In the Equation Workshop

Towards Indigenous-Led Infectious Diseases Modelling Research

February 18-19, 2025

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Background

The role of the National Collaborating Centre for Infectious Diseases (NCCID) is to provide infectious diseases-related knowledge mobilization to support public health practitioners. NCCID brings together researchers, public health practitioners, and decision-makers to respond to public health priorities such as influenza, sexually transmitted and blood-borne infectious, tuberculosis, and emerging diseases, among others. In the case of mathematical modelling, NCCID staff act as knowledge translators and brokers, building awareness for the value of modelling research and big data in public health programming.

Infectious disease modelling can be a valuable tool in providing evidence for health programming and decision-making, but it can also cause real harm to First Nations, Métis, and Inuit communities. Modelling research requires careful consideration of the questions being asked, the data and methods to be used, and how model outcomes should be interpreted and shared. When a model aims to answer infectious disease questions for Indigenous communities, it is critical that Indigenous data sovereignty, traditional ways of knowing, and the lived experiences of community members are central to every stage of the research process. However, the current systems of research, distrust resulting from past harms, and ongoing racism create challenges for true Indigenous leadership and meaningful engagement in modelling research. This workshop was planned to generate ideas for how these challenges can be addressed and to contribute momentum towards Indigenous-led infectious disease modelling research, rather than modelling research on Indigenous communities without community voices and wisdom.

The In the Equation Workshop was hosted by NCCID in Winnipeg, on the original lands of the, Anishinaabeg, Ininiwak, Anisininewuk, Dakota Oyate, Dene and Inuit, and on the National Homeland of the Red River Metis. The event brought together 30 community experts, researchers, mathematical modellers, representatives from First Nations, Métis, and Inuit organizations, as well as public health professionals. Participants and facilitators also included staff from the National Collaborating Centre for Indigenous Health (NCCIH) and the National Collaborating Centre for Determinants of Health (NCCDH). Participants joined the event from Nova Scotia, Ontario, Manitoba, Alberta, Saskatchewan, British Columbia, and Nunavut both virtually and in person. The event started at mid-day on Tuesday, February 18 and concluded in the mid-afternoon on Wednesday, February 19th, 2025.

The workshop agenda included presentations and facilitated small group discussions, with the goal of encouraging knowledge sharing and relationship building between representatives from Indigenous organizations, mathematical modellers, researchers, and decision-makers. The workshop presentations aimed to highlight projects and initiatives driving First Nations, Métis, and Inuit data sovereignty, research, and capacity building. Small group discussions were facilitated to engage participants in conversations related to the best-practices in collaborative modelling research, community identified infectious disease priorities, and opportunities for capacity building.

The specific workshop objectives were to:

1. Facilitate connections between First Nations, Inuit and Métis decision-makers and mathematical modelling researchers.
2. Share current knowledge on infectious diseases questions identified as areas of priority by First Nations, Inuit, and Métis communities.
3. Exchange knowledge on modelling methods and tools which can help to address these infectious diseases questions for public health decisions.
4. Identify capacity building opportunities and the resources and support required for Indigenous-led infectious diseases modelling research.

Guest speakers joined the event both in-person and virtually and the presentations were shared on Zoom for all participants. NCCID and NCCIH staff facilitated discussions for in-person attendees while Wendy Xie facilitated virtual discussion sessions.

Paige Boivin is a Métis graphic illustrator and artist originally from Winnipeg, now based in Roblin, Manitoba. Paige created original art and re-designed existing graphics from the NCCID Mathematical Modelling Project Stream (originally by Anatomii Studio) to be used in workshop documents and branding. Paige also attended the In the Equation workshop in Winnipeg to person to capture and illustrate key concepts from the presentations and discussions. The result is a unique visual knowledge map.

Day One, February 18th, 2025

The first half-day began with lunch followed by opening remarks. **Elder Charlotte Nolin**, Tastawiniyew Otipemisiwak and Elder in residence at Ongomiizwin – Indigenous Institute of Health and Healing, opened the workshop so that the event could begin in a good way. Margaret Haworth-Brockman, Senior Program Manager of NCCID, welcomed participants to the workshop, and provided some background on the work that NCCID has done in both modelling for public health and towards Truth and Reconciliation. Wendy Xie, KT Project Manager at NCCID, began introductions for Day One presentations.

Presentations

Modelling for Public Health and the First Nations COVID-19 Scenario Model

Dr. Sharmistha Mishra, University of Toronto
Cal Stewart, Chiefs of Ontario

In this first presentation, Dr. Sharmistha Mishra from the University of Toronto and Cal Stewart from the Chiefs of Ontario (COO) described how the First Nations COVID-19 Scenario model was conceptualized in collaboration with Dr. Jennifer Walker (McMaster University), Dr. Carol Mulder (COO), and communities, resulting from questions and concerns brought up by communities during the pandemic. Sharmistha described how they learned through engagement with communities that it was important for the COVID-19 Scenario model to include not only networks of individuals within communities, but also connections between communities. This resulted in a unique multi-layered model structure. Cal described the long partnership between COO and the Institute for Clinical Evaluative Sciences (ICES), where First Nations data are held in Ontario. Communities can request data sheets with COVID-19 vaccination coverage rates, prevalence, comorbidity, and age distribution data specific to their own community, which could be entered into the interactive COVID-19 Scenario model. This gives communities the power to ask questions about pandemic outcomes and interventions based on their own data to make informed decisions for the health of their community members. Cal explained that the development of the COVID-19 Scenario model continues to be an iterative, bidirectional process, where feedback is essential for modifications to further refine the model. Finally, Sharmistha and Cal reflected on the cycle of learning that encouraged them to confront common modelling assumptions, where these assumptions came from, and how they have been used and misused. Sharmistha emphasized that when you have built up trust in the relationships with communities, there is always a way to repair and do better, even when you have made mistakes along the way.

Reclaim: Winter Training Institutes and More

Dr. Jillian Waruk and Sidney Legget, First Nations Health and Social Secretariat Manitoba

In this second presentation, Dr. Jillian Waruk from the First Nations Health and Social Secretariat (FNHSSM) Manitoba described how the ongoing work with Sidney and the FNHSSM Reclaim team aims to improve the data sovereignty capacity of First Nations to support for their own decision-making and to inform and advocate for First Nations health programming. Jillian described how the Regional Health Survey (RHS), funded through the First Nations Information Governance Centre (FNIGC), is an important step towards true ownership, control, access, and possession (OCAP) of data by First Nations communities. The RHS will give First Nations the power to reclaim their own health data and use it to advocate for programs and policies which uphold traditional values and systems. There are 63 First Nations within Manitoba borders, and the data collected through the RHS will also enable unique research and support for distinct First Nations communities. Jillian expressed excitement for the first Winter Training Institute, a mobile course entirely taught by Indigenous researchers, epidemiologists, public health experts, and Grandmothers, to be held in March 2025. All participants of the first institute were First Nations or worked for a First Nations organization. Participants would learn about how their stories can be told through data, and how decolonized research and knowledge translation can be used to empower First Nations communities.

Jillian concluded with a quote by Carla Cochrane at FNHSSM, who said that “data has spirit”, and that the data we have about a person’s health has spirit attached to it. Jillian stressed that if you are running models using data, it is important to consider the spirit of every single person in the model.

First Nations Health Data Landscape and a Pathway to First Nations Data Sovereignty

Maria Santos, First Nations Information Governance Centre

In the final presentation of Day One, Maria Santos from FNIGC described the current First Nations data landscape and the role of FNIGC as the national stewards for the OCAP principles, with oversight from regional partners. Maria emphasized the importance of the First Nations Regional Health Survey in producing culturally important information to create change in communities, and to influence policies and programs to improve health outcomes. She went on to outline how a lack of quality data, data gaps, cultural barriers, difficulties accessing data, legislative and policy barriers and other challenges affect First Nations’ ability to make informed decisions to protect community members.

Maria continued to describe the envisioned network of First Nations Information Governance Centres which would address many of these current challenges. The proposed FNIGC network would partner with non-Indigenous organizations and all levels of government to serve First Nations communities in providing data stewardship and supporting data and planning capacities. Maria explained how the **First Nations Data Governance Strategy** (FNDGS) aims to move towards inclusive health information systems through the Regional Data Centres so that First Nations can hold, access, preserve, and leverage their own data.

Facilitated Discussion 1 Modelling Assumptions, Methods, and Analysis

Following these three presentations, the participants engaged in the first facilitated small group discussion. Since the presentations on this first day were focused on community-led modelling research, Indigenous data sovereignty the data landscape, the theme of the first facilitated discussion was about data and assumptions in modelling research. Participants were asked to reflect and comment on the following questions:

- How are data currently collected, held, and used in modelling research, and what are the essential steps required to uphold the principles of First Nations, Métis, and Inuit data sovereignty in this work?
- What are some important considerations for informing modelling assumptions, particularly those related to contact structures and public health interventions?

Participants were highly engaged in the topic of data sovereignty, especially concerning administrative or secondary data. Several participants noted that many existing datasets contain biases and were not collected with free, prior, and informed consent, and many individuals did not realize that their data would be used and shared in research studies. It was also noted that much of the existing data cannot capture lived experiences of Indigenous individuals. This ultimately means that much of the available data for modelling does not align with the principles of Indigenous data sovereignty.

The discussion highlighted the need for non-Indigenous researchers to develop strong relationships with Indigenous communities, and to engage with communities to determine what data should be collected, used, and shared in modelling research.

Participants emphasized that mathematical modelling may not be the most suitable tool to answer community identified infectious disease questions, especially when the modelling research serves to advance the career of the researcher rather than serving the community. Modelling researchers were encouraged to ask the **who, what, why,** and **how** before engaging with communities:

1. Who does this work serve, and who is conducting the research?
2. What are the implications of this research (potential for deepening stigma and causing harm or will it result in true contributions to communities)?
3. Why modelling research? Why does the model benefit the community?
4. How is the research conducted, and how does it complement Indigenous ways of knowing?

If modelling is determined by the community to be useful, participants stressed that researchers need to continue working closely with communities to deconstruct existing biases in data and modelling frameworks, decolonize the research process, and commit to incorporating of the social determinants of health in the model.

Engage with communities to understand the “who, what, why, and how” of modelling

WHO?
Who does this work serve?
Who is leading the research, and who is a part of this project?

WHAT?
What are the implications of this research?
What does it contribute to community?

WHY?
Why modelling research?
Why does the model benefit the community?

HOW?
How is the research going to be conducted?
How will the modelling research complement Indigenous ways of knowing?

Day Two, February 19th, 2025

Day Two of the workshop was focused on continuing the topic of how Indigenous data sovereignty and Indigenous-led research helps to address community identified questions and priorities.

Presentations

The Inuit-Led Research Agenda: Priority Setting, Capacity Building, and Data Sovereignty
Dr. Sandra Romain and Pauley Tedoff, Inuit Tapiriit Kanatami

We started the second day of this workshop with a presentation by Dr. Sandra Romain and Pauley Tedoff from Inuit Tapiriit Kanatami (ITK). Sandra began with an overview of the current public health priorities for Inuit communities which included tuberculosis (TB), sexually transmitted and blood-borne infections, and avoidable mortality.
She described the Economic Health Impact Model as an example of the power of data and research for the health and well-being of Inuit communities. The Economic Health Impact Model aimed to provide evidence for greater access to responsive, in-community health care and support for TB and births. Overall, the model showed that investing in Inuit paraprofessional health workforce would positively impact jobs and incomes in Inuit Nunangat, result in better health outcomes for both TB and births, and result in less time lost and higher productivity for patients and families.

Pauley went on to describe Qanuippitaa? the Inuit-led and Inuit developed National Inuit Health Survey focused on improving Inuit health and well-being. The survey is a permanent and ongoing project developed to provide high-quality, Inuit-owned data to monitor changes, identify strengths and gaps in health services, and inform decision-making and programming to improve health among Inuit in Canada. Pauley highlighted the guiding principles of the survey, which include collaboration, rigorous methods, innovation, Inuit self-determination, Inuit health and social equity, and a strengths-based approach. These guiding principles help to inform all activities in the development and implementation of the National Inuit Health Survey Program, ensuring that the program brings about positive changes for Inuit communities.

First Nations Data Sovereignty in Manitoba: Our journey toward a data governance lodge

Dr. Stephanie Sinclair and Carla Cochrane, First Nations Health and Social Secretariat Manitoba

For the last presentation at this workshop, Dr. Stephanie Sinclair and Carla Cochrane from FNHSSM shared exciting developments towards a First Nations data governance lodge in Manitoba. They open the presentation by noting that First Nations realities and stories remain hidden in data gaps, data biases, western research methods, and colonial policies and systems. Stephanie and Carla described four criteria for respectful research relationships with Manitoba First Nations: free, prior, and informed consent; First Nations ethical principles; the principles of OCAP; and First Nations benefits. They discussed various forms of data, which can also look like First Nations knowledges and cultural practices as well as community stories and history. Here, Stephanie and Carla emphasized that "data is not just numbers; it is our truths, our stories, our loved ones, our community, our ancestors". Stephanie and Carla shared how the Data Governance Lodge in Manitoba, housed at FNHSSM, will provide governance support, research, analysis, reporting, and capacity building in the form of both training and customized tools and infrastructures to meet the needs of First Nations.

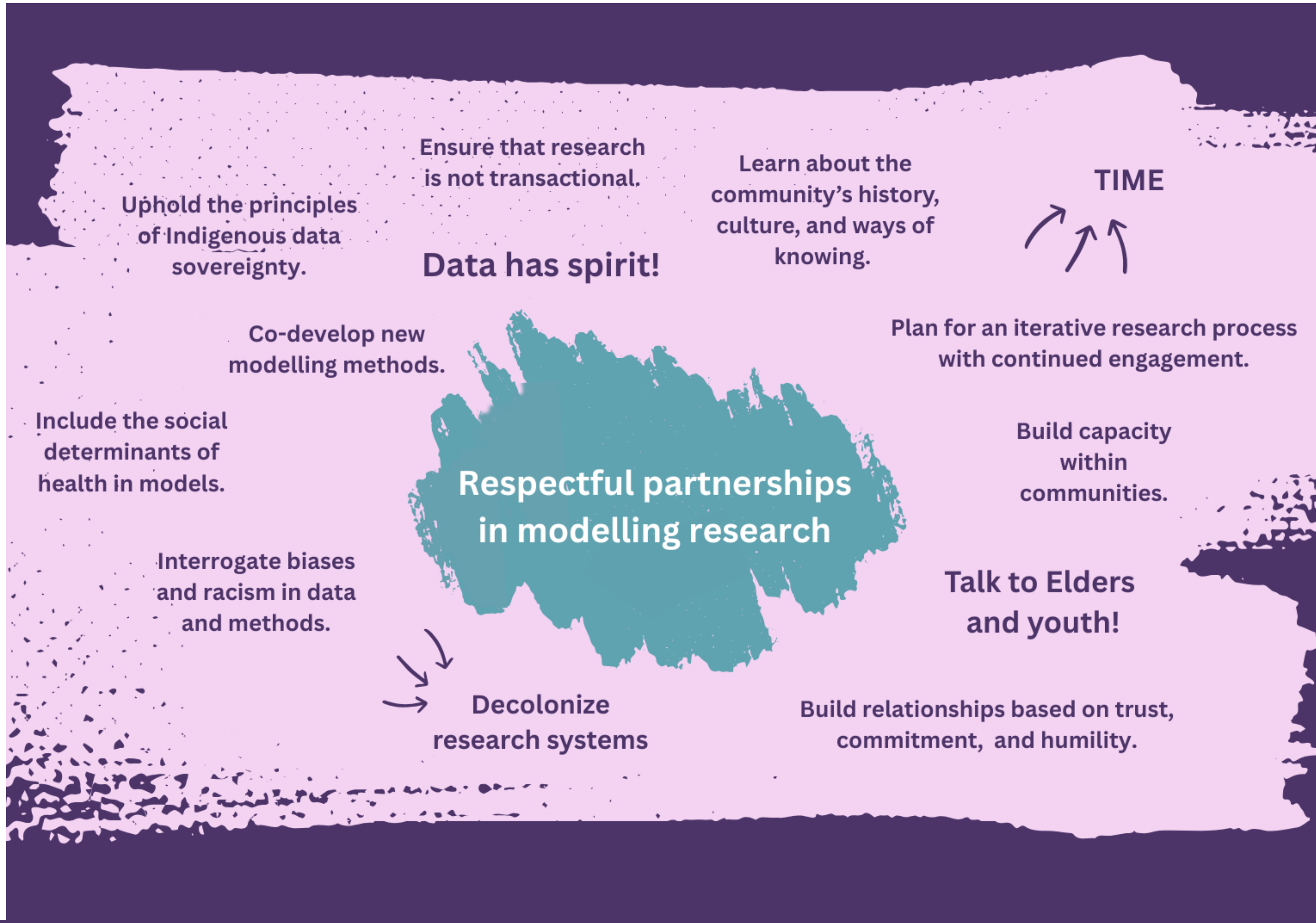
They concluded with words of wisdom for researchers looking to engage with First Nations communities for research; learn about the history, culture, population, and context, build relationships for better understanding, uphold First Nations ethics and ways, and ensure good partnerships by adhering to research ethics and defining partnerships.

Facilitated Discussion 2 Respectful Collaboration and Partnerships in Modelling Research

Following the insightful presentations by Sandra and Pauley from ITK and Stephanie and Carla from FNHSSM, participants engaged in the second facilitated discussion focused on respectful collaboration and meaningful partnerships in modelling research, which can be applied to all research with Indigenous communities. Participants were asked to reflect on the following questions:

- How can settler researchers develop and maintain long-term relationships and contribute respectfully in Indigenous-led and community-informed research?
- How do you see partnerships in math modelling research developing differently?
- How do existing systems and policies inherently work against Indigenous Sovereignty in infectious disease research, and how can we better center Indigenous ethics and community-led research?

Participants overwhelmingly emphasized the importance of time. They discussed the time required for settler researchers to learn about the history, culture, knowledge, and context of a community, the time needed to build relationships based on trust, time to decolonize their current understanding of research practices. In these discussions, participants identified many ways settler researchers can engage in collaborative research with communities in respectful ways. These included adopting a Two-eyed Seeing Approach, dismantling white supremacy in existing research practices and systems, and approaching communities with humility and in the spirit of service. Additionally, settler researchers should hold themselves accountable for a truly collaborative, iterative, and non-transactional process in research, rather than one-time consultations with no meaningful engagement.



The discussions also highlighted ways in which communities and researchers can uphold their inherent First Nations, Métis, and Inuit rights. These include capacity building for the future by training undergraduate and graduate Indigenous students to conduct research and calling on funding agencies to employ Indigenous staff to review research proposals involving Indigenous communities. In addition to advancing health and well-being as defined by distinct nations, it is also important to consider perspectives and voices the wider community in addition to community leadership and Elders.

Facilitated Discussion 3 Infectious Disease Research Priorities

The third small group discussion was a closed conversation to encourage respect and honesty. This format is intended to provide each participant with time and an opportunity to speak openly about their own stories without interruption. Active notetaking was paused during this activity out of respect for the personal experiences and knowledge offered by participants. Participants were asked to share about the infectious disease priorities, successes and challenges in data or research initiatives, and gaps in capacity based on their experiences from working in and with First Nations, Métis, and Inuit communities. The following questions were used to help guide the stories to be shared, but participants were encouraged to speak what was on their hearts:

- Based on your experiences working within communities, what do you think are the priorities for infectious disease research that can be addressed using modelling methods?
- What are some successes and challenges you have encountered when trying to collect or access data to address community-identified infectious disease research priorities?
- What kinds of support would you need to help make infectious disease modelling research initiatives possible?

As these discussions were closed conversations intended to improve understanding between participants in a safe environment, specific details of the conversations will not be shared in this report. Overall, it was clear that participants who had experience working in different settings found that health questions and challenges varied between communities, which means that solutions must also be community specific. Challenges are common in data collection, linkage, and storage, but participants indicated that these can be overcome through sustained resources for capacity building within First Nations, Métis, and Inuit organizations and communities. Community-based capacity building which can be further supported through respectful partnerships with non-Indigenous organizations which understand and uphold Indigenous data sovereignty and self-determination in health research.

Group Activity: Connecting the Dots

The final activity was a gallery walk, where the questions below were written on posters and participants were encouraged to leave comments under each question in groups. Once a group has completed their notes for each question, they could revisit previous posters and respond to notes that other participants had written. The questions for participants were focused on bridging the themes of Indigenous-led research, data sovereignty, and meaningful collaboration in infectious disease modelling research. Participants were also asked to write down anything that they felt was missing from the workshop. For virtual attendees, the questions were posted on the Whiteboard function in Zoom and participants were encouraged to write, draw, or include images of their responses for each question.

The questions for participants in this final activity and a summary of the responses from both virtual and in-person attendees were as follows:

How should a research question or study be conceptualized when it involves First Nations, Métis, or Inuit community members?

Settler researchers need to demonstrate humility, commitment, and open-mindedness (i.e., Two-eyed seeing approach) when working with First Nations, Métis, or Inuit communities in research. The entire research process should be iterative, engaging community members, subject matter experts, and researchers, but the questions and priorities must come from the community. Researchers must enter partnerships with the understanding that the project is not just transactional or extractive (to advance the career of the researcher) and must be based on meaningful relationship building. A part of this relationship building means that knowledge, time, and the efforts of community members are compensated accordingly. Community engagement and knowledge mobilization plans should be built into research proposals through a collaborative process, not added as an after-thought.

What are some best practices for data sovereignty and governance in modelling research?

“Data has spirit”. In modelling research, respecting the spirit of data can mean different things for different communities, but some examples of upholding Indigenous data sovereignty and the spirit of data are to:

- Ensure free, prior, and informed consent of data collection and use
- Learn about what data sovereignty means for the community, and understand who, what, when, where, how of the data being collected and used
- Disaggregate data where possible (e.g., between communities) and incorporate the social determinants of health
- Know and plan for sustainable community-based data infrastructure, analysis, and management from the beginning
- Create a formal data agreement to outline the rights holders, roles, and responsibilities of those involved in the project early on

Best practices for data sovereignty and governance in modelling research

- ○ Ensure free, prior, and informed consent of data collection and use
- ○ Understand community-specific principles of data sovereignty
- ○ Co-develop formal data agreements
- ○ Disaggregate data and incorporate the social determinants of health

What are important considerations for culturally safe interpretation and knowledge mobilization of modelling outcomes?

Conventional methods (journal publications) may not be applicable, so new methods for culturally safe and community-specific model interpretation and knowledge mobilization are required. It is important to allow the community to interpret the data or give approval of the analysis and interpretations, and develop a strengths-based, community-centered knowledge mobilization plan. Participants indicated that spending time with Elders and having Elders to guide any form of community engagement is essential in minimizing potential harms and working towards culturally safe knowledge sharing. Finally, the community holds the right to decide if the modelling results should be published, not the researcher, as publication does not necessarily further benefit the community and may cause harm to community members.

What is required to build capacity for Indigenous-led modelling research?

Participants reinforced the importance of capacity building within communities, which requires de-colonization of hiring and funding processes and the criteria of credibility to be accepted as a researcher, since the criteria for an Indigenous researcher may not be the same as a settler researcher. Within research projects, it is critical to review who holds the power, and redirect power if it is not held by the community. Small steps (or steps which work for the community) such as supporting liaison roles or co-developing strengths-based knowledge mobilization plans can accumulate over time and increase capacity for health research and trust in research partnerships.

Culturally safe interpretation, knowledge sharing, and capacity building

- ○ Spend time with Elders, youth, and community members to develop strengths-based, community-centered practices
- ○ Decolonize existing hiring, funding, and knowledge mobilization practices in research
- ○ Plan for sustainable community-based research and data management roles

Is there anything missing from these workshop discussions that should be addressed?

Participants were keen to discuss more examples of “good” collaborations, experimental design, and data sovereignty in infectious disease modelling research, and cases in which modelling research has benefitted communities. Participants noted that further exploration of how to incorporate Indigenous knowledge, land-based data, and community-specific needs into infectious disease modelling research is crucial. Many participants noted that including Elders and youth in these discussions will be essential. Methods for knowledge mobilization of modelling concepts (and misinformation) to rebuild trust in modelling research was also identified as a necessary next step. Finally, participants noted the need to explore strategies to push for more rapid changes in the systemic processes which do not respect Indigenous Sovereignty or meaningful relationship building for research collaboration.

Evaluation

Twenty-three of the 30 participants completed the workshop evaluation form. Of those, the majority were mathematical modellers (39%), 27% were Public Health policy makers, analysts, program managers, or epidemiologists, 17% were Indigenous researchers, and 17% did not fall under the above categories. Survey respondents reported an average of 4.3 when asked to rate their experience at the workshop on a scale from 1 (Poor) to 5 (Excellent). In terms of relevance, participants rated the workshop an average of 8 on a scale of 1 (Not relevant) to 10 (Extremely relevant). Overall, participants felt that the workshop met the event objectives, with an average of 63% of respondents indicating that they either “Agreed” or “Strongly agreed” that workshop objectives were met.

The survey also included two short answer questions. The first aimed to understand how participants would like the information from this workshop to be shared; 80% of respondents mentioned a summary report, while 30% also mentioned visual summaries, such as infographics. The second short question asked participants for specific comments or concerns related to the event. Participants felt that inclusion of more First Nations, Métis, and Inuit Elders and youth could contribute more perspectives on research ethics and approaches which reflect Indigenous ways of being and modelling priority topics. Additionally, respondents felt that the workshop objectives would have been better achieved with more time for facilitated discussions and for better representation of Métis perspectives. Respondents noted that it would be important to continue the discussions started at this event to maintain a community of practice and gain more momentum towards Indigenous-led modelling research. Finally, respondents noted that although this workshop was important for initiating discussions on Indigenous Sovereignty in infectious disease modelling research, further steps are required to move from discussion to implementation at provincial and federal levels of public health.

Conclusions

The In the Equation workshop highlighted the ongoing need for Indigenous leadership and community engagement in mathematical modelling and for research partnerships grounded in the principles of First Nations, Métis, and Inuit data sovereignty. This event was the first step in fostering a community of practice in which First Nations, Inuit, Métis, and settler public health decision-makers, researchers, and modellers develop respectful partnerships and leverage modelling methods to address community-driven infectious disease priorities.

The knowledge shared at this workshop reinforced the need for systemic changes in research methodologies and the wider research system and demonstrated that there is much more work to be done to bring about the necessary changes.

NCCID is committed to maintaining the momentum towards community-based capacity building for data sovereignty, health research, and Indigenous-led infectious disease modelling.

Artist Paige Boivin was commissioned to attend the In the Equation workshop and summarized key highlights from workshop presentations and discussions into the visual knowledge map. To view and download the file, please visit: https://nccid.ca/in-the-equation-workshop-towards-indigenous-led-infectious-diseases-modelling-research/

National Collaborating Centre
for Infectious Diseases

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Key Highlights

The key highlights from this workshop can be summarized into three main categories: data, relationships and collaborations, and those specific to modelling research. These highlights are summarized below:

Data

- Many datasets used in modelling contain deeply embedded biases and racist assumptions.
- Lived experiences and determinants of health of First Nations, Métis, and Inuit peoples cannot be captured in data alone. Data is not just numbers.
- Data Sovereignty and the rights holders must be considered at every step, even for secondary data.
- Data has spirit and needs to be treated with transparency and respect. There must be free, prior, and informed consent.

Relationships and collaborations

- Settler researchers need to put in the time towards building relationships, educating themselves, and dismantling colonial systems of research.
- The partnership does not start and end with the research project, nor is it a transaction.
- Two-eyed seeing approach to respectful partnerships that benefit communities.
- First Nations, Métis, and Inuit knowledge keepers, Elders, youth, and community members must be included in shaping model assumptions.

Modelling

- The who, what, why, how of modelling research.
- First Nations, Métis, and Inuit knowledge keepers, Elders, youth, and community members must be included in shaping model assumptions and model structure.
- Design new modelling methods based on community feedback as conventional methods may not be applicable.
- Settler researchers and modellers require formal training in OCAP and Truth and Reconciliation.
- Liaison roles can help to bridge gap between modellers and communities, build capacity, and ensure Indigenous Sovereignty in research.
- Consider alternate knowledge mobilization methods to share research outcomes.