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Health Data Exploration Network to Spur Research Using Personal Health Data

The Health Data Exploration project, from the University of California, San Diego (UC San Diego) and the University of California, Irvine (UCI), has been awarded a $1.9 million grant from the Robert Wood Johnson Foundation (RWJF), to create a network of researchers, scientists, companies and others to catalyze the use of personal health data for the public good. The Network will be spotlighted today in a presentation at Health Datapalooza by Matthew Bietz, PhD, lead co-investigator for the Health Data Exploration project.

The Health Data Exploration project's recent report Personal Data for the Public Good, found that many people who track health-related data are interested in sharing that data with researchers in medical and public health — provided adequate privacy controls exist.

The Network will bring together companies that collect and store personal health data, captured through the use of wearable devices, smartphone apps and social media, with researchers who mine these data for patterns and trends and other strategic partners. Through a set of research projects using personal health data, the Network will identify policies and best practices for using these new forms of data to produce transformative knowledge about health.

"Our preliminary explorations in this area demonstrated an extraordinary set of complementary experience, skills and assets among these groups," said Kevin Patrick, MD, MS director of the Health Data Exploration project and a professor of Family and Preventive Medicine in the UC San Diego School of Medicine. "The Network will bring together these partners to strategize, coordinate and experiment with using personal data to understand health."

Unlike traditional research data, personal health data is often spread across many different companies and repositories, making it difficult for researchers to identify, locate and access. Furthermore, few consumer-level devices have been validated for research-level data collection. As the Network explores ways to address these challenges through its research studies, it will update existing policies and procedures for managing risks and privacy as well as techniques for analyzing and interpreting this “big data.”

“We have high hopes that personal health data will provide a unique window onto the many factors that influence health on a daily basis” said Alonzo Plough, PhD, MPH, vice president for Research-Evaluation-Learning and chief science officer at RWJF. “By addressing the barriers to using these new forms of data in research, we expect that the work of the Network will help put us on a path to a better understanding of health and how we can build a national culture of health.”

The Network is seeking researchers and companies to participate in the Network. Click here for more information.

Commenting on the huge potential of personal health data for research, advisory board member for the Health Data Exploration project, Linda Avey, co-founder of 23andMe and personal data aggregator Curious, Inc., said “New sources of personal health data have the potential to transform our understanding of individual and population health. To this end, people are expressing interest in tracking and exploring their personal data in order to answer their own health questions and then share with others, including physicians and researchers. With the advent of wearable technologies, access to growing sources of bio-data and environmental feeds, it won’t be long before the notion of ‘big’ personal data is a reality.”

In commending the Network as a way to catalyze the use of personal data for the public good, Deborah Estrin, a professor of Computer Science at Cornell Tech and a professor of Public Health at Weill Cornell Medical College, said that “the ‘digital footprints’ people are leaving behind with wearable devices, shopping behaviors and a host of other data streams provide a novel perspective on human health and well-being. Personal health data can reveal the ways that everyday activities promote health or lead to disease and yield insights about the long-term, cumulative health effects of environment and lifestyle. When multiple data streams converge, personal health data can provide a more holistic view of the richness of human lives.”

The Health Data Exploration project is affiliated with the California Institute of Telecommunications and Information Technology (Calit2), which is based at both UC San Diego and UC Irvine. Dr. Patrick and Dr. Bietz are researchers at Calit2 at UC San Diego and the UC Irvine Department of Informatics respectively.

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