

Guidance for Use of the Internet and Social Media in Research

This guidance provides information about using the Internet and Social Media (e.g. Facebook, Twitter) during the conduct of Human Subjects Research.

1. How are the Internet and Social Media used in research?

Researchers use the internet in a variety of ways to collect data and interact with participants. While reviewing applications, the IRB finds it helpful to make the following broad distinctions:

- **Internet-Based Research:** Researchers often observe research participants and collect data in online spaces. It is now very common for researchers to collect data through online platforms like Qualtrics. However, an immense amount of primary and secondary research data are also available on the internet in other modes and sources. It is possible to collect observational or interventional data in online spaces where users provide comments and information, such as online forums, chat rooms, gaming environments, and marketplaces. In such cases, the Internet effectively functions as the research “site.”
- **Social Media in Research:** The use of Social Media (e.g. Facebook, Twitter, Instagram, WhatsApp, Baidu, etc...) has enhanced the ways researchers communicate and interact with research participants. Social Media can be an effective tool for research recruitment, though it is also possible to use Social Media as a space for Internet-Based Research.

2. What is the difference between Publicly Available and Private data?

Data are available on the internet in a wide array of formats and degrees of identifiability. When collecting data online, a researcher should be aware of how participants typically use a given space, forum, or platform and what expectations they have for observations or analysis of their data. Did participants intend for a research to access their data or for it to become part of a research study? Should a researcher consider data private or publically available? It can be difficult to decide what is “fair game,” and failure to adhere to regulatory definition of the difference between private and public can pose significant risks to participants or others in the research process.

The regulations imply a difference between data collecting from public observation and private data collected from interaction or intervention with a research participant.

- **Private Information** consists of data accessed through special permission, password protection, or registration. Private information “includes 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.” Researchers should have a clear understanding of the expectations participants have regarding their privacy as they use an online space. A website or platform’s Terms of Service often outline privacy expectations on behalf of users.

- “Public observation” occurs in spaces where a reasonable person does not have an expectation of privacy. This definition of “public observation” applies in online spaces when there is no assumption of privacy by those using, contributing to, or interacting in the online space. When publicly available sources are used, the data only remain publicly available if the researcher does not attempt to trace user names or profiles back to identifiable information.
- The following is a set of examples of Private and Public sources:

Examples of Private sources	Examples of Public sources
Facebook	Twitter (unless “locked” by user)
Listservs	Comments at news sites, blogs, etc...
Anything made private by the user	Forums with no registration requirement
When use violates Terms of Service	Blogs
Chat spaces in online games	Crowdsourcing sites (e.g. GoFundMe)
Live chat platforms	LinkedIn (excepting personal connections)
	Comments on Federal Notices
	Freely available Federal and State databases

3. How do Terms of Service apply to researchers?

The researcher is obligated to maintain compliance with the Terms of Service for any resource they access for data collection. The IRB will not review the Terms of Service for each application, unless a consultation is requested prior to IRB approval. Researchers are also responsible for ensuring their research does not violate revisions or updates to Terms of Service during the conduct of research.

4. How can a researcher use social media to recruit research participants?

Researchers must follow the same Lindenwood University IRB policies for recruiting participants through social media that apply to traditional media (e.g. flyers, bulletin boards, etc...). Any public posting or disclosure of health information or sensitive data are serious violations of HIPAA (Health Insurance Portability and Accountability Act) and human subject research regulations. The following are common methods used to recruit participants online:

- Posting flyers or advertisements on social media platforms. Researchers may place one-way or direct advertisements on Facebook or something similar. In such cases, a researcher must be careful to understand how potential participants may interact with that material in cases of research involving health information or potentially sensitive data. For example, it may be possible for participants to incidentally identify themselves to others as research participants by “liking” or commenting on a publicly visible social media post.
- Posting recruitment scripts in forums and social media spaces dedicated to specific causes or conditions. If a researcher is collecting data on a specific condition or interest, it may be possible to recruit participants directly from online spaces frequented by participants meeting those criteria. In these cases, researchers should seek permission to post information from site moderators.
- Initiating interactive recruitment on social media platforms. Researchers may initiate two-way communication through social media with potential participants. This type of

recruitment requires interaction over time through messaging. Researchers and research centers often create social media accounts specifically for this type of recruitment.

5. How can a researcher consent participants online?

Performing a consent process online can pose interesting challenges, though the same regulations and policies for consenting participants in human subjects research apply regardless of the format or venue. If obtaining consent in an online forum or chatroom, a researcher must ensure that the consent process does not alter the flow of conversation or use of that space. There are typically two strategies used for obtaining and documenting informed consent for an online survey or data collection process:

- Obtaining Written Documentation of Consent:
 - In cases where the IRB determines that written documentation of consent is required, a researcher will share a consent document with participants, which they will then sign and return by mail, email, or a similar format. In such cases, researchers will return a fully executed consent form, which also includes the researcher's signature and date, to participants.
 - Researchers will use available Lindenwood University IRB Consent Templates, which have been designed for this type of recruitment and consent.
 - If consenting minors as research participants, researchers will provide an assent and consent form for the minor participant and parent to sign and return prior to receiving the survey or participating in the research. Researchers should use survey questions to confirm that participants are either adults or minors during this process.
- Waiving Written Documentation of Consent:
 - In cases where the IRB determines that written documentation of consent is not required, a researcher may use a variety of options to allow participants to indicate that they are willing to participate in research.
 - In online surveys, researchers such create a landing page for the survey, which includes an Information Sheet or Consent Form. At the bottom of this page, the researcher will include buttons or checkboxes for participants to indicate that they agree or do not agree to continue with the survey. It is also acceptable to include a statement that clicking "next" constitutes consent to continue with the survey, as indicated in the Lindenwood University survey research consent form templates.

6. What are important Privacy and Confidentiality issues to consider?

A researcher should not simply assume they understand expectations for privacy in online environments. Notions of privacy can vary widely based on the type of online communication and nature of data presented. In addition, individual participants may have different senses of privacy in their online interactions.

Even though the same ethics apply, privacy and confidentiality risks in internet-based research may be more substantial than those encountered in traditional research. Third party survey vendors or websites may store collected data on backups or server logs, creating identifiable records of sensitive research data. Researchers may develop sensitive information online through the research process, such as through interactions in forums or social media. In addition, data we do not consider identifiable at the point of collection may become identifiable as technology develops.

Another unique feature of internet-based research is that researchers may be able to identify a participant's online presence in a way the participant did not intend. For example, researchers interested in political science questions may connect comments on an online news article to a participant's identifiable demographic information at another site. This associative risk can be minimized by following best practices:

- Researchers at Lindenwood should use Qualtrics to perform online survey research, as it allows users to anonymize data through a variety of settings. Alternative survey research platforms may be approvable on a case-by-case basis.
- Lindenwood University considers IP addresses identifiable information.
- If using social media to perform a research protocol, researchers should use options available to eliminate potential disclosure of information about participants.
- Screen names or online avatars are often identifiable, and researchers should use traditional coding practices to preserve anonymity of participants during the data collection process.
- If a researcher is offering compensation for participation, it is advisable to offer gift certificates from online retailers that use a certificate redemption number after the survey is completed. This will permit compensation without having to collect identifiable information from participants.
- When collecting data that would otherwise only exist in a temporary way, researchers should use practices to appropriately code and aggregate data in order to ensure the participant's intended use of those data are honored. There may be cases in which data regarding risky or illegal behavior should not be captured or deleted from a data set.
- Overall, the level of security used should be appropriate to the risk of the research. If sensitive data are being collected, standard security measures such as encryption or use of secured servers for data storage should be applied.

7. What are additional important ethical and regulatory issues to consider?

- Minors in Internet-Based Research:
 - If researchers are communicating with children online, these interactions are subject to the Children's Online Privacy Protection Act (COPPA). Researchers may not collect personal information from minors without a verifiable parental consent. It is best practice to exclude minors from internet-based research by using programs like SafeSurf or AdultCheck systems.

- Research in Forums and Chatrooms:
 - As Internet-Based Research does not occur in person, it can be difficult to ensure a participant is accurately representing their demographic information or status. It is important to consider how a researcher will confirm or authenticate a participant's self-representation.
 - If using a chatroom to collect data from participants, it is advisable for researchers to create a unique chatroom so that the research process does not interrupt the usual interactions in an established chatroom.
 - Researchers may encounter information about risky or illegal behaviors. It is important to consider prior to conducting the research how this kind of data will be treated, and when, if applicable, it would need to be reported to state or federal agencies.
 - If collecting data in a forum or chatroom, the researcher will need to consider their own identifiability. Will the researcher present himself or herself as someone present to observe interactions and record data? Will the researcher use a pseudonym to eliminate bias in natural interactions or correspondence?

8. What information should be included in the IRB Application?

In cases of internet-based research, researchers must define the nature of the recruitment and consent process, and the scope of their data collection very specifically in the IRB application. For example, the application should identify precisely what blogs or site comments they will access, and what additional information the research may attempt to glean about participants from profiles or other related websites. The following information should be presented in the IRB application:

- An itemized description of specific sources used during the research.
- A description of how the researcher will obtain consent or provide appropriate consent information to participants.
- A description of a user's typical expectation of privacy for data accessed or obtained during the research.
- A description of how the researcher will minimize privacy and confidentiality risks during the research process.
- A description of how the researcher will obtain, code, transfer, and store data.
- Affirmation that research use of the source does not violate the Terms of Service. The obligation for compliance with Terms of Service lies with each principle investigator, including compliance with any changes to Terms of Service during the research process.