

GUIDE TO DEMOGRAPHIC DATA COLLECTION 2021

Harrow Health Centre

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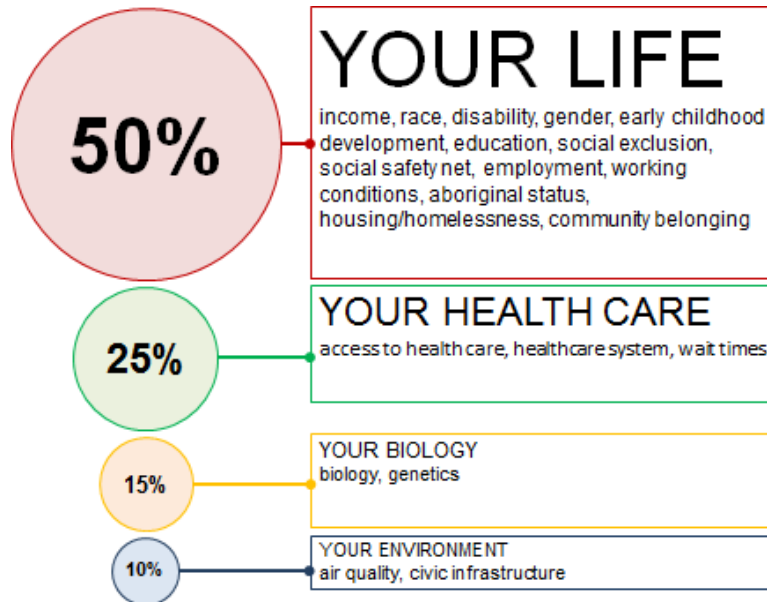
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OVERVIEW OF HEALTH EQUITY

Canada's Social Determinants of Health

The wellbeing of Canadians' health is strongly influenced by social determinants of health such as race, employment, language, etc. In Canada, income, race, and housing significantly impact individual and population health more than biological and environmental conditions



Resource: [Social Determinants of Health: The Canadian Facts](#)

What Is Equity?

According to the World Health Organization, health inequity are systemic differences in health status or accessing health resources that are unnecessary, avoidable, unfair, and unjust.

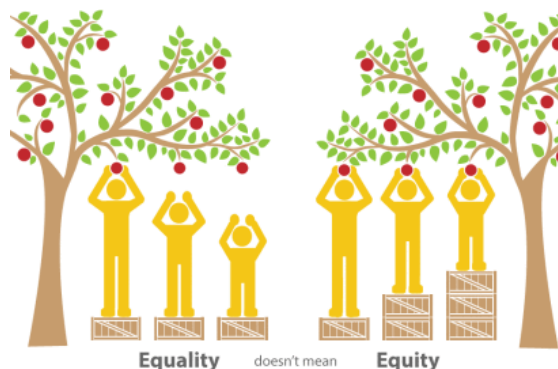
Health Quality Ontario states that “health equity allows people to reach their full health potential and receive high-quality care that is fair and appropriate to them and their needs, no matter where they live, what they have or who they are”

Health equity:

- involves the fair distribution of resources needed for health, fair access to opportunities available, and fairness in the support offered to ill people
- is not the same as health equality. Health equity is incorporating the unique needs that people may have due to language, income, gender, race into their care. Equal care is providing the same care to all which fails to acknowledge the unique needs of individual patients.

Understanding health inequities requires recognizing what the impact of the social determinants of health are and how they affect patients/clients, families, and health-care organizations.

- The primary factors that shape the health of Canadians are the living conditions they experience, not medical treatments or lifestyle choices



Resource: [Advancing Health Equity in Health Care](#)

Equity as a Component of Quality

The U.S. Institute of Medicine [IOM] identifies six pillars of quality healthcare: efficient, effective, safe, timely, patient/client-centred, and equitable.

- **Safe:** Avoiding harm to patients from the care that is intended to help them.
- **Effective:** Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
- **Patient-centered:** Providing care that is respectful of and responsive to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions.
- **Timely:** Reducing waits and sometimes harmful delays for both those who receive and those who give care.
- **Efficient:** Avoiding waste, including waste of equipment, supplies, ideas, and energy.
- **Equitable:** Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status

Healthcare research on the link between equity and quality also shows that:

- equity is embedded in all components of quality healthcare
- equity is a necessary condition for a “Culture of Quality” in healthcare
- unchecked inequity leads to increased pressure on health-care services, results in unmet patient/client needs, and reduces efficiency of healthcare provision

Resource: [Six Domains of Health Care Quality](#)

PATIENT AND CLIENT DEMOGRAPHIC DATA COLLECTION

HHC’s Vision

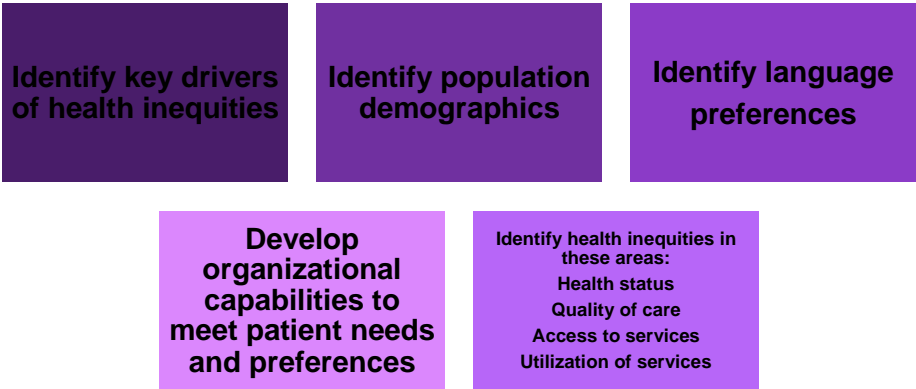
Harrow Health Centre aims to provide the best care possible to meet patients’ healthcare needs. A primary focus is to deliver improved access to primary healthcare services in Ontario.

Why Collect Patient/Client Data?

Data collection contributes to health equity in healthcare. Ensuring Health Equity in healthcare means:

- Collecting patient and client-level demographic data: This provides Harrow Health Centre a comprehensive picture of the community served, and characteristics of patients cared for. The demographic data will serve as a foundation for identifying health inequities and gaps in quality of care.
- Identifying and reporting inequities in care: The differences in health outcomes based on demographic variables such as race, language, and income are examined.
- Implementing solutions to reduce inequities: The unique needs of HHC patients based on language, disability, and other factors can be identified. Patients can be provided appropriate resources specific to their needs.

Below are examples of concrete goals for data collection outlined by the America’s Health Insurance Plans Association



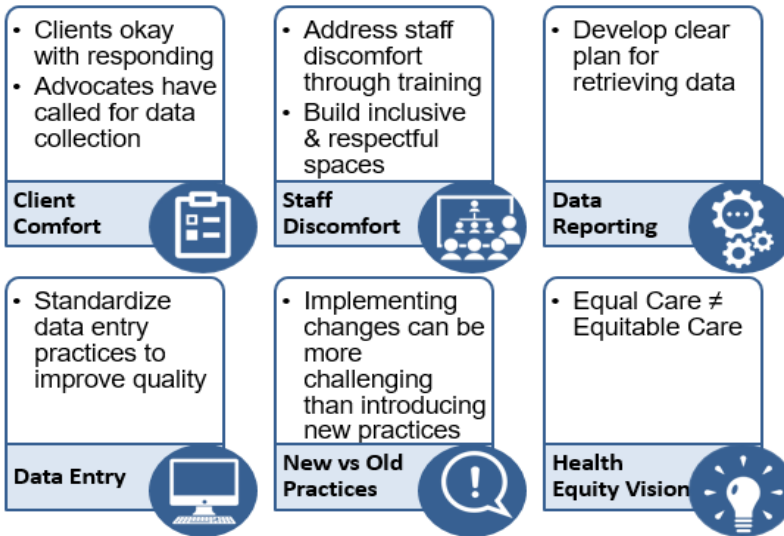
Is it legal to ask these questions?



Yes. Not only is it legal, it's encouraged by the Ontario Human Rights Commission.

- Demographic collection is used to keep track of outcomes and promote equity.
- Demographic information greatly impacts patient and client experiences and decisions about whether to use health care or not.
- You can't fully understand patients' and clients' health care experiences without knowing more about who they are.

Lessons Learned



SOCIO-DEMOGRAPHIC DATA COLLECTION QUESTIONS

Why these 9 questions?

These 9 questions are equity variables that significantly impact patient and client health outcomes. Language, born in Canada, race/ethnicity, gender, sex, sexual orientation, disability, and income all impact patient and client outcomes

LANGUAGE

Question: What language would you feel most comfortable speaking in with your healthcare provider?

1. Amharic	9. English	17. Korean	25. Somali	33. Urdu
2. Arabic	10. Farsi	18. Nepali	26. Spanish	34. Vietnamese
3. ASL	11. French	19. Polish	27. Tagalog	35. Other (please specify):
4. Bengali	12. Greek	20. Portuguese	28. Tamil	36. Prefer not to answer
5. Chinese (Cantonese)	13. Hindi	21. Punjabi	29. Tigrinya	37. Do not know
6. Chinese (Mandarin)	14. Hungarian	22. Russian	30. Turkish	
7. Czech	15. Italian	23. Serbian	31. Twi	
8. Dari	16. Karen	24. Slovak	32. Ukrainian	

What is 'preferred spoken language'?

The language that the patient/client would prefer to speak. Often, this may be their mother tongue. Patients may speak multiple languages, but the language they feel most comfortable speaking in with their healthcare provider is important to know.

Rationale

Language is considered one of the greatest barriers in access to quality of care for people of non-English-speaking backgrounds. Language barriers have been linked to variations in diagnostic testing, patient follow-up, pain management, medication prescription and chronic disease management. There is a significant relationship between poor access to primary care and having a first language other than English or French. Communication, patient satisfaction, and healthcare outcomes are optimal when trained professional interpreters are available.

Supplementary Resource: [Language Barriers in Access to Healthcare](#)

Additional points

If the patient does not see their language listed, they should check “other” and fill in the language name.

BORN IN CANADA

Question: Were you born in Canada?

YES NO Prefer not to answer Do not know

If NO, what year did you arrive in Canada? _____

What does “born in Canada” mean?

This question identifies whether the patient/client was born in Canada or has immigrated to Canada.

Rationale

Individuals who immigrate to Canada experience the healthy immigrant effect in which they arrive in Canada with a higher health status compared to those born in Canada. Two to five years after arrivals, immigrants start experiencing worsening health outcomes. The healthy immigrant effect diminishes, and health inequities associated with being an immigrant start to emerge. There is also a strong and consistent association between immigration status and lower rates of mental health access.

Supplementary Resource: [Migration and health in Canada: health in the global village](#)

Additional Points

Patients/clients may be hesitant to respond to this question in fear that their immigration status will be disclosed to Immigration Canada. Ensure that patients/clients understand HHC’s practices around sharing this information with their healthcare team.

Question: Are you working as an international agricultural worker?

YES NO Prefer not to answer Do not know

Rationale

Given the demographic and geography, there is an increase in international workers in Windsor-Essex County. Research states that many international workers have precarious access to healthcare. Health benefits coverage is dependent on country of origin and/or employer benefit plans. [Those laid off for any reason, including due to illness or injury, may lose health coverage or avoid seeking care for fear of being deported.](#) HHC can also determine additional programs and services available for international workers.

RACE / ETHNICITY

Question: Which of the following best describes your racial or ethnic group? Check ONE only

<input type="checkbox"/> 1. Asian - East (e.g. Chinese, Japanese, Korean)	<input type="checkbox"/> 12. Latin/Central American (e.g. Argentinean, Chilean, Salvadoran)
<input type="checkbox"/> 2. Asian - South (e.g. Indian, Pakistani, Sri Lankan)	<input type="checkbox"/> 13. Metis
<input type="checkbox"/> 3. Asian - South East (e.g. Malaysian, Filipino, Vietnamese)	<input type="checkbox"/> 14. Middle Eastern/West Asian (e.g. Egyptian, Iranian, Lebanese)
<input type="checkbox"/> 4. Black - African (e.g. Ghanaian, Kenyan, Somali)	<input type="checkbox"/> 15. White - European (e.g. English, Italian, Portuguese, Russian)
<input type="checkbox"/> 5. Black - Caribbean (e.g. Barbadian, Jamaican)	<input type="checkbox"/> 16. White - North American (e.g. Canadian, American)
<input type="checkbox"/> 6. Black - North American (e.g. Canadian, American)	<input type="checkbox"/> 17. Mixed heritage (e.g. Black - African & White -North American) Please specify: _
<input type="checkbox"/> 7. First Nations	<input type="checkbox"/> 18. Other(s): Please specify: _____
<input type="checkbox"/> 8. Indian - Caribbean (e.g. Guyanese with origins in India)	<input type="checkbox"/> 19. Prefer not to answer
<input type="checkbox"/> 9. Indigenous/Aboriginal - <i>not included elsewhere</i>	<input type="checkbox"/> 20. Do not know
10. Oceania	
11. Inuit	

What is race/ethnicity?

Race is a social construct. It has no biological basis and was created to categorize people into different groups based on visual traits such as skin colour, facial features, and hair type. The

[Ontario Human Rights Commission](#) expands that racism has become deeply embedded in systems and institutions that have evolved over time. It operates at a number of levels individually, systemically, and socially.

Rational: Ethnicity refers to the community's learned or adopted characteristics such as language, practices, and beliefs. Differentiating ethnic origin allows for a complex analysis of community experiences (e.g. Black African and Afro-Caribbean).

Race and ethnicity have an independent effect on health status, healthcare access and experiences, and health outcomes. The rate of health decline among immigrants is stronger among racialized groups than non-racialized immigrants. There are significant differences in health status between racialized groups and White Canadians even after controlling for gender, age, immigrant status, income, and educational attainment. There is a significant difference between white and non-white groups in Canada in regard to their satisfaction with healthcare received. Up to 30% of persons of racialized status report discriminatory encounters in healthcare in the Greater Toronto Area ([Black Health Alliance, 2005](#)). Indigenous people in both rural communities and urban environments have significantly lower life expectancy and experience the worst outcomes. Indigenous people are more likely to receive a diagnosis at a later point in a disease's progress. Indigenous people fear using impersonal medical services due to culturally inappropriate care in relation to their beliefs and traditions.

Supplementary Resource: [Health and Healthcare Implications of Systemic Racism on Indigenous Peoples in Canada](#)

Additional Points

Patients may be reluctant to identify their race for multiple reasons.

Some may believe that race is a discredited concept. Those who don't experience racism and those who've been harmed by racism may feel that race is irrelevant and only the "human race" exists. As a response, it can be stated that in some communities in Ontario it has been determined that certain groups in society are discriminated against because they are perceived to be different and often this is based on race.

Collecting racial identities can help track whether certain groups face more discrimination and may not be receiving the care they deserve. In some communities in Ontario, research has shown that during Covid-19 some racial groups had poorer outcomes if they were infected and there were communities who did not have access to testing and vaccinations. Best practice is allowing patients to self-identify. If their race is not listed, they should select "other" and fill in the section.

DISABILITIES

Question: Do you have any of the following disabilities? Check ALL that apply

- Chronic illness Sensory disability

- Developmental disability
- Drug or alcohol dependence
- Learning disability
- Mental illness
- Physical disability
- Other (Please specify)
- None
- Prefer not to answer
- Do not know

What is Disability?

“Disability” covers a broad range and degree of conditions, some visible and some not visible. A disability may have been present from birth, caused by an accident, or developed over time. There are physical, mental and learning disabilities, mental disorders, hearing or vision disabilities, epilepsy, drug and alcohol dependencies, environmental sensitivities, and other conditions.

Disability can be used to describe people with impairments living in an environment that doesn’t accommodate their needs.

Rationale

Individuals with disabilities encounter frequent barriers that generate health inequities. The presence of a disability may impact access to care and the healthcare experience. Individuals with disabilities are often dissatisfied with healthcare due to the attitudes and behaviours of healthcare providers and the healthcare environment. [1 in 5 persons with disabilities felt that their disability prevented them from receiving adequate healthcare.](#) Inaccessible environments, inadequate procedural accommodations (e.g. sign language interpreter), and health information in inaccessible formats are barriers to quality healthcare for individuals with disabilities.

Supplementary Resource: [Canadians with Disabilities](#)

Additional Points

Ensure that patients/clients select the relevant boxes that they self-identify with. Reassure patients/clients that their information is only shared with their healthcare team as they may be hesitant to reveal information about their disabilities. They also have the option to select “prefer not to answer”.

GENDER

Those 12 years old and younger may skip this question.

Question: How would you describe your gender? Check ONE only

- Woman
- Man
- Two-Spirit
- Other (Please specify)

- Non-Binary
- Prefer not to answer
- Transgender man (identifies as a man but was born as a biological female)
- Transgender woman (identifies as a woman but was born as a biological male)
- Do not know

What is gender?

- Socially constructed roles, behaviours, expressions and identities, of women, men, and gender diverse individuals, that influences:
 - how people perceive themselves and each other,
 - how they act and interact,
 - the distribution of power and resources in society.
- Gender is not confined to binary (woman/man).
- Gender is fluid and can change over time.

Rationale

With the recognition of diverse genders, there is evidence that the healthcare system is lacking appropriate responses to ensure access and quality of care. Transgender individuals face stigma and discrimination that can affect healthcare utilization. 21% of trans people reported having avoided the emergency room when they needed it because they were trans ([Trans Pulse Project, 2012](#)). Transgender individuals may also be vulnerable to specific health risks that need to be addressed.

Supplementary Resource: [Barriers to accessing healthcare among transgender individuals](#)

Additional Points

This question can be perceived to be intrusive. Individuals who are transgender or gender non-conforming may be concern with who has access to this information. Ensure that patients understand that this information will be used to help meet healthcare needs and equitable care, especially if their gender is different than their birth-assigned sex.

SEX

Question: What sex were you assigned at birth? Check ONE only

- Female
- Male
- Prefer not to answer
- Intersex

What is sex?

Sex refers to the set of biological attributes in humans primarily associated with physical and physiological features (ex. chromosomes, gene expression, hormone levels and function, and reproductive/sexual anatomy). Sex is categorized into female, male, intersex. Intersex refers to

a physical and/or chromosomal set of possibilities in which the features usually understood as belonging distinctly to either the male or female sex are combined in a single body.

Sex and gender are two different terms, often used interchangeably. Sex is the physical and physiological features and is determined at birth. Gender is a social construct. It is influenced by roles, behaviours, expressions and identities of women, men, and gender diverse people. Gender can change over time.

Rationale

There are health inequities faced by females in comparison to males, both in terms of health status (e.g., the higher prevalence of chronic disease and depression) and variations in access to and quality of healthcare.

Issues of stigma and discrimination can affect healthcare utilization by individuals who identify as intersex. Intersex individuals may also be vulnerable to specific health risks that need to be addressed, such as Frasier Syndrome, a condition that affects skin development and poses a cancer risk that can run as high as 60% ([Cools, Drop, Wolffenbuttel, Oosterhuis, & Looijenga, 2006](#)).

Supplementary Resource: [The Health of LGBTQIA2 Communities in Canada](#)

Additional Points

Like gender, this question can be perceived to be intrusive by individuals who are transgender or gender non-conforming. Ensure that patients/clients are aware that this information is confidential and will be used to ensure equitable care is provided.

Gender and sex are often used interchangeably. Ensure that patients/clients are aware that gender and sex are two separate terms therefore requiring separate questions.

SEXUAL ORIENTATION

Those 12 years old and younger may skip this question.

Question: What is your sexual orientation? Check ONE only

<input type="checkbox"/> Bisexual	<input type="checkbox"/> Two spirit
<input type="checkbox"/> Gay	<input type="checkbox"/> Queer
<input type="checkbox"/> Straight "Heterosexual"	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> Lesbian	<input type="checkbox"/> Do not know
	<input type="checkbox"/> Other (Please specify)

What is sexual orientation?

Sexual orientation is not the same as gender. It defines the emotional, physical, romantic, sexual and/or spiritual attraction, desire or affection for other people. Lesbian, gay, bisexual, queer, two-spirit and straight/heterosexual are all sexual orientations. Sexual orientation is also fluid and can change over time.

Rationale

Individuals who are not straight face multiple barriers to quality care based on their unique healthcare needs. LGB persons may delay or avoid seeking services because of their experiences of past discrimination or perceived homophobia within the healthcare system.

Mental health disorders, particularly depression and anxiety are of significant concern among gay and bisexual populations. LGB populations face increased risk of some cancers, which may go unrecognized. For example, healthcare providers may underestimate the risk of cervical cancer in lesbians while men who have sex with men are at risk for anogenital cancers.

Supplementary Resource: [Facilitators and barriers to healthcare for lesbian, gay and bisexual people](#)

Additional Points.

This question can be perceived as intrusive. Explain to the patient/client why collecting this information is important. The LGBTQ community has health needs that differ from the rest of the population. They experience higher rates of certain health issues compared to others. Patients/clients have the option to select 'prefer not to answer'.

INCOME

If the patient is under 18, patients and clients should be informed that the question is asking about the household income supporting the child.

Question 1: What was your total family income before taxes last year? Check ONE only

<input type="checkbox"/> \$0 - \$29,999	<input type="checkbox"/> \$150,000 OR MORE
<input type="checkbox"/> \$30,000 - \$59,999	<input type="checkbox"/> Do not know
<input type="checkbox"/> \$60,000 - \$89,999	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> \$90,000 - \$119,999	
<input type="checkbox"/> \$120,000 - \$149,999	

What is family income?

Family income is also known as household income. It is the total income earned by a group of individuals sharing the same housing. They may be related by blood, marriage (including common-law relationships) or adoption or people who live together and share resources.

Rationale

Low income is a strong predictor of poor health status and treatment outcomes. Access to primary care and inpatient hospital care is not strongly associated with low income, but a small number of studies indicate that low income affects differential access to specialty care. Life expectancy and health-adjusted life expectancy were consistently lower and infant mortality and unintentional injury mortality were consistently higher among those living in lower-income areas.

Supplementary Resource: [Key Health Inequalities in Canada: A National Portrait – Executive Summary](#)

Additional Points

Many Canadians are uncomfortable answering questions related to income for various reasons. Some people fear judgement. Some people fear being reported to the Canada Revenue Agency (or other authorities). Clarify to patients/clients that this information is protected who will have access to it.

Harrow Health Centre and Colchester are identified as areas of material deprivation. Additionally, these areas have “hotspots” for childhood poverty. Knowing a patient and their family are having financial struggles then allows members of the Team the opportunity to have discussions with the patient and link them with community resources where appropriate.

NUMBER OF PEOPLE INCOME SUPPORTS

Question: How many people does this income support?

_____ person(s) Do not know Prefer not to answer

Number of family members defined

The number of people who the family income is shared with. It can include people who are being supported abroad, the number of people who live together and share resources, and/or people who are related by blood, marriage (including common-law relationships) or adoption.

Points to remember

There may be reluctance to answer this question if there is an undocumented family member.

ANTICIPATED USE OF DATA FOR CARE, PLANNING AND QUALITY

INDICATOR	Spoken Language
Uses in Care	<ul style="list-style-type: none"> • To provide appropriate care delivery as required by the Charter of Rights and Freedoms • To acquire informed consent
Uses in Planning	<ul style="list-style-type: none"> • To improve access to care for those who do not speak/read English or French
Impact on Quality	<ul style="list-style-type: none"> • Use of interpreters and translators has direct impact on quality and safety
INDICATOR	Born in Canada
Uses in Care	<ul style="list-style-type: none"> • To address barriers and stress associated with migration and settlement
Uses in Planning	<ul style="list-style-type: none"> • To understand the types of supports or services needed
Impact on Quality	<ul style="list-style-type: none"> • Improves access to care for newcomers to Canada
INDICATOR	Racial/Ethnic Group
Uses in Care	<ul style="list-style-type: none"> • To provide targeted care and supports (e.g Middle Eastern populations and thalassaemia, First Nations and diabetes)
Uses in Planning	<ul style="list-style-type: none"> • To improve outreach to vulnerable groups who do not seek care at the same level as other groups • To address access challenges
Impact on Quality	<ul style="list-style-type: none"> • Outreach improves preventative care and reduces readmissions
INDICATOR	People with Disabilities
Uses in Care	<ul style="list-style-type: none"> • To fulfill organizational responsibilities around providing accommodation • To address histories of traumatic interactions with the health-care system
Uses in Planning	<ul style="list-style-type: none"> • To carry out accommodation planning • To work on preventing recurrence of exclusion
Impact on Quality	<ul style="list-style-type: none"> • Better accommodation leads to more efficient and effective care

INDICATOR	Gender & Sex
Uses in Care	<ul style="list-style-type: none"> • Both birth-assigned sex and gender are relevant to room assignment and other essential medical testing (e.g. hormone levels, pap smears, mammograms, etc.) • To accommodate the unique needs related to the gender identity of a patient or client
Uses in Planning	<ul style="list-style-type: none"> • To improve outreach to vulnerable groups who do not access care at the same level as other groups
Impact on Quality	<ul style="list-style-type: none"> • Better planning improves preventative care and health outcomes
INDICATOR	Sexual Orientation
Uses in Care	<ul style="list-style-type: none"> • To understand the unique needs of patients and clients who identify as lesbian, gay, bisexual, queer (e.g. living with discrimination)
Uses in Planning	<ul style="list-style-type: none"> • To create welcoming environments for lesbian, gay, bisexual (LGB) community members • To address known health inequities facing LGB patients and clients
Impact on Quality	<ul style="list-style-type: none"> • Providing a welcoming environment improves access and patient and client experiences
INDICATOR	Family Income and Number of People Income Supports
Uses in Care	<ul style="list-style-type: none"> • Relevant for discharge planning • Relevant for medical prescriptions
Uses in Planning	<ul style="list-style-type: none"> • To identify the levels of need among patient and client populations and ensure that low income households have the same access and opportunities to excellent and quality care as high-income households • To improve low income patients and client's access to primary and preventative health-care
Impact on Quality	<ul style="list-style-type: none"> • Improved healthcare for all

Resource: [Toronto Measuring Health Equity](#)

ASKING PATIENTS AND CLIENTS FOR DEMOGRAPHIC INFORMATION

Information to give patients and clients

Communicate to patients/clients these **3 key messages**

Purpose	"To find out who we serve."
	"To identify patient and client needs."
	"To understand patient and client experiences and outcomes."
	<i>"This initiative is a provincial priority and collection is endorsed by the Ministry of Health Ontario. As a provincially funded facility, we are ensuring that we are meeting this objective respectfully and within manageable timelines."</i>
Access to data	"Information can be seen only by the team taking care of you."
	"Information is protected like all your health-care information."
	"If used in research, data from all patients and clients is grouped together and no one will be able to identify individuals."
Voluntary	"Questions are voluntary."
	"You can choose "prefer not to answer" to any or all of the questions."
	"Choosing to not respond will not affect your care or access to services."

Resource: [Toronto Measuring Health Equity Guide](#)



- Ask the patient/client if they need help in completing the questions and provide them with assistance if required
- Always be mindful of privacy and discretion when asking the questions
- Be aware that some groups (i.e. racialized groups, LGB persons, trans individuals) may be hesitant to answer the questions due to previous experiences of discrimination and harassment

Responding to questions from patients and clients

It is essential that you have information on:

- The 3 key messages to share with patients and clients
- What the questions and categories refer to
- How to address discriminatory comments

Provide a brief explanation and note when the patient or client does not understand the question. Do not get into long discussions about the questions.

Points to use when discussing the “why”:

- “This data will help us provide you and everybody else with the best quality of care possible”
 - Expand: “and care that is equitable”
 - Expand: “and care that addresses any unique needs you have”
- “All this information has helped other healthcare organizations provide better services to patients and clients and we want to do that here”
- “We want to know who we serve and whether or not our patient and client population is representative of the community around us”
- “We understand that our patients/clients are all unique and by getting this information, we can plan for services that fit our patients’/clients’ needs”
- “This is about the best care possible and ensuring that we are providing quality and equitable care”
- “Research has shown that these variables can have an impact on the care that people get. We want to ensure that this is not happening here”
- “Based on this data, we can look at whether we have gaps in the services we provide

What **NOT** to say:

- I understand why you don’t want to answer
 - Discourages the patient/client from answering
- I don’t answer any of these myself
 - Discourages the patient/client from answering
- I’m sorry, I am being forced to ask you these questions

- Implies that the questions are irrelevant/unnecessary; can discourage the patient/client from answering

How to react to a patient or client who seems upset or excluded:

- Explain that the purpose of this is to be inclusive
- Assure them that you will make a note of their comment/concern and that it will get back to the organization; make them feel validated and assure them that their concern has been noted
- *Remind them that participation is completely voluntary and they can select “prefer not to answer”*

WHAT CAN A DATA COLLECTOR SAY?

LANGUAGE	
Script	“Knowing that a patient/client doesn’t feel comfortable speaking English is important to know for translation services.”
BORN IN CANADA	
Script	“This information will help us understand the experiences of newcomers to Canada. For example, do newcomers get the cancer screenings they need?” “We may know about newcomer services that we can refer patients/clients to.”
RACIAL/ETHNIC GROUP	
Script	“It’s helpful to know because depending on patient/client answers, it can give us information to help improve care such as knowing dietary habits or identifying a need for follow up tests (e.g. should we look into genetic testing?).” “It’s helpful for us to know because we can use this data to reach out to vulnerable groups that may be missing needed care or tests.”
DISABILITY	
Script	“We know that patients/clients may need additional support based on a disability so we ask to make sure that we have this information.” “We can plan for better care when we know what our patient/client needs are. This information will be helpful for that.”

GENDER & SEX

Script

“We can use this information to plan for medical tests and understand medical results such as blood tests.”

Comment: “Can’t you see I’m a man?” or “Isn’t it obvious?”

Response: “We don’t want to make any assumptions so we ask everyone.”

Comment: Patient or client laughs or makes jokes about trans people or others.

Response: “We ask because we welcome everyone here and don’t want to make assumptions.”

SEXUAL ORIENTATION

Script

“Having this data will help us ensure that all patients and clients are getting the best care possible.”

“Learning about sexual orientation will help us to deliver appropriate health services. Some people have different health needs than others.”

“It’s helpful for us to know because we don’t want to assume someone’s sexual orientation when we provide them with care or services.”

Comment: “I’m the normal one”

Response: “All sexual orientations are normal. Did you mean heterosexual?”

Question: “What is sexual orientation?”

Response: “Sexual orientation is how a person describes their emotional and sexual attraction to others.”

Comment: Client laughs or makes jokes about LGBTQ people or others.

Response: “Everyone is welcome here and we treat everyone with respect. We don’t make assumptions about our patients or clients.”

INCOME

Script

“It’s helpful for us to know because we want to understand the connection between income and healthcare.”

“Income is not shared with anyone. We ask because we know that income can have an effect on medication planning for some patients/clients. For example, a patient or client may not have housing or may need to explore options for affordable medications.”

“We want to learn about the connection between income and people’s health. Having this information will provide us with evidence for this question and help us plan better.”

Socio-Demographic Data Collection Script

Sample:

On the phone:

Hello, this is [name] from [organizations name]. May I please speak to [patient/client's name].

I'm calling in regards to a new initiative within the [clinic/ hospital/ organization], and we are looking to update our patients charts with some information that we can use to plan to serve you and our patient population better.

Do you have a few minutes to answer some questions?

IF YES

Great, I'd like to give you more information on why we are collecting this data. We're collecting this data so we can identify the patient population in which we serve and find any gaps within the care that we provide. Unfortunately, there are individuals who experience lower health outcomes based on these factors and we want to ensure our patients are all receiving access to care and the proper services they may need.

I'd also like to remind you that your participation is completely voluntary and at any time you can choose that you "prefer not to answer".

***Before we begin, can you please confirm your date of birth. ***

IF NO

If you'd like I can send you more information as to why we're collecting this data, and if you change your mind you can give us a call back. If not, thank you for your time and I will record that you've opted out. Have a great day.

Leaving a message:

"This message is for [patient/client's name], it's [name] from [organization's name]. I'm calling you in regards to a new initiative within the [clinic/ hospital/ organization], and I was hoping to ask you a few questions to update your chart with some information. If you could give me a call back at [phone number] [ext.] I'd greatly appreciate it. Have a good day."

****Script Subject to Change****

EDUCATIONAL RESOURCES



Happy to Ask, Happy to Tell

Staff handbook that discusses sociodemographic + importance divided into sections focusing on age, disability, gender (including transgender), race, religion/belief and sexual orientation.



E-learn Module

one-hour online training module that provides staff with the tools to effectively collect patient and client demographic information.



Measuring Health Equity videos

Provides training videos regarding the collection of demographic data



Guide to Demographic Data Collection

comprehensive guide to planning and implementing demographic collecting in health-care settings



Guidelines for Gender Affirming Primary Care with Trans and Non-binary Patients

guide discusses delivery of culturally competent care to trans patients in the context of primary care and the collaborative provision of gender-affirming medical interventions



Trans Health Guide

resource geared toward primary care and increasing the capacity of primary care providers to provide hormone therapy and other trans care



LGBTQ+ Inclusive Language

discusses what LGBTQ+ inclusive language is and why it's important in healthcare

PLAIN LANGUAGE GLOSSARY

DISABILITY

Disability is a physical (your body), mental (your mind) or intellectual (the way you process information) condition that limits your movements, senses or activities. Disability includes:

- **Chronic illness** is a disease or health condition that lasts for a long time (e.g. asthma, cancer, diabetes and HIV/AIDS).
- **Developmental disability** (also known as intellectual disability) affects your ability to reason, plan, think, communicate, and do everyday social and practical activities/tasks.
- **Drug or alcohol dependence** is the feeling that you need drugs or alcohol or are not able to control when you drink alcohol or take a drug.
- **Learning disability** affects the way your brain understands, remembers, organizes or uses information. It can create difficulty in the way you listen, speak, read, write and/or do math.
- **Physical disability** is a condition that affects physical movement
- **Sensory disability** is a condition that affects what you can hear or see (e.g. hearing or vision loss)
- **Mental illness** is a condition that affects the way you feel, behave, or think (e.g. depression, bipolar disorder, anxiety disorder)

GENDER & SEX

Gender identity is your sense of self, specifically your sense of being male, female, both, or neither. It may be different from your biological sex (i.e. anatomy, physical body) and includes:

- **Transgender man** is a person who identifies as male but was born as a biological female.
- **Transgender woman** is a person who identifies as female but was but was born as a biological male.
- **Two-Spirit** refers to Aboriginal lesbian, gay, bisexual and trans people. It means having both female and male spirits within one person.
- **Non-Binary** is a person who does not fall under the categories of man or woman

Sex is the biology aspect in humans primarily associated with physical and physiological features (ex. chromosomes, gene expression, hormone levels and function, and reproductive/sexual anatomy)

- **Intersex** is a sex that describes people whose bodies, reproductive systems, chromosomes and/or hormones are not easily grouped as male or female

RACIAL/ETHNIC GROUP

Race: social construct without biological basis and created to categorize people into different groups based on visual traits (ex. Skin colour, facial features, hair type) Examples of race include Black, white, Asian, Indigenous

Ethnicity: refers to communities' learned or adopted characteristics such as language practices beliefs. Examples of ethnicity include Chinese, East Indian, Italian, Filipino, Jamaican, Somali etc...

SEXUAL ORIENTATION

Sexual orientation is who you are attracted to romantically. People define their sexual orientation in various ways including:

- **Bisexual** is a person who is attracted to both men and women.
- **Gay** is a person who is attracted to people of the same gender; for example, a man who is attracted to men or a woman who is attracted to women. This term is used by both men and women although many women prefer to be referred to as 'lesbian'.
- **Heterosexual ("straight")** is a person who is attracted to the opposite gender; for example, a man who is attracted to women or a woman who is attracted to men.
- **Lesbian** is a woman who is attracted to other women.
- **Queer** is a positive term used by some non-heterosexual people.
- **Two-Spirit** refers to Aboriginal lesbian, gay, bisexual and trans people. It means having both female and male spirits within one person

Resource: [Toronto Measuring Health Equity Guide](#)

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