

# The Patient Diarist in the Digital Age

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William Howard Taft was obsessed with his health—an observation many will find surprising given that he is remembered as the nation's most obese president. But Taft kept a detailed diary of his diet, exercise, reflux symptoms, and bowel movements. He shared his logs with his personal physician, who used the information to provide feedback and, with this support, Taft lost nearly sixty pounds.<sup>1</sup>

Now, close to 70 % of Americans track some form of health-related behavior.<sup>2</sup> The traditional leather-bound diaries of Taft's era are less common, but personal journals are more popular than ever in the form of blogs, social media posts, and other online activities. A growing number of sensors, including wearable devices and smartphone apps, collect biometric data passively or with minimal inputs from users, supporting what is called “the quantified self,” with assessments of blood sugar, heart rhythm, or peak respiratory flow.<sup>3</sup> The majority of these platforms and devices are never intended to be seen by doctors; by reducing the effort of documenting health, they can help patients self-manage their care, make health goals, and track progress. However, some of these platforms, such as Apple's new HealthKit, which collect information about diet, exercise, sleep and other health measures, already have the capability to directly interface with electronic medical record (EMR) systems. With the growing use and power of digital diaries, is there anything useful in the immense amount of health information and, if so, how can physicians use it?

Many apps and web-based platforms aim to move information from the public to their physicians, but most of these approaches fail important design considerations. Seemingly important information (a heart rate that's too fast) doesn't necessarily mean there is a physician prepared to receive or immediately act upon it. In contrast, seemingly unrelated information obtained passively (a measurable decline in the use of social media, or less movement detected by an accelerometer on a smart phone) might provide a clear signal of a

health change, and one that someone might be able to act upon. Physicians need data that are accurate, but they also need information that meets standards.

These design flaws will hopefully improve by increasing physician engagement in the design process and by smarter dashboards that are able to aggregate, contextualize, and analyze data. How urgently this data is utilized by physicians may be affected by compensation (a similar conundrum that was faced as emailing providers became more commonplace) and the specialty involved. This technology could enable cardiologists to better monitor arrhythmia events, or allow pulmonologists to detect chronic obstructive pulmonary disease (COPD) flares earlier. However, this will be challenging to actualize in the absence of incentives or data demonstrating an improvement in outcomes. Similar to telemedicine consults, the health provider that responds, analyzes or monitors digital diaries may not be the primary provider, but rather an ancillary provider whose primary goal is to make sense of this information.

Yet, the ability to act on this data may not always fall on the physician. Careful alarms may contact pre-identified, informed friends, family, or opt-in emergency systems if an abnormality is detected. Other non-critical values could be reviewed by a primary care physician in the EMR at the patient's next office visit. Finally, digital diaries and wearable devices could potentially be used to reduce readmission rates by monitoring high-risk patients after discharge, allowing doctors to intervene sooner if, for example, a congestive heart failure (CHF) patient's weight starts to rise at home. Despite these potential benefits, there remain several important questions around this technology that physicians can play a key role in addressing.

Is the information provided by the right patients? As with anything new, the early efforts at bringing digital personal health monitoring to the public attracted those individuals who—through a fascination with technology, a tendency toward early adoption, or greater-than-average self-involvement—were willing to engage in the process. In contrast, the people we worry about most are often those patients who would not think to engage in this kind of self monitoring, or are not capable due to their fragile health or social circumstances. Even before health related information became increasingly digital, physicians often characterized those patients bearing notebooks of symptoms and signs as suffering from *La Maladie du Petite Papier*. The substantive challenge

in contemporary journaling is to capture information from those patients who most need close observation, and those patients are often the least likely to participate. These patients particularly need platforms that are effortless, passive, and integrated into their daily lives. There is no one-size-fits-all strategy for engaging disengaged patients, and this is a challenge in all areas of medicine as physicians aim to find new ways to motivate patients, equip them with the right resources, and reduce barriers to achieving health goals. The approach will be similar to other technology interventions and could incorporate behavioral economics and incentives, “gamification,” peer-to-peer support, and other validated techniques used in preventative care.

Is the information actionable and provided at the right time? Most questions asked by physicians happen when the patient is in front of them, and the tools for using that information are within reach. Digital information can be transmitted without the patient there and can arrive at inconvenient times. Despite the potential importance of alerting physicians to their patients’ blood sugars or heart rates, a physician can’t comfortably handle a live stream of patient information without established systems of support. This information would be a “hot potato,” leaving the physician with a sense of risk and responsibility, but without a plan to manage either. Most physicians still practice using systems that make patients largely invisible and unapproachable unless they are sitting face-to-face. The best platforms will give integrated data to doctors in settings where they can be used effectively, while also providing appropriate feedback directly to users and potentially their social networks. The best digital journaling will either report on information that can wait, or be paired with systems that can handle emergencies.

Is there an established contract for the information? Our health is now revealed in so many indirect ways. Some are obvious (e.g., supermarket purchases reveal diet), while others are subtle. Will slower or less frequent texting on our cell phone help an internist manage depression, or diagnose a movement disorder? Will erratic banking activity reveal cognitive decline? Physicians are accustomed to using the information patients inadvertently reveal (the unsuccessful efforts at hiding memory loss) and not just what they submit for examination. On a much wider scale, big data analysts could find health signals in the tracks left inadvertently by patients (e.g., in their supermarket receipts or banking habits) as patients increasingly broadcast information about their health—information that could be used just as effectively as the information patients unwittingly reveal now when they sit face-to-face with their doctors. Those signals might be strong and valuable, but the social contracts around their acceptance (by patients) or use by doctors are not established.

While so much money and attention has focused on the acceleration of electronic health records documenting medical encounters, much of real health-related activity occurs during

the 5,000 waking hours patients spend each year engaging in their everyday lives.<sup>4</sup> The digital diaries produced in those 5,000 hours offer considerable insight into individual and population health. Much of this data may be valuable only to the diarist (perhaps the process of tracking one’s health is as important as the actual data from the tracking). But the aggregate of these diaries may be a valuable tool to help physicians manage patient care. Just as there are user design considerations in facilitating patient recording of relevant health information, there are user design considerations in facilitating the effective receipt of that information by clinicians.

Now that health-related information is collected more easily, and more passively, the intersection between what patients communicate and what physicians can use is growing.<sup>5</sup> The best of connected health technologies acknowledge patient privacy and are patient-controlled, transparent, opt-in, and customizable. While many focus on the wearable devices and other technologies that enable this growing use of information, others focus on the big data analytic challenges of finding signals in increasingly complex data structures. Underlying both of these efforts is the need to ensure these processes fit comfortably and acceptably into the patterns of our lives and clinical practice.

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