

Guidance on the Use of Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada



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As CIHI works toward better health for all people in Canada, we acknowledge that we live and work on the traditional territories of Indigenous Peoples. Our work to support the health of <u>First Nations</u>, <u>Inuit and Métis Peoples</u> is grounded in cultural safety and humility, respectful engagement, and Indigenous-driven processes and partnerships.

Introduction

Race-based and Indigenous identity data is vital for the identification and monitoring of health inequalities that stem from racism, bias and discrimination, and to inform interventions to improve equity in health care access, quality, experience and outcomes.^{1–3} Currently, data collection on race, ethnicity and Indigenous identity is limited in the health care sector, and where data is available, the way it is collected often varies.

The Canadian Institute for Health Information (CIHI) has developed pan-Canadian minimum standards for collecting race-based and Indigenous identity data in health care, which are set out in this document. The purpose of these standards is to support harmonized, high-quality data collection and to help identify and address health inequities related to racism. Adoption within current health data collection systems is voluntary; however, implementation of the standards will facilitate monitoring, comparable analysis and reporting related to health care access, quality, experience and outcomes across racialized groups. The collected data can also be used to provide more appropriate and respectful care, and to inform policies and programs aimed at improving health equity.²

The race-based and Indigenous identity data standards align with standards developed by Statistics Canada for key surveys and resources, such as the census. In particular, the census provides important social, demographic and economic information about people in Canada.⁴ For population-based analyses, the CIHI standards can be mapped to Statistics Canada's population group and Indigenous identity standards, thus ensuring consistency across national data sources (Appendix A).

There are many benefits to collecting, measuring and analyzing race-based and Indigenous identity data, but there are also risks and barriers to assess and mitigate. Risks and barriers include potential discomfort, fear of self-identifying and the potential for stigma or discrimination to lead to unequal care or treatment. Prioritizing safe and appropriate collection and use of this data is an essential step in identifying and addressing inequities in health and health care. This document includes guidance for health care providers and authorities to mitigate the risks of harm and to ensure the safe and appropriate collection and use of this data, including data governance, community engagement, training for staff involved in data collection, and patient and public education.

Distinguishing race and ethnicity

The terms "race" and "ethnicity" are often used interchangeably or as a single, conflated construct — "race/ethnicity."^{5–7} However, race and ethnicity are distinct social constructs, and the measurement and reporting of racial and ethnic health inequalities should reflect these differences.^{8–10}

Race is a social construct used to judge and categorize people based on perceived differences in physical appearance in ways that create and maintain power differentials within social hierarchies. There is no scientifically supported biological basis for discrete racial groups.^{11, 12}

Racialization is the process by which people are judged and categorized into races primarily using differences in physical appearance. In this process, societies construct races as "real," different and unequal in ways that pertain to economic, political and social life.¹³

Ethnicity is a multi-dimensional concept referring to community belonging and a shared cultural group membership. It is related to socio-demographic characteristics, including language, religion, geographic origin, nationality, cultural traditions, ancestry and migration history, among others.¹¹

A glossary of key concepts and relevant terminology is in Appendix B.

Standards development process

This work has been ongoing for several years and has included a detailed review of the literature and engagement with many individuals and groups, including those who represent racialized and Indigenous communities, subject matter experts, research organizations, and federal, provincial and territorial governments. Stakeholders expressed interest in a measure that separates the concepts of race and ethnicity and is suitable for health care settings. Some important conditions were also outlined as part of the consultations, such as inclusion of a preamble to clarify why the data is being collected and how it will be used, the need for data governance agreements and community engagement, and a limited number of broad categories to make reporting on disaggregated data more feasible. CIHI determined that an approach that addressed these conditions would provide a valuable complement to Statistics Canada's information on population group categories and Indigenous identity.

CIHI released an interim standard for the collection of race-based data on May 29, 2020, in response to the urgent call to understand the impact of the COVID-19 pandemic within racialized communities. In July 2020, we released a discussion document, *Proposed Standards for Race-Based and Indigenous Identity Data Collection and Health Reporting in Canada*. ¹⁴ It featured a set of proposed standards and summarized constructs and issues related to data collection and reporting. Following the discussion document release, CIHI gathered feedback from a wide range of stakeholders and partners.

In 2021, CIHI also collaborated with researchers at the <u>Upstream Lab</u> to support the inclusion of the proposed questions on race and Indigenous identity in a new study. One of the objectives of the <u>Screening for poverty and related social determinants and intervening to improve knowledge of and links to resources (SPARK) study¹⁵ is to validate and standardize a set of questions on socio-demographic characteristics and social needs (e.g., housing). Findings of the SPARK study to date were incorporated in these standards.</u>

Overarching themes from the engagements are summarized in <u>Appendix C</u>. An updated version of the discussion document was published in March 2022 as a <u>supplementary report</u> accompanying this release.

Why is collecting race-based and Indigenous identity data in health care important?

"For too long, we have largely denied that we have, or even could have, systematic racial health inequities, because we like to think that a universal health care system, and multiculturalism as our official national policy, shield us from the racist conditions that produce health inequities, but we need data to move away from assumptions and towards uncovering systematic truths."

Dr. Arjumand Siddiqi, Professor and Division Head of Epidemiology,
 Dalla Lana School of Public Health, University of Toronto

Race-based and Indigenous identity data standards

CIHI's race-based and Indigenous identity data standards were adapted from standards published in 2018 by the Government of Ontario's Anti-Racism Directorate (ARD) for the identification and monitoring of systemic racism. The Ontario ARD supports standardized collection of race-based data to inform anti-racism efforts in the education, child welfare and justice sectors. CIHI's standards consist of a distinctions-based Indigenous identity question (Table 1) followed by a race-based question (Table 2). These standards will support the measurement of inequalities in care and the identification of health inequities that result from racism and discrimination.

Indigenous identity data

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) identifies Indigenous Peoples' unique rights to self-determination, autonomy and governance.^{17, 18} Bill C-15 commits the Government of Canada to implementing the Declaration.^{17, 19} Indigenous Peoples' rights include the rights to data sovereignty (e.g., ownership, control, access and possession [OCAP®]) and the right to "determine their own identity or membership in accordance with their customs and traditions."¹⁷ Within this context, the implementation of the Indigenous identity data standards should include data governance agreements, engagement with Indigenous groups, and processes related to culturally safe and appropriate data collection.

What are important considerations when using or interpreting race and Indigenous identity data?

"The most important consideration when interpreting disaggregated data by race and Indigenous identity is clarity on what is being measured. Disaggregated data is a critical tool that helps make visible the ways in which structural racism, systemic white supremacy and social exclusion both harm Indigenous and racialized peoples and sustain unearned privilege for white settlers. By collecting race and Indigenous identifiers, and ensuring they are used in a good way in partnership with BIPOC [Black, Indigenous and People of Colour] collectives, we can take collaborative actions towards our fully realized health and wellness through evidence-based and self-determined policies, programs, and services."

— Dr. Danièle Behn Smith, Deputy Provincial Health Officer, Indigenous Health, Ministry of Health, Government of British Columbia

Indigenous identity data standard

Table 1 Indigenous identity question and responses*

Question: Do you identify as First Nations, Inuk/Inuit and/or Métis?

Response categories (select all that apply)
Yes, First Nations
Yes, Inuk/Inuit
Yes, Métis
No
Do not know
Prefer not to answer

Note

^{*} The implementation of the Indigenous identity data standard should include data governance agreements, engagement with Indigenous groups, and processes related to culturally safe and appropriate data collection.

Race-based data standard

Table 2 Race-based question and responses*

Question: In our society, people are often described by their race or racial background. These are not based in science, but our race may influence the way we are treated by individuals and institutions, and this may affect our health. Which category(ies) best describes you? Check all that apply:

Response category	Examples
Black	African, African Canadian, Afro-Caribbean descent
East Asian	Chinese, Japanese, Korean, Taiwanese descent
Indigenous (First Nations, Inuk/Inuit, Métis)*	First Nations, Inuk/Inuit, Métis descent
Latin American	Hispanic or Latin American descent
Middle Eastern	Arab, Persian, West Asian descent (e.g., Afghan, Egyptian, Iranian, Kurdish, Lebanese, Turkish)
South Asian	South Asian descent (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan)
Southeast Asian	Cambodian, Filipino, Indonesian, Thai, Vietnamese, or other Southeast Asian descent
White	European descent
Another race category	Includes values not described above
Optional — please specify: [open text]	
Do not know	Not applicable
Prefer not to answer	Not applicable

Notes

- * The collection of race-based and Indigenous data should involve community engagement to mitigate the risk of harm to individuals and communities, and to ensure the safe and appropriate use of the data.
- † Individuals who identify as mixed race can select all categories that apply.
- ‡ Distinctions-based approaches that is, separately identifying First Nations, Inuit and Métis Peoples may be preferred. **Sources**

Government of Ontario Anti-Racism Directorate. <u>Data Standards for the Identification and Monitoring of Systemic Racism</u>. Updated November 2021.

Upstream Lab. <u>Screening for poverty and related social determinants and intervening to improve knowledge of and links to resources (SPARK) study.</u> Accessed January 27, 2020.

Options to collect more granular data

Both the race-based and Indigenous identity data standards are **minimum** data collection standards. More granular information on specific populations within each category may be collected, as long as consistency is maintained by having these subcategories roll up to the minimum standard for reporting. For example,

- "African Nova Scotian" could be included as a response option, but when reported in national comparisons, African Nova Scotians would be part of the "Black" group.
- For Indigenous identity, there may be a need for or interest in adding questions about specific communities or Nations, status or membership, or an optional write-in category to allow respondents to self-identify as they prefer.

Other variables, such as ethnicity, religion, preferred or spoken language and immigration status, can offer additional information to inform culturally safe and appropriate care. For example, collecting language data in addition to race-based and Indigenous identity data can help to determine the language translation resources needed for the local population and potentially identify additional barriers faced by racialized groups.

For examples of granular data collection options, please refer to Appendix D.

Guidance for health care providers and authorities

Based on feedback gathered from CIHI's consultations and engagement, the collection and use of race-based and Indigenous identity data by health care providers and authorities should involve the following elements:

- Data governance, including protocols for how the data will be managed;
- Appropriate and meaningful engagement with Indigenous and/or racialized groups; and
- Processes to ensure that information is collected in ways that are safe, respectful and do not cause harm (e.g., staff education and training, patient and public education and supports).

Data governance

In Canada's health systems, governance of data and information is critical. Strong data and information governance ensures that data is timely, trusted and accurate.¹⁸ Data and information governance mechanisms, including policies, processes, systems and practices, should be reviewed and revised, as needed, with special focus and consideration given to the impact on Indigenous Peoples and racialized groups, and on the collection of their data.

First Nations, Inuit and Métis Peoples have the right to freely determine their political status and pursue their economic, social and cultural development (self-determination). To Data and information about individual and community health and wellness are critical tools for self-determination. Indigenous data sovereignty principles (e.g., OCAP® principles) assert that First Nations, Inuit and Métis Peoples have collective sovereign rights and the fundamental authority to own and govern their data, regardless of where their data is housed. Engagement, partnerships and data governance agreements with Indigenous authorities are key to the safe and appropriate use of Indigenous data. This includes protocols for the collection, management, access and use of the data throughout its life cycle. 20

Explore the following resources for additional information on data governance best practices:

- Health Data and Information Governance and Capability Framework and toolkit,²¹
 Canadian Institute for Health Information.
 - The framework and companion toolkit contain foundational knowledge, a checklist of capabilities and guides for performing internal and network-based assessments. After completing these assessments, organizations can create a plan that, once implemented, allows them to better govern their data and information.
- <u>A Path Forward: Toward Respectful Governance of First Nations, Inuit and Métis Data Housed at CIHI</u>,²² Canadian Institute for Health Information.
 - This paper outlines some of the work that CIHI is doing to align our organizational policies and procedures with principles of Indigenous data sovereignty.
- The First Nations Principles of OCAP®,²⁰ First Nations Information Governance Centre (FNIGC).
 OCAP® principles establish how First Nations' data, information and cultural knowledge should be collected, accessed, used and shared.
- Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework
 for Health Data Collected from Black Communities,²³ Black Health Equity Working Group.
 A data governance and accountability framework developed by health experts in Black
 communities. This framework highlights the necessity for a new way of governing data
 in relation to Black communities in Ontario. It is structured around community needs
 and explicit partnerships.

Community engagement

Community engagement is best practice and foundational to the respectful collection and appropriate use of race-based and Indigenous identity data in health care. It is also a prerequisite for establishing data governance agreements with Indigenous Peoples and governments.

Community members and organizations are knowledgeable about the health priorities and broader social, political, economic and historical context of their communities. Where race-based and Indigenous identity data collection is being considered or planned, the community members (that is, people with lived experience and local knowledge) can provide valuable input. Health care organizations should engage representatives of racialized groups in meaningful dialogue to inform the data collection and reporting process. There are a number of ways to promote community involvement, including the creation of community governance tables, as advocated by the EGAP framework.²³ Consider using a framework such as the <u>IAP2 Spectrum</u>²⁴ in planning for engagement and the roles of various groups.

Explore the resources below for more information on frameworks, tools and techniques for engagement:

- Community engagement resources,²⁵ including the <u>Index of Community Engagement Techniques</u>²⁶ and the <u>Community Engagement Planning Canvas</u>,²⁷ Tamarack Institute.
 The Index of Community Engagement Techniques²⁶ is a comprehensive list of community engagement techniques that can be selected based on the planned level of engagement and a tool for working through several main considerations when planning to engage.
- Engagement, Governance, Access and Protection (EGAP): A Data Governance Framework
 for Health Data Collected from Black Communities,²³ Black Health Equity Working Group.
 A framework developed by Black health sector leaders and equity experts in Ontario to
 support the collection, management, analysis and use of race-based data from Black
 communities in ways that advance health equity.
- Engaging communities in your data collection initiative,²⁸ Health Commons Solutions Lab.
 An overview of community engagement in equity initiatives, common challenges and resources for getting started.
- <u>Let's Talk: Community Engagement for Health Equity</u>, ²⁹ National Collaborating Centre for Determinants of Health.
 - A resource that explores 5 key practices for meaningful community engagement for health equity, including strategies and examples.
- Regional Discussion Report: Review of First Nations, Métis and Inuit Questions on the Census, 30 Statistics Canada.

A report that describes the engagement process used to develop the questions about First Nations, Métis and Inuit populations in the 2021 Census.

Indigenous engagement

Colonialism and racism impact many areas of society, including research, data and measurement.³¹ Building and maintaining strong, sustainable relationships with Indigenous Peoples is essential for the respectful collection and appropriate use of Indigenous identity data. Respect, open communication and time are needed to build trust and mitigate any potential risks or harms.

CIHI's engagement with Indigenous partners, researchers and representatives of Indigenous organizations identified some important considerations, including the following:

Establish key partnerships

- Work with local partners to identify their data and information needs.
- Include representation from all appropriate groups and recognize and honour the unique needs of distinct populations.

Know your partners

- Understand and respect the history, culture, governance structure and needs of the communities you will be engaging with.
- Acknowledge colonialism and its impacts on health.

Engage early and often

 Maintain open and honest lines of communication throughout the process and engage at all stages of work.

Be transparent

- Communicate the purpose for collecting Indigenous identity data and provide clarity on the benefits/risks this may bring to the community.
- Work with the community to understand and use the data appropriately and ensure shared decision-making throughout the data life cycle

Processes for the safe collection of data

At the point of care, providing staff training and clear information to patients about the data collection process can facilitate culturally safe data collection. These practices reduce the risk of harm and improve the quality of collected data. The purpose of data collection should be clearly stated: to identify inequalities that may be the result of racism, bias and discrimination, and to support improvements to the quality of care.

Consultations with key partners and current evidence regarding best practices revealed the following recommendations for the safe collection of data:

Provide staff training and support for patients

- Provide education and training for staff who collect the data, with clear direction on how to do this respectfully and in a way that reduces the risks of harm (e.g., staff script for data collection and answers to frequently asked questions [FAQ], resources on topics such as implicit bias).
- Provide supports, information and culturally appropriate services for patients to help manage any potential harms caused by collecting the data (e.g., counselling services, information brochures).

Be clear about the purpose

- Explain why the data is being collected (transparency) and how the data will be used (accountability).
- Explain the benefits/risks of collecting the data.
- Give patients the choice to provide (or not provide) the information and ensure their decision does not impact their care.

Mitigate risks to privacy

• Put protocols, processes and infrastructure in place to ensure the privacy, security and confidentiality of the data.

The following resources provide further information related to the safe collection of data:

- Online training courses, National Collaborating Centre for Determinants of Health
 - Webinars on racism, anti-racism and racial equity³² include 5 webinar recordings as a primer on anti-racism and racial equity in relation to public health.
 - Introduction to health equity³³ is a 5-module introductory course aimed at helping public health professionals develop required skills for health equity work. Produced in collaboration with Public Health Ontario.
- <u>Cultural safety collection</u>,³⁴ National Collaborating Centre for Indigenous Health
 A repository of resources related to addressing barriers in accessing health and social
 services for First Nations, Inuit and Métis Peoples due to their experiences with racism,
 discrimination and marginalization.
- Measuring health equity: Demographic data collection in health care,³⁵ Sinai Health System, Health Equity Office
 - Reports and resources related to the collection of data about demographics (including race, ethnicity and Indigenous identity):
 - Training materials³⁶ for data collectors include training videos, e-learning modules and a training participant manual. Materials cover the rationale for data collection, how to frame questions for patients, and answers to FAQ.
 - Patient education materials³⁷ include a glossary of terms and brochures to inform patients about the questions being asked.
 - Guide to Demographic Data Collection in Health-Care Settings: A Comprehensive Guide
 to Planning and Implementing Demographic Data Collection in Health-Care Settings³⁸
 supports health care organizations through the process of implementing standardized
 data collection.
- Resources on race/ethnicity/Indigenous identity data collection,³⁹ Shared Health Manitoba
 - The training video <u>Collecting racial/ethnic/Indigenous identifiers during COVID-19</u>⁴⁰ includes explanations of race and racism in the context of health care, a rationale for data collection, and how to collect data using the provided script.
 - The <u>script for the collection of race, ethnicity, and indigeneity (REI) identifiers</u>³⁹ was created in the context of COVID-19 data collection. It provides the rationale for data collection and answers to patients' FAQ.

Next steps

CIHI will support provinces, territories and stakeholders within the health care system to enhance the collection of race-based and Indigenous identity data in health care. CIHI acknowledges that we are on a learning journey, guided by what we have learned, and continue to learn, from racialized groups and Indigenous Peoples, communities, governments and organizations. We will continue to learn from these collective efforts to identify best practices and refine the approach as needed. As suggested in the Government of Canada's Pan-Canadian Health Data Strategy, we need to collaborate to build an integrated health data system that focuses on the people it serves, with equity and data governance at its core.^{41, 42} Race-based and Indigenous identity data is one important tool to achieve this.

Appendices

Appendix A: Mapping CIHI's standards to Statistics Canada's population group and Indigenous identity standards

CIHI's race-based and Indigenous identity data standards can be mapped to Statistics Canada's population group and Indigenous identity standards for population-based analyses. The following table maps the CIHI standards to the 2021 and 2016 Census, as well as to the Canadian Community Health Survey.

Table A1 Comparison of CIHI's Indigenous identity data standard with Statistics Canada's census and Canadian Community Health Survey questions

CIHI's standard Question	Statistics Canada's 2021 Census	Statistics Canada's 2016 Census	Statistics Canada's 2021 Canadian Community Health Survey*
Do you identify as First Nations, Inuk/ Inuit and/or Métis? Select all that apply.	Is this person First Nations, Métis or Inuk (Inuit)? Note: First Nations (North American Indian) includes Status and Non-Status Indians. If "Yes", mark "x" the circle(s) that best describe(s) this person now.	Is this person an Aboriginal person, that is, First Nations (North American Indian), Métis or Inuk (Inuit)? Note: First Nations (North American Indian) includes Status and Non-Status Indians. If "Yes", mark the circle(s) that best describe(s) this person now.	Are you an Aboriginal person, that is, First Nations, Métis or Inuk (Inuit)? First Nations includes Status and Non-Status Indians. [and follow-up question] Are you First Nations, Métis or Inuk (Inuit)?
Response categories			
Yes, First Nations	Yes, First Nations (North American Indian)	Yes, First Nations (North American Indian)	First Nations (North American Indian)
Yes, Inuk/Inuit	Yes, Inuk (Inuit)	Yes, Inuk (Inuit)	Inuk (Inuit)
Yes, Métis	Yes, Métis	Yes, Métis	Métis
No	No, not First Nations, Métis or Inuk (Inuit)	No, not an Aboriginal person.	No
Do not know	Not applicable	Not applicable	DK
Prefer not to answer	Not applicable	Not applicable	RF

Note

^{*} The Indigenous identity categories presented include a combination of 2 questions within the Canadian Community Health Survey.

Table A2 Comparison of CIHI's race-based data standard with Statistics Canada's census and Canadian Community Health Survey questions

CIHI's standard	Statistics Canada's 2021 Census	Statistics Canada's 2016 Census	Statistics Canada's 2021 Canadian Community Health Survey
	Statistics Canada's 2021 Census	Statistics Canada's 2016 Census	Community Health Survey
Preamble and question	1		
In our society, people are often described by their race or racial background. These are not based in science, but our race may influence the way we are treated by individuals and institutions, and this may affect our health. Which category(ies) best describes you? Check all that apply:	This question collects information in accordance with the <i>Employment Equity Act</i> and its Regulations and Guidelines to support programs that promote equal opportunity for everyone to share in the social, cultural, and economic life of Canada. Is this person:	This question collects information in accordance with the <i>Employment Equity Act</i> and its Regulations and Guidelines to support programs that promote equal opportunity for everyone to share in the social, cultural, and economic life of Canada. Is this person:	You may belong to one or more racial or cultural groups on the following list. Are you?
	Mark "x" more than one circle or specify, if applicable.	Mark more than one circle or specify, if applicable.	
Response categories			
Black	Black	Black	Black
East Asian	Chinese	Chinese	Chinese
	Korean	Korean	Korean
	Japanese	Japanese	Japanese
Indigenous (First Nations, Inuk/Inuit, Métis)	Not applicable	Not applicable	Not applicable
Latin American	Latin American	Latin American	Latin American
Middle Eastern	Arab	Arab	Arab
	West Asian (e.g., Iranian, Afghan)	West Asian (e.g., Iranian, Afghan, etc.)	West Asian (e.g., Iranian, Afghan)
South Asian	South Asian (e.g., East Indian, Pakistani, Sri Lankan)	South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)	South Asian (e.g., East Indian, Pakistani, Sri Lankan)

CIHI's standard	Statistics Canada's 2021 Census	Statistics Canada's 2016 Census	Statistics Canada's 2021 Canadian Community Health Survey
Response categories			
Southeast Asian	Filipino	Filipino	Filipino
	Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai)	Southeast Asian (e.g., Vietnamese, Cambodian, Laotian, Thai, etc.)	Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian)
White	White	White	White
Another race category	Other group — specify	Other — specify	Other — specify
Optional — Please specify: [open text]			
Do not know	Not applicable	Not applicable	DK
Prefer not to answer	Not applicable	Not applicable	RF

Guidance for analysis

Racialized group and/or Indigenous identity may be used as equity stratifiers (or by groups) for measuring inequalities in health care access, quality, experience and outcomes. In <u>Measuring Health Inequalities: A Toolkit</u>, ⁴³ CIHI provides analytical guidance for selecting and calculating simple and complex inequality measures. As detailed in the toolkit, calculation of these measures requires counts or rates of total population reference groups (denominators). CIHI's race-based standards can be mapped to <u>Statistics Canada's population groups</u> so that Statistics Canada data can be used to obtain denominator data. Additional resources for planning, conducting and reporting equity analyses are provided in the toolkit.

The potential for disaggregating groups will depend on the available sample size of data for these groups. It is recommended to consult with community organizations to identify classifications of mixed-race individuals that are relevant to the local population. However, you must follow Statistics Canada's methods of categorization for mixed-race groups if you require denominators from Statistics Canada data.

i. If you are deriving denominator data from the Statistics Canada population group categories, note that denominators may be slightly undercounted for the following CIHI race-based categories: East Asian, Southeast Asian and Middle Eastern. This undercounting occurs because Statistics Canada classifies members of these groups who indicate that they belong to more than one population group category within their race category under "Multiple Population Groups." For example, a respondent who is Korean and Chinese will be considered by the CIHI standard as East Asian but will fall under the Statistics Canada classification as "Two Population Groups." Similar logic applies for respondents who identify in Statistics Canada databases as both Filipino and Southeast Asian, or Middle Eastern and West Asian.

Appendix B: Glossary

The table below presents a list of key terms and concepts used in this document, as well as their definitions. It is provided to clarify the language, avoid the conflation of concepts, and distinguish these terms and concepts from colloquial language and understandings, where applicable.

Concept	Definition
Colonialism	Colonization is not only a process of taking political control over Indigenous lands, but also a system designed to maintain power and influence (e.g., imposition of colonial institutions of education, health care and law). ⁴⁴
Culture	The overt and subtle value systems, traditions and beliefs that influence our decisions and actions. ⁴⁵
distinctions-based	An approach that aims to avoid conflating the Indigenous Peoples within Canada, and instead recognizes First Nations, Inuit and Métis as separate groups, each with their own diverse cultures, traditions, communities and histories. A distinctions-based approach ensures that the unique rights, interests and circumstances of each of these groups are acknowledged, affirmed and implemented. ⁴⁶
equity stratifier	A characteristic such as a demographic, social, economic, racial or geographic descriptor that can identify population subgroups for the purpose of measuring differences in health and health care that may be considered unfair or unjust. ⁴⁷
Ethnicity	A multi-dimensional concept referring to community belonging and a shared cultural group membership. It is related to socio-demographic characteristics, including language, religion, geographic origin, nationality, cultural traditions, ancestry and migration history, among others. ¹¹
health equity	The absence of unjust, avoidable differences in health care access, quality, experience or outcomes. ⁴⁷
health inequality	Differences in health between individuals, groups or communities. Measuring health inequalities is a first step toward identifying and reducing health inequities. ^{47, 48}
implicit bias	Unconscious thoughts, attitudes or reactions that precipitate unintentional discriminatory behaviour. ⁴⁹
Indigenous data sovereignty	The collective and individual rights of Indigenous Peoples to the self-governance and management of data from and about their communities, lands and individuals. ^{20, 50, 51}
race (or racial group)	A social construct used to judge and categorize people based on perceived differences in physical appearance in ways that create and maintain power differentials within social hierarchies. There is no scientifically supported biological basis for discrete racial groups. ^{11, 12}
Racialization	The process by which people are judged and categorized into races primarily using differences in physical appearance. In this process, societies construct races as "real," different and unequal in ways that pertain to economic, political and social life. ¹³

Concept	Definition
racialized group	A social construct describing groups that have racial meanings associated with them that affect their economic, political and social life. This term is sometimes preferred over "race" because it acknowledges the process of racialization. 11–13
Racism	Includes thoughts or actions that establish or reinforce the superiority or dominance of one racialized group over another. ¹³ Racism exists on a spectrum and acts on multiple levels — internalized, interpersonal and systemic.
	internalized racism: The acceptance by a marginalized racialized group of negative messages concerning their abilities and worth. ⁵²
	interpersonal racism: Racism that occurs when an individual experiences discriminatory behaviour from others. ⁵²
	systemic racism: Racism that occurs at societal and organizational levels, giving rise to the other forms of racism. ^{51, 52} It is often pervasive and subtle, and not always intentional. It is embedded in societal and institutional policies, regulations, legislation and ideologies that perpetuate racial disadvantage. ^{53, 54}
self-determination	A principle that concerns a person's or nation's right to determine and have control over their own future, political status, culture, economy and independence. 55, 56
social construct	An idea that has been created and accepted by the people in a society and that is not an intrinsic property of a person or thing. ⁵⁷

Appendix C: What we heard

CIHI engaged with many individuals and groups, including organizations representing racialized and Indigenous communities, subject matter experts, research organizations, and federal, provincial and territorial governments. Feedback from these engagements affirmed key themes outlined in our <u>supplementary report</u> and identified additional points for consideration. Below is a high-level summary.

More race-based and Indigenous identity data is needed

 Limited race-based and Indigenous identity data are currently collected in health care in Canada. Current registration systems in health care are not equipped to collect race-based data. This lack of data often results in organizations relying on linkages to Statistics Canada datasets to obtain information on population group or other variables (e.g., immigration status, spoken language). In some cases, data linkage is not seen as practical, timely or efficient.

The purpose for data collection must be clear

- Racism is a problem in health care; race-based and Indigenous identity data collection is one important tool to address this issue.
- There is an urgent need to collect race-based and Indigenous identity data in health care
 to identify, monitor and address inequities that stem from bias and racism. This objective
 should be clearly communicated whenever collecting or using race-based and Indigenous
 identity data. The purpose of the data collection needs to be clear so that patients feel safe
 in answering these questions.
- Race and ethnicity are distinct concepts but are often conflated. If data on ethnicity is
 required in addition to race, it should be collected separately. CIHI's <u>supplementary report</u>
 provides further detail on the social constructs of race and ethnicity.

Reduce the risks of harm and be open and transparent

- There are risks of harm associated with collecting and using race-based and Indigenous identity data. These risks should be identified and mitigated through data governance agreements, community engagement, and processes for the safe collection of data (e.g., staff training and patient and public education).
- A distinctions-based approach to Indigenous identity, where people have the option to identify as First Nations, Inuit, or Métis, is best practice and recommended by community representatives.
- Openness and transparency are key to building trust with communities and mitigating risks
 of harm. This includes establishing a clear purpose for collecting and using race-based data;
 disclosing that collection is voluntary; providing rigorous staff training; ensuring informed consent,
 as well as the privacy, security and confidentiality of the data; and engaging communities.

Some race-based categories needed to be refined

- Overall, there was support for the proposed preamble, categories and question; however, changes were recommended to better reflect how people self-identify. This feedback was used to make changes, where possible. In areas where data collection can be adapted (e.g., primary care settings), categories can be subdivided or relabelled to allow for flexibility and then rolled up to CIHI's data standards.
- Data for individuals who identify with more than one race category should be collected in a manner that allows for accurate disaggregated reporting.

Context is key in reporting data

- Race-based and Indigenous identity data should not be used in ways that reinforce stereotypes and harm individuals. This data should be used to understand the broader social context of systemic racism and appropriately attribute inequities to their true root causes.
- Consider the differences in experiences within racialized groups. Race needs to be analyzed
 with other variables such as sex, gender, housing, income, access to education and health
 care, and immigration status. For example,
 - There may be significant differences in health care access, quality, experience or outcomes among genders within a single race-based group, or differences between race-based groups may be explained by another variable, such as household size.
 In both circumstances, considering other variables in the analyses yields information relevant to the planning of interventions.
- The principles of intersectionality can help guide how analyses are contextualized.⁵⁸
 - People have multiple social identities (e.g., race, gender) that intersect.
 - An individual's multiple social identities interact with social discrimination (e.g., racism, sexism), to produce health inequalities.
 - Collecting race-based and Indigenous identity data is a critical step in addressing systemic racism, but it is equally important to consider this data in the context of intersecting identities, including socio-economic status, gender and language, among others.

Appendix D: Options to collect additional data

Option to collect additional Indigenous identity data

Table D1 provides examples of data that could be collected alongside the Indigenous identity data. Locally relevant questions may also be added to support the delivery of culturally safe and appropriate care.

Table D1 Examples of additional Indigenous identity data

Optional Indigenous id	dentifier questions
If yes, First Nations	Are you a Status Indian (Registered or Treaty Indian as defined by the Indian Act of Canada)? • Yes, Status Indian (Registered or Treaty) • No Source: Statistics Canada's 2021 Census If you identify yourself as a First Nations person, do you live on a reserve or off-reserve? • On a reserve • Off-reserve
	Are you a member of a First Nation or Indian band? • Yes, member of a First Nation or Indian band — Specify name of First Nation or Indian band: [open text] • No Source: Statistics Canada's 2021 Census
If yes, Inuk/Inuit	Are you enrolled under, or a beneficiary of, an Inuit land claims agreement? • Yes — Specify agreement: [open-text] • No Source: Statistics Canada's 2021 Census
If yes, Métis	Are you a registered member of a Métis organization or Settlement? • Yes — Specify organization or Settlement: [open-text] • No Source: Statistics Canada's 2021 Census

Option to collect complementary data

Table D2 provides examples of ethnic or cultural origin and ethnicity-related data that could be collected alongside the race-based data. The information below was collected by Statistics Canada through the 2021 Census. Please refer to Statistics Canada's variables for additional information.

Table D2 Ethnicity and ethnicity-related data

Sample ethnicity question

Ethnic or cultural origin of person

Definition: Ethnic or cultural origin refers to the ethnic or cultural origins of the person's ancestors. Ancestors may have Indigenous origins, or origins that refer to different countries, or other origins that may not refer to different countries.⁵⁹

Question: What were the ethnic or cultural origins of this person's ancestors?

For examples of ethnic or cultural origins, visit Statistics Canada's <u>Examples of ethnic or cultural origins web page</u>.

Category: Specify as many origins as applicable using capital letters: [open text]

Source: Statistics Canada's 2021 Census

Select ethnicity-related data

Religion

Definition: Religion refers to the person's self-identification as having a connection or affiliation with any religious denomination, group, body or other religiously defined community or system of belief. Religion is not limited to formal membership in a religious organization or group.⁶⁰

Question: What is this person's religion?

Indicate a specific denomination or religion even if this person is not currently a practising member of that group.

For example, Roman Catholic, United Church, Anglican, Muslim, Baptist, Hindu, Pentecostal, Lutheran, Presbyterian, Sikh, Buddhist, Jewish, Greek Orthodox.

For additional examples of denominations and religions, visit Statistics Canada's <u>Examples of religions and religious groups/denominations web page</u>.

Categories: Specify one denomination or religion only: [open text]; No religion

Source: Statistics Canada's 2021 Census

Sample ethnicity question

Select ethnicity-related data (continued)

Language

Definitions:

"All languages spoken at home" refers to all languages that the person speaks at home on a regular basis at the time of data collection.⁶¹

"Language spoken most often" at home refers to the language the person speaks most often at home at the time of data collection. A person can report more than one language as "spoken most often at home" if the languages are spoken equally often.⁶²

Questions:

- a) What language(s) does this person speak on a regular basis at home?
- b) Of these languages, which one does this person speak most often at home? Indicate more than one language only if they are spoken equally at home.

Categories: English; French; Other language(s) — specify: [open text]

Source: Statistics Canada's 2021 Census

Citizenship/ Immigration status

Definitions:

"Citizenship" refers to the country where the person has citizenship. A person may have more than one citizenship. A person may be stateless; that is, they may have no citizenship. Citizenship can be by birth or naturalization. ⁶³

"Canadian citizen by naturalization" refers to an immigrant who was granted citizenship of Canada under the Citizenship Act.

Questions:

- a) Is this person a Canadian citizen?
- b) Is this person a citizen of a country other than Canada?

Indicate more than one country of citizenship, if applicable.

Categories:

- a) Yes, a Canadian citizen by birth; Yes, a Canadian citizen by naturalization; No, not a Canadian citizen
- b) No; Yes Specify the country or countries of citizenship: [open text]

Source: Statistics Canada's 2021 Census

Sample ethnicity question

Select ethnicity-related data (continued)

Country of birth

Definitions:

"Place of birth" refers to the name of the geographic location where the person was born. The geographic location is specified according to geographic boundaries current at the time of data collection, not the geographic boundaries at the time of birth. 64

"Place of birth of parent" refers to the name of the geographic location where the father, mother or parent of the person was born. The geographic location is specified according to geographic boundaries current at the time of data collection, not the geographic boundaries at the time of birth.⁶⁵

Questions:

- a) Where was this person born? Specify one response only, according to present boundaries.
- b) Where were this person's parents born?

Specify the country or countries according to present boundaries.

Categories:

- a) Born in Canada [select province/territory]; Born outside Canada Specify country: [open text]
- b) All parents born in Canada; All parents born outside Canada Specify the country of birth of each parent: [open text]); One parent born in Canada and one parent born outside Canada Specify the country of birth outside Canada: [open text]

Source: Statistics Canada's 2021 Census

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