

ETHICAL CONSIDERATIONS RELATING TO THE REUSE OR SECONDARY USE OF SOCIAL MEDIA DATA

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‘Epidemiological research is part of a wider public health and health services research concerned with improvements of health and welfare in human populations and with improving the efficiency and performance of human health services. Public health and health services research are usually or often carried out with human participants, or data or biological samples from them, and provide important new knowledge that is not readily obtainable in other ways.’

NHMRC National Statement on Ethical Conduct in Research Involving Humans, 1999

NHMRC NATIONAL STATEMENT ON ETHICAL CONDUCT IN HUMAN RESEARCH, 2007 (Updated 2018)

For the use of stored biospecimens for research, researchers and human research ethics committee (HRECs) must:

‘consider the circumstances in which the biospecimens were obtained and any known limitations the donor(s) placed on their use during the consent process.’ (National Statement, 3.2.13)

In the case of social media data, which is to be accessed for secondary use and/or banked for such future use, researchers and ethics committees are required to:

‘understand the context in which the data or information was collected or disclosed, including the existence of any relationship of confidence or, if available on the internet, the privacy settings that apply’. (National Statement, 3.1.54)

ESTABLISHING CONTEXT AND ACCOUNTABILITY – BIOSPECIMENS

- Where biospecimens are exchanged from locally based biobanks that are governed by standards consistent with the National Statement. These standards and information on sample provenance including how samples were obtained and the extent of consent for research use, processes for accessing samples and oversight of the biobank.
- In the absence of any clear provenance, researchers are required to obtain a copy of the Participant Information and Consent Form (PICF).
- Other supporting information about the original sample donation such as, a copy of the original publication that uses the biospecimen or cell line, any laboratory records of when biospecimens or cell lines were collected.

CASE STUDY: THE DIGITAL OBSERVATORY

Mission: Enabling the understanding of the dynamic digital landscape by providing access to reliable and scalable research data infrastructure.

Human Research Ethics and the Digital Observatory

Databank Ethics

- Data collection
- Data tidying and pre-processing
- Data storage and archiving
- Data governance and custodianship

Research project ethics

- Research team data management
- Specific data requirements and methods
- Publication of data

- Research infrastructure at Queensland University of Technology
- Supporting researchers with social media data collection, processing, and analysis
- Social media: private/public debate; human research ethics
- Implementation: databank ethics, governance process, software + database platform

Terms of Engagement
Defines the project scope and responsibilities

CHALLENGES AND QUESTIONS?

- Are the principles or approach in the National Statement suitable for internet research or are other mechanisms or standards required?
- Does the minefield of reusing social media data in terms of contextual considerations, data ownership and privacy need more reassurance measures – regulation, standards?.
- How do HRECs face ongoing challenges to ensure research participants are protected?