

# Linking Personal Health Data to Genomic Research

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**I**N RECENT YEARS, RESEARCHERS HAVE been seeking new channels to gather health information from participants in order to aid in correlating phenotypic information with genetic markers and environmental data. The rise in use of self-tracking health devices by the public has opened up a new avenue for these correlations. The vast amount of personal health data collected by these devices can be immensely insightful, providing a means to quantify aspects of health and the environment like never before. Researchers can analyze heart rate and sleep pattern data, for example, and correlate them with specific genetic indicators.

However, researchers and ethicists alike have cited concerns about the use of personal health data in biomedical and behavioral research. Problems with data quality, privacy, and security; lack of interoperability; and an abundance of intellectual property issues have made it difficult for self-trackers to share their personal health data effectively. New tools are needed to make the process safer and more efficient. The use of these tools for personal health data sharing will accelerate the adoption of these data for genomic research use.

Healthcare professionals have only recently acknowledged self-tracking health devices as a viable avenue to collect data useful for research and development of treatments. Personal health data can be used to fill the gaps in more traditional clinical data collection, providing researchers with a more comprehensive health picture. A survey conducted by the Robert Wood Johnson Foundation and the Health Data Exploration Project demonstrated that individuals, researchers, and corporations all see the research potential of personal health data (Health Data Exploration Project 2014). Almost all respondents were enthusiastic about the prospect of using this information for research. Respondents from the research community suggested that they would consider personal health data to be of equal quality and importance with data collected from more traditional avenues. Despite the enthusiasm, however, all groups expressed concerns regarding the sharing of such information. Individuals have varying degrees of tolerance for how much personal data they are willing to share. Additionally, researchers and corporations have questioned the safety of practices for sharing personal health data and have expressed concern for conflicts over data ownership.

Many companies have created data platforms and portals to organize, gather, and analyze data collected from their re-

spective devices. Prominent devices, such as the Fitbit Tracker (<http://www.fitbit.com>), Jawbone UP (<https://jawbone.com/up>), and BodyMedia FIT ([http://www.bodymedia.com/the\\_interface.html?whence](http://www.bodymedia.com/the_interface.html?whence)), all have fully developed online platforms that individuals can access for personal use. The common feature that these platforms share is a strong focus on participant engagement. Although different in their approaches, these platforms all aim to keep participants involved in the process of improving their own health. For example, Nike + Fuel Lab, the UP Platform, and the BodyMedia FIT interface have game-oriented and social media features that encourage participants to compete with others to reach certain health objectives. Additionally, several of these interfaces allow participants to enter food logs in addition to health information and provide weight loss and/or activity guidelines to ensure that participants are fully aware of their health progress. Another example is one of the recently funded Patient-Centered Clinical Research Network (PCORnet), Health eHeart (<http://www.health-eheartstudy.org/technology>), which tracks heart health through measuring electrocardiograms using a monitor in one's smartphone. Apple itself has entered the fray with its HealthKit app, which purports to be a data store in one pocket, aggregating information from other apps.

Recent innovations online have resulted in tools capable of facilitating the safe transfer of personal health data for research purposes. The Platform for Engaging Everyone Responsibly (PEER), developed by Genetic Alliance, in conjunction with Private Access, serves as a prime example (Terry *et al.*, 2013). PEER is an online portal that uses a browser-based technology (mobile interface planned for 2015) to enable participants and caregivers to share health information. Currently, the system collects self-reported clinical data and laboratory-reported data but will expand to gather electronic health record data provided by the participants. The data collected can then be shared with researchers studying a variety of health and medical issues. This makes the data interoperable via a participant-created directive. PEER underlies the Community Engaged Network for All, another of the 29 funded PCORnet partners.

What sets PEER apart from other platforms is its participant-centric approach to health information sharing, making it an ideal gateway for sharing personal health data collected from self-tracking devices. PEER's PrivacyLayer feature offers participants the tools to decide their own sharing, privacy,

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and data access preferences. This honors individuals' contextual opinions on data privacy.

Some self-tracking device innovators have also anticipated the use of personal health data for research purposes and have made steps to address data ownership concerns. Zenobase (<https://zenobase.com>), a health data sharing platform that provides resources for pilot studies, has outlined in its consent documents that shared data remain under the ownership of the individual. Fitbit and TicTrac (<https://www.tictrac.com/>) require special permission from individuals to authorize the use of their data in research. However, these data platforms have to address lingering concerns. First, privacy settings as well as security features remain largely lackluster, raising the question of whether these platforms are safe enough to participate in the data transfer process. Second, the options for sharing are always on/off, rather than allowing for dynamic and contextual sharing. PEER allows an "Ask Me" setting, essentially introducing a "maybe" that gives individuals more control. Third, companies use different techniques and strategies to encode and analyze data. For the data collected to be useful to researchers, they must be interoperable and hence standardized. Solutions to these problems will emerge as consumers demand that these platforms become participant-centric.

The contributions personal health data collected from self-tracking health devices can make to biomedical and behav-

ioral research cannot be understated. Researchers can make good use of the participant-centric insights; therefore, the health self-tracking industry must significantly improve the process of sharing these data with researchers. Successful data sharing portals, such as PEER, have shown that this goal is well within reach.

## References

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