

© Copyright 2018

Chia-Fang Chung

Using Personal Informatics Data in Collaboration  
among People with Different Expertise

Chia-Fang Chung

A dissertation

submitted in partial fulfillment of the  
requirements for the degree of

Doctor of Philosophy

University of Washington

2018

Reading Committee:

Sean Munson, Chair

James Fogarty

Julie Kientz

Program Authorized to Offer Degree:

Human Centered Design & Engineering

University of Washington

**Abstract**

**Using Personal Informatics Data in Collaboration among People with Different Expertise**

Chia-Fang Chung

Chair of the Supervisory Committee:  
Sean Munson  
Human Centered Design & Engineering

Many people collect and analyze data about themselves to improve their health and wellbeing. With the prevalence of smartphones and wearable sensors, people are able to collect detailed and complex data about their everyday behaviors, such as diet, exercise, and sleep. This everyday behavioral data can support individual health goals, help manage health conditions, and complement traditional medical examinations conducted in clinical visits. However, people often need support to interpret this self-tracked data. For example, many people share their data with health experts, hoping to use this data to support more personalized diagnosis and recommendations as well as to receive emotional support. However, when attempting to use this data in collaborations, people and their health experts often struggle to make sense of the data.

My dissertation examines how to support collaborations between individuals and health experts using personal informatics data. My research builds an empirical understanding of individual and

collaboration goals around using personal informatics data, current practices of using this data to support collaboration, and challenges and expectations for integrating the use of this data into clinical workflows. These understandings help designers and researchers advance the design of personal informatics systems as well as the theoretical understandings of patient-provider collaboration.

Based on my formative work, I propose design and theoretical considerations regarding interactions between individuals and health experts mediated by personal informatics data. System designers and personal informatics researchers need to consider collaborations occurred throughout the personal tracking process. Patient-provider collaboration might influence individual decisions to track and to review, and systems supporting this collaboration need to consider individual and collaborative goals as well as support communication around these goals. Designers and researchers should also attend to individual privacy needs when personal informatics data is shared and used across different healthcare contexts.

With these design guidelines in mind, I design and develop Foodprint, a photo-based food diary and visualization system. I also conduct field evaluations to understand the use of lightweight data collection and integration to support collaboration around personal informatics data.

Findings from these field deployments indicate that photo-based visualizations allow both participants and health experts to easily understand eating patterns relevant to individual health goals. Participants and health experts can then focus on individual health goals and questions, exchange knowledge to support individualized diagnoses and recommendations, and develop actionable and feasible plans to accommodate individual routines.

Additionally, my dissertation examines ways of incorporating personal informatics data in the clinic. Many clinics have begun to encourage patients to self-collect data that is traditionally

collected by medical professionals, with the expectation of increasing clinic efficiency and promoting patient awareness. One example is the proliferation of self-service blood pressure kiosks. In a longitudinal, mixed-method study, I partnered with medical researchers to examine the adoption of self-service blood pressure kiosks in a family medicine clinic. Because of initial concerns raised by patients, staff, and clinicians, the clinic iteratively identified and addressed emerging challenges, provided timely solutions, and improved the overall workflow integration.

My dissertation research contributes empirical understanding, design guidelines, theoretical recommendations, and artifacts in human computer interaction, computer-supported collaborative work, and health informatics communities. It expands the existing understandings of how designers should design systems and workflows to support personal informatics data use in collaborative care and to improve patient-provider communication about their goals and expected use of this data. This work also provides a foundation for future researchers to study how personal informatics data can support management of other chronic diseases or preventive care, as well as how people with different expertise interact, communicate, and collaborate with each other.

# TABLE OF CONTENTS

TABLE OF CONTENTS.....	i
List of Figures.....	1
List of Tables .....	2
ACKNOWLEDGEMENTS.....	3
Chapter 1. Introduction.....	6
1.1 Thesis statements .....	7
1.2 Research questions and methodologies .....	8
1.3 Contributions .....	9
1.4 Dissertation overview .....	11
Chapter 2. Background .....	2
2.1 Personal informatics.....	2
2.2 Collaborations among people with different expertise .....	4
2.3 Patient-provider collaborations.....	6
Chapter 3. Research Context.....	11
3.1 Healthy eating.....	12
3.2 Irritable bowel syndrome .....	13
3.3 Blood pressure management using self-service kiosks.....	15
Chapter 4. Understanding How Patients and Providers Currently Collaborate using Personal Informatics Data.....	16

4.1	Methods.....	17
4.1.1	Provider interview.....	17
4.1.2	Patient survey.....	19
4.1.3	Patient interview .....	20
4.2	Results.....	21
4.2.1	What do providers expect from reviewing tracking data? .....	21
4.2.2	What are the barriers for providers to review tracking data in the clinic?.....	26
4.2.3	What do patients expect from reviewing tracking data?.....	31
4.2.4	How do providers and patients collaborate during the tracking process? .....	33
4.2.5	Tracking data and tools throughout the collaborative tracking process .....	39
4.3	Discussion.....	45
4.4	Summary of contribution .....	50
Chapter 5. Foodprint: Supporting Better Food-related Data Generation and Sharing .....		52
5.1	Design rationale .....	53
5.2	System design .....	54
5.2.1	Photo-based food tracking app.....	54
5.2.2	Web app for exploring relationships among food and health goals.....	55
5.2.3	Pre-visit note .....	58
5.3	Summary of contribution .....	58
Chapter 6. Identifying and Planning for Change: Patient-Provider Collaboration Using Foodprint in Healthy Eating and Irritable Bowel Syndrome.....		59
6.1	Methods.....	59

6.1.1	Study design.....	60
6.1.2	Participants.....	61
6.1.3	Analysis.....	64
6.2	Case studies.....	65
6.3	Results.....	67
6.3.1	Inclusion Artifact: Seeing eating patterns was useful for dietary consultation .....	68
6.3.2	Inclusion Artifacts: Pre-visit notes supported explicit communication about patient goals	70
6.3.3	Inclusion Artifacts: Photo-based visualizations enabled participants and health experts to exchange knowledge and context to support collaborative interpretation .....	72
6.3.4	Inclusion Artifact: Photo-based visualization and quantitative analysis visualization supported different collaboration goals .....	75
6.3.5	Structuring Artifacts: Seeing patterns and eating context enabled personalized, actionable plan development.....	77
6.4	Discussion.....	78
6.4.1	Supporting collaboration throughout different tracking stages .....	79
6.4.2	Considering participant goals and health expert roles when designing for collaboration .....	81
6.4.3	Tension between automated analysis and over-quantification .....	85
6.5	Summary of contribution .....	87
Chapter 7. Adopting Personal Informatics Technologies in Clinics: Implementation of a New Kiosk Technology for Blood Pressure Management.....		
7.1	Methods.....	88

7.1.1	Study setting .....	89
7.1.2	Study design and data collection.....	91
7.1.3	Provider, staff, and clinic leadership data collection .....	91
7.1.4	Patient data collection.....	92
7.1.5	Rooming time and BP data .....	92
7.1.6	Analysis.....	93
7.2	Results.....	93
7.2.1	Typical workflow after kiosk implementation.....	94
7.2.2	Benefits and challenges for the clinic .....	94
7.2.3	Benefits and challenges for the patients.....	97
7.3	Discussion .....	101
7.3.1	Barriers to and facilitators of BP kiosk adoption.....	101
7.3.2	Adopting personal informatics technologies in a primary care clinic .....	102
7.4	Summary of contributions.....	103
Chapter 8. Discussion and Opportunities for future work .....		105
8.1	Quantified-self and qualified-self .....	105
8.2	Tradeoff among automatic analysis, collaboration, and self-reflection.....	106
8.3	From personal health to collaborative community health.....	108
8.4	Understanding long-term use and unintended consequences of personal informatics data in collaborative health contexts.....	110
Chapter 9. Conclusion and Contribution .....		112
Bibliography .....		115

## LIST OF FIGURES

Figure 1. Patient-collected lifelog applications and paper-based journal .....	18
Figure 2. Patients integrated data before sharing with providers. Left: P10 used red pens to circle and wrote annotation on her paper diary. Middle: P4 put weight and calorie intake in the same chart to show correlation. Right: P8 created a personal report of his daily food intake and physical activity. ....	37
Figure 3. Foodprint for healthy eating. Left: Mobile app presenting recorded food. Middle: Mobile app asking for (optional) additional details about food. Right: Web app presenting food and mood relationships. ....	55
Figure 4. Foodprint for IBS. Left: Mobile app presenting recorded food. Middle: Mobile app asking for symptom severity. Right: Web app presenting food and symptom relationships based on symptom severity. ....	55
Figure 5. Bubble and bar chart in the IBS nutrient analysis report showing correlation between a nutrient (Starch) and a symptom (Abdominal Pain). ....	57
Figure 6. Left: Self-service blood pressure kiosks in the waiting room in the clinic. Middle and Right: BP printout with BP classification from the kiosk.....	90

## LIST OF TABLES

Table 1 Summary of research questions, approaches, and findings .....	1
Table 2 Provider interview participants.....	17
Table 3 Patient interview participants.....	20
Table 4 Healthy eating participant demographics, goals, and paired providers .....	62
Table 5 Healthy eating expert demographics.....	63
Table 6 IBS participant demographics, goals, and paired providers .....	64
Table 7 IBS provider demographics .....	64
Table 8 Timeline of data collection throughout BP kiosk adoption.....	91

## ACKNOWLEDGEMENTS

This is probably the easiest and hardest portion of this dissertation; I would not be where I am today without many smart, kind, and generous people who gave me their unconditional support, but it seems impossible to express how grateful I am within a few short paragraphs.

I am forever grateful for my advisor, Sean Munson, who was willing to take on someone who knew very little about HCI research and to support her throughout this journey. Sean not only taught me how to do research, but also how to think about a problem critically and thoughtfully. He always responded to my questions with more questions, which was painful at times when I desperately wanted an answer. However, it was through this process, I learned to keep things in perspective, pay attentions to detail, and communicate my thoughts more effectively. His advice applies more than research and teaching, and it influences me tremendously. I really could not have asked for a better advisor, mentor, and role model.

I also could not have asked for better dissertation committee members– Julie Kientz, James Fogarty, and Wanda Pratt – who continuously provided me with considerate suggestions as well as challenged me with new perspectives. Thanks to Julie, who always has her door opened for advice, whether it is for research, career, or life. I was fortunate to be part of Julie’s Chill lab when I first started as a junior PhD student. Being able to participate in those lab meetings and seeing the progress of her senior students helped me better understand what the next steps would look like. Thanks to James, who always knows how to structure my thoughts into logical and powerful statements. His advice on research and career helped me grow as an interdisciplinary researcher.

Thanks to Wanda, who is always an inspiration and a role model. She constantly ensured that my research served as a patient advocate and engaged with the health informatics community.

My research would not have been accomplished without various collaborators. In particular, I would like to thank various medical collaborators whom I had the honor to work with. Thanks to Jasmine Zia, who introduced me to IBS research, provided perspectives from both medical researchers and providers, and worked with me through various study designs, recruitments, data analysis, and paper writings. Thanks to Allison Cole, Beverly Green, Laura-Mae Baldwin, and Matthew Thompson, who provided me opportunities to conduct research in various family medicine contexts. I also want to thank various collaborators outside of medicine: Irina Shklovski, Nanna Gorm, Catalina Danis, Elizabeth Bales, Kristin Dew, Elena Agapie, Jessica Schroeder, Sonali Mishra, Chelsea Wang. Being able to work with them and learn from them made the process even more fulfilling and enjoyable.

It is with the support of my family that I have embraced every challenge and have never given up. Thanks to my parents, Frank Chung and Louise Chung, who supported every decision I made, from choosing unconventional fields of study that they did not understand, to dropping out from a promising career path and enrolling in a PhD program. I had the pleasure of growing up with two brilliant and considerate sisters, Laura and Joyce. Distance and time differences never stopped our messages, Skype calls, and love to each other. They never stop chasing their dreams, and that motivates me to do the same.

I would also like to thank all the prior and current members of Lab 423, personal informatics group, and iMed group, in particular: Matthew Kay, Eun Kyoung Choe, Jared Bauer, Kyle Rector, Hyewon Suh, Daniel Epstein, Kiley Sobel, Mia Suh, Kerem Özcan, Ravi Karkar, Lucas Colusso, Rafal Kocielnik, Arpita Bhattacharya, Sam Kolovan, Kai Lukoff, and Shefali Haldar. I am grateful

for the endless sessions of brainstorming, study design, paper swaps, and practice talks that we have done together. I am also grateful for their friendship and going through all the laughs and tears with me.

Six years ago I made the decision to join the department of Human Centered Design & Engineering to pursue my PhD, and it is still one of the best decisions I have ever made. It was through working with the faculty, students, and staff members in this department, as well as being supported and cared by them in various aspects of PhD life that I am where I am today. I also had great pleasure working with my students in the Directed Research Groups, and I would not have been able to accomplish many research projects without them. Thanks to everyone who has been part of this journey, but especially Gary Hsieh, Jennifer Turns, Charlotte Lee, Mark Haselkorn, Andrew Berry, Ray Hong, Mania Orand, Sarah Fox, Nan-Chen Chen, Tom Wilson, Pat Reily, Allen Lee, Leah Pistorius, Elaine Shelley, and Scott Rivers.

Many friends within and outside of research communities helped keep me sane and nurture me with knowledge, care, and sometimes even real food: Ana Caraban, Francisco Nunes, Andrew Miller, Gabe Marcu, Yi-Chen Sung, Aiko Lin, Tim Liao, Sean Chen, Cathy Hsu, and Alice Li.

Finally, I would like to thank Stephen, who tolerates my crazy life and happily rides along with me; whose dedication and creativity always inspire and motivate me; and whose consideration and care lifts me through every mile of this marathon.

Thanks to Mochi, who accompanied me through all the highs and lows. I wish she was here.

My dissertation research was generously supported by the Agency for Healthcare Research and Quality under award 1R21HS023654, the National Science Foundation under award IIS-1553167 and SCH-1344613, the Intel Science and Technology Center for Pervasive Computing, and UW Innovation Research Award.

## CHAPTER 1. INTRODUCTION

*Steve (pseudonym) had suffered from excessive bowel movements, constant bloating, and acid reflux for over a year. He worked with one doctor, Jeff (pseudonym), to begin an elimination diet and keep track of his food intake. In the first session, Jeff gave Steve a paper form with which to record the data. However, Steve felt that it was too troublesome to keep records on paper, and he gave up on it within one day. He then tried different tools, including Excel and various existing apps. He gave up using most of them within three days, then found the app mySymptoms. He used this app to keep records. The app's analysis function allowed him to reflect on possible correlations between food and his symptoms. He printed out one report using a standardized feature of the app and brought it to his follow-up visit three weeks later. Steve went over his diet records with Jeff. Jeff then provided him some high-level comments to ensure that Steve had at least three-to-four-day rotations on foods and that his diet was balanced. Steve returned to see Jeff after another three weeks, again bringing his data. However, Jeff did not look through the data this time and asked him to describe his diet verbally. After this experience, Steve stopped bringing in his data to appointments with Jeff.*

Nutrition and physical-activity-related health conditions, such as overweight/obesity, cardiovascular disease, and diabetes, are prevalent in the United States and the world (USDHHS 2015; WHO 2013). Self-monitoring and strategizing how to maintain lifestyle changes can be effective in fostering everyday behavior change (Bandura 1991) and addressing these health conditions (USPSTF 2014; USDHHS 2015). Like Steve, many people collect data about themselves with the goal of improving their health and wellbeing. They also often hope to work

with health experts—e.g., doctors, dietitians, health coaches—to make sense of the data they collected and to find opportunities for change based on the data (Health Data Exploration Project 2014). However, most commercially available self-tracking tools were not designed to support sharing or collaboration with health experts, which makes such collaboration time-consuming and even infeasible (Chung et al. 2015). Limited time and resources also prevent health experts in clinical practice from fully engaging with and reviewing data collected by patients (Deering 2013; Kushner 1995). As a result, many people are dissatisfied with provider engagement with the data and the feedback they receive from health providers on self-tracked data (Jamieson, Fletcher, and Schneider 2007; Health Data Exploration Project 2014).

Provider medical expertise and patient knowledge about their everyday routines are both important in interpreting personal informatics data in health (Ballegaard, Hansen, and Kyng 2008; Chung et al. 2015; Marcu, Dey, and Kiesler 2014; Mentis et al. 2017; Schroeder et al. 2017). The importance and potential of supporting individual's collaboration with health experts has hence motivated this dissertation research. Building upon two rich bodies of literature—personal informatics and patient-provider communication—I sought to (1) understand current practices and design opportunities to better support these practices; (2) design, build, and evaluate systems supporting patient-provider collaboration using personal informatics data; and (3) examine practice integrating collaborative use of personal informatics data in current clinical workflows.

## **1.1 THESIS STATEMENTS**

In this dissertation, I propose the following thesis statement and set out to examine these claims:

*Understanding how people currently collaborate with others with different expertise is important for identifying design opportunities to support individual health goals and*

*collaboration goals. Systems supporting collaborative use of personal informatics data should support explicit conversations about expected use of this data in a collaboration, provide summaries according to individual health or collaboration goals, and offer insights to develop actionable plans to achieve individual health goals.*

## 1.2 RESEARCH QUESTIONS AND METHODOLOGIES

To examine the above thesis statements, I studied the following research questions (RQ) following a human-centered design process using mixed methods:

RQ 1: How do individuals and health experts currently **collaborate** using personal informatics data?

RQ 2: How can **design** address current barriers to collaboration and support collaboration goals?

RQ 3: How should new technologies that collect personal informatics data be **adopted and integrated** in current routines and workflows?

To answer RQ1, I conducted a series of formative studies using interviews, surveys, and observations. These allowed me to understand patient and provider goal, needs, and challenges for using personal informatics data in clinical care. The resulting findings contribute implications for design with regard to supporting patient-provider interactions and experiences with personal informatics data, guidelines enabling patients and providers to collaborate using personal informatics data in current workflow, as well as theoretical recommendations on how to extend frameworks of personal informatics data use to patient-provider collaboration (Chapter 4).

To answer RQ2, I designed, developed, and deployed Foodprint, a photo-based food diary and visual summary system supporting low-burden data collection and collaborative reflection. By evaluating and examining how patients and providers use the system, I validated several design concepts and features focused on supporting collaboration, promoting conversations relevant to patient and provider goals, and helping them focus on these goals in the clinic visits (Chapter 5

and 6). Adopting technologies in clinics requires consideration of clinic workflows and patient perceptions. One type of personal data collection technology that is increasingly common in the clinic is the self-service blood pressure kiosk. These kiosks allow patients to collect their own blood pressure and have the potential to encourage patients to reflect on their own data individually or with health professionals.

To examine RQ3, I conducted a longitudinal study in a family medicine clinic to understand how workflow design iterations unfold and the resulting effects on self-service blood pressure kiosk adoption (Chapter 7).

### **1.3 CONTRIBUTIONS**

My dissertation makes three types of contribution: empirical findings, theoretical implications, and an artifact (Wobbrock and Kientz 2016). These contributions provide directions for future systems design, theoretical framework extension, and research in health communities as well as in the broader HCI and CSCW communities. Specifically, this dissertation provides the following contributions:

1. Design implications based on empirical findings that support collaboration using personal informatics systems. Future systems and workflow designs should incorporate the following objectives:
  - (1) Support communication about goals for collaborative use of personal informatics data. Individual and collaboration goals can affect people's decisions when preparing to track data as well as when collecting and integrating data. These decisions can eventually affect the efficiency and efficacy of collaborative review.

(2) Provide summaries tailored to collaboration goals. Individuals and their health experts often have limited time in review data. Summaries supporting collaboration goals can also help people and their health experts focus on actionable next steps instead of item-by-item review.

(3) Enable data curation based on collaboration goals and privacy preferences. People's expectation of what is appropriate to share might change when their data is shared with different experts in different collaboration contexts. Allowing people to curate their data before sharing can help manage these expectations.

(4) Account for the needs, interactions, and relationships among different roles in medical teams and health settings. Collaboration around personal informatics data can involve people with different roles. Designing and adopting these technologies should include supporting the adaptation of new routines and workflows.

2. Theoretical implications based on empirical findings to extend existing theory, specifically including the following:

(1) Extending personal informatics models to include collaboration considerations while people prepare for tracking as well as when they collect, integrate, reflect on, and act on the data.

(2) Including privacy considerations when boundary negotiating artifacts are formed and used in various collaborative health contexts.

3. Foodprint, a novel photo-based food diary and visual summary system. I designed and developed Foodprint to support lightweight data collection and collaborative reflection. In field evaluations I conducted, Foodprint enabled individuals and health experts to easily understand eating patterns related to individual health goals, to communicate individual and collaboration goals, and to develop individualized, actionable plans.

## 1.4 DISSERTATION OVERVIEW

In my dissertation, I sought to understand how to support people with different expertise in collaboratively using personal informatics data. In Chapter 2, I begin this discussion by reviewing current research and theoretical frameworks helping us understand and design personal informatics systems and promoting patient-provider collaboration. I then focus on one chronic condition (irritable bowel syndrome) and one preventive care example (healthy eating) to examine current practices when individuals share and review personal informatics data with health experts (Chapter 4). Based on the goals, needs, and challenges identified in this examination, I design systems that support these collaboration goals and practices. In Chapter 5, I introduce Foodprint, a photo-based food diary and visual summary system that I designed and developed to support people in collaborating and communicating with health experts about their diet related health goals. In Chapter 6, I then evaluated Foodprint via two field studies of individuals and health experts to understand how people use the system in collaboration. Realizing that integrating these new personal informatics technologies practices in collaborative health settings requires design considerations around clinic workflow, I studied the adoption of self-service blood pressure kiosks in a family medicine clinic (Chapter 7). I conducted surveys, convened focus groups, and collected observations over the course of eight months to examine the iterative workflow design process. Finally, I summarize the findings and contributions of this dissertation work in Chapter 8 and discuss opportunities for future work in Chapter 9.

Table 1 Summary of research questions, approaches, and findings

Research Questions	Approaches	Summary of Findings
How do individuals and health experts currently <b>collaborate</b> using personal informatics data?	<b>Formative studies:</b> Surveys and interviews with patients and providers (Chapter 4)	Individuals and health experts need support to: <ul style="list-style-type: none"> <li>• communicate individual and collaboration goals</li> <li>• focus review on information relevant to goals</li> <li>• develop insight that lead to actionable strategies</li> </ul> Future theories and frameworks need to consider collaboration and its impact, such as privacy impact, which can affect individual and collaborative practices.
How can <b>design</b> address current barriers to collaboration and support collaboration goals?	<b>System design and evaluation:</b> Design, development, and deployment of Foodprint (Chapter 5 and 6)	<b>Photo-based summary</b> helps individuals and health experts: <ul style="list-style-type: none"> <li>• focus on and understand relationships related to food and individual health goals</li> <li>• discuss contextual information important for identifying opportunities and strategies for behavior change</li> <li>• develop insight and provides examples for follow-up plans and strategies</li> </ul> <b>Pre-visit notes</b> helps individuals and health experts: <ul style="list-style-type: none"> <li>• reflect on eating behavior before the visit</li> <li>• include individual goals in the collaboration review</li> </ul> <b>Quantitative summary</b> helps individuals and health experts identify relationships between foods and symptoms that are difficult to see using photos
How should new technologies that collect personal informatics data be <b>adopted and integrated</b> in current routines and workflows?	<b>Longitudinal, mixed method studies:</b> Observations, surveys, and focus groups in a family medicine clinic with blood pressure kiosk (Chapter 7)	Integrating personal informatics technologies requires changes in the routines of patients, staffs, and health professionals in different roles. Iterative workflow and process adaptation is important to shape the perception and experience of adoption. Shifting clinic-focused data collection to patient-facing technologies can promote awareness and communication.

## **CHAPTER 2. BACKGROUND**

My dissertation builds on research on personal informatics systems and patient-provider communication to examine ways to better support individuals and health experts collaborate using personal informatics data. In this chapter, I first review research improving understanding around practices of collecting, integrating, and reflecting on personal informatics data. I then examine theories and frameworks describing decisions and information flow through different stages of self-tracking. Finally, I review research studying and supporting patient-provider collaboration and frameworks improving our understanding about this collaboration.

### **2.1 PERSONAL INFORMATICS**

The prevalence of smartphones and wearable sensors has made health tracking more convenient and accessible. One in three people worldwide uses an online or mobile app or a wearable device to track their health or fitness (Martin and Gerhardt 2016). Self-tracking movements also became popular in response to people's needs to further analyze and reflect on their tracked-data; for example, quantified-self community includes regular meetups for health-trackers to share their experiences, knowledge, and insights (Choe et al. 2014).

Numerous health-tracking applications have been designed to support various aspects of personal tracking, including food, physical activity, sleep, and other behavioral data (Ko et al. 2015; Consolvo et al. 2012). Despite the many available applications, people report difficulty maintaining a habit of tracking and making sense of this data. As a result, users often give up tracking before achieving their goals (Lazar et al. 2015; Clawson et al. 2015; Epstein, Ping, et al. 2015). Many systems have attempted to ease the burden of data collection and improve data presentation to support people's tracking goals. Semi-automated tracking, allowing users to

combine manual and automated data collection, can promote user awareness and decrease tracking burden (Choe et al. 2017; Kim 2017). Using visual analysis techniques, systems can promote self-reflection on personal data (Choe et al. 2017; Epstein et al. 2014). Using quantitative analysis and machine learning models, systems can help users correlate and identify factors that might influence their health behaviors and outcomes (Rabbi et al. 2015; Bentley et al. 2013).

People also use personal informatics data to diagnose and manage their chronic conditions. For example, IBS patients often keep track of their food and symptom data and perform trial-and-error to determine their symptom triggers. To provide more rigorous support for self-experimentation, TummyTrials helps IBS patients design, implement, and analyze results from self-experiments investigating whether a specific food could be a trigger to their symptoms (Karkar et al. 2017). Patients with diabetes also commonly track their food, exercise, and glucose level. These patients tend to follow their regular activities and routines until their symptoms or conditions disrupt their activities and create breakdowns in their routine. These breakdowns in routines create opportunities for patients to reflect on and make sense of their data (Mamykina et al. 2008; Mamykina, Smaldone, and Bakken 2015). However, for patients to be able to discover opportunities and strategies to change from their self-tracked data, they often need successfully complete various activities: selecting features/triggers that cause changes in glycemic control, hypothesizing relationships between those features and their perceived symptoms or glucose variations, examining collected data for evidence about the hypothesis, and setting future goals (Mamykina et al. 2017).

Many theoretical models have been proposed to describe how people track and make decisions around self-tracking. Li et al. proposed a stage-based model of personal informatics (Li, Dey, and Forlizzi 2010) that describes practices and barriers when self-trackers prepare, collect, integrate, reflect, and act on their personal information. They later expanded the reflection stage

to maintenance and discovery phases (Li, Dey, and Forlizzi 2011). By studying quantified-self practices and experiences, Choe noted that reflection often occurs during data collection (Choe 2014). Rooksby et al. proposed “lived informatics” (Rooksby et al. 2014) to describe the intertwined roles self-tracking plays in people’s everyday lives and the various goals people have while adopting self-tracking practices, such as behavior change, curiosity, or instrumental purposes (having a record, receiving incentives, and maintaining a relationship). Epstein et al. later developed the lived informatics model (Epstein, Ping, et al. 2015) to better describe people’s tool selection choices, the concurrent and iterative nature of collection, integration, and reflection, as well as the lapse or resumption of tracking. The lived informatics model has three major stages: (1) Deciding and selecting: In this stage, people make decisions about tracking and choose the tools they want to use. (2) Tracking and acting: People collect data about themselves, integrate that data (sometimes across several tools or data sources), and reflect on the data they collected. (3) Lapsing and resuming: People periodically forget, intentionally skip, or suspend tracking.

Most personal informatics systems and theoretical models are built to support individual use. However, people are increasingly sharing their data with health experts to help make sense of the data. In my dissertation, I set out to support collaborative use of personal informatics data for health behavior change and chronic condition management. I also build on existing personal informatics models and discuss potential extensions to include collaboration use in these models.

## **2.2 COLLABORATIONS AMONG PEOPLE WITH DIFFERENT EXPERTISE**

Collaboration across communities or groups who share similar expertise or knowledge has long been of interest to the field of computer-supported cooperative work (CSCW). In healthcare, many studies have examined how medical professionals with different expertise collaborate within hospital or telemonitoring settings (Fitzpatrick and Ellingsen 2013). To support chronic disease or condition

management that requires navigation across self-care, home care, and medical care, many studies also have examined how patients contribute their expertise or search for other experts in everyday care management (e.g., Civan et al. 2009). In other domains, such as research and science collaboration (Jirotko, Lee, and Olson 2013), cyber security (Goodall, Lutters, and Komlodi 2004), citizen science (Wiggins and Crowston 2011), or crime analysis (Goyal 2017), researchers have examined how individuals with different knowledge and skills collaborate on large-scale problems. These studies showed how individuals approach collaborative tasks, how they make sense of the information while working with others, and how the collaboration process succeeds or breaks down. Researchers also have developed theoretical models and frameworks to describe the collaboration processes and to suggest the potential collaborative behavior and phenomenon.

Among the many models describing aspects of these collaborations, my research draws in particular on boundary objects and boundary negotiating artifact. When individuals from diverse communities or backgrounds try to work together, they often use *boundary objects* to coordinate consensus or reconcile potentially conflicting concerns (Star and Griesemer 1989; Star 2010). These physical or conceptual objects are often loosely structured in ways that make sense within each community and are used to bridge the gaps between cooperating groups. Over time, the cooperating groups might reach a consensus and begin to standardized these objects, which then become infrastructure or standards (Star 2010). During the negotiating and coordinating process, individuals or groups might create *boundary negotiating artifacts* to support conversations and discussions (Lee 2007). Lee proposed five types of boundary negotiating artifacts: (1) *self-explanation artifacts* were created mainly for personal use; (2) *inclusion artifacts* were created from self-explanation artifacts and used to propose or present new concepts through discussions; (3) *compilation artifacts* were used to align ideas and develop shared understanding among

multiple communities; (4) *structuring artifacts* were created to direct and coordinate the activities; and (5) *borrowed artifacts* were artifacts taken from one community and used in another community in unanticipated ways.

In my dissertation, I build on these theoretical frameworks to study how people use personal informatics data with health experts and design systems to support this collaboration. As I describe in the next section, personal informatics systems are often designed for individuals to collect and review everyday behavioral data by themselves. Using this data in collaboration with health experts creates new challenges. My dissertation examines these challenges, extend current knowledge about collaboration among people with different expertise, and provides theoretical implications to extend these frameworks.

### **2.3 PATIENT-PROVIDER COLLABORATIONS**

Better communication in medical care correlates with better patient adherence (Haskard-Zolnierek and DiMatteo 2009) and other intermediate outcomes associated with improved health (Street et al. 2009). Research has identified important objectives of patient-provider communication, such as creating a good interpersonal relationship, exchanging information, and performing shared decision making (Ong et al. 1995). Technology can support these objectives. Studies of patient-care management tools for cancer (Patel et al. 2012) and diabetes (Aarhus, Ballegaard, and Hansen 2009; Smith et al. 2007) have shown how technology can support communication around care. In these studies, symptom-tracking data helped patients promote conversations with clinicians and empowered patients to control their interaction with doctors. Telemonitoring systems also have shown promise in various health management programs. These systems allow patients to collect their physiological data and allow providers to remotely monitor data and communicate with patients. For example, using tracked data between diabetic patients and their care team can help them

make sense of patient illness and care management trajectories (Mamykina, Smaldone, and Bakken 2015; Mamykina et al. 2008). Other features supporting collaboration also successfully provided necessary contextual information for diagnosis (Storni 2011), facilitate communication (Aarhus, Ballegaard, and Hansen 2009; Smith et al. 2007; Patel et al. 2012), engage patients in the shared decision-making process (Andersen et al. 2011), and support long-term care management (Lan et al. 2012; Radhakrishnan et al. 2013; Tang et al. 2013). However, most telemonitoring systems have been designed with providers as the primary users, and designers have overlooked patient roles in providing context and interpreting symptom data (Andersen et al. 2011).

Many people tracking their health data use one or more of the many consumer-focused self-tracking apps or wearable devices in the marketplace. In contrast to telemonitoring systems that are designed for medical professionals, these consumer apps and devices have been designed with the self-tracker as the primary user, independent of medical professionals or health experts. However, interpretation of self-tracking data often requires both provider medical expertise and patient knowledge about their contextual factors, such as their everyday routines (Ballegaard, Hansen, and Kyng 2008; Chung et al. 2016; Marcu, Dey, and Kiesler 2014; Mentis et al. 2016, 2017). As I will describe in Chapter 4, although people often collect data on their own, health provider involvement and collaboration can influence how people make decisions. Reviewing self-tracking data together helps providers and patients develop diagnoses and individualized treatment plans, increases patient adherence, and improves the relationship between the patient and provider (Chung et al. 2016; Chung et al. 2015; Mamykina et al. 2008; West et al. 2016). Deeper understanding of patient conditions and insight into patient behaviors between visits provides an opportunity for providers to revise plans without unnecessary clinic visits for patients (Cohen et al. 2016). Increased patient participation in collaboration with providers also might shift more

responsibility to patients themselves, which in turn can encourage and empower patients in sustainable behavior change (Gabriels and Moerenhout 2018).

Despite the potential of patient-tracked data, health providers often question the accuracy, reliability, and completeness of this data (Gabriels and Moerenhout 2018; Reading, Merrill, and Reading 2018; West et al. 2018, 2017). Many also think they do not have sufficient time to review patient-tracked data in short clinic visits (Chung et al. 2015; Deering 2013). While trying to make sense of this data collaboratively, patients and providers have different preferences for how the data are represented and summarized. They often gain different insights from the data or focus on different problems. These differences between patient and provider perspectives make the collaborative problem-solving process challenging (Raj et al. 2017). Across various clinical settings, providers perceive barriers to aligning patient and clinician goals, evaluating data quality, judging data utility, rearranging the data for interpretation, interpreting the data, and deciding on a plan (West et al. 2018). As I will discuss in Chapter 4, to develop a shared understanding about the data, patients and providers often use and transform patient-tracked data into various boundary negotiating artifacts: *inclusion artifacts* allow patients and providers to negotiate about including this data in medical decision making; *compilation artifacts* help combine patient-tracked data and data from other sources, such as medical examination; *structuring artifacts* support patients and providers to develop care plans following the visit (Lee 2007; Chung et al. 2016).

Researchers have started to design tools to better support patient-provider collaboration. *MAHI* enabled diabetes educators to teach reflective skills based on patient tracked and shared dietary and blood glucose data (Mamykina et al. 2008). By allowing patients with high risk of cardiac arrest to annotate their implantable cardioverter-defibrillator (ICD) data in *myRecord* (Andersen et al. 2011), clinicians were able to integrate patient interpretation of their condition and the sensed data into

decision making processes. Patient-provider collaboration has also been examined in Parkinson's disease, which may be treated with deep-brain stimulation. Presenting the deep-brain stimulation graph to patients and their providers helped providers include patient perception and feeling into treatment decision consideration (Mentis et al. 2016). *mFood* let patients log portion size; this data was then presented along with steps and sleep data tracked by wearable devices with the goal of supporting lifestyle consultation in the clinic (Kim et al. 2016). In an evaluation of *mFood*, provider involvement increased patient motivation for tracking, and clinicians thought the review process increased communication opportunities with patients. *DataMD* imported data from multiple personal informatics data sources and presented all graphs in a single-page view. In a study with one provider and 18 patients, the provider thought that *DataMD* allowed him to skim the data easily, asked questions around the data, and helped patients to set reasonable behavior change goals. The provider also reported that reviewing this data with patients helped him to have more in-depth conversation around the context of patient life (Kim et al. 2017). In a study with IBS patients, visually presenting correlations between food nutrients and a patient's symptoms allowed providers and patients to better understand the data and become more confident about the data quality and about each other's interpretation of the data (Schroeder et al. 2017).

This prior research shows potential for designs to support the use of personal informatics data in patient and provider collaboration, but it also highlights challenges. Providers need clinically valuable data (Kim et al. 2016) or actionable information (Schroeder et al. 2017) to help them make decisions or plans. Unfamiliarity with the type of data patients collect and the way it is presented also creates challenges for effective interpretation in the clinic (Kim et al. 2016; Schroeder et al. 2017; West et al. 2018). My dissertation contributes empirical knowledge and design implications based on needs and challenges from formative work (Chapter 4) and the

literature discussed above. I also designed and developed a novel system (Chapter 5), as well as conducted field evaluations (Chapter 6) to support these needs and challenges.

## CHAPTER 3. RESEARCH CONTEXT

For most of my dissertation research (RQ1 and RQ2), I focus on collaboration using personal informatics data in healthy eating (as an example of preventative care) and Irritable Bowel Syndrome (as an example of managing a chronic condition). Both contexts rely upon everyday choices and monitoring to identify opportunities to change behavior and individual symptom triggers. People with healthy eating goals often track their everyday behavior along with progress toward their health goals. They commonly work with nutritionists or health coaches to review and examine opportunities for behavior change. I began the formative studies by examining experiences and practices of people with weight management goals as an example of healthy eating. I then broadened the study context to include people with a more diverse range of healthy eating goals. People with IBS often collect data about their symptoms and various factors that might contribute to these symptoms. They also can also benefit from working with physicians, nurses, and dietitians to help them identify potential symptom triggers and develop management strategies.

To understand how the adoption of personal informatics technologies in clinical settings (RQ3), I examine the adoption of self-service blood pressure kiosks in a primary care clinic. Blood pressure management is another example of preventive care and chronic condition management that requires everyday behavior monitoring and change. The adoption of blood pressure kiosks changes a traditional clinical task to a patient task of personal data collection. It provides an opportunity for patients to access to their blood pressure measurement and reflect on this data individually and with health providers.

### 3.1 HEALTHY EATING

The prevalence of overweight, obesity, and other diet-related illnesses, such as cardiovascular disease and diabetes, are increasing in the United States (USDHHS 2015) and worldwide (World Health Organization 2015). These illnesses are typically associated with multiple factors, numerous comorbidities, and lower quality of life (Fontaine and Barofsky 2001; USDHHS 2015). They also often incur high healthcare costs. For example, direct and indirect healthcare costs associated with obesity in the United States were estimated at \$75 billion in 2003 and are projected to increase by \$22 billion by 2020 and \$66 billion by 2030 (Wang et al. 2011). A healthy diet is integral to preventing obesity and chronic illnesses (USDHHS 2015). Many people have thus adopted food-tracking practices, hoping to monitor and improve their diets. Researchers in human-computer interaction and health informatics also have explored approaches to improve accuracy and convenience of collecting food data. Many devices have been designed to automatically capture food intake, such as by detecting eating gestures or sounds. However, although these devices can potentially prevent users from having to complete tedious data entry, the cost of these devices and concerns about whether they are socially inappropriate often stop people from adopting these methods (Kalantarian, Alshurafa, and Sarrafzadeh 2017). Manual tracking also enables people to be mindful of what they eat (Choe et al. 2017). Manual food diaries continue to be the most widely adopted food tracking technologies (Kalantarian, Alshurafa, and Sarrafzadeh 2017).

Despite the rich details manual food diaries can provide for understanding individual diets, tracking using these diaries is difficult to sustain (Burke et al. 2005; Cordeiro et al. 2015). Healthy eating goals vary by person. Some people want to eat more vegetables and fruits; others want to have balanced diets or avoid processed foods. However, electronic diaries rarely allow users to tailor the diaries to their health goals (Cordeiro et al. 2015). Most food tracking diaries require

users to look up and manually enter food information, such as food names, nutritional data, and calorie counts. Even with features that allow users to scan product barcodes and access crowdsourced databases, most users find food tracking to be burdensome. These features also nudge them toward eating food that is easier to track (e.g., packaged food) rather than food that supports their health goals (e.g., fresh, homemade food) (Cordeiro et al. 2015). The emphasis on calories also encourages users to rely on food-tracking applications to decide their eating time, content, and portions, instead of understanding the needs of individual bodies (Griffin 2012).

Working with a health expert can help people achieve a variety of healthy eating goals. Working with health providers on healthy eating can help people interpret their own data (Reading, Merrill, and Reading 2018), implement behavior change (Berry et al. 2008), and achieve better health outcomes (Bennett et al. 2015). Addressing barriers to change, self-monitoring, and strategizing how to maintain lifestyle changes can result in significant, sustained weight loss (USPSTF 2014; Vinkers et al. 2014). Integration of consumer-collected data into treatment practices can increase and reinforce the effectiveness of behavior change efforts. However, primary care providers report that inadequate training and lack of time are significant barriers to providing behavioral counseling (Kushner 1995). Patients feel that providers often only offer general recommendations without customizing the plans to address their concerns or cater to their constraints and preferences (Ballegaard, Hansen, and Kyng 2008). These patient concerns can diminish patient-provider trust and lead to low adherence to recommendations (Ferrari et al. 2013).

### **3.2 IRRITABLE BOWEL SYNDROME**

IBS is a common health condition affecting 12-30% of the population (Wilson et al. 2004) and is associated with high healthcare costs. Direct and indirect costs of IBS in the United States have been estimated at \$1.9 billion and \$19.2 billion, respectively (Spiegel 2009). Patients with

IBS also have significantly reduced quality of life as large number of factors, including foods, nutrients, and stress might trigger symptoms, such as constipation, diarrhea, bloating and abdominal pain (Wilson et al. 2004; Mitra, Davis, and Baran 2011).

As in many chronic conditions, IBS management relies on self-management and collaboration with health teams. IBS patients have individualized responses to potential triggers, and therefore are often advised to keep a diary to monitor food intake and symptom severity (American Gastroenterological Association 2002). As with food tracking for healthy eating, patients find that looking up and filling out IBS-specific nutrient information is time-consuming and burdensome. As a result, patients often complete paper diaries long after they eat, which results in inaccurate and biased entries (Burke et al. 2005). Most patients do not have detailed knowledge of IBS specific nutrient information and therefore often rely on provider analysis. However, providers report challenges interpreting diaries during clinic visits (Heinonen et al. 2012). Current clinical diary review relies on providers manually skimming paper diaries to identify correlations between potential triggers and symptoms. However, there is also no objective, validated methodology for determining individual triggers from these diaries (Heinonen et al. 2012). As a result, many IBS patients are dissatisfied with the feedback they receive from providers reviewing their diaries (Halpert et al. 2010; Jamieson, Fletcher, and Schneider 2007).

IBS providers need better tools to support diary review. In our prior study, eight health provider participants reviewed 17 IBS journals and provided recommendations for potential triggers and management plans (Zia et al. 2017). Each individual provider often favored certain food triggers and written recommendations regardless of the different dietary records in the diaries. Providers also failed to agree on potential food triggers from the same patient diary. These findings reinforce the need for better tracking and review tools for IBS patients and their providers.

### **3.3 BLOOD PRESSURE MANAGEMENT USING SELF-SERVICE KIOSKS**

To provide more efficient and accessible care, primary care clinics are increasingly adopting health-centered technologies, including self-service technologies. Self-service kiosks are an example of this and have been used for medication reconciliation (Lesselroth et al. 2011), health education (Yvonne Chan et al. 2014), and measurement of vital signs (Lowe and Cummin 2010). While kiosks have the potential to save time for both staff and patients (Lowe and Cummin 2010), previous studies show that implementing them requires thoughtful integration with patient and clinic workflows as well as facilitation and support from clinic staff. Measurement of BP is one area where new self-service technology has the potential to transform primary care. BP measurement occurs routinely during most health care visits. In recent years, self-measurement in patient homes has become common, and home and 24-hour ambulatory BP monitoring have become more accurate than clinic-based measures in predicting cardiovascular events and death (Niiranen et al. 2010). Community-based BP measurement using a kiosk, such as those commonly found in pharmacies, is another alternative to clinic-based measurement (Fleming et al. 2015). One BP kiosk has been validated as accurate by the Association for the Advancement of Medical Instrumentation standards (Alpert 2004), and it produces results comparable to those of 24-hour ambulatory BP measurements (Padwal et al. 2015). However, despite the potential for such kiosks to replace or supplement standard BP measurements in primary care clinics, few have been introduced into this setting.

## CHAPTER 4. UNDERSTANDING HOW PATIENTS AND PROVIDERS CURRENTLY COLLABORATE USING PERSONAL INFORMATICS DATA

To answer the RQ1 (How do individuals and health experts currently collaborate using personal informatics data), I started my dissertation research by examining provider and patient expectations and current collaboration practices around self-tracking data. I used surveys and interviews with patients and providers to answer two research questions:

- How do self-tracking tools and patient-generated data currently support patient-provider collaborations?
- How do these tools and data currently support patients coordinating between self-care and care in the clinic?

I adopted the lenses of the stage-based model of personal informatics (Li, Dey, and Forlizzi 2010) and boundary negotiating artifacts (Lee 2007) to analyze survey results from 211 patients, follow-up interviews with 18 patients, and interviews with 21 health providers. The study provided an understanding of (1) provider and patient expectations for reviewing self-tracking data in the clinic; (2) how current collaboration practices across self-tracking stages support or fail to support patient and provider expectations; and (3) how boundary negotiating artifacts are created and used to support interactions during the collaboration process, as well as privacy perceptions around these artifacts. The research reported in this chapter was also published in the *Journal of Medical Internet Research* (Chung et al. 2015) and the *ACM Conference on Computer-Supported Cooperative Work* (Chung, et al. 2016).

## 4.1 METHODS

To understand patient and provider collaboration and use of personal informatics data, I use surveys and interviews with patients and providers. I examine this use with patients with IBS or healthy eating goals as well as providers with experience working with either condition.

### 4.1.1 Provider interview

I first conducted semi-structured interviews with 21 primary care providers, including family medicine physician, dietitians, nurses, behavioral psychologists, and gastroenterologists (Table 2). These providers had experience working at institutions including university-affiliated health systems, health maintenance organizations, and private practices.

I conducted ten interviews in-person and eleven by phone. All interviews lasted between 50 and 70 minutes and consisted of three portions. First, I asked questions around provider current practices of reviewing personal informatics data in the visits. I probed for what types of health conditions and data they had experience reviewing, how they reviewed the data with patients, and their best and worst experiences with the review process. If providers did not review personal informatics data in their patient visits, I also probed why that was the case. Next, I explored provider workflows for reviewing personal informatics data. I asked providers what benefits and challenges they encounter while reviewing this data, what goals they have in incorporating this

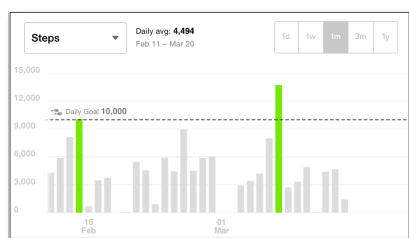
Table 2 Provider interview participants

<b>Affiliation</b>	<b>Specialty</b>	<b>Participant IDs</b>
University-affiliated health systems (1)	Family medicine physician	FM01 FM05, FM06, FM07
	Dietitian	D02, D11, D12, D13, D15
	Gastroenterologist	GM09, GM10, GM14, GM19
	Behavioral psychologist	BP03
	Nurse practitioner	NP04
	Health navigator	HN08
University-affiliated health systems (2)	Dietitian	D20
Health maintenance organization (1)	Family medicine physician	FM16, FM18
	Gastroenterologist	GM21
Independent	Dietitian	D17

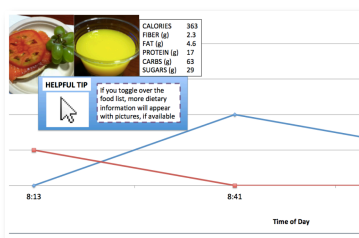
data in current visits, and what role the medical team and patients played in the review process. Finally, I presented three paper prototypes of personal informatics systems to providers to help understand provider reactions to specific examples. These systems include a dashboard of a popular physical activity trackers (Fitbit [Figure 1, left]), a mobile app supporting IBS patients to track symptom and triggers (Gut Guru [Figure 1, middle], Zia et al. 2013), and a conceptual app allows patients track and summarize symptoms between visits (Health Report, Cook 2014). For remote interviews, I shared the prototypes using screen-sharing features or email.

I audiotaped and transcribed all interviews. The full research team conducted an affinity diagram analysis (Holtzblatt 2004) to identify key themes. We transformed the interview transcripts into approximately 700 affinity notes. After several passes inductively organizing these notes into categories, we identified several themes regarding provider-perceived benefits and barriers to use of consumer-oriented, self-monitoring data.

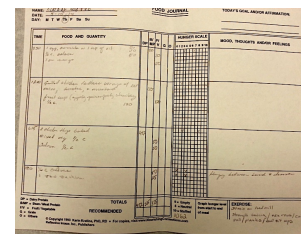
In addition to our affinity analysis, we coded each transcript through a mix of deductive coding, based on our research questions and themes identified in prior work, and inductive coding, to capture other emergent themes. A colleague and I independently coded the same transcripts and met to resolve ambiguities in the codebook and to add and refine codes reflecting emergent themes. After coding the remaining transcripts, we re-reviewed all transcripts to reflect the final codebook. In coding transcripts, we coded especially for goals and barriers to self-tracking data use.



Fitbit



Gut Guru



Paper food journal

Figure 1. Patient-collected lifelog applications and paper-based journal

#### 4.1.2 Patient survey

To understand patient practices and expectations for tracking and sharing data with health providers, I surveyed 211 patients with IBS or weight management goals. The survey included screener questions including gender, age, BMI, and whether the participants had been diagnosed with IBS. Potential participants were excluded from the survey if they had a BMI of less than 26 and had not been diagnosed with IBS. The main survey included a combination of open- and close-ended questions asking patients about their experience of tracking and sharing with healthcare providers and their expectations and concerns while sharing. The survey took around 20-30 minutes to complete.

I recruited patients by pre-screening the medical records of a university-affiliated health system with BMI greater than 26 or IBS-like symptoms. I sent 1841 email invitations and received 237 (13%) responses. After excluding 26 responses that did not pass the screener survey, the remaining 211 responses consisted of 147 (70%) females, 63 males, and 1 reported as other. Participants on average aged 44 (SD = 11.8, median = 45). There were 151 (72%) overweight (BMI  $\geq$  26) participants, 97 (45%) who had been diagnosed with IBS, and 23 (11%) having IBS-like symptoms but had not been officially diagnosed with IBS; this includes 66 participants were overweight and had IBS or IBS-like symptoms. The gender ratio and age distribution are consistent with our samples in pre-screened medical records.

To analyze the open-ended survey responses, colleagues and I first coded 20 responses using a priori codes related to our research questions, and then met to discuss consistencies and added or refined codes based on emergent themes. We iteratively coded all responses and focused on patient expectations and experiences of sharing tracked data with healthcare providers. The research team also created an affinity diagram to identify any emergent themes. We transformed survey responses related to experiences sharing self-tracked data with health providers into

approximately 350 affinity notes. We discussed the themes identified in the affinity diagram analysis in light of those identified in the coding process.

### 4.1.3 Patient interview

To further understand collaboration during the tracking process, colleagues and I conducted follow-up interviews with 18 survey participants who had experience tracking and sharing their tracked data with healthcare providers (**Error! Reference source not found.**). We purposefully sampled potential interviewees to strive for variety of tracking and sharing experiences as well as health management goals. All interviews were conducted by phone and lasted 40-75 minutes.

We developed the interview protocol to focus on patient experience of tracking and sharing tracked data with their healthcare providers. We asked participants to describe one or more

Table 3 Patient interview participants

ID	Gender	Age	Overweight or IBS?	Data they shared	Providers with whom they shared
P1	female	54	IBS	abdominal pain, food intake, physical activity, sleep, weight	gastroenterologist
P2	male	39	IBS	abdominal pain, acid reflux, food intake, medication	naturopathic physician
P3	male	48	overweight	food intake	dietitian, social worker
P4	male	46	overweight	calorie intake, physical activity, weight	dietitian, primary care physician
P5	female	61	overweight	food intake	dietitian
P6	female	56	overweight	food intake, weight	dietitian
P7	female	44	overweight	food intake, heart rate, physical activity, weight	dietitian, primary care physician
P8	male	57	overweight	food intake, physical activity, weight	dietitian, gastric bypass physician, nurse, primary care physician
P9	female	58	overweight	food intake, weight	dietitian, nurse, primary care physician, social worker
P10	female	44	overweight and IBS	food intake, medication, pain level, physical activity, sleep, symptoms, weight	gastroenterologist, primary care physician, naturopathic doctor
P11	female	50	overweight and IBS	bowel movements, food intake, sleep, stress, weight	dietitian, internal medicine physician, primary care physician, psychologist, social worker
P12	female	59	overweight and IBS	medical history record, physical activity, weight	gastroenterologist, primary care physician, medical assistant, nurse, psychologist
P13	female	54	overweight and IBS	abdominal pain, fatigue, food intake, heart rate, nausea, physical activity, sleep, stress, weight	gastroenterologist, internal medicine physician, nurse, primary care physician
P14	female	56	overweight and IBS	blood pressure, food intake, heart rate, physical activity, symptoms, temperature	gastroenterologist, internal medicine physician
P15	male	25	overweight and IBS	abdominal pain, weight	Primary care physician
P16	female	46	overweight and IBS	abdominal pain, nausea, weight	dietitian, gastroenterologist, primary care physician,
P17	male	37	overweight and IBS	food intake, medication, symptom, weight	physician, primary care physician
P18	male	45	overweight and IBS	abdominal pain, bowel movement, nausea, physical activity, sleep	gastroenterologist, internal medicine physician, nurse, primary care physician

experiences when they reviewed tracking data in clinic visits and probed with details about how they interacted with their healthcare provider and the tracking data. We also asked questions about sharing tracking data outside the clinic visit and among medical team members.

We audio-recorded and transcribed all interviews. We used the stage-based model of personal informatics systems (Li, Dey, and Forlizzi 2010) and boundary negotiating artifacts (Lee 2007) to analyze the data to help us understand when and how collaboration occurs throughout the tracking process and how current tools and practices support these activities.

## **4.2 RESULTS**

Overall, patients and providers had similar goals for reviewing personal informatics data together. However, current systems and clinic workflows often did not support these goals. Despite these challenges, patients and providers collaborated in all stages of self-tracking. Provider involvement and potential collaboration thus influenced patient decisions in each stage. To support collaboration, patients and providers used and transformed patient-tracked data into different formats. However, patients often lost privacy control about their data when it was transformed into new formats.

### **4.2.1 What do providers expect from reviewing tracking data?**

Overall, providers saw potential benefits for using patient-tracked data, but they rarely engaged with data from the apps many patients already use. All providers, except N04 and HN08, were familiar with food journals. All dietitians and BP03, FM01, FM05, FM16, FM17, GM18 had experiences with encouraging patients to track their physical activities or with patients bringing in their physical activity records. Providers also mentioned using or encountering other types of life logs, such as sleep logs (FM01, BP03, D12), stress logs (FM01, BP03, GM09, D15, FM16,

GM18), or mood diaries (BP03, D15, D17). MyFitnessPal, Weight Watchers, and Fitbit were the most common apps that patients had asked providers to review.

Providers noted that even patients tracking on their own—without review by providers—can be beneficial, but that their instruction and review can help patients overcome many obstacles to effective self-tracking. Simply encouraging patients to track the data, and later asking them how it is going, can overcome patient motivational barriers to tracking and managing chronic illness. Additional coaching on what to track, how to track, and how to review the data can help patients learn to track the right data in the right ways. Many providers—physicians, nurses, and dietitians—considered themselves responsible for educating patients on how to track and make use of data: *“We play a role of educating patients about the use of the data, so that they don’t overreact or underreact. Putting them into our perspective, and then being able to use that across the board”* (N04).

Providers also thought their review of patient-tracked data can offer a variety of further benefits. Many providers reported using or wanting to use patient-tracked data to make, modify, or confirm diagnoses. Others use the data to tailor treatment plans to patients’ routines.

### **Supporting diagnosis**

Providers working with patients in weight-management or chronic disease-management programs often rely on patient-tracked data across multiple visits to make and adjust their diagnosis and treatment plans. D15 described her process for weight-management dietary consultations: *“At an initial visit I probably spend 15-20 minutes on reviewing what they eat [using a diet recall] and pen that down. When they bring a food record in we’ll spend about the same amount of time going over that. Sometimes people will send me records then I follow up by emailing them and asking questions. Usually what I’ll do is look at the whole thing to pick typical days and a few other random days so that I can tell the difference between calories”*

(D15). GM09 described a similar approach for using food and symptom journals with potential IBS patients: *“If I see a patient for an initial encounter and if I think that they have IBS, I would give them a task to collect some data then see them back in a couple of months. Then I’ll review it with them and see if together we can come up with some trends or interventions that might be beneficial for them. Once we have a diagnosis and institute a treatment plan then my goal in each visit is to see if that’s working or if we need to adjust our management plan”* (GM09).

With multidisciplinary teams becoming increasingly important in primary care, providers also use patient-tracked data to support decisions about when to involve other medical team members. D12 believed that access to patient-tracked data by all medical providers allowed for a more cohesive team approach for patient care: *“If patient-collected data indicates that other psychological factors, not just dietary intake, are affecting symptoms, the dietitian gets support too because you got other providers working with the patient too”* (D12).

### **Personalized treatment**

Reviewing self-monitoring data together also provides opportunities for providers to learn about their patients. Understanding patient preferences and routines helps providers shape care to individual needs. D13 talked about her experience working with people who described dieting their whole lives but were still unable to lose weight. By working with them to understand their routines, she was able to tailor the diet suggestions based on their individual diet constraints or cooking habits.

IBS diagnosis and treatment is a complex process that requires excluding other conditions that produce similar symptoms, categorizing patient symptoms, and determining individualized, heterogeneous triggers. It also requires identifying which symptoms a patient most wants to address and what changes he or she is, and is not, willing to make to manage them. Communicating

around shared symptom and behavior logs can also help providers learn about their patients' priorities, both for symptoms and lifestyle.

### **Increasing motivation and accountability**

Directing patients to track data and coaching them on what to track benefits many patients, but many others continue to struggle with motivation. Providers find that reviewing data with these patients can show them *“why it’s valuable for [them] to collect those data”* (D11), leading to increased patient engagement with the tracking activity as well as with the overall treatment plan. This is especially the case when patients are unable to draw meaningful conclusions from the data on their own. Going to the effort of collecting data but not having it lead to improved health or a reduction in symptoms is a frustrating, tiring process. D02 emphasized the importance of reviewing data with patients in this situation: *“It’s more helpful if you have someone to review it with, because otherwise it might look like “Why am I doing this to myself? I’m just taking all this time for nothing”* (D02). Providers also felt their review of patient data could increase patient accountability and adherence to the treatment plan. One of D12’s patients noted, *“I know I have to turn it in so I’m going to eat healthier.”*

### **Learning about patients**

Many providers use patient-collected data and the review process to learn about their patients, to *“get an idea of what’s going on in their life”* (GM10). While this information can help identify alternative sources or triggers of certain symptoms, it also can reveal unarticulated patient values and goals. Data common in consumer self-tracking apps—*“What do you do? Do you live by yourself? How long is your commute? Who else lives with you? What kinds of obligations to your time do you have?”* (D13)—reveal constraints and opportunities for change. FM06 thought she could discover *“what the patient cares about”* from tracked data and conversations about that data,

and then use this information to motivate the patient to stay in the program. For example, D20 asked a patient to record the context of eating and found he ate more when he had peer pressure from cousins and friends. Therefore, instead of just telling him to eat less, they brainstormed ways to improve his diet without sacrificing his social life.

### **Facilitating discussion and managing visits**

Many providers use patient-tracked data to facilitate discussions during visits. If providers have access to the data prior to or at the beginning of the visit, they can plan the visit agenda around patient concerns or have a topic to initiate the conversation. For D02, the tracked data is particularly useful when patients do not have, or have trouble articulating, a clear reason for a visit: *“If they don’t know what the problem is, I at least have something to look at, and I can identify where to start to ask questions around rather than having a million things I can ask about but not knowing if any is relevant”* (D02).

Some providers prefer to have the data ahead of time so they can better prepare for the visit, particularly when a patient collects a considerable amount of data between visits: *“If I had seen this [report] beforehand, this would be really nice for me to know what she is planning on coming in and what she wants to talk about so it doesn’t catch me by surprise, so I can prepare for it too”* (D12). Others felt they would rarely have time to review patient data before a visit, so they preferred to engage with this patient data only during visits.

Some providers use patient journals to facilitate and create a record of conversations during visits. D13 showed us her favorite paper-based food journal (see Figure 1, right). She explained how she uses it to facilitate her conversations with patients. During a visit, she highlights certain columns to emphasize main points of the conversation or for follow-up. She crosses out other columns to alleviate unnecessary patient concerns and to help focus the conversation. Patients can

then take the annotated record and use it to reflect on their behavior. This gives patients an artifact that supports their memory of the conversation and can help them journal more efficiently in the future. BP03 has his patients practice cognitive behavioral therapy at home and send him their thought records before visits. When they are together in the clinic, BP03 shares his computer screen with his patients and they review the data together. This helps BP03 and his patients better understand each other's focus and correct any misunderstandings right away.

#### **4.2.2 What are the barriers for providers to review tracking data in the clinic?**

Despite the benefits of reviewing patient tracking plans and patient-collected data in clinical care, providers encounter many challenges when they try to use this data in their current practice. Primary care and gastroenterology physicians found it challenging, if not impossible, to review large amounts of data during short visits and they lack incentives to review it outside of office visits. They also questioned whether they have the appropriate expertise to review the data. Therefore, they prefer to delegate reviewing the data to other medical team members, such as dietitians. These providers typically have longer visits with patients and more expertise and experience in identifying problems using life logs, especially food diaries. However, dietitians experience their own time and workflow constraints to reviewing the data, complicated by electronic tools that do not support their needs.

##### **Lack of time and incentives**

Across providers we interviewed, the common clinic appointment in family medicine or gastroenterology lasts 15 to 20 minutes, leaving less than 5 minutes—more often 1 to 2 minutes—for a provider to review patient-tracked data. Many are skeptical about what they can meaningfully achieve in that time. For example, FM07 said she does not have enough time during a visit to explain what the data means, and so she chooses not to review it at all.

Some physicians we interviewed believe reviewing data between visits is valuable, but they also feel this work is not recognized because they could not bill the amount of time spent on data review<sup>1</sup>. As a result, they could not allocate much time to it. FM05 reported he could only spend 5 to 10 minutes per day reviewing patient-tracked data across all patients (around 20 patients per day). Current workflows and incentive structures pose “*a time barrier that discourages me from reviewing [patient-tracked data]*” (GM09).

Compared to physician visits, the typical patient visit with a dietitian lasts 30 to 60 minutes. This causes many physicians to delegate the review of patient-tracked data to dietitians and to focus on other topics during their short visits. Dietitians normally spend 15 to 20 minutes reviewing patient-tracked data—predominantly food journals, sometimes along with a physical activity or symptom diary—with patients and consider it a valuable part of their consultation.

Many dietitians also work with patients on their tracked data outside of clinic visits. Patient portals and other tools for online communication enable dietitians to review data, discuss barriers to tracking, and recommend changes to a treatment plan on an ongoing basis. Many dietitians believe this is the most effective way to help people to manage their diet for either healthy eating or IBS symptom control; however, they are hesitant to encourage this practice because this work is unbillable and unpaid across hospital systems. Providers are not normally paid for phone calls, emails, or any electronic communication outside of patient visits. BP03 said the incentive structure “*has a perverse, mixed message: collect the data but you don’t have time to do it.*”

---

<sup>1</sup> Effective on March 1st, 2017, American Medical Association has included several types of non face-to-face services—such as phone calls, emails, or other online services—into Current Procedural Terminology (CPT) codes for medical billing.

## Questions About Expertise and Benefits Offered

Most physicians reported that they are often the first person to see patient-tracked data, even if they have doubts about their time and expertise to engage with it. GM09 notes that there is often no alternative: *“There is no one [to help me review the data]. I review the data myself.”*

As with providers facing time constraints, providers who question whether they have sufficient expertise to review patient data often refer patients to dietitians. Dietitians have more expertise reviewing food journals and the review activity is *“more in line with the normal interaction”* (GM09). GM14 shared that even though she has a degree in nutrition, she does not consider it her strength to understand food types and nutrients efficiently: *“They [dietitians] ask all of those questions and I don’t. I’m not good at that. I could probably muddle my way through it but it wouldn’t be efficient and I wouldn’t get as good information out of it”* (GM14). This support, though, is not always available. While FM18 used to refer patients to dietitians for food-related concerns, there are currently no dedicated dietitians in FM18’s health maintenance organization, so he conducts this review himself.

Other physicians, however, find it more effective to review the records themselves rather than to delegate to other providers. Now that he reviews the data himself, FM18 feels that, as the only member of the medical team with regular and consistent interaction with patients, he is in the best position to use the data to offer advice and to enhance his relationship with patients. GM19 also used to refer patients to dietitians, but patients rarely followed up with them. Now he reviews patient-tracked data and offers feedback himself. Even limited review and feedback is better than a referral to which patients do not follow up.

### **Lack of Flexibility**

Tailoring tracking and a treatment plan for an individual patient is important for both healthy eating and IBS. However, providers reported that current consumer apps and provider tools, including mobile apps and web apps, do not provide sufficient flexibility for addressing the needs of both patients and providers. For example, for some patients it is necessary to track a myriad of factors and symptoms in detail, but others might only need to focus on a certain type of food. According to D13, systems that require or encourage patients to track and review more data than necessary often discourage patients from tracking. FM01 said a system should “*have the ability for the individual physicians to tailor it to the way they practice,*” otherwise it is difficult for providers to integrate it into their clinical workflow.

### **Lack of Standardization**

Patients often achieve some flexibility by choosing among the many apps available in the marketplace. However, this creates problems of data standardization when they try to share the data with health providers. Providers commonly use standardized forms or applications for some health data, such as glucose level, blood pressure, or symptom history. This standard, consistent presentation allows providers to accurately review data in a short amount of time. Consumer-oriented applications, on the other hand, often lack a standard format. Even when some applications do standardize some aspects of the data, they often reduce it to a factor that is not useful for patients nor the health providers (e.g., reducing food intake to calories for IBS patients). FM16 wanted to use “*physical activity as vital signs*” in her practice, but she found it difficult to compare or to define “*activity level*” among various types and levels of physical activities.

Many providers use standardized forms for patient food journaling. However, these forms are often difficult for patients to use in social settings and to carry around (Cordeiro et al. 2015), which

leads to incomplete records and recall bias. D5 describes her frustrating experiences with standardized food journals: *“We had food records as little booklets...but the problem is, how do we get that back to us? They either had to mail it to us, or they had to come in and drop it off, or, if we were seeing them again they could bring it. Half the time people forget to bring it. So, it became easier to just say, ‘Okay, why don’t you record it in any format you want and then either send it to me or bring it to me.’”*

Many providers thus do not provide patients with standardized forms unless patients request them. However, the free-form, inconsistently formatted data that patients tracked using their own diaries often creates challenges for providers to review. This free-form data also prevents providers from generating and viewing meaningful, actionable summaries. Having summarized views is often important for providers. For example, when many patients ask providers to review exercise logs, most providers have difficulty interpreting heterogeneous, detailed physical activity data. They find that having patients verbally summarize the data is still a more efficient way to gain insights from it.

### **Lack of mechanisms for sharing with providers**

Data portability offers one approach for bridging patient preferences for tracking and reviewing data with provider preferences for reviewing the data in other formats, but many consumer-based apps do not allow patients to export their data easily. This creates barriers to integrating patient-tracked data into provider practices, especially when they want to review it on a day-to-day basis or during patient phone calls. D15 had better experiences receiving photographed or scanned data from paper-based diaries than using mobile phone applications: *“[If it’s recorded on paper] I can keep it and look at it. If they email it to me I can go back and reference it. If it’s on somebody’s phone app then I can’t.”*

While some providers prefer to review patient-tracked data only during clinic visits, they also mentioned that the mere potential to access the data remotely might help them achieve more benefits from patient-tracked data. D12 thought accessing the data remotely could increase patient accountability: “[Patients] will not be held accountable for it because there would be no way I could see it before [the] appointment other than [if] they were emailing it in.” As a result, some providers hesitate to encourage patients to use consumer apps and prefer that they regularly email records or bring paper forms to visits.

#### 4.2.3 What do patients expect from reviewing tracking data?

In survey responses and interviews, patients described several intertwined expectations, spanning self-reflective, action-oriented, and affective aims, in tracking health data and in sharing it with their providers.

##### **Expectations to support diagnosis and treatment**

**Getting a complete picture of daily life.** Patients shared tracked with providers to give them a more complete picture between visits. “[I shared data with my provider to] assist my healthcare provider with health trends over time rather than the few samples gathered during infrequent office visits” (P19). In this way, self-tracking data is an important part of bridging the clinical and home care contexts. Patients also used the data to supplement their narratives during office visits, providing empirical support for their anecdotes and discussion: “Objective data about issues rather than just subjective verbal reporting” (P20).

**Making sense of data.** Many patients reported wanting provider input to help make sense of the data. “[It can] help highlight areas I believe I need assistance with looking for input from them to help” (P7). They wanted actionable insights into the connections between their symptoms and their behavior or medication: “I would hope they could review it and make recommendations on

*ways to improve or help look for patterns that may cause my abdominal pains*” (P256). Some patients also wanted help to see patterns and correlations among their multiple health issues or to use the data to look for undiagnosed problems: *“maybe shed some light into other health issues”* (P21).

**Providing personalized and actionable plan.** Patients also expected providers to engage with the data and provide a personalized treatment plan. *“That they might tell me specifically what to stop eating or how much exercise my specific body required”* (P22). Patients wanted concrete feedback and suggestions about what they should change in accordance with provider interpretation of the data and their personalized treatment plans. They wanted guidance on lifestyle modifications they can make between visits: *“knowledge of what things I can change in my daily routine/habits that will be of benefit to me being more active and healthy”* (P23).

### **Expectations to support affective needs**

**Self-awareness.** As described in personal informatics literature, patients looked to their data for self-awareness of their current lifestyle and described its value in terms of helping them see their habits (Li 2011). *“I clearly understand my current condition and behaviors, which I feel is important as I try to improve my diet and exercise habits”* (P4).

**Supporting accountability and motivation.** Some patients successfully track independently to make progress towards their goals: *“I struggle with weight. I have to monitor to hold myself accountable”* (P7). Other patients felt they needed to share tracked data with their providers to feel accountable for adhering to treatment plans: *“Failure to keep accurate data over an extended period of time might annoy or disappoint my doctor. I tend to look up to them”* (P24). Sharing tracking data with providers also *“provides motivation and positive reinforcement”* (P25). This is important for setting and meeting goals: *“it would solicit praise when I met each individual goal and thus provide external motivation”* (P26).

**Seeking recognition and emotional support.** Patients also wanted to use their data to get recognition for their efforts and to show their doctor they take their health plan seriously: “*I just wanted them to know that I wasn't ignoring my weight and my fitness*” (P27). Patients may also desire emotional support or empathy from their providers when sharing their data: “*to help them understand what I am going through*” (P13). They also used their health data as evidence of a problem, particularly if they perceived a lack of empathy from their providers: “... *[the doctor] took my concerns more seriously when he saw the amount of time I was sick and my symptoms*” (P28).

#### 4.2.4 **How do providers and patients collaborate during the tracking process?**

Understanding patient and provider expectations of sharing and reviewing tracking data provides insights into how patients and providers *want* to collaborate. I next turn my attention into how providers and patients *currently* collaborate, how tracking data practices are collaboratively set up, collected, and reflected on, and whether these collaborations support their goals. Using the stage-based personal informatics model (Li, Dey, and Forlizzi 2010), I analyzed the 117 survey responses from patients who had experience sharing data, 18 patient interviews, and 21 provider interviews to understand the collaboration process. In this section, I first present case studies of two patients who experienced different interactions with their providers and contrast experiences of patient-initiated tracking to those of provider-initiated tracking. These case studies present scenarios representative of those reported across all participants. I then discuss how these experiences illustrate collaboration in each tracking stage of the personal informatics model.

#### **Patient experiences tracking and sharing data on their own initiative**

**Sharing with multiple providers to prove lack a response to IBS treatment.** P17 had been struggling with IBS symptoms, such as severe abdominal pain and chronic diarrhea, for almost a year. He had tracked food intake after his bariatric surgery around 10 years ago. After he started

to have IBS symptoms, P17 resumed tracking. He used MyFitnessPal to track his food intake, medications, and symptoms, using custom entries. He shared the data with his pain management doctor, primary care doctor, and gastroenterologist because he wanted to prove that the medication did not help. All three doctors reviewed his data but with different levels of engagement. His pain management doctor went through his data thoroughly and took notes in the medical record. She also printed out her notes for P17 to reference her suggestion about vitamin supplements and instruction for pain medication. P17 put all the notes on his clipboard at home as a reminder and reference. His gastroenterologist always reviewed the data and the notes from other doctors and spent some time having a conversation with him about food intake, medication, and symptoms. His primary care doctor read the notes from other two doctors and asked him about the latest status but did not directly read the data he brought.

### **Patient experiences tracking and sharing by provider instruction**

**Working with a dietitian to setup and review tracking for weight loss.** P6 was in a weight loss program. She had been working with one dietitian, Katy (pseudonym), for two years. She visited Katy every six to eight weeks. Katy taught her to keep a record of her weight, beverages, and food intake one day in a week. Katy introduced MyFitnessPal to her and explained how to use the app in detail. Katy also answered her questions about using the app during each clinic visit. In the clinic, Katy would use P6's phone to login into her MyFitnessPal and review the data in detail. Katy would also ask for clarification about the data. Katy then took notes from the data and plotted the data into her spreadsheet on her computer. Then Katy would show P6 the trend and the pattern of her data and explain those to her. If Katy thought they needed to change the diet plan or calorie goal, she would just change that directly on P6's phone so she could follow the plan at home.

## Collaboration throughout the Personal Informatics Model

The experiences presented in the case studies depict different types of patient-provider interactions with shared patient-tracked data in current clinical practice. To further understand *when* and *how* these collaborations take place, I present the results of our analysis based on the five-stage model for personal informatics from Li et al. (2010): *preparation*, *collection*, *integration*, *reflection*, and *action*. I describe how sharing occurs between patients and providers on self-tracked data and how sharing influences tracking behavior in all stages.

**Preparation.** People plan for what and how they want to track in this stage. However, knowing what and how to track are common barriers for people to start tracking. Epstein et al. (2015) further divided the preparation stage into deciding to track and selecting tools.

For provider-initiated tracking and sharing, patients were normally given adequate motivations to track: monitoring for a specific treatment (e.g., elimination diet for P17) or for long-term performance (e.g., weight loss performance for P6). Patients also reported being asked to track their food intake to get approval for bariatric surgery (P9, P17, P29, P30, P31, P32, P33, P34, P35, P36, P37, P38) or gastric pacemaker implantation (P14, P39). Patients being considered for bariatric surgery were asked to do a trial of the recommended post-operative dietary guidelines and to track their diet for a defined period for compliance. Greater weight loss, and maintenance of this weight loss, is more promising for patients able to adhere to this diet post-operatively. For gastric pacemaker implantation in patients with gastroparesis (slow emptying of the stomach), providers reported wanting to make sure that patients have “maximized medical therapy,” which includes dietary management. These patients are therefore also asked to track their diet for compliance prior to being considered for a gastric pacemaker.

Providers sometimes recommended tracking tools to patients for clinical diagnosis and management. These included traditional paper-based diaries (e.g., bariatric surgery handbook, P8), a specific application (e.g., MyFitnessPal, P6), and, for one participant, a list of popular applications (P3). However, patients do not always follow those recommendations. Some patients have tools with which they are already familiar (P3, P9) or follow suggestions from friends or family (P40, P41). They may also have specific needs that the provider-recommended tool does not fulfill. For example, P2 hoped to self-identify correlations between his food intake, medication, and symptoms. However, he found it difficult to use the paper diary provided by his doctor and therefore used mySymptoms app instead. Tools selected by patients, however, do not always support collaborative review in the clinic. Many providers still preferred a paper diary for better interaction affordance. This sometimes created tension for later collaboration in the reflection stage.

Among patients who initiated tracking on their own, some chose specific items to track with eventual sharing in mind. For example, P4 started to track his weight and calorie intake again because he wanted to show his doctor his day-by-day effort toward weight loss. He did not feel that weighing in at the clinic every six weeks was enough to represent “*what’s going on in his life.*” He also chose a tool that allowed him to later integrate his data to support collaborative reflection in the later stage.

**Collection.** In the collection stage, people start to record their own information. This almost always only involved patients themselves. However, some patients said that having the ability to send questions to providers through a patient portal or email helped them to overcome barriers around tool use and accuracy. For example, P10 described sending how she was feeling and questions about perplexing data to her provider. Having the expectation of provider review also increased patient accountability and motivation. For example, P5 mentioned in the interview

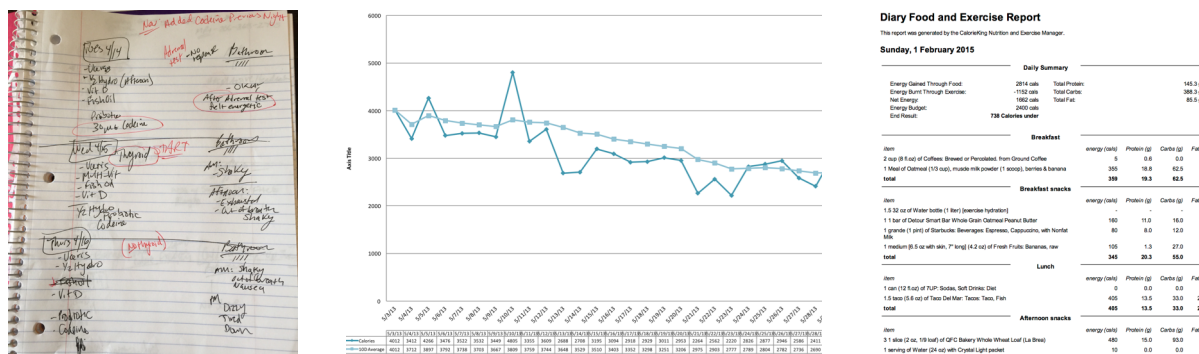


Figure 2. Patients integrated data before sharing with providers. Left: P10 used red pens to circle and wrote annotation on her paper diary. Middle: P4 put weight and calorie intake in the same chart to show correlation. Right: P8 created a personal report of his daily food intake and physical activity.

“knowing someone will look over the data forces me to be more aware of what I eat and what I write down.” P8 said he kept a more detailed record because he knew his dietitian and nurse cared about these data and would read through the data carefully.

**Integration.** People integrate their tracking data to support reflection in the later stage of the personal informatics model. Some patients did not need to spend much effort on integration because the apps they used supported this step. P2 used mySymptoms, which provides correlation features, and others used tools that include an integrated dashboard (e.g., MyFitnessPal, P6; LoseIt, P9). Some patients created their own integration by making their own report (e.g., P4 [Figure 2, middle], P8 [Figure 2, right]). One patient selected specific records to print for providers (P5). Others highlighted particular entries in their paper records to help focus the conversation (e.g., P1, P10 [Figure 2, left]). Other patients read through their notes and integrated data in their head before the clinic visit, where they provided a verbal summary to their health providers (e.g., P15, P16, P18).

To support collaborative reflection, patients need to integrate data based on both provider and patient goals. However, patients and providers did not always understand each other’s goals well. For example, providers sometimes encouraged patients to track to be aware of their own health

issues. Thus, they did not plan to thoroughly review the information and just had the goal of providing affirmation and emotional support. Patients, on the other hand, might expect providers to help make sense of their data and therefore bring pages of data to a clinic visit. Some patients felt frustrated afterwards when their providers did not help them understand the data (e.g., P2, P10, P42). It was also difficult for patients who initiated tracking and sharing to anticipate their provider's goal beforehand.

**Reflection.** In the reflection stage, people review their collected and integrated dataset to make sense of it. Patients in our interviews reported spending an average of five minutes (approximately 25% of the clinic visit) reviewing their data with their primary care physicians or gastroenterologists and 10-20 minutes (25% of the clinic visit) with their dietitians. Patients also often reviewed the data with multiple healthcare providers. Different providers might have had different review goals and therefore different approaches to reviewing patient-generated data. P17 described having a thorough review with one doctor and a brief verbal review with another. Similarly, P8's dietitian spent 20 minutes focusing on reviewing his day-to-day food intake while his bariatric nurse was more interested in his overall health. She therefore distributed her review time across a food diary, an exercise log, and other lab test results.

The reflection stage may also lead to another preparation stage where providers and patients decide on a change in treatment or a need for new treatment in response to monitoring. In this case, providers may suggest that patients track different items to help with better treatment.

**Action.** People decide what actions to take based on findings during reflection on the tracking record. Because chronic disease such as overweight/obesity and IBS require long-term care, patients might start another care cycle (Chen 2011) at this stage. Some patients used notes they

took (e.g., P16, P18) or were printed by providers (e.g., P11, P17) to assist them to follow the treatment plan or track new data points.

#### **4.2.5 Tracking data and tools throughout the collaborative tracking process**

Based on findings of how providers and patients collaborate, I started to analyze how tracking data and tools support collaboration in these stages. As patients and providers went through different collaboration stages, patient-tracked data was transformed into different physical or conceptual forms to support collaboration. I adopted the framework of boundary negotiating artifacts by Lee (2007) to reanalyze the survey responses, patient interviews, and provider interviews.

Lee defined five types of boundary negotiating artifacts that facilitate information transmission and collaboration: self-explanation artifacts, inclusion artifacts, compilation artifacts, structuring artifacts, and borrowed artifacts. I found different privacy needs and perceptions, as framed by the concept of contextual integrity, evolved while using and sharing these data over time. Upholding privacy as contextual integrity (Nissenbaum 2004) requires that the information shared be appropriate to the context; it also requires the information be distributed in a way that respects the norms of the context.

As Nissenbaum (2004) notes, the norms of appropriateness and distribution are complex in the healthcare domain. Looking at patient self-tracking data as boundary negotiating artifacts allows a clearer view of privacy questions. In patient-provider interactions with self-tracking data, discretion over what type and amount of information is shared is fluid; the provider may request data for diagnostic and treatment purposes, or the patient may offer her own data in order to optimize her care. As patient-provider collaboration recasts self-tracking data as different types of boundary negotiating artifacts, patient privacy expectations and needs change accordingly.

In the following section, I present a summary of the use of four types of boundary negotiating artifacts in patient- provider collaboration around self-tracked data.

### **Self-Explanation Artifacts**

Self-explanation artifacts are those created for personal use. The practice around the creation of this type of artifact is normally based on personal expertise and experience. Examples of self-explanation artifacts from Lee (2007) include personal sketches and notes that help to record, organize, and analyze personal ideas. Patient-tracked data can function as self-explanation artifacts, particularly when patients initiate self-tracking themselves. Patients are the experts of their own life routines, and after years of pursuing healthy eating goals and managing IBS, they also become experts of their personal health issues. They create tracking data that manifest these experiences and knowledge about themselves. These data do not necessarily come with a standardized format and sometimes are highly personalized based on individual health issues and their definition of meaningful, even when patients use the same tools. For example, P10 chose to record using paper notes because she was undergoing complex symptoms and following a diet plan, which made it hard for her to use a general tracking tool.

When patients create a tracking record, they start with a set of privacy expectations – while their data are still a self-explanation boundary artifact. In the case of patient-initiated tracking, initially they might not expect to share the data with others, even their health care providers. For provider-initiated tracking, patients expect that someone will read their data and this might change their behavior around the creation of this artifact. Alternatively, patients might not want to be judged for certain behavior, so they either change that behavior or choose not to record it. For example, P3's worst sharing experience was feeling blamed for having a beer after work. He gave

up the habit of drinking because he was tired of explaining, but he still considered that an unpleasant sharing experience.

Patients who initiate tracking themselves might also gather too much or irrelevant data. Or, they might collect data relevant for their personal use but irrelevant in the sharing. If the self-explanation artifact is later incorporated in a provider interaction, patients risk exposing information that is not needed in the context at hand. Viewed through the lens of contextual integrity, a patient collects data he or she deems appropriate for the context in which he or she is tracking. Incorporating these data in a provider visit may reveal self-explanation data that is out of the healthcare context, particularly if the patient initiated the self-tracking process. It is only after considering sharing or interacting with their providers that these patients can select the most relevant information to gather and share. Furthermore, for patients whose providers requested they start tracking, patients may not be fully aware of the privacy implications of self-tracking or the features of the tools they are asked to use, affecting their ability to provide consent to tracking and sharing potentially sensitive information.

### **Inclusion Artifacts**

Inclusion artifacts are created from self-explanation artifacts or other artifacts through a negotiation process to facilitate the discussion of new ideas. The inclusion process might involve presenting, accepting, and rejecting what comprises the inclusion artifacts. Patients create inclusion artifacts when they bring their data to the clinic visit. Verbal summaries play an important role in presenting tracking data because patients can explain it with personal narrative. In comparison to measurements in the clinic, patients believe the data provide a more accurate, day-to-day record of their health and wellness (e.g., weight and blood pressure), relationships between triggers and symptoms (e.g., certain foods and abdominal pain), and proof of their effort towards

certain health outcomes (e.g., physical activity and weight loss performance). They also expect that the data will help their health care providers better understand their daily life and create more personalized treatment plans.

For data that transitions from a self-explanation artifact to an inclusion artifact, contextual integrity highlights questions surrounding distribution of the data. Here there is a tension between the patient's right to control the disclosure of their own data and the provider's authority to request such information. Many patients believe being honest and open to their provider is necessary. They rely on providers to direct them about what to share or what not to share. For example, when asked why they did not share a particular type of data, some patients said that it was because their providers "*did not ask for it*" (P43).

Distributing confidential information via narrative is a norm in the healthcare context. Patients have traditionally done this by verbally filtering and summarizing their experiences, leaving what they reveal at their discretion, even when asked explicitly for information by their provider. Self-tracking data, particularly when it is difficult to edit or filter, can inhibit patient abilities to distribute their health information at their own discretion. For example, P5 only trusted one dietitian, with whom she had worked for six years, to review her data. She thought her food and symptom diary were very personal and she did not think she had the same relationship with other providers; therefore, she only verbally described the data to them.

### **Compilation Artifacts**

Compilation artifacts are used to facilitate sharing and coordinating information among parties. The process of creating compilation artifacts might include collecting information from different sources, organizing and discussing in a shareable state, and presenting and explaining the information to align the goals of all parties involved. This compilation process might also involve

practices to resolve conflict and confusion. By reviewing patient-tracked data, test results, disease history, and other clinical information, providers created a compilation artifact. These different sources of inclusion information sometimes conflict with each other or are unclear for medical decision-making, and therefore require that providers and patients collaboratively interpret the data. This process also sometimes involves multiple medical team members. The compilation object is commonly presented as a clinical note in the medical record, accessible by all healthcare providers caring for the same patient (e.g., P14, P17) or as printed patient instructions given to patients following a clinical encounter (e.g., P2, P4, P10).

Uncertainties around appropriateness and distribution are further compounded when self-tracking data becomes a compilation artifact. Once shared in a clinic visit, the data may be re-shared or visible to other parties (Haas et al. 2011; Perera et al. 2011; Burke et al. 2005; Terry and Francis 2007). Although providers and patients work together to create compilation objects, patients might not feel comfortable sharing the same information with every provider. However, with electronic medical records (EMR), self-tracking data can be shared among collaborating doctors without patient knowledge, or even many years later with providers who work with patients on an entirely separate concern, violating norms of appropriateness. For example, mental health data discussed in a primary care provider visit and captured in an EMR during that visit may later be visible to a gastroenterologist, for whom the most appropriate self-tracking data to review may be food intake and abdominal symptoms. This can disturb the patient's contextual integrity by overriding distribution norms (e.g., moving data collected in one context to many other healthcare spheres without their knowledge or explicit permission).

These privacy questions are compounded by regulatory uncertainty about self-tracking data. Under the Health Insurance Portability and Accountability Act (HIPAA) guidelines, an

individual's confidential information such as that contained in self-tracking data should only be accessed by the individual or their provider. While personal health information (PHI) found in EMRs and other clinical datasets are protected by HIPAA, the regulations and best practices surrounding self-tracking data brought into the clinical environment are less clear (Hall 2014). The Food and Drug Administration (FDA) has put forth guidelines on mobile apps being used like medical devices, but has said it will not regulate them (Food and Drug Administration 2013). Self-tracking data may not be considered PHI under current regulation (Hall 2014), and patients in our study were confused about whether these data are protected by HIPAA (P44, P45). More clarity is needed around self-tracked data transfer and storage in a clinical setting. If self-tracked data are requested by the provider, these issues may become even murkier.

### **Structuring Artifacts**

Structuring artifacts are created to coordinate information use and to direct and coordinate the activity of parties involved in the collaboration. It might also be used to structure the final product but depending on the view of participating parties, it might be used differently. After negotiating and compiling health information, providers and patients reached decisions that could then generate a structuring artifact or a new inclusion artifact. This often included a new plan or a new setup for tracking, a checklist of diet suggestions, a referral to other medical providers (e.g. a behavioral psychologist or a physical therapist), a physical activity prescription, or a change in medication. The old records might now carry notes or annotations from providers and serve as a structuring object for patients to refer to as they engage in behavior change at home. Some other artifacts, such as a printout of the provider's notes, an email, or patient notes on their own phones, can also function similarly to aid patients in executing the new plan.

### **Borrowed Artifacts**

Lee's boundary negotiating artifacts (2007) also include borrowed artifacts, which are those taken from the creator, augmented with other interpretation, and used in an unanticipated way. However, I did not identify the creation or use of borrowed artifacts in our analysis. One reason might be that personal informatics data is still underused in patient-provider consultation. As described previously in this section, providers and patients face many barriers using this data in collaboration, and many prefer using verbal summaries than reviewing the physical artifacts. With more systems supporting collaboration become available, future research should examine whether and how borrowed artifacts will be created and used.

## **4.3 DISCUSSION**

Collaboration occurred in all stages of the personal informatics model. Commercial tools support some of these collaborative activities less well than others, however. Our results identify opportunities for designers to support provider and patient goal implementation in the preparation and collection stage, goal-oriented and privacy-sensitive data curation in the integration stage, and tailored visualizations and interfaces to support collaborative review within and outside of clinic visits in the reflection stage. I also identify opportunities for researchers to further develop theories to support patient-provider collaborations.

### **Goal Implementation during Preparation and Collection**

The decision to share tracking data with providers can change patient tracking practices in both provider-initiated tracking and patient-initiated tracking. However, without clear communication about each other's goals, providers are overwhelmed by the excessive amount of data to review, and patients are frustrated by providers not valuing their collected data per their expectations (Deering 2013).

I do not claim that providers do not spend enough time and effort communicating with their patients. Many of our participants, in fact, thought their providers were very open to communication, despite frustration with their sharing experiences. What I do claim, however, is that providers and patients lack mechanisms to set mutual expectations and goals during the process of sharing patient-generated data. For example, even when providers specifically instruct patients to only record a specific type of food, the apps patients use may still require or encourage them to input and display other unnecessary information (e.g., calories), thereby creating barriers of high burden and excessive data for effective review. Systems instead could allow providers and patients to configure personalized templates for tracking. Similar to medication prescriptions and *HealthWeaver* (Patel et al. 2012)--which allows cancer patients to set up and customize individualized symptom tracking parameters, patients and providers using everyday behavior data collaboratively could set up tracking parameters, such as items and frequency, based on their sharing and reviewing goals. There are no standard metrics for tracking many everyday behaviors, which is different from medication or symptom tracking. Therefore, it is necessary to design templates while considering provider and patient goals. For example, if patients and their providers would like to confirm their suspicion about particular food triggers, they could decide to only record the specific type of food with a three-day elimination and three-day introduction. These templates could also be shared with self-trackers without having to meet with providers beforehand. For example, someone suspects his abdominal pain is triggered from a certain food and would like an evaluation from health professionals can use the template to track his food and abdominal pain with adequate detail and frequency.

## Goal-oriented and Privacy-sensitive Data Curation

To support their expectations regarding collaborative review with providers, our participants used various methods to curate their tracking data. Curation between tracking and review is important for patients to achieve their goals and resolve their privacy concerns. This creates design opportunities to better support these activities.

For a system to support goal-oriented data curation, it could provide mechanisms to integrate and summarize data from multiple sources, and to curate and filter data based on the goals and targets of sharing (Epstein et al. 2014). This provides flexibility for patients to use their preferred tracking tools that fit their preference and routine, but still allows them to achieve their goal – sharing and review with their providers. Diabetes patients who use *Tag-it-Yourself* can tag and categorize tracked data based on their own concerns and using their own words (Storni 2011). As previously introduced, *myRecord* allow patients flag and annotate on their ICD data to support collaborative interpretation with their cardiologists (Andersen et al. 2011). Similar to these approaches, future systems that support collaboration could help patients annotate and highlight data with questions or exceptional events to share with their providers. This could facilitate agenda setting if it is shared before the visit (Unruh 2010) or supply additional contextual information necessary to support conversations during the visit.

For a system to support privacy-sensitive data curation, it could provide sharing profiles based on the patient's relationship with the data recipient. Similar to privacy settings in social sharing (e.g., Facebook, Park & Chen, 2015), users should be able to tailor their sharing content based on which providers they would want to share and what their sharing goals are. Systems should also allow providers to request permissions from patients when necessary. This is particularly important for systems designed to integrate tracking data into EMR systems. Without the options to curate data before integration, it might infringe patient privacy of data sharing without their notice.

### **Tailored Visualizations & Interfaces for Collaboration**

Time is one of the most limited resources for reviewing tracking data in clinic visits. However, when asked whether there is sufficient time to review data, many patients we interviewed felt they were given enough time, but they were frustrated about not being able to focus on the questions important to them (e.g., P17). This demonstrates a design opportunity to create goal-oriented visualizations or summaries to help focus the collaborative review. For example, if providers and patients want to focus on calorie intake and weight for weight loss, there may be no need to present nutritional content. On the other hand, if the goal is to identify potential food triggers, then specific food nutrients or components are more important to analyze and present than calories.

To help with motivation and accountability, systems could also support reflection on missing data. Features such as anomaly identification have been used to help users self-identify their mistakes and explain irregular behaviors (Lee and Dey 2011). Similar features can support patient-provider conversations during collaborative review. For instance, combining patient annotation and contextual information about their routines, such as calendar events, could better allow providers and patients to identify barriers and challenges in tracking (e.g., frequent travel disrupting their tracking or actual routines), better manage their care outside of the clinic visit, and provide opportunities to personalize the patient care plan. Systems could also support patient reflection on unarticulated events in their lives by flagging missing data for their consideration, instead of just treating it as “bad” or “incomplete” data.

### **Reflecting Collaboration in Theories**

Using the stage-based model of personal informatics (Li, Dey, and Forlizzi 2010) and boundary negotiating artifacts (Lee 2007) helped us understand how providers and patients collaborate using patient-generated data. However, I also found a need to address issues uncovered for applying these

models and theories to patient-provider collaboration with self-tracked data. In this section, I reflect on the nature and process of patient-provider collaboration in tracking and sharing patient-generated data to suggest considerations for future development of these theories and models.

Reflecting on the stage-based model of personal informatics, I observe a need to extend the model with individual roles in each stage of what is, for many, a social and collaborative process. Although collaboration occurs in every stage of the personal informatics model, individuals might play different roles and conduct different types of activity independently and collaboratively. For example, in the preparation stage, providers might educate patients about what and how to track while patients might plan for adopting the tracking process into their daily routines; together they make a feasible tracking plan. Similarly, when collaboratively reviewing data, providers might examine tracking data for common symptom triggers while patients might reflect on contextual factors that affect their exposure to those triggers. When integrating both analyses, providers and patients can adopt actionable treatment plans and lifestyle changes.

There is also a need to plan for lapsing and stopping. Collaboration can be terminated by either party during or between stages. Patients might lapse in collecting data (Epstein, Ping, et al. 2015). Providers, facing time and compensation constraints, might not be incentivized to review the data as thoroughly or at all. This might in turn cause patients to stop bringing their data to the clinic. The lived informatics model suggests opportunities and possible strategies for designing for lapsing and resuming tracking (Epstein, Ping, et al. 2015). I emphasize the importance of designing not just for lapses in and resumption of individual tracking, but also in collaborative tracking. Further, it is possible for parties to asymmetrically lapse or resume. As seen among our participants, a provider might lapse in reviewing data before a patient is ready. A patient, facing a flare up in symptoms or weight gain, might resume tracking but without the provider support he or she previously had.

The social nature of collaboration work inevitably leads to privacy concerns, particularly in the context of health information. As different boundary negotiating artifacts are formed and transformed from patient-generated data throughout the collaboration process, patient perspectives of privacy change and need to be addressed accordingly. Reflecting on Nissenbaum's privacy as contextual integrity (Nissenbaum 2004), I caution practitioners and researchers to be attentive to the complex norms of appropriateness and distribution of patient-provider collaboration when applying both models. Future research should also extend collaboration around patient-generated data to include other members of their peer support and care networks and further develop the theories based on these nuances.

#### **4.4 SUMMARY OF CONTRIBUTION**

In this chapter, I observed and presented patient and provider expectations for sharing self-tracking data and how collaboration takes place in different stages building on the stage-based model of personal informatics. I also adopted the theory of boundary negotiating artifacts to describe how current tracking tools and data support provider and patient collaboration. Grounded in these theories, this chapter contributes an understanding of the design and use of self-tracking data in IBS and weight management patients.

Despite successful use cases, many barriers and concerns prevent patients and providers from performing individual activities or from collaborating effectively with each other. Designers of personal informatics systems should work to include features that better support patient-provider collaboration. These features should support goal implementation during preparation and collection stages, goal oriented and privacy-sensitive data curation during the integration stage, and tailored visualizations and interfaces for collaborative review during the reflection stage.

To avoid miscommunication, healthcare providers and patients should have explicit conversations about intended use of the data. Healthcare providers who integrate patient self-tracking data into their practice should consider the different roles their patients and they play in initiating, supporting, and terminating the collaboration. They should also be conscious of patient privacy needs and suggest appropriate granularity and duration of tracking and sharing.

Researchers need to further develop personal informatics models and the theory of boundary negotiating artifacts based on the social nature of patient-provider collaboration. Researchers should elaborate on personal informatics models to reflect the role self-trackers and their collaborators, including experts, play in each stage of the process and how these roles may shift. CSCW researchers should place importance on the norms, uses, and privacy needs associated with data when applying the theory of boundary negotiating artifacts to understand patient-provider collaboration and other collaborations involving personal data.

## **CHAPTER 5. FOODPRINT: SUPPORTING BETTER FOOD-RELATED DATA GENERATION AND SHARING**

To answer RQ 2 (How can design address current barriers to collaboration and support collaboration goals), I adopted the design, development, and evaluation process. Knowing the goals and challenges when patients and providers attempt to use personal informatics data collaboratively, I set out to support these goals and address these challenges through design. I approached the design problem through examining new ways of collecting and reviewing food intake. In this chapter, I present the design rationale and features of Foodprint, a photo-based food diary and visual summary supporting lightweight data collection and collaborative reflection

As described in Chapter 2 and Chapter 3, to support monitoring dietary intake, prior work has examined how photo-based diaries can ease the burden of data collection and support reflection on eating behavior and context (Baumer et al. 2012; Chung et al. 2017; Cordeiro et al. 2015) as well as support diabetes educators to help teach patients about diet analysis (Mamykina et al. 2008). To better understand how photo-based food diaries can support patient-provider collaboration, I designed and developed Foodprint. I designed two types of visual summary to support collaborative review: (1) summaries presenting photo diaries based on healthy eating goals and IBS trigger identification goals and (2) summaries presenting quantitative analysis of IBS triggering nutrient adapted from (Schroeder et al. 2017). My goal was to examine how to design photo-based diaries to support people throughout their tracking process so that they can use their data in collaboration as well as to support collaboration goals when people and health experts examine strategies to support healthy eating goals and identify symptom triggers.

## 5.1 DESIGN RATIONALE

I designed Foodprint based on results from Chapter 4 and other prior studies in understanding provider and patient needs with IBS and healthy eating (Schroeder et al. 2017; Zia et al. 2017). My goal was to support and empower both individuals and health experts individually and collaboratively. For individuals, I sought to lower their burden of data collection and enable them to integrate and reflect on their own data even before seeing health experts. For health experts, I sought to lower their burden of review unfamiliar and extensive amount of data during visits and support them to see patterns and actionable insights easily. For collaboration, I sought to help individuals and health experts include individual expectations and experiences into discussion as well as structure actionable plans. Results from Chapter 4 showed that patients and providers need a way to communicate their expectations and goals during the process of tracking and reviewing patient-tracked data. They also need to be able to curate their data based on these expectations and focus their data interpretation on individual and collaboration goals.

As discussed in Chapter 2, prior work has shown potential for using photo-based food diaries to support healthy eating (Cordeiro et al. 2015) or help people learn reflective skills from diabetes educator (Mamykina et al. 2008). I adapted the use of photo-based diaries from prior studies to focus on helping people communicate their healthy eating goals and progress with health experts. Using food photos to identify IBS triggers, however, is different than using photo based food diaries for general healthy eating goals (Chung et al. 2017; Cordeiro et al. 2015). Details about foods that are difficult to see in photos, such as spice, extra oil/dressing, or artificial sweeteners, can be potential triggers. Food preparation methods and sources are also important information for trigger identification. Finally, understanding patient preferences or constraints about food can help providers develop more personalized strategies. Therefore, rather than just reimplementing

existing photo-based food diaries, I designed ways for people to enter this IBS- and goal-specific information in the system to augment reviewing the food photos. I iterated the system design with ten pilot users and five health experts over the course of three months to refine design details and address usability issues.

## **5.2 SYSTEM DESIGN**

Foodprint consists of three tools: (1) a mobile app supporting in-the-moment, low-burden food capture, (2) a web app presenting relationships between food and health goals, and (3) a pre-visit note asking participant expectations to the visit.

### **5.2.1 Photo-based food tracking app**

Participants start to record their food intake by taking a photo of their food using the mobile app (Figure 3, left). They can then optionally annotate the photo with a caption and additional details about foods and their eating experience (Figure 3, middle). Participants can also reuse photos in their phones or upload a photo retroactively if they previously forgot. For IBS patients, the mobile app also prompts them to enter their symptoms between their previous symptom report and the time of eating or at a frequency patients determine (from one to three hours) (Figure 4, middle). Participants can input additional details at the time of eating using the mobile app or later using the web app. This flexibility allows people to decide how much time they want to spend tracking in the moment. They can enter more details while the experience is fresh in their memory or enter fewer when they cannot afford the time, such as when eating in a social situation.

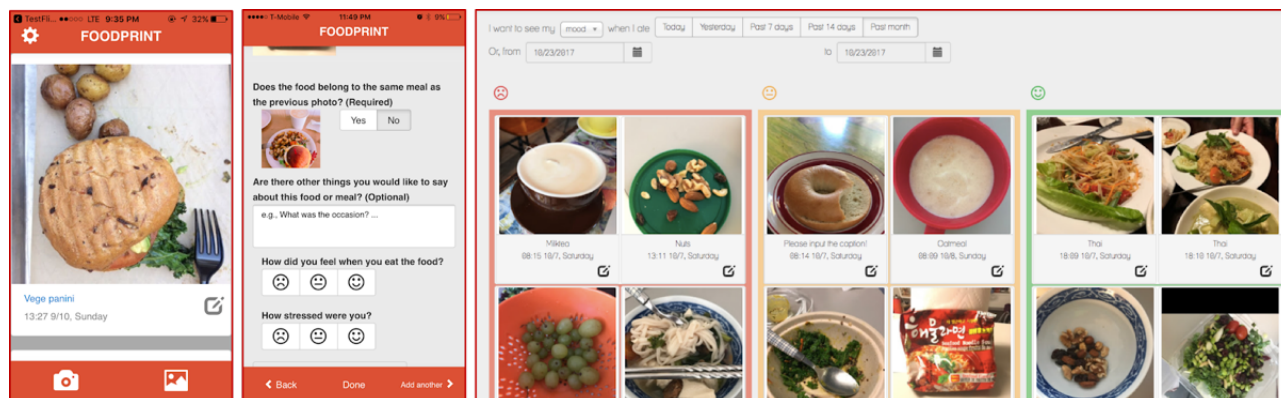


Figure 3. Foodprint for healthy eating. Left: Mobile app presenting recorded food. Middle: Mobile app asking for (optional) additional details about food. Right: Web app presenting food and mood relationships.

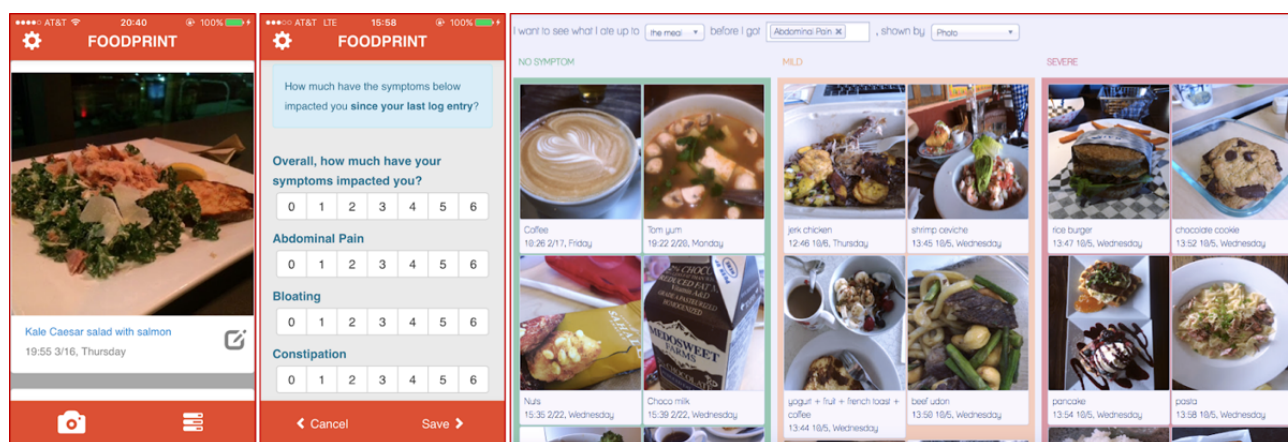


Figure 4. Foodprint for IBS. Left: Mobile app presenting recorded food. Middle: Mobile app asking for symptom severity. Right: Web app presenting food and symptom relationships based on symptom severity.

## 5.2.2 Web app for exploring relationships among food and health goals

As described in Chapter 4, current systems do not provide effective summaries to support patient health goals. Without these summaries, providers struggle to generate correct, individualized, and feasible recommendations. Recommendations are also inconsistent between providers and biased toward that provider's expectations (Zia et al. 2017). In Foodprint, I developed two types of visualizations to support patient-provider collaboration goals: (1) A photo-based visualization view that helps people and health experts review food photos based on participant health goals or symptom

severity and (2) an IBS nutrient analysis report that helps IBS patients and providers understand correlation between potential IBS triggering nutrients and patient symptoms.

### **Photo-based visualization view**

The web app presents participants with a visual summary of their data. For healthy eating participants, the web app presents foods categorized according to patient goals (Figure 3, right). For example, for participants who would like to eat more balanced meals, the web app categorizes food photos based on participant-tagged food groups (fruits, vegetables, grains, protein, dairy, oils (Choosemyplate.gov)). For participants who would like to monitor specific ingredients, the web app categorizes food photos by the ingredient amount specified by the participant (“none”, “some”, “a lot”, “not sure”). For participants who would like to understand the relationship between food and mood or stress, the web app displays food photos categorized based on their reported stress and mood level (“bad”, “okay”, “good”). I iterated these categories with health experts in the research team to ensure the categories were easy to collect and useful for dietary consultation.

For IBS patients, the visual summary presents relationships between foods and symptoms. Patients can see these relationships in multiple ways, designed to support different questions patients and their providers might ask. First, Foodprint categorizes their food based on symptom severity (Figure 4, right). Patients can see the foods they ate up to 4 hours, 6 hours, 8 hours, one meal, or two meals before symptoms were logged. They can also choose to categorize their foods based on the food source and the preparation type. These categorizations allow patients to explore what might contribute to their symptoms based on individual experiences, such as how soon patients usually experience symptoms after they ate or whether they might be sensitive to how their food was prepared. Second, patients can see their symptoms and the foods they ate over time. This allows

patients to reflect on their day, to identify eating patterns or symptom patterns, and to explore triggers by recalling factors that might interact with what they ate (e.g., stressful days vs. relaxed days).

### IBS nutrient analysis report

The IBS nutrient analysis report developed by Schroeder et al. (2016) analyzed and visualized correlations between nutrients and symptoms to support hypothesis formation of possible IBS triggers. In this study, colleagues and I adapted the bubble and bar chart visualization (Figure 5) from the original report as an example of a quantitative analysis visualization to allow providers and patients to explore high-level relationships between nutrients and symptoms.

A trained dietitian analyzed the food photos patients collected using the Nutrition Data System for Research (NDSR) and decomposed these foods into 19 potential IBS triggering nutrients. We then performed regression analyses with reported symptoms as the dependent variable. We defined the independent variables as the amount of nutrient reported within four hours preceding a symptom report, informed by the time IBS patients reported between their eating and symptom flare-up in prior studies (Posserud et al. 2013).

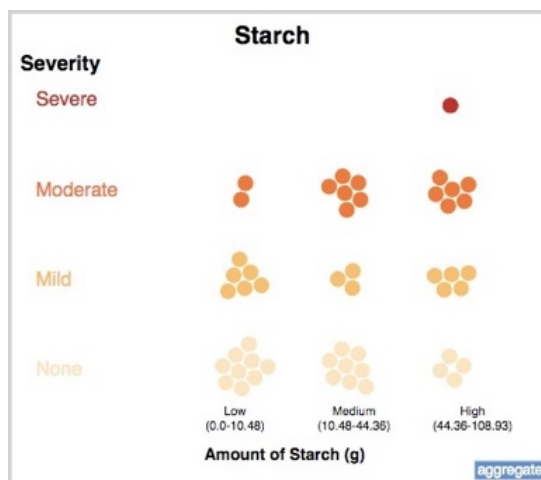


Figure 5. Bubble and bar chart in the IBS nutrient analysis report showing correlation between a nutrient (Starch) and a symptom (Abdominal Pain).

A NDSR analysis of a six-day patient-tracked data takes 3.5 hours on average, and scheduling this analysis caused a one to two-week delay before results were available. As a result, we were unable to provide real-time access to the IBS nutrient analysis report. We thus introduced the visualizations of quantitative analyses to patients and providers at the post-interview, and so patients did not have access to it while tracking or preparing their pre-visit notes.

### **5.2.3 Pre-visit note**

Prior research shows that understanding client goals helps providers collaboratively review self-monitoring data (Chung et al. 2016; Halpert et al. 2010). Therefore, I asked participants to fill out a pre-visit note summarizing their findings from the data, goals for the upcoming visit, and questions they would like to ask health experts in the visit. I designed the pre-visit notes as a paper-based artifact because health experts thought that paper provides better affordance (as described in Chapter 4) and allows them to refer to patient goals and questions while reviewing the patient-tracked data on the screen.

## **5.3 SUMMARY OF CONTRIBUTION**

In this chapter, I presented the design of Foodprint, a photo-based food diary and visual summary system that supports low-burden data collection and collaborative reflection. Building on formative studies described in Chapter 4, I designed Foodprint to support people and their health experts to communicate about individual goals and expectations, to exchange knowledge to support data interpretation, and to develop actionable plans. In the next chapter, I will present a field evaluation using Foodprint to support healthy eating and IBS.

## **CHAPTER 6. IDENTIFYING AND PLANNING FOR CHANGE: PATIENT-PROVIDER COLLABORATION USING FOODPRINT IN HEALTHY EATING AND IRRITABLE BOWEL SYNDROME**

In this chapter, I continue to examine RQ2 (How can design address current barriers to collaboration and support collaboration goals) by introducing a field evaluation. Building upon Chapter 4 in which I discussed supporting collaboration throughout personal tracking process: preparation, collection, integration, reflection, and action, I focus the design and research questions on supporting activities in these stages. Patients and providers often transform self-tracking data into various formats, such as annotated notes, in collaboration. They use these formats as part of including patient goals and constraints into discussion, collating information from various sources into clinical decision making, and structuring plans that patients can follow after visits. Therefore, through the lens of boundary negotiating artifacts (Lee 2007), I examine how photo-based diaries should be designed to support patient-provider collaboration. I focus on the following research questions as part of the investigation of RQ2 (How can design address current barriers to collaboration and support collaboration goals): How can photo-based food diaries be designed to serve as boundary negotiating artifacts to support people and health experts to collaborate?

### **6.1 METHODS**

I introduced Foodprint to 17 people with healthy eating goals and 8 health experts as well as 16 IBS patients and 8 health experts to understand its use in patient-provider collaboration. To understand tradeoffs between photo-based summaries and quantitative analysis summaries, I presented the quantitative analysis visualization to half of IBS patient-provider pairs (8 patients with 3 providers).

### 6.1.1 Study design

The study consisted of four stages:

**1. Pre-interview.** During this 30-45-minute session, colleagues and I interviewed participants about their experience pursuing healthy eating goals or managing IBS as well as tracking and sharing dietary intake data. We then introduced and installed the Foodprint mobile application on the participant's phone and explained the features of both the mobile application and the web application.

**2. Food tracking.** We requested that healthy eating participants track their food for three to four weeks, similar to prior studies of photo-based dairies (Baumer et al. 2012; Cordeiro et al. 2015). IBS participants were requested to track their food and symptoms for six days following current clinical protocols (Zia et al. 2016). For all participants, we recommended but not required that they follow a “three-days-on and three-days-off” protocol (i.e., they start by tracking their food for consecutive three days, then take a break for three days, and resume the tracking for another consecutive three days) to avoid data entry fatigue (Barney et al. 2010; Catsos 2012; Thompson and Subar 2008). We also instructed participants to take photos even when they previously forgot (e.g., empty plates, wrappers, or other objects).

**3. Post-interview.** 11 participants kept tracking until or beyond the post-interview. For the rest of the participants, the post interviews were scheduled between 4 to 84 (Median: 27) days and 4 to 12 (Median: 8) days after IBS and healthy eating participants finished their tracking, respectively. The duration is similar to the time patients spent on scheduling a return visit with IBS specialists or a general diet consultation (Thompson and Subar 2008). The post-interview consisted of two phases. In the first phase, we invited participants and health experts to review participant-tracked data separately using the Foodprint web application. Health experts also had access to client notes about their goals and questions to support their individual review. This phase took 30-45 minutes. In the

second phase, participants and their paired health experts were invited to review participant-tracked data together in a 15-20 minute visit, which is similar to the amount of time patients and providers would spend in a typical primary care visit (Tai-Seale 2007). We then asked participants and health experts additional questions regarding their experience of reviewing participant-tracked data together. All IBS post-interviews were conducted in-person. 11 out of 16 healthy eating post-interviews were conducted with remote health experts via video conferencing tools.

**4. Follow-up survey.** A month after the post-interview, we sent participants a survey asking what dietary or other behavior changes they intended to make after the study and what changes they had made since finishing the study.

### **6.1.2 Participants**

Across two studies, 33 patients and 16 health providers used Foodprint.

#### **Healthy eating participants**

We recruited 23 people with healthy eating goals and 8 health experts with dietary consulting experience (Table 4, Table 5). We recruited participants with healthy eating goals through social media and mailing lists associated with University of Washington. We asked potential participants to fill out a screening survey and used their responses to assign people into three different groups: balanced diet, ingredient monitoring, and lifestyle factor monitoring (e.g., stress or mood). We assigned people to the group matching the health goals they described in the survey to ensure their motivation and encourage participants to focus on one goal at a time. Participants were compensated with a \$30 gift card and a free consultation. We recruited 8 health experts through prior studies in University of Washington and snowball sampling. All health experts are certified in nutrition consultation with more than two years of professional experience. Health experts were compensated with a \$50 Amazon gift card.

Of all 23 people who participated in the pre-interview, two decided to prioritize other aspects of life over healthy eating goals during the second week of the study. Another four did not respond to our invitations for the post-interviews. These six people tracked for 6 days on average, ranging from 2 to 8 photos per day. In the following sections, I report findings based on the remaining 17 participants and their interactions with the health experts. Despite our effort in recruiting diversely, more of our participants were female (13) than male (4). The gender difference was potentially due to self-selection: women tend to eat healthier and choose healthy food more than men (Béland 2002; Hardin-Fanning and Gokun 2014). On average, these 17 participants tracked for 21 days (SD=7.6) with 3.5 photos per day (SD=2.1), which is more than our recommended number of tracking days.

Table 4 Healthy eating participant demographics, goals, and paired providers

No.	Age	Gender	Healthy Eating goals	Study period	Days of tracking	No. of photos	Paired expert
HP2	19	F	Balanced diet	36	27	46	HD9
HP4	21	F	Balanced diet	27	12	26	HD3
HP5	40	F	Balanced diet	28	19	80	HD5
HP6	21	F	Balanced diet	31	13	16	HD3
HP7	28	F	Ingredient monitoring (sugar)	30	29	70	HD7
HP8	20	F	Ingredient monitoring (lean protein)	47	26	52	HD5
HP10	30	M	Ingredient monitoring (sugar)	25	18	75	HD3
HP12	18	F	Balanced diet	35	26	53	HD5
HP16	25	F	Balanced diet	28	14	23	HD5
HP17	30	F	Balanced diet	22	14	50	HD5
HP18	26	M	Stress and mood monitoring	25	23	116	HD8
HP19	52	F	Balanced diet	27	27	259	HD7
HP20	66	M	Ingredient monitoring (sugar)	21	18	55	HD4
HP21	69	F	Ingredient monitoring (sugar)	26	14	20	HD5
HP23	27	F	Stress and mood monitoring	34	22	50	HD6
HP25	25	F	Stress and mood monitoring	40	40	247	HD10
HP26	25	M	Stress and mood monitoring	23	14	35	HD7

Table 5 Healthy eating expert demographics

No.	Gender	Expertise	Years of experience
HD3	F	Health coach	7
HD4	F	Clinical dietitian	10
HD5	F	College sport dietitian	9
HD6	F	Dietetic Intern	2
HD7	F	Dietetic Intern	2
HD8	F	Supermarket dietitian	11
HD9	F	Nutritionist	14
HD10	F	Nutritionist	3

### IBS participants

We recruited 16 IBS patients and 8 providers with experience working with IBS (Table 6, Table 7). Participant gender distribution was consistent with IBS diagnoses (Canavan, West, and Card 2014). We recruited patient participants through prior studies conducted at University of Washington and provider participants through our medical collaborators. Participants were compensated with a \$30 gift card and a free consultation. Providers were compensated with a \$50 Amazon gift card. We randomly assigned patients to a Foodprint only group (FP), in which patients used the Foodprint system with the photo-based visualization view throughout the study, and a nutrient analysis group (NA), in which patients used the Foodprint system with the photo-based visualization view throughout the study but had a chance to see the IBS nutrient analysis report during the post-interview. IBS patients and providers in the NA group could choose to review patient data using photo-based visualization view, IBS nutrient analysis report, or both views. On average, these 16 participants tracked for 12 days ( $SD=9.3$ ) with 5.1 photos per day ( $SD=2.4$ ).

Table 6 IBS participant demographics, goals, and paired providers

No.	Age	Gender	Years of symptoms	Study Period	Days of tracking	No. of photos	Study group	Paired provider
IP1	40	F	3	8	6	33	NA	ID7
IP2	36	F	15	22	23	123	NA	ID1
IP3	27	F	8	11	8	33	NA	ID2
IP4	37	M	10	9	6	29	FP	ID4
IP5	36	F	4	7	6	19	FP	ID3
IP6	74	F	30	15	10	33	FP	ID4
IP7	31	M	2	11	7	48	FP	ID5
IP8	43	F	24	11	8	44	NA	ID2
IP9	40	M	10	47	43	169	NA	ID1
IP10	34	F	12	20	13	53	NA	ID6
IP11	32	F	11	11	10	101	NA	ID2
IP12	64	F	50	10	8	33	FP	ID4
IP13	54	F	2	21	13	62	NA	ID6
IP14	27	F	17	17	10	60	FP	ID7
IP15	27	F	4	16	9	104	FP	ID7
IP16	27	F	2	15	9	35	FP	ID8

Table 7 IBS provider demographics

No.	Gender	Expertise	Years of experience
ID1	F	Dietitian	18
ID2	F	Gastroenterologist	20
ID3	F	Dietitian	21
ID4	F	Primary care physician	21
ID5	F	Nurse practitioner	34
ID6	F	Nurse practitioner	4
ID7	F	Gastroenterologist	10
ID8	F	Internal medicine physician	3

### 6.1.3 Analysis

We audio recorded and transcribed all interviews. We analyzed the transcripts using affinity diagram analysis (Holtzblatt, Wendell, and Wood 2004). From the transcripts, we created around 1800 affinity notes, which we iteratively organized into 80 first-level categories and 15 second-level categories. After iterative discussions, we focused on themes related to patient-provider collaboration and tradeoffs between different ways of collecting and reviewing food data to support healthy eating goals and IBS trigger identification.

## 6.2 CASE STUDIES

In this section, I first present four case studies that represent the 17 Healthy eating and 16 IBS collaborative reviews we observed in the study. These case studies illustrate how participants and health experts used Foodprint to collaboratively review food data as well as sharing their expertise and knowledge to support collaborative healthy eating strategies and IBS trigger identification.

**Weight loss as a medical student (HP10 and HD8):** HP10 wanted to lose weight and eat healthier. He had used MyFitnessPal to count calories before but found that he had problem fitting the food tracking and analysis process in his busy schedule. When he met with HD8 after using Foodprint for 18 days, HD8 was surprised that his photo views were full of granola bars, cereals, and peanut butter sandwiches. However, HP10 explained that he was a medical student on rotation and therefore did not have time to prepare food and did not have regular eating schedule. His main food source was the cafeteria in the hospital, which unfortunately did not provide many healthy eating options. Therefore, instead of providing general healthy eating recommendations, such as eating more vegetables or home-made food, HD8 spent time recommending specific alternatives to the cafeteria, such as healthy snacks or easily-made food that HP10 can incorporate to his routine.

**Balanced diet as a college student (HP6 and HD3):** HP6, a college student, wanted to make sure her diet was balanced. When HD3 reviewed HP6's Foodprint data, she found that HP6 only had one photo a day and suspected that she forgot to track her food. When HD3 met HP6, however, HD3 found that HP6 only made one (dinner) meal a day and ate it throughout the evening and the next morning. She also mentioned that she often forgot to eat during day time when she was occupied by school and her part-time job. Although HD3 thought each meal she ate was balanced, she also realized HP6's eating routine might have affected her sleep and energy level through

conversation with HP6. Therefore, HD3 worked with HP6 to brainstorm strategies and helped her to setup reminders to incorporate more frequent meals throughout her day.

**Identifying additional IBS triggers and finding food substitutions (IP2 and ID1):** IP2 has had digestive symptoms for 15 years and was diagnosed with IBS 8 years ago. She knew that she could not tolerate dairy, greasy food, or large portions of foods but still had symptoms even when she avoids these choices. When she met with ID1, ID1 first asked about her prior IBS diagnosis and experiences of symptom management. Then ID1 asked about what she found through IBS Foodprint. IP2 pointed out on the website that she had a severe symptom flare-up after a dinner in an Indian restaurant and explained that it might have been because Indian food tends to be greasier. However, ID1 looked across the food photos in the severe-symptom column and offered another observation: she asked if IP2 used onions and garlic in other food photos shown in the severe-symptom column. ID1 explained that onion and garlic looked like common ingredients in her foods, but they are also one of the common FODMAP (Fermentable Oligosaccharides, Disaccharides, Monosaccharides and Polyols) foods that can trigger IBS symptoms. ID1 then suggested that removing onions and garlic from her diet could be an easy next step and more feasible than adopting the whole low FODMAP diet or an elimination diet trial. Knowing that IP2 appreciates delicious food, ID1 also offered recommendations on substitutions for onions and garlic, such as scallions, olive oil infused garlic, and asafoetida. In the follow-up survey, IP2 responded that she had been experimenting with different recipes with garlic and onion substitution.

**Eating routine change to manage IBS symptoms (IP7 and ID5):** IP7 has had digestive issues for two years. After two visits with his primary care doctors and one visit with a dietitian, he determined that his IBS symptoms might be triggered by spicy food, dairy, and overeating. During his visit with ID5, they first went over his practices for recording food photos using IBS

Foodprint to understand how representative the 7-day record in the system was. Then ID5 noticed in the timeline view that P7's symptoms usually occurred during early morning and asked about IP7's routine from dinner time to the next morning. IP7 described that he suspected the portion size of his dinner or the coffee or tea in the morning might have contributed to his symptoms. D5 offered similar observations and asked what IP7 wanted to act on first. IP7 originally wanted to eliminate caffeine, but after discussing with ID5, he thought it might be difficult to overcome his caffeine dependence. IP7 then decided to try smaller, frequent meals but did not know how to start. ID5 offered some best practices based on other patient experiences and strategies for further food and symptom tracking to understand the influence of his new diet plan.

### **6.3 RESULTS**

As we can see in the case studies from the previous section, interpreting self-tracking data required both individual expertise about their routines and experiences as well as health expert medical expertise. Across all healthy eating and IBS visits, participants and health experts did not review ingredients or nutrients item-by-item, as they would have with text-based diaries. Instead, photo-based visualizations allowed them to quickly get an overview of eating patterns and context. Participants and health experts then were able to focus on communicating participant goals and expectations, exchanging observations and context to support collaborative interpretation, and developing actionable plans. Health experts said reviewing participant-tracked data using Foodprint was feasible in the visits and ten (ID1, ID3, ID6, ID7, ID8, HD3, HD5, HD6, HD7, HD8) asked to continue using Foodprint with other patients or clients.

As described in Chapter 5, I designed Foodprint as boundary negotiating artifacts to support collaboration between individuals and health experts. During collaborative review, participants and health experts used Foodprint as different types of boundary negotiating artifacts to support

collaboration. When participants started tracking, the mobile app and the web view served as *self-explanation artifacts* that allowed participants to record their food data and review the food relationship based on their health goals using the web view. When participants met with health experts, they reflected on their expectations to the visit using the pre-visit notes and used them as *inclusion artifacts* to include participant health goals, routines, and expectations for the visit into discussion. When developing symptom management plans or healthy eating strategies, participants and health experts used data in Foodprint as *structuring artifacts* to help participants follow plans. In this section, I focus on the collaborative use of Foodprint: how participants and health experts use Foodprint as *inclusion artifacts* and *structuring artifacts* to support collaboration.

### **6.3.1 Inclusion Artifact: Seeing eating patterns was useful for dietary consultation**

Similar to prior studies of photo-based diaries (Baumer et al. 2012; Chung et al. 2017; Cordeiro et al. 2015), all experts and participants thought it was easy to see overall eating patterns from photos. Working with healthy eating participants, who recorded an average of 75 photos across 21 days, experts and thought they could see the patterns of eating habits in a glance using the photos. HD8 started the conversation with HP18 by quickly summarizing his diet: *“I see your meal pattern here is pretty consistent as far as the spread through the day. Looks like you have three meals a day, and then you drink coffee and tea throughout the day and then...always a snack here and there?”* Similarly, IBS providers commented that being able to see overall eating patterns easily helped them develop hypotheses to discuss with patients. Seeing visualized photo summaries helped ID5 focus on overall food patterns: *“I really liked the pictures, because if you had brought me a list of what you ate, it would have been harder for me to go through. I mean, you may have almonds, papaya, chicken tofu, ... you know, it's kind of dry. This helps me know and think what food we're talking about here.”* Many IBS patients and providers found new relationships or confirmed suspected

relationships between food and symptoms using Foodprint. Of all sixteen IBS patients, nine patients (IP1, IP2, IP3, IP5, IP7, IP8, IP10, IP13, IP14) found new foods that might be potential triggers. Five patients (IP4, IP6, IP9, IP12, IP16) substantiated triggers they knew before participating in the study. Two patients (IP11, IP15) even identified non-food triggers.

Health experts thought that photos provided a more transparent view of what participants actually ate. Ten health experts (HD3, HD5, HD7, HD8, HD9, HD10, ID1, ID3, ID6, ID7) thought that compared with text-based journals, in which their clients often had problems filling out all the details about food, photos can present participant food intake more accurately and precisely. In turn, health experts thought these more accurate and objective records could help them conduct more in-depth probing and trust the data more: *“There's a sense of transparency because I'm seeing exactly what she's eating. I'm able at my work to ask more questions and I think that's great as opposed to like MyFitnessPal because you have just what they're saying. Like, 'I only had a half a slice of pizza' and in all reality the person had like three. Or, 'I had one scoop of ice cream, but no, I really had the whole pint.' I think there's no fibbing so you get a much more accurate aspect. I think also that could build a lot more of a connection and honesty and transparency in a client and nutritionist relationship”* (HD9).

All health experts and participants also thought photo-based diaries provided more food details that were useful in dietary consultation. As in previous studies focused on personal use of photo-based food diaries (Cordeiro et al. 2015), Foodprint participants found that instead of caloric information, photos captured more contextual information (e.g., when, where, how) and were more interpretable using general nutritional knowledge. Additionally, health experts in our study found that this information helped them to provide better assessment of participant eating behavior and personalized recommendations. HD7 compared the photo review experience in the study with her

prior experiences reviewing client MyFitnessPal records: *“I think you get more information of what things, what their meals look like. I think it's interesting to have the information of who are they eating it with, how were they feeling when they ate it, how did they prepare it? I think that, to me, is more useful than how many calories or grams of fat were in something.”*

### **6.3.2 Inclusion Artifacts: Pre-visit notes supported explicit communication about patient goals**

Understanding patient goals helps providers focus on patient priorities and manage visits to address patient needs (Chung et al. 2015). However, patient-provider communication in the visits are constrained by time, and patients and providers often have different concerns and cannot address all at the same time (Andersen et al. 2014; Berry et al. 2017). For example, in the pre-interview IP2 described her frustrating experience working with providers: *“doctors were like, ‘Oh my time's running short, here's a list of things like follow this, like here's the FODMAP diet.’ They would do all that, take a diary, do an elimination diet, all this stuff, and I'm like well but that still doesn't really give me any answers.”*

In Foodprint, to support patient-provider communication about goals, all health experts had access to patient pre-visit notes. These pre-visit notes served as an *inclusion artifact* that made health experts more aware of patient expectations and questions for their discussion. Many health experts started the visits by confirming the visit goals participants specified in the note or explicitly asking participants what they need help with. Being able to quickly see overall patterns using the photo-based visualizations also allowed participants and health experts to spend more time on patient goals. For example, instead of going through food photos item-by-item, HD6 spent time on talking about HP23's goals: *“I want to start first with like what your goals are in this visit before we even dove into the nitty gritty details of what you're eating and everything like that.”*

When HD6 realized that HP23 avoided fruits because she thought sugar in the fruit might hinder her from losing weight, HD6 emphasized the benefits of fiber in fruits and recommended fruits with less sugar to HP23: “[fruit] also has a ton of fiber and fiber will definitely help you like stay fuller longer. And it helps keep things flowing”. Similarly, IP2 wrote that her goal for the visit was “Find safe and tasty foods to eat that don’t cause IBS symptoms. Figure out what/why causes IBS.” Knowing that having tasty food is as important as eliminating symptoms, ID1 told IP2: “I really appreciate you taking the time to write out your goals, so that really makes it clear to me what you would like to accomplish.” They then spent time on discussing food substitutions to make sure IP2 can still enjoy her food while decreasing her symptom flare-up.

When we asked health experts and participants what helped during the collaborative review, many providers pointed to having the pre-visit notes so they could understand patient goals and focus during the 15-minute visit: “Because I could see her goals and so I had an idea of what I was going to talk about. And fit the session within the timeframe that we had. It’s nice to be able to see what the client wants to go over, and things that you’re gonna plan on talking with the client on” (HD5). ID7 mentioned that she could see that some fruits might have caused some mild symptoms for IP15 during the individual review. However, during collaborative review, IP15 expressed that she did not wish to restrict her diet more. ID7 and IP15 thus went on to talk about another finding IP15 listed on her note: her symptoms might be exacerbated by stress. Following up on this finding, ID7 and IP15 spent the rest of the visit brainstorming strategies for managing stress. Participants also appreciated that they could communicate their expectations and preferences to health experts. IP8 said that she was okay with mild symptoms, but she would like to know more strategies for mitigating severe symptoms. Having a conversation with ID2 helped

her identify how to choose food even when she has limited food options (e.g., volunteering in a summer camp) or when she has no control over what triggers her symptoms (e.g., menstrual cycle).

### **6.3.3 Inclusion Artifacts: Photo-based visualizations enabled participants and health experts to exchange knowledge and context to support collaborative interpretation**

Despite the importance of including contextual data and patient knowledge to interpret data (Andersen et al. 2011; Mentis et al. 2017; Schroeder et al. 2017), patients and providers find it difficult to incorporate this information when reviewing self-tracking data (Chung et al. 2015; Chung et al. 2016; Gabriels and Moerenhout 2018). Using Foodprint as an inclusion artifact, participants and health experts naturally exchanged their knowledge about healthy eating strategies and IBS management throughout the visits. For example, ID8 mentioned it was easy to learn about IP10's routine in the collaborative interview: *"I could ask for more clarification on the meal, and where he got it. I was able to get from him the reason why, and I wouldn't have known his schedule and his pattern, that he works overnights, and being in med school [without talking to him]."* Even though all health experts have extensive experience of dietary consultation and could identify patterns by looking at the photo-based visualizations, they often relied on participant experiences to support data interpretation.

All health experts asked participants questions about their overall eating routines and/or symptom patterns, as well as whether the recorded data was representative of the participant's everyday life. Health experts addressing healthy eating goals often wanted to know what strategies participants have tried and barriers they encountered to help contextualize the eating pattern shown in the photo-based visualization. For example, knowing that HP19 tried several types of diet plans but could not continue because she did not enjoy the food, HD7 focused on increasing the variety of choices aligned with her preference instead of limiting specific food or ingredient. ID2 similarly wanted to know what patients

had tried avoiding, so she could develop more precise hypotheses about potential triggers or understand patient preference. For example, knowing that IP11 ate a trigger food (cherries) out of preference rather than lack of knowledge, ID2 said she would not push her to eliminate cherries.

These questions about participant routines, combined with conversations about participant tracking practices, helped health experts understand how they should interpret the data. For example, HP26 had been on a low-carb diet for three years. He often worried that eating out might affect his established routine. Discussing these feelings led HD7 to realize that they could work on brainstorming choices when eating out and developing healthy mindset with food at the same time: *“Recognizing that you obviously are eating, really great, beautiful, delicious-looking vegetable-full food that, eating noodles once a week, it's not going to drastically affect your health in any way.”* IBS participants often have individual definitions of “severe symptoms” versus “mild symptoms.” Therefore, patients and providers often needed to clarify the definition during collaborative review. For example, IP2 only recorded her symptoms as binary—“severe” or “no symptom”—because it was easier for her to record and it better described the acuteness of her symptoms. On the other hand, IP9 described his symptoms as mostly “mild,” but occasionally he would have “severe” episodes that *“I barely made it [to the bathroom], and I couldn't get out of the bathroom for a really long time.”* Talking about these definitions with IP9 helped ID1 understand participant experience better and provide more individualized diagnosis and treatment. Some health experts also wanted to know how much time passed between eating and an individual patient symptom flaring up. ID7 thought that having a medical assistant go over these details could help her focus on setting the right filters in the system, which might provide a more specific dataset for collaborative review.

Many health experts and participants also discussed details about specific foods or meals, especially when participants had questions about particular foods, when experts explained their recommendations, or when these foods potentially trigger severe IBS symptoms. For example, when brainstorming easy ways to increase protein at breakfast, HD5 recommended nuts to HP16, explained the amount of protein and calories in different types of nuts, and suggested serving sizes for each. Similarly, ID3 found that IP5 had a very restricted low FODMAP diet but had nuts (a high FODMAP food) in most of her meals. When ID3 asked how well IP5 tolerated those nuts, IP5 explained that she found soaking the nuts helped with digestion, but she did not know why. ID3 then explained that soaking helps leach out some of the FODMAPs. She also went on to provide another food recommendation: *“We see that with tofu, too. Firm tofu is low FODMAP because they’ve kind of drained all that liquid out of there. And the FODMAPs and fermentable carbs tend to leach out with that. Whereas silken tofu, they blend that liquid in there so there’s more FODMAP content in there.”*

Health experts applied their knowledge about nutrition and their experience with other patients to help participants identify patterns or triggers they did not know about before. For example, both HD8 and HD5 pointed out that HP8 and HP10 ate more Cheetos and chips when they were stressed and tired. Both experts explained that from their experience, people tend to eat crunchy foods when they are stressed. Both experts recommended alternatives, such as dry roasted edamame or wasabi peas, to HP8 and HP10. On some occasions, IBS patients were aware of some foods that trigger their symptoms but were not able to identify the common themes across foods. For example, IP2 and IP9 did not know that foods causing their severe symptoms contained the common triggers onion and garlic until ID1 pointed them out. IP8 and IP11 knew that they could not have too many cherries and ID2 explained to them that stone fruits are high FODMAP foods that commonly trigger IBS symptoms. IP12 thought she was lactose intolerant and substituted her

milk to almond milk but still found she had inconsistent reactions to the almond milk. When she discussed this problem with ID4, ID4 looked over those photos and pointed out that it might be the cereal she commonly ate with milk causing her symptoms: *“it doesn't make sense to me that you would have symptoms with almond milk, and it makes me wonder: is it actually the wheat in the raisin bran oatmeal squares, rather than the milk?”*

#### **6.3.4 Inclusion Artifact: Photo-based visualization and quantitative analysis visualization supported different collaboration goals**

During collaborative review, all eight IBS patient-provider pairs who had opportunities to see the IBS nutrient analysis report (Figure 5) chose to review the photo-based visualizations first. Three patient-provider pairs (IP6, IP8, IP10) chose to use the IBS nutrient analysis report later. When we followed up about why and how they would use two systems in future visits, patients and providers described the tradeoffs they saw in each.

All IBS providers who had access to the IBS nutrient analysis report (ID1, ID2, ID6) thought that photo-based visualizations provided a good overview to start the conversations with patients. They also thought that going through photos helped patients remember the food details and eating context, which is helpful for trigger identification and symptom management. ID2 thought that talking about food through photos is a more natural conversation to start with than nutrient details: *“They [patients] can remember what they eat, and that's easier than pulling up something like, fructose, when you have to go explain what fructose is, and that's not something people talk about as much.”* However, if patients and providers cannot find clear relationships from the photos, ID2 appreciated having the visualizations of quantitative analyses to help her do more in-depth analysis: *“You can really go through every single thing and say, just by all the different foods you ate, with different levels of carbohydrates, we haven't found food that triggers it. Maybe it's not food.”*

All providers and patients also thought that photo-based visualizations might be easier for patients as they start looking for potential triggers, especially when patients were new to IBS. On the other hand, visualizations of quantitative analyses can help patients who struggle with identifying triggers to understand underlying nutrient-symptom relationships. IP8, who already knew some major food triggers and had limited her diet to avoid them, compared the two systems by reflecting on her own experiences: *“10 years ago probably the other one [Foodprint] would have been more helpful because I wasn't as aware of what my problems were, but this one [IBS nutrient analysis system] breaks it down more and would be helpful for me now.”* She was also motivated to track her food and symptoms longer and wait for extra processing time for the quantitative analyses: *“this isn't real time because someone has to analyze it, but it would be interesting to see a longer period of time what the breakdown would look like. ... I've had this for 20 plus years. Doesn't bother me to keep track of it for longer.”*

Providers and patients appreciated having two different systems to support IBS trigger management. However, patients stated that they would prefer to review the IBS nutrient analysis results with a provider rather than trying to understand it by themselves: *“there's a lot of information here, and I don't understand everything exactly. I like how it's broken down, but I think I would probably have ended up confusing myself a little bit”* (IP2). ID2 shared a similar concern regarding going through visualizations of quantitative analyses with patients who might not be familiar with it: *“For people who aren't as comfortable with this data representation, it may take a little bit longer to go through and to explain how we're interpreting it and why.”*

### 6.3.5 Structuring Artifacts: Seeing patterns and eating context enabled personalized, actionable plan development

Traditional diaries rarely provide effective summaries to help providers develop individualized, actionable recommendations (Chung et al. 2015; Schroeder et al. 2017). Because of this, many IBS patients said they only received generic recommendations based on the provider's training and aggregate experiences with prior patients: *"the main answer I got from him [primary care doctor] was, 'Yup, it sounds like a textbook case' and then we talked for a while about the different responses that people sometimes have. It was instructive, but in terms of pinpointing them [potential triggers] or anything else, it was more of me trial and error"* (IP11). In our study, health experts and participants were able to identify eating patterns or potential triggers quickly and used Foodprint as a structuring artifact to discuss actionable next steps.

Once health experts and participants identified potential food related triggers, they focused on eating strategies or trigger food substitutions. Most health experts had conversations with patients about their personal preferences, routines, and limitations to identify at least one thing they can try at a time. For example, HD8 found out from the photos that HP18 usually had takeout for lunch and knew that he wanted to improve that from the pre-visit note. She then asked what HP18's lunch routine looks like to understand what they could work on: *"maybe you don't have fridge at work and maybe you only have the option [eating out]. Socially too maybe that's what your coworkers are doing is going out to eat. So you certainly don't wanna miss out on that, but even with going out we can focus on healthy choices."* Knowing that IP7 wanted to adopt small, frequent meals, D5 asked about his work schedule: *"In the kind of work that you do, do you have control over your day, so that you could actually every two hours step out and do something or are you at a kind of job where you can take breaks at specified times?"* They also went back to the food photos and found examples of small-portion meals: successes that IP7 could replicate later. This conversation helped them design

strategies to split meals into smaller portion across a day. ID1 recommended IP9 read a recently published book on IBS diet research that provides substitutions and recipes for low FODMAP diet. ID3 thought IP5 had too restricted of a diet and tried to help her increase the variety of food in small quantities. To do so, she provided a handout and highlighted recommended portion of high FODMAP foods that IBS patients might be able to tolerate.

Health experts also suggested ways to experiment and understand the effects of these eating strategies or other factors that might trigger patient symptoms. HD5 encouraged HP16 to add more protein to her breakfast: *“Just experiment and see. Maybe for a week, try a slightly higher protein breakfast, and see if you feel a little bit more energized in the morning. Maybe you notice that you're not getting quite as hungry before lunchtime, too.”* ID4 asked IP12 to eat milk with a different type of cereal and take photos of those meals for two weeks to see if it was really the milk, not the cereal, causing her symptoms. ID7 and IP15 determined that stress might be the trigger that IP15 was most willing to change. ID7 asked IP15 to use IBS Foodprint to record her stress instead of food using photos: *“why don't we consider re-doing this: let's have you rate your symptoms with your fingers. You could put a five or four with your fingers to rate your stress at the end of the day so we can get a better sense.”*

## **6.4 DISCUSSION**

Foodprint supported participants as they collected food data relevant to their health goals and enabled them to reflect on their data as well as focus on their goals and questions when reviewing the data with health experts. There are opportunities for future systems and technologies to further support these collaboration processes. Future systems should continue to help people in their tracking process so that they can focus on their health goals and the collaboration goals. Designers should also examine how to help people transition among tools supporting different health goals.

With more technologies supporting automated analysis become available, more research is needed to understand the tradeoff between the benefit of processing huge amount of data more efficiently and the value of having conversation over and reflecting on data collaboratively.

#### **6.4.1 Supporting collaboration throughout different tracking stages**

As described in Chapter 4, individuals and health experts collaborate on using personal informatics data in every stage of self-tracking: preparation, collection, integration, reflection, and action (Li, Dey, and Forlizzi 2010). Foodprint supported these collaborations between participants and health experts. Foodprint prepared participants by helping them focus data collection on information relevant to healthy eating or IBS, minimizing the unnecessary data they collected while scaffolding them to collect sufficient data. Because I designed Foodprint with summary views for a larger screen, it also helped patients record their everyday experiences in a way they could later share with health experts. By providing a tool for low-burden, photo-based collection and accompanying it with additional questions relevant to their health goals, the system helped patients reflect while collecting data. Photo-based visualizations integrate self-tracking data to help participants and health experts see overview and patterns as well as reflect on these relationships individually and collaboratively. Participants and health experts were hence able to develop actionable plans to examine their hypotheses or for tuning their behavior.

I designed Foodprint to help participants focus on what they should track to support their health goals and the collaboration with health experts. Foodprint provided configuration based on the understanding of these goals and therefore minimized the consultation and user-directed configuration in the preparation stage. Future systems integrating prompts and reflective questions into tracking tools may further help people think about their data even without, or with fewer, face-to-face visits with health experts. Recording participant input in the pre-visit notes over time can

also present a history of hypothesis development, verification, and behavior modifications that might help health experts understand patient experience and provide educational opportunities. In practice, before more systems are available to help people scaffold decisions about what to track, encouraging people and health experts to have a conversation about individual tracking plans could better support later collaborative reflection.

Using Foodprint, participants and health experts iteratively built up stories and identified eating strategies or trigger management plans throughout every collaborative review session. While similar to when patients with Parkinson's disease and their providers review step data (Mentis et al. 2017), previous research reported that the collaboration in Parkinson's was largely physician-directed, while participants in our study took a more active role in interpretation and collaboration. I believe this was a result of participants having access to their photo visualizations throughout the study, being prompted to reflect on their data when filling out the pre-visit note, and making those notes visible to the health experts. At the same time, in remote consultation cases, the screen-sharing technology could potentially influence how people and health experts interact with the data. In nine out of eleven remote post-interviews, healthy eating experts shared their screens with participants; two participants shared theirs. In these cases, only the person who shared the screen could control the web view. While participants actively shared their interpretation based on their knowledge about the data and health experts acknowledged patient goals and questions from the pre-visit notes, technologies could better support these remote collaborations. Allowing both parties to simultaneously interact with a shared web view could help participants and health experts to be more engaged in the co-interpretation process during remote consultation.

#### **6.4.2 Considering participant goals and health expert roles when designing for collaboration**

Various factors can change expectations about collaboration. People sometimes have multiple health goals and different priorities in life. These priorities and goals, if not communicated between individuals and health experts, can sometimes lead to conflicting expectations about collaboration. For example, IP2 and IP11 would tolerate mild symptoms for foods they enjoyed. Without communication about these goals and choices, health experts might have recommended stricter diets for IP2 and IP11, contrary to their preferences. Health expert workflows might shape their interaction with patients, clients, and the systems supporting collaboration. For example, physicians who have short patient visits might expect that patients or systems can contribute overview and actionable insights than detailed information. In this section, I discuss future design and research opportunities to support collaboration with various health goals and various workflow constraints.

#### **Designing for collaboration using tools supporting different health goals**

Healthy eating participants often have more than one healthy eating goal. For example, participants who would like to monitor their sugar consumption also often care about whether their diet is balanced. All healthy eating participants mentioned in their pre-visit note that they would like to know if their diet is considered balanced and if there were other nutrients or types of food they should increase or avoid in their diet. Besides their primary goals, participants also wanted to increase energy (HP6, HP7, HP8, HP21), monitor portion size (HP4, HP12, HP23), understand relationships between food and health concerns (HP7, HP19, HP20, HP23), and find ways to accommodate their diet restrictions or preferences (HP2, HP10, HP18, HP26). Healthy eating participants and experts switched between the analysis page and the history page to answer different questions during visits. Health experts used the analysis page to get an overview of

participant eating patterns associate with particular goals (e.g., “*when you're stressed out what are you eating?*” (HD7 & HP26)) and then turned to the history page to see more general eating behavior (e.g., “*it's great like your normal routine is really consistent. we recommend three meals a day for sure*” (HD6 & HP23)).

On the other hand, IBS patients and providers mostly focus on trigger identification and management strategies and thus often stick to the analytics page. The interactive process IBS patients and providers went through were similar to the personal discovery stages in diabetes management (Albers et al. 2017): patients and providers often glanced at the overall pattern presented in the analytics page (feature selection), identified one or more potential triggers (hypothesis formation), and then quickly moved on to plans to confirm or manage these potential triggers (hypothesis evaluation and goal specification). However, contrary to the personal analysis stages that people with diabetes go through individually, IBS patients and providers had to explicitly communicate goals and exchange knowledge in all these stages to support collaborative review. IBS patients and providers switch to different visualizations in only five cases: when trigger identification was difficult using photo-based visualizations, three patients (IP6, IP8, IP10) and providers used quantitative visualizations to look into nutrient-symptom relationship; when visualizations showed that foods might not be triggers, two patients (IP11, IP15) and providers switched to the timeline view and discuss what other factors might contribute to patient symptoms.

There might not be any single system that can support the various goals people have. People who appropriate Instagram for use as a photo-based diary often use other tools concurrently to support their myriad healthy eating goals ( Chung et al. 2017). IBS patients might need different tools to support hypotheses formation and testing. For example, as described in section 6.3.5, when IBS patients and providers already narrow down their hypotheses to a few potential triggers, they

could use tools such as the self-experimentation tool *TummyTrials* (Karkar et al. 2016) to further test these hypotheses. To support long term use, future versions of Foodprint can allow people and health experts to collaboratively summarize their discussions and plans back to the system. People and health experts can then explicitly configure Foodprint to support subsequent tracking. They can also generate summary reports from Foodprint to serve as structuring artifacts to help people follow up on their plans using other tools. Many systems have proposed annotation features (Aarhus, Ballegaard, and Hansen 2009; Andersen et al. 2011) or summary sheets (Brubaker, Lustig, and Hayes 2010) that allow patients to integrate their knowledge into collaborative health decision making. Collaborative summarization and configuration can further help ensure both parties contribute their knowledge into the follow-up plans development and management.

Reviewing and summarizing using computer-based systems, however, might be still not as flexible as using paper-based tools. People and health experts, including many who participated in the studies in chapter 4, still rely on paper diaries because they can easily highlight or annotate data and can physically interact with these paper artifacts during face-to-face interactions. However, these advantages of paper diaries do not hold up when they are used in remote review. Notes also are easily lost as people transition from one tool to another, or from one week of the diary to the next. To support long-term collaboration using various tools, future research should continue investigate how to support people and health professionals to import, export, and integrate patient-tracked data among various tools.

### **Supporting health experts in different roles with different workflow constraints**

Health experts considered Foodprint useful for dietary consultations and many would use the systems outside of the study. They also considered reviewing photos before and during the visits to be much more efficient than reviewing text-based diaries. However, health experts have mixed

feelings about whether they should encourage their clients to review their own diaries beforehand. Some health experts thought that participants can recognize the trend on their own using photo-based diaries: *“I think that [HP7] was able to tie, being able to look at pictures of things and seeing or just having the visual and how that had affected her, like how she felt during the day”* (HD7). Others believed that reviewing data is their own responsibility, not clients’, and would prefer their that clients review the data with the experts: *“No. [I would not want my clients to review the data beforehand.] I just want them to live their life, record it, and then we talk about it together. Because I think people get bogged down with things and they get a lot of self-doubt and overwhelmed”* (HD3).

Many dietitians and nutritionists review diaries as their day-to-day job. They also have the nutritional knowledge for detail dietary review and 30-60 minutes to do so with their patients or clients. As a result, they considered photo-based diaries already saved their time and therefore do not need clients share more of the reviewing tasks. On the contrary, physicians normally have limited time to review diaries before or during a 15-20 minute clinical visit. Many physicians, as a result, expected their patients to review data before they met and would be able to provide more insights to help with review. Nevertheless, for both populations health professionals and participants believed collaboration played an important role in identifying patterns and developing actionable plans to address individual health goals. Clinicians in current and prior research (e.g., Chapter 4, Schroeder et al. 2017) have questioned who in the care team should review the data and can benefit the most from reviewing this data with patients. When multiple care team members are involved in decision making, systems summarizing and supporting one type of collaboration, goals, and workflow will also need to account for collaborations among care team members (Mishra et al. 2018). As self-tracking data becomes more common in the expert consultation or in the clinic, new roles might evolve to support collaborative review or data pre-processing.

Collaborative summaries that records review process, hypothesis generated, and plans developed can help other care team members follow up on further diagnosis and treatment design. Better integrating photos and summaries into electronic medical records can potentially help health experts more effectively include data from various source into decision making. Future research should continue to examine whether and how system designs can support or challenge existing/emerging workflows and routines in patient-provider collaboration.

#### **6.4.3 Tension between automated analysis and over-quantification**

Researchers (e.g., Albers et al. 2017; Pouladzadeh & Shirmohammadi 2017) have proposed ways to use automated filtering and analysis to help people review diaries more efficiently. More research is needed to develop and evaluate these automated mechanisms while retaining the value of photos and having people involved in the process.

Automated filtering could potentially help people and health experts focus on data most relevant to their health goals. For example, one IBS provider asked us if Foodprint could automatically hide photos of the same food if they appear in all “No Symptom”, “Mild Symptom”, and “Severe Symptom” columns, as it could indicate that this food might not be a trigger. However, each individual often has a personal threshold for FODMAP carbohydrates, meaning different people can tolerate different cumulative amounts. The ability to look at foods across a day instead of in a single meal provides a better understanding of what these thresholds might be, and so hiding some images could obscure this insight.

Automated analysis could potentially reduce the time people and health experts spend understanding the content of the food and support more detailed nutrient analysis. For example, not all people and health experts are familiar with FODMAPs, and they might appreciate having a system show them whether and what type of FODMAP each food photo contains. Automated

analysis could also possibly replace the process of the dietitians coding photos to support quantitative analysis, reducing costs and the delay between patients recording data and getting this feedback. However, automated analysis also can risk of over-quantifying self-tracking data and overlook the contextual information. Subtle differences in food preparation and context can result in different patient symptoms. Context captured in photos also often allows health experts to better understand their patients or clients, which is useful for identifying strategies for change as well as supporting affective needs. For example, ID7 found IP14 had photos showing the same breakfast in the car every day. These images did not help identify a relationship between foods and IP14's symptoms, but the photos communicated IP14's busy work routine. This discovery led them to have a conversation about how this work routine might have exacerbated P14's symptoms and what strategies they could adopt to address the situation.

Personal informatics researchers have questioned how much systems should automate the integration and reflection stages of tracking (Choe et al. 2017). Foodprint and its use surface additional tensions in deciding what analysis should be automated as well as who should engage in different integration and reflection activities when data from personal informatics systems are collaboratively reviewed. For example, more automated analysis could help save time in a short clinical visit, but at the risk of obscuring information that is necessary for identifying a trigger, for a patient receiving affective support from their provider, or for developing an appropriate plan to adjust one's diet.

Future research should continue investigate how to best design and integrate automatic filtering and analysis features into collaborative review. For example, comparing patient-curated view and automatic-filtered view in collaborative review sessions might reveal benefits, challenges, and additional needs when designing automatic features. Comparing summaries, questions, and plans generated from manual analysis and automatic analysis might also inform

what contextual data is important and how design can better support the collection and integration of this data into the analysis process.

## **6.5 SUMMARY OF CONTRIBUTION**

In this chapter, I evaluated the use of Foodprint between individuals and health experts via two field evaluations. The findings from these evaluations demonstrated design elements that can support people throughout their tracking processes for eventual collaboration. These findings also demonstrated design features that support collaboration goals: focusing on individual health goals, sharing knowledge and contextual information relevant to data interpretation, and developing actionable plans. As more technologies become available to improve ways people can collaborate with health experts on self-tracking data, researchers and designers should continue to examine how designs can account for various individual and collaboration goals, expert roles, and workflows.

## **CHAPTER 7. ADOPTING PERSONAL INFORMATICS TECHNOLOGIES IN CLINICS: IMPLEMENTATION OF A NEW KIOSK TECHNOLOGY FOR BLOOD PRESSURE MANAGEMENT**

To understand the process of adopting personal informatics technologies, I set out to answer RQ3 (How should new technologies that collect personal informatics data be adopted and integrated in current routines and workflows). Even with the benefits of thoughtful designs, adopting personal informatics technologies in existing workflows can be a significant problem. Especially in the collaborative health context, adopting personal informatics technology requires consideration and understanding of the routines and workflows of people in different roles as well as interactions among these roles. I examine RQ3 by investigating the barriers and facilitators to self-service blood pressure (BP) kiosks in a family medicine clinic. BP measurements in the clinic were traditionally conducted by medical assistants or nurses. With self-service kiosks, patients are required to take their own BP measurements. The adoption of self-service kiosks changes a clinical task into a patient task. As I will describe later in this chapter, the data provided by the kiosks also encourages patients to review and reflect on their own data individually and to discuss their blood pressure with medical professionals. The research reported in this chapter was also published in the *Journal of the American Board of Family Medicine* (Chung et al. 2016).

### **7.1 METHODS**

To understand the process of adopting BP kiosk technology, I partnered with a family medicine clinic and used a longitudinal, mixed-methods approach to explore the barriers and facilitators to implementation. We used the Consolidated Framework for Implementation Research

(CFIR) (Damschroder 2009) to guide our assessment of contextual factors that might influence the adoption of new workflows associated with BP kiosk use in primary care.

### **7.1.1 Study setting**

The study was conducted in a primary care clinic serving a small city and its outlying rural populations in Washington state. The clinic had six physicians, one physician assistant, eight medical assistants (MAs), and five front desk staff members. The clinic was part of a larger health system that includes a hospital and four other primary care clinics. The health system shares a quality improvement (Lean Six Sigma) team that helps to plan and evaluate clinic changes. The clinic is a member of the WWAMI region Practice and Research Network, a group of 50 primary care clinics in five northwestern states in the United States committed to collaborating with academic investigators on research that improves clinical practices. The investigators contacted clinic leadership about the opportunity to implement a self-service blood pressure kiosk. These leaders agreed to participate based on their interest in ensuring accurate BP measures throughout the clinic and in determining whether BP kiosk use shortens MA “rooming time,” allowing MAs to use that time to complete other clinic duties. Clinic leadership met with the Lean Six Sigma team to plan BP kiosk implementation and assessment.

In August 2014, the clinic installed two BP kiosks in the waiting room: one close to the front desk and one at the far end of the waiting room (Figure 6, left). The BP kiosk (PharmaSmart PS-2000; PharmaSmart, Rochester, NY) is cleared by the US Food and Drug Administration and is designed to be used without the help of a health professional. The BP kiosk obtains measurements with the individual seated to allow the feet to be placed on the floor and the arm supported at heart level, and it uses patented cuff technology that automatically adjusts to fit 97% of arm sizes. The BP kiosk has been validated as accurate compared with mercury manometer measurements (Alpert 2004) and 24-hour ambulatory BP monitoring (Padwal et al. 2015). The kiosk provides patients with a BP measurement printout and their classification according to the Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC7, National Heart Lung and Blood Institute 2004).

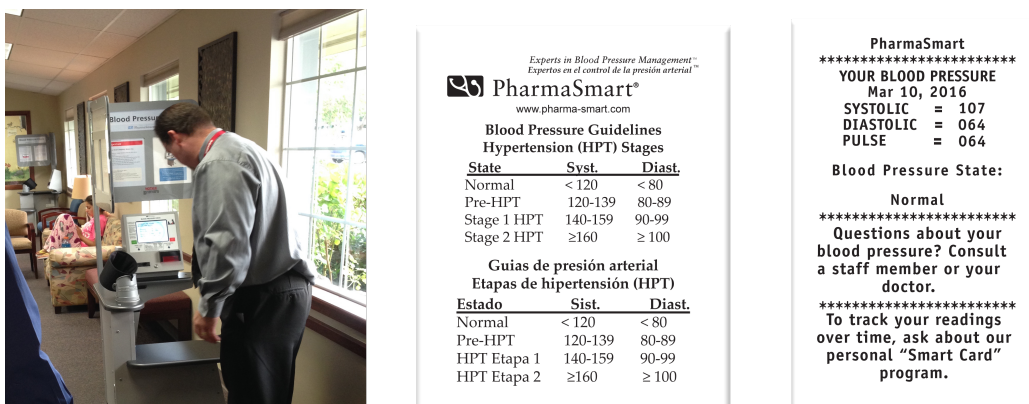


Figure 6. Left: Self-service blood pressure kiosks in the waiting room in the clinic. Middle and Right: BP printout with BP classification from the kiosk.

The clinic adopted the electronic health record (EHR) system in 2000. The clinic also implemented a computerized patient self-service check-in and billing system using a Phreesia tablet (Phreesia, New York City, NY) in 2014. Patients use the tablet at check-in to confirm their personal information (e.g., address, insurance) and pay their medical bills, a process that takes five

to ten minutes the first time and two to three minutes during subsequent visits. Our evaluation focused on the BP kiosk only.

### 7.1.2 Study design and data collection

I partnered with a multidisciplinary team, including primary care physicians, human-centered design experts, and quality improvement experts, and used a longitudinal mixed-methods approach to evaluate provider (physicians, physician assistants), staff (MAs, front desk staff), clinic leadership, and patient perspectives and experience of the first nine months of BP kiosk use (August 2014 through April 2015; **Error! Reference source not found.**).

Table 8 Timeline of data collection throughout BP kiosk adoption  
7.1.3 Provider, staff, and clinic leadership data collection

		Kiosk Adoption Process							
		Planning 6 months	Deployment (Months)						
		1	2	3	4	5	6	7	8
Study Team Data Collection									
Provider, staff, and clinic leader perspectives	Planning meeting observation								
	Lean Six Sigma team status update								
	Focus group sessions								
Patient perspectives	Clinic observations								
	Patient surveys								
Other data collection									
Patient rooming time	Lean Six Sigma team observations								
BP data	Vendor reports								

### 7.1.3 Provider, staff, and clinic leadership data collection

Focus group sessions were conducted with providers, MAs, and front desk staff members during the second and eighth months of kiosk implementation. At each time, we held two focus groups. One included providers and MAs; the other included MAs and front desk staff members. Each group included eight to ten participants. All meetings were audio recorded and transcribed.

#### **7.1.4 Patient data collection**

To understand patient experience with using BP kiosks, I observed patients using BP kiosks in the clinic and conducted patient surveys soliciting their opinions and thoughts.

I spent 18 hours during four days in the clinic observing patient use of the kiosks and workflow in the waiting room. Although the observations were focused on the patient kiosk experience (60 patients in month 2 and 92 patients in month 8), they also included patient, receptionist, and MA kiosk interactions.

Approximately two and eight months after kiosk implementation, front desk staff gave adult patients attending clinic visits a four-page anonymous questionnaire and asked them to return it to a closed collection box. The collection box was emptied daily until a minimum of 100 responses were obtained (after roughly two to three weeks). The clinic collected 103 questionnaires during the first survey and 125 during the second survey.

Both questionnaires included questions using Likert-type scales and open-ended questions that asked the patients whether they used the kiosk and how comfortable and confident they were in using it (e.g., using a five-option scale, from very comfortable to not at all comfortable). Questionnaires also included questions about what patients liked, what could have improved their experience, and how accurate they thought the kiosk was. The clinic placed a receptionist in the waiting room to help patients use the kiosk and the self-service check-in tablet between the two surveys. Therefore, the second survey asked patients about their experiences with the help of receptionist who was in the waiting room and whether the clinic should keep the kiosk.

#### **7.1.5 Rooming time and BP data**

The Lean Six Sigma team evaluated MA rooming time before and after BP kiosk implementation. A member of the Lean Six Sigma team used a stopwatch to track the amount of

time it took for the MA to greet the patients and prepare the patients in the examination room for a clinic visit (292 patients before and 370 patients after BP kiosk implementation).

The PharmaSmart BP kiosk is web enabled and anonymously collected all BP measurements each time it was used. The kiosk vendor provided the clinic and researchers with monthly reports of the number of BP measurements taken and the percentages categorized as normal, prehypertension, stage 1 hypertension, and stage 2 hypertension (based on JNC7 (National Heart Lung and Blood Institute 2004)).

#### **7.1.6 Analysis**

We analyzed the notes from the planning sessions and the transcripts from the two-month focus groups using a grounded theory approach to identify emerging themes. These themes were then combined with analysis of transcripts from the eight-month focus groups. The final themes combined the results from those of the two sets of transcripts and were used to analyze notes from observations of kiosk use. We analyzed the patient questionnaires using descriptive statistics such as frequencies, and we used  $\chi^2$  tests to compare categorical variables between surveys.

## **7.2 RESULTS**

The kiosks recorded 12,525 BP measurements during the first eight months of use. Of these measurements, 28.5% were categorized as normal, 24.3% as prehypertension, 34.7% as stage 1 hypertension, and 12.5% as stage 2 hypertension. Our observations demonstrated that many patients checked their BP more than once. Based on the timing of the measurements and focus group reports, this seemed to occur more often with high BP readings.

### 7.2.1 Typical workflow after kiosk implementation

When patients arrived at the clinic's front desk, receptionists greeted them, handed them the tablet for self-check-in, and instructed them on how to use the BP kiosk. The check-in tablet was unfamiliar to some patients and required receptionists to spend additional time showing them how to use it. After patients had used and returned the check-in tablet, receptionists notified the MAs, via the EHR, that the patients had completed check-in. Concurrently, the patients obtained their BP measurements at the kiosk and obtained the paper printouts of the BP results. When the MA summoned the patients from the waiting room, the patients then handed the BP printout to the MA.

Clinic staff deviated from this workflow when the clinic was busy or patients were late. For example, receptionists would immediately notify MAs of late arrivals and allow patients take the check-in tablet into the examination room. Depending on the purpose of the visit, patients might use the BP kiosk at the end of the visit or the physician or MA would obtain the BP in the examination room. During busy times at check-in, patients would sometimes stand in line to use the kiosk or use the kiosk before completing check-in via the tablet.

### 7.2.2 Benefits and challenges for the clinic

As the clinic leadership expected, the adoption of BP kiosks saved the MAs time. Providers also reported that both patients and themselves paid more attention to the BP measurements on the paper printouts. However, MAs also worried about the accuracy of the kiosks and whether this service would negatively affect their job security.

#### Benefits

**Kiosk use gave MAs more time.** The Lean Six Sigma team's measurements found that MAs spent an average of 1.5 fewer minutes rooming each patient after the kiosk was introduced. In the focus groups,

some MAs confirmed that time savings from patients self-measuring BP were substantial: *“Yeah, it does save time. You know, you call them back; they hand you their blood pressure slip. All you have to do is weight, height.... Just by that piece of paper, it saves quite a bit of time with blood pressure and pulse”* (MA, month 8). MAs reported that the time saved allowed them to spend more time preparing documents and educational materials as well as handling telephone calls and voicemails.

**Kiosk printouts prompted provider and patient awareness of BP.** In the focus groups, MAs reported that after entering the BP values into the EHR system, they usually left the kiosk printouts for the provider in the examination room. Providers reported that seeing the printout from the kiosk—rather than BP values in the EHR—focused their attention on the patient’s BP: *“I am much more likely to notice a little slip of paper lying on the top of the counter top than the one that’s in the vital signs on the chart”* (Provider, month 8).

Many providers and MAs reported that patients paid more attention to their BP readings and more often noticed when their BP was above the normal rate. This seemed to be partly a result of the printout: *“It is really positive that the patients now are thinking about their BP as they’re seeing the numbers. In the past, they never really saw the numbers so it was something that was told to them which may or may not have been received”* (Provider, month 8). We observed that some patients kept the printout as a reminder.

## Challenges

**Providers and MAs had mixed perceptions about kiosk accuracy.** When the clinic first introduced the kiosk, communication with clinic leaders revealed that some providers and clinic staff were concerned about the accuracy of measurements. To address these concerns, clinician leadership and a clinic administrator, the kiosk vendor, and one researcher met with clinic providers and staff to present validation studies of the kiosk accuracy and to answer questions. They encouraged

providers and MAs to compare averages of several kiosk measurements with those taken by MAs. Most providers and MAs found that BPs were similar, which increased their trust of kiosk measurements. One MA described her comparison experience in the focus group: *“Most of the ones that I’ve had to re-check are pretty close, within 5 points of that”* (MA, month 2).

In the focus groups, however, some providers and MAs reported that the kiosks tended to report higher BPs than they expected. One MA described her experience: *“The main problem I think is it’s off quite a bit and so then I get questioned. So I have to retake it in the room or if I notice it’s high, I will always recheck it. About 90% of the time, I recheck it”* (MA, month 2). Most MAs and providers reported rechecking BP for 10% to 20% of patients, although one MA reported that one day during the early adoption period, she checked or rechecked for 80% of patients because of her concerns about accuracy or differences from an expected BP for a given patient. The rechecks caused some staff members to question whether the kiosk actually saved time: *“[Whether the kiosk saves time] just depends on how many patients you have in a day that either won’t use it, don’t like it, or want it rechecked. Then, [using] it takes more time than if you were just checking it yourself”* (MA, month 8)

**Self-service technology shifted work responsibilities and created concerns about job security.** To take advantage of the time savings from adopting the kiosks and check-in tablets, the clinic administration reviewed what clinic staff did with their time. For example, MAs were able to spend more time entering patient medical history following the introduction of the kiosk.

In focus groups, some clinic staff voiced concerns that the clinic would need fewer staff as more tasks became automated, and that kiosk use resulted in impersonal service. One receptionist commented: *“It could be like the airport. They just walk in the door and you go over to the kiosk”*

(Receptionist, month 2). Clinic leaders reassured staff members that their goal was to redirect staff time to improve patient care rather than to reduce staffing.

### 7.2.3 Benefits and challenges for the patients

From the survey responses and observations in the clinic, we found that most patients were comfortable using the kiosks for clinic routine measurements and for everyday BP management. However, some patients thought the kiosk measurements were inaccurate and were confused about the information provided by the kiosks. Others thought that self-service machines were impersonal, and they were concerned about measuring their BPs in the public area.

#### Benefits

**Patients were comfortable using the kiosks.** In the second-month and eighth-month surveys, 82.2% and 88.8% of patients, respectively, reported feeling “comfortable” or “very comfortable” using the kiosk. Many patients commented that the kiosk was “convenient,” “easy and fast,” and that they can “repeat the test” and “do it myself.” During our observations eight months after kiosk implementation, many patients went to the kiosk directly without requiring help or instructions, a finding echoed by clinic staff in the focus groups: “*Some patients now have had enough experience with it where they’ll just go straight to it, and they know*” (Receptionist, month 8).

**Patients used kiosks for more self-service.** Clinic staff reported in focus groups that patients used the kiosks to support other needs, such as checking their BP in between scheduled clinic visits and calibrating home BP monitors. Both staff (in focus groups) and patients (in surveys) reported that the kiosk was convenient and a time-saver. Before kiosk implementation, between-visit BP checks often involved making an appointment or waiting until a nurse or MA was available. One MA compared the process patients took before and after kiosk deployment: “*Instead of doing nurse*

*visits, patients just come, check it, give it to the receptionists. They write their name on it and then they bring it back to us, or some leave it on the counter”* (MA, month 2).

In addition, we observed that the kiosk enabled individuals who accompanied patients to check their BPs. Additional unexpected uses reported in the focus groups and observed in the clinic included patients comparing the results of their own BP devices with those of the kiosk, which allowed patients to calibrate their devices. We also found clinic providers and staff members monitoring their own BPs on the kiosk. One receptionist described her experiences with patients bringing their own BP devices for comparison: *“They come in with their blood pressure machine and they say, ‘I need to check my blood pressure, check it using the kiosk against my own,’ I say go right ahead”* (Receptionist, month 8).

## **Challenges**

**Some patients were concerned about the accuracy of kiosk measurement.** While 80% of patient survey respondents thought kiosk BPs were as accurate or more accurate than those taken by clinic staff, at focus group meetings MAs reported that some patients thought the kiosk BP measurements were higher than expected and were unhappy using the kiosk. Approximately 40% of patients in each survey reported that their BP was retaken by a provider after they used the kiosk.

In the focus groups, clinic administrators, providers, and staff members discussed the higher-than-expected BPs and speculated that this might result from patients not having the chance to sit and wait in the reception area before measuring their BP: *“I think that we would get better readings if the kiosks were located in a different spot, not in the waiting room. If the patient had a chance to sit for a few minutes before they took their blood pressure, they would be all done with the Phreesia pad so that it was not causing them anxiety”* (Provider, month 8). Clinic teams reported that they addressed this by having receptionists instruct patients to relax and take deep breaths

before using the kiosk. In the second set of focus groups, the receptionists discussed how they had developed a standard script to encourage patients to take some time before measuring their BP. The 8-month patient observations showed that patients followed these instructions.

**Results showing prehypertension on kiosk printouts caused patient confusion.** In the focus groups, some providers and MAs reported that some patients were confused and concerned by the prehypertension notations (systolic BP, 120–139; diastolic BP, 80–89) on the kiosk paper printouts (Figure 6, middle and right). Some providers felt this created an opportunity to educate patients: *“It’s [the prehypertension notation] an opportunity to enhance some discussion between us and the patient on what that means and what steps they can take.”* (Provider, month 2). However, others felt this was not a good use of their time: *“It’s not that we don’t believe that their blood pressure should be better, it’s just we have so much competing for our time”* (Provider, month 8).

**Not all patients were able to use the kiosks.** In the focus groups, some providers and clinic staff reported that some patients with large or thin arms sometimes had difficulty using the kiosk. When we observed patients with thin arms use the kiosk, the cuff sometimes inflated multiple times but was unable to obtain a measurement. In addition, patients in wheelchairs or those who could not measure BP in their left arm could not use the kiosk. Providers mentioned that they advised patients with specific underlying conditions, such as lymphedema or dialysis, not to use the kiosks.

**Some patients preferred not to use the kiosks.** In the focus groups, MAs reported that some patients simply preferred not to use the kiosk. At the beginning of kiosk adoption, some of these patient concerns related to hygiene: *“We do have people that refuse to use it because of so many people, bacteria, germs.”* (MA, month 2). In response, the clinic provided wipes for patients to clean the cuff and screen before using the kiosk.

Providers and clinic staff also mentioned that older patients were somewhat more resistant to using the kiosk. They reported that some older patients took longer to use the new technology, whereas others felt the self-service technologies were impersonal: “*A lot of them [patients] just want to stand up there and talk. Before, you know, while we were checking them in, we could talk to them, but now we just tell them, you got to go do this and, I think it’s kind of taken away their social hour*” (Receptionist, month 2).

Clinic staff also reported that some patients had concerns about measuring their BP in public, in part because of the need to remove an arm from clothing or because of concerns about others seeing their BP readings. We observed that some patients chose to use the kiosk situated in the back of the waiting room, even when the closer one was available. A few patients mentioned in the survey that they would prefer the kiosk be “*in a private area.*”

**Adaptations and further opportunities for improvement.** Clinic administrators created a new role—a navigator—to assist patients with the new self-service technologies. The clinic felt that this might help reassure patients that the clinic was using the time and resources saved to provide better quality or more personal care.

In addition, the clinic administrative team was concerned that kiosk placement in the reception area might have contributed to privacy concerns and to higher BP measurements (as patients did not have time to relax after entering the clinic, as recommended by BP measurement experts). The clinic team discussed moving the kiosks closer to the examination rooms, which might also allow patients more time to rest before BP measurement. However, this would have limited kiosk use for BP self-checks, home BP machine calibration, and BP checks by others (e.g., family). Moving the kiosks to other areas might also create new workflow challenges, so the clinic did not make this change.

## 7.3 DISCUSSION

Successful adoption of personal informatics technology required addressing concerns that arose during the implementation process and making modifications to the kiosk, to workflows, and to staff roles. We used the CFIR (Damschroder et al. 2009) to guide our discussion of the contextual factors that seemed to influence adoption of the BP kiosks. CFIR allowed us to organize information gathered from our mixed-method, longitudinal evaluation to guide clinic administrators, clinicians, health information technology designers, and researchers regarding the implementation of similar technologies in primary care settings.

### 7.3.1 Barriers to and facilitators of BP kiosk adoption.

Adoption of new technologies in clinical settings is an iterative process that requires ongoing attention to the setting, individuals in that setting, barriers, and concerns that emerge. One barrier was individual knowledge of and belief in the intervention itself (characteristics of individuals, CFIR). Some staff and patients perceived the technology to be inaccurate and impersonal. However, the clinic was able to respond to these concerns quickly and addressed them through formal, Lean Six Sigma rapid cycle evaluation processes. For example, the clinic team addressed the accuracy concern by implementing standard patient instructions before BP measurement. The use of this reflection and evaluation process (process, CFIR) was highly valuable for implementation of the BP kiosks. The clinic also had strong leadership engagement and resources to support the adaptation process (inner setting, CFIR). Clinic leadership involved providers and staff in this process to identify problems and brainstorm solutions, which contributed to a positive implementation climate (inner setting and trialability, CFIR).

Overall, patients were very positive about the clinic keeping the kiosks. For most patients, the kiosks were easy and convenient to use and provided a way for them to efficiently monitor their BP.

From the clinic perspective, the kiosk not only saved MA time, but also increased provider engagement and provided opportunities for better BP monitoring and patient education. While some patients felt kiosks were impersonal, the clinic identified opportunities to provide a more personal experience, such as allowing MAs to spend more time taking patient histories and placing the navigator in the waiting room. Provider and MA endorsement of the kiosk also increased patient acceptance.

Our mixed-methods approach allowed us to understand the technology adoption process from the perspectives of both patients and the entire healthcare team during a period of 8 months. However, our study was conducted in a single primary care clinic with one particular self-service technology and might not be generalizable to all clinics or technologies. During the time of BP kiosk adoption, the clinic also adopted the check-in tablet, which might have affected the kiosk adoption process. Kiosk adoption is an ongoing process, and the navigator in the waiting area was added toward the end of our evaluation. Therefore, we were unable to observe and report on all adaptations made in response to this new technology.

### **7.3.2 Adopting personal informatics technologies in a primary care clinic**

Although patients were the primary users of the kiosks, the adoption influenced both provider and staff workflows. Building upon the design challenges described in section 4.2.2, findings from this study highlight that technology designers and developers must consider the interaction between different employees within a primary care setting and how the introduction of a new technology can affect these people and the relationships among them. As discussed in Chapters 4 and 6, health professionals often struggle with delegating the review of personal informatics data to others with both time and the right expertise. Findings from this study show that even staff members who are not directly involved in data review can be affected while clinical workflows are adapted to the new technology. Field evaluation is essential, and administrators and designers

must be prepared to further adapt technologies, workflows, and staffing as barriers and facilitators to successful use of the technologies are identified in practice.

As personal informatics technology becomes more prevalent in primary care settings, patients will have more opportunities to encounter information tasks (e.g., updating medications) or measurement tasks (e.g., BP measurement) originally designed to be performed and interpreted by healthcare professionals. At the same time, healthcare professionals also have more opportunities to encounter everyday behavior information that is primarily collected and curated by patients. When this happens, the task or the information generated from these tasks become a boundary object (Star and Griesemer 1989) or boundary negotiating artifact (Lee 2007; see examples in Chapter 4) that bridges the worlds of patient self-management and clinical care. Even something as simple as the design of a paper slip displaying a BP measurement has many opportunities. During this study, these slips prompted patient awareness of their BP status but also generated concerns, confusion, and anxiety. My field evaluations of Foodprint (Chapter 6) also showed how the presentation of information revealed eating contexts and patient routines that otherwise took more time and effort for health experts to assess. The information and conversation about this information have the potential to increase trust between patients and providers (Schroeder et al. 2017). Research from the OpenNotes initiative (Feldman et al. 2013; Nazi et al. 2015) shows that technology adoption in clinical settings can impact the interactions between patients and provider. Future research should examine these impacts while evaluating the adoption of personal informatics technology.

#### **7.4 SUMMARY OF CONTRIBUTIONS**

In this chapter, I presented a longitudinal, mixed-method study of the adoption of self-service BP kiosks in a primary care clinic. The adoption of these kiosks changed BP measurement from a clinical task performed by health professionals to a patient task of personal data collection.

However, the adoption also affected the workflows of clinic staff members who were not directly involved in this data collection and review. It also created unexpected concerns for providers, MAs, staff members, and patients. The results of this chapter highlight the need to consider workflows of people with different roles in the clinics and to conduct long-term field evaluations to understand the impact of new personal informatics technologies.

## **CHAPTER 8. DISCUSSION AND OPPORTUNITIES FOR FUTURE WORK**

In the future, as more personal informatics technology becomes available, we can expect more types of data to be used in making health and wellness decisions. In response to more complex types and uses of data, more roles and relationships will also be involved in making sense of that data. Building on the understandings, designs, and theoretical implications from this dissertation, there are some important directions future research should pursue to understand the tradeoff when designing personal informatics systems and supporting the individual and collaborative use of this data.

### **8.1 QUANTIFIED-SELF AND QUALIFIED-SELF**

While the prevalence of the self-tracking technologies enables people to collect and reflect on their personal data, researchers have raised concerns about over-quantification and data fetishism (Sharon and Zandbergen 2017; Lupton 2016). In my prior study investigating employee experiences in workplace wellness programs, employees also thought that current program designs often reduced health into only a few numbers that can be reliably collected from current health-tracking technologies (Chung et al. 2017). In response to these concerns, many people have proposed the concept of the “qualified-self” (Davis 2013; Boam and Webb 2014) that emphasize the experience of everyday life instead of quantified data.

As discussed in Chapter 6 and other prior studies (Cordeiro, Bales, et al. 2015; Baumer et al. 2012), photos revealed contextual information, such as location and dining companions. This information often better describes the eating experience and supports individual reflection than text-based food journals. It also helped health experts understand individual values and design recommendations to support these values. While our study in Chapter 6 has shown that with

experienced dietitian support, detailed, *quantitative* nutrition analysis from photos was feasible, photos also created opportunities to support *qualitative* data collection and reflection. The type of information that photos preserve and the low burden of photo taking have the potential to support a more mindful eating experience in the moment of eating (Grimes and Harper 2008) and to create records that allow people to remember these experiences better (Elsden, Kirk, and Durrant 2016). Capturing this contextual information through photos (e.g., Mamykina et al. 2008; Smith et al. 2007) or other formats (e.g., Kendall, Morris, and Tan 2015) can help people correlate factors that might influence their health individually and collaboratively with health experts. In the future, as technology advances, there might be other types of media that can capture rich data about people's everyday experiences and complement current forms of personal informatics data. However, there might be tradeoffs between the burden of collection and that of curation and review. For example, video records might capture even more contextual information than photos, but curating and reviewing videos might be time-consuming and requires additional skills. Future research should continue to examine tradeoffs between quantitative and qualitative data, when each is useful, and how they can be designed to complement each other to support individual and collaborative health.

## **8.2 TRADEOFF AMONG AUTOMATIC ANALYSIS, COLLABORATION, AND SELF-REFLECTION**

Automatic analysis might support individual reflection when expert recommendations are less timely or when access to medical resources is limited. Systems can analyze a large volume of personal informatics data and pose questions that prompt people to reflect on their goals and potential collaboration needs. They can then make decisions about what to track and how to track before seeing health experts. Automated analysis can also provide advice based on context when expert advice is not available or when systems can provide more timely advice than expert consultation. However, what

analysis should be automated and who should engage in the data integration and reflection is often unclear. More automation might save patient and provider time, but it could also reduce the benefits they can get from reflecting on this data and asking questions about it.

As discussed in Chapter 6, automatic analysis can also risk overquantifying personal informatics data and overlooking the diagnosis and relationship benefits from reviewing contextual information. For example, where individuals tend to eat or exercise might reveal constraints or preferences; events or special occasions captured in the tracking records (e.g., photos) might represent priorities or responsibilities in life. Future research needs to understand better how providers and patients currently communicate about contextual information to support collaborative reflection of personal informatics data. Future research should also continue to examine how to support the collection, integration, and reflection on contextual information in collaborative health contexts.

Collaboration with health experts is essential and useful when individuals are not capable of making sense of data by themselves. However, as theories suggested, people receive benefits when they reflect on their own data and develop strategies for sustainable behavior change (Bandura 1991; Li, Dey, and Forlizzi 2011). As described in Chapter 4, providers sometimes instruct patients to collect personal informatics data with the expectation that they would further develop self-awareness and self-accountability. In other words, providers did not expect to review data all the time but intended to use the opportunity for patient education. In this case, collaborations and systems supporting collaboration can be seen as “gateway tools” (Schwanda and Ibara 2011) that help patients learn new knowledge and strategies about health behavior as well as help providers learn about patient experience and routines. Overtime, patients might be able to “graduate” from collaboration and manage their own health goals without relying on health experts. There might be a tradeoff between resources as well as individual and collaboration goals that can influence

when and how long collaboration is useful. Building on prior systems that support teaching patients reflection skills through collaborative review (e.g., MAHI; Mamykina et al. 2008), systems should support individuals and health experts explicitly communicate about these expectations and provide long-term structured support.

### **8.3 FROM PERSONAL HEALTH TO COLLABORATIVE COMMUNITY HEALTH**

Interpreting health-related personal informatics data often requires both healthcare experts' medical knowledge and a patient's knowledge of their routine. This collaborative interpretation can be difficult for people with limited access to medical resources and for health professionals who have higher workload and shorter interactions with individual patients.

Providers, however, not the only people with whom people share their health tracking data. For example, some people share their health data with others in various types of communities and relationships, such as family members (e.g., Pina et al. 2017), coworkers (e.g., Chung and Danis 2016; Chung et al. 2017; Gorm and Shklovski 2016), local community (e.g., Parker 2014), or online communities (e.g., Newman et al. 2011; Epstein et al. 2015; Chung et al. 2017).

Tracking and maintaining health behaviors with other family members makes healthy habits more sustainable. Shared goals and contexts among family members also helps people make sense of data and complement missing entries (Pina et al. 2017). Many companies have also adopted workplace wellness programs to incentivize employees to track and share their personal health data. However, most of these programs are limited by what can be easily tracked (e.g., step counts) and do not address employees' diverse health goals (Chung et al. 2017). Even though many employees thought that sharing and contrasting their experience with other employees can be useful, they thought work and life routines and constraints (e.g., a sedentary job or parental

responsibilities) could better define “people like me” than common demographic information (e.g., age, gender, and weight) (Chung & Danis 2016).

Tracking and sharing food photos within local communities can inspire community members improve their healthy diet practice. By thinking about how to provide helpful food photos, people also reflect on their own food choices and preparation processes (Parker 2014). Thinking about what to share, how to share, and with whom to share on online communities or social network helps people receive appropriate support and motivation (Newman et al. 2011; Epstein et al. 2015). For example, women appropriating Instagram as food tracking tools benefit from receiving and providing support from others with similar goals (Chung et al. 2017). By tracking and sharing everyday food photos, participants learned food-related knowledge and provided motivation, accountability, and inspiration to each other. These social needs often influence personal tracking behavior and decisions, and participants made tradeoffs to balance both personal and social goals.

Taken together, these studies show that highlight the needs to extend current personal informatics models to consider more social relationships and interactions when people collect and share their data. As demonstrated in this dissertation, health providers are one such interaction around personal health data, but models should also consider people’s relationships with family, peers, coworkers, and organizations. With new personal informatics technologies emerging, people might also turn to new relationships and require different types of expertise to make sense of the data. Future research should examine what types, frequency, and granularity of personal informatics data are appropriate and useful to support individual health goals and peer collaboration goals.

#### **8.4 UNDERSTANDING LONG-TERM USE AND UNINTENDED CONSEQUENCES OF PERSONAL INFORMATICS DATA IN COLLABORATIVE HEALTH CONTEXTS**

Adopting personal informatics data often requires people to adjust their routines and workflows. As more data is used in collaborative health contexts, these new uses can influence how people interact with technologies and with each other. They also can surface issues that were previously obscure. For example, people might not worry about privacy until systems or wellness programs support collaboration (Chung et al. 2017), or perhaps until they experience an unexpected or undesired use of their personal data. As seen in my study of blood pressure kiosk adoption (Chapter 7), new technologies can influence the workflows and experiences of people beyond their primary users, introducing new benefits but also new challenges. Only with long-term, iterative observation and refinement can designers and administrators understand and address these unanticipated effects (Chung et al. 2016). Future research should continue to examine how people adapt their routines and use of personal informatics technologies in collaborative health contexts, such as in clinics, communities, or workplace health programs. Understanding how individual perceptions and interactions change over time can also provide implications about how systems or workflow processes should be designed to address these experiences better.

Reflecting on this dissertation research in the context of the broader HCI, CSCW, and health informatics communities, I hope the findings and future work discussed in this dissertation will help us better understand how to support the use of personal informatics data in collaborations. In particular, I hope future designers, policy makers, and researchers will take the variety of individual goals into account and support these goals in various collaborative settings, such as in family, workspace, communities, and expert consultations. I also hope in the future, people will be able to easily collect and review more types of data than what can be easily measured and quantified today.

In particular, I hope people will be able to make use of the data that describes the experience supporting their values and goals, such as family meal time or favorite ski trip. I hope technologies will help people prepare for and benefit from collaboration: when people need different expertise to reflect on or analyze their data, future technologies will help scaffold the process of tracking to support their collaboration with others; when people collaborate with each other, future technologies will help them communicate about and focus on individual and collaborative goals.

## CHAPTER 9. CONCLUSION AND CONTRIBUTION

In my dissertation research, I sought to help people with different expertise collaborate using personal informatics data. I did this by examining the current needs and challenges people face when they collaborate with health experts on personal informatics data tracking and review. I then designed and evaluated systems to support these needs and challenges. In addition, I investigated ways to integrate new personal informatics technologies into clinical workflow.

This dissertation research advances our knowledge of personal informatics data use in the collaborative health context. In Chapter 4, I examined RQ1 (How do individuals and health experts currently collaborate using personal informatics data). Through formative studies, I described goals for collaboration among people and health experts. I also presented challenges when people and health experts collaborate using current personal informatics systems. I provided design recommendations that can help create a new generation of personal informatics tools designed for collaboration from the start. Additionally, I make recommendations for practice that can help patients and providers make better use of both current and new personal informatics tools. I then discussed how to extend current theoretical frameworks to include collaboration and its effect on personal tracking practices as well as privacy consideration when using personal informatics data in collaboration in different health contexts.

My dissertation also contributes a novel system, Foodprint, that can be used even beyond the context of the current research. Foodprint is a photo-based food diary and visual summary system that helps people easily collect their dietary data and reflect on the relationship between food and individual health goals. I designed, developed, and evaluated Foodprint to examine RQ2 (How do individuals and health experts currently collaborate using personal informatics data) in Chapters 5 and 6. Chapter 5 describes, how, based on the understanding developed in Chapter 4, I designed

Foodprint to explicitly include individual goals and knowledge in collaborative reviews and to support the development of actionable strategies. By evaluating Foodprint in field studies (Chapter 6), I demonstrated how these designs supported people throughout the tracking process and prepared them for collaborative reviews. I also showed how the designs enabled people and health experts to use photo-based food diaries in different formats that support different collaboration goals. Although Foodprint was designed for healthy eating and IBS, my research provides insight to extend these findings to other health conditions and care contexts. Future research should continue to examine how the design choices in Foodprint can be adapted and applied to help people address other diet-related conditions, such as diabetes, cardiovascular diseases, or other gastrointestinal conditions. It also can be developed for other trigger identification scenarios, such as food allergies.

Finally, my dissertation research examines RQ3 (How should new technologies that collect personal informatics data be adopted and integrated in current routines and workflows) and presents insight in Chapter 7. Through an 8-month longitudinal study, I investigated self-service kiosk adoption in a family medicine clinic. I presented how the iterative process improvement shaped the patient, staff member, and clinician experience using these self-service kiosks. I also showed that, with adequate workflow design and support, the shift of clinical tasks to patients not only saved medical assistants time, but also improved patient awareness of and patient-provider communication about health management. With the prevalence of personal informatics technology and its increasing use in clinical care, technology designers and healthcare organization leadership should attend to its potential influence on workflows and routines of different employees. Researchers should continue to examine how these technologies influence long-term patient-provider interaction and care management.

Since the start of this dissertation research, there have been extensive discussions and research about the use of personal informatics data in health decision making. My dissertation research provides an important foundation for understanding current and future practices as well as novel designs to support health communities. While this dissertation research mostly focuses on IBS and healthy eating, its findings can be used to improve the use of personal informatics data in many disciplines, professions, and collaborative situations. For example, financial advisors review client financial data, personal trainers prepare workout plans and review journals, and many families review budgets and bills together. In citizen science projects, members of the public collect data and work with peer volunteers or scientists from larger organizations and government agencies. Hence, the results of this dissertation can be used to expand existing knowledge of HCI and CSCW communities. It provides insights about and shows future research directions for broader collaborative work and interactive system design to improve collaborative efforts within different areas of expertise.

## BIBLIOGRAPHY

- Aarhus, Rikke, Stinne Aaløkke Ballegaard, and Thomas Riisgaard Hansen. 2009. The EDiary: Bridging Home and Hospital through Healthcare Technology. In *Proceedings of the 11th European Conference on Computer Supported Cooperative Work (ECSCW'09)*, 63–83.
- Albers, David J., Matthew Levine, Bruce Gluckman, Henry Ginsberg, George Hripcsak, and Lena Mamykina. 2017. *Personalized Glucose Forecasting for Type 2 Diabetes Using Data Assimilation. PLoS Computational Biology*. Vol. 13. <https://doi.org/10.1371/journal.pcbi.1005232>.
- Alpert, B S. 2004. Validation of the Pharma-Smart PS-2000 Public Use Blood Pressure Monitor. *Blood Pressure Monitoring* 9 (1): 19–23. <https://doi.org/00126097-200402000-00005> [pii].
- American Gastroenterological Association. 2002. American Gastroenterological Association Medical Position Statement: Irritable Bowel Syndrome. *Gastroenterology* 123 (1): 2105–7. <https://doi.org/10.1053/j.gastro.2005.09.019>.
- Andersen, Tariq, Jørgen Bansler, Finn Kensing, Jonas Moll, and Karen Dam Nielsen. 2014. Alignment of Concerns: A Design Rationale for Patient Participation in EHealth. *Proceedings of the Annual Hawaii International Conference on System Sciences*, 2587–96. <https://doi.org/10.1109/HICSS.2014.327>.
- Andersen, Tariq, Pernille Bjørn, Finn Kensing, and Jonas Moll. 2011. Designing for Collaborative Interpretation in Telemonitoring: Re-Introducing Patients as Diagnostic Agents. *International Journal of Medical Informatics* 80 (8): e112–26. <https://doi.org/10.1016/j.ijmedinf.2010.09.010>.
- Ballegaard, Stinne Aaløkke, Thomas Riisgaard Hansen, and Morten Kyng. 2008. Healthcare in Everyday Life. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI 2008)*, 1807–16. <https://doi.org/10.1145/1357054.1357336>.
- Bandura, Albert. 1991. Social Cognitive Theory of Self-Regulation. *Organizational Behavior and Human Decision Processes* 50: 248–87. [https://doi.org/10.1016/0749-5978\(91\)90022-L](https://doi.org/10.1016/0749-5978(91)90022-L).
- Barney, Pamela, Margaret Heitkemper, Monica Jarrett, and Rona L. Levy. 2010. *Master Your IBS: An 8-Week Plan to Control the Symptoms of Irritable Bowel Syndrome*. AGA Press: Bethesda, MD, USA.
- Baumer, Eric P S, Sherri Jean Katz, Jill E Freeman, Phil Adams, Amy L Gonzales, John Pollak, Daniela Retelny, Jeff Niederdeppe, Christine M Olson, and Geri K Gay. 2012. Prescriptive Persuasion and Open-Ended Social Awareness: Expanding the Design Space of Mobile Health. *Proceedings of the ACM Conference on Computer Supported Cooperative Work (CSCW 2012)*, 475–84. <https://doi.org/10.1145/2145204.2145279>.
- Béland, Yves. 2002. Canadian Community Health Survey - Methodological Overview. *Health Reports* 13 (3): 9–14.
- Bennett, Wendy L., Nae Yuh Wang, Kimberly A. Gudzone, Arlene T. Dalcin, Sara N. Bleich, Lawrence J. Appel, and Jeanne M. Clark. 2015. Satisfaction with Primary Care Provider Involvement Is Associated with Greater Weight Loss: Results from the Practice-Based POWER Trial. *Patient Education and Counseling* 98 (9): 1099–1105. <https://doi.org/10.1016/j.pec.2015.05.006>.
- Bentley, Frank, Konard Tollmar, Peter Stephenson, Laura Levy, Brian Johns, Jones Robertson, Ed Price, Richard Catrambone, and Jeff Willson. 2013. Health Mashups: Presenting Statistical Patterns between Wellbeing Data and Context in Natural Language to Promote Behavior Change. *TOCHI* 20 (5): 1–27. <https://doi.org/10.1145/2503823>.

- Berry, Andrew B. L., Catherine Lim, Andrea L. Hartzler, Tad Hirsch, Edward H. Wagner, Evette Ludman, and James D. Ralston. 2017. How Values Shape Collaboration Between Patients with Multiple Chronic Conditions and Spousal Caregivers. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, 5257–70. <https://doi.org/10.1145/3025453.3025923>.
- Berry, Leonard L., Janet Turner Parish, Ramkumar Janakiraman, Ogburn-Russell Lee, Glen R. Couchman, William L. Rayburn, and Jedidiah Grisel. 2008. Physician and Why It Matters. *Annals Of Family Medicine*, 6–13. <https://doi.org/10.1370/afm.757.2>.
- Boam, Eric, and Jarred Webb. 2014. *The Qualified Self: Going beyond Quantification*. Design Mind. 2014.
- Brubaker, Jed R, Caitlin Lustig, and Gillian R Hayes. 2010. PatientsLikeMe : Empowerment and Representation in a Patient-Centered Social Network. *CSCW Research in Healthcare: Past, Present, and Future*, 715–22. <https://doi.org/10.1197/jamia.M2905>.
- Burke, Lora E., Melanie Warziski, Terry Starrett, Jina Choo, Edvin Music, Susan Sereika, Susan Stark, and Mary Ann Sevick. 2005. Self-Monitoring Dietary Intake: Current and Future Practices. *Journal of Renal Nutrition* 15 (3): 281–90. <https://doi.org/10.1016/j.jrn.2005.04.002>.
- Canavan, Caroline, Joe West, and Timothy Card. 2014. The Epidemiology of Irritable Bowel Syndrome. *Clinical Epidemiology* 6 (1): 71–80. <https://doi.org/10.2147/CLEP.S40245>.
- Catsos, Patsy. 2012. IBS-Free at Last. Change Your Carbs, Change Your Life with the FODMAP Elimination Diet. *Verlag: Pond Cove Press*,.
- Chen, Yunan. 2011. Health Information Use in Chronic Care Cycles. *Proceedings of the ACM 2011 Conference on Computer Supported Cooperative Work - CSCW '11*, 485. <https://doi.org/10.1145/1958824.1958898>.
- Choe, Eun Kyoung. 2014. *Designing Self-Monitoring Technology to Promote Data Capture and Reflection*. *Doctoral Dissertation*.
- Choe, Eun Kyoung, Saeed Abdullah, Mashfiqui Rabbi, Edison Thomaz, Daniel A. Epstein, Felicia Cordeiro, Matthew Kay, et al. 2017. Semi-Automated Tracking: A Balanced Approach for Self-Monitoring Applications. *IEEE Pervasive Computing* 16 (1): 74–84. <https://doi.org/10.1109/MPRV.2017.18>.
- Choe, Eun Kyoung, Bongshin Lee, Haining Zhu, Nathalie Henry Riche, and Dominikus Baur. 2017. Understanding Self - Reflection : How People Reflect on Personal Data Through Visual Data Exploration. *Proc. EAI International Conference on Pervasive Computing Technologies for Healthcare (PervasiveHealth '17)*.
- Choe, Eun Kyoung, Nicole B. Lee, Bongshin Lee, Wanda Pratt, and Julie A. Kientz. 2014. Understanding Quantified-Selfers' Practices in Collecting and Exploring Personal Data. *Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems - CHI '14*, 1143–52. <https://doi.org/10.1145/2556288.2557372>.
- Chung, Chia-Fang, Elena Agapie, Jessica Schroeder, Sonali Mishra, James Fogarty, and Sean A. Munson. 2017. “When Personal Tracking Becomes Social: Examining the Use of Instagram for Healthy Eating.” *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI 2017)*, 1674–87. <https://doi.org/10.1145/3025453.3025747>.
- Chung, Chia-Fang, Jonathan Cook, Elizabeth Bales, Jasmine Zia, and Sean A. Munson. 2015. “More than Telemonitoring: Health Provider Use and Nonuse of Life-Log Data in Irritable Bowel Syndrome and Weight Management.” *Journal of Medical Internet Research* 17 (8): 1–16. <https://doi.org/10.2196/jmir.4364>.

- Chung, Chia-Fang, and Catalina M Danis. 2016. Integrating Population-Based Patterns with Personal Routine to Re-Engage Fitbit Use. *Proceedings of the 10th EAI International Conference on Pervasive Computing Technologies for Healthcare*, 154–61. <https://doi.org/10.4108/eai.16-5-2016.2263334>.
- Chung, Chia-Fang, Kristin Dew, Allison Cole, Jasmine Zia, James Fogarty, Julie A. Kientz, and Sean A. Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing (CSCW 2016)*, 770–86. <https://doi.org/10.1145/2818048.2819926>.
- Chung, Chia-Fang, Nanna Gorm, Irina A. Shklovski, and Sean A. Munson. 2017. Finding the Right Fit: Understanding Health Tracking in Workplace Wellness Programs. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI 2017)*, 4875–86. <https://doi.org/10.1145/3025453.3025510>.
- Chung, Chia-Fang, Sean A. Munson, Matthew J. Thompson, Laura-Mae Baldwin, Jeffrey Kaplan, Randall Cline, and Beverly B. Green. 2016. Implementation of a New Kiosk Technology for Blood Pressure Management in a Family Medicine Clinic: From the WWAMI Region Practice and Research Network. *Journal of the American Board of Family Medicine* 29 (5). <https://doi.org/10.3122/jabfm.2016.05.160096>.
- Civan, Andrea, David W. McDonald, Kenton T. Unruh, and Wanda Pratt. 2009. Locating Patient Expertise in Everyday Life. *Proceedings of the ACM 2009 International Conference on Supporting Group Work - GROUP '09*, 291. <https://doi.org/10.1145/1531674.1531718>.
- Clawson, J., Jessica Pater, Andrew Miller, Elizabeth Mynatt, and Lena Mamykina. 2015. No Longer Wearing: Investigating the Abandonment of Personal Health-Tracking Technologies on Craigslist. *ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 647–58. <https://doi.org/10.1145/2750858.2807554>.
- Cohen, Deborah J, Sara R Keller, Gillian R Hayes, David A Dorr, Joan S Ash, and Dean F Sittig. 2016. Integrating Patient-Generated Health Data Into Clinical Care Settings or Clinical Decision-Making: Lessons Learned From Project HealthDesign. *JMIR Human Factors* 3 (2): e26. <https://doi.org/10.2196/humanfactors.5919>.
- Consolvo, Sunny, Predrag Klasnja, David W McDonald, and James A Landay. 2012. Designing for Healthy Lifestyles: Design Considerations for Mobile Technologies to Encourage Consumer Health and Wellness. *Foundations and Trends in Human-Computer Interaction* 6 (3–4): 167–315. <https://doi.org/10.1561/11000000040>.
- Cook, J. 2014. Chronologic: Tracking Stories of Illness in Chronic Care [Dissertation].
- Cordeiro, Felicia, Elizabeth Bales, Erin Cherry, and James Fogarty. 2015. Rethinking the Mobile Food Journal. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI 2015)*, 3207–16. <https://doi.org/10.1145/2702123.2702154>.
- Cordeiro, Felicia, Daniel A. Epstein, Edison Thomaz, Elizabeth Bales, Arvind K Jagannathan, Gregory D. Abowd, and James Fogarty. 2015. Barriers and Negative Nudges: Exploring Challenges in Food Journaling. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI 2015)*, 1159–62. <https://doi.org/10.1145/2702123.2702155>.
- Damschroder, Laura J., David C. Aron, Rosalind E. Keith, Susan R. Kirsh, Jeffery A. Alexander, and Julie C. Lowery. 2009. Fostering Implementation of Health Services Research Findings into Practice: A Consolidated Framework for Advancing Implementation Science. *Implementation Science* 4 (1): 1–15. <https://doi.org/10.1186/1748-5908-4-50>.
- Davis, Jenny. 2013. *The Qualified Self*. 2013.

- Deering, Mary Jo. 2013. Issue Brief: Patient-Generated Health Data and Health IT. *The Office of the National Coordinator for Health Information Technology*, 11.  
[https://www.healthit.gov/sites/default/files/pghd\\_brief\\_final122013.pdf](https://www.healthit.gov/sites/default/files/pghd_brief_final122013.pdf).
- Elsden, Chris, David S. Kirk, and Abigail C. Durrant. 2016. A Quantified Past: Toward Design for Remembering With Personal Informatics. *Human-Computer Interaction* 31 (6): 518–57.  
<https://doi.org/10.1080/07370024.2015.1093422>.
- Epstein, Daniel A., Felicia Cordeiro, Elizabeth Bales, James Fogarty, and Sean A. Munson. 2014. Taming Data Complexity in Lifelogs: Exploring Visual Cuts of Personal Informatics Data. *Proc DIS 2014*, 667–76. <https://doi.org/10.1145/2598510.2598558>.
- Epstein, Daniel A., Bradley H. Jacobson, Elizabeth Bales, David W. McDonald, and Sean A. Munson. 2015. From ‘Nobody Cares’ to ‘Way to Go!’ : A Design Framework for Social Sharing in Personal Informatics. *Proceedings of the ACM Conference on Computer Supported Cooperative Work & Social Computing (CSCW 2015)*, 1622–36.  
<https://doi.org/10.1145/2675133.2675135>.
- Epstein, Daniel A., An Ping, James Fogarty, and Sean A. Munson. 2015. A Lived Informatics Model of Personal Informatics. *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing (UbiComp 2015)*, 731–42.  
<https://doi.org/10.1145/2750858.2804250>.
- Feldman, Henry J., Janice Walker, Joseph Li, and Tom Delbanco. 2013. OpenNotes: Hospitalists’ Challenge and Opportunity. *Journal of Hospital Medicine* 8 (7): 414–17.  
<https://doi.org/10.1002/jhm.2052>.
- Ferrari, Renée M., Anna Maria Siega-Riz, Kelly R. Evenson, Merry K. Moos, and Kathryn S. Carrier. 2013. A Qualitative Study of Women’s Perceptions of Provider Advice about Diet and Physical Activity during Pregnancy. *Patient Education and Counseling* 91 (3): 372–77.  
<https://doi.org/10.1016/j.pec.2013.01.011>.
- Fitzpatrick, Geraldine, and Gunnar Ellingsen. 2013. *A Review of 25 Years of CSCW Research in Healthcare: Contributions, Challenges and Future Agendas. Computer Supported Cooperative Work: CSCW: An International Journal*. Vol. 22.  
<https://doi.org/10.1007/s10606-012-9168-0>.
- Fleming, Susannah, Helen Atherton, David McCartney, James Hodgkinson, Sheila Greenfield, Frederick David Richard Hobbs, Jonathan Mant, et al. 2015. Self-Screening and Non-Physician Screening for Hypertension in Communities: A Systematic Review. *American Journal of Hypertension* 28 (11): 1316–24. <https://doi.org/10.1093/ajh/hpv029>.
- Fontaine, K. R., and I. Barofsky. 2001. Obesity and Health-Related Quality of Life. *Obesity Reviews* 2 (3): 173–82. <https://doi.org/10.1046/j.1467-789x.2001.00032.x>.
- Food and Drug Administration. 2013. Mobile Medical Applications: Guidance for Industry and Food and Drug Administration Staff.
- Gabriels, Katleen, and Tania Moerenhout. 2018. Exploring Entertainment Medicine and Professionalization of Self-Care: Interview Study among Doctors on the Potential Effects of Digital Self-Tracking. *Journal of Medical Internet Research* 20 (1): 1–12.  
<https://doi.org/10.2196/jmir.8040>.
- Goodall, John R, Wayne G Lutters, and Anita Komlodi. 2004. I Know My Network: Collaboration and Expertise in Intrusion Detection. *ACM Conference on Computer Supported Cooperative Work*, 342–45.  
<https://doi.org/http://doi.acm.org/10.1145/1031607.1031663>.
- Gorm, Nanna, and Irina Shklovski. 2016. Steps, Choices, and Moral Accounting: Observations

- from a Step-Counting Campaign in the Workplace. *CSCW '16*.
- Goyal, Nitesh. 2017. Designing Tools for Collaborative Sensemaking. *Doctoral Dissertation*.
- Griffin, Meghan. 2012. Ruptured Feedback Loops: Body Image/Schema and Food Journaling Technologies. *Feminism & Psychology* 22 (3): 376–87.  
<https://doi.org/10.1177/0959353512445356>.
- Grimes, Andrea, and Richard Harper. 2008. Celebratory Technology : New Directions for Food Research in HCI. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems (CHI 2008)*, 467–76. <https://doi.org/10.1145/1357054.1357130>.
- Haas, Sebastian, Sven Wohlgemuth, Isao Echizen, Noboru Sonehara, and Günter Müller. 2011. Aspects of Privacy for Electronic Health Records. *International Journal of Medical Informatics* 80 (2): e26–31. <https://doi.org/10.1016/j.ijmedinf.2010.10.001>.
- Hall, Timothy S. 2014. The Quantified Self Movement: Legal Challenges and Benefits of Personal Biometric Data Tracking. *AKRON INTELLECTUAL PROPERTY JOURNAL*, no. 7: 27. <https://doi.org/10.3868/s050-004-015-0003-8>.
- Halpert, Albena, Christine B. Dalton, Olafur Palsson, Ae Carolyn, Morris Ae, Yuming Hu, Ae Shrikant, et al. 2010. Irritable Bowel Syndrome Patients' Ideal Expectations and Recent Experiences with Healthcare Providers: A National Survey. *Digestive Diseases and Sciences* 55 (2): 375–83. <https://doi.org/10.1007/s10620-009-0855-8>.
- Hardin-Fanning, F, and Y Gokun. 2014. Gender and Age Are Associated with Healthy Food Purchases via Grocery Voucher Redemption. *Rural Remote Health* 14 (3): 2830.  
<https://doi.org/10.1109/TMI.2012.2196707.Separate>.
- Haskard-Zolnieriek, Kelly B., and M. Robin DiMatteo. 2009. Physician Communication and Patient Adherence to Treatment: A Meta-Analysis. *Med Care* 47 (8): 826–34.  
<https://doi.org/10.1097/MLR.0b013e31819a5acc.Physician>.
- Health Data Exploration Project. 2014. Personal Data for the Public Good: New Opportunities to Enrich Understanding of Individual and Population Health. 2014.  
<https://www.rwjf.org/content/dam/farm/reports/reports/2014/rwjf411080>.
- Heinonen, Reetta, Riitta Luoto, Pirjo Lindfors, and Clas-Håkan Nygård. 2012. Usability and Feasibility of Mobile Phone Diaries in an Experimental Physical Exercise Study. *Telemedicine and E-Health* 18 (2): 115–19. <https://doi.org/10.1089/tmj.2011.0087>.
- Holtzblatt, Karen, Jessamyn Burns Wendell, and Shelley. Wood. 2004. Rapid Contextual Design: A How-to Guide to Key Techniques for User-Centered Design. San Francisco, US: Elsevier.
- Jamieson, Anne E, Paula C Fletcher, and Margaret a Schneider. 2007. Seeking Control through the Determination of Diet: A Qualitative Investigation of Women with Irritable Bowel Syndrome and Inflammatory Bowel Disease. *Clinical Nurse Specialist* 21 (3): 152–60.  
<https://doi.org/10.1097/01.NUR.0000270015.97457.9c>.
- Jirotko, Marina, Charlotte P. Lee, and Gary M. Olson. 2013. Supporting Scientific Collaboration: Methods, Tools and Concepts. *Computer Supported Cooperative Work: CSCW: An International Journal* 22 (4–6): 667–715. <https://doi.org/10.1007/s10606-012-9184-0>.
- Kalantarian, Haik, Nabil Alshurafa, and Majid Sarrafzadeh. 2017. A Survey of Diet Monitoring Technology. *IEEE Pervasive Computing* 16 (1): 57–65.  
<https://doi.org/10.1109/MPRV.2017.1>.
- Karkar, Ravi, Jessica Schroeder, Daniel A. Epstein, Laura R. Pina, Jeffrey Scofield, James Fogarty, Julie A. Kientz, Sean A. Munson, Roger Vilaradaga, and Jasmine Zia. 2017. TummyTrials: A Feasibility Study of Using Self-Experimentation to Detect Individualized Food Triggers. <https://doi.org/10.1145/3025453.3025480>.

- Karkar, Ravi, Jasmine Zia, Roger Vilardaga, Sonali R. Mishra, James Fogarty, Sean A. Munson, and Julie A. Kientz. 2016. A Framework for Self-Experimentation in Personalized Health. *Journal of the American Medical Informatics Association* 23 (3): 440–48. <https://doi.org/10.1093/jamia/ocv150>.
- Kendall, Logan, Dan Morris, and Desney Tan. 2015. Blood Pressure Beyond the Clinic. *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems - CHI '15*, 1679–88. <https://doi.org/10.1145/2702123.2702276>.
- Kim, Yoojung, Eunyong Heo, Hyunjeong Lee, Sookyoung Ji, Jueun Choi, Jeong-Whun Kim, Joongseek Lee, and Sooyoung Yoo. 2017. Prescribing 10,000 Steps like Aspirin: Designing a Novel Interface for Data-Driven Medical Consultation. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (CHI 2017)*, 5787–99. <https://doi.org/10.1145/3025453.3025570>.
- Kim, Yoojung, Sookyoung Ji, Hyunjeong Lee, Jeong-whun Kim, Sooyoung Yoo, and Joongseek Lee. 2016. ‘My Doctor Is Keeping an Eye on Me !’: Exploring the Clinical Applicability of a Mobile Food Logger. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI 2016)*, 5620–31. <https://doi.org/10.1145/2858036.2858145>.
- Kim, Young-Ho. 2017. OmniTrack: A Flexible Self-Tracking Approach Leveraging Semi-Automated Tracking. *Proc. ACM Interact. Mob. Wearable Ubiquitous Technol* 1 (3). <https://doi.org/10.1145/3130930>.
- Ko, Ping Ru T., Julie A. Kientz, Eun Kyoung Choe, Matthew Kay, Carol A. Landis, and Nathaniel F. Watson. 2015. Consumer Sleep Technologies: A Review of the Landscape. *Journal of Clinical Sleep Medicine* 11 (12): 1455–61. <https://doi.org/10.5664/jcsm.5288>.
- Kushner, Robert F. 1995. Barriers to Providing Nutrition Counseling Cited by Physicians: A Survey of Primary Care Practitioners. *Preventive Medicine* 24 (5): 546–52. <https://doi.org/10.1177/0884533610380057>.
- Lan, Mars, Lauren Samy, Nabil Alshurafa, Myung-Kyung Suh, Hassan Ghasemzadeh, Aurelia Macabasco-O’Connell, and Majid Sarrafzadeh. 2012. WANDA: An End-to-End Remote Health Monitoring and Analytics System for Heart Failure Patients. *Proceedings of the Conference on Wireless Health - WH '12*, 1–8. <https://doi.org/10.1145/2448096.2448105>.
- Lazar, Amanda, Christian Koehler, Joshua Tanenbaum, and David H. Nguyen. 2015. Why We Use and Abandon Smart Devices. *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing - UbiComp '15*, 635–46. <http://dl.acm.org/citation.cfm?doid=2750858.2804288>.
- Lee, Charlotte P. 2007. Boundary Negotiating Artifacts: Unbinding the Routine of Boundary Objects and Embracing Chaos in Collaborative Work. *Computer Supported Cooperative Work* 16 (3): 307–39. <https://doi.org/10.1007/s10606-007-9044-5>.
- Lee, Matthew L., and Anind K. Dey. 2011. Reflecting on Pills and Phone Use: Supporting Awareness of Functional Abilities for Older Adults. *Proceedings of the 2011 Annual Conference on Human Factors in Computing Systems - CHI '11*, 2095. <https://doi.org/10.1145/1978942.1979247>.
- Lesselroth, Blake J., Patricia J. Holahan, Katleen Adams, Zhen Z. Sullivan, Victoria L. Church, Susan Woods, Robert Felder, Shawn Adams, and David A. Dorr. 2011. Primary Care Provider Perceptions and Use of a Novel Medication Reconciliation Technology. *Informatics in Primary Care* 19 (2): 105–18. <https://doi.org/10.14236/jhi.v19i2.802>.
- Li, Ian, Anind Dey, and Jodi Forlizzi. 2010. A Stage-Based Model of Personal Informatics Systems.” *Proceedings of the SIGCHI Conference on Human Factors in Computing*

- Systems (CHI 2010)*, 557–66. <https://doi.org/10.1145/1753326.1753409>.
- Li, Ian, Anind Dey, and Jodi Forlizzi. 2011. “Understanding My Data, Myself: Supporting Self-Reflection with Ubicomp Technologies.” *Proceedings of the 13th International Conference on Ubiquitous Computing (UbiComp 2011)*, 405–14. <https://doi.org/10.1145/2030112.2030166>.
- Lowe, Charles, and Debbie Cummin. 2010. The Use of Kiosk Technology in General Practice. *Journal of Telemedicine and Telecare* 16 (4): 201–3. <https://doi.org/10.1258/jtt.2010.004011>.
- Lupton, Deborah. 2016. *The Quantified Self*. John Wiley & Sons.
- Mamykina, Lena, Elizabeth Heitkemper, Arlene M. Smaldone, Rita Kukafka, Heather Cole-Lewis, Patricia G. Davidson, Elizabeth D. Mynatt, Andrea Cassells, Jonathan N. Tobin, and George Hripcsak. 2017. Personal Discovery in Diabetes Self-Management: Discovering Cause and Effect Using Self-Monitoring Data. *Journal of Biomedical Informatics* 76 (September): 1–8. <https://doi.org/10.1016/j.jbi.2017.09.013>.
- Mamykina, Lena, Elizabeth D. Mynatt, Patricia R. Davidson, and Daniel Greenblatt. 2008. MAHI: Investigation of Social Scaffolding for Reflective Thinking in Diabetes Management. *Chi 2008: 26th Annual Chi Conference on Human Factors in Computing Systems Vols 1 and 2, Conference Proceedings*, 477–86. <https://doi.org/10.1145/1357054.1357131>.
- Mamykina, Lena, Arlene M. Smaldone, and Suzanne R. Bakken. 2015. Adopting the Sensemaking Perspective for Chronic Disease Self-Management. *J Biomed Inform* 56: 406–417. <https://doi.org/10.1016/j.jbi.2015.06.006>. Adopting.
- Marcu, Gabriela, Anind Dey, and Sara Kiesler. 2014. Designing for Collaborative Reflection. *Proceedings of the 8th International Conference on Pervasive Computing Technologies for Healthcare*. <https://doi.org/10.4108/icst.pervasivehealth.2014.254987>.
- Martin, Amanda, and S Gerhardt. 2016. A Third of People Track Their Health or Fitness. Who Are They and Why Are They Doing It? *GfK Global Studies*, 1–3. <http://www.gfk.com/global-studies/global-studies-fitness-tracking/>.
- Mentis, Helena M., Anita Komlodi, Katrina Schrader, Michael Phipps, Ann Gruber-Baldini, Karen Yarbrough, and Lisa Shulman. 2017. Crafting a View of Self-Tracking Data in the Clinical Visit. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems - CHI '17*, 5800–5812. <https://doi.org/10.1145/3025453.3025589>.
- Mentis, Helena M., Rita Shewbridge, Sharon Powell, Melissa Armstrong, Paul Fishman, and Lisa Shulman. 2016. Co-Interpreting Movement With Sensors: Assessing Parkinson’s Patients’ Deep Brain Stimulation Programming. *Human-Computer Interaction* 31 (3–4): 227–60. <https://doi.org/10.1080/07370024.2015.1073592>.
- Mishra, Sonali R, Andrew D Miller, Shefali Haldar, Maher Khelifi, Jordan Eschler, Rashmi G Elera, Ari H Pollack, and Wanda Pratt. 2018. Supporting Collaborative Health Tracking in the Hospital : Patients’ Perspectives. *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems - CHI '18*.
- Mitra, Debanjali, Keith L. Davis, and Robert W. Baran. 2011. All-Cause Health Care Charges among Managed Care Patients with Constipation and Comorbid Irritable Bowel Syndrome. *Postgraduate Medicine* 123 (3): 122–32. <https://doi.org/10.3810/pgm.2011.05.2290>.
- National Heart Lung and Blood Institute. 2004. The Seventh Report of the Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure. <https://doi.org/10.1111/j.1365-2796.2011.02356.x>.

- Nazi, Kim M., Carolyn L. Turvey, Dawn M. Klein, Timothy P. Hogan, and Susan S. Woods. 2015. VA Opennotes: Exploring the Experiences of Early Patient Adopters with Access to Clinical Notes. *Journal of the American Medical Informatics Association* 22 (2): 380–89. <https://doi.org/10.1136/amiajnl-2014-003144>.
- Newman, Mark W, Debra Lauterbach, Sean a Munson, Paul Resnick, and Margaret E Morris. 2011. 'It's Not That I Don't Have Problems , I'm Just Not Putting Them on Facebook': Challenges and Opportunities In. *Proceedings of the ACM Conference on Computer Supported Cooperative Work (CSCW 2011)*, 341–50. <https://doi.org/10.1145/1958824.1958876>.
- Niiranen, Teemu J., Marjo Riitta Hänninen, Jouni Johansson, Antti Reunanen, and Antti M. Jula. 2010. Home-Measured Blood Pressure Is a Stronger Predictor of Cardiovascular Risk than Office Blood Pressure: The Finn-Home Study. *Hypertension* 55 (6): 1346–51. <https://doi.org/10.1161/HYPERTENSIONAHA.109.149336>.
- Nissenbaum, Helen. 2004. Privacy as Contextual Integrity. *Wash. L. Rev.*, 101–39. [http://heinonlinebackup.com/hol-cgi-bin/get\\_pdf.cgi?handle=hein.journals/washlr79&section=16](http://heinonlinebackup.com/hol-cgi-bin/get_pdf.cgi?handle=hein.journals/washlr79&section=16).
- Ong, L M, J C de Haes, A M Hoos, and F B Lammes. 1995. Doctor-Patient Communication: A Review of the Literature. *Social Science & Medicine (1982)* 40 (7): 903–18. [https://doi.org/10.1016/0277-9536\(94\)00155-M](https://doi.org/10.1016/0277-9536(94)00155-M).
- Padwal, Raj S., Raymond R. Townsend, Luc Trudeau, Peter G. Hamilton, and Mark Gelfer. 2015. Comparison of an In-Pharmacy Automated Blood Pressure Kiosk to Daytime Ambulatory Blood Pressure in Hypertensive Subjects. *Journal of the American Society of Hypertension* 9 (2): 123–29. <https://doi.org/10.1016/j.jash.2014.11.004>.
- Park, Sun Young and Yunan A Chen. 2015. Individual and Social Recognition: Challenges and Opportunities in Migraine Management. *Proceedings of the 2015 Acm International Conference on Computer-Supported Cooperative Work and Social Computing (Cscw'15)*, 1540–51. <https://doi.org/10.1145/2675133.2675248>.
- Parker, Andrea Grimes. 2014. Reflection-through-Performance: Personal Implications of Documenting Health Behaviors for the Collective. *Personal and Ubiquitous Computing* 18 (7): 1737–52. <https://doi.org/10.1007/s00779-014-0780-5>.
- Patel, Rupa a, Predrag Klasnja, Andrea Hartzler, Kenton T Unruh, and Wanda Pratt. 2012. Probing the Benefits of Real-Time Tracking during Cancer Care. *AMIA Symposium 2012*: 1340–49. <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3540467&tool=pmcentrez&rendertype=abstract>.
- Perera, Gihan, Anne Holbrook, Lehana Thabane, Gary Foster, and Donald J. Willison. 2011. Views on Health Information Sharing and Privacy from Primary Care Practices Using Electronic Medical Records. *International Journal of Medical Informatics* 80 (2): 94–101. <https://doi.org/10.1016/j.ijmedinf.2010.11.005>.
- Pina, Laura R, Sang-Wha Sien, Teresa Ward, Jason C Yip, Sean A Munson, James Fogarty, and Julie A Kientz. 2017. From Personal Informatics to Family Informatics: Understanding Family Practices around Health Monitoring. <https://doi.org/10.1145/2998181.2998362>.
- Posserud, Iris, Hans Strid, Stine Störsrud, Hans Törnblom, Ulla Svensson, Jan Tack, Lukas Van Oudenhove, and Magnus Simrén. 2013. Symptom Pattern Following a Meal Challenge Test in Patients with Irritable Bowel Syndrome and Healthy Controls. *United European Gastroenterology Journal* 1 (5): 358–67. <https://doi.org/10.1177/2050640613501817>.

- Pouladzadeh, Parisa, and Shervin Shirmohammadi. 2017. Mobile Multi-Food Recognition Using Deep Learning. *ACM Transactions on Multimedia Computing, Communications, and Applications (TOMM)* 13 (3s): 36. <https://doi.org/10.1145/3063592>.
- Rabbi, Mashfiqui, Min Hane Aung, Mi Zhang, and Tanzeem Choudhury. 2015. MyBehavior: Automatic Personalized Health Feedback from User Behaviors and Preferences Using Smartphones. *Ubicomp '15, September 7–11, 2015, Osaka, Japan*, 707–18. <https://doi.org/10.1145/2750858.2805840>.
- Radhakrishnan, Kavita, Kathryn Bowles, Alexandra Hanlon, Maxim Topaz, and Jesse Chittams. 2013. A Retrospective Study on Patient Characteristics and Telehealth Alerts Indicative of Key Medical Events for Heart Failure Patients at a Home Health Agency. *Telemedicine and E-Health* 19 (9): 664–70. <https://doi.org/10.1089/tmj.2012.0307>.
- Raj, Shriti, Mark W Newman, Joyce M Lee, and Mark S Ackerman. 2017. Understanding Individual and Collaborative Problem-Solving with Patient-Generated Data: Challenges and Opportunities. *Proc. ACM Hum.-Comput. Interact.* 1 (CSCW): 88:1–88:18. <https://doi.org/10.1145/3134723>.
- Reading, Meghan J, Jacqueline A Merrill, and Meghan Reading. 2018. Converging and Diverging Needs between Patients and Providers Who Are Collecting and Using Patient-Generated Health Data: An Integrative Review (February): 1–13. <https://doi.org/10.1093/jamia/ocy006>.
- Rooksby, John, Mattias Rost, Alistair Morrison, and Matthew Chalmers. 2014. Personal Tracking as Lived Informatics. *Proceedings of the 32nd Annual ACM Conference on Human Factors in Computing Systems (CHI 2014)*, 1163–72. <https://doi.org/10.1145/2556288.2557039>.
- Schroeder, Jessica, Jane Hoffswell, Chia-Fang Chung, James Fogarty, Sean Munson, and Jasmine Zia. 2017. Supporting Patient-Provider Collaboration to Identify Individual Triggers Using Food and Symptom Journals. *Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing (CSCW 2017)*, 1726–39. <https://doi.org/10.1145/2998181.2998276>.
- Schwanda, Victoria, and Steven Ibara. 2011. Side Effects and Gateway Tools: Advocating a Broader Look at Evaluating Persuasive Systems. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*, 345–48. <https://doi.org/10.1145/1978942.1978991>.
- Sharon, Tamar, and Dorien Zandbergen. 2017. From Data Fetishism to Quantifying Selves: Self-Tracking Practices and the Other Values of Data. *New Media and Society* 19 (11): 1695–1709. <https://doi.org/10.1177/1461444816636090>.
- Smith, Brian K., Jeana Frost, Meltem Albayrak, and Rajneesh Sudhakar. 2007. Integrating Glucometers and Digital Photography as Experience Capture Tools to Enhance Patient Understanding and Communication of Diabetes Self-Management Practices. *Personal and Ubiquitous Computing* 11 (4): 273–86. <https://doi.org/10.1007/s00779-006-0087-2>.
- Spiegel, Brennan M R. 2009. The Burden of IBS: Looking at Metrics. *Current Gastroenterology Reports* 11 (4): 265–69.
- Star, Susan Leigh. 2010. This Is Not a Boundary Object: Reflections on the Origin of a Concept. *Science Technology and Human Values* 35 (5): 601–17. <https://doi.org/10.1177/0162243910377624>.
- Star, Susan Leigh, and James R. Griesemer. 1989. Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39. *Social Studies of Science*. <https://doi.org/10.1177/030631289019003001>.

- Storni, Cristiano. 2011. Complexity in an Uncertain and Cosmopolitan World. Rethinking Personal Health Technology in Diabetes with the Tag-It-Yourself. *PsychNology Journal* 9 (2): 165–85.
- Street, Richard L., Gregory Makoul, Neeraj K. Arora, and Ronald M. Epstein. 2009. How Does Communication Heal? Pathways Linking Clinician-Patient Communication to Health Outcomes. *Patient Education and Counseling* 74 (3): 295–301. <https://doi.org/10.1016/j.pec.2008.11.015>.
- Tang, Paul C., J. Marc Overhage, Albert Solomon Chan, Nancy L. Brown, Bahar Aghighi, Martin P. Entwistle, Siu Lui Hui, et al. 2013. Online Disease Management of Diabetes: Engaging and Motivating Patients Online with Enhanced Resources-Diabetes (EMPOWER-D), a Randomized Controlled Trial. *Journal of the American Medical Informatics Association* 20 (3): 526–34. <https://doi.org/10.1136/amiainl-2012-001263>.
- Terry, Nicolas P., and Leslie P. Francis. 2007. Health Records. *University of Illinois Law Review*, 681.
- Thompson, F.R &, and A.F. Subar. 2008. Dietary Assessment Methodology. *Nutrition in the Prevention and Treatment of Disease*. Vol. 2. <https://doi.org/10.4178/epih/e2014009>.
- USDHHS, US Department of Health and Human Services. 2015. 2015 – 2020 Dietary Guidelines for Americans. *Washington (DC)*, USDA. <https://doi.org/10.1097/NT.0b013e31826c50af>.
- USPSTF, U.S. Preventive Services Task Force. 2014. Final Recommendation Statement, May: 1–7.
- Vinkers, Charlotte D W, Marieke A. Adriaanse, Floor M. Kroese, and Denise T D De Ridder. 2014. Efficacy of a Self-Management Intervention for Weight Control in Overweight and Obese Adults: A Randomized Controlled Trial. *Journal of Behavioral Medicine* 37 (4): 781–92. <https://doi.org/10.1007/s10865-013-9530-9>.
- Wang, Y. Claire, Klim McPherson, Tim Marsh, Steven L. Gortmaker, and Martin Brown. 2011. Health and Economic Burden of the Projected Obesity Trends in the USA and the UK. *The Lancet* 378 (9793): 815–25. [https://doi.org/10.1016/S0140-6736\(11\)60814-3](https://doi.org/10.1016/S0140-6736(11)60814-3).
- West, Peter, Richard Giordano, Max Van Kleek, and Nigel Shadbolt. 2016. The Quantified Patient in the Doctor ’ s Office : Challenges & Opportunities. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems (CHI 2016)*, 3066–78. <https://doi.org/10.1145/2858036.2858445>.
- West, Peter, Max Van Kleek, Richard Giordano, Mark J Weal, and Nigel Shadbolt. 2018. Common Barriers to the Use of Patient-Generated Data Across Clinical Settings. April: 1–13. <https://doi.org/10.1145/3173574.3174058>.
- West, Peter, Max Van Kleek, Richard Giordano, Mark Weal, and Nigel Shadbolt. 2017. Information Quality Challenges of Patient-Generated Data in Clinical Practice. *Frontiers in Public Health* 5 (November 2017). <https://doi.org/10.3389/fpubh.2017.00284>.
- WHO. 2013. Global Action Plan for the Prevention and Control of Noncommunicable Diseases 2013-2020. *World Health Organization*, 102. [https://doi.org/978 92 4 1506236](https://doi.org/978%204%201506236).
- Wiggins, A., and K. Crowston. 2011. From Conservation to Crowd Sourcing: A Typology of Citizen Science. *44th Hawaii International Conference on System Sciences*, 1–10.
- Wilson, Sue, Lesley Roberts, Andrea Roalfe, Pam Bridge, and Sukhdev Singh. 2004. Prevalence of Irritable Bowel Syndrome: A Community Survey. *British Journal of General Practice* 54 (504): 495–502. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1324800/pdf/bjpg54-495.pdf>.
- Wobbrock, Jacob O., and Julie A. Kientz. 2016. Research Contributions in Human-Computer Interaction. *Interactions* 23 (3): 38–44. <https://doi.org/10.1145/2907069>.
- World Health Organization. 2015. Obesity and Overweight. Fact Sheet No. 311. Updated

- January 2015. *World Health Organization*. Available from: [Http://Www. Who. Int/Mediacentre/Factsheets/Fs311/En](http://www.who.int/mediacentre/factsheets/fs311/en).
- Yvonne Chan, Yu-Feng, Roxanne Nagurka, Suzanne Bentley, Edgardo Ordonez, and William Sproule. 2014. Medical Utilization of Kiosks in the Delivery of Patient Education: A Systematic Review. *Health Promotion Perspectives* 4 (1): 1–8. <https://doi.org/10.5681/hpp.2014.001>.
- Zia, Jasmine, Chia-Fang Chung, Jessica Schroeder, Sean A. Munson, Julie A. Kientz, James Fogarty, Elizabeth Bales, Jeanette Schenk, and Margaret M. Heitkemper. 2016. The Feasibility, Usability, and Clinical Utility of Traditional Paper Food and Symptom Journals for Patients with Irritable Bowel Syndrome. *Neurogastroenterology and Motility : The Official Journal of the European Gastrointestinal Motility Society*, September. <https://doi.org/10.1111/nmo.12935>.
- Zia, Jasmine, Chia-Fang Chung, Kaiyuan Xu, Yi Dong, Jeanette Schenk, Kevin Cain, Sean Munson, and Margaret Heitkemper. 2017. Inter-Rater Reliability of Provider Interpretations of Irritable Bowel Syndrome Food and Symptom Journals. *Journal of Clinical Medicine* 6 (11): 105. <https://doi.org/10.3390/jcm6110105>.
- Zia, Jasmine K, L Nguyen, M Heitkemper, and U Ladabaum. 2013. The Feasibility and Usability of a Novel Mobile Phone Application, a Food and Symptom Diary, for Irritable Bowel Syndrome Patients. Presented. In *17th Neurogastroenterology & Motility Scientific Meeting*. Huntington Beach, CA.