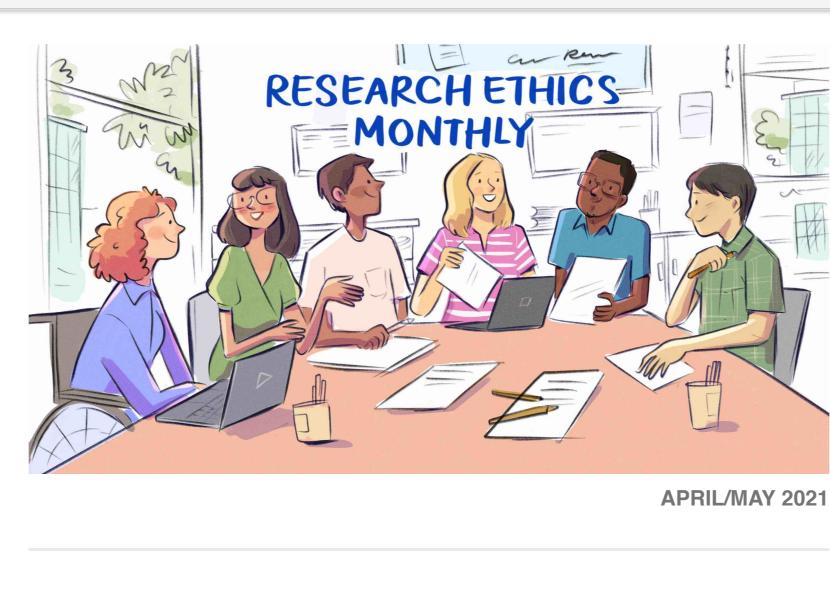
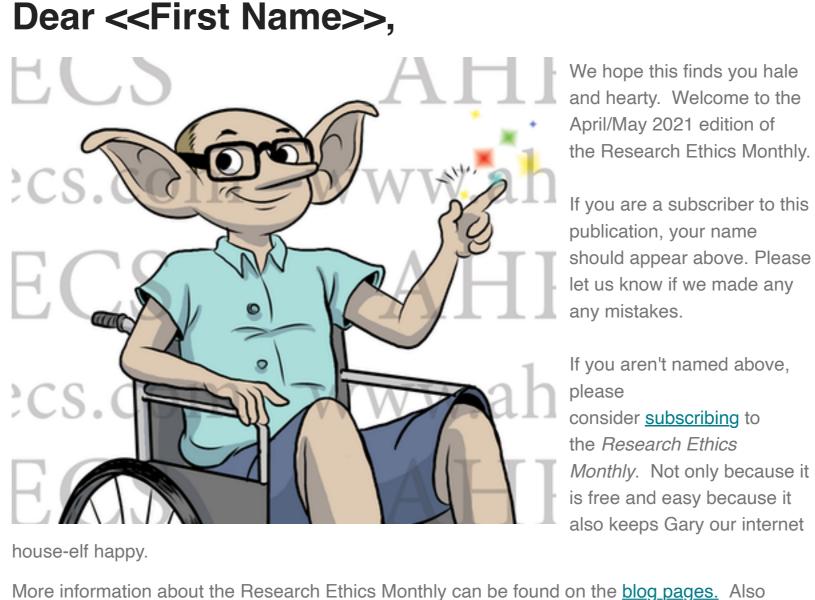
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and Community Involvement in health research? Mark Israel, Deborah Hersh and Ciara Shiggins Advocates in health research of Consumer and Community Involvement – a concept better known in the United Kingdom as Patient and Public Involvement (PPI) - argue

perspectives of a range of stakeholders, including patients and members of the

that it offers a way of building knowledge that incorporates the experiences and

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

suggest consumer and community involvement extends the remit for research ethics - raising ethical questions early, even before the design of a project, and having

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

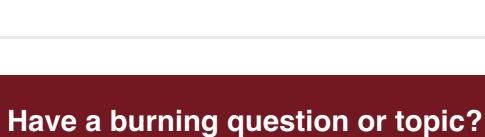
effects on the public long after a project has ended. We also argue that the shift towards acceptance and expectation of consumer and community involvement demands an equivalent shift in ethical considerations right across the research process. In a recent article focused on consumer and community involvement 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.

ELEMENT 1: ELEMENT 7: RESEARCH SCOPE, AIMS AFTER THE PROJECT · Disposal or retention of data Secondary use Ongoing relationship Benefit sharing **ELEMENT 2: ELEMENT 6:** INVITATION **DISSEMINATION OF ELEMENT ZERO:** RESEARCH PREPARING FOR INVOLVEMENT Authorship · Intellectual property · Level of involvement Accessible & timely · Education to inform attitudes, expectations, processes, choices phasia community for collaboration · Knowledge of aphasia **ELEMENT 5: ELEMENT 3:**

ACCESSIBILITY

ELEMENT 4: **COLLECTION, USE &** MANAGEMENT OF DATA

 Level of formality · Mode of consent · One-off or ongoing



That's okay, there's an over-the-counter ointment for that. In all seriousness, if you have an

research integrity, we'd be delighted to discuss covering those publications and linking to it.

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

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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?

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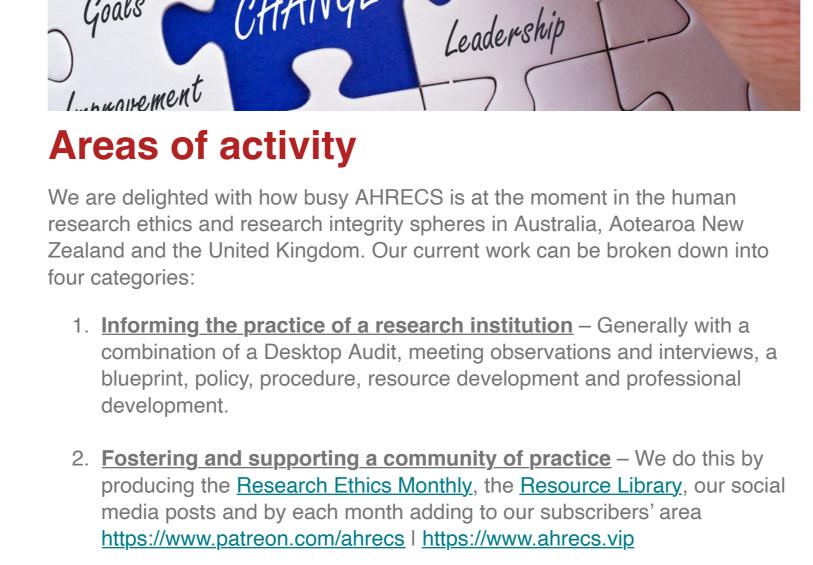
9. <u>Duped</u> - A research integrity commentary

Barwon Health

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.

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3. Helping with tricky questions – We do this through our on-call advisory

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01. Two retractions spotlight the ethical challenges of consent for case reports -

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

06. Differences between men and women have been ignored in COVID-19 vaccine and

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

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