

Pooling data from wearables could boost health benefits

By Dov Greenbaum and Mark Gerstein | February 24, 2017

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Photo: Michael Short, Special To The Chronicle

Store manager Hanalei Van Meter looks at her RunIQ watch as she runs on a treadmill during a launch event for the RunIQ wearable fitness watch at the New Balance store in San Francisco, CA on Tuesday, February 2, 2017.



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biomechanical and physiological data) can be used to predict an acute medical event such as a heart attack or the eventual onset of a chronic disease, such as diabetes.

This should be promising news. Patients from all socioeconomic backgrounds have access to this relatively cheap and available technology.

Additionally, the \$215 million federal **Precision Medicine Initiative**, which aims to collect genetic information associated with a health condition or disease, necessitates the correlation of that information with physiological data — optimally collected by step-counting fitness trackers and related devices.

In a similar vein, **Michael Snyder**, professor of genetics at Stanford University, used off-the-shelf wearables to diagnose his Lyme disease infection, and combined his genetic information with physiological data to predict and eventually follow the development of his own Type 2 diabetes, a diagnosis that might have been missed given his lack of risk factors or family history.

But it is not as good as it sounds.

Consumer wearables are notoriously inaccurate, often employing complicated algorithms to convert less-than-ideal proxy measurements to obtain final readings. Moreover, the wearables themselves typically rely on smartphones to collect and communicate the recorded data to third parties — often large corporations and sometimes health care providers. In some instances, the smartphones themselves double as wearables, using often non-standardized and non-calibrated onboard sensors to track and transmit data. This could result in unreliable data collection.

It is still possible to obtain useful health information though through some form of collective action. We suggest the creation of one or more data clearinghouses, rather than relying on governments or manufacturers to fix these problems of privacy, interoperability, standardization and accuracy. Apple's ResearchKit and HealthKit, a digital framework on which health apps are



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from consumer wearables.

These institutions would provide voluntary conduits for legitimate health-related data. They could enforce standardization, encryption and interoperability by refusing to accept and/or convey data that did not conform to agreed-upon or imposed standards. The system could also require that data-collection devices — either the smartphone or the wearables themselves — be calibrated and validated routinely. Market forces would encourage these voluntary conduits to become the default standard for wearable data.

Collecting scientifically usable data via these clearinghouses would address these concerns:

- Lack of standardization:** Raw data is rarely passed on via a wearable; rather wearables obtain values based on particular algorithms and subsequently provide processed data to third parties. Like the 1999 loss of the Mars Climate Orbiter, using different metrics to measure similar phenomena can lead to confusion and inability to interoperate with other data from different devices.
- Lack of regulation:** Wearables are a specific subset of medical and health-related devices within the larger group of technologies that make up the Internet of Things. For the most part, like the Internet of Things, these medical and health-related devices are unregulated.
- Lack of control over the data use:** With data still likely useful in the aggregate, companies may package and sell your data as likely stipulated to in hastily agreed to end-user agreements. The proposed clearinghouses would allow users to track where their data was sold.

Although there are numerous government agencies that could potentially regulate these devices, including the Federal Trade Commission, the Federal Communications Commission and the Food and Drug Administration, the nature of these devices make them harder to regulate.

Establishing a data clearinghouse would make the data usable, and it could provide much-needed transparency in the collection and distribution of consumer health data. Consumers whose data are uploaded to one of these agencies would be able to track and perhaps even control where the data are sold.



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