

Evolving power dynamics in an unconventional, powerless ethics committee

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Abstract

A previous research ethics article by the authors provided evidence to support the claim that the New Zealand Ethics Committee (NZEC) was a powerless ethics committee. Ethics review applicants were not formally obliged to seek ethics review, and any committee recommendations were given on a ‘take it or leave it’ basis. One year later, the capacity of applications has doubled, and NZEC finds its core assumptions challenged as funders and government agencies now compel contracted researchers to make use of this free service. Moreover, NZEC has expanded into research areas inhabited by market researchers, long shy of ethics review. Review requirements and remit expansion challenges some, but not all, aspects of NZEC’s assumption of powerlessness as NZEC remains committed to research ethics, not research governance, and it adheres to the principles of the New Brunswick Declaration to respect applicants the same way it expects applicants to respect participants. This annual survey of applicants makes NZEC accountable to its applicants, providing evidence once more that NZEC’s expeditious and cordial review of applications is considered different from traditional ethics review.

Keywords

ethics committees, market research, New Zealand, powerlessness, research ethics

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Introduction

A previous article in *Research Ethics* (Marlowe and Tolich, 2015; see Flanagan and Tulmity, 2015) claimed that the New Zealand Ethics Committee (NZEC), a non-profit organization, was unique with a *different* philosophy from traditional health- and university-based ethics institutions. NZEC is the only ethics committee that reviews applications focusing solely on an application's research ethics and not as traditionally practiced on research governance considerations (Iphofen, 2009). Social scientists have found research governance a frustration in ethics reviews (Bosk and De Vries 2004; Gunsalus et al., 2006, 2007), yet the 2015 article found that the New Zealand Ethics Committee could function outside an institutional frame focusing solely on research ethics. Whilst New Zealand university- and health-based researchers are compelled to submit their research for review by ethics committees, researchers based in central and local government, NGOs, and community-based researchers are exempt from standard ethics review.

This text reports on NZEC's second year of operation by returning to the 51 applicants who submitted an application in 2015, asking them why they sought ethical review when not mandated to do so. It also asks applicants if they experienced this review process as a new paradigm, and other open-ended questions to capture the impact that the ethics review had on their research participants, their funders, clients, and/or publishers. The findings of this survey were unexpected, and sometimes at odds with the first article's conclusions, representing evolving power dynamics between NZEC, its applicants, and the world of research in New Zealand. Much of this evolution was outside the control of the NZEC review process as now it reviews researchers in greater volume. The number of applications was up from 22 in 2014, and NZEC is now used by a different type of researcher, mostly university-trained professional researchers contracted by social agencies and government departments. If these individual researchers were not compelled to seek ethics review, in some circumstances their funders and clients made NZEC ethics review obligatory. Another unusual change was that some of these government agencies compelled market researchers to seek review. These researchers are traditionally governed by professional codes of ethics, and many had never previously considered making a formal ethics review application. Inadvertently, NZEC expanded the reach of ethics review into the nether reaches of commercial research, raising ethical considerations, with novices who welcomed the expansion of their informed consent protocols. A telemarketer asking 'is now a good time to talk' was no longer an acceptable approach to establishing informed consent.

This article documents how NZEC addressed these changing power dynamics brought about by this expanding and diversifying clientele while attempting to maintain its focus on research ethics, not reverting to a moral panic (Van den Hoonaard, 2001) or ethics creep Haggerty (2004). This article considers the wider ecology and interactions beyond that of the applicant and NZEC to consider the

evolving power dynamics that funders, publishers, and organizations wield. Whilst we previously recognized the importance of ethics review in community-based research in giving it greater legitimacy, we did not focus on the wider ecology of such research in terms of initial constraints upon applicants to seek our approval in the first place. These interactions bring into question NZEC's deliberate orientation of voluntarism to examine the ways in which wider politics surrounding community-based research imbue it with power at structural levels.

Ethics review in a wider ecology of community-based research

NZEC reviews applications, gratis, from all researchers excluded from formal ethical review, and as NZEC is not institutionally situated its goal is solely on research ethics, where the focus is upon the protection of the research participant rather than the host institution. A core assumption rendering NZEC a powerless ethics committee assumes researchers are free to accept or ignore the committee's advice. This ethos and the first NZEC evaluation (Marlowe and Tolich, 2015) led to the conclusion that this approach to ethics review moved towards a collaborative bridge-building function (as a form of research ethics) as opposed to that of gatekeeping (research governance) characterized by traditional ethics committees. Iphofen (2009) notes that research governance practices exist first and foremost as a mechanism to protect the institution (see also Stark, 2012). Seeing that pathways for ethical review have now been almost constrained to those of higher education and health-based institutions (with some exceptions) highlights the power of academic imperialism. Unless someone wanting to do community-based research co-opts an academic onto their research team (and often effectively handing over control to the university), they are not eligible for ethics review. This imperialism is also strengthened by publishing houses that require an author to tick a box that it has been reviewed by an ethics committee. Funders often require ethics approval before the associated money and resourcing is released. As community-based researchers have so few options, if any, for ethical review, it is easy to see how important research is excluded at the front and back ends of the design to the dissemination life cycle. This situation is concerning, recognizing that many organizations surviving under neoliberalism must increasingly justify their existence through evidence – some of which is achieved through research and evaluation, and much of this without any formal ethical oversight. While recognizing the complexities of community-based research and that ethical standards must apply, the fact that research and evaluation is becoming part of what agencies are supposed to do demonstrates that ethical review must extend beyond the confines of the academy. Here we define the notion of 'community' within community-based research as referring to those who are not eligible for ethics review from health and academic institutions.

A means of NZEC distancing itself from ethics creep, which Haggerty (2004) notes is the increasing tendency of ethics committees to continuously wield greater spheres of influence into research design, has been NZEC's endorsement of the New Brunswick Declaration (see Van de Hoonaard, 2013). Its key ethos states that ethics bodies grant researchers the same level of respect that researchers should offer research participants. Giving applicants the opportunity to anonymously document their positive and negative experiences with NZEC in open-ended questions demonstrates respect for applicants. But this survey also sets NZEC apart from most ethics committees who seek no feedback and no accountability from those they serve.

This article now presents the findings of a survey into the second year of NZEC's operation from the perspective of its applicants. Of particular note is the insight that the participants provide about the negotiation of power that exists in the relationship between the applicant and NZEC, but more importantly those who have influence on the funding, commencement and dissemination of the associated study. The article reflects on NZEC in this wider ecological context to explore whether the voluntary organization that provides ethical review is indeed as powerless as originally assumed.

Study design

Of the 51 applicants who submitted an application in 2015, 19 responded to the email invitation to take part in an open-ended set of questions sent out by the NZEC administrator. The information sheet informed applicants that whether or not they participated in the survey their standing with NZEC would be unaffected. The survey asked eight open-ended questions listed above, i.e. why you or your organization sought ethics review when they were not required to do so.

As the two authors are current members of NZEC it was an imperative that power dynamics be addressed in the study design. To achieve this, the administrator liaised with all participants and answered all of the respondents' queries.

Respondents typed their responses to the eight questions, and these were sent to the administrator, who de-identified them. The first author coded the 19 sets of eight questions in the series of themes (see Saldaña, 2009). We then wrote memos about the major themes, which were then discussed as a research team to ensure better consensus around the ensuing abstraction of the data. The open-ended survey questions were analysed first along the five themes of (i) motivations of seeking voluntary ethical approval, (ii) strengths and weaknesses of the review process, (iii) the impact of the review on their research, (iv) what value (if any) was added to the project through the review process, and (v) an open-ended catch-all for final comments. These themes were then further analysed as a form of second cycle coding to consider the associated power dynamics associated with ethics review in

an ecological context. This project had ethics approval from the first author's university institution. We now report the ways that power dynamics operate in more micro-level interactions between NZEC and the applicant and then within the wider contexts that applicants seek review.

Choice vs constraint: Motivations for seeking ethics review

When asked why applicants sought ethical approval when they were not legally required to do, two answers arose, one of which was at odds with the ethos of NZEC outlined earlier in the previous article (Marlowe and Tolich, 2015). There the authors claimed that NZEC's applicants were treated differently because they, too, had sought ethics review voluntarily when not compelled to seek it. The applicant could choose whether or not to take NZEC's advice. This voluntariness gave NZEC a sense of deliberate powerlessness. Respondents in this study, however, challenged this core assumption, suggesting that many of their applications were mandatory, based on the direction of a third party. These third parties were listed as funders, clients, professional bodies' codes of ethics, and an academic journal's requirement that submission have prior ethics approval, or they were applications compelled by a local or foreign ethics committee. The unintended consequence of this compulsion imbued NZEC with a power it did not seek, undermining part of the claim that its powerlessness was a unique defining feature of its point of difference. Thus the academic imperialism noted above is potentially perpetuated by professional and community-based organizations and associated funders, raising the question of whether applications to NZEC were actually a choice or a constraint. For instance, participants noted how funders used the NZEC review system.

At the request of the funding body, we were not able to start data collection until approval had been received.

What is clear in this directive is that NZEC had power thrust upon it. Whilst an applicant could choose to accept its decision and advice, ultimately they had to meet NZEC's criteria to get the go ahead for funding, project commencement or publication.

Additional evidence of compulsion to seek out ethics review was also sourced from internal motivators. University-trained applicants' culture is part and parcel of how postgraduate students are trained, making ethics review second nature. Here the motivation was both for others as much as for self:

To ensure [the project] was ethically sound to protect the participants, myself and the organisation I was working for. As it was my first job post uni work it was also good to ensure I was 'On the right track' so to speak and to protect my back.

Three respondents made secondary applications based on a previous review by an ethics committee, including one from Australia and one from the United States:

It was suggested to me by a couple of people that applying to the NZ Ethics Committee would not only be the ethical course of action but also would provide me with insights into key ethical concerns in NZ.

I didn't have an affiliation for this project, but felt it was important to have the project reviewed by a NZ entity. The standards may be different in the US than in NZ, and also as a sign of respect for the host country, it seemed like the right thing to do. Also as someone familiar with NZ, I wanted to ensure I was not doing anything that would offend Maori. I was pretty sure I wasn't, but figured that wasn't for me to decide.

Those compelled or voluntarily seeking ethics review identified NZEC as the only ethics review committee that could review them. NZEC was established at a time when the government was withdrawing from ethics review of health research (Tolich and Smith 2015), yet the need for ethics review continues. This assumption was sustained by respondents. NZEC is popular because it is the only choice available:

Our research was not covered by the HDEC [Health and Disability Ethics Committee] and we are not affiliated with a university so the NZ ethics committee provides us with ethical review for our research and evaluation projects, particularly those that involve consumers which really should have ethical approval.

Overall, the responses to what motivated submissions to NZEC was more on the research design and outcomes. Half of the 19 respondents mentioned an intention to publish the results, reporting 'publication is absolutely a motivating factor in gaining ethics approval for us' or 'for our organization, it gives legitimacy to our services and allows us to be taken seriously'.

As these participants and others highlight, NZEC's preference for deliberate powerlessness has been usurped by publishers, funders and other institutions. Whether the motivation of these third parties was about managing risk, ensuring a more ethical approach or something else remains unknown in this study.

As a distinct example, another applicant noted how they *used* the ethics review process both for their participants and as a safe way to challenge the advice of their employer or line manager who had advised an approach that had ethical concerns:

Feedback added to the legitimation of the project as I was forced to put something in the application, which I wasn't happy with ethically, which was picked up by the committee and in turn had my back. I was really glad the committee picked up on this and I was relieved. It was a nightmare working with one of my bosses and the ethics process sort of acted as a mediator between us.

What these participant comments highlight is that community-based research represents a diverse range of applicants. Some of these applicants come with strong

research backgrounds and even previous university-based work experience, others as private consultants and some who are completely new to research. Equally varied are the reasons and motivations for conducting research in the first place and for seeking ethical oversight. The next section considers these ecologies that extend beyond what most traditional ethics committees need to evaluate.

The ecologies of community-based research and ethics review

Interestingly, respondents challenged an additional assumption raised in the previous article: how the committee took pride commenting not just on ethical issues but on methodology, for example, to the point of correcting survey questions and suggesting alternative methods that would help address the associated research questions. Routinely researchers complain that ethics committees either know little about social science research methods or base their review on a biomedically inspired epistemology (Israel, 2014). In the 2015 survey, however, this assumption that applicants appreciated methodological advice was challenged by some of the more sophisticated, university-trained clientele. This finding has created tensions for NZEC going forward. One response to this criticism is to rewrite the application form allowing researchers to tick a box exempting themselves from unsolicited advice about methodology unless the methodology involves, for example, deception that compromises normal informed consent procedures. A second response is to bolster the expertise based on NZEC recruiting contract researchers whose research is primarily evaluation-based research. A third response would be to have applicants in the 2016 survey record their demographics: highest degree, contract researcher, community researcher or government employee.

Responses were not all positive about NZEC's decision to comment on methodology as well as ethical consideration:

From our perspective, the people who were reviewing our application seemed to have assumed that they knew how things worked in our sector and this affected their advice which was not always relevant to us.

These challenges did not overshadow the core belief in ethics review being primarily for the participants, but the diversity of respondents' motivations in this survey were different from the more altruistic motivations found in the previous article. This may have been because the previous ones were tape-recorded and transcribed, and these were self-typed responding to survey questions.

A number of respondents whom Israel (2014) would term 'the angry and frustrated' used the survey to contrast NZEC with previous experience with ethics review committees:

The process was painless. Considerably easier, and, interestingly, more interactive than previous [ethics review committee].

A strength is the participatory nature of the process, it does not feel punitive. The ability to discuss the feedback is also helpful.

A feature of the powerless ethics reviews was the open dialogue between committee and applicants:

Helpful and realistic reviewers, timely turnaround, approachability of reviewers, fair and reasonable feedback. Strengths were the ability to enter into dialogue about the application.

You guys did a great job in terms of the entire process. Most importantly, NZEC seems fluid in terms of understanding the need to support and help the research process. I think that the vast majority of researchers are not out to conduct unethical research, and my opinion at least is that ethics committees should be helping researchers to the methods to make sure that research has a minimal (or hopefully positive) impact on participants whilst not placing unrealistic or unhelpful additional demands on researchers. The worst ethics reviews I have seen focus on pedantic comments about correctly filling out the application forms and failing to actually recognize the sensitive aspects of the study and provide expert insight into how the study methods might be improved. I think this should really be the core focus of an ethics committee. In my view, the NZEC does this very well, which is a credit to you all.

Most respondents spoke in praise of how NZEC enhanced the value of their research project:

The review process meant that we discussed and substantially revised the introduction and ending of our questionnaire. This was something we were working on and found the ethics review process very helpful for that. We spent more time on the questionnaire design, including the ethics review process than we originally anticipated but I think that was partly to do with the quality/detail of the feedback and the work we needed to do with our provider to re-design parts of the survey. While this put pressure on our timelines, in the end, the review process did not affect the fieldwork start date.

The opportunity to submit an application for ethics review provided a reflective stage in the research design:

The review process does add time to the research process, but it always will. Reviews make sure that we have a sound understanding of how the research will take shape and proceed before we go blundering in.

One remarkable finding demonstrating the expanding role NZEC is having on New Zealand research is that it has brought researchers into the orbit of research ethics review for the first time. For example, a government department may contract a market research company to conduct its research subject to approval by

NZEC. These market research companies may adhere to a written code of ethics but be unfamiliar with research ethics committee review:

Being able to explain that our survey has ethics approval helps to mitigate internal discussions on risk associated with the survey and its outputs, and helps with putting together the business case to maintain the survey. Many of the changes to our survey were around the introduction and ending of the survey. For example, changes were made to the introduction to make it clearer/more explicit for the respondent on what the survey was about, in obtaining consent and informing them of their options. These were already in the survey but less detailed or more implied. While making the survey slightly longer I believe it has made the introduction much clearer/explicit for the respondent. So, yes, I would say that the process we went through to obtain ethics has improved the service delivery of our survey. We continue to look for ways to improve our survey and the changes made from the previous ethics process we went through are incorporated into the future survey planning.

If this outcome was positive, NZEC had a detrimental effect on one researcher's ongoing contractual relationship with their government agency. One applicant reported that the review process undermined her research in ways the funder did not appreciate:

The funder pulled funding in the final stages of ethical approval. I think this was partly about a ministry wanting to balance its budget for the forthcoming government budget round which had promised a surplus, but I wonder whether the ministry official did not want to comply with some of the ethical requirements and whether this contributed to the funding being pulled.

This again highlights the ecologies and interests of community-based research that go beyond NZEC, the applicant and associated participants in the study – these activities are also influenced by funders, managers, publishers and others that highlight the complex and contested space in which such ethics review occurs.

Discussion

Traditional ethics committees operate in a more controlled and predictable environment in terms of who can approach it for review. NZEC operates in a less certain but important space where research and evaluation does occur, and often does so without ethical oversight. The participants' responses highlight that NZEC is not the powerless committee that was originally envisaged. Several community-based funders now require ethical approval, and participants were clear that NZEC was the only real option. Other examples highlight how researchers used NZEC as a way of challenging the perspectives and desires of their managers or employers, particularly when concerned about the research designs they were asked to oversee. And as the number of applications to NZEC has grown, it is clear that there is a diverse clientele – some of whom are very experienced in research and others who need support that may also include methodological advice. Whilst it is

evident that NZEC fills a void for community-based research, it is also apparent that the organization operates in a wider ecological context that introduces new complexities that traditional ethics institutions may not need to navigate. There are both opportunities and signs that caution is needed in this regard.

Thus, an area for future research represents understanding the perspectives and needs of those who are often the gatekeepers of community-based research – whether this is at the front end in terms of approving and funding research or at the back end in relation to its dissemination and opportunities for impact. Though not entirely new, understanding the drivers that influence funders' and institutions' support for community-based research highlights an important gap in understanding the ecology of what is possible and constrained. The findings of this study (which only report on the themes related to power) also illustrate the value in ethics committees asking their applicants for feedback. As noted earlier, Van den Hoonaard (2013) argues in the New Brunswick Declaration that ethics institutions should show the same level of respect to their applicants as the committee expects that the applicant shows its associated participants. Embracing this feedback demonstrates a reflexivity and potential praxis that could better respond to the ecologies of which research is positioned.

Whilst we have argued that traditional ethics governance has unnecessarily narrowed the field in which research can occur, namely that of academic and health-based institutions, it also highlights the complexities of trying to accommodate the wider ecology of where research and evaluation can occur. The associated challenge (or perhaps more helpfully constructed as a compliment) to traditional ethics-based approaches does not suggest that it is 'anything goes' in community-based research. In fact, it is quite the opposite. The bottom line remains that research ethics is about ensuring the protection of all those involved in the business of conducting social science inquiry. The ways in which a more diverse applicant pool meet this standard and the associated internal and external motivators that generate a desire for ethical oversight in community-based research highlight that an intended powerless NZEC does at times have power to wield, albeit indirectly and reluctantly.

What is interesting to the authors is that, depending on the context (not of our making), NZECs are either relatively powerful or powerless – a third party largely decides this for us. And NZEC will continue to evolve, consumed by third party forces beyond its control. These forces are government agencies who mandate their contract researchers to seek ethics review from NZEC. NZEC's point of difference remains how expeditious and cordial the communication between applicants and the committee remains.

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