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Creation of First Nations Health Profiles Through Data Linkage in Manitoba

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Background

First Nation peoples (FNs) were not able to identify themselves within administrative datasets due to lack of FNs identifiers, which perpetuates a pan-indigenous approach in advocacy and evaluation capabilities. Linking databases improves the quality and accuracy of FNs health data and offsets the burden of survey fatigue in communities. Creating community profiles helps FNs in identifying health status priorities for communities, Tribal Council and other geographically defined areas.

Methods

A resolution was passed in September 2017 to link Indian Status Registry (ISR) file with Manitoba Health Registry, with First Nations Health and Social Secretariat of Manitoba (FNHSSM) and Health Information Research Governance Committee (HIRGC) oversight to create a Key Linked file which has First Nations specific information. Encrypted Personal Health Information Numbers (PHINs) were added to the Key Linked file to create a Manitoba First Nations Research file which is linkable to other databases. Information Sharing Agreements (ISA) have been developed with federal and provincial governments to mandate the processes for data linkage.

Results

A resolution was passed in September 2017 to link Indian Status Registry (ISR) file with Manitoba Health Registry, with First Nations Health and Social Secretariat of Manitoba (FNHSSM) and Health Information Research Governance Committee (HIRGC) oversight to create a Key Linked file which has First Nations specific information. Encrypted Personal Health Information Numbers (PHINs) were added to the Key Linked file to create a Manitoba First Nations Research file which is linkable to other databases. Information Sharing Agreements (ISA) have been developed with federal and provincial governments to mandate the processes for data linkage.

Conclusion

Data Linkage is a key process to assert self-determination, strengthen FNs data governance and achieve Data Sovereignty. Linking databases creates opportunities for FNs to access accurate data that will assist their Nations to lead their own health research and program evaluation that are driven by their own needs and priorities.