The Value of a Critical Approach to Personal Health Informatics

Abstract

Personal health informatics systems present data to encourage healthy decision-making through self-knowledge. However, some consequences of these personal health informatics systems have cast doubt on the “quantified self” movement: namely, difficulties with sustained engagement, concerns about whether these interfaces enable long-term behavior change, and narrowing the definition of “healthiness” to easily quantifiable metrics. We propose three design strategies for personal health informatics and speculate on how they can begin to meet these concerns. We are exploring how a critical design approach can be used to shift the focus of personal informatics from quantifiable behavior change to changes in personal outlooks on health. In this workshop, we hope to discuss these strategies with other personal informatics researchers and work both to develop evaluation plans for critical informatics systems and to begin integrating critical design approaches into the design of conventional personal informatics systems.

Introduction

The field of personal informatics has developed around the desire to make useful the growing amounts of data gathered about us by the technologies we use. Specifically, in the area health and wellness, designers of personal informatics systems have sought to support
healthy behavior change through the presentation of analytic interpretations of users’ data. Common practices in personal health informatics for health are grounded in the belief that such systems can, through the collection and presentation of personal information, promote individuals’ self-understanding, and that improving self-understanding leads consequently to self-insight, self-control, and positive, healthy behavior change. However, these systems have also had other consequences: concerns about sustained use and long-term behavior change have prompted questions about whether personal health informatics are succeeding by their own metrics in producing measurable, long-term behavior changes, while others have expressed skepticism about the accuracy and inclusiveness of the metrics themselves, and argued that the data presented as a measurement for healthiness is incomplete or even misleading.

Using data for self-improvement through confrontation of one’s data traces, however, represents but one possible approach to designing personal health informatics. A number of design approaches, such as value-sensitive design (e.g., [4]), reflective design (e.g., [10]), and critical design (e.g., [3]), have been developed specifically to identify ways that social values are embedded in system design and to consider alternative relationships between these systems and their users. We suggest a set of critical design strategies for approaching the design of personal health informatics and speculate on how they can be used to promote positive and productive relationships between users and their health data.

Related Work
There exists a wide variety of personal health informatics efforts in both the academic and commercial spheres. In order to support a user’s well-being, each of these tools is one composition of Li’s five stages (preparation, collection, integration, reflection, and action) [8]. The design decisions and compromises made during these stages result in three consequences common to personal health informatics systems. (1) Common to many domains, but perhaps especially healthy decision-making resolutions, is a rapid drop-off rate and lack of sustained engagement [1]. (2) Engagement is worth little without real health impacts, and there is a lack of evidence for long-term behavior change resulting from personal health informatics use [6]. At most, long-term impact is addressed via small demonstrated progress along psychological behavior change continua [e.g., 9]. (3) Thirdly, personal health informatics tools narrow definitions of health to what can be collected by the systems themselves - for example, BeWell interprets passively collected data from the accelerometer, microphone, and hours of charging time as representations of physical activity, sociality, and sleep respectively [7] while other systems rely on users active self-reports for collecting health data [1].

Three Design Strategies
We present strategies for making visible the expectations, limitations, and assumptions made by personal informatics for health, adapted from Khovanskaya et al. [5]. We illustrate these strategies through examples using self-reported data from a mobile social health application where users are prompted to take pictures of, rate, and share health decisions with other users [1].
Make it Strange - Personal informatics rarely highlight the role that they play in affirming mainstream relationships between individuals and their data (e.g., accountability, self-control). Making strange informatics draws attention to the embedded norms of such systems by suggesting alternative genres of personal informatics that emphasize humor and ludic engagement over self-optimization, while still using the familiar metrics and vocabulary of the existing infrastructure. Strange informatics aim both to playfully alleviate the judgmental aspects of self-knowledge and to fundamentally challenge the role of personal informatics as agents of confrontation. By presenting strange and deliberately obtuse alternatives, design can encourage sustained playful interaction and by doing so, counteract the discouragement and dread associated with informatics tools. Furthermore, presenting an alternative to conventional personal informatics can encourage individuals to reflect on the conventional values and expectations behind personal informatics design.

Make it Malfunction - Another strategy involves highlighting the inherent incompleteness of available health data. To be clear, we were not interested in deliberately misrepresenting users’ health data, but rather to make visible the inherent limitations of possible interpretations drawn from imperfect data sources. In the context of our system, malfunctioning informatics specifically foreground the limitations of quantifying data that is self-reported. Systems that rely on passive sensing could instead highlight the limitations of the sensors they use by identifying gaps, breaking points, and other technological “seams”[2]. With malfunctioning informatics, we hope to interrogate the assessment of success, both for individuals and personal informatics systems, by encouraging users to focus on recognizing the bounds of data mining. We hope to use malfunction to encourage users to reverse engineer and critique personal informatics interfaces and promote users’ self-efficacy as interpreters of their own data. By drawing attention to the limits of personal informatics and bounding the “know thyself” narrative, we can expand the goal of such systems to include reflection on the limitations of the data processes themselves.

Make it Presumptuous - The final strategy in place of our previous approach for personal informatics—displaying the "creepy" quality of passively gathered web-browsing data—instead makes visible the assumptions underlying presentations of health data in personal health informatics systems[5]. Presumptuous informatics overstate their significance and explanatory power by drawing conclusions that, while reasonable in some framings (such as in the quantification of health) seem ridiculous and amusingly satirical. Presumptuous informatics can also work to shift and extend the focus of personal health informatics by resisting the narrowing of definitions of health to measurable quantities. By presumptuously equating one standard metric for health, such as self reported healthiness of decisions, with other socially-accepted definitions of health

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users will begin to develop awareness of their own definitions of what it means to be healthy.

Future Work and Open Questions
Our work has raised two high-level questions: how does one evaluate the success of critically motivated personal informatics for health, and how can such informatics be productively integrated into other personal health informatics systems?

We are developing ways to evaluate critical informatics tools and their potential both to promote critical thinking about personal informatics and to encourage a user’s own interpretations of their personal data. We are incorporating these strategies into the design of a personal informatics system that we will deploy in the context of a mobile health study to see how effective our strategies are at inspiring reflection on and individual appropriation of personal health systems. We are also interested in whether the critical design can address some of the identified consequences by supporting alternative values and broadening relationship between users and health data. We would like to argue that critical design could be used in the personal informatics for health space to complement and challenge the “know thyself” narrative in a productive way.

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References and Citations