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Expanding data resources beyond “health care”: exploring options and implications

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Background

Population data science has a long history with health care data. Some data centres are expanding to include “health-related” data, including information on other publicly funded services (e.g. education, income and housing supports), and systems (e.g. criminal justice, children in care). We describe what enabled this expansion through three examples from Health Data Research Network Canada.

Methods

HDRN Canada members include data centres that provide access to linkable data sets for approved research projects. We use case studies to identify similarities, differences, and lessons learned from the process of expansion in the provinces of Manitoba, New Brunswick and British Columbia.

Results

The Manitoba Centre for Health Policy has 30+ years of experience with linked data, with a consistent focus on population health. Data sets expanded incrementally, through partnerships across government agencies. Population Data BC has a nearly 30-year history, with recent expansion to health-related data through partnership with a program of one government ministry that operates under distinct legislative authority. The New Brunswick Institute for Research, Data and Training is newer, and helped advocate for legislation changes that enabled an expanded set of linked data to be made available for research. All embed Five Safes principles, and commitments to inclusion, diversity, equity and accessibility and Indigenous data sovereignty in data governance.

Conclusion

A greater variety of data enables research to answer complex research questions. This kind of expansion can be accomplished through different mechanisms, but in all cases requires attention to ethical and legal principles of population data science.

