Recommended Guidelines on Using Social Networking Technologies for HIV Prevention Research

Sean D. Young
Department of Family Medicine, David Geffen School of Medicine, University of California Los Angeles, 10880 Wilshire Blvd., Suite 1800, Los Angeles, CA 90024, USA,
sdyoung@mednet.ucla.edu

Online social networking can be used as an innovative method of HIV prevention. As these technologies grow increasingly prevalent, standards must be established to ensure their safety and efficacy in research.

This manuscript presents the field of ''social networking for HIV prevention'' by highlighting (a) the purpose of social networking technologies, (b) methods of using the technologies for HIV prevention research, and (c) recommended guidelines to improve data quality and study efficacy.

Background on Social Networking and HIV Prevention

Online social networking sites, such as Facebook, are designed for people to build relationships and share information [1]. They allow users to create personalized profiles to share pictures, videos, and other forms of multimedia.

Social networking is widely used for social communication, enabling it to be used for HIV prevention among at-risk populations [2]. Approximately 800 million people used social networks worldwide in 2011, and this number is expected to reach over 1.5 billion in 2015 [3]. In the United States, African Americans and English-speaking Latinos are almost 1.5 times more likely to use social networking sites compared to the general adult population [4]. Gay, lesbian, and bisexual individuals use the technologies more frequently than heterosexual individuals [5].

Researchers have begun using social networking for HIV prevention [2, 6], primarily in 3 areas: (1) as recruitment tools, (2) as intervention platforms, and (3) as sources of publicly available data.

For example, Sullivan et al. [7] used the social networking site, MySpace.com, to recruit MSM to complete a sexual health-related survey. Targeting advertisements toward men who were over 18 years old and reported being gay, bisexual, or unsure, they placed over 8,000,000 banner advertisement impressions on Myspace and received over 30,000 clicks from potential participants. In less than 1 month, over 9,000 participants consented and 6,258 completed the survey.

Social networking technologies are also being used to deliver HIV interventions. For example, we conducted a randomized controlled trial to test whether Facebook could be used for peer-delivered HIV prevention [8]. MSM, primarily African American and Latino,

Correspondence to: Sean D. Young.

joined peer-led Facebook groups to measure whether receiving peer-led HIV prevention information over Facebook could increase testing and decrease sexual risk behaviors. Results showed that peer leaders could use Facebook to deliver HIV prevention, and that participants were willing to engage in an HIV intervention over Facebook [9]. Analysis of the longitudinal intervention is currently being conducted.

Finally, publicly available social networking data can be used for secondary analyses of HIV-related behaviors and transmission trends. For example, Moreno et al. [10] looked at content on 500 MySpace profiles and found that 24 % included references to sexual risk behaviors.

Influenza researchers are using public social networking data to understand and predict transmission trends [11]. Aramaki et al. used a machine-learning approach to extract and filter Twitter.com "tweets" associated with influenza. When comparing tweets to actual Japanese influenza reports, they found up to a 0.97 correlation. As a first step to this approach within HIV prevention, our team collected over 12 million sexual health and HIV-related Tweets in 2 weeks. While approaches combining HIV prevention, social networking, and computer science are just beginning, they highlight the ability for using real-time social networking data for predicting HIV-related outcomes.

Recommended Guidelines on Using Social Networking for HIV Prevention Research

While the above examples highlight the utility of social networking for HIV prevention, guidelines are listed on issues to address before undertaking research in this area.

1. *Include a research collaborator experienced using social networking technologies.*

   At least one collaborator should thoroughly understand social networks, including having technical proficiency and insights about new feature development. For instance, if the social network intends to change security settings during an intervention, researchers should be able to anticipate this change to notify participants and provide assistance on ways to maintain security.

2. *Create a plan for addressing duplicate respondents.*

   Participants in online studies often complete multiple (duplicate) surveys to receive additional incentives. This reduces data quality if duplicate observations are not filtered. Internet researchers have created methods for addressing multiple respondents, such as monitoring computer addresses [12].

   Multiple respondents also need to be addressed in social networking and HIV prevention studies. Data quality can be improved through traditional online approaches, as well as methods unique to social networking. Facebook Connect, an application that requests Facebook to verify a Facebook user's identity, can validate that each participant is a unique Facebook user. It might also be possible to view a participant's existing network of friends. Having a small number of friends (inferring a newly created or fake profile) can be incorporated into a filter as an additional validation check. Finally, participant demographic information can be viewed and verified, if the participant has enabled this for public access.

3. *Include a collaborator who understands the social networking business.*

   While social networking technologies are sources for entertainment, news, and research, they typically exist to satisfy investors. Business and research goals are sometimes incompatible. Researchers need to be aware of social networking

business perspectives and motivations, as the company owning the technology might terminate a study if it believes the study could negatively impact business objectives. For example, Facebook has become increasingly conservative about brand associations during their initial public offering to ensure investor participation. As HIV-related studies can be controversial, Facebook might decide to close an HIV prevention study in the middle of it. Understanding business objectives of the technology company, as well as gaining support from the business, will help to ensure study progress.

Researchers should also be aware of a technology's potential lifespan. While some social networking companies have operated for a decade, others have disappeared rapidly. Human subject approval and longitudinal interventions require time, making it important to accurately project whether the technology will continue to be used by the desired population throughout the study. Although Myspace had a larger number of unique visitors in July 2008, we decided to conduct a 1 year intervention over Facebook because we anticipated that Facebook would grow larger and more appropriate for our study needs. Accurate prediction of the lifespan of the social network will help make the study endure and the results generalize.

4. *Address participant privacy and confidentiality issues.*

Participant privacy and confidentiality must be addressed. Awareness of current privacy concerns associated with each technology will help alleviate participant concerns and maintain a confidential study environment. Facebook's privacy issues led to concerns from participants in our Facebook studies. Many were first-time HIV study participants and wanted to remain "discreet," as their Facebook networks did not know they were MSM. Understanding Facebook's current and intended future privacy settings helped alleviate concerns and created a more enjoyable and safer participant experience.

5. *Internal review boards (IRBs) should include a researcher who is knowledgeable about mobile technologies.*

HIV research is often late in studying both the impact of technologies on sexual risk, and ways of using technologies for prevention. Historically, as with social networking, research on the impact of technologies on sexual risk begins after the technologies are being used to facilitate sexual activity. Delays can be exacerbated if a review board requests changes based on lack of knowledge about the technology. It is therefore important that every IRB retains an investigator informed about technologies and willing to teach other board members. This small step can help decrease the lapse of time between when a technology begins facilitating the spread of sexual risk and when this same technology can be used to curb the increasing epidemic.

Conclusion

Social networking for HIV prevention is an exciting area that combines HIV prevention/ public health, engineering/technology, and business. Researchers must therefore form multi-disciplinary teams of experts to address the needs within each of these fields. Just as technology companies jointly establish standards for safe, effective, and compatible use of their technology, standards must be established for safe and effective use of social networking technologies for HIV research.

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