
Supporting Patient-Provider Communication and Relationships with Personal Informatics Data

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Abstract

Patients and providers increasingly turn to personal informatics data to help manage health challenges. Collaboration over personal informatics data has the potential to support medical decisions and patient-provider relationship. However, these new, evolving collaboration processes also come with challenges. Our research builds an understanding of patient and provider needs and challenges to advance the design of personal informatics systems and theoretical understandings of patient-provider collaboration. Through studies of patients with Irritable Bowel Syndrome and people who want to eat healthier, we study people's current tracking experiences and their collaborative review practices with providers. In this workshop paper, we highlight current needs and challenges, how current tools support patient-provider collaboration, and how trust evolves during these collaboration processes.

Author Keywords

Personal informatics; patient-provider communication; chronic disease management; self-tracking; health

Introduction

The prevalence of self-tracking applications and wearable sensing devices creates an opportunity for individuals to

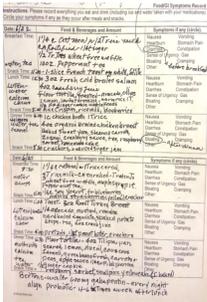


Figure 1 Paper-based diary



Figure 2 Mobile app diary

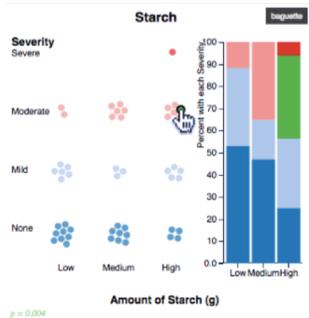


Figure 3. Nutrient-based visualization of IBS triggers

collect continuous, objective, and precise everyday health and lifestyle data to complement standard clinical measurements. However, many self-trackers who share their data with health providers are frustrated that their providers did not engage with this data [1,4]. Understanding current experiences, challenges, and design opportunities can help HCI and CSCW communities better support patient-provider collaboration and relationship building using personal informatics data.

Our research focuses on two populations who use personal informatics data to support everyday decisions: people with Irritable Bowel Syndrome (IBS) and people with healthy eating goals. IBS providers and patients commonly use journals to identify and manage personal triggers (Figure 1 and 2), and people with healthy eating goals similarly frequently use diaries to monitor lifestyle changes and their influence on health indicators, such as weight. In this workshop paper, we discuss how bringing personal informatics into the clinic influences patient-provider relationship building and the barriers of using these data to achieve these goals. Specifically, we discuss:

1. What expectations and challenges patients and providers face when using personal informatics data for clinical care and for supporting rapport building.
2. How current tools and clinical practices support or do not support patients and providers to collaborate using personal informatics data.
3. How trust between patients and providers evolves while reviewing personal informatics data collaboratively.

Patient and Provider Expected Personal Informatics Data Support Rapport Building

To examine some current uses of personal informatics data in the clinic, we conducted a series of studies with

providers and patients with IBS and weight management concerns. Through interviews with 21 providers [2], surveying 211 patients, and 18 patient interviews [3], we found that both providers and patients want to use personal informatics data to support diagnosis and to provide personalized treatment. Reviewing this data with patients in the clinic can also build rapport by surfacing a more complete view of patient lives, values, and priorities and by increasing patient motivation and accountability.

Some providers also valued reviewing patient-tracked data to reveal patient unarticulated goals as well as constraints and opportunities for change. These data are also helpful for facilitating discussions and supporting their conversations during clinic visits.

However, asking patients to track without persistent review can send mixed messages. Patients might think they no longer need to track when providers stop reviewing or asking about the data. On the other hand, providers might expect that patients could track and review by themselves. Some patients also do not believe they have the necessary skills and therefore are not willing to track and review data on their own. Similarly, some providers do not believe they can advise patients on tracking and reviewing personal informatics data.

Current systems and workflows often do not support the communication and implementation of these tracking and reviewing processes. Providers do not have enough time to review patient-tracked data in detail. They are also unsure who in the medical team can best incorporate the data review process in their workflow. Few current systems provide sufficient flexibility for providers and patients to focus on data most relevant for their needs and goals.

Textbox 1: Patients and providers collaborate during all stages of tracking [3]

Preparation: Patients make tracking decisions based on collaborative review goals. However, patients might not know what tools to use or what to track to better support these goals.

Collection: Provider review increases patient motivation and accountability. However, patients do not know what to expect from providers.

Integration: Patients want to curate data before sharing with providers. Current systems often do not support individualized, specific curation.

Reflection: Providers and patients attempt to review data together, but typically have less than five minutes per visit to do so.

Action: Providers make clinical recommendations and instructions, but patients do not know how to incorporate these into their tracking tools.

How Current Tools and Clinical Practice Support or do not Support Patient-Provider Collaboration using Personal Informatics Data

Despite the many challenges to integrating personal informatics data into clinic visit, some providers and patients find ways to use these data collaboratively. We used the staged-based model of personal informatics [6] and boundary negotiating artifacts [5] as lenses to understand how patients and providers collaborate with each other and what challenges they faced with personal informatics data. Using the stage-based model of personal informatics [6] to analyze our data, we found that providers and patients collaborate during every stage of tracking (Textbox 1). These personal informatics data were used as or transformed into various boundary negotiating artifacts [5] to support patient-provider collaboration. Transforming or moving these data through healthcare contexts creates patient privacy tensions that are often not adequately addressed (Textbox 2) [3]. For example, patients might only want to share sensitive personal informatics data with providers they trust or have better relationship with. However, current tools usually do not allow patients to easily filter these data. Once the data are input into the electronic medical record, patients also have no control over who will be able to access these data. Providers and patients need better support to communicate and review on data relevant to their goals and to address related privacy concerns.

Collaborative Review Facilitates Trust Building in Patient-Provider Relationship

Trust building is essential in building and maintaining patient-provider relationships. Bringing new source of data into clinical care can influence trust between patients and providers. In a study with 10 IBS provider-patient pairs

[7], we found that reviewing personal informatics data helped patients and providers develop trust in each other.

In this study, we showed patients and providers visualized nutrient and symptom correlations based on the patient's food and symptom diaries (Figure 3) and asked them to interact with the visualizations first separately then collaboratively.

During individual interviews, half of the providers expressed concerns that patients would not be able to understand the visualized data on their own and might draw inaccurate conclusions. Some providers also worried that they would not be able to interpret patient data or answer patient questions on the spot. However, during the collaborative interviews, providers found that patients could interpret the data, add contextual information from their experience, and help focus the discussions.

Both patients and providers thought reviewing personal informatics data together helped them gain trust in each other. For providers, having access to patient-tracked data helped them explain the basis for their recommendations. For patients, these personal informatics data gave providers evidence of their experiences and helped make their visit goals more concrete. Collaboration between patients and providers can help encourage provider trust in patient abilities in interpreting data, and can help patients trust that the provider is getting the overall picture of their experience.

To support this trust building, systems can help providers and patients navigate the data more efficiently and easily by providing interactive tutorials and visualizations with various complexities. Scaffolded interactions can also help patients and providers arrive at shared expectations for

Textbox 2: Personal informatics data are transformed into Boundary Negotiating Artifacts [3]

Self-explanation artifacts:

Personal informatics data were first collected for personal use, without knowledge about who will review the data.

Inclusion artifacts: Patients and providers discuss whether and how to include these data into medical decisions. However, current tools often do not allow patients to easily choose what to share, and patients often rely on providers to make these decisions.

Compilation artifacts:

Personal informatics data are input into the medical record. However, patients have no control over who can see these data beyond the current clinic encounter.

Structuring artifacts:

Providers deliver handouts or instructions for patients to follow at home.

what information will be shared, how it will be used, and what the desired outcomes are for the collaboration.

Conclusion

We studied patient current tracking experiences and their collaborative review practices with providers. Our findings provide an understanding of how including personal informatics data in clinical use influences and challenges current patient-provider communication and workflow practices. These findings also suggest how systems can better support patients, providers, and their collaboration in every stage of personal informatics tracking and review.

Patient-provider relationships influence and are influenced by the adoption and use of personal informatics data and tools. In this workshop, we hope to discuss how future systems and personal informatics models should incorporate these relationship and collaboration goals and account for the influence brought by these relationship and collaboration needs. We also look forward to extending the discussion to the data relationships among people with different expertise or from different communities.

Personal Biography

Chia-Fang (Christina) Chung is a fifth-year Ph.D. student in the Department of Human Centered Design and Engineering at the University of Washington and a member of the DUB group. Christina studies how ubiquitous computing and personal informatics data can be shared to support relationships, to motivate health behavior, and to support clinical care. She uses a combination of quantitative and qualitative methods in her work, including online and laboratory experiments, surveys, interviews, observational studies, and field deployments to understand how people make sense of their self-tracking data individually and collaboratively with health experts. Her work provides an

integral view of how providers and patients use self-tracking data in the chronic disease management care cycle and will bridge the gap between technologies and health improvement that relies on an understanding of patient-provider practice, workflow, and interaction.

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