Role of the Internet in Research

• **Internet as a Tool**
  - Used to *facilitate* research activities
  - e.g. to recruit, store database, or host surveys
  - Increasing popularity of mobile apps to inform participants and record data

• **Internet as a Source**
  - Used as an actual *data source*
  - e.g. observing forums/sites/blogs, manipulating online platforms, scanning social media
Regulations and Policies

• **Limited Guidance Exists**
  • No specific Emory policies on internet research yet; must interpret broader regulations to fit

• **Same Primary Considerations**
  • Nature of the study
  • Recruitment Procedure/Criteria
  • Obtaining Consent
  • Privacy and Security of Data
Regulations and Policies

• Raises Considerations Like:
  • Is observing a Facebook group “research?”
  • What information is “private?”
  • How can you ensure informed consent, is it necessary?
  • Can I verify a subject’s age?
Research Design

• The IRB Reviews **Research with Humans**
  • Research = investigation to find generalizable results

• Human Subject = living individual about whom a researcher obtains private information
Research Design

• **When is it “Research?”**
  • Basically, when it’s not QA/QI, clinical treatment, or public health surveillance
  • Tricky distinction for some product evaluation projects
Research Design

• Examples of what may be internet “research”
  • Online surveys
  • Behavioral studies in virtual worlds
  • Apps on hand-helds to gather data
  • Study of personal website content or social profiles
  • Niche social networking sites or forums like “mydiabetes.com”
  • Facebook page to retain subjects in cohort study
  • Online focus groups
  • Mechanical Turk
Research Design

• When are there “Human Subjects?”
  • Interaction or intervention with people
    • e.g. Surveys, social media contact, forums

• Individually identifiable private information
  • Private = information reasonably expected not to be observed/recorded, OR information provided for specific purposes expected to remain private (e.g. med records)
Research Design

• **Private Information**
  • Simply “Not Public”
    • Restrictions on access (e.g. “friending” or “following”)

• **Public but Specific Purpose**
  • e.g. Unrestricted social media profile, blogs, networking group
    • Confusing privacy settings an excuse?
    • How is this different from observing on the street?

A HELPFUL VENN DIAGRAM
Research Design

• Debate about the Space: Public vs. Private
  • Public?
    • “Authors” of public “documents” or “texts”
    • Anyone posting online must be aware that these systems are meant for storage, transmission, and retrieval of data
  
  • Private?
    • “Subjects” of research
    • Internet data expected to be “ephemeral,” not recorded
    • Many people just don’t know
Population

- **Primary Considerations:**
  - **How** will you recruit?
    - Targeted ads?
    - Mass emailing?
    - Join certain forums?
  - **What** screening procedures?
    - Series of questions? In what order?
    - Collecting PHI?
  - **Who** will you recruit?
    - Need to verify criteria are met?
    - Chance of enrolling minors?
Population

• Example of Recruitment with Screening

Compensated Depression Clinical Research Study Enrolling Today. (Atlanta, Smyrna)

Date: 2012-04-24, 10:37 AM EDT
Reply to: ferns.2576217661@job.craigslist.org

Are you or a loved one depressed and have a hard time functioning? If so, explore new and free treatment options with AcurianHealth.

NO RELIEF FROM DEPRESSION SYMPTOMS?

Quality for a clinical research study and you may receive:
Free depression medication, including 
FDA-approved medication
Compensation of up to $800 for your time

Act Now. Click Here.
www/yourdepressionOptions.com

We’re currently looking for people with depression who may be willing to participate in a research study. If you qualify, you may receive:

• Free depression medication ... in some cases, FDA-approved medication
Population

• When Recruitment Turns into Screening

WILL I BE IDENTIFIED?

No. We do not require you to provide any information that identifies you. We do ask you for your zip code and birthdate to make up a unique identifier that only you will know. This is necessary to register for the study. We will also ask you to provide an email address so we can contact you if there are any problems during the study. All email addresses will be deleted at the end of the study. Because we are asking sensitive questions, we have obtained a Certificate of Confidentiality from the National Institutes of Health. The researchers will use this certificate to challenge any demands for information that would identify you. For more information, press here.

I understand that the study is confidential, and that only an email address will be used to contact me during the study

I CONSENT and wish to enter the study →

← I DO NOT CONSENT and wish to leave the study
Population

- How NOT to recruit and screen before consent:
Informed Consent

**Private and Non-sensitive**
- Harmless info from FB page where user might treat it like private space
- Person talking about own experience of sexual abuse in a private discussion

**Public and Non-sensitive**
- Quote from person’s online journal article

**Private and Sensitive**
- Potentially damaging info from FB page where user might treat it like private space

**Public and Sensitive**

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OUTLINE

- Internet’s Role
- Regulations
- Research Design
- Population
- Informed Consent
- Data Security
- Examples
Informed Consent

• Can waive documentation (signature) for minimal risk research (45 CFR 46.117)

• Click a button or continue on to survey/intervention

• Is reading enough?

• Do people even READ on the internet?
Informed Consent

• Particular concerns about anonymity and confidentiality
  • Consider the following advice from Survey Monkey:

Informed Consent

• Be sure to include a consent form for your online survey. This should be on the first page of your survey. Here is a good example of a survey consent form: https://www.surveymonkey.com/consent

• Please be sure to include a data confidentiality statement in your consent form. Don’t make guarantees to confidentiality or anonymity.

• SurveyMonkey records the respondent time stamp. This is important especially for respondents that consented to taking your survey.

• The survey should allow for “no response” or “prefer not to respond” as an option for every survey question. A survey where a respondent cannot proceed without answering the question is in violation of the respondent’s right to withhold information.

• At the end of the survey, the respondent should be given an option to withdraw from survey.
Informed Consent

- This may be an area that you will want to consult with an IRB analyst during study submission
- May waive certain elements of consent
- Viewed on a case-by-case basis
Data Security/Privacy

• Additional Security Concerns Online
  • Use of avatars or alternate identities
  • IP address and the ability to track
  • Need to encrypt data
  • Standard security measures may not suffice
    • Simple virus protection or
    • Secure browser
Data Security/Privacy

- **Harvard T3 Facebook Study**
  - Collected data from 1,700 Facebook accounts
    - Thought to be public, no consent needed
  - Studied “students at an anonymous, northeastern American university”
  - Published entire “cleaned” dataset as required through NSF, but...turned out to be re-identifiable
Data Security/Privacy

- Harvard T3 Facebook Study
  - Also raised concerns about consent, should the researchers have obtained consent?
  - “The T3 research project might very well be ushering in “a new way of doing social science”, but it is our responsibility scholars to ensure our research methods and processes remain rooted in long-standing ethical practices. Concerns over consent, privacy and anonymity do not disappear simply because subjects participate in online social networks; rather, they become even more important.” – Michael Zimmer, information ethics and policy scholar at University of Wisconsin-Madison

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Examples

Facebook’s recent “social experiment”
• Users news feeds (main log-in screen) were modified to include more posts of a particular mood
• The researchers then tracked the user’s personal posts, to see if they matched the mood
• Raises questions of the need to consent, reliance on terms and conditions, and potential risk about altering subjects’ moods
Examples

Study where data is to be mined solely from public twitter accounts

• What would the IRB consider when reviewing such a study?
  • Is it “research involving human subjects?”
  • Is the information *truly* public?
  • Will identifiers be recorded?
  • How will data be presented following analysis? (e.g. direct quotes from tweets?)

• Practical advice is to go ahead and submit these types of studies for the IRB to review, even if not obviously human subjects research
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