Canada Health Infoway
Inforoute Santé du Canada

Towards Developing Standards on the Intersection of Racism and Discrimination, Material Hardship and Healthcare Access

A Summary Report by the Canada Health Infoway Social Determinants of Health Working Group

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We respectfully acknowledge that the land on which our members attended the meetings represent the ancestral territories of many First Peoples. With our working group's focus on addressing the social determinants of inequities, we recognize the colonial injustices of the past and those that continue today to affect the health and well-being of Indigenous people. We also want to stress the need to engage in anti-colonial practices. As such, the work of the working group aims to address the historical and ongoing inequities experienced by Indigenous communities.

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Preface

This report represents the work of a community-driven initiative, supported by Canada Health Infoway, to explore how to incorporate social determinants of health (SDOH) concepts into digital health systems from a Canadian perspective. The Working Group was co-facilitated by Drs. Antonio and Conklin, and involved a year-long process of monthly meetings 79 members from industry, community, practice, policy and academia (full list in Appendix A). About a quarter regularly attended our monthly meetings delivered over zoom.

Drawing on document review and group discussions, this report serves to inform further work on developing data standards for the collection, use and sharing of SDOH data within digital health systems to address health inequities. The report also provides an overview of the measures and constructs of racism and discrimination at the intersection with material hardship and healthcare access that may be of interest to a wider audience concerned with intersectionality and health. The work presented in this report reflects the collective output for the 2021-22 SDOH Working Group. Details of the current SDOH working group can be found at https://infocentral.infoway-inforoute.ca/en/collaboration/wg/sdoh.

The views expressed in this report belong solely to the authors, in consultation with Working Group members, and do not necessarily represent the views of Canada Health Infoway.

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Executive Summary

The inaugural SDOH Working Group is a community-led initiative with the goal of exploring the development of Social Determinants of Health (SDOH) data standards in Canada's healthcare system. Given the breadth of SDOH, the Group decided to focus on racism and discrimination and its intersection with material hardship and healthcare access. Through monthly discussions, we reviewed a recent report on Indigenous-specific racism in the BC healthcare system, as well as over 10 validated survey instruments used to explicitly measure experiences of racism and discrimination, including the *Intersectional Discrimination Index* applied to a Canadian sample.

Most measures identified in the literature used or built upon the *Everyday Discrimination Scale* and/or the *Major Experiences of Discrimination* survey, with questions evolving to include the specific wording of 'unfair' treatment. Adding the qualifier of unfair distinguished experiences that are unequal from those that are unjust and preventable. Newer scales added the constructs of microaggressions and anticipated discrimination as well as an individual's coping response to racism and/or discrimination. The majority of measures were developed in the 1990s and validated in the US population or subpopulations (e.g., Hispanic or African-American). Only two surveys were specific to Indigenous populations: the BC *Indigenous Peoples' Survey* and the Australian *Measure of Indigenous Racism Experiences*.

Multiple sub-domains of racism/discrimination were noted across all the measures, and rarely included any questions about anti-racism or cultural safety. We found that four core concepts incorporated into most measures we reviewed. These were: identity, setting, unfair action and response. Our intersectional lens revealed that most measures had items/questions that we deemed relevant to material hardship and/or healthcare access, and some measures had included a set of questions to create a subscale that was directly applied to the healthcare setting. However, it was not always unclear if the subscale was valid for use separate from the full measure.

We developed several diagrams to illustrate how health inequities (unfair health outcomes) are the result of a context of systematic forms of discrimination that are based on an individual's social identity characteristic(s). As we found no measures that included a strength-based approach to assessing racism and discrimination, we provide a final diagram that offers some insights into incorporating a strength-based (versus deficit-based) perspective on the intersection of racism, material hardship and healthcare access for future data standards. We recommend that dedicated resources support a community-based process of consensus to data standards development, and that an intersectional lens be applied to other domains of SDOH.

Introduction

Background

The COVID-19 pandemic illuminated how health inequities are perpetuated through our existing societal structures, including our digital health systems. Yet, the health impacts of socio-cultural, economic and political structures, as well as the built environment, have long been recognized in Canada. Nearly fifty years ago, Ottawa's Lalonde [1] recognized the impact of these structures on health outcomes and called for a transformation of our conceptualization of health. In 2008, the World Health Organization (WHO) further demonstrated how health should be conceptualized beyond biomedical indicators and patient behaviours to consider how social determinants can introduce inequities in health [2]. The social determinants of health (SDOH) go beyond individual socio-demographics and social identity to emphasize "*the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life*"[2]. With ongoing inequities further cemented by the COVID-19 pandemic, there is urgent need to develop SDOH data standards for health settings.

In Canada, people continue to experience unjust access to healthcare, and unfair health outcomes based on discrimination due to their sex and gender, racial/ethnic background, Indigenous identity and age. These health inequities are further exacerbated by immigration status, disability, income level, education level and geographic location [2]. Most notably, our history and legacy of British and French colonialism with its ongoing systemic discrimination has caused significant health inequities among the Indigenous population (First Nations, Métis and Inuit) compared to non-Indigenous people in Canada. The recent report '*Disaggregated demographic data collection in British Columbia: The grandmother perspective*'[3] details the systemic racial discrimination inherent in our healthcare system that continues to deny Indigenous Peoples fair access to safe, reaffirming, high-quality care.

Data aids in understanding how SDOH can affect a person's medical treatment and health outcomes. In June 2020, federal, provincial and territorial Human Rights Commissions called on the Government of Canada to develop a national strategy for disaggregated race-based data [4]. The Canadian Institute of Health Information (CIHI) has been working with communities to codify and standardize data on race, ethnic and Indigenous identity [5-7]. However, data and national measures on racism and discrimination are lacking in our healthcare system [8]. When data are collected to evaluate racism and discrimination, the focus is often on social identity as a demographic characteristic, rather than on how racialization of these characteristics results in experiences of racism and discrimination [9][1]. In November 2019, at the request of the community, Canada Health Infoway launched working groups to address the standardization of the collection and use of gender, sex and sexual orientation data in Canada's digital health systems [11].

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[1] Throughout this report we will use the term 'racialized populations' to reflect it is the unjust, harmful actions of systemic *racism* that should be of focus. In addition, we limit our reference to terms that reference one's social identity (e.g., *race*, *ethnic* and *Indigenous* identity) to ensure that the focus remains on the structures that perpetuate racism and discrimination [9,10].

To further support these ongoing calls and initiatives from the community, in June 2021 a working group on Social Determinants of Health (SDOH) was established through Canada Health Infoway [12]. Members came from diverse cultural backgrounds and varying lived experiences, while also bringing their professional experiences from industry, community, practice, policy and academia. The group's initial task was to decide on our area of focus for SDOH which were racism and discrimination, material hardship, and healthcare access. Over the first eight months of the group's work, we examined over 10 validated measures on racism and discrimination to explore their how each one intersected with the SDOH domains of healthcare access and material hardship. This report summarizes our group's review of these measures with a view to developing new SDOH data and standards for Canada's health and healthcare systems.

Intersectionality as our Theoretical Foundation

Many conceptual frameworks of SDOH [2, 13-15] emphasize the mutually reinforcing nature of these broader determinants, and how they interact to create a synergy that amplifies the health differences between social groups in a society. The complexity of health inequities has called for greater consideration and application of how these broader determinants intersect. Intersectionality Theory, developed by human rights lawyer Kimberlé Crenshaw [16], offers a Black feminist critique of the experiences of discrimination against Black women in the United States. In the context of health policy and research, taking an intersectional perspective on SDOH involves looking beyond single social identity categories and considering the complexity of multiple factors intersecting to generate health inequities [16]. Some recent examples of intersectionality applied in healthcare include:

(a) using the Statistics Canada Longitudinal Immigration Database to examine integration of Filipina immigrant women with labour market [17];
(b) a UK study that examined the relationship between six economic factors with social relationships and healthy eating in older adults [18]; and,
(c) a BC study that applied an intersectional lens to examine experiences of stigma and discrimination during emergency health care [19].

The Government of Canada (including the Canadian Institutes of Health Research (CIHR)) have also adopted intersectionality as its guiding framework for sex-and-gender-based analysis [20, 21]. As such, part of our goal with the group was to see how intersectionality could be applied to SDOH data standards. Specifically, we set out to look at the intersection between racism and discrimination, healthcare access and material hardship[2] (see Figure 1).

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[2] At the beginning of our work, our group had initially selected 'material circumstance' as one of our domains. After a couple of months after our work began, we switched to 'material hardship' to match with how Gravity had opted to approach this domain. The relationship between material hardship and material circumstance became a critical consideration for the development of our conceptual models.

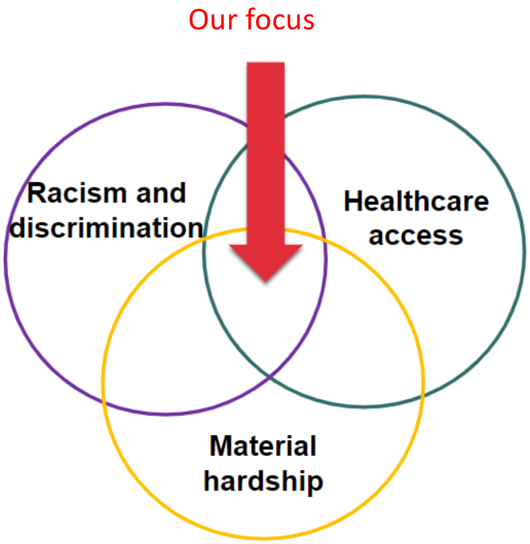

Figure 1 Our three areas for an intersectional focus on SDOH data for Canada's digital health system

The Gravity Project

The Gravity Project [22] is a US-based project consisting of over 2000 members who are working together to improve how SDOH data are collected, used and shared. The Gravity Project was conceptualized nearly five years ago, and involves a consensus-driven approach to developing and validating data standards [22]. In developing standards for new SDOH domains, the Gravity Project hosts bi-monthly meetings involving a presentation from domain experts, and a discussion of more than 200 regular attendees on the proposed definitions and data elements. Members are also encouraged to submit data elements through an excel sheet that contains categories for screening questions, diagnoses-assessed needs, goals, and interventions planned or completed.

As Terms of Reference, the Gravity Project established six data principles to guide the development all of the SDOH domains included in the project [22]:

1. improving personal health outcomes;
2. improving population health equity;
3. ensuring personal control;
4. designing appropriate solutions;
5. ensuring accountability; and
6. preventing, reducing and remediating harm"[22].

Gravity Project has examined the domains of food insecurity, housing instability, homelessness, inadequate housing, transportation insecurity, financial insecurity, material hardship, employment status, health insurance coverage status, veteran status, stress, social connection, intimate partner violence, elder abuse, medical cost burden and health literacy [22]. Future possible domains for the Gravity Project to include are racism, discrimination and bias as well as healthcare access.

Our Aims

The aims of Canada Health Infoway SDOH Working Group (the group) were to:

1) bring a Canadian perspective to the Gravity project to support future work on racism and discrimination; and
2) explore how to apply an intersectional approach to the use of data standards.

Our Approach

We began with an environmental scan of online sites that provided examples of Canadian organizations applying measures on racism and discrimination. Most of the reports were focused on collecting race and ethnicity, and Indigenous identity. However, we did find a few Canadian examples of measures specifically focused on evaluating rac*ism* and other forms of discrimination. With limited Canadian examples, we searched the broader academic literature using Google Scholar for "racism and discrimination", "healthcare" and "measures," and we found four systematic reviews that had been conducted over the past 15 years [23-26]. We opted to use the more recent systematic review [23] as a guide in selecting the measures we would review for our meetings.[3] Separate from this targeted search, we also reviewed two Canadian-specific examples identified early in our process [27, 28], as well as a microaggression scale [29] that was relevant to members' questions raised during our monthly discussions.

Over the year, the group reviewed one to two measures at each meeting (Table 1). Our breakout room discussions were guided by the following question: '*How do these measures relate to our three areas of SDOH focus on racism and discrimination, material circumstance/hardship and healthcare access?*'

Two excel documents were used to track and assess the measures (see Appendix B). The first document was used to track and record the responses during our monthly discussions, and to assist in conceptualizing how to apply an intersectional approach to develop SDOH data standards. The second document is based on the Gravity Project's data element template and is the main output of this work that our group will submit to the Gravity Project.

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[3] Bastos' et al. review[21] included 24 measures on racism of discrimination: 22 were informed by a theoretical framework; 8 reported their validation efforts; 16 had a reliability score greater than 0.70; 19 had at least 75% of the hypothesized relationship confirmed with the construct; and, 18 had their conceptual dimension supported through factor analysis.

Table 1 List of Measures Reviewed by the SDOH Working Group

Name of Report	Location	Populations
In Plain Sight Report – Indigenous Peoples' Survey [27]	British Columbia (Canada)	Indigenous People in BC
In Plain Sight Report – Health Workers' Survey [27][*]	British Columbia (Canada)	Indigenous and non-Indigenous healthcare workers in BC
Intersectional Discrimination Index [28]	Canada and United States	Asian, Black, Indigenous, Latin American, Middle Eastern and White individuals, and sexual and gender minorities
Measure of Indigenous racism experiences [30]	Australia	Indigenous peoples
Coronary Artery Risk Development in Young Adults (CARDIA IX_year30) / Experiences of Discrimination [31, 32]	United States	Blacks and Whites
Perceived Discrimination Scale [26]	United States	Black, Latino or Asian
Major and Everyday Discrimination Scale v0.3 [33]	United States	Asians, Blacks, Hispanics, Native Americans and Whites
Asian American racism-related stress inventory [34]	United States	Asian Americans (students and community adults)
Perceived racism scale for Latina/os [35]	United States	Latino students
Scale of ethnic experience [36, 37]	United States	African-Americans, Filipino Americans, Mexican Americans and White Americans
Racial Microaggressions Scale [29]	United States	African-Americans, Asian American/South Asian or Middle Eastern, Latinx and multiracial

[*] The first draft of our summary document was created when the CBC news story on Turpel-Lalond was being released. The Canada Health Infoway SDOH working group was uncertain how to reference this work and we have consulted with Indigenous scholars. We have included the reference as we frequently referred to the report during our monthly discussions and also to respectfully acknowledge the voices of the nearly 9000 Indigenous people who contributed to the In Plain Sight study. To recognize the context of how the report was developed, and that it was created with a Review Team representing Indigenous communities, we have added the following to the reference: Report created by an Independent Review Team requested by the BC Ministry of Health.

Definitions and Current Limitations

Early on in our process we selected the following definitions of each SDOH domain to guide our work:

- **Racism/discrimination** is any individual action, or institutional practice which treats people differently because of their skin colour and/or ethnicity. This distinction is often used to justify discrimination [38].
- **Material Hardship** is the lack of specific socially perceived basic physical necessities [22].
- **Healthcare Access** is the timely use of personal health services to achieve the best health outcomes [39].

Having these definitions is a foundation for data standards development [40]. However, our group also noted the need for definitions is only one approach which comes from a colonialist perspective, and that this work should encourage multiple ways of knowing. Specifically, this involves working with the communities affected by racism and discrimination in co-developing definitions and co-defining data standards. And so, while these definitions helped guide the scope of our work, they are not seen as the final definition. We recommend that these definitions serve as a starting point and must be reviewed with the communities impacted by racist and discriminatory actions to see if these definitions align with the community. A community review will also help determine whether this need for definitions represents a culturally-sensitive approach to addressing systemic racism.

Overview of the Measures

All the measures we looked at beyond the Canadian context had been tested for how well the tool actually measures racism and discrimination (i.e., validity). Most of these measures were developed in the US and validated prior to 2012 [29, 32, 34, 36, 41-47]; a couple of measures had recent updates [37, 48], or were a new short version of a previous measure [37, 49]. Not all of the publications detailed whether the validity of these measures would be impacted if a subset of questions (subscales) were used rather than the full scale. The majority of measures we looked at represented questions from the *Everyday Discrimination Scale* [31, 32, 41] and *Major Experiences of Discrimination* [33, 42] survey instruments.

We found that more recent applications of the measures have been with Asian-Americans [49], Latinx [35, 44], Indigenous peoples from Canada [27] or Australia [30], and adolescents [48, 50]. Our discussions also involved looking at several measures focused on ethnicity [24, 28, 36, 43, 49, 51] which included the construct of discrimination. More recent measures reference “microaggressions” [29, 49] or “anticipated discrimination” [28] as additional constructs to the everyday and major forms of discrimination used in earlier surveys. The systematic review we used as a key reference, included only one *Measure of Indigenous Racism Experiences* (MIRE) that was developed in Australia [30], and thus may not transfer to the experiences of racism of Indigenous Peoples on Turtle Island (North America).

Canadian Examples

Our group was aware of two Canada-specific sources for data collection on the intersecting SDOH we chose. First, we reviewed the *In Plain Sight* report [27] focused on addressing Indigenous-specific racism and discrimination in BC’s healthcare. When the working group met, it was one of the few examples of racism and discrimination measures being used at the provincial level, and one of the first examples of measuring systemic racism in our Canadian healthcare systems.

This report had two surveys which were developed with a Review team headed by two Indigenous women: 1) The *Health Workers' Survey* (HWS) asked healthcare workers about Indigenous Peoples' experiences of racism in their healthcare workplace, and included perspectives from non-Indigenous racialized populations; and 2) The *Indigenous Peoples' Survey* (IPS) was based on a tool developed by the Provincial Health Services Authority. It focused on Indigenous Peoples' experiences of racism in BC's healthcare system. Both the HWS and IPS included questions from the *Everyday Discrimination Index* [33], as well as questions with a more strength-based perspective that includes possible actions to address Indigenous-specific racism in healthcare. The IPS also asks specific questions about feeling safe across multiple healthcare settings and services, and processes for addressing complaints. The HWS asks about experiences of witnessing as well as personal experiences of racism and discrimination; cultural safety in the workplace; and possible actions to address them.

The Intersectional Discrimination Index (IDI) is the other Canadian measure we looked at and is a more recent measure that was validated in 1065 participants from Canada in addition to 1518 participants from the US [28]. The participants represented Indigenous peoples, and Asian, Black, Latin American, Middle Eastern and White individuals. In addition, sexual and gender minorities were oversampled [28]. The instrument was developed specifically to enable inter-categorical, intersectional analyses of discrimination in population health.

Scales and Response Options

The scales we reviewed had many different options for responses, and often focused on the frequency of lifelong discrimination:

- *regularly, occasionally, rarely, never*;
- *always, sometimes, rarely, never*; or
- *most of the time, some of the time, rarely or never*.

Scales about the frequency day-to-day experiences were asked over a specific time period:

- *almost everyday; at least once a week; a few times a month; a few times a year; less than once a year; never*; or
- *over the past year (number of times)*.

Other measures asked a '*yes or no*' response for having ever-experienced racism and discrimination. For a yes response, the question then branched into asking:

- *When was the last time this has happened?*
  - *past week; past month; past year; more than a year ago; or*
  - *how many times did this happen in your lifetime? (number)*; and
- *What do you think is the main reason for this experience?*
  - *your ancestry or national origins; your gender; your race; your age; your religion; your height or weight; your shade of skin color; your sexual orientation; your education or income level; a physical disability; other*.

It was unclear how these frequencies could be applied when people may only have one care experience per year (or less). Our group was unclear how this would impact the development of data standards for digital health systems, and is therefore an area that requires further exploration.

Validation of the Measures and Current Limitations

Through our discussions, we found that some of the measures had a broader scope than our three areas of focus, while also offering a subset of questions that were specific to healthcare access (Table 2). Many of these measures did not detail how their validity would be impacted if a subset of questions was selected. We discussed the needs for consideration on how to limit response burden on patients and providers by selecting questions that are most relevant, if these questions are to be asked in a care setting [52, 53].

Table 2 Questions on Healthcare Settings from Measures of Racism and Discrimination

Healthcare Experience
• *Ignored in health care settings*
• *Refused treatment*
• *Treated with disrespect*
• *Feeling unsafe*
• *Given the wrong or neglectful diagnosis, treatment, referral, discharge*
• *Given culturally insensitive services*
• *Not encouraged to practice traditional medicine*
• *Ignored in health care settings*

We also discussed the ongoing challenge of accessing validated measures with socially constructed concepts that evolve and change both across time and context. Many of the measures on racism and discrimination had been validated in the United States in the 1990s, and the MIRE was co-developed with Indigenous communities in Australia. During our working group meetings, it was noted that questions on a person's sense of belonging were distinctly missing in these earlier measures. The example was given about how asking people of colour "where are you really from," can be a form of othering and exclusion in Canada [54, 55]. This made us broaden our search to the more recent measures [28, 29] that might better represent everyday racist and discriminatory experiences in Canada. The *Racial Microagression Scale* [29] was a recent measure we found that specifically incorporates the statement, "*people ask me where I am from, suggesting that I don't belong,*" to evaluate Canadians' experiences of exclusion and sense of belonging.

Concepts in the Measures

Members who joined our monthly discussions worked together on the Excel documents to review and categorize each measure found in the literature. In these next sections, we review the concepts presented in these measures; the italicized words represent the terms used in the measures and the underlined words are the categories we proposed to help classify the concepts.

Sub-Domains Referenced in the Measures

As detailed in Table 3 below, many of the measures had their questions divided into subdomains that represented the different forms of racism and discrimination, and some common responses. The right column is our preliminary grouping of the categories to demonstrate the more frequent subdomains. The earlier measures introduced subdomains on *everyday experiences racism*, and *lifetime experiences of discrimination.* The more recent measures have expanded these categories to include *anticipated, general, perceived discrimination, individual racism* and *exposure to racism.* These more recent measures have also added categories focused on *social-historical discrimination*, *perpetual foreigner racism*, *sexualization*, *criminality*, and also included an individual's responses to the discrimination (which includes *stress* and *worry*). The last row in Table 3 is of note, as it represents a way to reconceptualize the predominant focus on racism in considering *anti-racism* and *cultural safety*.

Table 3 Subdomains of Racism and Anti-Racism Referenced in the Measures

Subdomains Reported in the Measures	**Working Group's Categorization**
Daily Racial Microaggression	Everyday Experiences of Discrimination
Day-to-day experiences of discrimination	
Day-to-day unfair treatment	
Everyday	
Everyday discrimination	
Everyday experiences	
Lifetime day-to-day discrimination	
Lifetime experiences of discrimination	
Lifetime exposure	Lifetime / Major Experiences of Discrimination
Lifetime Major Discrimination	
Lifetime major experiences	
Racism and life experiences / Perceived racism	
Major discrimination experiences	
Anticipated discrimination	*Anticipated Discrimination*
Anticipated experiences	
General Racism	*General Racism*
Perceived discrimination	*Perceived discrimination*
Personal experiences of racism or discrimination	Individual Experiences of Racism or Discrimination
Individual Racism	
Exposure to inter-personal racism	*Exposure to Racism*
Exposure to racism	
Exposure to racism	
Collective / Institutional Racism	Collective Racism
Vicarious and Collective Racism	

Subdomains Reported in the Measures	**Working Group's Categorization**
Cultural Racism	*Cultural Racism*
Socio-Historical Racism	*Socio-historical Racism*
Environmental	*Environmental*
Foreigner / Not Belonging	Foreigner Racism and Sense of Belonging
Perpetual Foreigner Racism	
Social Affiliation	*Social Affiliation*
Invisibility	*Invisibility*
Mainstream Comfort	*Mainstream Comfort*
Criminality	*Criminality*
Sexualization	*Sexualization*
Emotional response	*Reactions and Responses*
Reactions to interpersonal racism	
Response to unfair treatment	
Response to interpersonal racism	
Racism and Discrimination Stresses	*Stresses and Worry*
Within-Group Stresses	
Worry questions	
Anti-racism - Cultural safety in the workplace	*Anti-racism*

Concepts Referenced in the Measures

As we examined individual questions from each of the measures, we found that most measures incorporated four core concepts which we categorized as identity, setting, unfair action and response (see Figure 2).

Table 4 below provides a list of the social identities of individuals who may experience racism and/or discrimination that were referenced in the measures found in the literature. The core concept of **identity** represents who people are and includes race/ethnicity, and Indigenous identities that intersect with age, gender, physical disability, etc.

Table 4 List of Identities Referenced in the Measures

Identities
• *Ancestry or national origins*
• *Race*
• *Ethnicity*
• *Indigenous*
• *Obesity*
• *Gender*
• *Religion*
• *Height*
• *Weight*
• *Shade of skin colour*
• *Sexual orientation*
• *Education*
• *Income level*
• *Physical disability*
• *Other*
• *Some other aspect of your physical appearance*

Table 5 summarizes the types of settings or context in which a racist or discriminatory action might take place against an individual with a specific identity. The core concept of **setting** refers to the context (e.g., law enforcement) or location where people live, work and play (e.g., school), and was not always restricted to the healthcare setting (e.g., doctor's office).

Table 5 Types of Settings/Context Referenced in the Measures

Setting, organization or structure	**Examples referenced in the measures**
School	*Education and school setting*
Work/employment	*Work and employment; Includes being denied a job or promotion*
Law enforcement	*Examples include being harassed/unfair treatment by police or security, courts)*
Property	*Physical property including your home*
Housing	*Access to safe, affordable housing; being restricted to where you could live; includes having to move*
Health/medical care	*Health care setting or provider*
Government	*Government services*
Media	*Media such as television, newspapers, etc.*
Public	*General public settings*
Community	*Personal relationships in a person's local community home (e.g. family, romantic partner, peers, colleagues)*
Service	*Settings that provide services (e.g., restaurants, store, plumbing, etc.)*
Financial	*Getting credit, bank loans, etc.,*
Historical	*Early childhood or family history*

Table 6 below summarizes the types of unfair actions that are done based on racism/discrimination due to a person's identity. The core concept of **unfair action** was a more general term used in some measures, while others were more specific in referencing experiences of "exclusion", having to "conform", or made to feel "unsafe". We found there were numerous *unfair actions* being referenced in the measures. As such, we created a coding structure with definitions and examples that were used to systematically categorize the unfair actions referenced in a given measure (see the right column of Table 5).

Table 6 Types of Unfair (Racist or Discriminatory) Action Referenced in the Measures

Unfair Action	Definitions and Examples
Assimilated	Maintenance and participation in one's culture when in contact with broader society
Condescension	People act as if they are better than you, or you are made to feel inferior; treated as not serious
Avoided	People avoid you [51].
Made to conform	Act, look, behave more like the dominant culture
Disconnected	Loss of relationships and connections, having to move and lose connections;
Excluded	*Exclusion, rejection, denied, discouraged, prevented; made to feel like an outsider; pointed out (versus acceptance)*
Harassed	Threat of aggression, or being hassled or harassed
Ignored	Ignored, disregarded or forgotten
Insulted	Verbal rejection. Offensive comments aimed directly at you, being called names [51].
Lack of confidence	Not feeling like one has the ability to achieve / succeed
NS	Not specific, or unclear how to categorize
Abused / Attacked	Physical attack/harm to individual or property [51].
Non-representative	Not having representation of ones' race/ethnicity/Indigenous identity
Disrespected	Discourtesy/disrespect/rude
Intimidated / Made to feel unsafe	Feeling safe Note: this is slightly different to physical but refers to *feeling* safe.
Stereotyped	Assumptions, stereotyping, prejudices about *actions* Others having low expectations of you [51] For example, other having lower expectations for intelligence or work ethic, or people asking you or telling you about their assumptions and prejudices of different races/ethnicities. Questions may begin with "*because of who I am…*"
Stigmatized	Disvaluing around values e.g., trust, honesty, fear; treated with contempt
Treated differently	Treated better than you; denial of equal treatment, having to work twice as hard

Table 7 below gives the broad categories of the different responses to racism and discrimination that were used to organize the questions in the measures. The core concept of ***response*** indicated how the individual experiencing the racist and/or discriminatory action responded to it. The categories included emotional, interpersonal racism, and active coping. Emotional response referenced feelings of fragmentation, fear, loneliness, and confusion. There was some overlap with emotional response and interpersonal racism, although the responses to interpersonal racism had an expanded focus on mental (i.e., anxiety and depression) and physical (e.g., headache) health outcomes. Active coping involved losing one's identity, acting in response to the racist/ discriminatory action, or internalizing the action by suppressing one's emotions.

Table 7 Categories of Individual Responses to Racism/Discrimination Referenced in the Measures

Subdomain Referenced in the Measure	**Responses Referenced in the Measures**
Emotional	*Fragmented*
Emotional	*Afraid or silenced*
Emotional	*Confused*
Emotional	*Lonely, alienated, invisible, unsupported*
Emotional	*Rejected or hated*
Emotional	*Hurt*
Emotional	*Paralyzed*
Emotional	*Like I am struggling or stressed from proving my worth*
Emotional	*A deep loss of my homeland or identity*
Emotional	*Humiliated*
Emotional	*Disillusioned or disappointed*
Emotional / Interpersonal Racism	*Angry, annoyed or frustrated*
Emotional / Interpersonal Racism	*Depressed, sad or bad*
Emotional / Interpersonal Racism	*Helpless or powerless*
Interpersonal Racism	*Feel ashamed, humiliated, anxious or fearful*
Interpersonal Racism	*Feel amused, contemptuous or sorry for the person who did it*
Interpersonal Racism	*Get a headache, an upset stomach, tensing of your muscles, or a pounding heart?*
Active Coping	*Holding my emotions in*
Active Coping	*Ignoring it*
Active Coping	*Speaking up*
Active Coping	*Giving up or hiding my Latina/o identity*
Active Coping	*Talking about it with someone*
Active Coping	*Learning English*
Active Coping	*Struggling to prove my worth*
Active Coping	*Alienating myself from people who are not Latina/os*
Active Coping	*Praying, having faith in God*

Subdomain Referenced in the Measure	Responses Referenced in the Measures
Active Coping	*Remembering my hopes and aspirations of the future*
Active Coping	*Becoming physically aggressive*
Active Coping	*Trying to adapt to both cultures (Latina/o culture and majority culture)*
Active Coping	*Learning my rights and making a serious change (i.e., starting a work union or my own business)*
Active Coping	*Seeking professional help*

Figure 2 provides a visualization of how the four core concepts of identity, unfair action, setting and response link together. Crucially, the socio-demographics (two left light grey columns) of the diagram comprise the identities and the setting related to the discriminatory or racist action, but these characteristics are not themselves examples of racial injustice. Notably, much of the SDOH literature only measures these socio-demographic characteristics and therefore lacks true measurement of the lived experiences of racism and discrimination. In Figure 2, the Unfair and Unjust Outcome (two right columns in red) highlight the inequities of these social-level factors – these are the unfair actions that create unjust, avoidable disparities in health outcomes. Through this diagram we want to emphasize that it is the existing structures that reinforce racist or discriminatory experiences based on social-level characteristics of specific subpopulations, and thus social structures should be the focus of addressing racial injustices in Canada's healthcare and digital health systems. Details of each concept are given in the above Tables 3-6.

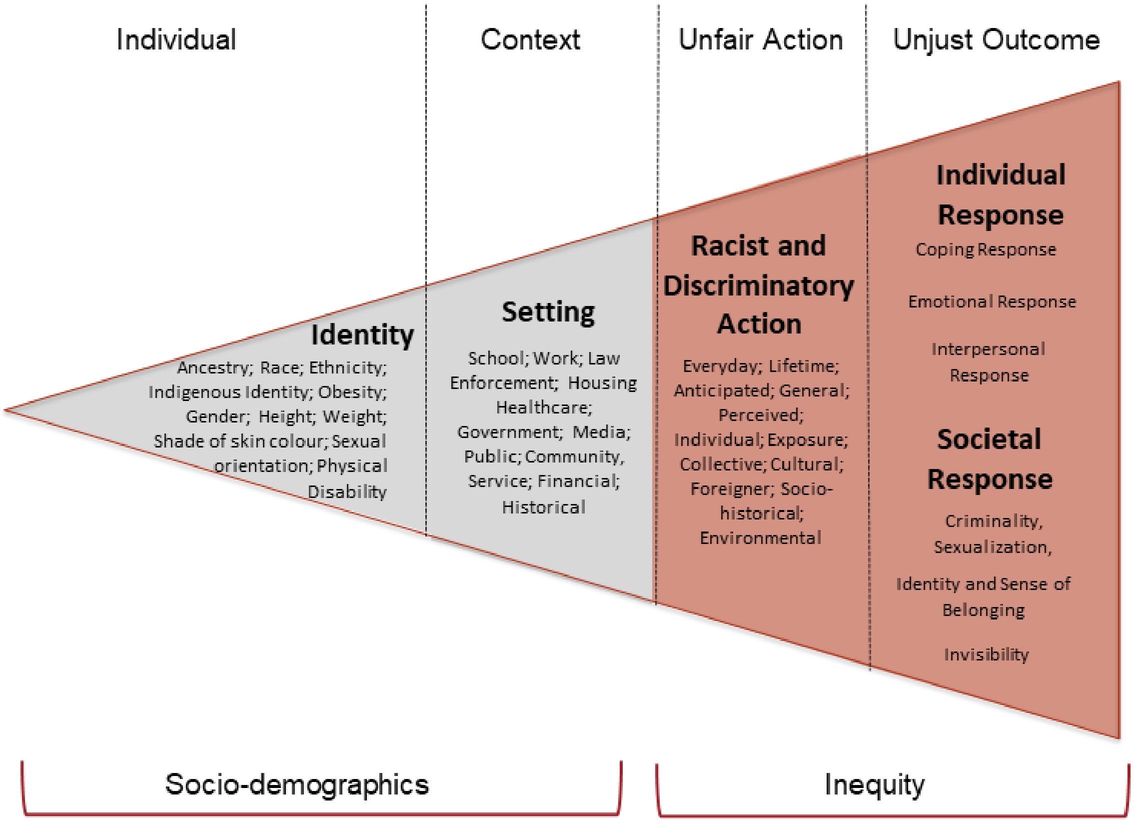

Figure 2 Core Concepts in the Measures on Racism and Discrimination

How to Apply the Measures

Evaluating when experiences are unfair

We found an evolution in wording around the questions collecting data on racism and discrimination: later publications included instruments that included the qualifying word “unfair” for greater clarity of the racist or discriminatory act. For example, questions were more explicit about the experiences people were being asked about, ‘*have you ever not been hired for a job for unfair reasons?*’. Our group discussed the significance of adding the word of “*unfair*”, as it highlights that not all unequal experiences may be unjust. For example, there are multiple reasons why someone may not be hired for a job that may not necessarily constitute unfairness.

In addition, patients may not know whether having a “discourteous experience” is a discriminatory action, as there may be other factors impacting the quality of care one receives on a given day. Having a way to evaluate these experiences can reveal the invisible processes at the individual and systemic levels that reinforce unjust, racist and discriminatory experiences [9, 10]. The *In Plain Sight* Report demonstrated one possible way by asking healthcare workers if they have witnessed repeated patterns of discourteous experiences for racialized groups [27]. However, during our working group discussions, it was also noted the that a patient-centered approach must ask patients about their experiences, rather than asking healthcare workers about patients’ experiences.

Examples of Unfair Experiences

During our discussions on the three intersecting SDOH domains of interest to the group, members provided multiple examples to illustrate how racist and discriminatory actions can intersect with healthcare access and material hardship.

There are the *everyday experiences* of racism and discrimination that may happen during a healthcare encounter that may discourage people from seeking care. This may include non-affirming care experiences when the patient's perspective and beliefs are ignored during a healthcare visit, or people are asked questions not related to their healthcare visit [9, 56]. There are also past *everyday experiences* that may be re-traumatizing during a healthcare encounter. For example, the presence of support staff (e.g., security staff) in a clinic may remind a patient of a previous negative experience with law enforcement. These everyday experiences may discourage people from accessing future care, including accessing early screening, treatment and diagnosis that can improve health outcomes.

The *major experiences* of racism and discrimination may create material hardship that results in disproportionate barriers to healthcare access. Multiple examples were given during our working group discussion. Racialized groups may be in occupations or have precarious employment which do not provide access to private healthcare insurance. The uneven justice system has created higher rates of incarceration for racialized groups [57, 58] which has resulted in differences in healthcare access through our prison system [59]. The eligibility requirements and complex funding structure of provincial programs for people with disabilities, and federal programs for Indigenous Peoples as well as veterans may deny or delay access to treatment and needed care supports [60-64]. A lack of access to transportation can also prevent Indigenous communities and older adults living in rural areas from accessing healthcare [65]. Despite the expansion of telehealth in response to the pandemic being a possible way to address transportation barriers to healthcare access, people on limited income or living in rural areas or reservations may lack reliable, affordable broadband internet services and thus not being to access virtual care [66].

Healthcare Applications of Measures on Racism and Discrimination

In considering the multiple ways that racist and discriminatory actions intersect with healthcare access and/or material circumstances to negatively impact health outcomes, we found three ways SDOH data on racism and discrimination could be used for data collection and evaluation in future. We provide an example for each of these approaches:

1) At the **population level**, by examining socio-demographics (e.g., Indigenous identity, race and ethnicity) to see if there are different healthcare outcomes and experiences across populations. The study by Siddiqi, Shahidi [67] provides one of the first Canadian example of using national Community Health Survey data for race categorization, discrimination and health outcomes. Importantly, Siddiqi's et al. study demonstrates how differences in health outcomes are the result of our socially-constructed systems that can perpetuate racism and discrimination and health inequities. The study found that that Blacks and Indigenous peoples were more likely to experience discrimination (e.g., being fear by others, being

treated less courteous or respect than others) than Asian or Whites–and that these experiences were a determinant of chronic conditions and chronic illness risk factors [67].

Although this is one of the most common approaches used in applying measures on racism and discrimination, there are limited examples in Canada. A 2015 systematic review and meta-analysis on 333 publications found only 7 studies from Canada [25]. However, the recent standards on race, ethnic and Indigenous identities developed by CIHI with racialized communities provides a way forward for more applications of this approach within Canada [5, 6].

2) At the **organizational level**, as a patient-reported experience measure (PREM) to evaluate whether patients have experienced racist or discriminatory actions within the healthcare system. Health system performance indicators (e.g., PREMs and other system-level measures) stratified with race-based and Indigenous identity data could reveal "invisible" racism within our healthcare system. Critically, this approach necessitates strong data governance to ensure that patients' anonymity is maintained and they are reassured that their data will not affect their ability to access care, or further perpetuate racist beliefs and biases in the system.

3) At the **individual/clinic level**, as a standardized measure in identifying patients who have had their mental, physical and emotional health impacted racist and discriminatory experiences, so that they can then be connected to trauma-informed services and programs. This more recent approach is demonstrated in the Diop, Taylor [68] review on how to talk to patients about racism. The screening questions in the review represented some of the questions we saw in the measures we examined, but also provided more specific questions for opening sensitive discussions with patients.

Conceptualizing Intersectionality

Intersection of the Measures

There were two main ways that we saw intersectionality appearing in our discussions. The first was introduced by the measures in allowing people to select multiple identities when indicating the main reason for these experiences. The second was in our overall goal of applying an intersectional lens to the collection and development of SDOG data and standards as our second objective.

Building on our previous diagram, Figure 3 illustrates the overlay of the three intersecting SDOH domains of racism and discrimination, material circumstance/hardship and (un)equal healthcare access. Figure 3 was developed by considering the examples of unfair experiences detailed on page 14, combined with the 4 core concepts we identified from the measures on racism and discrimination (i.e., identity, setting, unfair action and response). The inner triangle represents concepts from the measures on racism and discrimination, notably they are more focused on individual experiences. The outer triangle represents system-level concepts in considering how systemic racism results in unequal healthcare access and material hardship leading to unjust outcomes.

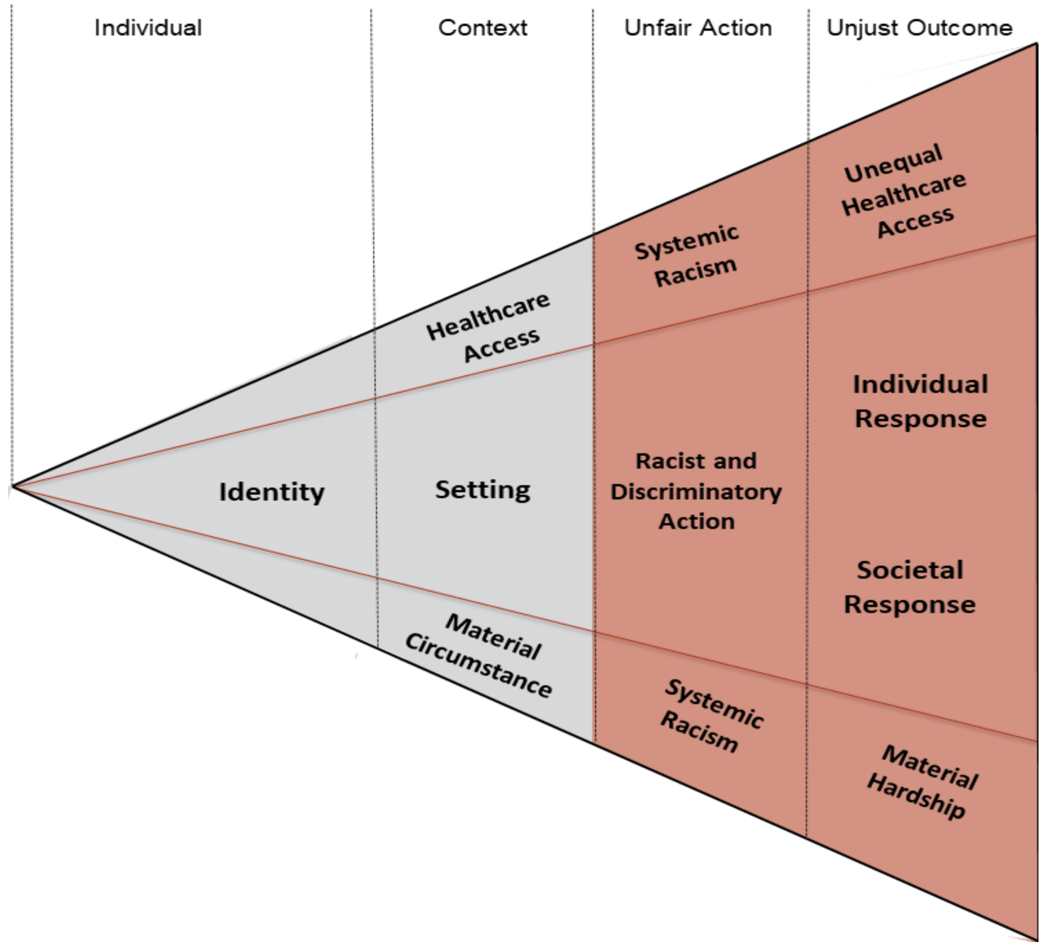

Figure 3 Intersection of Racism and Discrimination, Material Circumstances and Healthcare Access

Strength-based Approach as a Key Consideration in Developing SDOH Data Standards

Our initial goal for the working group was to apply a strength-based lens in examining SDOH data for future development of data standards in digital health systems. However, the majority of approaches tend to continue to use a deficit-based approach that considers only the harms of racism and discrimination. In May 2022, the 'Anti-Racism Data Act' introduced in British Columbia reinforced the need for strength-based approaches that support self-determination and involve Indigenous communities in dismantling colonialist laws. Given that the majority of measures were developed in the United States while Canada is beginning to develop data standards focused on racism and discrimination, we recommend greater attention to strength-based approaches to measure these intersecting SDOH domains in moving this work forward.

Our guest presentations in June 2022 provided examples of culturally-safe indicators [8] currently in development that can provide such a strength-based approach [69, 70]. To aid organizations in building culturally safe care and addressing Indigenous-specific racism, the First National Health Authority (FNHA) recently released the Health Standards Organization Cultural Safety and Humility Standards which was led and designed by a local Indigenous community [71]. CIHI's framework on '*Measuring cultural safety in health systems*' offers four categories for how culturally safe indicators could be used in evaluating health system interventions, experiences of health system and health system performance, and health and wellness outcomes [8]. There is also '*The First Nations Regional Health Survey*' that provides a Cultural Wellness composite index that asks the questions on knowledge of a First Nations language, eating traditional foods, use of traditional medicine, importance of traditional spirituality, participation in local community cultural events [72].

Figure 4 demonstrates how our intersecting model could be converted into a strength-based approach that could be used for the development of anti-racist SDOH data standards for digital health in Canada. To address unfair/unjust actions, there is the need for strong data governance and safe data collection [3, 73, 74], as well as ongoing community engagement, that supports culturally sensitive and trauma-informed care [68]. The resulting healthcare system would be one that provides equal access and culturally safe spaces, which leads to reaffirming care experiences, a sense of belonging, and representation across all levels of the healthcare system.

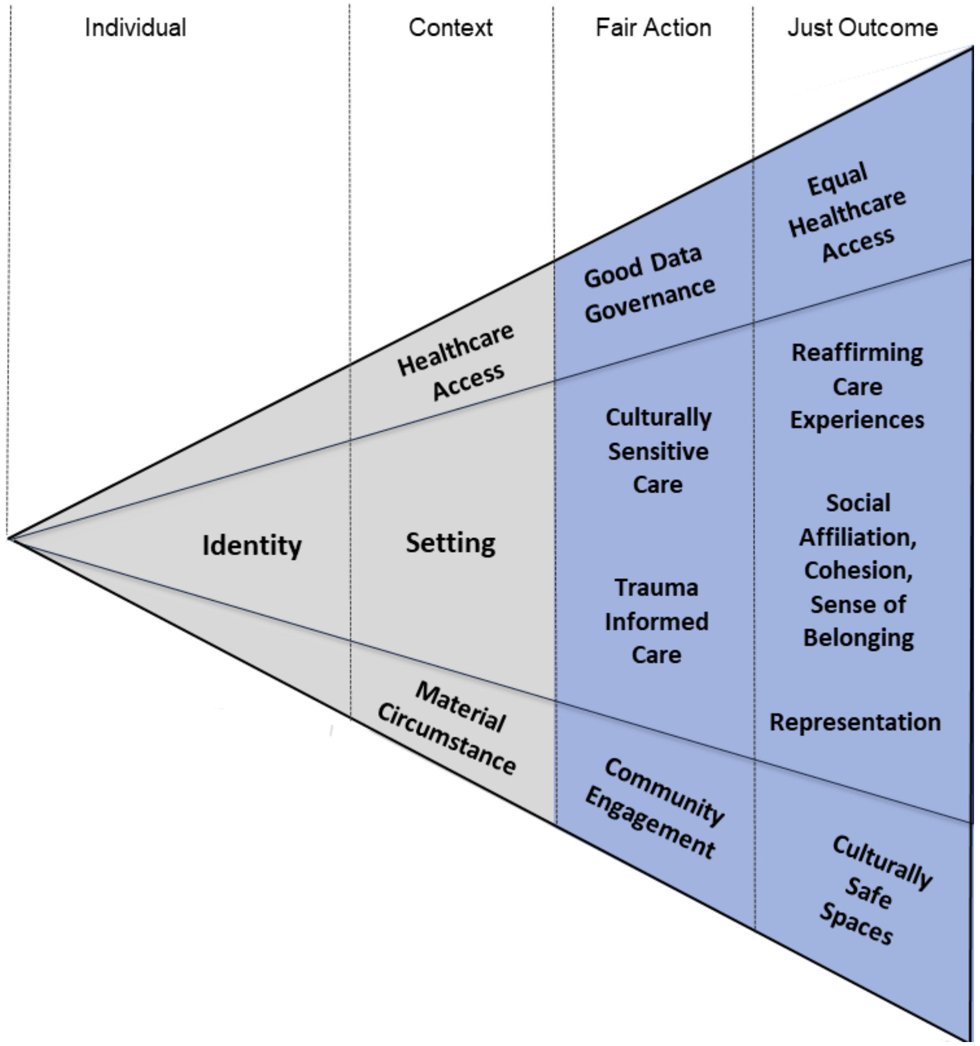

Figure 4 Strength-based Approach for Healthcare Access and Material Circumstances

Areas for Further Exploration

Our work focused on measures which identify *unfair action*. To address systemic racism and discrimination requires strategies to promote *just actions* across all levels of healthcare, and not only the measuring of unjust actions. In addition, standards need to be developed not only for identifying racialized groups impacted by SDOH, but for evaluating the impact of actions targeting inequities.

During our working group meetings, we discussed how current digital infrastructure may reinforce healthcare providers' biases and assumptions. For example, a patient's name in the electronic health record may result in underlying assumptions about the patient and how to approach their care. Previous studies on discriminatory hiring [75] and unfair publication practices [76, 77] have demonstrated how a person's name on an application introduces bias in assessing the qualifications of the person. The rapid adoption of remote care also raises concerns about how assumptions and biases may be reinforced when visits are conducted over a digital platform. A patient's primary language or dialect may result in unknown assumptions that impact providers' decisions on care strategies. In addition, visual and audio cues during a visit may create assumptions about a patient's home and social context. Although beyond the scope of our current project, many of the reviews and reports we cited in this document noted the limited resources focused on addressing discrimination in healthcare, and the need for structural competency, trauma-informed care, and intersectional approaches that address provider bias related to racism/discrimination.

There were areas we touched that were beyond the scope of our work for the first year. Our search was focused on racism and discrimination, yet there are multiple forms of discrimination towards one social identity as was reflected by some of the measures. During our meetings, the example was given of discrimination that is compounded across the life course for people living with a disability, and the continued invisibility of people living with a disability because of federal and provincial policies that discourage employment [78-80]. There is the need for further searches specific to the other forms of discrimination to determine how the concepts we found map to other forms of discrimination. The social identities we found referenced in the measures provide a starting point for search terms specific to other forms of discrimination (e.g., 'ableism', 'ageism', 'sexism', 'disability discrimination', 'age discrimination', 'gender discrimination', 'transphobia', 'weight discrimination', 'religious discrimination').

Recommendations and Next Steps

Our SDOH Working Group demonstrated how intersectionality theory may inform SDOH data standards development and implementation in Canada's healthcare system. The definitions, categories and models we proposed are preliminary, and require mapping and further validation with the communities impacted by the racist and discriminatory experiences. Based on our group's work, we propose the following recommendations for the development of SDOH data standards:

1) Map current measures on cultural safety indicators [8, 71] to promote a strength-based approach for addressing racial and discriminatory action leading to health inequities;

2) Expand the search to other forms of discrimination that were beyond the scope of our initial project;
3) Develop culturally-safe practices in standards development [8] that welcome multiple ways of knowing;
4) Reconcile intersectionality theory which offers the perspective of irreducibility of social identities with the categorical system of data standards [81];
5) Establish strong data governance where patients from racialized groups feel safe in reporting this information in the care setting where they had negative experiences [82];
6) Co-create a process of engaging communities impacted by the SDOH in the development of the standards.

This is only the first step in developing SDOH data standards from an intersectional perspective and does not fully capture all possible patient experiences of unfair treatment based on one's diverse social identities. The scope of the work in developing SDOH data standards is vast and requires federal, provincial and organizational commitment to move this work forward. Critically, it is not enough to measure racism and discrimination, but to develop actions towards addressing these inequitable experiences. In order to have lasting impact, we recommend a "Gravity North" which has dedicated resources to (a) support a community-based process for consensus, (b) ensure good data practice and data governance for SDOH data, and (c) be a hub for existing standards initiatives focused on addressing health inequities.

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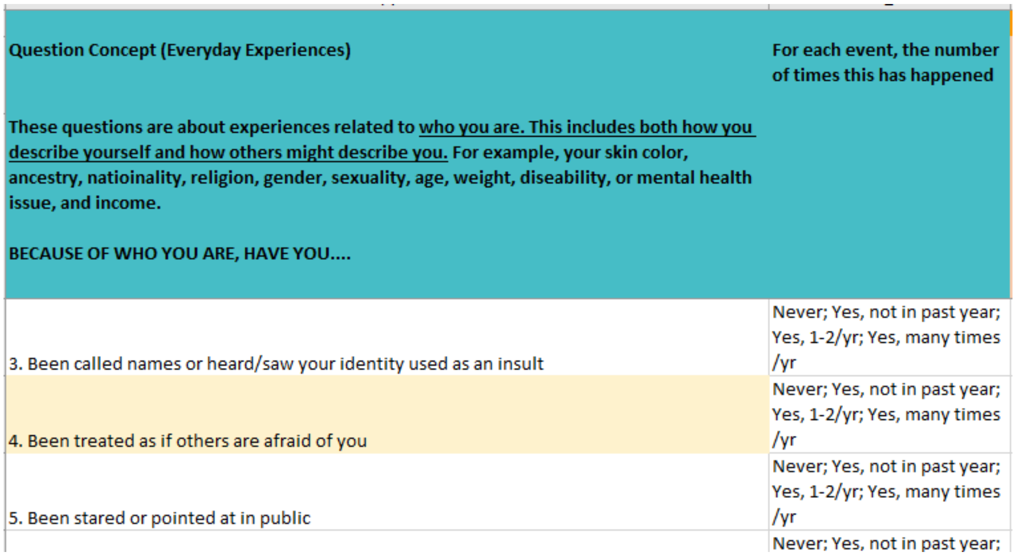
Appendix A: List of Organizations Represented by our Working Group Members

- Alberta Health Services
- Alberta Innovates
- Allscripts
- BC Ministry of Health
- Boundary Health Care Cooperative
- Canada Health Infoway
- Canadian Institute of Health Information
- Canadian Mental Health Association
- Canadian Partnership Against Cancer
- Centre for Distance Education
- Centre for Rural and Northern Health Research
- CGI Inc.
- Drummond Group
- Empower Health
- First Nations Health Authority
- Fraser Health
- Gevity
- Laroche Consulting
- London Health Sciences Centre
- McMaster University
- Ministère de la santé et des services sociaux
- Mustimuhw Information Solutions Inc.
- New Brunswick Department of Health
- Newfoundland and Labrador Centre for Health Information
- NucleusLabs IT Canada
- Ontario Health
- OntarioMD
- Parker Digital Health Consulting Inc.
- Provincial Health Services Authority
- Rainbow Health Ontario
- Sunnybrook
- University Health Network
- University of British Columbia
- University of Calgary
- University of Michigan
- University of Prince Edward Island
- University of Toronto
- University of Victoria
- Vancouver Coastal Health
- Xperterra

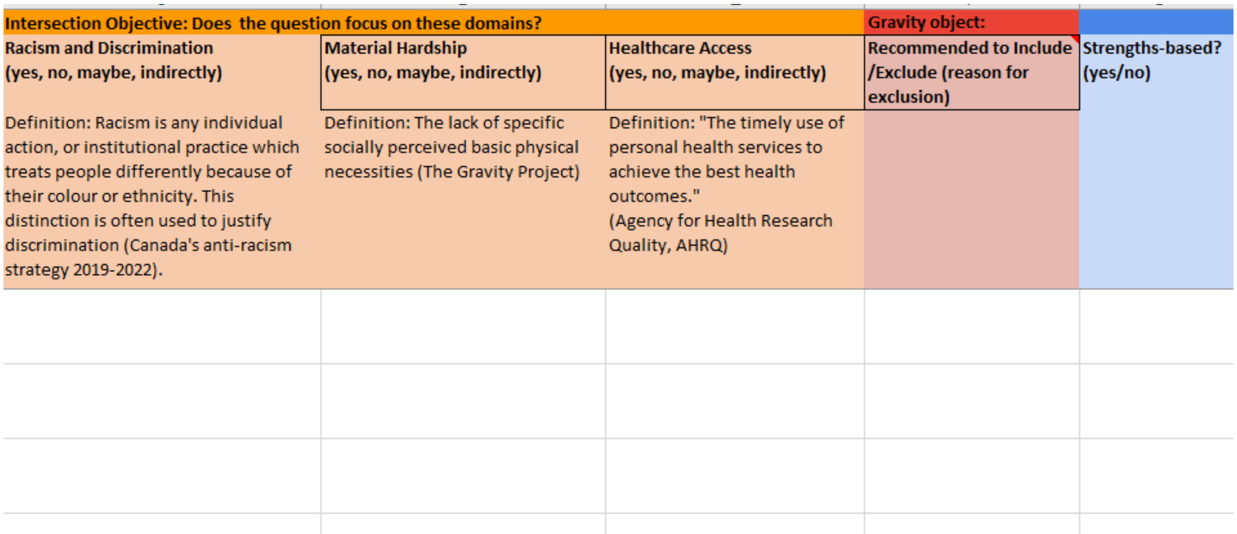
Appendix B: Templates used to Guide our Work

Below are screenshots of the templates we used to guide our work. The Excel templates can be accessed from the working group’s site at Canada Health Infoway: https://infocentral.infoway-inforoute.ca/en/resources/docs/sdoh/sdoh-working-documents

A. Working Group Discussion Template



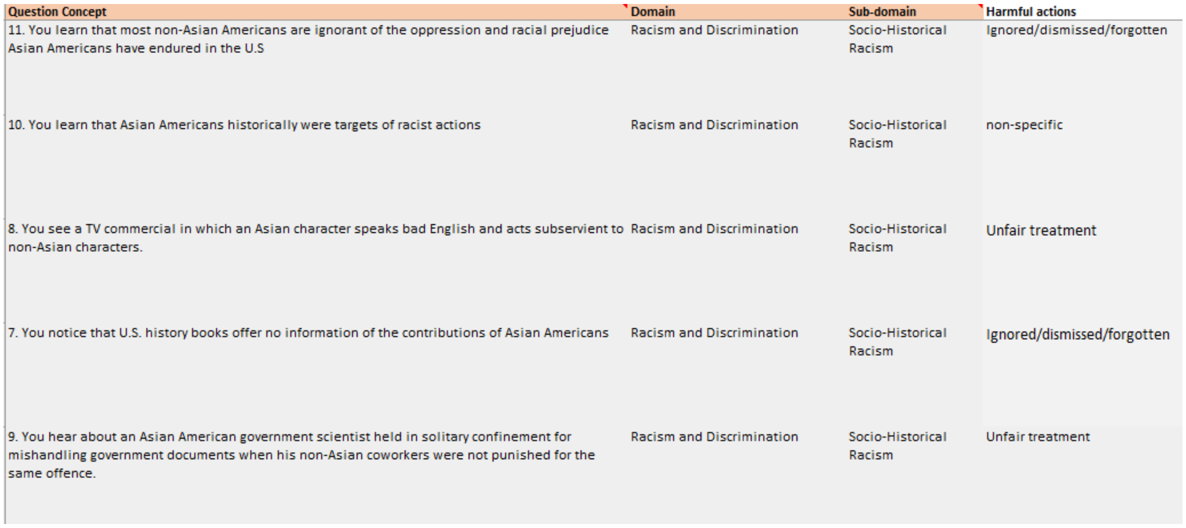
Question Concept (Everyday Experiences) **These questions are about experiences related to <u>who you are. This includes both how you describe yourself and how others might describe you.</u> For example, your skin color, ancestry, natioinality, religion, gender, sexuality, age, weight, diseability, or mental health issue, and income.** **BECAUSE OF WHO YOU ARE, HAVE YOU....**	**For each event, the number of times this has happened**
3. Been called names or heard/saw your identity used as an insult	Never; Yes, not in past year; Yes, 1-2/yr; Yes, many times /yr
4. Been treated as if others are afraid of you	Never; Yes, not in past year; Yes, 1-2/yr; Yes, many times /yr
5. Been stared or pointed at in public	Never; Yes, not in past year; Yes, 1-2/yr; Yes, many times /yr
	Never; Yes, not in past year;



Intersection Objective: Does the question focus on these domains?			**Gravity object:**	
Racism and Discrimination (yes, no, maybe, indirectly)	**Material Hardship (yes, no, maybe, indirectly)**	**Healthcare Access (yes, no, maybe, indirectly)**	**Recommended to Include /Exclude (reason for exclusion)**	**Strengths-based? (yes/no)**
Definition: Racism is any individual action, or institutional practice which treats people differently because of their colour or ethnicity. This distinction is often used to justify discrimination (Canada's anti-racism strategy 2019-2022).	Definition: The lack of specific socially perceived basic physical necessities (The Gravity Project)	Definition: "The timely use of personal health services to achieve the best health outcomes." (Agency for Health Research Quality, AHRQ)		

The template can be accessed from the working group’s site at Canada Health Infoway: https://infocentral.infoway-inforoute.ca/en/resources/docs/sdoh/sdoh-working-documents

B. Extraction of the Measures



Question Concept	Domain	Sub-domain	Harmful actions
11. You learn that most non-Asian Americans are ignorant of the oppression and racial prejudice Asian Americans have endured in the U.S	Racism and Discrimination	Socio-Historical Racism	Ignored/dismissed/forgotten
10. You learn that Asian Americans historically were targets of racist actions	Racism and Discrimination	Socio-Historical Racism	non-specific
8. You see a TV commercial in which an Asian character speaks bad English and acts subservient to non-Asian characters.	Racism and Discrimination	Socio-Historical Racism	Unfair treatment
7. You notice that U.S. history books offer no information of the contributions of Asian Americans	Racism and Discrimination	Socio-Historical Racism	Ignored/dismissed/forgotten
9. You hear about an Asian American government scientist held in solitary confinement for mishandling government documents when his non-Asian coworkers were not punished for the same offence.	Racism and Discrimination	Socio-Historical Racism	Unfair treatment

Setting, organization or	Introduced by	Organization	Relevant Screening Tool
Public	Marcy Antonio	Infoway SDOH Working group	Asian American racism-related stress inventory (AARRSI)
Public	Marcy Antonio	Infoway SDOH Working group	Asian American racism-related stress inventory (AARRSI)
Public	Marcy Antonio	Infoway SDOH Working group	Asian American racism-related stress inventory (AARRSI)
Public	Marcy Antonio	Infoway SDOH Working group	Asian American racism-related stress inventory (AARRSI)
Work/employment	Marcy Antonio	Infoway SDOH Working group	Asian American racism-related stress inventory (AARRSI)

The template was adapted from the Gravity template:
https://confluence.hl7.org/display/GRAV/Data+Element+Submission