INDIGENOUS PRIMARY HEALTH CARE COUNCIL

INDIGENOUS DATA GOVERNANCE

DRAFT POLICY HANDBOOK

2023

Table of Contents

Introduction

The Data Governance policy handbook is being designed to support the implementation of the Indigenous Primary Health Care Council's (IPHCC's) Data Governance Framework. At maturity, it will be a resource to organizations positioned at either the national (i.e. 'macro'-), provincial/regional (i.e. 'meso'-), or local (i.e. 'micro'-) levels of governance and contain policies, procedures (where necessary), and tools to support the appropriate governance of Indigenous data. Individual policies will be designed to be customized and adopted as appropriate to ensure that Indigenous data sovereignty is upheld within organizations.

About the IPHCC's Data Governance Framework

The IPHCC's Data Governance Framework was created in 2022 and established a coherent set of principles, objectives, roles, and responsibilities to govern the data, stories, knowledge, and insights that Indigenous Primary Health Care Organizations (IPHCOs) collectively create, collect, hold, handle, and share. Through the framework, which continues to evolve, the IPHCC aims to support its members to collect, manage, and share information that supports evidence-informed decision-making and continuous quality improvement, tell individual and collective stories on behalf of the sector, and support advocacy for change that will improve health outcomes and wellness for Indigenous people and communities in Ontario.

Development process

This handbook outline was introduced in November 2023 to solicit feedback about the resource that, at maturity, will support the implementation of the IPHCC Data Governance Framework. It contains a list of suggested policies for inclusion and a summary of the content of each, and is intended to support discussions of content and positioning of the final resource.

How to use this handbook

This document will be designed to be reviewed by designated organizational representatives and implemented in collaboration with relevant parties responsible for ensuring overall compliance with their respective Indigenous data governance frameworks. Customizable text will be highlighted and is intended to be examined and tailored according to the specifics of each organization.

Implementation considerations and assumptions

Once developed, this handbook will be supported by the IPHCC's Data Privacy and Security handbook and Data Governance indicator framework, which were collectively designed to support implementation of its Data Governance Framework.

It is highly recommended that the review, adaptation and implementation of the policies that will be included take place in collaboration with Indigenous Elders and other representatives of communities, and with designates of organizational leadership and clinical staff.

It is assumed that organizations who will utilize this handbook have adopted an Indigenous data governance framework and associated data governance structure to support its implementation.

Limitations of this handbook

This outline contains suggested policies that are intended to support the implementation of appropriate Indigenous data governance frameworks that support Indigenous data sovereignty, which the IPHCC defines as the right of Indigenous communities to control how their stories are shared, ultimately supporting positive health outcomes for their members. It will be further developed based on the IPHCC's Data Governance Framework, and at maturity, should be reviewed carefully and adapted to the specific data governance policies and principles relevant to each organization that utilizes it.

Preliminary list of suggested policies for inclusion

The following list of suggested policies was adapted from existing resources[1] developed to support the implementation of Indigenous data governance initiatives and is intended to provide a starting point for discussion about the comprehensiveness and appropriate alignment of the data governance policy handbook.

Data Governance decision-making policy

Outlines the processes for making decisions required to support the organization's Data Governance framework, as well as guidelines for making decisions that may fall outside the listed scenarios identified during development of the policy.

Data flow policy

Outlines responsibilities related to documentation of the flow of data within a given organization. It will support overall organizational planning related to data and information and further the organization's understanding of how data is shared and who it is shared with.

Data asset inventory

Outlines roles and responsibilities related to maintaining a current listing of data held by the organization, and key characteristics of that data.

Data sensitivity classification policy

Summarizes a classification method for determining the sensitivity of different types of data held by a given organization, and recommended minimum safeguards to ensure its security.

Data quality policy

Outlines procedures, roles and responsibilities related to assessing and addressing data quality issues applicable to the organization's data holdings.

Data standards policy

Establishes a consistent set of requirements (i.e. 'data standards') for all types of data collected for and by the organization, and associated responsibilities of parties to develop and uphold them.

Change management policy

Identifies roles, responsibilities and a guideline for evaluating requests to make changes to data while upholding the organization's Indigenous data governance framework.

---

[1] British Columbia First Nations' Data Governance Initiative (2015). Data governance framework – Privacy and Security Manual. Accessed on November 15 from: *https://www.bcfndgi.com/data-governance/#framework*

Data sharing and/or linkage policy

Outlines a process and associated roles and responsibilities related to responsible linkage of the organization's data assets to externally held data.

Data awareness and training policy

Summarizes requirements and tools for training data users about the organization's data governance framework.

Research policy

Outlines processes, tools, roles and responsibilities related to participating in research initiatives.

Policy on validating job descriptions

Details how staff are informed about their responsibilities to uphold the organization's Indigenous data governance framework. Includes detailed roles and responsibilities and associated tools.

Data Governance monitoring policy

Outlines a process for monitoring the organization's overall compliance with its Indigenous data governance framework including roles and responsibilities of relevant parties.