Case Study: An Ethics Case Study of HIV Prevention Research on Facebook: The Just/Us Study

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Objective To consider issues related to research with youth on social networking sites online.

Methods Description of the data collection process from 1,588 participants in a randomized controlled trial testing the efficacy of HIV prevention education delivered on Facebook. Using respondent-driven sampling, staff-recruited participants are encouraged to recruit up to three friends to enroll in the study. Results Researchers should (a) consider whether an online social networking site is an appropriate place to implement a research study; (b) offer opportunities to review informed consent documents at multiple times and in multiple locations throughout the study; and (c) collect data outside the social networking site and store it behind secure firewalls to ensure it will not be accessible to any person on the social networking site.

Conclusions Online social networks are growing in popularity. Conducting research on social media sites requires deliberate attention to consent, confidentiality, and security.

Key words ethical issues; health behavior; research design and methods.

Introduction

Young adults almost universally access and use social media sites that facilitate Internet-based communication, and they comprise diverse socioeconomic and racial communities (Lenhart, Purcell, Smith, & Zickuhr, 2010). The Internet in general, and social media sites such as Facebook and My Space in particular, offer potentially unprecedented access to millions of young people—to collect data, to interact with youth about health promotion messages, or simply to share and disseminate health information. With this potential comes unique ethical challenges. Using social media for research may allow researchers to readily access and engage network members; and requires utilization of rapidly evolving technical mechanisms to ensure confidentiality. It also requires utilization of new strategies to ensure that consent is truly informed.

The structure of social media allows for interaction among youth who are users of these sites, ranging from close friends to total strangers. Individuals can set up a profile on a social media site and then invite their regular (offline) friends and others to communicate online. Sites allow users to limit access to selected “friends.” Once an individual allows a new “friend” into their online social network, these friends have access to the details that the user posts on their profile, and can access information on who else is in an individual’s online social network. In order for other people, including researchers, to see information beyond an individual user’s name and profile photo, they need to obtain permission from the user; this is frequently done by sending an invitation for an individual to become your “friend”; a person either accepts such an invitation or declines it. If others want to connect with
someone in the user’s social network, they need to obtain permission directly from that person. Reconnecting with real world friends’ online and making virtual friends is similar to meeting friends in a mall or a park. However, the online world erases geographic boundaries, and removes certain social cues and visual information found in face to face encounters. It may allow for a greatly expanded social network; it may also allow persons who should not be in a network to gain entrée. This could happen if an individual does not maintain vigilance over who they accept as a “friend,” and who therefore is allowed access to personal profile information. We know little about what type, if any, stress this exposure to personal profiles would incur on social media users.

Social media sites also allow for a less intimate communication between individuals and groups or organizations. Youth can “like” (i.e., join) a group or become a fan of a group—say a band, a celebrity or a cause. Once a person “likes” this group, others who have “friended” in their social network can see that they “like” this group. However, other members of this group will only see that there is a new group “fan.” They will not gain access to the new fan’s social network. Social media sites also allow youth and adults to search for others online, and to retrieve basic information about individuals from such a search. For example, if a person was interested in identifying female graduates of the class of 2008 of Washington High School, Anytown, USA who had a user profile on a site, they could do so, assuming these women indicated in their profile that they graduated from this high school. Each social media site has different privacy settings, where users can decide who can see what information about them. However, the default setting is usually public, and many users rely on the default rather than restricting access. In addition, the privacy options rapidly change, as supposed enhancements to individual’s privacy.

This brief description raises a number of issues to consider for researchers who want to conduct research ethically using social media. In this article, we will describe an ethics case study of using Facebook to deliver a sexual education program to youth and young adults, with a focus on those issues highlighted in Table 1, which include a description of potential ethical risks related to beneficence, information and comprehension, equity and special populations, and confidentiality and security.

We are attempting to reach youth at highest risk for Human Immunodeficiency Virus (HIV) in the United States, including African American and Latino youth. These populations are not consistently engaged in HIV prevention research (Jemmott, III, Jemmott, Braverman, & Fong, 2005; Essien, Meshack, Peters, Ogunbade, & Osemene, 2005; Galvan, Davis, Banks, & Bing, 2008) and our recruitment efforts in the Just/Us study on Facebook are in part to remediate this deficit. Although our focus is on sexuality and sexual health education, we recognize that growing interest in using computers, the Internet and mobile phones for chronic disease management, promotion of healthy eating and physical activity, smoking and drinking interventions suggests this information could be relevant for numerous topics in health promotion (Rodgers et al., 2005; Brendryen & Kraft, 2008; Crutzen et al., 2008; de, Veling, Ton, De, & de Vries, 2008; Kim & Kim, 2008; Webber, Tate, & Quintiliani, 2008; Bennett & Glasgow, 2009; Swendeman & Rotheram-Borus, 2010).

The Just/Us Study: Using Social Media to Promote Healthy Sexual Behavior

The Just/Us study is funded by the National Institute of Nursing Research (R01NR01492). The aims of the study are to engage youth of color in sexual health education delivered via Facebook, one of the most popular online social networking sites (Lenhart et al., 2010). The study has enrolled 1,588 youth in a randomized controlled trial, and we plan to compare any change in attitudes towards, norms for, and implementation of healthy sexual behavior among those randomly assigned to access the Just/Us Facebook page compared to those randomly assigned to access a comparison Facebook page offering news and current events, called 18–24 News. Just/Us was so named after online community discussions revealed young people wanted a social media site to allow them to go beyond information sharing to explore in greater depth the issues of sexual and reproductive rights; “Just/Us” both connotes a space only for youth, and one that addresses social and sexual justice (Levine, Madsen, Barar, Wright, & Bull, 2010).

Human subjects protection training and initial and ongoing identification of potential risks and benefits were an important part of the research team’s periodic face to face meetings and weekly conference calls. For example, at our first research team meeting, we made an exhaustive list of potential risks and ways to minimize them.

Youth are contacted in three ways—in community settings where staff sit at a table with a banner advertising the study and youth approach for more information (e.g., at community events such as festivals and fairs, on community college campuses, 4-year college campuses, and in community-based organizations serving high-risk youth), through college newspaper advertisements in
Table I. Ethical Principles and how they may be Considered on a Social Networking Site

<table>
<thead>
<tr>
<th>Ethical principles and issues</th>
<th>Issues in evaluation of technology-based health promotion</th>
<th>How the Just/Us Intervention is addressing the issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beneficence</td>
<td>Special care needs to be taken to justify why the technology modality chosen is the best for the participant, not the health promoter.</td>
<td>Over 90% of youth access Internet and social media sites, so we have unprecedented opportunity to reach youth including out of school youth or hard-to-reach youth. We are using RDS to try to tap into networks of individuals; this could potentially extend reach and beneficence.</td>
</tr>
<tr>
<td>Comprehension in informed consent</td>
<td>Lack of immediate and real-time engagement with participants at the time of program enrollment online means researchers cannot readily assess comprehension.</td>
<td>Participants are offered a brief summary of the consent; links to the detailed consent; and an e-mailed copy of the consent. Links on Facebook allow them to click directly to the consent or short facts about the study. The first question on the baseline survey asks participants to indicate if they have read and understand the informed consent.</td>
</tr>
<tr>
<td>Information and comprehension related to study procedures</td>
<td>Because interventions and data collection occur online, we need to offer multiple opportunities for people to understand study procedures.</td>
<td>See information above on allowing access to informed consent materials. Participants are asked to offer feedback on the Facebook page or on their sexual health surveys re: their understanding of the study and what we are asking them to do. Because there are groups of youth who are at higher risk for HIV and STI infection (e.g., youth of color) we have made specific effort to recruit and enroll a higher proportion of our sample from these groups.</td>
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<tr>
<td>Equity</td>
<td>“Digital divide” issues mean that the benefits and risks associated with Internet-based health promotion are not equally shared across groups. Poor and minority youth have less access to new technology interventions and are at increased risk of HIV infection.</td>
<td>Participants only are asked to “like” a Facebook page, either the intervention page (Just/Us) or the control page (18–24 News). We do not invite participants to be our friend, thus we have no access to personal information on profiles, and only have access to what is already publicly available online. Participants can invite their friends to participate and are incentivized to do so. However, they have no access to data from friends’ sexual health assessment, and eligibility requirements do not reveal anything not already of public knowledge. Participants can post information to the study Facebook page as they see fit, pages are monitored multiple times each day and incorrect or inappropriate information removed.</td>
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<tr>
<td>Confidentiality</td>
<td>There is little control over privacy in situations where evaluation data are collected online or over the phone. Facebook in particular has been involved in public scrutiny over confidentiality of its’ site members.</td>
<td>Participants have no access to personal information on profiles, and only have access to what is already publicly available online. We do not invite participants to be our friend; thus we have no access to personal information on profiles, and only have access to what is already publicly available online. We do not invite participants to be our friend; thus we have no access to personal information on profiles, and only have access to what is already publicly available online. Participants can post information to the study Facebook page as they see fit, pages are monitored multiple times each day and incorrect or inappropriate information removed.</td>
</tr>
<tr>
<td>HIPAA Data security and privacy regulations</td>
<td>Data collected in a clinical setting are Health Insurance Portability and Accountability Act (HIPAA) regulated. When collecting data in community settings or online, institutions vary in requiring researchers to follow HIPAA regulations. HIPAA regulated investigators must store and transfer electronic data using current standards for encryption, password protection, and storage behind firewalls.</td>
<td>All assessments are collected through a secured Internet site, not housed on Facebook. Data are stored behind a secure firewall within the University of Colorado. Identifiable data from sexual health assessments is accessible only to the study team; participants have a study number that they are assigned; all information about participants is accessed via this number only, and other identifiable information is stripped from the study files.</td>
</tr>
<tr>
<td>Special protection for vulnerable populations</td>
<td>Ongoing concerns regarding participant verification may require additional standards to verify are who they say they are when they enroll or participate in a program.</td>
<td>We are including children in the research where the definition of children includes those younger than 21 years of age. This represents a substantial portion of Facebook users and overlaps with the population at highest risk for STI/HIV.</td>
</tr>
</tbody>
</table>

Local city newspapers in geographic areas where youth experience higher than average rates of sexually transmitted infection (STI) including HIV, and through personal networks of study staff, who send out advertisements via e-mail. Youth who approach staff or respond to an ad are screened for eligibility using a script (aged 16–25 years; able to speak and write English; have a Facebook page; live in the United States) and invited to join the study. They complete an informed consent by reading through it online; frequently asked questions (FAQs) about the study and consent process are posted on the Facebook page. We requested, and the IRBs at Columbia and
discussed options to address them in weekly meetings, and here. When issues arose, whether anticipated or not, we emerged that we had not anticipated. We distinguish each work in Table I. Several of these we anticipated; others

We have framed several ethical considerations related to this work in Table I. Several of these we anticipated; others emerged that we had not anticipated. We distinguish each here. When issues arose, whether anticipated or not, we discussed options to address them in weekly meetings, and decisions were detailed in meeting minutes that were sent to team members and our NIH project officer.

**Beneficence**

Beneficence is presented in the Belmont report as “acts of kindness or charity that go beyond strict obligation...two general rules have been formulated as complementary expressions of beneficent actions in this sense: (1) do not harm and (2) maximize possible benefits and minimize possible harms” (Department of Health, 1979). With regard to beneficence and conducting research on social networking sites, we consider two primary issues: First, using Facebook can offer a unique opportunity to connect with young people where they are online and deliver important health information. For sexual health education in particular, we consider that young people who may be at elevated risk for negative health outcomes do not have consistent and reliable sources for complete and accurate information about sexuality. Evidence suggests that many US secondary schools do not offer complete and comprehensive sexuality education (Santelli et al., 2006). Given this evidence, we consider it important to find a venue outside schools for delivery of comprehensive sexuality education. In addition, the information provided through the schools most often uses an expert-driven, top-down learning model (Landry, Darroch, Singh, & Higgins, 2004). This is in contrast to how youth communicate freely amongst themselves and expect open communication and opportunities to set and guide interactions in communication within and across networks on social networking sites (Livingstone, 2008).

Second, we considered a waiver of parental permission in our study to be necessary operationally and ethically. We perceived little harm in waiving permission and potential benefit by encouraging adolescent participation in a potentially beneficial intervention. Moreover, adolescents demonstrate considerable ability to provide informed consent themselves (Weithorn, 1983) and often crave privacy and autonomy in matters such as HIV/STI risk behavior. Minor adolescents in all states may independently consent for STI diagnostic and treatment services without parental permission (Santelli et al., 2003); in most communities adolescents can receive sex education and HIV prevention without parents’ permission. Likewise, minor adolescents frequently seek health information on the Web without parental permission. Our intervention attempted to facilitate parental discussions by encouraging conversations on the Just/Us study page among participants about their own family relationships and discussions they’ve had. We also provided links to informational content on how to talk to parents and other trusted adults about sexual health issues.

Colorado, approved a waiver of parental permission. As minors are allowed to consent for STD testing without parental consent, research risks were minimal, and requiring parental permission was unlikely to contribute to participant protection or safety and would likely decrease adolescent participation in this type of Internet-based research project. Once they have completed an informed consent, participants take a baseline sexual health assessment online, and are randomly assigned to either the Just/Us group or the 18–24 News group (control); it is a final eligibility requirement to “like” the Facebook group page to which they have been assigned. Once they like the group, they receive multiple updates each day when they log on to their own Facebook page. They can post a comment on the group page in reaction or response to any update. If they choose, they can click on updates to get more detail, whereupon they will be linked to the group web page. Here they can read blogs, watch topical videos, or follow links for more detailed information on any number of given topics. Once enrolled, we also ask youth to help us by recruiting up to three of their Facebook friends to join the study (called wave 1); these friends can each recruit an additional three friends (wave 2), and recruitment continues for up to five waves from the initial recruit. Initial recruits are considered “seeds” in this process of respondent-driven sampling (RDS) (Iguchi et al., 2009)—the seed is randomized to either Just/Us or 18–24 News; all the friends recruited by that seed and all waves emanating are retained in the same group as the seed in order to avoid contamination between the seed and their network.

After being exposed to either Just/Us or 18–24 News for 8 weeks, we ask participants in all groups to complete a second sexual health assessment, and we ask them to complete a third at 6 months following their enrollment. Between their 8-week and 6-month assessment, they can choose to remain engaged or not with the study Facebook pages. All participants receive incentives in the form of gift cards—for baseline enrollment (worth $15) and the 8-week ($15) and 6-month ($15) follow-ups; and for each friend recruited (worth $5 for each of up to three friends recruited, $15 maximum).

**Ethical Considerations**

We have framed several ethical considerations related to this work in Table I. Several of these we anticipated; others emerged that we had not anticipated. We distinguish each here. When issues arose, whether anticipated or not, we discussed options to address them in weekly meetings, and
Third, we may be able to facilitate benefit in this study by employing the RDS procedure described above. We anticipated this approach might generate higher enrollment of youth of color, who often have limited participation in research, and therefore have limited access to research benefit (Im & Chee, 2005). RDS has been used successfully to recruit “hard-to-reach” or “hidden” populations, and many researchers employing this technique have enjoyed some success in increased enrollment by hard-to-reach participants (McKnight et al., 2006; Malekinejad et al., 2008; Iguchi et al., 2009; Uuskula, Johnston, Trummal, & Des Jarlais, 2010). However, we anticipated a substantial downside to using this technique for this study. If respondents are asked to recruit individuals for research and those eligible will qualify only if they meet specific criteria that should remain confidential (e.g., those eligible should be sexually active; active drug users; recently incarcerated, etc.) then the seed in the RDS process could be exposed to confidential information about other participants. Even information that may seem more innocuous at first glance (e.g., parents are divorced) could be confidential. Thus, anyone employing RDS needs to ensure that seeds are not privy to any information about potential participants and actual enrollees that is not already publicly available. In our study, our team discussed this in detail and determined not to inform the “seeds” which of their friends joined the study. In addition, there are many fans on our Facebook page for Just/Us who are not enrolled in the study—so one cannot discern from the list of fans who is or is not enrolled.

Information and Comprehension

We have identified three unique issues related to using social media with youth in research and transparency, shown in Table I. The first, and potentially most critical, is with regard to information to facilitate comprehension in informed consent. The youth in our study must have transparent and easily accessible information about what exactly we are doing.

While it is possible that anyone participating in research online will experience limitations in an online informed consent, we believe the Just/Us program offers an innovative approach to assure participants receive and comprehend study information. Other researchers working in the Internet environment have identified strategic ways to address these limitations and outlined them in publications, including developing bulleted consent forms that have multiple pages—each page may contain a single issue or question (e.g., what are the benefits to participating in this research?). Participants can be required to click on an “I agree and wish to continue,” button before being allowed to proceed to the next question, or an “I don’t agree and wish to exit” button. Material is presented with three to five lines of text written at an eighth grade reading level in a large font. These and other strategies for online informed consent are detailed elsewhere (Rosser et al., 2009). For this research, we are following strategies such as these. However, during a pilot implementation of study procedures we observed that youth were not particularly interested in reading informed consent materials and didn’t express any concerns about why we were asking for sensitive information or what we would be doing with participant data. As we have had few inquiries into the informed consent process in other online research (Bull, Vallejos, & Ortiz, 2008), this experience was not unexpected. However, we did wish to ensure that youth could access informed consent documents easily and quickly at any time should they decide to do so, and therefore adopted an approach of making copies of the informed consent and summaries of the informed consent and study procedures available in multiple places—via e-mail, attached to the survey, and in multiple forms throughout the Facebook pages. Participants can click on a link on the Facebook page to read the consent in its entirety. We asked participants during their risk assessment if they have read the informed consent and agree to the study procedures; only those who state that they (a) understand the risks and benefits, (b) know the study is voluntary and (c) that they can choose to continue or stop any time are allowed to proceed with their sexual health assessment.

Equity and Special Protections for Vulnerable Populations

Because this is part of a research study, those persons enrolled as control group members will not be exposed to sexuality education. We have ensured, however, that persons in the control group will have the access and exposure to health information content offered to the Just/Us intervention group by offering them an invitation to join the Just/Us Facebook group when all study participants have completed their 6-month follow-up assessment. We observed a differential enrollment by study arm; close to 40% of the sample is enrolled in the control condition and 60% in the intervention. This differential was unanticipated, and we received anecdotal information from participants in the control arm who said they were disappointed about not being able to access sexual health information immediately.

Of particular concern on the Internet, in general, is the issue of digital divide; people with fewer financial resources may have less access to computers, the Internet, and high-speed bandwidth (Lorence, Park, & Fox, 2006; Jackson
et al., 2008), although public access through schools and libraries has eased access for many young people. There is also evidence, however, that social media and sites such as Facebook are utilized almost universally by youth, making this an ideal way to access youth via technology, and potentially reducing if not eliminating issues of digital divide with younger individuals. Teens from lower income families (those earning <$30,000 annually) are more likely to use online social networks than teens from wealthier households, with more than 80% of teens from less well-off households using social networks. They gain access through schools, at after-school clubs, or through mobile phones (Lenhart et al., 2010). The demographics of participants enrolled in our study are shown in Figure 1. Given the high rates of HIV and STI infection among African American youth, we are particularly gratified by the representation of African Americans in our sample. This result was unanticipated, inasmuch as other research on Internet-based interventions has consistently shown difficulties in enrolling high proportions of people of color (Im & Chee, 2005). In addition to the strategies for RDS named above, we infer this success in enrollment is also due in part to the staff working on the project and posting to the site, which include African-American youth. In addition, the college newspaper advertisements were targeted to colleges and universities with high African American and Latino enrollment, such as historically black colleges, etc. We are unable to determine if such high representation (compared to other HIV prevention studies, (see Essien et al., 2005) is due to our recruitment strategies, staff mix, the trust that may be established through the personal endorsement of research available with RDS, or some combination thereof. This does raise a question about whether Facebook or another social networking site is appropriate for other populations, including populations given special protection under the common rule such as prisoners and pregnant women. For the former, access to social media is likely extremely limited or non-existent, making such endeavors inappropriate; for the latter, if social media can enhance or be used appropriately to address a health concern among pregnant women, it also may be a way to extend equity and benefits of research to protected groups.

Confidentiality and Data Security

There are numerous issues related to confidentiality and data security when conducting research using social media. They are related both to the way users interact on a social media site, and who can see them interacting there. In addition, there are important considerations for confidentiality related to any study data that are obtained from study participants using automated online mechanisms. Facebook is a publicly available site, and has itself been a target for discussions related to privacy. Facebook has recently re-set their own privacy settings after concerns that Facebook users were making their information too public or were not easily able to limit their information when choosing to do so (Facebook, 2010). Conducting a research study on a topic as sensitive as sexuality in such an environment requires careful attention to confidentiality.

The Facebook environment, at the time of writing this article, allows for two levels of intimacy and privacy.

![Figure 1](image-url)

**Figure 1.** Racial and ethnic distribution of participants enrolled in the Just/Us trial, n = 1,588.
The first and more intimate is represented in the relationship you have with people you invite to be your “friend” on Facebook. These people have access to all the information you post about yourself and any updates to that information, including pictures, links, videos, etc. People can also see who else you are friends with, although they cannot access detailed information about those friends without their permission or invitation. The second and less intimate connection on Facebook is through organizations, where people can “like” an organization or entity without being their friend—thus, the organization has no access beyond what anyone else on Facebook sees regarding an individual. What anyone sees regarding the individual depends on that individual’s privacy account settings on their Facebook page. Based on these settings, an individual can allow anyone to see their entire page or see no information except their profile picture. People can “like” an organization, and that organization and all who “like” them are public, open to all on Facebook. When a person “likes” an organization, all within their network get to see that they have done so.

There is a possibility for people to have a level of intimacy in between “liking” a group and being a friend. On a group page, you can be invited not only to “like” an organization (a public activity, seen by all your friends); you can also join exclusive, invitation-only groups within that organization’s Facebook page. These groups can be very private, where the identity of group members is known only to a moderator, and the only communication is between individuals and the moderator; group members may also be known to each other and the moderator, and group members can see each others’ postings, while people outside the group cannot. These settings and options are shown in Figure 2.

While we had the option to create such a group on Facebook for Just/Us, we opted NOT to use this feature. We observed in a pilot test of our intervention that people introduced to our intervention would engage with us primarily when they logged onto Facebook and saw our posts to their own news feed (an update of what all their friends and groups they belong to are doing) on their own page; they only occasionally linked to our Facebook page from their to get more information or engage with other features of our sexual education program beyond our multiple daily posts (Bull et al., 2010). We believed that recruitment of disparate and unconnected networks of individuals to our study meant we would best connect with them on their news feed, and put most of our attention to the multiple daily posts that would show up on their Facebook pages. This also required us to ensure that we didn’t ask anyone to post sensitive or personal information. We had already observed that young people are not inclined to post personal information within the group environment, as these postings also show up in their network’s news feeds. The finding that people wanted to engage primarily through news feed was unanticipated, but we really had no way to judge how people would engage with the material as this is the first study of its kind on Facebook. We should consider for future work how to effectively engage youth in a Facebook group connected to an existing educational program that could be kept private—potentially this would be effective if working with a preexisting group that already knows one another and has a level of trust, e.g., a school group, Boys and Girls Club member, Boy Scouts, etc. Regardless of whether and how you set up interaction between individuals who “like” your organization, there should be some protocols established to monitor the postings and responses to postings by people you are engaging as part of your study. Because we chose to make the Just/Us page public, confidentiality regarding posts and comments does not exist. Therefore, we developed posting etiquette protocols, and shared these with all our participants. They are guidelines for what is appropriate to post, and what is not. To date, we have not had to remove any postings; however, constant monitoring of the page and review of every posting allows us to remain poised to take down any that offer incorrect or potentially confusing information.

With Just/Us, anyone can respond to a posting, and our postings are often intentionally provocative to evoke responses and conversation among participants (e.g., What is your opinion on staying abstinent until marriage? What advice would you give to your best friend if you learned he was gay?). However, we regularly monitor all responses to our postings and remove any that are potentially offensive, misleading, incorrect or inflammatory in any way. If we feel a particular post has been misunderstood, we will add another post clarifying the intention and meaning of a post. People can report inappropriate behavior via postings to Facebook, and Facebook will remove inappropriate postings per their Terms of Service agreement. We have not had this happen during the course of this study.

We have reported on specific strategies for maintaining data security in other work (Bull, 2010). It is imperative to keep all data collection separate from Facebook, and to conduct all data collection activities off the Facebook platform. In addition, data need to be kept behind a firewall and housed on a secure server, regardless of whether you are studying sexual risk behavior or any other topic. The privacy and security settings on Facebook are owned and controlled by Facebook—if you attempt to use a Facebook platform or create one for data collection within Facebook...
you will potentially make your data accessible to Facebook staff and hackers. All links to our study survey take users to a separate website, and all data collected via this site is housed behind a secure firewall on the University of Colorado server.

Discussion

We are not aware of other interventions which have recruited adolescents and young adults and delivered a program using Facebook, although we are confident that many will follow. We offer concluding considerations for ethical protection of participants enrolled in such interventions here:

- Make sure the use of social media is justified. Is this a place where you will reach more people than you otherwise would in a face-to-face or traditional Internet or mobile phone program? Are there members of your target audience in substantial numbers on a given social media site and are you likely able to interact with them there in a meaningful and engaged way?
- Make sure you consider information and comprehension in every aspect of your program from informed consent to study procedures, to program elements. Make informed consent documents available in a number of different formats, including video, so people have multiple options from which to choose to get this critical information. It is also possible to discuss key consent topics when talking with participants prior to enrollment. While we did NOT employ this approach, instead asking them to read materials we directed them to online, having at least a brief verbal consent could increase the likelihood that young people will be exposed to consent information.
- Make sure you work to protect confidentiality. If you have criteria for enrollment that would compromise confidentiality, consider making your intervention one that is by invitation only, where people will have to leave their own page to participate in your organization’s private group. When collecting any data on participants, do so outside the social networking site entirely, and make sure you house data on a secure server with firewall protection.

When recruiting youth and adolescents online, it will likely be necessary to consider how to engage parents to obtain parental consent. In the case of Just/Us, we obtained a waiver of parental consent given legal statutes
that allow youth to seek sexual health services and information as emancipated minors. However, when doing research on topics not covered by state minor consent laws, parental consent will be an additional challenge and currently is an area where we need more information and guidance on best practices. Additionally, early research on the use of the Internet for research suggested potential for harm related to such outcomes as isolation from limited physical social interaction (Flatley-Brennan, 1998). We did not explicitly investigate or identify any potential for harm in this case study, but other research on users of My Space, another popular social networking site, shows that users may not fully comprehend how visible and accessible very private and personal information can be online (Moreno, Fost, & Christakis, 2008; Moreno, Parks, Zimmerman, Britto, & Christakis, 2009). This suggests we do need a better understanding of how to ensure that what people post either is not publicly accessible or is vetted appropriately to avoid harm if it is accessible.

In the future, research will continue with technological devices such as cell phones and smart phones. With the advent of sites like Twitter, a cell phone platform for delivering information over the phone simultaneously to numerous people within a social network, we anticipate that research at the intersection of social networking and ubiquitous computing will emerge. Similar issues regarding ethics will frame this work; in addition, more issues of confidentiality will likely be raised. For example, if a person receives a text message related to sexual health, if the cell phone keypad is not locked or password protected, the message may be accessed by anyone who picks up the phone. We are aware of research where data was collected on individual’s geographic location using GPS-enabled phones; these combined with self-input data on sexual risk were used to assess the influence of environment on individual level sexual risk (Wiehe, Carroll, Haberkorn, Wilson, & Fortenberry, 2008). While this work was approved by the Colorado Multiple Institutional Review Board, there are many additional questions such work could raise regarding potential privacy violations, for example. Finally, we anticipate that future work outlining best practices for RDS, data confidentiality and obtaining informed consent in social media environments will emerge as the field grows and develops.

As young people born today are digital natives for whom the Internet, cell phones and social media will always be a part of their world, researchers should carefully consider these and other emerging ethical considerations for development, delivery, and evaluation of health promotion when using technology.

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