Chapter 77

Ensuring Privacy of Participants Recruited via Social Media:
An Australian Retrospective Visualisation and Roadmap

Chandana Unnithan
iD https://orcid.org/0000-0002-1832-8499
Torrens University Australia, Australia

Paula M Swatman
Swinburne University, Australia

Jo-Anne Kelder
iD https://orcid.org/0000-0002-8618-0537
University of Tasmania, Tasmania

ABSTRACT

Researchers worldwide are increasingly looking to recruit research participants via social media (particularly @Facebook and @Twitter) because they appear to offer access to a wider range of research participants and afford inherently convenient tools for recruitment. In Australia, the National Statement on Ethical Conduct in Human Research, together with the federal Privacy law and a number of state-based privacy statutes, provide support and guidance for this novel approach. This article offers a preliminary analysis and discussion of this trend from an Australian perspective, illustrated by an enquiry into the ethical challenges posed by social media-based recruitment, conducted in an Australian university in 2015. Leximancer™ was used as an analytical tool and the content from social media sites used for a small number of research studies conducted up to 2015, taken in conjunction with the various national human research ethics guidelines, offered a means of understanding how ethical challenges of privacy and anonymity can be addressed for responsible social media-based research.

INTRODUCTION

The fundamental principle that people who take part in research projects should be willing and informed participants was articulated as a response to (predominantly medical and psychological) experiments undertaken during the 20th century where participants were anything but willing and informed. Human Research Ethics was designed to protect participants involved in medical research (see, for example, UNLV, 2016). The first attempt to codify the important issues for human participants in medical research was the Nuremberg Code of 1947 (BMJ, 1966a) which emerged from the Doctors' Trials immediately post-WWII. Subsequently, two additional sets of principles – the 1964 World Medical Association's Declaration of Helsinki (BMJ,1966b) and the 1979 U.S. Belmont Report (HHS.gov, 1979) – further clarified and extended the fundamentals of protecting human subjects of research.

Several countries, including the USA, UK, Australia, New Zealand and Canada have since developed their own national set of guidelines for ethical research. Over time, these have expanded from their original, somewhat narrow, focus on medical research to cover social science research; and continue to expand still further to include other fields.

The Australian approach to ethical oversight of research involving humans is centred around Human Research Ethics Committees (HRECs) (NHMRC, 2015). HRECs review research proposals involving human participants to ensure they are ethically acceptable and accord with relevant standards and guidelines. In undertaking this role, Australia's 250+ HRECs strive to ensure the projects they review comply with relevant standards, most importantly the *National Statement on Ethical Conduct in Human Research* (2007, most recently updated in 2018 via a system of rolling reviews). The *National Statement* informs all Human Research Ethics (HRE) in Australia and provides the fundamental guidelines with which all research ethics applications must comply – whether submitted by a university, a hospital, a government agency, a local council, or a not-for-profit organization (NHMRC, 2015).

Australian HRE is governed by both the national statement as well as by the NHMRC's research integrity guidelines, the *Australian Code for the Responsible Conduct of Research* (NHMRC, 2007), together with the federal Privacy Act 1988 and any relevant State privacy acts; plus additional guidelines on specialist issues, such as research involving Aboriginal and Torres Strait Islander (ATSI) participants or issues (Values and Ethics: Guidelines for Ethical Conduct in ATSI Health Research (NHMRC 2003) and Guidelines for Ethical Research in Australian Indigenous Studies (AIATSIS, revised 2/E 2012). Some overlap between research ethics and research integrity is unavoidable and a number of the research integrity requirements identified by the Australian Code (most notably management of research data, peer review and conflict of interest) are also covered by the National Statement and, consequently, incorporated into HRE application forms.

The national statement was originally published in 1999 by the National Health and Medical Research Council (NHMRC, 2015) and, following significant revisions to the entire document in 2007 and 2013, is now updated on a section by section basis to reflect current thinking. For example, Section 3 relating to research methods was reviewed during 2016-17, with an updated version of this Section published in mid-2018: *"the draft chapters provide advice for both researchers and … HRECs addressing ethical considerations in the design, development, review and conduct of research (Chapter 3.1) [which now incorporates much of the material previously associated only with clinical trials] and ethical considerations specific to genomic research (Chapter 3.5)"* (NHMRC, 2016).

One of the most significant changes in approach by the National Statement has been the expansion of its coverage. Originally focusing predominantly on bio-medical research, the National Statement

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