

Lay members of New Zealand research ethics committees: Who and what do they represent?

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Abstract

Since the 1988 Cartwright Inquiry, lay members of ethics committees have been tasked with ensuring that ordinary New Zealanders are not forgotten in ethical deliberations. Unlike Institutional Review Boards (IRBs, or ethics committees) in North America, where lay members constitute a fraction of ethics committee membership, 50% of most New Zealand ethics committees are comprised of lay members. Lay roles are usually defined in very broad terms, which can vary considerably from committee to committee. This research queries who lay representatives are, what they do, and what if anything they represent. Our findings are based on data collection with 12 participants: eight semi-structured interviews with lay members from diverse types of ethics committees who described their roles, and commentary from four ethics committee chairs, three of these lay members who commented on this article's final draft. Findings indicate that the role of New Zealand lay persons – although distinctively valued – is otherwise similar to the documented role of lay persons within North American ethics committees. Lay members see their role as primarily protecting

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the research participant and at times offering a corrective to non-lay members' views and the interests of their institutions. However, in spite of their numbers, most lay members do not see themselves as representing any particular constituent groups or institutionally unaffiliated areas of concern. On tertiary education committees especially, there is a good deal of ambiguity in the lay role.

Keywords

Cartwright Inquiry, community member, lay member, New Zealand research ethics committees, non-affiliated member

New Zealand ethics committees and the role of lay persons

The creation of New Zealand ethics committees in 1988 is well documented (Authors, 2014; Cartwright, 1988; Coney, 1988; Rotondo, 1996). Ethics committees emerged out of a critical inquiry into the so-called 'Unfortunate Experiment' which took place at National Women's Hospital in Auckland, New Zealand, between 1966 and 1982 (Skegg, 2011). The Unfortunate Experiment withheld treatment from women with carcinoma in situ, a number of whom went on to develop cervical cancer and die. The study also disregarded the informed consent of patients (including parents of infants) who received cervical testing and biopsies (Coney, 1988).

Public disclosure of this significant breach of trust led to the Minister of Health calling for an inquiry into the conduct of involved researchers. The inquiry put forth recommendations that externalized public control over the medical profession (Paul, 2009). The presiding Judge, Sylvia Cartwright, stated in her recommendation that 'the focus of attention must shift from the doctor [researcher] to the patient' (Cartwright, 1988: 176). Part of this new focus was a mandate for non-medical persons to become more involved in determining the ethical parameters of health research.

As a result of the Cartwright Inquiry, 15 regional Health and Disability ethics committees tasked with reviewing health research were established, and the seven universities existing at that time were instructed to host their own ethics review committees (Rotondo, 1996). Judge Cartwright recommended that a significant number of lay persons be appointed to these ethics committees. She cited a growing trend at that time and existing guidelines on the matter as part of her recommendation, suggesting that ethics committees be comprised of:

men and women reflecting different age groups and includ[ing] at least five people as follows: a lay woman not associated with the institution, a lay man not associated with the institution, a minister of religion, a lawyer, and a medical graduate with research experience. ... A lay person

in this context is one who is not closely involved in medical, scientific or legal work ... (Cartwright, 1988: 146)

Cartwright added, 'these categories, although too restrictive ... give a good indication of the cross-section of lay representation that an ethical committee could strive to co-opt'. She also cited an expert view that: 'The emphasis on a diversity of membership should ensure the protection of the research subject from the narrowness of one professional perspective'. Term limits were also created: lay persons were to be appointed for a three-year term extendable only once, to a total of six years.

Prior to these recommendations, the sole 'lay person' on the National Women's Hospital ethics committee had been a retired coroner and a pharmacist (Coney, 1988).

Ambiguities in the lay role

As indicated by the explicit use of the term 'lay' for only two of Cartwright's five specified 'lay member' roles, the moniker 'lay member' is ambiguous. The term remains ambiguous today (Rotondo, 1996). Within tertiary education committees (hereafter referred to as 'tertiary' committees), it generally refers to a person not affiliated with the institution. But such a definition came about originally from medical contexts, and it does not always hold in tertiary education contexts. For example, one of the tertiary ethics committees represented in this article is constituted entirely by employees of the institution; its 'lay' members are those employees who hold non-academic roles. This scenario is not unusual. McNeill (1993) reports that lay persons in Canadian institutions of higher education are defined as being from a different academic department, e.g. sociologists serving on a psychology IRB. Health ethics committees stipulate that 'lay persons' are non-health professionals, while tertiary committees, which review applications for projects in a range of fields, allow for lay members to be health practitioners or health researchers.

One of this paper's authors embodied this ambiguity. Between 2004 and 2008 he was a lay member of New Zealand's Multi-Region Health and Disability Ethics Committee, serving as its designated 'ethicist'. He also served as Chair of the committee (chairpersons of all New Zealand health ethics committees are lay members). He was designated a lay person by virtue of not being a health professional. However, at the time, he was a social scientist researching medical ethics within committee processes and he was institutionally affiliated: 20% of the applications to his committee were sourced from his university.

The term 'lay' person is poorly defined also within international literature concerning research ethics committees. It is often defined by negation, signifying what a lay person is not, rather than exemplifying what one actually is (e.g. a lawyer or minister) (Bauer, 2000). But of course outside of research ethics committee

contexts lawyers and ministers would not ordinarily be considered lay persons; Cartwright considered such individuals necessary to protect research participants and integrity against the narrowness of professional *medical* perspectives, specifically, revealing a presumed medical paradigm for research requiring ethical deliberation. This presumption, in turn, has informed New Zealand's regulations about ethics committee membership.

Interestingly, in her report, Cartwright (1988: 146) cites one view that 'it can be an advantage to select the lay membership from those with a specific professional qualification (eg [sic] in law, philosophy or theology), since this also gives input to the discussion from another discipline', but she also cites guidelines (noted in the previous section of this article) indicating that lay persons in the strict sense of the word would *not* be involved in legal work – although these guidelines stipulate that a lawyer member should exist on ethics committees. The former view is labelling all non-medical and non-scientific committee members as 'lay', while the guidelines appear to be distinguishing amongst lay persons, persons involved in medical or 'scientific' work, and persons who are particular kinds of non-medical professionals (lawyers and ministers of religion).

In North America, lay persons are either non-affiliated, non-scientists, or both:

Sections 46.107 (c) and (d) of the federal regulations governing the protection of human subjects requires IRBs [ethics committees] to include "at least one member whose primary concerns are in non-scientific areas" and "at least one member who is not otherwise affiliated with the institution and who is not part of the immediate family of a person who is affiliated with the institution". (Canada. Public Works and Government Services Canada, 2005)

Klitzman (2012) reports that in many cases the non-scientific and non-institutional representative can be the same person. Clearly, in New Zealand, lay membership is relatively expanded and specified in more detail, but the role is equally ill-defined.

The ambiguity of the 'lay' role has resulted in a range of terms used in New Zealand to signify that role, which can vary from committee to committee. 'Lay' persons, 'non-affiliated' persons, 'externals', 'community members', and 'non-scientists' are all terms that refer to persons co-opted onto ethics committees. The term 'community member' is often used, because most 'lay' members are not in fact 'generic' persons. In New Zealand, as a result of the Cartwright legacy, the majority of committee guidelines specify lay committee membership as partial job descriptions including particular areas of practice or expertise, which Stark (2011) characterizes as 'warrants' for decision-making. Common specifications on tertiary committees include those of Māori (indigenous New Zealand) background, a lawyer, and a registered health professional. Yet as Klitzman (2012) points out, membership within a community or area of practice does not equate with active representation of a particular group's interests or views. One IRB chairperson commented on an American Indian representative who appeared not to know much

about American Indian culture(s). ‘We learned that just because someone says they’re an Indian ... doesn’t mean they know anything about doing research in Indian country. We made some assumptions in the expertise we called in’ (Klitzman, 2012: 982).

This article uses the term ‘lay’ person to denote non-institutional and non-scientific members of ethics committees. Thus the focus of this article is on lay representatives who are not employed in a given tertiary education institution or are non-health practitioners. Note that while all of our interviewees met one of these criteria, several did not meet both. As already mentioned, one was employed at her institution; another (non-affiliated) interviewee is a registered health care professional with an academic and research background. Interestingly, a third interviewee – a non-affiliated, non-health professional on a Health and Disability committee – refused to be labelled a community member or a lay member. Instead, she identifies as a lawyer member. We have included her in the study because, as noted above, lawyer members of Health and Disability committees are often categorized as lay members; Cartwright herself was ambiguous on this issue, and in this article we are explicitly interested in exploring such ambiguities.

Lay members’ experiences within the US

To date there is very little literature on the lay role within research ethics committees in the New Zealand context (see O’Connor, Banda and Grinter, 2014); however, there are accounts of the role in the US. In her research note ‘First Impressions: The Experiences of a Community Member on a Research Ethics Committee’, Slaven (2007) describes herself not as representing the community on the ethics committee, but instead as someone trying to ‘advocate’ for the research subject:

How can I represent a community that is multiethnic and multifaceted – old, young, white, brown, black, Catholic, Protestant, Jewish, Muslim, agnostic, and atheist? ... I do try to represent, advocate for, and guard the rights of the potential study participant. On the other hand, when I raise my hand to vote on acceptance or rejection of a protocol, I feel pretty sure that I represent only myself. (Slaven, 2007: 18)

Slaven’s advocacy role was thus limited. Lidz et al. (2012: 1) also found that community members did not represent constituent groups:

They did not appear to represent the community so much as to provide a non-scientific view of the protocol and the consent form. ... The regulations describe them as unaffiliated, suggesting protection against the parochial interests of the institution. Neither in the interviews nor in their behaviour in meetings did community members appear to see this as their role.

Anderson (2006) reported Porter’s (1986, 1987) survey findings that out of 198 non-affiliated and non-scientist IRB members 94% were considered ‘professionals’, 32%

held doctoral degrees, and an additional 40% held masters degrees. In the New Zealand context, O'Connor, Banda and Grinter (2014) note that of 29 community members surveyed, almost all held a tertiary education qualification, and two-thirds held a postgraduate qualification. Similarly the eight persons interviewed in this study are either professionals or retired professionals (although one of our interviewees did not have a tertiary qualification).

A second finding in Lidz et al.'s (2012: 6) study was that lay persons positioned themselves not as professionals but as servants of those recruited into the study. One of Lidz et al.'s informants said: 'My value to the committee is to try to stay as naïve as I can, you know, when I read this stuff ... how would a naïve person read this?' Other community members said: 'I read it with a viewpoint that I'm representing the layperson. See if they can understand it', and 'I think that's what my role is. I'm standing in for the subject'. Specifically, assessing the readability of the consent form was consistently mentioned as an important part of a lay member's job, including ensuring that consent forms are understandable to potential participants. One participant stated that the community member's job was to check to see that 'it's not too technical ... that they can comprehend what they're signing. You know what they're gonna do ... so they can be readable by a person without a college education'.

These sentiments capture the perspectives of the eight lay persons interviewed below. They too were there to advocate for the research subject. It is notable that in a recent survey of 29 community members within New Zealand ethics committees, ensuring informed consent, and doing so via lay language, were cited as topmost priorities – 90% and 75% of respondents, respectively, considered these issues 'very important' – whereas only 32% of respondents considered it very important to ensure 'that the community will benefit from the research' (O'Connor, Banda and Grinter, 2014: 4). This contrast is striking, and is only somewhat tempered by the fact that 64% of respondents considered it very important to ensure that 'research is culturally sensitive and relevant to the community'.

The purpose of the current study

This article examines how New Zealand ethics committee members and chairpersons define the lay role and account for who or what laypersons represent. Research is lacking on this question of representativeness, in spite of a growing interest internationally in the related area of public involvement in the conduct of health and social care research (Brett et al., 2014). Given the high number of lay persons on New Zealand ethics committees – 50% of committee membership on the majority of committees, as opposed to the US context where it is common for only two or even just one lone member of a given committee to be 'lay' – the authors of the current study wondered whether lay persons' particular areas of expertise or experience are visible or emphasized. This research finds that community-mindedness

or lay ‘warrants’ for decision-making are not, in fact, present for most participants. Similar to the conclusions of the US-based research above, New Zealand members assume the role of ‘protecting’ the research participant, and for the most part avoid highlighting their unique backgrounds or skills and also avoid associating themselves with representation of particular community interests. A common theme voiced in this article is that these members offer a distinctive, non-institutional perspective; however, this perspective is, by and large, weakly defined. Findings also demonstrate that lay roles are more clearly defined on health committees; they are more ambiguous on tertiary committees.

Methodology and ethics

The methodology for this study was the same as that reported in Gremillion, Tolich and Bathurst (2014), which examines the relative empowerment of lay members on New Zealand research ethics committees, as compared with their North American counterparts. The authors gained ethical approval from the University of Otago human ethics committee. A purposive sample covering each of the three types of committee in New Zealand was generated by contacting lay members on five ethics committees. Two committees specialize in health research, two are tertiary committees, and one is a committee established in 2012 to review social science research that is not eligible for review by either the health or tertiary ethics committees. Although one of the authors knew each participant, the recruitment involved an author who did not know the participants personally. Eight lay members took part in semi-structured interviews which lasted about one hour. Four interviews were face to face and four were telephone interviews.

Although the sample size for the study is small, the total potential cohort is not large: currently, there are approximately 120 lay members on research ethics committees in New Zealand across 23 tertiary committees, four Health and Disability committees, and one social science committee. Note that not all committees contain lay members, and committee composition is often in flux. A sample size of eight represents about 6% of the total population in question, and can be considered a good return rate for a qualitative study of this kind (Tracy, 2013). We have supplemented our interview data with email commentary from one current tertiary ethics committee chairperson (an academic), as well as three former lay chairpersons who commented on this article’s final draft – one of the latter representing a tertiary committee and two from Health and Disability committees. One of the former lay chairs is the current chair of the Health Research Council’s Ethics Committee, which does not review ethics applications but rather is the sole body which accredits New Zealand research ethics committees. With the exception of this latter participant, who holds a distinctive and easily recognizable position, all names used in this article are pseudonyms.

The interview schedule consisted of a mix of open-ended questions and topic-specific questions. The opening question presented the interviewee with a blank slate: 'If a potential lay member telephoned you and asked you about what an ethics committee did, and about the role of a lay member, what would you tell them?' This question was asked a second time at the end of the interview with marked results.

Specific questions asked if the interviewee called her or himself a lay person or a community member, and also asked about the perceived meanings of these labels. Additional questions explored who or what lay members represent in their role: the researcher, the institution, the participant, a combination of the three? Did they represent particular community constituencies?

Interviews were transcribed and a thematic analysis of the data was undertaken following the six-step process outlined in Braun and Clarke (2006). Initial codes with supporting extracts were recorded after achieving familiarity with the entire data set. Codes were then collated into themes, which were checked for accuracy against the previously recorded extracts. Finally, themes were refined in preparation for this written analysis, for which vivid, representative extracts were selected.

Representing who or what?

As outlined in Gremillion, Tolich and Bathurst (2014), all eight interviewees described what we would characterize as full and equal membership status on the ethics committees they served, which were uniformly represented as collegial and collaborative. As a former chair of a Health and Disability ethics committee put it, lay members 'were equally part of the committee – in numbers at least, and substantially in comments and decisions'. This situation, which is in marked contrast to that found in North American contexts, is most likely due not only to the sheer volume of community members appointed to New Zealand ethics committees, but also to the exalted role the Cartwright Inquiry gave them to rein in any displays of arrogance of the kind shown in the Unfortunate Experiment (Cartwright, 1988). However, in spite of lay members' experiences of equality and authority within New Zealand ethics committees, there remains a lack of clarity regarding who or even what is uniquely represented by lay roles.

As suggested above, this lack of clarity about the lay role can be explained in part by the Cartwright legacy. Cartwright was responding to unethical medical research, and in this context 'lay' implies 'not medical'. The former chairperson cited above substantiated this definition of the term 'lay' for Health and Disability committees: 'it was generally regarded that medical and/or health practitioners and researchers were viewed as non-lay'. In the wake of Cartwright, the presumption that health research is the paradigm for all research is an appropriate fit for health committees, but for tertiary ethics committees the matter of lay representation becomes all the more

vague. More often than not, applications for the latter are for social scientific or humanities research projects. What is the content of lay representation in these cases?

The authors asked one current and one former chairperson of two different tertiary committees what they looked for or expected in a lay person. Their answers focused on potential connections to the community. As the former chairperson put it, lay members ‘bring to the table community representation’. The current chairperson said:

We have specific needs for community members. We always require a person with a legal background but in general we are looking for three to four persons who have connections to the community. A candidate may have excellent skills but have little connection to the community. One man worked from home and that limited his community connections. I think what we are looking for in general [are] links into the community ... that the applicant would bring with them – so who [do] they represent, what stakeholders [do] they represent, and the wider their knowledge or the more connections with the groups, the better. (Chairperson)

One former chair of a Health and Disability committee we consulted agreed that lay members’ community positioning was important, if not always uniquely visible in ethical deliberations (we discuss the opposing views of the fourth chairperson participant below). However, it is noteworthy that with only one exception – an interviewee on the committee which reviews social science research outside of tertiary contexts – the ethics committee members interviewed for this study did not align with these views that they were somehow representative of specific community constituencies (but note that one of our interviewees was a lawyer, and the current chairperson cited above does allow for such an exception to representing particular ‘community’ interests).

Health ethics committees

The term lay person is more straightforward on health ethics committees. In this context, lay persons are any persons who are not medical practitioners or researchers. Marilyn and Laura Lee were both ‘lay members’ of two different health committees and were quite clear about who they represented when they reviewed ethics applications. It is telling that Marilyn was our only interviewee who identified her committee role clearly in terms of her area of expertise: she considers herself a lawyer member, and not a lay or community member. She said: ‘I know if there are any legal issues that come up, the whole table turns [to] me [for] comment’. Cartwright specifically recommended such a role for reviewing the ethical content of medical research. Conversely, Laura Lee was our only interviewee who described herself as a fully ‘lay’ community member, in the sense that she viewed her lack of a university education as a warrant to challenge the use of technical language in participant information sheets. She reported that her role was to ‘push

back, and say, hold on a moment, I don't understand this, and if I don't understand this then the people who you are wanting to do the research will not understand it either'. Unlike the US-based lay members cited above, Laura Lee was not putting aside a 'warranted' professional identity in order to take up this perspective. Although she does not represent any particular constituency, she commented that her appointment to the health committee on which she serves 'was a very important conjugate between the community and the academics', and she considered it a key part of her role to ask, 'is this [research project] good for the community? ... [Will it] make a difference in people's lives?'

It would seem that these two interviewees are fulfilling Cartwright's intentions outlined earlier in this article, challenging the potential narrowness of 'one professional perspective' in the context of medical research – one interviewee in her capacity as a lawyer, and the other as 'a lay woman not associated with the institution' (Cartwright, 1988: 146). It is significant that when Laura Lee and Marilyn described their roles on their respective committees, they often did so not only in terms of potential individual research participants' interests, but also with reference to sociomedical power. To provide one example, Marilyn stated that for some applications researchers can be:

under pressure from off-shore pharmaceutical companies, and it is really for us to push back because if we push back and say well, no we are not going to accept it, it means they can then go back to the pharmaceutical company and say we actually have to make changes to this document [for the New Zealand context].

Our interviews with Laura Lee and Marilyn did evidence some ambiguities in the lay role (but not the lawyer role) on health committees in that, under some conditions, lay members might experience role dilution. At times in her interview, Laura Lee suggested that a central feature of her lay role was not so much to challenge or re-frame medical terminology but rather render it accessible to potential participants: 'Are we seen as the committee that's pedantic about writing? Yeah, maybe that's my fault!' Such a grammarian focus could indicate accommodation to a medical paradigm (in the role of translator of terms). Marilyn pointed out that the longer a lay person sits on committee, the more likely it is that s/he will 'lose the perspective of being a lay person' because 'you become so knowledgeable. ... you certainly learn a lot of medical terminology', and one therefore becomes 'more of an expert' about medical content.

Tertiary ethics committees

In contrast to our health committee interviewees, the five lay members of tertiary ethics committees interviewed focused almost entirely on the protection of study participants' interests. No one highlighted the specific areas of practice or

community-based knowledge through which they were recruited onto their committees. The chair of the Health Research Council's Ethics Committee – the accrediting body for New Zealand research ethics committees – authorized this situation: 'Lay persons, theoretically, could but generally are not seen to be representing constituent entities' (Barry Smith, 2014, personal communication). He also stated that lay persons are meant to 'keep an eye on the "professionals" so as to prevent them from running things and generating decisions in support of their usually narrower agendas'; however, only one of our tertiary interviewees discussed unique forms of leverage in this vein that a lay person can exercise. While the lay role was acknowledged as important and valued, and distinctive in some way, it was differentiated only as a perspective or point of view defined primarily in the negative, as non-academic. On the whole, these interviewees painted a picture of ethics committees as groups of persons who are equals, with diverse and equally valued contributions to make. Any specificity to a lay contribution was lacking.

Routinely the responses to our opening question asking interviewees how they would tell a novice about the ethics committee produced a similar response to Slaven's (2007) from the US, in terms of her focus on her role of 'protecting' the research participant. Jenny, a six-year veteran of a university ethics committee, reported:

As a community member, I saw my role always as representing sort of people who might be participants in the research, so that I wanted to make sure that participants were treated well, that the expectations of participants were realistic, that the kind of things that they were asked weren't overly intrusive, that they were respected generally in terms of what they were doing, that their time wasn't being wasted, and all these kinds of things. So as a community member, I think the other role that was there ... was that we often brought a different perspective to the research.

Other interviewees' responses to this question were in alignment with Jenny's description of a lay person as research subject focused and tasked to bring another or 'the other' perspective to the deliberations.

Edith was a lay member on a tertiary committee in which all committee members are internal to the institution and therefore affiliated. She works at this institution as an administrator; however, she is an academically trained researcher in other contexts. Her interview, like her position as an affiliated 'lay' researcher, reflects a good deal of ambiguity about the lay role. Early in her interview, she said that the lay role is meant to provide an 'alternative perspective' – which she described in a very generalized way – to an academic one:

I think I am not supposed to represent like the other kind of people on the committee so I am trying to be the 'other'. Like I am not there to represent the institution, I am supposed to be the member that's thinking slightly more externally focused I guess?

By the end of the interview, this generalized representation became ‘a definite different perspective’, which she characterized as attentiveness to what might be called ‘relational positioning’. Her key example was a consideration of power relations between teachers and students when teachers are researching their pedagogical practices. It was clear in her interview that, as a lay member, Edith does not consider herself to be representing any particular community constituency but rather ‘potential participants in studies’. Nor did she describe a need to ‘keep an eye on the “professionals”’ (Barry Smith, 2014, personal communication).

Hilda and Jenny, representing two different tertiary committees, explicitly stated in their interviews that there was no role differentiation amongst committee members. Two other interviewees, Dennis and Jane, stated that the various roles and backgrounds of all committee members are, equally, different and valued – everyone provides a unique contribution. When asked who he represents as a lay committee member, Dennis stated ‘I wouldn’t say who, but rather what am I there for?’, which he specified as the ‘highest principles of ethical oversight ... I am not necessarily representing any particular domain of the community’. In response to a follow-up question on this topic, he clarified that *all* committee members are meant to strive for these principles, not just lay members, and he added that any committee member will bring only partial knowledge to the committee. In this way, he said, the committee as a whole is a microcosm of society. For him, as for most interviewees, community members are not uniquely differentiated therein. Jane indicated an utter lack of role differentiation on the committee she serves when she stated that committee members’ backgrounds were not apparent in its discussions; she added, ‘I don’t even know who [all] the other [lay] members are, to be honest’.

A few lay members did cite correctives they could offer to non-lay positions taken; however, these were not articulated on the basis of particular expertise or community representation. Hilda was paid a modest stipend to attend the meetings, which made her feel valued but also independent of the tertiary context. At times she expressed that independence by reminding her committee colleagues that a full review may be necessary rather than expediting a colleague’s research. On one occasion Hilda insisted that a health research project should be sent to a National Health Ethics Committee for full review. She said ‘I had to put my foot down’ to make that happen.

Dennis reported that community members could take up an independent role on his tertiary committee: ‘there is always the potential for some community members to feel like they’re dealing with a bunch of pointy-headed eggheads who don’t really know which way is up, and have concerns that are a bit precious’. When he added that academics can worry about things they do not need to, or ignore things they should not, the interviewer confirmed his view that, if anything, it is the position of the academic that is at times questioned, rather than that of community or

lay members. He said that this questioning was an accepted part of ethical deliberations on the committee he served. Hilda's and Dennis's experiences confirm the respected status of lay members on tertiary ethics committees in New Zealand, while also confirming a lack of specificity about what constitutes these roles.

An independent ethics committee

Samantha serves on a non-health, non-tertiary ethics committee, established in 2012, that is devoted to reviewing social science research that no other committees will review. Applications are sourced from local and central government, NGOs and community researchers. Given this context, it is perhaps not surprising that Samantha's interview revealed a strong focus on community representation. Samantha spoke to the importance of understanding on-the-ground, contextual and relational specificities of community-based research. She was adamant that her role was not to take up an academic perspective on research design. Instead, her focus was on protecting the community from dubious research, and at times this focus challenged standard ethical procedures. One example she shared involved committee deliberation over studies involving at risk children. Samantha commented that 'from a purely academic perspective', one would be risk averse to allowing children under the age of 16 (18 in the US) to provide informed consent without parental consent. From that academic perspective 'you might say straight away no, you always need parental consent'. But Samantha asked the committee, what are the implications of this point of view? She spoke from a community perspective, having 'actually worked with projects with at risk young people', and argued that gaining parental consent would be virtually impossible at times. So one must then consider for proposed research projects involving 'really vulnerable young people ... should their voices always be excluded from research?'

Samantha's interview was the only one in our study that grounded lay committee deliberations firmly in the realm of community representation. It is noteworthy that the committee on which she serves is quite unique, in that it often focuses on community research.

Discussion

The New Zealand experience shares with the North American one a lack of clarity about the role of lay members, as this role remains defined primarily by what it is not. All but two interviewees addressed the question of who or what they represent in a vague or generalized way; one of these interviewees identified herself as a lawyer member, not a lay member, and the other serves on a committee that is often focused on community research. So, overall, Lidz et al.'s (2012) finding that lay representatives in the US do not actually 'represent the community', but rather

provide a 'non-scientific view of the protocol', generally holds true in the New Zealand context as well (interpreting 'scientific' in a broad sense, as not only medical but also 'academic').

Across the interviews representing tertiary committees, lay members referred to being advocates for potential research participants. In keeping with the Cartwright legacy, at times they would achieve this goal by challenging institutional interests. Hilda insisted that an application heading for an expedited review be sent to another committee for health review. Edith questioned the inherent conflict of interest embedded in any research project involving relatively powerful teachers and their students. However, these challenges were not based on particular community interests or specialized knowledge, even though all our tertiary interviewees were professionals or retired professionals and were recruited onto their various committees on the basis of community or specialized knowledge. Ambiguities for the lay role surrounding the question of community representation in these contexts is evidenced by the fact that while both a current and former chair consider such representation to be key to this role, data supporting it is lacking from interviewees. Notably, the chair of the Health Research Council's Ethics Committee specifically eschews community representation as part of the lay role: he stated that ethics committees are '(largely) meant to be competence not representationally based' (Barry Smith, 2014, personal communication).

The two non-medical interviewees on the health ethics committees also took seriously their post-Cartwright roles: in their cases, keeping medical power in check to protect the welfare of potential participants. They pushed back researchers whose multi-page information sheets seemed to be written more for lawyers than research subjects. These interviewees also reported that some researchers, whose jargon-filled information sheets seemed written not by the applicants but by global pharmaceutical companies, appreciated the push back because it allowed them to return to the sponsor with an instruction from the ethics committee that the researchers supported. These interviewees were clearer than the tertiary interviewees about the content of their 'lay' roles; and although neither involved specific constituencies, both involved socially conscious perspectives. Cartwright's recommendations were designed for medical research and, according to our interviewees, they appear to be operating successfully for the two health committees represented in this article.

One can speculate that tertiary interviewees were particularly vague about the 'lay', 'community', or 'external' content of their roles because of the range of fields represented by research projects that are reviewed by these committees. It is all the more difficult to define lay or community representation, or even the role of 'external' expertise, within these circumstances. Also, perhaps the liberal democratic ideologies of equality and diversity of representation evident across these interviews serve to dilute the specificity of lay roles in these contexts. Such role

dilution is apparent in North America as well: Anderson (2006: 149) reports the views of Kate, a lawyer who has served on various IRBs during the past 15 years: 'I guess the idea of being a community member is that you bring values from the community to the meeting that maybe institutional people won't have, but I'm not sure I think that's more than a theoretical distinction'.

Lastly, although the Cartwright recommendations included the idea that lay members should indeed pay special attention to the interests and protection of potential participants, our sense from the interviewees who spoke to this issue is that such a focus is no longer seen as unique to the lay or community role. While lay members are, at times, especially attuned to the interests and protection of potential participants, all committee members appear governed by this concern. Respondents in Anderson's North American study of community IRB members sum up the situation in New Zealand as well: they 'often made sure to note that while the primary contribution of the community IRB member is to provide the perspective of the potential research participant, all committee members are equally concerned with protecting subjects' (Anderson, 2006: 149).

In sum, who and what lay members represent on ethics committees remains unclear, and the question is internationally relevant. Committees in New Zealand, with a recommended 50% lay membership, all with terms lasting for up to six years, may be uniquely positioned to reconsider the role. The current study suggests that such a reconsideration is particularly needed on tertiary committees. Best practice recommendations can emerge once clearer definitions of and terms of reference for the role have been better established.

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