

---

# Negotiating consent in the Facebook era: Insights from research on online health communities with youth

## **Jackie Bender MSc**

Dalla Lana School of Public Health  
University of Toronto  
Centre for Global eHealth Innovation  
190 Elizabeth Street, 4<sup>th</sup> Floor  
Toronto, ON CANADA M5G 2C4  
jackie.bender@utoronto.ca

## **Cameron Norman PhD**

Dalla Lana School of Public Health  
University of Toronto  
Health Sciences Building  
155 College Street, Room 586  
Toronto, ON CANADA M5T 3M7  
cameron.norman@utoronto.ca

## **Alejandro R. Jadad MD DPhil FRCPC**

Dalla Lana School of Public Health  
University of Toronto  
Centre for Global eHealth Innovation  
University Health Network  
190 Elizabeth Street, 4<sup>th</sup> Floor  
Toronto, ON CANADA M5G 2C4  
ajadad@ehealthinnovation.org

---

Copyright is held by the author/owner(s).  
CSCW, February 6-10, 2010, Savannah, GA, USA  
ACM 978-1-60558-246-7/09/04.

## **Abstract**

An increasing majority of health consumers, particularly those living with a chronic condition are looking for tailored, user-generated health information in disease specific websites, blogs and online communities. While research on the role of online health resources has flourished, there are few widely practiced conventions for the ethical conduct of Internet-based research in these dynamic social network environments. This paper aims to highlight some of the unique ethical challenges associated with negotiating consent to conduct research on social network sites involving youth and young adults. These insights, presented from a Canadian public health perspective are based on an investigation of the use and function of groups on Facebook related to breast cancer and on youth's experience using social networks for general health decision making, including additions, supported by a review of relevant health literature.

## **Keywords**

Internet, research ethics, social network sites, online health communities, adolescents

## **ACM Classification Keywords**

H5.m. Information interfaces and presentation (e.g., HCI): Miscellaneous. K.4.1 Public Policy Issues, K.7.4 The Computing Profession.

### **Case Study 1**

Characterization of the use and function of breast cancer groups on Facebook. Analysis was restricted to 'public' groups. Information was extracted on the name, purpose and administrator of the group as well as user-generated content. A coding scheme was developed to characterize the purpose of each group. The findings revealed that the majority of breast cancer groups on Facebook were used for fundraising and awareness, rather than supportive care. Many who did use the groups for supportive care were adolescents and young adults.

### **Case Study 2**

An examination of youth's perceptions of the risks and benefits associated with using social networks for information on cigarette use and other addictive behaviours. Ten focus groups were conducted to explore how young people used networked information technology tools to find, make sense of and apply information gleaned from social networks to health decision-making. Data was coded and analyzed for dominant themes, and indicated that youth use a variety of sophisticated strategies to assess quality and determine trustworthiness of sources- human and otherwise.

## **Introduction**

Several investigators have published articles outlining the unique ethical challenges involved in research on online health communities [1-7]. These articles highlight the difficulties in obtaining consent from users of online communities, protecting their privacy and anonymity, and ensuring confidentiality of the information collected. Although there is some guidance on how the Canadian Tri-Council ethics statement can be interpreted in Internet contexts, the dynamic and rapidly evolving nature of social network sites has made it difficult for researchers considering different options to engage young people in online research environments in an ethical manner. Social network sites introduce new ethical challenges related to their relative lack of anonymity compared to other online communities, as well as their typically younger user base, which often involves minors.

## **Public Versus Private**

The right to free and informed consent is a central tenet of ethical practice involving research with human subjects established by the Declaration of Helsinki [8] and reflected in the Tri-Council Policy Statement governing research conducted in Canada [9]. One exception to this principle is observational research of human behavior that occurs in a public domain, "since it can be expected that participants are aware of the public nature of the event or gathering" [9]. This exception also applies to Web-based research that "uses exclusively publicly available information for which there is no presumption of privacy" [9]. In these circumstances, ethical review is not deemed necessary and informed consent can be waived. However, as Eysenbach and Till [3] have pointed out, users of online

communities do not expect to be research subjects and are not necessarily seeking public visibility.

Are users of 'public' groups on Facebook aware of the public nature of their groups? Research from the focus groups with youth suggests that they do, however the full implications of information sharing in social networks may not be grasped. Enhanced use of privacy settings by Facebook users suggests that many have at least become aware of the public nature of their personal profiles. In the Facebook case study, all but one of the support group creators had restricted their profiles to the members of their networks. These findings are in contrast to previous research conducted in 2005 which found that only 0.06% of college students restricted the visibility of their Facebook profiles to members within their networks [10].

According to the Canadian Tri-Council Policy Statement, "web-based research where personal identifiable information is being collected or where individuals have a presumption of privacy" [9] falls under the oversight of an ethical review body. This rule applies to "virtual settings where individuals might have some limited expectation of privacy" [9]. If it is argued that Facebook group members are not aware that their behaviour as a member of the group is public or that they have some expectation of privacy, then informed consent is required. Perhaps the terms 'public' and 'private' require revised definitions in light of these views.

## **Negotiating Consent**

Negotiating consent to study an online community is not a simple task. Eysenbach and Till [3] recommend two approaches: 1) contact members of the community

prospectively to obtain permission to conduct the research, giving participants the opportunity to withdraw, or 2) contact members of the community retrospectively to ask permission to study the archives, giving them the opportunity to exclude themselves from the analysis. Yet, there are limitations to both of these approaches. The former carries the danger that a researcher's presence may unduly influence the behaviour of the community, while the latter is time consuming, as it may be challenging to contact users retrospectively and potentially introduce a new set of biases to the responses. Moreover, given the fluid membership of online communities, it may be necessary to repeatedly advertise the presence of a researcher and re-establish consent on a regular basis [4]. Obtaining permission from the community administrator or moderator is not considered adequate by some but rather a good first step as they would be most familiar with the norms of the group and the most effective way to obtain consent from group members [3].

Negotiating consent to study an online community involving minors may be an even more challenging task. Research ethics boards generally require adolescent assent and parental consent for participation in a research project [13]. In Canada, there is no age of consent to participate in research. Rather the capacity to meaningfully consent is judged based on the individual's ability to understand the nature and consequences, risks and potential benefits, of participating in a particular research project [9]. In general, health research communities and ethics board are more comfortable with the idea of assessing competence to provide informed consent in-person or by telephone contact. However, it has been argued that

if an adolescent chooses to set their profile settings in a social network site to 'public', then they are in essence consenting to allow anyone, including researchers to view that information [13]. The same argument could be made about an adolescent who may have a closed profile but who chooses not to restrict the search visibility of their profile therefore providing the community and the public with a means to locate and potentially contact them.

If parental consent is required to conduct research with minors via social networking sites, this could significantly stall and in some cases terminate or preempt a research study. Moreover, there may be situations in which the risk to benefit ratio for the adolescent may be more favourable if he/she is recruited without the involvement of the parent [13]. Consider, for example, a study examining the discourse around teen smoking, drug use or sexual behaviour on social network sites. Young people might put themselves at greater potential risk by seeking parental consent, subjecting themselves to unwanted scrutiny about sensitive behaviour, and further cutting themselves off from what may be one of the few sources of social support available to them.

## **Conclusion**

The Tri-Council Policy was revised and updated in 2008 to include among other things guidance with respect to the practice of Web-based research. Before this revision, there was no reference to Web-based research in the policy let alone practice guidelines for the study of online communities. Indeed, it may be worth considering ways to develop dynamic ethical practices that consider the changing pace and rapid evolution of information technology use for health and how youth

can be part of the solution as well as participants in research.

## References

- [1] King, S.A. Research Internet communities: Proposed ethical guidelines for the reporting of results. *Information Society*, 12, 2, (1996), 119-128.
- [2] Sharf, B.F. Beyond netiquette. The ethics of doing naturalistic discourse research on the Internet. In S. Jones (Ed.), *Doing Internet Research*. London: Sage Publications, 1999.
- [3] Eysenbach, G., and Till, J.E. Ethical issues in qualitative research on internet communities. *British Medical Journal*, 323, (2001), 1103-1105.
- [4] Sixsmith, J., and Murray, C.D. Ethical issues in the documentary analysis of Internet posts and archives. *Qualitative Health Research*, 11, 3, (2001), 423-432.
- [5] Brownlow, C., and O'Dell, L. (2002). Ethical issues for qualitative research in online communities. *Disability & Society*, 17, 6, (2002), 685-694.
- [6] Flicker, S., Haans, D., and Skinner, H. (2004). Ethical dilemmas in research on Internet communities. *Qualitative Health Research*, 14, 1, (2004), 124-134.
- [7] Whitehead, L.C. Methodological and ethical issues in Internet-mediated research in the field of health: An integrated review of the literature. *Social Science & Medicine*, 65, (2007), 782-791.
- [8] Norman, C., Guta, A., and Flicker, S. Engaging Youth in Health Promotion Using Multimedia Technologies: Reflecting on 10 Years of TeenNet Research Ethics and Practice. In: Luppigini R, Adell R, editors. *Handbook of Research on Technoethics*. Hershey, PA: Information Science Reference, 2008
- [9] Kitchin, H.A. *Research ethics and the Internet: Negotiating Canada's Tri-Council Statement*. Winnipeg, MB: Fernwood Publishers, 2007.
- [10] World Medical Association. *Declaration of Helsinki: Ethical principles for medical research involving human subjects*. (last amended Oct 2000). Retrieved November 2009 from <http://www.wma.net/e/policy/b3.htm>
- [11] Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. (2008). *2<sup>nd</sup> Edition of the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (with 2000, 2002 updates)*. Retrieved November 2009 from <http://www.pre.ethics.gc.ca/eng/policy-politique/initiatives/draft-preliminaire/>
- [12] Gross, R., and Acuiqisti, A. Information revelation and privacy on online social networks. In *Workshop on Privacy in the Electronic Society*. Alexandria, VA: ACM Press, 2005.
- [13] Moreno, A.M., Frost, N.C., and Christakis, D.A. (2009). Research ethics in the MySpace Era. *Pediatrics* 121, 1, (2009), 157-161.