

THE SELF-QUANTIFICATION MOVEMENT – IMPLICATIONS FOR HEALTH CARE PROFESSIONALS

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ABSTRACT

The growing phenomenon of self-quantification – people who observe certain aspects of their lives in great detail, analyze this data, and conduct self-experiments in the interests of improving their lives – is something health care professionals (HCPs) should be aware of. Many self-quantifiers' efforts are focused on health and HCPs may need to learn how best to interact with such deeply-engaged and knowledgeable patients. HCPs may also benefit from leveraging some of the tools and learnings that stem from the self-quantification movement. This paper examines the self-quantification phenomenon through the experiences of the Quantified Self, a leading organization in this movement, describes the key driving factors, and suggests some implications for HCPs.

Key words: Self-Quantification, Self-Experimentation.

Healthcare, and the medical scientific community, is guided by a deep respect for good science. Practices are established and new ideas are introduced only after extensive research has established a solid base of evidence. Randomized controlled trials, ideally with large populations followed over significant periods of time, are considered the gold standard for such evidence. The self-quantification movement may seem the antithesis of this, with experiments of $n=1$, conducted without professional expertise or oversight, and often grounded on lay opinions rather than established science. However, many health professionals are looking closely at this movement to see what might be learned. Recently the largest American philanthropic organisation focused exclusively on health has become involved, spurred both by the intriguing ideas of some self-quantifiers and by a desire to foster healthcare innovation¹.

The first meeting of the Quantified Self, a gathering of about 30 people at a private home near San Francisco in September 2008, encompassed much of the variety, potential and issues of the self-quantification movement. We began by compiling a list of things we'd like to hear about (Table 1).

One speaker had been tracking his time in great detail (e.g. 15 minutes eating dinner, 30 minutes watching TV, 10 minutes showering, etc.) for over three years, and showed some charts of this data. Interestingly, he didn't know what he could learn from what he had collected. He

Table 1

Topics for discussion at first meeting of the Quantified Self (partial list)
<ul style="list-style-type: none"> • How to make measurements in daily life? • What measurements are actionable? • What technologies are available? • How to visualize and analyze data? • What are meta effects of self-measurement? • What is the potential for group, or societal, benefits from individual experimentation? • How do self-quantification efforts interface with the medical system?

continued his self-monitoring effort in the hope that something useful could be learned. Many self-quantification efforts are like this, people collect information simply because they can, and out of curiosity. In contrast, another speaker had a clear objective and described his decade-long attempts to improve his pattern of sleep (he woke up too early, and could not go back to sleep). He had conducted many self-experiments, varying environmental factors, (e.g. foods, exercises, lighting) while keeping track of many subjective and objective measurements. He felt that he had discovered many things that improved his life and he shared his experiences through a blog and book². Another individual, an athlete, told of the extensive experimentation with treatments, exercises, diet, and medications that is common practice amongst professional athletes. Armed with two decades of detailed records, he claimed the ability to get his body back into whatever condition it had been at a particular point by going back to his regimen of that time. He too has published a book³ filled with suggestions for self-experimentation, as well as describing the treatments that have been most effective for him. Some of the ideas in the book would be considered highly controversial in the medical community. I described a tool in development at the time, aimed primarily at people managing complex chronic illnesses, to remember, track and analyze the full gamut of activities in their health regimen. Other speakers also described tools they had used, and often created, to make measurements, or analyze results, in order to improve some aspect of their lives.

The meeting was hosted by Kevin Kelly and Gary Wolf, both editors at *Wired* magazine and long-time observers and recorders of technology and its impact on society. As Wolf describes in a series of articles in *Wired*⁴, they founded the Quantified Self, a blog at first which subsequently led to meetings, after noticing that “a new culture of personal data was taking shape.”

Anthropologist J. A. English-Lueck notes how the same brew of ideas and contexts that shaped the home computer revolution also shapes Silicon Valley’s health culture: an ethos of experimentation, “a deeply medically diverse environment that combines sophisticated biomedical approaches with counter-cultural and immigrant-based modalities”. She foresees that “[individuals] will describe themselves by mixing an ethereal vocabulary of ‘wellness’ with a halo of medical metrics, the result of less expensive and more readily available monitoring

devices ... The coupling of health and productivity, which began with Silicon Valley's first wave of revolutionaries, will even more profoundly define [today's young adults]. Silicon Valley, reflecting both core American values and global trends, might once again be a bellwether for a recasting of what constitutes 'being and well-being.'"⁵

Since that first Quantified Self meeting, interest has expanded dramatically, with sometimes over 200 attendees at bi-monthly meetings, spin-off groups in 18 other cities around the world, and a lively blog⁶. Health related talks have covered a wide range of topics, such as sleep, chronic pain, alertness, and weight loss.

Several factors are contributing to the rise of self-quantification, and of self-experimentation, especially with respect to health: new technologies for gathering and analyzing data; more access and exposure to health knowledge; and decreasing confidence in relying solely on experts or HCPs.

Technologies for human measurement are no longer solely the province of professionals. One journalist endured nearly 250 medical diagnostic tests to explore what could be learned about his health using today's technology⁷. A computer industry veteran has spent the past decade documenting his life in as much detail as possible. For example he wears devices on a necklace that continuously record sound and video. The overall project is to understand how life changes when everything is recorded, and therefore memory doesn't fade away. He notes that his project has been most useful to him personally, for dealing with health issues⁸.

While some individuals have gone to extraordinary lengths to quantify themselves, many new commercial products are making it possible for anyone to gather some data easily⁹. A few years ago, an innovative use of a simple pressure sensor resulted in the Nike+ system which enabled runners to collect accurate data on speed and distance. Today smart phone 'apps' provide the same result using Global Positioning System (GPS) functionality. There is a plethora of devices that can be worn on the wrist, arm, or clipped on clothing, with sensors that capture movement, heart rate, skin temperature or galvanic response. There are an increasing number of consumer biochemical testing products such as those for measuring blood glucose or cholesterol, and consumers even have access to genetic testing through the efforts of some companies. Smartphone apps and websites can enable easy capture and charting of almost any user-observable health metric (eg. pills taken, mood, exercise and diet). There are also more tools available for consumer-accessible visualization and analysis of data, such as online spreadsheet and graphing, visualization, and statistical analysis software.

While some products bring technologies already in use in medical environments into a consumer environment, others are developed with consumer interests as the starting point. One product (Zeo), promoted as a "personal sleep coach" captures sleep data via a light headband, worn while sleeping, and a companion bedside-clock device. The concept began as an attempt to make a 'smart' alarm clock, one that would wake the user at roughly the desired time, but when in a sleep state most conducive to easy waking. The inventors realized they were capturing sleep data in the process, and felt consumers might find that interesting.

Some self-quantifiers have used the data to measure the effectiveness of different approaches to improving their sleep quality. As Zeo has reached a more mainstream audience, customers are requesting more coaching support. Some Zeo users are taking their charts to their doctors, but their doctors are unable to offer much interpretation or recommendation based on such data¹⁰. Another measurement product popular with self-quantifiers is a home weight scale (Withings). This scale focuses on making it easy and fun for the consumer to gather, analyze and share data from the scale. Unlike traditional medically-oriented tele-monitoring solutions which include functionality for HCPs to monitor and intervene as a fundamental system feature, Withings makes a point of not doing so. Withing's philosophy is more in line with the self-quantification movement – they provide measurement tools, users provide their own judgements¹¹. A third example is a smartphone app that helps with tracking personal health activities and measurements (Tonic¹²). Unlike clinically-driven “adherence” or “disease monitoring” apps, Tonic imposes no boundaries on what it can be used for. Users can just as easily monitor their intake of herbal tea as a prescription medication, track their weight or hours of television watched. This flexibility makes it more appealing to self-quantifiers.

A second major factor driving self-quantification is increased access to information and ideas about health, both through the Internet and increasingly diverse local environments. There are countless websites offering health and medical data, and numerous communities sharing health experiences and advice. Some communities stress conversations and anecdotes, while others stress data; all offer opportunities for an individual to learn about new treatment possibilities. For example, the website CureTogether¹³ allows users to learn from others with similar health conditions: what symptoms they have encountered, what treatments they have tried, and what other conditions they have had. Recently, users had noted 87 different treatments for depression, 35 for type II diabetes, 44 for lower back pain, and 194 for migraines – with each survey respondent noting the treatment's effectiveness from “made it much worse” to “major improvement”. Other popular health information websites, each with a unique approach, add to the more standard catalog of medical knowledge offered by sites like WebMD¹⁴. Author Michael Pollan used the web to ‘crowd-source’ a list of suggestions for healthy eating which he then published¹⁵.

Awareness of alternative ideas also contributes to a third major factor driving the self-quantification movement, which is an increasing appreciation of the limits of advice available from “experts” (including doctors). There are many popular books such as *Wrong*¹⁶, *The China Study*¹⁷, and *The Black Swan*¹⁸ offering critiques of established experts in many fields. Doctors are not exempt from this type of criticism. Recent magazine articles have highlighted the limits of medical knowledge and raised doubts about commonly-held medical wisdom¹⁹. Additionally, while much of professional medical science studies populations, self-quantification is very much about what works for the individual: ‘What is best for me, in my particular circumstances, with my particular desires?’ This leads many self-quantifiers to conclude that to answer those questions one has to self-experiment.

So, how might health professionals respond to patients who are self-quantifiers, and how might

they relate the efforts of self-quantifiers to interaction with other patients?

In one respect self-quantifiers are ideal patients, as they are engaged, and proactive in taking responsibility for their own health. Ironically, doctors are sometimes unprepared for patients who will think for themselves, want to make their own decisions, and ask a lot of questions. Some doctors may feel their authority is threatened, particularly if they may have to acknowledge the limitations of their own knowledge. If patients challenge the doctor's knowledge and do not follow the doctor's recommendations this may add to the sense of under-appreciation that doctors, at least in the US, are already feeling. A recent commentary in a medical journal categorized public perception of physicians as being either knaves (motivated by self interest), pawns (victims of circumstance), or knights (motivated by virtue), and concluded: "The modern US physician is regarded as either a knave or a pawn and is seldom regarded as a knight."²⁰

In such circumstances, it might be best for doctors to focus on the underlying goals: patients who are actively engaged in their own well-being; a strong, collaborative patient-doctor relationship; and using the doctor's special expertise to guide experimentation away from anything potentially dangerous.

It may be that today's Quantified Self participants, reflective of the broader self-quantification movement, are a harbinger of the future. People in the near future may be much more engaged in managing their own health and will be influenced by exposure to a wide variety of health knowledge, and so they may increasingly self-experiment with their health. In this future, doctors may have to learn how to be good partners and valued advisors while the patient is the primary care giver. Doctors could do more than simply await this change, they could help drive it. Doctors could learn about the tools self-quantifiers use to manage, measure and evaluate their health, and even introduce appropriate tools to some of their other patients. Doctors also need to be aware that people may want to self-experiment and they may need to advise such patients on the safe limits of such practices.

Disclosure: Rajiv Mehta is an advisor to the Quantified Self, and co-developer of Tonic

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