Social Media and Human Subjects Research

Human Research Protection Program & OIT Research Computing Support
Social Media & Human Subjects Research

Social media as a research site

Social media as a recruitment tool

Want to take a survey?

[YES] [NO]
SOCIAL MEDIA AS A RESEARCH SITE
Social Networking Sites

- Allows users to create public profiles within that site and form relationships with other users on the site who can access their profile.
  - Facebook
  - Twitter
  - YouTube
  - LinkedIn
  - Dating apps
  - Reddit
  - Tumblr
  - Twitch
  - Blog sites
  - Comment sections on public webpages, community-based forums, etc.
Social media as a Research Site

• If research using social networking sites involves either of the items below, then **MUST** submit IRB application

  Collecting data through intervention or interaction (e.g. surveys, manipulations),
  **OR**
  Collecting identifiable private information
Identifiable Information

- Name
- Email address
- Home address
- Phone number
- Pictures
- Usernames
- Direct quotes
- IP address
- Indirect identifiers
Private Information

- Information about behavior that occurs in a context in which an individual *can reasonably expect that no observation or recording is taking place*, and

- Information which has been provided for specific purposes by an individual and which the individual *can reasonably expect will not be made public*
Publicly Available Data

• Just because it’s on the internet does not mean it’s publicly available!
• Consider the **expectation of privacy**
• Some sensitive or personal information shared online may be publicly available but publishing it could cause embarrassment and/or reputational harm.
“Imagine Sam, an adolescent, makes a post in an online forum about their depression and struggles with drug and alcohol dependency, identifying themselves by their full name in the post. If this online forum is considered “public,” collecting and using Sam’s information for research purposes (including quoting it in publications in ways that identify Sam) may be exempt and not require informed consent from Sam. Other protections associated with IRB review, such as privacy and confidentiality safeguards, may also not be required. The same is true for any other sensitive posts made in a “public” internet space. Because of this, research using such information potentially amplifies privacy risks inherent in online and social media interactions, further calling attention to ill-advised posts and potentially leading to privacy risks and harms for internet users.”

https://www.advarra.com/blog/public-v-private/
## Type of IRB Review Required

<table>
<thead>
<tr>
<th>Study Characteristics</th>
<th>Review Likely not Needed*</th>
<th>May Meet Criteria for Exempt 4*</th>
<th>Expedited or Full Board Review Likely Needed*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Website Access</td>
<td>Publicly available with no log-in required</td>
<td>Log-in required, but users can choose to make information public</td>
<td>Log-in required; approval by group moderator required</td>
</tr>
<tr>
<td>Researcher interaction with person who posted</td>
<td>None</td>
<td>None</td>
<td>Yes</td>
</tr>
<tr>
<td>Subjects can be identified</td>
<td>Information is not identifiable or is identifiable but publicly available</td>
<td>Information is not identifiable or is not identifiable but publicly available</td>
<td>Information is identifiable and private</td>
</tr>
<tr>
<td>Disclosure of data could place subjects at risk</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
<tr>
<td></td>
<td>*all four characteristics must be met</td>
<td>*all four characteristics must be met</td>
<td>*if any of the four characteristics are met, expedited or full board review likely</td>
</tr>
</tbody>
</table>

*all four characteristics must be met
Social Media Scraping

• Software or programs that allow researchers to pull large quantities of user data from the internet
• Require account, subscription, payment to use
• Check with the IRB if using these tools
Best Practices when Scraping Data

• De-identify data when possible
  • direct quotes, images, and videos can be identifiers

• Use pseudonyms instead of real names when reporting results

• If applicable, submit the hashtags for IRB review

• Make sure you know whether you are pulling data from accounts that are set to private or public access
Data Collection using Wearables

- Participants wear or use a piece of smart technology, such as a smart watch, to collect research data
- Requires IRB review
SOCIAL MEDIA AS A RECRUITMENT TOOL
Social Media for Recruitment

Benefits
Easy access
Cost effective
Time efficient

Disadvantages
Privacy concerns
Control of recruitment
Quality vs. quantity
Social Media for Recruitment

- Use a JPEG for recruitment post on social media.
- Text of the post can contain the link and a brief description but place any mention of compensation in the JPEG.
- Submit to IRB as Word Document
  - Once approved make recruitment poster/script a JPEG.
- Harder for bots to scrape and auto-fill surveys.

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Social Robots for People with Alzheimer’s Disease

Researchers at the University of Tennessee invite you to conduct a research survey on social robots for assisting daily activities of people with Alzheimer's disease and related dementia. To participate, you will watch a short video (<3 mins) and answer some questions (<10 mins).

- Your participation is completely voluntary.
- The survey is truly anonymous.
- We do not know who is receiving the survey or who is responding.
- There are no foreseeable risks associated with this survey.
- You can skip any questions and quit the survey at any point.

Contact: Prof. Xiaopeng Zhao  
Department of Mechanical, Aerospace, and Biomedical Engineering  
University of Tennessee, Knoxville TN 37996  
Email: xzhao9@utk.edu

Here is the link for the survey:  
https://robot4adrds.questionpro.com

Detection, Care, and Treatment of Alzheimer's Research and Related Dementia.
Protecting Against Bots

- Include: attention checks
- Repeat: qualifying questions at the beginning and end
- Add: captchas
- Use: unique identifiers for different groups
Options to help reduce and identify fraudulent responses.

- **Security Settings:**
  - Bot detection (uses silent reCAPTCHA)
  - Security Scan monitor
  - ReleventID

- **reCAPTCHA question**
  - Can be inserted anywhere in the survey

If you recruit through social media and you are offering compensation for all completed responses, it is very likely you will receive some fraudulent responses.
Further Questions?
OIT Help Desk at 865.974.9900
or
HRPP at utkirb@utk.edu
865-974-7697