

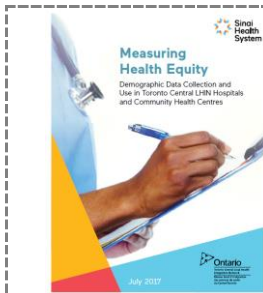
Guide to Demographic Data Collection in Healthcare Settings

A comprehensive guide to planning and implementing demographic data collection in healthcare settings

August 2017

About this guide

This document was written by the Human Rights & Health Equity Office at Sinai Health System and based on the experience of leading the [Measuring Health Equity in Toronto Central LHIN project](#)¹. In this role, the Office has led and coordinated demographic data collection in 16 hospitals and 17 Community Health Centres (CHCs) in the Toronto Central LHIN. In addition to sharing the lessons learned from leading the project for several years, this guide also draws from a literature review, a scan of global best practices, consultations with leading practitioners and researchers, and interviews conducted with hospitals in Canada, the United States, and the United Kingdom.



To learn more about the journey of leading demographic data collection across the Toronto Central LHIN, visit torontohealthequity.ca and download **“Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres”**.

Acknowledgements

Sinai Health System would like to recognize the Toronto Central LHIN for their support and funding of the Measuring Health Equity project. Thank you for the dedicated colleagues in hospitals and Community Health Centres who have sought and developed solutions to collecting and embedding data and generously shared their thoughts and stories. And our thanks to the patients and clients across the Toronto Central LHIN who continue to contribute to our journey and share their information. These collective efforts contribute to the work of improving health and health equity for all.

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¹ The Toronto Central LHIN is the regional health authority for the downtown/central Toronto area. To read more about the Toronto Central LHIN’s mandate and work, visit: www.torontocentrallhin.on.ca

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Chapter 1 – Introduction to the Guide

Poor understanding of data collection goals, challenges with IT solutions, staff discomfort with collecting demographic information, and patient/client reservations are all frequently cited as system-level and individual-level barriers to sustainable demographic data collection and use^{2, 3}. This guide was developed to help healthcare organizations overcome these challenges and embrace the opportunities in standardized demographic data collection. The goals of the guide are

1. explain the rationale for and importance of demographic data collection
2. highlight the impact of demographic data collection on improving health care quality
3. provide evidence-based guidance, tools, and resources for demographic data collection.

The advice in this guide is supplemented by the following



Case Studies: best practices, examples



Checklists: itemized lists to support and guide data collection



Resources: reports, research articles, presentations



Tools: handouts, data collection tools, communication materials



Attention: points to remember

Who is this guide for?

Senior Management

How is patient/client demographic data collection important to your organization?

CEOs and senior management are responsible for ensuring that their organization stays committed to providing the best care possible. In the face of diverse populations and varying needs, 'best care' requires an equity component. Equity is now a universally recognized pillar of quality care⁴ and governments are mandating demographic data collection as a precursor to equity planning⁵.

How will you benefit from this guide?

This guide reviews the challenges, opportunities and benefits of implementing a demographic data collection plan.

² Braveman P. (2014). What are health disparities and health equity? We need to be clear. *Public Health Report*, 2, 5-8.

³ Human Rights & Health Equity Office. (2017). *Measuring health equity: Demographic data collection and use in Toronto Central LHIN hospitals and community health centres*. Retrieved from Toronto Health Equity website, Sinai Health System: torontohealthequity.ca

⁴ Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: The National Academies Press. Retrieved from <https://doi.org/10.17226/10027>.

⁵ Whitehead M, Dahlgren G. (2006). *Concepts and principles for tackling social inequities in health: Levelling up part 1*. Geneva: World Health Organization.

Quality Improvement Specialists

How can demographic data collection be an important part of your quality strategy?

Evidence clearly points to the significant role of demographic variables, such as race and language, in shaping the quality of care experienced by patients/clients. With equity now universally recognized as a pillar of quality, providing excellent care cannot be achieved without integrating an equity component.

How will you benefit from this guide?

This guide will introduce you to research that links demographic information to healthcare outcomes. It will also provide you with an understanding of data collection tools and illustrate why this data is needed to identify gaps in quality care.

Data Collectors

How is your involvement key to successful demographic data collection?

Individuals collecting the data play a significant role in determining the success of the initiative. It's important that you are familiar with the project's objectives, can communicate them to patients/clients and caregivers, and are comfortable answering questions or addressing concerns.

How will you benefit from this guide?

This guide will help you understand the why and the how behind the data collection process so that you feel comfortable interacting with patients/clients and can answer any of their questions.

Information Technology Specialists

What is your role in supporting your organization's demographic data collection?

The IT component is key for determining what your options are for capturing, sharing, and reporting data. Increasing your familiarity with demographic data collection goals and processes will improve your capacity to answer questions and develop solutions.

How will you benefit from this guide?

In addition to identifying the important issues that impact IT solutions (e.g., privacy, access, data entry, etc.), this guide will also review the questions that need to be addressed when building demographic fields and reports.

Privacy Officers

What is your role in the implementation of demographic data collection?

Privacy officers need to be involved to ensure that the protocols are in line with organizational and regulatory mandates. Protecting patient/client privacy will be a key element of successful implementation.

How will you benefit from this guide?

This guide includes resources and tips you can refer to as you develop data collection protocols. It also includes a number of examples illustrating how other organizations have worked on data collection in a manner consistent with privacy legislation.

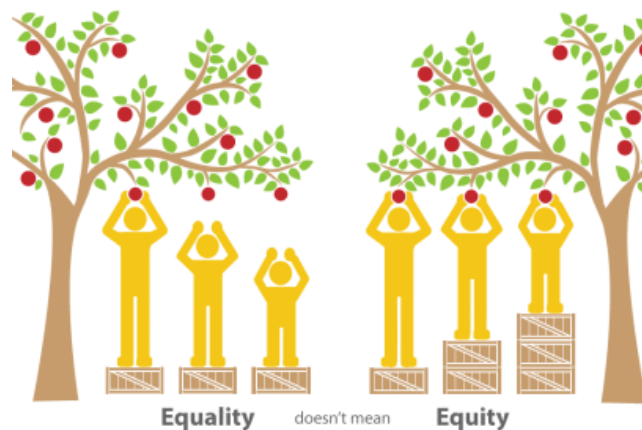
Chapter 2 – Health Equity Principles

2.1. What Is Equity?

According to Health Quality Ontario, “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 are⁶” (p.7). It’s about striving for the highest possible standard of health for all, with attention to the needs of those at greatest risk of poor health based on social conditions.

Research on “health inequities” reveals a number of common themes^{7, 8, 9}:

- Health inequities are differences in health that are “avoidable,” “unjust,” and “unfair.”
- 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.
- Equal care should not be confused with equitable care.
 - Equitable care incorporates unique needs that people may have based on language, income, gender, etc.
 - Equal care = same care and fails to achieve equitable care.
- Understanding health inequities requires recognizing what the impact of the social determinants of health are and how they affect patients/clients, families, and healthcare organizations.
 - The primary factors that shape the health of Canadians are not medical treatments or lifestyle choices but rather the living conditions they experience. These conditions have come to be known as the social determinants of health¹⁰(p. 7).



Source: Saskatoon Health Region. (2014, June). “Advancing Health Equity in Health Care”.

⁶ Health Quality Ontario. (2016). *Health equity plan*. Retrieved from Health Quality Ontario: http://www.hqontario.ca/Portals/0/documents/health-quality/Health_Equity_Plan_Report_En.pdf

⁷ Ibid.

⁸ Braveman P. (2014). What are health disparities and health equity? We need to be clear. *Public Health Report*, 2, 5-8.

⁹ Whitehead M, Dahlgren G. (2006). *Concepts and principles for tackling social inequities in health: Levelling up part 1*. Geneva: World Health Organization.

¹⁰ Mikkonen, J., & Raphael, D. (2010). *Social Determinants of Health: The Canadian Facts*. Toronto. York University School of Health Policy and Management.

What is the difference between ‘health inequity’ and ‘health disparity’?

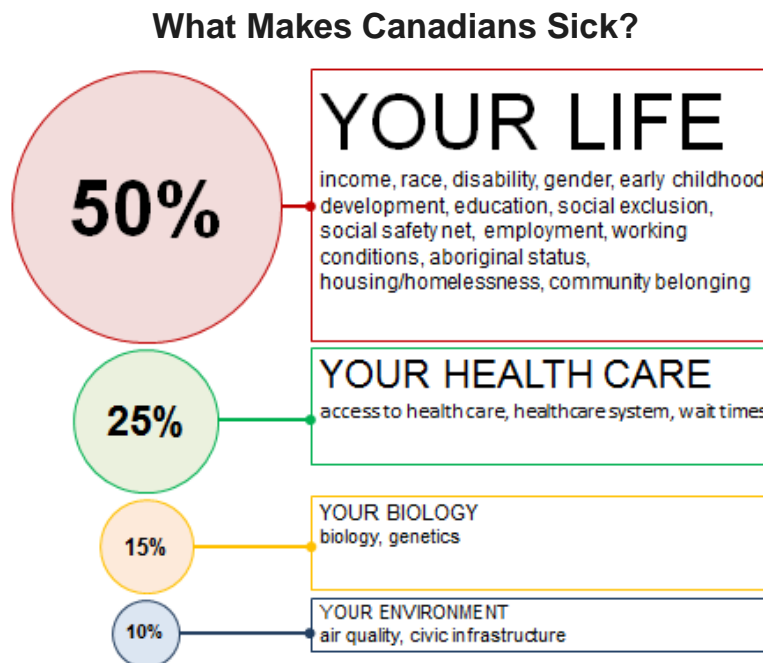
While sometimes used interchangeably, the terms reflect distinct interpretations for differences in health outcomes. The term “health disparities” refers to differences in health outcomes but does not indicate what the drivers of those differences may be, i.e., whether these differences are unfair or due to a disadvantage in care based on social or economic factors. On the other hand, “health inequities” imply differences in health that are unfair, unjust, and shaped by social or economic characteristics of the patient/client such as language, disability, gender, etc.



Tool – “[Towards an Understanding of Health Equity: Glossary.](#)” A glossary of health equity terms from Alberta Health Services

2.2. Canada’s Social Determinants of Health

It has long been acknowledged that Canadians’ well-being is largely determined by “life” factors such as race, employment, language, etc. In Canada, economic and social conditions such as income, race, and housing significantly affect Canadians’ physical and mental health beyond their lifestyle choices and medical treatments^{11, 12, 13}.



Adapted from Canadian Medical Association’s “Health Equity and the Social Determinants of Health”

¹¹ Canadian Institute of Child Health. (2000). *The Health of Canada’s Children: A CICH Profile - 3rd Edition*. Ottawa, Canada: Canadian Institute of Child Health.

¹² Mikkonen, J., & Raphael, D. (2010). *Social Determinants of Health: The Canadian Facts*. Toronto. York University School of Health Policy and Management.

¹³ Bierman, A. S. et al. (2012). Social determinants of health and populations at risk. *Ontario Women’s Health Equity Report: Improving Health & Promoting Health Equity in Ontario*.



Resource – “[Social Determinants of Health: The Canadian Facts.](#)” One of the most widely-cited Canadian publications on how social and economic conditions have paved the way to significant health inequities across Canada



Resource – “[Health Equity and the Social Determinants of Health: A Role for the Medical Professional.](#)” A Canadian Medical Association policy paper outlining needed action and recommendations for addressing health inequities

2.3. Equity as a Component of Quality

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

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

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



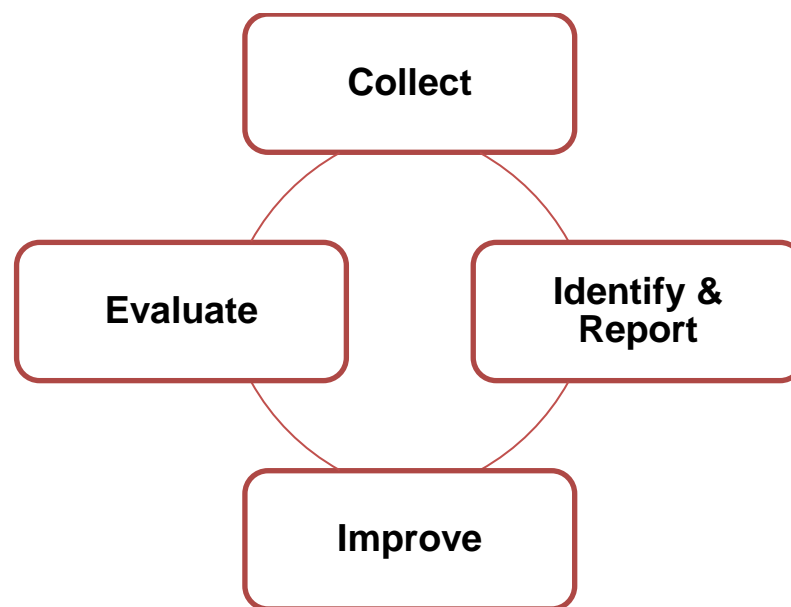
Resource – “[Crossing the Quality Chasm: A New Health System for the 21st Century](#)”
Read the IOM’s groundbreaking report that paved the way for the inclusion of equity as a pillar of quality.

Chapter 3: Laying the Groundwork

3.1. Link Demographic Data Collection to Health Equity

Making the case that data collection is an essential building block for ensuring equitable and quality care is critical. Below is a framework outlining the various components that make up an evidence-based and data-driven approach to planning and providing equitable health care. This framework was the result of a literature review, an environmental scan, and conversations with policy-makers, administrators, and various healthcare organisations using data to advance equity.

Framework for Data-Driven Equitable Health Care



- **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. When done properly, demographic data serves as a fundamental building block for identifying and tracking gaps in quality of 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 outcomes based on demographic variables such as race, language, and income.
- **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. Aggregating and analysing demographic data will also enable the development of programs to target populations disproportionately affected by adverse health outcomes.
- **Evaluate** data collection practices and intervention programs: Ensuring the collection of high quality demographic data necessitates evaluating data quality and improving practices as needed. Once an intervention is put in place to improve health equity, organizations should follow up and ensure changes or new programs have met their goals.



Case Study – CRC Navigator Program at Massachusetts General Hospital, an illustration of how demographic data was used to implement targeted programming

Objective

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

Strategy

Steps 1 – 2: Collect demographic data and **identify & report** inequities in care:

MGH stratified colon cancer screening data and found evidence of lower screening rates for low-income and non-English-speaking populations.

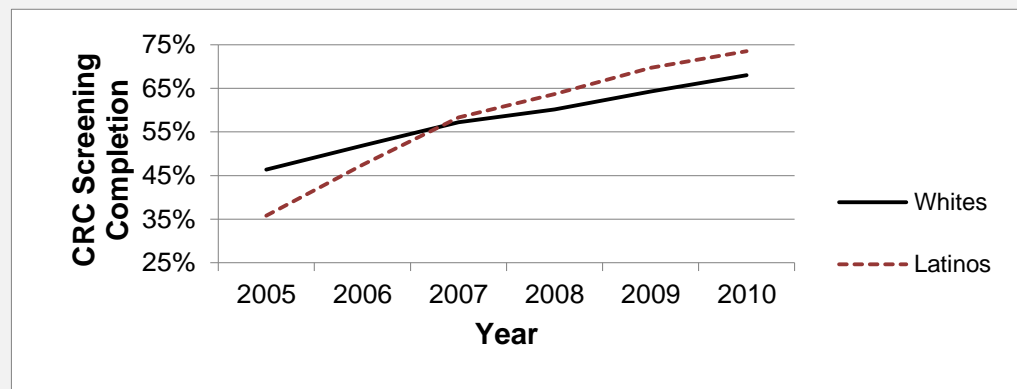
Step 3: Implement solutions to reduce inequities:

Navigator (staff member in the program) used hospital registry to identify patients, by race/ethnicity, who hadn't been screened for colon cancer.

Navigator worked with patient on providing targeted intervention (education, exploration of cultural perspectives, logistical issues).

Step 4: Evaluate effectiveness of solutions:

Program was associated with a significant increase in colon cancer among Hispanic patients.



Joseph Betancourt, J. R. (2012). Achieving health equity and providing quality care. Talk presented at *Measuring Health Equity in Toronto Central LHIN* symposium in Toronto, ON.

3.2. Project Lead & Steering Committee

Assign Project Lead

Project Lead Responsibilities

The Project Lead will oversee the planning and implementation of demographic data collection across the organization. This individual will

- lead Steering Committee meetings
- coordinate and/or provide demographic data collection training

- act as an internal champion for advancing equity through data collection
- oversee the development and progress of a work plan, including goals, deliverables, and timelines

Project Lead Qualifications

A key quality is the ability to engage management, staff, and patients/clients. The ideal Project Lead will also be

- knowledgeable on equity issues, including inequities in health care and existing access barriers
- familiar with the organization's structure and culture
- knowledgeable on health care quality principles
- comfortable sharing and discussing data

Form Steering Committee

Steering Committee Responsibilities

- develop a work plan that includes goals, objectives, and a timeline for the Initial Implementation of Demographic Data Collection
- identify organization stakeholders who are involved in or impacted by this project
- use feedback to improve data demographic framework
- identify and gain consensus on equity planning goals
- plan for the use of demographic data in equity planning



Tool – "[Steering Committee Mandate.](#)" A sample mandate that highlights the goals, operating principles, and membership requirement of the steering committee



Tool – "[First Meeting Agenda for Steering Committee.](#)" A sample mandate that highlights the goals, operating principles, and membership requirement of the steering committee

Steering Committee Expertise

Demographic data collection is a process that requires input from several key players. Below is a list of important expertise to consider.



Checklist – Steering Committee Expertise. A sample list of the expertise needed for the committee

- data administration or decision support
- registration/admission/clerical (the data collectors)
- privacy officer or person knowledgeable about organization's data privacy practices
- clinician – nursing, social work, physician, allied health, etc.
- IT person(s) who can speak to building the fields and pulling data in reports
- patient relations
- senior management

3.3. Internal Scan

Your organization may already be collecting various pieces of demographic data in silos or with no plan around data monitoring and use. Examples of such cases include clinicians who may ask about religion for chaplain or food preferences, or social workers who ask about income to assess patient/client assistance needs.

Rather than going back to the drawing board, Steering Committees can reach out to those who already collect some of this data to get information on what works and what does not. What advice can data collectors provide? What are best practices and lessons learned within your organization? Those consulted can also be invited to join the Steering Committee to share their insights on successful practices.

Chapter 4: 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

4.1. Define Goals for Data Collection

Link demographic data collection goals to vision

The majority of hospitals and CHCs include equitable and accessible care in their vision. Given that access to data is vital for data-driven planning and health care delivery, the organization's vision can be used to make a strong case for embedding data collection in the organization.

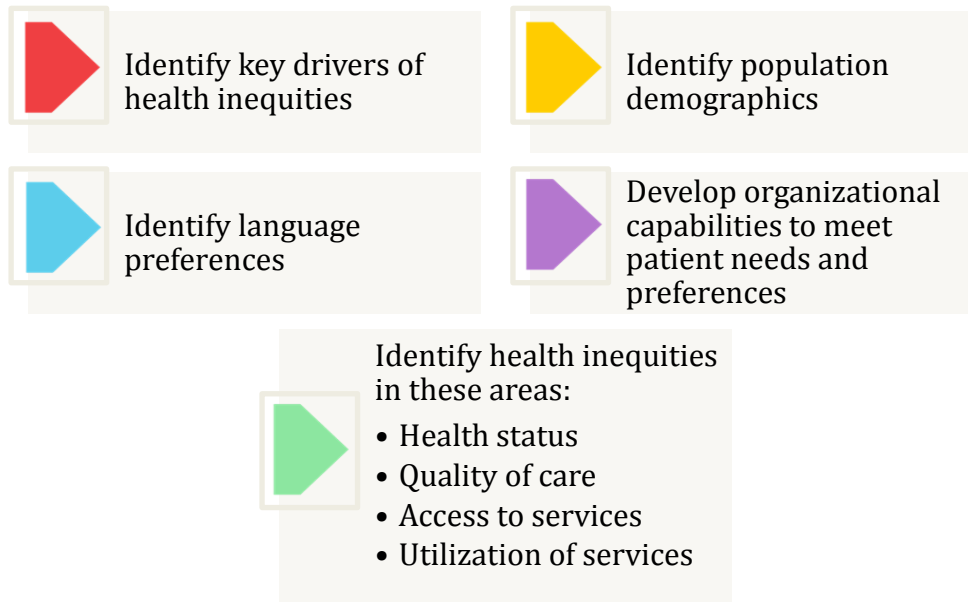
Identify goals

Two of the most common questions that come up when organizations plan for data collection are "why?" and "how are you going to use the data?". Having clear goals for data collection will provide those answers and function as a very effective engagement tool. Goals for collecting data can include two levels of use:

- Organizational-level use
 - develop a profile of the populations being served by your organization
 - stratify clinical indicators (e.g., cancer screening) by demographic data to identify inequities in screening rates
 - plan programs and services based on the communities being (or not being) served
- Individual-level use
 - identifying need for accommodation or language interpretation

- refer patient to services or supports
- interpret medical tests and treatments (e.g., for transgender individuals)

America's Health Insurance Plans association published a toolkit on using data to address health inequities. In the toolkit, they provided a number of concrete goals related to demographic data collection (see resource below):



Resource – [“Tools to Address Disparities in Health: Data as Building Blocks for Change.”](#)
A data collection and use toolkit for policy makers and healthcare organizations

Setting goals requires

- **A clear vision** – Identify how collecting patient/client demographic data can inform and/or improve care.
- **Measurable outcomes** – How will an organization evaluate whether it has accomplished its goals? In order to evaluate goals, the Steering Committee should think of deliverables they can identify and evaluate (e.g., participation rate targets). You can refer to the Sample Work Plan below for examples of goals and deliverables around demographic data collection.
- **A timeline** – Setting a timeline requires prioritizing goals and objectives. For the first year of data collection, a realistic approach will be to profile all patients/clients you serve. As your sample size grows and data quality improves you can start adding new milestones for data use.

The Health Equity Project Coordinators will help your organization identify

- Goals: What is the big-picture aim of this project for us?
- Objectives: What should the results look like?
- Strategies: What are the steps for achieving those results?
- Deliverables: What are the quantifiable/tangible products?
- Timeline: How long will objectives take to accomplish?



Tool – “[Work plan for initial implementation of demographic data collection.](#)” A work plan that lays out the key tasks and deliverables for implementing a demographic data collection initiative

4.2. Engage Senior Leadership

The environmental scan of U.S., U.K., and Canadian healthcare organizations revealed several common successful strategies for engaging senior leadership.

- Link demographic data collection to performance management by showing how it can be used to increase service delivery, efficiency, and effectiveness.
- Share evidence of how demographic data has been used to improve outcomes such as resource utilization, length of stay, complications, birth weight, and managing diabetes.
- Highlight the capacity for demographic data to enrich understanding of quality performance indicators.
- Develop a ‘concept paper’ communicating the essentials of the study and its benefits/necessity for the organization.



Resource – “[Improving Health Equity through Data Collection and Use: A Guide for Hospital Leaders.](#)” A report that targets hospital leaders and outlines the rationale for collecting demographic data; includes case studies and examples

4.3. Engage Patients/Clients and Staff

Engaging patients/clients

Based on input from patients, privacy officers, and organizations, healthcare organizations collecting demographic data should share **three** pieces of information:

WHY: Why is our organization collecting demographic data?

The consensus is that when patients/clients understand the importance of sharing their demographic data they are significantly more likely to share that information¹⁴. Share your goals for demographic data collection, such as outlining how the data can be used to plan services and provide actionable recommendations for staff (e.g., identify need for interpreter).

WHO: Who has access to your demographic data?

A significant piece of consent and comfort with sharing the data is knowing who will have access to it both internally (e.g., ‘your healthcare team’) and externally (e.g., ‘research’) and how you’re protecting it.

OPTIONAL: Do you have to respond to all questions?

We highly recommend that patients/clients have the option of ‘prefer not to answer’ to any or all of the questions. This respects their right to not participate and makes staff more comfortable about asking.

¹⁴ New Hampshire Health & Equity Partnership, (nd). Data: Key points, recommendations, current initiatives, and resources. Retrieved from <http://www.healthynh.com/nhhep-data.html>



Case study – Introduction to the ‘Toronto Central LHIN Demographic Questions.’ Below is the introduction that Toronto Central LHIN hospitals include in their demographic forms. It serves as one example of how the three message above can be worded.

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

Do I have to answer all the questions?

No. 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 this information?

This information will be visible only to your healthcare team and protected like all your other health information. If used in research, this information will be combined with data from all other patients and no one will be able to identify any of the patients.

For more examples on how to communicate with patients/clients about data collection, please refer to [Chapter 6: Staff Training](#).

You can additionally engage patients/clients through communication tools such as posters placed near data collection locations and brochures that address frequently asked questions.



Tool – [‘We Ask Because We Care’ patient/client poster](#). A poster that can be placed in area of data collection; available in French on torontohealthequity.ca/tools/



Tool – [‘We Ask Because We Care’ patient/client brochure](#). A brochure that is written in plain English and reviews the most common questions on demographic data collection; available in 11 languages on toronthealthequity.ca/tools/

Engaging staff

While early resistance to data collection tends to focus on patient/client reactions, organizations that have been collecting data for a long time indicate that staff resistance persists even after patients/clients are shown to be open to data collection. In fact, staff resistance is the most commonly cited barrier to demographic data collection¹⁵, and is often driven by

- poor and inconsistent training on asking demographic questions
- unfamiliarity with project goals
- failure to clearly communicate why we need the data and the workflow for collecting it
- discomfort with demographic data collection elements (e.g., gender, sexual orientation)

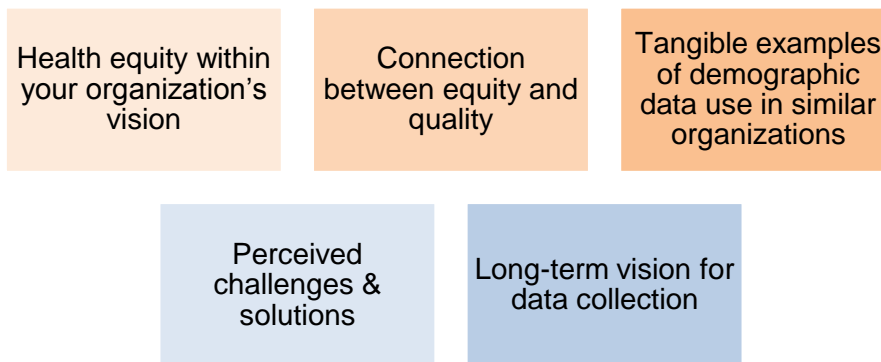
¹⁵ Interviews during the period of August–October 2012 with *Guwan Jones* (Director of Health Equity at Texas Baylor Health Care System), *Nancy Connery* (Director of Admitting and Registration Services at Massachusetts General Hospital), *Natalie Sabino* (Lehigh Valley Health Network Diversity/Cultural Liaison), *Romana Hasnain-Wynia* (Director and Scientific Program Leader at Patient Centered Outcomes Research Institute), and *Sarah Bowen* (Professor in the School of Public Health at the University of Alberta)

Presentations

Presentations tailored to the audience and the venue may be given at staff meetings and workshops. While the key messages will be the same, the focus may shift slightly depending on the group.

- Managers and supervisors may be most interested in learning about how access to demographic data can transform health care planning and delivery.
- Staff directly working with patients/clients will be looking for information on how data collection fits with their work flow and how patients/clients will respond to getting the questions.

Your presentation should include



Internal communication

Many organizations that started data collection shared the news through email, the intranet, or an online newsletter.

4.4. Maintain Ongoing Evaluation

To evaluate the demographic data collection project, you need a clear identification of vision and goals, usually located in work plans and objectives. The purpose of an evaluation is to

- monitor performance and make improvements
- justify changes to staff and patients/clients

While evaluation has traditionally been approached with apprehension, the health sector has invested considerable resources in devising tools that organizations can use.



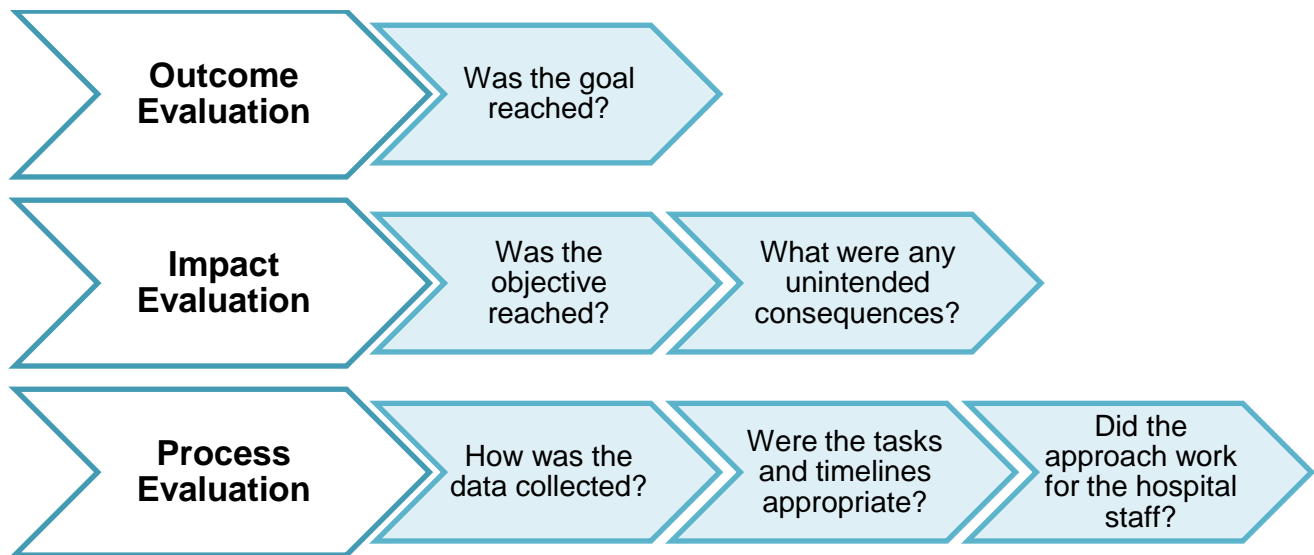
Resource – “[A Guide to Evaluation in Health Research.](#)” An evaluation guide written by Sarah Bowen for the Canadian Institutes of Health Research; adaptable to demographic data collection.

Setting deliverables and goals for evaluation can be a challenging process. Once hospitals gain access to patient/client demographic data they can use this information to identify health inequities and develop interventions to address them.

Ramirez *et al.* (see resource below) indicate that evaluating a health equity project must include

- developing reachable expectations among hospital stakeholders
- tracking actions and activities so you may try to link presence/absence of outcomes to the steps you took/missed
- identifying small, short-term milestones and/or objectives on the path to the long-term goal

Ramirez *et al.* also illustrate the forms of evaluation that organizations and communities should consider in equity planning. These forms may differ depending on the questions being asked:



Resource – [“Promoting Health Equity: A Resource to Help Communities Address Social Determinants of Health.”](#) This report by Ramirez, Baker, and Metzler (2008) for the American Centers for Disease Control and Prevention is a rich resource on how to evaluate health equity programs and use demographic data in developing plans/programs.

Chapter 5: Design Demographic Data Collection Model

When planning to roll out demographic data collection in your healthcare organization, you will need to work and plan around four components:



5.1. Demographic Questions

The eight demographic questions being used to collect patient and client demographic data in Central Toronto came out of a research project led by Mount Sinai Hospital, CAMH, St. Michael's Hospital, and Toronto Public Health. The project's aims included identifying which variables to collect, how to word the questions, and best practices in data collection practices. The results are an evidence-based demographic data tool that recommends eight variables: Spoken Language, Born in Canada, Racial/Ethnic Group, Disability, Gender, Sexual Orientation, Family Income, and # People Income Supports. It was adopted by the Toronto Central LHIN as part of its data collection mandate in hospitals and CHCs.



Resource – [“We Ask Because We Care: The Tri-Hospital + TPH Health Equity Data Collection Research Project.”](#) A summary report of the research that led to the eight demographic questions being used in data collection across the Toronto Central LHIN



Tool – [8 demographic questions for hospitals.](#) A list of the eight patient demographic questions mandated for demographic data collection across the Toronto Central LHIN hospitals



Tool – [8 demographic questions for CHCs.](#) A list of the eight client demographic questions mandated for demographic data collection across the Toronto Central LHIN Community Health Centres

5.2. Methodology and Procedures for Demographic Data Collection

Identify location for data collection

Healthcare organizations should consider two factors when selecting location for data collection:

- The ease with which asking demographic questions can be streamlined into existing workflows
 - Data collection is more easily incorporated into the roles of staff who regularly collect patient/client demographic information and collect forms
- The volume/percentage of patients/clients who can be reached in area of collection
 - Unless you start in a small area in order to learn lessons and gain experience in data collection, the recommendation is that you focus on casting a wide net and select busy areas. Doing so offers a better return on the investment of training staff and developing data collection solutions.

Setting: Primary, Acute, or Ambulatory Care

The majority of primary, acute, and/or ambulatory care organizations collect demographic data during registration or admission. The two main reasons for this approach were

- **Practicality:** The workflow at registration/admitting often requires collecting or confirming personal information with the patient/client. The addition of the eight demographic questions can be an extension of that work.
- **Timeliness:** Having access to that data at the point of arrival will enable an organization to anticipate patient/client needs ahead of the visit.

Setting: Rehabilitation/Complex Continuing Care

Given the nature of care in rehabilitation and complex continuing care facilities, patients/clients generally get more time with their healthcare providers and develop strong relationships with staff. As a result, we found that these types of organizations are more likely to collect the data through clinicians.

Starting small?

Organizations that start collecting data on a smaller scale in preparation for an organization-wide collection can use that opportunity to learn about the challenges and solutions of data collection.

There are several ways to start data collection on a smaller scale before expanding efforts:

- Collect data at specific times of the day when it's less busy.
- Collect data on a reduced number of days (e.g., 4 days a week).
- Collect data at one site (for organizations with multiple sites).



For hospitals, we recommend collecting in areas such as blood labs, medical imaging, ECG clinics, and others where patients go for tests before meeting with their clinicians. These areas tend to have high volumes and will provide with a wide reach into the hospital's departments without having to collect in individual clinics.

Select key messages to share

As mentioned earlier in section [4.3. Engage Patients/Clients and Staff](#), patients/clients are more likely to share demographic information when they

- understand why it is being collected (i.e., how it will be used)
- are informed on who gets access to the data and how it will be shared
- know that withholding the information will not negatively impact their care

Sample messages

Explaining why and how

We are currently collecting additional information from our patients/clients. It will help us understand our patient/client needs and provide relevant services. This information will also help us see how we can improve the quality of care for patients/clients. You can decline to answer any of the questions.

Explaining data is confidential and private

Your answers will only be seen by the team taking care of you. If shared for research, it will be protected and all your personal information will be removed. There will be no way to link the data to any individual.



Tool – [CHC Cheat Sheet – Handing Off Forms](#). A tool available for organizations collecting demographic data using paper forms; includes key messages and workflow information



Tool – [Hospital Cheat Sheet – Asking Directly](#). A tool available for organizations collecting demographic data by directly asking individuals the eight demographic questions; includes key messages and workflow information



Additional cheat sheet samples for CHCs and hospitals are available at <http://torontohealthequity.ca/tools/>

5.3. Patient and Data Privacy Considerations

The Steering Committee should include a privacy officer or someone familiar with issues around patient/client privacy and data sharing. They will help the organization understand the implications of demographic data collection and plan for a process that will respect and comply with privacy regulations. These privacy considerations should cover the various stages of the demographic data collection plan:

- **Data Collection Purpose:** How will the data be used by the organization?
- **Data Storage:** Where will the data be stored so that it remains private?
- **Data Retrieval:** Who can retrieve and see the data once it has been entered?



Checklist – Privacy principles and requirements to discuss around demographic data collection/storage/use¹⁶

<input type="checkbox"/> Accountability	Designate a contact person to identify privacy obligations, address requests for access to data, and respond to questions.
<input type="checkbox"/> Purpose	Inform patients/clients of demographic data collection purposes.
<input type="checkbox"/> Consent	Identify whether you can rely on implied consent. Otherwise obtain express consent when collecting/using/disclosing demographic information.
<input type="checkbox"/> Limiting Collection	Articulate how collection of demographic information is necessary for the identified purposes (i.e., health equity) or for the purposes that the Health Information Act, 2004 permits/requires.
<input type="checkbox"/> Limiting use & disclosure	Limit the use or disclosure of personal demographic information to the identified purposes, unless you obtain further consent or your use or disclosure is permitted by law.
<input type="checkbox"/> Accuracy	Take reasonable steps to insure data is accurate, complete, and up-to-date as is necessary for the purpose for which you use or disclose it.
<input type="checkbox"/> Safeguards	Implement appropriate technical, administrative, and physical safeguards to protect your patients' privacy and the confidentiality of their personal health information. Ensure your staff is informed about and understands privacy and confidentiality requirements.
<input type="checkbox"/> Openness	Develop and make available a written statement on your information practices (e.g., brochure that includes information about your collection, use, and disclosure of personal demographics collected).
<input type="checkbox"/> Access	In a timely manner, give your patients access to, and the ability to correct, their demographic data.
<input type="checkbox"/> Challenging compliance	Develop simple complaint procedures to allow individuals to challenge your privacy practices.



Resource – [“A Guide to the Personal Health Information Protection Act.”](#) A guide by the Information and Privacy Commissioner of Ontario that uses case studies and FAQs to help organizations understand their obligations under existing legislation

¹⁶ Adapted from: Ontario Hospital Association. (2004). “Hospital Privacy Toolkit, Guide to the Ontario Personal Health Information Act, 2004.

Leading up to the implementation of demographic data collection in the Toronto Central LHIN, Mount Sinai Hospital's Corporate Privacy Office & Freedom of Information Coordinator issued a memorandum describing how personal health information can be collected, used, and disclosed. The case study below provides more information.



Case study – "[Mount Sinai Hospital Privacy Memorandum](#)." A memorandum written by Mount Sinai Hospital's privacy officer outlining how the information can be collected, used, or disclosed in line with privacy legislation



Is up to each organization to ensure that you are collecting and using the data in compliance with the Ontario Personal Health Information Act (2004) and any other legislation.

Special consideration should be given to how data collected on Indigenous patients and clients is used and shared. Ensure practices respect and are in line with [OCAP principles](#).

5.4. IT Solutions in Demographic Data Collection

Any IT programs and solutions should be guided by the recommendations of privacy officers to ensure that patient/client data is securely stored. Therefore, IT and Privacy have a number of common questions that they will need to collaborate on. The questions focus on the entry, storage, and use of demographic data.



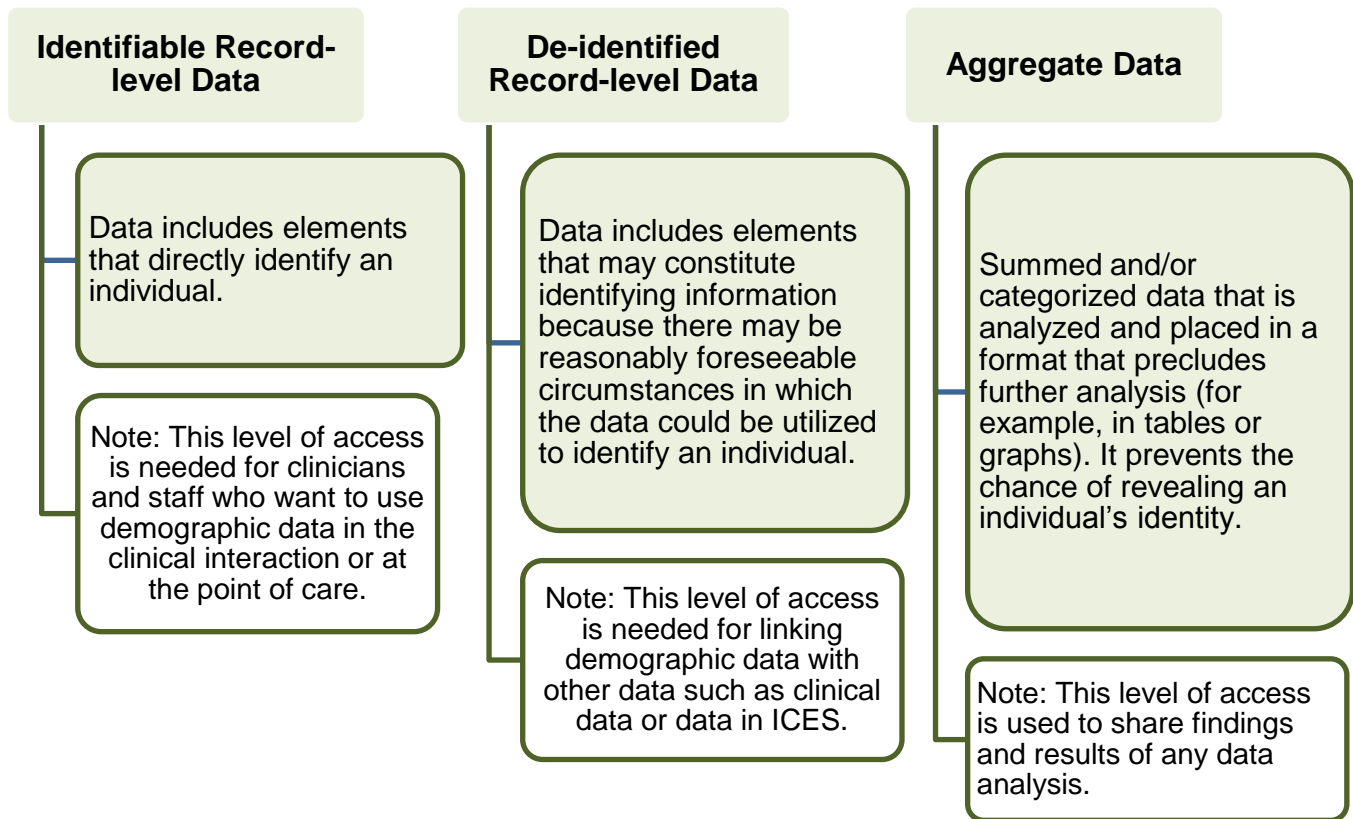
Checklist – The following is a list of questions that will shape your IT plan for capturing, using, and reporting demographic data (to be completed in consultation with your IT team):

- Who is going to collect/enter the data?
- Where is the best place for building the data fields to ensure easy access for staff?
- Is the data captured at the visit/encounter level or the patient/client level?
- Can you build in the ability to check if patient/client has already responded?
- What are the types of report you need? What will they look like? (e.g., report summarizing the data, report auditing participation rates, etc.)
- Who needs access to the demographic data reports?

Data retrieval

IT solutions around data retrieval should consider the form in which data needs to be accessed (e.g., identifiable, de-identified, in aggregate form, etc.). This is defined by who will see the data, what data linkages you make, and which items will remain visible for service provisions. This is a critical piece of information you must share with clients, patients, and staff.

The Data Use and Disclosure Standard report by Cancer Care Ontario (CCO) (see resource below) uses the following classifications for CCO data:



Resource – “[Data Use & Disclosure Standard](#).” A standard set out by Cancer Care Ontario that outlines expectations on using and disclosing data

Why standardize data collection?

The variation in research tools and data collection methodologies across Canada makes it difficult to compare findings and build on existing knowledge. A standardized method is therefore a key predictor of reliable, valid, and usable patient/client demographic data.



Canadian databases focus on population-level information and provide limited options for data use within organizations. For example, an organization that wants to understand who they serve, identify individual patient/client needs, or evaluate program effectiveness for certain patients/clients would have a difficult time accomplishing those goals without internally collecting individual-level demographic data.

Chapter 6: Staff Training

6.1. Develop a Training Program

Training is the cornerstone of successful demographic data collection. Below are the goals of the Sinai Health System demographic data collection training program:

1. Ensure staff develop an understanding of health equity principles, terminology related to the questions, and the purpose/scope of the project
 - Staff and data collectors have indicated that it's very important for them to understand the goals of demographic data collection.
 - Data collectors often reported feeling frustrated with poor communication from management about the purpose of collecting the data and how it would improve the organization's work.
2. Familiarize data collectors with protocols and tools for data collection
 - Through exposure to real-life scenarios and tips on how to answer questions and address difficult situations, staff will become more comfortable with the data collection process.
 - It is vital to make staff comfortable with data collection, as 'discomfort' and 'anxiety' are often cited as the top reservations in collecting sensitive demographic information from patients/clients.
3. Ensure the standardization of data collection practices
 - From a data quality perspective, standardizing tools and data collection methodology will minimize differences in responses that are due to data collection methods.
 - Using the same questions and similar methodologies will facilitate the ability to compare data across time and between organizations.

Training materials

The Sinai Health System training materials cover

- why we need to collect demographic data
- how to ask questions
- resources for building skills to collect demographic data
- supporting materials for collecting patient/client demographic data



Tool – [Participant Manual](#). This manual provides admitting, registration, and healthcare staff with the educational materials and resources they need to collect patient and client demographic data using the eight Toronto Central LHIN questions.



Tool – [Training Presentation](#). This presentation provides training on how to collect demographic data in health care and should be used alongside the Participant Manual (see tool above).

eLearning

In addition to in-person training materials, hospitals and CHCs also have access to a one-hour eLearning module that can be completed online. We recommend that this type of module be followed up with a one-hour session focused on role playing and addressing staff anxiety.



Tool – [eLearning module](#). This one-hour eLearning module provides Toronto healthcare staff with the tools to effectively collect patient and client demographic information.

Videos

Training should include tools beyond a presentation. The Sinai Health System team developed a number of videos on how to collect demographic data in a respectful and informative manner. The majority of people in the videos are staff collecting data in Toronto hospitals and CHCs.



Tool – [Training videos](#). This collection of videos illustrates various interactions between healthcare staff and patients/clients when asking questions about their demographic information.

Data collection supporting materials

Staff expressed the need for scripts and guides that provide them with clear wording to use when collecting demographic data and responding to patient/client questions on why we are asking about income, gender, etc. We recommend that you include these materials in the training and ensure that data collectors have access to them.



Tool – [Script for Demographic Data Collection](#). A script that staff can use to explain the purpose of demographic data collection and why it would be helpful to have data on the eight Toronto Central LHIN questions

6.2. Create Inclusive and Respectful Environments

Demographic data should be collected in an environment where patients, clients, and staff feel respected and safe. Moreover, developing the skills that would enable supporting someone who has experienced discrimination or harassment can be helpful.

The Sinai Health System team has worked on embedding principles of inclusion and respect in the various trainings and presentations designed for the demographic data collection mandate. A significant source of that content has been drawn from the “Are You an ALLY? Campaign” at Sinai Health System. This campaign aims to provide multimedia educational tools and resources to better understand the perspectives and experiences of people who experience discrimination and harassment.



Tool – [Are You an ALLY? Campaign](#). This website provides useful information, resources, and tools to help data collectors better understand the perspectives and experiences of members of marginalized groups. This perspective is critical for demographic data collection and use.

6.3. Highlight Challenges and Prepare Solutions

Patient/client concerns

Barrier

Patients/clients may have reservations or become upset about being asked demographic questions.

Response

Organizations collecting data have found that patients/clients are open to responding to demographic questions when the three key messages (who, why, voluntary) are communicated. In Toronto, 16 hospitals collected data on 261,000 patients and reported that complaints were less than 0.01%. In addition, all existing complaints were quickly resolved with information on why data is being collected.

Time

Barrier

Many organizations have stated time and cost as a primary reason for not collecting demographic data, particularly “time constraints during registration.”

Response

Organizations collecting demographic data have found that their early concerns about ‘time’ did not come up post-implementation. Training, increased familiarity with the process, and getting frontline staff feedback on the workflow are key elements for addressing time constraints.

Staff discomfort

Barrier

Staff discomfort is frequently cited as a major barrier to demographic data collection. It is often rooted in ambiguity regarding how to ask demographic questions and address any patient/client concerns.

Solution

Staff training on principles of health equity and data collection, in addition to practice on responding to patient/client questions, are prerequisites for addressing discomfort.

Legal barriers

Barrier

A common misconception is that asking questions on issues of race, religion, and income is illegal.

Solution

Concerns regarding the legality of asking demographic questions are unfounded. In fact, the **Ontario Human Rights Commission** encourages the collection of demographic data to improve equity.



Resource – “[Obtaining Data on Patient Race, Ethnicity, and Primary Language in Health Care Organizations: Current Challenges and Proposed Solutions](#)”. Publication stating that healthcare organizations should collect demographic information directly from patients or their family members; authors also propose solutions to common barriers

Chapter 7: Beyond Demographic Data Collection

7.1. Ensuring Data Quality

The extent to which we can use demographic data for health equity purposes is largely dependent on the quality of that data. Therefore, any efforts at data collection must be accompanied and followed with efforts to monitor and improve data quality.

To improve data quality, you will need to understand what is causing poor data. The first common method for improving data is to track the performance of different data collectors; this will give you the capacity to identify and work with individuals with higher missing data rates. Another common method is to ensure that your IT system can distinguish between patients/clients who were never asked versus patients/clients who declined to answer; once you know that poor data quality is due to patients not receiving the questions, you can work on addressing barriers.

Sinai Health System developed a number of tools that review the basic principles of data quality and provide a quick guide on how to monitor and address data quality issues:



Tool – [Data Quality Guide](#). A reference guide on how to ensure data quality when collecting demographic data



Tool – [Data Quality Audit Report](#). A data summary report template that can be used to assess data quality (e.g., missing data, participation rates, etc.)

7.2. Seeking Feedback

Re-visiting staff and patients/clients for feedback on staff training and ongoing data collection practices is vital for data quality and the long-term sustainability of data collection initiatives.

Feedback from staff

Feedback from staff will enable you to improve processes and share best practices.



Tool – [Data Collector Feedback](#). Focus group questions for collecting feedback from data collectors

Feedback from patients/clients

Constructive feedback from patients/clients should cover

- any difficulty experienced with answering questions
- comfort level when answering questions
- question clarity
- concerns about confidentiality
- option to add any other concerns

7.3. Looking Ahead: Linking Demographic Data to Equity Planning

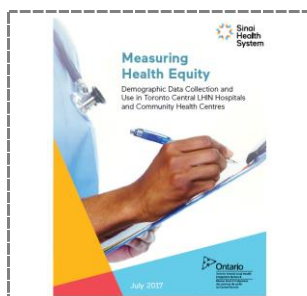
The purpose of demographic data collection is to provide access to actionable data that is essential for working on equity in health care.

To ensure that equity is embedded in healthcare access and delivery, demographic data is used to identify existing gaps, develop plans targeting those gaps, and evaluate performance. In short, the demographic data will be used to apply an equity dimension to the study health outcomes.



Resource – “[Creating Equity Reports: A Guide for Hospitals.](#)” A very insightful paper that uses case studies and research to outline how healthcare organizations can develop equity reports; demographic data collection is identified as a key component of that work.

It is important to remember that the work cannot end at data collection and that the ultimate goal is to use the data to achieve health equity. Download the report below for more information on the journey to demographic data collection in Toronto and to get a glimpse of how hospitals and CHCs have started using the data.



Visit torontohealthequity.ca to download “**Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres**”.