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# Research Ethics Review and Using Data from Social Media

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## Introduction

It is now common for researchers to use publically available data from popular social media venues such as YouTube, Facebook, Twitter, Snapchat, TikTok, Instagram, Reddit, Pinterest (and many others).

The [2018 National Statement on the Ethical Conduct in Human Research](#) (The National Statement) makes clear that

While such information is publically available, nonetheless Human Research Ethics review is required. In particular, Chapter 5.1 of the National Statement clarifies the only circumstances in which ethical approval is NOT needed.

## The only human participant research that can be exempted from review:

- a. Institutions may choose to exempt from ethical review research that:
  - a. is negligible risk research (as defined in paragraph 2.1.7); and
  - b. involves the use of existing collections of data or records that contain only non-identifiable data about human beings.( 5.1.22)

## Ethical Responsibility

5.1.23 Institutions must recognise that in deciding to exempt research from ethical review, they are determining that the research meets the requirements of this National Statement and is ethically acceptable.

Data and opinions from Facebook or Twitter or personal blog, or indeed videos from YouTube does not fall within the area of exempted research, as this information is unquestionably identifiable, even if it is de-identified by the researcher. Even in platforms where pseudonyms are commonplace identification can be possible through the analysis of content, posting history, metadata and context.

## Guidance

Clear guidance is also given in Chapter 3.1 of the National Statement (p.36)

Research may involve access to and use of data or information that was originally generated or collected for previous research or for non-research purposes...The main ethical issue arising from this use is the scope of consent provided or alternatively, the impracticability of obtaining consent.” Privacy concerns arise when the proposed access to or use of the data or information does not match the expectations of the individuals from whom this data or information was obtained or to whom it relates

These issues are especially complex in the context of the access to or use of information relating to individuals that is available on the internet, including social media posts, tweets, self-generated ‘lifelogging’ data emitted from mobile phones and other ‘smart’ appliances and data or information generated through applications and devices related to personal pursuits, such as fitness activity, gambling data and web-based gaming.

The guiding principle for researchers is that, although data or information may be publicly available, this does not automatically mean that the individuals with whom this data or information is associated have

Therefore, use of such information will need to be considered in the context of the need for consent or the waiver of the requirement for consent by a reviewing body and the risks associated with the use of this information.

## **How to obtain Human Research Ethics approval for data obtained from social media.**

A standard Human Research Ethics application needs to be submitted. In most cases this will include a request for a **waiver of consent** as part of the application in a statement attached in lieu of the Information to Participants' form.

In line with the National Statement, **this waiver application must address the following:**

- a. Involvement in the research carries no more than low risk to participants
- b. The benefits from the research justify any risks of harm associated with not seeking consent
- c. It is impracticable to obtain consent (for example due to the quantity, age or accessibility of records)
- d. There is no known or likely reason for thinking that participants would not have consented if they had been asked
- e. There is sufficient protection of their privacy
- f. There is an adequate plan to protect the confidentiality of data
- g. In case the results have significance for the participants' welfare there is, where practicable, a plan for making information available to them
- h. The possibility of commercial exploitation of derivatives of the data or tissue will not deprive the participants of any financial benefits to which they would be entitled
- i. The waiver is not prohibited by State, federal or international law. (National Statement: 2.3.10 a

## Recruiting participants via Social Media

Investigators proposing to recruit via social media are advised to take the following steps:

1. Provide the HREC with a statement describing the proposed social media recruitment techniques, including:
  - A list of the sites to be used
  - A description of whether recruitment will be passive and/or active.
  - If utilizing active recruitment, a description of how potential participants will be identified and approached, and their privacy maintained.
2. Ensure that the social media recruitment strategy complies with applicable federal and state laws.
3. Provide the HREC with a statement certifying compliance (or lack of noncompliance) with the policies and terms of use of relevant websites, OR if proposed techniques conflict with relevant website policies and Terms of Use.
4. Ensure that the proposed recruitment strategy respects all relevant ethical norms, including:
  - Proposed recruitment does not involve deception or fabrication of online identities.
  - Trials are accurately represented in recruitment overtures.
  - Proposed recruitment does not involve members of research team 'lurking' or 'creeping' social media sites in ways members are unaware of.
  - Recruitment will not involve advancements or contact that could embarrass or stigmatize potential participants.
5. If the research team intends to recruit from the online networks of current or potential study participants: Provide the HREC with a statement explaining this approach and describing plans to obtain consent and documentation of consent from participants before approaching members of their online networks or to invite the individual themselves to approach members of their network on the research team's behalf.
6. Consider whether a formal communication plan is needed for managing social media activities among enrolled participants
7. Seek to normalize social media recruitment to the extent possible, drawing analogies to traditional recruitment efforts.
8. Ensure that investigators will obtain consent from current participants before they approach members of their online network for recruitment via their network or invite individuals to approach members of their network on research team's behalf.
9. Ensure that a communication plan is in place for how the research team will handle online communication from enrolled participants that threatens the integrity of study
10. If the study is high risk, send advertisements to the Victoria University media office.

### **If you would like further information about the conduct of research or the human research ethics approval and review process, please contact:**

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