

Guide to Demographic Data Collection in Healthcare Settings

A comprehensive guide to planning and implementing demographic data collection in health care settings.

Revised November 2023



About this guide

Background

The first version of this guide was released in August 2017 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 (now Ontario Health Toronto¹) project. In addition to sharing the lessons learned from leading the project for several years, the guide drew 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

Rationale for updated guide

In 2021, Ontario Health released its [Equity, Inclusion, Diversity and Anti-Racism \(EIDA-R\) framework](#) of which Data Collection, Analysis and Use is a key foundational element. Ontario Health Toronto Region Health Service Providers (HSPs) have outlined in their Service Accountability Agreements (SAAs) obligations related to advancing EIDA-R, which includes continuing the Measuring Health Equity (MHE) project.

Through extensive consultations with the Ontario Health Toronto Data Collection, Analysis & Use Community of Practice, the [SPARK Study](#) team, subject matter experts, and research literature, the core adult patient demographic questions have been updated to be more reflective of contemporary language, diverse experiences, and identities. An updated list of “Additional” (optional) questions have also been provided for adoption by HSPs based on their needs and demographic data collection goals. Please see the Appendix for the full list of updated core and optional demographic questions. In addition, the Pediatric Measuring Health Equity Tool includes a caregiver and youth component which has also been updated to reflect the updated questions (Appendix). This was developed through a working group of pediatric hospitals in Toronto and Ontario, and Ontario Health Toronto, which was coordinated by the Kids Health Alliance.

In a partnership between Sinai Health, the University Health Network – Social Medicine, and Ontario Health Toronto, the *Guide to Demographic Data Collection in Healthcare Settings: A Comprehensive Guide to Planning and Implementing Demographic Data Collection in Healthcare Settings 2017*, has been updated to incorporate the updated Measuring Health Equity questions released in November 2022, and reflect new lessons learned in demographic data collection.

Acknowledgements

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- Alliance for Healthier Communities
- Pediatric Health Equity Data Working Group

Recommended citation (APA style) for this guide

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¹ Ontario Health Toronto connects and coordinates the health care system within the City of Toronto. To read more about Ontario Health Toronto Region’s mandate and work, visit: <https://www.ontariohealth.ca/about-us/our-programs/ontario-health-regions/toronto-region>

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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 patient² reservations are all frequently cited as system-level and individual-level barriers to sustainable demographic data collection and use^{3,4}. This guide was developed to support healthcare organizations to overcome these challenges and embrace the opportunities in standardized demographic data collection for both adult and pediatric patients/clients. The goals of the guide are to:

1. Explain the rationale for and importance of demographic data collection,
2. Highlight the impact of demographic data collection on improving health care quality and equity, and
3. Provide evidence-based guidance, tools, and resources for demographic data collection.

Included in this guide are 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 care⁵ and governments are mandating demographic data collection as a precursor to equity planning⁶.

² For the purpose of this document, the word patient is utilized in the technical term, however intended to refer to anyone who interacts with health and social services and resources including clients, family members and caregivers.

³ Braveman P. (2014). What are health disparities and health equity? We need to be clear. Public Health Report, 2, 5-8.

⁴ 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: torontohealthequity.ca

⁵ Six Domains of Healthcare Quality. (2022). Agency for Healthcare Research and Quality, Rockville, MD. <https://www.ahrq.gov/talkingquality/measures/six-domains.html>

⁶ *Quality Improvement Plan Guidance*. (2017). Retrieved from <https://www.hqontario.ca/Quality-Improvement/QualityImprovement-Plans/Quality-Improvement-Plan-Guidance>

How will you benefit from this guide?

This guide reviews the challenges, opportunities, and benefits of implementing a demographic data collection plan, as well as links to varying documents to support successful implementation.

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 is 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.

Change/implementation and equity leads

How will this guide support you as you lead the implementation of the data collection plan in your organization?

The change/implementation and equity lead also plays a significant role in the successful implementation of the new survey questions. This guide provides the foundational principles, as well as tangible tools and resources that can support you in your role overseeing the overall project plan for data collection within your organization.

How will you benefit from this guide?

This guide will provide you with important tools and resources for the successful implementation of the new survey questions, including key concepts and definitions of health equity and the social determinants of health, strategies for successful demographic data collection, guidance on methodology and process, and training and scripts for data collectors.

Data analysts, data governance

How can you ensure the safe governance and analysis of demographic data?

It is crucial to ensure the safe collection, governance, and analysis of demographic data in an ethical manner that upholds privacy and equity and prevents further bias and discrimination towards marginalized populations.

How will you benefit from this guide?

As you work to ensure appropriate data governance and analysis measures are in place, this guide provides additional tools and resources that can be adapted to your respective organizations.

Information technology and/or digital 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 specialists

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

Privacy specialists 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 several examples illustrating how other organizations have worked on data collection in a manner consistent with privacy legislation.

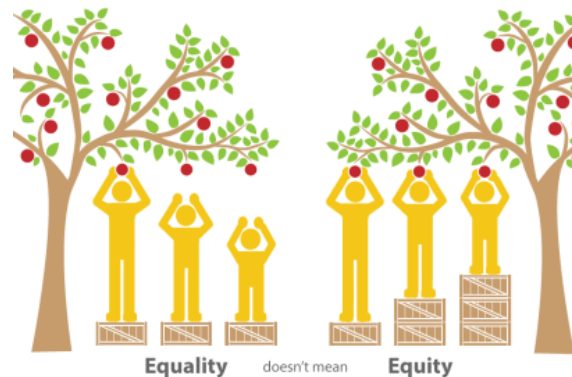
Chapter 2: Health equity principles

2.1. What is health equity?

According to Ontario Health (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 are⁷” (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 several common themes^{8,9,10}.

- Health inequities are systemic differences in health between populations, often defined in social, economic, demographic, or geographic terms.
- Health inequities are systemic, socially produced, 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.
- Health equality should not be confused with health equity. Equality refers to the division of resources into equal parts so that everyone gets the same. Equity involves people getting the resources they need to achieve the same outcome.
- Health equity recognizes that health is not distributed evenly and that some people may need more or different services than others to be healthy.
- Promoting health equity involves improving the living conditions that keep us healthy, while addressing the uneven distribution of power, money, and resources across society and health systems.



Source: Saskatoon Health Region. (2014, June). “Advancing Health Equity in Health 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 social determinants of health are a range of personal, social, economic, and environmental factors that impact one’s health.

⁷ 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

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 and/or economic characteristics of the patient/client such as language, disability, gender, etc.

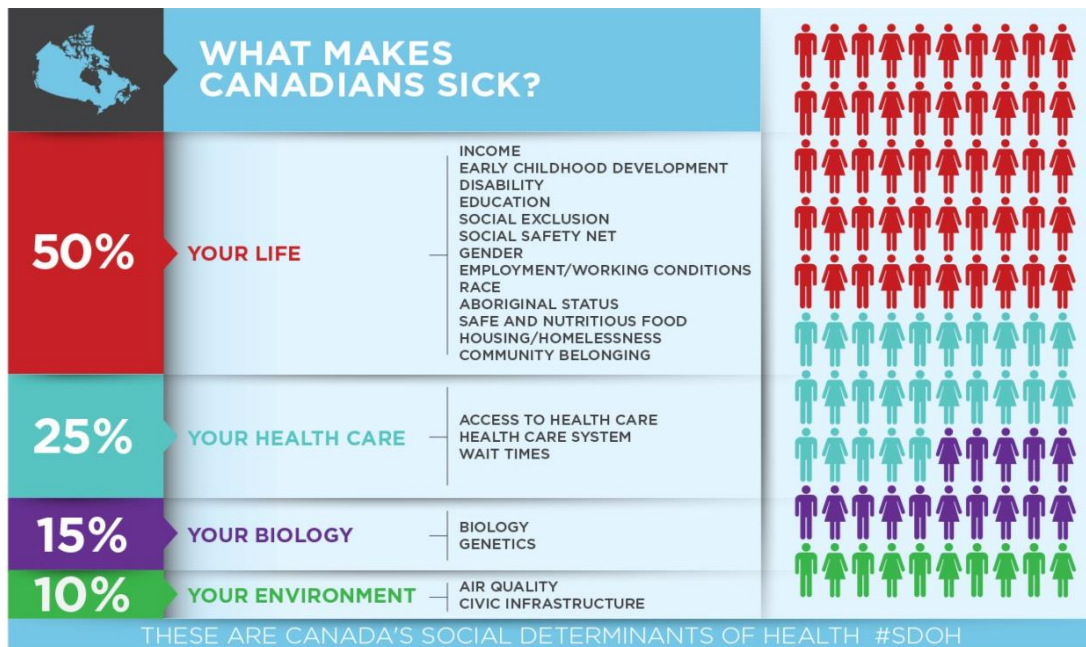


Tool: “[Towards an Understanding of Health Equity: Glossary.](#)” A Glossary of health equity terms from Alberta Health Services

2.2. Canada’s social determinants of health

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

What makes Canadians sick?



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 2020 and 2010.”](#) 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-centered, and *equitable*.

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

- Equity is embedded in all components of quality healthcare,
- Equity is a necessary condition for a “Culture of Quality” in healthcare, and
- 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 ground-breaking 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 policymakers, administrators, and various healthcare organizations using data to advance equity.

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. 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 access and 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 analyzing 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.

3.2. Project Lead & Steering Committee



Case Study: Using Equity Data to Improve Cancer Screening in Ontario CHCs

Objective

The goal was to create Cancer Screening measure for active primary care clients at CHC based on CCO criteria, including income and race data, presented on a dashboard for peer group comparisons and providing unscreened individuals' list to providers.

Strategy

An evaluation framework integrated standardized data elements including client demographics, visit details, and risk factors. Data was extracted nightly into a user-friendly data warehouse, proving dashboards, queries, and visualizations, linked with external data sources. Core cancer screening measures, equitable and stratified by income and race, were included for all Community Health Centres, facilitating improvement through peer group comparisons. Providers had access to unscreened individual lists for proactive intervention.

Conclusion

In summation, the comprehensive Evaluation Framework, encompassing standardized data elements and seamless data extraction, ensures equitable cancer screening through personalized care, by integrating equity-stratified measures for cervical, breast, and colorectal screening as core components across all CHCs, fostering a proactive and tailored approach.

Using equity Data to Improve Cancer Screening in Ontario CHCs | Alliance for Healthier Communities (2019).

Retrieved from <https://www.allianceon.org/research/Using-Equity-Data-Improve-Cancer-Screening-Ontario-CHCs>

Assign leads

Project Implementation Lead

Responsibilities: This is the person responsible for overseeing the overall project plan, implementing the new survey questions into 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, and
- Oversee the development and progress of a work plan, including goals, deliverables, and timelines.

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.

Digital Lead

Responsibilities: This is the person responsible for digital system updates, provides regular updates on progress and attends check-in meetings. This individual will:

- Analyze digital requirements of entering, storing, and retrieving demographic data in Electronic Health Records (EHRs),
- Lead the design of new registration conversation electronic health records including:
 - Update demographic questions in registration data entry form the EMR
 - Create flag/prompt for registration staff to ask patient to complete demographic survey if not completed within 24 months within the organization
 - Establish data entry workflow
 - Establish process for extracting data from EMR for analysis and use, incorporating process improvements
 - Complete Testing
 - Go-live
- Participate in Steering Committee Meetings, and
- Provide regular progress updates

Equity Lead

Responsibilities: If different from the Project Implementation Lead, this is the person responsible for aligning work to the strategic equity priorities.

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 steering committee:

- Data administration or data support
- Registration/admission/clerical (the data collectors)
- Privacy specialist or person knowledgeable about the 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 are already collecting some of this data to get information on what works and what does not. What advice can data collectors provide? What are the 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

Most hospitals and community health centres (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.

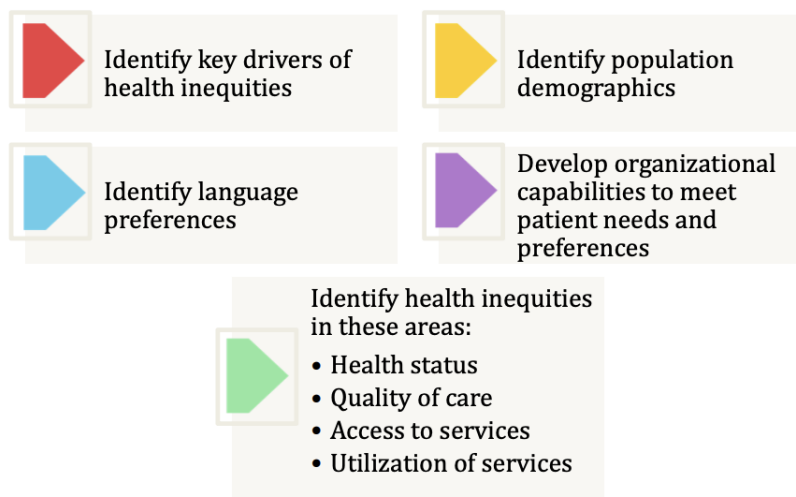
Identify goals

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 three levels of use:

- Health system use: Supports population health and system planning. Looking at results across a geography may illuminate gaps in service specific to local regions or smaller areas (which may not be a challenge across the broader region), or link patient population characteristics to utilization in new ways and measure disparities in service outcomes across equity seeking groups.

- Organizational-level use: Socio-demographic data, when aggregated to provider level, may flag unrecognized and emerging needs or populations that may require additional or customized support in their care delivery. This supports quality improvement initiatives and organizational planning and change to target health inequities that are identified. For example:
 - 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: Improving care for patients/clients and families at the point-of-care. Asking the socio-demographic questions allows the provider to quickly flag patient characteristics that may impact care delivery and planning. For example:
 - Identifying need for accommodation or language interpretation
 - Referring patient to services or supports
 - Interpreting 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 several 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 Project Implementation Lead and Equity Lead will help you to 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 (updated version – coming soon).

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.



Resource: “[Achieving Health Equity: A Guide for Healthcare Organizations.](#)” This white paper provides guidance on how healthcare organizations can reduce health disparities related to racial or ethnic group; religion; socioeconomic status; gender; age; mental health; cognitive, sensory, or physical disability; sexual orientation or gender identity; geographic location, or other characteristics historically linked to discrimination or exclusion; includes a case study and self-assessment tool.

4.3. Engage patients/clients and staff

Engaging patients/clients

Based on input from patients, privacy specialists, and organizations, healthcare organizations collecting demographic data should share **three** pieces of information (provided in the current updated MHE preamble):

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 and that their care will not be affected if they do not answer the questions. This respects their right to not participate and makes staff more comfortable about asking.

Pediatric settings

Access to Data – It is recommended to ask patients' permission to share their data with their caregivers after a certain age for privacy and confidentiality reasons. Depending on how and where this data is stored it is important to consider who has access to it. Each organization may have nuances to this 'age' and process.

This is relevant as some individuals may feel sharing information such as their gender, pronouns, or other medical health information may put them at risk in varying circumstances.

Patients with cognitive or other limitations may require a caregiver to access their data and support them in their medical journey.

Data governance

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. 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. 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.

Indigenous communities and Black communities in Canada have both established a strong foundation in conceptualizing community data governance strategies. For example, 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. Similarly, the [Black Health Equity Working Group](#) developed the EGAP framework to establish a data sovereignty framework for Black communities during the pandemic.

Canadian health leaders can benefit from looking at international examples of community data governance. The INSIGHT [Data Trust Advisory Board](#) in the United Kingdom assesses applications to assess data using predefined criteria and provides recommendations to INSIGHT Data Controllers based on their assessment. The [One London Citizen's Summit](#) convened to discuss and provide recommendations on health data use, access and control, analyzing data for proactive care, and policy planning and development. Furthermore, as part of the Learning and Action in Policy and Partnerships initiative, health agencies in [Arizona](#) and [Utah](#) partnered with social and healthcare organizations to develop a community-informed data process and improve population health outcomes for people experiencing homelessness and San Juan County elders respectively. They developed principles for data sharing, implemented a data exchange program to share patient records, and received community feedback to develop a culturally responsive referral system. [The Urban Institute's Data Walks](#) is a practical guide to present and discuss health data with racialized communities.

Sociodemographic data is essential for healthcare institutions to understand the communities that they serve. It will inform the composition and priorities of community data governance tables. Additionally, it is important to consider the community burden if institutions lead separate community governance activities as many health service providers may serve the same population. Partnerships with local agencies must be developed to reduce resource redundancies and enhance community integration in the health sector. Also, while privacy legislation prevents unauthorized access to personal health information, de-identified data can be presented to community members in accessible ways such as charts, graphs, and visual maps.

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.

Importance of engagement

HSPs are expected to partner with local FNIMUI leaders and advisors to implement the MHE core questions in a way that is appropriate, safe, and beneficial for Indigenous patients; organizations should seek guidance from their established First Nations, Indigenous, Metis and Urban Inuit (FNIMUI) governance, with the ultimate decision for inclusion up to the discretion of the organization. If the FNIMUI advisors determine that there needs to be further actions taken before

the MHE core questions can be asked, Ontario Health Toronto encourages HSPs to work in collaboration with the guidance of the FNIMUI advisors to take the necessary steps toward safety. Each HSP will need to go through this process separately and can determine the best approach for their specific site/organization.

The MHE core questions include a question and response options (i.e., Two-Spirit) specific to First Nations, Inuit and Métis, and Urban Indigenous (FNIMUI) identity. These were included so that individual patients could see themselves reflected in the survey and then exercise their right to identify or decline as they wish (all questions are voluntary for patients). Excluding the question and response options from the core MHE set would deny individual patients their right to self-identify, should they wish to.

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.

Indigenous cultural awareness training

Indigenous partners and communities have shared their challenges with mainstream health services for years. Access to cultural safety training for all staff involved in data collection, analysis and use is a foundational step in building staff/organizational capacity and education with First Nation, Inuit, Metis and Urban Indigenous partners to meet their needs and respond to priorities.

- [Inuit Qaujimajatuqangit: The role of Indigenous knowledge in supporting wellness in Inuit communities in Nunavut](#)
- [Ontario Health Indigenous Relationship and Cultural Awareness Courses](#)
- [Indigenous Primary Health Care Council Foundations \(IPHCC\) of Indigenous Cultural Safety Training \(ICS\)](#)
- [San’yas Anti-Racism Indigenous Cultural Safety Training \(ICS\) Program](#)

Governance for other communities (not FNIMUI) data

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.



Resource: [“A Data Governance Framework for Health Data Collected from Black Communities in Ontario”](#).



Case Study: Introduction to the ‘Toronto Central LHIN Demographic Questions’

Below is the introduction that hospitals located within the former Toronto Central LHIN included in their demographic forms. It serves as one example of how the three messages 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.

Pediatric consideration

Involving youth population/using relevant videos could be an effective method for engaging patients/clients.

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 cited barrier to demographic data collection¹⁴, and is often driven by:

- Poor and inconsistent training on asking demographic questions,
- Unfamiliarity with project goals,
- Failure to clearly communicate why data is needed and the workflow for collecting it,
- Discomfort with demographic data collection elements (e.g., gender, sexual orientation), and
- Limited health human resources.

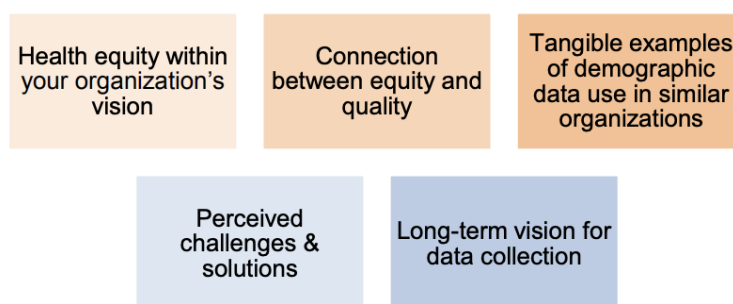
¹⁴ Interviews during the period of August–October 2012 with *Guwan Jones* (Director of Health Equity at Texas Baylor Health Care System), *Nancy Connery* (Director of Admitting and Registration Services at Massachusetts General Hospital), *Natalie Sabino* (Lehigh Valley Health Network Diversity/Cultural 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)

Education

Presentations tailored to the audience and the setting 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 workflow and how patients/clients will respond to receiving the questions.

Your presentation should include the following:



Training

Organizations should mandate new hires to complete data collection related training as part of their orientation. See *Chapter 6: Staff Training*.

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, and
- 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.



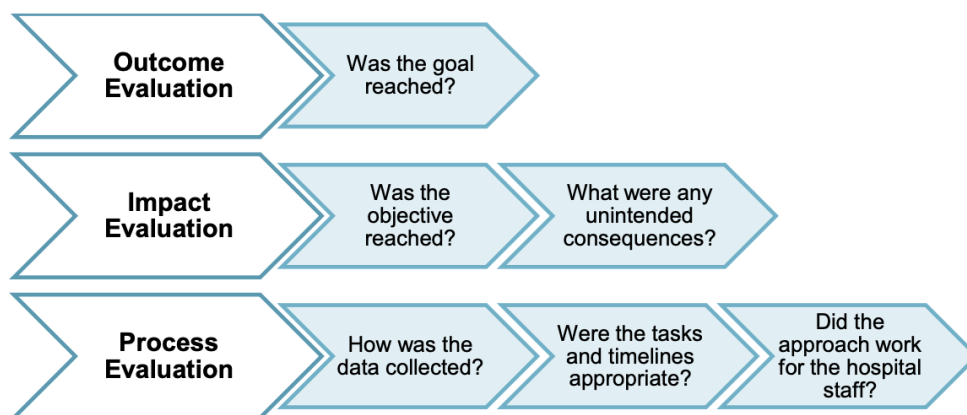
Resource: “[A Guide to Evaluation in Health Research](#).” An evaluation guide written by Sarah Bowen for the Canadian Institutes of Health Research; adaptable to demographic data collection.

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, and
- Identifying small, short-term milestones and/or objectives on the path to the long-term goal.

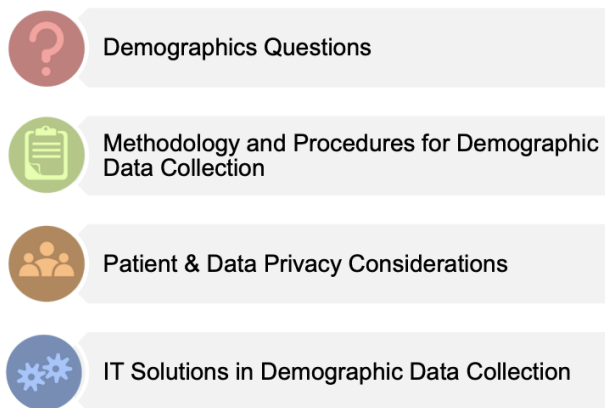
Ramirez *et al.* also illustrate the forms of evaluation that organizations and communities should consider in equity planning. These forms may differ depending on the questions being asked:



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 thirteen core demographic questions being used to collect patient and client demographic data in Toronto Region were developed through extensive consultations with the Data Collection, Analysis & Use Community of Practice, the [SPARK Study](#) team, subject matter experts, and research literature. **The core questions have been updated** to be more reflective of contemporary language, diverse experiences, and identities. An updated list of “Additional” (optional) questions has also been provided for adoption by hospitals based on identified needs and demographic data collection goals.

The aims of the consultations 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 thirteen variables: Language, Born in Canada, Indigenous Identity, Ethnicity, Race, Disability, Sex & Gender, Sexual Orientation, and Income. The recommendations were adopted by Ontario Health Toronto as part of its data collection mandate in hospitals and CHCs.



Tool: 13 demographic questions and 11 optional questions for hospitals/CHCs. A list of patient demographic questions mandated for demographic data collection across the Toronto Region hospitals and CHCs included in Appendix.



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 region.

Pediatric considerations

Ensure that appropriate language is factored into explanations, staff scripts and brochures and that patients are provided with the option to opt in and opt out to account for youth/caregiver privacy.

5.2. Methodology and procedures for demographic data collection

Existing settings

As outlined in Measuring Health Equity Expectations (see [Appendix B](#)), the intention is for all areas to collect this data using a phased approach.

New settings

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).



Attention: 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.

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 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 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.

Several organizations are also collecting data through patient portals and emails.

Setting: rehabilitation/complex continuing care

Given the nature of care in rehabilitation and complex continuing care facilities, patients/clients generally have 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.

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, and
- 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 data is private and confidential, and 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 sample tool available for organizations collecting demographic data using paper forms; includes key messages and workflow information.



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



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

5.3. Data governance

See Section 4.3 related to data governance considerations to factor into workflow.

5.4. 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/use.

<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.

Pediatric considerations

There is not a specific age of consent to participate in Ontario, rather it is about capacity. In similar scenarios related to access privileges to pediatric patient charts, many organizations have chosen 12 years old, as the age that the parents are removed as primary access owners to only still having access if that permission is granted by the patient 12-18 years old.

Leading up to the implementation of demographic data collection in Toronto region, 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, and/or disclosed in line with privacy legislation.



Attention: It is up to each organization to ensure that they 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.

5.5. Digital Lead: IT solutions in demographic data collection

Any IT programs and solutions should be guided by the recommendations of privacy specialists to ensure that patient/client data is securely stored. Therefore, IT and Privacy have several 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):

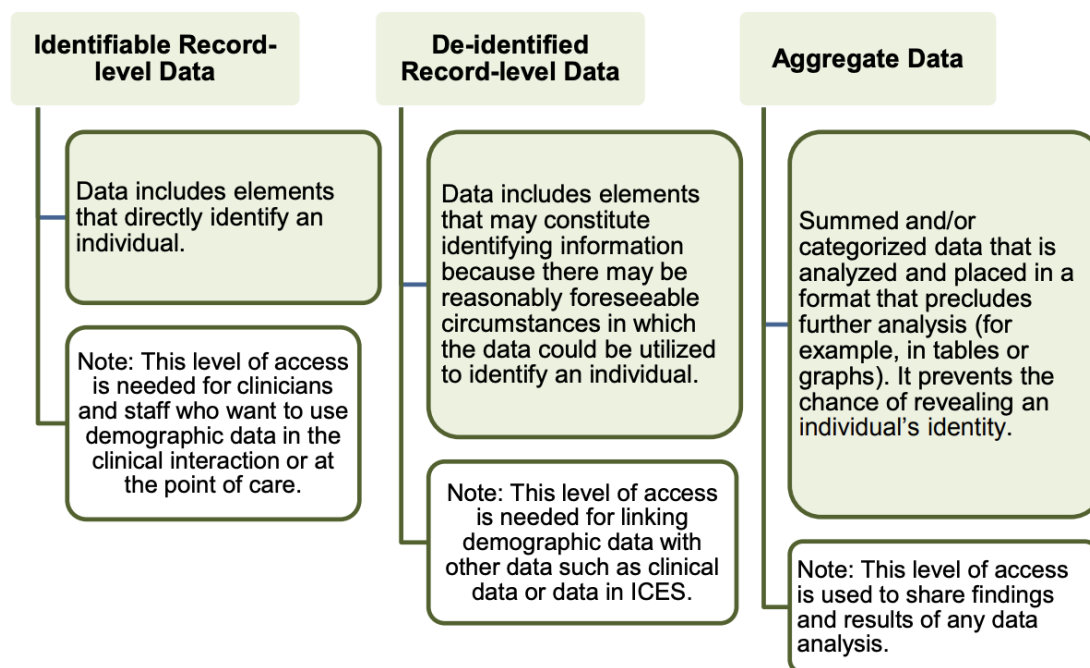
- Who is going to collect/enter the data?
- Where is the best place for building the data fields to ensure easy access for staff?
- Is the data captured at the visit/encounter level or the patient/client level?
- Can you build in the ability to check if patient/client has already responded?
- What are 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.). As outlined in the *Data governance* section of this guide, 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 Ontario Health (Cancer Care Ontario) (see resource below) uses the following classifications for CCO data:



Resource: "[Data Use & Disclosure Standard](#)." A standard set out by Canada 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.



Attention: 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 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.
4. Ensure staff has a good understanding of Equity Data Analysis and Use

Training materials

The Sinai Health training materials cover:

- Why we need to collect demographic data,
- How to ask questions,
- Resources for building skills to collect demographic data, including trauma informed care, and de-escalation training, and
- Supporting materials for collecting patient/client demographic data

Note: Ontario Health Toronto, in partnership with Sinai Health and University Health Network - Social Medicine, is currently in the process of developing training materials that will be made available once complete.

eLearning

In addition to in-person training materials, hospitals and CHCs can adapt the one-hour eLearning module below for their organizational needs. 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 healthcare staff with the tools to effectively collect patient and client demographic information.

Videos

Training should include tools beyond a presentation. The Sinai Health team developed several videos on how to collect demographic data in a respectful and informative manner.



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 team has worked to embed principles of inclusion and respect in the various trainings which include:

6.3. Highlight challenges and prepare solutions

Patient/client concerns

Barrier

Patients/clients may have reservations or become upset about being asked demographic questions due to a lack of culturally sensitive and safe environments.

- EGAP
- Indigenous Cultural Safety - see [Appendix B](#) for related FNIMUI resources, including training

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 2015, 16 hospitals in Toronto 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.

To enable data governance and the safe and respectful collection, storage, analysis, use and protection of equity data, see Section 4.3. Reviewing the Script for Demographic Data Collection will also support staff in addressing patient/client concerns and addressing discomfort.

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 developed several 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 sample data summary report template that can be adapted to assess data quality of the updated demographic questions (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.

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, and
- 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.

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.



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

Glossary

Anti-racism

An anti-racism approach is a systematic method of analysis and a proactive course of action. The approach recognizes the existence of racism, including systemic racism, and actively seeks to identify, reduce, and remove the racially inequitable outcomes and power imbalances between groups and the structures that sustain these inequities.^[ii]

Community engagement

Based on meaningful and authentic existing and ongoing relationships with communities, which is a core public health practice, allowing people who live with inequities to influence health system priorities and inform decisions about population and public health initiatives. Public health considers community members as partners rather than ‘service recipients’, recognizing that community members know best about what they need to be healthy and the solutions to address inequities.^[iii]

Diversity

The range of visible and invisible qualities, experiences and identities that shape who we are, how we think, how we engage with and how we are perceived by the world. These can be along the dimensions of race, ethnicity, gender, gender identity, sexual orientation, socioeconomic status, age, physical or mental abilities, religious or spiritual beliefs, or political ideologies. They can also include differences such as personality, style, capabilities, and thought or perspectives.^[iiii]

Downstream

When interventions and strategies focus on providing equitable access to care and services to mitigate the negative impacts of disadvantage on health.^[i]

Health disparity

A measurable difference in health outcomes between groups, communities and populations who experience relative advantage and disadvantage due to structural and social determinants of health. A disparity that exists across socioeconomic categories occurs when disadvantaged groups experience worse health outcomes and greater health risks than advantaged groups. Reduced health disparities between groups are evidence of progress toward reaching health equity.^[ii]

Health equity

When all people (individuals, groups, and communities) have a fair chance to reach their full health potential and are not disadvantaged by social, economic and environmental conditions.^[i]

Health inequality

Measurable differences in health between individuals, groups, or communities. It is sometimes used interchangeably with the term ‘health disparities’.^[i]

Health inequity

A sub-set of health inequality and refers to differences in health associated with social disadvantages that are modifiable and considered unfair.^[i]

Health

The physical, spiritual, mental, emotional, environmental, social, cultural, and economic wellness of the individual, family, and community. Individuals and groups define health

differently depending on their values, culture, experiences, and world view. Health is not an endpoint; rather, it is considered a resource for everyday living to support people to live dignified and fulfilling lives, despite the presence or absence of disease.^[iii]

Intersectionality

Considers how systems of oppression (e.g., racism, classism, sexism, homophobia) interact to influence relative advantage and disadvantage at individual and structural levels. An intersectional orientation recognizes that the experience of multiple forms of discrimination and disadvantage has a cumulative negative effect that is greater than the sum of the parts. The intersectional nature of oppression and privilege means that people may have privilege in one or more forms even if they experience oppression in other domains.^[iii]

Marginalization

Occurs when people are excluded based on social identities such as race, gender, sexuality, and social class as well as the inequitable distribution of social, economic, physical, and psychological resources. Individuals and communities are marginalized by, live in marginalized conditions, or are forced into marginalization rather than being labelled as marginalized people/populations/ groups.^[ii]

Marginalized populations

Groups and communities that experience discrimination and exclusion (social, political, and economic) because of unequal power relationships across economic, political, social, and cultural dimensions.^[i]

Midstream

Interventions and strategies reduce exposure to risk by improving material conditions or by promoting healthy behaviours. These changes generally occur where individuals who live with inequities are directed or referred to resources that support health at the regional, local, community or organizational level. Midstream approaches are about changing the root causes of health inequities.^[iii]

Population health

The health status of an entire population that results from interrelated factors including policy, primary care, public health, social and environmental factors, and the distribution of inequities. The three main components of population health are health outcomes, determinants, and policies. Population health strategies use diverse forms of knowledge and evidence to develop policies and interventions that improve the health and well-being of an entire population rather than of individuals.^[iii]

Protective factors and conditions

Increase the chances of good health by enhancing our ability to cope with challenges, mitigate the effects of negative influences and reduce the likelihood of poor health. A population health equity approach focuses on building protective factors to decrease the likelihood of experiencing the negative impact of risk conditions. A focus on protective factors aligns with an asset-based approach to health.

Racism

The race-based allocation of value, resources, opportunities, and status in cultural, political, institutional, economic, and social forms. Racism is subtle, reinforced by White supremacy and normalized by dominant White culture and practices. Racism differs from prejudice, hatred, or discrimination in that it requires one racial group to have systematic power and superiority over other racialized groups. Racism intersects with other systems of oppression (e.g., homophobia,

sexism, classism, Islamophobia), which affects decision-making power, cultural and symbolic images, and distribution of material resources (e.g., income and wealth).^[ii]

Risk conditions

Environmental and social factors that increase the chance an individual, group or community will have lower levels of health compared to the overall society.^[i]

Risk factors

Individual characteristics and behaviours that increase the chance a person will get sick or injured or die prematurely.^[i]

Social determinants of health

The interrelated social, political, and economic factors that create the conditions in which people live, learn, work and play. The intersection of the social determinants of health causes these conditions to shift and change over time and across the life span, impacting the health of individuals, groups, and communities in different ways.^[i] The social determinants of health include the following:

- Gender/gender identity
- Race/racialization
- Ethnicity
- Indigeneity
- Colonization
- Religion
- Migrant and refugee experiences
- Culture
- Discrimination/social exclusion/social inclusion
- Education/literacy
- Occupation
- Health literacy
- Income/income security
- Employment/job security
- Early life experiences
- Disability

Social exclusion

When people are not able to participate in society through inequitable access to resources, capabilities, power, and rights, leading to inequitable health impacts and outcomes.^[iii]

Social inclusion and exclusion

Refer to the dynamic and multi-dimensional social process at all levels (individual, group and community) that is driven by unequal power relationships across economic, political, social, and cultural dimensions. Unequal access to resources, capacities and rights leads to health inequities^[i]

Social inclusion

Improves participation in society of people who experience marginalization and vulnerability through equitable access to material (economic) and non-material resources required for living, including power and rights.^[iii]

Structural racism

A system in which public policies, institutional practices, cultural representations, and other norms work in ways to reinforce and perpetuate racial group inequity. It identifies dimensions of

our history and culture that have allowed white privilege and disadvantages associated with colour to endure and adapt over time. Structural racism is not something that a few people or institutions choose to practice. Instead, it has been a feature of the social, economic, and political systems in which we all exist.^[iii]

Systemic racism

Organizational culture, policies, directives, practices, or procedures that exclude, displace, or marginalize some racialized groups or create unfair barriers for them to access valuable benefits and opportunities. This is often the result of institutional biases in organizational culture, policies, directives, practices, and procedures that may appear neutral but have the effect of privileging some groups and disadvantaging others.^[iii]

Upstream

When interventions and strategies focus on improving fundamental social and economic structures to decrease barriers and improve supports that allow people to achieve their full health potential.^[i]

Vulnerable populations

Groups and communities at a higher risk for poor health as a result of the barriers they experience to social, economic, political and environmental resources, as well as limitations due to illness or disability.^[i]

^[i] National Collaborating Centre for Determinants of Health (2014). Glossary of essential health equity terms. Retrieved from: https://nccdh.ca/images/uploads/comments/English_Glossary_Nov17_FINAL.pdf

^[ii] National Collaborating Centre for Determinants of Health (2022). Glossary of essential health equity terms. Retrieved from: https://nccdh.ca/learn/glossary#collapse_2096

^[iii] Ontario Health (n.d.) Equity, inclusion, diversity, and anti-racism framework. Retrieved from: <https://www.ontariohealth.ca/sites/ontariohealth/files/2020-12/Equity%20Framework.pdf>

Appendix

Appendix A: Updated Measuring Health Equity Core & Additional Questions

We Ask Because We Care

We would like to ask you some questions to help us better understand our patients/clients. Your answers will help us provide you with the best care possible and help improve programs and services for everyone.

Why are you collecting this information?

These questions will help us to better understand our patients/clients and help us provide better care and services. Some questions may feel very personal or private; we are asking these questions because sometimes people have been treated differently because of who they are as a person. Being treated differently like this is discrimination and can affect our health.

Do I have to answer all the questions?

No. You can choose to answer these questions or not. You can stop answering the questions at any time, or ask us to remove your answers at any time. We will provide you with care whether you answer the questions or not.

Who will see this information?

Only people involved directly in your care will see your answers. It will be protected like all of your other health information. We will also take your answers and remove your name from them and combine them with the answers of all the other people we serve. Those combined answers may be used by us, as well as by researchers, to provide better care and services.

How long will this take?

It will take six to eight minutes to complete all 13 questions.

Do you agree to answer the questions?

- Yes
- No
- I prefer not to answer any of these questions, at this time

Updated measuring health equity core questions

1. What language do you feel most comfortable speaking in with your provider? (Check all that apply)

<input type="checkbox"/> English* (Canadian Official Language) <input type="checkbox"/> French* (Canadian Official Language) <input type="checkbox"/> Albanian <input type="checkbox"/> Amharic <input type="checkbox"/> Arabic <input type="checkbox"/> ASL (American Sign Language) <input type="checkbox"/> Bengali <input type="checkbox"/> Bulgarian	<input type="checkbox"/> Burmese <input type="checkbox"/> Cantonese <input type="checkbox"/> Czech <input type="checkbox"/> Dari <input type="checkbox"/> Farsi <input type="checkbox"/> Georgian <input type="checkbox"/> Greek <input type="checkbox"/> Gujarati <input type="checkbox"/> Hausa <input type="checkbox"/> Hindi	<input type="checkbox"/> Hebrew <input type="checkbox"/> Hungarian <input type="checkbox"/> Italian <input type="checkbox"/> Karen <input type="checkbox"/> Korean <input type="checkbox"/> Mandarin <input type="checkbox"/> Nepali <input type="checkbox"/> Pashto <input type="checkbox"/> Polish <input type="checkbox"/> Portuguese	<input type="checkbox"/> Punjabi <input type="checkbox"/> Rohingya <input type="checkbox"/> Romanian <input type="checkbox"/> Russian <input type="checkbox"/> Serbian <input type="checkbox"/> Slovak <input type="checkbox"/> Somali <input type="checkbox"/> Spanish <input type="checkbox"/> Swahili	<input type="checkbox"/> Tagalog <input type="checkbox"/> Taishanese/Toishanese <input type="checkbox"/> Tamil <input type="checkbox"/> Thai <input type="checkbox"/> Tibetan <input type="checkbox"/> Tigrinya <input type="checkbox"/> Turkish <input type="checkbox"/> Twi <input type="checkbox"/> Ukrainian	<input type="checkbox"/> Urdu <input type="checkbox"/> Vietnamese <input type="checkbox"/> Another language (please specify): _____ <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--	---	---	--	--	--

2. (a) Were you born in Canada?

- Yes
 No
 Do not know
 Prefer not to answer

(b) If no, when did you arrive?

- | | | |
|---|--|---|
| <input type="checkbox"/> Less than 5 years ago
<input type="checkbox"/> 5 to 9 years ago | <input type="checkbox"/> 10 years ago, or more
<input type="checkbox"/> Do not know | <input type="checkbox"/> Prefer not to answer |
|---|--|---|

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)

- | | |
|---|--|
| <input type="checkbox"/> Yes, First Nations (status or non-status)
<input type="checkbox"/> Yes, Métis
<input type="checkbox"/> Yes, Inuk/Inuit | <input type="checkbox"/> No
<input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|---|--|

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.

- Please specify _____
 Do not know
 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)

- | | |
|--|---|
| <input type="checkbox"/> Middle Eastern, Arab or West Asian (e.g., Afghan, Egyptian, Iranian, Lebanese, Persian, Turkish, Kurdish, etc.)
<input type="checkbox"/> Black (e.g., African, Afro-Canadian, Afro-Caribbean, Afro-Egyptian etc.)
<input type="checkbox"/> East Asian (e.g., Chinese, Korean, Japanese, Taiwanese, etc.)
<input type="checkbox"/> Latin American (Hispanic or Latin American descent)
<input type="checkbox"/> South Asian (e.g., Bangladeshi, Indian, Indo-Caribbean, Pakistani, Sri Lankan, etc.) | <input type="checkbox"/> Southeast Asian (e.g., Filipino, Vietnamese, Cambodian, Thai, Indonesian, etc.)
<input type="checkbox"/> White (e.g., European descent)
<input type="checkbox"/> Another race/ethnic group (please specify): _____
<input type="checkbox"/> Not Applicable (e.g., Identified as Indigenous in question #3)
<input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|--|---|

6. (a) Do you identify as a person with disability?

- | | |
|---|---|
| <input type="checkbox"/> Yes
<input type="checkbox"/> If you wish, please specify _____
<input type="checkbox"/> No | <input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|---|---|

(b) Could you benefit from support related to any of the following? (Check all that apply)

- | | | |
|--|---|--|
| <input type="checkbox"/> Alzheimer's Disease/Dementia
<input type="checkbox"/> Autism Spectrum Disorder
<input type="checkbox"/> Chronic Illness (e.g., sickle cell, diabetes etc.)
<input type="checkbox"/> Cognitive Disability
<input type="checkbox"/> Developmental Disability
<input type="checkbox"/> Drug or Alcohol Dependence | <input type="checkbox"/> Learning Disability
<input type="checkbox"/> Mental Illness
<input type="checkbox"/> Physical Disability
<input type="checkbox"/> Sensory Disability (e.g., low vision, blindness, deafness, hard of hearing etc.)
<input type="checkbox"/> Other (please specify) _____ | <input type="checkbox"/> None
<input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|--|---|--|

7. What was your sex assigned at birth? (Check one)

- Male
 Female
 Intersex
 Do not know
 Prefer not to answer

8. What is your gender identity? (Check all that apply)

- | | |
|--|--|
| <input type="checkbox"/> Genderfluid or genderqueer
<input type="checkbox"/> Man
<input type="checkbox"/> Nonbinary
<input type="checkbox"/> Two-Spirit
<input type="checkbox"/> Woman | <input type="checkbox"/> Questioning or unsure
<input type="checkbox"/> Another gender identity (please specify) _____
<input type="checkbox"/> Do not know
<input type="checkbox"/> 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.

Yes
 No
 Do not know
 Prefer not to answer

10. Which category(ies) best describe your sexual orientation? (Check all that apply)

<input type="checkbox"/> Asexual <input type="checkbox"/> Bisexual <input type="checkbox"/> Demisexual <input type="checkbox"/> Gay <input type="checkbox"/> Lesbian <input type="checkbox"/> Pansexual	<input type="checkbox"/> Queer <input type="checkbox"/> Questioning or unsure <input type="checkbox"/> Same gender loving <input type="checkbox"/> Straight/Heterosexual	<input type="checkbox"/> Two-Spirit <input type="checkbox"/> Another sexual orientation (please specify) _____ <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--	---	--

11. Do you currently have difficulty paying for basic needs?

Yes
 No
 Not applicable, I do not have to pay for basic needs
 Do not know
 Prefer not to answer

12. What was your total family income before taxes last year?

<input type="checkbox"/> \$0 - \$19,999 <input type="checkbox"/> \$20,000 - \$39,999 <input type="checkbox"/> \$40,000 - \$59,999	<input type="checkbox"/> \$60,000 - \$79,999 <input type="checkbox"/> \$80,000 - \$119,999 <input type="checkbox"/> \$120,000 - \$149,999	<input type="checkbox"/> \$150,000 or more <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
---	---	---

13. How many people does this income support?

_____ Persons
 Do not know
 Prefer not to answer

Updated measuring health equity optional questions

1. What is your current level of education?

- | | |
|--|--|
| <input type="checkbox"/> No formal schooling
<input type="checkbox"/> Grade school (grade 1-8)
<input type="checkbox"/> Some high school, but did not graduate
<input type="checkbox"/> High school or high school equivalency certificate (grade 9-12)
<input type="checkbox"/> Completed Registered Apprenticeship or other trades certificate or diploma (or ongoing) | <input type="checkbox"/> College, CEGEP or other non-university certificate or diploma (or ongoing)
<input type="checkbox"/> Undergraduate degree or some university
<input type="checkbox"/> Postgraduate degree or professional designation (e.g., Master's, PhD, MD)
<input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|--|--|

2. Please respond to the following statements:

(a) "Within the past 12 months, we worried whether our food would run out before we could buy or get more"

-
- Often True
-
-
- Sometimes True
-
-
- Never True
-
-
- Do not know
-
-
- Prefer not to answer

(b) "Within the past 12 months, the food we bought just didn't last and we could not buy or get more."

- | | |
|---|---|
| <input type="checkbox"/> Often True
<input type="checkbox"/> Sometimes True
<input type="checkbox"/> Never True | <input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|---|---|

3. In the past 12 months, were you unable to get medicine or medical supplies, or did you do anything to make them last longer because of the cost?

- | | |
|--|---|
| <input type="checkbox"/> Yes
<input type="checkbox"/> No
<input type="checkbox"/> Not applicable, I did not have to get any medicine or medical supplies in the past 12 months | <input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|--|---|

4. (a) What is your current housing situation?

- | | |
|--|--|
| <input type="checkbox"/> A place you or your family owns
<input type="checkbox"/> A place you or your family rents
<input type="checkbox"/> Social housing, Subsidized housing or Rent -geared -to - income
<input type="checkbox"/> Supportive housing or Group Home | <input type="checkbox"/> Long -term care facility
<input type="checkbox"/> Correctional facility
<input type="checkbox"/> Staying in someone else's place because you have no alternative
<input type="checkbox"/> Experiencing homelessness (e.g., shelter, living in a public place or vehicle) |
|--|--|

(b) Who do you live with? Select all that apply :

- | | |
|---|--|
| <input type="checkbox"/> Parent(s) or Guardian(s)
<input type="checkbox"/> Spouse or Partner
<input type="checkbox"/> Child(ren)
<input type="checkbox"/> Grandparent(s)
<input type="checkbox"/> Sibling(s)
<input type="checkbox"/> Other family | <input type="checkbox"/> Friends or Roommates
<input type="checkbox"/> Paid caregiver or attendant
<input type="checkbox"/> Alone
<input type="checkbox"/> Other (Specify) _____
<input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|---|--|

(c) In the past 12 months, was there a time when you were not able to pay the mortgage or rent on time?

- | | |
|--|---|
| <input type="checkbox"/> Yes
<input type="checkbox"/> No
<input type="checkbox"/> Not applicable, I did not have to pay rent or mortgage | <input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|--|---|

5. In the past 12 months, has lack of transportation kept you from medical appointments, meetings, work , or from getting things needed for daily living? Select all that apply:

- | | |
|---|--|
| <input type="checkbox"/> Yes, it has kept me from medical appointments or getting medicines
<input type="checkbox"/> Yes, it has kept me from non - medical meetings, appointments, work, or getting things that I need
<input type="checkbox"/> No | <input type="checkbox"/> Not applicable, I did not need transportation for these activities in the past 12 months
<input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|---|--|

6. Do you currently have consistent access to a phone or the internet?

- | | |
|---|--|
| <input type="checkbox"/> Yes, phone only
<input type="checkbox"/> Yes, internet only
<input type="checkbox"/> Yes, both | <input type="checkbox"/> No
<input type="checkbox"/> Do not know
<input type="checkbox"/> Prefer not to answer |
|---|--|

7. In the past 12 months, did you miss making a payment on any utility bills (e.g., electric, gas/oil, water) because of cost?

<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Not applicable, I did not have to pay utility bills in the past 12 months or utilities already included in rent	<input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
---	---

8. (a) Do you feel you have people who you can open up to or confide in?

<input type="checkbox"/> Yes, I always or sometimes have someone <input type="checkbox"/> No, I don't have anyone	<input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--	---

(b) Do you have people to rely on if you needed help?

<input type="checkbox"/> Yes, I always or sometimes have someone <input type="checkbox"/> No, I don't have anyone	<input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--	---

9. (a) Are you currently employed (this includes self-employed, full-time, part-time or other)?

<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--

(b) Are you currently looking for work?

<input type="checkbox"/> Yes <input type="checkbox"/> No	<input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
---	---

(c) Is your main job temporary or part-time (e.g., casual, contract, freelance, short-term, seasonal)?

<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--

(d) Do you feel that your current employment could be negatively affected if you raised concerns about your work (e.g., health, safety, rights)?

<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--

(e) In the past 12 months, did your income change a lot from month to month?

<input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--

10. What is your religious or spiritual affiliation? Select all that apply:

<input type="checkbox"/> Agnosticism <input type="checkbox"/> Animism or Shamanism <input type="checkbox"/> Atheism <input type="checkbox"/> Baha' I Faith <input type="checkbox"/> Buddhism	<input type="checkbox"/> Christian Orthodox <input type="checkbox"/> Christian, not included elsewhere on this list <input type="checkbox"/> Confucianism <input type="checkbox"/> Hinduism <input type="checkbox"/> Islam	<input type="checkbox"/> Jainism <input type="checkbox"/> Judaism <input type="checkbox"/> Native Spirituality <input type="checkbox"/> Pagan <input type="checkbox"/> Protestant	<input type="checkbox"/> Rastafarianism <input type="checkbox"/> Roman Catholic <input type="checkbox"/> Sikhism <input type="checkbox"/> Spiritual <input type="checkbox"/> Unitarianism	<input type="checkbox"/> Zoroastrianism <input type="checkbox"/> Other (Specify) _____ <input type="checkbox"/> Not Applicable, I do not have a religious or spiritual affiliation <input type="checkbox"/> Do not know <input type="checkbox"/> Prefer not to answer
--	--	---	---	---

11. In what language would you prefer to read healthcare information? Check one only.

<input type="checkbox"/> English <input type="checkbox"/> French <input type="checkbox"/> Amharic <input type="checkbox"/> Arabic <input type="checkbox"/> Bengali <input type="checkbox"/> Braille	<input type="checkbox"/> Chinese (Simplified) <input type="checkbox"/> Chinese (Traditional) <input type="checkbox"/> Czech <input type="checkbox"/> Dari <input type="checkbox"/> Farsi <input type="checkbox"/> Greek	<input type="checkbox"/> Hindi <input type="checkbox"/> Hungarian <input type="checkbox"/> Italian <input type="checkbox"/> Karen <input type="checkbox"/> Korean	<input type="checkbox"/> Nepali <input type="checkbox"/> Polish <input type="checkbox"/> Portuguese <input type="checkbox"/> Punjabi <input type="checkbox"/> Russian	<input type="checkbox"/> Serbian <input type="checkbox"/> Slovak <input type="checkbox"/> Somali <input type="checkbox"/> Spanish <input type="checkbox"/> Tagalog	<input type="checkbox"/> Tamil <input type="checkbox"/> Tigrinya <input type="checkbox"/> Turkish <input type="checkbox"/> Twi <input type="checkbox"/> Ukrainian	<input type="checkbox"/> Urdu <input type="checkbox"/> Vietnamese <input type="checkbox"/> Other (please specify) _____ <input type="checkbox"/> Prefer not to answer <input type="checkbox"/> Do not know
--	--	---	---	--	---	--

Appendix B: Indigenous Data Governance Guiding Principles

Ontario Health Indigenous Data Governance Guiding Principles (Nov 2022)

Guiding principles

- ✓ 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.

Guidance for HSPs

Internal

- Point of Care Services: Should Indigenous clients choose to self-identify, HSPs are expected to support culturally appropriate referrals and access to cultural practices and other needs.
- Do not analyze aggregated data of Indigenous patients without an Indigenous led internal governance process in place. Work with Indigenous partners to develop Indigenous led data governance models to support safe storage, analysis, use and protection.
- Commit to implementing thoughtful, critical Indigenous training opportunities and training related to Indigenous data governance.

External Use

- Remove all data for Indigenous patients when sharing or linking aggregate equity data externally (e.g., outside your organization or to administrative databases, etc.)

Indigenous Data Governance Matters

Ontario Health will be launching the Indigenous Data Governance Matters (IDGM) process to provide direction, accountability, and a standardized approach to appropriate Indigenous data use at Ontario Health. It will ensure that projects recognize the sovereignty of Indigenous data and adhere to the recommended process for respectful engagement with Indigenous partners.

Examples of Related First Nations, Inuit, Métis and Urban Indigenous Relevant Resources (hyperlinked)

Indigenous Charters & Rights	Indigenous Cultural Awareness Training	Indigenous Specific Research Principles
<ol style="list-style-type: none"> 1. United Nations Declaration on the Rights of Indigenous Peoples 2. Government of Canada: Charter Statement- Bill C-15: An Act respecting the United Nations Declaration on the Rights of Indigenous Peoples 3. Legislative Assembly of Ontario: Bill 76, United Nations Declaration on the Rights of Indigenous Peoples Act, 2019 	<ol style="list-style-type: none"> 1. Inuit Qaujimajatuqangit: The role of Indigenous knowledge in supporting wellness in Inuit communities in Nunavut 2. Ontario Health Indigenous Relationship and Cultural Awareness Courses 3. Indigenous Primary Health Care Council Foundations (IPHCC) of Indigenous Cultural Safety Training (ICS) 4. San'yas Anti-Racism Indigenous Cultural Safety Training (ICS) Program 	<ol style="list-style-type: none"> 1. The First Nations Principles of Ownership, Control, Access, Possession (OCAP) 2. Ontario Federation of Indigenous Friendship Centres. (2016). USAI Research Framework 3. National Aboriginal Health Organization. Métis Centre @ NAHO. (n.d.). Principles of Ethical Métis Research 4. Government of Canada. (2020, February 19). Tri-council policy statement: Ethical conduct for research involving humans – TCPS 2 (2018). Chapter 9: Research Involving the First Nations, Inuit, and Métis Peoples of Canada. Panel on Research Ethics. 5. Institute for Integrative Science & Health. Two-Eyed Seeing. 6. National Institute Strategy on Research

Appendix C: Expectations

Ontario Health Toronto Region Measuring Health Equity Project Minimum Expectations Reference Document

The need for improved health equity in Ontario was articulated through the Excellent Care for All Act (2010). In response, in 2013 the Toronto Central Local Health Integration Network, now Ontario Health Toronto Region, established the Measuring Health Equity (MHE) Project. The MHE tool has been supporting sociodemographic data collection and analysis over the last 10 years across hospitals and community health centres (CHCs) in Toronto Region (for more information on the MHE project, please visit: <http://torontohealthequity.ca/>).

In 2022, the [Ontario Health Data Council](#), submitted a vision for Ontario's health data ecosystem to the Minister of Health. This report includes a recommendation to "*promote health equity through appropriate data collection, analysis and use*" further underscoring the importance of continuing the Toronto Region MHE project.

Equity data collection remains a key priority at Ontario Health as is highlighted in the Ontario Health [Equity Inclusion Diversity Anti-Racism \(EIDA-R\) framework](#), as well as the Toronto Region Anti-Black Racism and Anti-Indigenous Racism Framework. The MHE questions were designed with a view towards providing an evidence-driven pathway to achieve equitable and quality care.

The MHE questions have been used by hospitals and CHCs to:

- Better understand who they are serving
- Understand potential inequities in quality of care, patient access and experiences and health outcomes
- Improve direct patient care and programs
- Support culturally appropriate care

Information collected by the MHE tool can support understanding more about the patients and communities we serve and where inequities lie that need to be addressed, for example, the following **use cases** could be explored:

- What percentage of the patients in our Women and Babies program are low-income?
- What percentage of patients receiving cervical and breast cancer screening identify as trans or non-binary and are their experiences in the program positive?
- What percentage of patients would appreciate interpretation services?
- Do the demographics of the patients coming to us for services reflect the community we are in?
- Are there a greater proportion of hospital acquired infections among specific populations?
- Are surgical wait times longer for patients from specific communities?
- Are hospital readmission rates higher among non-English speaking patients?

Over the last year, Ontario Health Toronto updated the MHE core questions to better reflect contemporary language, diverse experiences, and identities. The updated MHE core questions allow patients to see themselves reflected within the questions and answers.

Purpose

All organizations have made a commitment to advancing equitable health outcomes as a priority – the updated MHE questions are a foundational pillar of this priority. The updated questions are intended to improve patient access and quality of care and inform program and system level approach to health equity. This document outlines the minimum expectations for Health Service Providers (HSPs) (e.g. hospitals and community health centres) as they implement the updated MHE core set of questions within their organization.

Minimum Expectations for HSPs

SECTION 1: IMPLEMENTATION OF UPDATED MHE QUESTIONS

All hospitals are required to implement the *updated* core data set of MHE Questions (shared Nov 7, 2022). The following table outlines expectations when implementing the updated set of MHE questions.

Important Note: Implementation of Indigenous Identity question

The MHE core questions include a question specific to First Nations, Inuit and Métis (FNIM) identity. This question was included as a core question so that individual patients will see themselves reflected in the survey and can then exercise their right to identify or decline, as they wish (all questions are voluntary for patients). Excluding this question from the core Toronto Region MHE questions would deny individual patients their right to self-identify, should they wish to.

In the November 7, 2022 communication, Ontario Health Toronto outlined Indigenous data governance guidance principles related to OCAP®, Inuit and Métis, and Urban Indigenous (FNIMUI) approaches; organizations should seek guidance from their established FNIMUI governance, with the ultimate decision for inclusion up to the discretion of the organization. The appropriate resources relating to this information were also provided in the communication.

HSPs are expected to work with local FNIMUI leaders and advisors to implement the MHE core questions in a way that is appropriate, safe, and beneficial for Indigenous patients. If the FNIMUI advisors determine that there needs to be further actions taken before the MHE core questions can be asked, Ontario Health Toronto encourages HSPs to work in collaboration with the guidance of the FNIMUI advisors to take the necessary steps toward safety. Each HSP will go through this process separately and can determine the best approach for their specific site.

Expectation	Description	Rationale
1. Full Patient Coverage	<p>MHE questions are to be offered in high volume areas to all patients being served by hospitals. Answering these MHE questions are optional. Patients can decline to answer some or all of the questions without any impact to care.</p> <p>Questions are expected to be updated at specific intervals and not asked of the same patient at every appointment to be determined by the working group (e.g., every 3 years).</p>	<p>In the last ten years, data collection has been identified across different areas within organizations which has impacted the quality and rate of data collection.</p> <p>Given the learnings and the growth and maturity of organizations doing this work over this time, asking all patients</p>

	<p>To support organizational change management and readiness, hospitals can use a phased approach to meet the full patient coverage requirement- outlined below. These phases build on the existing Toronto Region Hospital Equity Data Collection Technical Specifications.</p> <p>Phase 1</p> <ul style="list-style-type: none"> • Inpatient and day surgery • 3 of the high-volume areas outlined in the Toronto Region Hospital Equity Data Technical Specifications <p>Phase 2</p> <table border="0"> <tr> <td style="vertical-align: top;"><u>Acute</u></td> <td style="vertical-align: top;"><u>Rehab/CC/Specialty</u></td> </tr> <tr> <td> <ul style="list-style-type: none"> • ED • Diagnostics • Women & Babies • All outpatient </td> <td> <ul style="list-style-type: none"> • Registration – all inpatient and outpatient </td> </tr> </table> <p>Collection rates will be reported based on total number of patients being served.</p>	<u>Acute</u>	<u>Rehab/CC/Specialty</u>	<ul style="list-style-type: none"> • ED • Diagnostics • Women & Babies • All outpatient 	<ul style="list-style-type: none"> • Registration – all inpatient and outpatient 	<p>as a requirement supports consistency for effective program and system planning to address health inequities collectively.</p>
<u>Acute</u>	<u>Rehab/CC/Specialty</u>					
<ul style="list-style-type: none"> • ED • Diagnostics • Women & Babies • All outpatient 	<ul style="list-style-type: none"> • Registration – all inpatient and outpatient 					
<p>1. MHE questions offered at Point of Patient Entry</p>	<p>MHE questions are to be offered at all high-volume entry points including where people may be waiting. Examples:</p> <ul style="list-style-type: none"> • ED (exclude CTAS 1 or 2 and/or trauma patients, critical care, etc) <p>HSPs are expected to determine their preferred approach in asking questions based on organizational workflow, processes, community feedback. (e.g. various points including registration, tablets, QR codes, translated surveys, using pre-screening online forms or patient portals such as MyChart, etc.).</p>	<p>Prioritizing high volume/traffic areas will cover most patients and demonstrate largest impact.</p> <p>Toronto HSPs that have been able to collect equity data on all patients, have had significant success with improving access to care and quality of care for their patients.</p>				
<p>2. Data is available within EMR</p>	<p>Data is electronically available within EMR and extractable for data analysis and use (see expectation 7 and 8).</p> <p>Format of data collection may vary based on site needs, however data must be uploaded into EMR to support use of data.</p>	<p>Electronic availability will support ease of pulling data for analysis and use including:</p> <ul style="list-style-type: none"> • Engagement of patients • Clinical care • Program analysis and use 				
<p>3. Data Governance</p>	<p>NB: As a reminder, this data governance expectation is not pertaining to FNIMUI data governance- see “Indigenous Identity Question” note on page 2 above.</p>	<p>Data governance provides appropriate interpretation of data and avoids harm and further stigmatization of patients through</p>				

	<p>Development of organizational capacity to understand data governance as it pertains to equity data analysis, use and development of solutions to improve services/programs.</p> <p>Includes existing data governance frameworks (e.g those for Black communities like the Engagement, Governance, Access and Protection (EGAP) framework).</p>	<p>misuse and misinterpretation of data.</p> <p>It also ensures community engagement related to the release of any equity data analysis as part of data governance.</p>
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SECTION 2: COLLECTION, INTERPRETATION & USE OF DATA

The updated MHE questions will provide an opportunity to review existing practices on how equity data is collected, interpreted, and used. The following table outlines the expectations as part of implementation planning when collecting, interpreting and using equity data.

Expectation	Description	Rationale
<p>4. Support Staff and Patients</p>	<p>Support staff in appropriate collection, analysis and use of equity data through a comprehensive training plan including resources for ongoing support, training specific to organizational processes, development of appropriate workflow to enable point of care use of data (e.g., clinician training on when and how to interpret patient specific information to be used within care planning etc.).</p> <p>As a baseline, training should include cultural and sensitivity training for all staff involved in collection, analysis, and use of equity data (e.g., patient facing staff, clinicians, health analysts, researchers, etc.).</p>	<p>Staff training provides the skills and tools to appropriately interpret data thus avoiding harm and further stigmatization of populations through misuse and misinterpretation of data.</p> <p>It also supports staff to understand the need for data collection and feel comfortable to ask/respond to questions from patients.</p> <p>Training increases organizational capacity to understand data governance as it pertains to equity data analysis and use and supports clinicians in culturally and sensitivity training with patients.</p> <p>In addition to the above, it also supports clinicians in responding to any potential questions/concerns from patients.</p>
<p>5. Point of Care Use</p>	<p>As a baseline requirement, cultural/sensitivity training should be completed by any clinician that is expected to use the equity data as part of point of care/care planning (e.g., at orientation, regular cycles of mandatory training etc.).</p> <p>Hospitals should determine the most appropriate workflow/process for when and how equity data should be made available in clinical care to improve patient care.</p>	<p>Using equity data at point of care supports better quality of care and health outcomes. Together, patients and clinicians are able to make informed care decisions.</p> <p>Prior to using equity data at point of care the appropriate training and structures need to be in place to support clinicians in providing care in a culturally safe and sensitive manner.</p> <p>It also avoids harm and further stigmatization of patients through</p>

		proper collection, analysis and use of data.
6. Program Planning & Analysis	<p>Hospitals are to create a structure to collect and analyze program level data across the organization to ensure strong data quality.</p> <p>Program level data is to be used to support comparisons and differential analyses of populations and programs based on sociodemographic differences, patient experiences (e.g., the use cases identified on page 1).</p> <p>As part of this process, impacted communities are to be engaged in analysis and use of data to improve services.</p>	<p>This data is to be used to identify and address disparities in quality of care, patient access to care, their experiences and health outcomes. Using equity data to improve services requires strong data collection practices to ensure good quality data is used for decision making.</p> <p>Understanding differential outcomes based on equity data will identify opportunities to engage communities and to develop targeted and culturally specific strategies to improve care.</p>
7. Monitoring & Performance Reporting of Equity Data Collection	<p>Internal monitoring of implementation of updated MHE data set is recommended for all hospitals (e.g., monthly reporting to senior team, etc.).</p> <p>Each hospital will submit performance reports at Q2 and Q4 to Toronto Region to monitor implementation progress.</p> <p>Performance reports will include:</p> <ul style="list-style-type: none"> • Collection rates • Quality of data (“Missing”, “Prefer Not to Answer” and “Don’t Know” indicators) 	<p>Strong performance reporting and monitoring will ensure successful implementation, data quality and use of equity data to improve care, including to executives, boards, and Toronto Region.</p> <p>Peer and (future) public reporting of data will improve engagement with communities and increase transparency.</p>