Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data

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ABSTRACT

Patient-generated data is increasingly common in chronic disease care management. Smartphone applications and wearable sensors help patients more easily collect health information. However, current commercial tools often do not effectively support patients and providers in collaboration surrounding these data. This paper examines patient expectations and current collaboration practices around patient-generated data. We survey 211 patients, interview 18 patients, and re-analyze a dataset of 21 provider interviews. We find that collaboration occurs in every stage of self-tracking and that patients and providers create boundary negotiating artifacts to support the collaboration. Building upon current practices with patient-generated data, we use these theories of patient and provider collaboration to analyze misunderstandings and privacy concerns as well as identify opportunities to better support these collaborations. We reflect on the social nature of patient-provider collaboration to suggest future development of the stage-based model of personal informatics and the theory of boundary negotiating artifacts.

Author Keywords

Personal informatics; self-tracking; patient-generated data; patient-provider collaboration; chronic disease management; boundary negotiating artifacts.

ACM Classification Keywords

H.5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous.

INTRODUCTION

To better address individual health concerns and coordinate long-term care planning, chronic disease care is moving from clinical care to home care [18] with increased focus on, use of, and even reliance on patient-generated data [14]. The prevalence of smartphone self-tracking applications (e.g., *MyFitnessPal*, *WeightWatchers*) and wearable sensing devices (e.g., *Fitbit*, *Apple Watch*, *Microsoft Band*) increases patient capacity for collecting health data and engaging with that data to support personal health and wellness goals.

These data have the potential to complement standard measures in the clinic with rich, everyday health behavior information. However, of the one-third of current self-trackers who share data with providers, most reported dissatisfaction with provider engagement with the data [24].

For patients with irritable bowel syndrome (IBS) or overweight and obesity, managing these conditions and achieving desired health outcomes relies upon everyday lifestyle choices and monitoring to identify individual symptom triggers or weight loss barriers. Self-management programs and lifestyle counseling are clinically effective in these two populations [25,61], and both of these approaches encourage self-tracking. However, limited time and resources inhibit providers in clinical practice from fully engaging with and reviewing data collected by patients. As a result, patients are dissatisfied with feedback received from healthcare providers on data obtained from such diaries [28]. In addition, most commercially available self-tracking tools were not designed to support sharing or collaboration within or outside of the clinic visit, which makes the collaboration even more time-consuming and infeasible [10].

This paper examines how to support providers and patients in their engagement with patient self-tracking data by answering the following questions:

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

We explore patient goals for sharing self-tracking data with their providers in a survey of 211 patients and more in-depth follow-up interviews with 18 patients. We also contrast patient views with provider perspectives in a re-analysis of 21 healthcare provider interviews [10]. We examine these combined datasets through the lenses of the stage-based model of personal informatics [34] and boundary negotiating artifacts [32]. Specifically, we contribute an understanding of:

- Patient expectations for sharing self-tracking data with their healthcare providers;

- How current collaboration practices across self-tracking stages support or fail to support patient and provider expectations; and
- How boundary negotiating artifacts are created and used to support interaction during the collaboration process, as well as privacy perceptions around these objects.

Patients describe expectations that collaboration with patient-generated data will support diagnosis and treatment needs as well as affective needs, consistent with prior analysis of provider goals [10]. Toward diagnosis and treatment, patients expect providers to have a complete picture of their daily life, to help make sense of the tracking data, and to provide a personalized and actionable plan. Toward affective needs, patients seek motivation, accountability, recognition, and empathy. We find that collaboration in all stages of self-tracking is influenced by whether tracking is patient-initiated or provider-initiated. We also find tracking tools and data are used as or transformed into various types of boundary negotiating artifacts to support the collaboration. However, there is a lack of means to address privacy concerns that change across the evolving collaboration context. We draw upon these findings to identify design opportunities in this space and to suggest future development of theories.

BACKGROUND
Prior research in the CSCW and CHI communities has examined personal informatics tools and patient-provider interaction. This section reviews some of the most relevant literature and related theoretical models.

Patient-Provider Collaboration Data
An increasing number of systems support patient-provider collaboration with patient-generated data. Telemonitoring systems allow patients to collect their physiological data and allow providers to remotely monitor data and communicate with patients. Mamykina et al. conducted a series of studies showing the value of using tracked data in diabetes care between patients and their care team and how patients used the data and tools to make sense of their illness and care management trajectories [38,39]. Many of these systems have demonstrated that features supporting collaboration can successfully provide necessary contextual information for diagnosis [55], facilitate communication [2,47,52], engage patients in the shared decision-making process [3], and support long-term care management [31,50,56].

On the other hand, personal informatics systems allow individuals to collect and reflect on personal information. As these systems become more prevalent, many people are tracking their health data without provider instruction or involvement. These tools are designed to help people independently correlate and reflect on lifestyle factors and health status [5,30] and to promote healthy behavior [12,37]. Knowing the value of everyday self-tracking data, many self-trackers have begun to share these data with their healthcare providers [24]. However, these self-tracker initiated attempts at collaboration often fail to engage providers, which can lead to frustrating experiences [8,24].

In our previous study [10], providers recognized the value and benefit of self-tracking data to help achieve five major goals: (1) *Supporting diagnosis*: Providers want patient-generated data to help identify barriers for weight management or triggers to IBS symptoms, which are difficult to diagnose without long-term observation. (2) *Personalizing treatment*: Similar to trigger identification, treatment choices are also subject to personal lifestyles and symptoms. Patient preferences and personal choices also influence behavior change suggestions. (3) *Increasing motivation and accountability*: Self-tracking can be difficult. Providers found that proper instructions, followed by requesting and reviewing the data, helps patients overcome motivational barriers and be accountable for their health issues. (4) *Learning about patients*: Providers also use patient-generated data to understand unarticulated goals or values in order to build rapport. (5) *Facilitating discussion and managing visits*: Having patient-generated data helps providers to plan the agenda or manage conversations in a visit. However, providers also reported barriers in current self-tracking systems, preventing them from using data to their fullest capacity. In another recent study, primary care providers also reported that electronic dietary assessment tools can improve patient awareness and motivation and increase efficiency in assessing diet [6].

To further understand when and how collaboration between providers and patients around self-tracking data occurs and breaks down, it is important to understand how self-trackers collect and reflect on their personal information. Li et al. proposed a stage-based model of personal informatics [34] that describes practices and barriers when self-trackers prepare, collect, integrate, reflect, and act around their personal information. Bringing self-tracking to the clinic encourages collaborative reflection [40], but we believe that patient-provider interaction will also influence tracking behavior and decisions in other stages. Other extended personal informatics models also proposed reflection across stages: By studying quantified-selfer practices and experiences, Choe noted that reflections often occur during data collection [9]. Epstein et al. [16] focused on self-tracker decisions about starting, stopping, and resuming tracking and found that these moments often include opportunities for reflection and advice. These models provide us a framework to explore patient-provider collaboration in light of self-tracking processes.

Boundary Objects and Boundary Negotiating Artifacts
Collaboration around patient-generated data requires knowledge and expertise from both patients and providers. Patients are the experts of their routine, lifestyle, and day-to-day health and wellbeing [4], while providers can help interpret data with their medical expertise and knowledge. Technology to bridge provider and patient expertise and experience is not new in the CSCW and CHI

community, with many using the boundary object [e.g., 2] or boundary negotiating artifacts [e.g., 1] to describe extending health information technology to home care. The concept of boundary object was first proposed by Star and Griesemer [54] to coordinate collaboration work between various practices. To account for collaboration lacking standardized structure, Lee later proposed boundary negotiating artifacts: artifacts that can be used for practices not necessarily agreed upon by the people who use them, that can facilitate crossing and pushing boundaries, that can change with context, that can be incorporated into another artifact, and that can be transformed into boundary objects [32]. We argue that the use of self-tracking data in patient-provider collaboration can be seen as the process of creating and using boundary negotiating artifacts to navigate tensions and boundaries between the patient and provider spheres of expertise.

Shared Self-Tracking Data and Privacy
Moving data collected daily in a private setting into the health care provider's office raises questions about patient rights to control what data is shared and how it is used. Personal data sharing preferences are motivated to a great extent by an individual's relationship to the person receiving the shared information [44,63]. While explicit regulations exist to protect patient privacy with rules about how medical data can be stored and shared, they have been interpreted to apply to data created and kept in a clinical context; in contrast, patient self-tracking data falls into a gray area [22]. We can better understand privacy questions surrounding shared self-tracking data as contextual integrity, or the idea that every space is governed by information-sharing norms, both implicit and explicit [43]. Previous work has explored the socio-technical dimensions of privacy in location disclosure [13] and collaborative awareness systems [48], while numerous context-aware privacy frameworks have been proposed [e.g., 21,27,29]. Rawasizzadeh [51] has also advanced a secure sharing model for self-tracking data in social networking applications. However, these systems do not address the unique complexities of the healthcare context and patient-provider collaboration with self-tracking data.

Weight Management and IBS
Obesity and IBS are resource-intensive chronic illnesses affecting a large proportion of the US population and requiring lifelong monitoring and management. More than a third of the US adult population is obese, having a body mass index (BMI) of 30 or more [19], while IBS is estimated to affect 10-20% [53]. Both are associated with high total healthcare costs. Direct and indirect healthcare costs associated with obesity in the US were estimated at $75 billion in 2003 and projected to increase by $22 billion by 2020 and $66 billion by 2030 [62]; direct and indirect costs of IBS in the US have been estimated at $1.9 billion and $19.2 billion, respectively [53].

Both illnesses are associated with multiple factors, numerous comorbidities, and lower quality of life [20,41]. Patients typically work with a multidisciplinary team of providers –

including primary care physicians, gastroenterologists, dietitians, psychologists and/or psychiatrists – to identify and manage the causes and symptoms. Behavioral interventions and self-management are integral to effective treatment [25,61], so patients may be asked to record food intake, exercise, stress, abdominal pain, heart rate, and sleep patterns, among other indicators. Prior work has examined self-tracking tools in various domains [e.g., myFitnessPal, 58; SleepCycle, 30], but their use in patient-provider collaboration is not well understood.

METHODS
To understand patient and provider collaboration and use of self-generated data in IBS and weight management, we used a combination of surveys and interviews with patients. We chose to focus on weight management and IBS patients because these two conditions are frequently affected by lifestyle choices; IBS patients and providers commonly use lifestyle diaries to identify and manage individualized symptom triggers, while self-monitoring diaries and tools help overweight/obese patients to identify barriers to lifestyle changes and maintenance. Our prior research focused on provider expectations for using patient-generated data in care for IBS and weight management [10]. We draw on these results and re-analyzed the data collected for that study in light of this paper's research questions.

Patient survey. We designed a patient survey to understand how patients currently track and share their tracked data with their healthcare providers and what they expect from this.

We recruited survey participants by pre-screening the medical records of a large academic medical system for patients with BMI greater than 26 or suspected to have IBS. This medical system serves both urban and rural areas, with a diverse patient population. We sent 1841 email invitations and received 237 responses (13% response rate). We compensated each participant who passed the screener questions and completed the survey with a $5 gift card.
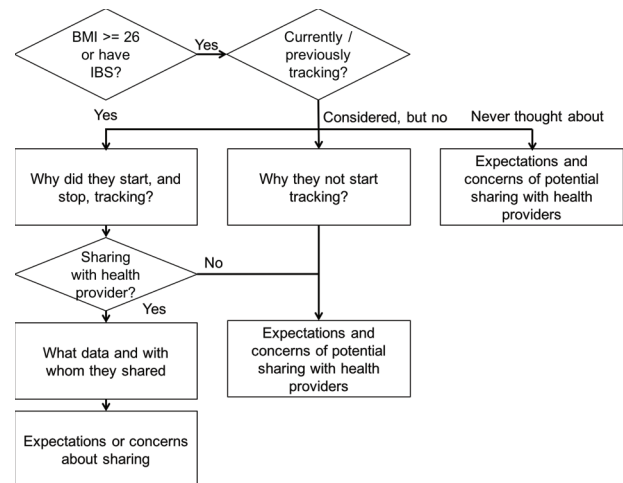

Figure 1. Patient survey flow.

The survey started with screener questions including gender, age, BMI and whether the participants have been diagnosed with IBS. If potential participants had a BMI of less than 26 and had not been diagnosed with IBS, they were excluded from the survey. The main survey consisted of 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. Figure 1 summarizes the survey question flow[1].

After excluding 26 responses that did not pass the screener survey, we had 211 valid responses. There were 147 (70%) females, 63 males, and 1 reported as other. Average age is 44 (*SD* = 11.8, *Median* = 45). 151 (72%) participants are overweight (BMI >= 26), 97 (45%) have been diagnosed with IBS, and 23 (11%) have IBS-like symptoms but have never been officially diagnosed with IBS; this includes 66 patients who are overweight and have IBS or IBS-like symptoms. The gender ratio and age distribution are consistent with our samples in pre-screened medical records.

There were 157 (74%) participants who are currently tracking or have previously tracked one or more health indicators, 36 (17%) who have considered tracking but never tried it, and 18 (9%) who never tried tracking. This percentage is similar to a recent nationwide survey [17]. Among participants who have previously tracked or are currently tracking, 117 (75%) have experience sharing the tracked data with a healthcare provider.

To analyze the open-ended survey responses, the research team 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.

Patient interviews. Among the 117 participants who had experience sharing their tracking data with healthcare providers, overweight patients most often shared their tracking data with primary care physicians, dietitians, and nurses; IBS patients most often shared with primary care physicians, gastroenterologists, and dietitians. Across all sharing experiences with providers, 39% of patients reported

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	dietitian, gastroenterologist, pain management 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

Table 1. Interview participants tracked a variety of health factors and shared with a variety of providers.

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[1] Available at: http://doi.org/10.5281/zenodo.30102

initiating the sharing, 38% of patients reported that their providers initiated the sharing, and 23% of patients did not recall who suggested the sharing. To further answer questions around collaboration during the tracking process, we conducted follow-up interviews with 18 survey participants who had experience tracking and sharing their tracked data with healthcare providers (Table 1). We purposefully sampled potential interviewees to strive for variety of symptoms, self-tracking tools, as well as sharing data, targets, and experiences. We compensated each participant with a $25 gift card.

We conducted an hour-long (range: 40-75 minutes) semi-structured phone interview with each participant. We developed our interview protocol to focus on patient experience of tracking and sharing tracked data with their healthcare providers[2]. We asked participants to describe one or more 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 [34] to analyze the data to help us understand when and how collaboration occurs throughout the tracking process.

Collaboration from patient and provider perspectives.
We reanalyzed the interviews from our previous study of health provider goals and practices [10] to complement these interviews, focusing on patient experiences and perceptions of the collaboration process. The dataset included 21 providers who work with people managing their weight and/or IBS patients in four different health organizations (two academic medical systems, one health maintenance organization, and one independent provider). These providers included six primary care providers, five gastroenterologists, seven dietitians, one nurse practitioner, one behavioral psychologist, and one health navigator (who helps patients find resources to support their care plan). In these hour-long interviews, providers reported their experiences, expectations, and concerns of using patient collected lifelog data in clinical care.

As we will discuss later in this paper, Lee's model of boundary negotiating artifacts [32] characterized much of the collaboration activity between patients and providers. To understand how tools and practices support these activities, we re-analyzed our patient survey and interviews, alongside our prior interviews with health providers [10], through the lens of boundary negotiating artifacts.

WHAT DO PATIENTS EXPECT FROM REVIEWING TRACKING DATA?
To understand collaboration using patient-generated data, it is important to start with an understanding of patient and provider expectations for care within and outside of clinic visits, for their current practices of using patient-generated data, and for future uses of such data. Patients described several intertwined expectations, spanning self-reflective, action-oriented and affective aims, in tracking health data and in sharing it with their providers. We analyzed survey responses regarding patient expectations and patient interviews.

Expectations to support diagnosis and treatment
Getting a complete picture of daily life. Patients shared with providers to give them a more complete picture of their daily life between visits and guide discussion during 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 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 the provider's 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
Patients also detailed affective goals in sharing their data with providers, such as self-awareness, accountability, seeking recognition, and a desire for emotional support.

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[2] Available at: http://doi.org/10.5281/zenodo.30102

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 [35]. "*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. Many patients could independently use tracking to regulate their 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: "*... he took my concerns more seriously when he saw the amount of time I was sick and my symptoms.*" - P28.

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. We next turn our 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 by Li et al. [34], we analyzed the 117 survey responses from patients who had experience sharing data, 18 patient interviews transcripts, and reanalyzed dataset from 21 provider interviews to understand the collaboration process. In this section, we first present case studies of four patients who experienced different interactions with their providers and how experiences of patient-initiated tracking are similar to or different from those of provider-initiated tracking. These case studies present scenarios representative of those reported across all participants. We then discuss how these experiences illustrate collaboration in each tracking stage of the personal informatics model [34].

Patient experiences tracking and sharing data on their own

Some patients started tracking and sharing on their own. However, their goals of sharing guided them throughout the tracking process and the interaction with their providers.

Case Study 1: P4 had been in different weight loss programs for six years. During the past six years he had been tracking his weight, calorie intake, and physical activity on and off. He used *FatSecret* to record his calorie intake, a wristband to count his steps, and a scale and a spreadsheet to record his weight. He stopped tracking around two years ago because he felt his weight was under control. He started to feel the need to track again and bring in the data to his primary care doctor because he felt the weight he got from the clinic scale did not represent his everyday life and did not help his doctor to understand his problem. Therefore, he plotted data (weight and calorie intake) on a chart (Figure 2, middle) and brought it to the clinic. His doctor was impressed and would look at the data before assessing it against the weight measurement in the office and used the calorie data to talk about if there is anything P4 needed to change. Because P4 did not plot his step count in the chart, he would normally just verbally summarize the average activity level when they had the conversation about physical activity.

P4's experience shows how his goals of sharing a complete picture of everyday life with providers motivated him to prepare and collect tracking data and how different ways of integration influenced his interaction with providers when reviewing tracking data.

Case Study 2: P17 had been fighting with IBS symptoms, such as severe abdominal pain and chronic diarrhea, for almost a year. He had experience and learned about how to track food intake after his bariatric surgery around 10 years ago. He did not keep tracking himself until recently, after he started to have IBS symptoms. 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.

P17 had a different goal for sharing tracking data with providers: providing evidence of his lack of response to a specific treatment. To achieve this goal, he shared data with multiple medical team members, and each interacted with the

data differently. These providers coordinated with each other using notes in the electronic medical record (EMR) system.

Patient experiences tracking and sharing by provider instruction

Some patients started tracking because their providers instructed them to do so. These providers often provided detailed instructions on how and what to track, suggested their preferred tools, or communicated their goals for reviewing tracking data. The communication influenced patient tracking behavior and interaction with providers.

Case Study 3: 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.

P6's dietitian worked with her in configuring the tools, answering questions while she collected data, showing her how to review data, reading through data, and directly inputting suggestions into her tools. These experiences provided the patient with knowledge about the tool and her health status, managed her expectations about reviewing data with the dietitian, and helped her follow advice outside of visits.

Case Study 4: P2 had suffered from excessive bowel movement, constant bloating, and acid reflux for over a year. He worked with one naturopathic doctor, Jeff (pseudonym), to start an elimination diet and keep track of his food intake. In the first session, Jeff gave P2 a paper for him to record the data. However, P2 felt it was too troublesome to keep records on paper and he gave up on it in one day. He started to try different tools including Excel and various apps in the market. He gave up using most of them in less than three days until he found mySymptoms. He used the app to keep records. The analysis function allowed him to reflect on possible correlations between food and his symptoms. He printed out one report using the standardized feature and brought it to the follow-up visit in three weeks. P2 went through his diet record with Jeff. Jeff then gave him some high-level comments to ensure he had at least three-to-four day rotations on foods and his diet was balanced. He went back to see Jeff after another three weeks with his data. However, Jeff did not look through his data this time and asked him to describe his diet verbally. After this experience, P2 stopped bringing in his data to Jeff.

Sometimes, even when tracking was instructed by providers, patients like P2 still make their own decisions about tool options and what specifically to track. However, P2's experiences showed that his providers had a different goal for reviewing data (empowering P2 to understand his diet plan) than from what he had (monitoring treatment plans and effects). This conflict resulted in termination of collaborative review before P2 was ready.

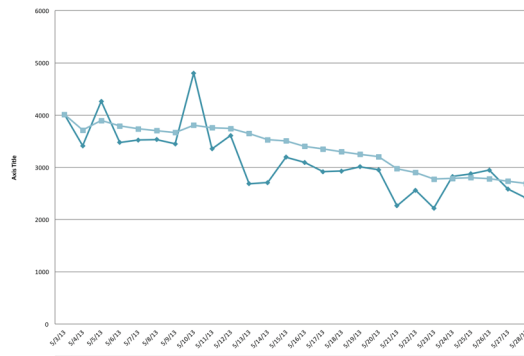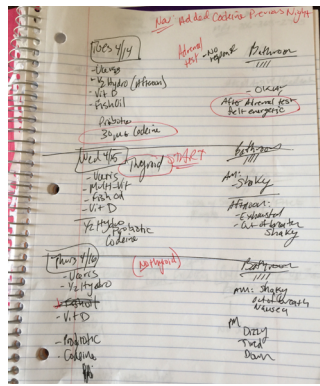**Collaboration throughout the Personal Informatics Model**

The experiences presented in the case studies depict different types of patient-provider interactions with shared patient-collected data in current clinical practice. To further understand when and how these collaborations take place, we present the results of our analysis based on the five-stage model for personal informatics from Li et al. [34]: *preparation*, *collection*, *integration*, *reflection*, and *action*. We describe how sharing occurs between patients and providers on self-tracked data and how sharing influences tracking behavior in all stages. To illustrate a range of experiences in patient-provider collaboration, we describe representative as well as suggestive examples from interviews and surveys.

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. [16] 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). For patients being considered for bariatric surgery, they were asked to do a trial of the recommended post-operative dietary guidelines and to track their diet for a defined time 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

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.

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 [10]. This sometimes created a tension for later collaboration in the reflection stage.

For 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 "*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 goal 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 the visit. Some patients felt frustrated afterwards when this goal was not obtained (e.g., P2, P10, P42). It was also difficult for patients who initiated tracking and sharing to anticipate their provider's goal beforehand, or providers might not have specific goals before seeing patient-tracked data.

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, consistent with our previous study with providers [10].

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 from reflection on the tracking record. Because chronic disease such as overweight/obesity and IBS require long-term care, patients might start another care cycle [7] 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.

TRACKING DATA AND TOOLS THROUGHOUT THE COLLABORATIVE TRACKING PROCESS

Based on our findings of how providers and patients collaborate, we started to analyze how tracking data and tools support collaboration in these stages. As patients and providers went through different collaboration stages, patient-generated data was transformed into different physical or conceptual forms to support collaboration. We adopted the framework of boundary negotiating artifacts by Lee [32] 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. We 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 [43] 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 [43] 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, we present a summary of the use of four types of boundary negotiating artifacts in patient-provider collaboration around self-tracked data. Appendix 1 also summarizes these results with examples.

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 [32] include personal sketches and notes that help to record, organize, and analyze personal ideas. Patient-generated 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 managing weight and 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 the 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 they 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 informed consent to track and for their provider to access 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 their tracking data because they help 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 and 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-generated 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 [e.g., 23,49,57]. Although providers and patients work together to create compilation objects, patients might not feel comfortable sharing the same information with every provider. However, with EMRs, self-tracking data can be shared among collaborating doctors without patient knowledge, or even many years later with providers who are not working with the patients, 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 only 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 [22]. 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 [60]. Self-tracking data may not be considered PHI under current regulation [22], and patients in our study were confused about whether these data are protected by HIPPA (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 [32] boundary negotiating artifacts also include borrowed artifacts, which are those taken from the creator, augmented with other interpretation, and used in an unanticipated way. However, we did not identify the creation or use of borrowed artifacts in our analysis.

DISCUSSION

Collaboration occurred in all stages of the personal informatics model according to our patient and provider surveys and interviews; however, some of the collaborative activities are less supported by current commercial tools. 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. We 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 [14].

We do not claim that providers do not spend enough time and effort to communicate with their patients. Many of our participants, in fact, thought their providers have been very open to communication, despite frustration with their sharing experiences. What we do claim, however, is providers and patients lack a mechanism to reach 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 [11]), 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 what Patel et al. proposed for cancer patient symptom tracking [47], patients and providers could set up specific parameters for tracking, such as items and frequency, based on their sharing and reviewing goals. Lifestyle behavior tracking, however, often

lacks standard metrics, which is different from medication or symptom tracking. Therefore, guiding template design with communication around provider and patient goals is necessary. For example, if the goal is to identify a specific trigger, patients and their providers can 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, if one self-tracker suspects his abdominal pain is triggered from a certain food and would like an official evaluation, he 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 [15]. 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. Similar to myRecord [3] and Tag-it-Yourself [55], during the curation period, these systems could also 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 [59], or supply additional contextual information necessary to support conversations in 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, 46], users should be able to tailor their sharing content based on which providers they would want to share and what their sharing goals are. This is particularly important for systems seeking 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 were frustrated about not being able to focus on the questions in which they were interested (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 [e.g., 33]. 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 office, and provide opportunities to personalize the patient's 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 [34] and boundary negotiating artifacts [32] helped us understand how providers and patients collaborate using patient-generated data. However, we 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, we 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, we 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 plan to educate patients about what and how to track while patients might plan to adopt 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 when applying the stage-based model to patient-provider collaboration on tracking and reviewing. Collaboration can be terminated by either party during or between stages. Patients might lapse in collecting data [16]. 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 by Epstein et al. suggests opportunities and possible strategies for designing for

lapsing and resuming tracking [16]. We 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 [43], we 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. While our study focuses on IBS and weight management populations, we believe that the opportunities to apply and extend current models and theory will be informative for other forms of collaboration using self-tracking data. For example, financial advisors review client financial data, personal trainers prepare workout plans and review journals, and many families review budgets and bills together.

Limitations
Our survey samples could have self-selection bias in favor of patients and providers who are more open to or interested in use of self-tracking data. However, these samples provided us an in-depth understanding of what currently happens in patient-generated data sharing with providers in populations with obesity and IBS. Our study is also limited to an analysis of self-reported patient and provider experiences and perceptions of their experiences with shared data. The collaborative experiences likely built upon the typical long-term relationships between the providers and patients in our study and organizational factors of the health system from which we recruited. Future observational studies could provide more insights on patient-provider interactions with self-tracking data in various clinical settings.

CONCLUSION
Building on the stage-based model of personal informatics, we observe and present patient expectations for sharing self-tracking data with their health care providers and how collaboration takes place in different stages. In addition, we adopted the theory of boundary negotiating artifacts to describe how current tracking tools and data support provider and patient collaboration. Grounded in these theories, our study 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 each party 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 by each party. 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.

We also suggest further development of models of personal informatics and the theory of boundary negotiating artifacts based on the social nature of patient-provider collaboration. Researchers should elaborate on personal informatics models (e.g., [16,34]) 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.

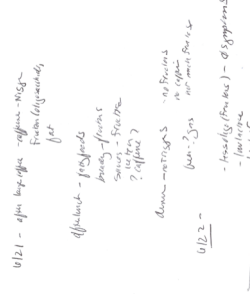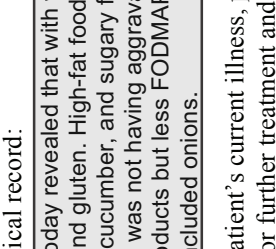## ACKNOWLEDGMENTS

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Appendix 1: Examples of boundary negotiating artifacts used in provider-patient collaboration with patient-generated data

Artifact type	Purpose	Example	
Self-explanation	Artifacts created for personal use. Patients usually track food intake and symptoms using their preferred tools and format, but sometimes use tools suggested by their health provider.		Some patients use paper diaries provided by health providers to track, such as this diary for food intake and symptoms.
Inclusion	Artifacts created through a negotiation process to facilitate discussion. Patients present and discuss self-tracking data in the clinic. Providers often make notes to capture information that complements tracked data.		One provider annotated the food journals based on her expertise and on the patient's verbal description. One provider took notes while reviewing data. The notes included details the patient verbally supplemented and the provider's medical assessment.
Compilation	Artifacts used to facilitate sharing and coordinate information among parties. After reviewing patient tracked data and assessing medical history and test results, providers create compilation artifacts.	One provider summarized her review of a patient diary in the medical record: Review of her food symptom journal that she brought with her today revealed that with worsening symptoms the patient's diet consisted more of high fat foods, FODMAP's and gluten. High-fat foods included foods such as steak, barbecue ribs. High FODMAP foods included onions, cucumber, and sugary foods. Gluten products included bagels. When this was compared to her diet when she was not having aggravated symptoms, patient also had evidence of some high-fat foods and gluten products but less FODMAP's. These high-fat foods included sausage and pork roast. High FODMAP foods included onions. The notes in the medical record also include a description of the patient's current illness, previous medical history, a series of test results, medication, and recommendation for further treatment and revisit.	
Structuring	Artifacts created to coordinate information use and activities involved in the collaboration. Providers and patients create plans after negotiating and compiling information. Providers offer handouts that can be structuring artifacts to help patients follow plans.		One provider and her patient decided to adopt the low FODMAP diet after reviewing patient's food and symptom diary. The review suggested patient's symptoms might be a result of poor absorption of FODMAP food. The provider printed a handout the patient could refer to help follow the diet plan.