



## Dear <<First Name>>,

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Please consider subscribing yourself [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 Mandarinian e2").

More information about the Research Ethics Monthly can be found on the [blog pages](#).

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## COVID 19, human research and human research ethics review

Prof. Colin Thomson AM  
AHRECS Senior Consultant



We at AHRECS, like all our friends, colleagues and clients, are becoming more and more aware of the immediate and probably long-lasting impact of this pandemic on almost every part of our lives. It has compelled researchers to vary methodologies adopted for both ongoing and planned human research. It has also been forcing institutions to adapt human research ethics review processes to enable responsible social distancing.



In this brief item, we are opening a conversation to offer assistance, ideas, successes and strategies to achieve these changes while maintaining the ethics and quality of human research and ethics review.

### Human research ethics review

A number of our clients have long been conducting ethics review meetings online because of geographical necessity. Australia's regional universities have led these innovations and acquired considerable experience in managing to achieve effective, efficient and quality ethics review. They use different online platforms and have experience of the strengths and weaknesses of several of these in running both synchronous meetings and asynchronous review processes.

They also have experience of assisting those committee members who have been reluctant to review digital applications. The current crisis may compel further limitations on such assistance; for instance, institutions may be unable to print and dispatch agenda papers and members may be less willing to receive them. Experience in enabling less IT-savvy members to adopt online processes with comfort could be a value now to other institutions making these changes.

There may also be substantive issues in addition to these ones of process. For example, how does COVID-19 change our perceptions of merit; what if it shifts the balance in an unfavourable direction after a project has been approved?

[Read more](#)

### AHRECS and COVID-19

[Gary Allen, Mark Israel and Colin Thomson](#)

To date, we are delighted to report the extended team is virus-free. Our best wishes go out to any member of the Human Research Ethics/Research Integrity community who are currently battling the awful pandemic. To the first responders, clinical staff on the frontlines and researchers working on a vaccine, thank you for your service.

Like the majority of small businesses in Australasia, AHRECS has taken a bit of a hit financially. Please consider becoming a subscriber, whether [institutional](#) (\$350/yr) or [individually](#) (from USD1/month). Your support during this difficult time would be hugely appreciated.

Send any enquiries to [enquiry@ahrecs.com](mailto:enquiry@ahrecs.com).

### Competition winner

We are delighted to report Lisa Fry of Barwon Health won the competition to share a thought, poem or reflection on human research ethics and research integrity in Australasia. Here entry is below. In case you can't live as to her inspiration, see <https://www.youtube.com/watch?v=HbK17y150IM>. It's a great book. Lisa won an annual subscription to <https://www.ahrecs.vip> for Barwon Health.

**The Researchers – they hooded!**  
And they hooded down with forms,  
And they hooded down with signatures,  
And they hooded down with bureaucracy, risk adversity and legal review of all!

And they hooded down with ERM,  
And they hooded down with contracts,  
And they hooded down with jurisdictional and site differences for all!

And they hooded up with trust,  
And they hooded up with talking,  
And they hooded up with transparency and accountability for all (not researchers alone)!

And they hooded up with training,  
And they hooded up with time,  
And they hooded up with well-funded healthcare embedded ethical research for all!

The rhyme is adapted from one of my favourite children's picture books – Tyrannosaurus Drip by Julia Donaldson.



## Why autism research needs more input from autistic people

Elle Loughran  
Student, Trinity College Dublin

Elle Loughran is a Laidlaw scholar studying genetics at Trinity College Dublin in Ireland

This post first appeared in [Spectrum](#), the leading site for autism research news.

I am a student and researcher studying evolutionary genetics, and I am autistic. I often come across papers on autism research, but unfortunately, reading them is rarely a positive experience.

Too much autism research fails to acknowledge autistics as people who can read and make valuable contributions to the field. Instead, it casts them as little more than passive study participants or recipients of treatment. This shortsightedness damages research and scientists' ability to help autistic people.

Reading autism research as an autistic person can feel like being treated as an alien. For example, consider a 2019 paper that stated: "This finding reinforces other work which shows that autistic people can have, maintain, and value close [romantic relationships and friendships](#)." Imagine how bizarre it would be to read that about yourself.

I do not mean to pick on that paper in particular, but on a research culture in which anyone would think that sort of statement needs to be made.

[Read more](#)



## Can I use your answers anyway?

Dr Gary Allen  
AHRECS Senior Consultant



Many national frameworks for human research ethics, such as the [National Statement \(2007 updated 2018\)](#) in Australia have respect as a core principle. An essential component of respect is obtaining the prior consent of potential participants.

The role of consent in ethical research can be traced back through the Belmont Report and the Declaration of Helsinki, back to the Nuremberg Code and earlier to philosophical, bioethics and clinical texts.

Recent egregious ethical breaches such as the [Cambridge Analytica](#), [Oxycodone](#) and [Emotional Contagion](#) cases highlight that consent problems in research are not just an issue for biomedical research and not just a 20<sup>th</sup> Century concern.

Where national and/or institutional policies discuss consent and questionnaire-based research, they will generally indicate that completion and return of a completed survey is a valid expression of consent.

Which is indeed reasonable, especially when it is important to conceal from the researcher who has participated in their research (e.g. where an academic is surveying their own students).

[Read more](#)

### While you are here...

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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 workshope).

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Subscriptions start at USD1/month and USD15/month gives you access to all materials. See <https://www.patron.com/ahrecs>

A few featured items from the subscribers' area:

1. [Authorship – A Research Integrity talk](#) by Prof. Mark Israel
2. [Consent: Who are they written for? – A Human Research Ethics discussion activity](#) - A Human Research Ethics discussion activity
3. [Public need and private pardon – A Research Integrity discussion activity](#) - A Research Integrity discussion activity
4. [Can I use your answers anyway?](#) - A Human Research Ethics resource
5. [When words matter](#) - A Human Research Ethics commentary
6. [Who passes along the message?](#) - A Human Research Ethics discussion activity
7. [New member of a research ethics committee resource sheets](#)
8. [The Meaning of Membership](#) - NMRECRS#01
9. [The categories of membership and their responsibilities](#) - NMRECRS#02
10. [Preparing for your first meeting](#) – NMRECRS#03
11. [Human research ethics](#) - NMRECRS#04
12. [What constitutes "quality" in preclinical biological studies? – A human research ethics commentary - A research integrity commentary](#)
13. [Quality in research ethics review](#) - A Human Research Ethics talk by Prof. Colin Thomson AM
14. [Human bycatch - A Human Research Ethics commentary](#)

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

- ANROWS
- Barwon Health
- Bendigo Health
- 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 Queensland
- The University of Sydney Ethics Office
- University of Wollongong Ethics Unit

## Things You May Have Missed...

### Our Resource Library

01. [Sideline by Scandal, a Top Disease Modeler Watches and Worries](#) – UnDark
02. [Strong caveats are lacking as news stories trumpet preliminary COVID-19 research](#) – [HealthNewsReview](#)
03. [A message for mentors from dissatisfied graduate students](#) – Nature
04. [1.2 Billion Records Found Exposed Online in a Single Server](#) – [Wired](#)
05. [Coronavirus is a Wakeup Call for Academic Conferences, Here's Why](#) – Scholarly Kitchen
06. [Does Research Have Any Value in a Refugee Crisis?](#) – [Scholarly Kitchen](#)
07. [Retraction: The "Other Face" of Research Collaboration?](#) - Paper
08. [Examining low-risk health and medical research from ethics reviews: comparing Australia, the United Kingdom, the United States and the Netherlands](#) - [Paper](#)
09. [Australian junior scientists report damaging lack of support at work](#) – Nature
10. [Flattening the Curve, Then What? – The Hastings Center – COVID-19 Infographic Now Available](#)
11. [APA chief publishing officer ignores paper removal request](#) - Eiko blog
12. [Insights into Publication Ethics: An interview with Professor Michael V. Dougherty](#) – Brill
13. [Is it right to out corners in the search for a coronavirus cure?](#) – The Guardian
14. [10 Types of Plagiarism in Research](#) – [Wiley](#)
15. [Articles in 'predatory' journals receive few or no citations](#) – Science

**There were more than 42 more great items in the last 50 days. Follow us on social media to get an alert when new items are added**  
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### Our Blog

1. [Towards a code of conduct for ethical post-disaster research](#)
2. [Working flexibly through the Coronavirus: Continuing professional development in research integrity or human research ethics?](#)
3. [Research ethics review during a time of pandemic](#)
4. [Endometriosis, women's health and the 'hysteria myth'](#)
5. [Plain English communications and the PICF – and beyond](#)
6. [Lost time may never be found again but is it time to talk about the duration of ethics approvals?](#)
7. [The Ethics and Politics of Qualitative Data Sharing](#)
8. [Conversations with an HREC: A Researcher's perspective](#)
9. [A user's perspective on the ethics application process in Australia: room for improvement](#)
10. [Question for Research Ethics Monthly readers: Win for your institution a...](#)

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Got an idea for a post or a suggestion for a guest? Send an email to [gary@ahrecs.com](mailto: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.

