

A Scoping Review of First Nations Data Governance Approaches Applied in Research Using Routinely Collected Health Data and Step Towards The DIFFERENCE Project



Sungkyung Linda Kim^{1,2}, Teyl Engstrom¹, Elton H. Lobo¹, Jinxiang Wang³, Howard Wong^{1,4}, Soo In Oh^{1,4}, Clair Sullivan^{1,5}

¹Queensland Digital Health Centre, Centre for Health Services Research, The University of Queensland, Herston, QLD ; ²Ochsner Clinical School, The University of Queensland, Brisbane, QLD – New Orleans, Louisiana ; ³Poche Centre for Indigenous Health, The University of Queensland, Brisbane QLD ; ⁴Faculty of Medicine, The University of Queensland, Brisbane, QLD ; ⁵Royal Brisbane and Women’s Hospital, Herston, QLD

Queensland
Digital Health Centre

Introduction

The utilization of electronic medical records (EMRs) within healthcare is steadily increasing.¹ EMRs have gained popularity since its introduction for its ability to present and retain patient information, treatment details, and medical history.^{2,3} Nevertheless, sharing patient information presents with significant challenges concerning data privacy, security, and governance. These challenges are accentuated in First Nations populations due to the intersecting impacts of colonization’s persistent legacy, inherent racism, biases, and a limited understanding of their rights. With the increasing amount of digital health data collected, there is a need to apply standards practically in research involving Indigenous communities.

This leads to the question: **What is the current practice for governance of First Nations routinely collected health data?**

Methods

A systematic review using studies from 2013 to 2022 was done on the data governance approaches employed during the access of routinely collected health data for First Nations people globally. Study characteristics, data governance approaches, approaches to consent, and advantages and disadvantages of using routinely collected data were extracted and analyzed.

Results

The searches identified 580 unique articles, 145 articles were included for full-text review, of which 85 studies were included. As outlined in Table 1, our study found that 65 (77%) papers described how First Nations people were involved in various aspects of the study and 60 (71%) papers were authored by First Nations focused organizations. Less than half of the studies reported an approach to consent (n=28, 33%) and on data sovereignty (n=35, 41%). 79 (93%) papers discussed ethics approval, but 18 (21%) studies cited which First Nation guiding principles were used.

References

- Dendere, R. *et al.* Patient Portals Facilitating Engagement With Inpatient Electronic Medical Records: A Systematic Review. *J Med Internet Res* 21, e12779 (2019).
- Li, Y. *et al.* BEHRT: Transformer for Electronic Health Records. *Scientific Reports* 10, 7155 (2020).
- Dash, S., Shakyawar, S. K., Sharma, M. & Kaushik, S. Big data in healthcare: management, analysis and future prospects. *Journal of Big Data* 6, 54 (2019).

Table 1. Frequency of First Nations Data Governance Approaches Described in Included Studies

First Nations data governance approach	Described in study n(%)	
	Yes	No
First Nations peoples and communities involved in research	65 (76.5%)	20 (23.5%)
Authored by First Nations focused organizations	60 (70.6%)	25 (29.4%)
Data sovereignty	35 (41.2%)	50 (58.8%)
Approach to consent	28 (32.9%)	57 (67.1%)
Ethics approval	79 (92.9%)	6 (7.1%)
First Nations guiding principles	18 (21.2%)	67 (78.8%)

Reflection and Future Direction

This systematic review indicates a developing area of reporting on data governance approaches in research studies utilizing routinely collected First Nations data. Drawing from existing data sources and establishing partnerships with diverse First Nations leaders and organizations can enhance First Nations health, facilitate strategic planning, and improve healthcare outcomes and services. However, data linking and integration across healthcare platforms is imperative to achieve higher quality findings.

This review serves as a foundational step towards the DIFFERENCE (Digital Infrastructure for Improving First Nations Maternal and Child Health) Project. The DIFFERENCE Project aims to improve maternal and perinatal health outcomes by developing standardized digital platforms aligned with First Nations data principles and governance.

