Research Involving Social Media Platforms

YU HUMAN PARTICIPANTS REVIEW COMMITTEE (HPRC) GUIDELINES

Preamble:

Social media platforms (such as Facebook, Twitter, Instagram, Snapchat, etc.) provide researchers with powerful tools to recruit participants, collect and analyze data, and disseminate findings. The benefits of this research center on the huge repository of easily accessible, seemingly public data, available at low cost.

This guideline is developed to assist researchers in remaining reflective, reflexive, and purposeful in employing methodologies that use social media (SM) as a site for research. This document should be used as a reference point for helping researchers to appraise key considerations and make decisions when designing projects which use SM data.

As YU HPRC advocates for a "case-based" perspective on use of social media in research, researchers are encouraged to contact ore@yorku.ca to discuss their specific research proposals.

Research using SM as primary source of information:

Researchers may directly interact with prospective participants on SM platforms, for example, by asking them to respond to surveys, to perform certain tasks, or use SM platforms to recruit participants to off-social media research activities. When information is directly collected from SM platform users for the purpose of research, it refers to using SM as primary source of information. Primary research using social media platforms must be conducted in accordance with the core principles laid out in the Tri-Council Policy Statement (TCPS 2): concern for welfare, respect for persons, and concern for justice.

- All SM recruitment materials, such as (i) tweets, (ii) Instagram posters/pictures, and (iii) Facebook advertisements, posts, videos, and messages, require REB review and approval.
- Researchers are responsible for ensuring that their SM recruitment tool protects the privacy and confidentiality of research participants. For example, Create Public Event" or "Create Private Event" features on Facebook should not be used as they do not protect participants' rights to their participation remaining confidential. The former allows for anyone with a Facebook account to be able to see who is interested in participating in a project, and the latter enables those individuals invited to participate in the project to see who is planning on participating in the project.
- Researchers should discourage participants from reading a recruitment post and commenting publicly to it. Unless researchers can justify to the HPRC otherwise, comment



sections related to recruitment messages/materials should be turned off. Rather, to protect confidentiality researchers should invite participants to reach out to researchers privately such as direct message and email.

- The HPRC discourages researchers from using a personal social media account (e.g., Facebook, Twitter, Instagram, Tiktok etc.) to conduct online recruitment. First, personal social media accounts tend to reveal private details about individuals (such as addresses, places of work, political affiliations/ideologies, etc.) that may put researchers at risk, especially if, for example, an adverse event occurs that negatively affects research participants. Second, using a personal social media account for recruitment purposes can be problematic because such accounts typically not only share personal information about the researcher, but also share details about the researcher's friends, family, and colleagues, who may not want such details revealed to potential research participants. Third, use of personal social media accounts for research purposes contributes to blurring of personal and professional boundaries which may lead to unintended consequences for both researchers and potential participants. Researchers are instead strongly encouraged to develop a research-specific Facebook or other social media profile.
- In some cases, however, it is possible that researchers may have compelling reasons to use personal social media accounts to conduct research-related activities. In these cases, the onus is on researchers to demonstrate to the REB that the recruitment method is professional in nature and does not pose any increased risks to the researcher, research team, or other individuals.

Research using SM as secondary source of information:

When researchers want to use information created by SM platform users that is originally created for a purpose other than research, likely personal in this context - for research purposes, it refers to research using SM as secondary source of information.

REB review is required in all human research using SM platforms, with one exception – when the information is in the public domain and participants have no reasonable expectation of privacy (TCPS2 Article 2.2b).

Determining if the information is in the public domain for research and users' expectation of privacy:

Tri council states "if the information is accessible to the public, it may be considered in the public domain. However, there is a spectrum of access and other issues to consider when determining whether something is in the public domain for research purposes." Just because a SM post is publicly accessible, it does not mean it is public for research purposes. Below is a list of suggested considerations for researchers to reflect on the publicness of SM data and users' expectation of privacy.



i. The characteristics of the online setting:

- Researchers should assess the characteristics of the online setting. For example, a password protected 'private' Facebook group can be considered private, whereas an open discussion on Twitter in which people broadcast their opinions using a hashtag (in order to associate their thoughts on a subject with others' thoughts on the same subject) can be considered public. Public content can include comments on YouTube videos or videos posted by public figures e.g., politicians, influencers, athletes, or actors, with the intent to make the videos accessible to others in the public domain and with no expectation of privacy. In such cases, the information is intended to be accessible to the public without the need to get additional authorization, permission, or consent, and is likely to be exempt from REB review.
- Questions to consider: Is the data you wish to access on an open forum or platform (such as on Twitter), or is it located within a closed or private group (e.g. within Facebook) or a closed discussion forum? Is the group or forum password protected? Would platform users expect other visitors to have similar interests or issues to themselves? Does the group have a gatekeeper (or admin) that you could turn to for approval and advice? How have users set up their security settings?

ii. Perceived Privacy of Users:

- In some cases, even though the data may be publicly available, SM media users may perceive their posts as private. For example, in some online spaces, users may have an expectation of only being observed by a specific audience. They may post private content by sharing family photographs and personal memories in what is technically a public post, and not expect it to be subject to scrutiny by others. Posts may include children, or seriously ill people.
- > Question to consider: Despite their technically "public" nature, do the posts appear to publicize "private" content, aimed at friends and/or family members, or specific intimate publics?
- Researchers should also consider the differing cultural perspectives on what is considered private versus public concepts of privacy. Something that is publicly accessible may be considered private in a prospective participant's culture (e.g., a religious or cultural group) or for a group of individuals with a specific medical condition.
- Questions to consider: Are you a part of the community you are studying? Are you using these social media users to represent that community? And how are you representing this group, drawing conclusions, or generalizations?



ii. The content of the research and its associated risks:

- Researchers should consider the nature of the research topic, the research question, and whether the data they want to collect is potentially sensitive. Is the data about mundane daily activities or opinions, is there the potential to cause harm to social media users, or should their data be exposed to new audiences? Less sensitive data might include postings about, for example: the weather, recipes or consumer preferences. More sensitive data includes postings about criminal activity such as driving offences or the use of illegal drugs; financial problems; mental health issues and feelings of suicide; extramarital sexual activity; controversial political opinions and activism.
- > The vulnerability of prospective participants should also be considered and included but is not limited to, a lack of awareness and capability because of age, cognitive impairment, or mental health challenges of users/prospective participants to draw the line between private and public information.
- For a review of the possible research scenarios, <u>please see TCSP-2 Guidance on Social</u>

 <u>Media</u>.

If your research uses SM as a secondary source of data and you are not sure regarding the publicness and users' expectation of privacy, please contact ore@yorku.ca to discuss your project.

Other considerations for researchers:

i. Terms of use of the platform:

Where the terms of use of the SM platform stipulate conditions that constitute restrictions for the generation, use, and distribution of information on the platform, this information may be accessible to the public but cannot be used for research purposes, unless the conditions of the SM platform's terms of use are met. Researchers should therefore be cognizant that terms of use of SM platforms may evolve, and that they must follow the updated policies governing data and site security when using those sites.

ii. Copyright/Intellectual property

In some cases, publicly accessible digital information may be accessible to the public but is subject to copyright, intellectual property rights or dissemination restrictions. This information is owned and protected by those controlling the information and must not be collected without their permission. Therefore, it would be required in these circumstances to obtain appropriately documented clearance from the legally authorized individual or entity before using the information for research purposes.

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General Guidelines for Research using SM as secondary source of information:

- > Where it is reasonable to argue that there is likely no perception and/or expectation of privacy, use of research data without gaining valid consent may be justifiable. However, particular care should be taken in ensuring that any data which may be made accessible as part of the research remains confidential, ensuring anonymity of the participants. For example, in dissemination activities or depositing data sets, researchers should paraphrase any verbatim quotes to reduce the risk of these being traced to source, and participants identified. If the research requires use of any verbatim quotes, the researcher should reconsider whether to seek informed consent.
- > Where data are particularly sensitive and/or more difficult to anonymise (e.g. data using detailed personal narratives) then risks to confidentiality increase. As the chance of violations of anonymity and confidentiality that could harm participants within a given research methodology increases, arguments that valid consent is not necessary are weakened. Researchers then should consider the principle of proportionality as the level of risk/harm must be weighed up against scientific value, the quality and authenticity of research findings.
- Risks should be assessed from a participant perspective, including risks related to reputation, employability, or financial standing, as well as embarrassment or even prosecution, if their information is disclosed. This risk of harm is most likely where a social media user's privacy and anonymity have been breached and is also greater when dealing with more sensitive data which when revealed to new audiences might expose a social media user to the risk of embarrassment, reputational damage, or prosecution (to name a few examples).
- ➤ Risks of harm might not be present in all instances in which a researcher wishes to cite social media data, for example when such data is shared by bodies or organisations, or when the social media user is clearly aiming for broad readership (e.g. by using hashtags in Twitter).
- Valid informed consent should be obtained where it cannot be reasonably argued that online data can be considered 'in the public domain', and/or users have reasonable expectation of privacy.
- If the original post that was included in data collection is subsequently deleted prior to the research being completed, it is likely that withdrawal procedures will not be needed, as long as the data obtained had met the principles of being deemed to have occurred in 'public' and was handled in accordance with other ethical principles.



These guidelines represent a framework for researcher to remain reflective, reflexive, and purposeful in employing methodologies that use social media for research. As YU HPRC advocates for a "case-based" perspective on use of social media in research, researchers are encouraged to contact ore@yorku.ca to discuss their specific research proposals.

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