

# Supporting Patient-Provider Collaboration to Identify Individual Triggers using Food/Symptom Journals

Jessica Schroeder<sup>1</sup>, Jane Hoffswell<sup>1</sup>, Chia-Fang Chung<sup>2</sup>, James Fogarty<sup>1</sup>, Sean Munson<sup>2</sup>, and Jasmine Zia<sup>3</sup>

<sup>1</sup>Computer Science & Engineering, <sup>2</sup>Human Centered Design & Engineering, <sup>3</sup>Division of Gastroenterology

DUB Group, University of Washington

{jesscs, jhoffs, cfchung, jaf1978, smunson, jasmine}@uw.edu

## ABSTRACT

Patient-generated data, and patient-provider collaboration in the interpretation of that data, has the potential to help providers make more accurate diagnoses and treatment decisions. Unfortunately, patients and providers often lack effective support for collaborative interpretation of such data. We examine the specific context of irritable bowel syndrome, a chronic gastrointestinal illness in which particular nutrients can aggravate symptoms. A high degree of patient-provider collaboration is often necessary to identify individual triggers using data from patient-collected food/symptom journals. We create two interactive visualizations to support exploratory analyses of food/symptom journals. We then observe and interview patients and providers as they used these visualizations to interpret food/symptom journals, both individually and collaboratively. We report our findings regarding trust in patient-provider collaboration, confidence in patient-collected data and its analysis and visualization, and the use of such visualizations within and beyond a clinic appointment. We then discuss these findings and present guidance for the design of tools to support patient-provider collaboration in interpreting patient-collected data.

## Author Keywords

Patient-Provider Collaboration; Patient-Collected Data; Self-Tracking; Interactive Visualization.

## ACM Classification Keywords

H.5.2 Information Interfaces and Presentation: User Interfaces

## INTRODUCTION

Providers often rely on patient data to inform the diagnoses they make and treatments they prescribe. Such patient data has traditionally been generated through verbal summaries from patients and infrequent clinical collection (e.g., vital signs, blood tests, sleep monitoring studies). However, many patients are increasingly interested in augmenting this data with patient-generated health data (e.g., food journals, physical activity logs) [14]. One recent study found 69% of U.S. adults report tracking a health factor, with 14% using technology to

do so [19]. Both frequencies are expected to increase, and many patients and providers believe that patient-generated data has the potential to capture a more complete, accurate, and longer-term understanding of a patient's health [11, 12].

Unfortunately, attempts to collaborate with patient-collected data in a clinical environment often leave both patients and their providers dissatisfied. Many patients who share data with their providers report feeling their providers were insufficiently engaged with their data [2]. Providers report encountering a myriad of barriers when attempting to use patient-generated data to inform diagnoses. For example, commercially available self-tracking tools (e.g., *Fitbit*, *MyFitnessPal*) present data in unstandardized formats and generally lack features to support sharing or collaboration [11]. Furthermore, many providers question the accuracy of such data, lack the time necessary to analyze it, or feel unequipped to interpret it [11, 47].

This work examines patient-provider collaboration using a patient-collected food/symptom journal to identify triggers for that individual patient's symptoms. We specifically focus on irritable bowel syndrome (IBS), a chronic illness that requires a high degree of patient-provider collaboration to diagnose and manage. Patients suffering from IBS experience episodic abdominal pain, diarrhea, and/or constipation despite normal blood tests, x-rays, and endoscopies. IBS affects up to 20% of the U.S. population, is one of the top ten reasons patients seek primary care, and accounts for a third of all gastroenterology consultations [15]. Up to 70% of IBS patients report certain foods as triggers for symptom flare-ups [21], and diets that eliminate common potential trigger foods can surpass medications in symptom reduction [22, 42]. An individual's symptoms can be triggered by particular nutrients (i.e., low-level elements found in different foods, such as lactose or starch). However, different nutrients can be more or less problematic for different individuals, so it can be challenging to determine what nutrients trigger an individual's symptoms and the dietary changes necessary to avoid those nutrients. People with IBS symptoms often turn to providers for help in overcoming these challenges.

We examine patient-provider collaboration in the interpretation of a patient's food/symptom journal, specifically in identifying nutrients correlated with a patient's IBS symptoms and foods in their diet that contain those nutrients. Our approach is based in decomposing food journal entries into their constituent nutrients, performing correlation analyses against journaled symptoms, and creating interactive visualization of identified relationships. Using nine days of food/symptom journal data collected by each of 10 patients with IBS [5], we created two

Under review for CSCW 2017.

Please do not distribute.

visualizations to explore design trade-offs in tools to support collaborative interpretation of the patient's data. We observed and interviewed: (1) these same 10 patients as they examined their data in our visualizations, (2) 10 providers as they examined a patient's data in our visualizations, and (3) pairs of patients and providers as they collaborated in interpretation of the data during a simulated clinic appointment.

We find that collaborative review and interpretation using interactive data visualizations helps patients and providers build trust and understanding, both in the data and each other. However, patients and providers need better support for making patient-collected data understandable and actionable, as well as for using such systems in the long-term management of a condition like IBS. By providing proper educational support and objective views of the data, designers can help providers and patients build confidence in collaboratively reviewing food/symptom journals. By providing context for data and support for considering potential hypotheses for individual symptom triggers, designers could also help patients and providers better understand and explore potential treatment decisions. We discuss these findings and their implications for the design of tools to support patient-provider collaboration in the interpretation of patient-collected data.

## BACKGROUND AND RELATED WORK

We review relevant work in self-tracking, patient-provider collaboration, and irritable bowel syndrome.

### Getting Value from Self-Tracking

Self-tracking, particularly in health applications, has become increasingly popular as technology has advanced to reduce burdens while allowing people to track more information. Li et al. present a stage-based model of personal informatics, describing self-tracking as stages of *preparation*, *collection*, *integration*, *reflection*, and *action* [28]. Our visualizations focus on the *reflection* and *action* stages by helping patients and providers understand collaboratively interpret patient food/symptom journals in deciding on diagnosis and treatment.

Many self-trackers struggle to find value in their data after collecting it. This is often due to a lack of time or skills needed to analyze the data as well as a lack of suitable analysis and visualization tools to help people interpret their data [10, 28]. Prior research has examined transforming self-tracking data into actionable information by showcasing aspects of the data in summary visualizations intended to present an actionable finding [16]. Visualizations can also help ensure data is considered objectively. For example, Reeder et al. studied older adult perceptions of self-tracking data and found that visual presentation was useful for objectively identifying trends in the data [40]. We similarly aim to support patients and providers in collaborative identification of relationships between nutrients and a patient's IBS symptoms.

In Choe et al.'s examination of self-tracker practices in collecting and exploring personal data, 35% of self-trackers reported having a health condition [10]. Although many of these participants were self-tracking to identify symptom triggers, they often encountered insurmountable barriers, such as a lack of relevant contextual information or insufficient

scientific rigor to form reasonable hypotheses regarding their triggers. We aim to help patients avoid these common and important pitfalls by scaffolding what information patients should track, performing statistical analyses to determine what nutrients are significantly correlated to their symptoms, and presenting results in exploratory visualizations appropriate for patient-provider collaboration in their interpretation.

### Patient-Provider Collaboration

One approach to overcoming barriers to interpreting self-tracking data is to seek expert help. Many self-trackers therefore attempt to bring their data to health providers [2]. Providers also commonly ask patients to track and review their lifestyle indicators in context of managing chronic diseases or conditions (e.g., heart failure [43], diabetes [3], IBS [6]). Reviewing this data can help providers understand the everyday behavior of their patients, allowing them to provide better diagnoses or personalized treatments [11].

Interpreting patient-collected data often requires collaboration between the patient and provider, as the provider contributes medical expertise to the collaboration while patients provide more detailed knowledge of their day-to-day lifestyle and routine [8]. Prior systems have supported such collaboration by helping patients engage in the decision-making process [4, 43] and by supporting long-term care management [27, 38, 45]. These systems help providers contextualize the information necessary for informed diagnoses [43] and facilitate communication between the providers and patients [3, 31, 36]. Our study builds upon this prior work to explore how to support IBS providers and patients collaboratively identifying and managing individual symptom triggers.

### Irritable Bowel Syndrome

Irritable bowel syndrome (IBS) is an example of an illness that requires a high degree of patient-provider collaboration to diagnose and manage. IBS is a chronic illness that causes gastrointestinal symptoms (e.g., abdominal pain, diarrhea, constipation, bloating) that cannot be explained by imaging, blood tests, and/or tissue samples. IBS affects up to 20% of the population [15], and the estimated total cost in the U.S. alone is \$30 billion per year [26, 30]. No cure currently exists, so people suffering from IBS often struggle to control their symptoms. People with IBS report a significantly lower quality of life than those without the syndrome [30].

Up to 70% of people with IBS report certain foods can cause or worsen their symptoms [21], but different foods and nutrients are problematic for different people, making population-level recommendations often inappropriate. Individuals with IBS must choose to either eliminate all nutrients that are thought to correlate with IBS symptoms (e.g., FODMAPS, gluten, caffeine [21, 33]), or try to identify particular nutrients that cause their individual symptoms. Dramatic elimination diets can be highly burdensome, sometimes leading to malnutrition (e.g., 12% of people with IBS were found to have an inadequate diet [21], IBS symptoms have been associated with low levels of vitamin B6 [29]). Many people with IBS therefore attempt to identify their personal food triggers rather than pursuing such dramatic elimination diets.

Unfortunately, identifying which nutrients are correlated with an individual's IBS symptoms is currently a difficult and unreliable process. The standard of care advised by the American Gastroenterological Association is for practitioners to help patients via “*symptom monitoring using a [journal to] help identify possible triggers*” [6]. However, no validated method currently exists to determine significant nutrients from such food/symptom journals. Patients and their healthcare providers must therefore hunt through pages of journals attempting to find plausible correlations.

Despite their intent to identify such correlations, providers often lack the time and the training necessary to do so [11]. Patients with IBS and their providers are also dismayed by a lack of tools that can help them see trends in their food/symptom journals [9, 12]. The majority of patients are dissatisfied with the feedback their healthcare providers give based on their journals [24]. An analysis of the recommendations given by 8 experienced providers after reviewing 17 paper food/symptom journals also found poor reliability in their recommendations. Recommendations for the same patient were inconsistent across providers, and individual providers showed bias toward identifying particular food triggers regardless of the patient's data [48].

## FOOD/SYMPTOM JOURNAL COLLECTION AND ANALYSIS

Motivated by the burden and difficulty of interpreting food journals to identify individual food triggers, we sought to analyze and visualize patient food/symptom journals in an understandable and actionable manner. Our research builds upon proposals for correlation analysis in food/symptom journals [5, 49] to produce interactive visualizations that support interpretation by patients and their providers.

Our current examination of patient-provider collaboration is based in recruiting 10 participants from a prior study of the feasibility of food/symptom journaling using paper journals for IBS patients [5]. Where prior work focused on collection and analysis of the journals, our current focus is on patient-provider collaboration in interpreting the journals and associated analysis. This section briefly reviews the journal collection and analysis process, with additional details available in [5]. The next sections will then introduce our interactive visualizations and our examination of patient-provider collaboration in their interpretation.

### Food/Symptom Journal Collection

The structure of journal collection by patient participants was intended to provide detailed capture of diet and symptoms while limiting journaling burdens. Consistent with established dietary protocol [39, 46], patients journaled for 3 sets of 3-day “on” periods, separated by 3-day “off” periods (i.e., a total of 9 days of food/symptom journals collected over a 15-day period). Patients were asked to record all food/drink consumed as well as the time it was consumed. Research team members, as trained by a registered dietitian, provided detailed instructions on how to record food. At each meal entry, and again at bedtime, patients were also asked to report their peak gastrointestinal symptoms since the prior entry (i.e., abdominal pain, bloating, diarrhea, constipation) using a 4-point scale (i.e., 0 = *None*, 1 = *Mild*, 2 = *Moderate*, 3 = *Severe*).

### Dietitian Food Journal Analysis

Trained research dietitians analyzed food journals using the Nutrition Data System for Research (NDSR) [1], decomposing each food in a journal into its constituent nutrients. Wherever possible, foods were broken into their component foods (e.g., “cheeseburger” would become “beef patty”, “bun”, “cheese”, toppings, and condiments). As prescribed by the NDSR's “Data Entry Rules” [7], standardized assumptions were made for missing information (e.g., portion size) or unfamiliar food. This allowed each food journal entry to be mapped to 19 nutrients believed to be correlated with IBS symptoms (e.g., sugars, caffeine, lactose, total calories).

Although perhaps expensive (i.e., approximately \$250 per patient, almost \$28 per day), this accounted for a trained research dietitian using the NDSR database. This cost may be justifiable, due to the tremendous cost of IBS (estimated \$30 billion per year in the U.S. alone [26, 30]). Available community-sourced databases also may lack important categories of food (e.g., healthy and organic [13]), may not track nutrients that are potential IBS triggers (e.g., soluble vs. insoluble fiber, sugar alcohols), or they may be missing for many entries (e.g., a person tracking only calories may not know or provide all nutrient fields when adding a new entry to a community-sourced database [13]). Future research might explore how to reduce cost (e.g., crowdsourcing-based nutritional decomposition [35]), though this strategy might also limit the potential nutrients that can be considered as triggers or otherwise impact completeness or reliability of data used in correlation analysis.

### Food and Symptom Correlation Analysis

For each patient's journal, regression analyses identified correlations between food and gastrointestinal symptoms. Analyses defined symptom rating as the dependent variable and food nutrients as independent variables. Informed by prior IBS patient reports on the timing of symptoms following foods they believe triggered those systems [18, 37], independent variables were defined as the sum of a nutrient in all foods reported within the 4-hour window preceding a symptom report. Symptom entries without corresponding meal entries in this 4-hour window were excluded.

Patient-specific feature selection was performed prior to regression analysis. Food nutrients have a high degree of collinearity, due to both natural co-occurrences (e.g., foods with higher total fat tend to have higher total calories) and personal dietary habits (e.g., some people always drink their caffeinated beverages with milk and a sweetener). However, regressions assume a high degree of independence between predictors. Any nutrients that had high pairwise correlations ( $>0.75$ ) with other nutrients in an individual patient's data were therefore identified, and the nutrient in each pair with the highest average correlation to other nutrients was removed. Regressions were then performed with the remaining nutrients.

For our visualizations, we define *significant nutrients* as those with  $p < 0.1$  and *non-significant nutrients* as  $p > 0.1$  (i.e., choosing a  $p$  value threshold to encourage inspection and consideration of potential triggers, rather than only extremely confident results). We also visualized data for *correlated*



**Figure 1.** Each nutrient plot consists of (A) a bubble chart and (B) a bar chart. (C) Hovering over a point shows the food in that meal highest in the nutrient for each plot. (D) Non-significant nutrients can be added from the dropdown in the menubar. (E) Each significant nutrient for the selected symptom is shown as a separate tab. (F) The nutrients correlated to the significant nutrient are shown in a table, from which they can be added to the visualization. (G) The  $p$  value of the nutrient appears when interacting with the plot. (H) Selecting points displays the food and nutrient information.

*nutrients*, which were excluded from analyses during feature selection due to their strong correlation with another nutrient. As these were not in the analyses, they have no  $p$  value. Nutrients with positive effect sizes (i.e., symptoms tended to get more severe as more of the nutrient was consumed) are described as *worsening*, and those with negative effect sizes (i.e., symptoms tended to get less severe as more of the nutrient was consumed) are described as *improving*.

## VISUALIZATION DESIGN

This section introduces and discusses the design of two interactive visualizations: a *bubble and bar chart visualization* and a *parallel coordinates visualization*. Both were created to help patients and providers interpret what nutrients correlate with an individual's IBS symptoms and what foods in the individual's diet contain those nutrients. Each design visualizes the same data, as analyzed via the previously described methods. We conducted pilot interviews with two patients with IBS, using their early feedback to implement modifications prior to our primary study.

### Design Decisions and Tradeoffs

A primary design goal was actionability: we want patients and providers to be able to determine what nutrients are highly correlated with a patient's symptoms and what foods in the patient's diet contain those nutrients. Toward this goal, the visualizations need to be simple. Early design exploration found designs that attempted to visualize all 4 symptoms and 19 nutrients together were overwhelmingly complex. However, we also wanted the visualizations to be exploratory, such that patients and providers could access the entirety of the data.

To balance this tradeoff, we decided all nutrients should be *available*, so that a person can view them if desired.

However, our visualizations default to showing only *significant* nutrients for each symptom (i.e., as determined by the previously presented correlation analyses). A person can add *non-significant* nutrients to the visualization from a dropdown menu. For example, a person may have a pre-existing belief that a nutrient will be significant, and therefore may want to inspect the relationship in light of a lack of significant effect.

We similarly want to support exploration of *correlated nutrients*, those removed during feature selection due to high correlation with other nutrients. Although they were excluded from an analysis, high collinearity with nutrients in the analysis might imply they are related to a patient's symptoms. For example, if "total fat" is found to be significant, and "total calories" was removed due to high correlation with "total fat", more data may be necessary to determine which is actually relevant to the symptom. Alternatively, both may be relevant. These possibilities are statistically indistinguishable in the current data, so supporting inspection of the underlying data is important to facilitate patient and provider interpretation of that data and decisions for future treatment options.

Motivated by the same high-level design considerations, our two visualizations emphasize a different tradeoff in complexity. The *bubble and bar chart visualization* emphasizes the exploration of high-level trends, sacrificing detail and the presentation of relationships in favor of simplicity. This visualization is more likely to be familiar, as its component visualizations are often covered in K-12 curricula [20]. In contrast, the *parallel coordinates visualization* exposes greater detail and more relationships in the data. Parallel coordinate plots are a good option for showing correlations among many variables (e.g., between symptoms and nutrients, among multiple nutrients) [23], but are less likely to be familiar.

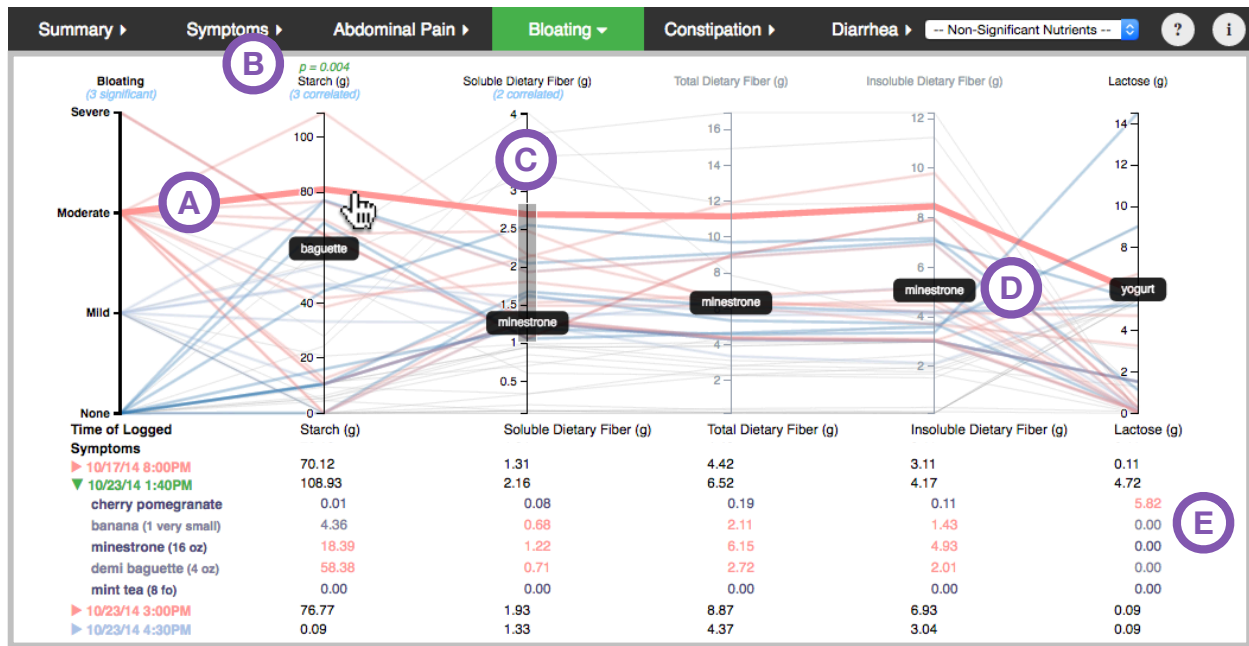


Figure 2. (A) A line corresponds to a single meal in the patient's journal. (B) The  $p$  value for a nutrient is shown on hover. (C) The user can specify a range of values to filter to only view meals within that range. (D) Hovering over a line fades the other lines out and shows annotations of the food in that meal highest in each nutrient, at the appropriate position on the axis for that food and nutrient. (E) The foods and nutrient values for the hovered line are expanded in the food table below the visualization. The other meals correspond to ones within the current filter.

In comparing both visualizations during our interview, we aimed to understand patient and provider preferences in terms of these tradeoffs. We were particularly interested in differences between patient and provider preferences, as well as whether preferences when viewing data alone are different from preferences when viewing the data collaboratively.

Finally, both visualizations include a *summary page* and a *symptom page*. The summary page presents a table of nutrients found to have a significant effect on each symptom, providing an overview of the primary results of the correlation analysis. The symptom page shows reported symptoms without any associated nutrient information, providing an overview of severity and the relationships among a patient's symptoms.

### Bubble and Bar Chart Visualization

This visualization emphasizes exploration of high-level trends and the relationships between symptoms and a nutrient. Each meal in a patient's journal is displayed in a faceted bubble chart (also called a gatherplot) (Figure 1A). Meals are bucketed by symptom severity (reported as *None*, *Mild*, *Moderate*, or *Severe*) and the amount of the nutrient in the meal (bucketed as *Low*, *Medium*, or *High*, divided into thirds according to the distribution in the individual patient's data). A stacked bar chart aggregates the information in the scatterplot to facilitate identification of trends (Figure 1B). Each stacked bar chart has three bars, one for each bucketing of nutrient amount. The size of each bar corresponds to the percentage of meals in the nutrient amount bucketing with the corresponding symptom severity. Points and bars are colored by symptom severity.

The visualization incorporates multiple bubble and bar chart units to facilitate comparison of different nutrients. Each symptom the patient experienced is presented on a separate

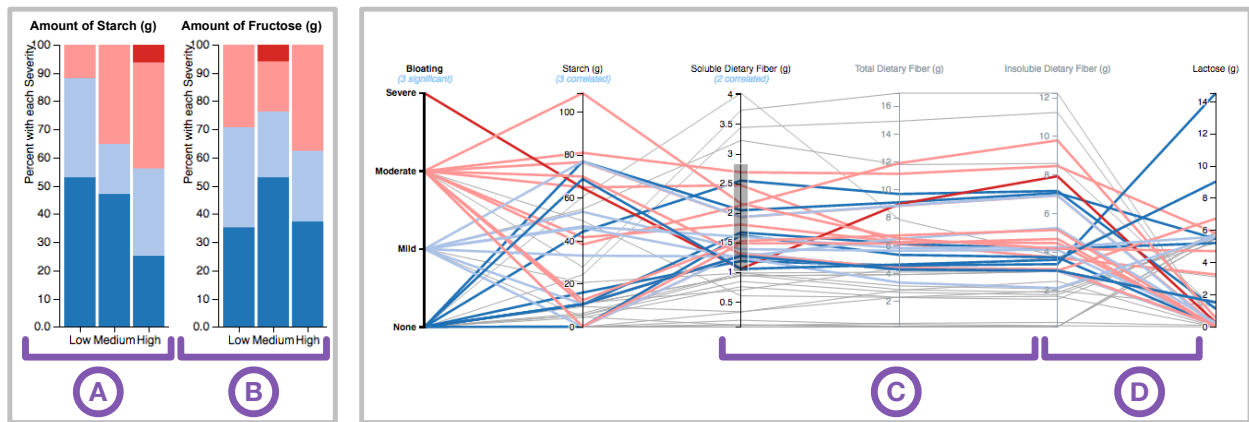
page. Each page shows a panel with tabs that correspond to nutrients that were *significant* in analysis of that symptom (Figure 1E). Tab color is based on whether the nutrient is associated with *improving* or *worsening* symptoms. Each tab displays the chart for the selected symptom and nutrient. A table (Figure 1F) lists all *correlated* nutrients, which can be added as separate charts (differentiated by a gray background). When a symptom has no significant nutrients, an empty tab is shown with a short description of why nothing is visible. *Non-significant* nutrients can be added to any symptom page via a dropdown in the menubar (Figure 1D).

Hovering over a meal highlights the corresponding bar. The food in the meal which contained the highest amount of the current nutrient is displayed in the upper right corner (Figure 1C), using food labels that were manually simplified to provide a more succinct label. Hovering over a bar highlights all meals in the corresponding bucket. Selecting a meal or bar selects the corresponding elements across all charts and displays a food table, which includes full food names and nutrient amounts for each visible nutrient (Figure 1H). Foods with a nutrient amount in the top 75% of the foods the individual consumed are highlighted in the color of the symptom severity for that meal. Shift-click allows the selection of multiple elements. Although the focus of the visualization is on interacting with the data itself, the  $p$  value calculated for a nutrient is shown in the lower left (Figure 1G).

### Parallel Coordinates Visualization

This visualization emphasizes relationships among nutrients and includes more detailed information about consumed nutrients (e.g., the range of nutrient amounts in the patient's journal). Similar to the bubble and bar chart visualization, the environment includes a separate page for each symptom. The





**Figure 3.** (a) A nutrient with worsening symptoms in the bar chart: the size of the red bars increases as the nutrient amount increases. (b) A non-significant nutrient does not show a strong trend: the bars are fairly equal for each symptom severity. (c) Correlated variables show mostly parallel lines between the axes in the parallel coordinates visualization. (d) Nutrients without a clear relationship are more jumbled.

symptom and each of its *significant* nutrients are shown as axes in a parallel coordinates plot. Each meal corresponds to a line through all the axes, thus showing the symptom severity and the amount of each nutrient consumed in that meal (Figure 2A). Lines are colored based on the symptom severity. *Non-significant* nutrients can be added from a dropdown in the menubar, and selecting a nutrient adds all of its *correlated* nutrients as additional axes in the visualization.

Axes can be rearranged to facilitate comparison by dragging an axis title. Hovering over an axis title shows the *p* value of the nutrient (Figure 2B). Dragging along an axis creates a filter that grays out all lines outside the filter (Figure 2C). A table below the plot shows all meals that pass any active filters (Figure 2E). As in the bubble and bar chart, foods with a nutrient amount in the top 75% of the foods the individual consumed are highlighted in the color of the symptom severity for that meal. Selecting or hovering a line expands the table to show foods and nutrient values for the meal (Figure 2E). Hovering over a line grays out all other lines and annotates each axis with the food from the selected meal that is highest in that nutrient (Figure 2D). If any filters are active, selection and hovering are only enabled for lines within all filters.

### Examining Correlations

Both representations aim to make correlations visually salient to support patients and providers in interpreting the impact of nutrients on the patient's symptoms. In the bubble and bar chart visualization, correlation is indicated by the relative area of the stacked bars (i.e., the amount of each shade of blue and red) for each nutrient amount (i.e., for each of the three bars). Figure 3A shows that, as the amount of starch in the patient's diet increases, so does the severity of their symptoms (i.e., the portion of red in the bar grows from left to right). In contrast, Figure 3B shows the amount of fructose does not seem to impact the distribution of symptoms (i.e., there is no clear increasing or decreasing trend in the bars). For the parallel coordinates visualization, Figure 3C shows a strong positive correlation between soluble dietary fiber, total dietary fiber, and insoluble dietary fiber (i.e., straight horizontal lines between these nutrients). A strong negative correlation would

Abdominal Pain				
Trend	p Value	Nutrient	Example from Patient's Diet	Correlated Nutrients
Worsening	0.0990	Starch (g)	Bread	Calories Total Carbohydrate (g) Sodium (mg)
Bloating				
Trend	p Value	Nutrient	Example from Patient's Diet	Correlated Nutrients
Improving	0.0248	Soluble Dietary Fiber (g)	Bread	Total Dietary Fiber (g) Insoluble Dietary Fiber (g)
Improving	0.0032	Lactose (g)	Yogurt	None
Worsening	0.0042	Starch (g)	Bread	Calories Total Carbohydrate (g) Sodium (mg)

**Figure 4.** The summary table provides an overall picture of the patient's symptoms and significant nutrients.

be indicated by a tight grouping of line crossings (i.e., an "X" shape). Figure 3D shows no clear correlation between insoluble dietary fiber and lactose (i.e., no clear trend in the slope of the lines between the pair of nutrients).

### Summary Page

During visualization development, pilot participants felt the visualizations supported interaction with the detailed journal information, but that it could be hard to know what to look for or how to start. One pilot participant noted:

*I think what would be really helpful is ... to just have your conclusion page that says like "lactose makes you better, starch makes you worse".*

We therefore introduced a summary page in the visualizations, showing the significant nutrients for each symptom, the symptom trend for that nutrient, correlated nutrients, and example foods (Figure 4). Example foods are taken from the patient's own data, selected by: filtering to meals which are *High* in the nutrient according to that individual's bucket ranges, identifying the food in each such meal that has the highest amount of the nutrient, choosing the most frequent such food as the example. Because the summary page is the starting point for interaction with the visualization, it can help orient patients and providers into the visualization. Given the overview of journaling results, selecting a symptom or nutrient of interest navigates to that view in the visualization.

## Symptom Page

A symptom page shows a patient's reported symptoms without relating those symptoms to nutrients (Figure 5). The bubble and bar chart visualization allows easy inspection of the symptom frequency and severity, supporting interpretation of which symptom is most problematic. However, determining how multiple symptoms relate is more difficult. The parallel coordinates visualization displays relationships between symptoms, better supporting understanding of which symptoms tend to co-occur. However, determining how often symptoms were experienced is more difficult.

## Patient and Provider Modes

During visualization development, one pilot participant felt “intimidated” by some of the presented data. They remarked:

*I bet you can tell people a lot what they need to know, I guess, without them having to know the p value ... I don't even know what a p value is.*

For most *patients*, a *p* value was an unfamiliar idea that provided more detail than necessary for viewing their results. However, *providers* considered this information essential to a more complete understanding of the presented information. We introduced two modes in each visualization. This mode was set *prior* to each session with patients and providers, and cannot be changed using the interface itself.

In patient mode, *p* values are hidden and *correlated* nutrients are described as “related”. In provider mode, *p* values are included for all nutrients, the term *correlated* is used as appropriate, and the summary table emphasizes that the provided example foods are taken from the patient's diet (versus being generic examples of foods high in that nutrient).

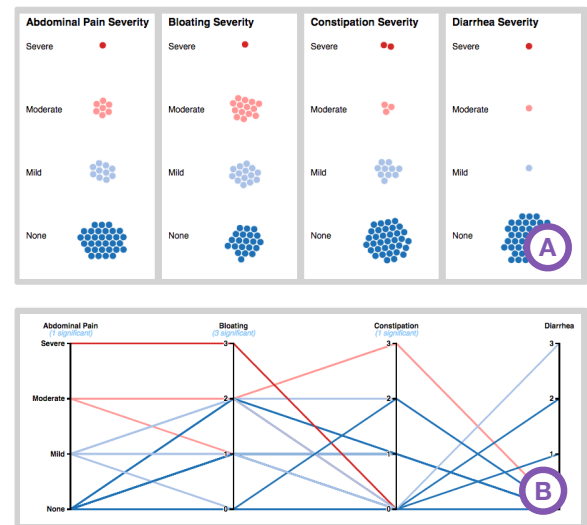
## Tutorial

Because these visualizations may be unfamiliar to patients and providers, we created tutorials that explain how to view, interpret, and interact with the visualization. The tutorial provides a concise introduction to the visualization's interactivity, using a simplified dataset and customized according to whether the visualization is being accessed in *patient* mode or *provider* mode. The tutorial pops up when the visualization is first accessed, and is then available from the menubar at any time. By familiarizing patients and providers with the mechanics of the interface, our goal was to help them be more comfortable with the technology and data interpretation. Our interviews then focused on how patients and providers respond to this technology, both individually and when using it to review the data together.

## PATIENT AND PROVIDER INTERVIEWS

We envision such analyses and visualization environments as collaborative tools for people with IBS and their providers. To examine the implications for patient-provider collaboration, we used our current prototype analyses and visualizations to conduct semi-structured interviews with patients and providers, both independently and together.

Because such visualizations are most interesting and relatable to the person who collected the data, we recruited our



**Figure 5.** The symptoms page shows a summary of the patient's symptoms. (a) The number and severity of symptoms is easy to see in the bubble and bar visualization. (b) Co-occurrences of symptom severity are easier to see in the parallel coordinates visualization.

current patient participants from participants who kept a food/symptom journal in a prior study [5]. The prior study was completed approximately 12 months before the analyses and visualizations were developed to support our current study, so the journal data was not recent. We nevertheless believed that personalizing the study with a participant's own data would be a good representation of the system's intended use, and therefore prioritized recruiting these same patient participants.

Provider participants all had experience working with patients with IBS, but had not met the patient participants prior to the study. It was infeasible to recruit an already-known provider for each patient participant, and we decided to be consistent in having all patient-provider pairings be new collaborations.

Interviews consisted of two phases. During the first, one researcher interviewed the patient while another researcher interviewed the provider. This initial phase lasted 40 minutes, with approximately 20 minutes dedicated to each visualization and followup questions. The order in which the visualizations were shown was held constant within a patient-provider pairing and counter-balanced across pairings. Participants completed the tutorial and then explored the visualization of the patient's data. They were encouraged to think aloud during their data exploration and to ask any questions they had. The researchers then asked about participant opinions of the visualizations, whether and when they would use them, and what conclusions they would draw from them.

During the second phase of the interviews, the patient and provider were brought together to explore and interpret the visualizations collaboratively, simulating a clinic appointment. Participants were given their choice of which visualization(s) to use, and were able to switch between them. They were then asked to compare their experiences using the visualizations alone versus collaboratively.

We recruited 10 patients with IBS (2 male, age *mean* = 33, *min* = 22, *max* = 46) and 10 providers with experience working with patients with IBS (4 male). Patients were compensated with a \$25 Amazon gift card, analysis and interpretation of their data, and free consultation with a provider experienced with patients with IBS. Providers were compensated with a \$50 Amazon gift card.

When quoting participants from these interviews, we refer to patients as *P#* and providers as *R#*. *P9* was uncomfortable with the prospect of a joint interview, expressing unease about “*bothering somebody to come in*”. We therefore interviewed *P9* and *R9* separately, without a joint interview. *P4* had no significant nutrients in their data. To help *R4* understand what the visualizations would look like with significant findings, we showed *R4* visualizations for both *P4* and *P3*. For privacy reasons, patients were only shown their own data.

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. A third researcher verified and discussed the themes that emerged with the rest of the analysis team. After discussion, we identified several key themes regarding patient-provider collaboration and use or non-use of the tool to support collaboration.

## RESULTS

Participants felt the presented analyses and visualizations would be an asset for patients and providers struggling to interpret food and symptom data. The interviews also surfaced requirements for successful patient-provider collaboration. These span from design necessities for systems to support patient-provider collaboration to issues of trust and feeling trusted in the collaboration. We discuss these themes below.

### Trust in Patient-Provider Collaboration

A recurring theme was the concept of trust in patient-provider collaboration to interpret patient data. Providers need to trust the abilities of their patients, but both patients and providers were concerned about whether the person they were collaborating with trusted them. Although the visualizations helped build trust in some cases, they also introduced new important considerations concerning trust.

#### Provider Trust in Patient Abilities

An important question for many of the providers was whether they could trust the patient to correctly interpret their data. Five providers (*R2*, *R6*, *R7*, *R8*, *R9*) mentioned worrying that the visualizations were too complicated for patients to interpret. This concern impacted how they expected to use the visualizations and whether they wanted the patient to be able to access the visualizations before the clinic appointment.

During individual interviews, *R7* and *R8* explicitly mentioned they would likely focus on the summary page during a clinic visit, only showing patients the data visualizations if they had been able to identify a clear trend or an example they wanted to emphasize to the patient. Four providers (*R2*, *R6*, *R7*, *R8*) indicated being wary of giving a patient the ability to review

the visualizations before the appointment, although three of the four (*R6*, *R7*, *R8*) indicated they still thought the patient should have access if they so wanted. *R7* believed that the patient should be allowed to do so, despite her worries, only because the patient should “*have the right*” to see their own data. Only *R2* said that he did not want a patient to be able to review the visualizations beforehand. When asked during the individual interview, he said the patient would find them too complicated and would end up fixating on irrelevant things.

#### Patient Demonstration of Abilities

The joint interview seemed to assuage many of the concerns providers initially had about patient abilities for data interpretation. *R2* had not wanted his patients to have independent access to the visualizations before the joint interview, but completely changed his mind. He appreciated that the patient was able to set his own agenda, bringing things he considered important to the provider’s attention. The patient’s familiarity with the data also allowed the patient to explain aspects of the data. The provider therefore felt more capable of making recommendations because the patient went through and contextualized the data. By combining the provider’s expert knowledge with the patient’s personal knowledge, they were able to have a deeper conversation about possible problems and solutions, instead of the provider just “*coming in and being like, here’s what I found*” (*R2*).

The other three initially skeptical providers (*R6*, *R7*, *R8*) also seemed more confident in the abilities of their patients. The patients they were paired with all stated they would want to review the visualization before a clinic appointment, and the providers agreed it would be helpful. *R8* commented that having both collaborators be familiar with the data would help “*focus [their] energies during the visit*”. She explained:

*I think the other thing that’s valuable about reviewing it separately is that I don’t like to deliver news to patients that is surprising if I don’t have to. If [the patient] saw this and [was] like, “Fiber and caffeine? That’s not what I expected”, [the patient] would be processing that while we were talking to each other as opposed to focusing on this is how I’m interpreting [their] data.*

#### Need to be Trusted by the Collaborator

Patients and providers both commented on the need for collaborators to trust what they say. Patients needed providers to understand their experiences, and providers needed patients to understand why they were making the recommendations they made. Six providers (*R2*, *R4*, *R6*, *R7*, *R9*, *R10*) and five patients (*P1*, *P5*, *P6*, *P7*, *P8*) described that being able to go through an objective view of the patient’s food and symptom data helped them feel like they could more successfully communicate these issues. *P1* and *P8* explicitly mentioned their belief that the tools provided a good way to explain the severity and frequency of symptoms they were experiencing. *P1* remarked that describing such information is “*kind of hard to put into words, but [the visualization] kind of quantifies it*”. Four providers (*R2*, *R4*, *R6*, *R9*) mentioned the importance of being able to show their patients concrete, personal data explaining their recommendations. *R4* explained:



*It really helps them understand how what they eat affects their symptoms, which is the most important thing. If they don't understand that then they can't change it, right? I think it's a really objective way to show them "you've been telling me that every time you have pizza your belly hurts, look, this is it, believe it, stop".*

However, the visualizations also caused some unease for R8 and R10, who mentioned being “embarrassed” or “anxious” about giving the impression that they lacked necessary knowledge to explain the visualizations. Although they found collaborative review of the data helpful, they also doubted their abilities to correctly interpret the data or describe what foods contain certain nutrients. They therefore needed the tool to have enough information for them to quickly answer questions that patients might have. Although the visualizations helped assuage some concerns for trust, systems designed to support patient-provider collaboration must also be careful not to introduce new concerns for trust in the collaboration.

### Confidence in the Data Visualizations

Some patients and providers expressed uncertainty regarding the data visualizations: in the quality and accuracy of the data, in the correlation analyses, or in the information presentation.

#### Possible Data Confounds

Two providers (R2, R7) and three patients (P6, P8, P10) expressed uncertainty not due to the correlation analyses or the visualizations, but because they lacked confidence in the patient's judgment of symptom severity during data collection. Similarly, four providers (R3, R4, R5, R8) and four patients (P2, P3, P5, P8) mentioned needing to know more about the context of the data in order to trust the data. Factors cited as possible confounds in the data included emotional and physical health, hydration, and exercise. P8 mentioned:

*[A]m I PMSing? If I am, maybe everything is terrible. I'm like, "Pain is terrible. Bloating terrible. Diarrhea? Didn't really happen, but it's terrible anyways."*

In addition, five patients (P1, P3, P4, P6, P8) mentioned feeling their personal experience was not accurately reflected in their data. As discussed in our correlation analyses, we defined potential food triggers in terms of the preceding 4-hour window and discarded any symptom entries that had no meal entries in that window. Patients may have had different experiences with their symptoms and potential triggers, or may have recalled symptoms that were not visualized. The time elapsed between data collection and our study may also have impacted patient recall and perspective on their data.

#### Personalized vs Population-Level Information

Many participants wanted to verify that regression results were biologically plausible. Three patients (P5, P9, P10) and two providers (R7, R10) mentioned wanting to see corresponding population-level data, because it would help them determine whether the individual data and results were “normal”. P10 said he needed to do more research about the significant nutrients from his analysis, learning whether they often cause IBS symptoms before deciding whether he trusted the results.

Participants were occasionally confused because nutrient analysis was based in the range observed in that patient's data, versus some population-level average range for a nutrient. For example, P7 was perplexed that her results indicated her symptoms improved when she consumed meals with higher fat. She knew from experience that she consistently feels worse when she consumes high-fat meals. Indeed, P7 already had that knowledge at the time of data collection and was already avoiding high-fat meals. Her analysis therefore did not suggest high-fat meals, but rather that she tended to experience reduced symptoms with meals that were higher in *her personal range* of fat content. Including “typical” diet information or population-level context may improve patient and provider understanding and confidence in personalized analyses.

#### Visualization Complexity

Our visualizations examine different tradeoffs of simplicity versus completeness. The bubble and bar chart visualization shows high-level trends, while the parallel coordinates visualization provides more detail. We had thought some clear preference might emerge in interviews, but found diverse reactions to the alternatives. Some participants felt both were simple and straightforward, some expressed a preference, and others felt both were overwhelmingly complex. Participant confusion with the visualizations sometimes had significant consequences regarding their interpretation. Two patients (P2, P5) and one provider (R2) indicated that their ability to interpret the visualization directly informed the trust they had in the presented symptom analyses. R2 explained:

*I feel more comfortable with the interpretation than I did before where I really don't think, even toward the end and answering all your questions, that I actually understand [the parallel coordinates visualization]. Whereas I feel like I can understand [the bubble and bar chart visualization] and make my own conclusions here.*

We also observed the opposite: some participants had *more* trust in a visualization they found confusing. For example, R6 started with the parallel coordinates visualization. Although he claimed to find it straightforward, he drew most of his conclusions from the summary page. When asked, he stated that he had confidence in the results. However, upon switching to the bubble and bar chart visualization, he expressed less confidence, saying he “*would probably say a medium amount of confidence. [It] relies on how accurate that data is that the person is inputting*”. P8 similarly stated that she had confidence in the bubble and bar chart visualization, but upon switching to the parallel coordinates visualization remarked “*this is a really clear visualization to me of the range of how much fiber did I eat. I ate a really wide range of fiber from my no symptoms*”, thus revealing that she had not understood her personal range of fiber with the prior visualization. We wanted the visualizations to provoke such critical thinking, as statistical analyses are limited (e.g., due to the possibility of overfitting, due to correlated nutrients, due to other potential confounds). Results therefore require

interpretation to determine if and how they likely apply for a particular patient. Confusion regarding the visualizations often limited such critical thinking, leading participants to rely on the summary page and de-emphasizing the backing data.

### Use Within and Beyond a Clinic Appointment

Although we intended the visualizations for collaboration in and surrounding a single clinic visit, participants identified opportunities and expressed desire for longer-term use.

#### Use During the Clinic Appointment

Patients and providers both wanted to use the visualizations collaboratively in clinic appointments. Providers valued learning more about the patient. Eight providers (*R1, R2, R3, R4, R5, R7, R8, R10*) mentioned that being able to talk to the patient helped their interpretation of the visualizations. They felt they needed to learn more about the patient to give effective recommendations: they were interested in patient goals, perception of their symptoms, opinion on their results, thoughts about their current diet, and willingness to change their diet. Patients liked having an expert talk to them about the results. Five patients (*P5, P6, P7, P8, P10*) mentioned valuing an expert's interpretation of their results, both to ensure that they were interpreting the visualization correctly (in some cases, telling them how to interpret it) and to verify that the results made sense to a provider with experience with IBS.

#### Use Before the Clinic Appointment

Participants also overwhelmingly wanted access outside of the clinic appointment. Eight providers (*R1, R2, R3, R4, R5, R6, R7, R8*) and six patients (*P1, P2, P4, P6, P7, P8*) wanted to be able to review the visualizations before a clinic appointment, because they felt that doing so would help them prepare. *P8* also expressed the need to be able to come to terms with any surprising or bad news. She explained:

*If something came up [in the visualization] that I was unhappy about ... for me to be able to be unhappy about it on my own, and then come to the visit with, "Okay, what are we going to do?" [would be helpful]. Either I think this is bogus and we should try it again, or I've come to terms with the fact that we need to do this.*

Four providers (*R3, R6, R8, R10*) mentioned that, although they wanted to be able to review the visualization before the appointment, they were unsure whether they would have time to do so. Future designs will therefore need to emphasize the ability to quickly understand and interpret the results.

#### Longer-Term Use Over Multiple Clinic Appointments

Eight providers (*R1, R4, R5, R6, R7, R8, R9, R10*) and six patients (*P1, P4, P5, P6, P8, P10*) expressed a desire for the visualizations to enable longer-term, iterative use. IBS is a chronic condition, and patients and providers both wanted to be able to view changes over time, in terms of both diet and symptoms. *R8* also mentioned a desire to be able to take notes about patients and review those notes before subsequent appointments. Although analyses and visualizations were designed for a single food/symptom journaling dataset, participants wanted it to extend into helping them with their ongoing management of IBS.

### Use as a Tool for Hypothesis Formation

Six providers (*R4, R5, R6, R7, R8, R10*) and one patient (*P8*) expressed a desire to use the data visualizations to form hypotheses about what nutrients may be impacting a patient's symptoms. They then wanted to follow up this hypothesis formation with an experimental step testing whether limiting the nutrient improved the patient's symptoms. *R4* remarked:

*It'd be interesting if you actually sort of did an experiment and you pick something that's really high in one of these things ... and see what happens to your symptoms.*

We believe there is an opportunity to integrate exploratory analyses for hypothesis formation with new approaches to hypothesis testing through self-experimentation [25]. Our discussion revisits this in terms of supporting actionable plans during long-term provider and patient management of IBS.

## DISCUSSION

Chung et al. found that patient-generated data is transformed into different types of boundary negotiating artifacts during patient-provider collaboration [12]. Building on the lens of this theory, we considered our visualizations as inclusion artifacts that summarize information to facilitate discussion between providers and patients. Providing computer-supported analysis and visualization reduces the time and effort demanded for a provider to perform on-the-spot mental analysis, therefore allowing more interaction with the patient. Our design focus on exploratory interactive visualization and interpretation also provides the flexibility for providers and patients to negotiate which potential triggers should be considered in a treatment decision. This section draws upon our interviews to discuss considerations for designing tools to support patient-provider collaboration in the interpretation of patient-collected data.

### Encouraging Provider Trust in Patient Abilities

Many providers were initially skeptical of whether a patient would be able to correctly interpret the data visualizations. Although this concern was often assuaged during the joint interviews, more dramatic differences between patient and provider visualizations might be helpful to mitigate the initial concern. Another approach to increasing provider confidence in patient abilities may be to support different levels of exploration with different levels of complexity. For example, we designed: (1) the summary page as an overview of the main takeaways, (2) the bubble and bar chart visualization as a simpler view of high-level trends, and (3) the parallel coordinates visualization as a more detailed view of the patient's nutrients and symptoms. By supporting different levels of complexity, patients who are comfortable exploring more complex visualizations can do so, while patients who are confused or intimidated can explore the simpler representations in accessing their data before a clinic appointment. When the patient then reviews the data with their provider, the provider could determine the patient's level of understanding by inquiring about the level of complexity they reviewed at home and what interpretations they formed during this review. The provider could therefore explain the data at an appropriate level, or could educate the patient with more complex data, depending on the purpose of the visit.

When providers are first introduced to patient-collected data, they often doubt patient ability to correctly collect or interpret data [47]. Recent research has also found that patients often have difficulty understanding common visualizations [34]. However, our study found that many patients were able to navigate a complex visualization with the help of a short interactive tutorial. Fully developed tutorials may therefore be another approach to support patient interpretation and help address provider concerns. As *R4* mentioned:

*We'd have to have a better tutorial to understand the data, right, because it's a little self-explanatory but not quite. You'd have to have some kind of a training with a patient so they understand the data.*

A related opportunity is suggested for provider-directed tracking (i.e., when a patient initiates tracking at the request of a provider, a common practice in IBS). Educational materials and protocols could help ensure patients develop the knowledge necessary to both collect and interpret data, while simultaneously helping mitigate provider concerns.

### Providing Objective Views

Both patients and providers had concerns their collaborator would not trust or understand what they said. Patients were concerned providers would not understand their symptoms, and providers were concerned patients would not believe provider recommendations if the patients could not understand the relationships in their data. In many ways, the visualizations provided an objective display of the data that helped assuage participant concerns for being trusted by their collaborator. As we previously discussed with *R4*'s explanation, the visualizations helped foster a feeling of collaboration by giving them something to go through together. Tools designed to help promote patient-provider collaboration should emphasize supporting such collaborative exploration.

However, the visualizations also introduced potential new concerns. Providers did not want to be seen as incompetent, and worried they might not be able to quickly and easily navigate and interpret visualizations in the presence of a patient. To ensure a provider is comfortable, systems should be fairly easy to understand and interpret, with educational information immediately accessible (e.g., in case a patient asks a question that a provider cannot answer). In addition, systems should support providers and patients reviewing data individually before an appointment, so that both are confident about the data and agenda during collaborative interpretation.

Systems should also surface objective views of data processing. Prior work in algorithm transparency has suggested that making system logic explicit may increase engagement [17, 41, 44]. We included details of data analysis as a help page available in the interface, and alerted participants to its existence during the tutorial. However, participants did not attempt to read this information. Participants may have not seen a need to consult this in the short interview study, but patients were sometimes confused about why the displayed data differed from their recollection. Reading about the details

of the data analysis likely could have addressed such confusion. The fact that participants did not access the information may therefore illustrate a need to better integrate it into the visualization itself, rather than presenting it as a separate page.

### Supporting Use Inside and Outside the Clinic

Patients and providers wanted to access visualizations before and during clinic appointments, and also expressed a desire for long-term use. Providers were concerned visualizations may take too long to interpret, which would hinder their ability to review data before a clinic appointment. A key requirement for supporting provider use before an appointment is therefore ensuring interpretation is easy enough for providers to quickly review and get a sense of the data between clinic appointments. Another approach is to help the provider prepare for the goals and questions a patient is bringing to an appointment. Prior research has found that patient-collected data prepares patients for questions and conversations in face-to-face and remote provider appointments [3, 4, 31]. If a system could support patient annotation before or between appointments, it might help providers understand a patient's goals and what questions they have for the appointment, thereby allowing the provider to efficiently prepare [11]. Future work should also further explore opportunities and challenges with longitudinal data.

### Providing Understandable and Actionable Information

The visualizations sometimes lacked the context important for understanding and interpretation. For example, five patients (*P5*, *P7*, *P8*, *P9*, *P10*) and one provider (*R10*) mentioned not knowing exactly what certain nutrients were. This confusion was exasperated by people tending to forget that data was based entirely on the patient's diet. *R10* was confused because the visualization indicated that coffee had a large amount of soluble fiber, which *R10* knew was false. However, that patient consumed little dietary fiber. The visualization indicated that coffee was *High* in soluble fiber only relative to that patient's diet, not relative to any absolute notion of a large amount.

Similarly, we have reported that *P7* was confused about the role fat played in their symptoms. If they understood that they tended to feel better when they ate meals that were *relatively* high in fat, that information might help them liberalize their diet (e.g., trying meals with slightly higher fat to see whether they continue to avoid symptoms). Even if *P7* did not want to experiment, better conveying the context for these analyses would at least prevent confusion over an indication that they tended to feel better with higher-fat meals. Providing the context necessary for interpretation is important for all data visualizations, and is particularly important for designing systems that are intended to provide actionable information.

Actionable information is most helpful to patient-provider collaboration, so supporting the translation of results into action is important. However, with data as complex as that considered here, designers should resist temptation to go beyond summaries and recommendations to automated plan generation. Three providers (*R6*, *R7*, *R10*) and two patients (*P5*, *P8*) wished the system had gone further. They wanted it to tell them exactly what foods the patient should avoid, and *R10* expressed their desire for the system "*to be smarter than a*

human and come up with its own recommendations at the end, which it could be, because it's a computer". Unfortunately, determining exactly what foods are causing an individual's IBS systems is extremely challenging and probably beyond what can be done with food/symptom journals of the type considered in this work (e.g., due to concerns for correlations and confounds). We did not want the presentation of an analysis to imply greater confidence than is warranted, but instead focused on using analyses to scaffold exploratory visualizations. Patients and providers can then collaborate in applying their knowledge and expertise to interpret the data.

One approach to actionability in the face of uncertain results might be to support hypothesis testing through new approaches to self-experimentation [25]. In terms of Li et al.'s stage-based model of personal informatics [28], our system was designed to support patients and providers in collaborative *reflection* and *action*. However, due to the busy nature of the clinic, many providers and patients expressed wanting to jump to system-recommended *action*, without the process of *reflection*. Although immediate conclusions regarding an individual's symptoms are often unwarranted, providers and patients note that IBS management is a long-term process that can involve iterative hypothesis formation and testing. Such long-term patient-provider collaboration should promote reflection in considering relevant information and potentially changing goals [32]. Integrating self-experimentation for hypothesis testing would provide a clearly actionable next step for patients who want to confirm whether changing their behavior based on the relationships identified with our visualizations will help with long-term management of their symptoms.

## CONCLUSION

Building upon prior research in supporting patient-provider collaboration, we developed two visualizations to explore how to support providers and patients with IBS in collaboratively identifying individual symptom triggers. We designed the visualizations to be exploratory, allowing providers and patients to collaboratively apply their knowledge and expertise in interpreting the visualizations to reflect, negotiate, and make treatment decisions. We found that collaborative review helps both providers and patients in better understanding the visualizations, increasing their confidence in the data, and in mutual trust of their relationship. We also revealed a need to use such tools beyond a single visit, individually and collaboratively, to help develop actionable plans.

Designers of such systems should help healthcare providers understand patient abilities for data interpretation and work with providers and patients through tutorials and other educational support. To help providers and patients build confidence in exploring the data together, designers should also strive to provide objective views of the data as well as the process of data collection and analysis. Situating tracking data into context can also help providers and patients make better interpretations and decisions. Finally, because symptom management is a long-term process, providers and patients need understandable and actionable support to help them test and adjust their decisions over the course of long-term care.

## REFERENCES

1. 2013. Nutrition Data System for Research (NDSR). Nutrition Coordinating Center, University of Minnesota, Minneapolis, MN. (2013).
2. 2014. Personal Data for the Public Good: New Opportunities to Enrich Understanding of Individual and Population Health. *Health Data Exploration Project* (2014).
3. Rikke Aarhus, Stinne Aaløkke Ballegaard, and Thomas Riisgaard Hansen. 2009. The eDiary: Bridging home and hospital through healthcare technology. In *ECSCW 2009*. Springer, 63–83.
4. Tariq Andersen, Pernille Bjørn, Finn Kensing, and Jonas Moll. 2011. Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents. *International journal of medical informatics* 80, 8 (2011), e112–e126.
5. Anonymized. Under Review. The Feasibility, Usability and Perceived Clinical Utility of Traditional Paper Food and Symptom Journals for Patients with Irritable Bowel Syndrome. *Please refer to the supplementary material in CSCW review system*. (Under Review).
6. American Gastroenterology Association. 2002. American Gastroenterological Association medical position statement: irritable bowel syndrome. *Gastroenterology* 123, 6 (2002), 2105.
7. M Austin, L Harnack, J Bhaskarani, S Kiesling, D King, J Klein, S Marrone, C Perry, J Pettit, K Pink, S Seftick, S Setten, M Stevens, J Stevenson, M Thor, and G Weil. 2013. Nutrition Data System for Research User Manual. (2013).
8. Stinne Aaløkke Ballegaard, Thomas Riisgaard Hansen, and Morten Kyng. 2008. Healthcare in everyday life: designing healthcare services for daily life. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 1807–1816.
9. Sorrel Burden. 2001. Dietary treatment of irritable bowel syndrome: current evidence and guidelines for future practice. *Journal of Human Nutrition and Dietetics* 14, 3 (2001), 231–241.
10. Eun Kyoung Choe, Nicole B Lee, Bongshin Lee, Wanda Pratt, and Julie A Kientz. 2014. Understanding quantified-selfers' practices in collecting and exploring personal data. In *Proceedings of the ACM conference on Human factors in computing systems*. ACM, 1143–1152.
11. Chia-Fang Chung, Jonathan Cook, Elizabeth Bales, Jasmine Zia, and Sean A Munson. 2015. More than telemonitoring: Health provider use and nonuse of life-log data in irritable bowel syndrome and weight management. *Journal of medical Internet research* 17, 8 (2015), e203.

12. Chia-Fang Chung, Kristin Dew, Allison Cole, Jasmine K. Zia, James Fogarty, Julie A. Kientz, and Sean A. Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. In *Proceedings of the ACM conference on Computer-Supported Cooperative Work and Social Computing (CSCW 2016)*.
13. Felicia Cordeiro, Daniel A Epstein, Edison Thomaz, Elizabeth Bales, Arvind K Jagannathan, Gregory D Abowd, and James Fogarty. 2015. Barriers and negative nudges: Exploring challenges in food journaling. In *Proceedings of the ACM Conference on Human Factors in Computing Systems*. ACM, 1159–1162.
14. Mary Jo Deering, Erin Siminerio, and Scott Weinstein. 2013. Issue Brief: Patient-Generated Health Data and Health IT. *Office of the National Coordinator for Health Information Technology* (2013).
15. Sigrid Elsenbruch. 2011. Abdominal pain in Irritable Bowel Syndrome: a review of putative psychological, neural and neuro-immune mechanisms. *Brain, behavior, and immunity* 25, 3 (2011), 386–394.
16. Daniel Epstein, Felicia Cordeiro, Elizabeth Bales, James Fogarty, and Sean Munson. 2014. Taming data complexity in lifelogs: exploring visual cuts of personal informatics data. In *Proceedings of the conference on Designing interactive systems*. ACM, 667–676.
17. Motahhare Eslami, Aimee Rickman, Kristen Vaccaro, Amirhossein Aleyasen, Andy Vuong, Karrie Karahalios, Kevin Hamilton, and Christian Sandvig. 2015. I always assumed that I wasn't really that close to [her]: Reasoning about Invisible Algorithms in News Feeds. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems*. ACM, 153–162.
18. Shanti Eswaran, Jan Tack, and William D Chey. 2011. Food: the forgotten factor in the irritable bowel syndrome. *Gastroenterology clinics of North America* 40, 1 (2011), 141–162.
19. Susannah Fox and Maeve Duggan. 2013. *Tracking for health*. Pew Research Center's Internet & American Life Project.
20. Susan N Friel, Frances R Curcio, and George W Bright. 2001. Making sense of graphs: Critical factors influencing comprehension and instructional implications. *Journal for Research in mathematics Education* (2001), 124–158.
21. Peter R Gibson and Susan J Shepherd. 2012. Food choice as a key management strategy for functional gastrointestinal symptoms. *The American journal of gastroenterology* 107, 5 (2012), 657–666.
22. Emma P Halmos, Victoria A Power, Susan J Shepherd, Peter R Gibson, and Jane G Muir. 2014. A diet low in FODMAPs reduces symptoms of irritable bowel syndrome. *Gastroenterology* 146, 1 (2014), 67–75.
23. Alfred Inselberg. 1997. Multidimensional detective. In *Information Visualization, 1997. Proceedings., IEEE Symposium on*. IEEE, 100–107.
24. Anne E Jamieson, Paula C Fletcher, and Margaret A Schneider. 2007. Seeking control through the determination of diet: a qualitative investigation of women with irritable bowel syndrome and inflammatory bowel disease. *Clinical Nurse Specialist* 21, 3 (2007), 152–160.
25. Ravi Karkar, Jasmine Zia, Roger Vilardaga, Sonali R Mishra, James Fogarty, Sean A Munson, and Julie A Kientz. 2015. A framework for self-experimentation in personalized health. *Journal of the American Medical Informatics Association* (2015), ocv150.
26. Uri Ladabaum, Erin Boyd, Wei K Zhao, Ajitha Mannalithara, Annie Sharabidze, Gurkirpal Singh, Elaine Chung, and Theodore R Levin. 2012. Diagnosis, comorbidities, and management of irritable bowel syndrome in patients in a large health maintenance organization. *Clinical Gastroenterology and Hepatology* 10, 1 (2012), 37–45.
27. Mars Lan, Lauren Samy, Nabil Alshurafa, Myung-Kyung Suh, Hassan Ghasemzadeh, Aurelia Macabasco-O'Connell, and Majid Sarrafzadeh. 2012. Wanda: An end-to-end remote health monitoring and analytics system for heart failure patients. In *Proceedings of the conference on Wireless Health*. ACM, 9.
28. Ian Li, Anind Dey, and Jodi Forlizzi. 2010. A stage-based model of personal informatics systems. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 557–566.
29. Solveig C Ligaarden and Per G Farup. 2011. Low intake of vitamin B 6 is associated with irritable bowel syndrome symptoms. *Nutrition Research* 31, 5 (2011), 356–361.
30. George F Longstreth, W Grant Thompson, William D Chey, Lesley A Houghton, Fermin Mearin, and Robin C Spiller. 2006. Functional bowel disorders. *Gastroenterology* 130, 5 (2006), 1480–1491.
31. Lena Mamykina, Elizabeth Mynatt, Patricia Davidson, and Daniel Greenblatt. 2008. MAHI: investigation of social scaffolding for reflective thinking in diabetes management. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*. ACM, 477–486.
32. Gabriela Marcu, Anind K Dey, Sara Kiesler, and Madhu Reddy. 2016. Time to reflect: Supporting health services over time by focusing on collaborative reflection. In *Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing*. ACM, 954–964.
33. KW Monsbakken, PO Vandvik, and PG Farup. 2006. Perceived food intolerance in subjects with irritable bowel syndrome—etiology, prevalence and consequences. *European journal of clinical nutrition* 60, 5 (2006), 667–672.



34. Jasmir G Nayak, Andrea L Hartzler, Liam C Macleod, Jason P Izard, Bruce M Dalkin, and John L Gore. 2015. Relevance of graph literacy in the development of patient-centered communication tools. *Patient education and counseling* (2015).
35. Jon Noronha, Eric Hysen, Haoqi Zhang, and Krzysztof Z Gajos. 2011. Platemate: crowdsourcing nutritional analysis from food photographs. In *Proceedings of the 24th annual ACM symposium on User interface software and technology*. ACM, 1–12.
36. Rupa A Patel, Predrag Klasnja, Andrea Hartzler, Kenton T Unruh, and Wanda Pratt. 2012. Probing the benefits of real-time tracking during cancer care. In *AMIA Annual Symposium Proceedings*, Vol. 2012. American Medical Informatics Association, 1340.
37. Iris Posserud, Hans Strid, Stine Störsrud, Hans Törnblom, Ulla Svensson, Jan Tack, Lukas Van Oudenhove, and Magnus Simrén. 2013. Symptom pattern following a meal challenge test in patients with irritable bowel syndrome and healthy controls. *United European gastroenterology journal* (2013), 2050640613501817.
38. Kavita Radhakrishnan, Kathryn Bowles, Alexandra Hanlon, Maxim Topaz, and Jesse Chittams. 2013. A retrospective study on patient characteristics and telehealth alerts indicative of key medical events for heart failure patients at a home health agency. *TELEMEDICINE and e-HEALTH* 19, 9 (2013), 664–670.
39. Suzanne M Rebro, Ruth E Patterson, Alan R Kristal, and Carrie L Cheney. 1998. The effect of keeping food records on eating patterns. *Journal of the American Dietetic Association* 98, 10 (1998), 1163–1165.
40. B Reeder, J Chung, T Le, HJ Thompson, and G Demiris. 2014. Assessing older adults’ perceptions of sensor data and designing visual displays for ambient assisted living environments: An exploratory study. *Methods of information in medicine* 53, 3 (2014), 152.
41. Rashmi Sinha and Kirsten Swearingen. 2002. The role of transparency in recommender systems. In *CHI’02 extended abstracts on Human factors in computing systems*. ACM, 830–831.
42. HM Staudacher, K Whelan, PM Irving, and MCE Lomer. 2011. Comparison of symptom response following advice for a diet low in fermentable carbohydrates (FODMAPs) versus standard dietary advice in patients with irritable bowel syndrome. *Journal of Human Nutrition and Dietetics* 24, 5 (2011), 487–495.
43. Cristiano Storni. 2011. Complexity in an uncertain and cosmopolitan world. Rethinking personal health technology in diabetes with the Tag-it-Yourself. *PsychNology Journal* 9, 2 (2011), 165–185.
44. Kirsten Swearingen and Rashmi Sinha. 2001. Beyond algorithms: An HCI perspective on recommender systems. In *ACM SIGIR 2001 Workshop on Recommender Systems*, Vol. 13. Citeseer, 1–11.
45. Paul C Tang, J Marc Overhage, Albert Solomon Chan, Nancy L Brown, Bahar Aghighi, Martin P Entwistle, Siu Lui Hui, Shauna M Hyde, Linda H Klieman, Charlotte J Mitchell, and others. 2013. Online disease management of diabetes: engaging and motivating patients online with enhanced resources-diabetes (EMPOWER-D), a randomized controlled trial. *Journal of the American Medical Informatics Association* 20, 3 (2013), 526–534.
46. Frances E Thompson and Amy F Subar. 2008. Dietary assessment methodology. *Nutrition in the Prevention and Treatment of Disease* 2 (2008), 3–39.
47. Peter West, Richard Giordano, Max Van Kleek, and Nigel Shadbolt. 2016. The Quantified Patient in the Doctor’s Office: Challenges & Opportunities. In *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*. ACM, 3066–3078.
48. Jasmine Zia, Chia-Fang Chung, Kaiyuan Xu, Yi Dong, Kevin Cain, Sean A. Munson, and Margaret Heitkemper. 2016a. Inter-rater Reliability of Healthcare Provider Interpretations of Food and Gastrointestinal Symptom Paper Diaries of Patients with Irritable Bowel Syndrome. *Digestive Disease Week* (2016).
49. Jasmine Zia, Jessica Schroeder, Sean Munson, James Fogarty, Linda Nguyen, Pamela Barney, Margaret Heitkemper, and Uri Ladabaum. 2016b. Feasibility and Usability Pilot Study of a Novel Irritable Bowel Syndrome Food and Gastrointestinal Symptom Journal Smartphone App. *Clinical and Translational Gastroenterology (In Press)* 7, 3 (2016), e147.