
What's Next for Quantified Health: In-Context Decision Support for People with Chronic Conditions

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Abstract

A growing number of people are living with chronic conditions, and tracking data about their health and bodies on a daily basis. There's an opportunity for the Quantified Self movement and future self-tracking solutions to not only help this population more effectively monitor and manage their conditions, but to provide real-time and in-context decision-making support for improved health and lifestyle outcomes. Designers will need to address unique requirements for people living with chronic conditions, as well as open issues around privacy, instinct, identity, and attention.

Author Keywords

Quantified Self; Self-tracking; Chronic Conditions; Decision Making; Medium Data

Introduction

60% of adults in the U.S. track a metric about themselves, such as diet, weight, or exercise; at the same time, 33% of adults in the U.S. track health indicators or symptoms, like blood pressure and sleep patterns [5]. With a growing number of wearable computing devices [1] and health-focused apps [9] available today, self-tracking has moved beyond medical and athletic domains and entered the mainstream. The Quantified Self is no longer an aspiration limited to a special interest group, but one

that is relevant to an expanding segment of the population.

However, while people have access to more data about themselves than ever before, it's unclear to what extent these data play a role in motivating and maintaining behavior change. It's possible that for many people these personal datasets do little more than fulfill a natural self-curiosity, and that the promise of the Quantified Self as a route to improved health and lifestyle dissipates as the novelty of tracking wears off.

It's time to push the boundaries of the Quantified Self movement beyond simply making self-tracking more accessible and toward helping people take action.

A call to Action-Taking

In [11], Swan describes four functional layers for the Internet of Things: Data Acquisition, Information Creation, Meaning-Making, and Action-Taking. These layers are relevant to the subset of "things" that help us track and monitor biometrics and other personal data.

The Quantified Self movement has generally been stalled in the Information Creation layer of this framework, and is just beginning to move into Meaning-Making. Action-Taking remains largely unaddressed by the Quantified Self movement to date. We argue, however, that transforming data into actionable insights is necessary for improved long-term wellbeing and health outcomes. People don't just need to understand the data they've collected, they need to know what to do next.

Action-Taking can be done in two ways: helping people initiate and complete planned action (achieving health-related goals over time), and providing decision-making support in real-time.

Data, decisions, and chronic conditions

Transforming data into actionable insights could especially benefit the growing population of people with chronic conditions. By 2030, an anticipated 171 million people in the U.S. will have at least one chronic condition, an increase of 36.8% since 2000 [8]. People with chronic conditions are more than twice as likely to engage in self-tracking as those without chronic conditions, and are more likely to update their data more regularly [5].

In addition to handling large volumes of data, people living with chronic conditions are making a range of daily decisions that may impact their health outcomes – such as what to eat, how much medication to take, and when to administer self-tests. When these decisions require making a choice that favors health, but conflicts with what a person really wants to do (e.g., choosing a salad over chips), it can result in the depletion of resources necessary for self-regulation (known as ego depletion, see [2]). This depletion of resources can impact a person's ability to make subsequent "good" choices moving forward. The presence of psychological conditions like depression result in additional challenges due to *misregulation*, where "the successful management of one condition conflicts with the successful management of the other" [3].

Turning data into real-time and in-context decision support has the potential to reduce cognitive burden for

people with chronic conditions, help them cope with misregulation, and improve overall health outcomes.

Added data for real-time decision support

Though people living with chronic conditions may benefit from real-time decision-making assistance, the power of making recommendations based on individual datasets assembled through self-tracking may be limited. Fortunately, a growing number of external datasets are available online, particularly as a growing number of objects and spaces become sensor-equipped and internet-connected [4]. These “things” lend to the creation of a “passive background layer of continuous monitoring that could be helpful in improving physical and mental health” [11].

By pairing data collected by connected things in a person’s environment with data gathered via self-tracking, as well as relevant “medium data” (e.g., data from populations with similar characteristics), we can uncover new correlations and make more informed, real-time recommendations. This powerful amalgamation of data could yield new insights and predictions about a person’s likely behavioral, emotional, and physiological outcomes. See [11] for a similar idea, the “Biometric Recommendation Engine.”

Design requirements

As the Quantified Self evolves to focus more on the needs of people with chronic conditions, several unique design requirements will need to be met:

Fit into users’ daily lives (non-clinical environments)

People living with chronic conditions deal with monitoring and management in a wide variety of environments – from homes, to outdoors, to crowded

public spaces. Medical devices and interventions, however, are typically optimized for use in hospitals. Patients are forced to invent awkward workarounds for these products, increasing burden of use.

Be accessible to non-experts

Care increasingly takes place outside the doctor’s office. Patients and family caregivers must be able to understand and use new solutions. At the same time, people’s expectations about how technology functions are increasingly influenced by mainstream consumer products; these expectations shape their interactions with medical devices and interventions.

Help users “cut through the noise”

People living with chronic conditions are handling their own personal data, along with a wide range of health information available online. It can be difficult to decide what to focus on, and what should be ignored.

Maintain continuity of care

Most patients with chronic conditions see several clinicians [8], and that number is growing with the rise of retail clinics [7]. This can cause continuity of care to break down. New solutions can help maintain continuity across providers, e.g., by keeping providers up-to-date, making data easy to export and share, and helping users track and reconcile different recommendations.

Enable a range of care team participation

Medical practitioners can contribute domain expertise and valuable knowledge of a patient’s medical history to new systems, and also need to remain informed about a patient’s status. However, time constraints and varying degrees of enthusiasm for consumer products suggest the need for flexible engagement models.

Additional considerations

In addition to the preceding design principles, there are several “open issues” that require further investigation:

Privacy expectations

What are users’ privacy expectations when it comes to sharing personal data and medical information with others? As people share a growing amount of personal information online, privacy expectations are in flux.

Personal instincts versus numerical data

Is an emphasis on numbers and “quantifying” the self diminishing the importance of listening to one’s body and trusting personal instincts [6]? Could a reliance on data prevent people from thinking for themselves?

Perception of identity

How does the concept of the self change as the body becomes enhanced by and supplemented with technology? How do self-tracking and monitoring devices impact identification with a larger population, patient or otherwise?

Attention to the body

As suggested in [6], self-tracking may make the body more ‘visible’ to users, for better or worse. Could self-tracking make patients with chronic conditions more acutely and continuously aware of their conditions, or might it help them offload the burden of monitoring?

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