

Queen's REB policy on the use of Social Media in Research

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Inquiries and permission requests for commercial use may be directed to:

Queen's University
Vice-Principal Research
Research, Compliance, Training, and Ethics
355 King Street West
Kingston, Ontario
K7L 2X3
chair.greb@queensu.ca, hsreb@queensu.ca
[Research Compliance, Training and Ethics](#)

Queen's University is situated on [traditional Anishinaabe and Haudenosaunee Territory](#).

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Purpose

The purpose of this policy is to:

- Provide clear guidance on recruiting for research via social media.
- Provide standardized information and guidance related to research and data collection involving social media.
- Promote and facilitate best ethical practices for the use of social media in research.

In this document, “social media” refers to any social online data and platforms (excluding email). This includes X (formerly Twitter), Facebook, Instagram, TikTok, Reddit, and other online forums or messaging platforms, along with any future and emerging platforms.

Background

Conducting research-related activities using social media has become increasingly common among researchers, as these platforms provide researchers with new methods to recruit participants, collect and analyze data, and disseminate results.

While this provides researchers with unprecedented opportunities to gather data efficiently, it is accompanied by the responsibility to consider how we use these modes to ethically obtain and use data.

When planning studies, researchers must consider not just, “What is the risk?” but “What is the risk introduced by the research?” This includes the risks posed by the online environment.

When is REB review required?

Research exempt from REB review

Using **publicly available** information from a social networking site (i.e., information accessible without an account or password) that was legally obtained is exempt from review under Article 2.2 of the TCPS 2.

Important note: This data may still be subject to copyright and/or intellectual property rights protections or dissemination restrictions imposed by the owners of the site.

Examples:

- Information on an open Reddit discussion thread.
- Information from a public Instagram account.
- Facebook page information that is accessible without logging in to the site.

Research requiring REB review

Using information from a social networking site where **accounts are required for access, even if the data is freely available to members of the site** (i.e., accessible using your login/password) require review under Article 2.2 of the TCPS 2. These sites are considered publicly accessible digital sites **where there is a reasonable expectation of privacy**.

Examples:

- Information from a Facebook group where membership is by request.
- Information from a discussion forum where posts are visible only to forum members.
- Facebook page information (photos, status, etc.) which requires login to view, whether or not the person is within your network.
- Information from a private Instagram account.

Social media competency

Researchers at Queen's who wish to conduct research activities using social media platforms must clearly describe to the Research Ethics Board (REB) their plans, showing that they know the subtleties of using social media. This includes awareness of privacy issues, relevant user settings, privacy settings and terms of service (ToS) on the platforms being used, as well as the effect of these on the privacy, confidentiality, and rights of potential research participants.

Researchers must thoroughly read and understand the terms and conditions for any social media platforms they propose to use, and remain updated on changes to these, as they may change frequently.

Privacy and confidentiality of participants

Consider how profiles were intended for use and how "public" the space is perceived to be. For example, posts on an individual's private profile account with 10 personal connections is regarded as more "private" than those of a celebrity profile or a profile with 500+ connections.

Respecting the privacy and confidentiality of participants means that potential participants can find out more about a study and participate without having their interest or participation made known to others. To help achieve this, examine the proposed social media platform and its privacy mechanisms to understand any potential limitations for participant confidentiality. Privacy and confidentiality must be protected unless participants consent to waive these protections. Also consider that as the risk(s) of participation in research increase (e.g., by involving more sensitive subject matter), privacy and confidentiality become critical requirements.

Importantly, note that ethical considerations about data access and use cannot be ignored simply because a service provider deems data as "public." The perception of privacy very much depends on each platform or group protocols and privacy boundaries, audiences, and aims, all of which vary significantly (e.g., between platforms, individuals, groups, and hashtags).

Research teams have a responsibility to protect participants' identities (e.g., anonymizing by removing direct and indirect identifiers (usernames, emails, gender, location, etc.)). This can be difficult, depending on the platform's data storage practices. Consider that some data and meta-data are searchable and stored for long periods of time. These considerations are especially pertinent when the research topic involves sensitive subject matter. As noted above, familiarity with the service's ToS and privacy policies is critical.

Collection and analysis of social media data

Be aware that although a social media platform may seem to be “public”, collecting and analyzing data from these sources is not that simple.

Researchers should do the following when conducting and analyzing social media data:

- Respect the privacy restrictions, user settings, and legal requirements of the particular social media platform they intend to use; and
- Seriously consider the potential risks associated with collecting and analyzing social media data.

Types of data

Research involving social media platforms generally focuses on one of two communication practices:

- The **content** of communication.
 - Has potential to be linked with other data, or potentially harmful if used outside of the context of the social media platform.
- The **form** of communication.
 - More focused on linguistic style rather than content; therefore, is lower in risk to participants.

In accordance with the TCPS 2, Article 2.9, research will be assessed by the REB according to a proportionate review related to risk vs. vulnerability of the target population.

Level of intrusiveness

The way in which researchers find data is important to consider in the realm of social media. Passive analysis of postings is less intrusive than direct involvement in communications with participants. Where feasible, researchers should aim for the least intrusive methods possible.

Recruitment

Social media platforms provide a venue to target populations that may not be accessible otherwise. Therefore, recruiting through social media is valuable, but researchers need to consider how recruitment will occur to protect privacy and be respectful of the target population.

For example, placing a study ad using a 'create an ad' function on a social media platform is considered the same as placing an advertisement in a newspaper and has a lower ethical concern than other methods.

When recruiting participants using social media platforms, as with any other recruitment method, researchers must abide by the core principles laid out in the Tri-Council Policy Statement (TCPS 2):

- Respect for Persons
- Concern for Welfare
- Justice

Most recruitment via social media is considered a passive method of recruitment where participants are self-identifying to be contacted further for research recruitment. Consider though, that actions such as creating a page for the research study on the social media platform of choice to recruit the target population may raise privacy concerns such as:

- If a potential participant posts on the page will the page become publicly associated with their social media handle?

As such, information about how the potential participants' interactions are associated with their profile and shared with others should be stated clearly.

Another aspect to consider when posting in an access-restricted/members-only group is the existence of group moderators. Where moderators exist and work to manage the content of the group, researchers should contact them directly before posting about research topics to determine whether this is appropriate. Some groups will allow for private chats to be set up, or the moderators may wish to inform members that research activities or data collection will be taking place during a specific time so that members may choose not to post during that timeframe. The specifics of this will depend on the topic at hand, the target population, and the limitations of the platforms.

In alignment with the expectations for any other recruitment method, all social media recruitment methods and documents must be submitted to the REB for review and approval (e.g., posters, scripts, captions, posts, etc.).

Questions to consider when determining whether to use social media for recruitment

- Why must the internet and social media be used to recruit participants for this project?
- What are the platforms' or applications' terms of use and privacy policies?
- What are users' privacy expectations regarding the platforms or applications?

Questions to consider when determining whether to use social media for research/data collection:

- Why is it necessary to use the internet and social media for this project?
- What is the study subject matter? Is the data personal information? Is it sensitive personal information? Is it health information?
- Who is the target demographic? Are there additional privacy measures required to protect vulnerable individuals?
- What are the platform's or application's terms of use and privacy policies?
- What are users' privacy expectations regarding the platforms or applications?
- Are you collecting the minimum amount of personal information required to answer your research question?

Informed consent vs. implied consent

There are two types of consent applicable to research involving social media: Informed and Implied.

Informed consent

Participant consent is essential to conducting ethical research. Informed consent is the process by which participants are provided comprehensive information about the study (study-specific consent), including its:

- Purpose
- Procedures
- Potential benefits
- Possible risks
- Voluntary nature

Informed consent ensures that participants are fully aware of what will be asked of them and what they can expect during the study.

Informed consent serves to protect the rights, autonomy, and well-being of individuals taking part in research studies.

Informed consent may be presented to participants in the form of:

- Written informed consent
- Verbal consent
- Implied consent
- Waiver of consent
- Broad consent
- Assent
- Opt-out consent

Examples:

Recruiting in a manner where participants must reach out (or recruited into) the study and written/verbal consent is obtained by the study team before data collection.

Implied consent

Implied consent occurs when individuals do not explicitly provide consent, but their actions imply agreement to participate. It is often assumed when participants take actions that demonstrate tacit agreement, such as showing up for an appointment or completing survey questions.

This is accomplished by providing the participant with all the necessary information at the beginning to inform them of the research project (for example, the information section could include a shortened consent form) but lacking the signature line. If the participants want to proceed with the study, they may do so independently. It is recommended that the implied consent information states: "If you return/submit this survey, it is understood you have consented to participate."

Examples:

Recruiting via a direct link to a survey where the first page/question of the survey is the consent process, and the participant chooses to proceed.

It is recommended that the implied consent information states something similar to: "By returning/completing/submitting this survey, it is understood you have consented to participate."

When discussing risk in the consent, Queen's REBs recommend including the following (if true):

"We anticipate that your participation in this survey presents no greater risk than everyday use of the Internet."

The Queen's REBs also advise researchers not to communicate directly with participants through social media platforms. Instead, where possible, potential participants should be encouraged to contact the research team outside of the social media platform mechanisms.

Summary of the main ethics issues to consider when designing, implementing, or assessing an internet-mediated research study

The table below was adopted from the following source, [Guest Editorial: Ethical Issues in Social Media Research](#).

Table 1 Summary of the main ethics issues to consider when designing, implementing, or assessing an internet-mediated research study.

Principle	Considerations
Respect for the autonomy, privacy, and dignity of individuals and communities	<p>Public/private distinction: The extent to which potential data derived from online sources should be considered in the public or private domain.</p> <p>Confidentiality: Levels of risk to the confidentiality of participants' data, and how to minimize and/or inform participants of these risks, particularly where they may potentially lead to harm.</p> <p>Copyright: Copyright issues and data ownership, and when permission should be sought to use potential data sources.</p> <p>Valid consent: How to implement robust, traceable valid consent procedures.</p> <p>Withdrawal: How to implement robust procedures which allow participants to act on their rights to withdraw data.</p> <p>Debriefing: How to implement robust procedures which maximize the likelihood of participants receiving appropriate debrief information.</p>
Scientific integrity	Levels of control: How reduced levels of control may affect the scientific value of a study, and how best to maximize levels of control where appropriate.
Social responsibility	Disruption of social structures: The extent to which proposed research study procedures and dissemination practices might disrupt/harm social groups.

Principle	Considerations
Maximizing benefits and minimizing harm	<p>Maximizing benefits: How each of the issues mentioned above might act to reduce the benefits of a piece of research, and the best procedures for maximizing benefits.</p> <p>Minimizing harm: How each of the issues mentioned above might lead to potential harm, and the best procedures for minimizing harm.</p>

Privacy notices and disclaimers

The table below was adopted (and modified) from the following source, [Ethics and Privacy Implications of Using the Internet and Social Media to Recruit Participants for Health Research: A Privacy-by-Design Framework for Online Recruitment.](#)

Table 2 Privacy notices and disclaimers

Medium	Privacy notice/disclaimer
Email	“Please note that the security of email messages is not guaranteed. Messages may be forged, forwarded, kept indefinitely, or seen by others using the Internet. Do not use email to discuss information you think is sensitive. Do not use email in an emergency since email may be delayed.”
Facebook Instagram Reddit TikTok, etc.	“Please also note that the privacy and confidentiality of content (text or pictures) shared on social media platforms is not guaranteed. Content may be forged, forwarded, kept indefinitely, or seen by others using the Internet, whether you share publicly to everyone or privately to specific people. Do not use social media to discuss information you think is sensitive. While you may share this information with a select group of people, someone in your networks may share it more widely without your consent.”
Twitter (character-limited)	“The security of social media is not guaranteed. Contact us about the study. Don’t post if concerned about privacy.”

Protecting the privacy and confidentiality of researchers

Researchers' use of personal social media accounts for conducting online recruitment and study activities poses unique challenges. Personal social media accounts tend to include private details about individuals (such as addresses, places of work, religious and political affiliations/ideologies, etc.) and details about third parties (such as friends, family members, colleagues, acquaintances, etc.).

Out of respect for those individuals who may indirectly feature in the researcher's social media account, personal social media accounts are discouraged from being used in research-related activities such as recruitment. Instead, Queen's REBs encourage researchers to develop research-specific profiles, or groups, as relevant.

It may be the case that researchers have a legitimate reason to use their personal accounts. In these cases, the study team must provide adequate justification to the REB that appropriate measures are in place to protect participant privacy and confidentiality and safeguard the researcher without posing any increased risks to them or their family/friends.

Additional resources

DMDS: [Social Media Research Data Ethics and Management](#)

Ethics and Privacy Implications of Using the Internet and Social Media to Recruit Participants for Health Research: [A Privacy-by-Design Framework for Online Recruitment](#)

Guest Editorial: [Ethical Issues in Social Media Research](#)

Internet Research: Ethical Guidelines 3.0, is found at [The Association of Internet Researchers Ethics Guidelines](#)

Social Media Research: [A Guide to Ethics by Townsend and Wallace](#)

Towards an Ethical Framework for Publishing Twitter Data in Social Research: [Taking into Account Users' Views, Online Context and Algorithmic Estimation](#)