
BP	6

Post

Type	Ranking
Activity	1
Meal	4
Weight	3
Sleep	6
Stress	2
BP	5

Figure 5.1: Semi-structured interviews. (A) Rankings determined by participants. (B) Template and cards used to make assumptions. (C) Transparencies on which participants data were printed to help them compare data.

sure (BP). Among such data, activity and weight data were tracked automatically through devices (i.e., wristband pedometer and smart scale, respectively) that we provided to participants. The other four types of data were manually tracked. The three subjective items were based on a 5-point Likert scale. Sleep duration and BP were logged in numbers with the proposed format (i.e., hours and minutes and systolic and diastolic, respectively).

Among the 40 patients who tracked their data, 20 were willing to participate in interviews. Participants were aged from 34 to 61 (*M*=49.2, *SD*=8.9). Gender was biased (male=17, female=3) because of the nature of the disease [217]. Participants' jobs were varied: self-employed (5), administrative (4), sales (3), manufacturing (2), service (2), specialized (2), and unidentified (2).

5.2.2 Study Procedure

To examine data-interpretation strategies, we conducted semi-structured interviews with 20 patients, which consisted of three sessions: 1) talking about a change of interest in data that participants wanted to review, 2) eliciting assumptions about more than two data types through card-sorting activities, and 3) exploring data by overlapping transparencies under a think-aloud protocol **(Figure 5.1)**. Each interview session lasted for 45–70 minutes. All interviews were conducted face-to-face and were audio-recorded and transcribed under the participant's consent.

Talking about Change of Interest in Data

Talking about Change of Interest in Data. Participants were asked to rank six types of data in order of their interest both before and after the study period.

The question was “Could you prioritize each data type based on your interest in reviewing it? (1: highest, 6: lowest)”, and there were six options: activity, meals, weight, sleep, stress, and BP **(Figure 5.1-A)**. Upon showing them the results, we asked them what made them change their interest (e.g., tracking experience, doctor’s advice). We also investigated their personal contexts and feelings.

Eliciting Assumptions with Card-sorting Activity

To articulate participants’ ideas, we used cards and a template. Because eliciting questions from scratch would have been too difficult to do in a short time, we decided to provide participants the following template: *I think there is a (blank) relationship between (blank) and (blank).* As some previous works suggested that correlations between data types are interesting to users, we thought the template could lead participants to come up with some ideas on the relationships between data [180, 178]. To help participants fill in the template, we also provided four types of cards: 1) level of strength of relationship (e.g., strong, weak, normal), 2) different types of data (e.g., activity, meals, weight), 3) sub-items of each data type (e.g., workout duration, meal size, sleep duration), 3) adjectives or adverbs (e.g., daily, regular, sudden increase), and 4) blank cards (on which participants were free to write down whatever they wanted). Participants were asked to fill in the template with a set of various cards **(Figure 5.1-B)**. They could make as many assumptions as they wanted. After building each assumption, we questioned them on how and why they made the assumption.

Exploring Self-tracking Data by Overlapping Transparencies

We printed each participant's own tracked data on transparencies, motivated by Tukey's exploratory data analysis approach [218]. We prepared each data type with line, bar, and stacked graphs, adding a trend line. By overlaying the transparencies, participants could either review one type of data or compare several kinds of data **(Figure 5.1-C)**. We asked participants to mark the interesting area on the transparencies with a pen during a think-aloud session. We also took observation notes on points in which they were interested. We examined what they focused on in the data and why they thought about the data in a certain way.

5.2.3 Data Analysis

We obtained four types of data: 1) responses to questions on change of interest, 2) sets of assumptions, 3) marked transparencies, and 4) interview transcripts. We analyzed them with three themes. First, to track the change of interest, we analyzed the results of responses with interview transcripts. Putting together interview transcripts and the result of change of interest, we categorized the pattern of change (e.g., change all rankings, change the first and second rankings). Second, to examine types and patterns of assumptions, we categorized assumptions depending on data pairs (e.g., sleep–stress) and identified used phrases (e.g., regular) to make assumptions. We also tried to find the sources participants were using to make assumptions. Lastly, we aligned the interview transcripts, observation notes, and marked transparencies of each participant to identify data-interpretation strategies. We mainly conducted a thematic analysis [219] based on interview transcripts, cross-referencing the other data (i.e., observation notes, marked transparencies). To analyze the qualitative data, we used a supporting tool, Reframer [220].

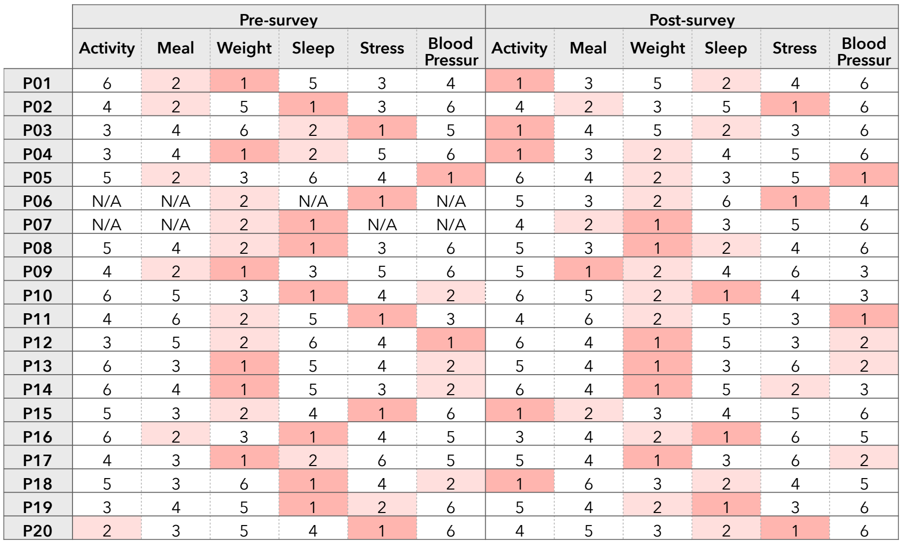
5.3 Results

5.3.1 Change of Interest in Data

The survey results revealed that the change of interest in specific data types differed across participants **(Figure 5.2)**. Most participants clearly explained their reasons for ranking an area they were concerned with higher, whereas they did not have specific reasons for lowering rankings. The most common reason they changed their interest in data was the self-tracking experience itself.

Change of Ranking

Focusing on the change in higher ranking (the first and second), we found that six participants changed both the first and second rankings (P01, P04, P07, P15, P17, P18). Four of them determined activity data as the first ranking. Twelve participants partially changed their rankings: three changed the first ranking (P02, P03, P11); six changed the second ranking (P05, P10, P14, P16, P19, P20), and three just changed the order of rankings between the first and second (P08, P09, P12). Two participants did not change the higher rankings (P06, P13). We found that among six participants who changed their second ranking, four participants changed the ranking of weight into the second (P05, P10, P14, P19).



	Pre-survey						Post-survey					
	Activity	Meal	Weight	Sleep	Stress	Blood Pressur	Activity	Meal	Weight	Sleep	Stress	Blood Pressur
P01	6	2	1	5	3	4	1	3	5	2	4	6
P02	4	2	5	1	3	6	4	2	3	5	1	6
P03	3	4	6	2	1	5	1	4	5	2	3	6
P04	3	4	1	2	5	6	1	3	2	4	5	6
P05	5	2	3	6	4	1	6	4	2	3	5	1
P06	N/A	N/A	2	N/A	1	N/A	5	3	2	6	1	4
P07	N/A	N/A	2	1	N/A	N/A	4	2	1	3	5	6
P08	5	4	2	1	3	6	5	3	1	2	4	6
P09	4	2	1	3	5	6	5	1	2	4	6	3
P10	6	5	3	1	4	2	6	5	2	1	4	3
P11	4	6	2	5	1	3	4	6	2	5	3	1
P12	3	5	2	6	4	1	6	4	1	5	3	2
P13	6	3	1	5	4	2	5	4	1	3	6	2
P14	6	4	1	5	3	2	6	4	1	5	2	3
P15	5	3	2	4	1	6	1	2	3	4	5	6
P16	6	2	3	1	4	5	3	4	2	1	6	5
P17	4	3	1	2	6	5	5	4	1	3	6	2
P18	5	3	6	1	4	2	1	6	3	2	4	5
P19	3	4	5	1	2	6	5	4	2	1	3	6
P20	2	3	5	4	1	6	4	5	3	2	1	6

Figure 5.2: Change of interest in data. There was no universal pattern to explain the overall change of interest. The change of interest in a specific data type varied across participants.

Reasons for Change of Interest in Data

Many participants remarked that the self-tracking experience itself, especially the type of tracking (e.g., semi-automated, fully manual) [27], contributed to the change of interest. They were interested in data from semi-automated tracking and were relatively skeptical of data from fully manual tracking. P18 noted, *"[Manual] food logging is quite a crude method, but step count is an exact number from the machine. It's natural that my concern changed."* On the other hand, two participants whose rankings had not changed already had strong ideas about the specific data type related to their past experiences. P06 said, *"I have the best knowledge of myself. I'm only concerned with two things, weight and stress."* This aspect is also presented in the sub-section on the grounds for assumptions.

5.3.2 Assumptions on Relationships between Data Types

Participants came up with diverse ideas with a card-sorting activity and made assumptions about the relationships between data types based on their personal experiences. The pair of meals–weight was the most frequently reported (19 times), but the specific meaning varied across participants **(Table 5.1**).

Expressions of assumptions

Twenty participants made a total of 49 assumptions about the relationships between more than two types of data (*M*=2.45, *SD*=2.2). Nine participants made one assumption, whereas 11 participants created two or more. As shown in **(Table 5.1**), the most frequent pair was meals–weight (observed 19 times), followed by the weight–activity pair (6). Regardless of the pair, the most frequently reported data type was weight, which represents most participants' interest.

Although participants often used the same pairs to make assumptions, the detailed meaning varied depending on each participant's ideas. Participants had seven different meanings for the meals data type **(Table 5.1**). P07 even wrote down a new data type to articulate her idea: *total amount of carbohydrates consumed*. Similarly, P17 made his own card that he considered the most important: *distance moved*. This indicates that some participants had very specific concepts about their data.

Many participants used phrases to represent the change, including *a sudden increase in* (10 times), *a sudden decrease in* (3), *a steady decrease in* (9), and *a steady increase in* (1). Interestingly, *a sudden increase in* and *a steady increase in* represent completely different perspectives. Participants who chose *a sudden increase in* considered the rapid rise a serious problem. P20 noted, *"The more anything, such as weight, food intake, and even stress, quickly goes up, the worse your health is. You have more time to fix it if the weight slowly increases."* On the other hand, P19 argued that a steady increase aggravates one's health status, as people are often unaware of the change. *"Five years ago, I drank every day and gained weight bit by bit, day by day. When I felt my pants were too tight, I realized I'd gained almost 15 pounds in a month. These slow changes can kill you."*

For the time expression, participants mostly used *daily* (observed 13 times) and *weekly* (2). There are two possible explanations for this result. First, participants might not be very interested in long-term data because, as the previous study explained, self-trackers tend to focus on the present and the future [88]. Second, the interface of the tracking app, designed to input data every day, could lead them to focus more on daily life.

Participants chose adjectives, such as *irregular* (observed 5 times), *regular* (3), and *very regular* (1), to express either problematic or desirable statements. Although they often chose the same adjectives, their meanings differed across participants. P02 explained irregular eating in terms of the number of meals per day, while P19 thought the same expression referred to an intake irregular amount at one meal. This demonstrates why normalizing assumptions with different contexts is challenging.

Six participants used blank cards either to explain more (e.g., faint) or to create more detailed data types (e.g., amount drunk, distance moved). P05 assumed that the subtle level of stress is related to the subjective quality of sleep. *"This card you suggested is not the exact word that I wanna say. I'm saying a really low level of stress, which means I sometimes can barely feel it, but I think it's a pretty* *significant factor influencing my sleep quality."* This case shows that people use sophisticated language when expressing their thoughts, which makes it hard to transform them into testable hypotheses.

Ground of Assumptions

Most assumptions were created based on specific past experiences. Fifteen participants suggested their personal experiences as grounds to explain 35 assumptions (71%). The personal experiences included both positive and negative experiences related to keeping healthy. Interestingly, negative experiences made people shape assumptions that were connotative of negative results and vice versa. For example, P16 suggested that sudden increase in weight and irregular total number of meals are very strongly interrelated, referring to his negative experience of having busy days while working for a company.

> *P16: When I was a sales rep, I used to skip meals or grab anything I could eat quickly when passing by a cafeteria. I remember I felt either good or bad depending on my weight every night in those days. I'm quite sure the irregular diet caused my sudden weight change.*

Similar to P16, many participants told very specific anecdotes related to their assumptions. P12 said she was rushed to the ER due to her high BP when she suddenly gained a lot of weight. P09 described that he drank whenever he was stressed out because of his boss in his company. Two participants made their assumptions based on their self-tracking experience. Such personal experiences led them to form strong assumptions between data types. Most participants chose strong (26 times) or very strong (20) when describing the strength

Table 5.1: Assumptions about relationships between data types. Twenty participants made 49 assumptions (*M*=2.45, *SD*=2.2) through card-sorting activities. Expressions marked with an asterisk were made by participants.

Data pair	#	Detailed data types	Phrases
meals–weight	19	amount eaten at each meal, total number of meals, total snack intake, frequency of late-night snacking, ratio of eating out, menu, total amount of carbohydrates consumed*, weight change	nightly, daily, irregular, regular, a sudden decrease in, a sudden increase in, a steady decrease in, a steady increase in
activity–weight	6	total step count, level of intensity, types of workout, total workout duration, continuous duration of activity, distance moved*, weight change	daily, weekly, regular, a steady decrease in
stress–sleep	4	total duration of sleep, subjective sleep quality, bedtime, level of stress, type of stress	daily, high, many (much), a sudden increase in, faint*
BP–weight	3	diastolic BP, average BP, frequency of BP measurement, weight change	regular, irregular, a sudden increase in
BP–stress	3	diastolic BP, frequency of BP measurement, level of stress	daily, a sudden increase in
BP–sleep	2	average BP, quality of sleep, total duration of sleep	high, many (much)
sleep–activity	2	a quality of sleep, an amount of activity	-
sleep–weight	2	a quality of sleep, a total duration of sleep	high, many (much)
drinking*–meals	2	frequency of drinking, amount eaten at each meal, total number of meals	nightly, irregular
stress–meals	1	level of stress, frequency of late-night snacking	daily, a sudden increase in
stress–weight	1	level of stress, weight change	high, a sudden increase in
drinking*–weight	1	frequency of drinking, weight change	-
drinking*–stress	1	frequency of drinking, type of stress	-
miscellaneous	2	all six types of data, health*	comprehensively*

of the relationship between data types. This implies that many assumptions were made based on personal experiences rather than rational evidence.

On the other hand, nine assumptions were based on a doctor's advice. Three participants remembered their doctors' advice, such as *''Measuring your weight every morning is helpful to lose weight"*, and made similar assumptions. There were three assumptions grounded in common knowledge, such as *"Late-night snacking might affect your weight."*

5.3.3 Data-Interpretation Strategy

We identified four strategies that participants adopt when interpreting self-tracking data **(Figure 5.3)**. Participants flexibly utilized strategies depending on their interest in data or confidence in assumptions rather than sticking to only one type of strategy.

Finding Supportive Evidence to Confirm Assumptions

We found that many participants actively attempted to find supportive evidence to confirm their assumptions **(Figure 5.3-A)**. This strategy was presented in two ways: highlighting overall trends and focusing on supportive local trends.

Participants felt that highlighting overall trends was an intuitive and quick way to support their assumptions. Some participants referred to an overall trend as *"a thing that works for everyone"* (P03) or *"a matter of common knowledge"* (P13). Participants tended to use this strategy soon after starting to review data. After assuming that there is a very strong relationship between a sudden increase in the total number of meals and daily weight, P16 immedi-

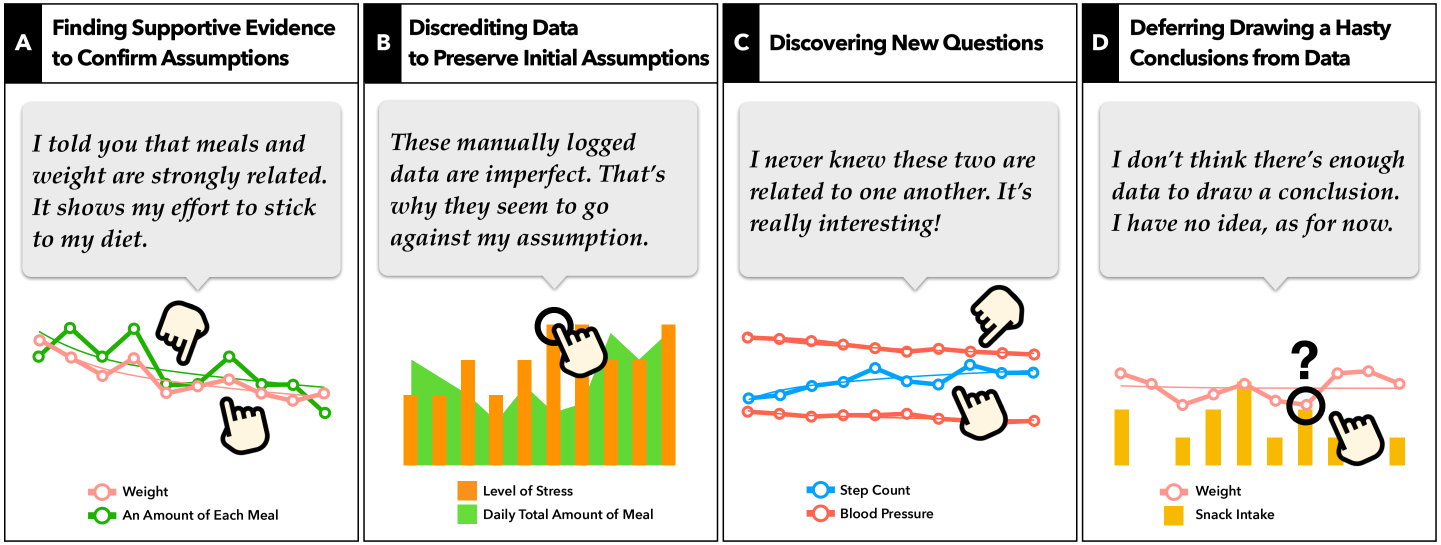


Figure 5.3: Four types of data reflection patterns.

ately found the overall trends that aligned with his idea **(Figure 5.3-A)**. He was excited that his idea was correct.

> *P16: Look at the trend lines. I told you. For the last two weeks, I didn't eat as much as before, and it worked. My weight decreased.*

However, sometimes participants failed to discover overall trends. Among such cases, a few participants moved transparencies to find overall trends, considering causation. P04 moved the weight data slightly to the right when overlapping it on the step count data. He remarked, *"I think a workout one day might influence my weight the next day."* Sometimes participants misidentified or exaggerated trends in their data. Although trend lines in graphs of sleep quality and stress data appeared to be parallel, P20 argued that there was a negative correlation between the two data types, following his initial assumption. He used his personal experience as grounds for his strong assumption.

> *P20: Since quitting my job and opening my store, I've felt more comfortable and settled. Since then, I think my stress has reduced, which makes me sleep well and feel refreshed every morning.*

This implies that there are rich personal stories beyond data. Some data collected in a relatively short period compared to one's lifetime might not reflect the various aspects of everyday life. At the same time, this also indicates the risk of bias [221, 222]. Concerning this strategy, we later discuss how a design can not only support personal experiences but also prevent bias. Contrary to addressing overall trends, participants also focused on specific supportive data points or local trends. They thought that some data points were the best-fit evidence to explain their assumptions. P19 paid attention to some data points that explained his assumption: *"Look at the data on these [four] days. Though these [days] are separated, they are similar in terms of increased step count and number of meals."*

In some cases, when participants hardly noticed any overall trends, they tried to discover a local trend. P03 said, *"I'm quite sure that I can see a correlation between these two [data types: step count and weight]. It's not as clear as I thought, but look at this: there are some trends in these three days and those two days."* Among such cases, some participants changed to the strategy of deferring drawing hasty conclusions.

Discrediting Data to Preserve Initial Assumptions

We found that participants often used the strategy of discrediting data to preserve initial assumptions **(Figure 5.3-B)**. In contrast to the first strategy (i.e., cherry picking what they wanted to see), the goal of this strategy is eliminating exceptions or justifying the results. Participants ascertained the points that contradicted their assumptions and paid attention to explain why the data was incorrect. They referred to some manually logged data as flawed or incomplete. This strategy enabled them to exclude all unexpected cases in an easy way. P02 assumed that there was a very strong relationship between sudden increase in stress level and total number of meals, but he found some data points where there were high levels of stress and small numbers of meals.

> *P02: (Pointing to the day when he recorded no snack intake) This is probably because I did not input my snack intake. I'm sure I had high-calorie fries late at night, 'cause my stress level was high. I always have some*

> *high-calorie snacks when I'm stressed out.*

Although some participants diligently input such data, they did not acknowledge them as valid data to be analyzed. They suggested reasons the data could not be considered valid. They thought the subjective level of stress and subjective sleep quality data were not valid to be analyzed because they were *"manually logged"* (P13, P18, P04) and *"too subjective"* (P08, P10, P20). Meals data were also considered imperfect because they not only lacked rich information (e.g., calorie intake, nutrients) but also were manually logged. P04 said, *"As long as it (menu and nutrient information) cannot be collected automatically, meals data are not meaningful to me.*

A few participants pointed out inaccuracy or variability even for semi-automated data types, such as step count and weight, arguing that some data were collected in variable conditions. P15 pointed out that he could not trust in weight data because the measurement conditions were inconsistent.

> *P15: For this week, step count and weight seemed to be opposite to what I thought they would be. It's because of the time at which I measured my weight. I sometimes took my weight in the morning, but sometimes in the evening. Considering its variability, it's natural that the data doesn't match my expectations.*

Similar to P15, P08 claimed that he walked more than the step count recorded by the wearable device. He expected that the data would not correspond to his assumptions even before reviewing his data.

Discovering New Insights

We found the strategy of exploring and discovering new insights while reviewing data **(Figure 5.3-C)**. This strategy was often observed when participants were reviewing data in which they were less interested. They felt a need to know more about new data when finding new insights that they had not expected. Each participant made various plans to examine new insights. P01 noted, *"You know, my blood pressure could have shot up from the shock, but I've never thought about the relationship between blood pressure and step count. (...) I should talk about this with my doctor."*

Some participants wanted to review their data in an objective way but did not give shape to do it. P09 came up with a new assumption, *"Why does my weight increase when my sleep duration decreases?"* and wondered how to examine it.

In a rare case, despite strong assumptions, a few participants appreciated new insights and even modified their assumptions, considering inaccurate data. P07 initially insisted that a weight change and a regular amount of meal had a very strong relationship. When exploring her data, P07 changed her mind.

> *P07: My thinking process might be wrong. It's different from my expectation. Although considering its inaccuracy, it doesn't seem like there is any relationship between those two (weight and regular number of meals).*

This strategy implies that it would be useful to discover questions that would give participants a chance to explore even less interesting data.

Deferring Drawing Hasty Conclusions from Data

The last strategy was deferring drawing any hasty conclusions from data **(Figure 5.3-D)**. Similar to the third strategy, participants utilized this strategy when reviewing less-confident assumptions. Participants reserved judgment of whether their assumptions were correct due to the lack of evidence. This appears to be related to the second strategy, discrediting data to preserve initial assumptions, but there is a difference in terms of the goal of the strategy. In this case, participants hesitated to conclude that their assumptions were correct.

> *P17: This line is too jagged to find a single trend. If you look at this point, you can see activity has decreased and weight has gone up, but in this section, it's the opposite. I can't confirm if my idea is right now.*

Some participants said that they needed more data. They were curious about how much and what types of data they needed to collect to draw sound conclusions. P13 made an assumption on the relationship between the number of meals and weight and desired to prove it. P13 said, *"It seems like my weight goes down when I have a small number of meals in some way, but I'm not sure it really does. I think so, but I need more data to prove it. How much data do I need? One month more? Or two months?"* This strategy is related to the third strategy of discovering new insights. When forming questions through these two strategies, they wanted to move on to the next stage but had difficulties identifying what to do next and how to do it.

A few participants gave up on finding insights or drawing conclusions. They stated that this was due to a lack of relevant knowledge or interest. P18 said, *"I have no idea about this data and graph stuff; actually, it's kind of a burden for me."* In addition, P10 told, *"I don't dare to make a conclusion 'cause I'm not even an expert."* Considering such cases, I might need a different design to help such participants explore data, such as utilizing a voice-user interface or artificial intelligence.

5.4 Limitations & Conclusion

Although our findings provide an understanding of data-interpretation strategies from the perspective of lived experience and provide some implications to enrich experiences with data, there are several limitations of this study. Because we focused on the specific context in which self-tracking was initiated by clinicians, our findings might not cover some aspects from different self-tracking contexts (e.g., self-initiated tracking, long-term tracking). In a similar respect, the gender of participants in this study was biased toward males due to the disease type [217], which might influence our findings. In future work, we plan to investigate people from different regions, of different genders/ages, with different disease types, and in different self-tracking contexts to enrich our findings.

In this work, we aimed to examine data-interpretation strategies from the perspective of lived informatics. Our findings revealed that people make sense of their data by interweaving their lived experiences with data. This teaches us that understanding each person's unique experience is necessary to help people interpret their data in a rich way. We believe this work can contribute to providing an understanding of data-interpretation strategies and expanding the perspective of lived experience by investigating data interpretation in self-tracking practice.

5.5 Summary of Chapter 5

In this chapter, I aimed to understand how people interpret various types of PGHD in light of personal experiences by examining 1) the data they are interested in reviewing, 2) the assumptions they have about their data, and 3) the way in which they explore their data. By conducting interviews with 20 chronic disease patients, I found that they shaped their interests and assumptions by incorporating prior experiences rather than logical evidence. I also identified four data-interpretation strategies: finding evidence to confirm assumptions, discrediting data to preserve initial assumptions, discovering new insights, and deferring drawing hasty conclusions from data. Lastly, I discussed the role of a design to resolve the tension between lived experience and data interpretation as well as some design implications to enrich data interpretation.

Chapter 6

Collaboration via Data: Deployment Study

This chapter[1] demonstrate how the system–a patient app and a clinician interface–can support doctor-patient collaboration through a deployment study. I first describe the design rationale of the patient app, MyHealthKeeper that reflects findings in Chapter 3. Next, I briefly presented the design of DataMD, referring to Chapter 4. Then, I report the results of a prospective randomized clinical trial in 80 outclinic patients. Starting from the clinical outcomes as an evidence of behavior change, I present adherence rate based on the analysis of patient's data collection, and finally describe how the system supported workflow integration and in-depth conversations though observation results. This chapter bridges the gap between the HCI field and the medical domain by incorporating both perspectives.

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[1] The preliminary version of Chapter 6 was published as a journal article in Journal of Medical Internet Research [223] and a conference proceeding [40] in the 2017 CHI Conference on Human Factors in Computing Systems.

6.1 Motivation

Triggered by the advent of smartphones and wearable devices, and the Quantified Self movement [32], self- tracking has become a common habit [35]. According to [134], 70% of Americans—especially those suffering from chronic diseases—track at least one of their or their spouses' health indicators. Many studies have been carried out to investigate how these data could be useful for health management [72, 224, 212, 225]. While addressing the difficulties of interpreting such data [65], researchers further emphasized the necessity of expert/clinical interventions [138].

This led to recent studies on data-driven consultations in which clinicians utilize patient-generated data within the clinical setting [38, 41, 13]. It has been identified that using patient-generated data has many benefits. Chung et al. [38, 50] asserted that patient-generated data could offer supporting evidence for diagnoses and positively influence the doctor–patient relationship. Above all, it could enable clinicians to learn about and motivate their patients [192] and thus provide them with personalized treatment [214].

However, there is still little empirical evidence through in-situ deployment studies, despite the growth of interests in doctor-patient collaboration via PGHD. Previous studies mostly have focused on investigating either patients or clinicians rather than designed and evaluated an integrated system for both clinicians and patients. As prior works already have identified the necessity of an integrated system, we[2] aim to implement the integrated system–patient app and clinician interface–and empirically evaluate the system in terms of collaboration through a deployment study. Based on the literature,

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[2] All uses of "we," "our," and "us" in this chapter refer to contributors of this research project.

collaboration can be evaluated by answering three questions: 1)Does collaboration via data promote patients' behavior change? 2) How does the patient app improve patient adherence? and 3) How does the clinician interface help workflow integration that facilitates collaboration during the medical checkups?

To address these questions, we first implemented an integrated system that consists of the patient app, MyHealthKeeper, and a clinician interface, DataMD. Then, we conducted a deployment study with two groups: a system-supported collaboration group and a non-system-supported collaboration group. We compared clinical outcomes between the two groups. Also, we analyzed adherence and workflow integration for the system-supported collaboration group.

6.2 System Design

To support collaboration via PGHD, we designed and developed a patient app, MyHealthKeepr, and a clinician interface, DataMD. MyHealthKeeper was designed to help patients track various types of PGHD through a semi-automated tracking mode, based on the findings from Chapter 3. DataMD was implemented as we presented in Chapter 4. Details are as below:

6.2.1 MyHealthKeeper: Patient App

The patient app was designed, reflecting the findings from Chapter 3 **(Figure 6.1)**. We remained the main traits, accessible button-based logging but adding a feature that allows users to retrospectively edit their logs. To manage heterogeneous data types more effectively, we added a dashboard and horizontally allocated eight screens. Also, we added a view displaying clinician's advice to remind clinical contexts, based on the finding (i.e., clinician's presence improves adherence) from Chapter 2. The followings are details of the rationale.

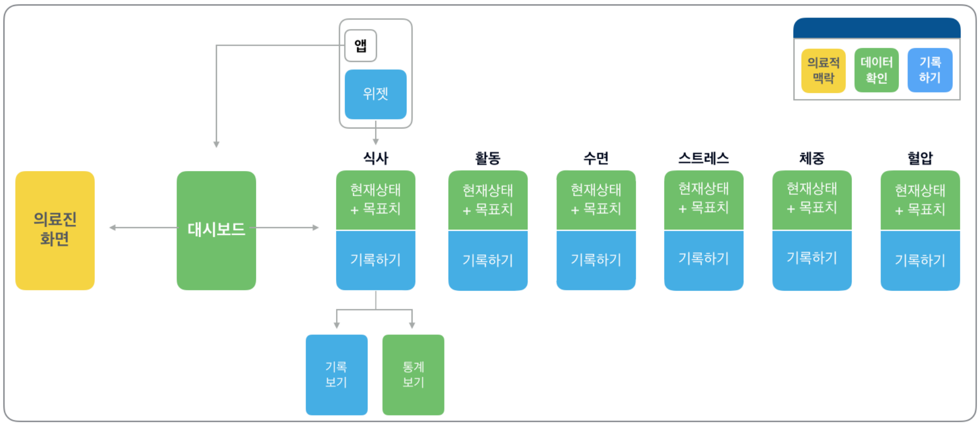
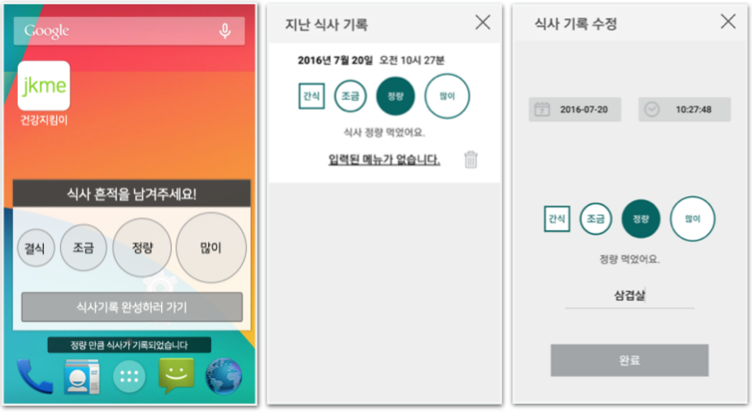


Figure 6.1: The information architecture of the patient app, MyHealthKeeper.

Provide a widget for retrospective editing and data completeness

In Chapter 3, we learned that accessibility and retrospective aspect are both important, regarding manual inputs. While participants positively reacted to button-based input methods, they also wanted to make detailed edits to the data later on in a retrospective manner. To meet this requirement, we decided to provide a function that can satisfy both accessibility and retrospective edits. Based on findings from Chapter 3, we remained three different sizes of buttons that represent the amount of food intake. Since meal logging is relatively frequent throughout the day, we provided a widget by which users can easily record a timestamp that can be a cue for later edit **(Figure 6.2)**. On the widget, a simple reminder that encourages users to add details is displayed, by placing a button on the widget that read *"Go to complete meal logging."*



식사 흔적을 남겨주세요!

정량 만큼 식사가 기록되었습니다

2016년 7월 20일 오전 10시 27분

식사 정량 먹었어요.

입력된 메뉴가 없습니다.

정량 먹었어요.

삼겹살

Figure 6.2: The widget design. User can capture the data at the moment and retrospectively edit the details of the data.

Help manage different types of data by thumbing through screens

This design enabled users to recognize different types of data as different things and manage them independently, while also enhancing the perception that all data is a common object of management **(Figure 6.3)**. Only one data was represented on each screen, and the background color of each data was distinguished to emphasize the difference. At the same time, I maintained the layout and structure at a similar level, and allowed users to swipe right to left, so that they could stream through the data without disturbing the common sense of data that needs to be monitored and managed. The order of the default data screen was arranged alternately between the automated track and the manual record, so as not to lose engagement, but to increase the degree of freedom, users could customize the order if they wanted to.

의료진 조언

지난 07월 07일 진료에서
[redacted]선생님의 조언입니다.

[redacted]선생님

식사

적절한 시각에 저녁을 드시네요. 지금처럼 19:00시 이전에 식사를 하도록 하세요.

목표 확인하기

지킴이 보드

생활습관 지키기 목표
현재까지 이만큼 달성했어요

39%

1끼 정량	3끼 정량
5836걸음	10000보
5시간 9분	7시간 0분
63.4kg	61.0kg

식사

오늘 목표 식사량 중
지금까지 이만큼 먹었습니다

1끼 정량

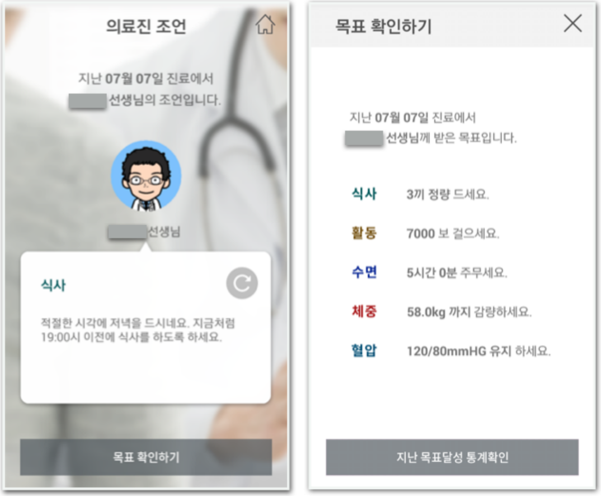
17%

식사를 기록하세요.

Figure 6.3: Horizontally allocated screens. Users can thumb through screens, which allows them to easily review various types of data.

Strongly show clinician's presence

The fact that this data collection took place in the medical context played a significant role in motivating users. This lead to the hypothesis that users would be better motivated if the doctors' presence was designed to appear in health tracking tools. Therefore, to remind the user of the medical context, three points were considered in the design. First, the 'clinician's advice' screen was designed and added independently. This screen was arranged in a different direction from other data screens, so that the user could regard the screen special (different from other screens) **(Figure 6.3)**. In addition, the user could immediately access this screen by swiping to the right, and the position was fixed. Second, the doctor's profile image was exposed to the front to enhance doctors' sense of presence. The profile image resembling the clinician and name were presented to make the connection between the clinical context and the service (application). Lastly, health advice consisting of comments and goals from the clinician was displayed with the synchronization with the EMR. This offered patients the perception of continuous caregiving from clinicians **(Figure 6.4)**.



지난 07월 07일 진료에서
[redacted]선생님의 조언입니다.

[redacted]선생님

식사

적절한 시각에 저녁을 드시네요. 지금처럼 19:00시 이전에 식사를 하도록 하세요.

지난 07월 07일 진료에서
[redacted]선생님께 받은 목표입니다.

식사	3끼 정량 드세요.
활동	7000 보 걸으세요.
수면	5시간 0분 주무세요.
체중	58.0kg 까지 감량하세요.
혈압	120/80mmHG 유지 하세요.

Figure 6.4: The view of clinician's advice. Users can see clinician's advice generated from EMR system and perceive the clinician's presence.

6.2.2 DataMD: Clinician Interface

As reported in Chapter 4, we designed DataMD and implemented it, tethering in the existing EMR **(Figure 6.5)**. Clinicians can prescribe goals for each data type. For example, the default goal for step count was initially set 10,000 but clinicians can adjust the goal during/after the medical consultation.

Figure 6.5: The final version of clinician interface, DataMD.

6.3 Study Design

We conducted a deployment study to investigate how the designed system including patient app, MyHealthKeeper, and the clinician interface, DataMD help patients and clinicians collaborate. This study was approved by the SNUBH Institutional Review Board (B-1504-296-302).

6.3.1 Participants

We conducted a prospective randomized clinical trial in 80 patients who visited the SNUBH outpatient clinic between the months of July and September 2016. We set the following inclusion criteria for enrollment in the trial: (1) patients who provided prior consent to complying with self-management, (2) patients without cardiopulmonary disease, cancer, or other acute diseases, and (3) patients with a body mass index (BMI) of over 23 kg/m^2 **(Figure 6.6)**.

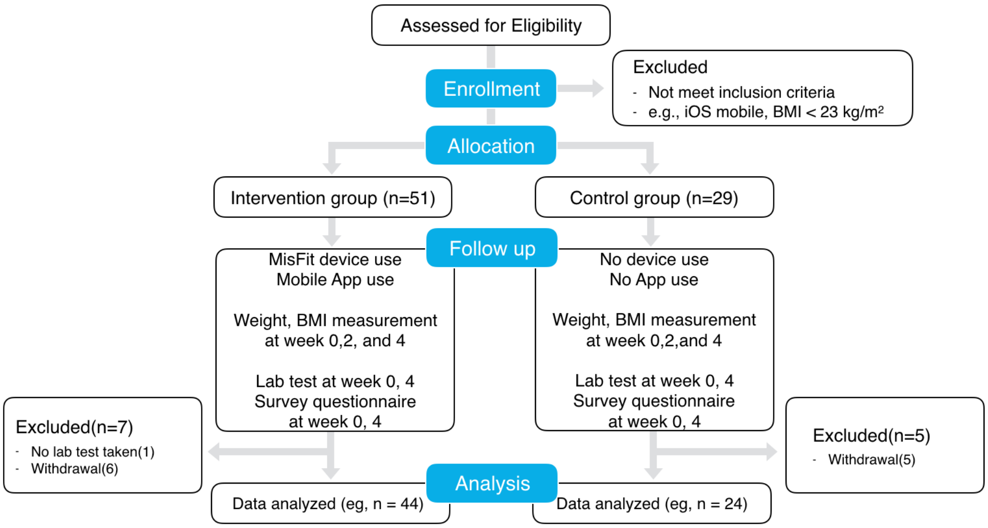


Figure 6.6: Overview of the study procedure.

We excluded patients who would not be able to use a mobile app and a wearable device and those who were pregnant. We obtained written informed consent from all participants. All study participants completed a paper-based survey, a laboratory blood test, a physical examination.

We partially conducted semi-structured interviews and observation of medical consultation for those who were willing to participate in. A total of 20 participants from the intervention group took part in interviews. A total of 24 participants (intervention group: 18; control group: 6) consented that we observed their consultations, and we ended up observing 32 cases (data-driven checkups: 26; normal checkups: 6).

6.3.2 Procedure

We aimed to evaluate whether and how the integrated system supports doctor-patient collaboration through this deployment study: (1) compare clinical outcomes between system-supported and not-supported collaboration groups; (2) examine adherence rate; and (3) investigate how workflow integration and in-depth conversation were supported. To this end, we randomly assigned enrollees to 2 groups: a system-supported collaboration group (intervention group) and a non-system-supported collaboration group (control group).

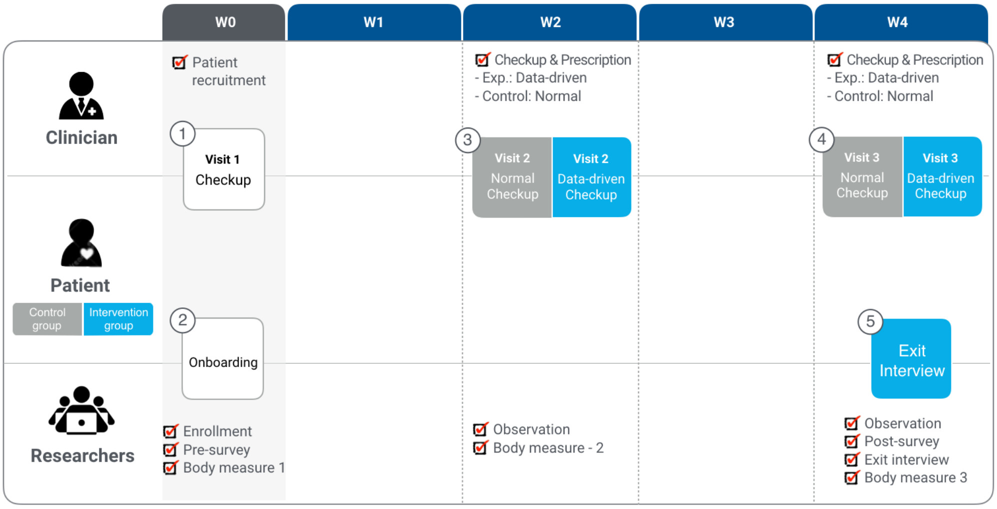


Figure 6.7: Overview of the study procedure.

The intervention group was provided the wearable device (Misfit), the patient app (MyHealthKeeper), and medical checkups based on PGHD. Participants were asked to collect six types of data (activity, meal, sleep, weight, stress, blood pressure) for four weeks. Individualized goals for diet and physical activity were prescribed for each participant by the clinician during a biweekly outpatient visit. During the visit, clinicians reviewed PGHD and discussed it with the patient by using DataMD. After the visit, the patient can see the clinician's advice synchronized with the inputs that the clinician made in the DataMD.

The control group of patients did not receive a system supported intervention, the wearable device, or the patient app. They received conventional care pertaining to lifestyle modification for achieving weight loss goals during the 4-week study period.

All participants completed the pre- and post-survey about their overall health condition and satisfaction of the care. Some participants consented to take part in the observation study and semi-structured interviews. Details are described in the following sub-sections.

Clinical Study Outcome Measure

The primary outcome measure of this clinical trial was weight change. Body weights before and after the clinical intervention were recorded and analyzed. We defined BMI as the body mass divided by the square of the body height, expressed in units of kg/m^2, and we analyzed the difference in BMI before and after the study at the end of the study period. We analyzed the secondary outcomes of the study—changes in blood biochemical parameters (cholesterol, triglycerides, high-density lipoprotein cholesterol, and low-density lipoprotein cholesterol)—for each participant. Any decrease in body weight during the study period (4 weeks) was defined as successful weight reduction. It is very important that the measurement be taken using the same method and in the same conditions to ensure uniformity between participants and in the same participant over time. In our study, a skilled nurse helped to measure the patient's body weight in the hospital health checkup center with the conventional health checkup process (place, dress). Fasting body weight was measured for laboratory checkup.

Observations

Among the recruited patients, we observed 26 checkups of 18 patients with their consent. Among the patients, eight of them visited twice in a month. Therefore, we could identify the change in the clinician's use of the interface with the same patient. In addition, we examined six cases without using our interface to compare and therefore identify the distinct role of the clinician interface, DataMD.

The office was equipped with several medical machines. Patients sat on the prepared chair **(Figure 6.8)**. A clinician and physician assistant (PA) were present in all cases. Researchers voice-recorded the conversations and counted the number of times the clinician and patient made eye contact, the clinician's interactions with the interface, and other nonverbal events.

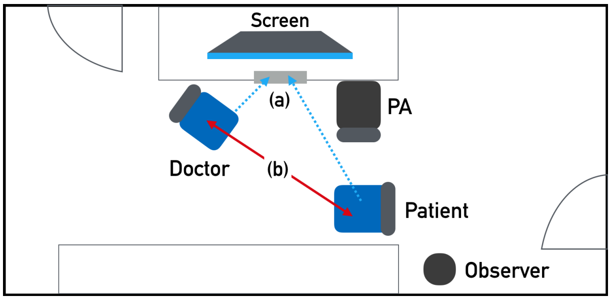


Figure 6.8: Layout of the observation site. The blue arrows (a) indicate line-of-sight if both patient and clinician want to. (b) infers an eye contact between patient and clinician.

Semi-Structured Interviews

The interview consisted of two parts. The first part was about the participants' experiences of the data-tracking application. Reviewing their usage logs that showed how often they launched the application and track each type of data, we investigated the patterns of and challenges in data tracking. Then, we inquired about the satisfaction of data-driven communication with a five-point Likert scale.

6.4 Data Analysis

We analyzed data in three ways: statistical analysis of clinical outcomes to validate behavior change; log analysis of app usage data to examine how patients and clinicians remotely collaborate; and qualitative analysis of observation data to investigate collaboration during the medical consultations.

6.4.1 Statistical Analysis of Clinical Outcomes

Results are presented as mean (SD). We analyzed differences in various parameters between the two groups using the chi-square test as appropriate. We used a paired t-test to examine changes in primary or secondary outcomes in the two groups. Statistical analyses were performed using IBM SPSS version 18.0 (IBM Corporation), and P<.05 was considered statistically significant.

6.4.2 App Usage Log

We collected activity and sleep logs automatically by the Fitbit and Misfit APIs and manual logs (meal, weight, stress, blood pressure) from the patient app (MyHealthKeeper). We analyzed the adherence rate of each data log. In the case of automatically collected logs, we calculated their "collection rate" by counting the days that had data input during the experiment. In the case of manual logs except for meal, we calculated the "journaling rate" by counting the days patients logged at least one more time. For meal data, we calculated the journal rate by counting the days patient logged meal data at least three more times, considering the usual frequency of eating. We also counted the frequency of views on the 'clinician's advice' and statistically analyzed it to find the relationship between the collection/ journaling rate and clinical outcomes. The statistical analyses were conducted by R studio.

6.4.3 Observation Data Analysis

After transcribing all the voice-recording files and collecting field notes, we conducted a thematic analysis [202] using a supporting tool named Reframer [?]. We aimed to explore the roles of the interface based on the initial perspective. Thereby, the transcription and field notes were coded according to the three essential requirements.

6.5 Results

The results are presented in three ways: (1) clinical outcomes to show patients' behavior change; (2) app usage log to examine adherence; and (3) observation results to evaluate workflow integration and communication support.

6.5.1 Behavior Change

We randomly assigned 80 participants to either the intervention group (n=51) or the control group (n=29). After exclusions and withdrawals **(Figure 6.7)**, 68 participants completed the study. **Table 6.1** and **Table 6.2** show the demographic and baseline characteristics of study participants.

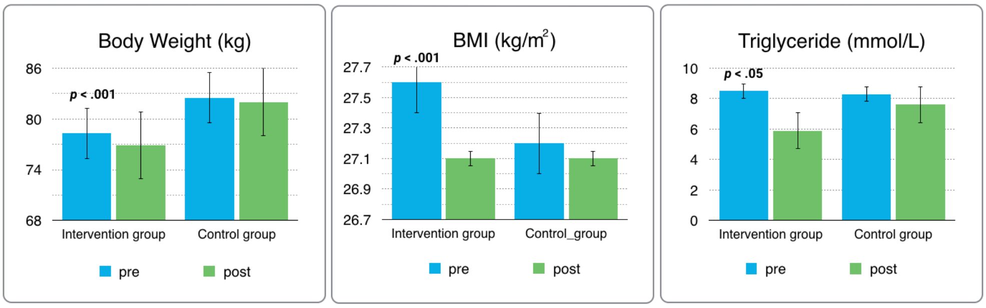


Figure 6.9: Changes in weight, body mass index (BMI), and triglycerides in the 2 groups before (pre) and after (post) the intervention. Error bars indicate 95% CI.

Only a few studies have attempted to integrate the self-monitoring sys-

Characteristics	**Intervention group** (n=44)	**Control group** (n=24)	**P value**
Age (years), mean (SD)	37.5 (8.7)	41.3 (11.2)	.30
Sex, n (%)			.68
Male	30 (68)	22 (92)	
Female	14 (32)	2 (8)	
Education level, n (%)			.64
High school degree	6 (14)	4 (17)	
College degree	32 (74)	15 (63)	
Master's or doctorate	5 (11)	5 (21)	
Occupation, n (%)			.13
Professional	10 (23)	7 (30)	
Office worker	15 (63)	10 (42)	
Self-employed	5 (11)	2 (8)	
Manufacturing or services	4 (9)	3 (13)	
Unemployed	10 (23)	1 (4)	
Living status, n (%)			0.60
Living with someone	37 (84)	23 (96)	
Living alone	7 (16)	1 (4)	
Marital status, n (%)			.30
Single	11 (25)	2 (8)	
Married	33 (75)	22 (92)	

Table 6.1: Demographic data of study participants (n=68).

Characteristics	**Intervention group** **Mean (SD)**	**Control group** **Mean (SD)**	**P value**
Weight (kg)	78.3 (11.8)	82.6 (8.4)	.13
Height (cm)	168.0 (8.7)	174.0 (8.0)	.01
BMI^a (kg/m^2)	27.6 (3.0)	27.3 (2.4)	.72
Cholesterol (mmol/L)	10.5 (1.8)	11.2 (1.9)	.12
HDL^b cholesterol (mmol/L)	2.8 (0.5)	2.8 (0.5)	.84
LDL^c cholesterol (mmol/L)	6.2 (1.3)	6.8 (1.5)	.07
Triglyceride (mmol/L)	8.5 (6.5)	8.2 (3.8)	.90

Table 6.2: Baseline clinical profiles of study participants. ^{a}BMI: body mass index. ^{b}HDL: high-density lipoprotein. ^{c}LDL: low-density lipoprotein.

Characteristics	**Prestudy value**	**Poststudy value**	**P value**
	Mean (SD)	Mean (SD)	
Weight (kg)			
Intervention group	78.3 (11.9)	76.9 (11.2)	<.001
Control group	82.5 (8.41)	82.0 (8.3)	<.05
BMI (kg/m^2)			
Intervention group	27.6 (3.0)	27.1 (2.8)	<.001
Control group	27.2 (2.4)	27.1 (2.4)	0.07
Cholesterol (mmol/L)			
Intervention group	10.5 (1.8)	10.4 (1.7)	0.61
Control group	11.2 (1.9)	11.3 (2.2)	0.79
HDL cholesterol (mmol/L)			
Intervention group	2.8 (0.5)	2.9 (0.5)	0.2
Control group	2.8 (0.7)	2.8 (0.5)	0.59
LDL cholesterol (mmol/L)			
Intervention group	6.2 (1.3)	6.3 (1.4)	0.67
Control group	6.8 (1.5)	6.9 (1.6)	0.92
Triglyceride (mmol/L)			
Intervention group	8.5 (6.5)	5.9 (3.0)	<.05
Control group	8.3 (3.8)	7.6 (3.8)	0.35

Table 6.3: Clinical profile changes in participants in the intervention (n=44) and control (n=24) groups.

tem into the existing EHR systems, which is called the EHR-tethered PHR system. A previous study examined the usability of an EHR-tethered PHR system tied in with patient clinical records, which functionally focused on finding an appointment time, reviewing test results, and managing medication dosages [226]. This study was performed as a Web-based patient portal use survey, including video-recorded post-study interviews for health management purposes, with a patient-centric viewpoint. Our study more focused on both patient and clinician experiences, with a fully integrated PHR module. Furthermore, we studied the impact of PHR-based clinical interventions on clinical profile changes in participants. Mishuris et al. [227] also studied PHR and EHR integration usability for clinical workflow design. They performed a qualitative study using two rounds of semi-structured interviews with primary care providers, health information software developers, and health care researchers. This study suggested a framework for how to integrate external data into provider workflow in an efficient and effective way. However, the researchers provided only a prototype design, not a complete implementation result.

Recently, several studies have been conducted on lifestyle intervention [228, 229, 230, 231, 232, 233]. A study protocol for a pragmatic randomized controlled trial for physical activity coaching in patients with the chronic obstructive pulmonary disorder, including management of the patient-centered daily activity, tracking of cardiovascular disease risk factors, and monitoring of the quality of life measures, was published. A different study used EHR data to evaluate a physician-developed lifestyle plan for obese patients in primary care [234, 232]. Simple lifestyle changes and dietary interventions were suggested in the plan, which was distributed to obese patients by a family physician as part of routine clinical care. This study reported significant weight loss in older men and a significant reduction in systolic blood pressure in all participants. Although the aim of the previous study and this work are the same, this work covers a broader context of a lifestyle intervention based on PGHD, including communication support and workflow integration.

6.5.2 Data-Collection & Journaling Rate

For automated tracking data, the average activity, sleep, weight data-collection were 59.8%, 79.6%, 25.3%, respectively. For the manual tracking data, food, stress, and blood pressure journaling rates were 39.5%, 55.0%, and 9.4%, respectively. Interestingly, the food journaling rate was higher than the automated tracking data-collection rate. This result is consistent with the prior work that suggests semi-automated tracking (mostly manual tracking) contributes self-awareness and engagement [60]. **Figure 6.10** also shows that participants sustained manual tracking data–meal and sleep satisfaction—longer (around until 80 days) than automated tracking data (35 days at maximum).

Data type	**Collection/Journaling Rate (%)**	
	Mean	*SD*
Step count	59.8	37.1
Sleep duration	79.6	35.1
Sleep score (satisfaction)	56.9	36.0
Meal	39.5	28.7
Weight	25.3	28.7
Stress	55.0	27,2
Blood pressure	9.4	21.4

Table 6.4: Average data collection/journaling rate of participants in the intervention group (n=44).

Figure 6.10: The data collecting patterns of 51 participants based on the app usage logs: step count, sleep, weight (automated-tracking data); meal, subjective sleep score, stress (manual tracking data). Blue dots represent total days from the enrollment date to the last date of the study. Gray dots display the maintaining period without intervention (after the study).

6.5.3 Workflow Integration & Communication Support

The results in this section report how collaboration supported by the system helped workflow integration and in-depth communication based on the observational sessions and patient interviews.

Helping clinicians make a new workflow

To our surprise, I observed that the physician created a new workflow around the interface. Three phases were identified: (1) skimming data, (2) asking questions, setting goals, and providing explanations, and (3) inputting goals.

The first step, skimming data, naturally integrated into the workflow. When the patient stepped into the medical office, the clinician engaged the patient in small talk and started using the interface to review self-logged data. When necessary, the clinician viewed lab reports or paper reports and briefly explained the results to the patient.

> **Doctor**: Did you do a good job?
>
> **Patient**: I tried, but I was on vacation, so I couldn't take a lot of walks.
>
> **Doctor**: (while looking at the EMR) Your cholesterol levels were high, but the numbers are even higher than usual. (switches windows, looks at the numerical summary on DataMD) I see you wore the device every day; that's good. You don't exercise, you eat two meals on an average day, and you sleep pretty well. You have to look after your weight; it is excessive. Mainly, you need to walk more.
>
> — Case no. 1 (sex: male, age: 43, visit 2, duration: 09:12)

The second phase was unique, because the clinician repeatedly asked questions, set goals, and provided explanations. After skimming information, the clinician asked for context, such as abnormal points or feelings. By doing so, the clinician set goals with the patient.

> **Doctor**: (while looking at the line graph on the meal component) Your meal patterns aren't dramatic. I mean the pattern hasn't really changed from before. (clicks on the snack tab) Oh, I see that you've been munching a lot. (looks at patient)
>
> **Patient**: Snacks... Yeah, I feel a bit guilty. Well, I ate a lot of snacks during vacation.
>
> **Doctor**: Oh, I see, during vacation. But besides that, you're doing good. (looks at the heat map in the meal component) What about keeping our goal as before? Or maybe we can cut down on the snacks a bit? (looks at patient)
>
> **Patient**: Good, I'll cut my snacks in half.
>
> — Case no. 14 (sex: male, age: 37, visit 3, duration: 02:21)

This process was repeated for each data type. However, goals were only set when the clinician decided that the patient needed behavior modification. By selectively setting goals, the clinician made effective use of the limited time.

During the third phase, the clinician did not type in the goals right away but waited until the end of the consultation and typed in all the goals at once, perhaps because typing during consultations would have hindered conversations with patients. This all-at-once behavior was possible, since the goals were simple numbers. The PA occasionally typed in comments in the EMR for the clinician. However, as for DataMD, the clinician took charge of setting goals and typing comments.

As a result, data reading and explaining integrated into the workflow as expected; however, goal setting did not. This conflict between DataMD and the existing EMR will be elaborated upon in the discussion section.

Improving Clinicians' Counseling Skills with Data

The clinician showed selective behavior with more experience with DataMD, which resulted in looking at the data he deemed important. This means that the clinician formed strategic approaches to read the data efficiently within a short period of time.

As the clinician's data-driven counseling skills improved, his overall strategy of using DataMD also changed. At first, he read the interface as intended by the designers. However, as time passed, he reduced the time spent on reading data and started to compare primary data and outcome data to interpret interrelations. The results of such interpretations were reflected in the goal setting.

> **Doctor**: (while looking at the line graph in the activity component) Your activity graph drops significantly (looking at the line graph in the food component), but your food intake is high. Not just the food intake, but I think you should start working out. That's why you're not losing weight. I think you should walk about 10,000 steps a day... (looks at the patient)
>
> — Case no. 23 (sex: male, age: 39, visit 3, duration: 03:04)

In addition, the data deemed important differed across patients. In the following case, the clinician interpreted high stress levels, along with changes in sleeping patterns, and recommended a medical test.

> **Doctor**: Are you going through a lot of stress lately?
>
> **Patient**: Yes, the company isn't going well these days.
>
> **Doctor**: I see that your sleep satisfaction scores are lower than before. Is it because of the stress?
>
> **Patient**: I can't sleep these days, because of the pressure. I'm too tense.
>
> **Doctor**: First of all... I think you should find a way to lower the stress. Maybe you can take some walks... (while looking at the snack graph in the meal component) But you have to stop eating at night. Let's wait and see how the polysomnography goes.
>
> — Case no. 13 (sex: male, age: 35, visit 3, duration: 02:37)

Data that was difficult to interpret, or which needed further experience, tended to be excluded. For instance, the trend summary was a relatively harder component to interpret. Therefore, the first two or three times, the clinician tried to read the trend summary graph as shown. However, after gaining experience, he excluded the trend summary graph and focused on interpreting other data. It implies that the clinician became skillful enough to manage his counseling time and select data content.

Facilitating In-depth Conversation

The DataMD interface supported and promoted doctor– patient communication within the medical office. The conversation naturally kicked off with the clinician asking the patient if they were logging data consistently. When the interface showed that the patient had diligently gathered data, the clinician would make eye contact with the patient and compliment them; otherwise, he would encourage them to do so.

> **Doctor**: (looking at the whole screen) Overall, you're doing a great job on collecting data. You've been doing especially great on logging your meals (makes eye contact with patient). Great, this is amazing. (looks back at the screen) But I can see a few days are empty.
>
> **Patient**: Oh, I was a bit busy during the weekend. It's difficult to log everything.
>
> — Case no. 5 (sex: male, age: 39, visit 3, duration: 03:06)

The DataMD interface became the center of attention, leading to the collaborative viewing of clinician and patient. Since the interface was on a fixed monitor screen, and the patient was sitting at a 45-degree angle (Figure 4), the interface was constantly viewable. The patients showed high interest in the fact that the doctor had reviewed the data that they had collected and actively asked questions.

> **Doctor**: You're the best patient I've seen so far. (looking at the heat map in the meal component) You started to deliberately eat less at night compared to before you came to the hospital, right?
>
> **Patient**: Yes, yes. How did you know? (looks at the DataMD screen) Can you tell?
>
> **Doctor**: Yes, can you see? The colors are different. (looks at the patient) We can see it at a glance, because the color fades. You did a great job at eating less.
>
> — Case no. 3 (sex: male, age: 37, visit 2, duration: 04:40)

The interesting point was that despite an additional screen (DataMD was used on top of the EMR), more eye contact was observed while using both systems compared to when the clinician only used the EMR. The clinician recursively asked patients questions, searched for new evidence, and tried to relate that to the medical values that appeared on the EMR. This shows that the use of an interface does not directly lead to less eye contact or human interaction. On the contrary, shorter appointments and less eye contact were observed in the existing workflow without DataMD. I also found that patients' responses were mostly short, such as yes/no, in the existing workflow. Therefore, it took longer to obtain the same context information (e.g., on vacations, lifestyle patterns). This result suggests that when appropriate data is shown, the doctor–patient relationship is enriched through increased eye contact and depth of conversation.

6.6 Limitations & Conclusion

There are several limitations to this study. Further research is to be conducted, as we found that data-driven consultation influenced both clinicians and patients. Future work will cover the patient's side. In addition, we did not observe various clinicians due to the lack of consent. Although the case study of one clinician with 32 cases provided several insights, it should be refined and enriched by other cases.

6.7 Summary of Chapter 6

This chapter provides an empirical understanding of how the system could support data-driven communication in terms of collaboration. The system including a patient app, MyHealthKeeper, and a clinician interface, DataMD was deployed in-situ clinical settings. Based on the randomized clinical control study with 80 outclinic patients, I found that the system-supported group (intervention group) succeeds in behavior change. Participants in the intervention group (n=44) showed better clinical outcomes (weight loss, decrease in cholesterol level) than the control group (n=24). Despite the low rate of data-collection and journaling rate, some participants showed remarkably higher collection rates, almost 100% except for blood pressure. Also, some participants sustained data tracking after the study period. Lastly, I found qualitative evidence of workflow integration and in-depth conversation promoted by the clinician interface, DataMD. Taken together, I expect that the findings in this chapter will offer insights for healthcare providers, designers, and HCI researchers to design a system to support collaboration via data.

Chapter 7

Discussion

Across the studies presented in this dissertation, I examined how to design technologies to supports doctor-patient communication mediated by data in healthcare services. Beginning with a series of empirical studies, I have designed an accessible button-based data tracking tool and a clinician interface suitable for clinical practices. Then, I conducted a deployment study and identify how doctors and patients collaborate and achieve behavior change in clinical contexts with those tools. Based on the findings of each chapter, I provide design principles to support data-driven communication and discuss opportunities for future work.

7.1 Towards a Design for Data-Driven Communication

This dissertation work provides unique design guidelines based on the implications of a series of studies.

7.1.1 Improve Data Quality for Clinical Applicability

Whereas usability is critical for the consistency of recording, the collected data should also be medically valuable, as the study in Chapter 3 shows. This predicament derives from the contradictory relationship between the two criteria: usability and usefulness. The validity of the collected data—which, in the case of food journaling, depends on how well the reports replicate actual intake—is the most important requirement of doctors. However, users find detailed reporting more arduous, since describing everything is labor-intensive. Therefore, doctors' attempts to obtain more accurate data may prevent them from obtaining any data at all. The opposite is also problematic, since oversimplified or invalid data is of no value, even if it is collected consistently. Thus, data collection by self-reported food journaling needs to balance user-friendliness and medical usefulness. "What kind of information?" and "How many times?" may be possible questions to ask to get closer to finding such a balance.

In the study of mFood Logger (Chapter 3), I focused on obtaining the simplest, yet meaningful, data to begin with so that we could collect a significant amount of data to explore its potential in a clinical context. That is why we focused on simplifying input and thereby lowering the burden of capture. In a wider sense, however, the possibility of enhancing usability not just by lowering the burden but also by helping users gain motivation is worthy of discussion. Increasing the perception of value and motivating users may be especially critical when they first start collecting data and therefore find it hard to generate any meaning from it. For instance, as more and more data was accumulated and especially after such data was used during medical checkups, patients showed higher tolerance to recording. Some patients even increased their burden of capture, because they were motivated by clinicians' comments. This shows that although usability and data usefulness may start off contradictory, the two can end up supporting one another after a certain balance is found.

Meanwhile, we should not overlook the fact that the usefulness of data in the clinical context also includes practical workflow issues. Even if the data is sufficient in size and high in credibility, such data cannot be used without considering the integration within the current workflow, system standardization, and visualization. A few additional issues were considered due to the site of the study (university hospital in South Korea): average medical checkup time being under five minutes, remote medical examinations being illegal, and EMR security issues. Similar issues, such as the medical laws of the applicable country and the degree of cooperation of field experts, should be checked beforehand, since these issues may also affect data accumulation and analysis. It is therefore important to conduct iterative field tests to collect and reflect requirements.

7.1.2 Support Accessibility of Data Collection

The study of mFood Logger showed that accessible data collection methods helped patients actively log their data over six weeks. Since most participants were elder people with low digital literacy, accessibility of logging data was considered more significant in this study. Indeed, many participants preferred a button-based logging interface, in that simple interaction was no hassle and easy enough to collect data every day. Consistent with the previous works [138, 68], the results imply that accessibility of data collection methods should be prioritized to support long-term data tracking when designing self-tracking tools. However, accessible methods are often too simple so that users sometimes lose their attention or forget to use the tool, as Chapter 3 and the prior work have reported [235]. I suggest that the issue can be addressed by leveraging ambient/explicit reminders and patients' attitudes towards doctors, incorporating findings from Chapter 3.

Provide Both Ambient and Obtrusive Reminders

In Chapter 3, one of the most important aspects of food journaling is reminding users to log. Previous studies have shown that forgetting often hinders consistent food journaling [67]. Therefore, many studies use notification reminders to support in-the-moment logging [65, 235]. This not only minimizes the possibility of forgetting but also builds self- awareness and supports behavior modification. The mFood Logger also used a reminder but selected an ambient reminder rather than a direct notification, as we were concerned that direct notification would increase stress or intensify passive attitudes. Therefore, by placing a small sticker on smartphones, we induced self-awareness.

Still, patients reported that they often forgot to record what they had eaten, which supported the findings of previous studies [67]. However, interestingly, patients often recalled their meals or snacks and recorded them later on when they saw the sticker. The log data shows that many entries were late. However, as mentioned, the journaling rate remained high, meaning that at some point, patients acknowledged that they had missed an entry and recorded their food intake retroactively.

Moreover, although not directly related to food journaling, some patients mentioned that the wearable devices acted as reminders to record. This is an interesting point that requires further investigation.

Leverage the Trusting Attitudes Towards Clinicians

The trusting attitudes that patients showed toward doctors' orders is another point worthy of discussion. The authority of the doctors positively influenced data collection. Patients' expectations that the doctors would review the reports turned food journaling into a sort of obligation. In Chapter 5, the average journaling rate of the 20 patients (81.04%) highly exceeded researchers' original estimates. Free text entries were also frequent, and some patients even made their input more detailed. This shows that the doctors served as both observers and motivators.

However, this alone cannot be considered an effective way of increasing data collection. The intervention of a clinician increased food-logging rates, but it simultaneously contributed to the formation of passive attitudes among patients. As for the doctors, correcting the behaviors of patients is their duty, and therefore, from that perspective, patients are expected to wait for their decisions to be made and recommendations to be given. This tendency may have appeared more strongly, since this study was conducted in an Asian culture country. According to Tanan et al., there exists a difference in the physician–patient relationship between America and Asia [236]. In Asian culture, the physician– patient relationship is more hierarchal and reciprocal rather than egalitarian and contractual. Moreover, patients within the Asian culture tend to show more respect and deference for physicians' authority and suggestions [236]. The doctor– patient relationship in Korea also shows similar aspects, and this may be an additional reason for the conforming attitudes witnessed during the field study. However, the authoritarianism of medical experts is not restricted to Asian cultures. Therefore, even if cultural issues are considered, the intervention of clinicians may still have affected the other-directed attitudes observed in our field study.

However, since building self-awareness is equally important in food journaling, absentminded, mechanical journaling should be avoided. Therefore, in the clinical context, challenges remain in terms of making patients more self-directed and self-aware. During the field study, patients initially showed other-directed attitudes, but after the first medical examination, the communication with doctors helped trigger self-directed attempts at sense making. Communication with doctors helped P15 become aware of his eating habits and improve them through self-regulation. Designers of healthcare technologies, including food journaling technologies, should consider the attitudes patients form in the clinical context.

7.1.3 Understand Clinicians' Preference for Familiar Data Representation

DataMD showed a specific case of design requirements in the research hospital located in South Korea, but I discuss some findings that can be generalizable for other contexts, considering situational constraints are similar in most hospital environments (e.g., lack of time).

Familiarity is the key to designing a clinician interface, in that clinicians do not want to change the existing practices and workflow due to the lack of time and information overload. Three design guidelines found in Chapter 4 reflect clinicians' preferences for sticking to the existing practices and legacy system (EHR). In the research hospital where the study was conducted, the current EHR displays a large amount of information at once on one large screen. Their requirements for conventional visualization are also based on preferences. Indeed, familiar visualizations improved the clinician's counseling skills. This still leaves some points on ways of visualizing the data open to discussion.

The graph with multiple trend lines, which was strongly suggested by clinicians, gradually became less used over consultations, because it required time and effort to read and interpret the data. It was explained that a similar graph containing many vital signs, such as blood pressure and body temperature, was currently in use, so reading a graph with six lines would not be a problem. This was, however, the least-used component. The gap between their expectations and actual use was caused by the unfamiliarity of PGHD [210, 237]. Clinicians have learned enough about vital signs in medical school and the hospital to be able to read patterns and discover unusual points without effort. In addition, vital signs do not fluctuate much from one individual to another, making them easy to identify. On the other hand, clinicians do not have enough knowledge of patterns represented in patient-generated data. PGHD changes dynamically, unlike vital signs, which increases the confusion in interpretation [65]. In short, this implies that the unique characteristics of PGHD should be identified through further study.

7.1.4 Embrace Lived Experience for Rich Data Interpretation

In Chapter 5, I realized that personal experiences were far more involved in shaping people's interests, assumptions, and data-interpretation strategies than

I had expected. As the perspective of lived experience has emphasized the felt aspects of personal tracking [88], participants sometimes relied more on anecdotal experience (i.e., it gave them a stronger impression) than on rational grounds. The first and second strategies **(Figure 5.3-A,B)** reveal that people actively tried to find evidence to preserve their assumptions. They shared stories related to data as proof of assumptions and became more interested in their data. This is in line with findings of prior work that self-trackers evoked their past experience to explain some of their data points [96]. This implies that people's assumptions lead them to actively engage with data but, at the same time, to maintain their assumptions.

On the other hand, in many cases of adopting the third strategy **(Figure 5.3-C)**, they found something unexpected from the data in which they had not previously shown interest. This strategy, discovering new insights from collected data, corresponds with the scope of previous work [96]. Regarding the sleep and weight data that one participant was not very confident in interpreting, he said, *"I haven't thought about the relationship between these two, but it seems interesting. Sleep time and weight loss appear to be connected."* This implies that even if people's engagement is low, it might make them more open-minded about the results.

Participants were also sometimes overwhelmed by data that seemed objective. The fourth strategy **(Figure 5.3-D)** implies that people might be more drawn to the data than their assumptions. Participants were sometimes less confident, referring to *"objectivity"*, *"statistics"*, and *"graph"*. In a similar vein, Lupton introduced a story of a self-tracker whose feelings were constructed by his data [33]. Diverse personal experiences that cannot be generalized are often considered a confusing factor to be eliminated or controlled to analyze data in an impartial manner, but completely separating personal experiences from data interpretation might drag people into focusing on meaningless numbers.

Regardless of whether people adopt a strategy, there is a tension between lived experience and data interpretation. Beliefs based on personal experience that appear to be biased might be right in a certain personal context. Hidden narratives that go beyond data can strongly empower people to take action to protect their health. Simultaneously, there is an undeniable risk of human bias, such as confirmation bias [221] and apophenia [222]. In the context of personal health tracking, I should take this issue seriously, as even a low possibility of risk cannot be allowed in this area. However, I still cannot judge which (data interpretation or lived experience) is less or more dangerous. I do not argue that data interpretation should always be accompanied by lived experience and vice versa. Rather, I insist that I redefine the role of design surrounding data interpretation. I think that the role of design is to pose questions to make people think about their data rather than giving exact answers from their data. By doing so, people can find new problems and explore more possibilities, which will lead to various approaches to the data.

Although previous works have attempted to link people's lives with the analytical approach, there are still various aspects of the world that are not easily converted into a testable form [94, 183, 182]. Supporting such findings, our findings also revealed that an individual participant's interests and assumptions continuously change as they go through various experiences. Furthermore, it was hard to find a universal pattern of changing interest in data types across participants. These findings show that it is not easy to unify or manipulate individuals' dynamic interests and assumptions due to their complexity.

To integrate lived experience and the analytical approach, I need to determine how to systemically translate people's everyday lives into testable hypotheses without losing personal context. Findings of Chapter 5 can serve as a starting point. I found that participants usually took the linguistic ambiguity for granted. They often forgot that some expressions are only clear in their own contexts when making assumptions about data relationships. As noted above in the Chapter 5, some phrases, such as *"irregular eating"* and *"a sudden change in weight,"* can have various dimensions. This linguistic ambiguity can be challenging not only in the analytical approach but also in the design that facilitates the interpretative approach. A similar issue has been found in previous works; that is, people usually want to make hypotheses in their everyday language even though the hypotheses should be operationally defined [94, 182].

Such a challenge suggests some avenues for future study. First, it is necessary to investigate and clarify the ambiguity in the used expressions when people pose questions about their data. Despite the domain difference, I can refer to the recent study examining the linguistic ambiguity in time expressions [238]. Second, I can design and evaluate an interactive interface or system through which users can clarify their interests and convert them into testable hypotheses. Although previous studies have already discussed a similar idea of a systematic wizard that assists in eliciting variables and effect size [94, 182], I need to empirically examine whether designed systems or interfaces can help people easily make hypotheses without the fatigue caused by many steps. This is not only an easy way to run clear analyses, but it can also lead users to learn more about their data. Because there are obvious advantages to leveraging the analytical approach, such as statistics, I suggest studying ways of translating everyday expressions into more manipulatable variables.

I suggest some specific design guidelines to take advantage of findings in Chapter 5. The important thing is to help people realize that there are various possibilities:

- Start with learning about a user's current interests and assumptions by providing a diverse set of phrases presented in everyday language in the form of hypotheses with various structures. Users can easily elicit their options with options and even create their own variables inspired by the provided options. During this process, a system could converse with a user to articulate and clarify the meaning of variables and the effect size. I suggest that this process be included in self-experimentation tools as well as visual exploration tools to reflect a user's context.

- Ask about their insights and compare them with their initial assumptions to reveal the strategy a user adopts to bridge a gap. If a user interacts with visual feedback (e.g., zooming out of/in on graphs) or numbers (e.g., checking details) on his/her personal informatics tool, the system could ask the user what insights s/he found based on the related initial assumptions. The types of insights can be listed by using the categories of prior work [96]. Then, the system could analyze the strategy the user utilizes when reviewing specific data types based on the user's responses. This result could be used for the next design implication.

- Help users diversify data-interpretation strategies by posing questions to encourage a user to utilize unused strategies. Designers and developers could design a system to generate questions to prompt users to utilize specific strategies. For example, it could ask, “What evidence do you suggest?” or “Do you think there is enough data to make a judgment?” This could help users engage more with their data and learn about the possibilities of their data.

7.1.5 Prioritize Workflow Integration for Successful Data-Driven Communication

Our main objective was to design and explore the role of a comprehensive interface that connects data-driven consultation to existing workflows. In the process, we discovered that tensions surrounding workflow integration still remain. Even though a time-crunched clinician unfamiliar with patient-generated data was able to review many patients’ data easily via the uniform interface, we found conflict between the new and old systems. We could not completely prevent the new interface from clashing with the existing system. For example, entering comments into the EMR and setting goals are similar tasks, yet they were separated in our implementation due to the differences in the reliability and completeness of lab data and patient- generated data. There has not been a proven correlation between patient-logged data and diseases, which makes patient-generated data less reliable [81, 213, 192]. In addition, clinicians chose not to view the two data types in the same window for the same reasons. In these circumstances, presenting patient-generated data with medically proven lab data may cause confusion among clinicians.

In short, this issue cannot be solved solely by designing an interface; rather, it requires collaboration among experts in both the medical and HCI fields. HCI researchers and medical experts can investigate whether patients' health could be improved by using patient-generated data. In this sense, the DataMD interface was designed to connect patients and clinicians like a translator. Specifically, the numeric input fields for setting goals can promote communication between patients and doctors. While setting goals, clinicians would acquire a deeper understanding of their patients' behaviors and thoughts. Adjusting and setting goals can affecte both clinicians and patients. Patients can explain their status and expressed their opinions to adjust the goals, which motivates patients to achieve them [237, 212, 158, 239].

This aspect of the design of DataMD provides several ideas for further research. First, the way in which patients are influenced by exam-room goal adjustments should be investigated. A one-sided order process, as in a conventional medical practice, can make patients too dependent on clinicians' instructions [84, 199]. Patients should be experts on their data and be able to adjust goals and change their habits independently [199]. Increasing goal type flexibility is strongly recommended to encourage patients to actively express their preferences and interest in their data. For example, the current goal of activity is only represented by steps, so patients cannot reflect their preferences, such as for swimming or cycling. It reduces not only patient interest but also their effort to adjust goals. Therefore, HCI researchers have to support both clinicians and patients by designing flexible clinician interfaces and self-tracking tools that promote in-depth conversations [198].

Second, it is necessary to consider how the adjusted goal in the exam room would be delivered to patients. We designed DataMD, where clinicians can simply enter numbers to set goals without wasting time. Conveying goals via numbers is much more precise and reliable, whereas natural language is much more expressive and easier to understand [65]. Both methods have trade-offs. Thus, patients' perceptions of, and preference for, the interaction type should be examined.

7.1.6 Consider Risks of Using Patient-Generated Health Data in Clinical Settings

In Chapter 6, the clinician could understand patients' status and provide advice to them through our interface, DataMD. However, there are several ethical issues that cannot be ignored. The typical problem is the risk of data misinterpretation, which can cause clinicians to endanger patients unwittingly. No correlations have been identified between certain diseases or symptoms and patient- generated data. It means that although clinicians carefully analyze and interpret patient-generated data, there is always a risk of making an erroneous decision. Therefore, both the technology and hospital policies should provide a safety net to lower that risk. For example, on the technology side, inventing algorithms to avoid mistakes could be a solution. On the hospital policy side, hiring experts on analyzing patient-generated data or educating nurses and PAs could prevent clinicians from making mistakes.

Another problem is the side effects of managing health via data. Patients might focus on just collecting data even if they continue to engage in unhealthy behaviors, because clinicians judge patients' status based on the data alone. For example, some patients could skip meals for convenience rather than eating healthy food. Clinicians should consider this kind of risk and encourage patients to talk about their difficulties with changing behaviors. Providing personalized recommendations also encourages patients to engage in healthy behaviors. Further research needs to investigate possible factors affecting patients' attitudes, such as clinicians' usage of data and changes in prognosis.

7.2 Opportunities for future work

Based on the lessons learned from a series of empirical studies, I suggest future opportunities from technological advances; summarize avenues for future research; and discuss cultural considerations for data-driven communication.

7.2.1 Leverage Ubiquitous Technology to Design Data Collection Tools

We are witnessing the remarkable development in mobile and healthcare technology, and it appears to be continued for a while [240]. These advances in technology offer us some possibilities and future research directions for data-driven communications.

The study covered in Chapter 3 was conducted five years ago, 2014, and unlike then, there have been a lot of changes such as data capture feasibility, data accuracy due to the advances of new devices and algorithms. In Chapter 3, I identified the feasibility of an accessible data collection tool, but also learned accessibility is a tradeoff between data accuracy. Rapid advances in healthcare technology can offset the tradeoff and provide opportunities to achieve data capture accessibility, accuracy, and validity at the same time.

Sensing technology continues to evolve over the years, and the algorithms become more sophisticated as data keeps being accumulated and analyzed. Indeed, the growth and enthusiasm in AI technology, including deep learning, enables us to collect data that we have not been able to capture before [139, 241, 242], or improve data accuracy [242, 243]. Some studies have already revealed techniques to improve accuracy in tracking activity through machine learning [243, 244]. Recent studies are further concerned with analyzing the vast amounts of data accumulated so far to predict the type of activity an individual is doing [241]. In addition, as already mentioned, there is a constant emergence of technologies that collect physiological data such as blood pressure and respiratory rate through a variety of wearable technologies like glasses, rings, and watches. In addition, attempts to measure PGHD without wearable devices through true ubiquitous technology are being implemented through deep learning. The recent research by Hsu et. al. analyzes spatial signals to track user movement and heart rate [241]. Adib et al. have demonstrated that Vital-Radio, a wireless sensing technology that monitors breathing and heart rate without body contact based on a machine learning technique [242]. As such, the potential for data capture technology is continuously increasing. Besides, these technologies are even rapidly commercialized and available for users at low prices. For instance, Apple's ECG capture technology is reliable enough in validity and reliance to be FDA approved [245].

In addition to sensing technology, data collection is becoming more accessible from the user perspective. Advances in vision recognition technology and speech processing allow analyzing unstructured data, which had not been possible to analyze before. For example, a photo-based tracking method often used for food journaling is user-friendly but has been criticized due to its difficulties in the data processing, which hinders providers from efficiently using them. However, the rapid development of vision recognition technology now allows extracting data such as menus and nutrition information from photos [246, 247]. In addition, the proliferation of conversational technology such as smart speakers and chatbots also enables to track data through natural language. For example, the Nutritionix application uses Alexa's skills to help users track their meals naturally through conversations with speech recognition [248]. In this context, the next step in the HCI community regarding the collection of PGHD will be how to combine these latest technologies to assist in data collection in any particular situation.

This advancement in AI technology and sensing technology makes it possible for users to collect more and more types of data more often and more easily, and thus increases the interest in researching data standards and health data platform integration. As each device and algorithm collects and utilizes data individually, ironically, data is stored in silos. In a recent study with me and my colleagues, we found that different apps and sensors store data according to their individual schemas, rather than following any kind of standardized manner [136]. There are ongoing discussions about PGHD and standards in related domains, and HCI communities will need to consider how much users can access the data—data granularity, how they can access—data access method, and how they can set permissions for the data they create and store based on those standards.

7.2.2 Provide Data-Interpretation Guidelines for People with Different Levels of Literacy and Goals

As technology advances and new data is acquired through new devices, difficulties arise in data representation and interpretation. This is not just a visualization problem. For example, diabetics typically measure glucose data at certain frequencies and at specific times, which is an indicator of their current status. The novel wearable sensor named GoBe developed by Healbe, Inc. claims that they can continuously track glucose data through impedance sensors [249]. However, challenges still remain. Visualizing and interpreting such kind of data is unfamiliar and confusing for many people. Also, since clinical validity has not been identified, there are still avenues to further investigate.

The challenges in interpreting new types of data are not limited to laypeople. As described in Chapter 4, even healthcare experts are confused, or sometimes overwhelmed with that unfamiliar data. No one has been trained to interpret such data, unlike healthcare experts are intensively educated to read and write the conventional data. Furthermore, it is not clear if it is correct to statistically analyze such data because it is collected from not controlled conditions [138]. As a result, statistical significance cannot be determined. Indeed, as Bentley et al. identified, there are no universally applicable data interpretation guidelines for such data [65]. Although ONC provides general guidelines on how to perceive PGHD [250], they do not suggest clinical evidence of how to interpret relationships between various types of PGHD. As an alternative, the N-of-1 trial method, in that PGHD is inherently individual.

The logical next step left for the HCI community, as suggested in Chapter 5, is to design a tool to help the n-of-1 trial in an easier way. While the N-of-1 trial facilitates interpretation, it is known that laypeople are not able to form testable hypotheses and stick to the rigorous procedure [251, 71, 184]. Moreover, since statistical interpretation still includes the possibility of errors, arbitrarily interpreting data and changing behavior without essential knowledge might harm their health. Therefore, designing user-friendly tools that promote n-of-1 trial and self-reflection is the HCI's next challenge with respect to PGHD representation and interpretation.

In addition to patients with low literacy, there are various stakeholders who are likely to review PGHD in the clinic, such as nurses or medical practitioners. They might have the expertise for regimen or care treatment but not for PGHD. As medical treatment usually is the collaborative process where all of those stakeholders take part in, it is necessary to examine those other experts' requirements and reflect them into the design. This dissertation work covers only specific medical experts, clinicians, and thereby future work should consider a broad range of medical experts who review PGHD, and also design adaptive interfaces which the experts can use depending on their situations and needs.

7.2.3 Consider Cultural Differences in Data-Driven Communication

Healthcare services are culturally constructed in many ways—legal constraints, doctor-patient relationship, medical practices, healthcare insurance system. Many related studies conducted in the U.S. [38, 56, 47] are often not applicable to other countries due to the cultural differences and conditions [41, 40]. In particular, in South Korea where this dissertation work was conducted, telemonitoring is illegal, which hinders from utilizing PGHD in practices [252]. In

Korea, telemedicine is still controversy.

Such institutional constraints cause big differences in practices. Commonly reported issues such as lack of time and information overload of clinicians are also known for obstacles to using PGHD, as reported in Chapter 3, 4, and 6. In South Korea, the issue is the same but more extreme. In the U.S., the counseling time is usually around 20 minutes, and many studies have reported it is "very short" to use PGHD [38, 13]. In South Korea, the average consultation time is less than 3 minutes. This is a critical issue and related to quality care but it is impossible for an individual clinician to address because this issue is connected to the national insurance system. In this situation, utilizing PGHD must be extremely difficult. In this sense, the interface proposed in Chapter 4, DataMD might be the result of cultural influence. This means that the results should be carefully applied to other contexts. However, despite its limitations, there are repeated themes observed in the literature across various cultures, such as familiarity and efficiency. Therefore, future studies need to investigate general guidelines for data representation.

In a broad sense, the essence of data-driven communication is the conversation that occurs between doctors and patients, which is inherently influenced by the culture. In Chapter 3, we observed a higher data-collection/journaling rate. It is because of cultural influence, according to the literature [137]. As previous research has shown, doctor-patient relationships in Asian and American cultures differ in terms of the power structure, expectations in a relationship, clinician's role, and patient's role [137]. As also shown in Chapter 3 and 6, patients in Asian cultures perceive their relationship with their doctors vertically as if they were a teacher-student. These differences in relationships can have a significant impact on how the tool should be designed. For example, as described in Chapter 6, adding a view of ’clinician’s advice’ strengthens the clinician’s presence and keeps reminding of clinical contexts, which can be more effective in Asian cultures.

Chapter 8

Conclusion

Across the studies presented in this dissertation, I investigated how to design technologies to support data-driven communication by using PGHD over four design spaces. Beginning with two empirical studies to design artifacts that can help both patients and clinicians share and utilize PGHD in the clinical setting, I have investigated what strategies patients adopted to interpret PGHD based on the artifact. Based on insights obtained from those studies, I finally conducted a deployment study to examine how the system could support doctor-patient collaboration mediated by PGHD in terms of behavior change, adherence, and workflow integration and conversation support. In this chapter, I summarize contributions I offer in this dissertation and areas of future exploration; and then close with concluding remarks.

8.1 Summary of Contributions

The core contribution of this dissertation work is an in-depth understanding of data-driven communication in healthcare services.

Empirical research contributions

In each study in this dissertation, I used empirical methods to address research questions. I used deployed the designed tools that support the whole process of data-driven communication. I also used interviews and observations to generate a deeper understanding of patients and clinicians interpret data representation and collaborate with each other through data. From the results of studies, I derived design guidelines for data-driven communication.

Artifacts contributions

I iteratively designed, developed, and evaluated the system that consists of the patient's data-tracking application and clinician interface. The designed clinician interface makes a novel contribution because the actual clinician interface for the PGHD use had not been fully implemented prior to this despite the growth and enthusiasm on this topic. Designs of data-tracking applications for patients also make a unique contribution as findings from this research were reflected in the actual Personal Health Record (PHR) system in the hospital.

Theoretical contributions

I have identified the concept and constructs of data-driven communication to lay the groundwork for building new theory in this space. Also, this dissertation research includes theoretical implications based on empirical findings to extend existing theory. By conceptualizing data-driven communication from the perspective of HCI, this research extends the use of PGHD to a part of the communication process.

8.2 Future Directions

Investigation of how the design can support data-driven communication provides significant opportunities for both the HCI and health communities. There still are several areas that need to be examined further.

First, mFood Logger showed a way to engage patients in tracking various types of PGHD in an accessible and sustainable way and how to reflect clinicians' requirements for clinical applicability of PGHD. The next logical step would be to extend and generalize the findings by conducting a longitudinal study, as well as integrating novel technology of data tracking in practical and clinically applicable ways. Although there are several studies on tracking PGHD in the HCI field, many of them have been conducted in a relatively short period. There was an interesting point from which future work can start. A few of our participants in Chapter 6 paused data tracking for two months but resumed the tracking later, which supports the lived informatics model that explains people are on the loop of start-pause-resume of tracking. This implies that more work is needed in terms of sustainable data tracking.

Second, DataMD was designed based on the results from the participatory design process and showed its feasibility and validity in the actual clinics. However, the design guidelines should be elaborated, considering it reflected only a specific context. As discussed in Chapter 7, since clinical practices are culturally constructed, design requirements can vary depending on different situations and cultures. However, the previous work supports that efficiency, familiarity, and learnability are the key aspects in clinical settings regardless of cultures or geographies. This draws us to the direction of diverse case studies and a meta-analysis to incorporate separated findings.

Lastly, the ultimate goal of the system supporting patient-doctor communication is two-fold: (1) to convey PGHD from patients to clinicians; and (2) to translate conventional clinical data from clinicians' side to patients' side. This dissertation work focused on the former, as investigating an accessible way to present clinical data was beyond the scope of this work. However, it is necessary to incorporate two different types of health data to improve patient–doctor communication. There are many studies on how to visualize health information for patients or give access to their health data via PHR systems. Future work should explore how these previous studies can be integrated into the findings of this work.

8.3 Final Remarks

There have been ample research opportunities for utilizing PGHD in healthcare services since the start of this dissertation work. Now, the discussion becomes mature enough to use PGHD in the actual clinic. This dissertation work lays the cornerstone of understanding current and future practices of utilizing PGHD as well as designing novel systems to improve patient–doctor communication. Although this work mainly focuses on designing a system to support patient–doctor communication via data, I believe that the findings from this work can be extended to different types of communication in other domains where customer-generated data emerges. For example, communication between students and teachers can be mediated by data generated from the learning process (e.g., test score, self-tracked progress). Or bank customers can ask their financial consultant to review budget/expenditure data that the individual bank customer tracked. All these types of communication can be data-driven, which needs appropriate systems for various stakeholders with different data requirements. Therefore, the findings of this dissertation work can be used to broaden the understanding of the HCI and healthcare communities, and communication studies.

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초 록

스마트폰과 웨어러블 기기의 보급으로 인해 환자 생성 건강 데이터(Patient-Generated Health Data; PGHD)가 크게 증가하였고, 이는 의사-환자 의사 소통을 개선하여 데이터 중심으로 발전 할 수있는 새로운 기회를 제공했다. PGHD를 사용한 데이터 중심 커뮤니케이션을 통해 환자와 의사는 기존 임상 데이터를 보완하여 이해의 차이를 메울 수 있으며, 환자 건강에 대한 포괄적인 관점도 획득할 수 있다. 그러나, 이러한 새로운 유형의 데이터와 기술을 기존 의료 커뮤니케이션에 통합하는 데에는 여전히 어려움이 남아 있다. 환자는 종종 데이터 수집에 대한 참여와 동기를 잃어버리며, 이에 따라 수집한 데이터는 불완전해지는 문제가 발생한다. 또한 PGHD가 온전하게 수집 되더라도 의사와 환자는 의료 관행에서 이러한 데이터를 활용하는 데 어려움을 겪게 된다. 또한, 시간과 정보의 부족으로 인해 현재 워크 플로우에서 환자와 의사 모두가 PGHD를 통해 협업하는 것은 매우 어려운 일로 알려져 있다. HCI 연구 관점에서, PGHD를 활용 한 데이터 중심 통신을 지원하는 시스템을 설계하면 이러한 과제를 해결할 수 있는 잠재력이 있으며, 이는 데이터 수집(collection), 표현(representation), 해석(interpretation) 및 협업(collaboration)의 네 가지 설계 공간(design space)에서 추가적인 탐색을 요구한다. 따라서, 이 논문에서는 시스템 설계 및 현장 배포 연구를 수행하여, 각 설계 공간에서 해결되지 않은 질문을 탐색하고 경험적 연구 결과 및 설계 지침을 제공하는 것을 목표로 한다.

먼저, 데이터 수집에 대한 설계 공간의 연구로서, 접근성 높은 데이터 추적 도구가 환자가 다양한 유형의 PGHD, 특히 식사 데이터를 수집하는 데 어떤 도움을 줄 수 있는지에 대해 연구하고자 하였다. 이를 위해, 접근성 높은 데이터 추적 도구인 mFood Logger을 디자인한 후, 20 명의 환자와 6 명의 임상의를 대상으로 실증적

연구를 수행했다. 그 결과, 환자와 임상의가 데이터 기반 커뮤니케이션을 위해 원하는 데이터 유형이 무엇인지 파악할 수 있었고, 임상적 맥락에서 데이터를 수집 할 때의 난점과 기회를 발견했다.

둘째, 임상의를 위한 데이터 표현을 파악하기 위해, 18명의 다양한 이해 관계자(e.g., 임상의, EMR 개발자)와 참여적 디자인(participatory design) 프로세스를 통해 PGHD를 표시하는 DataMD를 설계하고 구현했다. 참여적 디자인 워크샵을 통해 알아낸 것은, 의료적 상황의 제약 때문에 임상의가 원하는 데이터 표현 방식이 효율성과 친숙함으로 수렴된다는 점이었다. 임상의는 학습에 걸리는 시간 문제로 인해 새로운 시각화 방법을 사용하지 않았고, 한 번에 많은 양의 데이터를 보고 싶어했다. 이러한 요구 사항을 고려하여, 다양한 유형의 PGHD가 한 눈에 보여지며, 여러 가지 임상 상황을 고려한, DataMD를 설계하고 구현했다.

셋째, 데이터 기반 커뮤니케이션의 중요한 측면으로서, 환자를 위한 데이터 해석 전략을 제시하여 효과적인 데이터 해석을 돕는 설계 지침을 제공합니다. 20명의 만성 질환 환자와의 인터뷰를 통해, 환자들이 PGHD를 해석할 때, 논리적 증거가 아닌 자신의 과거 경험에 강하게 의존한다는 점을 밝혀냈다. 환자들은 자신의 신념과 경험에 따라 여러 데이터 사이의 관계를 가정하며, 이를 확인하기 위해 네 가지의 데이터 해석 전략을 구사했다. 이러한 이해는 설계자와 연구원이 데이터 해석을 지원하는 시스템 설계를 발전시키는 데 도움이 될 수 있다.

마지막으로, 데이터를 통한 협업을 지원하기 위해 앞선 연구에서 디자인한 시스템을 기반으로 PGHD를 공유하고 활용함으로써, 임상의와 환자가 어떻게 협업하는지를 조사하고자 했다. 환자의 데이터 수집 및 해석을 돕는 앱인 MyHealthKeeper와 임상의를 위한 인터페이스인 DataMD로 구성된 통합 시스템을 임상 현장에 배포했다. 80명의 외래환자와의 임상시험 결과에 따르면 PGHD를 통한 협력으로 환자가 행동 변화에 성공할 수있었다. 또한, 앱 사용 로그에 따르면 환자는 직접적인 상호 작용 없이도 임상의와 원격으로 협업 할 수도 있는 것으로 나타났다. 이러한

결과를 바탕으로, 이 연구에서는 임상의와 환자 사이의 협력을 지원할 수있는 주요 기회가 기존 임상 워크플로우에 PGHD 사용을 통합하는 것에 있음을 제시한다.

앞선 연구들을 통해, 데이터 기반 커뮤니케이션을 위한 디자인이 환자와 의사가 PGHD를 통해 협업하는 데 도움이 될 수 있음을 발견했다. PGHD가 네 개의 설계 공간 내에서 기존 의사-환자 통신을 데이터 중심 통신으로 개선 할 수있는 방법을 개념화함으로써, 이 연구는 환자와 의사 간의 데이터 기반 커뮤니케이션을 위한 디자인이 어떻게 도출되어야 하는지에 대한 새로운 시각을 제공할 것으로 기대한다. 이 작업은 HCI, CSCW과 건강 정보학 커뮤니티의 경험적 이해를 높이고, 실용적인 설계 지침을 제공하며, 이론적 확장에 기여한다. 또한, 이 연구는 향후 다른 분야에서 데이터 기반 커뮤니케이션을 지원하는 시스템의 설계가 어떻게 이뤄져야 하는지에 대한 기초를 제공한다.

주요어: 데이터 기반 커뮤니케이션; 환자-의사 커뮤니케이션; 환자 생성 건강 데이터; 헬스케어 서비스; 디자인 연구; 인간-컴퓨터 상호작용

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