

Ethical considerations relating to the re-use or secondary use of social media data

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Databanks are an important resource in the development of scientific knowledge and innovation in research. The National Health and Medical Research Council (NHMRC) National Statement on Ethical Conduct in Human Research, 2007 (revised 2018) (National Statement) defines a databank as 'a systematic collection of data' [1]. In human research, most databanks are comprised of collections of human tissue or biospecimens and/or a collection of information about humans and/or human activity, for example, health information. There are emerging databanks, however, that deal with collections of social media data.

When accessing data or biobanks to reuse stored material for research purposes, Human Research Ethics Committees (HRECs) and researchers are required to provide evidence to demonstrate that the data or samples have been obtained in an ethically acceptable way [2]. Considerations are where and how the data was derived and what it will be used for. In the case of biospecimens, this usually requires information relating to the donor's consent and/or other documentation that can demonstrate how the use of the specimen is governed or how the original sample was donated. In the case of social media data, which is to be accessed for secondary use research 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' [3]. In considering reuse and secondary use of social media data, understanding the context in which the data was obtained will require considerations of donor/author consent or expectations for future use of the data, the original purpose of the posting or activity which generated the data, and the potential for re-identification in subsequent re-use. In both types of bank, biomedical or social media, the principles of respect for donor consent and expectations are central. Often, these considerations involve a balance of competing values between respect for participant donors and the scientific value that can be derived from the databank resource. As highlighted in the National Statement consent for use of social media data in research is a challenging ethical consideration, just as it is for research on biospecimens [2,3].

This presentation will examine the ethical considerations relating to the re-use or secondary use of social media databanks. The presentation will provide an analysis of the ethical considerations of data re-use in the context of bio-banks, and how these ethical concerns also apply in social media research. In the context of social media, unique ethical considerations arise due to the complexities of consent associated with social media, what is understood by private versus public spaces, the impact of any terms of service that may apply [5], and the participants' perceptions [6].

REFERENCES

1. National Health and Medical Research Council, Australian Research Council, Universities Australia, 'National Statement on Ethical Conduct in Human Research 2007' (updated 2018) (Commonwealth of Australia, 2018) 101.
2. Ibid Chapter 3.2.
3. Ibid 3.1.54.
4. National Statement, above n2.
5. See, eg, Association of Internet Researchers (AoIR) *Ethical decision-making and Internet research* (2012) <http://aoir.org/reports/ethics2.pdf>.
6. Fiesler, C., & Proferes, N. (2018). "Participant" Perceptions of Twitter Research Ethics. *Social Media+ Society*, 4(1), 2056305118763366.