MOUNT SINAI HOSPITAL
Joseph and Wolf Lebovic Health Complex

FACILITATOR MANUAL

We ask because we care:
Collecting patient demographic data

Ontario
Toronto Central Local Health Integration Network
Réseau local d'intégration des services de santé du Centre-Toronto

CONTENTS

INTRODUCTION

The information presented in this manual will provide facilitators from Toronto hospitals with the educational materials and resources they need to train admitting, registration and healthcare staff to collect patient demographic data.

This facilitator's manual, the PowerPoint presentation and the trainee manual (Participant Manual) provide information on health equity, Toronto and international experiences with collecting patient demographic data, practice activities to help staff practice new data collection skills and resources to use when responding to patient questions or concerns.

> **!** NOTE: This manual is intended to be used as a supplement to the "Participant Manual" when training staff on demographic data collection in hospitals.

ACKNOWLEDGEMENTS

Mount Sinai Hospital acknowledges our partners in the Tri-Hospital + TPH Patient Demographic Data Collection Project — the Centre for Addiction and Mental Health, St. Michael's Hospital and Toronto Public Health. This project contributed valuable knowledge on how best to collect patient level demographic data to achieve health equity.

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MANUAL OVERVIEW

Section 1: Health Equity and Patient Demographic Data Collection
Section 2: Training Program (Tips, Introductions, Agenda, and Learning Outcomes, etc.)
Section 3: Bibliography

> **→** 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

> **🕐** This icon is used to point out an activity

SECTION 1

HEALTH EQUITY AND PATIENT DEMOGRAPHIC DATA COLLECTION

1.1 Health Equity

What is health equity?

Equity in healthcare refers to ensuring quality care regardless of race, religion, language, income or any other individual characteristic.

It is important to remember:

- Equity is about meeting patient needs while minimizing any avoidable differential outcomes based on individual characteristics.

- Health inequities are differences in healthcare outcomes that cannot be explained by access-related factors, clinical needs, relevance of intervention, or patient 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"[i].

- Children from low-income families require more hospital stays and show increased vulnerability to various illnesses, accidental injuries, and mental health problems[ii].

- Living conditions, age, income, immigrant status, and race significantly affect diabetes, cardiovascular disease, mental health, and self-reported health[iii].

- 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[iv].

- Inequity is expensive. A Public Health Agency of Canada report states "inequities are health system cost drivers" with approximately 20% of total healthcare spending being attributed to income inequality[v].

Ensuring Health Equity in Hospitals Means:

- **Collecting patient-level demographic data**: This step will give hospitals a comprehensive picture of the community they serve and the characteristics of patients 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[vi].

- **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: Hospitals can address special patient needs based on language, disability, religion, and other factors, and develop programs to target populations disproportionately suffering from adverse health outcomes.

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

1.2 Patient Demographic Data Collection

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

Developing Evidence-Based Training

The process leading up to this training program included a literature review, identification of international best practices, evaluation of past training models, and interviews with facilitators and staff managers in the US and the UK. We also incorporated learnings from the work of the Tri-Hospital plus TPH project [1], which saw data collectors approach over 2,000 patients for demographic data collection.

Summary of lessons:

1   Patients 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 questions and helping you feel confident when answering patient questions.

> 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.

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1   "Tri-Hospital plus TPH project": The Centre for Additions and Mental Health, Mount Sinai Hospital, and St. Michael's Hospital plus Toronto Public Health Patient Demographic Data Collection Pilot Project

> For **confidence with answering patient questions**: US hospitals have pointed to using 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".

3   Data collectors from the Tri-Hospital plus TPH project reported little to no problems or conflict when approaching patients about collecting this data[vii]. 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.

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

> **Patients may be more open** to sharing information than data collectors might expect.

Engaging Staff to Collect Data

A review of the strategies that Texas Baylor Healthcare System developed and implemented to ensure that their staff were engaged around demographic data collection.

BEST PRACTICE: Staff Engagement at Texas Baylor Healthcare System (a network of 27 Hospitals)

Challenge:
"A lot of pushback from staff (data collectors)" was identified as a major barrier to the initial implementation of demographic data collection at Baylor Healthcare System

Solution:
Baylor Healthcare System developed several strategies that proved successful in creating "consistent and constant engagement":

- A staff training program that focused on helping staff become comfortable with asking sensitive demographic questions
  - The program included specific wording for staff to use when approaching patients and describing project goals
- Ongoing presentations to refresh training and follow up on new challenges
- Sharing results around demographic data collection (e.g. basic graphs around patient information)

Source: Interview with Guwan Jones, Director of Health Equity at Texas Baylor Healthcare System.

For more information about demographic data collection including engagement tools, strategies for creating a data collection plan, and identification of best practices, please refer to the The Guide, which is available on www.torontohealthequity.ca

Using Demographic Data for Health Equity Planning

As outlined in "Ensuring Health Equity in Hospitals Means" (page 4), demographic data is essential for identifying inequities in health outcomes. Once demographic data is used to identify and report inequities, hospitals 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 peaking 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.
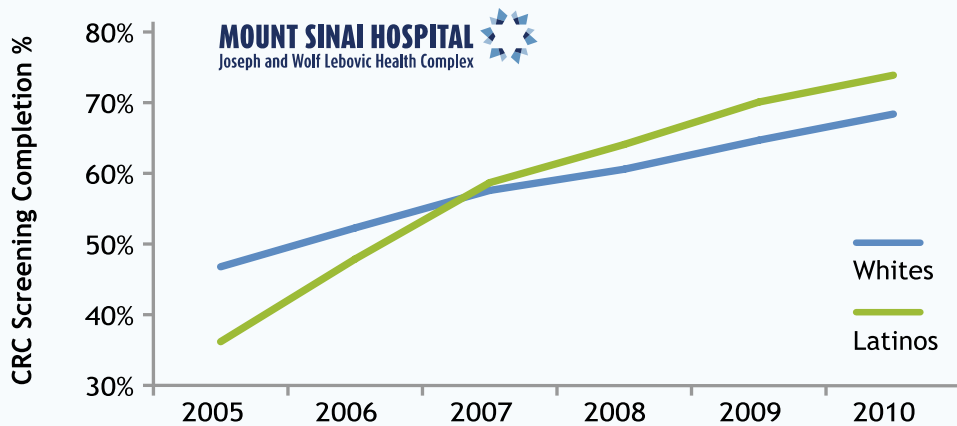
Source: Joseph Betancourt, J. R. (2012). Achieving health equity and providing quality care.
Talk presented at *Measuring Health Equity in TC LHIN* symposium in Toronto, Ontario.

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

SECTION 2

TRAINING PROGRAM

2.1 Points to Keep in Mind

Here are some points to keep in mind when delivering this training[ix]:

- Start by acknowledging the learners as experts who already have a great deal of valuable knowledge and experience

- When learners present obstacles to doing something new or different, be sympathetic, respectful and listen

- Any information presented should be directly relevant to what the learner has to do on the job

- The workshop's benefits to the learner, essentially *what's in it for them*, has to be clear from the outset and reinforced throughout the session

- The structure needs to be clear, learners must easily see the reasons behind the sequence of activities

- The content must make sense, be easy to understand, and provide solutions to workplace challenges

- It should be interactive allowing participants to get involved throughout the session

- Participants should have a variety of opportunities to learn from each other

- Participants should receive tools to apply the new learning to their workplace

- Participants must be able to immediately apply what they are learning

2.2 Learning Outcomes

At the end of today's 3-hr workshop participants will be able to:

- Define health equity

- Explain to patients what the demographic questions are

- Tell patients why hospitals need to collect demographic data

- Describe how hospitals may use demographic data to plan and improve services

- Explain the reasons for each of the 8 questions and 3 optional items

- Ask the questions in a respectful manner

At the conclusion of the workshop participants will be asked to evaluate the session; this will be their opportunity to let you know whether they think the initially stated outcomes have been met.

The evaluation will help you determine types of ongoing support that may be required. As mentioned previously, further training sessions will likely be required to sustain success.

2.3 Facilitator Agenda

Here is a step-by-step agenda for you to use. The amount of time for each activity is identified and the activities, method of presentation and expected outcomes are described.

We recommend that you:

- Allow for a 3-hour session so that learners have the time to learn, analyze and practice the new skills

- Ensure that there are at least 12 and no more than 20 participants

It is important that the session is large enough to have a variety of interactions and small enough for people to comfortably to ask questions.

3 HOURS	Facilitator Agenda
ACTIVITY 10 minutes	Introductions, Housekeeping, Learning Objectives, Ground Rules
FOR FACILITATOR: METHOD OF PRESENTATION	- Introduce yourself - Welcome group - Describe/identify reason for the workshop
EXPECTED OUTCOME	Facilitator sets welcoming tone, acknowledges expertise in the room
MATERIALS	PowerPoint Presentation: See slides 1-5
ACTIVITY 20 minutes	Statistics Walkabout Activity
FOR FACILITATOR: METHOD OF PRESENTATION	- Ask participants to walk around the room, read the stats on the wall and to stop by the stat that most surprises or affects them - Ask participants to introduce themselves to the group, explain why they stopped by a certain stat, and identify something they hope to learn during the session
EXPECTED OUTCOME	Participants will receive a graphic understanding of health inequities, and how they affect health and wellbeing Participants will identify some of their own personal learning goals, and may identify any initial questions they have
MATERIALS	PowerPoint Presentation: See slide 6 Sample statistics: See in this manual: - p. 14 (for activity description) - p. 23-27 (for examples of relevant statistics)

ACTIVITY 20 minutes	What is Health Equity? What is Demographic Data Collection? Overview of the Toronto Central LHIN data collection project including: - What is Health Equity? - Why collect demographic data? - What do we know about patient and staff experiences with demographic data collection? - How will the data be used? - What data will be collected? - How does one collect the data? - How will staff learn how to collect the data? - How will staff respond to patient questions or concerns?
FOR FACILITATOR: METHOD OF PRESENTATION	Present and discuss PowerPoint slides
EXPECTED OUTCOME	Participants will learn: - What health equity is and what hospitals need to do to achieve equitable health outcomes - Why hospitals need to collect demographic data - About patient willingness to share demographic data - About the experiences of data collectors - About the 8 questions developed after rigorous research and testing - About materials to support data collection, e.g. Patient Pamphlet
MATERIALS	PowerPoint Presentation: See slides 7-31
ACTIVITY 10 minutes (60m)	Review the Participant Manual
FOR FACILITATOR: METHOD OF PRESENTATION	Provide overview of the Participant Manual
EXPECTED OUTCOME	Participants will be familiar with resources in the manual
MATERIALS	Participant Manual
ACTIVITY 20 minutes	Illustration of Best Practices in Demographic Data Collection - explanation - description - instructions - modeling
FOR FACILITATOR: METHOD OF PRESENTATION	- Explain that the group is going to practice data collection - Ask for a volunteer to play the role of the patient - Provide script to the volunteer - Demonstrate best practice in asking patients demographic questions

EXPECTED OUTCOME	Participants will: - Begin to collect demographic information and respond to patient questions and concerns - Ask questions and raise concerns Facilitator will: - Teach best practices and offer solutions to participant concerns
MATERIALS	Group Practice Exercise: See page 17 of this manual
ACTIVITY 20 minutes	Video Observation: Video observation of 3 filmed scenarios, followed by discussion
FOR FACILITATOR: METHOD OF PRESENTATION	Ask participants to describe: - what they saw - what worked - what could have been done differently or done better
EXPECTED OUTCOME	This discussion, and the previous interactions, will help participants to feel comfortable and skilled when engaging in the practice sessions that follow
MATERIALS	TC LHIN-MSH Demographic Data Collection Training Videos (If not available: Happy to Ask, Happy to Tell - NHS DVD)
ACTIVITY 15 minutes (115 min)	BREAK
ACTIVITY 45 minutes	Practice Sessions and Debriefs Part 1 (5 min): Introduce practice sessions - **All participants** will have a chance to play each role in 3 different scenarios: Admitting Staff, Patient, Observer - Participants will practice three different scenarios Part 2 (45 min): Facilitate three practice exercises - Practice Exercise 1 (12-15 minutes) - Practice Exercise 2 (12-15 minutes) - Practice Exercise 3 (12-15 minutes)
FOR FACILITATOR: METHOD OF PRESENTATION	- Distribute 3 practice exercises to each group - Divide into groups of 3: Patient, Admitting staff, Observer - Provide the scenario handouts to the participants - Each participant plays each role (staff, patient, observer)

EXPECTED OUTCOME	Participants will: - Develop the skills and knowledge to administer the patient demographic data collection questions - Practice asking the questions, sharing the patient pamphlet, and responding to patient questions/concerns - Identify their strengths and areas for more learning
MATERIALS	Practice exercises See this manual: Pages 19-21
ACTIVITY 15 minutes	Wrap up & Next Steps What were some lessons learned? What do we need to know moving forward?
FOR FACILITATOR: METHOD OF PRESENTATION	Group discussion: - Identify key learnings from today - Identify the support you'd like going forward - Name any concerns you may still have
EXPECTED OUTCOME	Participants will be able to reflect on what they knew at the beginning of the session, and the skills developed at its conclusion Participants will be informed that more training and skill development will be forthcoming
ACTIVITY 5 minutes (180m)	Evaluation
FOR FACILITATOR: METHOD OF PRESENTATION	Participants complete a written evaluation form
MATERIALS	Evaluation Form: See Page 41 of Participant Manual

We have supplied you with a breathing and relaxation exercise your staff can use during stressful moments at work. It can be found in the Appendix of the Participant Manual. (Courtesy of Ishwar Persad at the Centre for Addiction and Mental Health.)

2.4 Facilitator Guide to the Agenda

➡ **In this section, we will review the components of the agenda (please refer to table under 2.3) by providing further details about the activities and explaining how to carry out different tasks.**

🕐 Activity: **Introductions, Housekeeping, Ground Rules**   10 minutes

This information will help you begin the workshop

- Introduce yourself and provide context for the training

- Provide information on the break (15 minutes), refreshments and location of washrooms

- We recommend you cover all of the information on the next 2 pages. You will be able to use the PowerPoint presentation as a guide

Key messages:

- Seventeen hospitals in the Toronto Central Local Health Integration Network are collecting patient demographic data using 8 common core items

- The questions were developed and piloted by the Tri-Hospital (Mount Sinai, CAMH, St. Michael's) + Toronto Public Health group; each of the questions was carefully analyzed as to its impact. The questions were chosen because of the information they could provide about health outcomes, and why some groups have poorer health outcomes than others

- There are a variety of reasons for collecting demographic data:
  1. To improve healthcare quality (equity is a component of quality)
  2. To determine the composition of our community of healthcare users
  3. To ensure healthcare responds to individual needs
  4. To ensure our services reach the entire community
  5. To fulfill our mandate to provide equitable care

- Toronto hospital staff involved in admitting and registration of patients will be trained to sensitively, respectfully and successfully obtain answers to the demographic questions in workshops like this

- The Toronto Central Local Health Integration Network has mandated the collection of patient demographic data in order to achieve health equity

- Health equity is achieved when people are treated differently according to what they need; it is achieved when everyone using the healthcare system has the same opportunity for positive outcomes. Working for health equity means working to overcome the inequities that are unfair, unjust and avoidable and which burden certain populations[x].

> **!** Data is key to health equity, without data there is no equity[xi].

Suggested 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:

It is important to outline expectations when working in a group and discussing issues of equity and diversity. Below are some suggested principles that all participants should agree to:

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*)

🕐 Activity: **Statistics Walkabout Activity** 20 minutes

We recommend:

- that you print the statistics out on different coloured paper, with each topic printed in the same colour

- that you use only 3-4 statistics per topic

This activity provides concrete information about health inequities. The information on the posters covers the topics of poverty, disability, immigration, health inequities, socioeconomic status, racism, sexual orientation and more.

Ask participants to walk around and view the posted data and statement clusters. Allow sufficient time for people to read all the statistics.

Next, ask them to stand beside the poster or group of posters that they are surprised or affected by.

Ask them to speak to why they are standing beside a particular statistic. Allow 10 minutes for this discussion.

Over time, you may wish to update or change the statistics. Please feel free to do so.

Alternative statistics exercise:

You can create a quiz using some of the statistics by leaving key information blank. Participants can fill in the blanks in pairs or small groups. Then discuss the answers as a large group. Here is an example:

Q: Over one in _____ patients discharged from a general hospital with a diagnosis of mental illness were readmitted within one year of their discharge.

2006 Canadian Institute for Health Information Report http://www.cmha.ca/bins/site_page.asp?cid=284-294-297-1637&lang=1

A: Over one in **three** patients (**37%**) discharged from a general hospital with a diagnosis of mental illness were readmitted within one year of their discharge.

2006 Canadian Institute for Health Information Report http://www.cmha.ca/bins/site_page.asp?cid=284-294-297-1637&lang=1

> 🕐   Activity: **What is Health Equity? What is Demographic Data Collection?**   20 minutes

This presentation explains the context for the workshop and provides some of the content. Please note:

- It has been prepared on blank slides so that you can put your organization's logo on each slide.
- The TCLHIN logo is on the front slide.
- You can find speaker notes throughout the presentation

In general, key slide topics are:

1   What is Health Equity?
2   Why collect demographic data?
3   What do we know about patient and staff experiences with demographic data collection?
4   How will the data be used?
5   What data will be collected?
6   How does one collect the data?
7   How will staff learn how to collect the data?
8   How will staff respond to patient questions or concerns?

> ➡   We advise you to give your staff a printed copy of your presentation so they can take notes during the presentation and discussion around helpful points or tips they can use.

At the conclusion of the PowerPoint remind participants there are supporting documents in their manual that will help them successfully collect patient demographic information.

> 🕐   Activity: **Review the Participant Manual**   15 minutes

Use the table of contents to go through the Participant Manual and ensure that participants are aware of the various resources they can go back to during and after data collection.

We recommend that you focus on the following sections of the Participant Manual:

- **Demographic Data Questions**
- **Asking Patients for Demographic Information**
- **Glossary of Terms**

	Activity: **Illustration of Best Practices in Demographic Data Collection**	20 minutes

Explanation:

Tell participants that research has demonstrated that active learning in training sessions is what learners remember. Practicing new skills is an example of active learning, allowing people to practice in a secure environment. Tell participants there won't be guess work, and there are no 'bad actors' in the practice session.

Ask for a volunteer "patient". Tell them you are going to play the role of the admitting clerk, and will explain and ask the questions. Tell the group that they are playing the Observer role, and to prepare to provide feedback about what they see.

Explain that the goal here is to show best practices. This is how data collectors should ask the questions of patients they interview.

Give the volunteer "patient" the script that follows. The practice session itself should not take more than about 6-8 minutes. You want to have enough time to debrief.

Patient Script

You have come to Day Surgery for a biopsy. You've been told that the results might lead to you being hospitalized and operated on; you are quite nervous.

The clerk seems friendly, but she wants to get your answers on the 8 questions. You agree, somewhat reticently, and she launches into the questions.

You become uncomfortable almost immediately – you are worried that if you don't answer it might affect your care. However, you are really unwilling to answer the questions. In your background people don't ask about income, sexual orientation and race. Besides, aren't some of the answers to these questions obvious?

The interaction becomes tense. You question the reasons behind every question because you don't 'get' how the questions relate to why you are in the hospital.

If the clerk interacts with you in a patient and understanding way, you can provide the answers to the questions. If not, continue to raise concerns.

Goal:

The goal of the practice session was to demonstrate best practices, and to clearly explain the reasons for the questions. By doing so, the patient opens up and answers most of the questions. They also explain to you why they feel uncomfortable, allowing you to offer reassurance about how the information will be used.

To debrief the exercise, ask the group the following questions:

1   What did you see happening?

2   How do you think the patient felt when answering the questions? What indicated that to you?

3   What did the interviewer do or say that encouraged the patient to answer the questions?

> 🕐   Activity: **Video Observation of 3 Scenarios**   20 minutes

Tell the group you are going to show them *3 brief interactions* between a patient and an admitting clerk. Explain that these come from Scotland's National Health Services Training program entitled: *Happy to Ask, Happy to Tell*. Let them know that there will be a discussion following each scenario.

SCENARIO 1: Patient requests assistance and admitting clerk unwilling to help

Discussion questions:

- What do you think was happening in this scenario?
- Why do you think the patient wouldn't complete the questions on his own?
- How would you evaluate the admitting clerk's interaction with the patient?

Some key points:

The admitting clerk was not helpful. It didn't seem that she could present the reasons for the questions and that she was flippant in her responses.

- The patient didn't want to complete the questions on his own; he mentioned that he had arthritis. There could also have been issues related to literacy, he may have been unable to read the questions.

SCENARIO 2: Trans woman feels uncomfortable about answering the questions

Discussion questions:

- What do you think was happening in this scenario?
- Why do you think the patient felt uncomfortable about the questions?
- How would you evaluate the admitting clerk's interaction with the patient?

Some key points:

The admitting clerk was friendly and wanted to be helpful. He answered the patient's questions respectfully.

- He offered to move away from his physical area to one where the patient would have privacy.
- He clearly explained the reasons for the questions, and how patient treatment would be tailored to respond to the individual patient's needs.

SCENARIO 3: **Patient feels uncomfortable answering questions about race, ethnicity, religion**

Discussion questions:

- What do you think was happening in this scenario?
- Why do you think the patient felt uncomfortable about the questions?
- How would you evaluate the admitting clerk's interaction with the patient?

Some key points:

- The admitting clerk was friendly and wanted to be helpful. She answered the patient's questions respectfully.
- She clearly explained the reasons for the questions.
- She clearly explained that the purpose of the questions was to ensure that healthcare would be able to recognize and respond to the needs of different groups, e.g. mentioning diabetes and South Asian community.

⏲ BREAK	15 minutes

⏲ Activity: **Practice Session**	50 minutes

Explanation:

Tell participants that everyone will have an opportunity to play each role, **using three different practice session scripts (Practice Exercise 1, Practice Exercise 2, Practice Exercise 3)**.

- Patient
- Admitting Clerk
- Observer

Let them know that this activity will give them an opportunity to explain and present the questions to the patient, ask the questions, and respond to resistance and patient concerns.

Indicate to participants that they can use the materials in their training manual to assist them.

These are the:

- Overview of Demographic Data Collection Questions
- Patient Pamphlet
- Glossary of Terms

Instructions:

Tell participants they will have 30 minutes in total, and can spend up to 10 minutes on each practice session.

Tell them they need to switch roles as they move through the practice sessions; for example the patient in the first session is the admitting clerk in the second session and the observer in the third session.

Let them know that you will be walking around the room to watch the interactions, and that at the end of the activity there will be an opportunity to debrief.

Practice Exercise 1

Patient:

You are 25 years old, from a racialized group, and have a disability requiring you to use a cane. You have an appointment with an orthopedic surgeon, but first you need to get through the busy admitting area and check in with the clerk.

You need to get to work, and you're worried that you will be delayed at the doctor appointment because the waiting room is packed.

You've been here before, but now it seems the clerk wants to ask you a few questions. You are frustrated and just want to get to your appointment and leave. Plus, you don't want to answer Demographic Data Collection questions; the hospital already has your information because you've been here before.

Let the clerk know you're frustrated, and that you really don't like answering unnecessary questions. After all, don't some of the questions have obvious answers?

Admitting Clerk or Interviewer:

You work in a busy admitting department, registering/admitting patients who are coming for check-ups.

It is 8:30 am, and the room is crowded and people are waiting. This is a challenging job, because a lot of the patients who come here are in pain due to chronic joint problems. Sometimes people are irritable, and don't understand why they have to wait.

A patient is in front of you and you need to register them for a clinic appointment. You recognize his face, he's been here before. You want to get his answers to the demographic questions, but it's obvious he seems in a rush.

Explain what you need to do, so that you can begin asking the demographic questions. Respond to the patient's concerns.

Observer:

Your job is to listen and watch the admitting clerk. Here are some questions to guide your observation:

- How well does the admitting clerk explain the questions to the patient?
- How well does the admitting clerk respond to the patient's expressed discomfort?
- How well does the admitting clerk respond to the patient's resistance to answering the questions?
- How well does the admitting clerk use the glossary to explain a word or term to the patient?
- How well does the admitting clerk explain what happens to the data gathered?
- What advice do you have for this admitting clerk?

Practice Exercise 2

Patient:

You are a 60 year old patient with limited English language proficiency and limited ability to read English. You hate going to the hospital but your family forced you to because you've been sick all day, complaining of pain. You are alone in the hospital, your daughter has dropped you off.

You want to see a doctor, you don't feel good. You don't completely understand what the woman behind the desk wants. This is an Emergency Department and she seems to want to chat. You've already given her your OHIP card.

You've been to this hospital before and the service used to be very good. You don't understand why she's looking at a form and your face, you just want to lay down. You know that somewhere in your patient record it must say that you don't speak English and need help from an interpreter.

Admitting Clerk:

You are an admitting clerk in the Emergency Department. It's Saturday night, and you've been extremely busy.

A woman, approximately 60-65 years of age enters and looks upset. She tells you she's in a lot of pain and wants to see a doctor. Or this is what you understood – you aren't sure because her English is heavily accented, you aren't even sure if she can provide you with information.

You start to explain the admissions process, and she seems to be looking at you blankly. You aren't sure if you can communicate with her. You need to get the patient's demographic information, the questions are in front of you and you're trying to explain their purpose.

You find out what language the patient speaks, and then contact a telephone interpreter to help you. You use a three-way phone and explain the demographic questions to the interpreter, who in turn interprets your comments to the patient.

Observer:

Your job is to listen and watch the admitting clerk. Here are some questions to guide your observation:

- What does the admitting clerk need to do in this situation?
- How well does the admitting clerk respond to the patient's demonstrated lack of (English language) understanding?
- How well does the admitting clerk respond to the patient's expressed discomfort?
- How well does the admitting clerk explain the situation to the telephone interpreter?
- How well does the admitting clerk explain key points to be interpreted?
- What advice do you have for this admitting clerk?

Practice Exercise 3

Patient:

You are 45 years old and have come to the Rehab Clinic for a series of outpatient physiotherapy sessions. The doctor has told you it's a crowded clinic, but that they will be able to help you with painful back problems.

It's your first time there, so you're not surprised that they want to ask you questions. The clerk seems friendly and lets you know it won't take long. However, when you hear the actual questions, you start feeling angry and anxious. You also can't figure out how she can want you to answer the questions with a line of people behind you.

What really annoys and puzzles you are the questions on gender and sexual orientation. You need to ask the clerk what intersex and two-spirit mean. Later, you don't understand why anybody would ask you about your income, you've already provided insurance information. You clearly stated that fees will be covered by your insurance company and there was no problem with the number of sessions involved.

Admitting Clerk:

You are alone working in a busy rehab clinic. The lines of patients to check in, particularly on Mondays, are always long.

You've been told you have to start asking patients the demographic questions. You feel you learned how to ask and explain the questions during a training session, but this being your first day, you feel anxious and hope the patients are willing to respond.

There is a line up behind the first patient who has come for physiotherapy to relieve back pain. You follow up registration questions with the new demographic questions and the patient seems receptive. However he starts to look uncomfortable, and seems to look irritated and angry as you proceed with the questions.

You become flustered when the patient asks you how the information will be used and what some of the words mean.

Observer:

Your job is to listen and watch the admitting clerk. Here are some questions to guide your observation:

- How well does the admitting clerk explain the questions to the patient?
- How well does the admitting clerk respond to the patient's expressed discomfort?
- How well does the admitting clerk respond to the patient's resistance to answering the questions?
- How well does the admitting clerk use the glossary to explain a word or term to the patient?
- How well does the admitting clerk explain what happens to the data gathered?
- What advice do you have for this admitting clerk?

🕐 Activity: **Wrap Up & Next Steps**   15 minutes

Explanation:

- Facilitator summarizes how learning objectives have been met, and facilitates a closing discussion.
- Facilitator asks participants to identify what they have learned and what type of support they'd like going forward.
- Facilitator closes by announcing the next learning session and next meeting to identify any knowledge or skill gaps, continue learning and improving participants' interview skills.

Goal:

The purpose of the wrap-up session is to remind participants of the information and skills they have picked up during the session, to provide avenues for support as they start collecting the data, and to ensure that all final questions are addressed.

🕐 Activity: **Evaluation**   5 minutes

Finally, ensure that you give participants a chance to provide feedback so you can plan for future support, improve training and better meet the needs of your data collectors.

SECTION 3

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APPENDIX STATISTICS

➡ **Please find below a number of statistics you can use in your training; we recommend selecting examples that particularly apply to your patient population.**

Instructions:

Use one statistic per coloured sheet of 8x11 paper. Post them on the wall together by topic. You can also develop a quiz using some relevant statistics. Participants can complete the quiz in pairs or small groups.

TOPIC: Aboriginal Health

Aboriginal women and men were more likely to report fair or poor health, multiple chronic conditions and activity limitations than women and men in other ethnic groups. 45% of women who self-identified as Aboriginal reported that their activities were limited by a chronic health condition. 2009: http://www.powerstudy.ca/webfm_send/41 Bierman AS, Ahmad F, Angus J, Glazier RH, Vahabi M, Damba C, Dusek J, Shiller SK, Li Y, Ross S, Shapiro G, Manuel D. Burden of Illness. In: Bierman AS, editor. Project for an Ontario Women's Health Evidence-Based Report: Volume 1: Toronto; 2009.

Compared to the general Canadian population: **Infant mortality rate is 4 times higher among Inuit**. *Indigenous Children's Health Report: Health Assessment in Action* (2009). Available at www.crich.ca. Also featured in *Summer/Fall 2009 CRICH Research Flash*.

Compared to the general Canadian population: **Sudden Infant Death Syndrome is 3 times more common among BC First Nations with status**. I*ndigenous Children's Health Report: Health Assessment in Action* (2009). Available at www.crich.ca. Also featured in *Summer/Fall 2009 CRICH Research Flash*.

Compared to the general Canadian population: **Injury rates are almost double for First Nations**. *Indigenous Children's Health Report: Health Assessment in Action* (2009). Available at www.crich.ca. Also featured in *Summer/Fall 2009 CRICH Research Flash*.

Compared to the general Canadian population: **Obesity rate is 4 times higher for First Nations**. *Indigenous Children's Health Report: Health Assessment in Action* (2009). Available at www.crich.ca. Also featured in *Summer/Fall 2009 CRICH Research Flash*.

Compared to the general Canadian population: **Aboriginal children suffer higher rates of ear infections, dental problems, and respiratory tract infections. Inadequate housing conditions, including poor ventilation and crowding, directly contribute to a child's risk of respiratory tract infection**. *Indigenous Children's Health Report: Health Assessment in Action* (2009). Available at www.crich.ca. Also featured in *Summer/Fall 2009 CRICH Research Flash*.

TOPIC: People with Disabilities and Health

24.3% of Canadian adults with disabilities who visited at least one health professional in 2005-2006 had out-of-pocket expenses for those visits. Among adults with disabilities who had out-of-pocket costs for health professional visits, the average amount was $642.58. 2010: http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2010/page08.shtml

Of adults with very severe disabilities, 30% have unmet healthcare needs, compared to 7% of those with mild disabilities. Adults with severe to very severe disabilities are more likely than those with milder disabilities to not know how or where to obtain the healthcare they need. 2010: http://www.hrsdc.gc.ca/eng/disability_issues/reports/fdr/2010/page08.shtml

People with disabilities experience delayed detection and diagnosis of cancers, often because physicians attribute symptoms to pre-existing conditions. Further, treatment can be very complicated for individuals with disabilities, with negative drug interactions occurring, and physicians not understanding enough about the interplay of the disability and cancer treatment. 2010: http://www.partnershipagainstcancer.ca/wp-content/uploads/3.2.2.4-Disability-in-Cancer-Care_ENG.pdf

Women with disabilities experience barriers to breast, colon, and cervical cancer screening. These include non-adjustable examination tables, inaccessible mammogram machines, inadequate communication supports for women who were deaf and women with intellectual disabilities, and print materials (e.g., consent forms and brochures) that were not provided in alternate formats such as Braille, large print or plain language. Devaney, J, Barry, N, Odette, F, Muraca, L, Fernando, S, Chandani, S, et al. (2008). *Gateways to cancer screening project report: Preliminary findings*. Toronto: Centre for Independent Living Toronto and Canadian Cancer Society - Ontario Division.

Women interviewed stated that in many clinical encounters, health professionals did not address preventive healthcare at all. Instead, the focus was on the disability as the 'presenting issue', regardless of whether or not the women were seeking medical advice about disability. Devaney, J, Barry, N, Odette, F, Muraca, L, Fernando, S, Chandani, S, et al. (2008). *Gateways to cancer screening project report: Preliminary findings*. Toronto: Centre for Independent Living Toronto and Canadian Cancer Society - Ontario Division.

TOPIC: **Health of Immigrants and Racialized People**

11-14% of South Asians have diabetes, compared to 5-6% of non-racialized Ontarians. (Shah, 2008; Manuel and Schultz, 2003) 2010: A Diagnosis for Equity: An initial analysis of South Asian health inequities in Ontario, Council of Agencies Serving South Asians (CASSA)

South Asian Canadians have a 3-5 times greater risk of death from cardiovascular or heart disease compared to white Canadians. *Less likely to see specialist or go to emergency for cardiac symptoms*. (Gupta et al, 2006b; Bierman et al, 2009) 2010: A Diagnosis for Equity: An initial analysis of South Asian health inequities in Ontario, Council of Agencies Serving South Asians (CASSA)

A recent study of neonatal mortality of Canadian born infants found that the mortality rate for South Asian infants is over three times the rate of non-racialized infants in neonatal intensive care units (NICU) despite adjusting for factors such as small-size for gestational age, outborn status and having a gestational age less than or equal to 28 Weeks. *Low income and unequal access to care, less visits to specialists than non-racialized*. (Claydon et al, 2007, 449) 2010: A Diagnosis for Equity: An initial analysis of South Asian health inequities in Ontario, Council of Agencies Serving South Asians (CASSA)

Available research points to a clear link between mental health and migration. A recent study found that only 10% of Tamil Sri Lankan participants who qualified for a PTSD diagnosis had received treatment of any kind. (Beiser et al, 2003) Source: 2010: A Diagnosis for Equity: An initial analysis of South Asian health inequities in Ontario, Council of Agencies Serving South Asians (CASSA)

In 2010, Canada allowed 182,322 temporary foreign workers to enter Canada to meet employers' needs. They have few rights (of which they are often unaware). They do not have access to healthcare services available to other immigrants. 2009: http://www.theglobeandmail.com/report-on-business/economy/economy-lab/the-economists/canadas-immigration-policy-who-is-on-the-guest-list/article1913178/

The majority of Ontarians (85%) have no difficulty accessing care from their family doctor, but this varies by ethnicity: 1 in 3 West Asian and Arab women report difficulties versus 1 in 5 white women 2010: http://www.powerstudy.ca/webfm_send/121 Bierman AS, Angus J, Ahmad F, Degani N, Vahabi M, Glazier RH, Li Y, Ross S, Manuel D. Access to Health Care Services In: Bierman AS, editor. Project for an Ontario Women's Health Evidence-Based Report: Volume 1: Toronto; 2009/10

TOPIC: Lesbian, Gay, Bisexual, Trans Health

19% of lesbian women and 24% of bisexual women do not have a regular doctor, as opposed to only 12% of heterosexual women. 2008: http://www.statcan.gc.ca/daily-quotidien/080319/dq080319b-eng.htm

12% of bisexual men and 16% of bisexual women report fair or poor health. These levels are significantly higher than the roughly 8% of men and women in the heterosexual population who report the same health status. 2008: http://www.statcan.gc.ca/daily-quotidien/080319/dq080319b-eng.htm

Gay men and bisexual women tend to report more chronic conditions than does the heterosexual population. 2008: http://www.statcan.gc.ca/daily-quotidien/080319/dq080319b-eng.htm

Bisexual men and women were more likely than heterosexual men and women to perceive their mental health as fair or poor. And all sexual minority groups reported levels of mood or anxiety disorders above those for the heterosexual population. 2008: http://www.statcan.gc.ca/daily-quotidien/080319/dq080319b-eng.htm

Lesbian women are less likely to get pap smears and have later detection of cervical cancer than heterosexual women. Often, this is because the typical messaging relating to sexual health excludes LGBT experiences, and this exclusion can lead to misinformation about risks as well as barriers to access for lesbian women. McIntyre, Lynn , Szewchuk, Andrea and Munro, Jenny(2010) 'Inclusion and exclusion in mid-life lesbians' experiences of the Pap test', Culture, Health & Sexuality, 12: 8, 885 — 898.

Trans people often experience a high degree of mental and emotional distress due to experiences of social marginalization and transphobia. Some trans people experience trans-related discrimination and violence every single day. Source: 2011 Trans PULSE Study (http://transpulseproject.ca)

TOPIC: Health of People with Mental Illness

In Canada, a study using administrative health databases in Nova Scotia found that psychiatric patients had similar incidence of most cancers but were more likely to die of cancer (even when incidence rate was controlled). *Delays in detection or initial presentation leading to more advanced staging at diagnosis, and difficulties in communication or access to health care.* Kisely, S, Sadek, J, MacKenzie, A, Lawrence, D, and Campbell, LA. (2008). *Excess cancer mortality in psychiatric patients.* Canadian Journal of Psychiatry, 53(11), 753-761.

Of all persons with disabilities, those with a serious mental illness face the highest degree of stigmatization in the workplace, and the greatest barriers to employment. (2011: Canadian Mental Health Association: Employment and Mental Illness http://www.cmha.ca/BINS/content_page.asp?cid=3-109)

Canada, teenagers and young adults aged 15-24 experience the highest incidence of mental disorders of any age group in Canada. (2011: Canadian Mental Health Association: Education and Mental Illness http://www.cmha.ca/BINS/content_page.asp?cid=3-110&lang=1)

Mental illness affects people of all ages, educational and income levels, and cultures.(2011 - Canadian Mental Health Association: Fast Facts: Mental Health/Mental Illness http://www.cmha.ca/bins/content_page.asp?cid=6-20-23-43)

Suicide is one of the leading causes of death in both men and women from adolescence to middle age. (2011: Canadian Mental Health Association: Fast Facts: Mental Health/Mental Illness http://www.cmha.ca/bins/content_page.asp?cid=6-20-23-43)

One-third to one-half of people with mental illness report being turned down for a job for which they were qualified after they disclosed their disability, were dismissed from their jobs, and/or were forced to resign as a result of their mental illness.Ontario Human Rights Commission (January 2011) http://www.ohrc.on.ca/en/resources/discussion_consultation/mentalhealthpr/pdf

Over one in three patients (37%) discharged from a general hospital with a diagnosis of mental illness were readmitted within one year of their discharge. 2006: Canadian Institute for Health Information Report http://www.cmha.ca/bins/site_page.asp?cid=284-294-297-1637&lang=1

TOPIC: **Poverty and Health**

Only 61% of women living in the lowest-income neighbourhoods get screened for cervical cancer, compared to 75% among those in the highest income neighbourhoods. 2009: http://www.powerstudy.ca/webfm_send/60 Krzyzanowska MK, Barbera L, Elit L, Kwon J, Lofters A, Saskin R, Yeritsyan N, Bierman AS, Cancer: In: Bierman AS, editor. Project for an Ontario Women's Health Evidence-Based Report: Volume 1: Toronto; 2009.

Women and men from the lowest-income areas are almost twice as likely to be hospitalized for depression than those from the highest-income areas. 2009: http://www.powerstudy.ca/webfm_send/83 Lin E, Diaz-Granados N, Stewart DE, Rhodes AE, Yeritsyan N, Johns A, Duong-Hua M, Bierman AS, Depression: In: Bierman AS, editor. Project for an Ontario Women's Health Evidence-Based Report: Volume 1: Toronto; 2009.

Among women aged 66 and older, those from lower-income neighbourhoods who started antidepressants were less likely to have had the recommended number of follow up physician visits than women from higher-income neighbourhoods. *Limited due to cost of transportation, competing responsibilities, and language limitations.* 2009: http://www.powerstudy.ca/webfm_send/83 Lin E, Diaz-Granados N, Stewart DE, Rhodes AE, Yeritsyan N, Johns A, Duong-Hua M, Bierman AS, Depression: In: Bierman AS, editor. Project for an Ontario Women's Health Evidence-Based Report: Volume 1: Toronto; 2009.

Among Ontarians who had been hospitalized for depression, people who lived in higher-income neighbourhoods were more likely to have a post-discharge physician visit for depression (and to do so more quickly) than those from lower-income neighbourhoods. 2009: http://www.powerstudy.ca/webfm_send/83 Lin E, Diaz-Granados N, Stewart DE, Rhodes AE, Yeritsyan N, Johns A, Duong-Hua M, Bierman AS, Depression: In: Bierman AS, editor. Project for an Ontario Women's Health Evidence-Based Report: Volume 1: Toronto; 2009.

Low-income populations have a higher risk of developing diabetes and have worse outcomes once they have it. The risk of diabetes is also higher in certain immigrant and ethnic groups, such as those of South Asian, African, Hispanic and Aboriginal descent. 2010: http://www.powerstudy.ca/webfm_send/151 Booth GL, Lipscombe LL, Bhattacharyya O, Feig DS, Shah BR, Degani N, Johns A, Ko B, Bierman AS. Diabetes In: Bierman AS, editor. Project for an Ontario Women's Health Evidence-Based Report: Volume 2: Toronto; 2010.

In Ontario, teenage mothers who live in the lowest income neighbourhoods have live birth rates that are over five times higher than teenagers who live in the highest-income neighbourhoods (20.6 versus 3.6 per 1,000 women aged 15-19, respectively) *Lack of opportunity and hope for the future, children of teenage mothers more likely to be teenage mothers themselves, cycle of poverty and lack of education about sexual choices.* 2011: http://www.powerstudy.ca/sites/powerstudy.ca/files/reprohlth_highlights_sm.pdf Dunn S, Wise M, Johnson L, Anderson G, Ferris L, Yeritsyan N, Croxford R, Fu L, Degani N, Bierman AS. Reproductive and Gynaecological Health In: Bierman AS, editor. Project for an Ontario Women's Health Evidence-Based Report: Volume 2: Toronto; 2011.

Food insufficient households are households that have inadequate food intake and quality of food due to lack of financial resources. 2008: http://archpedi.ama-assn.org/cgi/reprint/155/4/508.pdf

Food insufficient households were 80% more likely to report having diabetes, 60% more likely to report high blood pressure, and 70% more likely to report food allergies than households with sufficient food. Mikkonen, J., & Raphael, D. (2010). Social Determinants of Health: The Canadian Facts. Toronto: York University School of Health Policy and Management. The publication is available at http://www.thecanadianfacts.org/

In Canada, childhood hospitalization rates for poisoning and for being cut or pierced were significantly higher in the lowest-income neighbourhoods than in the highest. Similarly, hospitalization rates for injuries caused by fires tended to rise as neighbourhood income fell. 2010: http://www.statcan.gc.ca/daily-quotidien/101020/dq101020b-eng.htm

- First generation racialized Canadian men earn 68.7% of what non-racialized first generation Canadian men earn

- First generation racialized Canadian women earn 48.6% of what non-racialized first generation Canadian men earn

- Second generation racialized Canadian women earn 56.5% of what non-racialized Canadian men earn

- Second generation racialized Canadian men earn 75.6% of what non-racialized Canadian men earn

The Colour Coded Labour Market 2011 http://www.policyalternatives.ca/sites/default/files/uploads/publications/National%20Office/2011/03/Colour%20Coded%20Labour%20Market.pdf

- Those who identify as Korean earn 69.5 cents for every dollar a non-racialized worker earns, with an annual earnings gap of $11,403

- Those who identify as Latin Americans earn 70.3 cents for every dollar a non-racialized worker earns, with an annual earnings gap of $11,091

- Those who identify as West Asian earn 70.4 cents for every dollar a non-racialized worker earns, with an annual earnings gap of $11,053

- Those who identify as Black earn 75.6 cents for every dollar a non-racialized worker earns, with an annual earnings gap of $9,101

- Those who identify as South East Asians earn 77.5 cents for every dollar a non-racialized worker earns, with an annual earnings gap of $8,395

- Those who identify as Chinese earn 88.6 cents for every dollar a non-racialized worker earns, for an annual gap of $4,251.

The Colour Coded Labour Market 2011 http://www.policyalternatives.ca/sites/default/files/uploads/publications/National%20Office/2011/03/Colour%20Coded%20Labour%20Market.pdf

TOPIC: **Women's Health**

Ontario women earn 71% of what Ontario men earn. This 29% pay gap compares to a 10% pay gap in Sweden, a country with strong pay equity laws and family friendly work policies. *Ontario's gender pay gap cheats women workers* http://www.thestar.com/comment/article/500415 (2008)

Racial minority women earn 36% less than men and aboriginal women earn 54% less than men. *Ontario's gender pay gap cheats women workers*. http://www.thestar.com/comment/article/500415 (2008)

Female high school graduates earn 27% less than male graduates. Female university graduates earn 16 per cent less than male graduates. *Ontario's gender pay gap cheats women workers* http://www.thestar.com/comment/article/500415 (2008)

Ontario granted women the vote in 1917. (http://archives.cbc.ca/politics/rights_freedoms/topics/1450-9562/) (2004)

71% of all incidents of workplace violence are physical assaults. In addition, 24% of sexual assaults occur in the workplace. While men may also be victims of sexual assault, women are disproportionately affected. http://www.owjn.org/owjn_2009/index.php?option=com_content&view=article&id=112&Itemid=107 (2008)

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NOTES

FACILITATOR MANUAL
We ask because we care:
Collecting patient demographic data

Understanding Research Heal Access Health Supportive Planning Language Safe Research Ally Comfort Evidence Accommodate Sexual orientation Access No harassment Accommodate Heal Interpreters Compassion Advocate Awareness Vision Interventions Disability Research Advocate Voices Race Carefulness Health Vision Religion Access Safe Translation Quality Evaluation Health Awareness Ally Equity Health Remove barriers Stand up Respectful Forgiving Disability inequities Stand No harassment Ally Access Solidarity up Accessible Heal Translation