‘Lay’ roles on research ethics committees: North American vs. New Zealand experiences

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Introduction

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Introduction

Unique situation in NZ: in the wake of the 1988 Cartwright Inquiry (extreme abuse of medical power in research), 50% of committee composition is lay

Keep in check researcher and institutional power

Also, power to the “ordinary New Zealander” (layperson)

This research project: experiences of lay members (so, internal to committee process)
Across five ethics committees in NZ, lay members are empowered, fully valued members.

In sharp contrast to the North American experience: limited grammarian roles and often alienated, if not intimidated in committee.

Yet, ambiguity of lay role, particularly in tertiary committees: who is a ‘lay’ person? (on Health and Disability Ethics Committees [HDECs], clearer: ‘non-medical’). What or whom do they represent in tertiary contexts?
Herbert Green’s ‘study’, which ignored informed consent, was approved by an ethics committee with one lay person: a retired coroner and pharmacist.

Cartwright Inquiry has been called a “full-frontal challenge to the medical establishment, and to the model of professional autonomy and self-regulation that held sway in New Zealand” (Patterson, 2010, p. 6)
Cartwright stipulated 50% lay membership, comprising at least five persons 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… The emphasis on diversity of membership should ensure the protection of the research subject from the narrowness of one professional perspective” (Cartwright, 1988, p. 146).
Ambiguity of the Term ‘Lay’

Only two of the five listed here are denoted ‘lay’.
Ambiguity remains today, reflected in a range of alternate terms that vary cttee to cttee: lay persons, externals, non–scientists, non–affiliated members, community members, and non–health professionals (on HDECs) all refer to persons co–opted onto an ethics cttee.
Ambiguity of the Term ‘Lay’

Today, in keeping with the Cartwright legacy, committee guidelines specify ‘lay’ member positions as partial job descriptions including certain areas of expertise: i.e. a person with a Māori background, a lawyer, and a registered health professional on a tertiary cttee.
Currently no existing literature on NZ experiences of the lay role
Interviews with lay members to compare their experiences with lay member roles on North American IRBs
Far fewer lay members in N. American contexts: there, often one lone lay cttee member represents both ‘non-institutional’ and ‘non-scientific’ perspectives
We therefore expected NZ lay members to be more empowered
Marcia Slaven’s (2007, p. 18) account of her experience on a Canadian IRB: “Am I a rubber stamp? Am I a necessary bum on a chair or hand in the air required by some government regulation? Am I simply a grammarian, rearranging awkward sentences, correcting spelling errors, and throwing in punctuation marks where appropriate? Can I actually contribute anything meaningful to this process?”
Bauer (2001, p. 7) writes of her cttee experience in the U.S.: “In the alphabet-soup world of the highly credentialed, the input of... singleton community members is easily overlooked – or worse, discounted.”

One study found that 88% of lay members had at least occasionally felt intimidated and disrespected by other cttee members on IRBs (Sungupta and Lo, 2003)
North American Experiences

Others have found that lay members in North American contexts are ancillary; they are rarely given primary responsibility to review applications, and find themselves limited to narrow roles (Anderson, 2006; Lidz et al., 2012)
The Current Study

Ethics: University of Otago Human Ethics Cttee
Eight interviews across five committees: two HDECs, two tertiary, and the NZ ethics committee (e.g. for NFP evaluation research)
Semi-structured interviews: the lay role, recruitment, training or induction, experiences at the first meeting, interactions between lay and non-lay members
Comments from five cttee chairs as well
Pseudonyms
The Lay Role in NZ

All eight participants described full and equal membership status. Committees described as collegial and collaborative. Readership roles and committee responsibilities did not vary from other committee members. No stories of intimidation or “lack of voice”. Likely due, in part, to sheer volume.
Dennis, a current NZ ethics cttee member and a former chair of a tertiary cttee: “community members… always had the potential of contributing valuably and in nearly all cases did. They brought knowledge from outside... the institution” that, he said, was integral to sound decision-making.
The Lay Role in NZ

No one reported limited roles: in fact, Edith created a new template for her cttee which ensures that any criticism of an application is accompanied by a specific recommendation to the applicant.

Unanimous view, lay persons add a healthy breadth of ideas and scope for debate. Some went further, citing correctives to what could be, at times, narrow academic or institutional interests. Examples follow:
Samantha: necessary at times to question a “pure academic perspective” on ethics from a community-based point of view. E.g., parental consent for a project with youth at risk. Academic cttee members: yes, always. But community members: if not possible (living on the street), we need to consider the ethical implications of excluding youth voices from research. Proactively seek ways the research can be safe and ethical without parental consent.
Hilda: academic members can push for expedient review to allow their colleagues to get on with their research, while she as a lay member is more inclined to say, “hold on, the reputation of [this tertiary institution] is at stake, the safety of participants is at stake.”
Lack of Role Clarity for Tertiary Cttees

In spite of NZ lay members’ experiences of equality and influence, there is a lack of clarity about the role, particularly on tertiary cttees. Lay membership is ill-defined, which can be explained in part by the Cartwright legacy. In the wake of Cartwright, ‘lay’ means ‘non-medical’ (presumed health paradigm for research).
Lack of Role Clarity for Tertiary Cttees

In the literature as well, ‘lay’ is ill-defined, often represented by what it is not: non-scientific, non-affiliated

For tertiary ethics committees, the issue here is all the more vague, since many applications are for social scientific or humanities research projects (e.g.)

What is the content of lay, or community, representation in these cases?
Role Clarity Outside Tertiary Cttees

The HDEC and NZ Ethics Cttee interviewees were the clearest about their unique role, which they characterized as challenging researcher, academic, or institutional power or assumptions.

The NZ Ethics Cttee is explicitly about community research. So not surprising, questioning “pure academic perspectives” (earlier, question of parental consent)
Role Clarity Outside Tertiary Cttees

HDEC interviewees cited examples of taking a stand to challenge what we might call socio-medical power.

E.g., when a research project reflected a foreign drug company’s commercial interest: requests to remove “Americanisms” and any “reference to federal law in the U.S.” NZ applicants could then go back to a powerful pharmaceutical company and say, as one interviewee put it:
“No, this is NZ here; [what you proposed initially] is what you might do in America but this is not what you do in New Zealand.”

HDEC interviewees also discussed their perceived unique role thinking outside the box: e.g. asking a researcher to seek information “above and beyond the immediate requirements” of ethical review to support potential participants who have a mental health diagnosis
Both HDEC interviewees explicitly referred to “push back” as part of their roles. At the most general level, this meant asking the researcher “why are you doing this [research]”, beyond receiving funding to do so? Will it “make a difference in people’s lives”? Is it “good for the community”?
In contrast, for all our interviewees on tertiary committees (5), lay membership was differentiated from other committee roles only as a generic “perspective” or “point of view.”

On the whole, the view here is that various roles and backgrounds on the committee are equally valued, and make up a diverse whole for a given committee.
Lack of Role Clarity for Tertiary Cttees

Liberal democratic ideologies: “we’re all equal.” Not what Cartwright had in mind

Also, it is still a work in progress to develop approaches to ethics that suit a range of (non–medical) disciplines and research approaches

The unique meanings of a ‘lay’ person role in this context is perhaps quite stretched
Lack of Role Clarity

Recent survey of 29 community members in NZ (O’Connor, Banda & Grinter, 2014):
90%: top priority to ensure informed consent
75%: to ensure protocols are in lay language
Only 32%: to ensure that the research will benefit community/communities.
(64%: culturally sensitive and community relevant)
Consider implications for challenging institutional power in ethical deliberations


References


