

Study reveals teenage patients attitude towards social media and privacy

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A study of how chronically ill teenagers manage their privacy found that teen patients spend a great deal of time online and guard their privacy very consciously. "Not all my friends need to know": a qualitative study of teenage patients, privacy and social media, was published this summer in the *Journal of the American Medical Informatics Association* and co-authored by Norwegian and Canadian researchers.

The study, which conducted interviews with patients aged 12 to 18 at the Children's Hospital of Eastern Ontario (CHEO), is the first to focus on how teenage patients view [privacy](#) issues in their online life while in hospital.

Many healthcare institutions and professions have guidelines about email communication with patients, but the authors note that teenage patients use other messaging systems, not email.

For that reason, and because "social network-based communications between (teenage) patients and between patients and [health care providers](#) will likely increase, there's a need for guidelines on such communication," according to Dr. Khaled El Emam, the Canada Research Chair in [Electronic Health](#) Information at the University of Ottawa and the Children's Hospital of Eastern Ontario Research Institute. The study results also imply the need to strengthen "age appropriate" privacy education, useable and transparent [privacy settings](#), and recognition of teenage patients' social and psychological privacy needs.

Hospital staff should be aware of the risk of "outing" patients by encouraging them to "like", link or comment on hospital and disease-specific sites.

"I just think that if people want to know [about my health], they should ask me. They should not just read it [on Facebook]."—female, 17 years old.

Social media plays a central role in the lives of all 20 patients in the study, with Facebook ranked the most popular. The group of patients ([girls and boys](#)) in the study had Facebook accounts, used its private messaging function instead of email, and had registered with their real name and date of birth. All but two of the patients had changed their Facebook privacy settings to friends-only, with the other two allowing friends of friends.

The study found that most did not reveal any personal health information on Facebook because the site is a place to be a "regular", rather than a sick teenager.

"Facebook users often let each other know where they are or what they are doing. However, most teenage patients do not write status updates on Facebook when they are at CHEO or return to CHEO," continued El Emam.

Half of the patients interviewed said that they are online "all the time" when not with visitors or hospital staff, while all the interviewees said they spend more time online—searching the internet and using Facebook, Youtube, Twitter and Skype— in hospital than at home.

Social and psychological privacy were very important to the teenage patients, but informational privacy—the collection of personal information by governments and companies—was not among their

concerns.

All patients felt they are in control of their privacy on Facebook, including the two who regularly share personal [health information](#). Only one patient "questioned Facebook's access and use of personal information for targeted personalized advertisements."

Provided by Children's Hospital of Eastern Ontario Research Institute

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