Measuring Health Equity (MHE): Collecting Patient and Client Demographic Data in Toronto

[Insert Organization Name]
[Insert Date]

Agenda

- Discussion Guidelines and Training Goals
- Health Equity Principles
- Laying the Groundwork
- Strategies for Demographic Data Collection and Data Governance
- Demographic Data Collection Model
- Staff Training Resources
- Beyond Demographic Data Collection

Discussion Guidelines

1. Speak from your own experience and understand that everyone comes from different lived experiences.
2. Discuss issues that are raised in the workshop.
3. Put your phone on silent.
4. When needed, ask for clarification or examples.
5. Respect confidentiality.

What We Want To Accomplish Today

Understanding of health equity principles

Understanding of the purpose of the health equity standardized questions

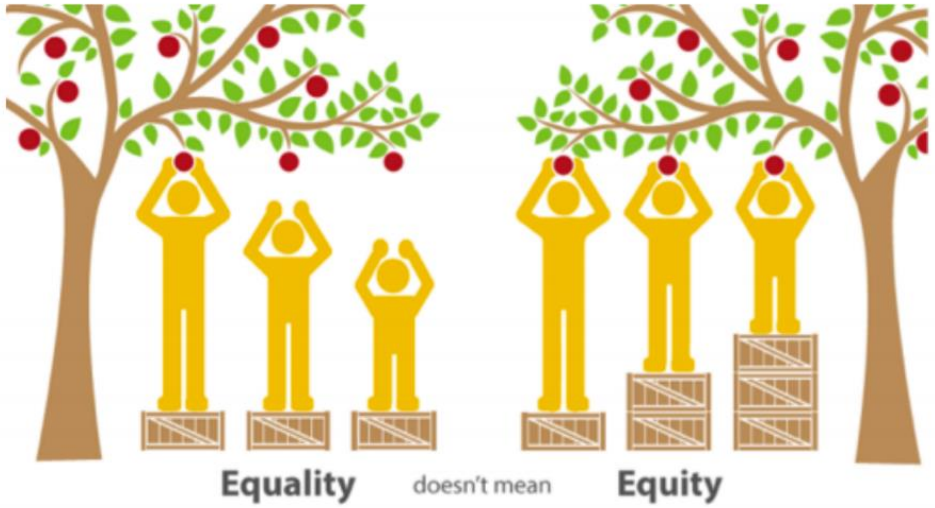
Knowledge on best practices in demographic data collection specific to community health centres (CHCs) and hospitals

Ability to answer questions from patients/clients, staff, community partners, etc. (e.g., resources, where to get answers)

Health Equity Principles

Health Equity

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



"Advancing Health Equity in Health Care" by Saskatoon Health Region. (2014)

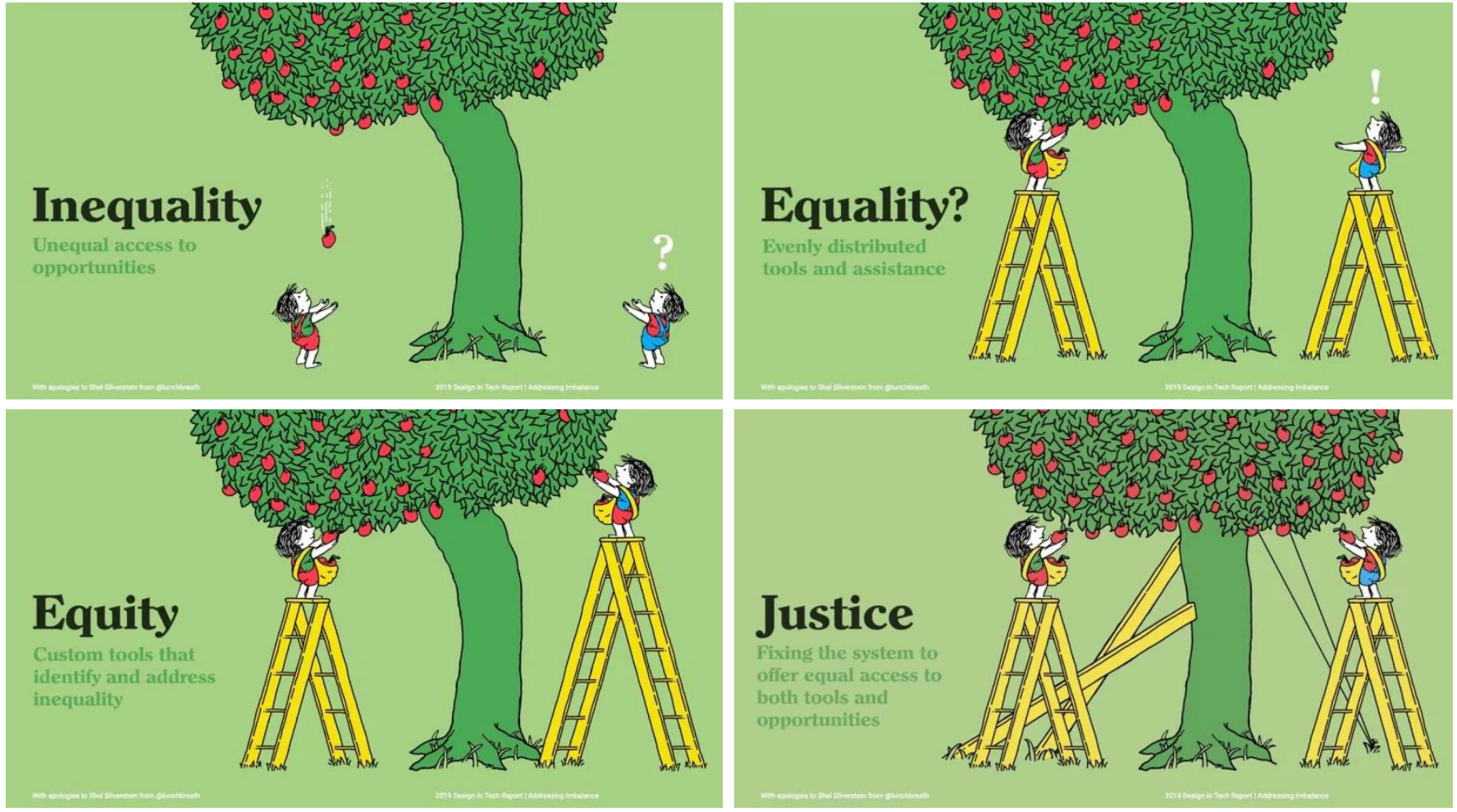
Health Inequities And Health Disparities

The term “health disparities” refers to differences in health outcomes but does not indicate what the drivers of those differences may be (such as whether these differences are unfair or due to a disadvantage in care based on social or economic factors).

The term “health inequities” implies differences in health that are unfair, unjust, and shaped by social and/or economic characteristics of the patient or client (such as language, disability, gender, etc.)

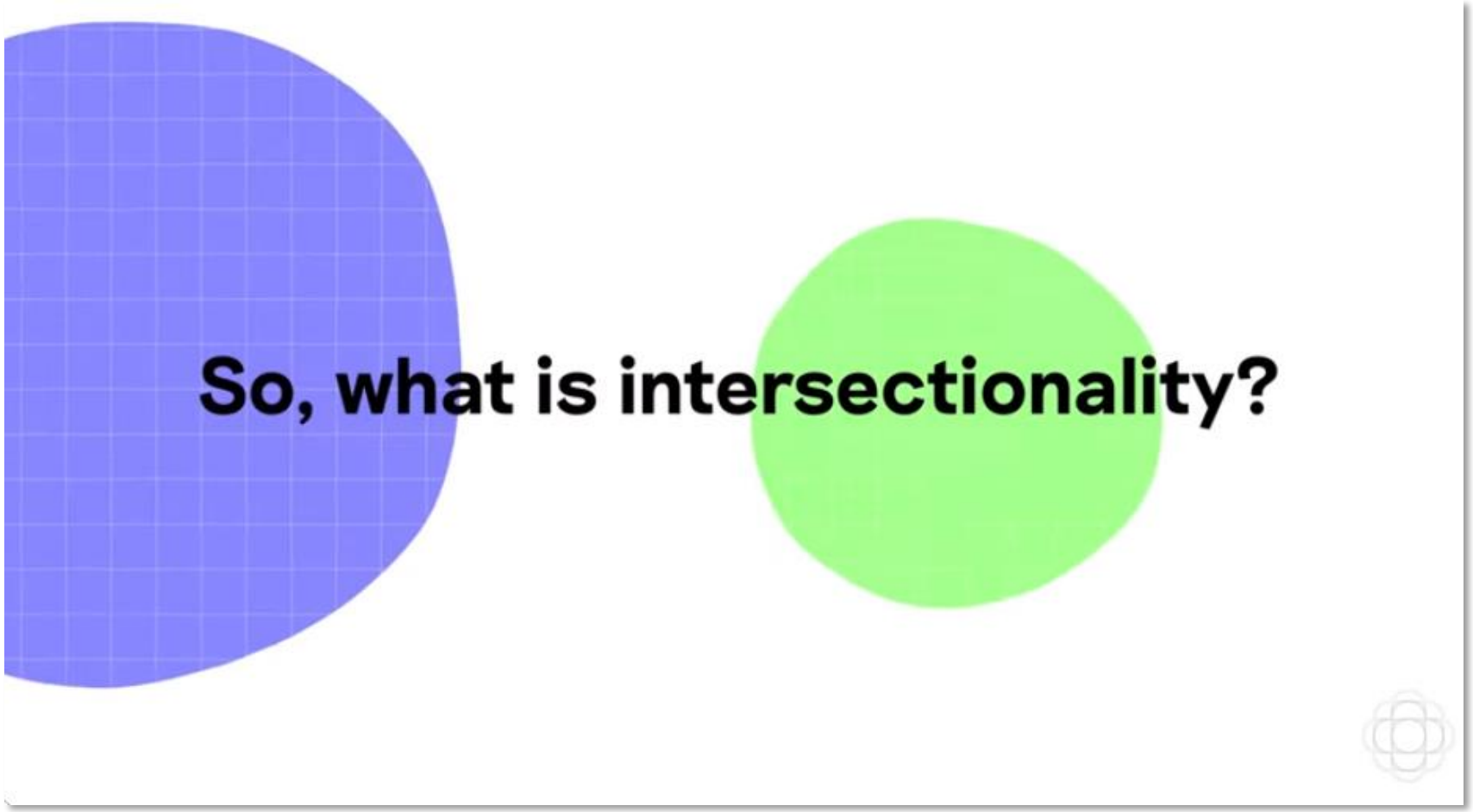
“Toward an Understanding of Health Equity: Glossary” by Alberta Health Services. (2011)

Inequality, Equality, Equity And Justice



2019 Design in Tech Report, *illustration by Tony Ruth (2019)*

“What is Intersectionality?” Video



So, What is Intersectionality? video by the Canadian Broadcasting Company (CBC) (2021)

Laying the Groundwork

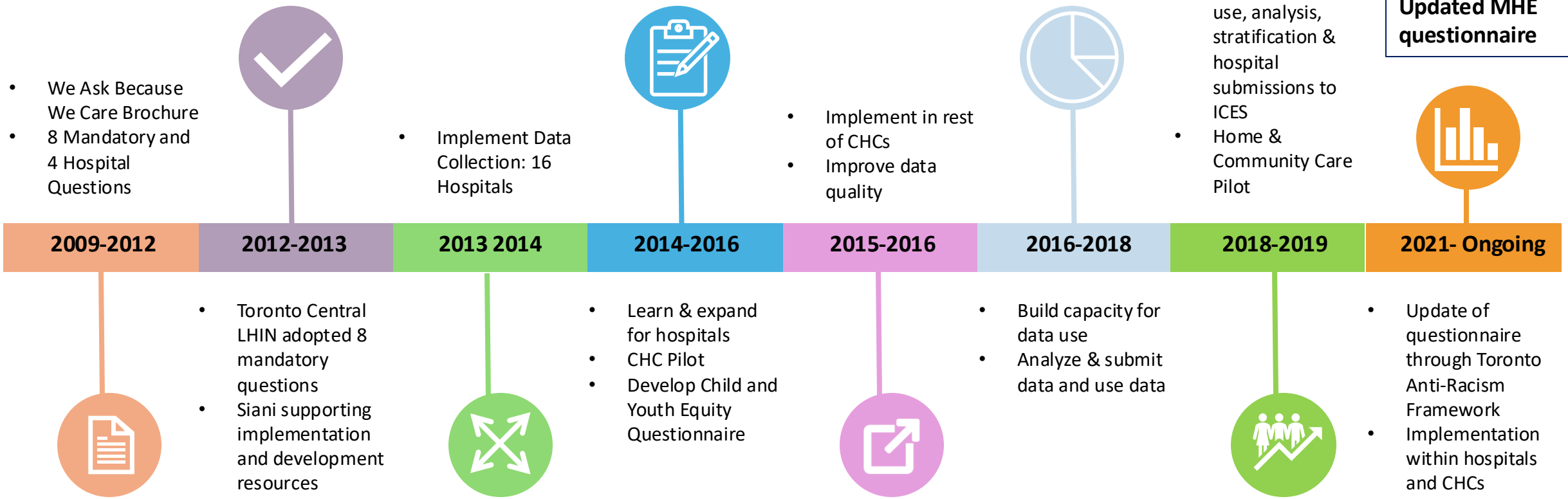
History of Measuring Health Equity Project

1. Toronto Region (TC LHIN**) began implementation of equity demographic questions** in hospitals & CHCs

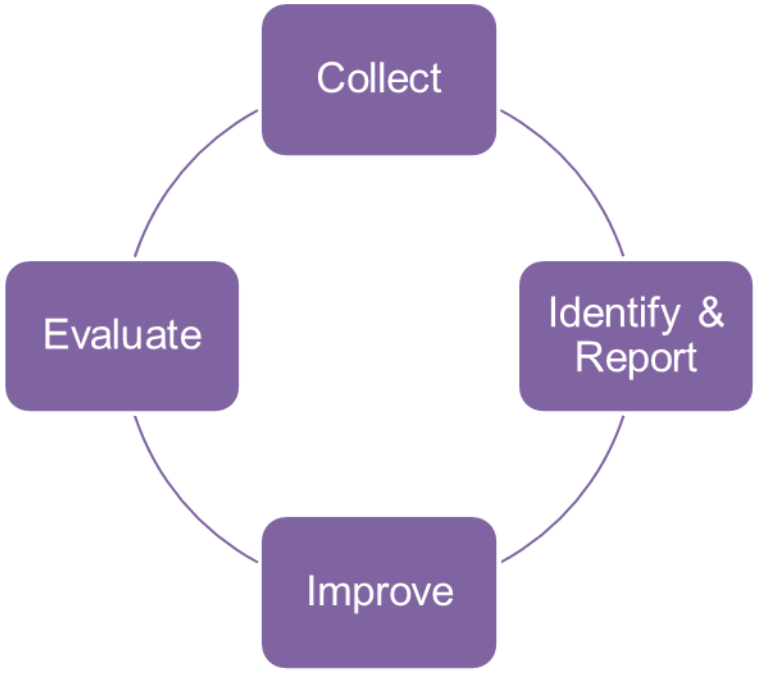
2. **Funded** Measuring Health Equity through Sinai's Health Equity team to support with training, data analysis, materials, etc.

3. **Mandated Data Collection:** Integrated Equity Data Collection into SAAs

4. Launch of **Updated MHE questionnaire**



Framework for Data-driven Equitable Healthcare



- **Collect patient/client-level demographic data**: This step will give healthcare organizations access to individual-level data on their patients/clients and pave the way for an evidence-based approach to providing equitable quality care.
- **Identify & report inequities in care**: Once access to data is secured, organizations can develop a demographic profile of the patients/clients being served and examine differences in health access and outcomes.
- **Improve care based on identified inequities and patient needs**: Healthcare organizations can address special patient/client needs based on language, disability, religion, and so forth.
- **Evaluate data collection practices and intervention programs**: Ensuring the collection of high-quality demographic data necessitates evaluating data quality and improving practices as needed.

Common Research Themes Of Health Inequities

Systemic differences in health are often defined in social, economic, demographic, or geographic terms.

Health inequities are socially produced, avoidable, unjust, and unfair.

Distribution of resources, access to opportunities available, and support offered to people when ill is uneven.

Health equality should not be confused with health equity.

Some may need more or different services than others to be healthy.

Need for improvement in healthy living conditions, and distribution of power, money, and resources across society and systems.

Six Pillars Of Quality Care

1. Safe
2. Efficient
3. Effective
4. Timely
5. Person-Centred
6. Equitable

Crossing the Quality Chasm: A New Health System for the 21st Century - PubMed (nih.gov) by The Institute of Medicine (2001)

Strategies for Successful Demographic Data Collection

Overview of Key Strategies

Define goals for data collection	**Provides all stakeholders with a tool for communicating the project's vision**
	Ensures that the short-term and long-term goals are articulated
Engage Senior Leadership	**Builds an organization-wide dedication to demographic data collection**
	Maintains sustainability and accountability
Engage Staff and Patients/Clients	**Ensures that the people who connect the data, and the patients/clients who share their information, stay connected to the project**
	Staff training on data collection is a key success factor and the most effective way for improving staff engagement
Commit to Ongoing Evaluation	**Ensures that the project stays committed to its purpose**
	Helps organizations address any barriers and capitalize on opportunities
	Provides ability to continually review, improve and monitor the project

Data Governance

What

Community data governance is the collaborative process of managing health data with patients and community members in the decision-making processes related to data collection, analysis, and use.

Why

Community data governance ensures that health data reflects needs and priorities of communities, and that it is used in an ethical manner that upholds privacy and equity.

How

Typically, advisory boards or tables are created to include community members, health experts, and institutional intermediaries. They establish protocols for data sharing, criteria for data access and use, and guide data collection, analysis, and reporting.

The Importance of Data Collection

Sociodemographic data is essential for healthcare institutions to understand the communities that they serve.

Sociodemographic data collection will inform the composition and priorities of community data governance tables.

Consider the community burden if institutions lead separate community governance activities.

Partnerships with local agencies must be developed.

De-identified data can be presented to community members in accessible ways such as charts, graphs, and visual maps.

Examples in Canada

The First Nations Principles of OCAP website

The First Nations Information Governance Centre created the First Nations Principles of OCAP® to support ownership of First Nations data, which was designed specifically to suit the priorities and needs of First Nations communities.

Indigenous data governance & sovereignty

What is Indigenous data?

- Indigenous data is any information about First Nations, Inuit, Métis, and urban Indigenous (Indigenous) peoples. Indigenous data is rich and diverse; beyond numbers, they can include knowledge on resources, land, community stories, culture, and history. Indigenous data sovereignty is the right of Indigenous people to control how their data is collected, protected, and used.

There is a need to ensure Indigenous data sovereignty as historically, Indigenous health research and data use has not benefited Indigenous communities and has been conducted unethically. Even contemporary health research has harmed Indigenous people by using Indigenous data without the consent or engagement of the communities it belongs to. It is important to recognize the importance of data governance principles concerning the safe and respectful collection, storage, analysis, use and protection of equity data. This includes the need for appropriate and meaningful community engagement to ensure data are used in ways that do not cause harm.

Indigenous data governance & sovereignty

The following Indigenous Data Governance Guiding Principles from Ontario Health are provided as a resource for your organization:

Respect for Indigenous People's right to self-determination and self-governance as stated in the United Nations Declaration on the Rights of Indigenous People which has been endorsed by Canada and enshrined in Ontario.

Commitment to store, collect, analyze, and use Indigenous data to bring benefit to and advance health and wellbeing outcomes for Indigenous communities in adherence to data governance principles.

Responsible data management is an opportunity to build trust, empower individuals and community, build capacity and understanding of data governance principles.

Examples in Canada

The Black Health Equity Working Group website

The Black Health Equity Working Group developed the EGAP framework to establish a data sovereignty framework for Black communities during the pandemic.

Governance for other communities

This report introduces the **Engagement, Governance, Access, and Protection (EGAP) Framework**, developed by Black health sector leaders and health equity experts in Ontario to guide the collection, management, analysis, and use of race-based data from Black communities in ways that advance health equity.

Black Health Equity Working Group. (2021). Engagement, Governance, Access, and Protection (EGAP): A Data Governance Framework for Health Data Collected from Black Communities. Blackhealthequity.ca

Demographic Data Collection Model

Why Collect Demographic Data Through Standardized Questions?

Having a standard set of questions is considered the ‘gold standard’ of health equity practice for the following reasons:

1. Standardizes the way we capture data in multiple sectors, allowing for equal data comparison

2. Enables the tracking of inequities in access and outcomes across the system, leading to better planning

3. Goes beyond independent research projects and “knowing who we serve” and instead drives systematic action

The four components of data collection

When rolling out demographic data collection in our organization, we have worked and planned around four components:

Demographics Questions

Methodology and Procedures for Demographic Data Collection

Patient & Data Privacy Considerations

IT Solutions in Demographic Data Collection

Utilizing The Data At Various Levels

Individual level

Organizational level

Systems level

Measuring Health Equity: Core Questions

Language	• What language do you feel the most comfortable speaking in with your provider?
Birthplace	• Were you born in Canada?
Indigeneity	• Do you identify as First Nations, Metis and/or Inuk/Inuit?
Ethnic or Cultural Background	• What is your ethnic or cultural background?
Racial Background	• Which of the following best describes your racial group?
Disability	• Do you identify as a person with a disability?
Sex Assignment at Birth	• What was your sex assigned at birth?
Gender Identity	• What is your gender identity?
Transgender Identity	• Do you identify as transgender?
Sexual Orientation	• Which category/ies best describe your sexual orientation?
Basic needs	• Do you currently have difficulty paying for basic needs?
Income	• What was your total family income before taxes last year?
People that income supports	• How many people does this income support?

Measuring Health Equity: Optional Questions

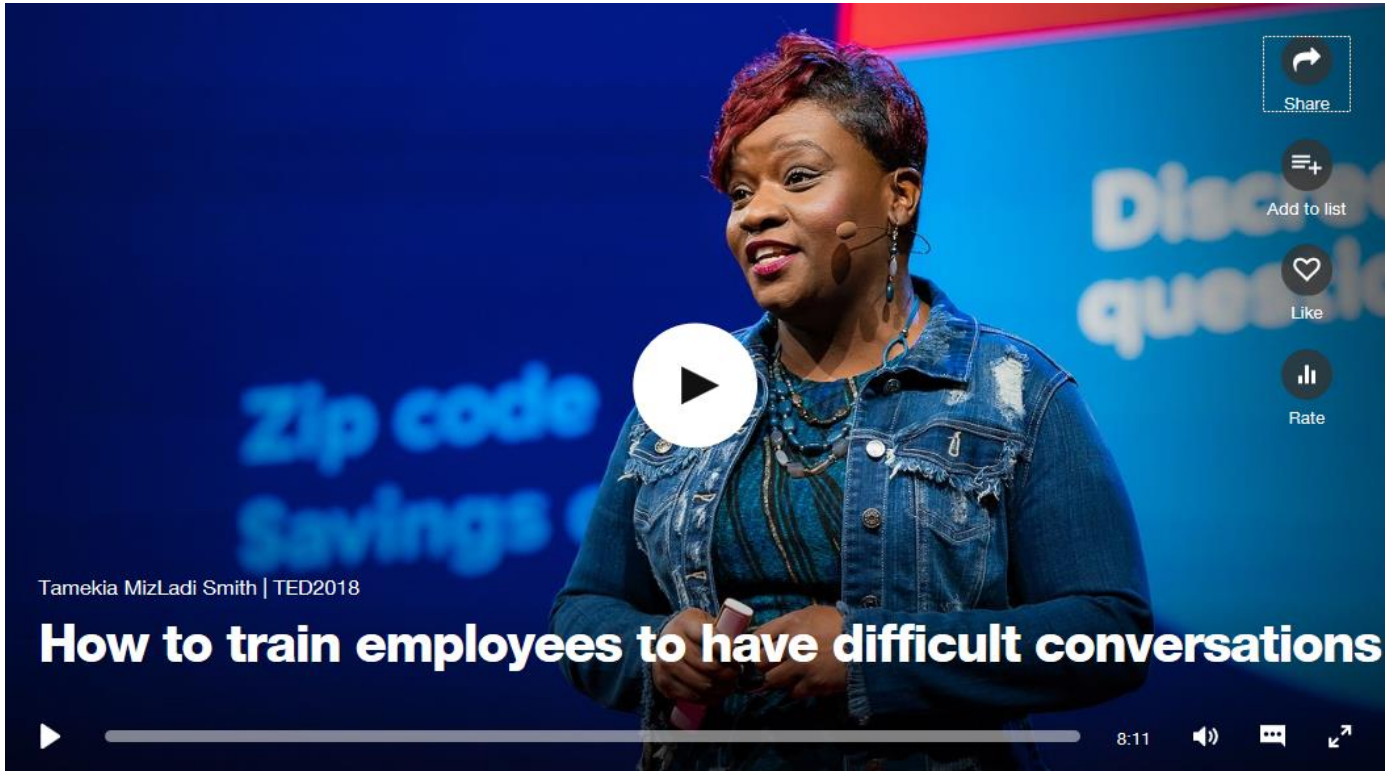
Education	• What is your current level of education?
Food security	• In the past 12 months, worried that food would run out before getting more • In the past 12 months, food bought didn't last and could not buy or get more
Access to medicine	• In the past year, were you unable to get medicine or medical supplies, or did you do anything to make them last longer because of the cost?
Housing	• What is your current housing situation? • Who do you live with? • Was there a time when you were not able to pay the mortgage or rent on time?
Transportation	• In the past 12 months, has lack of transportation kept you from medical appointments, meetings, work or from getting things needed for daily living?
Phone and internet access	• Do you currently have consistent access to a phone or the internet?
Utility bills	• In the past 12 months, did you miss making a payment on any utility bills because of cost?

Measuring Health Equity: Optional Questions

Community	• Do you feel you have people who you can open up to or confide in? • Do you have people to rely on if you needed help?
Employment	• Are you currently employed? • Are you currently looking for work? • Is your main job temporary or part-time? • Do you feel that your employment could be negatively affected if you raised concerns about your work? • In the past 12 months, did your income change a lot from month to month?
Religion	• What is your religious or spiritual affiliation?
Preferred language	• In what language would you prefer to read healthcare information?

Staff Training: Questions

How We Ask Is As Important As W*hat We Ask*



Measuring Health Equity Core Questions:

What do they mean and why do we collect them?

Language

1. **What language do you feel most comfortable speaking in with your provider? (Check all that apply)**					
1 English* (Canadian Official Language) 2 French* (Canadian Official Language) 3 Albanian 4 Amharic 5 Arabic 6 ASL (American Sign Language) 7 Bengali 8 Bulgarian	9 Burmese 10 Cantonese 11 Czech 12 Dari 13 Farsi 14 Georgian 15 Greek 16 Gujarati 17 Hausa 18 Hindi	19 Hebrew 20 Hungarian 21 Italian 22 Karen 23 Korean 24 Mandarin 25 Nepali 26 Pashto 27 Polish 28 Portuguese	29 Punjabi 30 Rohingya 31 Romanian 32 Russian 33 Serbian 34 Slovak 35 Somali 36 Spanish 37 Swahili	38 Tagalog 39 Taishanese/Toishanese 40 Tamil 41 Thai 42 Tibetan 43 Tigrinya 44 Turkish 45 Twi 46 Ukrainian	47 Urdu 48 Vietnamese 49 Another language (please specify):_____ 88 Do not know 99 Prefer not to answer

If someone filling out the form asks: "Why do you want to know?"

You can say:

- We can use this information to provide interpreters

Birthplace

2. (a) Were you born in Canada?		
1 Yes 2 No 88 Do not know 99 Prefer not to answer		
(2b) If no, when did you arrive?		
1 Less than 5 years ago 2 5 to 9 years ago	3 10 years ago, or more 88 Do not know	99 Prefer not to answer

If someone filling out the form asks: "Why do you want to know?"

You can say:

- This information will help us understand the health care experiences of newcomers to Canada – for example, what types of supports would be helpful?

Indigeneity

3. Do you identify as First Nations, Métis and/or Inuk/Inuit? (check all that apply). This question is about how you identify yourself (e.g., includes status or non-status)	
1 Yes, First Nations (status or non-status) 2 Yes, Métis 3 Yes, Inuk/Inuit	4 No 88 Do not know 99 Prefer not to answer

If someone filling out the form asks: "Why do you want to know?"

You can say:

- We can use this information to provide culturally appropriate healthcare for you and your family. We have put/are putting practices into place to ensure that there is Indigenous data governance and sovereignty when we collect this information.

Ethnicity, Culture And Race

4. What is your ethnic or cultural background? For example: Canadian, Chinese, East Indian, English, Filipino, French, German, Irish, Italian, Jamaican, Jewish, Polish, Portuguese, Scottish, etc.	
1 Please specify _____ 88 Do not know 99 Prefer not to answer	
5. Which of the following best describes your racial group? (Check all that apply, for example If you are multi-racial or mixed race)	
1 Middle Eastern, Arab or West Asian (e.g., Afghan, Egyptian, Iranian, Lebanese, Persian, Turkish, Kurdish, etc.) 2 Black (e.g., African, Afro-Canadian, Afro-Caribbean, Afro-Egyptian etc.) 3 East Asian (e.g., Chinese, Korean, Japanese, Taiwanese, etc.) 4 Latin American (Hispanic or Latin American descent) 5 South Asian (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan, etc.)	6 Southeast Asian (e.g., Filipino, Vietnamese, Cambodian, Thai, Indonesian, etc.) 7 White (e.g., European descent) 8 Another race/ethnic group (please specify): _____ 9 Not Applicable (e.g., Identified as Indigenous in question #3) 88 Do not know 99 Prefer not to answer

If someone filling out the form asks: "Why do you want to know?"

You can say:

- This can provide information on patient diets or need for genetic testing
- We can use this data to reach out to vulnerable groups that we know get less screening tests – for example, cancer screening

Disability

6. (a) Do you identify as a person with disability?	
1 Yes 2 If you wish, please specify 3 No	88 Do not know 99 Prefer not to answer

(6b) Could you benefit from support related to any of the following? (Check all that apply)		
1 Alzheimer's Disease/Dementia 2 Autism Spectrum Disorder 3 Chronic Illness (e.g., sickle cell, diabetes etc.) 4 Cognitive Disability 5 Developmental Disability 6 Drug or Alcohol Dependence	7 Learning Disability 8 Mental Illness 9 Physical Disability 10 Sensory Disability (e.g., low vision, blindness, deafness, hard of hearing etc.) 11 Other (please specify) ____	12 None 88 Do not know 99 Prefer not to answer

If someone filling out the form asks: "Why do you want to know?"

You can say:

- Knowing the types of accommodations or accessibility we need will help us provide and plan for better care

Sex Assigned at Birth and Gender Identity

7. What was your sex assigned at birth? (Check one)				
1 Male	2 Female	3 Intersex	88 Do not know	99 Prefer not to answer

8. What is your gender identity? (Check all that apply)	
1 Genderfluid or genderqueer 2 Man 3 Nonbinary 4 Two- Spirit 5 Woman	6 Questioning or unsure 7 Another gender identity (please specify) _____ 88 Do not know 99 Prefer not to answer

9. Do you identify as transgender? Transgender is an umbrella term used to describe people whose gender identity or gender expression differs from the sex they were assigned at birth.
1 Yes 2 No 88 Do not know 99 Prefer not to answer

If someone filling out the form asks: “Why do you want to know?”

You can say:

- It provides information we need for things such as room assignment or types of tests to plan for (e.g., pap smear, blood test interpretation)
- We can use this data to understand the health care experiences of vulnerable groups such as trans clients

Sexual Orientation

10. Which category(ies) best describe your sexual orientation? (Check all that apply)		
1 Asexual 2 Bisexual 3 Demisexual 4 Gay 5 Lesbian 6 Pansexual	7 Queer 8 Questioning or unsure 9 Same gender loving 10 Straight/Heterosexual	11 Two-Spirit 12 Another sexual orientation (please specify) _____ 88 Do not know 99 Prefer not to answer

If someone filling out the form asks: "Why do you want to know?"

You can say:

- We can look at this data to ensure that all clients are getting the best care possible
- We don't want to assume clients' sexual orientation when we provide them with care and services

Income

11. Do you currently have difficulty paying for basic needs?		
1 Yes 2 No 3 Not applicable, I do not have to pay for basic needs 88 Do not know 99 Prefer not to answer		
12. What was your total family income before taxes last year?		
1 $0 - $19,999 2 $20,000 – $39,999 3 $40,000 - $59,999	4 $60,000 - $79,999 5 $80,000 - $119,999 6 $120,000 - $149,999	7 $150,000 or more 88 Do not know 99 Prefer not to answer
13. How many people does this income support?		
1 _____ Persons 88 Do not know 99 Prefer not to answer		

If someone filling out the form asks: "Why do you want to know?"

You can say:

- We want to understand the link between income and health care
- Information on how much a client makes could be relevant to medical prescriptions or access to certain items (e.g., access to a refrigerator), or ability to make it to the hospital

Staff Training: Key Messages

3 Key Messages To Share

Why?

- We are collecting social information from patients/clients to find out who we serve and what unique needs our patients/clients have.
- We will also use this information to understand your experiences.

Voluntary

- The questions are voluntary and you can choose ‘prefer not to answer’ to any or all questions.
- This will not affect your care.

Who will see the information?

- This information will be accessible only to your health care team.
- If used in research, information will be combined with data from all other patients/clients and no one will be able to identify any patient/client.

Sample Messages

It will help us improve services and ensure quality care

Your information will be kept confidential and will only be available to people taking care of you.

These questions will tell us who our patients are

This will take a few minutes. It's completely voluntary, so you can choose 'prefer not to answer' to any of the questions

Sample Workflow: Paper and Electronic-Based Collection

1. Staff hands out form and pen

- Introduce questions to client

2. Staff receives form

3. Staff checks form

- Follow up with client on missing data

4. Staff enters data

Sample Workflow: Interview-Based Collection

1. Staff asks questions

- Introduce questions to client

2. Client provides demographic information

- Staff addresses client questions and concerns

3. Staff enters data

- Staff uses data codes

Critical Steps for Interview-Based Collection

Staff collects the demographic information

Scripts and training materials are provided for staff

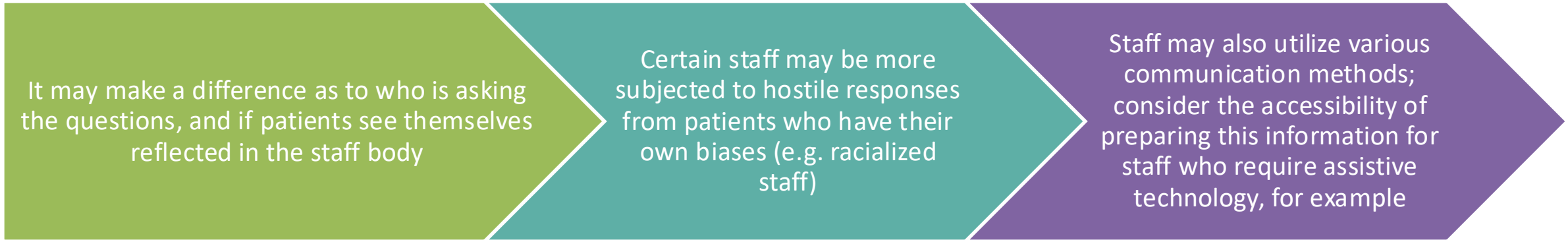
The information collected **SHOULD** be entered the day it is collected.

The information provided by the report is translated into actionable information (i.e., entered somewhere that reception staff can easily access).

Interview-Based Points To Remember

- If a client is unable to respond questions, collect from support person on behalf of the client when possible. If they do not want to answer the questions on the patient's behalf, **bypass the questions.**
- **Do not bypass** if the client looked at the questions, **understood what is being asked**, and refuses to participate. **Select "Prefer Not to Answer" for every question**.
- If the client speaks a different language, **use one of the 16 translated** question forms.

Staff Considerations and Sensitivities



Staff Resources: Role Playing Scenarios

Asking The 8 Core Demographic Questions: Hospitals

https://youtu.be/kSz1B7zDaWs

- What did you like about the interaction between the staff member and patient?
- What do you think could have been done differently or better?

Asking The 8 Core Demographic Questions: CHCs

https://youtu.be/nEiRF9tdby4

- What did you like about the interaction between the staff member and patient?
- What do you think could have been done differently or better?

Practice Session

- **Optional demo: ‘patient/client’ volunteer needed**
- Form groups of 3: Patient/Client, Staff, Observer
- Review practice exercise

  This is a chance to practice:

  - Introducing/presenting the Demographic Data Form
  - Answering any questions or responding to any concerns patients/clients may present

Scenario 1: Hospital Staff Member Role

Today was a bit more challenging than usual, because it was your first day of administering the new demographic questions with patients.

Patients have been receptive so far and no one has refused to answer the questions. They have hardly asked you anything about the new questions and no one has complained or gotten angry. You are not worried about the new questions, you are confident and comfortable.

You greet the next patient and their partner warmly. The patient is in a lot of pain; unable to focus or answer the questions. The patient asks their partner to complete all necessary forms on their behalf. The patient's partner is trying to comfort their loved one and slightly annoyed that registration is taking longer.

Their response is:

- Why do they have to answer all these questions when they're registering?
- What is the purpose of knowing the patient's gender, sexual orientation, income?

Respond to the patient/partner and explain the form.

Scenario 1: Patient Partner Role

You and your loved one have just moved to Toronto and have no social network. You are both anxious as your loved one is experiencing severe pain. You feel the effects of being without your family and you are trying your best to be comforting and supportive. When you and your loved one arrive to register, you receive a package of forms including the health equity demographic questions. Since your partner is in too much pain and too distressed to complete any forms, you do so on their behalf. While you are reading the Patient Information form, you start to feel uncomfortable and unsure of how much time this will take.

You ask the staff member:

- Why does the patient have to answer the questions to register?
- Why do you need to know the patient's gender?
- Why do you need to know the patient's sexual orientation?
- What does the patient's income have anything to do with their right for care?

Tell them you just want to register your partner and move forward with the process.

Scenario 1: Hospital Reviewer

For Evaluating Staff Observer(s):

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/patient's partner?*
- *How well does the staff member respond to the patient/partner's expressed discomfort?*
- *How well does the staff member respond to the patient/partner'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?*

Scenario 2: CHC Receptionist Role

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 that you have adequately 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 couldn't 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 hand out the form to the next 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. Provide information about the questions on gender, sexual orientation and disability as the client doesn't understand why the questions are being asked.

Scenario 2: CHC Client Role

You are 35 years old and have come to the Community Health Centre to participate in a Prenatal Program. You have heard that it is often crowded at the health centre but that their programs are inclusive and helpful.

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 confused 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.

Scenario 2: CHC Reviewer

For Evaluating Staff Observer(s):

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 explain what happens to the data gathered?*
- *What advice do you have for this intake staff member?*

Practice Introducing The Form

We are collecting information to tell us who our patients/clients are.

The questions are voluntary.

Your responses will be protected and stored with your health-care information.

Beyond Demographic Data Collection

Lessons From Data Collection

Client Comfort

- Clients ok with responding
- Advocates have called for data collection

Staff Discomfort

- Address staff discomfort through training
- Build inclusive & respectful spaces

Data Reporting

- Develop clear plan for retrieving data

Data Entry

- Standardize data entry practices to improve quality

New Vs Old Practices

- Implementing changes can be more challenging than introducing new practices

Health Equity Vision

- Equal care does not equal equitable care

Data Quality - Overview

For the Measuring Health Equity project, we want to assess whether our data allows us to:

- Understand who we serve,
- Identify patient and client needs,
- Identify existing health inequities, and
- Provide basis for developing services and health inequity interventions.

"The totality of features and characteristics of a data set that bear on its ability to satisfy the needs that result from the intended use of the data"[1]

[1]Arts, D. G. T., De Keiser, N. F., & Scheffer, G. (2002). Defining and improving data quality in medical registries. Journal of the American Medical Informatics Association, 9, 600-611.

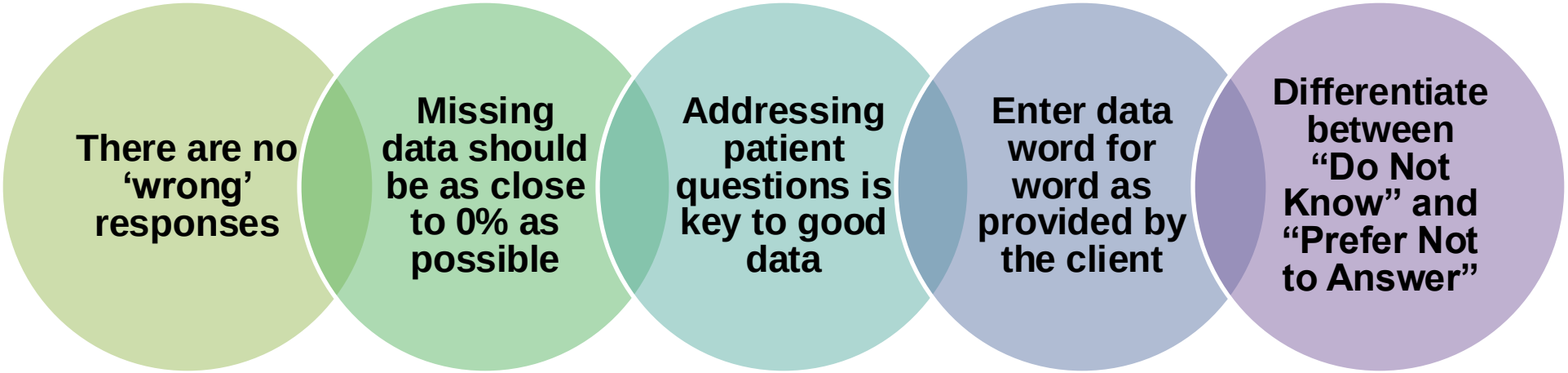
Data Quality Indicators

Participation Rate: ≥75%

- Missing Data Rate
- Prefer Not to Answer Rate: <10%
- Do Not Know Rate

Feedback from staff collecting data and clients

Data Quality



Wrap Up

Takeaway Points

- The demographic questions are additional health related questions
- Patients and clients are willing to share this information
- Some patients and clients are likely to have experienced discrimination and harassment and may be reluctant to answer questions
- Best Practice: Data collection should include follow-up/interaction with patient/client
- The approach of the data collector is the best predictor of patient and client engagement
- Embed data collection into ongoing practices

Contact Information

- **For more information and support:**

  [insert name of key contact person]