



**NEWFOUNDLAND AND LABRADOR
INDIGENOUS ADMINISTRATIVE DATA
IDENTIFIER STANDARD**

**Department of Health and Community Services
Newfoundland and Labrador Centre for Health Information**

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DOCUMENT APPROVAL

The following signatures represent agreement and approval of the Newfoundland and Labrador Indigenous Administrative Data Identifier Standard described within this document.

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Acknowledgements

The contribution of each organization that participated in the development of this data Standard is gratefully acknowledged. Participants of the original working group shared a common understanding of the value of an Indigenous Administrative Data Identifier in achieving the vision of improving the health and well-being of Indigenous people in Newfoundland and Labrador.

The efforts of individuals within the Regional Health Authorities, along with Government of Newfoundland and Labrador departments and agencies who will enable the adoption of this data standard within key health information systems are also recognized with gratitude.

1. Introduction

1.1 Purpose

The need to identify the records of Indigenous persons within regional, provincial, territorial and national health information systems has been raised by various stakeholders for many years. Such an identifier would support health service planning, delivery, evaluation and research related to Indigenous health issues; the ultimate goal being to improve the health and well-being of Indigenous persons within Newfoundland and Labrador (Province).

In the absence of a means to specifically identify the records of Indigenous persons within health information systems such as hospital records, health surveys, and vital statistics records proxy methods have been used. These methods typically rely on postal or geographic codes to identify individuals from communities predominantly populated by Indigenous persons. These types of proxy identifiers are of value for some smaller communities but do not have the capacity to identify Indigenous persons living in urban centres, significantly limiting their usefulness.

In January 2010, a Provincial Aboriginal Administrative Data Identifier Working Group was formed with representatives from the following Indigenous communities and organizations:

- Miawpukek First Nation
- Mushuau Innu First Nation
- Nunatsiavut Government
- NunatuKavut Community Council
- Qalipu Mi'kmaq First Nation
- Sheshatshiu Innu First Nation
- Department of Health and Community Services
 - Aboriginal Health Liaison Division
 - Public Services and Administration-MCP
 - Policy Development and Legislative Affairs Division
- Intergovernmental and Aboriginal Secretariat
- Newfoundland and Labrador Centre for Health Information
 - Data Quality and Standards Division, Clinical Information Programs and Quality Department
 - Research and Evaluation Department
- Service NL
 - Vital Statistics Division
- Labrador-Grenfell Health Aboriginal Identifier Project

In keeping with common standards development practices, significant research was undertaken to determine if Indigenous Administrative Data Identifiers were already in existence and if an existing standard could be adapted to meet the needs of Newfoundland and Labrador (NL). In Canada, the term 'Indigenous' generally refers to three diverse groups: First Nations, Inuit and Métis. The self report identification questions used by Statistics Canada in various survey instruments and the British Columbia Government Standard for Aboriginal Administrative Data (v1.0 March 2007) provided the foundation for the NL Standard, and have been adapted to meet local needs.

The working group developed a method to identify the records of Indigenous persons within key provincial health information systems and an approach to support adoption of the identifier. Implementation of this data Standard will enable the records of Indigenous persons to be specifically identified, enabling users of data to more accurately plan, deliver, and measure the effectiveness of programs and services provided to Indigenous persons in Newfoundland and Labrador as well as monitor health outcomes.

1.2 Rationale

To achieve the greatest value from an Indigenous Administrative Data Identifier, a consistent method of identification of Indigenous persons should be used within the information systems used to support health care delivery and management of the health system. This document provides definition and guidance for implementation of the Standard.

Adoption of this Indigenous Administrative Identifier Data Standard within key health information systems ensures information collected is complete, comparable and useful for planning and reporting purposes. It will enhance inter-agency coordination of service planning, delivery, evaluation and research. The need for special surveys or access to specialized data sets will be significantly reduced or potentially eliminated over time.

A stakeholder survey conducted in 2010 identified the following potential uses for data containing such an identifier:

- Demographic analysis
- Health services utilization management
- Health services planning
- Health promotion and education
- Health services evaluation
- Health status indicator development and analysis
- Chronic disease surveillance
- Communicable disease surveillance
- Health research
- Health related funding requests
- Other uses (e.g. data quality, health human resource planning, etc)

Implementation of the Standard will enable the records of members of each specific Indigenous community within the Province to be identified within key health information systems, which is of great importance to the Indigenous communities themselves. In addition, the records can be mapped to the Statistics Canada groupings for national/provincial/territorial comparisons where applicable.

Similar questions are used by Statistics Canada to identify Indigenous groups in the Census and in other surveys, such as the Indigenous Peoples' Survey. These data sources can be used to supplement provincial data sources in which the Standard has been implemented.

While this section identifies anticipated uses of the Standard, all uses will in reality be restricted/prescribed by applicable governing legislation, as determined by the circumstances – *i.e.*, who is collecting the data and for what purpose, etc. See section 1.6 and 2.0 for further details.

1.3 Scope

The scope of this Standard is limited to defining the data required to provide consistency to Indigenous identification in provincial and regional health administrative data sources.

This Standard is not intended to limit the collection of data a regional health authority, government department or agency, Indigenous government or community may require to fully support regular business functions.

1.4 Ownership of this Standard

The Department of Health and Community Services (DHCS) is the owner of this Standard and as such is responsible for its ongoing maintenance and monitoring its use within health information systems. The Newfoundland and Labrador Centre for Health Information (NLCHI) will support the DHCS in fulfilling its responsibilities by managing the review and revision process and for ensuring the Standard is used appropriately within the health information systems for which it is custodian.

1.5 Guidelines for Review and Revision of this Standard

This Standard provides for alignment and consistency with federal initiatives, in particular those of Statistics Canada (Vital Statistics Council) and the Canadian Institute for Health Information (CIHI). The owner of the Standard will:

- monitor use of the Standard over time,
- monitor changes to census questions by Statistics Canada or to Indigenous identifiers used in databases managed by CIHI, and
- review, revise and re-issue this Standard as necessary to ensure ongoing relevance.

Future review and revision of this Standard will include engagement with Indigenous stakeholders, Regional Health Authorities, Government departments, agencies and others as appropriate.

1.6 Intended Users of this Standard

This Standard is intended for use primarily, but not exclusively, by Indigenous communities, DHCS, related agencies including NLCHI, and Regional Health Authorities responsible for the delivery of health services and programs. Organizations that monitor and measure health outcomes will also find the Indigenous Administrative Data Identifier valuable.

It is the responsibility of all users to collect, use and disclose this information in accordance with applicable legislation, regulations, policies and land claims agreements.

In the future, this Standard may be considered for use by other Departments or other programs and services within participating organizations. These situations will be identified as part of the regular review cycle and communicated by the owner of the Standard. At the time of writing, the scope of application of this standard is limited to use in health information systems and the public health system.

2. Legislative Background

As stated previously, uses of the Standard will be circumscribed by applicable, governing legislation, depending on who is collecting the data and for what purpose. It is the responsibility of the user of this Standard to ensure awareness of all applicable legislation, agreements, and policies. Potential impacting legislation includes, but is not limited to:

- The *Personal Information Protection and Electronic Documents Act, 2000* (PIPEDA), which requires private sector organizations to collect, use and disclose personal information legally, with consent, and for purposes that are stated and offer reasonable protection;
- The *Access to Information and Protection of Privacy Act, 2015* (ATIPPA), which ensures citizens have the information required to participate meaningfully in the democratic process; increases transparency in government and public bodies so that elected officials, officers and employees of public bodies remain accountable; and protects the privacy of individuals with respect to personal information about themselves held and used by public bodies;
- The *Personal Health Information Act* (PHIA), a health-sector specific privacy law that establishes rules for the collection, use and disclosure of personal health information that protect the confidentiality of that information and the privacy of individuals with respect to that information. PHIA sets out the rights of residents of the province regarding obtaining access to and exercising control of their personal health information. The *Act* also establishes mechanisms to ensure the accountability of persons having custody or control of personal health information and to safeguard the security and integrity of the personal health information in their custody or control;
- The *Regional Health Authorities Act*, which regulates the activities of the regional health authorities;
- The *Medical Care and Hospital Insurance Act*, which regulates the activities of MCP;
- The *Centre for Health Information Act*, which governs the activities of the Newfoundland and Labrador Centre for Health Information;
- The *Vital Statistics Act, 2009*, which governs activities related to vital events information in the province of Newfoundland and Labrador;
- The *Labrador Inuit Land Claims Agreement Act* and the Labrador Inuit Land Claims Agreement which set out the rights of Labrador Inuit respecting land ownership, co-management, resource sharing and self-government; and
- Other related statutes or agreements.

Data elements that form a part of this Standard could constitute either “personal information” under ATIPPA, “personal health information” under PHIA, or even “personal information” under the federal PIPEDA, depending on the circumstances of their collection. For example, if a collecting entity is a “custodian” under PHIA, and the data are being collected as part of a packet of “personal health information”, then that custodian may only collect, use, and disclose the data as permitted by

PHIA. Similarly, if the collecting entity is a “public body” under ATIPPA, then the public body may only collect, use, and disclose the data as permitted by ATIPPA.

3. The NL Indigenous Administrative Data Identifier Standard

This Standard focuses on the common data elements, data values and rules required to consistently identify the records of Indigenous persons within health information systems used in Newfoundland and Labrador.

Organizations require the flexibility to collect and structure data based on their services, business processes, method of soliciting client information, etc. Therefore this Standard does not restrict how the data is defined within specific databases (e.g. size, format, naming, or data model structure).

3.1 Guidelines for Using this Standard

Users may implement the data elements outlined in Section 3.2 according to their own data administration policies with the exception of the data element name, description, set of data values and data rules which must conform to this Standard.

Forms used to collect this information from individuals, and whenever possible implementers’ internal processing forms, should be designed to ensure the data meets the Standard as described in this document. It is recognized discrepancies (e.g. a response of “yes” and “no” to the same question) may be unavoidable particularly if the information is collected on a paper form. If the discrepancy cannot be resolved, data should be entered as it was provided and interpreted when it is used for reporting. Section 3.3 identifies a set of consistent reporting rules which address these potential discrepancies.

Individuals may change their response over time. It is up to each implementer to determine if it is necessary to keep a history of responses.

3.2 Required Data Elements

The following Indigenous administrative data must be collected for an individual in the following manner:

Data Element: Indigenous Identity Indicator

Description: Indicates if a person identifies as an Indigenous person.

Standard Question

- a) Do you identify yourself/your child as an Indigenous person?

NOTE: There will be situations where an adult may respond to this question on behalf of a child or other adult.

Standard Data Values

The information system must be able to store data that represents the following three values:

- Individual identifies as being an Indigenous person.

- Individual does not identify as being an Indigenous person.
- Individual's response to Indigenous identity question is either unknown or not provided.

Implementation

Field name: Indigenous Identity Indicator

List of values: YES, NO, blank (i.e. unknown or no value provided)

Default value: blank

Standard Data Rules

One and only one value can be chosen. For example an individual can identify as an Indigenous person or as a non-Indigenous person, but not both.

Data Element: Indigenous Group Membership/Beneficiary Indicator

Description: The specific Indigenous group, self-government or land claim agreement of which a person is a member or beneficiary.

Standard Questions

- a) Are you a member/beneficiary of the:
- Labrador Inuit Land Claims Agreement?
 - Miawpukek First Nation?
 - Mi'kmaq First Nation Assembly of Newfoundland?
 - Mushuau Innu First Nation?
 - NunatuKavut Community Council?
 - Qalipu Mi'kmaq First Nation?
 - Sheshatshiu Innu First Nation?
 - Indigenous community, but none of the above?

Definition/Standard Data Values

The information system must be able to store data that represents the following values:

- Individual identifies as a beneficiary of the Labrador Inuit Land Claims Agreement.
- Individual's response to Labrador Inuit Land Claims Agreement beneficiary identity is either unknown or not provided.

- Individual identifies as a member of the Miawpukek First Nation.
- Individual's response to Miawpukek First Nation is either unknown or not provided.

- Individual identifies as a member of the Mi'kmaq First Nation Assembly of Newfoundland.
- Individual's response to Mi'kmaq First Nation Assembly of Newfoundland is either unknown or not provided.

- Individual identifies as a member of the Mushuau Innu First Nation.
- Individual's response to Mushuau Innu First Nation is either unknown or not provided.

- Individual identifies as a member of NunatuKavut Community Council.
- Individual's response to NunatuKavut Community Council is either unknown or not provided.

- Individual identifies as a member of the Qalipu Mi'kmaq First Nation.
- Individual's response to Qalipu Mi'kmaq First Nation is either unknown or not provided.

- Individual identifies as a member of the Sheshatshiu Innu First Nation.
- Individual's response to Sheshatshiu Innu First Nation is either unknown or not provided.

- Individual identifies as a member or beneficiary of an Indigenous group, self-government or land claim agreement of another type other than those listed above. E.g. an Indigenous group from another province/territory.
- Individual's response to 'Indigenous community, but none of the above' is either unknown or not provided.

Implementation

Field name: Indigenous Group Membership/Beneficiary

List of valid value code and description:

- 01 Labrador Inuit Land Claims Agreement
- 02 Miawpukek First Nation
- 03 Mi'kmaq First Nation Assembly of Newfoundland
- 04 Mushuau Innu First Nation
- 05 NunatuKavut Community Council
- 06 Qalipu Mi'kmaq First Nation
- 07 Sheshatshiu Innu First Nation
- 80 Indigenous, but none of the above groups
- 90 Unknown or not provided (default)

Standard Data Rules

An individual cannot be assigned to more than one group, self-government or land claim agreement at any one point in time. It is recognized that the group, self-government or land claim agreement to which a person may affiliate may change over time.

An individual may identify as an Indigenous person but not specify the group with which he/she is a member or beneficiary. The number of people who may do so is expected to be very small and will not limit a person's access to health services.

An individual may not identify as an Indigenous person but specify the group with which he/she is a member or beneficiary. The number of people who may do so is expected to be very small and will not limit a person's access to health services.

3.3 Reporting Rules

The following rules identify how to handle discrepancies in the data should they appear and require interpretation.

1. Count an individual as Indigenous if:

Individual identifies as an Indigenous person (e.g. Indigenous identity indicator = yes) but does not identify as one of the following:

- 01 Labrador Inuit Land Claims Agreement

- 02 Miawpukek First Nation
- 03 Mi'kmaq First Nation Assembly of Newfoundland
- 04 Mushuau Innu First Nation
- 05 NunatuKavut Community Council
- 06 Qalipu Mi'kmaq First Nation
- 07 Sheshatshiu Innu First Nation
- 80 Indigenous, but none of the above groups

2. Count an individual as Indigenous if:

Individual does not identify as an Indigenous person (e.g. Indigenous identity indicator = no) but does identify as one of the following:

- 01 Labrador Inuit Land Claims Agreement
- 02 Miawpukek First Nation
- 03 Mi'kmaq First Nation Assembly of Newfoundland
- 04 Mushuau Innu First Nation
- 05 NunatuKavut Community Council
- 06 Qalipu Mi'kmaq First Nation
- 07 Sheshatshiu Innu First Nation
- 80 Indigenous, but none of the above groups

4. Implementation Plan

4.1 Health Information Systems of Interest

The majority of information needs identified by stakeholders to date would be met if the following provincial and regional health information systems contained the Indigenous Administrative Data Identifier:

- MCP (particularly the Beneficiary Registry)
- NLCHI Live Birth System
- NLCHI Mortality System (including stillbirths)
- NLCHI Health Data Management System (e.g. inpatient, day surgery, rehab data)
- Provincial Cancer Registries
- Regional Meditech Systems
- Client and Referral Management System

There are many other provincial and regional systems that would also benefit from having such an identifier but the scope of use or the level of priority is less than the ones noted above. There are also many national surveys/files that would benefit from the addition of an Indigenous Administrative Data Identifier but the content of these are not within local control to the same degree and will not be a priority for implementation.

4.2 Implementation Approach

Various approaches to adoption of the Standard can be taken such as:

1. Incorporate collection of the data at source for EACH system.
2. Collect the data once and through linkage files, import the identifier into other databases where feasible.
3. Collect data more than once only where data linkage/import is not possible or an organization has a specific need.

Each approach has implications for cost, effort, complexity and timeliness of implementation.

In an effort to implement the Standard in the most cost effective and efficient manner, the preference is to collect the information through the MCP application, renewal and update processes by including the self-report questions on the forms. This process would take approximately five years to complete. The information will be shared electronically through the provincial Client Registry. By storing the information in the Client Registry, it can be further shared with the key information systems of the regional health authorities (Meditech and CRMS) and linked to the provincial electronic health record and health datasets managed by NLCHI on behalf of the Province, supported by appropriate data sharing agreements. Through additional data linkage initiatives, the information could also be added to other important provincial health datasets managed by other organizations e.g. the Provincial Cancer Registries managed by Eastern Health.

It is anticipated the implementation through the MCP processes will meet the majority of needs of potential users of this information. Only when linkage/import is not feasible should separate data collection processes be pursued. Any other data collection processes in NL that require Indigenous identity data should also follow the direction of this Standard. E.g. an approved research questionnaire.

As data collection proceeds, the existing member/beneficiary registration information held by the Indigenous groups may be shared with NLCHI for quality assurance purposes only.

As implementation planning and adoption proceed, changes to this approach may be required to address technical or business/workflow challenges. Flexibility will be required in the approach taken as each information system may pose different technical and resource challenges.

An advisory group has been formed to support the DHCS and NLCHI regarding maintenance and implementation of the Provincial Indigenous Administrative Data Identifier within key provincial health information systems. The following organizations are engaged in this advisory capacity:

- Miawpukek First Nation
- Mi'kmaq First Nation Assembly of Newfoundland
- Mushuau Innu First Nation
- NunatuKavut Community Council
- Nunatsiavut Government
- Qalipu Mi'kmaq First Nation
- Sheshatshiu Innu First Nation
- Labrador-Grenfell Health
- Eastern Health

- Department of Health and Community Services, including MCP
- Intergovernmental and Indigenous Affairs Secretariat
- Service NL (Vital Statistics division)
- Newfoundland and Labrador Centre for Health Information

5. References

Government of British Columbia: British Columbia Government Standard for Indigenous Administrative Data, 2007.

Statistics Canada: How Statistics Canada Identifies Aboriginal Peoples, 2007

Questions regarding this Standard can be directed to:

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