

Growing Stronger Together: A Brain Health Community Report



2024



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Purpose

Our aim is to share knowledge on brain health that is culturally relevant for File Hills Qu'Appelle Tribal Council communities, with the hope that this information can be used as a tool to strengthen the wellness journeys of community members.



As Indigenous populations age globally, there is an increasing number of Indigenous people experiencing age-related cognitive decline and dementia. Further contributing to this rise is a higher-than-average risk of dementia that is underpinned by the ongoing forces of colonization and the intergenerational impacts of trauma on inflammation, cardiovascular disease, diabetes, and other conditions.¹

In Canada, dementia rates are increasing more quickly in First Nations populations compared with other populations, and the average age of people living with dementia is younger in First Nations populations.¹

Dementia prevention has been identified as a priority for First Nations community leadership, health care providers that serve First Nations people, and community members. Despite this high priority, there is a lack of widely accessible brain health education that is developed by and intended for Indigenous communities.

This report details the process of developing culturally relevant brain health education materials for community members in File Hills Qu'Appelle Tribal Council.

File Hills Qu'Appelle Tribal Council

File Hills Qu'Appelle Tribal Council (FHQTC) provides health services to the 11 First Nations in Treaty 4 Territory, Saskatchewan, Canada. FHQTC is comprised of diverse cultural and linguistic peoples, including the Cree, Dakota, Nakoda, Lakota, and Saulteaux.

The 11 Member Nations are:

Nekaneet First Nation
Wood Mountain Lakota First Nation
Piapot First Nation
Muscowpetung Saulteaux Nation
Pasqua First Nation
Little Black Bear's Band of Cree & Assiniboine Nations
Okanese First Nation
Star Blanket Cree Nation
Peepeekisis Cree Nation
Carry-The-Kettle Nakoda Nation
Standing Buffalo Dakota Nation



The FHQTC First Nations Health Services Program's goal is to deliver culturally respectful, patient-centred and wholistic services to community members. The Health Services Program offers a variety of services including:

- Canadian Prenatal Nutrition Program
- Community Health Nursing
- Diabetes and Wellness
- Environmental and Public Health Program
- Home and Community Care
- Information Technology/Telehealth
- Jordan's Principle support
- Lactation Consultant Services
- Maternal Child Health
- Rehabilitation Therapies



Community Research Advisory Committee

In 2016, FHQTC established the Community Research Advisory Committee to address their dementia and brain health research priorities. The Committee has met monthly since that time and has carried out several brain health projects, including an adaptation of the Canadian Indigenous Cognitive Assessment (CICA) for Nakoda communities.⁴

In 2021, the Committee determined that accessible and culturally grounded dementia prevention education would be their priority for the final years of their dementia focused work.

The Community Research Advisory Committee was eager to guide the FHQTC to implement brain health promotion programs that integrated First Nations perspectives and research findings, but no such program existed.

As such, the Canadian Consortium on Neurodegeneration in Aging (CCNA) research team worked with the Committee to evaluate and consider adapting an emerging evidence-based brain health promotion platform called the Brain Health Support Program (Brain Health PRO). Rather than creating an adaptation, the Committee blended Brain Health PRO information with Indigenous Ways of Knowing to create new brain health education materials



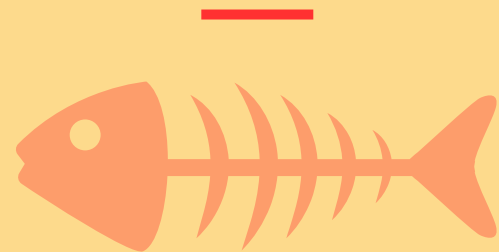
The Community Research Advisory Committee is made up of an Elder, Knowledge Keepers, community members, health care professionals, and educators.



Brain Health Support Program

The Brain Health Support Program (Brain Health PRO) aims to reduce the risk for cognitive decline through online modules designed to educate older adults on preventative health measures for modifiable risk factors. The platform has not included First Nations perspectives in its program development, and therefore does not reflect the needs of First Nations communities.²

The Community Research Advisory Committee reviewed Brain Health PRO for its content and approach. Committee members found the platform to be insightful, but it failed to have cultural relevancy.



Brain Health PRO

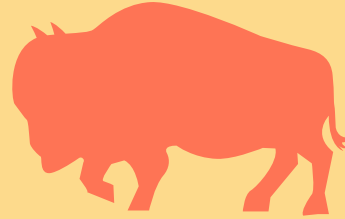
Brain Health PRO focuses on seven modifiable risk factors to cognitive decline, including physical health, nutrition, vision & hearing, sleep, cognitive engagement, social & psychological health, and vascular health. Up to 40% of dementia cases can be attributed to modifiable risk factors.²

To learn more about the Brain Health PRO visit:
brainhealthpro.ca/



Plan of Action

Project Framework



This community-based participatory research project grew from a partnership between FHQTC and the Canadian Consortium on Neurodegeneration in Aging (CCNA) researchers. The partnership was grounded by a Research Collaboration Agreement established between McMaster University and FHQTC that outlined details such as how the team would honour First Nations data governance principles⁷ and Indigenous relational research methods⁸ that emphasize wholism and strengths-based approaches.

Community-based participatory research involves community members in every stage of research.³



Gathering Information



The research team collaborated with the Community Research Advisory Committee members through a series of focus groups, held monthly from October 2022 to August 2023 in person at the All Nations Healing Hospital in Fort Qu'Appelle, Saskatchewan. Committee members consented to participate either through verbal or written informed consent.

Committee members had the option to attend remotely through a video conference but rarely chose this option. Each Committee member was provided with log-on access to the Brain Health PRO platform, so they had voluntary access to the full program in addition to the materials presented and discussed in the focus groups. Each focus group was designed to focus on a different risk factor included in the Brain Health PRO. Initially, the focus group sessions started with the group coming together to view one or two videos from the Brain Health PRO modules for a given risk factor (e.g., nutrition, physical activity, sleep, etc.) followed by a facilitated discussion with questions about how the material resonated and how informative and accessible the video content was for each Committee member.

Mental health supports were shared at the beginning of each meeting with the understanding that in-depth conversations about health and healing can lead to uncomfortable memories or emotions.



Thematic Analysis



Thematic analysis identifies patterns or themes in data.⁶

Focus group discussions were recorded and transcribed then analyzed using thematic analysis with NVivo software. To involve Committee members in the data analysis process, an adaptation of the Collective Consensual Data Analytic Procedure (CCDAP) was used with the Community Research Advisory Committee. The CCDAP enables participants to pull important experiences and ideas from transcripts, develop codes, and sort them as a collective to reveal broader themes alongside researchers.⁵

To better collaborate with Committee members, researchers used visual and physical materials when sorting codes into themes. Quotes taken from data collection meetings were written on paper leaf cutouts and disseminated among Committee members. A large tree was drawn on poster paper with branches labeled with sub-themes; some branches were also left blank for new suggestions. During the two data analysis meetings, Committee members discussed their interpretation and memories of the quotes, and placed them onto the branch they believed best fit. After each quote was categorized, research staff clustered them into broader themes. The two sessions were not enough to complete the data analysis but the Committee members guided the research team to continue on the path to analyzing the rest of the data and presenting it back to them for confirmation.

Knowledge Sharing

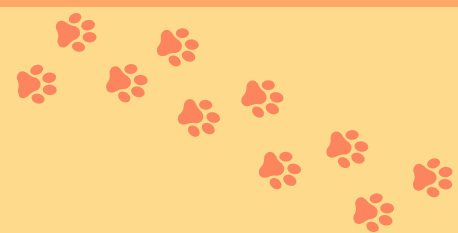
Materials are available at allnationshealinghospital.ca/departments/research/

Community Research Advisory Committee members and researchers co-developed materials to share their knowledge with FHQTC and community members. This was done in three ways. First, a series of pamphlets that blended Brain Health PRO information with knowledge and perspectives from community members was developed and shared. The series included seven pamphlets that build on the seven Brain Health PRO modifiable risk factors. Second, a video featuring interviews with Committee members reflecting on brain health promotion was produced and shared widely. Third, a community brain health fair was hosted in May, 2024 at the FHQTC.





**Memory
and Brain
Health**



**Sleep
and Brain
Health**

**Vision &
Hearing
and Brain
Health**



**Kinship
and Brain
Health**

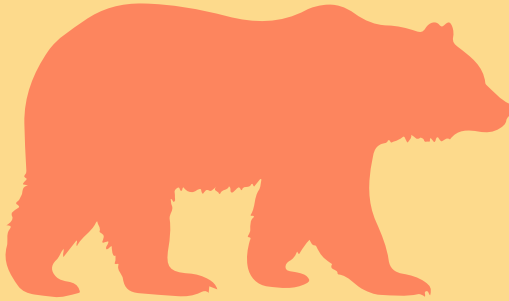


**HEART
AND
BRAIN
HEALTH**





PHYSICAL ACTIVITY & BRAIN HEALTH



Caring for your Brain
in Indigenous Communities

FHO
Tribal Council

Video player controls: play/pause, stop, next, volume, and progress bar.



NUTRITION AND BRAIN HEALTH



Project Reflections

One of the earliest assertions by the Community Research Advisory Committee members was that the delivery of the program, through entirely online modules, was not the preferred method of sharing information. Instead, education materials that people could hold and opportunities for in-person gatherings were preferred. Despite having access to the online Brain Health PRO platform, none of the Committee members were interested in logging on to the platform. Reasons reported for this were lack of access to a computer, the platform was not accessible by mobile phone, and the concerns and preferences for in-person meetings and discussions cited above.

Community members also highlighted the lack of relevancy of the content presented, such as the exclusion of Indigenous Traditional Knowledge and medicines, land-based teachings, and spirituality. Although Committee members appreciated the evidence-based information presented in the Brain Health PRO, without a connection to Indigenous ways of knowing, the modules failed to connect overall.

The images and examples used in the online modules also did not seem to relate to the Committee. Committee members noted they would like to see images of First Nations people featured on the platform, and examples of daily living that more closely resembled their own in File Hills Qu'Appelle, Saskatchewan.

The original Brain Health PRO did not include concerns that are unique to Indigenous people, such as anti-Indigenous racism in the healthcare system. Committee members were especially concerned with the amount of medication being prescribed by health providers and how it may affect brain health. Ultimately, many relevant brain health concerns highlighted by the Committee members were out of the scope of this project.



Lessons

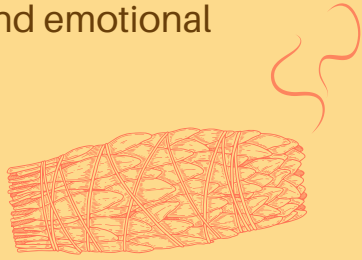
“*When you are spiritual, you know that a lot of the healing comes from the land. It's not necessarily the knowledge keepers, but everything we need to heal ourselves comes from our environment. Do we know how to access it? No. But we know what's there. And that's what's in our spirit that can guide us.*”

- Community Research Advisory Committee Member



Wholistic Health Must Include Spirituality

Brain health programs must also include ways to improve spiritual health, along with physical, mental and emotional health.



Prioritize Indigenous Ways of Healing

Traditional Indigenous medicines are not just complementary or alternative to Western medicines, they are primary sources of healing.



There are concerns about medications

The Community Research Advisory Committee had concerns about the number of medications being prescribed by health providers, as well as medications that can be abused and bought without a prescription.

There are concerns about the effects of the environment on dementia risk

Many health concerns raised by Committee members were related to environmental concerns, including health risks related to polluted drinking and fishing waters.



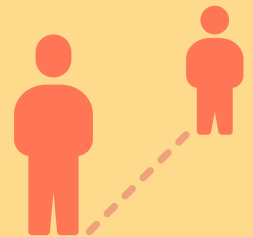


Brain injury is a risk factor for dementia

The Brain Health PRO did not include information on brain injury prevention, but Committee members felt that it is a very important part of brain health promotion.

In-person learning is valuable

Committee members were given the opportunity to join meetings through Zoom but felt that attending in-person provided more ways to feel connected to the information and other members.



Everyday tools are helpful for memory and staying engaged

It is not necessary to buy expensive equipment to stay healthy; walking or gardening are ways people can stay physically active. And people can keep their minds active by socializing with friends and writing down reminders.



Information should have an equivalent meaning in Cree, Dakota, Nakoda, Lakota, or Saulteaux

When creating brain health promotion materials in English or French for Indigenous language speakers, it is important to ensure all of the information has an equivalent meaning in someone's language.

“If you're fluent in your language, if you have a real understanding in your language, somebody in English tells you a whole bunch of words, like even the word 'cognitive', it doesn't register in your mind. As Nehiyaw people, we have very, very precise, exact understanding. But it has to be through your language.”

- Community Research Advisory Committee Member



Brain Health information is important at every age

Brain health programming is often targeted towards older adults, as they are most at risk for dementia, but this information can be useful to people of all ages.

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