CONTENTS

Introduction .................................................................................................................................................. 3

Section 1 Health Equity and Demographic Data Collection ........................................................................ 4
  Health Equity .............................................................................................................................................. 4
  Patient and Client Demographic Data Collection ..................................................................................... 5

Section 2 Training Principles ........................................................................................................................ 8

Section 3 Agenda and PowerPoint Presentation .......................................................................................... 9
  Agenda ....................................................................................................................................................... 9
  PowerPoint Presentation ............................................................................................................................... 10

Section 4 Demographic Data Collection Questions ..................................................................................... 18
  Demographic Data Questions ..................................................................................................................... 18
  1 Spoken Language ..................................................................................................................................... 19
  2 Born in Canada ......................................................................................................................................... 19
  3 Racial/Ethnic Group ................................................................................................................................. 20
  4 People with Disabilities ............................................................................................................................. 21
  5 Gender ..................................................................................................................................................... 22
  6 Sexual Orientation ...................................................................................................................................... 23
  7 Family Income ......................................................................................................................................... 23
  8 Number of People Income Supports ......................................................................................................... 24
  Three Optional Questions ............................................................................................................................ 24
    - Reading Language .................................................................................................................................. 24
    - Religion or Spiritual Affiliation .............................................................................................................. 25
    - Housing ................................................................................................................................................. 25
Section 5  Asking Patients and Clients for Demographic Information ...................................................... 26
      Information to Give Patients and Clients ..................................................................................... 26
      Responding to Questions from Patients and Clients ........................................................................ 27
      Anticipated use of Data for Care, Planning and Quality ................................................................. 28
      Patient and Client Pamphlet ........................................................................................................... 29

Section 6  Glossary of Terms .................................................................................................................. 31

Section 7  Resources and Bibliography .................................................................................................. 36
      Further Resources ............................................................................................................................ 36
      Bibliography ................................................................................................................................... 37
      The Hospital Questions ..................................................................................................................... 38
      The CHC Questions ........................................................................................................................... 41
      Tips for Managing Stress or Fatigue at Work .................................................................................... 43
      Training Evaluation Form ................................................................................................................. 45
INTRODUCTION

The information presented in this manual will provide admitting, registration and health-care staff in Toronto with the educational materials and resources they need to collect patient and client demographic data.

This manual and the PowerPoint presentation provide information on health equity and Toronto and international experiences collecting patient and client demographic data. Workshop activities have been created to help you practice new data collection skills when responding to patient and client questions or concerns.

ACKNOWLEDGEMENTS

Mount Sinai Hospital’s Human Rights & Health Equity Office would like to acknowledge the Toronto Central Local Health Integration Network (TC LHIN) for the funding received to prepare these training materials and other related resources.

Mount Sinai Hospital would also like to acknowledge its partners: Centre for Addiction and Mental Health, St. Michael’s Hospital, and Toronto Public Health for the work that went into the Tri-Hospital plus Toronto Public Health (TPH) Pilot Project. Their efforts have opened up the way for real changes in how we will approach health equity in Toronto and provided valuable knowledge on how demographic data collection should be done.

This icon is used to point out brief reminders and remarks

This icon is used to point out important notes

This icon is used to point out evidence

With funding and support from
HEALTH EQUITY AND DEMOGRAPHIC DATA COLLECTION

Health Equity

What is health equity?

Equity in health care is striving for the highest possible standard of health for all people and giving special attention to the needs of those at greatest risk of poor health, based on social conditions.¹

It is important to remember:

• Health equity is about meeting patient and client needs while minimizing any avoidable differential outcomes based on individual characteristics.
• Health equity involves the fair distribution of resources needed for health, fair access to the opportunities available, and fairness in the support offered to people when ill.²
• Health inequities are differences in health-care outcomes that cannot be explained by access-related factors, clinical needs, relevance of intervention, or patient/client preferences.
• Health inequities are differences in health that are “avoidable”, “unjust”, and “unfair.”

Health Equity in Canada:

• Health equity research in Canada tells us that: “Equity-relevant variables such as income and race matter more than health behaviour in determining Canadians’ health outcomes”.³
• Children from low-income families require more hospital stays and show increased vulnerability to various illnesses, accidental injuries, and mental health problems.⁴
• Living conditions, age, income, immigrant status, and race significantly affect diabetes, cardiovascular disease, mental health, and self-reported health.⁵
• Economic and social conditions such as income, education, race, and housing significantly affect Canadians’ physical and mental health beyond their lifestyle choices and available medical treatments.⁶
• Inequity is expensive. A Public Health Agency of Canada report states “inequities are health system cost drivers” with approximately 20% of total health-care spending being attributed to income inequality.⁷
Ensuring Health Equity in Health Care Means:

- **Collecting patient and client-level demographic data**: This first step will give health-care organizations a comprehensive picture of the community they serve and the characteristics of patients and clients in their care. When done properly, demographic data will serve as “a fundamental building block” for identifying health inequities and gaps in quality of care.\[^{iv}\]

- **Identifying and reporting inequities in care**: The second step is to examine differences in health outcomes based on demographic variables such as race, language, and income.

- **Implementing solutions to reduce inequities**: Health-care organizations can address special patient/client needs based on language, disability, religion, and other factors, and develop programs to target populations disproportionately suffering from adverse health outcomes.

Collection of Patient and Client Demographic Data is the gold standard in health equity planning. Without demographic data, we cannot speak of evidence-based health equity planning.

**Patient and Client Demographic Data Collection**

Patient and client demographic data has been collected in the United States, the United Kingdom, and Australia for a number of years. Extensive health care and academic research is available on the positive outcomes obtained. Today, not only can we rely on evidence that successful demographic data collection in health-care organizations is possible, but that it leads to better patient and client outcomes.

**Developing Evidence-Based Training**

The process leading up to this training program included a literature review, the identification of international best practices, evaluation of past training models, and interviews with trainers and staff managers in the US and the UK. It also incorporated learnings from the work of the Tri-Hospital plus TPH project, which saw data collectors approach over 2,000 patients for demographic data collection.

**Summary of lessons:**

1. Patients and clients are willing to provide data and to have their demographic information linked to the health chart.

   - The Tri-Hospital plus TPH pilot project revealed a patient participation rate of 82.5%, providing strong evidence that patients in Toronto are willing to share demographic information.

2. Successful training in demographic data collection is about helping you feel comfortable when asking patient and client questions and helping you feel confident when answering questions of patients and clients.

   - To increase comfort when asking questions: focus groups with data collectors at Mount Sinai Hospital revealed that the opportunity to take part in practice exercises was vital in increasing and improving their comfort level.

   - For confidence with answering patient and client questions: US hospitals used pamphlets and posters to help empower staff, while those who were trained for the Tri-Hospital plus TPH project found having a glossary of terms at their fingertips to be “a life saver”.

\[^{iv}\] iv
Data collectors from the Tri-Hospital plus TPH project reported little to no problems or conflict when approaching patients about collecting this data. These individuals had all participated in educational workshops that prepared them to understand health equity and its link to demographic data collection.

Lesson #3 confirms what other hospitals have told us: Patient demographic data collection is attainable through consistent staff training.

Demographic questions that data collectors have most reservation about asking (‘sexual orientation’ or ‘gender’) do not match findings on what patients/clients are least likely to share (‘income’).

Patients and clients may be more open to sharing information than data collectors might expect.
Using Demographic Data for Health Equity Planning

As discussed before, demographic data is essential for *identifying inequities* in health outcomes. Once demographic data is used to identify and report inequities, health-care organizations can use that data to develop **evidence-based** programs and interventions to improve health outcomes.

Here is an example of a ‘best practice’ in using patient demographic information to identify health inequities, address them, and evaluate intervention programs.

**THE PROGRAM: “CRC Navigator Program” at Massachusetts General Hospital (MGH)**

**Objective:** Increase colorectal screening among low income and non-English speaking populations

**Steps:**

1. MGH identified lower colorectal cancer screening rates among low-income and non-English speaking patients in comparison to higher-income and English speaking patients.
2. MGH developed the “CRC Navigator Program” where a ‘Navigator’ (staff member):
   - Used hospital registry to identify patients by race/ethnicity who hadn’t been screened for colon cancer
   - Contacted patient and used program guidelines to determine key barriers
   - Worked with patient on providing targeted intervention (education, exploration of cultural perspectives, logistical issues,...)
3. Program was evaluated and found to be successful in improving colorectal cancer screening rates.


There is strong evidence that health inequities exist in Canada along a wide range of demographic factors. Without consistent demographic data, health-care organizations in Toronto have been unable to identify or track this kind of knowledge within their own organizations.
Learning Outcomes

At the end of today's workshop you will be able to:

- Define health equity
- Explain the demographic questions
- Tell patients and clients why health-care organizations need to collect demographic data
- Describe how demographic data may be used to plan and improve services
- Explain the reasons for collecting information on 8 questions and 3 optional items
- Ask the questions in a sensitive, respectful manner

Ground Rules

- Listen carefully while others are speaking
- Speak from one's own experience - e.g. “I think”, rather than “Everyone knows”
- No personal attacks - challenge the perspective, not the individual
- Try not to blame - look for solutions that group members can act on
- Discuss issues that are raised in the workshop
- Put devices on silent function, use respectful etiquette
- Ask for clarification from group members or the facilitators, when needed
- Share frustrations with facilitators. This is your workshop
- Take breaks as needed
- Respect confidentiality

Principles of Group Work

1. We recognize and respect the diversity of experience here.
2. Being committed to equity, we will challenge discriminatory attitudes and behaviours when they arise.
3. We want to ensure everyone's participation by eliciting trainees' needs and putting any adjustments into place.
4. We will maintain confidentiality and respect people's confidences in the context in which they were shared.
5. We will listen attentively and value time set aside for reflection and sharing ideas.
6. We will challenge behaviour, rather than the person.
7. It's okay not to know everything, to make mistakes and ask questions.
8. We will take responsibility for our own needs, and where we feel they are not being recognized, we will ask for them to be met.
9. We value humour and fun while recognizing that they should not be at the expense of others.

(Adapted from Happy to Ask, Happy to Tell DVD and Manual for training Frontline Staff in Diversity Monitoring.)
## WORKSHOP AGENDA (3 HOURS)

**How to Collect Patient and Client Demographic Information**

<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 minutes</td>
<td>Introductions, Housekeeping, Learning Objectives, Ground Rules</td>
<td>Facilitator presents</td>
</tr>
<tr>
<td>20 minutes</td>
<td>Statistics Walkabout Activity</td>
<td>Group Activity followed by Discussion</td>
</tr>
<tr>
<td>20 minutes</td>
<td>What is Health Equity?</td>
<td>PowerPoint and Supporting Documents</td>
</tr>
<tr>
<td></td>
<td>What is Demographic Data Collection?</td>
<td></td>
</tr>
<tr>
<td>10 minutes</td>
<td>Review Training Manual</td>
<td>Facilitator led</td>
</tr>
<tr>
<td>20 minutes</td>
<td>Practice session: Illustration of Best Practices in Demographic Data Collection</td>
<td>Facilitator and volunteer led, followed by group discussion</td>
</tr>
<tr>
<td>20 minutes</td>
<td>Video Observation of 3 scenarios</td>
<td>Group Discussion</td>
</tr>
<tr>
<td>15 minutes</td>
<td>Break</td>
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</tr>
<tr>
<td>45 minutes</td>
<td>Practice Sessions and Debriefs</td>
<td>Group Work</td>
</tr>
<tr>
<td>15 minutes</td>
<td>Wrap Up &amp; Next Steps</td>
<td>Group Discussion</td>
</tr>
<tr>
<td>5 minutes</td>
<td>Evaluation</td>
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</tbody>
</table>
### SLIDE 1

**Demographic Data Collection in Health Care Training**

With funding and support from

[Ontario logo]

### SLIDE 2

**3-hour Agenda**

- Introduction
- Learning Objectives and Ground Rules
- Health Equity Statistics Exercise
- Demographic Data Collection, what research shows
- How to ask the questions
- Practicing demographic data collection
- Answering frequently asked questions
- Your questions
- Evaluation

### SLIDE 3

**Learning Outcomes**

At the end of today’s session you’ll be able to:

- Define health equity
- Explain what the demographic data collection questionnaire is
- Tell patients and clients why health-care organizations need to collect demographic data
- Describe how health-care organizations will use the data
- Explain the 8 questions (and 3 optional items, if applicable)
- Administer the questionnaire in a sensitive, respectful way

### SLIDE 4

**What do we hope to accomplish here today?**

- Clarify the objectives of the demographic data collection process
- Prepare you to administer the demographic data questionnaire in your organization
- Give you a chance to practice asking demographic data collection questions
- Identify best practices in the collection of demographic data
**SLIDE 5**

**Principles of group work**

1. We recognize and respect the diversity of experience here.
2. Being committed to equity, we will challenge discriminatory attitudes and behaviours when they arise.
3. We want to ensure everyone's participation by eliciting trainees' needs and putting any adjustments into place.
4. We will maintain confidentiality and respect people's confidences in the context in which they were shared.
5. We will listen attentively and value time set aside for reflection and sharing ideas.
6. We will challenge behaviour rather than the person.
7. It's ok not to know everything, to make mistakes and ask questions.
8. We will take responsibility for our own needs, and where we feel they are not being recognized, we will ask for them to be met.
9. We value humour and fun while recognizing that they should not be at the expense of others.

(Adapted from Happy to Ask, Happy to Tell, DVD and Manual for Training Frontline Staff in Diversity Monitoring)

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**SLIDE 6**

**Statistics Activity**

- Learning about health inequities

  - Please walk around the room, read the statistics on the wall, and then stand beside the group of statistics that most affects, surprises or interests you
  - We will then spend a few minutes sharing...

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**SLIDE 7**

**The Toronto Central Local Health Integration Network and Health Equity**

- As part of its initiatives around Health Equity, the Toronto Central LHIN has mandated that all TC LHIN hospitals and community health centres should collect patient and client demographic information

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**SLIDE 8**

**What is health equity?**

- Equity in health care refers to ensuring quality care regardless of race, religion, language, income or any other individual characteristic.
- Does anyone know of any examples of health inequities?
### SLIDE 9
**When does health equity happen?**

Health Equity happens when health-care organizations engage in the following:

- Collect demographic data of patients and clients
- Identify and report inequities in care
- Implement solutions to reduce inequities

### SLIDE 10
**Why do we want to collect demographic data?**

- To improve health-care quality
- To determine who we are serving
- To ensure health care responds to individual needs
- To make certain our services reach the entire community
- To fulfill our mandate to provide equitable care
- To analyze things like re-admission rates, incidence of diabetes, who participates in cancer screening
- To develop evidence-based quality improvement interventions for reducing health inequities

### SLIDE 11
**What do we know about demographic data collection in health care?**

- Patients are willing to share this information (based on research in 3 Toronto Hospitals)
- Patient demographic data collection already occurs in the U.S., Australia and the United Kingdom
- Collecting demographic information is about sensitively, respectfully asking key questions for the right reasons
- Demographic data has led to well-documented positive changes in health-care planning and delivery

### SLIDE 12
**How have hospitals used demographic data?**

- The next slide presents some information about patient demographic data collection in the United States
- The findings provide some key information about health equity and demographic data collection
THE PROGRAM: CRC Navigator Program at Massachusetts General Hospital (MGH)

OBJECTIVE: Increase colorectal screening among low income and non-English speaking populations

STEPS:
1. MGH identified lower colorectal cancer screening rates among low-income and non-English speaking patients in comparison to higher-income and English speaking patients.
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   - Contacted patient and used program guidelines to determine key barriers
   - Worked with patient on providing targeted intervention (education, exploration of cultural perspectives, logistical issues,...)
3. Program was evaluated and found to be successful in improving colorectal cancer screening rates.

Demographic Data Collection in Toronto

CAMH, Mount Sinai Hospital, St. Michael’s Hospital, and Toronto Public Health conducted a research study to determine:
- Which socio-demographic data to collect
- How to ask questions
- The most effective ways to gather sensitive personal information

The 8 core items
1. What language would you feel most comfortable speaking in with your health-care provider?
2. Were you born in Canada? (If no, what year did you arrive?)
3. Which of the following best describes your racial or ethnic group?
4. Do you have any of the following?
5. What is your gender?
6. What is your sexual orientation?
7. What was your total family income before taxes last year?
8. How many people does this income support?

THREE OPTIONAL ITEMS:
ADD IF YOUR ORGANIZATION IS USING ANY:
1. Language (reading)
2. Religion
3. Housing
How do we make patients and clients comfortable?

Patients and clients will feel more comfortable answering the questions if they know:
- The questions come from a place of concern, and that the data will serve a positive and valuable purpose
- Their care will not be affected
- They do not feel forced to provide the information

Maximizing comfort level

- We realize patients and clients might be concerned and/or feel uncomfortable.
- They will have questions and comments.
- We want staff to feel comfortable answering questions from patients and clients.
- The best course of action is to use a non-confrontational approach, and not push patients or clients who do not want to respond to any of the questions

Engaging patients and clients

- Depending on the context, health-care organizations will have different strategies for engaging patients and clients with these questions

Sample for admitting staff:

- Treat this as part of your admissions process; many hospitals already ask religion and language so expand the list to include these questions rather than treating them as a stand-alone project.
- When approaching a patient or client always be ready to:
  - Explain that this information will be used by the organization for monitoring and to ensure everyone receives quality care
  - Explain that all patients and clients are being asked these questions
  - Explain who will see the data
  - Remind patients and clients that they can skip questions

Asking patients and clients for information

- Some of the groups referred to in this data collection process are likely to have experienced discrimination and harassment, and may be reluctant to answer questions from health professionals
Quick Guide to Conducting a Demographic Data Interview

- Explain the purpose of the demographic data collection:
  “Our hospital is preparing to regularly collect information about all our patients to help us plan for patient-centered services and improve the quality of our care.”

Suggested message to patient/client:
- These questions will tell us who you are by providing us with information on language, race/ethnicity, and so forth.
- This will take a few minutes. It’s completely voluntary, so you can decline to answer any of questions.

Explain what will happen to the data:
- We recommend organizations explain who will see the information and where it will be stored.
- Each organization will determine the answer to this question in accordance with their own privacy policies and research practices.

Good to know: Anticipated use of Data for Care, Planning, and Quality

**INDICATOR: Spoken Language**

**USES IN CARE:**
- To provide appropriate care delivery as required by the Charter of Rights and Freedoms
- To acquire informed consent

**USES IN PLANNING:** To improve access to care for those who do not speak/read English or French

**IMPACT ON QUALITY:** Use of interpreters and translators has direct impact on quality and safety.
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<thead>
<tr>
<th>SLIDE 24</th>
<th>Good to know: Anticipated use of Data for Care, Planning, and Quality</th>
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</thead>
<tbody>
<tr>
<td><strong>INDICATOR:</strong> Born in Canada</td>
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<tr>
<td>USES IN CARE: To address barriers and stress associated with migration and settlement</td>
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<tr>
<td>USES IN PLANNING:</td>
<td></td>
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<tr>
<td>- To understand the types of supports or services needed</td>
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<tr>
<td>IMPACT ON QUALITY: Improves access to care for newcomers to Canada</td>
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<th>SLIDE 25</th>
<th>Good to know: Anticipated use of Data for Care, Planning, and Quality</th>
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</thead>
<tbody>
<tr>
<td><strong>INDICATOR:</strong> Racial/Ethnic Group</td>
<td></td>
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<tr>
<td>USES IN CARE: To provide targeted care and supports (e.g. Middle Eastern populations &amp; thalassaemia, First Nations &amp; diabetes)</td>
<td></td>
</tr>
<tr>
<td>USES IN PLANNING:</td>
<td></td>
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<tr>
<td>- To improve outreach to vulnerable groups who do not seek care at the same level as other groups</td>
<td></td>
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<tr>
<td>- To address access challenges</td>
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<tr>
<td>IMPACT ON QUALITY: Outreach improves preventative care and reduces admissions</td>
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<tr>
<th>SLIDE 26</th>
<th>Good to know: Anticipated use of Data for Care, Planning, and Quality</th>
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<tbody>
<tr>
<td><strong>INDICATOR:</strong> People with Disabilities</td>
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<tr>
<td>USES IN CARE:</td>
<td></td>
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<tr>
<td>- To fulfill organizational responsibilities around providing accommodation</td>
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<tr>
<td>- To address histories of traumatic interactions with the health-care system</td>
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<tr>
<td>USES IN PLANNING:</td>
<td></td>
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<tr>
<td>- To carry out accommodation planning</td>
<td></td>
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<tr>
<td>- To work on preventing recurrence of exclusion</td>
<td></td>
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<tr>
<td>IMPACT ON QUALITY: Better accommodation leads to more efficient and effective care</td>
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<tr>
<th>SLIDE 27</th>
<th>Good to know: Anticipated use of Data for Care, Planning, and Quality</th>
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<tbody>
<tr>
<td><strong>INDICATOR:</strong> Gender</td>
<td></td>
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<tr>
<td>USES IN CARE:</td>
<td></td>
</tr>
<tr>
<td>- Both sex and gender are relevant to room assignment and other essential medical testing (e.g. hormone levels, pap smears, mammograms, etc.)</td>
<td></td>
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<tr>
<td>- To accommodate the unique needs related to the gender identity of a patient or client</td>
<td></td>
</tr>
<tr>
<td>USES IN PLANNING: To improve outreach to vulnerable groups who do not access care at the same level as other groups</td>
<td></td>
</tr>
<tr>
<td>IMPACT ON QUALITY: Better planning improves preventative care and health outcomes</td>
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</tbody>
</table>
SLIDE 28  
**Good to know: Anticipated use of Data for Care, Planning, and Quality**  
**INDICATOR: Sexual Orientation**  
USES IN CARE: To understand the needs of patients (e.g., living with discrimination)  
USES IN PLANNING:  
- To create welcoming environments for lesbian, gay, bisexual (LGB) community members  
- To identify LGB friendly community partners  
IMPACT ON QUALITY: Providing a welcoming environment improves access and patient and client experiences

SLIDE 29  
**Good to know: Anticipated use of Data for Care, Planning, and Quality**  
**INDICATOR: Family Income and Number of People Income Supports**  
USES IN CARE:  
- Relevant for discharge planning  
- Relevant for medical prescriptions  
USES IN PLANNING: 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  
IMPACT ON QUALITY:  
- Improved health care for all

SLIDE 30  
**Remember...**  
Patients and clients will feel more comfortable if they know:  
- The questions come from a place of concern and that the data will serve a positive and valuable purpose  
- Their care will not be affected  
- They do not feel forced to provide the information

SLIDE 31  
**Time to review...**  
Content:  
- Responding to Questions from Patients and Clients  
- Patient and Client Pamphlet

SLIDE 32  
**Time to practice**
This section will provide you with appropriate information and resources to support you in asking patients and clients socio-demographic questions.

For each of the 8 items, participants will learn about:
- Item wording
- What the item intends to capture/measure
- Important points to remember
- Health equity evidence

Health-care organizations collecting additional information on preferred language (reading), religion/spiritual affiliation, and housing, will receive similar information.

Please refer to the Glossary of Terms on page 31 to better understand and be able to explain the content of these questions.

DEMOGRAPHIC DATA QUESTIONS

The questions were developed by the Centre for Addiction and Mental Health, Mount Sinai Hospital, St. Michael’s Hospital, and Toronto Public Health based on:
- A literature review
- An environmental scan of best practices
- Consultations with community members and subject area experts
- The findings of the Tri-Hospital plus TPH pilot project

Why these 8 core items?

These 8 items were chosen because they are widely accepted as “equity variables” that have a significant impact on patient and client health outcomes. Language, born in Canada, race/ethnicity, gender, sexual orientation, disability, and income have all been found to impact patient and client outcomes, sometimes with devastating effects.
1  Spoken Language

The question: What language would you feel most comfortable speaking in with your health-care provider? Check ONE only.

- Amharic
- Arabic
- ASL
- Bengali
- Chinese (Cantonese)
- Chinese (Mandarin)
- Czech
- Dari
- English
- Farsi
- French
- Greek
- Hindi
- Hungarian
- Italian
- Karen
- Korean
- Nepali
- Polish
- Portuguese
- Punjabi
- Russian
- Slovak
- Somali
- Spanish
- Tagalog
- Tamil
- Russian
- Serbian
- Tigrinya
- Turkish
- Twi
- Ukrainian
- Urdu
- Vietnamese
- Other (Please specify) __________________________
- Prefer not to answer
- Do not know

What is the preferred spoken language?

The language that the patient/client would prefer to speak in, which may be their mother tongue.

People may speak many languages, including English, but the one they feel most comfortable speaking in with their health-care provider is important to know.

Points to remember

If the patient or client doesn’t see their preferred language, they should check “other” and fill in the name of the language.

If there are languages listed that you don’t recognize or whose pronunciation you are uncertain, please go to http://aboutworldlanguages.com to read more about them.

Health equity evidence


2  Born in Canada

The 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 do we mean by “born in Canada”?

Identifies whether the patient or client was born in Canada or has immigrated to Canada.
Points to remember

Patients and clients might be reluctant to answer this question fearing that you are trying to identify their citizenship status. They may believe that the health-care system will communicate with Immigration Canada in order to locate people who are not in Canada legally. Ensure that the patient or client is aware of your organization’s practices around sharing this information with his/her/their health-care team.

It is up to your organization and your privacy officer to determine how demographic information will be stored and whether it is visible.

Health equity evidence


3 Racial/Ethnic Group

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

- Asian - East (e.g., Chinese, Japanese, Korean)
- Asian - South (e.g., Indian, Pakistani, Sri Lankan)
- Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
- Black - African (e.g., Ghanaian, Kenyan, Somali)
- Black - Caribbean (e.g., Barbadian, Jamaican)
- Black - North American (e.g., Canadian, American)
- First Nations
- Indian - Caribbean (e.g., Guyanese with origins in India)
- Indigenous/Aboriginal not included elsewhere
- Inuit
- Latin American (e.g., Argentinean, Chilean, Salvadorian)
- Métis
- Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
- White - European (e.g., English, Italian, Portuguese, Russian)
- White - North American (e.g., Canadian, American)
- Mixed heritage (e.g., Black - African and White - North American)
  (Please specify) _______________________________________________________________________
- Other(s) (Please specify) ______________________________________________________________________
- Prefer not to answer
- Do not know

What is racial/ethnic group?

Race continues to be mistakenly used as a marker of how human beings are socially and/or biologically different from one another. Historically, such difference has been assigned on the basis of colour, appearance, culture, ethnicity, socio-economic status and area of origin.
While both scientists and human rights activists have been successful in discrediting the validity of race as a concept for understanding human difference, racial categorization and racial discrimination continue to shape the lives and opportunities of those who are categorized as ‘racialized people’.

**Points to remember**

Patients and clients may be reluctant to identify racially for a variety of reasons. Research tells us that about one in four people are uncomfortable identifying their racial or ethnic background.

Some may believe that race is a discredited concept and that refusal to speak in terms of race will help us to gain racial equality. People who do not experience racism and some people who have been harmed by racism may also feel that race is irrelevant and may say that they “belong to the human race”.

You can respond by saying that we know that certain groups in society are discriminated against because they are perceived to be different and that race is often the basis for this discrimination.

However, having information about people’s racial identity can help us track whether certain groups may face more discrimination and may not receive the care that they deserve. The best practice is to have people self-identify racially. If they do not see a designation on the list that reflects their racial identity, they should provide one in the space for “other”.

For more information about “race”, see the Glossary of Terms on page 33.

**Health equity evidence**


### 4 People with Disabilities

The question: **Do you have any of the following? Check ALL that apply.**

- □ Chronic illness
- □ Developmental disability
- □ Drug or alcohol dependence
- □ Learning disability
- □ Mental illness
- □ Physical disability
- □ Sensory disability (i.e. hearing or vision loss)
- □ None
- □ Other (*Please specify*)
- □ 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.¹

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Disability is often described as the social oppression faced by people with impairments living in an environment that is not organized to accommodate their needs. While many people with disabilities are in good health, the vast majority faces barriers in utilizing the health-care system. Most of us will develop some sort of disability during our lifetimes, with the risk increasing as we age.

Points to remember

Patients and clients should select the relevant boxes for the disabilities that they self-identify with. They may have more than one disability. Again, there may be some reluctance to divulge information on disabilities, or alcohol or drug dependencies. Patients and clients should be reassured that their information will only be shared with members of their health-care team and that they can respond “prefer not to answer” to any of the questions.

Health equity evidence


5 Gender

The question: What is your gender? Check ONE only.

- Female
- Trans - Female to Male
- Other (Please specify) _________________________
- Intersex
- Trans - Male to Female
- Prefer not to answer
- Male
- Do not know

What is gender?

Gender refers to those social behaviours, activities and characteristics that a society believes are appropriate for men and women. Until recently, gender has been understood to be determined solely by a person’s anatomy. However, there is increasing acceptance that for many people, their bodily characteristics conflict with their gender identity.

Some people born with female sex organs may identify more strongly with a male gender identity and some who were born with male sex organs may feel more comfortable identifying with the female gender. Gender identity is linked to a person’s sense of self, and the sense of being male, female, both or neither.

Points to remember

Some people may find this question intrusive. People who may be transitioning from male to female, or from female to male, may be concerned about who will have access to this information.

Patients and clients have the option to skip the question by selecting “prefer not to answer” and you should reassure them that their data will be taken care of in the same manner that all their other sensitive information is.

“Two-spirit” is a term used in Aboriginal cultures to describe a person who has received a gift from the Creator - the privilege of housing both male and female characteristics within their spirit. Today, it is an umbrella term used mostly by some First Nations and Métis people to describe, from a cultural perspective, people who are known in non-Aboriginal society as either gay, lesbian, bisexual, intersex, or trans. Some Aboriginal people may self-identify their gender as “two-spirit”.

If you have questions about gender identities, please refer to the Glossary of Terms on page 32.
6 Sexual Orientation

The question: What is your sexual orientation? Check ONE only.

- Bisexual
- Lesbian
- Other (Please specify) _______________________
- Gay
- Queer
- Prefer not to answer
- Heterosexual (“straight”)
- Two-Spirit
- Do not know

What is sexual orientation?

Sexual orientation is a term for the emotional, physical, romantic, sexual and spiritual attraction, desire or affection for another person.

Points to remember

Some people may find this question intrusive. Explain who will have access to the information and how their privacy will be protected. Patients and clients also have the option to skip the question.

Health equity evidence


7 Family Income

The question: What was your total family income before taxes last year? Check ONE only.

- $0 to $29,999
- $30,000 to $59,999
- $60,000 to $89,999
- $90,000 to $119,999
- $120,000 to $149,999
- $150,000 or more
- Prefer not to answer
- Do not know

What is family income?

Family income, also known as ‘household’ income, is the total income earned by a group of individuals sharing a common dwelling unit who are related by blood, marriage (including common-law relationships) or adoption.

Points to remember

Many Canadians are uncomfortable answering a question about family income so clarify who will have access to this information and how privacy will be protected. There may be many reasons for patients or clients to feel uncomfortable answering this question, including fear of being judged and fear of being reported to Canada Revenue Agency or other authorities. Patients and clients have the right to skip the question/prefer not to answer.
Health equity evidence

8 Number of People Income Supports

The question: How many people does this income support? _______ person(s)
☐ Prefer not to answer     ☐ Do not know

Number of family members defined

The number of people in a household 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.

Note for Community Health Centres: the gender and income questions are slightly different but the above information is still applicable. Please see the CHC Questions on page 41.

THREE OPTIONAL QUESTIONS

Reading Language

The question: In what language would you prefer to read health-care information? Check ONE only.

☐ Amharic                ☐ Arabic                    ☐ Bengali
☐ Braile                 ☐ Chinese (Simplified)   ☐ Chinese (Traditional)
☐ Czech                  ☐ Dari                      ☐ English
☐ Farsi                  ☐ French                    ☐ Greek
☐ Hindi                  ☐ Hungarian                 ☐ Italian
☐ Karen                  ☐ Korean                    ☐ Nepali
☐ Korean                 ☐ Polish                    ☐ Portuguese
☐ Nepali                 ☐ Prefer not to answer    ☐ Do not know
☐ Other (Please specify) ☐ Russian                   ☐ Slovak
☐ Somali                 ☐ Spanish                   ☐ Tagalog
☐ Spanish                ☐ Tigrinya                 ☐ Turkish
☐ Somali                 ☐ Ukrainian                 ☐ Ukranian
☐ Tagalog                ☐ Urdu                      ☐ Vietnamese
☐ Other (Please specify) ☐ Prefer not to answer    ☐ Do not know
Religion or Spiritual Affiliation

The question: What is your religious or spiritual affiliation? Check ONE only.

☐ Animism or Shamanism  ☐ Confucianism  ☐ Islam  ☐ Roman Catholic
☐ Atheism  ☐ Hinduism  ☐ Native Spirituality  ☐ Sikhism
☐ Baha’i Faith  ☐ Jainism  ☐ Pagan  ☐ Spiritual
☐ Buddhism  ☐ Jehovah’s Witnesses  ☐ Protestant  ☐ Unitarianism
☐ Christian Orthodox  ☐ Judaism  ☐ Rastafarianism  ☐ Zoroastrianism
☐ Christian, not included elsewhere on this list  ☐ Other (Please specify)

☐ I do not have a religious or spiritual affiliation  ☐ Prefer not to answer  ☐ Do not know

What is religion?

Religion can be defined as a community created by a common core of shared beliefs and rituals exercised in their obedience to, or worship of, a supernatural power. Spirituality relates to all aspects of our lives and encompasses our physical, mental and social states.

Points to remember

Patients and clients should choose from the list, or fill in the space for “other”, “prefer not to answer” or “do not know”. Some patients or clients may ask questions about the different religions/spiritual affiliations listed. If you are unfamiliar with the religions listed, please refer to the Glossary of Terms on page 34.

Housing

The question: What type of housing do you live in?

☐ Boarding Home  ☐ Own Home  ☐ Shelter/Hostel
☐ Correctional Facility  ☐ Renting Home  ☐ Supportive Housing
☐ Group Home  ☐ Other (Please specify)  ☐ Do not know
☐ Homeless/on street  ☐ Prefer not to answer

What is housing?

The type of housing a patient or client may live in can range from owning, renting, living with friends or family, living in temporary housing such as a shelter or hostel, being homeless or living in correctional facility.

Points to remember

Some people may be reluctant to answer this for a number of reasons, including not wanting to disclose homelessness. Let patients and clients know that they can choose the option “prefer not to answer” but that we will treat this information with respect and use it to understand their needs.
SECTION 5

ASKING PATIENTS AND CLIENTS FOR DEMOGRAPHIC INFORMATION

INFORMATION TO GIVE PATIENTS AND CLIENTS

Listed below are some sample guidelines to use when asking the 8 questions to patients and clients:

- Introduce yourself and explain that you are going to ask a few questions. Ask if they would like to answer the questions in a language other than English.
- Before you ask the questions, explain that you are collecting information from them, which will only be used by the organization to ensure that everyone receives quality care.
- Explain that all patients and clients are being asked these questions, that the information given will be treated with the same level of confidentiality as all the other information they provide and that they are free to skip any question by selecting “prefer not to answer”.
- Be aware that some of the groups referred to in this data collection process are likely to have experienced discrimination and harassment and therefore may be reluctant to answer questions from health professionals.
- Ask the patient or client if they need any help in completing the questions and provide them with assistance if required.
- Always be mindful of privacy and discretion when asking the questions.

You can use the Patient and Client Pamphlet to help introduce the project and to pro-actively address any questions that may come up.

For health-care organizations that have chosen to have patients or clients fill out the questions themselves, staff should ensure that this information is provided using alternate methods (e.g. written materials, comprehensive introduction).
RESPONDING TO QUESTIONS FROM PATIENTS AND CLIENTS

It is essential that you have information on:
- Why you are collecting this specific information
- What the questions and categories refer to
- What your organization’s privacy policy will be (data storage and visibility)
- 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 health-care 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 and act if otherwise”
- “Based on this data, we can look at whether we have gaps in the services we provide”

Remind patients and clients that this information is not only about their care right now, but about improving future care for them and contributing to improving care for all other patients and clients.

What NOT to say:
- I understand why you don’t want to answer
- I don’t answer any of these myself
- I’m sorry, I am being forced to ask you these questions

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 they can skip a question

“You can choose not to answer” should not be the first response to patient or client concerns:
- Patients and clients have the right to know why we need this data and how it will be used
- It is important to help patients and clients see that their information is very valuable for the care we provide and that it will be treated with respect
## Anticipated Use of Data for Care, Planning and Quality

<table>
<thead>
<tr>
<th>Indicator</th>
<th>Spoken Language</th>
</tr>
</thead>
</table>
| **Uses in Care**   | • To provide appropriate care delivery as required by the Charter of Rights and Freedoms  
                     • To acquire informed consent                                                      |
| **Uses in Planning** | • To improve access to care for those who do not speak/read English or French       |
| **Impact on Quality** | • Use of interpreters and translators has direct impact on quality and safety          |
| Indicator          | Born in Canada                                                                  |
| **Uses in Care**   | • To address barriers and stress associated with migration and settlement           |
| **Uses in Planning** | • To understand the types of supports or services needed                         |
| **Impact on Quality** | • Improves access to care for newcomers to Canada                                |
| Indicator          | Racial/Ethnic Group                                                              |
| **Uses in Care**   | • To provide targeted care and supports (e.g. Middle Eastern populations & thalassaemia, First Nations & diabetes) |
| **Uses in Planning** | • 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** | • Outreach improves preventative care and reduces readmissions                      |
| Indicator          | People with Disabilities                                                          |
| **Uses in Care**   | • To fulfill organizational responsibilities around providing accommodation         
                     • To address histories of traumatic interactions with the health-care system       |
| **Uses in Planning** | • To carry out accommodation planning                                              
                     • To work on preventing recurrence of exclusion                                    |
| **Impact on Quality** | • Better accommodation leads to more efficient and effective care                  |
### PATIENT AND CLIENT PAMPHLET

**Quick Answers to Frequently Asked Questions (FAQ)**

The answers to frequently asked questions below are included in a pamphlet format. Please note that we **strongly recommend** that you review all the answers to ensure they fit with your own policies around data use, privacy, storage, etc.

**Why are you asking me these questions?**

A team of Toronto researchers worked on choosing each question. They carefully reviewed information about quality and equitable care. By asking these questions, we will continue to know our patients and clients and become better at providing care and services. Also, sometimes people experience discrimination in health-care settings. We want to make sure that is not happening. If it is, we want to correct that.
I’m only here for a quick test. How is this relevant to my care?
It is important for us to know who we serve, whether patient and client needs match the care we provide for all. This information will help us understand and plan care not only for your future visits, but for other patients and clients who may have similar needs as yours. This gives us a full picture of the population we serve.

Is it legal to ask these questions?
Yes, the Ontario Human Rights Commission strongly encourages organizations to collect and use demographic information to keep track of outcomes and promote equity. Also, Ontario’s Excellent Care for All Act, 2010 is a law that holds hospitals responsible for delivering quality health care. This law has hospitals collect information from patients about their experience. We learned that demographic information greatly impacts patient and client experiences and decisions about whether to use health care or not. We believe that we cannot fully understand health-care experiences without knowing more about who we are serving.

How will you use this information?

Each organization should confirm that this answer is in accordance with their own privacy policies.

• We will study whether factors such as language, disability, gender and so on are linked to health outcomes.
• We want to learn more about the link between how long you have been in Canada and health outcomes.
• We will review and use your information to develop programs and do service training.
• Members of your Health-care Team may refer you to services, give you information, or identify any unique needs, such as:
  - interpretation services
  - health information
  - treatment programs
  - accommodation for disabilities
  - care information

Who can see my demographic information?

Each organization should confirm that this answer is in accordance with their own privacy policies and research practices.

We take your privacy very seriously. Only your Health-care Team will see the information. It will be treated with the same level of confidentiality as all other information you share. If used in research, the information from all patients and clients will be combined and researchers will not be able to identify who any of the patients or clients are.

What if there are questions that I don’t want to answer?
You can answer “prefer not to answer” to any or all questions. This will not impact the care you receive here.

2 & 3  Response to this question is based on the practices at Mount Sinai Hospital.
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, drug and alcohol dependencies, environmental sensitivities, and other conditions.

Disability is often described as the social oppression faced by people with impairments living in an environment that is not organized to accommodate their needs. While many people with disabilities are in good health, the vast majority face some barriers in utilizing the health-care system. Many of us will develop some sort of disability during our lifetime with the risk increasing as we age. Disability includes:

Chronic illness is a disease or other health condition that is persistent or long-lasting in nature. The term chronic is usually applied when the course of the disease lasts for more than three months. Common chronic diseases include asthma, cancer, diabetes and HIV/AIDS.

Developmental disability (also known as intellectual disability) refers to lifelong disabilities attributable to mental or physical impairments, manifested prior to age 18. Developmental disabilities can affect one’s capacity for independent living, economic self-sufficiency, learning, mobility, use of language, self-care, and self-direction.

Drug or alcohol dependence occurs when a person develops a physical or emotional “need” for a drug or for alcohol and is unable to control its use despite the negative impact it has on their life.

Learning disability refers to a number of disorders which may affect a person’s ability to acquire, organize, remember, understand or use verbal or nonverbal information. Learning disabilities often affect individuals who possess at least average abilities for thinking and/or reasoning. Learning disabilities can affect a person’s ability to listen, speak, read, write and/or do math. They can also be associated with difficulties with social and emotional skills and behaviours.

Mental illness refers to a significant pattern of changes in thinking, behaviour or emotions that may affect a person’s ability to work or function socially. Common disabilities include depression, seasonal affective disorder, and anxiety disorders. A person with a mental health disability may experience reduced stamina, ability to handle stress and/or a lack of concentration, but may find it difficult to express this or even identify the disability. Social conditions such as poverty, income disparities, homelessness and housing instability, income insecurity, racism, sexism, and homophobia negatively impact mental health.

Physical disability is any impairment which limits the physical function of one or more limbs or fine or gross motor ability. It also includes impairments which limit other facets of daily living, such as respiratory disorders and epilepsy.

5 http://en.wikipedia.org/wiki/Physical_disability#cite_note-0
**Sensory disability** usually refers to hearing impairment and visual impairment. Hearing impairment is the category of physical impairment that includes people who are deaf, deafened or hard of hearing. Visual impairment refers to those who suffer from various injuries to their eyes and/or impairments to their eyesight including partial or total blindness.

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**Gender and Gender Identity**

**Gender** is a social construct that is defined in various ways and can include any or all of the following categories: physical anatomy (or sex organs), secondary sex characteristics that develop at and after puberty, behaviour and conduct, sense of self, and clothing.

**Gender identity** is linked to a person's sense of self, and particularly the sense of being male, female, both, or neither. Some people's gender identity is neither masculine nor feminine and for others, their gender is fluid, rather than fixed on any point along the gender spectrum. A person's gender identity may be different from their birth-assigned sex and is separate from their sexual orientation. Gender identity includes:

- **Intersex** refers to people whose bodies, reproductive systems, chromosomes and/or hormones are not easily characterized as male or female. Most intersex people identify as either male or female, but not all intersex people identify with the sex they were assigned at birth, and some choose to identify themselves as intersex. While intersex and trans people may share some overlapping experiences and perspectives, the terms and issues are not the same. Many intersex persons do not identify as trans, and should not be referred to under the heading of trans unless they request it.

- **Trans** is an abbreviation, which includes but is not limited to, transgender, transsexual, gender non-conforming and gender questioning persons. Trans can mean transcending beyond, existing between, or crossing over the gender spectrum. It is an umbrella term used to describe individuals who, to varying degrees, do not conform to what society usually defines as a man or a woman.

  - **Trans - Female to Male** describes a trans person who is assigned female at birth but self-identifies as male.
  
  - **Trans - Male to Female** describes a trans person who is assigned male at birth but self-identifies as female.

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The term “two-spirit” has traditionally been used in Aboriginal cultures to describe a person who has received a gift from the Creator - the privilege of housing both male and female characteristics within their spirit. Today, it is a generic term used mostly by some First Nations and Métis people to describe, from a cultural perspective, people who are known in non-Aboriginal society as either gay, lesbian, bisexual, intersex, or trans. As an umbrella term, Aboriginal people may self-identify their gender as “two-spirit”
Racial/Ethnic Group

Race continues to be mistakenly used as markers of how human beings are socially and/or biologically different from one another. Historically, such difference has been assigned on the basis of appearance, culture, ethnicity, socio-economic status and area of origin. While both scientists and human rights activists have been successful in discrediting the validity of race as a concept for understanding human difference, racial categorization and racial discrimination continue to shape the lives and life chances of those who are categorized as ‘racial minorities’.

This list provides information on different racial/ethnic groups. However, it is important to remember that each individual will be self-identifying. Use this information to help someone identify their own race/ethnicity if they are unsure, but do not tell them what their race/ethnicity is.

- **Asia - East**: *East Asian* people have origins in a sub-region of Asia that is geographically comprised of the following countries: China, Japan, Mongolia, North Korea, South Korea, Taiwan, and Tibet.

- **Asia - South**: *South Asian* people have origins in the southern region of the Asian continent that is geographically comprised of the following countries: Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka.

- **Asia - South East**: *South East Asian* people have origins in a sub-region of Asia, consisting of the following countries: Brunei, Cambodia, East Timor, Indonesia, Laos, Malaysia, Myanmar (formerly Burma), Philippines, Singapore, Thailand, Vietnam.

- **Black - African**: *Black Africans* are people who self-identify as Black from Sub-Saharan Africa including the following countries: Angola, Ethiopia, Nigeria, Republic of the Congo, Rwanda, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, Tanzania, and Zimbabwe.

- **Black - Caribbean Region**: *Black Caribbeans* are people from the Caribbean Region whose ancestry is African.

- **Black - North American**: *Black North Americans* are people who are residents of Canada or the United States whose ancestry is African.

- **First Nations**: This term describes the original peoples of Canada and their descendants (also known as “Aboriginal Peoples” or “Indigenous People”) who are not Inuit or Métis. *First Nations* are one of three peoples recognized as Aboriginal in the Constitution Act of 1982 along with Inuit and Métis\(^6\).

- **Indian - Caribbean**: *Indian Caribbeans* are people who have their ancestry in the Indian subcontinent and have migrated to the Caribbean where people from India have lived for many generations.

- **Indigenous/Aboriginal not included elsewhere**: There are indigenous people (original inhabitants) through the world. Some indigenous peoples include: Mayans from Mexico and Central America.

- **Inuit**: *Inuit* are one of Canada’s recognized Aboriginal Peoples and originally inhabited the Arctic regions in Canada (Northwest Territories, Nunavut, northern parts of Québec, and throughout most of Labrador). *Inuit* is a plural noun, the singular is Inuk.

- **Latin Americans** are people from countries south of the United States including Argentina, Brazil, Chile, Costa Rica, Mexico and Peru.

- **Métis** are recognized by Canada as one of the Aboriginal Peoples and the term has been used since the 18th century to refer to people of mixed Aboriginal and European ancestry.

- **Middle Eastern** people, includes people from North African countries and Middle Eastern countries: Afghanistan, Algeria, Armenia, Bahrain, Cyprus, Egypt, Iran, Iraq, Israel, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Palestine, Qatar, Saudi Arabia, Syria, Tunisia, United Arab Emirates, Yemen. Many Middle

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\(^6\) [www.itk.ca/note-terminology-inuit-metis-first-nations-and-aboriginal](http://www.itk.ca/note-terminology-inuit-metis-first-nations-and-aboriginal)
Eastern people, but not all, may also identify as Arab or Farsi (Persian).

**Mixed heritage**: People whose ancestries come from more than one racial background may identify as mixed race and/or multiracial.

**White - European** also referred to as Caucasians, are people whose ancestry is from Europe and trace back their heritage to countries such as Albania, England, Greece, Ireland, Romania and Russia.

**White - North American** also referred to as Caucasian, are people whose ancestors migrated from Europe and trace back their heritage to countries such as Albania, England, Greece, Ireland, Romania and Russia.

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**Religion/Spirituality**

**Religion** can be defined as a community created by a common core of shared beliefs and rituals exercised in their obedience to, or worship of, a supernatural power. **Spirituality** relates to all aspects of our lives and encompasses our physical, mental and social states.

- **Animism**: A form of religion centered on relating to spiritual powers or beings who permeate the world.
- **Atheism**: A belief that any God or supreme supernatural being does not exist.
- **Baha’i Faith**: A monotheistic religion founded in Iran in the second half of the 19th century that emphasizes the spiritual unity of humankind.
- **Buddhism**: A religion based on the teachings of Buddha, promoting a life of mental and moral self-purification as a path to reducing suffering and attaining enlightenment. It is widely practiced throughout Southeast and East Asia with strong ties to Tibet.
- **Christianity**: A religion centered on belief in Jesus as the Son of God. It has many denominations including:
  - **Christian Orthodox** (or Eastern Orthodox Christianity): One of the three major branches of Christianity.
  - **Protestant**: One of the three major branches of Christianity. It includes: Amish, Anglicans, Baptists, Congregationalists, Lutherans, Mennonites, Methodists, Pentecostals, Presbyterians and Quakers.
  - **Roman Catholic**: One of the three major branches of Christianity.
- **Confucianism**: An East Asian spiritual and ethical tradition that originated with Confucius at the end of the sixth century B.C.E.
- **Hinduism**: A collection of beliefs and philosophical principles that express a belief in reincarnation and a devotion to worshiping one or more gods and goddesses. These principles and beliefs arose and are especially practiced in the Indian subcontinent.
- **Islam**: The second largest religion in the world, it is based on the Qur’an. People who practice the religion are called Muslims.
- **Jainism**: This is the oldest ascetic religious tradition. Its 4 million followers are located mainly in India. They believe in karma, in reincarnation, and in avoiding violence.
- **Jehovah’s Witnesses**: A Christian denomination founded in the United States during the late 19th century in which active evangelism is practiced, the approach of the millennium is preached, and war is opposed under conscientious objection.
- **Judaism**: The religion centered on the covenant revealed to Moses at Mount Sinai and preserved in the Torah, the first five books of the Hebrew Bible.
- **Native Spirituality**: The spirituality of the indigenous people of the world. They represent many languages, cultures, and religions.
**Paganism** represents a wide variety of traditions that emphasize reverence for nature and a revival of ancient polytheistic and animistic religious practices. Wiccans, Druids, Shamans, Sacred Ecologists, Odinists and Heathens all make up parts of the Pagan community.

**Rastafarianism**: A religious and political movement that began in Jamaica among people of African descent. Its adherents regard Africa (particularly Ethiopia) as the Promised Land and Ras Tafari (Haile Selassie, an Emperor of Ethiopia) as a messiah.

**Shamanism**: A system of religious and medical beliefs and practices that centers on the shaman.

**Sikhism**: A monotheistic religion that promotes seeking community connections, living honestly, and caring for others. It was founded in the Punjab area by Guru Nanak around 600 years ago.

**Spiritual**: This term is defined quite differently by monotheists, polytheists, humanists, followers of new age, Native Americans, etc. A common meaning is “devotion to metaphysical matters, as opposed to worldly things.” Another is “Activities which renew, lift up, comfort, heal and inspire both ourselves and those with whom we interact.”

**Unitarianism**: Rooted in Christianity, Unitarianism represents a belief that God is one being (rather than adhering to the doctrine of the Trinity). Followers stress the importance of individual freedom of belief and advocate for the use of reason in religion.

**Zoroastrianism**: A religion begun in Iran by the prophet Zarathustra. Its followers worship only one God, Ahura Mazda. Zoroastrianism teaches that the world is the site of a struggle between good and evil.

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**Sexual orientation**

Sexual orientation is a term for the emotional, physical, romantic, sexual and spiritual attraction, desire or affection for another person. People define their sexual orientation in various ways including:

**Bisexual**: a person who is attracted to both men and women.

**Gay**: a person who is mainly attracted to those of the same gender. This term is used by both men and women although many women prefer to be referred to as lesbian.

**Heterosexual (“straight”)**: a person who is primarily attracted to members of the opposite gender. Heterosexual people are often referred to as “straight.”

**Lesbian**: a woman who is primarily or exclusively attracted to other women.

**Queer**: formerly a term of disrespect, “queer” has been used recently by those who generally reject traditional sexual orientations and/or who find sexual identities such as gay, straight, lesbian or bisexual too restrictive. The term “queer” is often used by those who feel that mainstream culture is oppressive to those who reject heterosexual norms.

**Two-Spirit**: traditionally in Aboriginal cultures, this person was one who had received a gift from the Creator - the privilege of housing both male and female characteristics within their spirit. Today, it is a generic term used mostly by some First Nations and Métis people to describe, from a cultural perspective, people who are known in non-Aboriginal society as either gay, lesbian, bisexual, intersex or trans.

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7 Adapted from Asking the Right Questions 2: Talking with Clients about Sexual Orientation and Gender Identity, Paricipants Manual. Centre for Addiction and Mental Health, Toronto
SECTION 7

RESOURCES AND BIBLIOGRAPHY

FURTHER RESOURCES

Measuring Health Equity: Demographic Data Collection in Health Care website by Mount Sinai Hospital
http://torontohealthequity.ca

Happy to Ask, Happy to Tell: Handbook for Trainees by NHS Health Scotland

Measuring the Gaps: Collecting Data to Drive Improvements in Health Care Disparities by Center for American Progress

A Toolkit for Collecting Race, Ethnicity and Primary Language Information from Patients by Health Research and Educational Trust
http://www.hretdisparities.org/Coll-4166.php

Unequal Treatment: Racial and Ethnic Disparities in Health by Institute of Medicine

Race, Ethnicity, and Language Data: Standardization for Health Care Quality Improvement by Institute of Medicine

Collecting and Using Race, Ethnicity and Language Data in Ambulatory Settings by the Commission to End Health Care Disparities

Social Determinants of Health, The Canadian Facts by Juha Mikkonen and Dennis Raphael
http://www.thecanadianfacts.org

Profile of Low Income in the City of Toronto by City of Toronto

Sociodemographic Data Collection in Healthcare Settings: An Examination of Public Opinions by Centre for Research on Inner City Health
BIBLIOGRAPHY


iv Institute of Medicine, Committee on Quality of Health Care in America, IOM (2002). Crossing the Quality Chasm. Washington, DC: National Academy Press.


THE HOSPITAL QUESTIONS

Will you please provide us with information about yourself? This information will be used to increase access to services and improve the quality of care.

Answering these questions is voluntary. You can choose “prefer not to answer” to any or all questions. This will not affect your care.

1 What language would you feel most comfortable speaking in with your health-care provider? Check ONE only.

- Amharic
- Arabic
- ASL
- Bengali
- Chinese (Cantonese)
- Chinese (Mandarin)
- Czech
- Dari
- English
- Farsi
- French
- Greek
- Hindi
- Hungarian
- Italian
- Korean
- Nepali
- Polish
- Portuguese
- Other (Please specify) __________________________

2 Were you born in Canada?

- Yes
- Prefer not to answer
- No
- Do not know

If no, what year did you arrive in Canada? __________

3 Which of the following best describes your racial or ethnic group? Check ONE only.

- Asian - East (e.g., Chinese, Japanese, Korean)
- Asian - South (e.g., Indian, Pakistani, Sri Lankan)
- Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
- Black - African (e.g., Ghanaian, Kenyan, Somali)
- Black - Caribbean (e.g., Barbadian, Jamaican)
- Black - North American (e.g., Canadian, American)
- First Nations
- Indian - Caribbean (e.g., Guyanese with origins in India)
- Indigenous/Aboriginal not included elsewhere
- Inuit
- Latin American (e.g., Argentinean, Chilean, Salvadorian)
- Métis
- Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
- White - European (e.g., English, Italian, Portuguese, Russian)
- White - North American (e.g., Canadian, American)
- Mixed heritage (e.g., Black - African and White - North American) (Please specify) __________________________
- Other(s) (Please specify) __________________________
- Prefer not to answer
- Do not know
4  Do you have any of the following? Check ALL that apply.

- Chronic illness
- Developmental disability
- Drug or alcohol dependence
- Learning disability
- Mental illness
- Physical disability
- Sensory disability (i.e. hearing or vision loss)
- None
- Other (Please specify) __________________________
- Prefer not to answer
- Do not know

5  What is your gender? Check ONE only.

- Female
- Trans - Female to Male
- Male
- Trans - Male to Female
- Intersex
- Other (Please specify) __________________________
- Prefer not to answer
- Do not know

6  What is your sexual orientation? Check ONE only.

- Bisexual
- Lesbian
- Queer
- Trans - Lesbian to Male
- Heterosexual (“straight”)
- Trans - Heterosexual to Male
- Gay
- Trans - Gay to Male
- Other (Please specify) __________________________
- Prefer not to answer
- Do not know

7  What was your total family income before taxes last year?

- $0 to $29,999
- $30,000 to $59,999
- $60,000 to $89,999
- $90,000 to $119,999
- $120,000 to $149,999
- $150,000 or more
- Prefer not to answer
- Do not know

8  How many people does this income support? ____________ person(s)

- Prefer not to answer
- Do not know
### OPTIONAL ITEMS

**1 In what language would you prefer to read health-care information?** Check ONE only.

- [ ] Amharic
- [ ] Arabic
- [ ] Bengali
- [ ] Braille
- [ ] Chinese (Simplified)
- [ ] Chinese (Traditional)
- [ ] Czech
- [ ] Dari
- [ ] English
- [ ] Farsi
- [ ] French
- [ ] Greek
- [ ] Hindi
- [ ] Hungarian
- [ ] Italian
- [ ] Karen
- [ ] Korean
- [ ] Nepali
- [ ] Polish
- [ ] Portuguese
- [ ] Punjabi
- [ ] Russian
- [ ] Serbian
- [ ] Slovak
- [ ] Somali
- [ ] Spanish
- [ ] Tagalog
- [ ] Tamil
- [ ] Tigrinya
- [ ] Turkish
- [ ] Twi
- [ ] Ukrainian
- [ ] Urdu
- [ ] Vietnamese
- [ ] Other (Please specify)
- [ ] Prefer not to answer
- [ ] Do not know

**2 What is your religious or spiritual affiliation?** Check ONE only.

- [ ] Animism or Shamanism
- [ ] Atheism
- [ ] Baha’i Faith
- [ ] Buddhism
- [ ] Christian Orthodox
- [ ] Christian, not included elsewhere on this list
- [ ] Confucianism
- [ ] Hinduism
- [ ] Jainism
- [ ] Jehovah’s Witnesses
- [ ] Judaism
- [ ] Islam
- [ ] Native Spirituality
- [ ] Pagan
- [ ] Protestant
- [ ] Rastafarianism
- [ ] Other (Please specify)
- [ ] I do not have a religious or spiritual affiliation
- [ ] Prefer not to answer
- [ ] Do not know

**3 What type of housing do you live in?**

- [ ] Boarding Home
- [ ] Correctional Facility
- [ ] Group Home
- [ ] Homeless/on street
- [ ] Own Home
- [ ] Renting Home
- [ ] Other (Please specify)
- [ ] Shelter/Hostel
- [ ] Supportive Housing
- [ ] Prefer not to answer
- [ ] Do not know
THE CHC QUESTIONS

Will you please provide us with information about yourself? This information will be used to increase access to services and improve the quality of care.

Answering these questions is voluntary. You can choose “prefer not to answer” to any or all questions. This will not affect your care.

This information will only be seen by your health-care team and will be kept confidential like all your other health-care information. If used in research, your information will be combined with data from other patients and you will not be identified.

1. What language would you feel most comfortable speaking in with your health-care provider? Check ONE only.

- 1. Amharic
- 2. Arabic
- 3. ASL
- 4. Bengali
- 5. Chinese (Cantonese)
- 6. Chinese (Mandarin)
- 7. Czech
- 8. Dari
- 9. English
- 10. Farsi
- 11. French
- 12. Greek
- 13. Hindi
- 14. Hungarian
- 15. Italian
- 16. Karen
- 17. Korean
- 18. Nepali
- 19. Polish
- 20. Portuguese
- 21. Punjabi
- 22. Russian
- 23. Serbian
- 24. Slovak
- 25. Somali
- 26. Spanish
- 27. Tagalog
- 28. Tamil
- 29. Tigrinya
- 30. Turkish
- 31. Twi
- 32. Ukrainian
- 33. Urdu
- 34. Vietnamese
- 35. Other (Please specify): ________________

Staff use only:

- 98. Do not know
- 99. Prefer not to answer


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

3. Which of the following best describes your racial or ethnic group? Check ONE only.

- 1. Asian - East (e.g., Chinese, Japanese, Korean)
- 2. Asian - South (e.g., Indian, Pakistani, Sri Lankan)
- 3. Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
- 4. Black - African (e.g., Ghanaian, Kenyan, Somali)
- 5. Black - Caribbean (e.g., Barbadian, Jamaican)
- 6. Black - North American (e.g., Canadian, American)
- 7. First Nations
- 8. Indian - Caribbean (e.g., Guyanese with origins in India)
- 9. Indigenous/Aboriginal not included elsewhere
- 10. Inuit
- 11. Latin American (e.g., Argentinean, Chilean, Salvadorian)

Continues page 42
| 12. Métis |
| 13. Middle Eastern (e.g., Egyptian, Iranian, Lebanese) |
| 14. White - European (e.g., English, Italian, Portuguese, Russian) |
| 15. White - North American (e.g., Canadian, American) |
| 16. Mixed heritage (e.g., Black - African and White - North American) |
| (Please specify)  |
| 17. Other(s) (Please specify)  |
| 98. Do not know  |
| 99. Prefer not to answer |

### 4. Do you have any of the following? Check ALL that apply.

- 1. Chronic illness
- 2. Developmental disability
- 3. Drug or alcohol dependence
- 4. Learning disability
- 5. Mental illness
- 6. Physical disability
- 7. Sensory disability (i.e. hearing or vision loss)
- 8. Other (Please specify):  
- 9. None
- 98. Do not know
- 99. Prefer not to answer

### 5. What is your gender? Check ONE only.

- 1. Female
- 2. Intersex
- 3. Male
- 4. Trans - Female to Male
- 5. Trans - Male to Female
- 6. Two-Spirit
- 7. Other (Please specify):  
- 98. Do not know
- 99. Prefer not to answer

### 6. What is your sexual orientation? Check ONE only.

- 1. Bisexual
- 2. Gay
- 3. Heterosexual (“straight”)
- 4. Lesbian
- 5. Queer
- 6. Two-Spirit
- 7. Other (Please specify):  
- 98. Do not know
- 99. Prefer not to answer

### 7. What was your total family income before taxes last year? Check ONE only.

- 1. $0 to $14,999
- 2. $15,000 to $19,999
- 3. $20,000 to $24,999
- 4. $24,000 to $29,999
- 5. $30,000 to $34,999
- 6. $35,000 to $39,999
- 7. $40,000 to $59,999
- 8. $60,000 or more
- 98. Do not know
- 99. Prefer not to answer

### 8. How many people does this income support?

__________________ person(s)
- 98. Do not know
- 99. Prefer not to answer
TIPS FOR MANAGING STRESS OR FATIGUE AT WORK

The following information was shared by Ishwar Persad, who works at the Centre for Addiction and Mental Health. It is being made available here so that you can help your staff manage any anxiety they may have about interacting with patients or clients.

Share with your staff these suggestions for coping with challenges at work and regaining energy.

Incidents involving emergency medical issues, or aggressive or suicidal behaviour, may leave you with feelings of exhaustion, anger, self-criticism, cynicism, negativity, irritability or helplessness. You may need some coping skills to regain energy and restore well-being. The following can be potential sources of help:

Focus on Your Body

- Slowly scan your body and relax all your muscles, starting with your feet and moving slowly up to your face.
- Tell yourself to let go of the tension as you focus on each area of your body.
- When you have finished, think of yourself as relaxed and comfortable.
- Notice/feel your feet on the ground to help re-ground in your body.
- Notice/feel where your hand is making contact on your body or the desk.
- Gently squeeze one wrist with your other hand and breath, bring your attention to your body, release and repeat. Switch hands and repeat.

Focus on Your Breathing

- Breathe out.
- Breathe in slowly—way down into your abdomen/belly.
- Breathe out slowly.
- Try this with your hand on your abdomen/belly to be more aware of your breathing.

Focus on Images

- Picture a calm, peaceful scene (e.g., imagine yourself sitting or lying on a beach feeling the warmth of the sun).
- Think of yourself as completely relaxed. Enjoy the sensation. Notice where you may be holding tension and just breathe... do not judge yourself!

* Try one of the above techniques, or all of them together, to help you sleep or deal with anxiety, or to reduce a tension headache. (Herie, Marilyn A., Watkin-Merek, Lyn, 2006)
Thank you for participating in the Measuring Health Equity project. For more information, please visit our website at http://torontohealthequity.ca.
TRAINING EVALUATION FORM

1 Overall, how helpful was this training session in preparing you to collect demographic data in the health-care setting? Check one:

☐ Very helpful ☐ Helpful ☐ Somewhat helpful ☐ Not very helpful

2 Overall, how would you rate the performance of the session facilitators?

☐ Excellent ☐ Good ☐ Mediocre ☐ Poor

3 What suggestions do you have for improving the facilitators’ performances?

4 Please list the topics/materials that were most useful to you:

5 What additional activities or topics would you like to see added to this training session?

6 How prepared do you now feel to train others to carry out the collection of demographic data?

☐ Very prepared ☐ Prepared ☐ Somewhat prepared ☐ Not prepared

7 Is there anything else you would like us to know?
Participants: please fill out, detach and hand in the Training Evaluation Form on reverse side of page