

How Consumers and the Healthcare Industry Respond to Data from Personal Devices

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Johan Ketkar

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

Johan Ketkar

Sociotechnical advisor: Peter Norton, Department of Engineering and Society

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The personal and wearable device market is growing dramatically. Gartner (2021) estimates that consumer spending on wearable devices will total \$81.5 billion in 2021, identifying increased interest in health monitoring as a significant factor driving market growth. Many of these devices can track an individual's health related data such as sleep schedule, heart rate, activity level and more. The average personal device user is likely to generate over 1 million gigabytes of data in their lives (UIC, 2019). The existence of this data alone does not guarantee its usefulness or acceptance by the medical community and users. Researchers at the PervasiveHealth 2017 Workshop outlined challenges to making use of such data including cultivating sustainable data collection and ensuring the clinical relevance of such data (Choe et al., 2018). The data are available to consumers, insurance companies, and healthcare providers, but because their interests diverge, how they view and make use of the data is complex and contested. Adoption of this data is common amongst health insurance companies; however, healthcare providers and consumers are split into groups who see immediate value in the data and those who have hesitations to generate or use it.

Review of Research

There is potential value identified in health data generated from personal devices. The data can be used to study the relationship between different health behaviors such as activity level and sleep (Hicks et al., 2019). The personalized data could assist with self-diagnosis and behavior change interventions (Piwek et al., 2016). While potential medical uses of this data are

well researched, how professionals in the medical community who would integrate said data into their practices view and currently use the data must also be investigated.

At Otani University, researchers implemented a system using wearables and personal devices to collect vital data about student's sleep, activity, and heart rate (Ueda et al., 2016). Eventually such a system could provide insight on student health and performance; however, the significance of the data generated is unclear and requires a more thorough analysis. The advantage of the data must be evident before consumers voluntarily participate in a system to collect their data using personal devices. There are advantages of using data from wearable devices to improve fitness on an individual scale. When individuals use personal devices to track their fitness progress it gives them a better sense of what their body needs and a sense of validation when their data improves. This motivates them to continue their routines (Hardey, 2019).

Insurance companies could devise plans to use this data before onboarding a customer and to decide what premium value a customer must pay (Nayak et al., 2021). A proof of concept model for scoring individual's health based on the data from wearable devices was developed in 2018. This model demonstrated some predictive qualities of measurements from wearables that could be incorporated into insurance pricing models (McCrea et al., 2018). The potential for using health data from personal devices is well documented in concept. This paper will answer how key participants view the potential for data in their own realities, beyond models and proof of concepts.

Despite so much opportunity for use of the data from personal devices, there remain challenges preventing the opportunities from being fully realized. One such challenge is knowing whether data recorded by personal devices is sufficiently accurate to produce meaningful outputs

(Knowles et al., 2018). The reliability and accuracy of popular devices in the eyes of medical professionals is important to know for the predictions to be made about such device's future in the medical industry. As the amount of data generated from personal devices increases, high computational power and large storage are required to maintain it. This usually involves a distributed system involving multiple entities which increases the risk of privacy violations (Mehmood et al., 2014). No federal statute currently protects health data generated from wearable devices.

Conflicting Views Amongst Healthcare Providers

Professional Concerns Regarding Data Accuracy and Relevancy

Some healthcare providers contend that health data from wearables and personal devices can be inaccurate and impractical. Windt et al. found that some healthcare professionals distrust data from personal devices, suspecting they may not “inherently communicate a message.” In fact, Doctor Neel Chokshi (2019) said using a patient's device generated data at the doctor's office becomes “just a data dump.” So much information is provided from personal devices the important features might be hard to find and doctors may become liable to malpractice risks (Erwin et al., 2020). Because the collected data are necessarily incomplete, they can be insufficient or even hazardous, physicians may find wearables of little practical use (Windt et al., 2020). In a survey, Kong et al. (2020) found that while most physicians perceive valuable possibilities in mobile health apps, most agree that they need more validation and better integration into medical record keeping systems. The accuracy of measurements by wearable devices is unknown to doctors, making it risky to incorporate into a legitimate practice. A Stanford Medicine study (Dushek, 2017) tested 7 different devices and none was able to

accurately measure energy expenditure within a 5 percent error. Almost 500,000 people took part in an Apple Watch study to detect cardiac arrhythmias yet the watches were only able to detect a handful of people with any sort of arrhythmias, suggesting that there were many which were not detected (Turakhia, 2020). Dr. Joseph Kvedar sees the potential in such data but believes that healthcare systems need to figure out the best use for it, stating, “If we don’t, we are leaving so much useful information about our patients on the table” (Kvedar, 2014).

Integrating data into clinical practices or health systems requires that doctors are adept at prescribing the correct devices and leveraging the data. Doctors will need training in fields not traditionally included in medicine such as data analytics. Llyod Minor, Dean of the Stanford School of Medicine, recognizes the potential of data from personal devices, but cites the need for additional training as a challenge that might “stymie progress” (Minor, 2020). A Stanford Medicine Health Trends report found that 73% of medical students want additional training in how to use digital health technologies (Wicklund, 2020). Stanford Medicine officials said, “The rise of the data driven physician represents an opportunity to positively transform medicine and improve health outcomes by bringing new technologies and insights to the patient bedside. However, as it stands today, medical professionals still feel insufficiently trained to do so.” (Wicklund, 2020).

Immediate Value to Clinical Practices

Other doctors and hospitals who value personal health data see the immediate value in integrating it into their practices and services. For example, doctors at the Mayo Clinic have used Fitbit devices to remotely track the activity level of cardiac-surgery patients following surgery (DeAngelis, 2015). A survey conducted by AT&T and the Healthcare Information and Management Systems Society found that 47% of hospitals are providing wearables to patients

and conducting remote monitoring (AT&T, 2021). Endocrinologist Dr. Florence Comite (2017) works at the Comite Center for Precision Medicine and says that to her “wearables are almost like magic” because they can continuously measure things such as heart rate and glucose levels as opposed to a one-time measurement that may not necessarily indicate a patient’s true status.

Health systems are dependent on digital databases of patient records called electronic health records (EHRs). EHRs, due to their digital nature, lend themselves well to integrations with health data generated from personal devices. The National Institute of Health identified a total of 16 health systems that are partnered with companies who are developing or have developed technology to integrate wearable health technology with EHRs (Eysenbach, 2019).

Adoption by doctors could also be trending in the upward direction. A Stanford Medicine Health Trends Report (Wicklund, 2020) surveyed medical students and residents around the country and found that almost 80% believed that data from mobile health technologies holds value in clinical care. Although it will take time before these doctors can integrate device generated health data into their real clinical practice, an indication of their genuine trust in the data is that 71% from the same survey said they use digital health data to inform decisions about their own health.

The Covid-19 pandemic placed a unique strain on medical resources and provided an opportunity for personal devices to provide remote monitoring. WHO guidelines suggest that the most important measurements to monitor for a Covid-19 patient are respiration rate, oxygen saturation, and temperature. The Mayo Clinic is working with makers of existing wearable technology to make clinical grade wearables to monitor covid-19 patients and reduce the strain on their health system (Erwin et al., 2020). Companies like Masimo corporation adapted existing wearable technology to provide a product that can monitor these critical measurements without

the patient going into the doctor's office (Masimo, 2020). Heart disease patients like Heidi Dohse (2021) say the pandemic has presented more obstacles for her to get in person appointments and instead she uses data insights from her wearable devices to inform her doctors and make healthcare decisions.

Eager Adoption by Insurance Companies

Health insurance companies have begun to integrate health data into their insurance models with little evidence of concerns similar to those of healthcare providers described above. Some insurers, such as John Hancock (Ingraham, 2018) offer incentives to beneficiaries who use devices to document health regimens. UnitedHealthcare, Aetna, Qantas Assure, and Oscar Health also have programs which offer rewards to beneficiaries who measure adequate physical activity using a personal device (Landi, 2019). UnitedHealthcare's motion program provides users with a free wearable fitness tracker and gives rewards for achieving specific activity goals (UnitedHealthcare, 2021). This could be a "win-win" situation for insurance companies and health-conscious individuals. It could also hurt individuals who do not engage in measurable and healthy behaviors. Theoretically, some insurers may eventually require such data, and even penalize those whose data indicate deficient regimens (Raber, McCarthy, & Yeh, 2019). Health insurance is viewed as a 'grudge purchase' as the industry suffers from poor customer relationships and a lack of public trust. Integrating customer generated data could increase customer engagement and improve insurer and customer relationships (Farrell 2020). Another avenue available to insurance companies to make use of such data is by purchasing the data to reveal medical conditions of their customers. Insurance companies could use these revelations in insurance underwriting (Loria, 2019).

Just like doctors, insurance companies must also be wary of using inaccurate or incomplete device data being used to determine insurance policies. Insurers could also run into ethical dilemmas when offering incentives to use health devices. For example, say an insurer gives a policyholder a device in order to track fitness activity and reduce the customer's monthly payments. If the device reveals a heart condition the company will then face an ethical dilemma of whether or not to increase the monthly payments for the customer (Farrell, 2020).

Privacy Concerns Amidst Personal Benefit for Consumers

Consumer Concerns Regarding Data Privacy

Consumers are hesitant to buy health data generating devices because of concerns over their data privacy. Concerns can be traced to the fact that health data collected from personal devices are in a “gray area” when it comes to compliance of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) (Greenstone, 2018). HIPAA is a federal law that stops patient health information from being shared or disclosed without the consent of the patient (CDC, 2018). If health data is generated for personal use, such as monitoring one's own activity level on an apple watch, HIPAA does not protect the data from being disclosed without consent from the individual (Marbury, 2020). This means that companies with access to health data generated from personal devices can legally use or sell the data as long as it was generated for personal use. Companies have incentives to use this personal health information. Dr. Deborah Peel (2019), the founder of a patient privacy advocacy group, said that “Health data is the most valuable of all.” This data can be used to personalize ads, market products based on health-based behaviors, and to make investment decisions for pharmaceutical companies on which diseases and drugs to research (Frazee, 2019).

Privacy is important to consumers. A study by Tealium found that 97% of consumers are somewhat or very concerned about protecting their personal data (Berger, 2020). When Fitbit was acquired by Google in 2019 users feared their health data would be exploited. One said “I tossed my Fitbit in the trash today” and another said “I intend to sell my Fitbit and delete my account.” (Paul, 2019). Not all consumers understand the privacy issues when using personal devices. A Healthline survey found that 1 in 4 Fitbit users and 1 in 10 apple watch users expressed concerns about their health data being stored on a device or app (Mills, 2019). Liezel Cilliers (2019) conducted a study which found that, of the wearable device users surveyed, half did not understand the need to protect health information and there “also appeared to be a general lack of awareness among respondents about the information security issues surrounding their data collected by wearable devices.”

Personal Benefit to Consumers

Individuals see health data generated from wearable and personal devices as a tool to stay healthy and reach their goals. 41% of Apple Watch buyers surveyed by Healthline said they bought their device for health or fitness reasons. 80% of Fitbit users from the same survey said their device helps them stay motivated and stick to their exercise routine (Mills, 2019).

Kaiwaiola C. uses a Fitbit to track his sleep to ensure he gets enough rest (Kaiwiola, 2017).

Device user Breigha Adeyemo, bought the Fitbit Charge 4 wearable because she “wanted to be able to track daily and exercise calorie expenditure, steps, and heart rate.” (Adeyemo, 2020)

Health related data generated from personal devices has some immediate value and the potential to be an integral part of the healthcare industry. In order for more doctors to adopt using data from these devices in their practices, manufacturers and regulators need to ensure

measurements are accurate. When developing new iterations of these devices, manufacturers should further investigate what sort of data is relevant to the medical community and design devices accordingly. As the wearable and personal device market grows, more data will be generated and will need to be protected. Consumer groups will need to push for government action to protect the privacy of individuals so that their information is not shared without consent or stolen. Health data generating devices are a fast-growing technology and for its value in the medical community to grow governments, manufacturers, doctors, and consumers must push for accuracy, relevancy, and privacy protections.

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