

Social Identification of Race in Canada Policy Brief



POLICY BENCH

Fraser Mustard Institute for Human Development

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Executive Summary	i
1.0 Introduction	1
1.1 The issue of race-based data collection in Ontario	1
1.2 Why is the issue important?	
1.3 Overview of this policy brief	2
2.0 Objectives	2
3.0 Research Methods	3
3.1 Overview of methods and search strategy	3
3.2 Note on terminology	
4.0 Background	
4.1 Race and racial identity	
4.2 Dimensions and measurement of race	
4.3 Race-based data collection	
4.4 Other considerations for race and identity data collection	
4.5 Indigenous data governance	
5.0 Race Data Collection in Ontario – Policies and Practice	
5.1 Timeline of relevant policies and events	
5.2 Examples of race-based data collection initiatives and outcom	
Ontario	
5.3 Data collection during the COVID-19 pandemic6.0 Race Data Collection in Canada and Other Countries	
6.1 National data collection: Statistics Canada	
6.2 National data collection: health sector	
6.3 Data collection in the United States7.0 Benefits and Challenges in Race Data Collection	
7.1 Benefits and uses of race and identity-based data	
7.2 Challenges and concerns with collecting race and identity-bas	
8.0 Empirical Results from the Literature	
8.1 Overview of results	
8.2 Studies of race and identity-based data collection practices	
8.3 Studies of the association between racial identification and he	
8.4 Other studies of race and social identification	
8.5 Studies of Indigenous identity	
9.0 Conclusions and Implications	
9.1 Summary of findings from the literature	
9.2 Implications of the findings	
9.3 Limitations of existing research	
9.5 Future research	
10.0 Recommendations	
11.0 References	46
Appendix A - Ontario's Anti-Racism Data Standards	52
Appendix B – Identity-Based Data Standard for Children's Aid Societ	

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Issue: How do the ways in which individuals are categorized or assigned to racial/ethnic identities in different contexts – by others and by themselves – affect their lived experience, and what are the implications for the collection and use of data on race and identity by public service providers?

Background: Canada is currently lagging in the collection of population-based, disaggregated, and high-quality race and identity-based data, including Indigenous identity. There is a need for better inclusion of data on race and ethnicity to enhance our understanding of equity and diversity issues; however, there are concerns about appropriate procedures for collecting this information. For example, child welfare workers are often asked to populate these fields based on their own observation or perception of people's identities, including their race and Indigenous status – a practice known as social identification or participant observer identification (POI). While this method may increase the amount of data available, there are associated costs, including a lack of standardization and the potential for bias. There are also valid concerns about accountability, governance, ethics, and protections against the misuse of data – particularly for data relevant to First Nations, Métis and Inuit peoples in Canada. Given the importance of identity-based data as well as the current lack of standardization in data collection procedures in Ontario and across the country, there is a need for more evidence-informed strategies for the collection of racial identity data by service providers which can be used to improve policies and services in ways that promote equity.

Methods: A scan of the literature was conducted to identify and synthesize information relevant to the issue of identity-based data collection. The objectives were to: a) examine the literature on the practice and accuracy of social identification of race and identity and its associated outcomes; b) provide an overview of existing practices and policies across fields and jurisdictions; and c) discuss implications for research, policy and practice.

Results: Overall, the findings demonstrate that any research conclusions about racial disparities will be affected by which measure of race is used and how the data were collected. Both self-identification and social identification have been shown to be associated with outcomes relevant to health and social services across studies; however, studies are not always consistent with respect to which measure has a stronger association with disparities in outcomes. While there is growing support for enhanced collection of race and identity-based data, there is still no single agreed upon method or "gold standard" for the process of collecting this data. While most strategies have moved towards selfidentification as the ideal practice, the available literature on social identification of race suggests that relying on only one measure can lead to data inaccuracies, as a single measure may not adequately represent the multidimensionality of race. Research from other countries also shows that observer identification often doesn't match individuals' self-identities. resulting in inconsistencies between different measures or dimensions of race for the same individuals – and this is more likely among certain groups, including those who identify as multi-racial or Indigenous.

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Based on this evidence, researchers have suggested using multiples measures which may all contribute to different experiences of race to better capture different dimensions of racial identity.

Implications: A better understanding of the process of social identification of race and how it differs from self-identification would help inform strategies for the measurement and collection of race-based data – including who should collect such data and how it should be collected. This issue is especially important given the increasing racial and ethnic heterogeneity in Canada and the growth in multiracial identities. In particular, the rapid growth in Indigenous populations means that Indigenous peoples may be especially at risk of the negative social, psychological and health consequences of identity mismatch. However, in order to collect this information effectively, tools must first be developed to accurately measure each separate dimension of racial identity and to help ensure that the most appropriate measures are used. The collection of Indigenous identity requires additional considerations to ensure the use of culturally appropriate, informed and relevant data collection strategies and practices.

Social Identification of Race in Canada

1.0 Introduction

1.1 The issue of race-based data collection in Ontario

Canada is currently lagging in the collection of population-based, disaggregated, and high-quality race data. Across the country, there is a lack of accurate, reliable data on the racial or ethnic identity of service users or populations who are affected by public policies. Even in Ontario, where the *Anti-Racism Act* (2017) has mandated the collection of race and identity-based data over the past five years, there are still challenges with implementation and issues with incomplete data – particularly for Indigenous populations. Improved processes for collecting race-based data are needed for purposes such as assessing and monitoring racism and discrimination, evaluating the effectiveness of programs and services, removing systemic barriers, and creating more equitable systems and service delivery for all families and individuals.

Accordingly, there have been recent calls for changes to data collection practices across public sectors in Ontario, including child welfare. Specifically, there is a need for better inclusion of data on race and ethnicity to enhance our understanding of equity and diversity issues. However, there are concerns from various groups about the appropriate procedures for collecting this information. Child welfare workers in particular must balance the rising demands to populate race and identity fields against the risks of misidentifying individuals in the absence of known data or information on their identity. For example, workers are often asked to populate these fields based on their own observation or perception of people's identities, including their race and Indigenous status – a practice known as social identification or participant observer identification (POI). While this method may result in more data being available, there are also potential costs, such as a lack of standardization and accuracy of the data. Furthermore, racial identification based on perceptions may lead to bias in the ways that people are treated by service providers as they move through the system, which can lead to even greater

inequalities in outcomes.

In addition to questions about the data collection itself, there are also valid concerns about accountability, governance, ethics, and protections against the misuse of data. Issues of data governance are especially relevant and important for First Nations, Métis and Inuit (FNMI) peoples in Canada, who have inherent jurisdictional rights to own any data pertaining to Indigenous identity or status and to control the collection, use and transmission of this information.



1.2 Why is the issue important?

The issue of race-based data collection and social identification is important for several reasons. First, in racialized societies such as Canada, the ways in which individuals are categorized and assigned by others to racial/ethnic categories influences their lived experiences (Cormack et al, 2013). Therefore, understanding the impacts of socially-assigned race identities may be useful in examining the effects of racism and discrimination more broadly. Second, understanding how race is interpreted in different contexts also has implications for the types of data that are collected and

how the data are interpreted (Roth, 2010). Third, better race data collection procedures are needed to understand gaps and inequities in the areas of health, education, and social services across the population in order to address and reduce these inequities. Fourth, any data about race and identity in the Canadian context must consider the additional political ramifications related to defining and measuring Indigenous identity, and should respect and comply with the sovereign inherent jurisdiction of FNMI leaders. Finally, Canada's racial and ethnic diversity continues to grow each year, especially the population of people who identify as Indigenous (CIHI, 2020b). These changing demographics have fuelled even greater awareness and interest in monitoring and understanding racial identities and inequities.

Given the importance of identity-based data as well as the current lack of standardization in data collection procedures in Ontario and across the country, there is a need for more evidence-informed strategies for the collection of racial identity data by service providers which can be used to improve policies and services in ways that promote equity. This is especially important in the context of the recent COVID-19 pandemic, in order to identify and reduce health disparities and outcomes for those who are impacted to a greater extent by COVID-19 infection and pandemic-related health measures and responses.

1.3 Overview of this policy brief

This policy brief reviews the literature on the collection of race-based data in Ontario with a focus on any available evidence on the practice of social identification of race, as well as any evidence specific to Indigenous identity. Examples of recent initiatives and data collection methods used in various sectors within the province and from other jurisdictions (e.g. health care, schools, police services, social services, government) are examined and compared to help inform our understanding of best practices and challenges with the collection and reporting of reliable data on

race, ethnicity, and Indigenous identity. Findings from the literature in the US and Canada on the accuracy of social identification and its relation to other measures of race, including the concordance of various measures of race identity, and the association between social identification and outcomes such as health are also reviewed. Finally, implications and recommendations based on the available literature are provided.



2.0 Objectives

The main objectives of this policy brief are:

- To examine the literature on the practice and accuracy of the social identification of race and identity, and its associated outcomes
- 2) To provide an overview of existing practices and policies for the collection of race-based data in the fields of social services, health, and education and compare practices in Ontario with other provinces and jurisdictions
- 3) To discuss implications for research, policy, and practice and develop recommendations based on the literature

3.0 Research Methods

3.1 Overview of methods and search strategy

An initial scan of the literature was conducted from August to September 2021¹ to determine the breadth of information available and to identify and synthesize information relevant to the issue of identity-based data collection. Various search engines, research portals, and institution-specific websites were utilized for the collection of relevant data. Two main sources of data sources were selected: 1) peer-reviewed journals found in electronic databases; and 2) internet-based grey literature, including published reports, websites of relevant organizations or groups; working papers; presentations or webinars; and government publications and legislation.

Sources were included in the literature review if they were found to contain variables of interest and keywords relevant to the research question and objectives. A hand search of reference lists from relevant studies was also used to supplement searches. Data sources were limited to those published in English. In addition, in order to gather the most current information, the search was largely focused on data sources published after the year 2000, or within the last five years for policy-relevant information. Given the limited amount of research published in Canada on the topic, we included sources published in other countries where relevant.

A list of keywords and search terms used in the literature scan is provided below. Throughout the search process, keywords were added, deleted, or modified as needed to enhance the search strategy.

Keywords: race, data collection, social identification, racial identity, racial identification, identity-based data collection, child welfare, social construction of race, Indigenous, Ontario, Canada

Finally, information was updated as needed throughout the development of this document. This included an extensive consultation and approval process with Indigenous partners and other research collaborators through active participation and engagement, with relevant feedback acknowledged and incorporated throughout the brief.

3.2 Note on terminology

Throughout this report, the term "Indigenous" is used to refer to all Aboriginal peoples of Canada. The Canadian Constitution recognizes three groups of Aboriginal peoples: First Nations (including those registered under the *Indian Act* of Canada and those who are not), Métis, and Inuit (FNMI). These categories are also the most commonly used within race-based or ethnicity data collection tools. However, we acknowledge that these may not be the preferred community or nation-specific labels (CIHI, 2022c). Moreover, although the term "Indigenous" is often used as a collective term for all Indigenous peoples and identities and there may be some commonalities between First Nations, Métis, and Inuit peoples, Indigenous peoples are not a homogenous group. Rather, they are a diverse population comprised of many distinct groups, bands and communities — each with their own histories, languages, cultural practices and beliefs. It is also important to note that FNMI peoples are also constitutionally recognized sovereign nations with inherent rights to self-determination, autonomy and governance (Government of Canada, 2023). We recognize that due to this rich diversity, the meaning, understanding, and impacts of Indigenous identity and social identification may differ for each individual; as well as between communities (i.e. those living on versus off-reserve).

¹ Following the initial literature search, references and information were updated as needed, up to January 2023.

4.0 Background

4.1 Race and racial identity

Historically, race was viewed as a biological construct, based on observable phenotypic characteristics or physical traits of individuals that were believed to be inherent. However, race is now increasingly understood primarily as a social construct, one that is developed and shaped by socio-historical contexts (Stepanikova & Oates, 2016; Macintosh, 2013).

Researchers in social and health sciences have thus moved past the interpretation of race as a single, permanent or static entity to a construct that is multidimensional, multifaceted and fluid, meaning that it can change over time and across contexts and social relationships (White et al., 2020; Campbell & Troyer, 2007, Veenstra, 2011; Roth, 2016). As described by White et al. (2020), the social construction of race is a function of "appearance, societal interactions, institutional dynamics, stereotypes, and social norms."

Race vs. ethnicity

While the terms 'race' and 'ethnicity' are both used to categorize and characterize populations or groups, it is important to note that they are not always synonymous. As described above and by researchers such as Veenstra (2011), race is primarily defined through racialization processes and power relations that serve to benefit some groups over others; while ethnicity refers more broadly to a shared culture or background – which may be defined through a common language, nationality, way of life, religion, material forms such as clothing and food, and cultural products such as art and music. In countries such as Canada with diverse populations, racial identities do not strictly match ethnic identities, meaning that individuals who identify as the same race may claim several different ethnicities. For example, Black Canadians may be first or second generation immigrants with roots in various African and Caribbean nations; Indigenous peoples are comprised of hundreds of bands representing a multitude of different ethnicities; and White Canadians may also belong to several ethnic backgrounds from different European or other countries (Veenstra, 2011).

Indigenous identity

There are additional considerations and complexities related to the identification of Indigenous

peoples in Canada due to the political ramifications of Indigenous identities. There are currently a number of ways to define Indigenous status, which can all vary from each other but may also intersect. This includes legal definitions, such as the constitutional definition of Indigeneity or case law definitions; as well as family and community-based definitions, which may be based on genealogy, tradition, or location (Kesler, 2020). Furthermore, each Indigenous person may hold their own individual understanding or knowledge of these definitions, which can impact how they interpret and respond to questions about their identity. These understandings may sometimes be based on inaccurate beliefs that have been perpetuated through colonialism and assimilation. Therefore, any public service organization or worker (i.e. child welfare workers) must be aware of these different definitions and the potential impact of each one on the people they are identifying - including how one's Indigenous identity or status affects their legal and jurisdictional rights as well as their day-to-day experiences.



4.2 Dimensions and measurement of race

The concept of race as multidimensional has implications for the way that racial identity is understood and measured. Broadly, there are two main approaches to the identification of race:

- 1) *Self-identification* one's own internal or subjective understanding of belonging to one or more racial or ethnic categories
- 2) *Social identification* describes how race is externally assigned or imposed by others through observation, inference or perception

Social identification may be based on physical characteristics of individuals or other contextual factors or available indicators such as an individual's name, language, nationality, religion, or region. In addition, measures of socially-assigned race within the literature may be based either on self-report (i.e. respondents' perceptions of how others classify their own race) or observer report (ie. how an observer actually classifies another person's race).

Past and current practices for the collection of this information vary across sectors and jurisdictions. While self-identification is generally now the accepted norm in race data collection in the United States, some datasets in past relied on observer identification, while others include both self-identified and socially-identified indicators of race (Ford, 2019).

Despite the wide acceptance among researchers of the concept of race as socially constructed, the notion of a biological basis continues to influence the experiences, interactions, and treatment of individuals in racialized societies – where "race/ethnicity remains a salient externally-imposed category that continues to draw on discredited notions of biology, blood and genes" (Harris et al., 2013). As a result, some scholars believe that relying only on one's self-identified race as a form of measurement does not adequately capture the contextual and relational nature of race that includes the lived experience of racial and ethnic groups, or the "individual and structural components of experiencing race in a racialized society" (White et al., 2020). Furthermore, self-identified race may not represent the heterogeneity of experiences of race and racism across individuals within that racial or ethnic group, as these experiences can vary greatly depending on how others perceive them (White et al., 2020).

Multidimensionality of race

Beyond these two broad types of racial identity, some researchers have proposed that there are numerous aspects or dimensions to race. For example, according to Roth (2010, 2016), an increasing number of people experience race not as a single identity but as many conflicting dimensions – including how an individual self-identifies, how they are perceived or classified by others, how they believe they are classified by others, the category that one checks among limited options on a survey, their racial appearance, racial ancestry, and how they present themselves to others. Moreover, while these various aspects of race influence one another and may sometimes align, they are not necessarily the same and do not always correspond.

Example of the multidimensionality of race (Roth, 2010):

"Salvador, a restaurant worker in New York, identifies his race as Puerto Rican. Phenotypically, he is dark-skinned with Indigenous features, leading some Americans to view him as Black. He believes that Americans view him as Hispanic, based on his accent and name. Yet on the census, Salvador checks White for his race because no listed option fits his identity and in Puerto Rico his mixed racial ancestry allowed him to consider himself closer to White than to Black."

Table 1 shows the typology of the various dimensions of racial identity identified by Roth (2010).

Table 1: Dimensions of racial identity (Roth, 2010)

Aspect	Description	Typical Measurement
Internal	Subjective self-identification	Open-ended self-identification
Expressed	The race you readily express to others	Closed-ended self-identification
Reflected	The race you believe others assume you to be	Questions such as "What race do most people think you are?"
Observed	The race others actually assume you to be	Closed-ended interviewer classification
a) Appearance- based	Based on readily observable characteristics (e.g. phenotype, clothing, style, or obvious status markers)	Interviewer instructions for classification on first observation
b) Interaction-based Based on characteristics revealed through interaction (e.g. accent, language ability, name, knowledge of family members, or comments about background)		Interviewer instructions for classification after interaction
Phenotype	Physical appearance	Ratings of skin colour or features, coded by interviewer

As a result, some researchers such as Roth have argued that none of these single dimensions are sufficient to capture the full concept of 'race', and there is no such thing as one's 'true' or 'correct' race. Rather, each of these dimensions may represent different aspects of one's complete race identity and measures different components of the way that individuals experience race and its implications or outcomes through social processes of racialization.

4.3 Race-based data collection

Identity-based data refers to sociodemographic information about a person including, but not limited to, their Indigenous identity, race, ethnicity, religion, gender identity, and sexual orientation (OACAS, nd).

There is growing recognition in Ontario and across Canada of the importance of collecting race and identity-based data in all public and social services for identifying, understanding, and addressing inequities. Specifically, the collection of this data can help with the following purposes (OACAS, n.d.; Ontario Human Rights Commission, 2010):

- Improving the ability of organizations to understand the people they are serving and their needs;
- Addressing racial gaps and barriers in the provision of and access to services and opportunities;
- Improving the allocation of resources to promote equitable service delivery and programs;
- Assessing outcomes and impact of services and programs on different population groups and implementing action plans to improve these outcomes; and
- Developing anti-racist strategies and policies.

Organizations may also be mandated to collect data due to legislative policies or in response to specified needs and circumstances. This may include responding to allegations or evidence that systemic barriers or discrimination exist, or evidence on the effect of a similar policy or practice from other organizations or jurisdictions (Ontario Human Rights Commission, 2010).

However, the collection of identity-based data alone is not sufficient to enact change. As noted by the Chief Commissioner of the Ontario Human Rights Commission, "collecting data on its own is not a solution. It's a tool." (Ontario Association of Children's Aid Societies, 2016). Furthermore, the quality of the data, how it is collected, and how it is used must also be considered (Rizvic, 2020). For example, data on the number of reported cases of COVID-19 in Indigenous communities across Canada as of May 2020 varied significantly depending on the source and methods of the data collection – community-sourced data reported nearly three times as many cases compared to data from Indigenous Services Canada. Reasons for this discrepancy may be related to a lack of coordinated and disaggregated data collection based on race across provincial and federal governments, as well as differences in whether Indigenous peoples who do not live on reserves were included in the data (Rizvic, 2020; Skye, 2020).

Sources of data

Two types of identity-based data can be collected and used in research to produce meaningful information and results: (Ontario Human Rights Commission, 2010)

- 1) *Quantitative* data in the form of numbers, such as incidence or prevalence of people who are identified as a certain race or identity
- 2) *Qualitative* data in the form of words; provides descriptive details and context

Both types of data can be collected from various sources depending on the goals, context, and resources available, including: (Ontario Human Rights Commission, 2010):

- *Pre-existing or official data* data that has already been documented or created during routine operations or record-keeping procedures
- *Survey data* any measurement procedures that involve asking respondents questions
- *Focus groups* a group of people is brought together to facilitate discussion on a research topic of interest
- *Interviews* involve a standard set of questions asked on a one-on-one basis
- *Observation* data gained through observation of research subjects by a trained researcher

4.4 Other considerations for race and identity data collection

Multiracial identity

Recent years have seen a growth in mixed race/ethnicity populations in many countries, due to a number of factors such as globalization and the rise in international migration; increases in interracial unions; and more social acceptance of multiracial identification (Aspinall, 2018; Charmaraman et al., 2014). Indigenous populations have also become more diverse due to increases in mobility and mixed ancestries (i.e. blended families from two different nations or communities), and these combinations of place, lineage, and self-identity can have important implications for data collection and governance (Jacobs, 2019; MCCSS, 2022).

As a result, there is an increased need for appropriate data collection strategies to include mixed race and Indigenous identities. However, the diversity of multiracial individuals as well as the unique social and political histories of each multiracial subgroup creates methodological and definitional challenges in studying this population, and approaches to the measurement of people who identify as mixed or multiple races varies across jurisdictions (Aspinall, 2018; Charmaraman et al., 2014; Woo et al., 2011). Furthermore, some studies and data collection tools either do not allow respondents to report a multiracial/multi-Indigenous identity or do not report data from multiracial participants (Charmaraman et al., 2014).

According to Charmaraman et al. (2014), even small differences in measures can result in large differences in estimates of the multiracial population. A review of methods by Aspinall (2018) found that there is no single "gold standard" method of capturing the mixed race population in national censuses and surveys, and that existing methods each have their own potential issues. For example, while the multi-ticking method provides more detailed data on the composition of mixed identities, it has been found to have poor reproducibility.

Examples of current approaches to collecting information on multiple races or ethnicities in national censuses are provided in Table 2.

Table 2: Existing international approaches to the measurement of mixed race identities (Aspinall, 2018)

Approach	Examples of Countries and Census Years	Description
"Tick all that apply" approach	New Zealand (1996-2013), US (2001, 2010), Canada (1996-2016)	Respondents may select more than one response across predesignated racial categories
Prespecified combinations	England and Wales (2001, 2011), Bahamas (2010), Jersey (2011)	Predesignated combinations of specified races are provided as a response option (e.g. "white and black Caribbean"; "black and other")
Open response/ write-in question	Scotland and Northern Ireland (2001, 2011)	Respondents are provided an option to describe their race(s) in their own words; although some countries restrict the number of groups that can be specified
Single closed term	Grenada (2001), Jamaica (2011), Barbards (2010)	Predesignated generic "mixed" option provided

Woo et al. (2011) developed a multidimensional model to reconceptualize the assessment of multiracial status in the US. The authors propose that multiracial status is a complex construct with three different dimensions that can be assessed using various measures: 1) ancestry or genealogic history; 2) self-reported identification (i.e. as used in the Census); and 3) socially-assigned identification. These dimensions represent distinct but overlapping populations and may be associated with unique outcomes. However, each approach to measurement has limitations. For example, both self-identification and socially-assigned identification methods may result in data that underestimates the multiracial population. Some researchers suggest that the optimal way to assess multiracial status depends on the purpose of the data collection and the research question (Woo et al., 2011; Charamaraman et al., 2014).

Intersection of identities

It is important to consider how race and Indigenous identity may intersect with other social identities when examining racial inequities and disparities. For example, people's experiences of race and racism may vary depending on their additional overlapping or intersecting social identities, such as their gender identity, sexual orientation, age, religion, socioeconomic status, language, and disability status. The collection and analysis of multiple social identities may therefore be useful in identifying and understanding factors that impact outcomes for various racial groups – and is encouraged by the Ontario identity-based data standards (Government of Ontario, 2020, Section 7).

4.5 Indigenous data governance

As a result of past histories of exploitation and inequities in research and data, Indigenous peoples have raised concerns around the challenges of incorporating Indigenous ways and priorities into data practices and policies and the need to produce data that better reflects their interests and governance needs (Carroll et al., 2020).

In the current Canadian context, any data collection initiative that includes information about race and identity must take into account additional considerations specific to the collection and management of information about Indigenous identity and communities (see box on the right). For example, beyond the implications of how Indigenous identity is defined (see Section 4.1), there are also important procedures for interacting with the data that must be respected and followed. This involves ensuring that FNMI peoples have ownership and control over data collection processes and the data itself, including how it is used and shared.

Indigenous data governance principles may vary between communities and organizations; however, their ultimate aim is to help ensure that information collected about Indigenous identity is used to promote positive community outcomes, such as supporting Indigenous cultural expression and advancing self-determination (Government of Ontario, 2020). While it is beyond the scope of this report to describe the full details and principles behind Indigenous data governance and sovereignty, an overview of some of the key principles in Canada and at the global level is provided in the box on page 10.

Key Concepts around Indigenous Data Governance

Indigenous data:

- Data on and about Indigenous peoples and territories, as well as information about Indigenous communities and the individuals that live within
- May be generated by Indigenous peoples or by governments and other institutions

Indigenous data sovereignty:

 An assertion of the rights and interests of Indigenous peoples in relation to data about them and their communities

Indigenous data governance:

- Includes both the stewardship and processes needed to implement Indigenous control over Indigenous data
- i.e., the collection, storage, management, analysis, use, dissemination

Source: Carroll et al. (2020)

The increasing acknowledgement and incorporation of Indigenous data governance principles such as OCAPTM in research projects and practices across Canada represents a positive shift towards the recognition and acceptance of Indigenous data sovereignty and allowing Indigenous peoples to reclaim control of Indigenous data. However, it is important to note that these are still fairly new concepts and the development of data principles specific to other Indigenous groups and communities is an ongoing process. For example, the OCAPTM principles are specific only to First Nations; they do not officially cover other Indigenous populations or communities in Canada. While all Indigenous peoples may support the underlying basis of the OCAPTM principles, it will be important to establish data governance principles that apply specifically to Métis and Inuit peoples as well.

Examples of Indigenous Data Governance Principles

1) **OCAP**TM (First Nations) (Source: First Nations Information Governance Centre, n.d.)

OCAPTM is a tool to support data governance and sovereignty specifically for First Nations data and information. The principles of OCAPTM assert that First Nations control data collection processes in their communities and have the right to own and access First Nations data and make decisions about how the information is used, interpreted, and shared.

Components of OCAPTM:

- **Ownership:** refers to the relationship of First Nations to their cultural knowledge, data, and information. This principle states that a community or group owns information collectively in the same way that an individual owns his or her personal information.
- **Control:** affirms that First Nations, their communities and representative bodies are within their rights in seeking to control over all aspects of research and information management processes that impact them. First Nations control of research can include all stages of a particular research project-from start to finish. The principle extends to the control of resources and review processes, the planning process, management of the information and so on.
- Access: First Nations must have access to information and data about themselves and
 their communities, regardless of where it is currently held. The principle also refers to
 the right of First Nations communities and organizations to manage and make decisions
 regarding access to their collective information. This may be achieved, in practice,
 through standardized, formal protocols.
- **Possession:** refers to the physical control of data. Possession is a mechanism by which ownership can be asserted and protected

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2) CARE Principles (Global) (Source: Carroll et al., 2020)

Drawing on the FAIR¹ principles and the OCAP™ principles, Indigenous Data Sovereignty networks in New Zealand, Australia, and the United States (along with other Indigenous scholars and leaders) developed a set of global principles for the governance of Indigenous data, called the CARE principles:

- **Collective benefit**: Indigenous data must facilitate collective benefit for Indigenous peoples
- **Authority to control**: Indigenous peoples must have access to data and the authority to control and govern such data
- **Responsibility**: working with Indigenous data involves a responsibility to nurture respectful relationships with Indigenous peoples that advance the first two principles
- Ethics: ethical data practices must include representation and participation of Indigenous peoples to ensure Indigenous peoples' rights and well-being are upheld

The CARE principles differ from existing mainstream frameworks by focusing more on the 'people' and 'purpose' aspects. However, the goal is for data users to implement both the FAIR and CARE principles in tandem.

¹ The FAIR Guiding Principles for scientific data management and stewardship (Findable, Accessible, Interoperable, Reusable) serve to guide data producers and publishers and are not specific to Indigenous data (see Wilkinson et al., 2016 for more information).

5.0 Race Data Collection in Ontario - Policies and Practice

The collection of identity-based data existed in various forms within some public sector organizations and agencies in Ontario for many years; however, it was not collected in a standardized manner, which limited comparability across sectors and the ability to use data to measure and address inequities (Toronto Central Local Health Integration Network, 2014).

Ontario lacked a systematic approach to race and identity-based data collection until 2017, with the passage of the *Anti-Racism Act* (ARA) and its subsequent Data Standards, which mandated public sector organizations (PSOs) ² within child welfare, education, and justice to collect and report race-based data within specified timeframes (Anti-Racism Act, 2017). Prior to the ARA, the collection of race and identity-based data across public sectors was also stimulated by the release of a new guide on the collection of identity-based data from the Ontario Human Rights Commission in 2010, which helped to dispel the myth that collecting and analyzing data that identifies people on the basis of race is not permitted under the Ontario Human Rights Code. ³

5.1 Timeline of relevant policies and events

A timeline of relevant policies, projects, reports, and outcomes in the recent history of race-based data collection in Ontario, including Indigenous identity, is provided below:

- 2007 The Ontario Ministry of Education released the *Ontario First Nation, Métis, and Inuit Education Policy Framework* which called for school boards to collect voluntary self-identification data from First Nation, Métis and Inuit students in Kindergarten to Grade 12 schools.
 - The data was to be used at the local level to plan policies and programs to better support student achievement, assess progress, and inform policy and funding decisions; with progress reports to be published every three years. (Ministry of Education, 2007)
 - The Framework also recommended involving Indigenous parents, families and communities in school board policy development
- **2010** The Ontario Human Rights Commission (OHRC) launched "*Count me in!*" a new guide on collecting human rights-based data in a wide variety of sectors across the province.
 - The guide provides "a plain language, common-sense framework for collecting data in a way that can build trust and encourage proactive solutions", as well as best practice examples (OHRC, 2010)
- **July 2015** The Children's Aid Society of Toronto was the first child welfare agency in the province to publicly share race-based data.
 - Results were used to understand and address disproportionality, disparity and discrimination in child welfare services provided to Black families. For example, the data

² PSOs include ministries, municipalities and local boards, school boards, universities and colleges, local health integration networks, service providers under the Child, Youth and Family Services Act, and correctional institutions (https://www.ipc.on.ca/wp-content/uploads/2018/09/2018-08-22-york-university-faculty-of-education-web.pdf)

³ The Ontario Human Rights Code permits the collection and analysis of data based on race and other grounds provided that the data is collected for purposes consistent with the Code, such as monitoring discrimination, identifying and removing systemic barriers, addressing historical disadvantage, and promoting equality. In fact, the OHRC states that "In the context of racial discrimination, data collection and analysis can be a necessary or even an essential tool" (http://www.ohrc.on.ca/en/racism-and-racial-discrimination-data-collection-fact-sheet)

revealed that 29% of ongoing service cases and 31% of children in care in 2013 self-identified as Black, even though only 8.5% of the population in the city of Toronto self-identified as Black according to 2011 Census data (Children's Aid Society of Toronto, 2015).

- **Dec 2015** The Truth and Reconciliation Commission of Canada (TRC) released its final report. Within the report's calls to action were calls for governments in Canada to commit to reducing the number of Indigenous children in the child welfare system, and to prepare and publish annual reports on the number of Indigenous children in care.
 - In response to the TRC report, the OHRC committed to using its mandate to support the calls to action and examine the overrepresentation of Indigenous and racialized children in the child welfare system. As a first step, this would include learning which data and data collection practices are used by children's aid societies across the province (OHRC, 2015).
- **Feb 2016** The Ontario Government established the Anti-Racism Directorate, which leads the government's initiatives to eliminate systemic racism in policies, programs and services.
- Sept 2016 The "One Vision One Voice" project launched a practice framework to support improved outcomes and equitable services for African Canadians in the child welfare system, with funding from the Ministry of Children and Youth Services through the Ontario Association of Children's Aid Societies.
 - Recommendations to address systemic racism and overrepresentation of Black children in the child welfare system resulting from this work included the collection and reporting of race-based data within the sector. Specifically, child welfare agencies were called on to:
 - 1) Collect disaggregated race-based data for each family and child and input this information into the Child Protection Information System (CPIN) ⁴ or the organization's system for data collection
 - 2) Regularly analyze and report on this data to identify disproportionality and disparities at each decision point on the child welfare continuum and monitor change
 - o 3) Ensure staff have the knowledge and skills to gather race-based data
- Mar 2017 Ontario released the three-year "Anti-Racism Strategic Plan", which includes a plan
 for developing a standard framework and guidelines for the collection of race-based
 disaggregated data across government-funded programs and policies.
- May 2017 OHRC released its report on racial profiling in Ontario, titled "Under Suspicion".
 - The report continued and reinforced the OHRC's call for the collection of race-based data to understand and address concerns about racial profiling in the child welfare sector, particularly how it affects Black and Indigenous families.
- **June 2017** Ontario passed the *Anti-Racism Act, 2017* to promote equity for racialized and Indigenous peoples in policies, programs and services, which mandated the collection of racebased data.

Policy Brief 12

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⁴ CPIN refers to the new provincial information management system used by Children's Aid Societies in Ontario to store information needed to deliver child protection services

- **Dec 2017** The Ontario Government released the "Anti-Black Racism Strategy" with the aim of eliminating disparity outcomes for Black Ontarians in the child welfare, education and justice sectors by 2024.
 - Initiatives included leveraging existing race-based data and research; developing progress targets based on available data; and training on identity-based data collection within school boards.
- **Dec 2017** The Ontario Ministry of Children and Youth Services⁵ issued a policy directive (CW005-17) which sets out requirements for Children's Aid Societies to collect and report identity-based data about the children and youth they serve using CPIN, beginning in February 2018.
 - Identity-based data was to be collected directly from children and youth through selfreport, using the standardized questions in the Identity-based data standard
 - The collection of identity-based data under this directive was not meant to alter or replace CAS's existing non-standardized data collection practices, including collection of sociodemographic information through third parties or official documentation.
 - However, issuing the new directive without specifically changing the practices that were already in place raises concerns with respect to the consistency and reliability of data collection methods across the sector as well as the resulting data.
- **Feb 2018** The Ontario Public Service Anti-Racism Policy was released, and came into effect in April 2018. The Policy established mandatory requirements and responsibilities to ensure the accountability and sustainability of the government's anti-racism commitment.
 - The Policy recognizes the need for enhanced disaggregated race data collection, analysis and reporting to address racism in employment and inform evidence-based strategies.
- April 2018 OHRC released a report on findings from its inquiry into the overrepresentation of Indigenous and Black children in Ontario's child welfare system (called "Interrupted Childhoods: Over-representation of Indigenous and Black children in Ontario child welfare")
 - Key findings from the report included: 1) Race-based data collection processes and practices were a patchwork across the child welfare sector; and 2) Indigenous and Black children were over-represented in admissions into care at many child welfare agencies in the province (OHRC, 2018)
 - The findings confirmed previous concerns from other reports such as the TRC report and the One Vision, One Voice project and called on the Ontario government to develop a provincial strategy to identify and address racial disparities and racial profiling in the child welfare system, including improved processes for collecting race-based data.
- April 2018 Ontario's Anti-Racism Data Standards were released to help identify and monitor racism and racial disparities within the public sector and enable specific public sector organizations (PSOs) within child welfare, education and justice to fulfil their obligations under the ARA.
 - The Standards set out the requirements for the collection, use, disclosure, de-identification, protection and management, publication and reporting of information, including personal information related to Indigenous identity and race.

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⁵ Note: this name is no longer in use. In 2018, the Ministry of Children and Youth Services merged with the Ministry of Community and Social Services to form the Ministry of Children, Community and Social Services.

- Note: Race categories used in the Standards are those commonly used as social descriptors in Ontario (see Appendix A for categories).
- The Standards also set out specific requirements for the collection, management and use of Participant Observer Information (POI) as a type of indirect collection, which refers to an individual's perception of another individual's race. POI collection may only occur in certain circumstances and under specified conditions and purposes, such as assessing racial profiling ⁶ or bias within a service, program, or function (see Appendix A))
- **July 2019** Ontario's Youth Justice sector began collecting race-based data, in compliance with the Anti-Racism Data Standards.
- **Jan 2020** Ontario's police services began collecting perceived race-based data on individuals on whom force was used.
- **June 2020** The Ontario Ministry of Health approved an amendment to the *Health Protection* and *Promotion Act* (under Regulation 569) which requires the collection of new sociodemographic data on race, income level, language and household size for individuals who test positive for a novel coronavirus, including COVID-19.
 - This information is collected alongside other case investigation questions as per routine public health unit practices, and individuals may choose not to answer any questions. Information is collected under the authority and protection of the *Personal Health Information Protection Act* (PHIPA).
 - The question about race includes six categories. Individuals may select all that apply, or "another race category", "don't know", or "prefer not to answer".
 - Public health units report the information using the integrated Public Health Information System (iPHIS).
 - The Ministry of Health resolved to with Indigenous partners to determine whether collecting information about Indigenous identity would be also be beneficial for addressing health inequities (Public Health Ontario, 2020a)
- March 2021 Ontario's Ministry of Health began collecting voluntary socio-demographic data from people receiving the COVID-19 vaccine, including race.
 - Legislation to support timely reporting to the Ministry of all relevant data from COVID-19 vaccination sites (including voluntary socio-demographic data) was passed in June 2021
- **June 2021** The Ontario Ministry of Children, Community and Social Services issued a new policy directive (<u>CW003-21</u>; see Appendix B) for the collection and reporting of identity-based data by children's aid societies, replacing CW005-17.
 - Changes included: updates to fully align with requirements of the Anti-Racism Data Standards under the *Anti-Racism Act, 2017* and replaced the Identity-based data standard with an updated version
 - Notably, there was also a specification that Indigenous societies on CPIN are **not** required to
 collect and report identity-based data under the policy directive, in respect of ongoing
 discussions with Indigenous societies and partners on Indigenous data governance.

⁶ The OHRC currently defines "racial profiling" as: any action undertaken for reasons of safety, security or public protection, that relies on stereotypes about race, colour, ethnicity, ancestry, religion, or place of origin, or a combination of these, rather than on a reasonable suspicion, to single out an individual for greater scrutiny or different treatment (http://www.ohrc.on.ca/en/what-racial-profiling-fact-sheet)

- Therefore, while the Ministry began collecting race-based data through CPIN following the directive, Indigenous data has been excluded⁷ as an interim approach until a new Indigenous data governance strategy is in place. As a result, the Ministry is still unable to count the number of Indigenous children and youth in the child welfare system (MCCSS, 2022).
- According to the Ministry, the collection of standardized identity-based data will allow
 societies and the Ministry to better understand who is receiving child protection services
 and outcomes for specific children and youth; and to support planning across the child
 welfare system, including work to address ongoing disparities and disproportionalities
 experienced by some children, youth, and families. Furthermore, by providing children and
 youth with a voice in how they choose to identify themselves, child protection workers will
 be more informed in their case planning that is more responsive to individual's unique
 needs (MCCSS, 2021)
- **July 2021** as of July 1, specified children's aid societies listed in the ARA (which does not include any Indigenous societies) were required to begin collecting race-based data in accordance with the Act and the Anti-Racism Data Standards.
- **Sept 2021** the Ontario government released an annual progress report on the province's Anti-Racism Strategic Plan. Some highlights of the report's findings include (Government of Ontario, 2021):
 - 18 school boards now collect race-based data through a student census a significant improvement since 2017, when only one school board (Toronto District School Board) had collected comprehensive student demographic data.
 - Compliance rates for the collection of race-based data within the justice system were high for example, 100% of program areas in the Youth Justice Division and all Ontario correctional institutions, probation offices and parole offices are now collecting race-based data from individuals as part of their intake processes. Response rates ⁸ across sectors remain slightly lower.
- **November 2022** The Ontario Health Data Council released their report to the Ministry of Health outlining a vision for the management and use of health data in the province.
 - The Ministry of Health is reviewing the recommendations in the report, which include strengthening health data to improve health equity outcomes, building data stewardship capacity and supporting Indigenous data sovereignty (Ontario Health Data Council, 2022).
- **January 2023** as of January 1, all school boards in Ontario are required to collect race-based data under the ARA and data standards.
 - Specifically, boards must collect this data as it relates to academic performance; special education received; and suspensions, expulsions, or refusal of admittance of students (Government of Ontario, 2022).

⁷ This includes excluding the use of data from Indigenous children's aid societies, as well as filtering out Indigenous data from non-Indigenous societies in CPIN using defined fields (i.e., ethnic origin, population group, status under Indian Act, FNIM community and identity).

⁸ **Compliance rate** measures whether race-based data was requested from a subject and **response rate** measures whether race-based data was voluntarily provided by the subjects.

Highlights of Ontario's Data Standards for the Identification and Monitoring of Systemic Racism (Anti-Racism Data Standards, 2018)

- Public sector organizations (PSOs) must collect personal information directly from the individual to allow for voluntary expressed consent – or from another individual who is legally authorized to act on their behalf.
- Information must be collected using methods and processes that are accessible, culturally safe, protect confidentiality and privacy, and respect individual dignity. Methods should also be responsive to the needs of individuals and communities, such as administering the collection in other languages.
- PSOs should work with Indigenous communities and partners to help determine best practices for collecting information about Indigenous identity. Questions and responses may be allowed to vary to meet the needs and requests of Indigenous communities, for example, to allow for Indigenous people to self-identify in other, more specific ways.
- To capture multiple race identities, it is more accurate to allow for multiple selection of categories rather than using a generic "mixed race" category option.
- It is not recommended to include non-response options (e.g. "don't know" or "prefer not to answer") unless such responses would provide useful or valid information. Online collection methods should avoid forcing responses and may allow for a non-response in such cases.
- To promote higher response rates, PSOs should ensure all clients understand the purpose of the data collection and how their information will be used and protected.
- The information should be collected at the earliest appropriate time in an individual's interaction with a program or service, which helps to monitor their outcomes throughout their participation and ensure they receive relevant supports.
- To protect personal privacy and confidentiality (for both individuals and communities), access to information is limited to those who require it to perform their job duties. Procedures must also be in place to allow individuals to request access to or removal of their own information. Personal information must also be de-identified prior to any public reporting or release of data.
- Order of questions on race and Indigenous identity:
 - The Standards contain a specific question about Indigenous identity that allows for flexibility in the way Indigenous people may choose to self-identify, recognizing that they may not self-identify as belonging to one Indigenous group. The Indigenous identity question is distinct from the question about race (which also includes an "Indigenous" category).
 - The order of these questions affects how people respond. To promote higher accuracy of responses and improve response rates, questions about Indigenous identity and ethnic origin should be asked immediately prior to asking about race.

¹ "De-identification is the process of removing or transforming personal information in a record or dataset so that there is no reasonable expectation in the circumstances that the information could be used, either alone or with other information, to identify an individual. PSOs should take into account other available information and datasets that might be used with the de-identified data to re-identify individuals (Source: Anti-Racism Data Standards, 2018)

5.2 Examples of race-based data collection initiatives and outcomes in Ontario

The following examples and cases of race and identity-based data collection initiatives across public sectors in Ontario demonstrate some of the successes and challenges with data collection.

Examples from child welfare services:

- 1) **Children's Aid Society of Toronto** (Source: OACAS, n.d.; Children's Aid Society of Toronto, 2015):
 - In 2015, The Children's Aid Society of Toronto (CAST) became the first child welfare society in the province to publicly share race-based data.
 - The data revealed that African Canadian children and youth were significantly overrepresented in the child welfare system (i.e. African Canadians represented 40.8% ⁹ of children in care but only 8.5% of the total population in the city of Toronto).
 - The information gained from this data resulted in a more focused effort to assess and address racism and racial disparities within the current service delivery models to improve outcomes for African Canadian children, youth and families.
 - Examples of actions taken as a result of the examination of race-based data by CAST included creating a stakeholders advisory group and identifying patterns of referral.
 - Initial signs of success of these efforts are demonstrated by a reduction in the number of African Canadian youth admitted to care two years later in 2017.

2) Children's Aid Society of Ottawa – (Children's Aid Society of Ottawa, 2020)

- In response to the Ontario Anti-Racism Act, 2017 and Data Standards, the Children's Aid Society of Ottawa began reporting race-based data as part of their new five-year (2020-2025) strategic plan to support improved services to families from Black, racialized, and Indigenous communities.
- Evidence from race-based data collected in 2020 revealed disproportionalities among Black, racialized, and FNMI families. For example, Black families were overrepresented and White families were underrepresented among investigated families and families receiving ongoing services compared to the population of the city of Ottawa. Black children and Indigenous children were also overrepresented among admissions into care.
- However, an important finding was that a large proportion of the files did not have an identified race, significantly impacting data outcomes. For instance, 24% of files on families receiving ongoing care and 55% of files on investigations did not have race data. These results revealed the limitations of existing race-based data collection and reporting and the need to prioritize these efforts to reduce the amount of incomplete data.

Examples from education:

1) **Métis student self-identification in Ontario's school boards** (Source: Anuik & Bellehumeur-Kearns, 2014)

As mentioned in Section 5.1 (see pg. 11), the Ontario Ministry of Education released a framework in 2007 to support the voluntary self-identification of FNMI students. An evaluation study of this framework examined progress in its implementation across Ontario's 76 school boards, focusing on self-identification of Métis students (Anuik & Bellehumeur-Kearns, 2014). The researchers used a mixed method study design to collect data through surveys, interviews and site visits with schools and school leaders in 2011. Findings from the exploratory study included:

 $^{^9}$ 31% of children in care were Black, and another 10.8% were of a mixed race that included a Black parent.

- Compliance with the self-identification policy was high, as 32 out of the 33 school boards that responded to the survey confirmed they had collected data or were in the process of implementing data collection through self-identification registration forms.
- A majority (67%) of school boards reported having an Aboriginal Education Advisory Council and most had developed their self-identification forms through consultation with the councils and other community members or agencies, demonstrating an encouraging level of community engagement. However, only 52% of boards had a Métis representative involved in school governance and 30% had education officers and teachers responsible for FNMI learning.
- Many school boards created supporting fact sheets to accompany the self-identification forms and posted their policies on websites to provide more information.
- A key finding that emerged was that self-identification involves more than just responding to a one-time survey question and should be a part of school climate as a whole, including curricula, buildings, staff, and other school practices that must reflect and represent Métis students. By creating learning environments that encourage all students and their families to feel more comfortable and welcome, self-identification policies will be more effective.
- School boards that had collected data for more than one year indicated that the number of families identifying their children as Métis had grown each year that the self-identification policy was administered, which may suggest that families were becoming more comfortable self-identifying. However, the number of self-identified students remained far below the actual number of Métis students in Ontario's schools. These discrepancies between self-identification data and Census data could be related to fear and mistrust among families due to persistent racism, or delays in receiving official confirmation of their ancestry both of which could be barriers in self-identifying.
- The authors suggested that additional research is needed to understand causes of underreporting and improve the accuracy of self-identification data so that it can be relied on for purposes such as allocating resources to support Métis students.

2) **Keewatin-Patricia District School Board** (KPDSB) (source: OHRC, 2010)

- The KPDSB in northwestern Ontario was one of the first school boards in the province to establish a voluntary and confidential self-identification policy for FNMI students to identify, collect and aggregate student achievement data.
- The purposes of collecting Indigenous identity data were to: 1) monitor the achievement and areas of need among Indigenous students from Kindergarten to Grade 12, and 2) allocate targeted resources in particular areas of need based on the data. In addition to improving achievement and program delivery for Indigenous students, the data collection system seeks to monitor and evaluate potential discrimination; identify and remove systemic barriers; and prevent or reduce disadvantage for FNMI students (Keewatin-Patricia District School Board, 2015).
- Data has shown that approximately half (53%) of students in the school board self-identify as Indigenous (KPDSB, 2014).
- Challenges with data collection included gaining the trust and support of Indigenous families and communities. Overcoming these challenges required efforts such as extensive community consultations and targeted communication strategies (OHRC, 2010).
- Thus far, the policy has helped KPDSB to identify an academic achievement gap between
 Indigenous and non-Indigenous students; design and implement programs and supports for
 Indigenous students and their families; demonstrate that Indigenous students can achieve
 at the same level as their non-Indigenous peers; and foster stronger working relationships
 with Indigenous stakeholders and the community (OHRC, 2010).

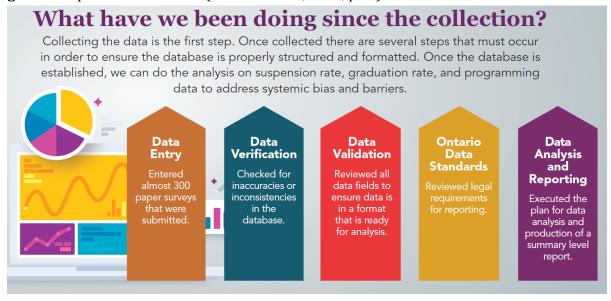
3) Ottawa-Carleton District School Board (OCDSB) (OCDSB, 2020)

In 2020, the OCDSB released a summary report of its identity-based student survey called "Valuing Voices: Identity Matters!". The data was collected from 2019 to 2020 and represented the first survey conducted by an Ottawa-based school board since the introduction of the Ontario ARA and Data Standards.

- The survey was informed by focus group discussions with parents and students, as well as by community groups and agencies. The information gained through this initial consultation process helped the OCDSB to identify important themes and understand the context in which disparities operate within the system, and to shape the data collection process.
- The results demonstrated the diversity of the student population. ¹⁰ For example, while the majority of students from Kindergarten to Grade 12 identified as White, there was representation from all response options for the question about race. In addition, about 3.5% of respondents identified as First Nations, Métis, or Inuit.
- Findings will be used to understand racial disparity in student outcomes and experiences; to inform the school board's commitment to equity; and to allow them to take evidencebased action to address structural racism and systemic barriers.
- Future steps include meeting with community partners and organizations and other stakeholders to understand and interpret the data; linking the survey data to other datasets; and preparing future reports to examine patterns and trends related to racial or other disparities (see Figure 1).
- The OCDSB also recognized that community groups and organizations must be included in the establishment of appropriate methods for analyzing the data and for the development of data sharing protocols, in accordance with the Data Standards. This includes the rights of Indigenous communities to have ownership, control, access, and possession of their data.

"Identity is complex and multifaceted, and we heard that it matters. Providing a space that allows people to express their identity is a critical first step for the District to understand the unique and diverse characteristics of the student population it serves." (ODCSB, 2020; p.16)

Figure 1: Steps in data collection (Source: ODSCB, 2020; p.10)



 $^{^{}m 10}$ Note that parents/guardians completed the survey on behalf of younger students, grades JK-6

Example from justice:

1) **Toronto Police Services Board** (TPSB, 2019)

The TPSB responded to Ontario's ARA and Data Standards by implementing a new policy on race-based data collection, analysis and reporting in September 2019. The TPSB recognized "the importance of collecting, analyzing and reporting on data related to the race of those with whom police interact", which is critical to the goal of eliminating racial bias and discrimination in the delivery of police services and for assessing the effectiveness of initiatives aimed at reducing bias.

- The TPSB adopted a phased approach to implementation of the policy, beginning with collection of race-based data on the use of force starting in January 2020, and then expanding to other areas (i.e. stops, questioning, arrests, charges, and other interactions).
- Procedures for race-based data collection must "ensure that data is collected in a consistent, transparent and meaningful manner to inform evidence-based decision- making and public accountability in the context of community safety and policing services" and would be subject to external review.
- In developing these procedures, TPSB incorporated the use of two types of data: 1) service members' perception data defined as information derived from a member (i.e. police officer) using their own perception to determine an individual's race by observation; and 2) self-identification data information derived from an individual providing their race in response to being asked this information by a service member.
 - o Perception data is to be collected in every case, using members' best assessment.
 - Self-identification data is to be incorporated with a phased-in approach, recognizing that this data will allow for proper evaluation on an ongoing basis.
 - Race categories correspond to those listed in Ontario's Anti-Racism Data Standards.
 For perception data, only one category can be selected, and non-response options are only permitted for self-identification data.
- All TPSB service members must receive comprehensive training, which was to be developed in consultation with the community and in regards to international best practices, and should be provided as an ongoing, continuous program of learning.
- In addition to conducting its own analyses of the data, the TPSB plans to engage in an
 ongoing partnership with an independent academic or other organization to allow another
 organization to conduct analyses and report to the board with its findings and
 recommendations.

Example from health:

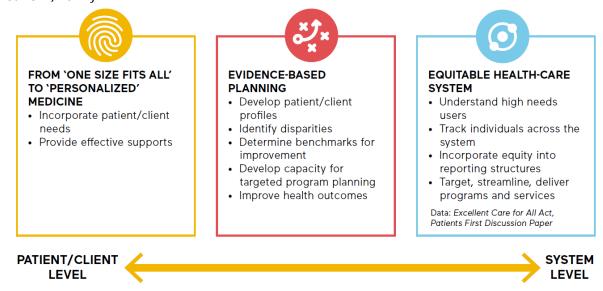
1) Measuring Health Equity - Toronto Central LHIN and CHCs

The Toronto Central Local Health Integration Network (LHIN) began collecting patient level demographic data (including ethnicity/race and seven other variables) in 2013 under the Measuring Health Equity project – a "transformative and first of its kind Canadian effort" which mandated the standardized collection of demographic data from patients and clients as part of a system-level approach to promoting health equity (Toronto Central Local Health Integration Network, 2017).

• The mandate began with 16 hospitals in the network and was expanded to Community Health Centres (CHCs) the following year. A pilot project conducted with four CHC's was first completed to evaluate the use of the standardized questions for demographic data collection and a number of recommendations based on the evaluation were developed. These included the need for staff training; and a focus on reducing missing data rates by

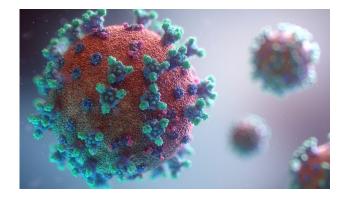
- directly asking the questions to clients as the ideal method of data collection, rather than asking clients to complete the questionnaire themselves. (Toronto Central Local Health Integration Network, 2014)
- In addition, findings from the initial experience in hospitals revealed that *how* questions were asked was as important as *what* was asked, meaning that data collection practices had a significant impact on participation. Overall, patients were open to responding to demographic questions, especially when asked with respect and care. Higher participation rates from clients were found when staff were well trained and engaged; patients were followed up with to ensure completion; and had access to staff for any questions.
- The project represents the first time in Canada that hospitals built data collection into their day-to-day patient registration, providing unprecedented information about patients and clients. In addition, the breadth of demographic questions included allows for intersectional analyses.
- Access to this data can be used for several purposes, including: tracking treatment and
 outcomes; informing clinical care and developing more customized programming;
 stratifying service utilization and outcome data; and monitoring the impact of policies or
 programs.
 - For example, breast cancer screening rates can be stratified by racial group to identify missed targets; and race data can be used to discuss nutrition with pregnant patients.
- Next steps for the project were identified as: improving and expanding data collection and quality; using the information to identify high needs populations; collaborating with stakeholders on using the data to improve patient outcomes and quality of care; and sharing best practices and educational efforts.

Figure 2: Levels of demographic data use (Source: Toronto Central Local Health Integration Network, 2017)



5.3 Data collection during the COVID-19 pandemic

In 2020, the COVID-19 pandemic further underlined the importance of collecting race data to fill existing gaps and brought the issue to the forefront of pandemic response and recovery planning in Ontario. While COVID-19 has severely impacted the lives, health and well-being of all people in Canada and globally, racialized populations have experienced a disproportionately greater risk of infection and adverse health outcomes from the virus (McKenzie, 2020; Pinto & Hapsari, 2020). This increased risk is



largely due to structural and systemic racism and discrimination which impacts access to healthcare and resources for key priority populations who are already marginalized in other ways (Alliance for Healthier Communities, 2020; Pinto & Hapsari, 2020).

However, the lack of disaggregated race and ethnicity data in Canada at the start of the pandemic limited the ability of policymakers and public health agencies to identify or monitor health disparities and to develop evidence-based interventions to reduce these inequities in the context of COVID-19 (McKenzie, 2020). As noted by McKenzie (2020), pandemic policy responses can be more effective by focusing not only on flattening the overall curve in the number of infections, but also on understanding who is under the curve – a strategy that relies on socio-demographic data collection.

In April 2020, a group of 192 organizations called on the Ontario government to mandate the collection and use of sociodemographic and race-based data across health and social services sectors during the pandemic to address health inequities – stating that "we cannot address what we cannot measure" (Alliance for Healthier Communities, 2020). The Black Health Equity Working Group (BHEWG) also formed to link Black communities, academics, service providers and policy specialists in highlighting the need for data on race/ethnicity during the COVID-19 public health response, such as at tracing and testing (McKenzie, 2021). The BHEWG developed a data collection strategy which included suggestions for tools for data collection and a data governance framework, with the aim of achieving a more equitable pandemic (McKenzie, 2021). In response to this growing pressure from community organizations as well as emerging evidence from other countries such as the US and UK on racial differences in COVID-19 rates, efforts to collect race and ethnicity data increased within local public health units and provinces in Canada. However, by the end of the first wave of the pandemic in 2020, only two provinces (Manitoba and Ontario) were routinely collecting this information (McKenzie, 2020).

As more data became available, it became clear that disparities in COVID-19 infection rates existed for racialized groups in Ontario. For example, in a geographical study exploring neighbourhood-level trends in Ontario, infection rates were found to be three times higher; hospitalization rates were four times higher; and death rates were twice as high in areas with a higher proportion of racialized people (Public Health Ontario, 2020b). Data from Toronto Public Health also revealed that racialized groups were overrepresented among COVID-19 cases and hospitalizations in the city (City of Toronto, 2020). These findings highlighted the need for a data-driven health equity approach to protect racial and ethnic minority groups from experiencing further harms from COVID-19 by ensuring more equal access to and equitable outcomes from interventions.

As vaccine administration expanded in Ontario beginning in 2021, further efforts were taken to ensure equitable access to vaccines and support the prioritization of at-risk groups. This included the collection of race data alongside other demographic questions during the vaccination process. The purpose of this data collection was to inform and monitor vaccine roll-out in communities that were disproportionately impacted by the pandemic; tailor strategies to improve uptake where needed; and expand opportunities for research and analysis (Public Health Ontario, 2021b). Preliminary analyses following the initial implementation of sociodemographic data collection by the Ministry of Health suggested that the vast majority of people were willing to provide consent and answer the questions (Public Health Ontario, 2021b).

However, the data collection did not include information on Indigenous status, despite the recognition of the disproportionate outcomes and barriers in accessing care for Indigenous communities during the pandemic. In March 2021, the Ontario Ministry of Health stated that they would continue to work with the Ministry of Indigenous Affairs and other Indigenous partners to address health inequities for Indigenous peoples and ensure that data collection processes were respectful and culturally appropriate (Public Health Ontario, 2021c). At the federal level, in May 2020 Indigenous Services Canada also announced \$250,000 in funding towards improved data collection efforts about COVID-19 among FNMI peoples (Skye, 2020). While the federal government is now able to track vaccine rates among First Nations populations on reserves, similar vaccine monitoring efforts among urban Indigenous populations (who make up more than half of all Indigenous peoples in Canada) are not in place (Osman, 2021; Smylie et al., 2022).

6.0 Race Data Collection in Canada and Other Countries

6.1 National data collection: Statistics Canada

Historically, the Canadian government has been "reluctant to ask directly about race", resulting in a lack of nationwide disaggregated race data (Lau, 2021). The national Census began collecting information about race and ethnicity in 1996 by incorporating a question about whether Canadians identified as a 'visible minority', including a list of 11 population groups in line with the Employment Equity Act. These population categories have remained the same since they were first asked and are now part of Canada's national statistical standards (see Table 3). However, critics of this term have argued that it is imprecise and groups diverse communities together (Lau, 2021; Patel, 2021). Moreover, the question is now asked only on the long-form Census (known as the National Household Survey ¹¹), meaning that 75% of Canadians did not answer the question in 2021 because they received the short-form Census (Patel, 2021).

The Census also measures Indigenous identity, including questions about whether individuals self-identify as Indigenous, Registered or Treaty Indian status, and membership in a First Nation or Indian band (see Table 3). In 2021, changes were made to the Census to reflect feedback on these questions. Specifically, the collective term "Aboriginal" was replaced with "First Nations, Métis or Inuk (Inuit)" to align with the preferred distinctions-based approach identified by stakeholders (Statistics Canada, 2020a). New questions were also added to collect information on whether respondents are registered members of a Métis organization or Settlement; and whether respondents are enrolled under an Inuit land claims agreement.

Table 3: Questions about race and Indigenous identity in the 2021 Canadian Census

¹¹ The long-form census was made voluntary in 2011, which resulted in lower participation rates and concerns about missing data. The government returned to the mandatory format with the next census in 2016. (https://www.cbc.ca/news/politics/mandatory-census-mail-out-1.3557511)

o, not First Nations, Métis or Inuk (Inuit) es, First Nations (North American Indian) es, Métis es, Inuk (Inuit) hite outh Asian (e.g., East Indian, Pakistani, Sri Lankan) ninese ack lipino rab ottin American outheast Asian (e.g., Vietnamese, Cambodian, Laotian, nai) est Asian (e.g., Iranian, Afghan) orean panese cher group — specify:
outh Asian (e.g., East Indian, Pakistani, Sri Lankan) ninese ack lipino rab etin American outheast Asian (e.g., Vietnamese, Cambodian, Laotian, nai) fest Asian (e.g., Iranian, Afghan) orean panese
- 8 9
o es, Status Indian (Registered or Treaty)
oes, member of a First Nation or Indian band
es, registered member of a Métis organization or estlement ame of Métis organization or Settlement Métis Nation of Ontario Manitoba Metis Federation Métis Nation — Saskatchewan
e

The federal government has committed to stronger efforts to enhance data collection efforts in response to the growing demand for disaggregated race-based data. For example, the 2021 federal budget included \$172 million over five years to implement a disaggregated data action plan, and more funding is earmarked for data collection efforts that would inform Canada's justice system and the RCMP (Patel, 2021). Statistics Canada is also improving race-based data collection and analysis efforts, such as adding special crowdsourced surveys, increasing sample sizes of marginalized people, and enhancing analyses of different population groups (Lau, 2021). Other recent efforts to address gaps in the data include the creation of the Centre for Gender, Diversity and Inclusion in 2018/19 which would support evidence-based policy and programming by

** Only asked to those who responded 'yes' to Question 1.

monitoring and reporting on gender, diversity and inclusion; and funding for activities under Canada's Anti-Racism Strategy in 2019/20, such as expanding the General Social Survey on social identity. (Statistics Canada, 2020b; Government of Canada, 2021).

 Specifically, Canada's Anti Racism Strategy for 2019-2022 (called "Building a Foundation for Change") includes steps and funding to increase reliable, precise collection and measurement of data regarding racism and discrimination. This includes enhancing the collection of disaggregated data that can be broken down by meaningful race categories; and strengthening impact measurement and performance reporting. (Government of Canada, 2021)

6.2 National data collection: health sector

Within the health sector, recent efforts to standardize the collection of sociodemographic data across Canada have come from organizations such as the Canadian Institute for Health Information (CIHI) and the Upstream Lab.

CIHI has recognized the need for information about patient demographics in order to understand health inequities for several years. In May 2020, CIHI proposed new Canadian standards for collecting race-based and Indigenous identity data in health systems, as well as detailed considerations for the appropriate collection and use of this information. The standards (see Figure 3) were developed in response to growing interest and calls for the measurement and understanding of racial health inequalities and the impact of the COVID-19 pandemic within racialized communities, as well as the current lack of standardized race data in Canada – particularly in the health sector. The standards were based on extensive research and consultation with a wide variety of stakeholders, including researchers, clinicians, government and organizations representing racialized communities, and were adapted from Ontario's Anti-Racism Data Standards (CIHI, 2020a). Feedback on the initial document released in 2020 was also solicited from a range of additional stakeholders and partners, resulting in updates to form the final standards as well as a guidance document outlining their appropriate use (CIHI, 2022a). The standards also align with existing national standards from Statistics Canada, to allow for integration and comparability of the information with other important national data sources (CIHI, 2020b).

"Pan-Canadian standards can help ensure that high-quality racial and ethnic data is collected, analyzed and reported using a harmonized approach. In addition to data standards, measures are needed to enhance cultural safety, facilitate consent and appropriate use, support the staff who are collecting the data and implement data quality assessments. It is also important to ensure ongoing dialogue with communities to support collection and interpretation." (CIHI, 2020a; p.2)

CIHI's race standard also acknowledges that the collection and measurement of Indigenous data and health inequalities needs distinct consideration and recommends that a distinctions-based Indigenous identity question is used (which includes response categories for First Nations, Métis and Inuit), along with community engagement and data governance agreements (CIHI, 2020a).

- Importantly, the recommended approach includes two methods of collecting data on Indigenous identity (shown in Figure 3): 1) including "Indigenous" as its own category in the race-based question, to measure how Indigenous peoples may be racialized by society; and 2) an additional, independent question about Indigenous identity, to allow flexibility in how Indigenous people choose to self-identify. (CIHI, 2020b)
- CIHI also acknowledges that the question and response categories for Indigenous identity should be decided in collaboration with the appropriate Indigenous groups (depending on the jurisdiction) to ensure culturally safe and appropriate data collection. At a minimum,

the distinctions-based approach shown in Figure 3 is recommended; however, the Guidelines document notes that more detailed and locally relevant information may also be collected based on the goals and priorities of the data collection initiative. For example, more specific information about membership or status for specific communities or Nations may be added through either additional questions or optional write-in categories (CIHI, 2022b; 2022c).

Additional strengths of the standard include the following (CIHI, 2020b; p.13):

- It better delineates the concepts of race and ethnicity by using commonly recognized race categories rather than ethnic origin categories and avoids mixing the two.
- The race categories (which are adapted from Ontario's Anti-Racism Data standards) map to Statistics Canada's Population Group and Aboriginal Group standards and are consistent with the Upstream Lab's SPARK study (see below). This allows for comparisons of outcomes with those from a population-based reference group.
- It enables the recognition of multi-racial and mixed Indigenous identities by allowing multiple responses for each question.
 - According to guidelines for reporting health inequities developed by CIHI in June 2022,¹² an Indigenous identity stratifier should at **minimum** follow a distinctions-based approach that recognizes FNMI peoples as distinct groups, with the option of reporting "mixed Indigenous identity" for those who have selected more than one category (CIHI, 2022c).

In line with the development of CIHI's proposed standards for the collection of race-based data, the Upstream Lab research group ¹³ is also working towards the development of a national standard for socio-demographic data collection in primary care as one of the goals of their SPARK Study

(Screening for Poverty And Related social determinants and intervening to improve Knowledge of and links to resources). The five-year study began in 2018 and has developed and piloted a set of questions that are consistent with those proposed by CIHI. Further research to evaluate the psychometric properties of the data collection tool and to understand its implementation in diverse clinical settings is also being planned (Pinto & Hapsari, 2020).



¹² The reporting guidelines were developed as part of a toolkit on measuring health inequalities, which included several resources for the analysis and reporting of data. The Indigenous identity stratifier is part of CIHI's pan-Canadian guidance on equity stratifiers (e.g. demographic characteristics) to support disaggregated and harmonized reporting on health inequities.

¹³ The Upstream Lab is a research team focused on addressing the social determinants of health. The lab is based in MAP/Centre for Urban Health Solutions, within the Li Ka Shing Knowledge Institute at Unity Health Toronto; but collaborates with partners from five provinces (Ontario, Saskatchewan, Manitoba, Nova Scotia, Newfoundland and Labrador) on the SPARK Study.

Figure 3: Race-based and Indigenous identity data collection standards from CIHI (CIHI, 2022b, pp. 8-9)

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.

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.

6.3 Data collection in the United States

In the United States, data on race and ethnicity is collected at the federal and state level through various data sources as part of their health program administration, and through the national Census. Government-wide standards for race and ethnicity data collection were issued in 1997, which are included in most data collection initiatives by the Department of Health and Human Services (Office of Minority Health, 2021). However, some large federal surveys have used more a granular categorization strategy beyond the minimum standard categories, particularly for Hispanic and Asian subpopulations. The standards specify that self-identification is the preferred method for gathering information; that separate questions for race and ethnicity should be used where feasible; and that respondents may choose more than one race (there is no "multi-racial" category) (Office of Minority Health, 2021).

While the racial categories used in the US are based on the political and social climate and may not be as relevant for Canada, some examples of approaches and applications of race-based data collection across public sectors in the US are described below.

1) National surveys:

• According to Roth (2010), nationally representative surveys in the US have rarely differentiated between the multiple dimensions of race. In the US Census, the question about race has changed considerably over time due to both political pressures from various groups and changes in social beliefs about race and ethnicity (Roth, 2010; Brown, 2020). In addition to changes in the wording and categories used for the Census race questions, there was a shift from interviewer observation to self-identification once the Census began to be mailed out starting in 1960. Later, a movement to allow for multiracial identification led to the option of selecting multiple races beginning with the 2000 Census; and in 2020, write-in areas were added for the first time for those who identify as "Black" or "White" to give more information about their origins (Brown, 2020). However, some research suggests that the Census race question is ambiguous and does not reflect the realities of race and racial identities in the US, leading to different interpretations of the question. As a result, some researchers such as Roth (2010) suggest caution in using and interpreting Census data on race.

2) Education sector:

• Schools are required to report racial and ethnic data to state and federal governments in the US. This information is typically collected through forms that families complete when students are enrolled in public schools. When the question about race is left blank, the government mandates that school personnel select a racial or ethnic identification for the student through the process of observer identification (Ford, 2019). However, implementation of this policy varies greatly across states and some states do not provide any guidelines for how schools should collect information about students' race, despite the requirement for them to do so (Ford, 2019). According to Ford (2019), education researchers lag behind other fields in examining the accuracy of data collected by observer identification, creating a potential validity problem in education datasets that combine self-identification with observer identification data.

3) Health sector - Massachusetts:

Standardized collection of race-based data by hospitals is common across the US. One
example of how this information has been used to improve quality of health care comes
from the Massachusetts General Hospital (MGH), which has been publicly reporting racebased results since 2005 (e.g. results on patient outcomes and experiences stratified by

race). One finding from this data was that Black women had a higher rate of Caesarian section (C-section) births than White women, even after adjusting for other factors. These findings stimulated a campaign by the hospital to raise awareness of inequities in outcomes and care among providers and staff. As a result, the difference between Black and White women in C-sections was no longer significant by 2018 (two years after the campaign). (CIHI, 2020b; p.12)

4) Child welfare sector - Washington:

- Existing race data collection practices across child welfare programs and services in Washington State have shown broad inconsistencies, such as differences in whether staff are directed to provide their own observation and which reporting standards are followed. In response to the lack of standardization, the Office of Innovation, Alignment and Accountability (OIAA) of the Department of Children, Youth, and Families (DCYF) in Washington state developed a roadmap for improving agencywide data collection, reporting, analysis and research to promote racial equity in services, programs and outcomes for children and their families. This includes a commitment to reporting data by race and ethnicity wherever possible as well as establishing a standard approach for data collection and reporting practices. (Cummings et al., 2021).
- The DCYF recognizes the importance of the source and method for the collection of race and identity-based data and have established the method of self-report (or parent/caregiver report in the case of young children) as the gold standard in all program data collection across the agency (Cummings et al., 2021, p.6). Furthermore, they aim to eliminate the practice of observer report or worker inference of race when the client or parent/caregiver are available, even when the client declines to answer the question. ¹⁴ As stated in their report, observer report methods are subject to bias, have validity issues, and may not represent the preferences of multiracial people. Furthermore, clients have the right to choose whether to share their identity by self-report without having their identity inferred by others (Cummings et al., 2021; p.6).
- As a result, the DCYF recommends the "unknown" category be available in all agency data collection systems. If a service provider has the client's race/ethnicity information in their administrative records from prior interactions, they may include that information in instances when the client/caregiver is not present, in order to ensure data is as complete as
 - possible. Existing data governance systems will be transitioned away from allowing observer report and instead including an "unknown" category (Cummings et al., 2021; p. 7).
- In addition, while agency data collection systems do not include a 'multiracial' category, the data collection standards ¹⁵ require them to have the capacity for more than one race to be recorded to allow for people to identify as multiple races.



¹⁴ Note: Collection of preliminary race/ethnicity data when a referral is made by a third party (as in a CPS Intake) is acceptable, however; in such instances, the information should be confirmed or revised based upon client self-report or parent/caregiver report.

 $^{^{15}}$ According to the Washing State Racial Disproportionality Advisory Committee (WSRDAC) race/ethnicity reporting standard, which was adopted in 2011 and modified in 2020.

7.0 Benefits and Challenges in Race Data Collection

7.1 Benefits and uses of race and identity-based data

As discussed throughout this report (e.g., see Section 4.3), there is growing interest and support for the collection of race and identity-based data in Ontario for several purposes, ranging from improving our understanding of gaps and inequities to informing policy and practice in a way that will address racial disparities and improve service outcomes. For example, according to the OHRC, the regular collection of identity-based data allows organizations to not only address issues proactively, but also to evaluate, modify and improve services and interventions over time (OHRC, 2010). Credible data is also a key component of strategies to engage decision-makers and stakeholders and secure their support for policies and programs.

In addition to the value of race data collection itself, there are also important benefits of establishing consistent data standards such as CIHI's proposed race standard and Ontario's Anti-Racism Data Standards — which the Ontario Minister responsible for the Anti-Racism Directorate has noted are "critical for driving evidence-based decision-making and ensuring public accountability" (Anti-Racism Directorate, 2021).

The benefits of race data collection may also be specific to different public service sectors. For example:

- In the health care sector, collecting patient and client demographic data helps to identify inequities in health care access and utilization and monitor targeted interventions (Toronto Central LHIN, 2017).
- In the child welfare sector, agencies collect and analyze data to measure the extent of racial disparities, identify underlying causes and evaluate progress towards improving outcomes for African Canadian children, youth and families (Turner, 2016).
- In addition, child welfare services and programs must be informed by the actual populations being served in order to enhance service effectiveness. For example, child welfare workers should provide services that meet the unique needs of each child, youth, or family and are culturally appropriate (OACAS, 2018). This can only be achieved by collecting race-based data to better understand the issues and realities of different communities and populations (OACAS, 2016). The Child, Youth and Family Services Act (CYFSA) in Ontario also states that services to children and youth should take into account the child's race, ancestry, place of origin, colour, ethnic origin, and citizenship, among other identity-based factors such as disability, sex, sexual orientation and gender identity (CYFSA, 2017, s. 1(2)).
- Race-based data can also lead to better placement of children and youth in the child welfare system and more targeted recruitment of foster caregivers (OACAS, 2016).

7.2 Challenges and concerns with collecting race and identity-based data

It is also important to consider any potential challenges, concerns, and harms related to the collection and use of race-based data. Some of these concerns representing various perspectives are described below. However, despite these potential challenges, collecting race and identity-based data using appropriate methods and for appropriate purposes remains a useful and essential tool for achieving equity-focused goals (OHRC, 2010).

Concerns from a research perspective:

While researchers have largely supported the collection of race-based data for the purpose of documenting health disparities, some researchers from health and medicine have also argued against the use of racial or ethnic categories since the classification of people by race may serve to reinforce racial/ethnic differences or divisions in society (Kaplan & Bennett, 2003). Therefore,

researchers and health professionals must use caution when studying and reporting on race-based data to avoid reinforcing stereotypes or making assumptions about any individual's or group's racial identity. Specific recommendations to reduce harm that have been proposed within the biomedical field include always specifying the reason for studying and analyzing race to justify its inclusion and specifying the approach to measurement (i.e. the way categories are defined and the way individuals are assigned to them) (Kaplan & Bennett, 2003).

Similarly, concerns over race data collection for epidemiological analyses have led to debate over the issue of race as a social rather than a biological construct. For example, proponents of an initiative to ban the collection or use of racial data by government agencies in California argued that race-based data should not be collected because race is not a "real" biological category and the continued use of the term "race" could actually perpetuate racism (Kreiger, 2004; CIHI, 2020b). However, opponents of the proposition – largely led by public health advocates and researchers – argued that the absence of data would ignore the social realities of race as a socially constructed category which helps to expose inequalities due to ongoing racism.

Other challenges with race-based data collection and research, which will be discussed further in the Limitations section (see Section 9.3) include: considerations of the complexity of racial identities – especially Indigenous identities – and recognizing that not all individuals can be placed into mutually exclusive categories; a lack of consistency across studies and data sets; imprecise definitions of racial categories; and questions around the reliability and validity of self-reported data.

Concerns from the service provider perspective:

Some of the challenges with race data collection for service providers include the need for sufficient resources and training to collect and analyze the data – which may be a complex and technical process in some cases (OHRC, 2010).

Concerns from the public and client perspective:

Concerns from individuals from whom data is being collected may also arise, including feelings of anxiety or distrust due to the sensitive nature of sharing personal identity information, and concerns about privacy and confidentiality of the data (OHRC, 2010).

These concerns may be valid based on prior negative experiences associated with research and data collection and histories of discrimination and racism (Pinto & Hapsari, 2020). This is particularly relevant for Indigenous peoples, who may be justifiably hesitant to participate in government data collection efforts because of the government's role in enforcing assimilation and other discriminatory policies (Government of Ontario, 2020).

• For example, as described in Section 5.2 (see pg. 18), when the Keewatin-Patricia District School Board in Ontario began collecting self-identification data for First Nations, Métis and Inuit students, they faced challenges in gaining the trust and support of Indigenous families and communities who had negative experiences with data collection in the past. These challenges were overcome through extensive community consultations and communication strategies (OHRC, 2010).

According to Ontario's Anti-Racism Data Standards, extra care must be taken to ensure that information about Indigenous identity is collected and managed in ways that are culturally appropriate and is used in ways that benefit Indigenous communities. This includes training for anyone responsible for collecting the data to raise awareness about Indigenous histories and current realities as causes of possible mistrust (Government of Ontario, 2020). It is also important to consult with and involve affected communities about the need for data collection to increase support and to help inform the development of appropriate methods (OHRC, 2010). Community

engagement is also critical for building trust, helping to interpret the findings and develop solutions, and holding organizations accountable to take action (Pinto & Hapsari, 2020).

In addition to staff training, other strategies to address client concerns include gaining informed consent prior to data collection and ensuring the privacy, security and confidentiality of the data (CIHI, 2020b).

Other patient concerns that have been identified in the literature include fear of reinforcing stereotypes through the use of race and identity-based data and the risk of receiving worse care as a result (CIHI, 2020b).

Finally, the OHRC (2010) has noted that organizations pursuing race and identity-based data collection for equity purposes may face resistance due to the perception that equity programs and policies may result in discrimination against dominant groups – known as "reverse discrimination". To address these perceptions, it is crucial for organizations to clearly communicate the purpose and benefits of the data collection. According to the OHRC (2010, section 5):

"Regardless of the data collection method used, the people data is being collected on and the broader public in general should be advised of why such information is being gathered and its potential uses. They should also be told how the data will be collected, the steps taken or that will be taken to protect privacy and confidentiality, the benefits of collecting data, and the progress reached in achieving stated goals and objectives."

8.0 Empirical Results from the Literature

8.1 Overview of results

As described in Section 3.1, a scan of published literature was conducted to examine evidence related to the practice and consequences of the social identification of race. Most of the literature that was reviewed came from the fields of health and psychology and explored the sociopsychological processes and outcomes in relation to racial identity and the implications of using different measures of race and identity in research. In addition, most of the evidence came from the US and focused on racial categories relevant to the American context. However, some results on Indigenous identity from New Zealand and a few studies from Canada are also reviewed.

8.2 Studies of race and identity-based data collection practices

Some studies have examined the feasibility and acceptability of tools and methods for race and identity-based data collection. Most of the Canadian literature in this area focuses on the patient demographic data collection initiative that started in downtown Toronto hospitals in 2013 following the "Measuring Health Equity" mandate (see Section 5.2). There are limited studies evaluating other more recent data collection efforts in Ontario since the *Anti-Racism Act*, or studies from other public sectors.

Canadian studies in health care settings:

• Pinto et al. (2016) evaluated the use of a sociodemographic data collection tool in a family medicine clinic in Toronto, Ontario. Data on a range of social determinants of health (including race) were collected through a self-administered survey using an electronic tablet provided to patients in the waiting room. The data collection process was integrated into the standard registration process and data were uploaded directly to existing systems to link the information to patients' electronic medical records. The researchers determined that the data collection process was both feasible and acceptable by patients, with only 7% of patients declining to participate out of over 10,000 patients overall, and less than 2%

- declined to answer the race question. Following this pilot study, small changes 16 were made to the questions and in December 2012, all hospitals within the Toronto LHIN were directed to collect the data.
- In a qualitative study by Kiran et al. (2019), semistructured interviews were conducted in 2016 with patients attending an urban primary care clinic in Toronto to understand their perspectives on answering questions about their race and ethnicity. The clinic has been routinely collecting sociodemographic information since 2013 ¹⁷ through a questionnaire given after registration for their appointment. Findings showed that patients were not uncomfortable responding to the question about race, although some reported different interpretations of the question and experienced challenges selecting a response particularly those with mixed heritage.

Together, these studies show the value of collecting race and identity-based information within a primary health care setting – where practitioners are ideally situated to take action to improve care and reduce health inequities (Kiran et al., 2019; Lofters et al., 2017). However, a limitation of these studies is that they did not specifically explore the perspectives of Indigenous patients, who may have different experiences within the health care setting based on prior histories of discrimination.



Within the same primary care context, Lofters et al. (2017) used patient-level sociodemographic data collected through the same methods tested by Pinto et al. (2016) (i.e., a self-administered survey in the waiting room of a family practice in Toronto) to examine the relationship between social determinants of health and cancer screening. Patients who were eligible ¹⁸ for at least one type of screening (colorectal, cervical, and breast cancer) and who had answered at least one question on the sociodemographic survey were included in the analyses, and characteristics of those who were up to

date on screening for each cancer type were compared to those who were overdue. Overall, patients who completed the sociodemographic survey were more likely to be up to date on all three types of cancer screening compared to those who did not complete the survey, suggesting that study participants were not representative of all patients in the practice. For instance, participants who were willing to answer a survey in a waiting room may also be more likely to visit the doctor for appointments or more motivated to take part in screening and prevention efforts. No differences in screening rates were found based on race (White vs. other races), but some differences were found for other sociodemographic variables, including income level and housing status.

This study revealed potential opportunities with using sociodemographic data to gain useful information for health care systems and treatment. However, some challenges were also encountered, such as a high amount of missing data for the income variable and small cell sizes for many of the ethnicity categories, which limited the ability to conduct analyses by ethnicity. The authors suggested that further research on how to best categorize race to gain more meaningful results should be explored (Lofters et al., 2017).

¹⁶ Changes included asking about "racial or ethnic group" due to some confusion over the term "race"; and expanding the category of "Aboriginal" to four separate categories (First Nations, Inuit, Métis, and 'Indigenous not included elsewhere').

 $^{^{17}}$ The questionnaire is part of the Measuring Health Equity project in the Toronto LHIN.

¹⁸ Eligibility was based on age and screening guidelines as of June 30, 2015. Data on cancer screening eligibility was from a monthly cancer screening report provided by the provincial cancer agency to Ontario family physicians.

8.3 Studies of the association between racial identification and health

Most of the literature examining racial identification and its consequences has focused on associations between racial identities and various health outcomes and disparities, such as perceived discrimination in health care, reported health screenings, and self-reported health.

Canadian studies:

In one of the only published studies examining racial identification in Canada, Veenstra (2011) built on the framework described by Roth (2010) (see Table 1 on pg. 6) to examine associations between two types of racial identities and health inequities in Toronto and Vancouver. Findings from survey data showed differences between respondents' *expressed* versus *reflected* ¹⁹ racial identities for large proportions of self-expressed Black and South Asian respondents (only 74% and 66% matched on these dimensions, respectively), and a lower likelihood of mismatch for White and Asian respondents (96% and 91% matched, respectively). Furthermore, mismatched racial identities corresponded with a higher risk of poor health outcomes (i.e. hypertension, self-reported mental health and overall physical health). This study suggests that mismatches between expressed and reflected racial identities can affect health and well-being; and that incorporating various facets of racial identities into research can contribute towards understanding health disparities. While this study was limited to examining two kinds of racial identification vs. *reflected* identity, would be even more strongly related to health outcomes (Veenstra, 2011).

Studies from the US:

- Using data from the Behavioral Risk Factor Surveillance System (BRFSS) ²⁰ collected by the CDC from 2004 to 2013, Stepanikova and Oates (2016) examined associations between perceived discrimination in health care a risk factor for minority health and two dimensions of racial identity: self-identified vs. perceived attributed race. ²¹ Results showed that both types of racial identities independently contributed to respondents' perceived discrimination in health care in the past 12 months, although perceived attributed race was a better predictor of discrimination. The authors suggest that these two dimensions of race are correlated but not interchangeable, and that the findings support the inclusion of multiple measures of race when studying health risks, health disparities, or racial discrimination in health care settings.
- Macintosh et al. (2013) analyzed cross-sectional data from the 2004 BRFSS to examine
 relationships between socially-assigned race and healthcare outcomes including reported
 healthcare discrimination and receipt of selected preventive services (i.e. influenza and
 pneumococcal vaccinations). Results varied depending on how respondents both selfidentified their race and were socially identified. After controlling for other possible
 predictors of healthcare outcomes, those who were socially assigned as White were less
 likely to report healthcare discrimination and more likely to receive preventive vaccines
 compared to those who were socially assigned as minority regardless of how they self-

 $^{^{19}}$ As described by Roth (2010), expressed identity refers to a person's self-identification with a race that he or she will readily express to others when asked to fit into racial classifications; and reflected identity refers to the race that a person believes others tend to perceive him or her as.

²⁰ The BRFSS is an annual state-based system of telephone-based health surveys administered to a large representative sample of US adults, and is coordinated by the Centers for Disease Control and Prevention (CDC). The Reactions to Race module includes questions to measure socially assigned race and self-identified race along with other questions related to race consciousness and racial discrimination.

²¹ Perceived attributed race refers to respondents' perceptions of how they are classified by others.

identified. These findings suggest that self-identified minorities who are socially-assigned as White have better health outcomes than those who are socially assigned as non-white. However, self-identified minorities who were socially assigned as White (M/W) still reported more discrimination than those who self-identified as White (W/W) – suggesting a unique experience within the healthcare setting for the M/W group. While further research is needed to understand the mechanisms by which socially-assigned race can lead to biases in healthcare, this study shows the importance of assessing both self-identification and socially-assigned race in understanding how race influences health outcomes and inequities.

- Another study that used data from the 2004 BRFSS examined discordance on self-identified vs. socially assigned race and its relation to general health status more broadly (Jones et al., 2008). Findings showed that the level of agreement between socially assigned and self-identified race varied across racial groups, and that within each group, self-rated health was related to socially-assigned race. Similar to the findings from Macintosh et al. (2013), those who were socially identified as White by others had a significant advantage in health status, even if they did not self-identify as White.
- While the studies described above were limited to measures of socially assigned race based on self-report (i.e. how the respondent thinks that others classify them), Saperstein (2009) was able to examine differences between self-identification and actual interviewer classification of respondents' race in relation to reported health screenings among women, using data from the 1988 National Survey of Family Growth. ²² Results showed that differences in interviewer-classified race were more closely related to disparities in health screenings than self-identified race, with women who were perceived as Black being more likely to receive screenings (i.e. pap smears, breast exams, and blood pressure checks) than women who were classified as either White or 'other'. In contrast to Macintosh et al. (2013), women who self-identified as Black but were perceived as White were the least likely to receive any of the health screenings. These findings add to the literature on the role of racial discrimination in clinical settings and highlight the importance of using multiple measures of race in health care research.

Finallly, given the growing interest in studying the multidimensional nature of race and the role of social perceptions of race in health inequalities, White et al. (2020) conducted a scoping review of research on socially assigned race and its relationship with health and health-related outcomes conducted up to 2019. Most of the reviewed studies (largely from the US) were found to demonstrate a positive association between social assignment as a disadvantaged racial group and poorer health. These findings suggest that studies should incorporate a measure of socially-assigned race to examine and address racial health disparities.

8.4 Other studies of race and social identification

Several studies from the US have assessed different methods of measuring racial identity by examining levels of congruence or discordance between different measures. Most of these studies have focused on self-identification compared to social identification of race, as well as factors that might affect consistency between measures. As described below, the evidence from these studies

²² The NSFG is a cross-sectional study of family formation and maternal and child health outcomes in the US that has been conducted six times between 1973 and 2002. The 1988 cycle was selected for this study because it included the most information about health screenings in addition to the two different measures of race. Interviewers were instructed to code respondents' race using only three categories (White, Black, and Other). Interestingly, the interviewer-classified measure of race appears to have only been used internally and has not been reported by other studies using the data.

shows that individuals' own self-identity can vary greatly from the racial identity that is perceived by others, with particular challenges observed for classifying multiracial individuals.

Studies of adult racial identities:

- In a qualitative study of racial classification systems and the lived experience of race, Roth (2010) analyzed data from interviews with Hispanics in New York and found considerable inconsistencies between different components of race (i.e., their expressed race vs. their internal race and observed race). These discrepancies were most often found for people who self-identified as Hispanic but whose appearance led others to classify them as White or Black. This finding demonstrates that for Hispanics in particular, racial self-identification is not always an accurate measure or proxy for how individuals are perceived or classified by others based on appearance. According to Roth (2010), it is important to capture the multiple dimensions of race in social surveys for the purpose of monitoring racial discrimination, as different measures of race can result in significantly different conclusions based on the data.
- Porter et al. (2016) examined patterns and predictors of matches between an individual's self-identity and outsider perception of race using linked data records from the 2000 and 2010 US Census. Data from two measures of race (one from each of the census years) were analyzed one provided by the household member and one by a knowledgeable census proxy respondent. ²³ Results showed high consistency between household-reported and proxy-reported race across the time points for some groups (i.e. Whites, Blacks) but lower consistency for others (i.e. Native Americans, multiracial people). Interestingly, proxies were more likely to report children as multiple races compared to elders, indicating that there may be age-related societal ideas about what kinds of people identify as multiracial (Porter et al., 2016). In general, the findings suggest that proxy reporters tend to rely on outside cues to determine an individual's race/ethnicity, such as age, household structure, and the local area. Specifically, the researchers described four factors that may predict a matched response: (a) socially defined ideas about who "belongs" in which group, (b) observations or knowledge about the household, (c) local racial composition and urban status, and (d) local socioeconomic standing.
- Through an analysis of observers' classifications of photos on the dating website Match.com, Feliciano (2016) examined how phenotype and observer characteristics influence racial categorization and divergence between self-identities and others' classifications. A contribution of this study was the use of multiple observers' assessments of race rather than relying on only one interviewer to examine the level of agreement, as well as the role of observers' own gender and race in shaping racial classifications. Similar to other studies (such as Herman (2010) described below), findings showed that despite the recent growth in multiracial populations, observers still tend to place individuals into monoracial categories. In addition, while observer characteristics influenced assessments of race to a degree, relationships between self-identification and observer classification did not vary substantially by observers' own race or gender.

²³ In the US Census, if an enumerator tries to reach a resident unsuccessfully at least three times, or if the household refuses to participate, the enumerator can find someone else to serve as a proxy. A proxy respondent must be at least 15 years old and have knowledge about the status of the household on census day. A proxy respondent is usually a neighbor, rental agent, building manager, or person who recently moved into the address. In this study, only proxy respondents who provided the full name of the focal person were included (Porter et al., 2016).

Studies of youth racial identities:

In one of the few studies that examined racial identification of youth, Herman (2010) sought to understand how observers perceive multiracial adolescents based on photos of their faces, as well as which factors affect congruence between self vs. observer racial identification. Participants were asked to identify the race of other people based on high school yearbook photos of students who had responded to a prior survey that contained questions about their own racial identity, allowing the researchers to examine the level of congruence between responses of observers and targets. Results showed that about half of multiracial targets were perceived as monoracial, although patterns differed across groups. The findings suggest that observer perceptions of race in the US are only modestly congruent with self-identifications and tend to maintain a simple black-white



dichotomy. Similar to the results from Feliciano (2016), this study also found that the demographic and environmental characteristics of observers had no effect on the congruence of their racial perceptions, even though some theories from the literature suggest that both characteristics of the target and the observer would be relevant.

From the perspective of racial identities being fluid, socially constructed and contextspecific, Harris & Sim (2002) examined patterns of racial classifications among a nationally representative sample of adolescents in grades 7-12 using data from the 1994-1995 National Longitudinal Study of Adolescent Health (Add Health). The Add Health survey includes multiple measures of self-reported race collected through different interviews, and allows for multiple races to be selected. ²⁴ The researchers assessed levels of consistency across the multiple indicators of race and found systematic differences between self-report answers as well as between self-reports and parent-based measures, resulting in significantly different estimates of the proportion of multiracial adolescents. For example, the school-based interview data revealed that 6.8% of youth were multiracial, but only 3.6% of the same youth self-identified as multiracial when interviewed at home; overall, about 88% of youth expressed the same racial identities across both contexts. The study also examined factors that predicted responses to the single race question for those who identified as multiracial and found that individual and family-level factors (including age, sex, and parents' education) had little effect on the choice of 'best single race'. However, contextual factors (i.e. region and neighbourhood racial composition, and whether family members were present during the interview) did affect racial self-identification among youth. These findings illustrate the challenges in classifying multiracial youth using different measures.

²⁴ The measures and sources of race include self-identification questions about students' race in school interviews and in home interviews; and a question about their parents' race through a parent/caregiver interview. In addition, if more than one race is selected in the home interview, youth are asked which single race best describes them. While the measures of race were the same in the school and home-based surveys, responses may differ due to the different environments the survey took place in.

8.5 Studies of Indigenous identity

Within the literature on self- versus social identification, a few studies have focused on processes and dimensions of Indigenous identification and the outcomes associated with mismatches between these dimensions. However, published studies have come only from the US and New Zealand, with no studies found examining Indigenous identity in Canada. Similar to the studies reviewed above, the findings described in this section demonstrate that self-identification and social identification measures must both be considered in research related to racial identity for Indigenous peoples as these measures often do not align, leading to stress and poorer health outcomes.

Studies from the US:

Using data from the National Longitudinal Survey of Adolescent Health in the US, Campbell & Troyer (2007) examined the social-psychological consequences of racial misclassification or mismatch – that is, being perceived by others as a different race than one's own selfidentification. The authors hypothesized that conflict between different dimensions of one's racial identity can create stress – particularly for groups that tend to have higher rates of mismatch such as American Indians. For instance, it is more difficult to maintain a strong ethnic identity and sense of belonging when one's identity is often misunderstood by others, which may lead to negative emotional or psychological consequences. Findings showed that adolescents who self-identified as American Indian were the most likely overall to be racially misclassified by an observer (i.e. the interviewer) – for example, over 35% of American Indians were classified as another racial group, compared to less than 5% of those who identified as White, Black, or Asian. Furthermore, this misclassification was found to contribute to higher rates of psychological distress – misclassified American Indians were more likely to report distress on four out of five measures (i.e. suicidal thoughts and attempts, use of counselling services) compared to correctly classified American Indians. These findings point to the importance of intersections between identity and appearance and suggest that neither self-identification nor observer identification measures of race are sufficient to fully capture racial identity or how individuals experience race and racism.

Studies from New Zealand:

Like Canada, New Zealand has a history of colonization, with persistent inequities in health and other social outcomes between the dominant (i.e. European) and minority ethnic groups (i.e. Māori). According to Harris et al. (2013), racialization processes affect Maori at both an individual level – through racial discrimination that is linked to adverse health outcomes, and at a structural level – through unequal distribution of socioeconomic resources in the country.

Cormack et al. (2013) examined associations between socially-assigned ethnicity, self-identified ethnicity and health using data from the 2006-07 national health survey in New Zealand. ²⁵ Results showed varying levels of agreement between self-identified vs. socially-identified ethnicity among participants – for example, concordance rates were only 80% for Māori respondents compared to 98% for Europeans. Moreover, those who both self-identified and were socially identified as belonging to the dominant European group had

²⁵ Note that in New Zealand official statistics, there has been a shift in terminology away from 'race' to more use of the term 'ethnicity'. Therefore, in this study, which is based on the New Zealand Health Survey, the term 'ethnicity' is used instead of 'race'. Ethnic categories included Māori, Pacific, Asian, Other, and European.

higher self-rated health and lower levels of psychological distress than all other groups. ²⁶ The health advantage associated with being identified as a dominant racial/ethnic group was found to be partly due to lower socioeconomic disadvantage and self-reported exposure to racial discrimination. These findings demonstrate the complex relationship between self-identified and socially-assigned race/ethnicity and show that both measures may be important for measuring and understanding health inequalities and the health impacts of racialization at a societal level.

• In a similar study, Harris et al. (2013) also used data from the 2006-07 New Zealand Health Survey to look at the relationship between socially-assigned ethnicity, health and racism for Māori. Data showed that participants who self-identified as Māori but were socially assigned as European had higher self-reported health and lower psychological distress, demonstrating the health advantage associated with being classified as the dominant racial/ethnic group in a racialized society. In addition, self-identification as Māori was not associated with health when adjusted for socially-assigned identity, suggesting that measures of socially-assigned race may contribute more to our understanding of racial discrimination than self-identification. ²⁷ These findings are consistent with those found by Cormack et al. (2013) and highlight the role of racism as an underlying determinant of health for Indigenous peoples.

9.0 Conclusions and Implications

9.1 Summary of findings from the literature

A common theme that emerged throughout this review is that while there is growing support for the collection of race and identity-based data in research and across public service sectors, there is still no single agreed upon method or "gold standard" for the process of collecting this data. Procedures and approaches to race data collection in Canada currently vary across sectors and jurisdictions, as they have largely been developed within specific contexts or for specific purposes. For instance, a sociodemographic data collection process developed for the primary care setting by a group of hospitals in Toronto has been shown to be feasible and accepted by patients and may be useful for developing more effective health care systems and treatment (Pinto et al., 2016; Kiran et al., 2019; Lofters et al., 2017).

While recent efforts to standardize the collection of sociodemographic data within Ontario (e.g. the 2018 Anti-Racism Data Standards) and at the national level (e.g. the data standards developed by CIHI and the Upstream Lab) are encouraging, more work is needed to improve race-based data collection and analysis efforts – especially in the context of the ongoing COVID-19 pandemic which has further exposed inequalities between racial groups and highlighted the need for more disaggregated data to address these inequities. In addition, considerations for Indigenous data collection have been lagging in some areas (such as vaccine monitoring and child welfare statistics) and require further research and consultations to ensure that such data is used and managed in culturally appropriate ways that would benefit the impacted communities.

While most data collection strategies have moved towards self-identification of race as the ideal practice, the available literature on social identification of race suggests that relying on only one

²⁶ Other groups included those who self-identified as the dominant ethnicity but were socially assigned as minority; those who self-identified as minority but were assigned as dominant; and those who both self-identified and were assigned as minority.

²⁷ However, it is important to note that in this study, the measure of socially-assigned ethnicity was still based on self-report from the participant, rather than observer report.

measure can lead to inaccuracies in the data as a single measure may not adequately represent the multidimensionality of race (White et al., 2020). While there are limited studies from Canada, research from the US has shown that observer identification of race often does not match individuals' own self-identities, resulting in inconsistencies between different measures or dimensions of race for the same individuals. Evidence suggests this mismatch is more likely among certain racial groups, such as those who self-identify as multi-racial, Hispanic, and Indigenous peoples; whereas levels of agreement between measures tend to be higher for those who self-identify as White or Black.

Studies that have examined the factors associated with discordance have found that observers tend to rely on outside cues such as social cues or the environment to determine another individual's race, which may lead to biases when these cues are associated with stereotypes (Roth, 2016). Moreover, data may even be affected by the observer or interviewer's own race or background; however, most datasets do not include information about the observer and some evidence suggests that observer characteristics do not affect assessments of race (Feliciano, 2016; Herman, 2010). Social identification of race tends to be more accurate when the observer has more interaction with or knowledge of the individual; yet the conditions in which many surveys that include sociodemographic questions take place do not always facilitate such interaction and instead may be based solely on physical characteristics or other readily available indicators (Roth, 2016). Not only can observer identification of race change depending on the conditions, but racial self-identity has also been shown to be fluid and transient – especially for youth whose identities may still be forming. This means the race or races that an individual identifies with can change over time and across different contexts – including school versus home environments, and whether they are alone or with family or friends (e.g. Harris & Sim, 2002).

Studies that have examined the relationships between racial identity and health have demonstrated that inconsistencies between the various dimensions of one's identity not only have implications for research and data collection, but they also have implications for health. Evidence shows that when an individual's self-identity does not match how others perceive them (or how they believe others classify them), they are more likely to experience poorer health and psychological outcomes.

Overall, the findings from the literature demonstrate that any research conclusions about racial disparities will be affected by which measure of race is used and how the data were collected. Both self-identification and social identification have been shown to be associated with outcomes relevant to health and social services across studies; however, the literature is not always consistent with respect to which measure has a stronger association with disparities in outcomes (Roth, 2016). For instance, some studies have shown that social assignment of race has a larger effect on disparities in health outcomes such as participating in preventive health measures (i.e. vaccinations and health screenings) compared to self-identification measures (e.g. Macintosh et al., 2013; Saperstein, 2009). Studies from New Zealand have also shown that in racialized societies, one's perceived or socially assigned race/ethnicity may contribute more to our understanding of the experience of race and the effects of racial discrimination. In contrast, other studies have shown that both measures are important as they can influence each other.

Based on these findings, researchers suggest that there is no one 'correct' measure of racial/ethnic identity, but rather various measures which may all contribute to different experiences of race and can be used to capture different dimensions of racial identity as well as the impacts of racialization (Cormack et al, 2013). Indeed, evidence from several studies supports the inclusion of multiple measures of race/ethnicity when studying racial disparities, particularly in the area of health outcomes and disparities.

9.2 Implications of the findings

The findings from this review have important implications for research, practice and policy – some of which are discussed in this section.

Implications for research and data collection:

A better understanding of the process of social identification of race and how it differs from self-identification would help to inform strategies for the measurement of race and the collection of race-based data – including *who* should collect such data and *how* it should be collected. Any discussions of race within research and real-world settings should recognize its multidimensional nature and the various social processes that influence racial identity. This includes using language that is not only respectful of individual identities but also clearly communicates the methods that were used and the dimensions of race that are being described (i.e. whether the term 'race' is referring to internal race, expressed race, observed race, or another dimension) (Roth, 2010).

This issue is especially important given the increasing racial and ethnic heterogeneity in Canada and other countries and the growth in multiracial identities. Some researchers (e.g. Macintosh et al., 2013) suggest the need for expanded definitions of racial categories in surveys and other research to improve data accuracy, as broad classifications may obscure differences between and within groups. The greater diversity of racial identities also suggests that mismatches between self and observer identification of race will continue to grow as well, which may have harmful social, psychological, and health consequences. Indigenous populations may be especially at risk of these negative consequences for two reasons: 1) Indigenous peoples are the fastest growing population in Canada, and the number of people identifying as Indigenous is expected to continue to grow over the next twenty years (CIHI, 2020b; Statistics Canada, 2021); and 2) evidence suggests that Indigenous peoples are more likely to experience conflict between dimensions of their identity compared to other racial groups.

Implications for service providers:

At a broad level, improvements in identifying and measuring race will have significant practical implications for the delivery of more equitable and effective health and social services. Given the potential validity problems associated with observer identification of race and identity, allowing service providers (i.e. educators, child welfare workers) to assign a race to others could have consequences for the public reporting and interpretation of aggregate data, such as school-level or agency-level information about race, since results might vary depending on how the information was collected (Ford, 2019). While including both self-identification and social identification measures of race would provide more complete information, training and guidance would be needed for anyone who is collecting the data to improve its consistency and reliability.

Findings in the literature showing that social identification of race is a predictor of health care outcomes suggest the need to examine interactions between health care providers and their patients, including any racial stereotypes health professionals may hold that might affect patient care, as these implicit biases could explain some of the observed racial disparities in outcomes (Saperstein, 2009). For example, health screenings require in-person interaction with a health professional and thus could potentially be impacted by how the health professional perceives the patient's race; therefore, any study of disparities in health screenings would benefit from including multiple measures of race to examine whether socially assigned race affects rates of screening differently than self-identification.

Implications for policy:

Since policy decisions that aim to reduce racial disparities are often based on race identity data, the utility of race data depends on its validity (Ford, 2019). Therefore, methods to improve the accuracy and validity of data collection measures should be developed and implemented to enhance their ability to inform policy. This includes promoting a multidimensional conception of race identity, as different dimensions of race may be more strongly associated with various policy-related outcomes of interest. For example, according to Veenstra (2011), social policies in Canada that are informed by Census data are usually applied based on *expressed* race identities (the race one expresses to others in surveys), but experiences of racial discrimination may be more influenced by *observed* racial identities; and *internal* race identity may be related to other economic and social factors (e.g. social relationships, jobs) that affect health and well-being.

The collection of data and information about Indigenous identity and Indigenous communities has further policy implications for two key reasons discussed in this report: 1) the complexities of defining Indigenous identity have resulted in different definitions which may vary across contexts (i.e. legal definitions, service definitions, community definitions), and the impact of identifying or being identified as Indigenous will depend on the definition that is applied; 2) there are additional legislative requirements and obligations tied to identifying FNMI peoples that must be complied with, including both provincial and federal legislation and the sovereign inherent jurisdiction of Indigenous leaders.

9.3 Limitations of existing research

There are several gaps in the existing literature on the social identification of race which limit our ability to understand and develop evidence-based best practices in race and identity-based data collection. Some of these gaps identified in this review include a lack of studies from Canada and a lack of studies from fields other than health (e.g. education, child welfare). Comparisons of findings from the available literature are also limited by differences in the measurement, definitions and categorization of race across studies. For example, even when studies include a measure of social identification, this may be collected either by self-report or by observer/interviewer classification. Moreover, each of these primary methods may be subject to its own potential biases or validity issues. According to Lee (2009), most researchers and scientists recognize the importance of including race in their analyses, yet they remain divided over the meaning of race within research and policymaking and some still do not provide explanations of any findings of racial differences. Finally, within existing datasets that do include information about race, many lack complete information about how the data was collected and other information that could help with interpretation of the results, such as the characteristics of the interviewers themselves.

9.5 Future research

To overcome the limitations of the existing research and provide a clearer understanding of the issue of the social identification of race, it is recommended that more research is conducted to examine the accuracy of social identification across various contexts and populations and whether estimates of race-based data and outcomes vary depending on how race is assessed and who the classifiers are (Feliciano, 2016). Further research using different research designs (such as qualitative or mixed methods study designs) is also needed to better understand the mechanisms or pathways through which different measures and dimensions of race are linked to outcomes such as health disparities. In addition, the notion of race as fluid suggests the need for more longitudinal research to assess possible changes in racial identities over time.

Given the challenges with studying the growing mixed race population (see Section 4.4), another essential direction for future research is to develop more comprehensive measures of multiracial

identities to help identify and address the unique experiences and needs of multiracial populations. This may include specifying various components of racial subgroups rather than combining all subgroups into one 'multiracial' category, which could overgeneralize or obscure health risks and outcomes. The measurement of multiracial identities would also be improved by further qualitative research to understand how multiracial people conceptualize their own racial status or identity (Woo et al., 2011).

Finally, as mentioned, much of the existing literature comes from the United States and is focused on adults. More studies are needed examining other racial/ethnic groups around the world and in Canada, including multi-racial and Indigenous populations; as well as more studies that include child/adolescent populations.

10.0 Recommendations

Based on the available evidence from the literature reviewed in this brief, the following recommendations for race and identity-based data collection are provided.

Recommendations for data collection practices:

As discussed in Section 9.1 (Summary of findings), methods for collecting race and identity-based data should not rely solely on a single measure or dimension of race, such as a self-identification question or observer identification; rather, researchers have recommended including more than one measure to better capture the multidimensional and fluid nature of racial identities. For example, datasets could include a measure of socially-assigned race in addition to self-identification questions. The benefits of including multiple measures include the ability to answer different research questions and greater precision in examining patterns and trends in outcomes such as health disparities, which could otherwise be obscured.

However, in order to collect this information effectively, tools must first be developed to accurately measure each separate dimension of racial identity and to help ensure that the most appropriate measures are used based on the research question or purpose of the data collection (Roth, 2010). This requires critical thinking about definitions and categories and designing questions that more precisely measure what is intended (Harris & Sim, 2002). The OHRC (2010) recommends using predetermined categories such as those developed by Statistics Canada, which would not only improve comparability and reliability of results, but would also likely represent how the majority of people in Canada would self-identify. However, there are some limitations to using the Census categories, as they may be too broad and some respondents may not identify with them. Ultimately, the choice of racial categories may depend on the goals of the research as well as other considerations such as the geographical location and population of interest.

The collection of data about Indigenous identity requires additional considerations to ensure that Indigenous perspectives and priorities are incorporated. This includes engaging with Indigenous partners and communities to inform the development of culturally appropriate and relevant data collection strategies and practices, including the questions and response categories used (CIHI, 2020b). For example, CIHI's standards for race-based and Indigenous identity data collection recommend that a distinctions-based Indigenous identity question (i.e. that includes response options for First Nations, Métis and/or Inuit identity) is included independently of other questions about race to "allow for flexibility in the way Indigenous peoples choose to self-identify, which may be tied to an individual's clan, community, nationhood or language family." (CIHI, 2020b, p. 13). In addition, questions about Indigenous identity should be asked prior to other questions about race.

Community engagement is critical not only for collecting data on Indigenous identity, but also for other racialized groups, including Black communities. As an example, consulting with Black communities could provide useful information about how members of the community identify and

perceive their own identities, which would then inform the development of appropriate terms and categories to use in survey questions (i.e. 'Black' vs. 'African') (CIHI, 2020b). Overall, any strategies that aim to address racial discrimination and inequities must include consultation with the affected communities from the outset in order to build trust and support, increase participation, and gather higher quality data that will be useful in developing actual solutions based on the data (Pinto & Hapsari, 2020; CIHI, 2020b; Black Health Equity Working Group, 2021).

Finally, as discussed in Section 7.2 on challenges and concerns with data collection, strategies to mitigate any potential risk of harm from the collection of race and identity-based data must be considered and implemented whenever possible. This includes gaining informed consent from participants; ensuring the privacy, security, and confidentiality of the data; and being transparent about the purpose and use of the data collection (ORHC, 2010). Another strategy could be avoiding the re-occurrence of race and identity-based data collection for individuals who have already provided this information at an earlier time or visit (Black Health Equity Working Group, 2021). Rigorous training, education and guidance is also needed for any staff or researchers who will be collecting the data - especially in situations where observer or interviewer identification of race is allowed.

In addition to these general recommendations, a few other specific suggestions to improve race data collection that have been offered include:

- At a minimum, any datasets that include data on racial identity should specify how the data was collected and measured, i.e., whether the information represents self-identified or socially-identified race (Kaplan & Bennett, 2003).
- Questions about race and ethnicity should allow for multiple responses to be selected to enable the recognition of multi-racial identities (CIHI, 2020b).
- Any surveys that rely only on observer identification of race from one interviewer should consider how the observer's own characteristics and biases might potentially influence the data. For example, information about the observer's own race and other relevant demographics could be included in the dataset (Feliciano, 2016).
- Based on evidence showing that the way race-based questions are asked is equally
 important as the questions themselves, staff should be trained to ask race and identitybased questions with respect and care; to follow up with respondents; and to be available to
 answer any questions in order to increase compliance and completion rates (Toronto
 Central Local Health Integration Network, 2017).
- The age and developmental level of the participants should also be considered in choosing the most appropriate assessment method or measure (Charmaraman et al., 2014). For example, children's understanding of race and racial identity may not be fully developed; therefore, parents' reports of their child's race or measures of parents' own racial identification may be more appropriate.

Recommendations for policy:

First, race and identity-based data collection should be collected, analyzed, and reported at all levels of government (McKenzie, 2020). According to McKenzie (2020), sociodemographic information should be analyzed and published where it is already collected (e.g. by federal agencies such as CIHI and Statistics Canada) and should be added to any other national surveys, including the short-form Census. At the provincial level, data on race could be included in health systems, for example, by collecting information about race and identity when people apply for or renew provincial health insurance cards (McKenzie, 2020; Black Health Equity Working Group, 2021). Ideally, any datasets that contain data on race should also include sufficient sample sizes within each racial category to allow for disaggregated analyses (McKenzie, 2020).

A coordinated national framework for race-based data collection that includes standards and guidance would also improve the consistency and reliability of race and identity-based data across sectors and jurisdictions. Moreover, greater consistency and standardization would help to avoid any issues with data accountability resulting from variance in practices. Overall, stronger efforts to encourage and accelerate ongoing initiatives to enhance data collection at the national level, such as CIHI's pan-Canadian data standards and the recent Anti Racism Strategy, are needed to promote the development of population-wide, high-quality race data in Canada.

The need for race-based data is even more urgent in the context of the ongoing COVID-19 pandemic, as information about racial disparities in COVID-19 related outcomes could help to shape more effective public health responses and recovery. As recommended by Pinto & Hapsari (2020), questions about race and other social determinants could be quickly developed and incorporated into standard procedures by hospitals, assessment centres, and local public health units.

Without race based data, Canada cannot identify those at risk of poor health, social, economic and other outcomes. However, race-based data collection on its own is not sufficient to address racial inequities – the data must be linked to policy action in order to have an impact (McKenzie, 2020; Black Health Equity Working Group, 2021). This requires using the data to not only gain a better understanding of the varying needs and risks across racial groups but also to develop effective strategies to reduce these risks and promote equity. Subsequent data collection efforts must then be continued on a regular basis to monitor and evaluate the effectiveness of interventions. According to the Black Health Equity Working Group (2021, p.11), "without effective action to address health and other social needs, data collection, surveillance, and commodification in service of institutions becomes an example of anti-Black racism in and of itself."



Finally, another critical component of the process of race and identity-based data collection beyond the actual collection of the information itself relates to the proper management, control, storage, and transmission of the data. This is especially important for data on Indigenous identity, which must follow Indigenous data governance principles such as the OCAPTM principles, the CARE principles, or any other principles or structures recommended by each group, such as the Inuit principles of Qaujimajatuqangit (Ontario Health Data Council, 2022). For instance, the Ontario Health Data

Council (2022) has called for the Government of Ontario to respect and support First Nations, Métis and Inuit rights to data sovereignty by supporting FNMI peoples in the design, development, and implementation of their own data governance capacities. This must involve engaging with FNMI peoples to determine their needs and preferences regarding their respective health data, in accordance with the TRC's Calls to Action and the United Nations Declaration on the Rights of Indigenous Peoples Act (UNDRIP), which was passed in Canada in 2021. It is also essential to recognize the diversity of FNMI peoples through a distinctions-based approach that allows each group to develop their own separate and unique data governance models. Data sharing agreements and partnerships between public service organizations and Indigenous communities are also recommended as an effective approach to respect Indigenous data sovereignty; however, any agreements must also comply with other applicable legislation (i.e. provincial legislation such as the *Anti-Racism Act, 2017* and privacy laws) (Government of Ontario, 2020).

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Appendix A - Ontario's Anti-Racism Data Standards

Under the Anti-Racism Data Standards, public service organisations (PSOs) must collect information about race and Indigenous identity following the questions and response rules set out below.

Indigenous Identity Ouestion and Categories

Question: Do you identify as First Nations, Métis, and/or Inuit? If yes, select all that apply. *Values (valid code list):*

- No
- Yes, First Nations
- Yes, Métis
- Yes, Inuit

Optional Value: Prefer not to answer (permitted only in oral interview processes to record that the question was asked and the respondent chose not to answer).

Response rules:

If yes, respondents may select multiple options – First Nations, Métis, and/or Inuit. Respondents may not select both no and yes.

Race Question and Categories

Pre-amble: In our society, people are often described by their race or racial background. For example, some people are considered "White" or "Black" or "East/Southeast Asian," etc.

Question: "Which race category best describes you? Select all that apply."

Table 1. Valid values for race categories

Tuble 1: Valid Valdes for face categories	
Race categories*	Description/examples
Black	African, Afro-Caribbean, African-Canadian descent
East/Southeast Asian (Optional**: may collect as two separate categories - East Asian and Southeast Asian)	Chinese, Korean, Japanese, Taiwanese descent; Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent
Indigenous*** (First Nations, Métis, Inuk/Inuit)	First Nations, Métis, Inuit descent
Latino	Latin American, Hispanic descent
Middle Eastern	Arab, Persian, West Asian descent, e.g. Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish, etc.
South Asian	South Asian descent, e.g. East Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean, etc.
White	European descent
Another race category	Another race category (Optional: allow write-in response)
Prefer not to answer (Optional value)	Permitted only in oral interview processes to record that the question was asked and the respondent chose not to answer.

Response rule: Respondents may select all that apply.

Notes:

- * A separate standard for race categories applies for POI data (Section 7 Standards for Participant Observer Information).
- ** Organizations may collect 'East/Southeast Asian' as two separate categories, with appropriate examples provided, where there is evidence this would improve data quality.
- *** If providing examples on the form, then "First Nations, Métis, Inuit" need only be included once.

POI Race Question and Categories

Participant observer information (POI) is a type of indirect collection authorized under Standard 6. PSOs must collect POI only for the specific purpose of assessing racial profiling or bias within a service, program, or function and must use the following question and categories.

Question: "What race category best describes this individual?" (select only one)

- 1. Black
- 2. East/Southeast Asian
- 3. Indigenous (First Nations, Métis, Inuit)
- 4. Latino
- 5. Middle Eastern
- 6. South Asian
- 7. White

Response rule: The representative of the organization (the respondent) providing the POI may only select one valid response in relation to a particular individual. "Don't know" and "Prefer not to answer" are not valid response options.

Note: the collection of POI may only occur in circumstances that meet the following conditions:

- 1. The PSO has published a plan as described in Standard 38; and
- 2. There is a discrete interaction between an individual employed or retained by the organization ("representative of the organization") and an individual client or member of the public that leads to a decision that determines an outcome; and
- 3. The representative of the organization involved in the interaction described above has the authority to exercise discretionary decision-making powers over the individual that can have a significant outcome for the individual; and
- 4. Decisions and/or outcomes arising from that interaction can be measured or documented, such as an individual's receipt of benefits, penalties, or services, and treatment and/or experiences within a service, program, or function.

Appendix B – Identity-Based Data Standard for Children's Aid Societies in Ontario

The Identity-based Data Standard provides standardized questions and answers to support the collection of standardized identity-based data across children's aid societies. The following Child Protection Information Network (CPIN) Field Tool can be used to administer the data standard to children and youth receiving services.

Note: Only those questions relevant to race, ethnicity and Indigenous identity are shown below. Other questions include questions about language, religion, sex, gender, sexual orientation, and disability status.

1. Do you identify as First	Nations, Métis and/or	Inuk/Inuit? (If yes,	select all that apply.	Cannot
select both Yes and No.)				

- If you identify as First Nations, Métis and/or Inuk/Inuit, are you: (Select all that apply)
 - First Nations
 - Métis
 - Inuk/Inuit
 - Another Indigenous identity (please specify): _____ (write in response)
- No
- Do not know
- Prefer not to answer

Note: These categories reflect the Anti-Racism Data Standard question and categories for Indigenous in Ontario (Anti-Racism Directorate).

- 3. What is your ethnic or cultural origin(s)? (Specify as many ethnic or cultural origin(s) as applicable)
 - O Please specify: ______ (write in response)
 (For example, Anishnaabe, Canadian, Chinese, Colombian, Cree, Dutch, East Indian,
 English, Filipino, French, German, Guyanese, Haudenosaunee, Inuk/Inuit, Iranian, Irish,
 Italian, Jamaican, Jewish, Korean, Lebanese, Mi'kmaq, Métis, Ojibway, Pakistani, Polish,
 Portuguese, Scottish, Somali, Sri Lankan, Ukrainian, etc.)
 - o Do not know
 - o Prefer not to answer

Note: These categories reflect the Anti-Racism Data Standard question and categories for ethnicity in Ontario (Anti-Racism Directorate).

- 4. In our society, people are often described by their race or racial background. For example, some people are considered 'White' or 'Black' or 'East/Southeast Asian,' etc. Which race category best describes you? (Select all that apply)
 - o Black (e.g. African, Afro-Caribbean, African-Canadian descent)
 - East/Southeast Asian (e.g. Chinese, Korean, Japanese, Taiwanese, Filipino, Vietnamese, Cambodian, Thai, Indonesian, other Southeast Asian descent)
 - o Indigenous (e.g. First Nations, Métis or Inuk/Inuit descent)
 - o Latino/Latinx (e.g. Latin American, Hispanic descent)
 - Middle Eastern (e.g. Arab, Persian, West Asian descent e.g. Afghan, Egyptian, Iranian, Lebanese, Turkish, Kurdish etc.)
 - o South Asian (e.g. Indian, Pakistani, Bangladeshi, Sri Lankan, Indo-Caribbean etc.)
 - White (e.g. European descent)
 - Another race category (Another race category not described above) (please specify): _____ (write in response: should not be used to indicate mixed race)
 - Do not know
 - Prefer not to answer

Note: These categories reflect the Anti-Racism Data Standard question and categories for Race in Ontario (Anti-Racism Directorate).

Source: Policy Directive CW003-21 of the Child and Family Services Act: Collection and Reporting of Identity-Based Data. Issued June 28, 2021; Effective July 1, 2021.

(http://www.children.gov.on.ca/htdocs/English/professionals/childwelfare/cyfsa/policy directive cw003-21.aspx)