

## Guidance on Research using Social Networking Sites

### PURPOSE

Social networking sites (SNS), which include social media websites, have become increasingly popular in human subjects research, in large part because of the high accessibility and low cost. This document, which does not encompass all scenarios, serves as guidance for those who are conducting or reviewing research that involves SNS. SNS research conducted with identifiable subjects should observe special precautions and may be subject to IRB oversight. These guidelines serve to encourage IRB-compliant SNS research while ensuring that social media ethics do not result in indirect censorship of important research.

### DEFINITIONS

**Social Networking Sites (SNS):** Any website that enables users to create public profiles within that website and form relationships with other users of the same website who can access their profile. Social networking sites can be used to describe community-based websites, online discussion forums, and social media websites.

Some examples include, but are not limited to: Facebook, Twitter, Instagram, YouTube, LinkedIn, dating websites and apps, Reddit, Tumblr, 4Chan, Twitch, TikTok, WeMe, Omegle, and blog sites and comment sections on public webpages.

**Human subjects research:** A living individual about whom an investigator (whether professional or student) conducting research obtains:

1. Data through intervention or interaction with the individual, or
2. Identifiable private information.

If research using SNS involves either of the above, then the investigator MUST submit an application to the College's IRB.

**Intervention:** 1) Physical procedures by which data is gathered (e.g., surveys, focus groups, experiments, etc.) and 2) manipulations of the subject or subjects' environment performed for research purposes.

**Interaction:** Any communication or interpersonal contact between investigator and subject through any medium.

**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.

**Expectation of Privacy:** Privacy is the expectation that confidential personal information disclosed in a private place will not be disclosed to third parties, when that disclosure would cause either embarrassment or emotional distress to a person of reasonable sensitivities. Information is interpreted broadly to include facts, images (e.g., photographs, videos), social media postings, and disparaging, controversial, or personal opinions.

The right of privacy is restricted to individuals who are in a physical place that a person would reasonably expect to be private (e.g., home, hotel room, telephone booth) or in select online settings (such as private (i.e., protected) social media accounts, private forums, or information posted under an anonymous username). Online privacy settings may vary based on individual site rules and intent (e.g., a public Twitter account will have different expectations of privacy than an anonymous Reddit thread or Instagram account placed on “private”). The intent of the post or expectation of the poster may also be considered when determining privacy. For example, usage of a hashtag in a Tweet clearly aims for broad readership and the user is unlikely to expect privacy.

A post in a Facebook group or similar forums has additional considerations. First, it is important to consider the privacy settings for that group. A post in a public Facebook group or public forum would not have an expectation of privacy, whereas a secret group or one with posted rules about not sharing users’ posts would have an expectation of privacy. In addition to the privacy settings, the number of users in a group or forum can also impact whether there is an expectation of privacy. For example, there would not be an expectation of privacy for a post in a Facebook group that is private but has thousands of members.

**Celebrities or public officials** who use social media do not have an expectation of privacy. Any information gathered from these users’ social media postings should be considered publicly available data.

## **TYPES OF RESEARCH USING SNS**

### **1. Passive Information Gathering**

Passive information gathering or data mining will be considered human subjects research if there is collection of identifiable private information.

#### ***Terms of Service***

It is important to check the legal requirements, often called the Terms of Service, with the social networking site. For example, Twitter’s Privacy Policy has included the use of tweets as research since 2014. Some sites are more restrictive than others. Some sites may require the researcher to be a member before they are granted access while others are accessible without a login.

Some forums may not have official rules but have moderators who control the information within the forum. It is important to have permission from the site moderator before conducting research in those sites. In addition, platform terms and conditions should be consulted to determine limitations on sharing datasets.

#### ***Public Observation***

It is important to understand what is considered Public Observation when observing online spaces. If the research activity consists of Public Observation then the IRB application may qualify for Exempt review. For IRB consideration, only webpages that are accessible without a user login are considered Public Observation.

Some social media, such as Twitter and TikTok, are entirely public, as tweets and videos can be accessed without having an account or being logged in. Other social media, like Facebook, are a

mixture of public and private. Facebook consists of public pages and private groups, so it is important to include what the privacy settings are in the IRB application, if review is required.

### ***De-identification***

It is best practice to de-identify research data, even if it is considered a public observation. It is important to consider that direct quotes, images, videos, or more from research subjects obtained through public observation online can allow for re-identification through search engines. Because of this, it is best practice to request permission from the research subject before using direct quotes, imagery, or videos. If it not feasible to contact the subject, a waiver of consent may be appropriate if justifiable.

### ***Use of pseudonyms, Avatars, and personas***

The use of pseudonyms online, sometimes called Avatars or personas, is common practice on some SNS. Personas are considered human subjects and should be treated as such. It is not appropriate to identify the real person behind an online persona.

### ***Data repositories***

See Guidance on Using Pre-Existing Data and Public Data Sets

### ***Waiver of informed consent***

A waiver of informed consent may be appropriate for minimal risk studies.

## **2. Interacting with the research participant or modifying their environment**

### ***Manipulation of the media environment***

This type of research involves interaction or intervention of the human participant's environment; therefore, it is considered human subjects research. An IRB application must be submitted. One example of manipulation of the media environment is the 2014 Facebook Emotional Manipulation Study, in which Facebook altered users' feeds without consent to reflect either majority negative or positive posts and monitored their subsequent site activity.

### ***Interviews using randomized chat forums***

This type of research involves connecting with randomly assigned users on chat forums such as Omegle or Chatroulette. Researchers can use these SNS to connect with potential research participants to interview. Informed consent must be provided by the participant before any data collection can begin. In these instances, the IRB recommends requesting a Waiver of Documentation of Consent so that consent can be provided orally by potential participants.

### ***Deception***

Deception in SNS research must be described in the IRB application. See Deception in Research Guidance.

### ***Stand-alone Applications***

Research that requires a participant to install an app for data collection on the participant is considered human subjects research.

### ***Wearables or Other Smart Devices***

Research that requires a participant to wear or use a piece of smart technology, such as a smart watch, for data collection purposes is considered human subjects research.

### **3. SNS as a Recruitment Tool**

Due to the ease of use and potential reach from SNS, it is common to use social media for recruitment of research participants. It must be described in the IRB application, and the text of the recruitment post, including any hashtags or images, must be submitted along with the application.

### ***Informed Consent***

Informed consent must occur independent of the recruitment procedures. Data cannot be collected prior to consent.

### ***Waiver of Informed Consent***

The research team is not required to obtain consent orally or through documentation. For minimal risk studies, a waiver of informed consent may be appropriate, and participants can be informed of the research purpose in the recruitment document only. For example, if a researcher is using a scraping tool to analyze Tweets, it may not be possible to contact all the data subjects. Waiver of informed consent must be justified in the IRB application.

### ***Waiver of Documentation of Consent***

The study team must provide a subject with the required consent information, but the study team is not required to obtain the subject's signature on the informed consent document. In other words, consent may be obtained orally; applicable when the only identifiable link between the subject and study would be a signature. Examples include: a social media post by the researcher that states that "replies to this post will be part of the research data" would qualify as a waiver of documentation of consent.

### ***Vulnerable Populations***

Safeguards must be considered for vulnerable populations, especially children in SNS settings. Parental permission is required for participants under 18. Federal research regulations require parental permission and minor assent from study participants under the age of 18 years, unless a waiver of parental permission is obtained. The IRB will consider the risk level and content of studies that involve collecting data from minors on social media sites.

This is a topic best addressed on an ad hoc basis based on whether or not minors are the targeted population.

### **4. Anonymous survey websites**

Sites such as MTurk, Qualtrics and Prolific offer recruitment, consent, and research in the same locale. These online recruitment and research sites vary in privacy settings, tools, and more. Participants may be recruited through (but not limited to) minimal payment, crowdsourcing, and advertising on SNS. For

more information on recruitment and research practices, guidelines, and potential obstacles of anonymous survey websites, see the guidance on Anonymous Surveys.

**DATA SECURITY**

See SOPs on [Data Security](#) and the [General Data Protection Regulation](#).

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

**RESOURCES**

- <http://wp.lancs.ac.uk/social-media-research-ethics/>
- <https://www.thehastingscenter.org/social-media-privacy-research-muddled-landscape/>
- <http://ukrio.org/wp-content/uploads/UKRIO-Guidance-Note-Internet-Mediated-Research-v1.0.pdf>

**SACHRP considerations:**

[https://www.hhs.gov/ohrp/sites/default/files/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet\\_research.pdf](https://www.hhs.gov/ohrp/sites/default/files/ohrp/sachrp/mtgings/2013%20March%20Mtg/internet_research.pdf)

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