
Patient and Provider Goals and the Using Patient-Generated Data in IBS and Weight Management

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Abstract

More and more patients collect health information using smartphone applications and wearable sensors, and they often bring these data to their healthcare providers. To understand provider and patient expectations and collaboration practices around patient-generated data, we surveyed 211 patients and interviewed 18 patients and 21 providers who work with the chronic conditions irritable bowel syndrome and overweight/obesity.

Providers reported using these data to support their communication with patients, to motivate and educate them, and to develop diagnoses and personalized treatment plans. Similarly, patients reported expecting better diagnoses, education, and emotional support from the exchange of these data with their providers. Both parties described collaborative processes and interactions throughout patient tracking stages and care cycles. However, barriers to regular and effective use of these data are still common. Current self-monitoring tools lack flexibility, standardized formats, and mechanisms to share data between providers and patients. Providers are often short of time to review detailed records, question their expertise for reviewing these data, and are sometimes skeptical of the benefits of reviewing these data.

We used the stage-based personal model of personal informatics and the theory of boundary negotiating artifacts to analyze misunderstandings and privacy concerns. We reflect on the social nature of patient-provider collaboration to identify opportunities to better support use of patient-generated data and development of theories.

Summary

This research highlight presents results of two publications [1,2]. Together, these publications present an integral view of how provider and patients current use patient-generated data to manage the chronic conditions, irritable bowel syndrome (IBS) and obesity, what they expect from collecting, sharing, and reviewing the data, what challenges they face, and how they use these data in their collaboration.

We hope that this highlight can foster conversations about the challenges and opportunities for better integrating patient-generated and patient-tracked data into chronic disease management. With self-monitoring technologies becoming more prevalent, and new frameworks supporting data integration and sharing, we believe this is an important topic for the WISH community. We are also developing designs to address challenges and opportunities we have identified, and we would benefit from feedback from researchers in the community.

Our submission to WISH does not conflict with the policies of the venues where the research was originally published.

References

1. Chia-Fang Chung, Jonathan Cook, Elizabteh Bales, Jasmine Zia, 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), e203. <http://doi.org/10.2196/jmir.4364>
2. Chia-Fang Chung, Kristin Dew, Allison Cole, Jasmine Zia, James Fogarty, Julie A. Kientz, Sean A. Munson. 2016. Boundary Negotiating Artifacts in Personal Informatics: Patient-Provider Collaboration with Patient-Generated Data. 2016. The 19th ACM Conference on *Computer-Supported Cooperative Work and Social Computing (CSCW 2016)*. <http://dx.doi.org/10.1145/2818048.2819926>