



RESEARCH ETHICS MONTHLY

DECEMBER 2019

Dear <<First Name>>,

HAPPY END OF 2019!!! As we plough through the silly season (of hurried grant applications, sabbaticals and guilty binge-watching) we wanted to send our best wishes for the holidays. Thank you to our amazing clients, Research Ethics Monthly subscribers, <https://www.ahrecs.vip> and [Patreon](#) patrons, and our peers across Australasia and the world. We few, we happy few, we clan of human research ethics & research integrity nuts. Whether it's nobler... Okay, we'll stop butchering the bard and just say ***happy holidays and thank you for an amazing year.***

Please consider subscribing [at this link](#), because it is incredibly affirming and would be greatly appreciated. Subscribing is free, easy and keeps our in-house internet elf happy ("Gary stop zooming around the office in your wheelchair and stop bringing to work your digital countdown to The Mandalorian E8"). More information about the Research Ethics Monthly can be found on the [blog pages](#).





Advances in Medicine often require innovation in ethical thinking too

Nik Zeps
AHRECS Consultant



Breakthroughs in medicine often highlight the existing limitations of the frameworks established to manage the ethical responsibilities arising in healthcare. The contraceptive pill, organ transplantation, assisted reproductive technology, gene therapy and more recently gene editing are notable examples that have stimulated major debates and, in several instances, prompted changes to not only ethical guidelines but also legislation. However, there are also more subtle ethical issues that arise from doing established activities in a different context or scale. Think of so-called Big Data applied to health care or to uses of machine-based learning which promise to revolutionize practice but are really just larger scale applications of business as usual using more sophisticated technology than before. One result of these two developments is the amassing of personal data online which coupled with improvements in reidentification techniques present challenges to how we manage the privacy of individuals. These have prompted amendments in regulation that facilitate the use of personal data whilst also strengthening protections for individuals ([link to GDPR](#)).

Less well known, are changes in the way we evaluate existing healthcare practices to ensure they are truly safe, effective and economical. One such example is the increasing focus on Comparative Effectiveness Research (CER). These studies compare two or more existing practices that are in

widespread use and have been found safe and efficacious. CER is an extension of audit/QI practices in that it uses clinical trial methodology and the power of randomisation to remove the biases inherent in the observed outcomes in a population of non-randomised patients receiving a particular health service. These studies generally include large numbers of patients (sometimes several thousand) so that they can detect differences between the interventions that, while relatively small, can nonetheless be clinically meaningful at a population level.

There is an over-riding ethical need to do this work constantly within what can be termed a 'learning healthcare system'. Conceptually this means that every single instance that a person interacts with the health system should be captured in a manner in which it can be evaluated to make sure that optimal care is provided. Both patients and health system leaders expect this to be happening and yet in truth, the lack of standardisation in data capture, storage and interoperability means that few do this efficiently and effectively as part of routine healthcare activity. Moreover, existing research ethics frameworks impede the integration of healthcare and research by failing to recognise the differences between studies that involve standard care treatments from studies testing novel interventions with unknown safety profiles. One example is the requirement to apply to comparative effectiveness studies informed consent processes that differ so greatly from routine consent to treatment they are impossible to integrate into routine clinical workflows.

[Read more](#)

Manager/policy officer going on leave?

If the manager or senior policy officer in your human research ethics/research integrity team is going on leave, even if you have a less experienced person acting in that role, you can use the AHRECS on call advice service to assist. The AHRECS team includes three of the most familiar names in Human Research Ethics and Research Integrity, as well as six other very experienced research office, research ethics committee chairs and members of national committees. This service can be used to provide independent expert advice on matters, drawing upon best practice across Australasia. Advice can be purchased in blocks of 10 (\$230/h) 20 (\$200/h) and 30 (\$170/h) hours. Amongst the things the service can be used for are commenting on material that has been produced in-house or conducting administrative reviews of ethics approval requests. The purchased hours never expire. Send an email to enquiry@ahrecs.com to discuss further.

AHRECS professional development at/for your institution

Engaging AHRECS to conduct human research ethics or research integrity professional development for your institution may be cheaper than you think. Some priced items are below. We would also be delighted to discuss developing a bespoke activity with a fixed-price quotation to meet your needs.

- 7h on-site **workshop** for research ethics committee members/Research Ethics Advisers/Research Integrity Advisers/decision-makers/research office staff - \$3200
- 4h webinar and materials \$2500
- 4h on-site workshop - \$1850
- 30min remote in-meeting research ethics committee briefing and materials - \$900
- 90min remote co-facilitated workshop - \$700

We can also work with you to develop a longer range professional development plan that includes capacity building of your staff to maintain on-going activities.

Send an [email to enquiry@ahrecs.com](mailto:enquiry@ahrecs.com) to discuss further.



It's the hand you're dealt: Copyright card games and publishing board games are in!

Nerida Quatermass | University Copyright Officer | Project Manager, Creative Commons Australia at Queensland University of Technology



As a university copyright officer, I provide copyright information for research and scholarly communication – from ethics applications to publication.

What's up, Doc?

Copyright questions can often be a manifestation of a larger issue than copyright. For example, a question about the mining or use of Twitter posts while involving third party copyright is also a matter of contract – what use of content is allowed under platform terms. Alternatively, the question might be about copyright, but it's one where the law doesn't provide the answer – does the scope of the fair dealing for research exception extend to publication? These types of enquiries illustrate that researchers need to understand copyright and a range of related issues relevant to research and communication.

Myth-busting

Couple these uncertainties with the fact that there is no harmony in copyright laws between jurisdictions in a global research and communication community, and it means there are sure to be some persistent copyright [myths to de-bunk](#) in order to understand what is allowed. For example, the concept of “fair use” of copyright is well known globally and researchers in Australia often ask if the use they want to make of third-party copyright is a “fair use”. They are not aware that they cannot rely on it in Australia and are not generally aware of the “fair dealing” provisions that are available to them. Misinformation combined with limited confident knowledge about re-use rights leave researchers confused and anxious about copyright matters.

[Read more](#)



Question for Research Ethics Monthly readers: Win for your institution a new 12-month subscription to <https://www.ahrecs.vip>

Prof. Mark Israel and Dr Gary Allen

We would like to encourage institutions to try out the [ahrecs.vip](https://www.ahrecs.vip) set of resources. We also would like to crowdsource additional material and request the help of members of the research ethics community of practice. People like you. So, if you would like an opportunity to win a new 12-month subscription to [ahrecs.vip](https://www.ahrecs.vip), please send us your answer to one of the following questions:

1. The best thing our HREC ever did was...
2. The most important change I'd make to how my institution deals with research ethics is...

Your response to either of these questions should be between 50 and 500 words and can take the form of a short briefing note, a poem or a video recording with emphasis on either entertainment or information or both. Your submission must be received by 5pm Friday 31 March 2020.

[Read more](#)

While you are here...

Did you enjoy this edition? Would you like to support the work we do? If so, please consider helping us cover the cost of matters such as hosting the Research Ethics Monthly and other web development by becoming an AHRECS Patron.

In addition to the warm glow from supporting our work, you will be subscribed for monthly updates of useful material (such as resources for use in your local workshops).

An institutional subscription is \$350.

Individual subscriptions start at USD1/month and USD15/month gives you access to all materials.

A few profiled items from the subscribers' area:

1. [Human bycatch](#) - A Human Research Ethics commentary
2. [Group recruitment/consent](#) - A Human Research Ethics discussion activity
3. [Flow to determine whether research on material published to the web/social media posts require research ethics review/consent?](#) - A Human Research Ethics resource
4. [Dracula attacks: Consent for wider use of blood](#) - A Human Research Ethics discussion activity
5. [Brainstorming - A Human Research Ethics discussion activity](#) - A discussion activity about the ethical conduct of research with brain organoids.
6. [Questionable publishers - Shell ppt with speaking notes for your modification | AHRECS version with an embedded audio by Mark Israel. Material includes a further reading sheet](#) - A research integrity professional development resource
7. [Talking about data sharing in research integrity professional development and resource material: A commentary on a Nature piece and reflecting on the epochs of ways of discussing data sharing](#) - A Research Integrity and Human Research Ethics Commentary

Please join us in saying a big thank you to our new Gold Patrons:

- Bendigo Health
- Bond University
- CanTeen
- Central Queensland University
- James Cook University
- The internal Ethics Review Panel of the Department of Employment, Skills, Small and Family Business (Commonwealth)
- Torrens University
- University of Melbourne
- University of Southern of Queensland
- The University of Sydney Ethics Office
- University of Wollongong Ethics Unit

Things You May Have Missed...

Our Resource Library

01. [Predatory journals: no definition, no defence](#) - Nature
02. [\(US\) Politics and Open Access](#) - Scholarly Kitchen
03. [International Policy Frameworks for Consent in Minimal-risk Pragmatic Trials](#) - Paper
04. [‘A long and lonely process:’ Whistleblowers in a misconduct case speak out](#) - Retraction Watch
05. [\(China\) Ideological ‘rectification’ hits social sciences research](#) - University World News
06. [\(China\) Five ways China must cultivate research integrity](#) - Nature
07. [The science institutions hiring integrity inspectors to vet their papers](#) - Nature
08. [\(China\) China’s Genetic Research on Ethnic Minorities Sets Off Science Backlash](#) – New York Times
09. [A consensus-based transparency checklist](#) - Paper
10. [Disaster-zone research needs a code of conduct](#) - Nature
11. [Citizen scientists ‘deserve more credit’](#) – Cosmos
12. [Lycoming College's "Plagiarism Game" receives a one-up through new coding](#) - Northcentral PA
13. [We’re All ‘P-Hacking’ Now](#) – Wired
14. [\(China\) Chinese ministry investigates duplications in papers by university president](#) - Nature
15. [Disgraced tracheal transplant surgeon is handed 16 month prison sentence in Italy](#) - Paper

Our Blog

1. [The research use of online data/web 2.0 comments](#)
2. [Inclusion of Culturally and Linguistically Diverse populations in Clinical Trials:](#)

3. [A preliminary genealogy of research ethics review and Māori](#)
4. [Clergy service to HRECs: the useful paradox within secular governance of research involving human participants](#)
5. [Fighting Fiction with Fiction: A novel approach to engaging the public in bioethics of medical research](#)
6. [Pondering on whether to submit your research output to a journal?](#)
7. [Empowering and enabling participation in human research: Reflections from two Queenslanders living with Multiple Sclerosis](#)
8. [Should we Reframe Research Ethics as a Professional Ethics?](#)
9. [Ethics, Security and Privacy – the Bermuda Triangle of data management?](#)
10. [The need to seek institutional approval to survey staff – was this a misunderstanding of the purpose of Guideline 2.2.13 in the National Statement on Ethical Conduct in Human Research?](#)



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Got an idea for a post or a suggestion for a guest? Send an email to gary@ahrecs.com



Do you have a view, feedback or some constructive criticism on this or other posts? Every item has comment link so you can have your say and continue the conversation.



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