Sharing patient lifelog data with the primary care team for two patient populations: preventative care & chronic disease management

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Structured Abstract

Purpose
We employed human-centered design to understand needs and attitudes for sharing lifelog data – data collected through user journaling and sensors – with healthcare providers, to improve healthcare management and decision-making.

Scope
We focused on patients with IBS and/or healthy eating goals. These two conditions have high prevalence and high direct and indirect costs. They also both often require understanding of and changes to everyday eating, and so collaboration and coordination using patient-tracked data is may be particularly important.

Methods
To understand current practices, we interviewed with health providers, asked health providers to review patient food and symptom journals, and surveyed and interviewed patients. We applied the results of this formative research to the design of novel systems, including a photo-based food diary and a self-experimentation system for use by IBS patients and their providers and a photo-based food diary for use by people with healthy eating goals and their providers.

Results
Our results find considerable aspiration and potential for collaboration using patient-generated health data. Providers and patients currently face considerable barriers to doing so, including unclear communication and coordination around tracking, limited time, and tools designed for individual rather than collaborative use. Tools designed to support coordination around goals, to reduce the burden of synthesizing patient data, and sharing can mitigate these barriers and support effective and efficient collaboration.

Key Words
Irritable bowel syndrome, obesity, healthy eating, patient-generated health data, collaboration

Purpose

In this project, we employed human-centered design to understand needs and attitudes for sharing lifelog data – data collected through user journaling, smartphone sensors, and devices – with healthcare providers, to improve healthcare management and decision-making. Specifically, we sought to understand:

- Patient attitudes, values, and goals for sharing lifelog data – including food, physical activity, stress, and if applicable, symptom data – with their health providers.
- Provider attitudes, values, and needs for integrating patient-collected data into care.

For each aim, sought seek to understand the differences and similarities between obese/overweight patients and irritable bowel syndrome (IBS) patients. We hypothesized that patients who are symptomatic from a disease such as IBS will have greater motivation to track and a greater desire to share their data compared to relatively asymptomatic obese/overweight patients. We also anticipated there being barriers to use, including integration with the medical team's workflow and patients' privacy needs, which must be considered in the design of sharing tools.

We then developed data analysis tools to support these uses of patient-collected data and evaluated their appropriateness and feasibility in a field deployment involving doctors and patients. From the results of our investigation into provider and patient attitudes and our deployment, we identify transferable design principles and opportunities for integrating patient-collected data in care, which can inform current clinical practice, the design of health and wellbeing applications, and future research projects.

Scope

In this research, we studied patient and provider needs and attitudes for using patient-generated health data for both preventative medicine and managing a chronic illness. Patient-generated data – either journaled by individuals or objectively measured through sensors in phones and other devices – has the potential to make more accurate and more precise data available for use in clinical care. Collecting this data electronically also allows for automated analysis and summarization of the data. We a focused IBS and weight management because these conditions have personal costs and high direct and indirect economic costs.

Overweight and Obesity

The prevalence of overweight and obesity are increasing in the United States (Flegal et al. 2010, Ogden 2012). Overweight and obesity are associated with increased risk of cardiovascular diseases, type 2 diabetes, certain cancers, respiratory problems, and osteoarthritis (CDCP 2012, Guh 2009, Lenz 2009, Lungvall 2012).

In June 2012, The United States Preventive Services Task Force published guidelines recommending primary care physicians screen all adult patients for overweight and obesity and offer or refer patients with a body mass index$>30kg/m^2$ for intensive, multicomponent behavioral interventions (Moyer 2012). Addressing barriers to change, self-monitoring, and strategizing how to maintain lifestyle changes have been effective in weight loss or maintenance. Large trials have confirmed that groups that provide counseling for change in diet and physical activity result in significant weight loss that is sustained for at least one year with few side effects (USPSTF 2012). Though effective, these types of multicomponent programs are resource intensive. To address the resource intensity of in person behavioral weight loss programs, technology enabled approaches to behavioral weight loss programs are increasingly common. A recently published Cochrane review found that compared to no intervention, interactive, computer-based interventions were more effective than no treatment, but modestly less effective than in-person

programs at helping overweight and obese adults lose weight (Wieland 2012). However, because of lower implementation costs, computer-based approaches may be more cost-effective (Krukowski 2011).

Despite ample evidence supporting behavior change programs in treating obesity, additional research is needed to understand efficient methods of implementing evidence based treatment recommendations. Primary care providers report inadequate training and lack of time as significant barriers to providing counseling for weight loss (Kushner 1995). Multidisciplinary teams are increasingly important in primary care. Management of obesity often includes treatment by primary care providers and nutritionists (Anand et al. 2010; Fletcher 1982; Frank 1998; US Preventative Services Task Force 2012). Integration of consumer-collected data with healthcare provider routines may increase the efficacy of behavior change efforts, but design and treatment practices to support use of this data are currently unknown.

Irritable Bowel Syndrome

IBS is a chronic functional disorder characterized by the presence of episodic abdominal pain associated with diarrhea and/or constipation. It affects up to 20% of the US population (Elsenbruch et al. 2011). It is one of the top ten reasons why patients seek primary care and accounts for a third of all gastroenterology consultations (Elsenbruch et al. 2011). Patients suffering from IBS report a lower quality of life and consume 50% more health care resources than their non-IBS counterparts (Ladabaum et al. 2012; Longstreth et al. 2003; Mitra et al. 2011). The total estimated annual cost of IBS in the US is $30 million (Ladabaum et al. 2012).

Prior studies have demonstrated the benefits of self-management programs for IBS patients (Heitkemper et al. 2004). These 8-week comprehensive self-management programs empower patients to take charge of their own health though behavioral interventions such as elimination diets, increased frequency of eating, decreased portion sizes, or determining individualized trigger foods (Barney et al. 2010). IBS patients completing the 8-week program achieved significant symptom reduction and an overall improvement in quality of life (Heitkemper et al. 2004). The effectiveness of these IBS management strategies was equivalent when conducted over the phone or via internet-based programs (Jarrett et al. 2009; Andersson et al. 2011). Compliance with all recommended IBS behavioral interventions is difficult, however. Fortunately, elimination of all known IBS triggers is often not necessary. An IBS patient's response to certain triggers varies, aggravating symptoms in some patients but not others (Jamieson et al. 2007).

The American Gastroenterological Association (AGA) medical position statement on IBS advises practitioners to help their patients by "using a diary [to] help identify possible triggers to symptom exacerbation" (American Gastroenterological Association 2002). Known IBS symptom triggers include certain foods (gluten, poorly absorbable carbohydrates such as lactose and fructose, high-fat), stress/anxiety, and lack of physical activity (Gibson et al. 2012; Barney et al. 2010; Johannesson et al. 2011). Identification of IBS symptom triggers is currently done by manually scanning a patient's paper food, sleep, activity, stress level and symptom diary for correlations. This process is flawed by the following issues: 1) paper diaries are typically handwritten with incomplete, disorganized, and unreliable data; 2) providers do not have the time to interpret the disorganized data presented from such a diary; and 3) there is no objective, validated methodology for determining an individual's symptom triggers from these diaries (Jhaveri et al. 2007; Heinonen et al. 2012). As a result, 62.5% of IBS patients report dissatisfaction with healthcare providers feedback based on their diaries (Jamieson et al. 2007).

IBS patients and their providers need a more efficient and effective way to individualize lifestyle modifications for bowel symptom reduction and improved quality of life from the data collected from these diaries. Despite the AGA recommendation for IBS patients to track their symptoms in a diary, limited research has been conducted on the perspectives of both IBS patients and their providers on the goals for sharing and using lifelog data. Sparse research has also been conducted on the feasibility and usability of these diaries as data collection tools from IBS patients. As a consequence, IBS patients and

their providers are limited in their ability to represent this patient-collected data in a meaningful way for the ultimate goal of bowel symptom reduction and improved quality of life.

Health Information Technology & Lifelogs

As of 2012, The Pew Research Center estimated that 46% of US adults own a smartphone, up from 35% in 2011 (Pew 2012). Among priority populations, such as African-Americans and Latinos, smartphone adoption among adults is similar to the national average (Pew 2012). Though lower than the national average, rates of smartphone adoption among individuals with low income increased rapidly between 2011 and 2012 (Pew 2012). An effective smartphone application to promote weight loss or manage IBS symptom flare-ups could be effectively disseminated to large proportions of the US populations and has the potential for a large public health impact.

People increasingly turn to smart phone applications and other devices for collecting and tracking personal health data. Personal informatics tools have been developed and studied in a variety of domains, including physical activity (e.g., *FitBit*, Consolvo et al. 2006, Consolvo et al. 2008), sleep (e.g., *SleepCycle*), food consumption (e.g., *MyFitnessPal*, Tsai et al. 2007). Tools also combine and help track multiple types of data, such as the combination of location and physical activity in *Moves*. Electronic diaries for other medical conditions have resulted in improved compliance rates, more complete and higher quality entries and better user satisfactions when compared to paper diaries (Jhaveri et al. 2007; Heinonen et al. 2012; Palmblad et al. 2004). They have also resulted in speedier handling of the data with reduced total workload (Jhaveri et al. 2007). 69% of U.S. adults report tracking a health factor with 14% currently using technology to do so (Fox & Duggan 2013). We expect this number to increase as technology becomes more ubiquitous and capable and is designed to offer greater benefits. In the proposed research, we will focus on helping people get the most possible value out of the health information they track by understanding how to integrate these lifelogs into clinical care.

Methods

Our research was divided into two phases. The first focused on examinations of current data tracking and sharing practices among people with weight loss/management goals and IBS patients. The second stage consisted of designing and fielding prototype systems based on the results of this initial investigation. We also conducted additional exploratory studies in between the formative work and the design and feasibility evaluation; those are not reported here due to space limitations but can be found in the products section at the conclusion of this report.

Understanding Needs and Current Practices

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 and providers.

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 patient 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 completed the survey with a $5 gift card.

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 20–30 minutes to complete.

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 (Fox & Duggan 2013). 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 team also created an affinity diagram to identify 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 in light of those identified through coding.

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 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 understand 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. 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 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. 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 (Li et al. 2011) to analyze the data to help us understand when and how collaboration occurs throughout the tracking process.

Provider Interviews
We recruited 21 primary care providers through word-of-mouth recruitment with colleagues. We focused on health providers in a large, university-affiliated health system (1). To gather perspectives from providers in other health systems, we also interviewed providers in a second university-affiliated health system (2), a health maintenance organization (1), and one independent dietitian. Many providers also had experience working in other university-affiliated health systems, another health maintenance organization, and other private. Some of these organizations were in other states. Participants included 6 family

medicine physicians, 1 behavioral psychologist, 1 nurse practitioner, 5 gastroenterologists, and 7 dietitians. We compensated each participant with a US $30 gift card.

The family medicine physicians, dietitians, nurse, and behavioral psychologist we interviewed work with patients on a variety of concerns, including IBS and obesity/overweight, while the gastroenterologists work specifically with patients with digestive problems, such as IBS. Our results describe practices, goals, and barriers experienced by a variety of health providers. We believe the results describe most US health systems, though we note where we identified differences between health systems. Further, because the providers we interviewed practice at a variety of clinic sites, we were able to learn about experiences providing care to patients with diverse backgrounds and socioeconomic statuses. This is important, as personal informatics tools are commonly critiqued, for the most part, as tools for technically savvy, well-off individuals.

We conducted an hour-long semi structured interview with each participant. We interviewed 10 participants in person and 11 by phone. To help providers react to specific examples of different types of data, including providers who were less familiar with personal informatics tools, we used three paper prototypes in the interviews. These included a dashboard for a physical activity tracking device currently on the market (*Fitbit*), a mobile app to help IBS patients track symptoms and triggers (*Gut Guru* – Zia et al. 2016), and *Health Report* (Cook 2014), a conceptual app that allows patients to track symptoms between visits and then summarize their data before a clinic visit. For remote interviews, we presented prototypes using video chat features or sent screenshots by email.

We audiotaped and transcribed all interviews. The research team conducted an affinity diagram analysis (Holtzblatt et al. 2004). We transformed the interview transcripts into approximately 700 affinity notes. After several passes inductively organizing these notes into categories, we identified 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 (based on our research questions and themes identified in prior work) and inductive coding to capture other emergent themes. Two researchers 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 reviewed all transcripts to reflect the final codebook. In coding transcripts, we coded especially for goals and barriers to patient data use.

Understanding the current baseline for review of IBS journals
There are currently no standardized methods for identifying trigger food(s) from irritable bowel syndrome (IBS) food and symptom journals. The primary aim of this study was to assess the inter-rater reliability of providers' interpretations of IBS journals. A second aim was to describe whether these interpretations varied for each patient. Eight providers reviewed 17 IBS journals and rated how likely key food groups (fermentable oligo-di-monosaccharides and polyols, high-calorie, gluten, caffeine, high-fiber) were to trigger IBS symptoms for each patient. Agreement of trigger food ratings was calculated using Krippendorff's α-reliability estimate. Providers were also asked to write down recommendations they would give to each patient. Providers were also asked to "think aloud" as they reviewed an IBS journal. We also asked whether they thought journaling was a valuable experience for them and their patients. During the exit interview, they were asked to describe their journal review practice and challenges.

Designing and Deploying Systems to Support Patients and Providers
We designed, built, deployed, and validated the feasibility of prototype applications to help patients collect data and, working with it, analyze it to gain new understandings about their health.

Irritable Bowel Syndrome
For irritable bowel syndrome, we designed and built a suite of applications, focused on helping people form hypotheses about which foods might trigger their symptoms and then to test their hypotheses.

Quantified Analysis Tool
For irritable bowel syndrome, we first designed a set of visualizations that could help patients and providers explore the correlations between nutrients patients eat and the symptoms they experience. The first, a bubble and bar chart, emphasizes exploration of high-level trends and the relationship between a selected symptom and a selected nutrient from a patient's data. Each meal from the patient's journal is displayed as a point in a faceted bubble chart. Meals are bucketed by symptom severity and the amount of the nutrient in the meal. A stacked bar chart aggregates the information in the bubble chart to facilitate identification of trends. The visualization incorporates multiple bubble and bar chart units to facilitate comparison across nutrients. The second, a parallel coordinates visualization emphasizes relationships between nutrients and includes more detailed information (e.g., explicitly showing nutrient ranges in the patient's journal). Each meal corresponds to a line through the axes, thus showing the symptom severity and the amount of each nutrient consumed in that meal. Dragging vertically along an axis creates a filter that grays all excluded lines. Each visualization as designed to support four principles identified through our formative work: flexibility, simplicity, support for exploration, and actionability.

To evaluate these visualizations, we recruited 10 providers with experience working with patients with IBS and 10 patients with IBS. Patients were compensated with a $25 Amazon gift card, analysis and interpretation of their data, and a free consultation with a provider experienced in working with patients with IBS. Providers were compensated with a $50 Amazon gift card. Because visualizations of personal data are most meaningful to the person who provided the data, we recruited patients from participants in a prior study that involved keeping food and symptom journals (Zia et al. 2016). The prior study was completed about a year before our analyses and visualizations were developed, so the journals were not recent. At the time of the prior study, all patient participants met the Rome III criteria for IBS and had experienced IBS symptoms within the previous month (Longstreth 2006).

Interviews included two phases: individual and collaborative. In the first, one researcher interviewed the patient while another interviewed the provider. This phase lasted 40 minutes, with approximately 20 minutes dedicated to each visualization and follow-up questions. Participants completed the tutorial and then explored the visualization of the patient's data. They were encouraged to talk aloud during their data exploration and to ask any questions they had. Researchers then asked about participant opinions of the visualizations and what conclusions they would draw from them. In the collaborative phase, the patient and provider were brought together to explore and interpret the visualizations, simulating a clinic appointment. Participants were given their choice of which visualization(s) to use, and were able to switch between them at any time. They were then jointly asked to compare their experiences using the visualizations alone versus collaboratively.

We audio-recorded and transcribed all interviews. We then conducted an affinity diagram analysis to identify emergent themes. Two researchers transformed interview transcripts into approximately 800 affinity notes and iteratively organized these notes into 75 categories. We then identified several key themes regarding patient-provider collaboration and use or non-use of the tool to support collaboration.

Foodprint
To support people without specific hypotheses about a food or nutrient that triggers their symptoms, we build a photo-based mobile food journal. We recruited 16 IBS patients and 8 providers with experience working with IBS. We recruited patient participants through prior studies conducted and provider participants through our medical collaborators. We randomly assigned patients to the Foodprint only group, in which patients use IBS Foodprint system throughout the study, and nutrient analysis group, in

which patients use IBS Foodprint system throughout the study but have a chance to see the IBS nutrient analysis system during the post-interview. All patients participated in four stages of the study.

1. Pre-interview. During this 60-minute session, we interviewed patients about their IBS history, prior food and symptom tracking and sharing experience, and their goal for using this food and symptom tracking data. Then we introduced and installed the IBS Foodprint mobile application on the patient's phone and explained the features of both the mobile application and the web application.

2. Food and symptom tracking. Patients were requested to track their food and symptoms using IBS Foodprint for six or nine days. They followed a three-days-on and three-days-off protocol (i.e., tracking their food and symptoms for consecutive three days, then take a break for three days, and resume the tracking for another consecutive three days). Patients who tracked for a total of nine days therefore had two tracking breaks. Patients were free, but not required, to track more days. As our formative work demonstrated that understanding client goals is key to supporting collaborative review of self-monitoring data, we also asked participants to fill out a pre-visit note summarizing their findings from the data, goals of the upcoming visit, and questions they would like to ask health experts in the visit.

3. Post-interview. The post-interview consisted of two sessions. In the first session, we invited patients and providers to review patient-tracked data separately using IBS Foodprint web application. Providers also had access to patient notes about their goals and questions to support their individual review (Appendix 2). For patients in the NA group, we also introduced them and their paired providers to the IBS nutrient analysis system. They then had the opportunity to review both the visualizations and the IBS Foodprint photo-based visual summaries. This session took 30-45 minutes. In the second session, patients and their paired providers were invited to review patient-tracked data together in a 15-20 minute visit. Patients and providers in the nutrient analysis group could choose to review patient data using IBS Foodprint, IBS nutrient analysis system, or a combination of both systems. We then followed up the visits with questions regarding patient and provider experience of reviewing patient-tracked data together.

4. Follow-up survey. A month after the post-interview, we sent out a patient survey asking what dietary or other behavior changes patients have made since the study.

TummyTrials
For patients with a hypothesis that a particular nutrient or food triggers their symptoms, we designed and evaluated *Tummy Trials*, a system that walks a person through the process of configuring, conducting, and understanding the results of a self-experiment. We conducted a feasibility study to assess the practicality, usability, and user burden of TummyTrials while gathering participant feedback in a primarily qualitative study, a best practice for evaluating early-stage health technologies (Klasnja, Consolvo, Pratt 2011). We recruited participants by emailing 1100 randomly selected patients with food intolerances resulting in gastrointestinal symptoms from a list of a patients in a large medical system acquired under a HIPAA waiver. Of 190 patients who replied, we filtered to 41 eligible participants based on those who owned an iPhone, were between 18 and 70 years of age, and met the Rome IV IBS criteria (Palsson et al. 2016). Of 41 eligible patients, 18 enrolled for the study and 15 completed their experiment within the study window. 5 participants reported being Asian and 10 reported being White. A majority of participants were women, but IBS patients are more likely to be women (Canavan et al. 2014).

Study participants received guidance from the researchers as to what hypotheses they might test and how to interpret the results of the self-experiment. This guidance is consistent with current practices in patient-provider consultation (e.g., in the context of an elimination diet or a food and symptom journal), where a provider may give instructions, ask a patient to keep a record, and collaboratively review the record. Our goal was to determine whether TummyTrials can successfully support people in completing a self-experiment and discover any challenges people encounter throughout it.

Healthy Eating
During our field study, and based on our preliminary research, we broadened our overweight/obesity population to those with healthy eating goals. This includes people who are working to reduce their weight as well as those who want to prevent weight gain, along with people trying to adjust intake a nutrient (e.g., adopt a low-sodium diet) or to tune their behavior on other ways (e.g., eat less processed food) to increase their health. For this population, we adapted *Foodprint* to remove tracking of and analysis by IBS-specific symptoms and food triggers, while adding common measures for common healthy eating goals.

We recruited 23 people with healthy eating goals and 8 health experts with dietary consulting experience. We recruited people with healthy eating goals through social media and mailing lists associated with University of Washington. We asked potential participants to fill out a screener and used their responses to assign people into three different groups: balanced diet, ingredient monitoring, and lifestyle factor monitoring. We purposefully assigned people to the group matching the health goals they described in the survey to ensure their motivation and encourage participants to focus one goal at a time. We recruited six expert participants through prior studies in University of Washington and snowball sampling. The study consisted of four stages, which paralleled the stages in the Foodprint IBS deployment study.

Results
Our results find considerable aspiration and potential for collaboration using patient-generated health data. Providers and patients currently face barriers to doing so, including unclear communication and coordination around tracking, limited time, and tools designed for individual rather than collaborative use. Tools designed to support coordination around goals, to reduce the burden of synthesizing patient data, and for sharing can mitigate these barriers and support effective and efficient collaboration.

Current Practices
To understand and design for 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. 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." 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.

Making sense of data. Many patients reported wanting provider input to help make sense of the data. 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." 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."

Providing a personalized and actionable plan. Patients also expected providers to engage with the data and provide a personalized treatment plan. 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."

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.

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 et al. 2011). "I clearly understand my current condition and behaviors, which I feel is important as I try to improve my diet and exercise habits."

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." 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." Sharing tracking data with providers also "provides motivation and positive reinforcement."

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." Patients may also desire emotional support or empathy from their providers: "to help them understand what I am going through." 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."

How do providers and patients collaborate during the tracking process?
The experiences described by patients and providers depict different types of patient-provider interactions with shared patient-collected data in current clinical practice. We present our analysis based on the five-stage model for personal informatics from Li et al. (2011): 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. (2011) further divided the preparation stage into deciding to track and selecting tools.

For provider-initiated tracking and sharing, patients typically had adequate motivations to track: monitoring for a specific treatment (e.g., elimination diet) or for long-term performance (e.g., weight loss performance). Patients also reported being asked to track their food intake to get approval for bariatric surgery or gastric pacemaker implantation. 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
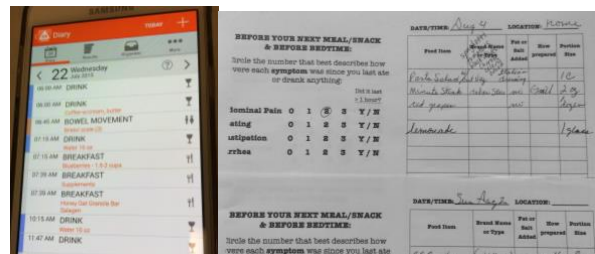

Figure 1. Examples of electronic & paper food diaries.

for patients able to adhere to this diet post-operatively. For gastric pacemaker implantation in patients with gastroparesis, 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), a specific application (e.g., MyFitnessPal), and, for one participant, a list of popular applications. However, patients do not always follow those recommendations. Some patients have tools with which they are already familiar or follow suggestions from friends or family. They may also have specific needs that the provider-recommended tool does not fulfill. For example, one patient 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 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, on participation resumed tracking his weight and calorie intake 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 later.

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. Having the expectation of provider review also increased patient accountability and motivation, for example, one patient 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. For example, mySymptoms, provides correlation features, and other tools include an integrated dashboard (e.g., MyFitnessPal, LoseIt). Some patients created their own integration by making their own reports. One patient selected specific records to print for providers. Others highlighted particular entries in their paper records to help focus the conversation. 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.

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. 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; this is consistent with provider reports.

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. One patient described having a thorough review with one doctor and a brief verbal review with another. Similarly, another'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 (Chen 2011) at this stage. Some patients used notes they took or were printed by providers 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 (2007). 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.

The norms of appropriateness and distribution are complex in the healthcare domain (Nissenbaum 2004). 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.

Evaluation of Food Journal Review for IBS Trigger Identification
In our study of provider review of paper-based diaries, we found that providers consider journaling a valuable process as it improves provider-patient relationship, holds patients accountable, and increases patient awareness and knowledge. Most providers use other tools to support their interpretation. They break down nutrients, tally occurrence of potential triggers, and write down their hypotheses on the journal or a separate sheet of paper. Providers also use various strategies to analyze the data. Most providers read through the first few journal entries and developed initial hypotheses of potential triggers. Some then focus the rest of their review on verifying these hypotheses by skimming the rest of the journal entries. Others develop new hypotheses during the review process.

However, they struggled to interpret these diaries reliably or consistently. Providers found it difficult to manually correlate food and symptoms. Some found journal interpretation difficult because they lacked the knowledge of detailed nutrient information for certain meals. Some providers wanted additional information, such as stress levels, baseline GI symptoms, and non-GI symptoms to help them better understand a journal. Even though food triggers are individualized, most providers gave similar trigger food likelihood ratings for over half the food groups. Four providers gave the same written recommendations to over half the patients. Inter-rater reliability of provider interpretations of IBS food and symptom journals was poor. Providers favored certain trigger food recommendations across patients,
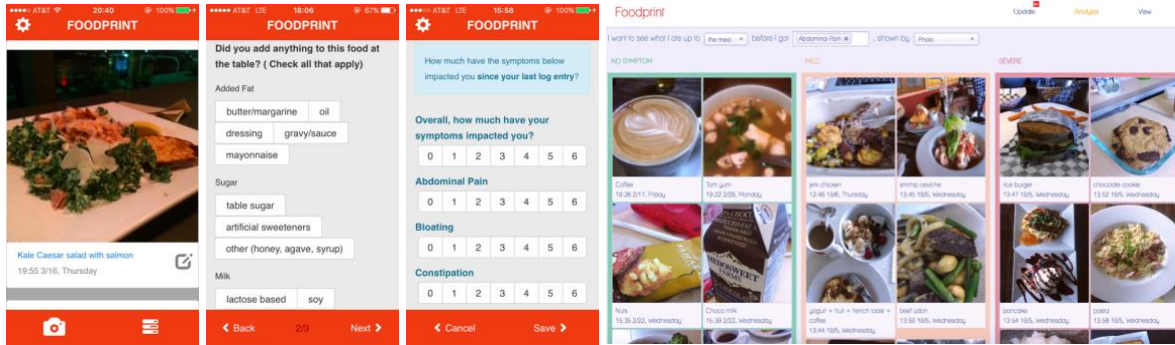
Figure 2. IBS patients can record data on the Foodprint mobile application (left three screens) and analyze it on their own or in collaboration with providers using the Foodprint website (right).

while different providers gave the different advice based on the same diary. This supports the need for a more standardized method for interpreting these journals and/or more rigorous techniques to accurately identify personalized IBS food triggers.

Design of Journaling and Collaboration Tools

Our results show that patient-generated data – including non-traditional data types, such as food photos – can enhance collaboration between patients and providers. This collaboration is most effective when tools scaffold some of the analysis, allow patients and providers to each bring as share their own expertise, and are tailored to the patient and providers' current questions. Additionally, people or the tools must support explicit communication and coordination about goals.

Irritable Bowel Syndrome

IBS patients were highly motivated to use the tools and to share the resulting data with providers. Overall, we found that both our tools for exploration and hypothesis formation and for hypothesis testing were successful. Their successes highlight the importance of patients and providers communicating about goals for tracking, having and configuring tools that support a patient's particular goals, in scaffolding tracking the right data to achieve those goals.

Foodprint: Photo-based journals and the Quantified Analysis

We report on results of the quantified analysis tool and Foodprint together (Figure 2). Of all 16 patients who used Foodprint, all confirmed existing hypotheses (5 participants) or identified new possible triggers to try changing (11 participants). Of the eight participants who also had access to the quantitative analysis, three used it to find insights beyond what they could see in the photos. Participants discussed managing identified triggers with their providers. Following the study, 11 patients continued using IBS Foodprint to continue tracking.

Interpreting patient-generated data required both patient expertise about their routines and experiences as well as provider medical expertise. Patients and providers focused on communicating patient goals and expectations, exchanging observations and context to support collaborative interpretation, and developing actionable plans.

Supporting communication about patient goals and expectations solidified collaborative review. To support patient-provider communication about goals, all providers had access to patient notes about their goals and questions. Many providers started the visits by confirming the goals patients specified in the note or explicitly asking patients what they need help with.

When we asked providers and patients what was helpful during the collaborative review, many providers pointed to patient notes helping them understand patient goals. Photo-based diaries also enabled patients and providers to exchange knowledge and context to support collaborative interpretation; patients and

providers exchanged their knowledge about IBS management throughout the visits. Even though all providers had extensive experience working with IBS patients and could identify patterns by looking at the photo-based visualizations, they often relied on patient experiences to support data interpretation. To supplement the diaries, all providers asked patients questions about their overall eating routines and symptom patterns, as well as whether the recorded data was representative of the patient's everyday life.

These questions about patient routines, combined with conversation about patient tracking practices, helped providers understand how they should interpret the data. Patients often have individual definition of "severe symptoms" versus "mild symptoms." Talking about these definitions helped providers better understand patient experiences and provide more individualized diagnosis and treatment. Some providers also wanted to know how much time passed between eating and an individual patient symptom flaring up. They wondered if having a medical assistant go over these details might help set the right filters in the system and prepare a more specific dataset for collaborative review.

Many providers and patients also discussed details about specific foods or meals, especially if these foods potentially trigger severe symptoms or the symptoms bother patients the most. Through these conversations, provider knowledge about nutrition and common IBS triggers also helped patients identify triggers they did not know about before. On some occasions, patients were aware of some foods that trigger their symptoms but were not able to identify the commonalities across foods.

Seeing patterns and eating context allowed patients and providers to develop actionable plans for IBS management. During the collaborative review stage, most providers and patients were able to pinpoint potential triggers quickly and spend more time discussing actionable next steps. Once providers and patients identified potential food-related triggers, they focused on eating strategies or trigger food substitutions. Most providers had conversations with patients about their personal preferences, routines, and limitations to identify at least one thing they can try at a time. Providers also suggested ways to experiment and understand the effects of changes on symptoms.

When is photo-based visualization vs. quantitative analysis visualization useful? Providers and patients both appreciated having two different systems to support IBS trigger management. During the collaborative review stage, all eight patient-provider pairs who had opportunities to see the visualizations of quantitative analyses chose to review the photo-based visualizations first. Photo-based visualizations gave providers 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. However, when patients and providers could not find clear relationships from the photos, they appreciated having the visualizations of quantitative analyses to help with more in-depth analysis.

While initially skeptical of photo-based journals, providers commented that they were able to see patient overall eating patterns easily and develop some hypotheses to discuss with patients. "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." They also thought that photos provide a more complete and objective record of patient diet: "[With IBS Foodprint] I get an idea of what their overall diet is like. I think when people do a diary, sometimes they're not entirely truthful, or they always say, 'I eat really healthy.' So, if they take a picture, then maybe it's a little bit better record." In particular, providers found it helpful to see food photos categorized by symptom severity and time.

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. To complement this, quantitative analyses can help patients who struggle with identifying triggers to understand underlying nutrient-symptom relationships. One participant, 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 (Foodprint) would have been more helpful because I wasn't as aware of what my problems were, but (the nutrient analysis system) breaks it down more and would be helpful for me now."

Photo-based diaries supported individual tracking and interpretation. Although our goal was to investigate collaborative review of patient-generated data by patients and providers, participants also found IBS Foodprint supported individual use. In particular, patients reported that photo-taking eased the burden of data collection compared to traditional diaries. Both patients and providers could see eating patterns, identify potential triggers or non-triggers, and develop questions for collaborative review by looking at photo-based visualizations individually.

IBS Foodprint also made food and symptom tracking easier. Corresponding to findings from other photo-based diaries (Cordeiro et al. 2015, Chung et al. 2017), many of our patient participants commented that taking photos was an easy way to record what they ate. They also considered the additional time answering questions specific to IBS trigger identification reasonable. Most participants considered taking photos more socially appropriate than writing down or inputting food content in other forms of diaries on the spot. However, some participants identified occasions on which taking photos of their food was difficult. For example, some participants had no-phone-at-the table rules for family meals or dinners. Some participants used the need to explain their photo taking behavior as an opportunity to communicate their IBS experiences with family members and friends and to receive support from them.

With photo-based visualizations provided by IBS Foodprint, many patients also found new relationships or confirmed suspected relationships between food and symptoms on their own. Patients who considered themselves in control of their symptoms also thought they would use the system when their routines change or if they would like to try new foods. One participant thought seeing photo-based visualizations would be helpful when she travels to new places, and others thought it would be useful to use from time to time to see how their symptoms have changed.

TummyTrials
Participants had positive experiences with self-experimentation and TummyTrials (Figure 3). Compared to their prior attempts to identify triggers, participants appreciated the structure and support: "I would say that, it provided the structure, it provided the discipline and it provided the reminders." They described the tool usable and low-burden. Participants were instructed to avoid testing known triggers, and generally tested foods they doubted were triggers but wanted to verify. Consistent with their expectations, most did not find evidence that the tested food was a trigger. Our experiment and analysis were designed for one-sided analysis (i.e., to detect if something is a trigger rather than to rule it out), but many participants interpreted "no evidence" of a food worsening their symptoms as proof that the food was not a trigger (e.g., "I'm glad they didn't show any evidence because it means I can eat more things").

Participants also encountered ways in which scientific rigor conflicted with the lived experience. We designed Tummy Trials to achieve a level of rigor common in scientific research, though many participants were happy making at least initial decisions about whether to consume a food based on less rigorous results. Many participants were willing to relax some of the validity of the experiment to make it fit better with their lives. In most cases, these were reasonable changes: e.g., shifting a day's schedule back a few hours to accommodate sleeping in, though
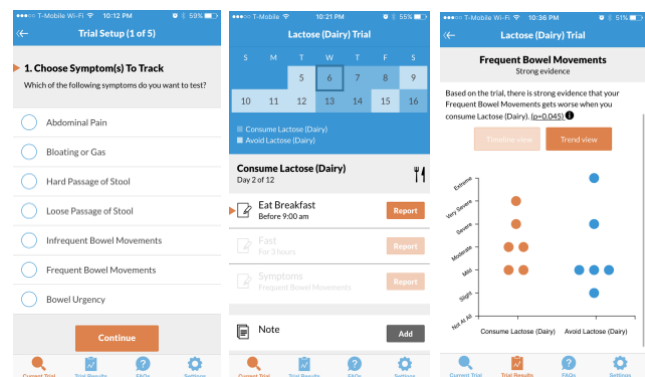

Figure 2. Tummy Trials walks IBS patients through configuring, conducting, and analyzing a self-experiment.

some made food substitution choices that invalidated their results. Overall, self-experimentation is a promising approach for understanding the relationships between specific foods consumed and the symptoms one experiences. It is a complement to the hypothesis formation tools offered by Foodprint. Future research is needed on flexible experimental designs and analysis methods that will better answer people's personal questions and better integrate into their lives.

Healthy Eating
As anticipated, people pursuing healthy eating goals faced more motivational challenges in using the tools and sharing with their providers than IBS patients. Of all 23 participants, two participants decided to prioritize other aspects of life over healthy eating goals in the middle of the study. Another four participants did not respond to our invitations for the post-interviews and were lost to follow-up. These six participants tracked for 6 days in average, ranging from 2 to 8 photos per day. For the remainder of this section, we report on the 17 participants who used the tool, but we note this self-selection bias.

Photo-based visualizations provide transparency and detail about eating habits
Experts and participants thought they could see the patterns of eating habits in a glance. Dieticians could quickly summarize what they saw in a client's diet and then use that as a starting point and shared understanding for the conversation.

The dieticians also thought that photos provided a transparent view of what participants actually ate. Many health experts thought that, compared with text-based diaries in which clients often had difficulty describing relevant details about food, photos can present participant food intake more accurately and precisely: "There's a sense of transparency because I'm seeing exactly what she's eating. It holds the person accountable. I'm able at my work to ask more questions and I think that's great as opposed to like MyFitnessPal, there isn't as much accountability because you have the person, just what they're saying. Like, 'I only had a half a slice of pizza and in all reality the person had like three.'… 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."

Dieticians and patients also considered photo-based diaries provided more details about food that are useful in dietary consultation or eating behavior change. Participants in previous studies of photo-based diaries (Cordeiro et al. 2015) found that instead of caloric information, photos captured more contextual information (e.g., when, where, how) and were interpretable using their general nutritional knowledge. Health experts in our study confirmed that this information helped them to provide better assessment of participant eating behavior and personalized recommendation. One dietician compared reviewing photos 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
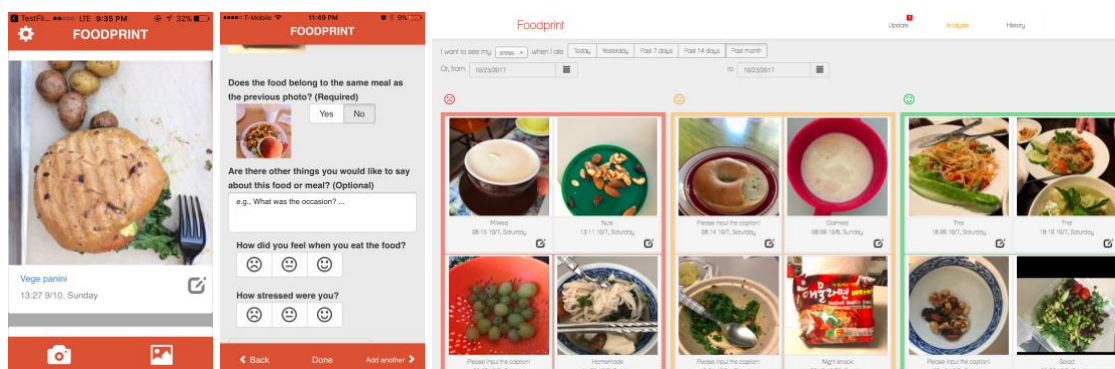

Figure 4. Foodprint for Healthy Eating supports lightweight food capture and analysis to support a variety of healthy eating goals, such as understanding the relationship between foods and mood/stress.

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."

Participant goals affect how photo-based visualizations were used
Participants often have more than one healthy eating goal. For example, participants who would like to monitor their sugar consumption also often cares about whether their diet is balanced. All participants mentioned in the pre-visit 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, monitor portion size, understand relationships between food and health concerns, and find ways to accommodate their diet restriction or preference.

In response to questions supporting various healthy eating goals, we found health experts and participants switched between the analysis page and the history page during the 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?") 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").

Although most health experts and participants thought photo-based visualizations helped them see participant eating patterns and talk about strategies to support these goals, two dieticians expressed difficulty reviewing sugar monitoring information. They thought that in some cases they might not know the amount of sugar in particular foods from photos if it was homemade. In cases when participants ate packaged foods or fruits, they knew enough to talk about it without the analysis.

Participants and experts can easily see trends, but collaboration is still necessary
Both participants and health experts thought that collaboration provides necessary contextual information to support interpretation and individualized recommendations. Participants thought reviewing data with health experts helped them confirm whether their eating habits were appropriate: "It is what I eat every day and I don't know the meanings behind it. Doing it together, actually, helps me knowing what is okay, what is probably not okay." Patterns revealed in the photos also allow dieticians to recognize participant effort toward healthy eating goals and encourage them to maintain this behavior: "You're doing a nice job in incorporating vegetables at lunch and even incorporating fruit and veggies a fair amount at breakfast."

Knowing participant routines, preference, or constraints also helped providers understand why participants made specific food choices. For example, one patient wanted to know if his diet contains enough protein and vitamins because he was "semi-vegetarian." He then explained his food choices by pointing to examples food photos. His dietician able to understand where he obtained protein and particular vitamins and provide other food recommendations.

Comparing use of Foodprint for IBS and for Healthy Eating
In both the healthy eating and IBS use cases, both patients and providers found that collecting and collaboratively reviewing the data was helpful for identifying patterns and developing actionable plans to address individual health goals. As the different groups came in with different questions, though, their uses also differed. IBS patients and providers focused primarily on trigger identification and management, and thus focused on using the data to identify potential causal relationships. Healthy eating patients and their health providers spent more time discussing potential goals and reviewing the data to identify and consider various possibilities.

Compared to gastroenterologists and many other providers working with IBS patients, dieticians helping people work toward healthy eating view reviewing food diaries as a regular part of their consultations. Because reviewing photo-diaries replaced review of paper diaries, dieticians saw Foodprint as saving time and increasing their efficacy – and so not all saw a need for clients to review the data to further increase that efficiency. "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." In contrast, IBS clinicians have limited time to review diaries before or during clinical visits. Many IBS clinicians, as a result, wished their patients reviewed data before they met and would be able to provide more insights to help with review.

List of Publications and Products

Chung CF, Cook J, Bales E, Zia J, Munson, SA. More than telemonitoring: Health provider use and nonuse of life-log data in irritable bowel syndrome and weight management. *J Medical Internet Res* 2015; 17(8). PMC4642406.

Chung CF, Dew K, Cole A, Zia J, Fogarty J, Kientz JA Munson SA. Boundary negotiating artifacts in personal informatics: Patient-provider collaboration with patient-generated data. *Proceedings of the 2016 ACM Conference on Computer-Supported Cooperative Work & Social Computing*, 770-786. PMC5432205.

Chung CF, Agapie E, Schroeder J, Mishra S, Fogarty J, Munson SA. 2017. When Personal Tracking Becomes Social: Examining the Use of Instagram for Healthy Eating. *Proceedings of the 2017 SIGCHI Conference on Human Factors in Computing Systems*: 1674–1687. PMC5432132.

Epstein DA, Lee NB, Kang JH, Agapie E, Schroeder J, Pina LR, Fogarty J, Kientz JA, Munson SA. Examining Menstrual Tracking to Inform the Design of Personal Informatics Tools. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* 6876-6888. PMC5432133.

Epstein DA, Caraway M, Johnston C, Ping A, Fogarty J, Munson SA. Beyond abandonment to next steps: understanding and designing for life after personal informatics tool use. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 1109-1113. PMC5428074.

Epstein DA, Kang JH, Pina LR, Fogarty J, Munson SA. Reconsidering the device in the drawer: lapses as a design opportunity in personal informatics. *Proceedings of the 2016 ACM International Joint Conference on Pervasive and Ubiquitous Computing*, 829-840. PMC5432203.

Epstein DA, Cordeiro F, Fogarty J, Hsieh G, Munson SA, Crumbs: lightweight daily food challenges to promote engagement and mindfulness. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 5632-5644. PMC5428072.

Epstein DA, Ping A, Fogarty J, Munson SA. A Lived Informatics Model of Personal Informatics. *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing*. ACM, 731–742.

Karkar R, Schroeder J, Epstein DA, Pina LR, Scofield J, Fogarty J, Kientz JA, Munson SA, Vilardaga R, Zia J. TummyTrials: A Feasibility Study of Using Self-Experimentation to Detect Individualized Food Triggers. *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems*, 6850-6863. PMC5432136.

Schroeder J, Hoffswell J, Chung CF, Fogarty J, Munson SA, Zia J. Supporting Patient-Provider Collaboration to Identify Individual Triggers using Food and Symptom Journals. *CSCW: Proceedings of the 2017 Conference on Computer-Supported Cooperative Work*. PMC5432206.

Zhang X, Pina LR, Fogarty J. Examining Unlock Journaling with Diaries and Reminders for In Situ Self-Report in Health and Wellness. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 5658-5664. PMC5553980.

Zia J, Chung CF, Xu K, Dong Y, Schenk JM, Cain K, Munson SA, Heitkemper MM. Inter-Rater Reliability of Provider Interpretations of Irritable Bowel Syndrome Food and Symptom Journals. *Journal of Clinical Medicine* 2017, 6(11). PMC5704122.

Zia JK, Schroeder J, Munson SA, Fogarty J, Nguyen L, Barney P, Heitkemper M, Ladabaum U. 2016. Feasibility and Usability Pilot Study of a Novel Irritable Bowel Syndrome Food and Gastrointestinal Symptom Journal Smartphone App. *Clinical and Translational Gastroenterology* 7, 3 (2016), e147.

Additional manuscript(s) describing the results of the Foodprint IBS and Healthy Eating deployments are in preparation with planned submission in January 2018. An RWJF-sponsored report describing this project will also be released in early 2018.

Additional References

Anand SG, Adams WG, Zuckerman BS. Specialized care of overweight children in community health centers. *Health Aff.* 2010; 29(4):712-7. PMID: 20197305.

Andersson E, Ljotsson B, Paxling B, Hedman E, Lindefors N, Andersson G, Ruck C. Cost-effectiveness of internet-based cognitive behavior therapy for irritable bowel syndrome: results from a randomized controlled trial. *BMC Public Health* 2011; 11:215. PMID: 21473754.

Barney P, Weisman P, Jarrett M, Levy RL, Heitkemper M. (2010). *Master Your IBS: An 8-Week Plan to Control the Symptoms of Irritable Bowel Syndrome*. Bethesda: American Gastroenterological Association.

Palsson OS, Whitehead WE, van Tilburg MAL, Chang L, Chey W, Crowell MD, Keefer L, Lembo AJ, Parkman HP, Rao S, Sperber A, Spiegel B, Tack J, Vanner S, Walker LS, Whorwell P, Yang Y. (2016). Rome IV Diagnostic

Questionnaires and Tables for Investigators and Clinicians. *Gastroenterology*, 150(6), 1481–1491

Centers for Disease Control and Prevention. Healthy Weight: Effects of Overweight and Obesity. 2012.

Chen Y. Health information use in chronic care cycles. Proceedings of the ACM 2011 *Conference on Computer Supported Cooperative Work*. ACM; 2011, 485–488.

Consolvo S, Everitt K, Smith I, Landay JA. Design Requirements for Technologies that Encourage Physical Activity. *Proceedings of* CHI 2006, 457-466.

Consolvo S, McDonald DW, Toscos T, Chen MY, Froehlich J, Harrison B, Klasnja P, LaMarca A, LeGrand L, Libby R, Smith I, Landay JA. Activity Sensing in the Wild: A Field Trial of UbiFit Garden. *Proceedings of CHI* 2008, 1797-1806.

Cook J. Chronologic: Tracking Stories of Illness in Chronic Care. Seattle, WA: University of Washington; 2014.

Elsenbruch, S. Abdominal pain in Irritable Bowel Syndrome: a review of putative psychological, neural and neuroimmune mechanisms. *Brain, Behavior, and Immunity*. 2011;25(3):386-394. PMID: 21094682.

Flegal KM, Carroll MD, Ogden CL, Curtin LR. Prevalence and trends in obesity among US adults, 1999-2008. *JAMA* 2010; 303(3): 235-41. PMID: 20071471.

Fletcher AM. The nutritionist as the primary care provider in a team approach to obesity. *J Am Diet Assoc.* 1982; 80(3): 253-5. PMID: 7056974.

Fox S, Duggan M. Tracking for Health. *Pew Internet & American Life Project*, 2013, 1-32.

Frank A. A multidisciplinary approach to obesity management: the physician's role and team care alternatives. *J Am Diet Assoc.* 1998; 98(10): S44-8. PMID: 9787736.

Gastroenterology. American Gastroenterological Association medical position statement: irritable bowel syndrome. 2002;123(6):2105-7. PMID: 12454865.

Gibson PR, Shepherd SJ. Food Choice as a Key Management Strategy for Functional Gastrointestinal Symptoms. *Am J Gastroenterol* 2012; 107:657-666. PMID: 22488077.

Heitkemper MM, Jarrett ME, Levy RL, Cain KC, Burr RL, Feld A, Barney P, Weisman P. Self-management for women with irritable bowel syndrome. *Clin Gastroenterol Hepatol* 2004; 2(7):585-596. PMID: 15224283.

Holtzblatt K, Wendell JB; Wood S. *Rapid Contextual Design: A How-to Guide to Key Techniques for User-Centered Design* 2004. Morgan Kaufmann.

Jamieson AE, Fletcher PC, Schneider MA. Seeking control through the determination of diet: a qualitative investigation of women with irritable bowel syndrome and inflammatory bowel disease. *Clin Nurse Specialist* 2007; 21(3):152-160. PMID: 17495550.

Jarrett ME, Cain KC, Burr RL, Hertig VL, Rosen SN, Heitkemper MM. Comprehensive Self-Management for Irritable Bowel Syndrome: Randomized Trial of In-Person versus Combined In-Person and Telephone Sessions. *Am J Gastroenterol* 2009; 104(2):3004-3014. PMID: 19690523.

Jhaveri M, Lee E. Performance of electronic diaries in diabetes clinical trials measured through overall satisfaction of site coordinators. *J of Diabetes Science and Tech*. 2007; 1(4):522-30. PMID: 19885115.

Johannesson E, Simren M, Strid H, Bajor A, Sadik R. Physical activity improves symptoms in irritable bowel syndrome: a randomized controlled trial. *Am J Gastroenterol* 2011; 106(5):915-22. PMID: 21206488.

Klasnja P, Consolvo S, Pratt W. How to evaluate technologies for health behavior change in HCI research. *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 2011.

Krippendorff KH. *Content Analysis: An Introduction to Its Methodology, 3rd edition* 2012. London: SAGE.

Krukowski RA, Tilford JM, Harvey-Berino J, West DS. Comparing behavioral weight loss modalities: incremental cost-effectiveness of an internet-based versus an in-person condition. *Obesity* 2011; 8:1629-35. PMID: 21253001.

Kushner RF. Barriers to providing nutrition counseling by physicians: a survey of primary care practitioners. *Prev Med* 1995; 24:546-552. PMID: 8610076.

Ladabaum U, Boyd E, Zhao WK, Mannalithara A, Sharabidze A, Singh G, Chung E, Levin TR. Diagnosis, comorbidities, and management of irritable bowel syndrome in patients in a large health maintenance organization. *Clin Gastro and Hepatology* 2012; 10(1):37-45. PMID: 21871250.

Lee CP. Boundary Negotiating Artifacts: Unbinding the Routine of Boundary Objects and Embracing Chaos in Collaborative Work. *Comput Supported Coop Work*. 2007; 16(3): 307–339.

Li I, Dey AK, Forlizzi J. A stage-based model of personal informatics systems. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* 2010. ACM, 557-566.

Li I, Dey AK, Forlizzi J. Understanding my data, myself: supporting self-reflection with Ubicomp technologies. *Proceedings of the 13th International Conference on Ubiquitous Computing* 2011. ACM, 405–414.

Longstreth GF, Wilson A, Knight K, Wong J, Chiou CF, Barghout V, Frech F, Ofman JJ. Irritable Bowel Syndrome, Health Care Use, and Costs: A U.S. Managed Care Perspective. *Am J of Gastroenterol* 2003; 98(3):600-607. PMID: 12650794.

Longstreth GF, Thompson WG, Chey WD, Houghton LA, Mearin F, Spiller RC. 2006. Functional Bowel Disorders. *Gastroenterology* 130, 5 (2006), 1480–1491.

Moyer AM. Screening for and management of obesity in adults. US Preventive services task force recommendation

statement. *Annals of Internal Medicine* 2012; 157: 373-378. PMID: 22733087.

Mitra D, Davis KL, Baran RW. All-cause healthcare charges among managed care patients with constipation and comorbid irritable bowel syndrome. *Postgrad Med*. 2011; 123(3): 122-32. PMID: 21566422.

Nissenbaum H. Privacy as contextual integrity. *Washington Law Review*. 2004;79(1)

Ogden CL, Carroll MD, Kit BK, Flegal KM. Prevalence of obesity in the United States 2009-2010. *NCCHS data brief* 2012; 82. Hyattsville, MD: National Center for Health Statistics. PMID: 22617494.

Tsai CC, Lee G, Raab F, Norman, GJ, Sohn T, Griswold WG, Patrick K. Usability and Feasibility of PmEB: A Mobile Phone Application for Monitoring Real Time Caloric Balance. *MONET* 2007; 12(2-3): 173-184.

US Preventive Services Task Force. *Screening for and Management of Obesity in Adults: U.S. Preventive Services Task Force Recommendation Statement*. AHRQ #11-05159-EF-2. June 2012. PMID: 22733111.

Wieland LS, Falzon L, Sciamanna CN, Trudeau KJ, Brodney S, Schwartz JE, Davidson KW. Interactive computer-based interventions for weight loss or weight maintenance in overweight or obese people. *Cochrane Database Syst Rev*. 2012; 15:8. PMID: 22895964.