

# Quality varies in social networking websites for diabetics

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Nearly one-half of U.S. adults who use the Internet participate in social networks. While these increasingly include health-focused networks, not much is known about their quality and safety. In one of the first formal studies of social networking websites targeting patients, researchers in the Children's Hospital Boston Informatics Program performed an in-depth evaluation of ten diabetes websites.

Their audit found large variations in quality and safety across sites, with room for improvement across the board. As reported online January 24 in the *Journal of the American Medical Informatics Association*, only 50 percent of the sites presented content consistent with diabetes science and clinical practice. Even fewer offered both scientific accuracy and patient protections such as safeguarding of personal health information, effective internal and external review processes and appropriate advertising.

For instance, seven of the ten sites did not allow members to restrict the visibility of their profiles. Five carried advertisements that were not labeled as such. And three sites went as far as to advertise unfounded "cures."

"We saw that people are sharing incredible amounts of [personal health](#) information on these sites, including highly identifiable information," says Elissa Weitzman, ScD, MSc, lead author on the study and an assistant professor in the laboratory of Kenneth Mandl, MD, MPH. "They are eager to accelerate their understanding of the disease, obtain

support, find treatments and see if their experience is common or different."

"There is on the one hand an enormous focus in the U.S. on health information privacy," Mandl adds. "But privacy in a social network is somewhat of an oxymoron. On the whole, these networks tend to be about exposing your information online."

The team evaluated diabetes websites that appeared prominently in Google searches and allowed members to create personal profiles and interact with each other. They looked at four key factors:

1. agreement of content with diabetes science and clinical practice standards,
2. practices for auditing content and supporting transparency,
3. accessibility and readability of privacy policies, and
4. the degree of control members had over the sharing of personal data.

The average number of members per website was 6,707. Activity ranged widely among the sites, from over 100 new posts per day to less than 5 new posts per day.

The majority of sites studied did not include a "disclaimer" encouraging patients to discuss their care regimen with a healthcare provider. Many sites also missed opportunities to communicate essential diabetes information, such as the definition of "A1c"—a biomarker commonly used by diabetics to access blood glucose levels.

In addition to recommending improvements in these areas, the authors saw a need for increased moderation, for the credentials of moderators to be more visible and for periodic external review. Further, potential conflicts of interest—such as ties to the pharmaceutical industry—needed to be more clearly disclosed, and privacy policies easier to understand.

Diabetes is only one illness in the rapidly growing list for which there are online social networks with thousands of users. The researchers chose to study diabetes-related networks because they were among the earliest to emerge and remain among the most active. They and colleagues in the Children's Hospital Informatics Program are further studying how these sites are used—how people choose to interact with them and how specifically they share their medical information. Last year, Mandl and Weitzman developed an application for the [social networking](#) website TuDiabetes that allows users to submit their A1c levels to be displayed in a worldwide map, as part of an effort to encourage [diabetes](#) management and inform public health efforts and research.

The two believe that the emergence of online health communities and their large number of participants reveal unmet needs for information and support of patients and families. "Social networking activity is clearly replacing or adding value that is missing in the standard healthcare system," Mandl says.

"We sought to jump start a conversation about how to balance patients' safety with their autonomy," Weitzman says, "as we're in an era where terrific levels of healthcare communication are happening outside of the usual channels."

## **Safety Tips for Patients Using Online Social Networks**

- Look for sites where the basic description of the disease and how to care for it is consistent with information provided by your doctor. Be very cautious of sites that advertise miracle "cures."
- Find the privacy policy of any website where you register as a member, and make sure that you understand it.
- Try to use sites where you have maximal control over the sharing of your health data—where you can designate whether the information you disclose will be available to anyone online, members only or members who are "friends."
- Look for websites that clearly label advertisements and disclose conflicts of interest.
- Try to use sites that have moderators and at least periodically undergo external review.
- Always remember that going online is not a replacement for visiting your doctor.

Provided by Children's Hospital Boston

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