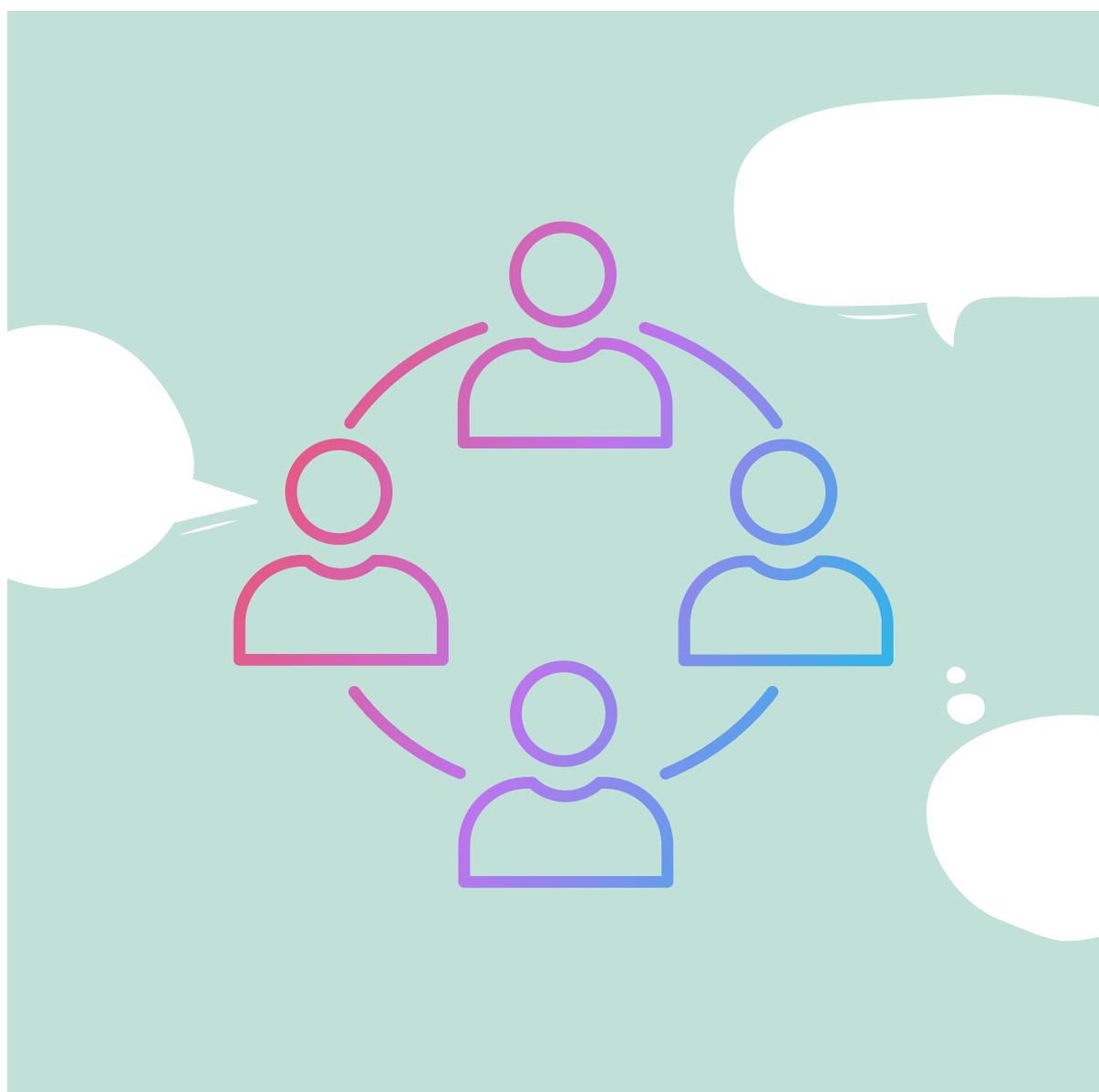# COMMUNITY-LED RESEARCH GOVERNANCE WORKSHOP: *ENVISIONING THE FUTURE THROUGH DIALOGUE*

SUMMARY REPORT 2022

The Workshop

This virtual, two-day workshop showcased several innovative and radical strategies of community-led research governance across Canada. The first day hosted panel presentations by Indigenous and urban communities who shared with us their experiences with research, their community-based research ethics governance strategies, and their perspectives on how to re-envision current systems of research oversight for meaningful community involvement. The second day offered interested communities, researchers, and those working in the research ethics space the opportunity to join each other in conversation. Folks from all across Canada took part in this discussion session. We opened and closed both days with a land acknowledgment and a prayer by an Elder from the Mohawk community of Kahnawà:ke.

Link to the recording from the first day: https://www.youtube.com/playlist?list=PLfMfJihLOASUGugqzcO8754Zb5u15fhLG

Summary of Discussion Session

In this report, we offer a summary of the discussions held during the second day, where we collectively considered challenges, responsibilities, and potential ways forward in terms of expanding community voice in research governance in Canada. Several anonymous quotations are included throughout to highlight participant contributions.

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What does 'research governance' mean to you?

We started off the discussion by talking about the history of how communities have been considered in research ethics in Canada. Some participants who were involved in drafting the original Tri-Council Policy Statement (TCPS) spoke of early discussions of community concerns related to *"helicopter scientists"* taking away information and knowledge and never returning it to communities, and how they sought to establish rights for communities in research ethics review. However, this proposal was met with enormous resistance from academics, and concerns were expressed about drafting guidelines for research ethics about (especially Indigenous) communities, but not by them. This history reminded us of how long we've been grappling to give communities a voice in research governance in Canada and that *"we must keep the pressure on"* to actualize change.

As the discussion unfolded, we soon realized that in order to answer our prompt, we first had to re-direct the question to something much deeper:

What does 'research' mean to you?

A community organizer shared her perspective:

"Research and its governance are about storytelling. It's about people's lives and people's way of being and seeing the world. Communities have been telling stories for a long time, but their way of existing has been discounted."

She encouraged us to consider the history of research tied to colonialism and capitalism, exploitation and extraction. As a result, thinking about research governance may require us to think about research in a more fundamental way: Why are we doing research? Who is it for, and whom is it benefitting? Do we always need more? Who is telling the community's story? Communities are speaking but are we listening?

"To me, governance is all about the power to make binding decisions on research that directly impacts you and your community/territory. It needs to mean community power to conduct their own research, their own research ethics review processes and lay out the terms of engagement for researchers who want to access the community." (Community-based researcher)

We then separated into breakout groups of similarly situated stakeholders to address this question:

> **What are the *responsibilities* that come with my role as a _____ (e.g., community member, research ethicist/ policy maker, researcher) when it comes to community voice in research governance? What *challenges* do I face?**

It is important to note that the community members, researchers, research ethics board members, and policy makers who participated in this discussion session were individuals who are interested in community-led research governance, and so may not represent the diversity of experiences and perspectives on this topic.

community member

researcher

REB member

policy maker
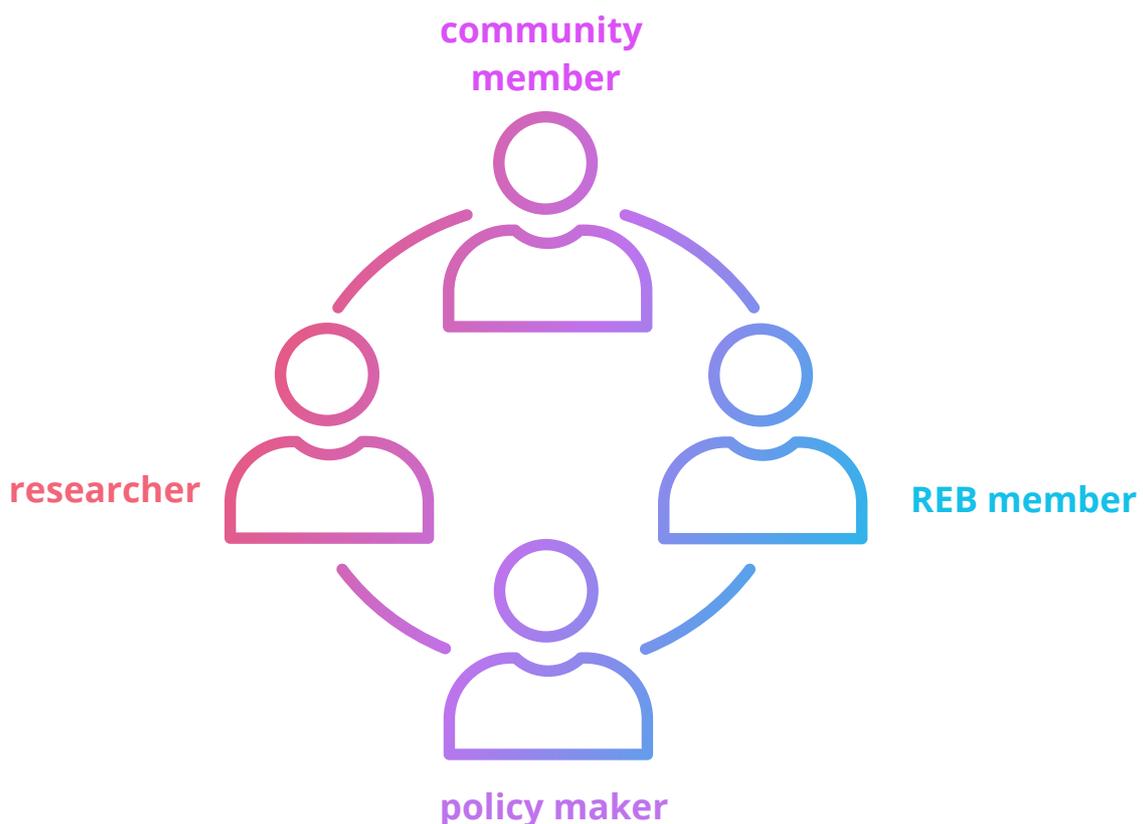
Responsibilities:

- Ensure that those at the table represent the community.

- Express solidarity with Indigenous communities, Indigenous sovereignty, and the broader goals laid out in the Truth and Reconciliation report:

  "We felt that we had to acknowledge the specific agenda of Indigenous people in the DTES [Downtown Eastside neighborhood in Vancouver]. We [suggested] an amendment to the Manifesto stating that we are willing to cooperate, as that is the only way we will move forward. Returning the remains of the children will take a lot of research, and we will be at the table when that happens."

- Sustain the collective energy of the community to keep pushing for community rights in research.

- Be accountable to the community and advocate on its behalf:

  "Academia is not a priority in some Indigenous communities. The priority is to use research for improving services and healthcare in our communities. This means that it's our responsibility to be accountable to our community and think about the benefits of the research to the community, not just in academic terms."

Challenges:

- Representation and tokenism:

  "How do you make sure that the 4 people at the table are validated when there are 100 other voices that aren't on the table? ... When there are not enough people at the table two things can happen, either their ideas can be used to generalize the whole community, or their voices can be dismissed since they are not enough people as representing the whole of community."

- Trusting and building relationships with researchers and the academy, especially within the predetermined and limited timelines and agendas of researchers:

  "The loyalty of the academic is always under question, and rightfully so... It is challenging to change that."

  "It's been very challenging because we want to pay our community members for participating; however, research ethics committees don't want us to. As a community member, I'm thinking: 'where is our voice in the process'?"

"The current infrastructure at the university is not set up for that type of work [community-engaged research]. The community also has not set up that capacity, so a lot of times it is just signing the agreement, and it says the university has the right to speak, publish, and present. There is a lot of intimidation when working with the academy."

Researcher

Responsibilities:

- Include communities in the research governance process by reaching out to community organizations, initiating advisory committees, and initiating conversations surrounding governance based on already existing guidelines and models.

- Maintain open and honest communication with communities throughout the project's lifecycle.

- Build long-term, trusting relationships with the community:

  "It takes time to build trust with a community. Relationship building is important, and it takes the community time to respond. Each community has a struggle guided by different principles and protocols." (Community member, speaking on relationships with researchers)

- Establish a research agreement with the community to set out guidelines surrounding power and data ownership, data stewardship, and publications.

- Be proactive in providing spaces and resources for community members to be involved in research and its governance, especially if they do not have prior experience with research.

  "When conducting research with Indigenous communities who don't have access to resources, researchers can bring in OCAP representatives to the communities and pay for training. OCAP will then come in, represent them, and negotiate for them. In some instances, we have paid for lawyers [on behalf of communities]."

Challenges:

- Balancing responsibilities to communities with inflexible institutional requirements, professional demands, reward structures, funding requirements, and timelines:

  "The researchers hold the purse, and the structures of universities often do not allow communities to hold the purse… There isn't equality of governance between the community and researchers. It is built into the very fabric of it."

- When communities do not have experience with research:

  "What happens in communities who do not see value in research? Not every community has the [resources] to participate in institutional forms of research."

- Building trust in contexts where it is lacking.

- Adapting research processes (design, questions, governance) to suit community needs.

"Any work that genuinely involves voices of communities requires building relationships that are long-lasting. At the beginning of my journey, I felt like an impostor but came to be recognized as someone who responds to the community needs."

Research ethicist/policy maker

Responsibilities:

- Ensure that researchers include community engagement in their study planning and design.

- Advocate on behalf of communities within the research institution.

Challenges:

- The capacity and commitment of the institution to allow Research Ethics Boards (REBs) to include communities in the governance process:

    "When you think about the community, it's either representation on the REB or going out into communities – both take a lot of time and resources. Policies like OCAP [Ownership, Control, Access, and Possession] etc. are being rejected on a fundamental policy level. It feels like you have to walk against huge brick walls before you get someone who will listen and change something at the institutional policy level (e.g., allowing the data to be stored elsewhere)."

    "I put the community first in every spot in the legal memorandum of understanding, and people were telling me that no, the university should be first. There was a lot of pushback and negotiation – but it didn't change any structures. It was more like an exemption."

- Limited support and funding for those advocating for change from within institutional spaces (e.g., to support community participation in conferences and other activities).

- The biomedical system's resistance to bottom-up and collaborative approaches.

"Some REB members insist on seeking input from the community, but there is a biomedical bias and biomedical research is more resistant to inclusiveness and diversity."

After the full-group share-out, we went into breakout groups of *mixed* stakeholders to address the following questions:

What resources do we have when it comes to community voice in research governance?

What needs to change moving forward?

Resources:

- Community research governance strategies already created and published by communities:
    - Existing research and research governance that community members and Elders are aware of
    - Common experiences
    - Training for both communities and researchers offered by community-based organizations

    "Individuals have their organization-specific research codes – so let's share!" (Community member)

- Resources and funding available in the academy that can be mobilized to support communities through community-academic partnerships (e.g. Secretariat on Responsible Conduct of Research (SRCR) Education and Training Support Grant).

- Researchers and the expertise and resources they bring to a project:

    "I think of research like a toolkit – I am a professional beggar for money. I partner with communities and identify issues that are important for them – my role is to go out and get the money and improve the issues they want to improve. I could not explain this model to my colleagues -- they would say I am not creating rigorous academic research. For example, with random control trial (RCT) models, because you have a control group, you have one group that does not have the intervention. I believe that RCT models should not be used in Indigenous communities." (Researcher)

- Greater awareness and opportunities within research institutions for community engagement and community-based participatory research.

"One resource is recognizing common experiences...When people recognize shared experiences, we realize that we don't have to deal with this [unethical research] alone." (Community member)

- Develop stronger rationales and practices for community-engaged research and research governance within the academy:

   "There is competition for resources at universities -- you need rationales, pressure, examples for how it could be done better for the university to pay attention to the need for change." (Researcher)

- Change the reward system within institutions for researchers (e.g. re: hiring and promotions):

   "The time spent having tea with the community is not rewarded by the university for tenure and promotions." (Policy Maker)

- Make information on research rights widely available and accessible:

   "Communities often do not know what they need to do regarding their rights in research. They need to be informed so that they are not powerless." (Community member)

- Hold institutions accountable for respecting existing community research governance strategies.

- Work on creating publishing models that authentically and ethically incorporate community voices in academic literature.

"Very rarely are researchers thought of as resources for communities. What if instead of the researcher's trajectory or interest guiding research, it was the needs of the community?" (Researcher)

Finally, we ended our session by answering the following question:

If you had to make one recommendation, what would it be and who would you make the recommendation to?

To funders:

Make funding available for community research ethics governance.

"[Community research governance] is a form of infrastructure we need to invest in." (Researcher)

Make funding available for responsible community-engaged research, with compensation for community engagement and relationship building.

"Including the right voices in all levels of review will take time and money, and commitment needs to mean more than words." (Community member)

Create guidelines and expectations around community involvement for funding; follow up on this.

Make long-term, radical changes in the way that the academic enterprises operate.

"We need to move beyond a business model so that we can do better work." **(Researcher)**

Create a payment structure for community partners that is independent of academic requirements.

Create a "Community Links Bureau" where researchers and communities can share projects and resources for community engagement, partnership-building, and navigating funding structures.

"Community members are not shown that they are valued ...while our reward systems benefit researchers or companies massively." **(Community member)**

Provide training to researchers and students to do more community-based work.

Show that you value communities and their expertise practically (with money and opportunities) and by establishing research partnerships.

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Listen to community voices and speak to them about amendments to studies.

Be more culturally safe in your review of community-based research.

Extend the trust you have in researchers to community groups.

Include community groups and their governance processes in ethics applications.

To all:

"[Create] more spaces like this [workshop] for people doing this work across Turtle Island to meet each other, compare notes, share strategies, funding streams, and more." **(Researcher)**

If you have any questions about this report, the workshop, or to get in touch regarding community-led research governance, please reach out to the following people:

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