HOW TO ASK

Measuring Health Equity - Demographic Data Collection in Lane County Health & Human Services

Adapted with permission from the Toronto Central Local Health Integration Network and Sinai Health System Manual ‘Measuring Health Equity: Demographic Data Collection in Health Care’
## CONTENTS

**INTRODUCTION & ACKNOWLEDGEMENTS** ................................................................. 5

**SECTION 1**

HEALTH EQUITY, SOCIAL DETERMINANTS OF HEALTH & DEMOGRAPHIC DATA COLLECTION .......................................................................................................................... 6

Health Equity in Lane County ..................................................................................... 6

Social Determinants of Health .................................................................................... 7

Patient and Client Demographic Data Collection ....................................................... 8

**SECTION 2**

DEMOGRAPHIC DATA COLLECTION QUESTIONS ................................................... 13

DEMOGRAPHIC DATA QUESTIONS ........................................................................... 13

1. Spoken Language ................................................................................................. 14
2. Written Language ................................................................................................ 15
3. Preferred Name .................................................................................................... 15
4. Pronouns ............................................................................................................... 16
5. Race/Ethnicity ...................................................................................................... 16
6. Gender .................................................................................................................. 19
7. Sexual Orientation ............................................................................................... 20
8. Military Service ................................................................................................... 21
9. Disability .............................................................................................................. 22
10. Housing Situation ............................................................................................... 23
11. Income ............................................................................................................... 24
12. Question for healthcare settings: Assigned sex at birth .................................... 25
HEALTH EQUITY STATISTICS ........................................................................................................66
TIPS FOR MANAGING STRESS OR FATIGUE AT WORK .........................................................67
BIBLIOGRAPHY .....................................................................................................................68
INTRODUCTION

The information presented in this manual will provide facilitators and staff from Lane County Health & Human Services with the educational materials and resources they need to train staff to collect patient and client demographic data.

This manual provides information on health equity, collecting patient and client demographic data, and activities to help staff practice new data collection skills and resources to use when responding to patient and client questions or concerns.

ACKNOWLEDGEMENTS

This manual has been adapted with permission from the Toronto Central Local Health Integration Network and Sinai Health System Manual 'Measuring Health Equity: Demographic Data Collection in Health Care'. We express gratitude to the Toronto Central Local Health Integration Network and Sinai Health System and further extend acknowledgement to their collaborators;

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.
HEALTH EQUITY

*What is health equity?*

"Health equity means that everyone has a fair and just opportunity to be healthier. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and healthcare.

– Robert Wood Johnson Foundation

*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.
- 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 Lane County:

The primary findings of the Lane County Health Equity Report (2017) were:

- Health inequity and health disparities exist in Lane County, and oftentimes the differences are greater than national and state levels.
- The population of Lane County will continue to diversify. Should health disparities among racial and ethnic populations persist, the burden of health disparities will become even greater.
- Compared to people who are White, all other racial and ethnic groups experience greater rates of poverty. With fewer economic resources marginalized populations have fewer opportunities to access healthcare and other supports to maintain their well-being.
- While most people who are Hispanic/Latino graduate from high school, people who are Hispanic/Latino have significantly lower high school graduation rates compared to all other racial and ethnic groups.
- Tobacco use has profound effects on rates of disability and death among the African-American and American Indian/Native Alaskan populations. These populations die younger and more often from tobacco related deaths compared to people who are White.
- People who are American Indian/Native Alaskan or Hispanic/Latino are 50% more likely to be teenage mothers compared to people who are White. Teenage pregnancy may affect the health of the child. In addition, it may impact the health and economic opportunity of the mother and her family.
- People who are African American have two to six times the rates of gonorrhea, chlamydia and chronic hepatitis C compared to the general population.

The health disparities reported here are the consequences of multi-generational social, economic and environmental inequities. The results persist today. These inequities have a greater influence on health outcomes than either individual choices or one's ability to access health care. A universal commitment to improve health for all is not enough to change the health inequities. Only committed social justice actions, and changes in policies, practices and organizational systems can improve opportunities for all Lane County residents. The structure of our community fosters health inequity, but what our community does it can also undo by responding to promote equity for those who are marginalized.

Read the full report here: [https://preventionlane.org/health-equity-lane-county](https://preventionlane.org/health-equity-lane-county)

**SOCIAL DETERMINANTS OF HEALTH**

*What are Social Determinants of Health*

Social Determinants of Health are “the conditions in which people are born, grow, work, live, and age." -WHO

These circumstances are shaped by the distribution of money, power, and resources at global, national and local levels." - WHO
Social Determinants of Health are predictive of poor health outcomes.

Social determinants are not the same as social needs as determinants are systems-level factors and needs are the resulting individual-level deficits.

Racism, discrimination, and arguably greed result in unequal social, environmental, and economic conditions, producing deep-rooted health disparities that impact generations.

**Ensuring Health Equity in Health & Human Services Means:**

- **Collecting patient and client-level demographic data:** This first step will give health & human services a comprehensive picture of the community we serve and the characteristics of patients and clients in our care. When done properly, demographic data and social determinants of health data will serve as “a fundamental building block” for identifying health inequities and gaps in quality of care. Vii

- **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, 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, Australia, and Ontario Community Health Centers 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**

Sanai Health Systems developed the initial training through a process which 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, and data collection experiences from 34 health-care organizations (hospitals and CHCs) in the TC.
LHIN who have collected data from over 280,000 patients and clients since 2012.

**Modifications**
The 2018 Equity Committee, through the work of the training subcommittee (and with the support of the Shift Service Delivery to Ensure Equity & Decrease Disparities subcommittee) modified this training in order to incorporate local data, to provide questions and answers that are culturally responsive in this region, and to incorporate local priorities. The initial training was designed for healthcare settings and modified for use across health & human services.

**Summary of lessons:**

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

   - There is strong evidence that patients and clients are willing to share demographic information. (Findings from Toronto)

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: evidence reveals that participating 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 training participants in Toronto found having a glossary of terms at their fingertips to be “a life saver”.

3. Data collectors have reported little to no problems or conflict when approaching patients and clients about collecting demographic 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 organizations have told us: Patient and client 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/clients are least likely to share (‘income’).
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

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 & human service 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 and client 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, etc.)

3. Program was evaluated and found to be successful in improving colorectal cancer screening rates.


There is strong evidence that health inequities exist in the United States along a wide range of demographic factors. Without consistent demographic data we will be unable to identify or track this kind of knowledge within our own organizations.
This data collection framework covers the main components of planning and implementing a demographic data collection plan. The recommendations within the framework are guided by two broad goals: ensuring the collection of high quality data and promoting the sustainability of data collection practices.

Staff training and education is an essential building block for successful demographic data collection. Lack of training and education has been shown to directly undermine data collection efforts and lead to poor data quality.
SECTION 2
DEMOGRAPHIC DATA COLLECTION QUESTIONS

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 items, participants will learn about:

- Item wording
- What the item intends to capture/measure
- Important points to remember
- Health equity evidence

Please refer to the Glossary of Terms on page 42 to better understand and be able to explain the content of these questions.

DEMOGRAPHIC DATA QUESTIONS

The Lane County Health & Human Services Equity Committee in 2018 took on the work of developing recommendations for questions we ask at Health & Human Services. Questions pertain to:

- Demographic and Social Determinants of Health Questions were developed by:
  - Surveying each program at H&HS to better understand questions currently asked.
  - Requesting support and input from Public Health Epidemiology & Quality & Compliance on considerations for meeting data comparison requirements, reporting requirements, etc.
  - Reviewing examples and literature around questions considered best practice including recommendations from the Oregon Health Authority (REAL+D), 8 questions developed by the Centre for Addiction and Mental Health, Mount Sinai Hospital, St. Michael's Hospital, and Toronto Public Health, census questions, HUD & Human Service Division recommendations, and recommendations by the CDC.
  - Consultations with community members and subject area experts from within H&HS and from local organizations including the NAACP, Trans*Ponder, and Centro Latino
Americano. Incorporation of feedback when indicated.

Why these questions;

Many of these questions were chosen because they have a significant impact on patient and client health outcomes. Language, race/ethnicity, gender, sexual orientation, veteran status, and income have all been found to impact patient and client outcomes, sometimes with devastating effects. Additional questions were added to ensure we are providing space for all people to be acknowledged and addressed by their preferred name and pronouns while they are engaging with Health & Human Services.

1 Spoken Language

Question 1: What language do you feel most comfortable speaking or using here? (Examples: ASL, English, Spanish, Mandarin, Arabic, Korean, French, Hindi, Tagalog, Mam, etc.)

Please write in____________________________________

What is the language that is most comfortable?

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.

What if this sentence is not understood?

If the response or body language of the patient or client indicates they do not understand, showing the examples on the handout (including ASL and some examples of languages) is one way to promote understanding.

If understanding is not reached, an alternate question taught in many basic English courses is; ‘Do you speak English?’. This alternate question is suggested due to recognizability, however take special care to ensure the volume and tone stay consistent and respectful.
2 Written Language

Question 2: **Do you need written materials in a different language or format** (Spanish, Mandarin, braille, large print, audio recordings)?

- No
- Yes, please write in: _________________________
- Do not know
- Prefer not to answer

⚠️ Points to remember

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

Health equity evidence


3 Preferred name

Question 3: **What is your preferred name?** _________________________

⚠️ Points to remember

While it may be relevant to ask and record a legal name for purposes such as billing, it is important to recognize and respect the names that patients and clients prefer we use in order to convey respect to those we serve and provide trauma informed services. There are many reasons someone’s preferred name might not be documented as a legal name, and range from nicknames to economic or systemic barriers in accessing a name change.

Being called by a legal name or former name can have significant negative impact on individuals who are gender diverse such as transgender or non-binary individuals. In order to support positive engagement in services, create a safe space for the LGBTQ community, and demonstrate respect it is important to ensure we are asking for and using preferred names when we speak to, speak about, or write about our clients or patients.
4 Pronouns

Question 4: **What are your pronouns?**
- He, Him, His
- She, Her, Hers
- They, Them, Theirs
- Ze, Hir
- Not listed, please write in______________
- Do not know
- Prefer not to answer

**Points to remember**

As with names, pronouns are a way we refer to individuals that can demonstrate respect, or demonstrate disrespect. By asking individuals to share with us what their pronouns are, we have the opportunity to reference them in respectful ways, create a safer space, and support positive engagement in services.

If any of the listed pronouns, or pronouns that are written in, are new or feel challenging to use practice is key. Searching for online resources (for example search: ‘how to use they/them pronouns’) can offer examples of use, and opportunities to practice, or you can use simple tricks like referring to pets by new pronouns to practice. Even with extensive practice, mistakes are sometimes made. If a mistake is made please correct yourself as soon as you catch the mistake, and make an effort to demonstrate correct pronoun use moving forward.

Please also be aware that gender diverse individuals such as transgender and non-binary people experience high rates of discrimination and barriers in access. Having the wrong name or pronoun used can have negative impact, and can also bring up negative past experiences. By asking for pronouns, ensure pronouns are visible to everyone interacting with patients or clients, and using pronouns consistently we demonstrate respect to the diverse populations we serve.

5 Race/Ethnicity

Question 5: **Which of the following best describes your racial or ethnic group?**

*Please select one:*
- American Indian or Alaska Native (American Indian, Alaska Native,
Canadian Inuit, Metis, or First Nation, Indigenous Mexican, Central American, or South American
Asian (Asian Indian, Chinese, Filipino/a, Hmong, Japanese, Korean, Laotian, South Asian, Vietnamese, Other Asian)
Black or African American (African American, African (Black), Caribbean (Black), Other Black)
Hispanic or Latino/a (Hispanic or Latino/a Central American, Hispanic or Latino/a Mexican, Hispanic or Latino/a South American, Other Hispanic or Latino/a)
Middle Eastern/Northern African (Northern African, Middle Eastern)
Native Hawaiian or Pacific Islander (Guamanian or Chamorro, Micronesian, Native Hawaiian, Tongan, Other Pacific Islander)
White (Eastern European, Slavic, Western European, Other White)
Multiracial
Not listed, please write in___________________________________
Doesn’t know
Prefer not to answer

Question 5b: **If you selected multiracial, please select all that apply:**
American Indian or Alaska Native (American Indian, Alaska Native, Canadian Inuit, Metis, or First Nation, Indigenous Mexican, Central American, or South American)
Asian (Asian Indian, Chinese, Filipino/a, Hmong, Japanese, Korean, Laotian, South Asian, Vietnamese, Other Asian)
Black or African American (African American, African (Black), Caribbean (Black), Other Black)
Hispanic or Latino/a (Hispanic or Latino/a Central American, Hispanic or Latino/a Mexican, Hispanic or Latino/a South American, Other Hispanic or Latino/a)
Middle Eastern/Northern African (Northern African, Middle Eastern)
Native Hawaiian or Pacific Islander (Guamanian or Chamorro, Micronesian, Native Hawaiian, Tongan, Other Pacific Islander)
White (Eastern European, Slavic, Western European, Other White)
Not listed, please write in___________________________________
Doesn’t know
Prefer not to answer

What is a racial or ethnic group?
“Race” is used to categorize people into different groups, usually based on observable physical characteristics (e.g. skin color) but can also include characteristics such as accent, dress, beliefs, etc. These differences have no basis in biology (humans share 99.9% of DNA) and race is now recognized as a social construct. While race is not biologically identifiable, “certain groups have become racialized through a social process that marks them for unequal treatment based on perceived differences.”ix While race is a construct, the experience of living with racism is real. Racism has become deeply embedded in systems and institutions that have evolved over time. Racism operates at a number of levels, in particularly, individual, systemic, and social.” Therefore, racial categorization and racial discrimination continue to shape the lives and opportunities of those perceived as people of color.

While “race” is not disconnected from ancestral or familial ties, “ethnicity” is now the dominant term to refer to groups of people who share a common ancestry and/or cultural heritage.x While interconnected, race and ethnicity can provide unique pieces of information (e.g. Black- African, Black- Caribbean).

Considering both race and ethnicity is considered a standard practice in health care and provides an added level of granularity that is needed to understand needs and outcomes of patient and client subpopulations.xi

Points to remember

Patients and clients may be reluctant to identify race and ethnicity 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 directly and some people who do 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 race and ethnicity. If they do not see a designation on the list that reflects their racial identity, they should provide one in the space stating ‘Not Listed, please write in’.

For more information about “race”, see the Glossary of Terms on page 42.

Health equity evidence

6 Gender

Question 6: What is your gender?

☐ Female
☐ Gender Non-conforming
☐ Male
☐ Non-Binary
☐ Transgender
☐ Two Spirit
☐ Gender Queer

Gender Fluid
☐ Questioning
☐ Not listed, please write in___________
☐ Do not know
☐ Prefer not to answer

What is your gender?

Gender is a social construct that is defined in various ways and includes any or all of the following categories: identity, sense of self, expression, presentation, and social expectations.

Gender Identity is an important aspect of gender, and is linked to a person’s sense of self, and the sense of being male, female, both or neither.

Gender is fluid and may change over time.

Points to remember

Some people may find this question intrusive. People who are trans-identified or gender non-conforming may be concerned with who will have access to this information. It is important to explain that this information will be used to help meet health-care needs and equitable care.

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 stored in the same manner as their other health information.

If you have questions about gender identities, please refer to the Glossary of Terms on page 42.

Health equity evidence

Diaz-Granados, N., Blythe Pitzul, K., Dorado, L. M., Wang, F., McDermott, S.,
7 Sexual Orientation

Question 7: What is your sexual orientation?

☐ Asexual  ☐ Two Spirit
☐ Bi-sexual  ☐ Questioning
☐ Gay  ☐ Not listed, please write in___________
☐ Heterosexual (Straight)  ☐ Do not know
☐ Lesbian  ☐ Prefer not to answer
☐ Pansexual
☐ Queer

What is sexual orientation?

Sexual orientation is a term for the emotional, physical, romantic, sexual and/or spiritual attraction, desire or affection for other people. Lesbian, gay, bisexual, queer, pansexual, and heterosexual are all sexual orientations. Sexual orientation is not to be confused with gender.

Points to remember

Some people may find this question intrusive so it is important to explain who will have access to the information, how their privacy will be protected and why collecting this information is important. Patients and clients also have the option to skip the question by choosing “prefer not to answer”.

Every patient/client has unique health needs. Research shows that lesbian, gay, and bisexual people have some health needs that differ from the rest of the population, and have higher prevalence of some health conditions. Nationally and statewide we know that sexually diverse youth have higher risk for negative outcomes including suicide and homelessness, and can experience additional barriers in access to services. Learning about sexual orientation will help you to speak confidently with patients and clients about their lives and unique needs, and will help to deliver appropriate health and human services and equitable care.

Sexual orientation is fluid and may change over time.
Health equity evidence


8 Military Service

Question 8: Have you served in the military?

Yes
No
Do not know
Prefer not to answer

What is military service?

Military service refers to any time serving in the armed forces such as in the air force, army, navy, marines, coast guard, reserves, etc.

Points to remember

The term Veteran is sometimes used to define someone who has served in the military, and sometimes used to describe individuals who meet specific eligibility criteria such as with the Veterans Association (VA). As our primary purpose to ask is to better understand the experiences and outcomes of this population we ask about any service in the military. If veteran status with the VA is important for eligibility an optional follow up question is “Do you have a DD214?”

Lane County Veteran Services is available to provide assistance to individuals who have served in the military in obtaining military records and applying for veteran specific benefits. Lane County Veteran Services: 151 W 7th Ave Ste 460 Eugene OR 97401, 541-682-4191, Walk in hours M/T/W 9-11am and 1-4pm.

Note: Two Spirit is a term used by American Indian, Alaska Native, and First Nations individuals, but the term does not perfectly map onto western definitions of sexual orientation and/or gender identity. We recommend inclusion of two-spirit as an option under both gender and sexual orientation for this reason.
9 Disability

Question 9: Do you have a physical mental or emotional condition that impacts your life?

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

What is disability?

Disability covers a broad range and degree of conditions, some visible and some not visible. A disability may have been present from birth, caused by an accident, or developed over time. There are physical, mental and learning disabilities, mental disorders, hearing or vision disabilities, epilepsy, drug and alcohol dependencies, environmental sensitivities, and other conditions. Disability is often described as the social oppression faced by people with impairments living in an environment that is not organized to accommodate their needs. The vast majority of people with disabilities face 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 answer they self-identify with. There may be some reluctance to divulge information on disabilities. Patients and clients should be reassured that their information will only be shared with members of their team and that they can respond “prefer not to answer” to any of the questions.

Health equity evidence

10 Housing Situation

Question 10: What is your current housing situation?

- Doubled Up (such as couch surfing)
- Housed (living in an apartment, house, or long-term situation)
- Streets, car camping, camping, similar location
- Transitional Housing (Short-term/time-limited housing)
- Shelter
- Not listed, please write in_____________________
- Do not know

⚠ Points to remember

This question relates to social determinants of health, and gives us information on conditions that individuals live in that have direct and indirect impacts on health outcomes. By capturing if someone is housed, is not housed, and if someone is precariously housed we better understand if we are reaching these populations with the services we offer, and can better understand the experiences and outcomes for those we serve.

✅ Health equity evidence


11 Income

Question 11: What is your families monthly income before taxes? ____
How many people does that income support? ______________

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/domestic partnership/ common law relationships or adoption.

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

**In the case of patients under 18, patients and clients should be advised that the question is asking about the “household income supporting the child.”

Points to remember

Many individuals 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 the Internal Revenue Services or other authorities. There may be reluctance to answer this question if there is an undocumented family member. While it is appropriate to address confidentiality of information and protection of healthcare records patients and clients have the right to skip the question/prefer not to answer.

Health equity evidence

FOR HEALTHCARE SETTINGS:

Additional question to be asked if needed for medical care

12. What sex were you assigned at birth?
   - Female
   - Intersex
   - Male
   - Not listed (please write in) _________________________
   - Do not know
   - Prefer not to answer

Sex refers to a combination of bodily characteristics including: chromosomes, hormones, internal and external reproductive organs, and secondary sex characteristics. Often we think of sex as a classification, and when people are born they are usually classified as male or female, and sometimes intersex, based on the appearance of their external anatomy.

This information can be important to know in the medical field; however knowing someone’s sex assigned at birth does not tell us a person’s gender or current information about their bodily characteristics which can change over time or due to gender transition. This question can also feel invasive as it primarily reveals information about the appearance of external anatomy when someone was born. For these reasons it is recommended that this question only be asked when the information is needed for medical purposes, and that the answers be reviewed alongside data about the person’s gender. If this information is NOT needed for medical purposes, just skip this altogether.
SECTION 3

ASKING PATIENTS AND CLIENTS FOR DEMOGRAPHIC INFORMATION

INFORMATION TO GIVE PATIENTS AND CLIENTS

Listed below are the three key messages for patients and clients. These messages were developed based on provincial guidelines and patient feedback on the pieces of information they want to receive when responding to demographic questions:

**Purpose**

"To find out who we serve."

"To identify patient and client needs."

"To understand patient and client experiences and outcomes."

**Access to data**

"Information can be seen by the team taking care of you."

"Information is protected like all your health-care information."

"If used in research, data from all patients and clients is grouped together and no one will be able to identify individuals."

**Voluntary**

"Questions are voluntary."

"You can choose "prefer not to answer" to any or all of the questions."

"Choosing to not respond will not affect your care or access to services."

- 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.

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.

You can use the demographic hand-out help introduce the project and pro-actively address any questions that 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:

- The 3 key messages to share with patients and clients (see page 26)
- What the questions and categories refer to
- How to address discriminatory comments

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

Points to use when discussing the “why”:

- “This data will help us provide you and everybody else with the best quality of care possible”
  - Expand: “and care that is equitable”
  - Expand: “and care that addresses any unique needs you have”
- “All this information has helped other 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”
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 your first response to concerns:

- Patients/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
Sample script on how to respond to patient or client questions

<table>
<thead>
<tr>
<th>Question</th>
<th>“What does this have to do with my care?”</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>“We want to provide care based on patient/client needs. We don't want to make any assumptions about patient/client needs or who our patients/clients are. For example, when we know a patient/client doesn't speak English, we will obtain interpreter services.”</td>
</tr>
<tr>
<td></td>
<td>“Having this information gives us an idea of who receives our services”</td>
</tr>
<tr>
<td></td>
<td>“In some case depending on the patient/client and the situation, knowing this information means providing better care. E.g. getting an interpreter for non-English speakers.”</td>
</tr>
<tr>
<td>Question</td>
<td>“I'm just here for a quick appointment.”</td>
</tr>
<tr>
<td></td>
<td>“This information is for both now and future visits as well”</td>
</tr>
<tr>
<td>Question</td>
<td>“This has nothing to do with me - so what if I say _ (e.g. straight)?”</td>
</tr>
<tr>
<td></td>
<td>“We don’t want to make any assumptions so we ask everyone these questions.”</td>
</tr>
<tr>
<td></td>
<td>“Depending on the patient/client, we may be able to refer them to services or discuss needs they may have.”</td>
</tr>
<tr>
<td>Question</td>
<td>“I don’t want to answer any of these questions.”</td>
</tr>
<tr>
<td></td>
<td>“I understand, can I put all your responses as ‘prefer not to answer’?”</td>
</tr>
<tr>
<td>INDICATOR</td>
<td>Spoken Language</td>
</tr>
<tr>
<td>------------------------</td>
<td>----------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>USES IN CARE</td>
<td>• To provide appropriate care delivery as required by the Health Equity Policy and applicable laws</td>
</tr>
<tr>
<td></td>
<td>• To acquire informed consent</td>
</tr>
<tr>
<td>USES IN PLANNING</td>
<td>• To improve access to care for those who do not speak/read English or French</td>
</tr>
<tr>
<td>IMPACT ON QUALITY</td>
<td>• Use of interpreters and translators has direct impact on quality and safety</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INDICATOR</th>
<th>Racial/Ethnic Group</th>
</tr>
</thead>
<tbody>
<tr>
<td>USES IN CARE</td>
<td>• To provide targeted care and supports (e.g. Middle Eastern populations &amp; thalassemia, Native American populations &amp; diabetes)</td>
</tr>
<tr>
<td>USES IN PLANNING</td>
<td>• To improve outreach to vulnerable groups who do not seek care at the same level as other groups</td>
</tr>
<tr>
<td></td>
<td>• To address access challenges</td>
</tr>
<tr>
<td>IMPACT ON QUALITY</td>
<td>• Outreach improves preventative care and reduces readmissions</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INDICATOR</th>
<th>People with Disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>USES IN CARE</td>
<td>• To fulfill organizational responsibilities around providing accommodation</td>
</tr>
<tr>
<td></td>
<td>• To address histories of traumatic interactions with the healthcare system</td>
</tr>
<tr>
<td>USES IN PLANNING</td>
<td>• To carry out accommodation planning</td>
</tr>
<tr>
<td></td>
<td>• To work on preventing recurrence of exclusion</td>
</tr>
<tr>
<td>IMPACT ON QUALITY</td>
<td>• Better accommodation leads to more efficient and effective care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>INDICATOR</th>
<th>Gender</th>
</tr>
</thead>
</table>
| USES IN CARE | • Both birth-assigned sex and gender are relevant to some essential medical testing (e.g. hormone levels, pap smears, mammograms, etc.)  
|             | • To accommodate the unique needs related to the gender identity of a patient or client |
| USES IN PLANNING | • To improve outreach to vulnerable groups who do not access care at the same level as other groups |
| IMPACT ON QUALITY | • Better planning improves preventative care and health outcomes |
| INDICATOR | Sexual Orientation |
| USES IN CARE | • To understand the unique needs of patients and clients (e.g. living with discrimination) |
| USES IN PLANNING | • To create welcoming environments for lesbian, gay, bisexual (LGB) community members  
|             | • To address known health inequities facing LGB patients and clients |
| IMPACT ON QUALITY | • Providing a welcoming environment improves access and patient and client experiences |
| 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  
|             | • To ameliorate the impact of income on access to primary and preventative health-care |
| IMPACT ON QUALITY | • Improved health care for all |
Quick Answers to Frequently Asked Questions (FAQ)

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

Why are you asking me these questions?

A Health & Human Services Equity Committee worked on developing these questions. They reviewed information about quality and equitable care and social determinants of health. 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 and human service 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 appointment. 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, we are encouraged to use demographic information to keep track of outcomes and promote equity. We have 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 and human service 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 view collection of demographic and social determinant of health information to be a pre-requisite to analysis concerning the populations we serve. Without such information we cannot be data driven in our responsiveness to the needs of those we serve. This information will allow future initiatives such as:
  - Study of whether factors such as language, disability, gender and so on are linked to health outcomes.
  - Development of programs and service training.

- This information will also allow for members of your team to 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
We take your privacy very seriously. Your (Health-care) Team will see the information and it will be treated with the same level of confidentiality as all other health information you share. If used in research, data from all patients and clients is grouped together and no information that could identify individuals will be shared.

**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.
SECTION 4
SAMPLE TRAINING AGENDA AND ACTIVITIES

Points to Keep in Mind as a Trainer

Here are some points to keep in mind when delivering training on demographic data collection:

- 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.

Sample Facilitator Agenda (2 HOURS)
How to Collect Patient and Client Demographic Information

Here is a sample training 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 2 to 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 ask questions.

<table>
<thead>
<tr>
<th>2 HOURS</th>
<th>Facilitator Agenda</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>ACTIVITY</strong></td>
<td><strong>Introductions, Housekeeping, Learning Objectives, Ground Rules</strong></td>
</tr>
<tr>
<td>10 minutes</td>
<td></td>
</tr>
<tr>
<td><strong>FOR FACILITATOR:</strong> METHOD OF PRESENTATION</td>
<td></td>
</tr>
<tr>
<td>- Introduce yourself</td>
<td></td>
</tr>
<tr>
<td>- Welcome group</td>
<td></td>
</tr>
<tr>
<td>- Describe/identify reason for the workshop</td>
<td></td>
</tr>
<tr>
<td><strong>EXPECTED OUTCOME</strong></td>
<td>Facilitator sets welcoming tone, acknowledges expertise in the room</td>
</tr>
<tr>
<td><strong>MATERIALS</strong></td>
<td>PowerPoint Presentation</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Statistics Activity</th>
</tr>
</thead>
<tbody>
<tr>
<td>15 minutes</td>
<td></td>
</tr>
<tr>
<td><strong>FOR FACILITATOR:</strong> METHOD OF PRESENTATION</td>
<td></td>
</tr>
<tr>
<td>- 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</td>
<td></td>
</tr>
<tr>
<td>- 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</td>
<td></td>
</tr>
<tr>
<td><strong>EXPECTED OUTCOME</strong></td>
<td>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.</td>
</tr>
<tr>
<td><strong>MATERIALS</strong></td>
<td>PowerPoint Presentation</td>
</tr>
</tbody>
</table>

**Sample statistics:**

See in this manual:

- p. 40 (for activity description)
- p. 66 (for links to relevant statistics)
| ACTIVITY  
15 minutes | What is Health Equity? What is Demographic Data Collection?  
Overview of data collection project including:  
– What is Health Equity?  
– Why collect demographic data?  
– What do we know about patient/client and staff experiences with demographic data collection? |
| FOR FACILITATOR:  
METHOD OF PRESENTATION | Present and discuss PowerPoint slides |
| EXPECTED OUTCOME | Participants will learn:  
– What health equity is and what hospitals and CHCs need to do to achieve equitable health outcomes  
– Why it’s important to collect demographic data  
– About patient/client willingness to share demographic data  
– About the experiences of data collectors |
| MATERIALS | PowerPoint Presentation |
| ACTIVITY  
35 minutes | Review TC LHIN Questions  
– What data will be collected?  
– How does one collect the data?  
– Anticipated use of data for care, planning and quality  
– Key terms and definitions |
| FOR FACILITATOR:  
METHOD OF PRESENTATION | Present and discuss PowerPoint slides  
Video observation |
| EXPECTED OUTCOME | Participants will learn:  
– About the questions developed  
– What are the main issues for each question  
– What is the question trying to capture and what do the categories mean |
<p>| MATERIALS | PowerPoint Presentation; Video |</p>
<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Collecting Demographic Data</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 minutes</td>
<td>- Key messages to share with patients and clients</td>
</tr>
<tr>
<td></td>
<td>- Sample workflow to collect the data in person or by paper</td>
</tr>
<tr>
<td></td>
<td>- Overview of resources</td>
</tr>
</tbody>
</table>

| FOR FACILITATOR: METHOD OF PRESENTATION | Present and discuss PowerPoint slides |

<table>
<thead>
<tr>
<th>EXPECTED OUTCOME</th>
<th>Participants will learn:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- What patients and clients want to hear about collecting the data</td>
</tr>
<tr>
<td></td>
<td>- Best practice examples in collecting the data</td>
</tr>
<tr>
<td></td>
<td>- About materials to support data collection, e.g. Patient/Client Brochure</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MATERIALS</th>
<th>PowerPoint Presentation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Measuring Health Equity Resources (Patient/Client Brochure, Poster, Cheat Sheet, etc.)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Practice Session and Debriefs</th>
</tr>
</thead>
<tbody>
<tr>
<td>20 minutes</td>
<td>Part 1 (5 min): Introduce practice sessions</td>
</tr>
<tr>
<td></td>
<td>- Participants will have a chance to play each either the role of staff or patient</td>
</tr>
<tr>
<td></td>
<td>- Participants will practice one scenario</td>
</tr>
<tr>
<td></td>
<td>Part 2 (15 min): Facilitate one practice exercise</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>FOR FACILITATOR: METHOD OF PRESENTATION</th>
<th>- Divide participants into groups of 2: Patient/Client and Staff</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- Distribute 1 practice exercise to each group</td>
</tr>
<tr>
<td></td>
<td>- Review practice exercise. This is a chance to practice:</td>
</tr>
<tr>
<td></td>
<td>- introducing/presenting the Demographic Data Form</td>
</tr>
<tr>
<td></td>
<td>- answering any questions or responding to any concerns patients/clients may present</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>EXPECTED OUTCOME</th>
<th>Participants will:</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>- Practice asking the questions, and respond to questions/concerns</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>MATERIALS</th>
<th>Practice exercises</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>See this manual: Pages 56-59</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>ACTIVITY</th>
<th>Wrap up &amp; Evaluations</th>
</tr>
</thead>
<tbody>
<tr>
<td>5 minutes</td>
<td></td>
</tr>
</tbody>
</table>
Sample Participant Agenda (2 HOURS)
How to Collect Patient and Client Demographic Information

<table>
<thead>
<tr>
<th>Activity</th>
<th>Duration (mins)</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Welcome &amp; Introductions</td>
<td>10</td>
<td>Facilitator presents, group activity, video</td>
</tr>
<tr>
<td>Statistics Activity</td>
<td>15</td>
<td>Group activity</td>
</tr>
<tr>
<td>Health Equity and Demographic Data Collection</td>
<td>15</td>
<td>Facilitator presents</td>
</tr>
<tr>
<td>Review TC LHIN Questions</td>
<td>35</td>
<td>Video, facilitator presents, PowerPoint and group discussion</td>
</tr>
<tr>
<td>Collecting Demographic Data</td>
<td>20</td>
<td>PowerPoint and supporting documents</td>
</tr>
<tr>
<td>Practice Session</td>
<td>20</td>
<td>Group work</td>
</tr>
<tr>
<td>Wrap-Up &amp; Evaluations</td>
<td>5</td>
<td>Group discussion and individual Feedback</td>
</tr>
<tr>
<td><strong>TOTAL TIME</strong></td>
<td><strong>2 hours</strong></td>
<td></td>
</tr>
</tbody>
</table>
Sample Activities

In this section, we will review the components of the agenda by providing details about the activities and explaining how to carry out tasks.

Activity: **Introductions, Housekeeping, Ground Rules**

This information will help you begin the workshop:

- Introduce yourself and provide context for the training
- Provide information on learning outcomes, 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

**Learning Outcomes**

At the end of a 2-hour workshop, participants will be able to:

- Define health equity
- Explain to clients and patients what the demographic questions are
- Tell clients and patients why hospitals and CHCs need to collect demographic data
- Describe how hospitals and CHCs may use demographic data to plan and improve services
- Explain the reasons for each of the questions
- 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.

**Key messages:**

- Health & Human Services is collecting patient/client demographic data
- The questions were evaluated by the 2018 Health & Human Services Equity Committee through the work of the training subcommittee in order to incorporate local data, to provide questions and answer that are culturally responsive in this region, and to incorporate local priorities. The initial training was designed for healthcare settings and modified for use across health & human services.
- There are a variety of reasons for collecting demographic data:
  1. To improve health-care quality (equity is a component of quality)
  2. To determine who we serve
  3. To ensure health care responds to individual needs
  4. To ensure our services reach the entire community
  5. To fulfill our mandate to provide equitable care
- Health equity is achieved when people are treated differently according to what they need; it is achieved when everyone using the health-care 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.

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

Activity: Statistics Activity 15 minutes

Preparation:

- Select 3-4 statistics per topic
- Print and laminate individual statistics on a sheet of 8x12 paper
- Post statistics on the wall throughout the training room

This activity provides concrete information about health inequities. The information on the posters highlights inequities around a number of topics such as poverty, disability, immigration, 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.

Alternative statistics exercise for groups >20:

In the case of large groups it may be easier to do the statistics exercise together. Create a statistics quiz by putting up a few statistics on a slide leaving key information blank. Participants can work in groups to fill in the blanks before sharing. 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.
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.


Sample scenarios for the practice session and videos on collecting demographic data can be found in section 6.

Online E-Learning Module

The Measuring Health Equity e-learning module “HOW TO ASK: Collecting Patient and Client Demographic and Social Determinants of Health Data” is a one-hour online training module that provides staff with the tools to effectively collect patient and client demographic information.

After completing this module, you will be able to:

- Explain what health equity is to patients and clients
- Outline how patient and client demographic data will support health-care organizations to deliver equitable, high quality care
- More effectively collect patient and client demographic data

To access the e-learning module, log into LEAP and search for 'How to Ask'.

The How to Ask In person training is also available for registration in LEAP and should be completed after the e-learning module is complete.
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 behaviors.

**Mental illness** refers to a significant pattern of changes in thinking, behavior 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.⁴

**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.

---

**Gender, and Gender Identity**

**Assigned sex at birth** refers to the designation given to a person at the time of their birth, typically male, female, or intersex. This may or may not align with a person's gender.

**Intersex** refers to people whose bodies, reproductive systems, chromosomes and/or hormones do not align in every way with characterizations of 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.

**Gender** is a social construct that is defined in various ways and can include any or all of the following categories: identity, sense of self, expression, presentation, and social expectations.

**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 Expression** an individual’s characteristics and behaviors such as appearance, dress, mannerisms, speech patterns and social interactions that are typically perceived as masculine or feminine. A person’s gender expression is what people most frequently respond to when they react negatively to a person’s sexual orientation or gender identity.

**Some terms individuals use to describe their gender are;**

- **Cisgender** is a term for people whose gender identity and/or expression fits cultural expectations based on the sex they were assigned at birth.
Female can be a legal or medical term, and is often used synonymously with girl or woman depending upon the person’s age. Individuals who identify as female can be transgender or cisgender.

Male can be a legal or medical term, and is often used synonymously with boy or man depending upon the person’s age. Individuals who identify as male can be transgender or cisgender.

Non-Binary/ Genderqueer/ Gender non-conforming are terms used to describe a person whose gender falls outside of typical cultural definitions of being either a man or a woman. This person may identify with multiple genders, no gender, and/or with notions of gender outside of the mainstream. Some nonbinary/genderqueer/gender non-conforming individuals identify as trans or transgender, and some do not. *Non-binary is a legal designation in the State of Oregon

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.

Transgender An umbrella term for people whose gender identity and/or expression differs from cultural expectations based on the sex they were assigned at birth.

Trans (or transgender) – Female to Male (FTM) describes a trans person who is assigned female at birth but self-identifies as male. Many individuals prefer the term transman or man.

Trans (or transgender) – Male to Female (MTF) describes a trans person who is assigned male at birth but self-identifies as female. Many individuals prefer the term transwoman or woman.

Transman – A man who is also transgender. Transmen were not assigned male at birth and have had the life experience of transitioning (transition varies widely and does not always include medical changes).

Transwoman – A woman who is also transgender. Transwomen were not assigned female at birth and have had the life experience of transitioning (transition varies widely and does not always include medical changes).

Transsexual is a term that has been used to describe a person who does not identify with their sex assigned at birth and typically has or desires to alter sex characteristics, often through hormones and/or surgeries. The term is increasingly seen as clinical and (as with all gender labels) should only be used to describe someone who self-identifies with this label.

Hijra / khawaja sara is a term that applies to a diverse and distinctive subcultural sex/gender grouping in South Asia, who identify with this terminology rather than with being either male or female.

Two-Spirit is a term developed and used within indigenous North American cultures and can describe having both female and male spirits within one person. The term is used within Native American, Alaskan Native, and First Nations communities to describe people who fulfill a traditional or gender variant ceremonial role in their culture. The term two spirit does not perfectly map onto
western definitions of gender or sexual orientation, and is included as an option under both categories in order to be inclusive and create space for individuals with this identity.


Race/Ethnicity

Race is a term used to separate people into groups based on skin color and other physical traits. ‘Race’ is not based on biology but on differences that society has decided are important. People may be perceived as a race that is different than the race a person identifies as, or different than their ethnicity. Perceptions of race have been, and continue to be, used to treat people differently.

Ethnicity is a term used to separate people into groups based on cultural factors such as nationality, religion, culture, ancestry, and language. The US Census defines ethnicity as “whether a person is of Hispanic origin or not” however ethnicity can be understood more broadly.

Sexual Orientation

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

Bisexual is a term to describe a person who is attracted to both men and women, or to two or more genders.

Gay is a term to describe a person who is attracted to people of the same gender, for example, a man who is attracted to men or a woman who is attracted to women.

Heterosexual (“straight”) is a term to describe a man who is attracted to a women or a woman who is attracted to men.

Lesbian is a term to describe a woman who is attracted to other women.

Asexual is a term to describe a person without sexual attraction towards any gender.

Queer is a positive term used by some people who are not heterosexual. It is an ‘umbrella term’ that encompasses many ways of being and experiencing attraction. While this term has been used as a derogatory term and can cause offense, it has been reclaimed by many as a positive identity.

Two-Spirit is a term developed and used within indigenous North American cultures. One definition of two-spirit is “having both female and male spirits within one person”. The term is used within Native American, Alaskan Native, and First Nations communities to describe individuals who fulfill a traditional or gender
variant ceremonial role in their culture. The term two spirit does not perfectly map onto western definitions of gender or sexual orientation, and is included as an option under both categories in order to be inclusive and ensure space for individuals with this identity.

**Questioning** refers to a person who may be unsure or exploring their sexual orientation.

---

**Sexual Orientation and Gender Identity**

*LGBTQ+*, is an acronym for Lesbian, Gay, Bisexual, Transgender, Queer, Plus. Often letters are added or rearranged in order to be more inclusive or to ensure a specific group is included, or it can be shortened, such as using LGB to describe a population researched when only Lesbian, Gay, and Bisexual identities were within the research pool. The acronym can include A for asexual, Q for questioning, TS for two-spirit, N for Non-binary, P for pansexual, and many more. A common use is in the phrase “LGBTQ+ community” which includes groups which have historically and continue to experience discrimination, barriers in access, and marginalization due to sexual and/or gender diversity.

**SOGI** simply means ‘Sexual Orientation and Gender Identity’.
SECTION 6
VIDEOS & SCENARIOS

Collecting Demographic Data Videos

Sample Activity

Activity: Video Observation of 3 Scenarios 20 minutes

Tell the group you are going to show them 3 brief interactions between a patient/client and a health-care staff. Let them know that there will be a discussion following each scenario.

SCENARIO 1: 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 staff’s interaction with the patient?

Some key points:
- The health-care staff was friendly and wanted to be helpful. She answered the patient’s questions respectfully.
- She immediately pulled the curtain offering the patient privacy when answering the questions.
- She clearly explained the reasons for the questions, and how patient treatment would be tailored to respond to the individual patient’s needs.

SCENARIO 2: Patient feels uncomfortable answering questions about race/ethnicity
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, and how patient treatment would be tailored to respond to the individual patient’s needs.
- 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 the Aboriginal community.

SCENARIO 3: Client feels uncomfortable answering question on sexual orientation

Discussion questions:

- What do you think was happening in this scenario?
- Why do you think the client felt uncomfortable about the questions?
- How would you evaluate the intake worker’s interaction with the client?

Some key points:

- The health-care staff was friendly and wanted to be helpful. She answered the client’s questions respectfully.
- She clearly explained the reasons for the questions, and how client treatment would be tailored to respond to the individual client needs.
- She gave a numbered card to the client to follow along and respond by corresponding number to allow for privacy during intake in a public waiting room without having to say the answer out loud.
**Video Guide**

This collection of videos illustrates various interactions between health-care staff and patients/clients when asking questions about their demographic information. [http://torontohealthequity.ca/training/](http://torontohealthequity.ca/training/)

**Measuring Health Equity Overview Video**

URL: [http://youtu.be/jBGOm-jtDVc?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/jBGOm-jtDVc?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

An overview video explaining the Measuring Health Equity Project in Toronto Central LHIN by the Human Rights and Health Equity Department at Mount Sinai Hospital.

**Disability (Hospitals)**

URL: [http://youtu.be/v94hRjlJmbq?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/v94hRjlJmbq?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

This video demonstrates an interaction between admitting staff and a patient in a hospital Emergency Department, discussing the disability question.

**Gender Identity (Hospitals)**

URL: [http://youtu.be/1nt34oP1kOs?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/1nt34oP1kOs?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

This video demonstrates an interaction between health-care staff and a patient in Medical Imaging, discussing the gender question.

**Racial/Ethnic Group (CHCs)**

URL: [http://youtu.be/bzBTDfGTOas?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/bzBTDfGTOas?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

This video demonstrates an interaction between an intake worker and a client at a Community Health Centre, discussing the racial/ethnic group question.

**Income (Hospitals)**

URL: [http://youtu.be/IJr8yo0LB4M?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/IJr8yo0LB4M?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

This video demonstrates an interaction between health-care staff and a patient in a hospital Pediatrics Department, discussing the income question.

**Asking the 8 Core Demographic Questions (Hospitals)**

URL: [http://youtu.be/lxrtfk5CZU0?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/lxrtfk5CZU0?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

This video demonstrates an interaction between health-care staff and a patient at a hospital Family Medicine Department, discussing the 8 core demographic questions.

**Asking the 12 Demographic Questions (Hospitals)**

URL: [http://youtu.be/IrQe1CKd1Yw?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/IrQe1CKd1Yw?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

This video demonstrates an interaction between a social worker and a patient in a hospital Ambulatory Care Department, discussing the 8 core demographic questions and 3 optional questions.

**Asking the 8 Core Demographic Questions (CHCs)**

URL: [http://youtu.be/nEiRF9tdby4?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/nEiRF9tdby4?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

This video demonstrates an interaction between a medical secretary and a client at reception in a Community Health Centre, discussing the 8 core demographic questions.

**Sexual Orientation (CHCs)**

URL: [http://youtu.be/-jf2Eqfna1o?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt](http://youtu.be/-jf2Eqfna1o?list=PLRbcirij8JZc8SRvL__C8ydfqxib2DVlt)

This video demonstrates an interaction between intake staff and a client registering for a group program at a Community Health Centre, discussing the sexual orientation question.
Practice Scenarios

Sample Activity

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/client”. Tell them you are going to play the role of a ____ staff, 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/client” 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.

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/client 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/client 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?

Practice Scenarios

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/Client
- Staff member
- 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:

- Demographic Data Collection Questions
- Plain Language 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 Scenario 1 (Paper)

Patient:
You are a trans woman who just lost their job and are struggling with mental health issues. You feel scared and nervous. You are worried about a medical procedure and your recovery and how you will be treated.

You received a package ahead of your visit, including the Patient Information Form. When you read the form, you started to feel uncomfortable and anxious and decided to leave some of the answers blank.

When you arrive on your procedure date, the Admitting staff member begins reviewing the Patient Information Form with you. You try to explain why you don’t want to answer the questions. You are so depressed you just want to get the surgery over with, without answering so many questions.

You ask the staff member:
- Why you have to answer the questions.
- Why do you need to know if I have a disability?
- What does your income have anything to do with your right for care?
- Why do you need to know my sexual orientation?

Admitting Staff Member:

It has been a bit more challenging than usual because today was your first day of administering the new demographic questions with patients.

Patients have completed the questions at home and so far and you have only had a few cases of missing responses. Patients haven’t had a lot of questions so you have started to get comfortable with collecting and checking the form.

You greet the next patient warmly. You notice they have left the disability, sexual orientation and income questions blank. You ask the patient if they skipped the questions by mistake or if they have any questions about the form. You also ask if they would like to respond “Prefer not to answer” for these questions.

The patient asks you:
- Why do they have to answer all these questions when all they want to do is register?
- (patient is annoyed) What is the purpose of disability, sexual orientation, income?

Respond to the patient and explain the form.

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

- How well does the staff member explain the questions to the patient?
- How well does the staff member respond to the patient’s expressed discomfort?
- How well does the staff member respond to the patient’s resistance to answering the questions?
- How well does the staff member explain what happens to the data gathered?
- What advice do you have for this staff member?

**Practice Scenario 2 (in person) Patient:**

You are a 60 year old female patient with limited English language proficiency and limited ability to read English. You hate going to see service providers but your family forced you to because they think you need it. You are alone in the waiting room, your daughter has dropped you off.

You want to see someone soon, you don’t feel good. You don’t completely understand what the woman behind the desk wants, all she seems to want to do is chat. You’ve already given her your insurance card.

You’ve been here 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. 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 Scenario 3 (Paper)

**Patient:**

You are a woman of color, a refugee, and anxious. You feel insecure and lost without your family. Since coming to the US you have found it hard to navigate the American health-care system.

You’ve done nothing but answer questions and complete documents since your arrival in Springfield. Your most pressing anxiety is being deported, you’ve heard about other refugees whose claims have been denied.

You received a package of forms ahead of your visit, including the Patient Information Form. When you read the form, you started to feel uncomfortable and anxious and decided to leave some of the answers blank.

When you arrive on your appointment date, the Admitting staff member begins reviewing the Patient Information Form with you. You try to explain why you don’t want answer the questions. You just want to get the visit over with, without answering so many questions.

You ask the staff member:

- Why you have to answer the questions.
- Isn’t the question on race illegal?
- What do the sexual orientation responses mean and why do you need to know?

**Staff Member:**

It is close to the end of the day. Today was a bit more challenging than usual because today was your first day of administering the new demographic questions with patients.

Patients have completed the questions at home and so far and no one has returned a blank form. You are getting comfortable with collecting the Patient Information Form.
You greet the next patient warmly. You notice they have left the racial/ethnic group and sexual orientation questions blank. You ask the patient if they skipped the questions by mistake or if they have any questions about the form. You also ask if they would like to respond “Prefer not to answer” for these questions.

The patient asks you:

- Why do they have to answer all these questions when all they want to do check in?
- (patient is annoyed) What is the purpose the racial/ethnic group and sexual orientation?

Respond to the patient and explain the form.

Observer:

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

- How well does the staff member explain the questions to the patient?
- How well does the staff member respond to the patient’s expressed discomfort?
- How well does the staff member respond to the patient’s resistance to answering the questions?
- How well does the staff member explain what happens to the data gathered?
- What advice do you have for this intake staff member?

CHC Scenarios

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).

- Client
- Staff member
- Observer

Let them know that this activity will give them an opportunity to explain and present the questions to the client, 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:
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 client in the first session is the staff member 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.

CHC Practice Exercise 1 (Paper)

Client:

You are 35 years old and have come to the Community Health Center to participate in a Prenatal Program. You have heard that it is often crowded at the health center but that their programs are inclusive and helpful as you prepare for your new baby.

It’s your first time here, so you’re not surprised that they want more information about who you are. Upon arriving at reception, the staff member hands you the registration form and asks you to fill it out.

You take a look at the questions and start feeling angry and anxious. What really annoys and puzzles you are the questions on gender and sexual orientation. You’re very annoyed by the question on sexual orientation as your personal life is personal to you. You also don’t know what intersex and two-spirit mean.

You ask the receptionist why you have to answer so many personal questions when all you want to do is participate in the program, and that you’ll answer the question on disability the next time you see a doctor.

Receptionist:

You are the receptionist and distribute and explain the registration form to new clients. You’ve been told you have to start asking clients a different set of demographic questions from the ones you are used to. You feel you learned how to respond to client questions during a training session.
You are ready to serve the next client in line. Your last client was in severe pain and wasn’t able to provide you with all the information you needed. You have had a good day so far administering the new demographic questions but you are feeling a bit frustrated from your experience with your last client.

When you handout the form to the client, you notice that she starts to look uncomfortable, and seems to look irritated and upset as she reads through the questions. **Respond and explain the demographic questions, in particular, provide information about the questions on gender, sexual orientation and disability as the client doesn’t understand why the questions are being asked.**

**Observer:**

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

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

---

**CHC Practice Exercise 2 (in person)**

**Client:**

You are a single parent and have 2 children. You work two part-time jobs and were recently diagnosed with diabetes.

You are seeking health care and health-care programs for yourself and your children, and go to the nearest CHC. Upon your arrival, you are told that you need to meet with an intake worker and answer some questions.

When the intake worker tells you about demographic questions that are now being asked of all clients, you are curious and have some questions of your own. You want to know why the center needs this sort of information from you. You don’t see what your race, language or if you were born in Canada have to do with health-care services.
You tell the intake worker that you work really hard, two jobs, and don’t understand why how much you earn matters when seeking a doctor’s appointment. You tell the intake worker you just want a doctor for yourself and children, and you don’t know why the answers to some of these questions matter.

**Intake Worker**

It is close to the end of the day and by this hour, you have seen several clients who have come in for many different reasons. Today was a bit more challenging than usual because today was your first day of going through the new demographic questions with clients.

Clients have been receptive so far and no one has refused to answer the questions. Clients have hardly asked you anything about the new questions and no one has complained or gotten angry over them. You are no longer anxious about asking the new questions, you are confident and quite comfortable.

You greet the next client warmly. The client looks tired but agrees to answer the questions. When you begin asking the new questions, the client looks curious and begins to ask a lot of questions about why the center needs to collect this sort of demographic information.

**Observer:**

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

- How well does the intake worker explain the questions to the client?
- How well does the intake worker explain to the client why each individual question is being asked?
- How well does the intake worker respond to the client’s resistance to answering the questions?
- How well does the intake worker explain what happens to the data gathered?
- What advice do you have for this intake worker?

**CHC Practice Exercise 3 (paper)**

**Client:**

You are a 25 year old man of color and have just recently arrived in the United States. You have
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.

Upon arriving, you learn that you can’t see your doctor until you fill out a registration form and answer personal questions. You are frustrated and just want to get to your appointment and leave. When you read the questions on the form, you start to feel uncomfortable and anxious.

You ask the staff member:

- Why you have to answer the questions.
- Why do you need to know if I was born in Canada?
- Isn’t the question on race illegal?
- Why do you need to know my sexual orientation?

Receptionist:

You work at a busy time of day registering clients who are coming for appointments and check-ups.

It is 8:30 am, and the room is crowded and people are waiting. This is a challenging job, because sometimes people are irritable, and don’t understand why they have to wait. A client is in front of you and you need to register them for an 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. You hand him the form and provide information on filling out the registration form.

The client takes the form, looks at it and looks curious. The client asks you why they have to answer all these questions when all they want to do is see a doctor. In particular, the client is annoyed by the question on if they were born in Canada, racial/ethnic group and sexual orientation. Respond to the client and explain the form

Observer:

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

- How well does the staff member explain the questions to the client?
- How well does the staff member respond to the client’s expressed discomfort?
- How well does the staff member respond to the client’s resistance to answering the questions?
- How well does the staff member explain what happens to the data gathered?
- What advice do you have for this staff member?
SECTION 7

RESOURCES AND BIBLIOGRAPHY

FURTHER RESOURCES

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


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


Profile of Low Income in the City of Toronto by City of Toronto http://www.toronto.ca/demographics/pdf/poverty_profile_2010.pdf

Demographic Questions: We Ask Because We Care

We are gathering information to find out who we serve and what unique needs our clients have. We will use this information to better understand experiences and outcomes for the people we serve.

Do I have to answer all the questions? No. The questions are voluntary and you can choose ‘prefer not to answer’. This will not affect the service you receive. We are happy to help you with the questions if there is something you do not understand.

Who will see this information? This information can be seen by the team providing services and care for you, and is protected like all your health care information. If used in research, data from all patients and clients is grouped together and no one will be able to identify you or information about you.

1. What language do you feel most comfortable speaking or using here? (Examples: ASL, English, Spanish, Mandarin, Arabic, Korean, French, Hindi, Tagalog, Mam, etc.) Please write in____________________________________

2. Do you need written materials in a different language or format? (Examples: Spanish, Mandarin, braille, large print, audio recordings)?
   - No
   - Yes, please write in: ____________
   - Do not know
   - Prefer not to answer

3. What is your preferred name?___________________________________________

4. What are your pronouns?
   - He, Him, His
   - She, Her, Hers
   - They, Them, Theirs
   - Ze, Hir
   - Not listed, please write in__________________________
   - Do not know
   - Prefer not to answer

5. Which of the following best describes your racial or ethnic group? Please select one:
   - American Indian, Alaska Native, or First Nations People (American Indian, Alaska Native, Canadian Inuit, Metis, First Nation, Indigenous Mexican, Central American, or South American)
   - Asian (Indian, Chinese, Filipino/a, Hmong, Japanese, Korean, Laotian, South Asian, Vietnamese, Other Asian)
   - Black or African American (African American, African (Black), Caribbean (Black), Other Black)
   - Hispanic or Latino/a (Hispanic or Latino/a Central American, Hispanic or Latino/a Mexican, Hispanic or Latino/a South American, Other Hispanic or Latino/a)
   - Middle Eastern/Northern American (Northern African, Middle Eastern)
   - Native Hawaiian or Pacific Islander (Guamanian or Chamorro, Micronesian, Native Hawaiian, Tongan, Other Pacific Islander)
   - White (European, Slavic, Other White)
   - Multiracial
     - Not listed, please write in______________________________________________
     - Doesn’t know
     - Prefer not to answer

5b. If you selected multiracial, please select all that apply:
   - American Indian, Alaska Native, or First Nations People (American Indian, Alaska Native, Canadian Inuit, Metis, or First Nation, Indigenous Mexican, Central American, or South American)
   - Asian (Indian, Chinese, Filipino/a, Hmong, Japanese, Korean, Laotian, South Asian, Vietnamese, Other Asian)
☐ Black or African American (African American, African (Black), Caribbean (Black), Other Black)
☐ Hispanic or Latino/a (Hispanic or Latino/a Central American, Hispanic or Latino/a Mexican, Hispanic or Latino/a South American, Other Hispanic or Latino/a)
☐ Middle Eastern/Northern American (Northern African, Middle Eastern)
☐ Native Hawaiian or Pacific Islander (Guamanian or Chamorro, Micronesian, Native Hawaiian, Tongan, Other Pacific Islander)
☐ White (European, Slavic, Other White)
☐ Not listed, please write in______________________________
☐ Doesn’t know
☐ Prefer not to answer

6. What is your gender? Please select all that apply
☐ Female
☐ Transgender
☐ Not listed, please write in__________
☐ Male
☐ Gender Queer
☐ Do not know
☐ Gender Non-conforming
☐ Two Spirit
☐ Prefer not to answer
☐ Non-Binary
☐ Gender Fluid

7. What is your sexual orientation? Please select all that apply
☐ Asexual
☐ Lesbian
☐ Not listed, please write in__________
☐ Bi-sexual
☐ Pansexual
☐ Do not know
☐ Gay
☐ Queer
☐ Prefer not to answer
☐ Heterosexual
☐ Two Spirit
☐ Questioning
☐ (Straight)

8. Have you served in the military?
☐ Yes
☐ Male
☐ Transgender
☐ Not listed, please write in__________
☐ No
☐ Two Spirit
☐ Do not know
☐ Gender Non-conforming
☐ Gender Queer
☐ Prefer not to answer

9. Do you have a physical mental or emotional condition that impacts your life?
☐ Yes
☐ Lesbian
☐ Not listed, please write in__________
☐ No
☐ Pansexual
☐ Do not know
☐ Gender Non-conforming
☐ Queer
☐ Prefer not to answer

10. What is your current housing situation?
☐ Yes
☐ Male
☐ Two Spirit
☐ Not listed, please write in__________
☐ No
☐ Gender Queer
☐ Do not know
☐ Doubled Up (such as couch surfing)
☐ Gender Fluid
☐ Prefer not to answer
☐ Housed (living in an apartment, house, or long-term situation)
☐ Questioning
☐ Streets, car camping, camping, similar location
☐ Intersex
☐ Do not know
☐ Do not know
☐ Not listed, please write in_____________________

11. What is your monthly income before taxes? _______________________
☐ Yes
☐ How many people does this income support? __________________
☐ No
☐ Do not know
☐ Do not know
☐ Prefer not to answer

12. What sex were you assigned at birth?
☐ Yes
☐ Female
☐ Not listed (please write in)
☐ Intersex
☐ Male
☐ Do not know
☐ Not listed, please write in_____________________
☐ Male
☐ Prefer not to answer
### WHAT CAN A DATA COLLECTOR SAY?

<table>
<thead>
<tr>
<th>Question</th>
<th>What does this have to do with my care?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Script</td>
<td>“We want to provide care based on our client needs. We don’t want to make any assumptions about client needs or who our clients are. For example, when we know a client doesn’t speak English, we will obtain interpreter services.”</td>
</tr>
<tr>
<td></td>
<td>“Having this information gives us an idea of who visits our health center.”</td>
</tr>
<tr>
<td></td>
<td>“In some cases, depending on the client and the situation, knowing this information means providing better care. E.g. getting an interpreter for non-English speakers.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>“I’m just here for a quick appointment.”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Script</td>
<td>“This information is for both now and future visits as well”.</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>This has nothing to do with me - so what if I say (e.g. straight)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Script</td>
<td>“We ask everyone these questions. Depending on the client’s response, we may be able to refer them to services or talk to them about any needs they have.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Do I have to answer these questions?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Script</td>
<td>“No, it’s completely voluntary and you can choose ‘Prefer not to answer’ to any or all of the questions.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>Who will see this information?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Script</td>
<td>“Your provider(s) will see this information, and it will become part of your medical record. In addition, a few other staff will have access to this information. Your information is confidential and protected by law, just like all of your other health information.”</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Question</th>
<th>How will this information be used?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Script</td>
<td>“Your provider(s) will use this information to help meet your health care needs. In addition, gathering this information from all clients allows the health center to see if there are gaps in care or services across different populations. Learning this tells us if we need to improve the care we give to our clients.”</td>
</tr>
</tbody>
</table>
### WHAT CAN A DATA COLLECTOR SAY?

**LANGUAGE:** What language would you feel most comfortable speaking in with your health-care provider?

**Script**

“Knowing that a client doesn’t feel comfortable speaking English is important to know for translation services.”

**RACIAL/ETHNIC GROUP:** Which of the following best describes your racial or ethnic group?

**Script**

“It’s helpful to know because depending on clients’ answers, it can give us information to help improve care such as knowing dietary habits (e.g. is a pregnant client getting the right vitamins?) or identifying a need for follow up tests (e.g. should we look into genetic testing?).”

“It’s helpful for us to know because we can use this data to reach out to vulnerable groups we know are missing needed care or tests.”

**DISABILITY:** Do you have any of the following?

**Script**

“We know that clients may need additional support based on a disability so we ask to make sure that we have this information about our clients.”

“We can plan for better care when we know what our clients’ needs are. This information will be helpful for that.”

**GENDER:** What is your gender?

**Script**

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

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

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

**“Client laughs or makes jokes about trans people or others.”**

“We ask because we welcome everyone here and don’t want to make assumptions.”
<table>
<thead>
<tr>
<th><strong>SEXUAL ORIENTATION: What is your sexual orientation?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Script</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><strong>INCOME: What was your total family income before taxes last year? &amp; How many people does this income support?</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Script</strong></td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
HEALTH EQUITY 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 colored 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.

**Local Level:**
- Lane County Equity Report (LCPH)

**State Level:**
- Oregon State Health Assessment (OHA)

**National Level:**
- Health Disparities & Equality Report (CDC)
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 in Ontario, Canada. 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.

Incidents involving emergency medical issues, or aggressive or suicidal behavior, 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)
BIBLIOGRAPHY


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


x  ibid.
