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NEW ZEALAND ETHICS COMMITTEE TE ROOPU RAPU I TE TIKA.

Origins and new Directions

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<https://www.nzethics.com/>

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- ▶ Application Fee \$500 waived
- ▶ Help build NZEC capacity

Community Research Code of Practice

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- ▶ 'To develop, cultivate, and maintain principled relationships is integral to ethical practice.'
- ▶ NZEC wants to be part of that relationship

Historical background

- ▶ The Unfortunate Experiment
- ▶ An institutional Response
 - ▶ Tertiary Sector
 - ▶ Hospital Boards
- ▶ A National Response
 - ▶ Canada and Australian National Statements

Personal Background

- Massey University human ethics committee
- Manawatu Wanganui health and disability ethics committee
- Multiregion health and disability ethics committee

- The ethical vacuum

Formation of NZEC

- Tindal Foundation
- Ministry of Social Development seeding grant
- Former HDEC Chairs and Committee members
- The committee has about 14 members. 6 of them are Maori.
- Tolich, M., & Marlowe, J. (2017). Evolving power dynamics in **an unconventional, powerless ethics committee**. *Research Ethics* 13(1) 42-52
- Tolich, Martin & Marlowe, J. & Tolich, M. (2015) Shifting from Research Governance to Research Ethics: A Novel Paradigm for Ethical Review in Community Based Research, *Research Ethics*

Why do researchers come to the New Zealand ethics committee when it's not compulsory?

- ▶ We wanted to do this right. We needed to know that our project was sound and we needed to know that it was ethically valid I suppose.
- ▶ I think because you know you're gonna go through an independent review committee you do try and make sure you've got set up everything properly rather than trying to wing it, so it does put [...] more rigour into how you're setting everything up.

Is methodology off limits? No.

- ▶ The review itself gave us a few good ideas in terms of tweaking the survey to become more balanced ... So it definitely enhanced the design of the study.
- ▶ The further we got into [the project], we realized the survey actually wasn't meeting the need out there and so we revised the survey and so that meant going back to the ethics committee and informing them ... That's actually where we got most of our help around the questions and how they were framed up. The convener gave quite a bit of really good advice around that and made quite a few changes as a result of that so yeah, so things did change once we were out there but that was purely because of the tool we were using not working for us really.

Honouring Participants

- ▶ I feel like we honoured and valued our research participants more and we were able to demonstrate that because we had gone through that extra process that we didn't have to go through. We did it because we wanted to make sure we weren't unconsciously or accidentally being exploitative or inappropriate in any way so I kind of felt that going through this ethics process with an independent ethics body that wasn't linked to how good it would make the university look if we did this research, really – it really helped us feel stronger about what we were doing and yeah, we felt that it was a way of valuing our participants.

Why Community Researchers have problems with Institutional Ethics Review

How researchers use NZEC

- ▶ All reasons mentioned above
- ▶ Also, to overrule a Boss

Take away message

- ▶ Reference groups

Dan's Story

- Dan as part of a longitudinal study of rural youth. At the age of 11, 14 and 17 Dan shared his views on school, parents, growing up in a rural area and other stuff. The interviews were tape recorded and transcribed.
- When the researchers contacted Dan when he was 17 they discovered that he had passed away. This is a big ethical moment. What should the researchers do?
- Surely they would take the beautiful tape recordings and transcripts that Dan had shared at aged 11 and 14 and give them to his parents as mementos.
- What about Dan's privacies and about the stories he would have told about his relationship with his parents. Should we protect Dan's privacy and his relationship with his parents.
- Edwards, R. & Weller, S., (2016) Ethical dilemmas around anonymity and confidentiality in longitudinal research data sharing: the death of Dan. In Tolich, M. (Ed) *Qualitative Ethics in Practice* (pp. 97-108). London: Routledge.

New Directions for Ethics

- ▶ The limits of informed consent
 - ▶ Participants can leave the research at any time
 - ▶ Is that enough
 - ▶ Ongoing Consent or Process consent
- ▶ How do researchers exit a research site?
 - ▶ Do they
 - ▶ What is the relationship
- ▶ The limits of confidentiality
 - ▶ Small town New Zealand

New Zealand Ethics Committee: Origins and Directions

- To fill a vacuum
- Create a different Ethics Committee
- See ethics a part of a relationship

- Next year NZEC will facilitate training for researchers.
- Join the NZEC—Community Members Please

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