

Chapter XX

Engaging Youth in Health Promotion Using Multimedia Technologies: Reflecting on 10 Years of TeenNet Research Ethics and Practice

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ABSTRACT

New information technologies are creating virtual spaces that allow youth to network and express themselves with unprecedented freedom and influence. However, these virtual spaces call into question traditional understandings of private and public space and open up new tensions for institutions (e.g. schools and law enforcement) trying to maintain safe spaces. For adolescent health researchers, these virtual spaces provide exciting opportunities to study youth culture, but also challenge the utility of ethical guidelines designed for a non-networked world. At issue are tensions between the realities of 'natural' interactions that occur online, often in full public view, and creating ethical research environments. These tensions and issues will be explored within this chapter, through an overview of the TeenNet project, a discussion of anonymity and confidentiality within social networking technologies and software (including Friendster, Facebook, and Myspace), and a discussion of ethical considerations for researchers engaged in adolescent health research and promotion.

INTRODUCTION

Time Magazine broke with tradition and named “You” its 2006 Person of the Year. The magazine’s cover featured a glossy computer monitor that reflected the reader’s own image, as if displayed on the Internet for all to see. This was an acknowledgment of the unprecedented way in which contributions from individuals around the world are expanding our knowledge, providing entertainment and enhancing our problem-solving capabilities through networked media and linked information technology. The ubiquity of hardware applications (such as laptop computers and wireless handsets) blended with social media tools (like wikis and blogs) has resulted in a mix of text, image, sound, and video allowing people with limited technical skill to become part of a wider landscape of information producers and consumers – or ‘prosumers’ (Wurman, 2001). This rapidly changing environment provides an unprecedented medium for dialogue and communication, yet also introduces profound ethical questions regarding the risks and benefits that these media present. This is particularly so in the area of health information. This chapter explores these ethical challenges through the lens of engaging youth, a population on the forefront of using these new technologies, in health promotion. We draw on more than a decade of research and action with TeenNet, a youth-focused research group based at the University of Toronto.

Adolescence is the developmental period during which complex decisions about health issues are first independently made, requiring skills to manage risks and negotiate options (Gardner, 2005). It is also a social time of life when peer influence is high and life experience is relatively limited. Many of the behavioral patterns initiated in adolescence become lifelong habits. While most move through this stage without serious problems, some gravitate towards riskier behaviours, have fewer supports and options available, and experi-

ence the consequences of poor decision making well into adulthood (Hutchinson & Stuart, 2004). This potential for lifelong harm has contributed to the perspective of viewing youth as a vulnerable population and thus, from a research and care perspective, to be treated as a group in need of special protections (Tri-Council of Canada, 1998; United States Department of Health and Human Services, 2005). For example, Canadian regulations stipulate that “subject to applicable legal requirements, individuals who are not legally competent shall only be asked to become research subjects when: the research question can only be addressed using individuals within the identified group(s); and free and informed consent will be sought from their authorized representative(s); and the research does not expose them to more than minimal risk without the potential for direct benefits for them”(Tri-Council of Canada, 1998). This model views young people as lacking the competence to make informed decisions pertaining to their wellbeing with regards to research and, implicitly, for health treatment, including procurement of health information. And yet, with more than 80% of young people regularly using information technology for health and communication (Lenhart et al., 2003) the supposed safeguards provided by these guidelines become problematic.

The proliferation of new technologies is creating contested spaces that allow for unprecedented creative youth expression and networking. However, these new spaces also challenge the utility of ethical guidelines designed for a non-networked world. At issue are tensions between the realities of ‘natural’ interactions that occur online, often in full public view, and creating ethical research environments. These tensions and issues will be explored below and discussed with reference to the work done in connection with TeenNet research projects.

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