



Published in final edited form as:

J Empir Res Hum Res Ethics. 2014 February ; 9(1): 58–70. doi:10.1525/jer.2014.9.1.58.

Social Networking and Online Recruiting for HIV Research: Ethical Challenges

Brenda L. Curtis

Treatment Research Institute, Philadelphia

Abstract

Social networking sites and online advertising organizations provide HIV/AIDS researchers access to target populations, often reaching difficult-to-reach populations. However, this benefit to researchers raises many issues for the protections of prospective research participants. Traditional recruitment procedures have involved straightforward transactions between the researchers and prospective participants; online recruitment is a more complex and indirect form of communication involving many parties engaged in the collecting, aggregating, and storing of research participant data. Thus, increased access to online data has challenged the adequacy of current and established procedures for participants' protections, such as informed consent and privacy/confidentiality. Internet-based HIV/AIDS research recruitment and its ethical challenges are described, and research participant safeguards and best practices are outlined.

Keywords

ethics; Internet research; online recruitment; social media; privacy; informed consent

Social networking sites such as Myspace, Facebook, Twitter, Grindr, Google+, and LinkedIn have changed how people interact with one another. Users are able to provide real-time information about their daily lives from their computers, tablets, and cell phones. In 2012, 81% of adult Americans used the Internet, 85% owned a cell phone, and 67% used social networking sites (Duggan & Brenner, 2013).

Social networking sites have created a new "HIV risk environment" where people can seek to evaluate risk of infection and negotiate safer sex practices prior to meeting potential partners (Fishbein et al., 2004; Hennessy et al., 2007; Hooper et al., 2008; Horvath, Rosser, & Remafedi, 2008; Rietmeijer & McFarlane, 2009). Social networking sites also provide an "HIV research environment" where participant recruitment, behavioral surveillance, and

© 2014 by joan sieber. all rights reserved.

Address correspondence to: Brenda L. Curtis, PhD, MSPH, Health Communication Research Scientist, Treatment Research Institute, 600 Public Ledger Blvd., 150 Independence Mall, Philadelphia, PA 19106. Phone: 215-399-0980; Fax: 215-399-0987; bcurtis@tresearch.org.

Research Agenda

Challenges to the ethical conduct of online recruitment will continue to evolve rapidly as the online technology evolves and as societal privacy concerns and research regulatory structures change throughout the world. Research should continue to track and evaluate informational risks, and to seek procedural solutions to the protection of the confidentiality of data and the personal privacy of those whose data are captured for research purposes.

interventions have taken place (Beymer, 2012; A. M. Bowen et al., 2008; Bull et al., 2011; Burrell et al., 2012; Fernandez et al., 2004; Jaganath et al., 2012; Ko et al., 2013; Landovitz et al., 2012; Rice et al., 2012; Voytek et al., 2012; Young & Jaganath, 2013; Zhang et al., 2008). While research utilizing social networking sites provides HIV researchers access to people representing almost every group within society (Nosek, Banaji, & Greenwald, 2002; Subrahmanyam et al., 2008; Thelwall, 2008), use of this technology has challenged the adequacy of participant protections provided through traditional informed consent, privacy, and confidentiality procedures. It has also called into question the validity and reliability of the data collected.

Internet recruitment efforts, particularly those that use social networking sites, are increasing in prevalence because they allow the researcher the ability to better target their intended audience (Fernandez et al., 2004). Researchers rely on the many tools provided by social networking companies to target participants and collect data, and the information provided by potential participants can in turn be used by the social networking companies for other purposes. While this targeting may result in greater efficiencies, it also raises ethical concerns because information that may traditionally be thought of as private and personally identifiable is gathered before the participant is enrolled in the study. In addition, many individuals are unaware that the act of showing interest in a research study through clicking on a recruitment advertisement is providing data to third-party companies and leaving an identifiable trail. Researchers and ethics committees are also often unaware of the privacy risks involved. This should be of particular concern to HIV and AIDS researchers due to the sensitivity of the topic, where privacy and confidentiality are key elements of the relationship of trust and respect that exist between the researcher and the participant.

As an example, DoubleClick was used in a recent CDC national campaign, “testing makes us STRONGER,” promoting HIV testing among black gay and bisexual men. DoubleClick, an advertising company that is owned by Google, deposits small persistent “cookies” (which contain unique alphanumeric codes) on users’ computers. These persistent cookies remain on the users’ computers after they have left the site and turned their computers off. Persistent cookies are used with session cookies to trace users as they move about the Internet in order to deliver targeted ads with the assistance of web beacons. Web beacons are embedded into websites and are not seen by the viewer. These tracking tools enable the website owners to know what content the user has viewed. This information is pooled across the many websites a user has visited and combined with information the user supplies to websites, forming a data profile that is made available to third-party advertisers.

When a user clicked on the “testing makes us STRONGER” ad, DoubleClick was immediately provided with (at a minimum) information that the user was interested in HIV testing. A click on the ad also increases the probability that the user will be identified by DoubleClick as black and gay or bisexual. DoubleClick maintains that the personal information it collects includes (but is not limited to) “name, address, telephone number, email address, social security number, bank account number, and credit card number” (www.google.com/doubleclick/). DoubleClick’s privacy policy states they will obtain a user’s consent to (1) link their name or personally identifiable information to their DoubleClick cookie and (2) associate their DoubleClick cookie with sensitive topics such as

race, religion, sexual orientation, and health. It is clear from the example above that, in some instances, by clicking on the “testing makes us STRONGER” ad, individuals may have unknowingly added personal and sensitive information to their persistent cookie that subsequently became part of their online profile that is available to third-party advertisers, businesses, and researchers who use an online company to send ads to black and gay or bisexual men and persons who might be interested in HIV testing.

The Uniqueness of Online Recruitment

The technique used by DoubleClick is called online behavioral advertising (OBA). OBA reflects a broad range of activities that companies use to collect information about our online activities (e.g., webpages we visit, links we click on, and search terms we use). The tracking, collection, and sale of online information occur every day and much of this information is provided by the individual user. However, the user may not know this information is being collected and sold and that, currently, few legal regulations exist. With the privatization of research and advances in online marketing, recruitment has increasingly become a business, and many niche-market companies have established themselves as recruitment experts (Epstein, 2008; Wright, 2006).

Researchers have turned to this online advertising industry to reach potential participants (Bull et al., 2011; Carpenter et al., 2011; Curtis, 2012; Graham et al., 2008; Hagan, 2010; Voytek et al., 2012). OBA companies give researchers the tools they need to effectively recruit many hard-to-reach populations into research studies. Typical information available to researchers upon which they can build a sample include, but is not limited to, demographic data, education, employment history, interests, location histories, and topics the user has searched on in the past (see Table 1).

While there are similarities between traditional recruitment (hard-copy flyers, mailed materials, inperson meetings) and Internet recruitment, Internet recruitment is a fundamentally different recruiting technique, and this technique is further complicated by social networking sites and the use of OBA. For example, social networking sites are able to use OBA to aggregate individual online activities and personal data obtained from individuals, their families, and friends to create individual user profiles that contain sensitive and personal information (see Table 1).

A DIFFERENT TRANSACTION

In the past, recruitment tended to be a relatively untargeted public call for research participants displayed in traditional media such as newspapers or radio announcements, university bulletin boards, or on the sides of subways and buses (Figure 1). Traditional recruitment model was a straightforward transaction between the researcher and the prospective participant: an researcher posted or purchased an advertisement and a prospective participant, who saw the advertisement and was interested, contacted the researcher—normally by phone.

In addition to the simplicity of this transaction, there was widespread familiarity with the logistics of each step in the process. Researchers generally knew what was involved with

placing an advertisement and were familiar with the technology and the parties involved in the transaction. Because of this familiarity, both researchers and ethics committees could realistically be expected to understand the ethical considerations of a recruitment program and act accordingly.

Online recruitment is a much more complex transaction. Not only are there many more parties involved in any single transaction online, but the transactions tend to be much more opaque. Jon Leibowitz, chairman of the Federal Trade Commission in 2009, produced a set of “data flow charts” to demonstrate to the consumer the practices employed by social networking, cloud computing, online behavioral advertising, mobile marketing, and the collection and use of information by retailers, data brokers, third-party applications, and other diverse businesses. What should be of particular interest to HIV researchers and ethics committees is the circular transmission of information (Figures 2 and 3). The online behavioral advertising ecosystem (e.g., Google search engine ads, website banner ads) details the transmission and aggregation of profile, demographic, interest, and behavior data through the use of tracking software to create highly individualized and detailed user profiles that are made available to ad networks, merchants, and secondary ad networks (Figure 2). For the social networking chart (Figure 3), when a person clicks on an ad (e.g., interest in participating in an HIV study for MSM), this information is sent back to the ad servers and third-party apps and a person’s public facing profile may also contain this information (e.g., “Like” feature on Facebook).

It can be extremely difficult to discern the interests, ethical guidelines, or even the participating parties in any given online transaction (flow of information). Additionally, every online transaction is routinely captured as data, disseminated, and increasingly aggregated into ad networks, analytic providers, merchants, and profiling services databases. What used to be a relatively simple and confidential process is now rife with the potential for unintended disclosures. As the technology continues to evolve, not only will more parties join this transaction, but the quality and quantity of the data collected by and available to these parties will increase. While this increased access to data allows researchers to target online recruiting to segments of the population that are oftentimes hard to reach by traditional recruiting techniques, it presents a challenge to researchers and ethics committees seeking to quantify and qualify the ethical considerations of online recruitment.

REACH

Another difference between online recruitment and traditional print recruitment advertisements is “reach,” which refers to the number of different people who are exposed to an advertising message at least once. “Coverage” is the potential number of people exposed to an advertising message. Reach is limited by the circulation’s coverage area (posting of flyers, direct mail, newspapers, and magazines). On the Internet, a single website or online advertisement can, in principle, reach participants anywhere in the world—that is, have global coverage. Online advertisements can potentially recruit participants from more places and allow researchers to recruit participants far outside their local area.

The population of participants HIV researchers are interested in reaching are oftentimes participating in risk-taking behaviors that are stigmatized or illegal in the society at large.

This results in the lack of a cohesive geographic sampling frame from which to recruit a sample or “subpopulation.” These “hidden subpopulations” are crucial to preventing the spread of HIV (Magnani et al., 2005). Social networks on the Internet allow for recruitment of these “hidden subpopulations” by using snowball sampling strategies (ibid.) through advertising on interest-targeted (e.g., MSM) blogs, message boards, and drug use, dating, and social networking sites such as Grindr, Facebook, Adam4Adam, Bluelight, and Drugs-Forum.com (A. Bowen, Williams, & Horvath, 2004). This increased reach and coverage has given HIV researchers access to these hard-to-reach subgroups of people.

Examination of Online Recruiting for HIV Research and Best Practices

Investigators and ethics committees are facing major challenges in the research environment due to use of the Internet as a participant recruitment tool (Buchanan & Ess, 2009; Buchanan & Hvizdak, 2009). Online behavioral advertising techniques and increased reach raise ethical, implementation, and logistical issues for investigators and ethics committees. According to Fowler-Dixon, “this new emphasis on Internet research has left some IRBs looking for ways to catch up to the technology and to learn how to approach the special challenges involved” (“Internet research raises unique ethical concerns for IRBs,” 2008, p. 25). These challenges that relate to online recruiting have been categorized into two types of ethical issues: privacy and confidentiality and informed consent (Buchanan & Ess, 2009; “Internet research raises unique ethical concerns for IRBs,” 2008). The following sections examine these ethical challenges for online recruitment within four popular contexts: search engines, websites, social network sites, and e-mail.

PRIVACY AND CONFIDENTIALITY

Respecting participants’ rights to privacy is a fundamental principle guiding national regulations across the world (Rehman, 2010). For example, in the United States, “The Right to Privacy” was one of the most influential law journal articles of the nineteenth century, in which Samuel D. Warren and Louis D. Brandeis (1890) described their frustration with how newspapers, then considered a new technology, had increased journalists’ abilities to report on the private lives of individuals. In their article, privacy was defined as “the right to be let alone” and characterized as a freedom from exposure to or intrusion by others, and they argued that current laws and regulations inadequately addressed threats to privacy caused by the use of the new technology. In a series of decisions, the U.S. Supreme Court affirmed that there is, indeed, a right to privacy in the United States that is contained in the “penumbras” and “emanations” of other constitutional protections (*Griswold v. Connecticut*, 1965). This right has been extended to the right of information privacy which allows individuals to limit the kinds of information that others know about them (Stevens, 2001).

When HIV researchers are collecting data online, it is important that they have control over access to this information and that they do not compromise the confidentiality of the data and the privacy of the participant before consent into the research study. There are three main confidentiality and privacy threats arising from using social networking sites for recruiting subjects into HIV studies (see Table 2): (1) lack of confidentiality when evaluation data are collected online; (2) poor user privacy and confidentiality protections of

social networking sites; and (3) threats related to the collection of protected health information.

Using a study where at-risk Hispanic men who have sex with men were recruited to participate in community-based HIV studies as an example, recruitment occurred in online chat rooms (Fernandez et al., 2004). Recruiters used a script that consisted of five parts: (1) introductions; (2) preliminary screening process (ethnicity, gender, sexual preference, location, age); (3) consent to proceed; (4) study description; and (5) procedures for enrollment (sending participant to another page to complete a contact form). Because these communications occurred in the online chat rooms, the transcripts of the chat sessions were available to the social networking site provider and to any third party that the site allowed access.

In another HIV prevention study, among predominantly minority youth, researchers required participants to “like” the study’s Facebook page after they were assigned to a study condition and to recommend the study to three Facebook “friends” (Bull et al., 2011). Although the researchers report they did not allow participants to be their friends, because they did not want to have access to the personal information on the participants’ profile pages, they actually may have had access to this information inside Facebook Insights—depending on when Facebook introduced this feature to Insights and when the researchers conducted the study. Facebook stores “like” information and makes this information available to the page administrator and to advertisers. Page administrators, if they chose to, can view their “likes” photos and profiles (Figure 4).

Table 2 presents recommendations for addressing the three main confidentiality and privacy threats. These best practices include: (1) allowing the study team sole access to identifiable data; (2) using ID numbers instead of user profile names when online data are collected; (3) not connecting participants to the study’s social network site; (4) not using contact forms and signup forms inside social networking sites; (5) regularly reviewing participant posts to ensure identifiable information is not posted; and (6) ensuring any protected health information is collected according to national and international requirements. Researchers must regularly review terms of agreement, privacy and confidentiality policies, and features available to advertisers, businesses, and other third parties for companies they plan to use during the recruitment process. Researchers should contact these companies and ask them to remove from their databases any information pertaining to the study—including which users received, viewed, and responded to the recruitment advertisements. In addition, researchers should use landing pages that are secured to prevent the capturing of any user information—including responses and page viewing history.

INFORMED CONSENT

At minimum, the informed consent must include the following information necessary for a potential participant to make an informed, rational, and voluntary decision: (a) the risks and potential benefits of research participation; (b) the extent and limits of confidentiality protections; and (c) the right to refuse to participate and to withdraw from the research without penalty or loss of benefits to which the participant is otherwise entitled (Krogstad et al., 2010; Stultiens et al., 2007).

Using the Internet to recruit research participants for HIV prevention and intervention research presents several concerns regarding consent (see Table 3). Many countries have national regulations that do not permit children or adults who have been declared legally incompetent to consent to research participation without the permission of a guardian (Krogstad et al., 2010; Stultiens et al., 2007). However, when a person is recruited online and consent is obtained electronically, it is difficult, if not impossible, for a researcher to verify the age, competency, and comprehension of the potential participant. This is of special concern regarding topics covered in HIV research (e.g., HIV risk topics including drug use, commercial sex work, human trafficking, and other sexual activity), and the possibility of minors responding and participating to an online study involving inappropriate materials for their age without the researcher's knowledge. These challenges are not unique to the Internet. For example, the stock screener question "Are you at least 18 years of age?" used in both telephone and mail surveys is not a reliable way to verify the validity of a prospective participant's status as an "adult" who can give legal "consent." Yet, there are several techniques available to researchers that allow for age verification through cross-checking with other available information (see Table 3). Most social networks have software tools that allow almost any website or third party to authenticate users and verify age through their system (e.g., Facebook Connect, Twitter API, and Google Accounts).

Improving How We Evaluate Consent Comprehension—Traditional forms of recruitment have the same problems regarding competency and comprehension. To assume otherwise, assumes that visual cues are adequate to judge whether a person can understand the consent information. In this regard, online recruitment creates a unique opportunity to allow for computerized ways to ensure the informed consent process is understood. HIV researchers oftentimes work with drug using populations, populations with limited English proficiency, and those with psychiatric problems. Through methods similar to a "teaching then testing" technique used in substance abuse research (Aldridge & Charles, 2008), HIV researchers can produce web-based interactive and consent procedures. Educational design principles can be used to support learning and comprehension of the study information, procedures, risks, and benefits. Participants can view this information at an educational level and language specifically tailored to them; and they can be asked to demonstrate competency before they are able to advance. When participants report incorrect information, they can receive corrective feedback; the specific information they are having problems understanding can be viewed again (or they may choose to withdraw from the process). This tailoring of the consent content to meet the educational and language needs of participants through the use of audio-visuals and to assess comprehension are features unique to the use of an online consent process. The use of technology also allows for participants to provide researchers with information about the consenting procedure so that their experiences can be fed back into the system and to allow for the adaption of information—promoting content that is easy to understand (Table 3).

Conclusion

Internet-based recruitment allows researchers to reach concealed, disparate, vulnerable, and hidden populations (Kirchhoff & Kehl, 2007; Souder, 2009). This ability to include hard-to-

reach populations is one of the fundamental principles of research ethics, “justice,” as defined in the Belmont Report (1979); research ethics also requires researchers to maximize possible benefits from the research and minimize burdens to their participants. “Benefits” are gains to society or science through a contribution of factors that include empowerment of the individual by giving him or her voice and useful information as well as treatment. These ethical requirements have especially important consequences for “vulnerable” groups of research subjects.

According to established standards of practice, research should be designed with administrative, management, and technical safeguards to control authorized use and disclosure of information and to protect against unauthorized disclosure of information. As a general principle, information is not to be disclosed without participant consent. However, due to the increasing use of online behavioral research advertising, specifically social networking sites, concerns are warranted regarding the researchers’ responsibilities to actively protect against disclosure of private information, not just for their own purposes but for third-party service providers. As online recruitment employs a range of behavioral marketing techniques—search engines, websites, social networks, various forms of instant messaging, and e-mail—researchers, research participants, and ethics committees will encounter ethical questions only broadly covered in current regulations. These challenges are likely to relate to privacy and confidentiality, informed consent, and the collection of valid and reliable data. For example, the mere clicking on an advertisement to find out more about an HIV vaccine research study may disclose a person’s sensitive and private information (be it accurate or not) that is likely to be recorded and combined with a person’s online user profile—all of this before the formal informed consent process has been initiated by the researcher. Therefore, researchers’ research practices should aim at reducing the possibility of disclosures of private information, and ensuring that informed consent is obtained and that data are reliable and valid. Ethics committees should be aware of these issues so that they are able to regulate the flow of private information, thus minimizing potential risks to the research participants in studies they review.

Acknowledgments

This paper was supported in part by the Fordham HIV Prevention Research Ethics Training Institute (RETI), a five-year training grant sponsored by the National Institute on Drug Abuse (#1R25DA031608-01, Principal Investigator, Celia B. Fisher, Director Center for Ethics Education). The content is solely the responsibility of the author and does not necessarily represent the official views of the Treatment Research Institute or the Fordham HIV Prevention Research Ethics Training Institute.

Biography

Brenda Curtis is a Health Communication Research Scientist at the Treatment Research Institute. Her principal research interests have been in the fields of Health Communication and Public Health with a special interest in technology. She is interested in providing scientifically tailored health information using new media that is evidence based.

References

- Aldridge J, Charles V. Researching the intoxicated: Informed consent implications for alcohol and drug research. *Drug and Alcohol Dependence*. 2008; 93(3):191–196. [PubMed: 17945437]
- Beymer, M. Grindr and other geosocial networking applications: Advent of a novel, high-risk sexual marketplace; Paper presented at the 2012 National STD Prevention Conference; Minneapolis, MN. 2012.
- Bowen A, Williams M, Horvath K. Using the Internet to recruit rural MSM for HIV risk assessment: Sampling issues. *AIDS and Behavior*. 2004; 8(3):311–319. [PubMed: 15475678]
- Bowen AM, Williams ML, Daniel CM, Clayton S. Internet-based HIV prevention research targeting rural MSM: Feasibility, acceptability, and preliminary efficacy. *Journal of Behavioral Medicine*. 2008; 31(6):463–477. [PubMed: 18770021]
- Buchanan, EA. Conducting research on the Internet: Emerging ethical, regulatory, and practical considerations; Paper presented at the Clinical Research Seminar Series; University of Pittsburgh, PA. 2010.
- Buchanan EA, Ess CM. Internet research ethics and the institutional review board: Current practices and issues. *ACM SIGCAS Computers and Society*. 2009; 39(3):43–49.
- Buchanan EA, Hvizdak EE. Online survey tools: Ethical and methodological concerns of human research ethics committees. *Journal of Empirical Research on Human Research Ethics*. 2009; 4(2): 37–48. [PubMed: 19480590]
- Bull SS, Breslin LT, Wright EE, Black SR, Levine D, Santelli JS. Case study: An ethics case study of HIV prevention research on Facebook—The Just/Us study. *Journal of Pediatric Psychology*. 2011; 36(10):1082–1092. [PubMed: 21292724]
- Burrell ER, Pines HA, Robbie E, Coleman L, Murphy RD, Hess KL, et al. Use of the location-based social networking application GRINDR as a recruitment tool in rectal microbicide development research. *AIDS and Behavior*. 2012:1–5. [PubMed: 21476006]
- Carpenter MJ, Sterba KR, Boatright AS, West R. “Closet” quit attempts: Prevalence, correlates and association with outcome. *Addiction*. 2011; 106(2):2214–2220. [PubMed: 21672072]
- Curtis B. Understanding tailored Internet smoking cessation messages: A reasoned action approach. *Annals of the American Academy of Political and Social Science*. 2012; 640(1):136–149.
- Duggan, M.; Brenner, J. The demographics of social media users—2012. Pew Research Center; 2013. Retrieved from <http://pewinternet.org/Reports/2013/Social-media-users/The-State-of-Social-Media-Users.aspx>
- Epstein S. The rise of “recruitmentology”: Clinical research, racial knowledge, and the politics of inclusion and difference. *Social Studies of Science*. 2008; 38(5):801–832. [PubMed: 19227822]
- Ess, C.; Aoir Ethics Working Committee. Ethical decision-making and Internet research: Recommendations from the AOIR Ethics Working Committee. 2002. approved 27 November 2002. Retrieved from www.aoir.org/reports/ethics.pdf
- Fernandez M, Varga L, Perrino T, Collazo J, Subiaul F, Rehbein A, et al. The Internet as recruitment tool for HIV studies: Viable strategy for reaching at-risk Hispanic MSM in Miami? *AIDS Care*. 2004; 16(8):953–963. [PubMed: 15511727]
- Fishbein M, Hennessy M, Yzer M, Curtis B. Romance and risk: Romantic attraction and health risks in the process of relationship formation. *Psychology, Health & Medicine*. 2004; 9(3):273–285.
- Graham AL, Milner P, Saul JE, Pfaff L. Online advertising as a public health and recruitment tool: Comparison of different media campaigns to increase demand for smoking cessation interventions. *Journal of Medical Internet Research*. 2008; 10(5):e50. [PubMed: 19073542]
- Griswold v Connecticut, 381 US. 1965; 479
- Hagan, AM. Doctoral dissertation. University of Michigan; 2010. The influence of support groups and identity on goal setting and achievement in persons with type 2 diabetes. Retrieved from <http://deepblue.lib.umich.edu/handle/2027.42/75845>
- Hennessy M, Fishbein M, Curtis B, Barrett DW. Evaluating the risk and attractiveness of romantic partners when confronted with contradictory cues. *AIDS and Behavior*. 2007; 11(3):479–490. [PubMed: 17028997]

- Hooper S, Rosser BR, Horvath KJ, Oakes JM, Danilenko G, Men's Internet Sex II (MINTS-II) Team. An online needs assessment of a virtual community: What men who use the Internet to seek sex with men want in Internet-based HIV prevention. *AIDS and Behavior*. 2008; 12(6):867–875. [PubMed: 18401701]
- Horvath KJ, Rosser BR, Remafedi G. Sexual risk taking among young Internet-using men who have sex with men. *American Journal of Public Health*. 2008; 98(6):1059–1067. [PubMed: 18445804]
- Internet research raises unique ethical concerns for IRBs. *IRB Advisor*. 2008; 8(3):25–28.
- Jaganath D, Gill HK, Cohen AC, Young SD. Harnessing Online Peer Education (HOPE): Integrating C-POL and social media to train peer leaders in HIV prevention. *AIDS Care*. 2012; 24(5):593–600. [PubMed: 22149081]
- Kirchhoff KT, Kehl KA. Recruiting participants in end-of-life research. *American Journal of Hospice and Palliative Care*. 2007; 24(6):515–521. [PubMed: 17601835]
- Ko NY, Hsieh CH, Wang MC, Lee C, Chen CL, Chung AC, Hsu ST. Effects of Internet Popular Opinion Leaders (iPOL) among Internet-using men who have sex with men. *Journal of Medical Internet Research*. 2013; 15(2):e40. [PubMed: 23439583]
- Krogstad DJ, Diop S, Diallo A, Mzayek F, Keating J, Koita OA, Touré YT. Informed consent in international research: The rationale for different approaches. *American Journal of Tropical Medicine and Hygiene*. 2010; 83(4):743. [PubMed: 20889858]
- Landovitz RJ, Tseng CH, Weissman M, Haymer M, Mendenhall B, Rogers K, et al. Epidemiology, sexual risk behavior, and HIV prevention practices of men who have sex with men using GRINDR in Los Angeles, California. *Journal of Urban Health*. 2013; 90(4):729–739. [PubMed: 22983721]
- Magnani R, Sabin K, Saidel T, Heckathorn D. Review of sampling hard-to-reach and hidden populations for HIV surveillance. *AIDS*. 2005; 19:S67–S72. [PubMed: 15930843]
- Nosek BA, Banaji MR, Greenwald AG. E-Research: Ethics, security, design, and control in psychological research on the Internet. *Journal of Social Issues*. 2002; 58(1):161–176.
- Rehman, J. *International human rights law*. 2. New York and London: Longman; 2010.
- Rice E, Tulbert E, Cederbaum J, Adhikari AB, Milburn NG. Mobilizing homeless youth for HIV prevention: A social network analysis of the acceptability of a face-to-face and online social networking intervention. *Health Education Research*. 2012; 27(2):226–236. [PubMed: 22247453]
- Rietmeijer CA, McFarlane M. Web 2.0 and beyond: Risks for sexually transmitted infections and opportunities for prevention. *Current Opinion in Infectious Diseases*. 2009; 22(1):67–71. [PubMed: 19532082]
- Souder E. Recruiting for research. *Research in Gerontological Nursing*. 2009; 2(4):226. [PubMed: 20077976]
- Stevens, GM. Online privacy protection: Issues and developments. 2001. Retrieved from www.law.umaryland.edu/marshall/crsreports/crsdocuments/RL30322.pdf
- Stultiens L, Goffin T, Borry P, Dierickx K, Nys H. Minors and informed consent: A comparative approach. *European Journal of Health Law*. 2007; 14(1):21–46. [PubMed: 17566319]
- Subrahmanyam K, Reich SM, Waechter N, Espinoza G. Online and offline social networks: Use of social networking sites by emerging adults. *Journal of Applied Developmental Psychology*. 2008; 29(6):420–433.
- Thelwall M. Social networks, gender, and friending: An analysis of MySpace member profiles. *Journal of the American Society for Information Science and Technology*. 2008; 59(8):1321–1330.
- U.S. Department of Human and Health Services. The Belmont report: Ethical principles and guidelines for the protection of human subjects of research. 1979. Retrieved from www.hhs.gov/ohrp/humansubjects/guidance/belmont.html
- Voytek CD, Jones KT, Curtis BL, Fiore DT, Dunbar D, Frank I, et al. Using an Internet consumer marketing strategy to reach men who have sex with men for participation in a preventive HIV vaccine clinical trial. *Retrovirology*. 2012; 9(Suppl2):119.
- Warren SD, Brandeis LD. The right to privacy. *Harvard Law Review*. 1890; 4(5):193–220.
- Wright KB. Researching Internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web survey services. *Journal of Computer-Mediated Communication*. 2006; 10(3)

- Young SD, Jaganath D. Online social networking for HIV education and prevention: A mixed-methods analysis. *Sexually Transmitted Diseases*. 2013; 40(2):162–167. [PubMed: 23324979]
- Zhang D, Bi P, Hiller JE, Lv F. Web-based HIV/AIDS behavioral surveillance among men who have sex with men: Potential and challenges. *International Journal of Infectious Diseases*. 2008; 12(2): 126–131. [PubMed: 17884663]

Best Practices

Below are 10 recommended or “best” practices for social networking and online recruiting of participants for HIV research.

1. All data assessments should be collected through a secured Internet site that is outside of the social networking site, and data should be accessible only to the study team. This includes “contact us” forms and pre-screening questions.
2. Researchers should not ask participants to e-mail contact information or survey data as that is not a secure form of communication (Buchanan & Hvizdak, 2009).
3. Researchers will stay abreast of social networking sites and advertiser privacy and confidential policies and terms of service. Researchers are cautioned in conducting recruitment with adolescents and/or on sensitive/illegal topics on social networking sites with a history of poor privacy and confidentiality policies.
4. By spending time learning about the features available to businesses and third-party advertisers, researchers will have a better idea of what data are being collected and sold about users of that social networking site.
5. Researchers will contact social networking sites and ask them not to record (or immediately delete) data regarding their advertisements.
6. Health information will be collected and stored according to the national and international regulations.
7. If participants are allowed to post information to the study social networking site, postings will be monitored multiple times each day; identifiable or inappropriate information will be removed.
8. Researchers will avoid asking participants to “like” their study page and sending their online “friends” invites to join the study through the software provided by the social networking sites.
9. There are techniques to verify age and authenticate users on most social network sites. Researchers can also use offline techniques to verify age and authenticate users.
10. Informed consent comprehension and competency can be improved through the use of interactive consenting procedures that provide corrective feedback and are tailored to the users’ educational and language preferences. Participants can be provided with various versions of the consent form—one version can be brief with hyperlinks to the more detailed version.

Educational Implications

Educational offerings such as workshops and webinars for ethics committee members and HIV researchers could be designed to enhance their abilities of developing and accessing online recruitment strategies. Using this adapted set of questions that Ess (2005) and Buchanan (2010) recommend we ask when undertaking Internet research, ethics committees and HIV researchers will be able to address participants' privacy and confidentiality concerns and issues of transparency in connection with online behavioral advertising and social networking sites.

Where does the interaction/communication/study take place? What ethical expectations are established by that venue?

- The greater perceived privacy of the participant and/or the less privacy afforded by the venue, the greater need to protect individual privacy, confidentiality, right to informed consent, etc.

Who are the participants?

- The greater the vulnerability of the participant, the greater the obligation of the researcher to protect the participant.

When will the informed consent process start?

- Ideally, protecting participants' rights to privacy, confidentiality, autonomy, and informed consent should start at the beginning of any data collection.

How long does the third-party provider and ISP preserve the data and where?

- The researcher should make every effort to (a) not store data by ISPs and third-party providers and (b) if it is being stored, have the data removed as soon as possible.

What third-party policies impact the research?

- Has the researcher read the terms and services of the sites and providers? Can the researcher provide adequate information to the participants and/or ethics committee concerning how the third party will protect their data?

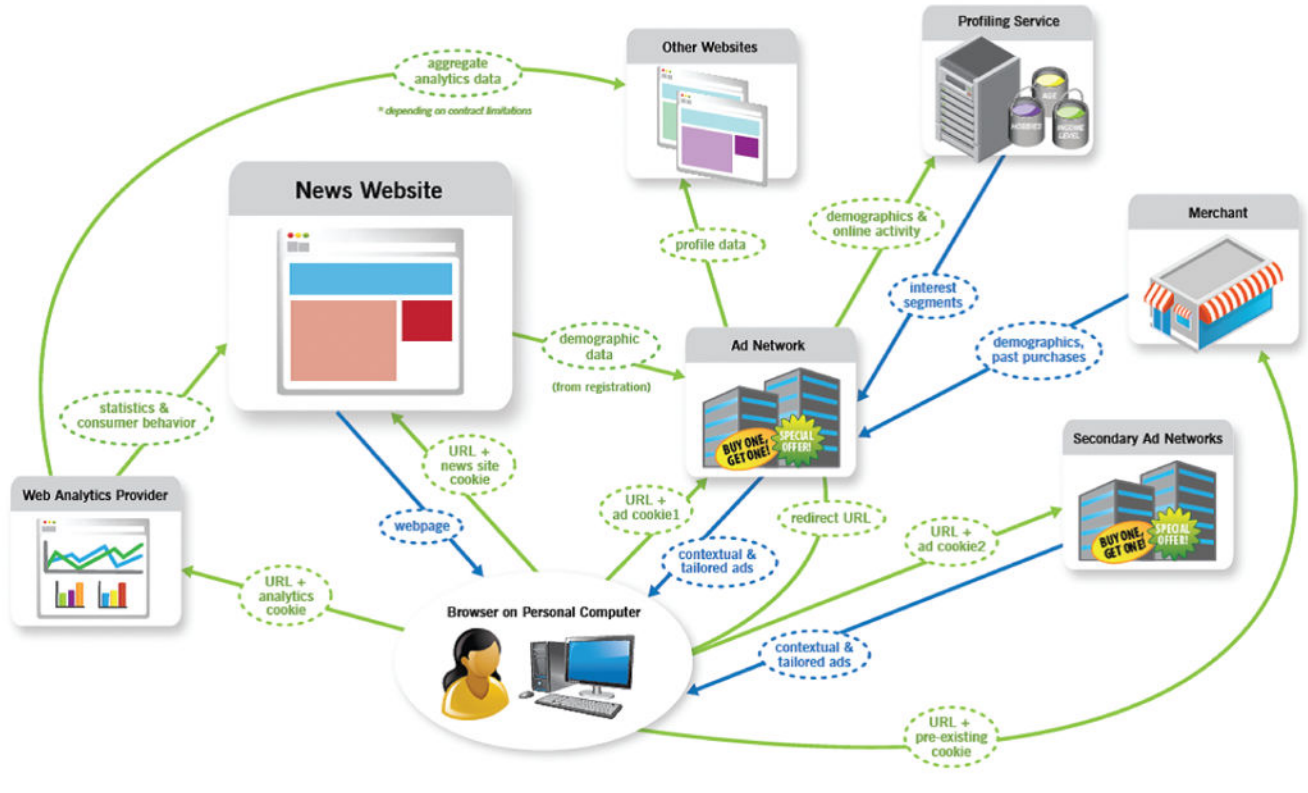
Is the researcher able to provide control to the participant?

- All behavioral advertising practices should contain clear descriptions of online advertising practices and provide the participant with the ability to opt-out (or opt-in in the case of ISPS and toolbar applications) of such practices. Researchers should test to ensure they work and the participant can truly opt-out/in.



Fig. 1.
Example of a Traditional Recruitment Advertising Transaction.

Online Behavioral Advertising

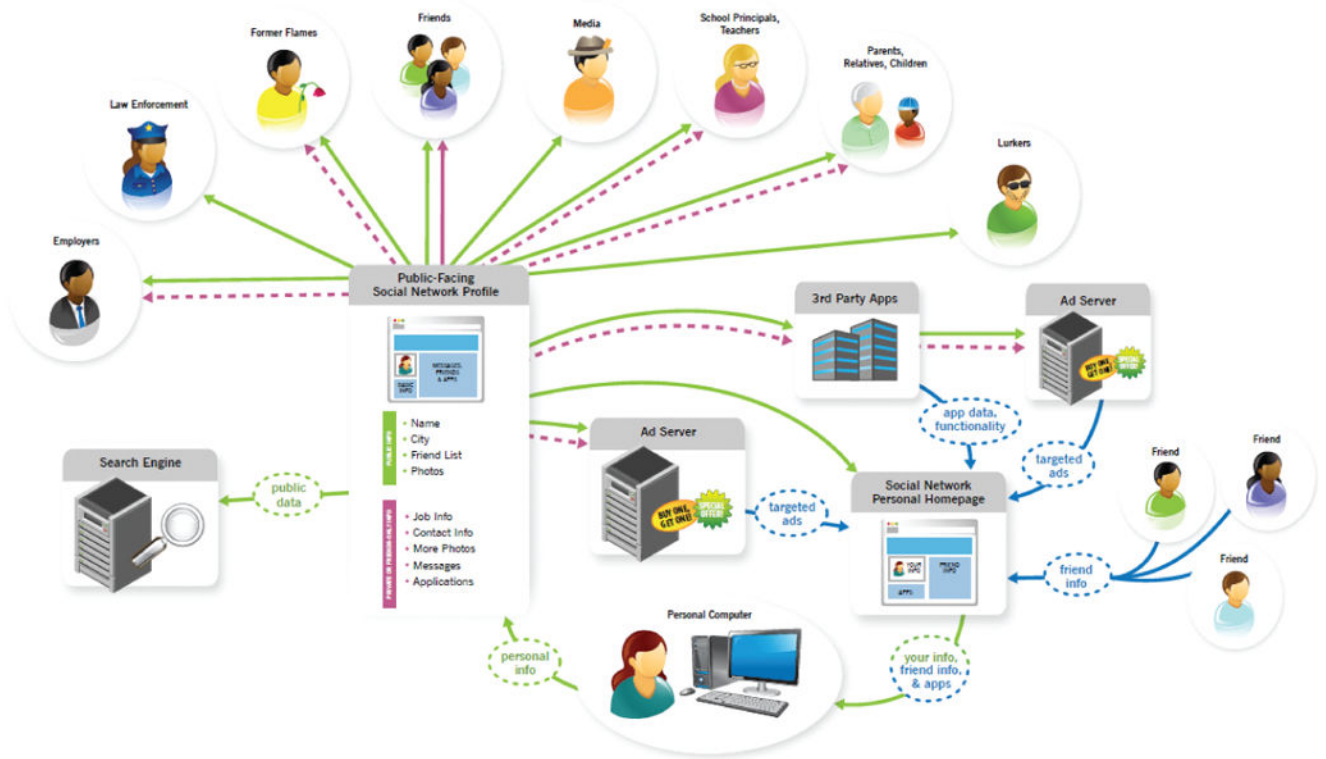


- Green arrows represent the flow of consumer data.
- Blue arrows represent the flow of 3rd party information & offerings.
- * This diagram represents a typical flow of information related to some online behavioral advertising. Not all online behavioral advertising operates exactly like this diagram.



Fig. 2.
Online Behavioral Advertising.

Social Networking



- Pink arrows represent the flow of private consumer data.
 - Green arrows represent the flow of public-facing consumer data.
 - Blue arrows represent the flow of 3rd party information & offerings.
- * This diagram represents a typical flow of information related to some social networks. Not all social networks operate exactly like this diagram.



Fig. 3.
Social Networking Advertising.



See Likes: See Likes shows you photos of users who liked your page. Clicking the drop-down menu in the top-left corner of the "See Likes" popup will allow you to see Pages that liked your Page, admins, and banned users.

Fig. 4. FaceBook Insights Screenshot of Users that "Like" Your Page.

Table 1

Information Collected by Profiling Services and Ad Networks and Made Available to Researchers.

| | |
|-------------------------------|--|
| Demographic data | Age, gender, country, city, zip, income, relationship status, age, birthday, sexual orientation |
| Education | Specific schools attended, degrees, graduation years, majors |
| Employment history | Past and current employers |
| Broad and specific interest | Friends; content downloaded including apps and games; activities and hobbies; friends; group memberships |
| Location-based search history | Businesses searched for; GPS information tagged to photos and social media posts |
| Past search history | Sites visited in the past; time spent on sites; images viewed; ads clicked on; purchases made; videos viewed |

Table 2

Confidentiality and Privacy Recommendations.

| Confidentiality and Privacy | | |
|---|---------------|--|
| Issue | Best Practice | |
| There is little control over confidentiality in situations where evaluation data are collected online. | 1 | Identifiable data from online assessments should be accessible only to the study team. |
| | 2 | ID numbers can be assigned to participants offline and all online information about participants is accessed via this number. |
| Social networking sites with poor privacy and confidentiality protections (e.g., Facebook and Instagram members' confidentiality rights). | 1 | Research teams should not invite participants to be their online "friends" or to "like" them—thus they will not have access to personal information on profile pages and can only access information that participants make publicly available. |
| | 2 | The "Contact Us" and/or "Sign Up" should not be located on social networking sites. When researchers would like participants to sign up or to invite their friends to participate, the research team should send prospective participants to a site landing page that is secure and not connected with the social networking site. |
| | 3 | If participants are allowed to post information to the study social networking site, postings must be monitored multiple times each day and identifiable or inappropriate information should be removed. |
| | 4 | Regularly review sites' privacy and confidentiality policies and advertiser, business, and third-party features. |
| The collection of health information (Health Insurance Portability and Accountability Act [HIPAA] regulated). | 1 | All assessments should be collected through a secured Internet site, not housed by social networking sites. |
| | 2 | Storage and transfer of electronic data must use current standards of encryption, password protection, and be stored behind a secure firewall. |

Table 3

Informed Consent Recommendations.

| Informed Consent | | |
|--|----------------------|---|
| Issue | Best Practice | |
| Comprehension of study information, procedures, and informed consent form. | 1 | Participants can be provided a brief summary of the consent, linked to the detailed consent, and e-mailed a copy of the consent. |
| | 2 | Facts about the study can be shortened into digestible FAQs that are on the study landing page. An FAQ section can also be placed on the social networking site page. |
| | 3 | Participants can be asked to provide feedback about the information provided so that researchers can adapt the information to be better understood. |
| Legal age | 1 | Age verification through cross-checking with other information (e.g., Facebook Connect; parents, guardians, schools, or third parties vouching for minors). |
| Competency | 1 | Online quiz regarding the content of the consent form and purpose of the study to validate competency (and comprehension). |
| | 2 | Correct answers to quiz questions required before participant can proceed to study. |