

International Journal of Population Data Science

Journal Website: www.ijpds.org



Indigenous community engagement in administrative data research: Lessons from the Qanuinnngitsiarutiksait study

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Objectives

The Qanuinnngitsiarutiksait program of research was developed at the request of and in partnership with a group of Inuit Elders, to document patterns of service utilization (health, social services, housing, justice) of Inuit living in Manitoba, and traveling to Manitoba to access health services.

Method

In this retrospective cohort study, we used administrative data routinely collected by Manitoba agencies. Ethical oversight was provided by the university of Manitoba Ethics Board and by an Inuit organization located in Manitoba. We developed an algorithm to identify Inuit in administrative datasets. Inuit Elders were involved at every step, providing feedback on planned analyses by sharing stories related to the research questions to ensure that the direction of the data extraction resonated with their experience. In addition, analytical conferences were held with elders, to ensure that researchers' understanding of the findings resonated with Elders.

Results

The group of Elders (6) we worked with had a variety of strengths: some had served as members of parliament and were comfortable with data presentations; others could provide a wealth of knowledge around Inuit knowledge and experiences, but remain intimidated by data. At the onset, we spent time creating a protocol with Inuit elders to explore how they wanted information to be shared with them (graphs, infographics, stories). We settled for a variety of means to accommodate different skill sets and support their own development. Having stories informing planned analyses ensured that we focused on what was important to this community. Stories also provided invaluable context to our analyses, and informed the need for analytical refinement and supportive program development.

Conclusion

Canada has become a leader in requiring that Indigenous communities be actively engaged in research aiming to document their needs and concerns. Our project demonstrates that meaningful Indigenous engagement is essential and possible in all research.



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