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Standardizing health data stewardship principles and practices in Canada

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Objectives

Canada is a constitutional federation, and responsibility for delivery of health and social services rests primarily with provinces and territories. This creates variation in legislation, regulation, policies and practice, including for governance and stewardship of health and social data. We describe collaborative efforts led by CIHI to reduce variations.

Conclusion

Data stewardship responsibilities rest with a large number of people across health care institutions, organizations and providers. A principles-based approach establishes broad and clear commitment to a common “north star”. The required transformation in data stewardship will take time and willingness to change, including more inclusive and shared decision-making.

Method

The starting points were recommendations from a pandemic-inspired expert advisory group on a pan-Canadian Health Data Strategy and an associated Pan-Canadian Health Data Charter. The Charter identifies 10 principles that “honour the duty to put people and populations at the core of all decisions about the disclosure, access and use of health information.” These resources were augmented with: a data stewardship framework crafted over eight months by a committee of all levels of government; a literature review; and interviews with key exemplars such as England’s National Data Guardian. The development process included engagement with many different interest holders.

Results

There is widespread recognition that standardizing approaches to data stewardship requires a shift in mindsets and collective culture. It will also require a redistribution of power, but it is less clear if that is widely accepted or understood. There is broad agreement on a definition of data stewardship and a set of principles for data sharing. Together, these highlight, among other things: the need to consider (and define) public benefit; the duty to share; the need for transparency; attention to privacy and safety for both individuals as well as groups and communities; and a commitment to safeguarding and nurturing data for now and for the future. There is also a commitment to uphold principles of Indigenous data sovereignty, as those are defined by Indigenous Peoples.

