



JANUARY/FEBRUARY/MARCH 2022

Dear <<First Name>>,

Welcome to the Research Ethics Monthly - January/February/March 2022 edition of the Research Ethics Monthly.

Our apologies for the break since the last edition, Gary's trip to the emergency department and hospital stay threw our routines out a bit. We are delighted to report that he's doing much better - though he is taking it slow and listening to his body.

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More information about *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.

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Samaritans UK: Developing ‘fit for purpose’ research ethics processes within a large third sector organisation

Simon Anderson (Simon Anderson Consulting/AHRECS associate)

Liz Scowcroft (Head of Research & Evaluation, Samaritans UK)

How can third sector organisations develop research ethics processes and practices that are genuinely fit for purpose and not simply ‘transplanted’ from approaches developed elsewhere? A recent project conducted within Samaritans UK provides some potential pointers and, indeed, suggests that some of the challenges and possibilities of research ethics in the third sector may have wider relevance.

Samaritans’ vision is that fewer people die by suicide. It is best known for its telephone helpline, providing emotional support to anyone in emotional distress, struggling to cope, or at risk of suicide throughout the United Kingdom and Ireland (though it also provides support through a range of other channels). But the organisation also has a large research function, and undertakes, commissions and collaborates on research to inform its services, other activities, and policy and influencing work (with the ultimate aim of helping to save more lives). Not surprisingly, given the nature of the support the organisation provides and the populations it serves, there has long been a concern to ensure that such work is conducted ethically and, in particular, that the rights, dignity, welfare and wellbeing of participants are respected.

To that end, Samaritans has had a formal [Research Ethics Policy](#) in place since around 2009. The policy has been reviewed and updated several times, to reflect both changes in the external research environment (e.g. the increasing use of online methods) and in the volume and character of projects involving the organisation (e.g. a shift from largely student projects to ones directly commissioned by the organisation). It was not until 2018, however, that the organisation put in place an independent Samaritans Research Ethics Board (SREB) and associated processes. Prior to that, external research projects were reviewed for ethical issues by members of the research team but there was no independent scrutiny of projects conducted internally. When the new processes were established, a commitment was also made to review how they were working within three years. In 2021, Samaritans appointed Simon Anderson Consulting and AHRECS (who are now collaborating to offer human research ethics consultancy in the UK) to conduct that review.

input into the SREB came from external academic experts, together with Samaritans [volunteers](#). Perhaps not surprisingly, then, the system seemed to be working well for 'traditional' research projects which looked and behaved like those typically conducted within the higher education sector – for example, projects with well-defined methods, reasonably lengthy timescales and clear start and end points.

But as Samaritans has evolved, it has found itself increasingly involved in other kinds of 'research-like' activities – for example, user experience ('Ux') research aimed at understanding the thoughts, feelings and behaviours of the people who use a specific product or service, wider processes aimed at introducing a 'lived experience' perspective into the design or delivery of services, or work to inform campaigning or fundraising activity.

These projects often involved relatively short timelines, iterative, open-ended and dynamic ways of working, and staff and partner organisations (such as digital agencies) without previous experience of ethics review processes. The result? Widespread uncertainty about whether ethics approval was required or not, problems relating to timescales, and a sense that members of the research ethics board and applicants were talking different languages. There was also a concern about overly risk-averse decision-making, and especially the possibility that some groups (especially those of the more vulnerable) were effectively being prevented from participating in research – for example, by exclusion criteria based on experience of suicidal thoughts. As a result, the already hard-pressed Samaritans research team found itself in a difficult position – both in terms of workload/capacity (as everything had to flow through them), and because of the risk that ethics scrutiny became seen as something that they were imposing on the rest of the organisation.

Working closely with the research team and staff from elsewhere within the organisation, the review team developed and agreed a blueprint loosely based on AHRECS 'resourcing reflective practice approach'. The main elements of that blueprint are outlined below.



[Read more](#)

PANELFIT Face to face training course (fully online), aimed at researchers within ICT and journalists - Understanding GDPR: the rights and the principles 29 March 2022 | 11.00 – 12.15 CET

17.00 for WA;
19.00 for Qld;
20.00 for Sydney and Melbourne;
22.00 for NZ

Register now by contacting

Monica.loyo@ehu.eus

29 March 2022

11.00 – 12.15 CET 11.00 – 11.10 Welcome and Introduction to PANELFIT, by Prof. Iigo de Miguel Beriain (Distinguished researcher, Ikerbasque, Faculty of Law and PANELFIT Deputy-Coordinator, University of the Basque Country - UPV/EHU).

11.10 – 11.55 The Principles, by Iigo de Miguel (UPV/EHU)

11.55 – 12.15 The Rights, by Alessandro Ortalda (PhD Researcher, Faculty of Law and Criminology, Vrije Universiteit Brussel - VUB)

12.15 Closure of the course

PANELFIT has received funding from the European's Union Horizon 2020 Research and Innovation Programme under Grant Agreement no 788039



Investigating an ethical barrier – should HRECs require gatekeeper approval from universities before external research?

Kate Christian

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along the way the many individual site approvals for single projects, then the relative joys of single site, multi-centre approvals; and different approval systems and requirements from every state for a single project. Later we even cracked approvals for access to PBS and Medicare data. I know about ethics, and support the merits of research ethics approval to protect participants.

My PhD project involved data collection via a national on-line survey of early career researchers employed in research institutes and universities across Australia, and some interviews. I received ethics approval on the first application, but was taken aback by the HREC's condition that I must obtain gatekeeper approval from every institution before contacting potential participants. We have discussed this requirement [before](#) in *Research Ethics Monthly* (Christian et al., 2019); but it led to a great deal of work for both me and the institutions, and probably also resulted in sample bias.

I have to admit I was angry and frustrated; I felt this requirement was ethically both unnecessary and wrong but as a PhD student I did as I was told, and quietly fumed. I determined to write a paper about it, demanding change. Slowly the need to shout diminished, and, guided by my patient supervisors, we approached the discussion about this ethical barrier academically ([Christian et al., 2022](#)).

On the way, we explored why we have gatekeepers. Are they there for protection of the participants (people inside the gate) or the people who own the property (the institutions) ([Singh & Wassenaar, 2016](#))? What happens when the site is virtual? Does the gate still apply (Hedgecoe, 2016)?

[Read more](#)

We are thrilled to welcome Amanda to the team

AHRECS is expanding our team to create AHRECS Animal, a new animal ethics group. As part of this, we are thrilled that [Dr Amanda Fernie](#) has joined AHRECS. Based in Queensland, Amanda was the manager of Research Ethics and Research Integrity at Griffith University. Prior to that, she was the Secretary of Griffith University's AEC and IBC.

Her doctorate was in animal welfare, and she has considerable experience in this field.

Welcome aboard, Amanda, we are delighted to be working with you.

In the coming weeks, we will be adding details of our animal ethics services to the website.

If you want to find out more, send an email to Erich von Dietze - erich.vondietze@ahrecs.com.

You can find Amanda's profile at - <https://ahrecs.com/consultants/amanda-fernie/>.



Adele's Adventures in Wonderland*: Reflections on a 12-year journey in ethics, research integrity and so much more

Adele Kay

"Alice was beginning to get very tired of sitting by her sister on the bank, and having nothing to do: once or twice she had peeped into the book her sister was reading, but it had no pictures or conversations in it, "and what is the use of a book" thought Alice, "without pictures or conversations?" So begins the classic tale by Lewis Carroll and with it my biggest learning from my career thus far spent working in human research ethics, animal ethics, research integrity, biosafety and biosecurity, defence export controls and clinical trial governance at a University.

As research administrators and managers it is our role to bring to life the words written in our framework documents. Be it the *National Statement on Ethical Conduct in Human Research*, the *Australia code for the care and use of animals for scientific purposes*, the *Australian Code for the Responsible Conduct of Research* or the (seemingly infinite) list of legislation, regulations and institutional policy and procedure that inform the practice of an array of research activities. But without us and the people we work with they are only words on a page. Just like the joy of reading is to be found in the characters we bring to life in the reading (be it in our head or out loud to others), so too the best bits of our work are to be found in the people we work with; be it our colleagues in our teams, our colleagues in our sector, the people involved in the review process or the people we seek to support.

1. *Down the Rabbit-hole*

I started my career in a human research ethics administrator role fresh from being admitted to practice law. One of my primary motivations in studying law when I had to make the choice during the tender years of high-school was because it seemed like a logical and straightforward career pathway. Study law and become a lawyer. Easy. But just as Alice follows the White Rabbit down "a large rabbit-hole under the hedge... never once considering how in the world she was to get out again", I too had no idea that I would spend the next 12 years of my career (and life) working in the same team.

We asked our readers for their picks

We asked some of our readers what is their favourite cartoon was on the [FridayArvoFunny page](#).

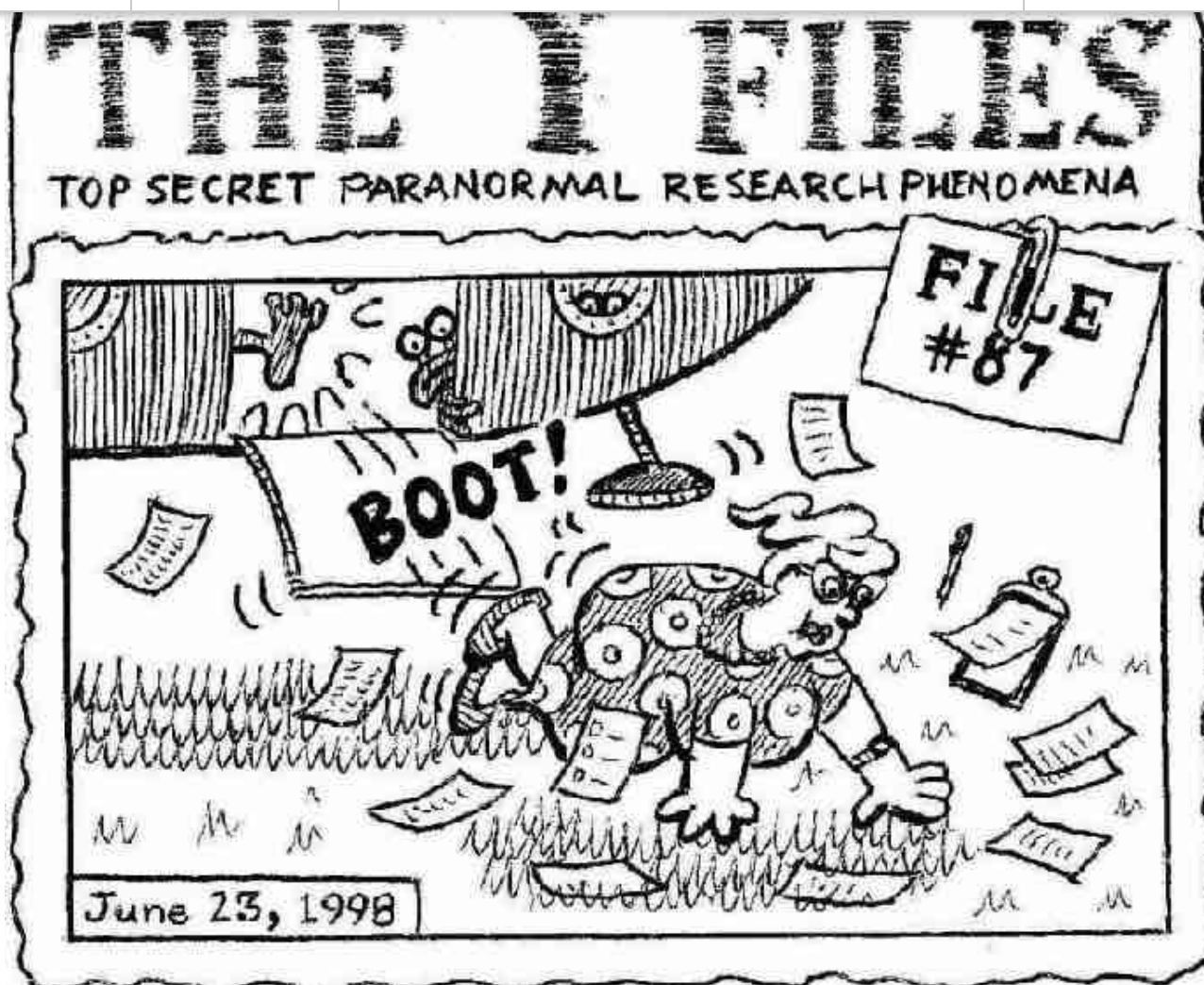


Adele Kay, Former Manager, Research Ethics Unit, University of Tasmania I Made me chuckle. I think as research managers we are often tasked with obtaining expert opinions and I think that this is a great reminder that sometimes conflicts of interest may be very obvious, but other times they may not be.... But sometimes we may really struggle to someone to give an expert opinion who isn't conflicted so making the conflict known to the decision makers can be the best (and only) way of fulfilling their request for the advice.



Artwork © 2000 by Don Marquis. All Rights Reserved. Unauthorized Duplication Prohibited. Contact: dontoon@aol.com

Conor Brophy, Adjunct Professor; Chair, University Human Research Ethics Committee | The image which appeals to me is attached. It is the understanding of context in research which I find particularly important in ethics review. This cartoon demonstrates the relevance of context: where is the study being run, who are being approached or likely to be interested, and will the participants amount to a sample reflective of the population to which the study would apply? So often a broad overview of a study does not sufficiently illuminate the ethical issues, and questions to explore how a study will be conducted are important ones for a HREC to ask. Having a clear and detailed research proposal which elucidates study conduct and context saves time in anticipating such questions.



Intrepid regulatory consultant, Mabel Wiggins, is abducted by aliens for their grisly experiments on humans. After she explains applicable regulations, and performs a detailed compliance assessment, they hastily return her to earth, and retreat to conquer another galaxy.

Mark Israel, Senior Consultant | 1998 was an interesting year. John Howard refused to answer a question on whether GST would affect the price of heroin, Katherine Gorge overflowed, and It was the final series of the first run of the X-Files. Thankfully, the Y-Files took over and showed us an outsider's view of research ethics bureaucracy or, alternatively, how human research ethics requirements would save the world.



You must be this ethical...

Gary Allen

Many of us will recall the unease of approaching a fun ride and being measured to judge if we were tall enough to get onto the ride. If we don't remember ourselves, we may remember our child/grandchild/family member being tested for height.

Such a measure is a quick assessment to judge whether an individual will be safe on the ride or is old enough to deal with the psychological challenges.

However, this is not a critique of using height to judge capacity or the limitations of one-size-fits-all safety equipment and risk mitigation strategies. This is a reflection on whether we need something similar for our human research ethics arrangements.

Hopefully, we are all using proportional review arrangements for our ethics review of new projects, variations, ethical conduct reports and responses to review feedback. If you are not, **you should be**.

[Read more](#)

A firm by any other name

About 15 years ago, after collaborating together on Human Research Ethics consultancies, Gary and Mark decided to set up a business to, amongst other things, professionalise their work – and AHRECS began. Very quickly, in addition to Human Research Ethics, they started doing work in the Research Integrity space but decided to leave their name unchanged while they were building brand recognition of AHRECS. About 12 years ago, they formalised frequent collaborations with Colin Thomson AM by creating a combined company with the same name.

In the years and now decades since, the work of AHRECS has continued to include Human Research Ethics and Research Integrity.

Just recently, with the addition of Erich von Dietze, AHRECS has started working in the Animal Ethics space. This once again raises the question of whether continuing with the AHRECS name is the best move. We are conscious that AHRECS has built strong recognition in Australasia as a quality consultancy firm in this area of work.

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UK, Kazakhstan.

Therefore, we have been thinking about whether the AHRECS name encompasses all that we offer – or if a rebrand would be a good idea. Rather than add letters to our name and end up with a common name that is impossible to pronounce like A&IHRIAECs (extra points for guessing what the acronym stands for!), we would probably choose a new name.

As valued members of the AHRECS community, we are interested in hearing your thoughts. Please email one of the members via our Executive Team (gary.allen@ahrecs.com, kim.gifkins@ahrecs.com and mark.israel@ahrecs.com).

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).

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A few profiled items from the subscribers' area:

01. [How to avoid passive-aggressive mischief in a lab – A Research Integrity commentary](#)
02. [You have been screened – A Human Research Ethics commentary](#)
03. [The role and recognition of advisers/technicians/assistants in human research – A Human Research Ethics commentary](#)
04. [Blinding and a trial that was too successful – A Human Research Ethics commentary](#)
05. [You can't sue us mechanism – A Human Research Ethics discussion activity](#)
06. [What does the wording of research recruitment material really mean? – A Human Research Ethics discussion activity](#)
07. [Impostor syndrome and HDR candidates – A Research Integrity commentary](#)
08. [Notes for a report from a human research ethics committee to an institutional governing body – A Human Research Ethics resource](#)
09. [Human research ethics and risk, the role of research ethics committees – A Human Research Ethics talk](#)
10. [Making Human Research Ethics professional development fun – A Human Research Ethics discussion activity](#)

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- [Marcus Oldham College](#)
- [The internal Ethics Review Panel of the Department of Employment, Skills, Small and Family Business \(Commonwealth\)](#)
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Things You May Have Missed...

Our Newsroom

01. [How to find evidence of paper mills using peer review comments](#) – **Retraction Watch**
02. **(Australia with international connections)** [Sports concussion expert who resigned amid plagiarism claims accused of copying more articles](#) – **The Guardian**
03. **(Australia)** [Animal Welfare Advisory Committee appointed](#) – **Government of Western Australia (February 2022)**
04. **(EU)** [Europe's Proposed Limits on AI Would Have Global Consequences](#) – **WIRED**
05. [Games researcher retracts one paper, corrects three others, for plagiarism](#) – **Retraction Watch**
06. [The Rise of Science-Based Investigative Journalism](#) – **Global Investigative Journalism Network**
07. **(US)** [How the FDA could save 2,700 clinical trials from becoming research waste](#) – **TranspariMED**
08. **(France)** [French ocean institute goes public about authors who forged their researchers' names](#) – **Retraction Watch**
09. **(Russia)** [Global research community condemns Russian invasion of Ukraine](#) – **Nature**
10. [Paleontology 'a hotbed of unethical practices rooted in colonialism', say scientists](#) – **The Guardian**

There were more than 120 more great items in the last 90 days. Follow us on social media to get an alert when new items are added ([LinkedIn](#) | [Twitter](#) | [Facebook](#))

Our Resource Library

01. [Big Data and National Security: A Guide for Australian Policymakers](#) – **Lowy Institute**
02. **(Australia)** [Factsheet: Research Governance](#) - Resource: The Institute of Internal Auditors Australia
03. [Balancing openness with Indigenous data sovereignty: An opportunity to leave no one behind in the journey to sequence all of life](#) - **Paper**
04. [The Use of Questionable Research Practices to Survive in Academia Examined With Expert Elicitation, Prior-Data Conflicts, Bayes Factors for Replication Effects, and the Bayes Truth Serum](#) - Paper
05. [Continued Use of Retracted Publications: Implications for Information Systems and Scientific Publishing](#) - **Paper**

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[07. Publishing of COVID-19 preprints in peer-reviewed journals, preprinting trends, public discussion and quality issues - Paper](#)

[08. The impact of retracted randomised controlled trials on systematic reviews and clinical practice guidelines: a meta-epidemiological study - Preprint Paper](#)

[09. The role of collegiality in academic review, promotion, and tenure - Preprint paper](#)

[10. Dialogical teaching of research integrity: an overview of selected methods - Paper](#)



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