Towards Self-Experimentation in Personalized Health

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This research highlight presents our recent publication '*A Framework for Self-Experimentation in Personalized Health',* appearing in the Journal of the American Medical Informatics Association [1].

Original Article Abstract

Understanding individual variation and treating individual needs is important in medicine and clinical science, an approach also known as *personalized medicine*. We have developed an interdisciplinary and methodological framework for applying single case study designs to self-experimentation in personalized health. An in-depth literature review was performed to develop the framework and to identify absolute and desired health condition requirements for the application of this framework. We examine the framework's applicability to various health conditions and present an initial case study with irritable bowel syndrome (IBS). We developed mobile application prototypes, storyboards, and process flows of the framework using IBS as the case study. We conducted three focus groups and an online survey using a human-centered design approach for assessing the framework's feasibility.

All six focus group participants had a positive view about our framework and volunteered to participate in future studies. Most stated they would trust the results

because it was their own data being analyzed. They were most concerned about confounds, nonmeaningful measures, and erroneous assumptions on the timing of trigger effects. Survey respondents ($N = 60$) reported they were more likely to be adherent to an 8- vs 12-day study even if it meant lower confidence results.

Using mobile technology to guide people through self-experimentation to investigate health questions is a feasible and promising approach to advancing personalized health. Given the results from our initial case study, we believe this framework can be applied to other health conditions. Considerations include the learning curve for teaching self-experimentation to non-experts and the challenges involved in operationalizing and customizing study designs.

Relevance to WISH

Current self-tracking applications support the capture and access of data related to various dimensions of life, including physical activity, food, and sleep. However, most applications still fall short in providing meaningful and actionable feedback. Instead, self-trackers are often left to draw their own insights. Due to a variety of challenges (e.g., no scientific background), many reach false conclusions or focus on dubious correlations.

Our framework examines how to support everyday people in successfully applying self-experimentation to understand the cause of their symptoms as well as how to then take effective action. Although self-experiments may be more complex than simple self-tracking, it is our hope that this framework can both: (1) reduce the burdens of tracking through targeted data collection, and (2) also provide more concrete answers to specific health questions. For example, we are applying the framework in a mobile application aimed at helping IBS patients design, conduct, and analyze their own self-experiments to identify their personalized triggers.

We look forward to engaging with other attendees in discussing self-experimentation, its potential benefits, its potential challenges, and opportunities for tool support. We also hope to hear thoughts from others on what other health challenges might benefit from self-experimentation. The WISH community seems like the ideal venue to have such a discussion.

Statement of Non-Conflict with Policies

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

Reference

1. 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*. http://dx.doi.org/10.1093/jamia/ocv150