



Research Ethics Monthly

The complex art of benefit-sharing

In community-based participatory action programs (programs which have a research component but which are also focussed on community development and empowerment), it might be possible to identify a link between a research project and a benefit to the participating community. Over and above conducting the study, in research on domestic violence, studies have provided emotional and practical support for victims, offering information about, and organizing access to, formal and informal services, providing feedback to the study community and relevant agencies, and supporting or engaging in advocacy on behalf of abused (Usdin et al. 2000). Work on victims of state violence has also advocated for broader political change (Stanley 2012).

However, in other circumstances it may be far more likely that participants may contribute to research but gain very little direct or even no benefit from it. The lack of reciprocity may be particularly problematic if participants are drawn from vulnerable groups.

For example, members of poorer communities have a right to feel aggrieved if research

undertaken in their communities is only likely to be of benefit to wealthier societies. This is most obviously the case where multinational pharmaceutical corporations trial drugs or procedures in the Global South that are in the end likely to be priced out of the reach of participant communities or which were never relevant to their needs. Not surprisingly, therefore, the concept of benefit-sharing has been most widely developed in discussions of health and genetic research.

In response, international agreements and statements related to biomedical research such as the [Declaration of Helsinki](#) (from 2000 onwards) and non-human genetic and bioprospecting research such as the legally-binding Convention on Biological Diversity (1992), formalised in the [Nagoya Protocol](#) (Convention on Biological Diversity, 2010), instituted obligations relating to benefit-sharing for projects that fell within their jurisdiction. These agreements recognised that:

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Release of the National Statement on Ethical Conduct in Human Research 2007 (updated 2018) – With interview

Content of the updated National Statement

The National Statement consists of a series of guidelines made in accordance with the National Health and Medical Research Council Act 1992 and is subject to rolling review. This means that parts of the National Statement are updated as needed, in accordance with strategic planning, or in response to user feedback or national or international developments in research or ethics.

Since 2007, Section 3 of the National Statement has addressed ethical considerations specific to research methods or fields. The 2018 revision provides a new structure for Section 3, based on the elements of a research project (from conception to post-completion). The revised Section 3 begins with a chapter that addresses ethical issues in all research, followed by specialised guidance for research involving human biospecimens, genomics and xenotransplantation.

This approach emphasises that researchers, Human Research Ethics Committees (HRECs) and other users of the National Statement must take account of the principles and major themes in research ethics addressed in Sections 1 and 2 of the document as the foundation of the guidance in Section 3 and then, in turn, consider the guidance provided in Chapter 3.1 as a base for the guidance provided in the other chapters included in this section... [More](#)

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Research Ethics in Australia: A Story

Have you ever needed to find a history of human research ethics, whether for personal study or for use in professional development work with human research ethics committee members or researchers?

Motivated perhaps by George Santayana's often paraphrased 'those who cannot remember the past are condemned to repeat it', we at AHRECS have often needed to refer to the history of the emergence of ethics in human research but have found repeatedly that the readily available histories focus on international, European and (predominantly) United States events. Conventionally, they begin in the 18th century and recount a litany of unethical research and, apparently consequential, increases in regulation, whether in the form of revised and strengthened guidelines, additional review processes or even legislation.

A typical pattern is to begin with Edward Jenner's smallpox work in the late 18th century, Claude Bernard's early 19th-century cautions about avoiding harm, Walter Reid's yellow fever study in Havana in the early 1900s, the start of the Tuskegee syphilis study in the early 1930s, the Nuremberg experiments and the Code (and the mere lip-service paid to it in the US Army's atomic energy studies in the 1950s) and, sometimes, the Japanese Unit 731 biological and chemical warfare studies in the 1940s. Then, in the 1960s, Henry Beecher's *New England Journal of Medicine* article, Maurice Papworth's human guinea pigs article and book, what Martin Tolich referred to as the 'unholy trinity' of Stanley Milgram's authority study, Laud Humphrey's tearoom trade study and Philip Zimbardo's Stanford prison experiment, and the Declaration of Helsinki. Then the 1970s brings disclosure and cessation of the Tuskegee syphilis study, the US National Research Act, the first common rule regulations, the President's Commission and the Belmont Report. Sentinel events in the 1990s include the Pfizer Trovan study in Nigeria, the clinical trial deaths of Jesse Gelsinger and, since 2000, the death of Ellen Roche, the Northwick Park TGN 1412 study and the disclosure of the Guatemalan sexually transmitted disease studies, and controversy over Napoleon Chagnon's Amazon bioprospecting and the US military's Human Terrain System. There are of course other US and international events that could be added, but, in our experience the ones mentioned tend to recur most.

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Notice of Editors' Decision on Take-Down Request with respect to James and Cleland (2018)

14 July 2018

Under the terms of *Research Ethics Monthly's* Take-Down Policy, the Editors (listed below) received a written complaint and request on 5 July 2018 that they take down:

James M. and Cleland L. (22 June 2018) [Vigilance versus vigilantism in science: Are ethics no longer important?](#) *Research Ethics Monthly*.

We had decided to publish the article because we considered that public and institutional policies relating to the role and conduct of whistle-blowers in research misconduct was a subject worth wider discussion.

Among other matters, the request argued that this article and the report of the Sulan inquiry described in the article were factually inaccurate.

As editors, we decided not to take down the article by James and Cleland because after a thorough assessment of the complaint and of the original article, we determined that, as the request provided inadequate evidence to support the arguments, there was insufficient merit in the Take-Down request to warrant doing so.

However, recognising the importance of robust and independent decision-making procedures, we offered to seek independent review of our decision not to take down the article if the complainant agreed in writing. The complainant did not take up the offer within the period specified. The offer has now lapsed, and this has been communicated to the complainant. Our earlier decision therefore stands and is final.

AHRECS is an Associate Member of the [Committee on Publication Ethics](#) (COPE). COPE notes that journals should have a clearly described process for handling complaints against the journal, its staff, editorial board or publisher (COPE Core Practice #3). *Research Ethics Monthly* will be publishing its complaints process.

Gary Allen, Mark Israel and Colin Thomson
Editors, *Research Ethics Monthly*

Things You Have Missed...

Resource Library (<https://ahrecs.com/ahresources>)

1. [Te Mana Raraunga Statement on 2018 New Zealand Census of Population and Dwellings: A Call for Action on Māori Census Data](#)
2. [\(US\) Here's the sexual harassment report that felled a famed geneticist – and his defense – Science](#)
3. [Systems Matter: Research Environments and Institutional Integrity – Harvard](#)

Law

4. How to review a manuscript

5. The Ethics of Research on Leaked Data: Ashley Madison – Discover

Blog (<https://ahrecs.com/blog>)

1. New resources coming soon from AHRECS

2. Vigilance versus vigilantism in science: Are ethics no longer important?

3. Australian Code 2018: What institutions should do next

4. The inclusion of retracted trials in systematic reviews: implications for patients' safety

5. Stop centring Western academic ethics: deidentification in social science research

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This month we give a merry shout-out to gold sponsor ECU. Thank you!



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