
Waiver of Consent, Human Research Ethics

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). Researchers may also use data sets from other sources where the chain of consent is not clear.

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

necessarily granted permission for its use in research.

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 without clear consent

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.

The waiver should be attached in section 11 of your Ethics application along with other supporting documentation. The waiver should be clearly titled 'Application for waiver of consent'

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:

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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