



APRIL/MAY 2021

Dear <<First Name>>,



We hope this finds you hale and hearty. Welcome to the April/May 2021 edition of the Research Ethics Monthly.

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house-ell happy.

More information about the Research Ethics Monthly can be found on the [blog pages](#). Also there are links to our previous editions all the way back to May 2015.



Element Zero: What's missing from the National Statement to support Consumer and Community Involvement in health research?

Mark Israel, Deborah Hersh and Clara Shiggins

Advocates in health research of Consumer and Community Involvement – a concept better known in the United Kingdom as Patient and Public Involvement (PPI) – argue that it offers a way of building knowledge that incorporates the experiences and perspectives of a range of stakeholders, including patients and members of the public. Such involvement can improve the experience for research participants, enhance the process of informed consent, aid research impact and dissemination. It might also avoid the waste of resources on findings that have little relevance to end users or that cannot be implemented. Adopting consumer and community involvement focuses on justice, both *procedural* in relation to fair treatment during the research, and *distributive* in terms of fair allocation of the benefits and possible burdens of research. This position has found favour among consumer advocates, researchers, editors and research funders. As a result, consumer and community involvement is increasingly expected and is a bureaucratic prerequisite for research to occur in some countries. For example, within the United Kingdom evidence of patient and public involvement is essential for those seeking [National Institute for Health Research funding](#). Similarly, in Australia, the National Health and Medical Research Council (NHMRC) and the Consumer Health Forum of Australia have developed the [Statement on Consumer and Community Involvement in Health and Medical Research](#) (2016).

CONSUMER AND COMMUNITY INVOLVEMENT AND RESEARCH ETHICS

However, our guidelines on research ethics have not kept up, human research ethics statements traditionally focus on the relationship between researchers and research *participants*, particularly on protecting participant rights, and ensuring that they are treated properly. Consumer and community involvement requires new thinking because of the shift in that relationship. When patients and members of the public are partners, the ethical questions and choices that arise in relation to a study will diverge from those associated with individuals who are research participants. We suggest consumer and community involvement extends the remit for research ethics – raising ethical questions early, even before the design of a project, and having effects on the public long after a project has ended. We also argue that the shift towards acceptance and expectation of consumer and community involvement demands an equivalent shift in ethical considerations right across the research process.

In a recent article focused on consumer and community involvement with people who have aphasia ([Hersh et al., 2021](#)), we used the 2018 revision of the Australian [National Statement on Ethical Conduct in Human Research](#) (2007) as a framework to guide an in-depth consideration of the ethics associated with consumers and members of the community as research partners. We examined the need to stretch ethical thinking to a point before Element 1 in the National Statement to prepare both researchers and partners for their collaboration, roles, and relationship.



Have a burning question or topic?

That's okay, there's an over-the-counter ointment for that. In all seriousness, if you have an idea for a future edition of the REM we'd be thrilled to hear from you. Drop us a line at enquiry@ahrecs.com. If you or your colleagues have published on research ethics or research integrity, we'd be delighted to discuss covering those publications and linking to it.

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Nobody expects... Spanish Inquisition Human Research Ethics audit

by Dr Gary Allen

When research with current ethics approval is periodically monitored, it is typically a passive process. Institutions, often via their research ethics administration, will ask researchers to self-report on the continued ethical acceptability of a project (and compliance with any conditions of approval). It would not be unreasonable to conclude that self-reporting is not the most effective way to identify if there have been problems with approved projects. Indeed, if things have gone wrong, it is at least possible that the most troublesome researchers might not be entirely honest about what has happened or why.

So, what is the alternative?

Conducting random audits of a small number of active projects can be a great way to obtain a snapshot of what is actually happening with approved research. This need not be a statistically significant number of projects to be effective. The impact should be felt further than the projects actually being audited. The mere fact that researchers are on notice that they might be audited could have a positive impact of researchers realising that the committee will be interested in their project beyond the initial research ethics review. This can be achieved by placing a note in all research ethics forms that the project might be selected for audit. Those researchers who are audited may also tell their colleagues they were selected for random audit.

Read more



Areas of activity

We are delighted with how busy AHRECS is at the moment in the human research ethics and research integrity spheres in Australia, Aotearoa New Zealand and the United Kingdom. Our current work can be broken down into four categories:

- 1. Informing the practice of a research institution** – Generally with a combination of a Desktop Audit, meeting observations and interviews, a blueprint, policy, procedure, resource development and professional development.
- 2. Fostering and supporting a community of practice** – We do this by producing the [Research Ethics Monthly](#), the [Resource Library](#), our social media posts and by each month adding to our subscribers' area <https://www.patreon.com/ahrecs> | <https://www.ahrecs.vip>
- 3. Helping with tricky questions** – We do this through our on-call advisory service, research ethics committee coaching and Research Ethics Committee Chair/Ethics Officer mentoring.

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A few profiled items from the subscribers' area:

1. **Template for a human research ethics audit process** – **A Human Research Ethics resource**
2. **Responding to criticisms of precedent** – **A Human Research Ethics commentary**
3. **Artificial Intelligence and your job** – **A Human Research Ethics/Research Integrity commentary**
4. **Recruitment and risk** – **A Human Research Ethics Discussion activity**
5. **Principles of Māori & Indigenous research ethics (An annotated bibliography by Dr Lily George)** – **A Human Research Ethics resource**
6. **Who watches the watchers?** – **A Human Research Ethics discussion activity**
7. **It's a slippery slope to research misconduct** – **A Research Integrity resource**
8. **An Australian history of human research ethics I A ppt produced by Colin Thomson AM - A Human Research Ethics resource**
9. **Is my application ready for research ethics review?** - **A Human Research Ethics resource**
10. **Duped** - **A research integrity commentary**
11. **Setting up a monitoring arrangement for human research** - **A human research ethics talk by Kim Gilkins**

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Things You May Have Missed...

Our Newsroom

01. **Two retractions spotlight the ethical challenges of consent for case reports** – **Retraction Watch**

02. **An archaeology society hosted a talk against returning Indigenous remains. Some want a new society** – **Science**

03. **Medicine's Privileged Gatekeepers: Producing Harmful Ignorance About Racism And Health** – **HealthAffairs**

04. **How to safeguard online data collection against fraud** – **Spectrum**

05. **(China) You want to do what? Paper on anal swabs for COVID-19 retracted for ethical issues** – **Retraction Watch**

06. **Differences between men and women have been ignored in COVID-19 vaccine and treatment trials** – **Crikey**

07. **How to conduct ethical research on sexual exploitation involving children** – **WePROTECT Global Alliance Blog**

08. **A powerful blow against misconduct** – **Chemistry World**

09. **Why did it take so many decades for the behavioral sciences to develop a sense of crisis around methodology and replication?** – **Stat Columbia**

10. **Without stronger ethical standards, predatory publishing will continue to be a permanent feature of scholarly communication** – **London School of Economics Impact Blog**

There were more than 40 more great items in the last 30 days. Follow us on social media to get an alert when new items are added ([Linkedin](#) | [Twitter](#) | [Facebook](#))

Our Resource Library

01. **Ethical concerns in suicide research: thematic analysis of the views of human research ethics committees in Australia** - **Paper**

02. **Citation of retracted publications: A challenging problem** - **Paper**

03. **Cooperation & Liaison between Universities & Editors (CLUE): recommendations on best practice** - **Paper**

04. **Resequencing for impact factors and high publication charges** - **Paper**

05. **(Australia) UTas Guidance for the Six Values for Ethical Conduct in Aboriginal and Torres Strait Islander Research – Guidance and resource material**

06. **Let's do better: public representations of COVID-19 science** - **Paper**

07. **The open access effect in social media exposure of scholarly articles: A matched-pair analysis** - **Paper**

08. **A Quality Checklist for the Responsible Conduct of Research (RCR): Education: A proposal to complement the Predictive Modeling Tool** - **Paper**

09. **Predatory Publishing in Scopus: Evidence on Cross-country Differences** - **Paper**

10. **Ten principles for generating accessible and useable COVID-19 environmental science and a fit-for-purpose evidence base** - **Paper**

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