

CANADIAN BRAIN RESEARCH STRATEGY

CBRS Indigenous Initiatives: Interim Synthesis

Meeting Dates: July 2022 – March 2023

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BACKGROUND

The Canadian Brain Research Strategy ([CBRS](#)) is building a collective national strategy to inspire and guide the Canadian government to invest in a major brain research initiative. Amplifying the unique and diverse voices of Indigenous peoples in this country will allow for enriched brain research, as these voices have long been silenced via the colonial structures of Canada. CBRS Indigenous Initiatives strives to acknowledge the past (including historical injustices), recognize the present (appreciate Indigenous strengths in culture and language), and envision the future (healthy reciprocal relationships between Indigenous Peoples and Canada) in encompassing Indigenous Peoples in the Canadian brain research landscape.

CBRS Indigenous Initiatives held its first phase of Indigenous Outreach and Engagement in July 2022 through March 2023, including seven Introductory Sessions and focus groups on three of the six [CBRS Strategic Focus Areas](#): Neuroethics, Diversity & Team Science, and Transdisciplinary Training. The 39 participants were recruited for cross-representation and included: Traditional Knowledge Holders (Anishinaabe and Metis Elders), academics - researchers, including early career and trainees, heads of Indigenous research organizations, community organization representatives, health administrators and other key stakeholders. We employed outreach methods like networking, utilize current contacts, and the National Collaborating Centre for Indigenous Health (NCCIH) database. Some participants were non-Indigenous but able to provide insight and feedback from an Indigenous perspective as their field of research and/or work involved direct connections to Indigenous peoples. Overall, we have built a foundation for us to begin work on our Two-Eyed Seeing Through Compound Eyes Workshop.

Over the course of seven introductory sessions and three focus groups, individuals were asked to discuss the successes, challenges, and opportunities for brain research in Canada and to assess the current and future potential to impact on the lives of people living with brain conditions. They were also asked to provide feedback on the Strategic Focus Areas outlined in the emerging national strategy. For the Focus Groups, we asked more in-depth questions pertaining to Inspire, Guide, and Forecast, which will allow for a breadth of knowledges to shape the Canadian Brain Research Strategy, moving forward. Additional introductory sessions and focus groups will continue in 2024; however, we want our Two-Eyed Seeing Through Compound Eyes Workshop to be a spark to more widespread engagement.

CHALLENGES IN BRAIN RESEARCH

Structure of Research Funding

The current rigidity of research funding for Indigenous communities can create discomfort for Indigenous communities, as it operates on timelines which make it difficult to make lasting and continuous relationships for researchers and participants. Flexibility needs to be practiced and exercised to reflect the diversified needs of the heterogeneity Indigenous communities.

Governments and politics influence the way research is conducted and funded; change would have to start at the policy level, which means examining and being cognizant of how these relationships should be developed and maintained. Further, non-Indigenous researchers are being allocated funds meant for Indigenous research, which continues the cycle of Indigenous voices being silence; indeed, it should be a legal requirement for research grants to be given to Indigenous PIs and/or co-PIs. If there is lack of Indigenous MA and Ph. D researchers (required by the grant), then Indigenous peoples with work and life experience equivalent to those with required degrees should be granted equivalency to apply as a co-PI.

Accessibility

The level of access to resources and equipment for Indigenous communities was an issue which was highlighted. Lack of availability to diagnoses of brain illness allow the challenges of these conditions to persist, permeate, and pass on to next generations. Increasing access to tools, skills, and partnerships in healthcare and research could help overcome some of the institutional barriers that underlie health disparities between Indigenous peoples and the rest of Canada.

Intergenerational Trauma

Personal exploration, growth, and healing is needed by Indigenous peoples, as well as the rest of Canada, to overcome the institutional barriers of bias, discrimination, and racism which continues to persist in all layers of the fabric of Canadian society. In academic institutions, the need to subdue the rise of “pretendianism” is required to ensure that the voices of Indigenous peoples are recognized, affirmed, and celebrated.

Domination of Western Approaches to Research

Overcoming the insistence and reliance on Western methodologies of data collection and analysis would allow for better collaboration between researchers and Indigenous participants and communities. Our ways of seeing the world are inherently different, and when Western approaches take precedence over the needs of Indigenous peoples, it leads to a feeling of resentment and oppression, which is highly reflective of the continued colonialism experienced by the people we are seeking to help.

People over Policy vs. Policy over People

Far too often our traditional ceremonies are pushed out of mainstream, colonial spaces (such as office spaces/universities), where it becomes difficult to be seen or heard. For instance, smudging is a tool and process which cleanses or spirits from any negative, harmful energies which may hinder

or impair our ability to walk in harmony; thus, when we are told we cannot practice our ceremonies in these spaces, it further inhabits our ability to want to join the activities of institutions such as universities. Also, when privacy policies (which are supposed to “protect” individuals) become such a burden on delivery of treatment, then is the policy serving its purpose in protecting, or merely causing more harm.

Misunderstanding and Disregard for Traditional and Cultural Teachings

The heterogeneity of Indigenous knowledges has a richness and complexity, which is at times hard for Western ways of thinking to comprehend. Beliefs in different realms (such as the dream world), existence of beings on different planes (which co-exist with our physical world), as well as continuums of time (seven generations of ancestors/descendants), are not often in alignment with Western quantitative methods of research. However, the blatant disregard (and frankly, disrespect) of these knowledges and teachings, cause Indigenous peoples to seek protection and safety away from the domineering nature of Western protocols, procedures, and practices. Allowing spaces and room for flexibility for Trainees and Early Career Researchers to engage with these teachings in a meaningful way, while still being recognized and honored by Western institutions in their academic achievements, is the only way for true reconciliation to occur.

OPPORTUNITIES FOR BRAIN RESEARCH

The following themes were brought up by participants in the Introductory Sessions and Focus Groups on how the CBRS and the Strategic Focus Areas can advance brain research in Canada and support Indigenous peoples.

1. Building, Maintaining, and Reaffirming Community Relationships

In a similar manner to treaty-making, the relationships developed between researchers and community should be developed by creating a reciprocal relationship, rather than being one-sided where researchers are taking from community. Co-creating solution-based approaches to the research being explored is necessary and working with communities throughout the whole research process will lead to higher quality partnerships and connections.

2. Capacity Building

It is essential that tools, such as platform development, are created alongside with Indigenous communities to better tailor the needs of each unique people and place. Creating trainee mentoring, high school outreach, and academic support programs would lead to higher quality research.

3. Ownership, Control, Access, and Possession (OCAP)

The principles of OCAP (developed by the First Nations Governance Information Centre) should be constantly recognized and affirmed. The quality of any research project is diminished without community leadership of how research is conducted. Ensuring that Indigenous partners are in command of all aspects of data collection and analysis will lead to continuous and richer collaborations.

4. Cultural Adaptability

The need for Western research to think outside the confines of the scientific method is imperative for there to be any meaningful relationship-building between Indigenous communities and Western institutions. Our perspectives are fundamentally different, and these differences should be honored and respected, so that Indigenous peoples feel empowered in their belief systems, cultures, languages, and ways of knowing and seeing.

5. Indigenous Awareness of Brain Illness/Conditions & Mental Health

Support in outreach and awareness of brain illness and conditions will allow for diagnoses for Indigenous peoples. Improved identification and classification of brain conditions will lead to better help and support services in the medical field. Finally, creating this awareness can lead to more diverse solutions for the complex barriers affecting Indigenous peoples.

6. Varying Geographies and Politics of Demographics

There needs to be recognition that Indigenous peoples come from varying backgrounds and demographics, such as on-reserve, off-reserve, urban, status, non-status, Metis, and Inuit people. Indigenous-led research, including methodology should take precedence over governmental records, at certain times. For instance, a study of on-reserve populations in Alberta from the federal government, states there were 89,000 on-reserve; however, a conflicting report from First Nations Information Governance Centre lists 138,000 people on-reserve (note: there are varying reasons why some individuals do not register with the government, under the Indian Act). This affects funding models, levels of support, and research practices; thus, we should be able to conduct our own research, and these numbers be accepted by institutions and organizations.

7. Acceptance of Differing Perspectives of Wellness

Spirit exists outside of heart and brain; however, there is interconnectivity between these aspects of being. Research and Clinical applications need to be aware that measures of wellness and health may be differing from what has been established by Western institutions. Widespread acceptance of self-care methods such as praying, meditation, knowledge-sharing, and language transmissions (and how they are measured) should be accepted by Indigenous communities, organizations, and Western institutions; traditionally, these were ways of how we took care of ourselves and each other. Two Eyed Seeing may sometimes overlook, or take for granted, the importance of how these methods are employed and utilized by individuals and communities. Theories of interconnectedness (knowledge translation to Western institutions) may be lost, without proper collaboration between individuals and researchers; unless, those researchers fully partake in the processes.

8. Knowledge Mobilization

There needs to be continuous, ongoing, and relevant data sharing amongst Indigenous researchers, communities, and organizations. Opening dialogues and forums of discussion about how research can be utilized as healing. Increased awareness of various brain conditions, and the availability of treatments, would allow for there to be deployment of ongoing and diversified research techniques

which could potentially find solutions to the multitude of ailments afflicting Indigenous populations. Sharing how our environmental (spiritual, physical, social, and emotional/mental) backgrounds shape our health, including the brain; could influence the next generation of researchers to address the negative aspects of these environments, while guiding us to a more balanced well-being. Lists of recognized cultural practitioners to be utilized would be beneficial to weed out any nefarious individuals who seek their own personal benefit.

9. Co-Creation and Continuums with Research and Care

Allowing Indigenous communities to take lead on presented models of research, would enhance their ability to take ownership of the solutions co-developed in the community. Downloading responsibility to Indigenous communities, does not forebode well to a success of a project, if not enough resources (financial, human, and capital) are given to researchers, communities, and organizations within, to lead proposed projects properly and efficiently. Allowing more flexibility in time, for culturally-based solutions to evolve and grow within the community, will be more meaningful; thus, the rigidity of institutional practices must bend for prosperous progression in both research and care to occur.

SUCSESSES IN RESEARCH

Indigenous-Led Research Ethics Boards

The Manitoulin Anishinaabek Research Review Committee (MARRC) is an Indigenous created and led research ethics board, which services the seven Anishinaabe territories of Manitoulin Island: Wiikwemkoong, Mchigeeng, Aundeck Omni Kaning, Whitefish River, Sheshegwaning, Sheguiandah, and Zhiibaahaasing. The current chair is Lorrilee McGregor, who is an Associate Professor based out of the Northern Ontario School of Medicine (NOSM). MARRC acts as liaison between each respective Chief and Council, Principal Investigator(s), Organization and/or Institution.

Partnerships with Established Neurological Institutions

The Indigenous Cognitive Health Program (ICHP) initiative, through CCNA (led by Jennifer Walker), which seeks to establish capacity in a network of partnerships between Indigenous communities, researchers, and/or institutions, regarding dementia research. ICHP will provide mentorship and guidance from CCNA investigators to Indigenous communities, in a reciprocal relationship, to ensure the research occurs in a culturally relevant manner.

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CBRS STRATEGIC PRIORITY AREAS

Participants in the Introductory Sessions were asked to reflect on each CBRS Strategic Focus Area and to discuss its potential to impact brain research and the lives of Indigenous peoples. Two focus groups were held additionally on Neuroethics and Diversity & Team Science. The following are the major takeaways:

1. Open Science

Indigenous peoples need to have tools, equipment, and expertise to share data and knowledge amongst each other, to support our traditional methods of communication. Thoughts, intentions, and words are all powerful “data” for Indigenous people, and need to be acknowledged by Indigenous researchers. Protecting the sovereignty of how Indigenous data is collected, as well as ensuring that present and future partners respect how Indigenous peoples want to advance and develop, will ensure that they are an integral part of a better future for brain science.

Participants believe that open science should involve:

- Principles of OCAP and work with organizations such as the First Nations Information Governance Centre (FNIGC) on data sovereignty
- Creating centralized repositories of research findings, resources, and information
- Accessibility to data information and analysis (in non-jargon terms) would allow Indigenous participants, researchers, and communities to have more ownership and control
- The complexity and uniqueness of the brain requires an open science approach and incorporation (including knowledge sharing) to accelerate knowledge in the different areas
- Be open to new ideas and possibilities in Indigenous research
- Open science does not necessarily address inequity - better methods, platforms, access needs to be instituted/developed to allow for Indigenous people to fully participate.

2. Platform Science

Envisioning places and mechanisms to incorporate Indigenous Knowledge with brain research in physical and virtual spaces where those can be applied, such as land-based learning opportunities and Indigenous language retention via video conferencing. Sharing ways of how Indigenous Knowledge is applied via tools, data, and expertise will allow research to be more equitable, collaborative, innovative, and productive.

Participants believe that platform science should:

- Collaborate with different communities (based on need) to develop unique training programs for individuals to utilize the platform in efficient and effective manner
- Create awareness of the varying platforms and how they could shape, alter, and assist communities
- Be open to multiple approaches, not just biology, to bring together different perspectives

- Social media (e.g., Facebook) can be explored or deployed as a platform to connect with people
- Platforms require technology and is not equitable for everyone – this should be considered/kept in mind in relation to engaging communities.

3. Diversity & Team Science

Incorporating Indigenous peoples into research opportunities, ventures, and spaces, allows for knowledge bridging between Western and Indigenous Perspectives. Removing barriers and obstacles in research, as well as supporting Indigenous peoples in these roles will allow for more robust and higher quality data and information.

Participants believe that Diversity & Team Science should:

- Create mentorship models at varying levels of education and workspaces (high school outreach, trainee co-ops, and work exchanges)
- Respect and appreciate the richness of Indigenous language and culture via elder engagement, cross- cultural opportunities, and institutional collaborations
- Help provide more knowledge to the community and support families and caregivers. It will give people with brain conditions more opportunities to engage in research.

4. Neuroscience-AI

Artificial intelligence (AI) tools are rapidly growing, with the potential for Indigenous Knowledge and ways of thinking about the brain to benefit and to shape its development but also to be harmed via exploitation.

Indeed, establishing principles and pillars of how Indigenous peoples want their knowledge incorporated into these tools is essential to ensuring a healthy, mutually beneficial, and sustainable relationships are advanced in research.

Participants believe that Neuroscience-AI:

- Could have huge benefits in assisting the retention and teachings of traditional languages. Language learning is beneficial for life-long brain health and doubles as a positive cultural outcome
- May be missing intuition – it needs to bring Indigenous ways of thinking
- The multifaceted and interconnected ways that Indigenous peoples view the world needs to be protected, reflected, and celebrated in the processes of Neuroscience-AI; ensuring Indigenous peoples are at the helm and involved throughout this journey will be beneficial to all parties.
- Virtual reality can be leveraged in developing solutions for people with health conditions. The available data could be negative as opposed to the needed positive data, thus utility and purposefulness should be kept in mind

5. Transdisciplinary Training

Indigenous peoples view the world in a holistic sense, where we understand that all our relationships (physical, environmental, familial, and spiritual) are tied and bound to each other in how they affect us on an individual and community level. Collaborating between disciplines (such as hunters, tanners, and craft makers) has been inherently part of Indigenous identity for millennia, and applying this way of thinking in training the next generation in biology, physics, computer science, social science, and the humanities, will allow for greater and faster advances in understanding the brain.

Participants believe that Transdisciplinary Training should:

- Allow for Indigenous methodology; co-create programs with Indigenous scholars to tailor to their unique needs and challenges (cultural communication, life experiences, and perspectives)
- Implement broader education for researchers and research ecosystem (not only those working with Indigenous participants and communities)
- Include proper compensation and recognition for those scientific researchers working in communities, as well as for those Elders sharing their knowledge with institutions
- Consider Indigenousizing how we engage with scientific knowledge, but also recognize that not all scientific knowledge and approaches can be Indigenousized. Both Indigenous and Western research methods can co-exist and interact as need be.
- Including more people in the research process may be beneficial but may also slow down the process/outcome. We should be strategic in which partners are brought in, and how they are utilized

6. Neuroethics

Indigenous Traditional Knowledge encompasses spaces, concepts, and ideas which are foreign to Western research, and vice-versa. Building guidelines, touch points, and protocols between Indigenous Traditional Knowledge and research will be key to understanding the ethical, legal, and social issues raised by our continuously advancing knowledge of the brain. To make the best use of neuroscience and mental health research, it is important to look at the potential benefits, risks, and broader social impact on individuals and communities.

Participants believe that a Neuroethics approach should:

- Involve training for members of Research Ethics Boards to understand how to assess ethical components of Indigenous research
- Be mindful of past transgressions that can lead to mistrust; Trust is needed for meaningful engagement
- Take the time to build a reciprocal relationship with communities based on respect and bi-directional exchange of knowledge
- Recognize the heterogeneity of Indigenous cultures and communities across Canada

- There are unique concepts to working with Indigenous communities (e.g., at ceremonies and events); having a firsthand experience gives perspectives that would be missed/misunderstood otherwise by not attending