



Pervasive Health

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Creating Meaning in a World of Quantified Selves

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The urge to document our lives isn't new, and as readers of this column, you're no doubt well aware of the many new self-tracking technologies—particularly those related to health. A large part of the appeal of health tracking devices stems from their seeming objectivity. Built on sensors and algorithms, these systems appear neutral and consistent, impervious to human frailties and whims. Yet for many, use of these self-tracking techniques and technologies isn't straightforward. Here, we unpack four tensions surrounding self-tracking and discuss the role of quantification in understanding ourselves.

TENSIONS SURROUNDING SELF-TRACKING

We identified four tensions through a meta-analysis of a variety of empirical studies conducted over the last decade—including studies that involved deploying personal health informatics tools. The identified tensions relate to translating numbers into meaning, evolving norms, the intermingling of selves with others, and the inherent “leaving out” of opting out.

Meaning and Numbers

Many forms of self-exploration encourage development of self-knowledge through journaling or talking with a therapist. These activities elicit spoken language, writing, imagery,

and introspection. Self-trackers, on the other hand, focus on numbers, such as step counts, sleep logs, body mass indices, and mood scores. Numbers can be seen as rational, sensible, and irrefutable. Thus, self-quantification can appear on the surface to be fundamentally more powerful than these less “objective” ways people often reflect on their lives. According to Gary Wolf, founder of the Quantified Self, “electronic trackers have no feelings.” He further explains that this “objectivity of a machine can seem generous or merciless, tolerant or cruel. Designers of tracking systems are trying to finesse this ambivalence.”¹

For some self-trackers, numbers provide a route to personal insight and self-knowledge, particularly through “life hacking” experiments, in which individuals measure themselves while they change their diets, routines, or environments. These practices can be seen as an attempt to subvert traditional structures of knowledge production that prioritize population-level generalizability and that concentrate power and medical expertise in the hands of a few elite scientists.² At the same time, these new approaches are now strongly influencing modern medicine, which increasingly calls for personalization.

This hope for radical personalization, however, is in conflict with the limited tracking technologies available

in the commercial marketplace. Self-quantification devices measure that which is technologically tractable and cost-effective. These numbers (such as step counts) often fail to capture the nuance of the investigated phenomena (the user's overall health, for example) and the richness of how we actually live.³ By creating proxies for what we want to know, technologies of quantification can shift our focus toward things that are easy for machines to count—and away from what might be most meaningful.

Normativity

The quest for self-improvement drives much of the design and use of self-tracking technology. Data can help us get fit, be more productive, and improve our quality of life. However, these promises imply an easily defined, universal “best self.” Tools for personal health and self-tracking are often designed with this commonality in mind. Degrees of personalization are possible, but values are embedded in these systems that push for universal “goods,” like being more active and weighing less. For individual users, there are times when these goals might not apply as well as times when they could be damaging.

For example, in a study involving users of fitness trackers, one normally active informant told us about her recent knee surgery and how her

rehabilitation required her to walk as few steps per day as possible. She was encouraged by her physician to walk no more than 3,000 steps per day, so she lowered her Fitbit goal accordingly to match her rehabilitation goal. Her Fitbit, however, joyfully congratulated her on hitting her goal of 3,000 steps and encouraged her to walk even more. In this case, the fitness technology left no room for the possibility that the goal might be to walk less, not more.

In another instance, a pregnant woman's "smart" scale could not account for her appropriate and healthy weight gain, causing her distress. Gaining too little was cause for concern for her obstetrician, while gaining too much resulted in negative feedback from her scale. More distressing, in a study conducted by one of us (Margaret Morris) involving a woman who previously struggled with anorexia, the step counter on her iPhone triggered a latent compulsion to over-exercise. Although fully recovered, she experienced the step count as a reprimand to increase her activity. For her, the number was not a neutral indicator of steps; it was a sign that she never walked enough. She couldn't ignore it, and her phone wouldn't let her delete the app. Consequently, an app that was designed to help users take control of their own health felt coercive and oppressive in its demands for increased and quantified exercise.

In response to this kind of pressure, people might opt out of use—an issue we tackle later—or push back against these experiences actively. In our work, we have seen two types of pushback: social activism or radical acceptance. As an example of social activism, the woman who had recovered from anorexia but was triggered by her Health app on her iPhone used Twitter to request that Apple make this feature optional, garnering support from her social network. Apple eventually allowed the Health app to be

deinstalled (presumably in response to many such requests).⁴ As a byproduct of her efforts and perceived effectiveness, she has more confidence in her ability to make a difference in the world.

In terms of radical acceptance, some have embraced the power these devices have over their thoughts, behavior, and self-evaluation. To obtain a device's approval on a given day, some shake their FitBits for extra steps or omit snacks from their diet logs. One informant even understated exercise and exaggerated his diet in an effort to keep the system challenging him.⁵ The two paths explored here—social activism and radical acceptance—show alternatives to blind obedience to our devices.

Other People and Self-Tracking

"Self"-tracking technologies frequently implicate a wide range of actors that extend beyond the purview of any given individual. Points of demarcation between single human beings and their broader networks become fuzzy when information about friends, family, and colleagues is incidentally captured during the course of tracking. The mother who donates a saliva sample to learn more about her genetic composition lays bare heritable conditions for her children; the co-worker who tracks his work team's fitness achievements reveals information about the health and activity levels of colleagues. Additionally, numerous situations in our everyday lives require that we not only implicitly track others as a type of "self"-tracking but that these records be kept or shared explicitly. Whether incidental or explicit, the idea that "self"-tracking is always about oneself creates an unease about the boundaries of the self and the self's data.

Families are particularly vulnerable to boundary blurring as a result of one individual's self-tracking or measurement by a clinician. Collecting, aggregating, and possibly sharing indi-

vidual data nonetheless leads to the sharing of intimate indicators about family life. One of us (Gillian Hayes) conducted research with families of preterm infants over a five-year time span, during which the research team spent substantial time in the homes of families coping with medically fragile infants. An infant and its mother's health are tied intimately. Thus, an explicit goal of the research project was to help mothers understand how their own health affected their infants and vice-versa, as indicated through data collected about both mother and infant.

However, mother and infant were never the only people living in the home or involved in the care of the infant. Although the clinicians treating these families and the research team were only collecting data about the mother and the infant (or infants, in the case of twins), a variety of other family members were implicated in the data. For example, undocumented family members living in the homes of research participants had to be carefully assured of the ways in which collected data would be handled, including protections available in the case of a subpoena by an immigration officer. Federal law and institutional review boards provide some protection in these situations, such as through certificates of confidentiality, when the work is conducted as part of research. It's unclear, however, what protections might exist for data that should remain private—data that families consider intimate but that isn't legally defined as protected (by Health Insurance Portability and Accountability Act or the Family Educational Rights and Privacy Act, for example).

For many, the sociality of self-tracking is a benefit, and many of the makers of self-tracking apps have included features that let users share personal data with friends and social networks. Sharing data can become an opportunity for motivation through social support or friendly competition for

the most steps or longest bike rides. Some informants told us how they used shared step counts as a relatively unobtrusive monitor of their elderly parents' health. Within the Quantified Self movement, attending a meeting of fellow self-trackers, sharing data, and engaging in collective sensemaking around data's meaning and impact are key facets of community membership.

Beyond incidental or explicit capture lies the broad information acquisition by a future healthcare system that will rely on personal health data and self-tracking. Higher-order inferences arise from the aggregation of individual data: Researchers want to use data from Fitbit and other personal devices to address public health questions. Although intelligent health planning is a laudable goal, anxiety can emerge from the unknown—and largely unknowable—flows of information accessible to new third parties across social contexts.

Despite our best efforts to assiduously read the terms of service and privacy disclosure policies, we often have only a faint idea of what entities might actually receive intimate self-tracking information about us, or what the “rules of the game” will be in terms of permissibly processing, using, and sharing the information. Will it be viewable by employees of the tracking device company who might know us or our friends? Will it be received by human resources personnel at our employment institutions, who determine health insurance rates? Will our insurance companies or marketers gain access to it to determine policy eligibility or send us advertisements for new running shoes? Will our information be kept confidential, or will it be sold to third parties? Will it be retained indefinitely?

Any of these futures are possible. The proliferation of devices that enable near-ubiquitous tracking and sharing of information has grown into a broad ecosystem of interoperable “smart” devices, apps, and services. Dataflows

that enable the creation and ongoing operation of the self-quantification environment introduce a suite of new actors, data types, and transmission principles into formerly well-understood exchanges. For example, a recent study of mobile health and fitness apps found that third-party vendors receive detailed information about users' physical states and behaviors, as well as identifiers for both the device and the individual.⁶ These third parties often have their own policies and procedures about maintaining and selling such data to yet more organizations. With such a diffuse flow of information, it's no wonder that consumers and clinicians alike are often confused.

Although health tracking provides a wide variety of opportunities at the individual, family, community, and societal levels, these benefits must be tempered in light of open questions around privacy, trust, data control, and the incomplete regulatory framework surrounding information flows. Individuals, responding to imagined fears or past experiences, might not take up these technologies in the first place or might abandon them.

Opting Out and Being Left Out

“If it bothers you, why don't you just opt out?” It was once plausible to not self-track by simply not using dedicated devices or turning off apps that track. But tracking is increasingly embedded in mainstream devices and applications. Most of the digital devices we use leave behind traces of our activities, which infer things about us. Smartphones are powerhouses of personal quantification, packed with a variety of sensors and algorithms to measure our activities. With the rise of the Internet of Things, we're monitored by our beds, refrigerators, cars, thermostats, gas meters, televisions, and more.

Opting out is further challenged by limited knowledge of tracking. Mandatory terms of service, “consent” agreements, long and incomprehensi-

ble privacy notices, and absent or confusing user dashboards make understanding your own data extremely difficult. Even if it were simple to know all of the places in which data about you exists, and even if users could delete all of this data quickly and easily, problems remain.

Resistance becomes more challenging as quantification increasingly becomes the norm. Opting out can make people appear “criminal,”⁷ reduce options for participation in the labor market,⁸ and lead to adverse economic effects.^{9,10} Finally, opting out—or being left out by lack of access to devices and tracking systems—means that whole sets of people might not be included in “data-based” policy decisions. When society is shaped by these datasets, how will we account for those outside our data-generation systems?¹¹

DISCUSSION

Self-tracking holds enormous promise for individual empowerment and public health. The tensions described here should be explored to realize that potential. Efforts at improvement must go beyond the design of a particular device or app to reconsider the implications of a market that treats information as an “ownable” commodity, of a policy environment that sees person-generated data as less deserving of privacy protection than clinical or financial data, and of a legal “Wild West” concerning appropriate government and corporate uses of data. Our research indicates that the promise of self-tracking lies in disentangling, understanding, and acting on our sense of self, but also our sense of where society is and where it could be.

Despite the adage that “numbers don't lie,” digital devices and their tracking schemes are frequently poor or insufficient proxies for the things we want to track. Designers, technologists, and self-quantifiers should actively shift their focus away from things that are easy for machines

to count and toward a broader, more holistic exploration of meaning-making for a diverse array of individuals, groups, and communities. The most thoughtful and successful self-quantifiers accomplish this goal, often by focusing on quality-of-life experiences and taking the insights of institutional science, individual data-gathering, and the values and patterns of the collective seriously. It's time for the rest of us to follow suit. ■

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