

Social Networking Sites - They're Not Just for Revolutions Anymore

by [Harley Geiger](#) [1]

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Social networking sites are growing in importance as tools for individuals seeking health care information and support. Last week, the California Healthcare Foundation (CHCF) and the Pew Research Center jointly issued an interesting [study](#) [2] describing how individuals use health-related social networking sites - and when they prefer to tap the expertise of health care professionals. While the study indicates that social networking over the Internet can be a beneficial component of a treatment and support regimen, other studies signal a related need for organizations using or providing social networking tools to maintain consistent privacy and safety standards.

An [earlier study](#) [3] from CHCF/Pew showed that 80% of Internet users search for health information online, but this most recent study shows that at least one in five Internet users turn to the Internet specifically to find others with similar conditions or situations. This activity is pronounced among Internet users with chronic health conditions, with almost a quarter of that population looking online for others who share their health issues. Nearly a quarter of Internet users who have experienced a recent medical emergency - whether their own or that of someone else - also go online to find people in similar situations. These numbers are reduced for Spanish-speaking populations and users older than 65.

There continues to be [some concern](#) [4] that patients use the Internet to diagnose or medicate themselves without professional input. Still, the CHCF/Pew study indicates that most people are supplementing - not replacing - professional services with the information they gather through the Internet and social networking sites. According to the CHCF/Pew study, participants in a surveyed online patient group overwhelmingly look to doctors and nurses for accurate medical diagnoses (91%), information about prescription drugs (85%), information about alternative therapies (63%), and recommendations for doctors or medical facilities (62%). Despite its power to connect people, the Internet is no substitute for the key role professional providers play for individuals in their care.

Instead, the study participants found online services shored up other important areas of their health care management. A majority of the surveyed participants found their connections with similar patients, as well as friends and family, more useful than professional providers for emotional support (59%) and quick remedies for everyday health issues (51%). [Studies](#) [5] show that emotional support and the size of an individual's overall social network can be critical for recovery from some conditions, so the benefits to proper use of health-related social networking sites can be significant. Unfortunately, hospitals are [reportedly](#) [6] not yet using social media to effectively engage their patients, although many patients clearly have an appetite for health-related social networking and are taking advantage of available services themselves.

Consistent Privacy, Transparency Standards Missing

As more patients use online social networking services for information and support, the privacy and safety features of those services may draw closer scrutiny. A [recent study](#) [7] from the Children's Hospital Boston Informatics Program points to inconsistencies in the quality of information and privacy protection among ten social networking sites related to diabetes. The study found that only three of the ten sites had readable privacy policies, seven did not allow users to limit the visibility of their site profiles, and five featured advertisements from unknown sources. The study found almost no effort among the sites to ensure secure transmission and storage of data. Disturbingly, misinformation about cures for diabetes appeared on four of the ten sites.

The lead author of the study of diabetes social networking sites [predicted](#) [8] that users will ultimately demand higher standards with regard to privacy, data security and transparency. The FDA [announced](#) [9] it would release guidance encouraging greater transparency in pharmaceutical

advertising on social media, but the rules are unclear for now. While voluntary guidelines on transparent advertising and user demand for greater privacy would be useful, such actions provide limited protection without enforcement – which is notoriously difficult in the ever-changing landscape of online social media.

The issue of user privacy, data security and transparency on health-related social networking sites is another symptom of the growing overlap between health and consumer privacy. Digitized health information – generated by both patients and providers – is increasingly being used by entities outside the jurisdiction of HIPAA, the nation’s foremost health privacy law. (“Personal health records” are another example of this – see our [policy post](#) [10] on the subject.) A major regulatory challenge for the future will be to establish a comprehensive framework of privacy and security rules that provides strong protection to individuals’ health information regardless of what economic sector is using the information. While the privacy requirements for health care entities need not be precisely the same as the requirements for purely commercial entities, protection should be seamless as patient data drifts between the two.

- [Transparency](#)
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- [3] <http://www.pewinternet.org/Reports/2011/HealthTopics.aspx>
- [4] <http://www.ctv.ca/CTVNews/Health/20110301/google-internet-diagnosis-110301/>
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