Accessing and Using Data from Wearable Fitness Devices

Save to myBoK

By Harry Rhodes, MBA, RHIA, CHPS, CDIP, CPHIMS, FAHIMA

A rapidly aging global population in many industrialized countries accompanied by an increase in chronic diseases and the high cost of managing such diseases has led many to turn to a technological solution to ease the burden on healthcare professionals and provide useful tools to the elderly and chronically ill. An increased emphasis on preventing hospital admissions and allowing patients to receive care in their own homes also has encouraged the healthcare industry to evaluate how remote mobile technology implementations can help.

All of these socio-economic forces, and many more, are driving the development of personal health devices that allow people to not only monitor their own conditions but communicate health information obtained through devices to healthcare professionals and other caregivers.

One rapidly growing segment of this mobile health market is wearable consumer devices. With Google Fit, Apple HealthKit, Samsung Gear, and others all rolling out wearable consumer devices, there exists a genuine state of hype surrounding the ability of empowered health consumers to track, manage, and seize control of their own health issues and goals. For HIM professionals, the question remains of how to access this new health information, and whether or not it should become part of a patient’s formal health record.

The Quick Rise of Wearables

A recent study of 6,800 iPhone and iPad health and fitness app users conducted by the mobile analytics and optimization vendor Flurry revealed that use of health and fitness apps is growing 87 percent faster than the entire mobile industry. Consumer use of mobile health and fitness apps in the first half of 2014 is almost double that of the mobile platform market in general. Activity in the health and fitness sector has shown a 62 percent increase over the past six months on the Flurry platform alone, according to an article published in *Health Data Management*.[1]

The same article says Mike Mytych, principal at Health Information Consulting, believes the real benefits of mobile/wearable applications will result from the socialization and education of healthcare consumers coping with similar medical conditions. These connected and empowered consumers, bolstered by the insight and support of online communities, will embrace the opportunity to manage their health information in the long run and ultimately benefit from access to this health data. As a result, consumers might feel more empowered. Mytych believes the healthcare industry is witnessing an evolution of the personal health record (PHR), which will allow whole families of healthcare consumers to access and control their personal health information. Access by medical researchers to the data captured by wearable consumer devices, and the resulting aggregated health data across all device owners, will have a direct impact on individual health, wellness, care planning and medication compliance, the article concludes.

Wearable Devices Could Transform Medicine

In early 2013, the Pew Foundation’s “Tracking for Health” study found that 69 percent of Americans track some form of health-related information and 21 percent of them use some form of digital device to do so.[2]

Individuals are tracking a variety of health-related data via a growing number of wearable devices and smartphone apps. More data relevant to health are also being captured passively as individuals communicate with one another through social networks while shopping, working, or any number of other activities that leave “digital footprints.”

Eric Topol, MD, chief academic officer of Scripps Health and professor of genomics at the Scripps Research Institute, recently told the *Wall Street Journal* what he predicts the healthcare landscape will look like in 20 years.[3]

"Hospitals, except for certain key functions like intensive-care units and operating rooms, will be completely transformed to data-surveillance centers. People will look back and laugh about the old physical office visit and the iconic 'stethoscope' along with the way so much of health care was rendered in the pre-digital era," Topol said.

Almost all of these forms of personal health data are outside of the mainstream of traditional healthcare, public health, or health research. Traditional sources of medical, behavioral, social, and public health research still largely dominate as sources of health data, such as those collected in clinical trials. Data is still primarily collected by sifting through electronic health records or conducting periodic surveys.

The immediate benefit of self-tracking data is that it can provide better measures of everyday behavior and lifestyle, filling the gaps in more traditional clinical data collection and presenting a more complete picture of health.

Healthcare consumers embracing the use of digital self-tracking data tend to have more education and higher household incomes than the general population, research shows. Research also reveals a population that is more inclined to be white, Asian, and female than the general population.[4]

The social trend of participating in online communities devoted to sharing health and disease experience is called "biosociality" by researchers. Biosociality also includes self-tracking data and sharing this information amongst participants.

Individuals willing to share their self-tracking data for research believe the data will advance knowledge in the fields related to personal health data such as general healthcare, public health, computer science, and social and behavioral science. However, the majority of self-tracking participants do so with the expectation that their information only be shared anonymously. Among consumers no singular privacy consensus exists. Instead researchers must contend with a wide range of privacy policies, opinions, and concerns.

SmallStepsLab serves as an intermediary between the data-rich company Fitbit and academic researchers via a "preferred status" application programming held by Fitbit. Researchers pay SmallStepsLab for this access as well as other enhancements that they might want.

These promising early examples foreshadow a much larger set of activities with the potential to transform how research is conducted in medicine, public health, and the social and behavioral sciences, according to findings from The Health Data Exploration Project—a study performed by the California Institute for Telecommunications and Information Technology and supported by the Robert Wood Johnson Foundation.[5]

Work Remains to Optimize Personal Health Data

With so many vendors competing in the personal health data space, and no real effort to establish a common set of interoperable standards, healthcare consumers will quickly come face to face with a very real interoperable barrier preventing the exchange of their health data across disparate platforms or with provider health IT systems.

There is still work to be done to enhance mobile interoperability and standards before the full knowledge potential of personal health data is realized, say researchers from the Health Data Exploration Project. As part of the project, they identified key areas that need to be addressed in order to optimize all forms of health data:

Privacy and Data Ownership

While many consumers were not concerned about the ownership of the data they generated, the vast preponderance of consumers insisted on sole ownership or at least shared ownership of the data with a mobile device company that collected it.[6] Customer surveys revealed that among individuals that agreed to make their personal health data available for research, 57 percent would only do so on the condition that their privacy would be protected. Over 90 percent of respondents indicated the importance of anonymity of the data contributor.

Informed Consent

Consider that most privacy policies are provided on the device vendor's terms and conditions contract. Colloquial wisdom indicates that the majority of consumers will click through product terms and conditions without reviewing them. The straightforward question becomes: Does informed consent exist at all? Presently, consumer excitement over the potential of personal health data has blinded the public to potential privacy risks. Meanwhile, the industry assures us that a variety of new informed consent constructs are being evaluated to ensure favorable outcomes for all stakeholders.

Data Sharing and Access

One cultural driver of personal health data research is a growing appeal, enthusiasm, and occasion to share data with an ever expanding audience of individuals interested in learning more about specific health conditions. One common trend is sharing data with others with similar medical conditions on Internet-based groups such as PatientsLikeMe or Crohnology. The immediate benefit is an increased knowledge about mutual health concerns, as well as participation in an intrinsic emotional brotherhood of shared experiences. In the online health information sharing environment, the decision to share information—and to what degree—involves the same individual cognitive mental process involved in making a decision about revealing private information in an interpersonal context.[7]

Data Quality

The lack of consensus on industry standards and information governance conformance criteria highlights some healthcare experts' concerns about the validity of personal health data. Industry leaders believe that concerns regarding standardization and information governance will be addressed as the wearable consumer health device, apps, and services market matures. Considering the rapid growth of this mobile device market segment, the industry is rapidly reaching a tipping point. The exponential growth in the number of people tracking their health, and the growing number of tracking apps and devices on the market, will soon force the issue of industry standards and information governance to be addressed.

Wearable Device Data and Information Governance

To maximize personal health data for the public good, the industry must develop creative solutions that provide individual privacy and security safeguards while ensuring access to high-quality, timely, and relevant personal health data for research. Going forward, standardization is paramount to the establishment of transparent and open public, private, and academic sector collaborations that will balance the needs and concerns of privacy, confidentiality, security, intellectual property, and science.

One additional indicator of the momentum behind the movement to produce and collect data about our personal health experiences is evident in the small but growing Quantified Self Initiative, which has brought together proponents of self tracking activities. Quantified Self is a driver in the growing relevance, eagerness, and occasion to share personal health data with others.

One common denominator in all of the current data aggregation activities is that the devices, apps, and service that capture and store them are owned by entities that are outside of the mainstream of traditional healthcare, public health, or health research. This includes everything from small start-ups to globally active consumer electronics, telecommunications, computer, and social network corporations.

Medical, behavioral, social, and public health research still largely relies on traditional sources of health data, such as those collected in clinical trials funded by the pharmaceutical industry or the National Institutes of Health, sifting through electronic health records, or conducting periodic surveys of representative samples of individuals to make inferences about broader behavioral, social, or public health trends. But almost by definition these traditional methods of health research can't capture the multidimensional and continuous nature of the behavioral, social, and environmental influences that are increasingly recognized as critical to human health.

Proponents of consumer health devices have come to realize that incompatible systems are a barrier to their widespread use and acceptance. With the slow roll-out of useful personal health devices, proponents have begun to embrace interoperability and functionality standardization.

AHIMA has said it is committed to the growth of the personal mobile health market through standardization and development of information governance principles. AHIMA has been working on initiatives at Health Level Seven and the International

Organization for Standardization (ISO). In addition AHIMA supports the work underway at the IEEE Standards Association, and the IEEE-EMBS affiliated 11073 Personal Health Data Working Group, which is formulating standards for data formats and communications to ensure device interoperability.

Notes

1. Goedert, Joseph. "Can Google Succeed with Health Apps?" *Health Data Management.* July 2014. http://www.healthdatamanagement.com/news/Can-Google-Succeed-with-Health-Apps-48247-1.html.
2. Duggan, Maeve and Susannah Fox. "Tracking For Health." Pew Research Internet Project. November 26, 2013. http://www.pewinternet.org/2013/11/26/part-three-tracking-for-health/.
3. *Wall Street Journal*. "Eric Topol on the Future of Medicine." July 7, 2014. http://online.wsj.com/articles/eric-topol-on-the-future-of-medicine-1404765024.
4. Duggan, Maeve and Susannah Fox. "Tracking for Health."
5. California Institute for Telecommunications and Information Technology. "The Health Data Exploration Project (2014) Personal Data for the Public Good." http://hdexplore.calit2.net/wp-content/uploads/2015/08/hdx_final_report_small.pdf.
6. Xu, Heng et al. "Information Privacy Concerns: Linking Individual Perceptions With Institutional Privacy Assurances." *Journal of the Association for Information Systems* 12, no. 12 (December 2011): 798-824.
7. Ibid.

References

Rabinow, Paul. "Artificiality and Enlightenment: From Sociobiology to Biosociality." *The Science Studies* Reader New York: Routledge, 1999, p. 407.

Clarke, Malcolm et. al. "Developing a Standard for Personal Health Devices based on 11073." *29th Annual International Conference of the IEEE* (2007): 6175–6177.

Glass, Thomas A. and Matthew J. McAtee. "Behavioral Science at the Crossroads in Public Health: Extending Horizons, Envisioning the Future." *Social Science & Medicine* 62 (2006): 1650–1671.

Harry Rhodes (harry.rhodes@ahima.org) is a director of HIM practice excellence at AHIMA.

Article citation:
Rhodes, Harry B.. "Accessing and Using Data from Wearable Fitness Devices" *Journal of AHIMA* 85, no.9 (September 2014): 48-50.

Driving the Power of Knowledge