

The Stories We Rarely Hear: How Canadian IRB/REB Staff and Board Members Describe Reviewing Participatory and Community-Based Research

Adrian Guta, MSW, PhD(c)
Sarah Flicker, PhD
Robb Travers, PhD
Joshua Jayasundata, MSC(c)

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Agenda

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Oppositional Discourse

- Much of the literature on bioethics and participatory research immersed in the 1970's.
- Only recently have the two discourses started to cross paths (e.g. *Journal of Empirical Research on Human Research Ethics, ACME*)
 - Much of the literature portrays the goals of collaborative research and formal ethics review as being in stark opposition.
- Difference in language and culture?

Key Informant Interviews

- **Data Source: “Improving the Accessibility of Research Ethics Boards for Community-Based Research in Canada”**
 1. Content Analysis
 2. **Key Informant Interviews**
 3. CBR Practitioner Interviews

- **Method** – to date, 12 in-depth semi-structured qualitative interviews with REB key informants from across Canada.
- **Participants** – Staff, Chairs, Community & Student Members
- * Preliminary Analysis

Misconceptions of Ethics Review

- Researchers continue to misunderstand the purpose of ethics review, and the role of REBs (despite significant education and outreach).
 - ...um but to me it is just because people don't know, and what I find when I go through department to department, those you know people will continue to think even though they come and it is voluntary that you know, **that the process is an arbitrary one, it is legalistic, it is medicalized, it is inflexible...**part of that is just explaining to people and being proactive and explain this is what we are doing, this is why we are doing it and this is how it is working and when people get really nasty go well if you don't do it, you won't get your cookie, you will have to sit on the stairs for a long time..."(BM/C)
 - CBR/PAR is characterised by a high degree of emotional investment.

“Community”

- Representation

“if they were feeling overwhelmed by a study where they felt that the science was beyond them, but I don’t think that that puts them in a position where they shouldn’t be reviewing protocols. **I think that is actually the most important role. I think it is dangerous too.** this is maybe more than you are interested in hearing but I think what’s dangerous is that just the term community member is um it is problematic that they use it so freely because I think it gives people the impression when they join and REB and they come in and we say you are the community member, they may sort of gain a sense that they are speaking for the community where it’s like they are supposed to be cognoscente of the way that members of the community might see the research as opposed to. **I don’t really know how to express it properly, but I think it probably confused people in that they think that whatever they think is the community perspective, instead of trying to understand what the community perspective might be.**” (SM)

- Outreach

Reviewing CBR/PAR

- Finding Appropriate Reviewers.

- As often as possible we tried to have the membership of the REBs reflect the protocols that were coming in...(SM)
- “...who the hell wants to look through all those damn protocols” (BM/C)

- Differences in the review process – Discussions Around the Table

- **Yeah, some of them but again it raises eyebrows around the table cause they want someone to think objectivity and distance is the be all and end all,** um, and sometimes, like sometimes, it actually is the case, like talking to, you know, women who are being abused by their domestic partners, might, maybe they don’t need it to be known in their communities. **Sometimes it is good to have someone who is completely removed sure, but let’s ask those questions right, so like I actually think people avoid doing that cause like if you do get the question like who’s doing the interviews? Who’s transcribing? Who’s translating? Translators are often seen as a conduit to breach confidentiality, but no if they’ve signed a piece of paper then it’s fine.** (SM)

- Differences in the review process - Accommodations

- **“Well I think we’re pretty sensitive to that, um, we certainly don’t have the same kind of rigid um approach that we used to have and I think that the um, we’re often quite open to people saying give us an idea of how you’re going to recruit, like they’ll be certain things like for participatory research um, you can’t lay out exactly what’s going to happen before you start because it emerges as you go so then we encourage researchers to um to lay it out as best they can how do you think it’s going to go but also to be respectful of their participants in a participatory study they have to be very clear that they aren’t, necessarily going to be in control of it so what has to be really clear more than anything is that individuals um were taking part that we’ve scanned it for possible risks but the some of the formatting of what am I trying to say, an ethics board looks at a proposal, I think they’re misguided in trying to apply the same sort of rigid rules to the same kind of study, to me it seems that a clinical trial is a clinical trial, there’s going to be certain things that you absolutely have to make clear, uh, it’s not going, those things are not going to be the same for a participatory study the risks are going to be different”** (BM/C)

Policies & Guidelines

- Formal

- **“my job description did say that I had to be knowledgeable about policies, guidelines etc that informed research ethics review, it certainly didn’t list which of those policies I was supposed to be aware of...I mean, any time I found something that I thought was relevant I would share it with the other people in the office...so yeah, I mean a lot of it was self directed in terms of what I did, um, but it wasn’t as though my job description said I had to be knowledgeable in OCAP...and any of these other guidelines, it was up to me to find them”** (SM)

- Informal

- we’re trying to increase the amount of discussion time we have at our meetings, that are much more kind of philosophical, that are not necessarily driven by a particular protocol, but driven by trying to develop best practices for consistency and for, um, for communication and transparency with researchers. (BM/C)
- “so those evolve but they are not, there are standard operating procedures but we call them guidelines, they are not policies because policy is, it is in stone for one thing, and [guidelines] recognizes the fact that all research is unique” (SM)

• Critique

- "...but, like you get in this rut where...policies are not even official policies, but small policies and procedures are developed within the context of the board and you assume that's the way that everybody does it..."(SM)
- "I do think that there needs to be increased flexibility and I think we need to get away from these ideas of norms and not having necessarily 'a standardized process', like, I think because originally it was supposed to be...ethical principles, and then it just ballooned and ballooned because people want policies and procedures and the [US] it's legislated, it is even worse down there, we've taken away the flexibility and not for the better I don't think." (SM)

Role Constraints - Complex Roles

• Coordinators - 'between ethical guidance and ethics creep'

"And you know that is the general description and within that it would be managing the flow administrative kind of flow of applications, **also um doing a lot of individual providing guidance to faculty and researchers**, students, about their study and uh educating the research community about process and policy and structure of research ethics, not just within uh the university but also on a kind of national level as well, so that researchers or new researchers can understand what the role of a review system is, what the structure and why, why it is there, and researchers can understand what their responsibilities are to their institution and their participants and also what the institutions responsibilities are in undertaking when a research project is being conducted" (SM)

Institutional Constraints

- Status of Ethics Review
- Fiscal Issues - *Cutting already tight budgets*

"as the volume has increased and they've laid off staff, I definitely have a more bureaucratic role."(SM)

"I have never heard back from a single researcher...my requests have always been ignored, for a variety of reasons, I believe they are ignored for a shortage of labour, we only have 1 administrative staff member on this board and so that is a lot to ask of 1 individual, so be this nexus of coordination between however many members sit on the board and I think each person gets 3 or 4 expedited reviews twice a week and not to mention very two months now, at least 1 review that is a full review..."(STM)

- Timelines & Budgets (REB vs. Researcher)

Practices which Support the Effective Review of CBR/PAR

- **Open Lines of Communication**
 - Contacting researchers directly
 - Encouraging researchers to contact REBs
- **Ethical Guidance**
 - Proactively creating policies and guidelines for CBR/PAR
 - Finding solutions to emerging ethical issues in CBR/PAR
- **Creating Space for "Ethical Imagination"**
 - Allowing researchers to attend meetings
 - Alternative forms/review processes
 - Including community perspectives (ethical consultation)
- **Education and Outreach**
 - For Board Members
 - For Researchers

Study Limitations

- Sample Composition
- Recruitment Challenges
- Institutional Barriers

Considerations for the TCPS 2

- "Aboriginal Research" – and other 'communities' of *ethnicity, shared culture, geography, etc.*
- Making the transition to more flexible research processes.

- **PIs**

- Sarah Flicker, York University
- Robb Travers, Wilfrid Laurier

- **Co-Is**

- Stephanie Nixon, University of Toronto
- Jacque Gahagan, Dalhousie University
- Patricia O'Campo, St. Michaels Hospital, University of Toronto
- Claudia Mitchell, McGill University
- Catherine Worthington, University of Calgary
- Louise Binder, Canadian Treatment Action Council
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- Adrian Guta, University of Toronto

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Adrian Guta, MSW, PhD(c)
Dalla Lana School of Public Health
University of Toronto
adrian.guta@utoronto.ca

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