Guidance for the Collection and Use of Sociodemographic Data for Equity Analytics

ONTARIO HEALTH | June 2024

Ontario Health

Table of Contents

Introduction

Overview

Health care disparities in Ontario persist, resulting in unequal access to and variations in the quality of care received by individuals due to their social and demographic characteristics, such as ethnicity, gender identity, or belonging to a racialized group.

Ontario Health is committed to mitigating these health inequities and recognizes that the collection and utilization of sociodemographic data are crucial elements in the pursuit of equitable, accessible, and quality care for all individuals. As an integral part of this commitment, Ontario Health is proud to present this guidance document, crafted to provide clarity and direction to our valued partners across the sector.

Purpose

This document contains high-level guidance for standardizing the collection and utilization of sociodemographic data within health care encounters. It is not meant to be prescriptive. By delineating clear protocols and methodologies, our aim is to foster greater consistency and comparability in data collection practices across the sector. Through this harmonization, partners can more effectively leverage sociodemographic data to drive evidence-based decision-making, identify disparities, and tailor interventions to meet the diverse needs of communities.

Central to our collective efforts is the recognition of the importance of data governance and sovereignty. We urge all stakeholders to approach the collection and use of sociodemographic data with a commitment to privacy, security, and ethical principles. By upholding rigorous standards of data governance, we not only safeguard individual rights but also fortify the integrity and trustworthiness of our data infrastructure.

Scope and Intended Audience

The scope of this guidance was initially intended for internal use. However, we felt the benefits would extend beyond the walls of Ontario Health, and we are sharing to offer guidance to health service providers and planners who aspire to collect sociodemographic data for non-clinical, health system planning purposes. Whether you aspire to collect sociodemographic data to assess population health trends, allocate resources, or design targeted interventions, this document offers guidance to inform your endeavors.

Ontario Health itself currently oversees several distinct initiatives that gather sociodemographic data elements, extending beyond the commonly collected age, sex, and postal code information found in administrative datasets. Each of these initiatives has their own histories and evolution, and we have noted inconsistency in data collection approaches and standards. For instance, questions may be phrased differently, or the response options may vary, including the use of free-text or different sets of acceptable response values. This variation hampers our ability to paint an accurate and cohesive

picture of health care disparities across various initiatives and settings (e.g., comparing outcomes of minority groups across programs can be difficult if different categories are used), and we are committed to continuous improvement in this regard.

As we embark on our own journey toward standardization, we hope this guidance will help others establish their own standard practices. Together, we can harness the power of sociodemographic data to build a healthier, more inclusive health care for all Ontarians.

Acknowledgement

Much of this guidance builds on a rich history and experience developed by the Toronto Measuring Health Equity Initiative.[1] While our standard has evolved slightly from the initiative, we owe a debt of gratitude to the Initiative for leading by example and demonstrating the power addressing health inequities through the collection of patient demographic data. The Toronto Region, serving a diverse population, has prioritized health equity and implemented standardized data collection to identify and tackle disparities systematically, and Ontario Health aims to build on this tradition.

---

[1] https://torontohealthequity.ca/wp-content/uploads/2013/02/Measuring-Health-Equity-Demographic-Data-Collection-Use-in-TC-LHIN-Hospitals-and-CHCs-2017.pdf

Understanding Sociodemographic Data

What is Sociodemographic Data?

Sociodemographic data encompasses a broad array of characteristics, including but not limited to age, sex, gender, racialized group, ethnicity, income, education, language, housing status, employment, and geographic location. These data points not only provide a snapshot of individuals' social identities but also offer critical context for understanding the multifaceted determinants of health within communities and for measuring differences in health and health care that may be considered unfair or unjust.[2]

Sociodemographic data in health care decision-making

Benefits of collecting sociodemographic data have long been established by, for example, the Ontario Human Rights Council[3] and the Anti-Racism Directorate.[4] The importance of sociodemographic data in health care decision-making cannot be overstated. By illuminating patterns, disparities, and inequities across diverse population groups, sociodemographic data empower stakeholders to tailor interventions, allocate resources, and design policies that address the unique needs of communities. For instance, understanding the socioeconomic status of a population can inform strategies to mitigate barriers to access, while acknowledging cultural factors can enhance the relevance and effectiveness of health care interventions.

Moreover, sociodemographic data serve as vital tools for advancing health equity initiatives. By systematically collecting and analyzing data on social determinants of health, health care organizations can identify gaps in care, advocate for marginalized populations, and drive transformative change toward more equitable health outcomes. Indeed, harnessing the power of sociodemographic data is not merely a technical endeavor but a moral imperative in the pursuit of justice and equity in health care.[1]

In essence, sociodemographic data form the bedrock upon which informed, equitable health care decisions are built. As we navigate the complexities of modern health care systems, we must recognize the richness of sociodemographic data as a cornerstone of our commitment to promoting health and well-being for all individuals and communities.[5]

Ontario Health's Sociodemographic Data Standard

To foster uniformity and comparability in the sociodemographic data collected across various programs, populations, and care settings, Ontario Health has developed a sociodemographic data standard.

Our internal standard includes details on core (and optional) sociodemographic data elements, encompassing definitions, rationale, question wording, standardized response values, and logic frameworks. The establishment of this standard was a collaborative effort, shaped by the insights and contributions of our Core Sociodemographic

---

[2] https://www.cihi.ca/sites/default/files/document/defining-stratifiers-measuring-health-inequalities-2018-en-web.pdf
[3] https://www.ohrc.on.ca/en/count-me-collecting-human-rights-based-data
[4] https://www.ontario.ca/page/anti-racism-directorate
[5] https://www.wellesleyinstitute.com/wp-content/uploads/2017/10/Collecting-Socio-demographic-Data.pdf

Data Standard Working Group, guided by the insights of the Sociodemographic Data Collection and Governance Advisory Committee, and informed by subject matter experts both within and outside of Ontario Health.

In the spirit of openness and collaboration, we are releasing this internal guidance to the system in hopes of fostering greater alignment across the sector.

Data Elements and Response Values

Core Set

This section outlines the core set of sociodemographic data elements collected within Ontario Health-led datasets that currently capture sociodemographic data. Programs already collecting at least one of these data elements will now move toward collecting all core data elements, collected in the standardized way outlined herein.

The core set of sociodemographic data elements (in no particular order) includes:

- Indigenous Identity*
- Racialized Group
- Ethnicity
- Born/Arrived in Canada
- Income
- Language
- Disability Status
- Sexual Orientation
- Gender Identity
- Transgender Identity

NOTE REGARDING AGE, SEX, AND LOCATION

It is worth noting that in our endeavor to standardize the collection of sociodemographic data, Ontario Health has deliberately excluded age, biological sex, and location. This decision is informed by the recognition that date of birth, biological sex, and geographics variables (such as postal code) are routinely collected in a standardized manner across health care encounters, thus minimizing the need for additional guidance in this regard.

Although these data elements are not explicitly included in our standard, we acknowledge their continued importance as fundamental demographic variables with significant implications for health outcomes and health care delivery. Health care organizations are encouraged to maintain their

existing protocols for collecting date of birth, sex, and place-based data in accordance with established standards and best practices.

NOTE REGARDING INDIGENOUS IDENTITY*

The inclusion of Indigenous identity as a core data element, as well as how the questions are asked, is undergoing discussion and being reviewed via the Ontario Health Indigenous Data Governance Matters (IDGM) process that is being developed with First Nations, Inuit, Métis and urban Indigenous partners. These questions should not be used at Ontario Health until they are approved by First Nations, Inuit, Métis and urban Indigenous partners through this process. In addition, any subsequent use of the validated questions and the resulting data generated in work led by Ontario Health must go through the Ontario Health IDGM process.

Indigenous Identity

DEFINITION

First Nations, Inuit and Métis are distinct nations with constitutionally recognized inherent rights to self determination.[6][7] While Indigenous identity can be grouped into First Nations, Inuk (Inuit) and/or Métis groups, a person may identify with one or more of these groups, and/or with a more specific community or nation.[8] Additional complexity, for example based on registration status, place of residence, and approaches to self-identification may also impact Indigenous identity data.[9][10]

RATIONALE

Ontario Health has made important commitments to First Nations, Inuit, Métis, and urban Indigenous peoples through its Annual Business Plan.

Collecting this information helps us understand how First Nations, Inuit, and Métis persons access health care services, and can be useful for exploring barriers and opportunities for addressing health and well-being outcomes for First Nations, Inuit, Métis, and urban Indigenous communities.

QUESTIONS AND RESPONSE VALUES

[PENDING DISCUSSION, REVIEW AND APPROVAL WITH INDIGENOUS PARTNERS]

---

[6] https://social.desa.un.org/sites/default/files/migrated/19/2018/11/UNDRIP_E_web.pdf
[7] https://laws-lois.justice.gc.ca/eng/const/page-13.html
[8] https://www.cihi.ca/sites/default/files/document/race-based-and-indigenous-identity-data-supplementary-report-en.pdf
[9] https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4716822/pdf/nihms5289.pdf
[10] https://ijcis.qut.edu.au/article/view/29/29.html

Racialized Group

DEFINITION

Race[11] is a social construct used to categorize people based on physical traits, such as skin colour, hair texture, and facial features. In this document, we instead use the term "racialized group" to describe those affected by racism, as opposed to "race" which is often seen as an inherent trait.

Racialized groups may encounter a range of racisms, resulting in disparate health and societal consequences. Racialized group categories may vary over time and place and can overlap with ethnic, cultural, or religious groupings.

RATIONALE

Ontario Health has made important commitments to collecting racialized group-based data through the Black Health Plan and its Annual Business Plan. Collecting this information helps us understand the diversity of racialized groups accessing health care services and can be useful for identifying the potential barriers and health inequities that exists because of racism.

QUESTIONS AND RESPONSE VALUES

Source: Anti-Racism Directorate

Which of the following best describes your racialized group? (check all that apply, for example if you belong to multiple racialized groups)
☐ Black ☐ East Asian ☐ Latin American ☐ Middle Eastern ☐ South Asian	☐ Southeast Asian ☐ White ☐ Another race group (please specify): _____ ☐ Do not know ☐ Prefer not to answer

QUESTION TYPE

This question allows multiple selections and includes the option of providing another racialized group in a free-text response field.

---

[11] Adapted from Anti-Racism Directorate, 2022

Ethnicity

DEFINITION

Ethnicity[12] is a concept that attempts to capture socio-cultural identity. It can include place of origin and aspects of culture. Ethnic groups share common identity, heritage, ancestry, or history, often with identifiable cultural, linguistic, and/or religious characteristics. Ethnicity is distinct from racialized group.[13]

RATIONALE

Collecting this information helps us understand the ethnic diversity of people who are accessing health care services and can be useful for identifying barriers and health inequities among different cultural groups. Systemic discrimination may include organizational culture, policies, directives, practices, or procedures that exclude, displace, or marginalize some ethnic groups or create unfair barriers for them to access valuable benefits and opportunities.

QUESTIONS AND RESPONSE VALUES

Source: Anti-Racism Directorate (question); Canadian Census 2021 (response values)

What is your ethnic or cultural origin(s)? (specify as many ethnic or cultural origin(s) as applicable).	
☐ **Origins referring to countries (see Appendix: Ethnicity)** ☐ **Other ethnic or cultural origins (see Appendix: Ethnicity)**	☐ **Another ethnic or cultural origin (please specify): _____** ☐ **Do not know** ☐ **Prefer not to answer**

QUESTION TYPE

This question allows multiple selections and includes the option of providing another cultural or ethnic group in a free-text response field.

LOGIC

There are 386 distinct ethnic and cultural origins available to select, all derived from options available in the Canadian Census. Each of these options should appear for selection, ideally from a drop-down list.

---

[12] Adapted from Anti-Racism Directorate, 2022: https://www.ontario.ca/document/data-standards-identification-and-monitoring-systemic-racism/collection-personal-information

[13] For example, "Black" is a racialized group category that includes people of diverse cultures and histories. "Jamaican", by contrast, is an ethnic group with a widely shared heritage, ancestry, historical experience, and nationality.

IMPORTANT NOTE

The 124 Indigenous origin response values that were included in the Canadian Census 2021 were removed completely from the ethnicity question. A separate set of questions are included in the Indigenous Identity section, which is undergoing discussion and being reviewed via the Ontario Health IDGM process that is being developed with First Nations, Inuit, Métis and urban Indigenous partners. These questions should not be used at Ontario Health until they are approved by First Nations, Inuit, Métis and urban Indigenous partners through this process.

Born/Arrived in Canada

DEFINITION

Born/arrived in Canada status refers to a person's origin and/or arrival into Canada.

RATIONALE

Collecting this information helps us understand the quality and access to health care services among Ontario residents and immigrants and can help identify the potential barriers and health inequities that may exist for vulnerable groups, such as newcomers and refugees. For example, it may be used to develop targeted health care policies and programs for newcomer populations.

QUESTIONS AND RESPONSE VALUES

Source: Measuring Health Equity (Toronto Region)

Were you born in Canada?
☐ Yes ☐ No ☐ Do not know ☐ Prefer not to answer

If no, when did you arrive in Canada?
☐ Less than 5 years ago ☐ 5 to 9 years ago ☐ 10 years ago, or more ☐ Do not know ☐ Prefer not to answer

IMPORTANT NOTE

Ontario Health is currently in discussion with Immigration, Refugees, and Citizenship Canada (IRCC) to acquire the Permanent Resident's database. Access to these data would allow us to obtain this information via linkage instead of requiring novel collection.

Family Income

DEFINITION

Family income[14] refers to the total income of all adult[15] family members. By contrast, household income refers to the total income of a physical household, which may consist of one or more families, or of unrelated individuals.

RATIONALE

Income is one of the most studied determinants of health. By collecting information pertaining to income, Ontario Health can monitor and address health inequities associated with income as well as advance equitable health care services. Ontario Health will also collect information on how many people are supported by the family income, to better understand the economic well-being of the family and the potential impact of the family income on the living standards of its members.

QUESTIONS AND RESPONSE VALUES

Source: Measuring Health Equity (Toronto Region)

What was your total family income before taxes last year (among adults 16 and older)?
☐ $0 to $19,999   ☐ $20,000 to $39,999   ☐ $40,000 to $59,999   ☐ $60,000 to $79,999   ☐ 80,000 to $119,999   ☐ $120,000 to $149,999   ☐ $150,000 or more   ☐ Do not know   ☐ Prefer not to answer

How many people does this income support (including yourself)?
☐ _____ person(s)   ☐ Do not know   ☐ Prefer not to answer

---

[14] Adapted from Statistics Canada: https://www150.statcan.gc.ca/n1/pub/75f0011x/2012001/notes/fam-eng.htm
[15] Adults are defined as individuals 16 or older.

Language

DEFINITION

There are many aspects of language. In this standard, we focus on the language individuals are most comfortable speaking. This refers to the language in which an individual feels most at ease, relaxed, and proficient when communicating. It is the language that someone typically prefers to use when they want to express themselves with the least effort, stress, or self-consciousness. This language is often the one in which the person has the most fluency and is most culturally and emotionally connected. This concept can vary from person to person, and it may be their native language or a second language in which they have become highly proficient and feel a strong sense of linguistic and cultural belonging.

RATIONALE

Ontario Health has made a commitment to establish a French Language Health Strategy to improve access to high-quality French Language Health Services and enhance experience and health outcomes for Francophones.

Collecting this information helps us understand the complex relationship between language and health outcomes. Language is a significant obstacle to obtaining high-quality care, particularly for non-English speakers. In Ontario, individuals who speak only French are more likely to report poor health than those who speak only English, or who speak English and another language.[16]

QUESTIONS AND RESPONSE VALUES

Source: French Language Health Planning Entities (partner); response options from Ontario Health using ISO language codes and Census 2021 for data on languages spoken in Ontario. Methodology available upon request.

What language are you most comfortable speaking?
• **Extensive list (see Appendix: Language)**

[Indigenous language question]
• **[PENDING DISCUSSION, REVIEW AND APPROVAL WITH INDIGENOUS PARTNERS]**

---

[16] Wellesley Institute: https://www.wellesleyinstitute.com/wp-content/uploads/2017/10/Collecting-Socio-demographic-Data.pdf

If you are most comfortable speaking in a language other than French or English, in which of Canada's official languages are you most comfortable?

☐ **English**
☐ **French**

QUESTION TYPE

This question permits single select and includes the option of providing another language in a free-text response field.

LOGIC

The first question will appear by default. The third question will appear if the answer to the first was neither English nor French.

Disability Status

DEFINITION

Disability[17] refers to the functional limitations an individual experiences and the barriers they encounter in their environment, including social and physical obstacles that make daily functioning more challenging.

RATIONALE

Collecting this information helps us understand how individuals with a disability access health care services and the relationship between their disability and health outcomes. Ontarians with disabilities report less access to health care and greater unmet health care needs than those without disabilities.[18]

The Ontario Disability Support Program (ODSP) is a social assistance program that provides income support and employment support to individuals with disabilities. Not all individuals with disabilities are enrolled in the program,[19] so it is not viable alternative for novel data collection.

QUESTIONS AND RESPONSE VALUES

Source: Adapted from Measuring Health Equity (Toronto Region)

Do you identify as a person with disabilities?	
☐ Yes ☐ No	☐ Do not know ☐ Prefer not to answer

If you wish, please specify the type of disability (select all that apply)	
☐ Alzheimer's Disease/Dementia ☐ Autism Spectrum Disorder ☐ Chronic Illness (e.g. sickle cell, diabetes etc.) ☐ Cognitive Disability ☐ Developmental Disability ☐ Drug or Alcohol Dependence ☐ Learning Disability	☐ Mental Illness ☐ Physical Disability ☐ Sensory Disability (e.g., low vision, blindness, deafness, hard of hearing etc.) ☐ Other (please specify): _____ ☐ None ☐ Do not know ☐ Prefer not to answer

---

[17] Adapted from Statistics Canada: https://www150.statcan.gc.ca/n1/pub/11-627-m/11-627-m2022062-eng.htm
[18] Wellesley Institute: https://www.wellesleyinstitute.com/wp-content/uploads/2017/10/Collecting-Socio-demographic-Data.pdf
[19] Auditor General: https://www.auditor.on.ca/en/content/annualreports/arreports/en19/v1_309en19.pdf

QUESTION TYPE

Second question allows multiple selections and includes the option of providing another disability support the individual can benefit from in a free-text response field.

LOGIC

First question appears by default. Second question appears if the answer to first question is "Yes".

Sexual Orientation

DEFINITION

Sexual orientation[20] refers to a person's emotional, romantic, and sexual attraction to others. It encompasses a wide range of identities, including but not limited to gay, lesbian, bisexual, and heterosexual orientations.

RATIONALE

Collecting this information helps us identify potential barriers and health inequities that exist within the health care system, particularly for 2SLGBTQIA+ community members. This data can highlight vulnerable groups that do not have equal access to care and help eliminate systemic barriers related to sexual orientation.

QUESTIONS AND RESPONSE VALUES

Source: Adapted from Measuring Health Equity (Toronto Region)

Which category (or categories) describes your sexual orientation? (select all that apply)
☐ **Asexual**
☐ **Bisexual**
☐ **Demisexual**
☐ **Gay**
☐ **Lesbian**
☐ **Pansexual**
☐ **Queer**
☐ **Questioning or unsure**
☐ **Same-gender loving**
☐ **Straight/heterosexual**
☐ **Two-Spirit***
☐ **Another sexual orientation (please specify): _____**
☐ **Do not know**
☐ **Prefer not to answer**

QUESTION TYPE

This question allows multiple responses, and the option of providing another sexual orientation in a free-text response field.

---

[20] Adapted from Ontario Human Rights Commission:
https://www3.ohrc.on.ca/sites/default/files/attachments/Policy_on_discrimination_and_harassment_because_of_sexual_orientation.pdf

IMPORTANT NOTE*

The response value of 'Two-Spirit' is kept as a placeholder for now, until this question is reviewed and approved by First Nations, Inuit, Métis and urban Indigenous partners through the Ontario Health IDGM process. Any subsequent use of this value at Ontario Health will also need to go through this process.

Gender Identity

DEFINITION

Gender identity[21] an individual's internal sense of being a woman, a man, both, neither or anywhere along the gender spectrum, regardless of the sex assigned at birth. It is distinct from sexual orientation.

RATIONALE

Collecting this information helps us understand how a person's gender identity impacts their health care needs and experiences. This information can help identify potential barriers and inequities that these communities may face when accessing health care services, as well as the outcomes of health care they experience.

QUESTIONS AND RESPONSE VALUES

Source: Adapted from Measuring Health Equity (Toronto Region)

What is your gender identity? (select all that apply)
☐ **Genderfluid or genderqueer**
☐ **Man**
☐ **Nonbinary**
☐ **Two-Spirit***
☐ **Woman**
☐ **Questioning or unsure**
☐ **Another gender identity (please specify): _____**
☐ **Do not know**
☐ **Prefer not to answer**

QUESTION TYPE

This question allows multiple selections and includes the option of providing another gender identity in a free-text response field.

IMPORTANT NOTE*

The response value of 'Two-Spirit' is kept as a placeholder for now, until this question is reviewed and approved by First Nations, Inuit, Métis and urban Indigenous partners through the Ontario Health IDGM process. Any subsequent use of this value at Ontario Health will also need to go through this process.

---

[21] Adapted from Ontario Human Rights Commission: https://www.ohrc.on.ca/en/policy-preventing-discrimination-because-gender-identity-and-gender-expression

Transgender Identity

DEFINITION

Transgender[22] is an umbrella term used to describe people whose gender identity or gender expression differs from the sex they were assigned at birth.

RATIONALE

Collecting this information helps us identify potential barriers and health inequities caused by systemic discrimination toward transgender individuals. This discrimination may manifest as policies, procedures, and practices that exclude, displace, or marginalize the transgender community, hindering their access and contributing to poorer outcomes.

QUESTIONS AND RESPONSE VALUES

Source: Adapted from Measuring Health Equity (Toronto Region)

Do you identify as transgender?
☐ Yes   ☐ No   ☐ Do not know   ☐ Prefer not to answer

QUESTION TYPE

This question permits a single response.

---

[22] Definition from transgender identity question used by the Toronto Measuring Health Equity project.

Optional Set

This section outlines the optional set of sociodemographic data elements to be collected within Ontario Health-led datasets that capture sociodemographic data. These sociodemographic data elements can be collected alongside with the core sociodemographic data elements and are meant only to drive standardization if these optional data elements are collected across different programs.

The optional set of sociodemographic data elements (in no particular order) includes:

- Educational Attainment
- Employment Status
- Housing Status
- Religion/Spiritual Affiliation

Educational Attainment

DEFINITION

Educational attainment[23] refers to the highest level of education that a person has successfully completed. Successful completion of a level of education refers to the achievement of the learning objectives of that level, typically validated through the assessment of acquired knowledge, skills, and competencies.

RATIONALE

Collecting this information helps us understand the relationship between educational attainment and health care access and outcomes. Canadians with lower educational attainment experience poor health outcomes, such as lower life expectancy, poor mental health as well as higher rates for suicide mortality and unintentional injury mortality.[24]

QUESTIONS AND RESPONSE VALUES

Source: Adapted from Measuring Health Equity (Toronto Region)

What is your current level of education?
☐ **Grade school (grade 1-8)**
☐ **Some high school, but did not graduate**
☐ **High school or high school equivalency certificate (grade 9-12)**
☐ **Completed Registered Apprenticeship or other trades certificate or diploma (or ongoing)**
☐ **College, CEGEP or other non-university certificate or diploma (or ongoing)**
☐ **Undergraduate degree or some university**
☐ **Postgraduate degree or professional designation (e.g., Master's, PhD, MD)**
☐ **Not applicable**
☐ **Do not know**
☐ **Prefer not to answer**

---

[23] Adapted from Statistics Canada: https://www23.statcan.gc.ca/imdb/p3Var.pl?Function=DEC&Id=85134
[24] Public Health Agency of Canada, "Key Health Inequalities in Canada: A National Portrait – Executive Summary", Retrieved from: https://www.canada.ca/en/public-health/services/publications/science-research-data/key-health-inequalities-canada-national-portrait-executive-summary.html

Employment Status

DEFINITION

Employment status[25] refers to an individual's current participation in the labour force. An individual is considered employed if they are currently working for pay or profit or have a job and are absent from work. An individual is considered unemployed if they are currently without work.

RATIONALE

Collecting this information helps us understand the relationship between employment status and health outcomes. Canadians who are unable to work experience poor health outcomes, such as a higher prevalence of arthritis, asthma, disability, and poor oral health.[26] Data pertaining to employment status can help identify health risks associated with under employment.

QUESTIONS AND RESPONSE VALUES

Source: City of Toronto: Data for equity strategy

Which of the following best describes your current employment status?
☐ **Employed – full time (permanent)**
☐ **Employed – part time (permanent)**
☐ **Employed – casual, on-call, temporary or seasonal**
☐ **Unemployed or looking for a job**
☐ **Stay at home caregiver**
☐ **Student**
☐ **Retired**
☐ **Unable to work**
☐ **Other (please specify): _____**
☐ **Do not know**
☐ **Prefer not to answer**

---

[25] Adapted from Statistics Canada: https://www160.statcan.gc.ca/prosperity-prosperite/employment-emploi-eng.htm
[26] Public Health Agency of Canada, "Key Health Inequalities in Canada: A National Portrait – Executive Summary", Retrieved from: https://www.canada.ca/en/public-health/services/publications/science-research-data/key-health-inequalities-canada-national-portrait-executive-summary.html

Housing Status

DEFINITION

Housing status refers to whether an individual owns or rents their residence, lives in social or subsidized housing, or in a facility, or is underhoused or experiencing homelessness.[27]

RATIONALE

Collecting this information helps us understand the impacts of housing on a person's ability to access care and to achieve good outcomes from the care they receive. It can also be useful for understanding where social services such as supportive housing may play an important role in addressing inequities.

QUESTIONS AND RESPONSE VALUES

Source: Measuring Health Equity (Toronto Region)

What is your current housing situation?
☐ **A place you or your family owns**
☐ **A place you or your family rents**
☐ **Social housing, subsidized housing or rent-geared-to-income**
☐ **Supportive housing or group home**
☐ **Long-term care facility**
☐ **Correctional facility**
☐ **Staying in someone else's place because you have no alternative**
☐ **Experiencing homelessness (e.g., shelter, living in a public place or vehicle)**
☐ **Other (please specify): _____**
☐ **Do not know**
☐ **Prefer not to answer**

---

[27]

Adapted from: SPARK Study (https://docs.google.com/document/d/1uEGP6g7aQdMb26IluJ6ZbkeT7dSFC7BYzm1T0F1dRu0/edit?pli=1) and Housing and Health: Time Again for Public Health Action (https://ajph.aphapublications.org/doi/full/10.2105/AJPH.92.5.758)

Who do you live with? (select all that apply):

- ☐ Parent(s) or guardian(s)
- ☐ Spouse or partner
- ☐ Child(ren)
- ☐ Grandparent(s)
- ☐ Sibling(s)
- ☐ Other family
- ☐ Friends or roommates
- ☐ Paid caregiver or attendant
- ☐ Alone
- ☐ Other (please specify): _____
- ☐ Do not know
- ☐ Prefer not to answer

In the past 12 months, was there a time when you were not able to pay the mortgage or rent on time?

- ☐ Yes
- ☐ No
- ☐ Not applicable, I did not have to pay rent or mortgage
- ☐ Do not know
- ☐ Prefer not to answer

QUESTION TYPE

Second question allows multiple selections and includes the option to specify individual(s) who are living with the respondent in a free-text response field.

Religious/Spiritual Affiliation

DEFINITION

Religion/spiritual affiliation[28] refers to the aspect of a person's identity rooted in a particular religious denomination, group, sect, or other religiously defined community or system of belief and/or spiritual faith practice.

RATIONALE

Collecting this information helps us better understand and address health disparities within and between religious groups. This can enable the development of targeted interventions and policies to ensure that all individuals receive equitable and culturally sensitive care. Additionally, collecting data on religion can help identify patterns of discrimination and bias in health care settings and inform efforts to promote diversity, inclusion, and anti-racism.[29]

QUESTIONS AND RESPONSE VALUES

Source: Anti-Racism Directorate

What is your religion and/or spiritual affiliation(s)? (select all that apply)
☐ Buddhist
☐ Christian
☐ Hindu
☐ Jewish
☐ Muslim
☐ Sikh
☐ No religion
☐ Another religion/spiritual affiliation (please specify): _____
☐ Do not know
☐ Prefer not to answer

QUESTION TYPE

This question allows multiple selections and includes the option of providing another religion/spiritual affiliation in a free-text response field.

---

[28] Adapted from Statistics Canada: https://www23.statcan.gc.ca/imdb/p3Var.pl?Function=DECI&Id=113619
[29] Anti-Racism Directorate: https://www.ontario.ca/document/data-standards-identification-and-monitoring-systemic-racism/collection-personal-information

Data Collection Best Practices

Guidelines for Collecting Sociodemographic Data During Health Care Encounters

Standardization

Establish standardized protocols for collecting sociodemographic data to ensure consistency and comparability across encounters and settings. Clear guidance should be provided to health care staff regarding the types of sociodemographic data to be collected, the appropriate data fields or forms to use, and the preferred methods for data entry.

Integration into Workflow

Integrate the collection of sociodemographic data seamlessly into existing health care workflows to minimize disruption and enhance efficiency. Incorporate data collection prompts or reminders into electronic health record systems, intake forms, or registration processes to facilitate systematic data capture during patient encounters.

Person-Centered Approach

Adopt a person-centered approach to data collection, emphasizing the importance of respectful communication, informed consent, and sensitivity to individual preferences and needs. Provide clear explanations to people regarding the purpose of data collection, how their information will be used, and their rights regarding data privacy and confidentiality.

Cultural Sensitivity

Cultivate cultural competence among health care providers to ensure respectful and culturally appropriate interactions with patients from diverse backgrounds. Recognize the importance of cultural factors in shaping individuals' perceptions of health, health care seeking behaviors, and willingness to disclose sociodemographic information.

Importance of Accurate and Comprehensive Data Collection

Enhanced Understanding

Accurate and comprehensive data collection enables health care providers and policymakers to develop a more nuanced understanding of the social determinants of health and their impact on health outcomes. By capturing a wide range of sociodemographic variables, including racialization, language, income, and geographic location, stakeholders can identify patterns, disparities, and inequities that may otherwise go unnoticed.

Equity and Justice

Adopt a patient-centered approach to data collection, emphasizing the importance of respectful communication, informed consent, and sensitivity to individual preferences and needs. Provide clear explanations to patients regarding the purpose of data collection, how their information will be used, and their rights regarding data privacy and confidentiality.

Informed Decision-Making

High-quality sociodemographic data serve as critical inputs for evidence-based decision-making in health care delivery, resource allocation, and policy development. By leveraging robust data sets, health care organizations can identify priority areas for intervention, target resources effectively, and tailor services to meet the unique needs of diverse patient populations.

Guidelines for Collecting Sociodemographic Data during Health Care Encounters

Data Security Measures

Implement robust data security measures to safeguard patient privacy and confidentiality throughout the data collection process. Encrypt electronic health records, establish access controls, and adhere to industry best practices for data storage, transmission, and disposal to mitigate the risk of unauthorized access or breaches.

Anonymization and De-Identification

Protect patient privacy by anonymizing or de-identifying sociodemographic data whenever possible, particularly when sharing data for research or population health analysis purposes. Remove or suppress personally identifiable information to minimize the risk of re-identification and maintain confidentiality.

Informed Consent

Obtain informed consent from patients prior to collecting sociodemographic data, ensuring that individuals understand the purposes of data collection, how their information will be used, and their rights regarding data privacy and confidentiality. Provide opportunities for patients to ask questions, express concerns, and exercise autonomy over their data.

Conclusion

Adherence to best practices in the collection of sociodemographic data is essential for promoting transparency, accountability, and trust. By following standardized protocols, prioritizing accuracy and comprehensiveness, and upholding principles of patient privacy and confidentiality, health care providers can harness the power of sociodemographic data to drive positive health outcomes and advance health equity for all individuals and communities.

Recommendations for Implementation

Background

Why Health Equity Data Community Governance?

Ontario has used individual patient data to establish evidence informed practices to improve care with considerations of protection of personal health information as required by privacy legislation and policies. As awareness about health inequities increases over time among policy makers, researchers, and service providers, attempts have been made to draw attention to disparities and inequities experienced by equity deserving communities through the collection, interpretation, and sharing of disaggregated health data at the community level. However, without engagement of equity deserving communities in the process, community level health data can be misused and misinterpreted causing harm to and further marginalization of communities. The proposed recommendations contained in this section are intended to supplement Ontario Health's existing individual-level data governance framework and processes.

Ontario Health acknowledges that disaggregated health data at the level of equity deserving communities can be used not only to raise awareness of disparities, but also to mitigate them and bring about equitable health outcomes. We also know that full engagement of equity deserving communities throughout the data cycle including the data governance system and in the development of follow up actions is critical to bring about health equity for all.

What is a Health Equity Data Community Governance System?

A health equity data governance system brings strong partnership between equity deserving communities, planning bodies, organizations, and researchers to eradicate misuse of data and exploitation of communities. It is a system where through various structures and processes, equity deserving communities are jointly involved with planning bodies, providers, and organizations to make decisions throughout the data cycle from the design, collection, interpretation, reporting, and utilization stages to access health data that belong to the communities.

At its core, a health equity data governance system is centred around establishing strong partnerships to eradicate misuse of data and exploitation of communities. It is a system where through various structures and processes, equity deserving communities are jointly involved with planning bodies, health service providers, researchers and other organizations to make decisions throughout the data cycle. To access health data that belong to the communities, all key partners should be engaged across the design, collection, interpretation, reporting and utilization stages.

The key elements of a health equity data community governance system include the following:

- **Guiding Principles** – to inform and ground all aspects of the system.
- **Community Engagement Processes** – to ensure that equity deserving communities are staying informed and involved through various methods and at all stages of the data cycle.
- **Dedicated Staff and Resources** – to carry out the community engagement processes and support the work of the committee structures.
- **Data Governance Committee Structure(s)** comprised of community members and experts, as well as OH partners – to provide a platform for joint discussions and decisions to direct staff.
- **Communication Strategy** – to enable broader engagement and participation from all relevant stakeholders.

Guiding Principles of a Health Equity Data Governance System

Six (6) key data governance principles that should guide all stages of the Health Equity Data Governance System are: **Know** Your Communities; **Reflect** Your Communities; **Respect** Your Communities; **Recognize** and **Reciprocate** Your Communities, **Targeted Universalism** and **Ethical Treatment of Communities**. Each of the principles is discussed briefly below.

KNOW YOUR COMMUNITIES

Know your communities at the local, regional, and provincial levels.

REFLECT YOUR COMMUNITIES

Reflect your communities by ensuring our teams at Ontario Health reflect the diversity of the communities we serve and through meaningful engagement throughout the data cycle process.

RESPECT YOUR COMMUNITIES

Respect your communities by having an ongoing commitment to engaging with them.

RECOGNIZE YOUR COMMUNITIES

Recognize your communities by ensuring communities' contributions are acknowledged and valued.

RECIPROCATE YOUR COMMUNITIES

Reciprocate your communities: the contributions of communities should be reciprocated by OH with investments in capacity building, training and development opportunities for equity deserving groups, as well as investing in targeted programs and services.

TARGETED UNIVERSALISM

Targeted Universalism, which aims to ensure that all groups and communities enjoy the benefits of universal policy goals that address health and social problems to achieve collective aspirations.

ETHICAL TREATMENT OF COMMUNITIES

Community governance of data is to ensure that ethical standards and principles such as "do no harm" are strictly adhered to throughout the data cycle. It will also prevent commercialization of data for profit-driven motives.

Dedicated Staff and Resources

Supporting community data governance system requires dedicated staff and resources from your organization. Supports to plan and coordinate, engage the communities, and to provide training are critical success factors. Therefore, building internal capacity to develop the skills, knowledge, and expertise in these areas should be a priority.

Resources must be budgeted to cover all the costs and expenses related to the establishment and operations of the governance system, especially for community engagement, capacity building, and remuneration of community contributions.

Considerations include:

- What is the desired frequency and level of engagement with governance committee?

- How will communications be coordinated and released?

- What are the training needs of the people involved in advancing this work within the organization and/or local communities?

Community Engagement Processes

Engaging equity-deserving communities is imperative to ensure data is not used to cause harm or to mistreat individuals or communities. Communities should be engaged during the collection, use, and interpretation of their health data.

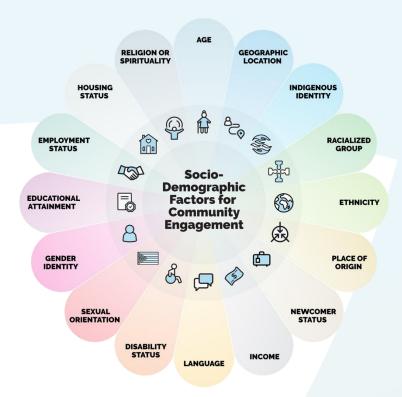The foundational principles for authentic community engagement processes are:

- Involvement of people with the "lived reality" who are most affected by an issue/problem.
- Two-way or multi-directional communication, rather than didactic approaches that inform or "educate" people with no venue for their active engagement.
- Equitable participation of diverse people, voices, ideas, and information.
- Community organizations and government should work with —rather than for —the community.
- Experts and professionals should not drive problem solving or decision making but are partners.
- Transparency about decision-making processes, who is involved, what decisions are made, and how they will be implemented (Gibson, 2017).

Building trust and authentic relationships with equity deserving communities takes time; it is a "journey and not a quick fix". Positive outcomes can be achieved by:

- Active listening
- Transparency in reasons for type of engagement and purpose of data
- Commitment to reflect and revise – actions, approaches, documents, etc.
- Remuneration and compensation for input and feedback
- Conveying realistic expectations and never over-committing
- Recognizing OH's limitations

Ontario Health has developed the below diagram that list sociodemographic factors that should be taken into account when establishing a community governance committee.

Socio-Demographic Factors for Community Engagement

AGE
GEOGRAPHIC LOCATION
INDIGENOUS IDENTITY
RACIALIZED GROUP
ETHNICITY
PLACE OF ORIGIN
NEWCOMER STATUS
INCOME
LANGUAGE
DISABILITY STATUS
SEXUAL ORIENTATION
GENDER IDENTITY
EDUCATIONAL ATTAINMENT
EMPLOYMENT STATUS
HOUSING STATUS
RELIGION OR SPIRITUALITY

Data Governance Committee Structure(s)

Community-oriented data governance and accountability structures are a form of engagement which can promote more accessible, democratic, and impactful practices in design, collection, analysis, reporting and utilization of data (Shakya et al., 2022). Setting up community governance structures with membership that is "appropriate" or "representative" and has the approval of stakeholders is difficult and requires a commitment to continuous learning and improvement. Partnering with and getting advice from informal/formal groups or organizations who have established relationships and gained the trust of communities will facilitate connections in a meaningful way. Must consider the type and level of community engagement required to collect data that belongs to the community, as this will vary across the stages of the data cycle.

Best practices for establishing a committee:

- **Terms of Reference**: Include a clearly stated mandate, accountability, authority, responsibilities, functions, size, leadership, rules and term of engagement, decision making process etc.

- **Membership**: Must have an open recruitment process, selection criteria, consider intersectional identities, socioeconomic status, etc.

- **Term**: Should include a staggered appointment process, term should be long enough for members to familiarize, learn and contribute, while allowing for ongoing engagement of new members representing diverse communities

- **Leadership**: Consider using a co-chair model with leaders from your organization and the community

- **Training and Support**: Ensure committee members have access to training programs and/or resources to develop a foundational understanding of a data governance health system and the stages of the data cycle. Ongoing support may also be required to facilitate meaningful engagement.

- **Responsibilities**: Committee members will be expected to develop policies and procedures to govern the data at each stage of the data cycle. A plan must exist to monitor disparities that are identified in the data

- **Compensation**: Community members serving on the committee should be adequately and appropriately compensated for their contributions in ways that are meaningful and resonate with them.

- **Reporting**: Transparency and accountability structures must be embedded at all stages of the data cycle. The committee must produce a report at a regular interval to outline how the data is being collected, interpreted and used to advance equitable outcomes and demonstrate compliance with the policies and procedures

Communication Strategy

Your communication approach should be tailored to suit the specific needs of your organization and the communities you serve. Here are some key considerations:

- **Consistent Voice**: Maintain a unified voice across all communications to ensure clarity and coherence.

- **Regular Updates**: Keep stakeholders informed by communicating frequently and using various formats to update them on progress. Clearly outline the next steps in your communications.

- **Inclusive Distribution**: Ensure that all relevant partners and interested parties receive the communications to foster transparency and inclusivity.

- **Community-Centric Content**: Develop content that amplifies the voices of the target population or communities involved. This ensures that their perspectives and experiences are accurately represented.

- **Co-Creation and Review**: Involve community members in the creation and review process of public-facing materials. This collaborative approach ensures that the content resonates with the community before broader distribution.

By adhering to these principles, you can effectively engage with external partners and advance your sociodemographic data collection initiative.

Appendix: Ethnicity

Origins referring to countries					
Afghan	Cape Verdean	Greek	Lithuanian	Puerto Rican	Trinidadian/Tobagonian
Albanian	Caymanian	Greenlandic	Luxembourger	Réunionnais	Tunisian
Algerian	Central African	Grenadian	Macedonian	Romanian	Turkish
American	Chadian	Guadeloupean	Malagasy	Russian	Turkmen
Angolan	Chilean	Guatemalan	Malawian	Rwandan	Ugandan
Anguillan	Chinese	Guinean	Malaysian	Saint Helenian	Ukrainian
Antiguan	Colombian	Guyanese	Malian	Salvadorean	Uruguayan
Argentinian	Comorian	Haitian	Maltese	Samoan	Uzbek
Armenian	Congolese	Honduran	Manx	Saudi Arabian	Venezuelan
Aruban	Costa Rican	Hong Konger	Martinican	Scottish	Vietnamese
Australian	Croatian	Hungarian	Mauritanian	Senegalese	Vincentian
Austrian	Cuban	Icelandic	Mauritian	Serbian	Welsh
Azerbaijani	Cypriot	Indian (India)	Mexican	Seychellois	Yemeni
Azorean	Czech	Indonesian	Moldovan	Sierra Leonean	Zambian
Bahamian	Danish	Iranian	Mongolian	Singaporean	Zimbabwean
Bahraini	Djiboutian	Iraqi	Montenegrin	Slovak	
Bangladeshi	Dominica Islander	Irish	Montserratan	Slovenian	
Barbadian	Dominican	Israeli	Moroccan	Somali	
Belgian	Dutch	Italian	Mozambican	South African	
Belizean	Ecuadorian	Ivorian	Namibian	South Sudanese	
Beninese	Egyptian	Jamaican	Nepali	Spanish	
Bermudian	English	Japanese	New Zealander	Sri Lankan	
	Eritrean	Jordanian	Nicaraguan	St. Lucian	

Origins referring to countries					
Bhutanese	Estonian	Kazakh	Nigerian	Sudanese	
Bolivian	Ethiopian	Kenyan	Nigerien	Surinamese	
Bosnian	Faroese	Kittitian/Nevisian	Northern Irish	Swazi	
Brazilian	Fijian	Korean	Norwegian	Swedish	
Bruneian	Filipino	Kosovar	Omani	Swiss	
Bulgarian	Finnish	Kuwaiti	Pakistani	Syrian	
Burkinabe	French	Kyrgyz	Palestinian	Tahitian	
Burmese	Gabonese	Laotian	Panamanian	Taiwanese	
Burundian	Gambian	Latvian	Papua New Guinean	Tajik	
Byelorussian	Georgian	Lebanese	Paraguayan	Tanzanian	
Cambodian	German	Liberian	Peruvian	Thai	
Cameroonian	Ghanaian	Libyan	Polish	Togolese	
Canadian	Gibraltarian	Liechtensteiner	Portuguese	Tongan	

Other ethnic or cultural origins

Acadian	Buddhist	French Canadian	Luba	Prince Edward Islander	Ulster Scot
Afar	Cape Bretoner	Frisian	Luo	Punjabi	United Empire Loyalist
African	Carib	Fulani	Maghrebi	Québécois	Uyghur
African American	Caribbean	Ga-Adangbe	Maharashtrian	Quechua	Walloon
African Canadian	Catalan	Galician	Malay	Rohingya	West African
African Caribbean	Caucasian (White)	Gaspesian	Malayali	Roma	West Asian
African Nova Scotian	Celtic	Goan	Malinké	Ruthenian	West Indian
Afrikaner	Central African	Greek Cypriot	Manitoban	Sami	Western European
Akan	Central American	Gujarati	Maori	Saskatchewanian	Wolof
Albertan	Central American Indigenous	Harari	Mapuche	Scandinavian	Xhosa
Alsatian	Central Asian	Hausa	Maroon	Serer	Yazidi
Amhara	Chaldean	Hawaiian	Mayan	Shona	Yoruba
Amish	Channel Islander	Hazara	Mennonite	Sicilian	Yugoslavian
Anglo-Indian	Chechen	Hindu	Middle Eastern	Sikh	Zoroastrian
Arab	Chin	Hispanic	Moravian	Sindhi	Zulu
Arawak	Christian	Hmong	Mossi	Sinhalese	
Ashanti	Circassian	Huguenot	Muslim	Slavic	
Asian	Coptic	Hutterite	Ndebele	Soninke	
Assyrian	Cornish	Hutu	New Brunswicker	South American	
Baloch	Corsican	Igbo	Newfoundlander	South American Indigenous	
Bambara	Creole	Igorot	Norman	South Asian	
Bamileke	Czechoslovakian	Ilocano	North African	Southeast Asian	
Bantu	Dinka	Indo-Caribbean	North American	Southeast European	
Baoulé	Doukhobor	Indo-Fijian	Northern European	Southern European	
Bashkir	East African	Indo-Guyanese	Nova Scotian	Swahili	
Basque	East Asian	Jatt	Nubian	Tamil	
Batswana	Eastern European	Javanese	Oceanian		
		Jewish	Ontarian		

Other ethnic or cultural origins					
Bavarian	Edo	Kabyle	Orcadian	Tatar	
Bengali	Esan	Karen	Oromo	Telugu	
Berber	Eurasian	Kashmiri	Pacific Islander	Tibetan	
Black	European	Kashubian	Pashtun	Tigrian	
Bohemian	Ewe	Khmer	Pennsylvania Dutch	Transylvanian	
Bosniak	Fante	Kikuyu	Persian	Tswana	
Breton	Flemish	Kurdish	Pipil	Turkish Cypriot	
British	Franco Ontarian	Latin American	Polynesian	Tutsi	
British Columbian					

Appendix: Language

Non-Indigenous languages					
English	Danish	Armenian	Luba-Lulua	Iranian Persian	Thai
French	German	Igbo	Ganda	Polish	Tigrinya
Afrikaans	Dinka	Iloko	Malayalam	Portuguese	Turkish
Assyrian Neo-Aramaic	Estonian	Indonesian	Marathi	Parsi-Dari	Uighur
Akan	Ewe	Icelandic	Morisyen	Dari	Ukrainian
Amharic	Persian	Italian	Macedonian	Pushto	Urdu
Arabic	Quebec Sign Language	Jamaican Creole	Malagasy	Romano-Greek	Uzbek
American Sign Language	Fijian	English	Maltese	Rohingya	Vietnamese
Assamese	Filipino	Wojenaka	Mongolian	Tarifit	Vlaams
	Finnish	Japanese	Mossi	Romanian	Waray (Philippines)
	Northern Frisian	Kabyle	Malay (macrolanguage)	Rusyn	Mwani
		Kannada		Rundi	

Non-Indigenous languages					
Azerbaijani	Eastern Frisian	Kashmiri	Burmese	Russian	Wolof
Baluchi	Western Frisian	Georgian	Min Nan Chinese	Sango	Wu Chinese
Bambara	Fulah	Kazakh	South Ndebele	Sinhala	Yiddish
Belarusian	Ga	Kachhi	North Ndebele	Slovak	Yoruba
Bengali	Scottish Gaelic	Khmer	Low German	Slovenian	Yue Chinese
Bikol	Irish	Kikuyu	Nepali	Shona	Chinese
Bini	Swiss German	Kinyarwanda	(macrolanguage)	Sindhi	
Tibetan	Gujarati	Kankanaey	Dutch	Soninke	
Bosnian	Hakka Chinese	Konkani	Norwegian	Somali	
Bulgarian	Harari	(macrolanguage)	Nuer	Spanish	
Bilin	Haitian	Korean	Oriya	Albanian	
Catalan	Hausa	Krio	(macrolanguage)	Serbian	
Min Dong Chinese	Hebrew	Kinaray-A	Oromo	Swahili	
Cebuano	Hiligaynon	S'gaw Karen	Odia	(macrolanguage)	
Czech	Hindi	Kurdish	Old Saxon	Swedish	
Chaldean Neo-	Mina (Cameroon)	Lao	Pangasinan	Tamil	
Aramaic	Croatian	Latvian	Pampanga	Tulu	
Mandarin Chinese	Hungarian	Lingala	Panjabi	Telugu	
Coptic		Lithuanian	Pennsylvania German		
Welsh			Plautdietsch		