IS PRIVACY DEAD?:
ETHICAL CONSIDERATIONS FOR ONLINE RESEARCH

Nick Getzendanner, MEd, CIP
Coordinator, Social and Behavioral IRB
Evanston, IL
“People have really gotten comfortable not only sharing more information and different kinds, but more openly and with more people. That social norm is just something that has evolved over time.”

-Facebook CEO Mark Zuckerberg, in a 2010 interview
OBJECTIVES:

1. To describe the online environment and the different types of Internet research.

2. To describe the challenges Internet methodology poses on traditional IRB thinking.

3. Present guidance on ethical considerations for protecting participants and your research when working online.
The IRB’s sole mission is to ensure that the rights, safety, and welfare of participants in research are protected.
Factors that inform the IRB re: the ethical conduct of research:

- Codes of Ethics
- Standards of practice
- NU HSPP 5.0
- Moral philosophy
- Framework for ethical decision making
- Moral Virtue
- Academic / Professional Values
- Ethical decision making
- Legal / Regulatory Standards
- CFR, FDA, FERPA, HIPAA, MHDDCA
The Online Environment
DEFINING “INTERNET RESEARCH:”

1. Using the internet to collect data or information through online interviews, surveys, archiving or data scraping.*
   a. Mobile devices: Geo-location, in the moment feedback

2. Studying how people use the Internet through collecting and observing activities or participating in social media:*
   a. Communication: blogs, forums, chat rooms, reviews, social media such as Facebook, LinkedIn, etc.
   b. Entertainment: YouTube, music, games, and virtual worlds (Second Life, World of Warcraft, etc.)
   c. Collaboration: project and document management, cloud, wiki’s, Google docs, data repositories, etc.

*From PRIM&R webinar, 3-12-2013
**BENEFITS OF ONLINE RESEARCH:**

**For surveys:**
1. Much larger sample size is possible, including international participants
2. Cost effective, with easy to use online survey tools which help manage data
3. Can more easily find rare populations, or use existing subject pools.
4. Participants tend to be more honest about socially undesirable behaviors.

**For observation of internet use:**
1. Massive amounts of data available to be mined
2. Can observe w/o disturbing the environment
THE ETHICAL CHALLENGES OF ONLINE RESEARCH:

- It’s easy to collect more data than you need

- Information can travel quickly across sites/platforms

- Information is traceable (trackback-able?)

- Information can be merged from multiple contexts and multiple venues online.
ETHICAL CHALLENGES ONLINE (CONT):

Re: participants:
1. Harder to foresee harms.
2. Verifying participants is difficult.
3. Fraud is easier.

Re: methodology:
1. Confidentiality can be harder to protect.
2. Concerns about the reliability and validity of the data.
3. If not set up correctly, dissatisfied participants can slam a study with negative comments and/or bogus data.
4. When using third party sites/apps, researchers are at the mercy of ever-changing Terms of Service (TOS).
TRADITIONAL IRB CONCERNS:

1. Voluntary participation.
2. Privacy and confidentiality.
3. Informed consent.
4. Risk / benefit analysis.
5. Use of deception.
6. Data Collection, data management and data protection.
7. Protection of vulnerable populations.
KEY AREAS WHERE ONLINE RESEARCH CHALLENGES
OUR IRB THINKING:

1. Private vs public forum?
2. People or text?
3. Virtual world or virtual environment as ‘place.’
4. What is “identifiable information” in a virtual world?
PRIVATE VS PUBLIC FORUM

- Conventional thinking: Behavior in the public domain may be observed and researched w/o consent.
  - Offline: one can see who is around them, and physical features define space
  - Online: unclear who’s watching
- Consider: What is the person’s expectation of privacy?
  
  Ex) Colon Cancer Support Group vs Patients Like Me website
PEOPLE OR TEXT?

• **Human subject**: a living individual about whom an investigator conducting research obtains (1) data through intervention or interaction with the individual; or (2) identifiable private information.

• Is an internet post akin to a private diary or a published work?

• Are researchers to keep subject identity confidential, or is it a violation of intellectual property to not credit the author.

  -No easy answer. Again, consider the intended audience, expectation of privacy, site norms.
EXAMPLE: “TASTES, TIES, AND TIME” DATASET

In 2008, Harvard researchers* release T3 dataset, containing info and posts of 1,700 students’ Facebook accounts, collected at 1 year intervals over their 4 years of college.

Study received IRB-approval, the approval of the college, and complied with Facebook’s terms of service.

Per research team: all collected data were publicly available and all identifying information was anonymized.

However...

Within days, numerous users were able to determine Harvard was the school, and many individual students were able to be identified.

Certain RAs were “friends” with some students in dataset, had access to private information that was then made public.

Study of public behavior online is very different than offline (Permanency of online data vs limited observations in real world)
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Real world applications:
RESEARCH METHOD: RECRUITING PARTICIPANTS:

IRB issues: transparency, voluntary participation.

1. Similar issues as with any way of recruiting: IRB needs to review information presented to subjects.
   - Using social media and micro blog advertising (i.e. Twitter) has to lead to a typical flyer or information sheet.

2. Recruitment can spread beyond your control.

3. Depending on risk: need to have a way to determine that subjects are who they say they are.
RESEARCH METHOD: COLLECTING SURVEY DATA ONLINE:

IRB issues: Consent; minors; confidentiality and data security; compensation; International considerations.

1. Most typical: subjects submit survey data using a third party site such as SurveyMonkey, Qualtrics, Amazon M-Turk, etc.

2. First page of survey is the consent. IP addresses?

3. Collection of identifiers for compensation—separate from data

4. Invitation for further data collection via offline interview.

5. If asking about suicide, have a plan to monitor data regularly, intervene when appropriate.
RESEARCH METHOD: TRANSMISSION OF DATA:

IRB issues: confidentiality; informed consent.

1. Having an adequate data security plan for the collection and transmission of data can require some skills that not all have.

2. Cloud computing.

3. Understanding where data ‘resides’ and who owns it is not always clear.

4. International travel can affect data security.
DEALING WITH FRAUD

• Compensation amount, recruitment method, and nature of study tasks influence likelihood

• Collecting IP Address, failed eligibility screener data can help, but not foolproof

• If study involves multiple tasks, segment payment

• If using survey, add dummy questions: ex “Please select ‘c’ for this item”
How to think about research online
QUESTIONS TO ASK WHEN UNDERTAKING ONLINE RESEARCH (ADAPTED FROM: ASSOCIATION OF INTERNET RESEARCH, 2002):

The environment:

1. “Where” does the interaction or communication under study take place?

2. What ethical expectations are established by the venue? Read the agreements / ask moderators and get permission when appropriate.

3. Who are the subjects / authors / creators of the material and/or interactions under study?
   • You have to contend with whether an Avatar or an online identity is a “person”.
QUESTIONS TO ASK WHEN UNDERTAKING ONLINE RESEARCH (CONT.):

Voluntary participation and Informed consent:

1. What are the expectations/assumptions of the authors/people being studied?
2. Regardless of that, what ethically significant foreseeable risks does the research entail for the subject(s)?
3. Are there unforeseeable risks?
4. What are the ethical traditions of researchers and subjects’ culture and country?
WHAT NU-IRB THINKS ABOUT THESE THINGS:

1. No, privacy is not dead.
2. Online research is great for Exempt, minimal risk projects.
3. We have not figured out a way to get parental permission online for their minor child to participate.
4. There is an increase in research using apps. Not sure where this will go but we work with researchers on a case-by-case basis.
5. We are evolving in our understanding of the possibilities—make your case. We will listen.
The BIG Question

How does Belmont apply?

Respect for Persons
Beneficence
Justice
QUESTIONS?
Nick Getzendanner, MEd, CIP
IRB Coordinator II
PH: 847-467-2203
n-getzendanner@northwestern.edu

Kathleen Murphy, PhD, CIP
IRB Manager
PH: 847-467-1723
kemurphy@northwestern.edu

Chambers Hall, 2nd Floor
www.research.northwestern.edu/oprs/irb