This work examines patient-provider collaboration using patient-generated food and symptom journals to identify nutrients that trigger an individual patient’s symptoms. This practice is an example of diagnostic self-tracking, which prior research in the Quantified Self community has found broadly important but also difficult and error-prone.

We contribute two exploratory, interactive visualizations that represent different design trade-offs in supporting collaborative interpretation of patient-generated food and symptom journals. By applying visualization techniques to the domain of patient-generated health data, we created novel opportunities to help patients and providers discover and examine trends in the data and identify dietary changes that might help the patient manage their symptoms.

We further contribute an examination of patient-provider collaboration in the interpretation of patient-generated data using exploratory interactive visualizations.

We believe our results apply more broadly to patient-provider collaboration to interpret patient-generated data, but we provide background on IBS to situate our current work.

Design Goals and Tradeoffs

Flexible, Simple, Exploratory, Actionable. In short the visualizations offer both detailed and not detailed explanations. Both representations aim to support patient and provider interpretation by make correlations visually salient.

During our early informal iterations, we found that patients often found p values unfamiliar and somewhat intimidating. However, providers considered p values essential to a more complete understanding of the information.

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.

In the individual phase, researchers then asked about participant opinions of the visualizations, whether and when they would use them, and what conclusions they would draw from them.

Results:

An important question for many providers was whether they could trust patients to correctly interpret their data.

The collaborative interviews assuaged many of the concerns providers initially had about patient abilities regarding data interpretation.

Patients and providers both commented on the need for their collaborators to trust what they say. Patients needed providers to understand their experiences, and providers needed patients to understand why they made certain recommendations. P1 remarked that such information is “kind of hard to put into words, but [the visualization] kind of quantifies it”.

Visualizations helped patients and providers raise questions regarding the quality of data collection and analysis with respect to their original expectations.

Many participants wanted to verify regression results were biologically plausible.

Our visualizations illustrate different tradeoffs in simplicity versus expressiveness. The bubble and bar chart visualization shows high-level trends, while the parallel coordinates provide more detail. We thought some clear preference might emerge, but found diverse reactions to the alternatives.

Patients and providers both wanted to use the visualizations collaboratively in clinic appointments.

Participants overwhelmingly wanted to be able to access and review the visualizations before a clinic appointment.

Although the analyses and visualizations were designed for a single food and symptom journal dataset, participants wanted to extend the system to aid the ongoing management of their IBS.

**They then wanted to follow up this hypothesis formation with an experimental step testing whether limiting the nutrient improved the patient’s symptoms.**

However, our study found that many patients were able to navigate a complex visualization when aided by a short interactive tutorial. Fully developed tutorials could support patient interpretation and help address provider concerns.

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 is to support hypothesis testing with self-experimentation [25]. IBS management is a long-term process that often involves iterative hypothesis formation and testing, as well as changes in the habits and goals of the patients [33]. Our visualizations provide support for identifying potential relationships between nutrients the patient eats and their subsequent symptoms. Utilizing self-experimentation for hypothesis testing would then provide actionable next steps for patients to determine whether dietary changes based on these relationships will help with the long-term management of their symptoms.