

Manitoba First Nations Information Sharing Agreement with the Province of Manitoba during COVID-19

Background

- Through the long-standing oversight and governance of the mandated committee established by Manitoba Chiefs in Assembly, the Health Information Research Governance Committee (HIRGC) and Manitoba First Nations have a long history that recognizes the importance of data governance and data sovereignty.
- The HIRGC is comprised of First Nation health directors, First Nation academics, and has provided oversight and governance over information and research since its original mandate provided by Manitoba Chiefs in Assembly since 1998.
- The Manitoba First Nation COVID-19 Pandemic Response and Coordination Team worked in partnership with HIRGC to negotiate an information sharing agreement between FNHSSM and the Province of Manitoba that was signed on April 28th, 2020.
- This information sharing agreement was negotiated based on the approval provided by the Health information Research Governance Committee (HIRGC) on April 1, 2020 to utilize the First Nations identifiers collected within the COVID-19 intake form and data linkages with the Indian Status Registry to verify First Nations cases to inform specific COVID-19 planning and response tables.
- “The data sharing process was approved by our committee and authorized FNHSSM to negotiate and begin working with partners to develop a critical data gathering tool and process to support First Nations and other organizations in their planning and monitoring of First Nations covid-19 cases. This is a collaborative partnership with the Province that recognizes First Nations self determination and governance of our own data and utilizes the OCAP® [ownership, control, access and possession] Principles to determine the standards and parameters of how First Nations data is used for the benefit of our people”, stated **Doris Young, Opaskweyak Cree Nation, HIRGC Co-Chair**.
- Based on HIRGC approval the First Nations Health and Social Secretariat of Manitoba successfully negotiated an information sharing agreement with the Province of Manitoba that respects the principles of data OCAP® and First Nations data sovereignty.
- In previous approvals provided by HIRGC, Manitoba First Nations have successfully utilized First Nations data to highlight health disparities within “The Health Status of and Access to Healthcare by Registered First Nation Peoples in Manitoba http://mchp-appserv.cpe.umanitoba.ca/reference/FN_Report_web.pdf and the First Nations community profiles. The limitations of these reports did not include non-status First Nations, familial connections and kin who are often missed and not included in reports based on the colonial definitions of a status Indian that have further excluded many of our women and children.
- As First Nations we have collectively come together with the Province of Manitoba and FNHIB/ISC to start collecting identifiers by offering our people the opportunity to self declare as Status and non-status when they test positive for COVID-19, to count those that have been overlooked and undercounted in many datasets is something we celebrate.
- This information sharing agreement is unprecedented and sets the standard for future agreements with the Province of Manitoba that respects the First Nations principles Ownership, Control, Access and Possession (OCAP®) and First Nations data sovereignty.
- The number of positive First Nations COVID-19 cases are based on voluntary self declaration of status and non status and linking to the Indian Status Registry.
- The parameters of the agreement further outline how First Nations data is accessed, how reports are generated and how information is shared, and respects all applicable privacy and information laws. The agreement was negotiated to ensure data accuracy to inform pandemic planning and preparedness and confirm the willingness of parties to work together at various levels to support First Nations data sovereignty.
- Information on the number of confirmed cases of COVID-19 for First Nations citizens living in Manitoba will be released through the Manitoba First Nations Pandemic Response Coordination Team every Friday starting May 15, 2020.

Anyone with further questions regarding the information sharing agreement or the role of HIRGC can contact Leona Star, Director of Research, First Nations Health and Social Secretariat of Manitoba at lstar@fnhssm.com or (204) 946-9739.