

Social networking approach to public health research raises hypoglycemia awareness

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Hypoglycemia may be a much larger problem among patients with diabetes than is currently realized, according to a study of members of a diabetes-focused social network conducted by researchers in Boston Children's Hospital's Informatics Program (CHIP). The study shows how engaging patients in research through social networking may help augment traditional surveillance methods for public health research, while simultaneously offering opportunities to promote healthy behaviors among participants.

The study team, led by Elissa Weitzman, ScD, MSc, and Kenneth Mandl, MD, MPH, of the Intelligent Health Laboratory (IHL) in CHIP, published their findings online on Feb. 11 in the journal *JAMA Internal Medicine*.

Hypoglycemia is a serious side effect of diabetes treatment where a patient's [blood sugar level](#) goes too low. Hypoglycemic episodes can be unpredictable and can lead to unconsciousness, accidents and injuries. Worries about hypoglycemia can also severely impact patients' work, activities and quality of life.

However, the true extent of hypoglycemia and its effects among people with diabetes is not well understood, as the only surveillance numbers for hypoglycemia come from [emergency room visits](#) and clinical trial reports.

"We don't know much about how populations with diabetes in general

experience insulin effects and complications like hypoglycemia," said Weitzman, a social-behavioral scientist at Boston Children's and the study's director. "Insulin is widely used, but we don't have a grasp of how many patients experience hypoglycemic episodes that are not severe enough to merit [emergency treatment](#). Learning more about hypoglycemia requires engaging a broad pool of patients as collaborators in health research—a model enabled by social media."

Recognizing the limitations of traditional surveillance methods and systems for collecting population-level data on [diabetes complications](#), Weitzman and Mandl turned to a cohort of people with diabetes recruited through the online social network TuDiabetes.org. The researchers had previously worked with TuDiabetes to develop and launch a [social networking](#) app called TuAnalyze and engage TuDiabetes members in real time, participatory surveillance of hemoglobin A1c levels (a health metric used to measure diabetes control over a prolonged period of time), feeding back data to participants using maps and graphs. TuAnalyze is based on CHIP's Indivo personally controlled health record platform and implements controls that let users preserve the privacy of their personal health information.

This time, the pair called on TuDiabetes members to use TuAnalyze to share information about the frequency with which they experience episodes of hypoglycemia. They also asked members reporting recent or severe [hypoglycemic episodes](#) for details about their lifetime experiences of significant impacts or harms (e.g., vehicle crashes, withdrawal from daily activities in order to avoid hypoglycemia) caused by hypoglycemia.

In a break from typical surveillance and reporting methods, data from the cohort were aggregated and posted back to the participants as they were analyzed via a research blog within TuAnalyze, a participatory approach that Mandl and Weitzman have long advocated. "This new

approach, which we call participatory surveillance, establishes a bidirectional communications link between [public health](#) and consumers," explained Mandl, who directs the IHL. "It lets us tap the community for crowd-sourced information, but also feed results back and implement behavior change strategies."

Of the 613 TuAnalyze users who offered up data for the study (representing about a quarter of all TuAnalyze users), nearly half reported more than four episodes of "going low" in the previous two weeks and about 30 percent reported at least one severe hypoglycemic episode—one resulting in unconsciousness or seizure, or one which required glucagon, medical treatment and/or help from another person—within the last year. More than half of the respondents reported experiencing more than one impact or harm related to [hypoglycemia](#), including avoiding exercise, daily debilitating worry and accidents or injuries.

Measures of engagement on the part of the cohort showed that the participants both exhibited great interest in the study's findings and acted quickly on them.

"People in the community picked up on the data and started talking about how to better manage their diabetes day to day," Weitzman said. "Seeing that conversation, we could make midstream corrections in how we presented the data to the community so as to increase the health impact and keep them more aware of what was going on."

"With this participatory approach, we're taking a platform developed for a research purpose and turning it into a way to help promote and manage care," she continued. "People are talking about how the results and the discussion online around them make them think about their health behaviors and care. The burden is now on us as researchers and public health practitioners to devise strategies to encourage these conversations

and build tools that are impactful and effective for promoting better health outcomes."

Mandl added, "We see the participatory surveillance approach as a new model for public health reporting across conditions and health issues."

Provided by Children's Hospital Boston

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