



FEBRUARY 2021

## Dear <<First Name>>,

Welcome to the February 2021 edition of the Research Ethics Monthly. If you are a subscriber to this publication, your name should appear above. Let us know if there are any mistakes.

If you aren't named above, please [subscribe](#) to the *Research Ethics Monthly*, because it would definitely make our day.

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.



## The Tower of Babel and Human Research Ethics

Gary Allen & Mark Israel

Much human research is conducted in languages that are not the same as that used by the research ethics review body or the chief investigators. This can manifest in a number of ways including:

- Recruitment and consent materials;
- Data collection tools (surveys, interview instruments and observation matrices); and
- Collected data.

There is literature on the ethics of interpreting and translation (Drugan, 2017) as well as on the ethics of research in those fields (Tiselius, 2019). However, for our purposes, we want to focus on the first two situations.

The Australian [National Statement](#) (5.2.17) states that information needs to be provided to participants in ways that enable them to make good decisions about whether to participate, and that the way in which this is done considers 'the need for accurate and reliable translation (written and/or oral) into a participant's first language or dialect' (5.2.17b) and 'culture and its effects on how language (English or other) is understood' (5.2.17c). This, in itself, does not offer much help to a research ethics committee seeking to assess the appropriateness of recruitment, consent and data collection instruments.

A review body will need to use a variety of approaches in this situation. Any approach should be proportional to the following factors. The:

- level of risk associated with the proposed research project;
- ethical sensitivity of the proposed research project;
- nature of the potential participant pool;
- research topic; and
- context

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## Friday afternoon funnies

Have you visited our [FridayArvoFunnies](#) [LinkedIn](#) page – <https://www.linkedin.com/showcase/53189674> recently?

Most Friday afternoons we lead a new funny item onto our [LinkedIn](#) page. Most times it will be a cartoon by the talented Don Mayne.

A lot of them are a good chuckle, if not a laugh-out-loud. All of them prompt a little reflection on a human research ethics or research integrity topic.

Following the page will ensure you will receive an alert when new items are added.

As long as you include the acknowledgment to Don Mayne, you can use these images in your own professional development and other material.

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## Assisting researchers

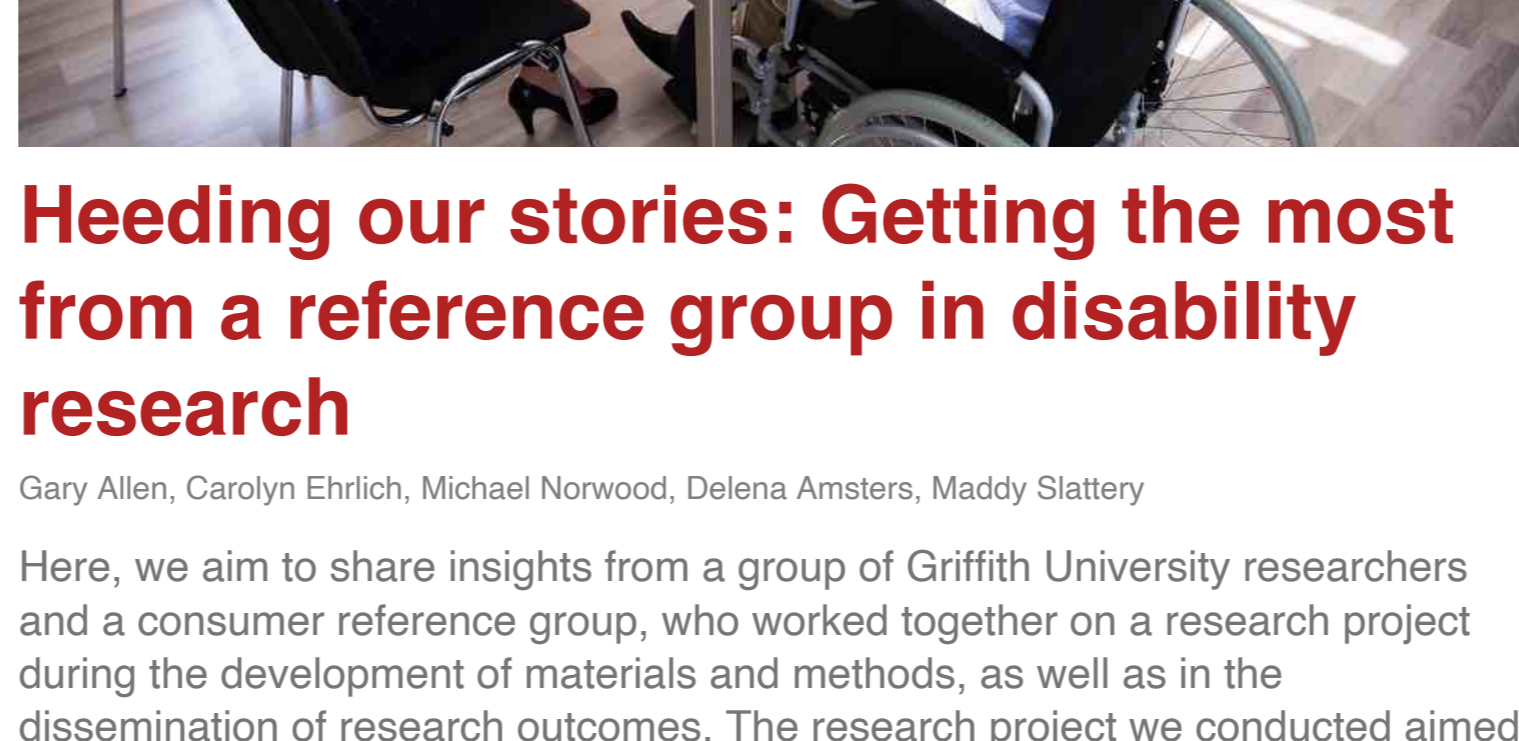
Are you struggling with preparing a research ethics application, or need to respond to some challenging feedback following review?

In recent months, AHRECS has assisted individual researchers and research teams with the following:

- Preparing an application for research ethics review;
- Responding to review feedback from the institution's research ethics committee; and
- Applying to vary/modify an ethics approval.

This work was done at the rate of \$340/h. Typically, the work can be done in a handful of hours.

Send an email to [enquiry@ahrecs.com](mailto:enquiry@ahrecs.com) if you would like to know more.



## Heeding our stories: Getting the most from a reference group in disability research

Gary Allen, Carolyn Ehrlich, Michael Norwood, Delena Amsters, Maddy Slattery

Here, we aim to share insights from a group of Griffith University researchers and a consumer reference group, who worked together on a research project during the development of materials and methods, as well as in the dissemination of research outcomes. The research project we conducted aimed to explore the research experience of people with acquired disability. We wanted to understand what researchers could do better to be more inclusive of people who are often described as vulnerable or marginalised by the National Statement and subsequently Human Research Ethics Committees. We wanted to know how to best include them as participants *in*, rather than subjects *of*, research.

This is not a post advocating for the use of reference groups for research involving those with disability and chronic health conditions. Calls for respectful inclusion have already been eloquently made. Documents such as [Consumer and community engagement](#), recognise their importance, value and celebrate their significance in terms of justice and dignity. Researchers such as [Joan Carlini, Kristen Ransie, Noela Baglot and Laurie Grealish \(2019\)](#) have written about how involving a reference group can enhance research relevance and impact.

Rather than speaking to whether a reference group should be used, this post reflects on the practicalities and logistics of such an engagement.

From the outset, we understood how important it was to engage with consumers who live with disability to guide the research that impacts them. We wanted to know what decisions people with disability made when they were approached to be involved in research and how they made those decisions. But most importantly, we wanted to walk our talk and actively involve consumers with disability in a research consumer reference group that would guide our research. We entered this space of research consumer reference groups armed with good and wise knowledge that is available in the literature. We needed to understand and be cognisant of...

[Read more](#)

## Don't miss out on some great Creative Commons items produced by AHRECS

Every month, AHRECS adds at least one new item to our patrons' area. Recent additions include the bibliography about Māori ethics and research, Nik Zepp's talking about e-consent and a discussion activity about facial recognition. It also includes Colin's orientation sheets for new HREC members.

Institutional subscriptions are \$350/year and provide a Creative Commons license for to use the material internally.

Individuals can also subscribe from USD 1/month (USD 15/month gives access to all materials). See <https://www.ahrecs.vip> and <https://www.patreon.com/ahrecs> for more. Email any enquiries to [patron@ahrecs.vip](mailto:patron@ahrecs.vip).

## The advantage of being social

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## Meet the AHRECS team

### SENIOR CONSULTANTS

- [Gary Allen](#)
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A few proffered items from the subscribers' area:

- [Recruitment and risk – A Human Research Ethics Discussion activity](#)
- [Principles of Māori & Indigenous research ethics \(An annotated bibliography by Dr Lily George\) – A Human Research Ethics resource](#)
- [Who watches the watchers? – A Human Research Ethics discussion activity](#)
- [It's a slippery slope to research misconduct – A Research Integrity resource](#)
- [An Australian history of human research ethics | A ppt produced by Colin Thomson AM - A Human Research Ethics resource](#)
- [Is my application ready for research ethics review? - A Human Research Ethics resource](#)
- [Duped - A research integrity commentary](#)
- [Setting up a monitoring arrangement for human research - A human research ethics talk by Kim Gilkiss](#)
- [A summary consent sheet - A Human Research discussion activity](#)
- [eConsent - A Human Research Ethics talk by Nik Zepp](#)

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- The University of Sydney Ethics Office

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## Things You May Have Missed...

### Our Newsroom

- [Risk of being scooped drives scientists to shoddy methods – Science](#)
- [Publishers claim Plan S repository rules will bankrupt journals – Times Higher Education](#)
- [In a copy-and-paste world, plagiarism can still do long-lasting damage – National Post](#)
- [Patient involvement in medical publications – Pharma Times](#)
- [\(UK\) Research misconduct ruling on historian's Holocaust affair claim – Times Higher Education](#)
- [Richard Smith: Peer reviewers – time for mass rebellion? – BMJ Opinion](#)
- [\(Poland\) Fears for Polish Holocaust research as historians ordered to apologise – The Guardian](#)
- [Fauci: 10K Pregnant Women Have Had Covid Vaccines. With 'No Red Flags' – KHN](#)
- [Indicating the role each author played can be particularly important for early-career researchers – Nature Index](#)
- [\(Russia\) Unethical Practices in Research and Publishing: Evidence from Russia – Scholarly Kitchen](#)

There were more than 50 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

- [\(Australie\) A framework for preferred practices in conducting culturally competent health research in a multicultural society – Papers](#)
- [\(US\) Informed Consent in the U.S. Indigenous Peoples Context: A Systematic Literature Review – Papers](#)
- [Communicating Scientific Uncertainty in an Age of COVID-19: An Investigation into the Use of Preprints by Digital Media Outlets – Papers](#)
- [Practices for Research Integrity Promotion in Research Performing Organisations and Research Funding Organisations: A Scoping Review – Papers](#)
- [Standardizing terminology for text recycling in research writing – Papers](#)
- [The lack of meaningful boundary differences between journal impact factor quartiles undermines their independent use in research evaluation – Papers](#)
- [\(US\) Who's writing open access \(OA\) articles? Characteristics of OA authors at Ph.D.-granting institutions in the United States – Papers](#)
- [\(Australia\) The ethics approval took 20 months on a trial which was meant to help terminally ill cancer patients. In the end we had to send the funding back: a survey of views on human research ethics reviews – Papers](#)
- [Principles of Māori & Indigenous research ethics \(An annotated bibliography by Dr Lily George\) – Resource](#)
- [\(EU\) Educating PhD Students in Research Integrity in Europe – Paper](#)

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