**Past Issues** 

Translate **▼** 



**AUGUST 2021** 

## Dear <<First Name>>,

Can you believe it's August already? Welcome to the August 2021 edition of the Research Ethics Monthly.

If you are a subscriber to this publication, your name should appear above. Please let us know if we made any mistakes. Know someone who you think might like the REM? Please encourage them to subscribe.

If you aren't named above, please consider subscribing to the Research Ethics Monthly. It's free and we generally only send one email every month.

More information about the *Research Ethics Monthly* can be found on the <u>blog pages</u>. Also there are links to our previous editions all the way back to May 2015.







Past Issues

Translate ▼



# Regulation of human epigenetic editing: ensuring international frameworks for governing Human **Genome Editing don't impede vital** medical research

Nik Zeps

The ability to manipulate the genomes of organisms has been available for nearly 50 years, ever since the earliest reported uses of genetic recombination technologies (Cohen, Chang et al. 1973) laid the foundations for the emergence of the biotechnology industry that has revolutionised medicine and agriculture. These early discoveries were made in a bacterium called Escherichia coli, more commonly known as the abbreviation E. coli. It is perhaps poetic then that the discovery of repetitive DNA sequences now known as CRISPR was also made in E.coli (Ishino, Shinagawa et al. 1987). The acronym stands for "Clustered regularly interspaced short palindromic repeats" (CRISPRs) and trips off the tongue much more readily than the literal description does (thanks to Mojica and Jansen who proposed it). For an excellent review of the history of CRISPR, one should read the historical review paper (Ishino, Krupovic et al.) by Yoshizumi Ishino who first discovered it.

CRISPR is most often used with the suffix 'Cas9', which refers to the enzyme it is most frequently associated with that is used to cut DNA sequences at highly specific places under the direction of a guide RNA molecule. The discovery and development of the CRISPR-Cas9 system into an everyday tool for researchers to manipulate genomes by Emmanuelle Charpentier and Jennifer Doudna led to their award of the Nobel Prize for Chemistry in 2020. It is worth watching Prof. Doudna's acceptance speech for a masterclass in understanding how science progresses; "if I have seen further it is by standing on the shoulders of Giants" as Newton put it so eloquently. Her co-awardee's <u>speech</u> should also be watched to appreciate the breathtaking advances we have made in comprehending and manipulating biological processes.

Subscribe Past Issues

genes on and off in living organisms as a form of 'gene therapy'. However, prior to the pandemic distracting us all, CRISPR technologies received significant adverse press in 2018 due to the reports of its use to edit human embryos that were allegedly implanted and that led to the birth of two children in China harbouring a gene that was related to enhanced resistance to HIV infection. In January 2020, the doctor at the centre of the scandal, He Jiankui, was sentenced to three years in prison for <u>'illegal medical practice'</u>. His two colleagues were also jailed for lesser terms. His rap sheet was a litany of improper practice; practising medicine without a license, using assisted reproductive technologies in people with HIV and forging ethics documents related to his research. The response to the announcement by He and his colleagues prompted calls for greater regulation of CRISPR technology in human gene editing. An excellent review of the steps taken since 2018 is presented by Owen Schaefer and colleagues (Schaefer, Labude et al. 2021) as well as a consideration of the options in registering and reporting on such activities.

Unfortunately, human genome editing has somewhat fallen off the radar of the public of late and there are scant stories relating to it in the media. This is hardly surprising given the global pandemic due to COVID-19 and its variant strains. Nevertheless, it remains an important subject and in July 2021 the WHO issued three documents; a position paper, recommendations and a framework for governance, containing new recommendations on human genome editing. Peter Mills, the Assistant Director of the Nuffield Council on Bioethics and a member of the WHO expert advisory groups responsible for the reports wrote a blogpost on their release on the 14<sup>th</sup> July that summarised the key findings and identified important elements about the recommendations. The central issues he identified in his post were:

#### **Read more**

# Open/free and creative commons and the Resource Library

The AHRECS team has decided that we will only add items to the Resource Library (<a href="www.ahrecs.com/resources">www.ahrecs.com/resources</a>) if they are open access (of any colour), free access or any kind of creative commons. We will keep an eye out for questionable publishers and exclude them. Let us know if any slip through.

Any paid items that we especially like, we might list a link to them in the newsfeed (<a href="https://ahrecs.com/feeds/">https://ahrecs.com/feeds/</a>), noting that they are behind a paywall.

## https://www.ahrecs.vip server, content, access and

Translate ▼

Past Issues

Translate ▼

Over the last few days we moved our patrons' are to a new, faster and more robust server. We think all of our patrons have had their access accounts copied across. If you are experiencing difficulties, email us at <a href="mailto:patron@ahrecs.vip">patron@ahrecs.vip</a>.

A few of the most recent items didn't make it across. We are working to restore them.

We have engaged our talented web folk to support the patrons' website (looking after plug-in updates, site back-ups and malware checks).

As you can imagine, none of this is cheap. If you aren't one already, please consider becoming an institutional subscriber \$350 per year (tax invoice will be provided) Please email us at <a href="mailto:patron@ahrecs.vip">patron@ahrecs.vip</a> to discuss.

## **COVID-19** gutted your internal expertise?

Has the pandemic gutted the Human Research Ethics expertise of your HREC, the Research Integrity or Human Research Ethics expertise in your research office/committee secretariat?

The AHRECS team brings together decades of experience in Human Research Ethics and Research Integrity. We have served on peak NHMRC and ARC committees; been involved in the framing of, and revisions to, the National Statement; served as grant and journal peer reviewers; have served on, Chaired and been Secretary to a **LOT** of HRECs.

AHRECS provides on and offline professional development; Chair/Secretary mentoring; committee coaching; and an on-call advisory service.

Email us at enquiry@ahrecs.com to discuss.



Why resourcing practice is a better

**Past Issues** 

Translate >

## compliance

by Gary Allen

Over the course of the last three decades, institutions have been paying far more attention to institutional risk if their researchers do not adhere to national human research ethics or research integrity standards (such as in Australia National Statement on Ethical Conduct in Human Research and Australian Code for the Responsible Conduct of Research). Those of us who practice in these spheres have done a good job in highlighting to directors and the executive level the risks of the regulator, the government and/or the media concluding that an individual researcher has breached the national standards.

Perhaps we have done too good a job, because it is being approached as a matter that needs to be policed, with institutional sanctions for researchers who are deemed not to have met the national standards.

Evidence of this can be found in institutional professional development strategies that almost exclusively focus upon the sanctions that are associated with an individual failing to meet those standards.

There is logic in this for an institution because it is reducing the harm an institution might suffer. But it is an argument that at least some researchers won't find compelling. Nor does it do anything to help improve the way they design, conduct or report the results of their research.

For some researchers, the whole topic and its impact for their research can seem esoteric at best. In addition, professional development activities can often rely on the use of examples of research misconduct that are not Australian and/or of limited relevance to the broad range of research disciplines at an institution.

We also need to get beyond form filling and box-ticking in our thinking and in our approach. We are not fans of expensive 'off the shelf' packages that use multiple choice questions and that rarely acknowledge disciplinary/methodological differences.

To be of perceived value, professional development strategies need to be focused upon good practice and building a positive reputation...

**Read more** 

**Past Issues** 

Translate >



# AHRECS professional development events in Perth November 2021

by Erich von Dietze

#### **Wed 3 Nov for Animal Ethics workshop**

Theme – Managing large groups of animals incl laboratories, farms & in the wild Researchers are adept at managing numbers of (laboratory) animals, but when the numbers are very large things can become complex. Further, when there is overlap between research and the management of a farm or when research is focused on the needs of wildlife the complexities of managing animals as part of research grow. What are the key issues an AEC needs to focus on and how is this best approached?

Speakers TBA

### Wed 17 Nov for Human Ethics workshop

Theme – What I wish I knew before I started.

A former Head of discipline, HREC member and research will reflect on 'lessons learned', thinking about a holistic picture and what we should be equipping the next generation of HREC members with.

A researcher will speak on their research and interactions with several HRECs over the years - What is the HREC process like for a researcher's perspective? What ethical issues need to be considered when relatively simple research becomes contentious or generates substantial community reactions?

There will be opportunities for discussion amongst HREC members, and meeting people with similar category appointments on other committees.

Both events will take place on the **Mt Lawley campus of ECU**, with a COVID plan to utilise Teams if for any reason face-to-face is not possible.

To reserve your spot or email your questions to erich.vondietze@ahrecs.com

Past Issues

Translate ▼



# Ethical and legal issues in researching the digitisation of childhood

https://scholarships.curtin.edu.au/Scholarship/?id=5456

The successful applicant for this PhD scholarship will be conducting research that informs the practices and ethical decision-making occurring in projects running within the ARC Centre of Excellence for the Digital Child (www.digitalchild.org.au) and focusing on the digitisation of childhood and young children's engagement with digital technologies.

The PhD research program will support the interrogation of ethical and legal issues surrounding children's active citizenship and participation in the digital era.

The PhD research activities should inform ethical questioning and pragmatic decision-making in relation to capturing children's digital play and learning; and subsequent data storage, surfacing, analysis and dissemination strategies.

Disclosure: Karen Murcia, who is the project lead, used to be at ECU and I've worked with her before. I have her permission to share information about the scholarship. She would be very happy to talk to anyone who might be interested.

## 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).

**Past Issues** 

Translate ▼

Fayments can be made by credit card over the phone, EFT or via FayFai. To become a patron email patron@ahrecs.vip

#### **INDIVIDUAL**

Subscriptions start at USD1/month and USD15/month gives you access to all materials. See <a href="https://www.patreon.com/ahrecs">https://www.patreon.com/ahrecs</a>

A few profiled items from the subscribers' area:

- 1. <u>Impostor syndrome and HDR candidates</u> A Research Integrity commentary
- 2. <u>Human Research Ethics talk</u>
- 3. <u>Making Human Research Ethics professional development fun</u> A Human Research Ethics discussion activity
- 4. <u>Notes for a report from a human research ethics committee to an institutional governing body</u> A Human Research Ethics resource
- 5. Responding to criticisms of precedent A Human Research Ethics commentary
- 6. <u>Artificial intelligence and your job</u> A Human Research Ethics/Research Integrity commentary
- 7. Recruitment and risk A Human Research Ethics Discussion activity
- 8. <u>Principles of Māori & Indigenous research ethics (An annotated bibliography by Dr Lily George)</u> A Human Research Ethics resource
- 9. Who watches the watchers? A Human Research Ethics discussion activity
- 10. It's a slippery slope to research misconduct A Research Integrity resource

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

- ANROWS
- Ballarat Health Services
- Barwon Health
- Bendigo Health
- CanTeen
- Central Queensland University
- James Cook University
- · Marcus Oldham College
- The internal Ethics Review Panel of the Department of Employment, Skills, Small and Family Business (Commonwealth)
- Queensland University of Technology
- RAND Australia
- Torrens University
- University of Canterbury (NZ)
- · University of Melbourne

By their generosity, they keep Research Ethics Monthly free and ad-free

## Things You May Have Missed...

**Past Issues** 

Translate ▼

- 01. (UK) <u>"Positively Disrupt(ing) Research Culture for the Better": An Interview with Alexandra Freeman of Octopus</u> Scholarly Kitchen
- **02. (US)** A Caltech scientist has apologized for damaging a sacred site. Is it enough? Los Angeles Times
- 03. (Australia) <u>'Devastating career event': scientists caught out by change to Australian Research Council fine print</u> The Guardian
- **04. (US)** <u>A Famous Honesty Researcher Is Retracting A Study Over Fake Data</u> **BuzzFeed News**
- 05. Al datasets are prone to mismanagement, study finds VB
- **06. (UK)** <u>Major U.K. science funder to require grantees to make papers immediately</u> free to all  **Science**
- 07. 'We need to talk': ways to prevent collaborations breaking down Nature
- **08.** <u>'We're problem solvers': research administrators offer guidance to working scientists</u>  **Nature**
- 09. Putting a Stop to the Papermills, Part 2 Wiley
- **10.** Controversy flares over informing research subjects about 'incidental' genetic findings **Science**

There were more than 70 more great items in the last 60 days. Follow us on social media to get an alert when new items are added (<u>LinkedIn I Twitter I Facebook</u>)

## **Our Resource Library**

- 01. <u>Journal citation reports and the definition of a predatory journal: The case of the Multidisciplinary Digital Publishing Institute (MDPI) Paper</u>
- **02.** <u>Strengthening research integrity: which topic areas should organisations focus on? Nature</u>
- 03. Dealing with predatory journal articles captured in systematic reviews Paper
- **04.** (Canada) <u>"I know it's bad but I have been pressured into it"</u>: Questionable research practices among psychology students in Canada Preprint Paper
- 05. The raw truth about paper mills Paper
- **06.** (Australia) <u>Strengthening the incentives for responsible research practices in Australian health and medical research funding Paper</u>
- 07. Exploring the Gray Area: Similarities and Differences in Questionable Research Practices (QRPs) Across Main Areas of Research Paper
- **08. (UK)** Research misconduct complaints and institutional logics: The case of Hans Eysenck and the British Psychological Society Paper
- 09. Defining authorship in your research paper Paper
- 10. (UK) An Introduction to Research Integrity Presentation

**Past Issues** 

Translate **▼** 



Research Ethics Monthly? Please encourage them to subscribe now and help us grow this community.



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

Copyright @ 2021 Australasian Human Research Ethics Consultancy Services (AHRECS), All rights reserved.

We hate spam and definitely don't want to bother you with unwanted emails. You can update your preferences or unsubscribe from this list.

This newsletter is authorized by the AHRECS team, click here for contact and other details.

We would never divulge your details to anyone else, including not disclosing you're a subscriber, without your permission.

