Ethical Challenges Using Social Media for HIV Prevention Research Involving Youth

Brian Mustanski, PhD
Fordham HIV Ethics Institute, 2017
Overview

• My experience
• Why use the Internet for HIV and other health research?
• What are the risks of everyday internet use and how to people approach privacy?
• Case study
<table>
<thead>
<tr>
<th>Year</th>
<th>Study Title</th>
<th>Recruitment Method</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1999</td>
<td>LGBT College Student Survey of how “having sex” is defined</td>
<td>Recruited through LGBT University Student Organizations. Online survey.</td>
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<tr>
<td>2002</td>
<td>Online daily diary study</td>
<td>Recruited through free banner ads on high volume gay websites. Online survey and diaries.</td>
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<tr>
<td>2007</td>
<td>Project Q2</td>
<td>Recruited using respondent driven sampling (RDS). Follow up surveys could be done online.</td>
<td></td>
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<tr>
<td>2007</td>
<td>KEEP IT UP 1.0</td>
<td>Recruited when testing HIV negative at clinics in Chicago. Online intervention RCT.</td>
<td></td>
</tr>
<tr>
<td>2011</td>
<td>KEEP IT UP! 1.5</td>
<td>Recruited through Chicago community organization. Online intervention service.</td>
<td></td>
</tr>
<tr>
<td>2012</td>
<td>Queer Sex Ed</td>
<td>Recruited online with Facebook ads. Online sexual health education.</td>
<td></td>
</tr>
<tr>
<td>2012-2014</td>
<td>KNOW AT HOME</td>
<td>Recruited online through banner ads. Evaluation of rapid at home HIV testing</td>
<td></td>
</tr>
<tr>
<td>2012-2014</td>
<td>KEEP IT UP</td>
<td>Recruited when testing HIV negative at clinics in Atlanta, Chicago, and New York. Online intervention RCT.</td>
<td></td>
</tr>
<tr>
<td>2012-2016</td>
<td>G2G</td>
<td>Recruited online through LGBT youth oriented websites. Focus groups and text intervention RCT.</td>
<td></td>
</tr>
</tbody>
</table>
Why use the internet/technology for HIV and other health research

• High rates of use.
• Some aspects of data collection are facilitated
  – No need for data entry (still an issue offline?)
  – 24/7 data collection
• Access to geographically diverse populations
• Assess to “hard to reach” populations (sometimes through direct advertising on “mainstream sites” and sometimes through specific websites).
<table>
<thead>
<tr>
<th>Percentage</th>
<th>Topic</th>
</tr>
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<tbody>
<tr>
<td>55%</td>
<td>Specific disease or medical problem</td>
</tr>
<tr>
<td>43</td>
<td>Certain medical treatment or procedure</td>
</tr>
<tr>
<td>27</td>
<td>How to lose weight or how to control your weight</td>
</tr>
<tr>
<td>25</td>
<td>Health insurance, including private insurance, Medicare or Medicaid</td>
</tr>
<tr>
<td>19</td>
<td>Food safety or recalls</td>
</tr>
<tr>
<td>16</td>
<td>Drug safety or recalls</td>
</tr>
<tr>
<td>16</td>
<td>A drug you saw advertised</td>
</tr>
<tr>
<td>15</td>
<td>Medical test results</td>
</tr>
<tr>
<td>14</td>
<td>Caring for an aging relative or friend</td>
</tr>
<tr>
<td>12</td>
<td>Pregnancy and childbirth</td>
</tr>
<tr>
<td>11</td>
<td>How to reduce your health care costs</td>
</tr>
<tr>
<td>20</td>
<td>Any other health issue</td>
</tr>
<tr>
<td>72</td>
<td>at least one of the above topics</td>
</tr>
</tbody>
</table>

Source: Pew Research Center’s Internet & American Life Project, August 7-September 6, 2012 Survey. N=3,014 adults. Margin of error for internet users (N=2,392) is +/- 2.6 percentage points.
The internet as diagnostic tool...

1. 59% of U.S. adults have looked online for health information in the past year.

2. 35% of U.S. adults say they have used the internet to try to figure out what medical condition they or another may have. We call them “online diagnosers.”

3. 53% of online diagnosers talked with a clinician about what they found online.

4. 41% of online diagnosers had their condition confirmed by a clinician.
Impact of tracking

- 34% of self-trackers say their data collection has affected a health decision
- 40% of self-trackers say it has led them to ask a doctor new questions or seek a second opinion
- 46% of self-trackers say it has changed their overall approach to health

All health app users (n=254)

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Exercise, fitness, pedometer or heart rate monitoring</td>
<td>38%</td>
</tr>
<tr>
<td>Diet, food, calorie counter</td>
<td>31%</td>
</tr>
<tr>
<td>Weight</td>
<td>12%</td>
</tr>
<tr>
<td>Period or menstrual cycle</td>
<td>7%</td>
</tr>
<tr>
<td>Blood pressure</td>
<td>5%</td>
</tr>
<tr>
<td>WebMD</td>
<td>4%</td>
</tr>
<tr>
<td>Pregnancy</td>
<td>3%</td>
</tr>
<tr>
<td>Blood sugar or diabetes</td>
<td>2%</td>
</tr>
<tr>
<td>Medication management (tracking, alerts, etc)</td>
<td>2%</td>
</tr>
<tr>
<td>Mood</td>
<td>*</td>
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<tr>
<td>Sleep</td>
<td>*</td>
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<tr>
<td>Other</td>
<td>14%</td>
</tr>
</tbody>
</table>
What are the risks of every day internet/technology use?
How do teens think about privacy online?

% of teen social media users who say they post the following to the profile they use most often ...

- Photo of yourself: 79% (2006), 91% (2012)
- School name: 49% (2006), 71% (2012)
- City or town where you live: 61% (2006), 71% (2012)
- Email Address: 29% (2006), 53% (2012)
- Cell phone number: 2% (2006), 20% (2012)
Facebook privacy settings

Among teen Facebook users, the % with the following privacy settings ...

- Private: 60%
- Partially Private: 25%
- Public: 14%
- Don't know: 1%
### Third party access concern: Demographics

Among teen social media users, the % who express concern over third party access to their personal information, by demographic group

<table>
<thead>
<tr>
<th></th>
<th>Very Concerned</th>
<th>Somewhat Concerned</th>
<th>Not too concerned</th>
<th>Not at all concerned</th>
</tr>
</thead>
<tbody>
<tr>
<td>All teen social media users (n=632)</td>
<td>9</td>
<td>31</td>
<td>38</td>
<td>22</td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a Boys (n=308)</td>
<td>9</td>
<td>30</td>
<td>36</td>
<td>25</td>
</tr>
<tr>
<td>b Girls (n=324)</td>
<td>10</td>
<td>33</td>
<td>39</td>
<td>19</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>a 12-13 (n=151)</td>
<td>17&lt;sup&gt;b&lt;/sup&gt;</td>
<td>20</td>
<td>37</td>
<td>24</td>
</tr>
<tr>
<td>b 14-17 (n=481)</td>
<td>6</td>
<td>35&lt;sup&gt;a&lt;/sup&gt;</td>
<td>38</td>
<td>21</td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>a Less than $50,000/year (n=241)</td>
<td>12&lt;sup&gt;b&lt;/sup&gt;</td>
<td>24</td>
<td>34</td>
<td>29&lt;sup&gt;b&lt;/sup&gt;</td>
</tr>
<tr>
<td>b More than $50,000/year (n=351)</td>
<td>6</td>
<td>37&lt;sup&gt;a&lt;/sup&gt;</td>
<td>43</td>
<td>14</td>
</tr>
</tbody>
</table>
Teens don’t always have a good understanding about how their personal data is used:

Middle Schooler: “Anyone who isn’t friends with me cannot see anything about my profile except my name and gender. I don’t believe that [Facebook] would do anything with my info.”

High Schooler: “I don’t know if Facebook gives access to others. I hope not.”

High School Boy: “I don’t think [Facebook] should give anyone access to profile information.”

High School Girl: “It depends on what kind of profile information they’d share. If it was only my age and gender, I wouldn’t mind. If they went into detail and shared personal things, I would mind!”

High school boy: “I don’t think it would be fair because it is my information and should not be shared with others, unless I decide to.”
Parental concern over child's online presence

% of parents with online teens who reported varying levels of concern for their child about ...

- Very concerned
- Somewhat concerned
- Not too concerned
- Not at all concerned
- Does not apply (VOL)

Interaction with Strangers Online
- 53
- 19
- 10
- 9
- 8

Reputation Management
- 49
- 20
- 16
- 15

Information Available to Advertisers
- 46
- 35
- 12
- 7

Impact on Future Opportunities
- 44
- 26
- 18
- 11
A majority of parents check their teen’s web history or social media profile, while nearly half look through their teen’s cellphone history; fewer use tech-based parental controls.

Among parents of teens ages 13 to 17, the % who have ever...

- Checked which websites their teen visited: 61%
- Checked teen’s social media profile: 60%
- Looked through teen’s phone calls records or messages: 48%
- Used parental controls for blocking, filtering or monitoring their teen’s online activities: 39%
- Used parental controls to restrict teen’s cellphone use: 16%
- Used monitoring tools to track teen’s location with his/her cellphone: 16%

Nearly half of parents know their teen’s email password; roughly a third know the password to at least one of their teen’s social media accounts.

Among parents of teens ages 13 to 17, the % who know the password to their teen’s...

- Email account: 48%
- Cellphone: 43%
- Social media accounts (at least one): 35%


PEW RESEARCH CENTER
Impactprogram.org: What our analytics show

Repository for IMPACT’s innovative research

Sexual health resources for LGBT youth

Original videos

Weekly blogs for youth and researchers
• Keywords searched for
• How they got to site
• What network they are on (e.g. Comcast, Northwestern, US Department of Justice, etc).
Iteratively Developing an mHealth HIV Prevention Program for Sexual Minority Adolescent Men

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2Department of Medical Social Sciences, IDeCUT Program, Northwestern University, School of Medicine, Chicago, Illinois
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Original article
Ethical Considerations in Recruiting Online and Implementing a Text Messaging–Based HIV Prevention Program With Gay, Bisexual, and Queer Adolescent Males

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Article history: Received November 8, 2015; Accepted March 7, 2016
Keywords: LGBT; MSM; RTC; HIV prevention; Gay, bisexual, queer; Ethics; LGBT

Abstract
Purpose: There is a dearth of HIV prevention/health and sexuality programs developed for adolescent gay and bisexual males (AGBM) as young as 14 years old, in part because of the myriad ethical concerns. To address this gap, we present our ethically sensitive experiences implementing Gay2Gay, a text messaging–based HIV prevention/health and sexuality program, in a randomized controlled trial of 18-24-to-18-year-old sexual minority males.

Methods: Potential risks and efforts to reduce these risks are discussed within the framework of the Belmont Report: Respect for persons (e.g., risks and benefits), and justice (e.g., fair distribution of benefit and burden).

Results: To ensure “respect for persons,” online enrollment was coupled with telephone consent, which included assessing decisional capacity to consent. Consent was promoted by obtaining a waiver of parental permission and using a self-assessment instrument to help youth evaluate their risk in seeking peer support through efforts to develop and test the program among those who would be most likely to use it if it were publicly available (e.g., youth who own a cell phone and are enrolled in an unlimited texting plan), along with the use of recruitment targets to ensure a racially, ethnically, and regionally diverse sample.

Conclusions: It is possible to safely implement a sensitive and rigorous ethical protocol in place with minority youth as young as 14 years old when a rigorous ethical protocol is in place.

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Conflicts of interest: The authors do not have a conflict of interest to declare.

Disclosure: The views expressed in this study are those of the authors and do not necessarily represent the official views of the National Institute of Mental Health.

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Technology is infused in youth’s everyday lives [1], leading researchers to integrate technology into their work [2-4]. This presents unique ethical challenges, particularly in terms of confidentiality (e.g., ensuring privacy in adolescents’ study interactions) and ensuring truly informed consent [5] because youth are a group deemed by the Belmont Report to face diminished autonomy [6]; attention to these issues is crucial.
Tailoring a text-based HIV prevention program:

**Developmental phase**

1) Online focus groups
   - To develop program content and logistics
   - To tailor program for GBQ men ages 14-18

2) Youth Advisory Council
   - To test content

3) Pilot randomized controlled trial (RCT) across the U.S.
   - Test acceptability and feasibility (recruitment/retention)
   - Test efficacy (3 mos post-intervention)
Using Online Focus Groups

- Asynchronous, bulletin-board style format
- Questions posted 2x daily for 3 days
Concerns about privacy and “outing”

**QUESTIONS:** What kinds of worries do you have about texts/info on your phone “outing” you?

I think the combination of using a lock and keeping the phone on our person is the easiest way to prevent "outing."

My parent's are extremely protective...they read my texts on a regular basis. It makes me feel violated and ashamed, because I have a lot if inner turmoil about my sexuality.

“I think that the only danger would be getting outed. But, a guy who signs up for this should likely know that as a repercussion for getting such messages...you guys should make sure that these repercussions are known...”
Guy2Guy (G2G): Text-messaging HIV-prevention program:

**Aims:** To deliver healthy sexuality and HIV prevention information specifically *relevant to young men (14-18) who identify as gay, bisexual, queer (GBQ).*

- 6 healthy sexuality modules focused on supporting HIV preventive behavior:
  - Condom use
  - Abstinence
  - Healthy sexual decision-making
- A “text-buddy” program
  - Guys connect via text with other guys
- Other Resources
  - Website for parents and teachers
  - G2Genie
RCT design

- Randomized controlled trial (n=302), balanced on sexual identity and sexual experience.
- We purposefully recruited the sample to be 50% sexually experienced and equivalent across age groups (i.e., 40% were 14-15 years of age)
- Control group was blinded and attention matched
- Intervention content tailored on sexual experience
Eligibility criteria

• 14-18 years of age
• Cisgender (male sex assigned at birth and male gender identity)
• Self-identify as: gay, bisexual, and/or queer
• Owns cell phone
• Enrolled in unlimited text messaging plan
• Has texted for at least 6 months
• Plans to have cell phone number for at least 6 months

Image from: http://newsfeed.time.com/2011/05/08/fox-affiliate-is-glee-gay-teen-propaganda/
**Participant demographics (n=302)**

<table>
<thead>
<tr>
<th>Personal characteristics</th>
<th>Control (n=152)</th>
<th>Intervention (n=150)</th>
<th>P-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic characteristics</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age (Range: 14-16)</td>
<td>16.3 (1.4)</td>
<td>16.0 (1.3)</td>
<td>0.07</td>
</tr>
<tr>
<td>Non-white race</td>
<td>34.2% (52)</td>
<td>30.7% (46)</td>
<td>.51</td>
</tr>
<tr>
<td>Hispanic ethnicity</td>
<td>23.7% (36)</td>
<td>20.7% (31)</td>
<td>0.53</td>
</tr>
<tr>
<td>Sexual identity</td>
<td></td>
<td></td>
<td>0.74</td>
</tr>
<tr>
<td>Gay</td>
<td>69.1% (105)</td>
<td>76.0% (114)</td>
<td>0.18</td>
</tr>
<tr>
<td>Bisexual</td>
<td>39.5% (60)</td>
<td>36.7% (55)</td>
<td>.62</td>
</tr>
<tr>
<td>Queer</td>
<td>7.9% (12)</td>
<td>8.7% (13)</td>
<td>0.81</td>
</tr>
<tr>
<td>Sexual experience</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vaginal sex</td>
<td>14.5% (22)</td>
<td>11.3% (17)</td>
<td>.42</td>
</tr>
<tr>
<td>Receptive anal sex</td>
<td>36.8% (56)</td>
<td>38.0% (57)</td>
<td>0.84</td>
</tr>
<tr>
<td>Insertive anal sex</td>
<td>36.2% (18)</td>
<td>31.3% (47)</td>
<td>.37</td>
</tr>
<tr>
<td>Belmont Report components</td>
<td>Potential ethical issue</td>
<td>How Guy2Guy addressed them</td>
<td></td>
</tr>
<tr>
<td>--------------------------</td>
<td>----------------------------------------------------------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Respect for Persons</td>
<td>Obtaining informed assent with an online recruitment protocol</td>
<td>Enrollment occurred over the phone so that research staff could gauge whether the participant understood the assent.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Obtaining informed assent from a group with diminished autonomy (i.e., children)</td>
<td>The assent form was written in easy-to-understand language, and the capacity to consent ensured that all children who enrolled understood the risks and voluntariness.</td>
<td></td>
</tr>
<tr>
<td>Benefit</td>
<td>Require parental permission can potentially harm sexual minority youth, due to discrimination and stigma</td>
<td>We requested and were granted a waiver of parental permission by both IRBs involved in the study.</td>
<td></td>
</tr>
<tr>
<td>Privacy and confidentiality</td>
<td>If youths’ phones are lost or intercepted, the text messages on the phone could result in a loss of confidentiality of their sexual identity</td>
<td>We created a self-safety assessment to help youth determine whether they could take part in the study safely. We also provided how-to instructions to help youth change the settings on their phone to increase their privacy (e.g., adding a password).</td>
<td></td>
</tr>
<tr>
<td>Justice Fair distribution of benefits and burdens</td>
<td>The choice of participants needs to be considered carefully to ensure that groups are not selected for inclusion mainly because of easy availability, compromised position, or manipulability</td>
<td>Although we used Facebook as our main recruitment source, which means we attracted youth who were easily available and perhaps manipulable (e.g., they clicked on our advertisement); we developed a complex and rigorous safety protocol.</td>
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<tr>
<td></td>
<td>Equity: The digital divide may mean that those who are least likely to have access to HIV prevention programming designed for AGBM are also least likely to be in the recruitment pool</td>
<td>We used Facebook, the most popular social network among adolescents, to increase the likelihood of reaching a wide pool of AGBM.</td>
<td></td>
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<tr>
<td></td>
<td>When research leads to the development of new treatments, procedures, or devices, justice demands both that:</td>
<td>Our hypothesis is that text messaging represents an opportunity to put sexual health and HIV prevention programming in the hands of youth. As such, we thought it important to develop and test the program among those most likely to take part in a similar program in the “real world”: those who currently own their own phone, use text messaging, and are enrolled in an unlimited text messaging plan.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• These advancements are provided to those who can benefit from them, and</td>
<td>The enrollment algorithm also set targets based upon race and ethnicity.</td>
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<td></td>
<td>• The research should involve persons from groups who are likely to benefit from subsequent applications of the research</td>
<td>We included participants as young as 14 years old, and our enrollment algorithm ensured that 14- to 15-year-olds represented 40% of the study sample.</td>
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</tbody>
</table>

The descriptions of Belmont Report components and the potential ethical issues were based on those presented in the National Institutes of Health online human subjects research course [22].

AGBM = adolescent gay and bisexual males; IRB = institutional review board; YMSM = young men who have sex with men.
Implementing protections

• Enrollment/consent
  – Safety assessment (consequences of if someone saw messages) and privacy assessment (who has access to phone, tech to increase privacy).
    • If in doubt, don’t participate.
  – “How to” guides written on how to protect privacy.
  – 2 YMSM decline to participate during this assessment.

• Text Buddy
  – Code of conduct
  – Paired by level of sexual experience
  – Messages routed through our server; no images; flagged words and contact information. Ongoing monitoring on interactions.
  – Live far apart
  – Interactions:
    • 1/3 received warnings about code infractions.
    • 54% discussed intervention content
    • 27% shared coming out stories
    • 4% disclosed self-injury behaviors
Thank you

• brian@northwestern.edu
• Impactprogram.org
Thank you funders and Institutional Support

Thank you staff

IMPACT SUPPORTS #SPIRITDAY