Measuring Cultural Safety in Health Systems: Lessons Learned From Providence Health Care in British Columbia

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A partnership between Providence Health Care in British Columbia and the Canadian Institute for Health Information (CIHI). Report co-developed by Laurel Lemchuk-Favel, Harmony Johnson sɛƛakəs and CIHI.

Note: The recommendations described in this document will evolve over time based on ongoing engagement, feedback from users and continued learning about wise practices in measuring cultural safety.

Executive summary

Racism and discrimination against Indigenous Peoples in Canada's health systems are widespread and lead to traumatic experiences and poor outcomes, including preventable deaths.[1–9] Despite the serious consequences, there is little data to bring attention to this issue, nor are there pan-Canadian measurement guidelines or standards that have been designed to facilitate comparisons, monitor progress and support change. Measuring cultural safety and anti-Indigenous racism in health systems and institutions can help drive improvements, address systemic racism and improve health outcomes. This work is successful when done in partnership with Indigenous Peoples.

In 2021–2022, Providence Health Care in Vancouver, British Columbia, completed a demonstration project to advance the measurement of cultural safety. The goal of the project was to identify a suite of indicators to measure cultural safety and address anti-Indigenous racism within Providence Health Care's services.

The project highlighted that the measurement of cultural safety must be grounded in Indigenous data sovereignty through Indigenous data governance. Indigenous data governance provides mechanisms for ensuring Indigenous Peoples' rights and interests are reflected in policies and practices when working with Indigenous data. This can include informed organizational data management processes, an advisory council, data-sharing agreement(s), policies and mechanisms for Indigenous Peoples' decision-making. It requires engagement with Indigenous rights holders throughout.

The measurement of cultural safety requires a process for collecting information about Indigenous identity. To date, this information has primarily been collected through informed self-identification processes. For self-identification to feel safe to Indigenous persons, the organization needs to build trust and confidence through many supportive interventions (e.g., physical space design, signage, training for those posing self-identification questions).

Finally, indicators for the measurement of cultural safety need to be selected, developed and monitored over time. The core of this process involves co-development of indicators with Indigenous Peoples.

This report provides context and lessons learned from Providence Health Care in B.C. It is based on the experiences of 1 organization at a given point in time and is unique to its context. The information is primarily intended to support other health service organizations and health authorities in their journey toward eliminating anti-Indigenous racism in Canada's health systems. It will also inform CIHI's work in developing a core set of cultural safety indicators in partnership with Indigenous Peoples.

Introduction

In 2021, CIHI released *Measuring Cultural Safety in Health Systems*, a discussion paper that includes a framework and list of potential indicators to measure cultural safety in health systems. The paper was based on the work of Harmony Johnson sɛ�akəs (tiskwat/Nohotout Consulting). In 2021–2022, Providence Health Care in Vancouver, British Columbia, with support from CIHI, completed a demonstration project to implement cultural safety measurement.

The objectives of the project were as follows:

1. Introduce Indigenous data sovereignty principles and processes to the organization's data governance;
2. Review existing processes to collect Indigenous identity information across services and develop recommendations to improve and harmonize them; and
3. Identify a suite of cultural safety indicators to measure progress and accountability toward addressing anti-Indigenous racism within the organization.

This document outlines considerations and lessons learned from the project in these 3 areas. The information is primarily intended to support other health service organizations and health authorities working to address anti-Indigenous racism.

Racism and discrimination in health systems

The tragic death of Joyce Echaquan, who was subject to racist abuse in a hospital, and the death of Brian Sinclair while waiting for care have brought attention to racism experienced by Indigenous Peoples in health systems. In November 2020, B.C. released a report[i] that found widespread systemic racism against Indigenous Peoples in health systems with a range of negative impacts, including death.[2] With respect to the implementation of the report's recommendations, Indigenous Peoples shared a clear and consistent message — *while those who experience racism must be involved in developing and evaluating solutions, the primary responsibility and burden of this work lies with non-Indigenous individuals, organizations and governments*.[10] The report also found that there were no accountability mechanisms for eliminating Indigenous-specific racism in the B.C. health care system. It identified a need for indicators to measure and monitor progress toward the provision of culturally safe care.

Indigenous Peoples: In this document, the term "Indigenous" is used in reference to individuals of First Nations, Métis and Inuit ancestry. CIHI recognizes that First Nations, Métis and Inuit are diverse and are each distinct, rights-bearing peoples, and commits to a distinctions-based approach to ensure that the unique rights, interests and circumstances of these 3 distinct groups are acknowledged, affirmed and implemented.

Anti-Indigenous racism: This is defined as the ongoing race-based discrimination, negative stereotyping and injustice experienced by Indigenous Peoples in Canada.[11]

Cultural safety: This is ultimately defined by the patient experiencing care — care is safe when it is experienced as respectful and safe, without discrimination or racism.[12]

Organizational readiness

Before jumping to the development of indicators or to the collection of data, a level of organizational capacity in cultural safety is necessary to prevent harm. This capacity can include formal commitments at the board and executive levels, education and training at all levels, action plans, supportive human resources policies, and respectful engagement with Indigenous subject matter experts, Knowledge Holders, representatives and rights holders. An organizational readiness assessment (see Appendix C) can help to determine whether the timing is right to initiate discussions about data related to the care experiences of Indigenous Peoples.

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i.   The *In Plain Sight* report reflects the voices of 2,780 Indigenous people and 5,440 health care workers, and data from about 200,000 First Nations, Inuit and Métis individuals. Its findings bring visibility to the problems of widespread and systemic racism against Indigenous Peoples in the B.C. health care system and resonate across Canada.

1. Indigenous data governance: A prerequisite

Indigenous data sovereignty and Indigenous data governance

A key prerequisite for cultural safety measurement is the co-development of respectful data governance processes, policies and protocols. These provide the foundation for working safely and respectfully with Indigenous data. The application of Indigenous data sovereignty principles in health systems is an emerging area and unique challenge for both Indigenous Peoples who seek to reclaim and use data, and health organizations that hold their data. The considerations provided here are an attempt to respect Indigenous data sovereignty while also adhering to legislative and privacy requirements pertaining to personal health information; and furthermore, to provide a mechanism to support Indigenous Peoples to access data and information on their populations.

Indigenous data sovereignty recognizes the fundamental rights of Indigenous Peoples to self-determination, including the right to govern, control and exercise authority over their data, information and knowledge, irrespective of where it is held. It is linked with Indigenous Peoples' right to maintain, control, protect and develop their cultural heritage, Traditional Knowledge and traditional cultural expressions, as well as their right to maintain, control, protect and develop their intellectual property over these.[13]

Indigenous data governance enacts data sovereignty, providing mechanisms for ensuring that Indigenous Peoples' rights and interests are reflected in policies and practices. It includes the protocols and procedures necessary for the respectful collection and use of Indigenous data.[14, 15]

Fundamental to Indigenous data sovereignty and governance is the right of Indigenous Peoples to be in control of the information collected on and about them. Indigenous data governance is directly associated with increased self-determination and assertion of inherent rights for First Nations, Inuit and Métis Peoples.[16] The right to self-determination is enshrined in the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP),[17] and affirmed in B.C.[18] (2019) and federal (2021) legislation as the framework or road map for reconciliation. In addition, B.C.'s *Anti-Racism Data Act* (2022) sets out a framework for the collection, use and disclosure of data. The act includes provisions for the development of a data governance model with Indigenous institutions and governments in support of self-determination and sovereignty.[19]

Indigenous Peoples recognize the power of data to inform and enhance well-being. Indigenous data governance is at the foundation of efforts among Indigenous Peoples to ensure the appropriate and respectful use of their data. The misuse of Indigenous data and information has resulted in harms and mistrust among Indigenous Peoples and communities.[20, 21] Accordingly, a key prerequisite in measuring cultural safety in health systems is the co-development of respectful Indigenous data governance processes, policies and protocols. Expressions of Indigenous data sovereignty are found in a number of guiding principles and frameworks. In Canada, these include OCAP®, OCAS and AOC. Appendix A includes details and other frameworks.

Engagement for Indigenous data governance

Given the constitutionally protected and inherent collective rights of Indigenous Peoples, consideration must be given to identifying and engaging with rights holders and representative authorities. In the health care context, where people from many different communities receive care at urban facilities, identifying those who can speak on behalf of Indigenous Peoples is necessarily complex and requires a depth of engagement and relationship building that takes time and patience. It usually makes sense to start with local Indigenous communities and organizations and representatives of the nation(s) on whose land your health care facility sits.

Engagement related to Indigenous data governance may also include Indigenous patients, caregivers, community representatives, organizations, health professionals and others. Early engagement activities can inform the creation of a governance structure that creates space for respectful protocols for working with Indigenous Peoples' data, relationship building and dialogue on shared interests.

Data governance mechanisms

A variety of practical mechanisms can be adopted to address and formalize Indigenous data governance. Some examples, which may be used in combination or with others, include the following:

Data-sharing agreement

A data-sharing agreement or similar agreement between Indigenous rights holders and a health service organization can be a particularly effective tool that articulates a shared commitment to Indigenous data sovereignty. It helps provide transparency across a range of sometimes complex considerations. The process of negotiating and signing the agreement can also be important to relationship building. Key elements of a data-sharing agreement are provided in Appendix B, and other tools and resources are provided in Appendix C.

Indigenous data governance committee

A data governance committee or similar body can serve as a focal point for guidance on issues related to Indigenous data, such oversight of data collection, indicators, data analysis, interpretation and data release. A group of this sort can help to ensure the involvement of and accountability to Indigenous Peoples. Depending on available resources and expertise, it may be appropriate to build the functions into an existing committee or as part of a partnership table.

Policies

Organizational policies or protocols aligned with Indigenous data sovereignty principles can also help ensure transparency and consistency and can address a range of considerations, similar to those covered in a data-sharing agreement. As an example, CIHI implemented a policy in 2020 that requires approval from First Nations, Inuit and Métis authorities before the release or reporting of any data that can identify Indigenous persons or communities.

Program or office

A program or office responsible for providing Indigenous-specific services and/or engaging with Indigenous patients and communities can help provide some of the resources required to manage Indigenous data governance processes. While an Indigenous office is important, aligning organizational practices with Indigenous data sovereignty requires the involvement and commitment of people from across the organization and strong support from leadership. At Providence Health Care, the Indigenous Wellness & Reconciliation (IWR) office is responsible for liaising with Indigenous rights holders.

Key data governance functions

Irrespective of the process or mechanism used to apply Indigenous data governance (e.g., data-sharing agreement, committee, policy), key functions should at minimum include the following:

1. Ability to articulate and apply Indigenous data sovereignty principles and governance frameworks for the Indigenous-specific and/or identifiable data that the organization holds; and

2. Development and oversight of Indigenous data governance policies, procedures, systems, practices and standards across the data life cycle of the organization.

   • The data life cycle includes data collection and stewardship, data processing, data analysis and interpretation, data dissemination and data storage/destruction — a detailed guide to assist thinking this through in more detail is included in Appendix D.

Some examples include

- Methods for collecting Indigenous identity data and the application of standards across the organization;

- Guidance on stewardship of the Indigenous data, including roles of individuals involved and the policies around the data and its usage;

- Processes in place to manage the data and its quality;

- Guidance on selecting, reviewing and reporting on data, analysis and indicators of cultural safety;

- Context, interpretation and messaging related to the release and reporting of Indigenous data;

- Privacy of individuals and communities; and

- Processes and policies on the storage and destruction of the data, including management of the privacy and security of the data.

For more details on data governance practices that health organizations or networks can use to generate greater value from health data and information, see *CIHI's Health Data and Information Governance and Capability Framework*.

2. Collecting Indigenous-identifiable data

Measuring and reporting on certain cultural safety indicators requires identifying Indigenous patients in the data. Race-based and Indigenous identity data is vital for the identification and monitoring of health inequalities that stem from racism, bias and discrimination. It can also inform interventions to improve equity in health care access, quality, experience and outcomes.[22] Currently, data collection on race, ethnicity and Indigenous identity is limited in health care systems and, where data is available, the way it is collected often varies. Some examples of identification of Indigenous Peoples in health systems include the following: patient self-identification, identification using the health card, linkage with Indigenous registries or lists, and geographical identifiers.

Patient self-identification

The patient provides the information at the point of care, typically through an intake or registration form, with an information or health care professional (e.g., clerk, nurse). In each of these cases, it is essential that there are processes in place to ensure that identifiers are collected in ways that are safe and respectful and do not cause harm (e.g., staff education and training, patient and public supports).

CIHI's *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada* provides information for those organizations looking to collect data using self-identification methods. The standard is a distinctions-based question, for comparability across the country. Additional local questions or customization may also be helpful.

Learnings from Providence

At Providence Health Care, Indigenous identity data is collected through self-identification at registration. Sometimes, patients self-identify at other points during their stay.

Focus groups were held with the registration clerks and with the IWR patient liaisons to understand the process of self-identification. The focus groups provided a practical lens on the process of registering patients and receiving consults for liaison services. They also were valuable in understanding the challenges and limitations in these processes and what has been working well. When asked about improvements to the existing self-identification process, clerks recommended the following:

- Provide key messages so clerks can share why patients are being asked to self-identify.

- Minimize the number of self-identification questions.

- Improve communications about services available to Indigenous Peoples.

- Consider other opportunities in the patient care journey to ask self-identification questions. The bedside may present a calmer, stable environment for sensitive inquiries. The patient no longer needs to worry about being seen, they are in a relatively private location and their overall anxiety may be lessened, making them feel more comfortable answering these questions.

- Develop mandatory training for all clerks and their managers, so that all staff are trained on the self-identification process.

Other identification methods

While Providence's approach was based on patient self-identification, elsewhere Indigenous identity has been integrated into the health card renewal process or established through linkages with Indigenous registries or citizenship/membership lists. In some cases, geographical information has also been used.

Health card

In this scenario, a province or territory collects Indigenous identity information when people apply for or renew their provincial/territorial health cards. The collection of identity through the health card is provincially/territorially managed, with the necessary infrastructure and privacy protections.

This approach reduces potential discomfort from self-identifying and risks of discrimination related to self-identification at the point of care. At the same time, by not self-identifying, opportunities to provide tailored services and supports may be missed.

Linkage with Indigenous registries or lists

In some provinces, existing membership lists, citizenship lists or registries, such as the [B.C. First Nations Client File](#), are linked to administrative health records for analytical purposes. Agreements, governance and privacy provisions are negotiated to manage and safeguard the use of the linked file.

As with the health card, the linkage approach reduces risks related to self-identification and can offer a more inclusive data set for analysis. It also has the benefit of identifying a population that may have access to specific rights and programs and for whom there may be discrete political representation.

Geographical identifiers

Sometimes geographical identifiers (such as postal codes or census subdivisions) are used to identify patients from Indigenous communities or areas where the proportion of Indigenous Peoples is high (often based on a certain percentage cut-off). For example, Bougie et al. used this approach, selecting dissemination areas in the 2006 Census where First Nations persons made up at least 33% of the population.[23]

This approach has limitations in that the areas typically include (sometimes a significant number or proportion of) non-Indigenous individuals. The areas also typically exclude Indigenous Peoples living in urban areas, representing more than half of all Indigenous Peoples in Canada.

3. Steps for selecting useful and meaningful indicators to measure cultural safety

There are several potential indicators that can be used to help measure cultural safety, such as those listed in the addendum to CIHI's discussion paper. For practical and strategic reasons, one generally needs to identify and then measure a short, focused list. Providence Health Care worked through a process to define and identify its indicator list, outlined below.

Figure 1   The indicator selection process

Scope indicators ▶ Select indicators ▶ Finalize indicator definitions ▶ Measure progress over time and assess continued relevancy

Indigenous engagement and data governance
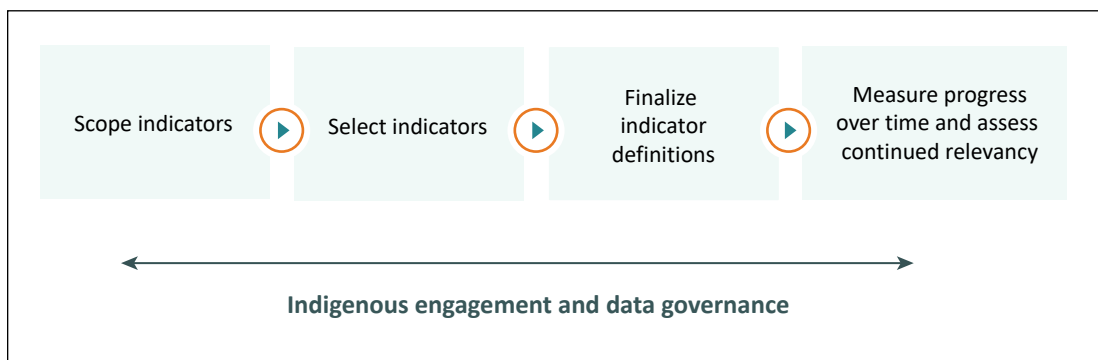
Cultural safety is, ultimately, defined by the patient experiencing care. Care is safe when it is experienced as respectful and safe, without discrimination or racism.[12] Recognizing that no indicator or set of indicators can adequately reflect (the lack of) cultural safety, a thoughtful indicator selection process can still help to identify and understand gaps, monitor progress and help drive improvements.
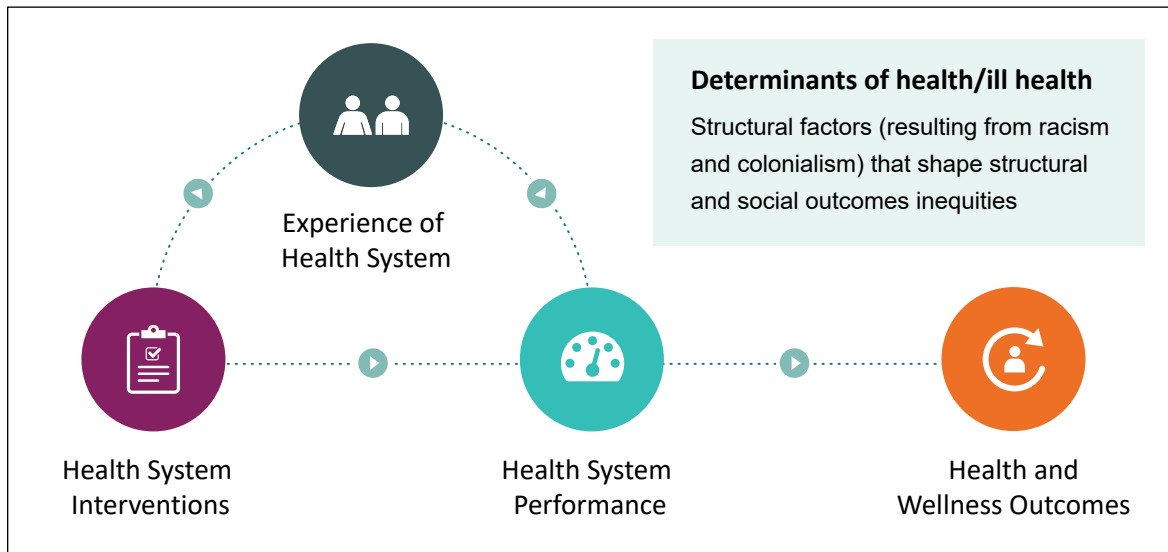
Engagement

Engagement with Indigenous Peoples is essential throughout the indicator selection process. These partners may include Indigenous rights holders, authorities, organizations, health care professionals, patients and academics, among others.

Step 1: Scope indicators

During this initial scoping phase of the process, potentially useful indicators or measures are identified. A framework on health system measurement, such as CIHI's *Measuring Cultural Safety in Health Systems*, can help ensure a comprehensive approach. CIHI's framework suggests that cultural safety interventions contribute to culturally safe experiences, which in turn lead to improved system performance and outcomes, all of which are influenced by broader determinants.[24] The framework includes 4 categories: Health System Interventions, Experience of Health System, Health System Performance, and Health and Wellness Outcomes. There are several themes captured under each category. These have been used to categorize and evaluate potential cultural safety indicators.

Figure 2   Framework for Measuring Cultural Safety in Health Systems

Experience of Health System

Determinants of health/ill health
Structural factors (resulting from racism and colonialism) that shape structural and social outcomes inequities

Health System Interventions

Health System Performance

Health and Wellness Outcomes

A wide range of frameworks and resources can help during the indicator scoping period. Appendix C provides a suite of tools and resources.

Some other important steps during the scoping process can include

- Brainstorming, reviewing other lists and compiling an initial list of prospective indicators for consideration;
- Assessing alignment of the indicators within your chosen framework and identifying data gaps;
- Engaging with key partners and stakeholders on the topics for consideration (e.g., local Indigenous organizations, patients, health professionals, federal/provincial/territorial/ regional/local health authorities);
- Determining the quality and availability of the data available for each potential indicator; and
- Determining your methods for identifying Indigenous patients in the data and associated limitations for indicators that require Indigenous identity information.

Step 2: Select indicators

The next step involves refining the indicator list. The process can include the following activities:

- Define a process to select, evaluate and reduce the identified indicators to a short-list.
  - This can involve filtering indicators based on a defined set of criteria (see examples below), considering what other organizations are using and gathering feedback from key partners and stakeholders.

Indicator selection

The indicator selection process may include a review of the indicators based on certain criteria and an engagement process with internal team members, key experts, rights holders and Indigenous authorities, Indigenous patients and other groups to arrive at a consensus for a finalized set of indicators.

Criteria may include the following:

Relevance: Degree to which the indicator is relevant to health organizations/systems when advancing equity and cultural safety in the Indigenous patient population

- Is the indicator inequitable between Indigenous and non-Indigenous patients? If so, could lack of cultural safety be a reason?

Impact: Degree to which the indicator is a bellwether or sentinel in the health care system, in that it can drive activities that lead to change

- Are we able to use the findings from the indicator to change how we deliver care?

Useability: Degree to which the indicator is actionable in the organization (i.e., do we have the statistical volumes and technical ability for the indicator to be feasible?)

- Are there other considerations that would limit an indicator's feasibility for Indigenous patients?

A Likert scale (1 to 5, from not relevant to extremely relevant, etc.) could be used to evaluate each indicator. An option to select not applicable can also be provided for those reviewers who do not have the knowledge to review an indicator's criterion.

- Validate the indicator short-list internally with senior levels of the organization, and externally with Indigenous partners, patients and rights holders through your established engagement mechanisms.
- Evaluate data gaps in the short-list and determine where new data collection methods might be required.

Learnings from Providence

At Providence, the following key phases were involved in the indicator selection process:

1. Internal consultation: Internal teams and departments were engaged for data sources, indicators and indicator definitions.

2. Regular reporting: Indicators already reported at management and board levels were examined for relevance to Indigenous cultural safety.

3. Alignment: Potential indicators were aligned with the domains in CIHI's [framework for measuring cultural safety](). Where gaps were identified, aspirational indicators were identified.

4. Indigenous data: The potential for Indigenous-specific indicators considered whether Indigenous data was already reported (separately), Indigenous data could be reported or Indigenous data was not available.

5. Selection and evaluation of indicators: Each indicator on the initial lists was reviewed and scored by internal teams. Assessment criteria were based on relevance, impact, useability, clarity, interpretability and reliability as well as availability of Indigenous identity information. Individual reviewers could skip a score if unsure. Indicators were short-listed based on minimum score cut-offs and availability of data.

Step 3: Finalize indicator definitions

After confirming the indicator list and the indicators selected to measure cultural safety, the next step will include refining and finalizing indicator definitions and their sources. This can involve the following:

- Developing working groups to refine indicators with key experts (e.g., internal team members, health care professionals, Indigenous patients, federal/provincial/territorial/local health authorities, rights holders, Indigenous authorities);

- Defining the specific criteria (inclusion/exclusion) for the indicators under selection (e.g., population, data adjustments, standardization);

- Identifying data quality issues with the indicators (e.g., small cell sizes, limitations of Indigenous identifiers) and where reporting might not be feasible; and

- Determining specific sources for the data.

Learnings from Providence

At Providence Health Care, there were a few important considerations related to the indicators selected and their methodology:

CIHI's framework on health system performance and health outcome indicators includes those that are population based. Single stand-alone institutions cannot evaluate health system performance on a population basis; therefore, indicators in this project had to be either admission-based or adaptable to using admissions as a denominator in rate calculations.

Considering that Indigenous patients will typically represent less than 10% of hospital admissions in urban environments, it is vital that as many of these patients as possible are identifiable in data sets. Hospitals that serve small numbers of Indigenous patients may need to aggregate data with data from other small hospitals or combine data over multiple years, particularly for statistical comparisons with non-Indigenous patients.

Some indicators may simply not have sufficient data for statistical rigour, even in larger hospitals. In some cases, statistical processes and constructs for small populations may need to be integrated into the hospital's analytical approach. As an example, some Indigenous cultural safety indicators may not have sufficient data for age standardization necessary to compare with non-Indigenous data, but crude rates might be reported or reporting might be restricted to age groups with sufficient data. Other options include using multi-year analyses and/or rolling averages.

Data from electronic medical records does not lend itself to strength-based health and wellness indicators. In this work, the emphasis on empowerment, equity, reciprocity and respect in the Experience of Health System indicator category has served to counterbalance the deficit orientation in the Health System Performance and Health and Wellness Outcomes indicator categories.

Step 4: Measure progress over time and assess continued relevancy

During this step in the process, the organization has selected its indicators to measure progress and performance related to cultural safety.

Some important considerations during this step include

- Piloting and testing the selected indicators (especially indicators that require new data collection);

- Working closely with your established engagement process and Indigenous data governance mechanism to ensure the data is managed safely and respectfully;

- Determining your reporting and communication plan (with key partners, patients, rights holders, etc.);

- Contextualizing the information to support the development of respectful and accurate narratives when preparing the data for dissemination (see Data analysis and interpretation);

- Ensuring the privacy and confidentiality of individuals and communities; and

- Measuring progress and implementing changes as required to address cultural safety within your organization.

A plan to evaluate the progress and continued relevancy of the chosen indicators is useful to ensure that they are meeting user needs and supporting improvements in care and culturally safe health systems.

Learnings from Providence

At the time of writing, the selection process is set to continue, informed by external engagement with nations, Indigenous patients and key partner organizations such as those delivering care within the geographic region where Providence operates.

Conclusion

Anti-Indigenous racism in Canada's health care systems is widespread and results in traumatic experiences and negative health outcomes, including preventable deaths like those of Joyce Echaquan and Brian Sinclair.[1–9] Despite the serious consequences, there is little data to bring attention to the issue or hold health systems accountable. The measurement of cultural safety can drive improvements in health systems when done in partnership with Indigenous Peoples.

This report provides context and lessons learned from Providence Health Care in B.C. and its experience measuring cultural safety. This is the experience of 1 organization at a given point in time and is unique to its geographic context. It describes reflections and learnings in selecting and measuring indicators of cultural safety. Key learnings about the measurement of cultural safety in this health service organization include the following:

1. Respectful Indigenous data governance processes and protocols are a prerequisite. Indigenous rights holders must be engaged and lead the decision-making along the way.
2. Safe, consistent methods for collecting Indigenous identity information (or another appropriate way to identify Indigenous patients) is vital.
3. Thoughtful criteria, processes and engagement are needed to select the most helpful and appropriate indicators.

Advancing the measurement of cultural safety in health organizations is an important component of the collective work to address anti-Indigenous racism in health care systems.

Feedback

CIHI is committed to supporting the health and well-being and data priorities of First Nations, Inuit and Métis Peoples. This includes work to support the measurement of cultural safety across health systems. We recognize that this is an evolving area, that we are all learning and that each context is different. In that spirit, we welcome your feedback on this paper and your advice on advancing the work of cultural safety measurement.

Please email us at IndigenousHealth@cihi.ca.

Appendices

Appendix A: Indigenous data sovereignty principles

OCAP® principles

The First Nations principles of ownership, control, access and possession — more commonly known as OCAP® — assert that First Nations have control over data collection processes, and that they own and control how this information can be used. These principles, created and stewarded by the First Nations Information Governance Centre, were established in response to the historical and continuing misuse and misappropriation of First Nations data and intellectual property.[25]

OCAS principles (Manitoba Métis Federation)

The Manitoba Métis Federation adapted OCAP® into OCAS principles, substituting stewardship instead of possession for the last principle. These principles speak to issues of responsible planning and management of resources.[26] However, in B.C., Métis Nation British Columbia has temporarily adopted the OCAP® principles for its own data governance, until Métis-specific principles are developed.

Inuit Qaujimajatuqangit

Inuit Qaujimajatuqangit is a body of knowledge that encompasses Inuit world views and is guided by a series of principles that form a foundation for relationships with non-Inuit.[27] It is meant to capture local and community-based knowledge, as well as ecological knowledge (both traditional and contemporary) that is rooted in the daily life of Inuit.[28]

AOC (Inuit Tapiriit Kanatami)

The National Inuit Strategy on Research affirms principles of access, ownership and control (AOC) over data and information.[29]

Table A1   Examples of Indigenous data sovereignty principles
that have been identified in Canada and internationally

Indigenous data sovereignty principles	Source
Ownership, control, access and possession (OCAP®) principles[25]	First Nations Information Governance Centre
Ownership, control, access and stewardship (OCAS)[26]	Manitoba Métis Federation
Principles describing Inuit world views, which form a foundation for relationships with non-Inuit[27]	Inuit Qaujimajatuqangit
National Inuit Strategy on Research includes principles ensuring access, ownership and control over data and information[29]	Inuit Tapiriit Kanatami
Application of OCAP® principles[30]	British Columbia First Nations' Data Governance Initiative Framework
CARE principles: Collective benefit, authority to control, responsibility and ethics[31]	Global Indigenous Data Alliance
Checklist when reporting health research involving Indigenous Peoples: governance, prioritization, relationships, methodologies, participation, capacity, analysis and interpretation, and dissemination[32]	The CONSIDER statement
SEEDS principles: self-determination, exercise of sovereignty, adherence to ethical protocols, respect for data stewardship and governance, and support for reconciliation[33]	International Population Data Linkage Network
Māori principles of data sovereignty: authority (control, jurisdiction, self-determination); relationships (context, data disaggregation, future use); obligations (balancing rights, accountabilities); collective benefit (capacity, connect); reciprocity (respect, consent); and guardianship (ethics, restrictions)[34]	Te Mana Raraunga
Exercise control of the data ecosystem; data that is contextual and disaggregated; data that is relevant and empowers sustainable self-determination and effective self-governance; data structures that are accountable to Indigenous Peoples and First Nations; data that is protective and respects individual and collective interests[35]	Maiam nayri Wingara Aboriginal and Torres Strait Islander Data Sovereignty Collective

Appendix B: Data-sharing agreement

Data-sharing agreements are formal agreements with provisions and requirements around the collection and use of data. They can be established with Indigenous rights holders and communities with interests to ensure the respectful collection and use of Indigenous data.

General elements of data-sharing agreements include a preamble, definitions, objectives, data to be shared, use of the data, data-sharing mechanisms, data ownership, publication and dissemination, confidentiality and security, information retention and disposal, intellectual property, duration and renewal, and termination of the agreements. Additional elements to consider include

- Methods of collaboration between the data custodian/steward and Indigenous rights holder;
- Roles of all parties to the agreement;
- Privacy impact assessment;
- Processes to ensure Indigenous control over the data and their ability to access the data;
- Training requirements (e.g., cultural safety) for all persons who access or analyze the data; and
- Indigenous cultural interpretation and involvement/partnership in overall interpretation and in report sharing/dissemination.

There may be circumstances where data governance principles do not align with existing legislation on privacy and access to personal health record information. This may require additional engagement and innovative solutions.

Additional resources:

Alberta First Nations Information Governance Centre, *Framework for a Data Sharing Agreement*

Appendix C: Tools and resources

CIHI, *Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada*: This document provides pan-Canadian minimum standards for collecting race-based and Indigenous identity data in health care, along with guidance on the safe and appropriate use of the data.

CIHI's *Health Data and Information Governance and Capability Framework*: Polices, processes and data governance practices that health information organizations or networks can use to generate greater value from health data and information.

CIHI, *Measuring Cultural Safety in Health Systems*: This paper introduces a framework for and identifies examples of measuring cultural safety and anti-Indigenous racism in health systems. It is paired with a list of potential indicators.

Health Standards Organization, cultural safety standards in B.C.: Cultural safety standards for health service organizations in B.C.

Indigenous Patient-Centred Measurement, BC Patient-Centred Measurement: Survey tools, results and information about the BC Patient-Centred Measurement program.

Indigenous Primary Health Care Council resources: Toolkits and resources to support the implementation of cultural safety in health service organizations.
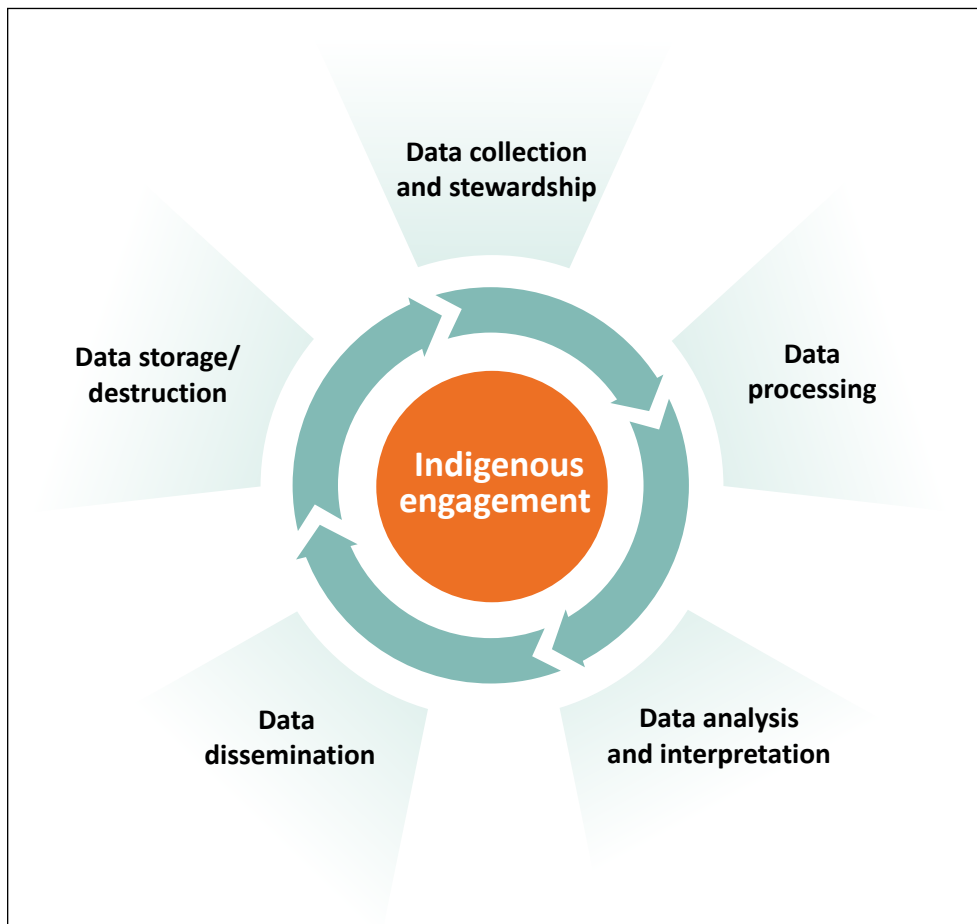
National Collaborating Centre for Indigenous Health knowledge resources and publications: A repository of resources on cultural safety and other topics.

Northern Health Indigenous Health, Assessment tool: Northern Health cultural safety and system change assessment tool.

Appendix D: Indigenous data governance across the data life cycle

Indigenous data sovereignty and governance considerations extend across the functions of the data life cycle, from collection to reporting and ultimate disposal of data. As noted, optimally, Indigenous rights holders are involved in decision-making in all steps relating to the functions of their data, formalized in a data-sharing agreement. In the interim, Indigenous data governance considerations can be accommodated through the governance structure agreed upon. This is a useful tool for organizations to think through in considering how to address Indigenous data governance at each stage.

Figure D1 Indigenous data governance across the data life cycle

Data collection
and stewardship

Data storage/
destruction

Data
processing

**Indigenous
engagement**

Data
dissemination

Data analysis
and interpretation

Note

Adapted from *CIHI's Information Quality Framework*.

Data collection and stewardship

Creation and capture of data usually occurs through a health care provider (e.g., clerk, nurse), information professional (e.g., analyst, coder), institution or professional organization. During this stage, the people generating the data are central to its overall quality and compliance with standards.[36] Where Indigenous identity data is being gathered and stewarded by non-Indigenous organizations, all components of the data collection process should be informed by Indigenous rights holders or their designates, including question formulation and review, informed consent process (in the case of surveys), ethical review of the proposed data collection and method of approaching Indigenous respondents. Some important questions to consider during this stage include but are not limited to the following:

- Who represents the Indigenous population in the data (i.e., urban Indigenous population, specific community, etc.), and how can it best be represented through the Indigenous data governance process?

- Who is the custodian/steward of the data? What mechanisms have been established to support Indigenous data governance processes (e.g., council, committee)?

- Are Indigenous Peoples' rights to data and interests recognized? If so, how will Indigenous rights holders access data?

- Are Indigenous intellectual property rights to Traditional Knowledge and traditional cultural expressions recognized?

- Is there clarity on the purpose and use of the Indigenous data (collection), and is this communicated to the patient population being queried?

- What different mechanisms exist to identify Indigenous patients?

- Will Indigenous identity be collected, and if yes, how? Does it include information collected on nations/communities? Will the organization use established standards to collect this data? Is there thoughtful consideration regarding the minimum identity information required, so as to limit respondent burden?

- How will the risks of harms in the data collection process be mitigated?

- What processes will be put in place to ensure the safe collection of the data? What will the informed consent process look like?

- What training and education will staff receive on cultural safety and Indigenous data governance and the safe collection of data?

[Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada](#)

Data processing

During this stage, data is put through verification, cleaning and other preparation for use in statistical analyses.[36] Indigenous rights holders, through the established governance structure, can provide a review body and sounding board for important quality issues identified. Some important questions to consider during this stage include but are not limited to the following:

- What quality, cleaning and transformation processes will the data undergo?
- What is the quality of the data captured? Does it include identifying information?
- What data is at risk of small cell sizes and how will this be managed? What processes will be used to de-identify the data?
- How will the data be categorized for meaningful and respectful analysis?
- Does the data being captured describe what it is intended to?
- Are the standards that were established for the data being respected?

Data analysis and interpretation

At this stage, the processed data is used to generate information, such as selecting and developing indicators of cultural safety and generating data tables, analytical reports, infographics and interactive reporting tools, etc.[36] Before analyses can be shared externally, pre-circulation for review and comment to representative entities of Indigenous Peoples described in the data may be part of the established Indigenous data governance process. Some important questions to consider during this stage include but are not limited to the following:

- Is the analysis responding to needs identified by the Indigenous Peoples, and does it reflect an Indigenous wellness priority?
- Does the analysis support Indigenous models of well-being?
- Does the analysis involve monitoring Indigenous service utilization and improving Indigenous health outcomes?
- Does the analysis fill a knowledge gap (i.e., is it adding to knowledge)?
- Is this analysis culturally safe? For example, will the results of this analysis be potentially stigmatizing or triggering? If so, how will the information be contextualized and shared, and how will the risks be mitigated?
- Is the analysis relevant to advancing equity and cultural safety in the Indigenous patient population? Will it identify areas where Indigenous individuals are experiencing discrimination and/or racism?
- Will the results of this analysis drive activities that lead to change? What targets and health system performance goals are selected for indicators of cultural safety?
- Does the analysis provide contextual information necessary to fully understand the indicators' findings in an Indigenous population and to clarify possible differences with the non-Indigenous population?

Data dissemination

At this stage, data and/or analyses are distributed for use by others (partners, community members, organizations, etc.). Indigenous engagement (and perhaps co-development) at this stage is fundamental to ensure that the messaging is safe and respectful. Some important questions to consider during this stage include but are not limited to the following:

- How will the information be contextualized to support the development of respectful and accurate narratives when preparing data for dissemination?
- What formal review process will take place prior to the dissemination of data?
- How will rights holders, communities with interests and other key partners be informed and engaged?
- What supports and resources will be available to individuals using the information (e.g., language accommodations, contextual data)?
- Are Indigenous Peoples involved in decision-making for issues related to Indigenous data?
- How will the privacy and security of individuals be protected, and how will risks of unintended disclosures be mitigated?
- What sign-offs are required prior to the release of the data and information?

Data storage/destruction

Data storage and destruction guidelines are typically considered as part of the data-sharing agreement established with rights holders. Indigenous rights holders' wishes should be sought regarding the length of time that their data is available and its mode of long-term storage. Some important questions to consider during this stage include but are not limited to the following:

- How will the data be stored and where?
- What processes are established for governing the privacy and security of the data? How will data be protected from unauthorized use and disclosure? What are the legislative requirements in place for the privacy and security of the data?
- What is the length of time the data will be kept before it is destroyed? How will the data be destroyed safely?

Privacy and security

Organizations are responsible for protecting the personal health information of individuals and communities throughout the life cycle of data and information.

The method of de-identifying data is an important consideration, given Indigenous Peoples' experiences with data being used to stigmatize and control. Best practices in data de-identification (necessary when sharing health data of individuals) should be applied to protect patient data privacy. This can include documenting the de-identification process, involving an expert in the de-identification method selected and defining identifiers that can then be deleted, or pseudonyms created.[37]

A note about qualitative data

To date, this discussion has centred on quantitative data. However, survey data often has a qualitative component in the form of open-ended questions that seek additional input from respondents and may contain experiences of services received during care. Due to the extremely personal nature of much of this data that could describe negative interactions or outcomes, and the inability to completely remove identifiable components and still retain the integrity of this information, this data may require collection, analysis, access, storage and destruction protocols that are different from those used for quantitative data.

Appendix E: Text alternative for figures

Figure 1: The indicator selection process

This includes 4 key steps: scope indicators, select indicators, finalize indicator definitions, and measure progress over time and assess continued relevancy. Indigenous engagement and data governance should occur throughout this process of indicator selection.

Figure 2: Framework for Measuring Cultural Safety in Health Systems

This is a framework for measuring Indigenous cultural safety in health systems. It illustrates a process whereby culturally safe health system interventions contribute to culturally safe health system experiences, which in turn lead to better health system performance and health outcomes. The whole process is influenced by the determinants of health. The 4 categories (Health System Interventions, Experience of Health System, Health System Performance, and Health and Wellness Outcomes) can be broken down into more specific themes, each with their own set of indicators for measuring cultural safety.

Figure D1: Indigenous data governance across the data life cycle

The data life cycle was adapted from *CIHI's Information Quality Framework* to suit the purposes of this report. It includes the following important stages: data collection and stewardship, data processing, data analysis and interpretation, data dissemination and data storage/destruction. Indigenous engagement should occur throughout the life cycle.

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