

Online social network members donate personal data for public health research

April 27 2011

Using a combination of Facebook-like tools and personally controlled health records, researchers at Children's Hospital Boston have engaged members of an online diabetes social network as participants in public health surveillance. In an article published April 27 in *PLoS ONE*, Elissa Weitzman, ScD, MSc, and Kenneth Mandl, MD, MPH, of the Children's Hospital Informatics Program (CHIP) show that health-focused social networks can be viable resources for chronic disease surveillance.

"There is growing recognition that online communities not only provide a place for members to support each other, but also contain knowledge that can be mined for public health research, surveillance, and other health-related activities," said Mandl, director of the Intelligent Health Laboratory at CHIP and co-principal investigator of the project along with Weitzman.

Members of TuDiabetes.org were invited to participate in a "data donation drive" and share data about their [hemoglobin A1c](#) (or A1c) status, a health metric used to measure [diabetes control](#) over a prolonged period of time.

Through an application called TuAnalyze, based on CHIP's Indivo personally controlled health record, TuDiabetes members were able to share their health data anonymously or publicly. All of the submitted data was aggregated and displayed on state- or country-level maps in near real-time.

"We were hoping to gauge the community's willingness to share their personal data for public health surveillance," said Mandl, an associate professor at Harvard Medical School,"and give them a tool that allowed them to securely share their data, all the while supporting socially-based encouragement and a sense of community activism."

Within three months, 17 percent of total active TuDiabetes members and 21 percent of active users in the United States had signed on to TuAnalyze. Among all TuAnalyze users, 81.4 percent chose to share their A1c data in aggregate, while 34.1 percent also chose to display their personal A1c data on their TuDiabetes profile. The average unadjusted A1c reported by TuAnalyze users in the United States was comparable to that reported in the most recent National Health and Nutrition Examination Survey (NHANES) by the Centers for Disease Control and Prevention (CDC).

Early adopters (i.e., those who signed on to TuAnalyze within the first two weeks of launch) reported lower average A1c values than those signing onto the application later, as did members who shared their A1c data openly on their TuDiabetes profiles versus those who only shared their data in aggregate, and members who shared multiple A1c values versus those who only shared one.

"TuAnalyze has allowed the members of TuDiabetes that have used it to share their diabetes data and connect as a community around it," said Manny Hernandez, founder of TuDiabetes and president of the Diabetes Hands Foundation, the nonprofit that runs the site. "This application has given us an initial glimpse of the kinds of things we can learn as a community, and caused us to focus our time and resources on matters that are pressing and relevant to our members."

Mandl commented that, "Our experience with this project tests certain fundamental assumptions about how we can conduct science across

populations, including people's willingness to share data for [public health](#) research for their community, as opposed to for themselves, and what we need to do to encourage that. In this instance, we have demonstrated a tool that respects member confidentiality preferences while securely allowing aggregation of data to benefit the community at large."

"While they produce high-quality data, large, structured population-based reporting systems are not nimble, and provide no opportunity for interaction or feedback," added Weitzman, an assistant professor at Harvard Medical School. "Science is changing and there is emerging an expectation and desire among participants for a continued research relationship and an opportunity to learn more about their own disease, for which online networks provide a platform."

Weitzman noted, "If we are serious about understanding and ameliorating disease, we need to find a way to engage entire populations in health research cost-efficiently, to understand the experience and patterns of illness and the ways in which patient populations are undertaking and responding to treatments."

Going forward the CHIP team is collecting more complex data on quality of care and adverse events within the population using TuAnalyze and exploring how to engage the community in a more permanent and longitudinal way.

TuAnalyze was developed with support from the U.S. Centers for Disease Control and Prevention.

Provided by Children's Hospital Boston

Citation: Online social network members donate personal data for public health research (2011, April 27) retrieved 27 April 2024 from <https://medicalxpress.com/news/2011-04-online-social->

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