National Collaborating Centre for Determinants of Health
Centre de collaboration nationale des déterminants de la santé

Building community capacity by mobilizing knowledge shared through the Cost of COVID study

The Department of Family Medicine at Queen's University stretched institutional boundaries through its Cost of COVID research project by prioritizing collaboration in research protocols. Hiring an Indigenous research associate, incorporating Indigenous ways of knowing and establishing an oversight committee that meaningfully included the voices of the Indigenous community resulted in relevant and actionable research. The results of this study validated the significance of Indigenous-led community-based programming that led to the launch of programming to meaningfully address some of the social and emotional "costs of COVID-19."

Our research team within the Department of Family Medicine at Queen's University initially received an internal grant that provided funding to support rapid responses to COVID-19. With this funding, we embarked on "The Cost of Covid: A Study to Understand the Social and Emotional Impacts of the Pandemic" to look at the social and emotional impacts of the pandemic on community members, including Indigenous People.

The goal was to conduct research that would break the confines of theory and academia — that is, research that would be relevant to the lives of real people and their everyday circumstances living in the community. From the beginning, our team was on the same page about conducting the research in a good way, even if it would take longer. Even though we didn't know the exact

This Equity in Action story is distilled from an interview with:

- Dr. Eva Purkey, Family Doctor, Department of Family Medicine, Queen's University
- Dr. Imaan Bayoumi, Family Doctor and Clinician Researcher, Department of Family Medicine, Queen's University
- Dr. Colleen Davison, Epidemiologist, Department of Public Health Sciences, Queen's University
- Autumn Watson, Director of Programs, Indigenous Diabetes Health Circle

The interview took place in August 2022, and its details should be considered within the context of that time period.

trajectory that we needed to get there, this shared understanding allowed us to take our time and move forward together.

The strength of collaboration with Indigenous community partners

We recognized that, to do robust and meaningful research, we needed to intentionally seek input and feedback from the local Indigenous community. During the beginning phases of the research, we presented the study to the Indigenous Health Council. Autumn, a member of the Indigenous Health Council, joined the project team in a volunteer capacity, initially providing feedback on research design. Additional funding was then secured from the Physician Services Incorporated Foundation to second Autumn from the Indigenous Diabetes Health Circle and sustainably integrate her position into the research team.

Obtaining the funding to support Autumn was critical to implementing the Cost of COVID project. When academic institutions or researchers work with Indigenous communities, there is often a lack of true, sustainable relationship-building. Autumn played a key role in developing the project and building meaningful engagement with the local Indigenous community directly and consistently.

Indigenous communities can sometimes be intimidated by or mistrustful of research or the idea of working with academics, which is understandable given historical and ongoing colonial practices. Because she is trusted in the community, Autumn was a bridge to build community openness to and capacity for community-based research. With the help of the team's resources, Autumn would attend land-based activities and introduce community members to the Cost of COVID study, address their questions and discuss the implications of this research. It was critical that we did not just collect information from the community but, rather, took the time to talk about the research.

Autumn is known and trusted within the community, so this formal partnership was instrumental to the success of the research. Our team was committed to the principles of Indigenous data governance, which led to the development of an Indigenous community-based oversight committee. This committee represented a cross-section of individuals from the community, who guided the analysis and dissemination of project findings.

Overcoming institutional structural barriers and allowing time for relationship-building

As we moved through this project, institutional and systemic barriers that can hinder meaningful community engagement within community-based research became apparent. For example, consent forms can contain intimidating language, and booking 1-hour interview slots, which is common practice, may not provide enough time for relationship-building. Part of being intentional about building capacity and creating meaningful engagement was understanding that interviewing a community member takes time. There could be an exchange of asemaa [tobacco] or a need for a smudge.[a] Relationship-building needed to take place before diving into the interview questions.

Flexibility in research processes to allow for spending time and building relationships with the community is critical for community-based research. We must respect that community needs time to absorb information in order to move forward. All too often, there is pressure put on researchers to obtain results fast. We had support from this team, but also from Queen's University, to begin to make the necessary changes within the broader system so that research processes facilitated rather than prevented engagement with the local Indigenous community. In turn, the results we collected were richer and more comprehensive.

a Smudging is a spiritual ceremony performed by Indigenous Peoples around the world. For the Anishnaabeg (Ojibwe) People, smudging is the burning of the Four Sacred Medicines: tobacco, cedar, sage and sweet grass. (https://www.georgiancollege.ca/wp-content/uploads/Smudging-StaffNews.pdf)

Sharing the results with community to honour new relationships

Too often, research is done by the researcher and then taken away; the community doesn't hear about it again. At the end of the project, we had an abundance of data for different audiences to demonstrate what the "cost of COVID" was. Flexibility in the collection methods, which included interviews captured using digital story capture software, allowed for a rich, thorough and holistic understanding of the community needs, perspectives and priorities.

In October 2021, we led a large community sharing circle out on the land at Lake Ontario Park in Kingston, Ontario.[b] The day was opened by Grandmother Kate Brant, a respected Knowledge Holder within the Katarokwi region. Students and researchers shared the project results, the Indigenous oversight circle voiced their experiences with the research study, and the community celebrated with a traditional feast and giveaway. This knowledge dissemination circle brought together everyone involved in the project but also extended beyond the team to include external researchers and community members.

In addition to the written report, we had infographics to represent the results in accessible formats. To be able to pull the knowledge translation piece together for the community was great. The biggest feedback that we received from community members in attendance was that it was nice to see their voices reflected in the research and that they appreciated that it came back to community in a way that was understandable.

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Image: "Knowledge Dissemination Circle Poster – Cost of COVID team"

b This gathering respected public health pandemic protocols that were in place at the time.

Actioning the research with local leadership

The effort invested into developing translatable and accessible findings allowed the team to extend the reach of our work to local community partners, planning organizations, and public health organizations and authorities. Overall, our dissemination process propelled us into an unanticipated follow-up project, the Aki Gimiinigonaa Mshkooziiwin Initiative or "Aki project" in partnership with Kingston Indigenous Languages Nest and Indigenous Diabetes Health Circle, and funded by Canadian Institute for Health Research. In the Aki project, some of the results from the Cost of COVID study are being actioned.

For example, one of the findings that was clear out of the Cost of COVID project was that food security was important for Indigenous Peoples in Kingston. Access to ceremony and land, two key aspects of food security, had been further undermined during the pandemic. Because this finding came through so strongly, as a result of our holistic research processes, we were able to rapidly secure funding to support the implementation of innovative, strengths-based, Indigenous-led and land-based food security programming. Another action piece that came from this project was the development of a research consent postcard, in response to community feedback that existing consent forms were intimidating. We created a simple one-page consent form that highlighted some key pieces around consent to make it more accessible for the Indigenous community and other community groups.

It was important to recognize that plans for how the overarching findings would be put into action needed to be developed at the local level. Meaningful implementation of programming requires an understanding of the specific community needs and contextualization of the information that could not be led by the academic institution. It would only happen through the local partnerships we built and through local leadership.

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Just the beginning: more work ahead to achieve equity-driven academic research

Through this project, we developed meaningful partnerships that recognized, respected and included the local Indigenous community in all stages of planning, development, implementation and evaluation. Our team started to overcome some institutional barriers in order to meaningfully engage with community, and we are eager to continue this progress. There was no hierarchy within the team, and we all had an incredible open-mindedness that allowed us to keep moving forward together with the bigger picture in mind. We were, and still are, motivated by the knowledge that the results from this study and the processes we developed for community-based research and engagement will contribute to the push for equity in academic research.

LESSONS LEARNED:

1. Take the time needed to meaningfully engage with the Indigenous community for relevant and holistic results that can inform action.
2. Formalize positions for Indigenous community members within academic teams (e.g., as a research associate or oversight circle member), through proper compensation and involvement.
3. Share results of participatory research with the community as a critical component of the research process to honour the voices that are shared within the research.
4. Academic institutions can support Indigenous-based organizations to lead and action research results. The community knows their history and context best and is well positioned to understand and action research findings.

BACKGROUND

The Indigenous Health Council is a group of individuals at the community level that came together to support and address key issues in the community, including service access and health equity.

RESOURCES

Cost of COVID study infographics:

- Child and family wellbeing during the COVID-19 pandemic
- The impact of COVID-19 on financial worry
- Food worry & mental health during the COVID-19 pandemic
- Importance of spirituality and community belonging among Indigenous people

KEYWORDS

COVID-19, Community engagement, Indigenous health, Intersectoral action

To learn more about the initiative described in this story, contact the National Collaborating Centre for Determinants of Health, at nccdh@stfx.ca.

Do you have an idea for an Equity in Action story? If you have heard of other health equity-promoting initiatives in Canada that we should share, please let us know.