

Measuring Health Equity

Demographic Data Collection and
Use in Toronto Central LHIN Hospitals
and Community Health Centres



Ontario

Toronto Central Local Health
Integration Network

Réseau local d'intégration
des services de santé
du Centre-Toronto

July 2017

About This Report

The Toronto Central Local Health Integration Network (Toronto Central LHIN) provided financial support to establish the Measuring Health Equity Project and has called for recommendations on health equity data use and a sustainability approach for future data collection.

This report describes the journey Toronto Central LHIN and Sinai Health System have taken to embed demographic data collection in hospitals and Community Health Centres. It also summarizes the potential impact of embedding demographic data collection into Ontario health-care delivery and planning. And finally, it describes the use of this data, the lessons learned, and provides recommendations for moving forward.

Acknowledgements

Sinai Health System would like to recognize the Toronto Central LHIN for their support and funding for the Measuring Health Equity Project. Thank you to our dedicated colleagues in hospitals and Community Health Centres who sought and developed solutions to collecting, analyzing and using standardized demographic data. And our thanks to the patients and clients across the Toronto Central LHIN who saw the value of this work and shared their own personal information. These collective efforts contribute to the work of improving health and health equity for all.



CONTENTS

Executive Summary	2
Introduction	5
Measuring Health Equity in Toronto Central LHIN	6
Laying the Groundwork	7
Hospitals	7
Community Health Centres	7
Areas of Support	8
Initial Implementation of Data Collection	9
Hospitals	9
Community Health Centres	10
Learn and Expand	10
Improve Data Quality	11
Findings and Discoveries	11
Community Health Centres	11
Hospitals	12
Reflecting on the Findings and Discoveries	13
Using the Data	14
LHIN's population health and health equity strategies	15
Understanding Data Use: Three Case Studies	15
Case Study 1: Flemingdon Health Centre	15
Case Study 2: West Park Healthcare Centre	15
Case Study 3: St. Michael's Hospital Academic Family Health Team	16
Beyond the Toronto Central LHIN	16
Moving Forward: Embedding the Collection and Use of Demographic Data	17
Conclusion	19
References	20
Appendix A Eight Standardized Questions for Hospitals	21
Appendix B Eight Standardized Questions for CHCs	24
Appendix C Pediatric Health Equity Data Collection Instrument	27
Appendix D List of Participating Hospitals and Community Health Centres	36
Appendix E CHC Advisory Group	37



EXECUTIVE SUMMARY

Measuring Health Equity: Demographic Data Collection and Use in Toronto Central LHIN Hospitals and Community Health Centres

This paper presents a summary of the Measuring Health Equity in Toronto Central LHIN Project, a transformative and first of its kind Canadian effort to mandate the standardized collection of demographic data from patients and clients. The collection of this data represents an evidence-driven pathway to achieving equitable and quality care. The Measuring Health Equity Project has shown the operational feasibility of data collection and that the clear majority of patients and clients are amenable to being asked demographic questions.

The Toronto Central LHIN focus on health equity is to ensure that all residents have equitable, quality-driven care while maintaining a focus on a sustainable health-care system. The Toronto Central LHIN has the most diverse patient/client population in the province. In 2012, the Toronto Central LHIN mandated the collection of patient and client demographic data to help achieve health equity across the system and within health-care organizations. This project focuses on standardized demographic data collection in hospitals and Community Health Centres (CHCs). The eight questions being collected are: preferred language, whether born in Canada, racial/ethnic group, disabilities, gender, sexual orientation, income, and number of people supported by income.

Data collection began in 2013 across 16 hospitals and the following year in 16 CHCs. Hospitals and CHCs were given the target of reaching 75% of their patients and clients by the end of fiscal year 2016/17. Some of the main challenges facing data collection include: identifying the number of patients/clients seen in hospitals, entering and extracting data in IT systems, and expanding collection into outpatient hospital areas. The prevalent opportunities have been the broad commitment to data collection despite resource constraints, a shared passion for health equity, and emerging best practices and materials.

Summary of hospital data collection participation rates

- As of November 2015, more than 261,000 patients had been approached for data collection.
- Contact rate (the percentage of patients approached out of all patients in the targeted areas) varied by hospital. The average for hospitals was 94 per cent with multiple hospitals reaching a 100 per cent contact rate and one outlier reporting 9.7 per cent.
- The average participation rate over a two-year period was 48 per cent ('participation rate' being the percentage of patients from whom hospitals have collected data). One hospital had a 100 per cent participation rate. The reasons for gaps in data include patients declining to participate, being unable to participate, or not being asked, which usually accounts for the largest portion of missing data.
- Data has been averaged over a two-year period, however, data submissions in 2015 have higher participation and contact rates compared to 2014.

Summary of CHC data collection participation rates

- As of March 2016, 25,443 clients had provided responses to the Toronto Central LHIN health equity questions.
- The participation rate average across 16 CHCs was 39 per cent. Rates ranged from 18 to 82 per cent.
- For the first two quarters of 2016/17, CHCs had an increase in participation rates, averaging 49.1 per cent.
 - 9 CHCs have demographic data on 25%-50% of their clients.
 - 5 CHCs have demographic data on 51%-75% of their clients.
 - 2 CHCs have demographic data on 76%-100% of their clients.

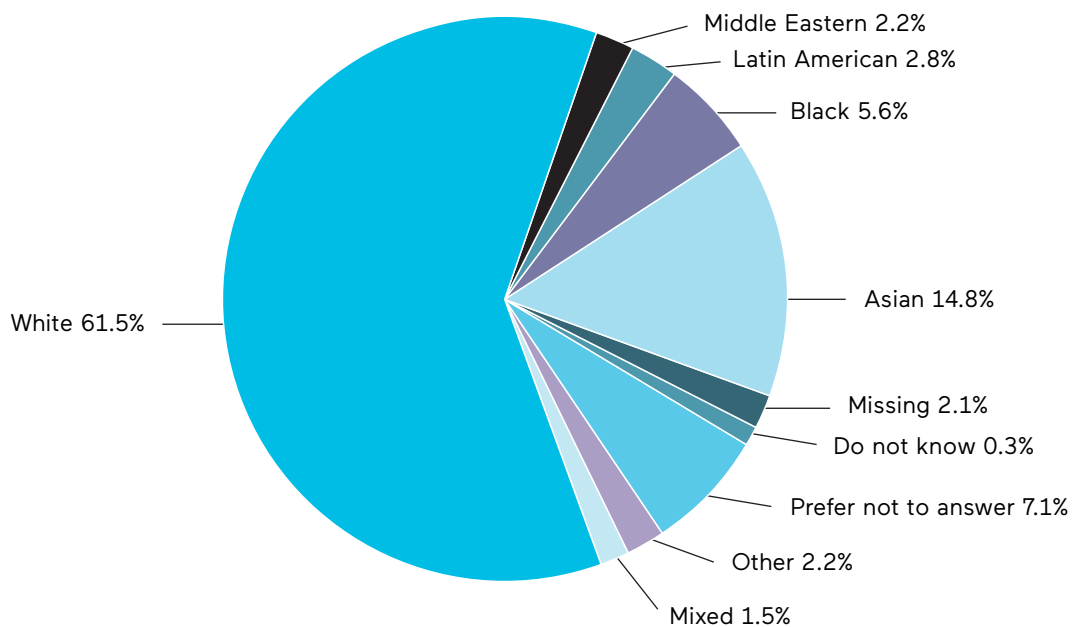
This project has major significance because it is the first time in Canada that hospitals have built data collection into their day-to-day patient registration. CHCs had been collecting similar data fields previously, however, this initiative sought to connect the work of hospitals and CHCs through mandating the same questions and promoting evidence-based data collection methods.

The Measuring Health Equity Project is also unique internationally because of the breadth of data variables being collected. This breadth of data opens potential for intersectional analysis.

This data has provided the Toronto Central LHIN with unprecedented information about its patients and clients, including racial/ethnic groups.

The scope of the data continues to grow with ongoing data collection. As of March 2017, hospitals now have data on over 389,000 patients and CHCs have data on over 46,000 clients. While the new data is currently being analyzed, the figures and statistics in this report highlight hospital data as of November 2015 and CHC data as of March 2016.

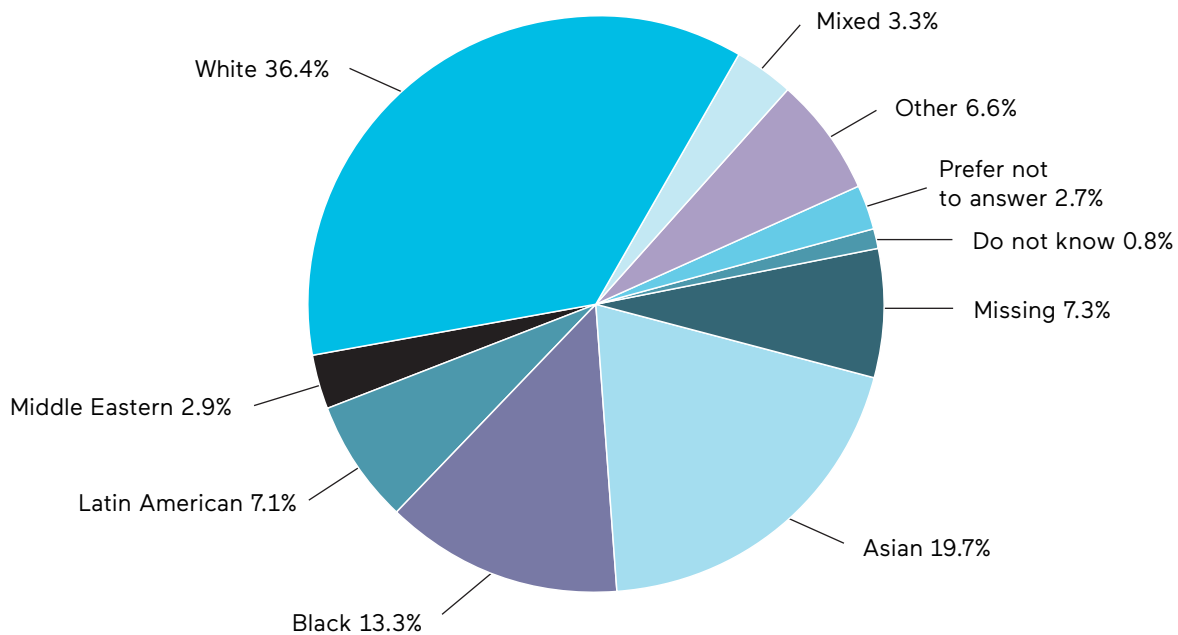
Figure 1.
Toronto Central LHIN hospital data on racial/ethnic group from 261,000 patients



Variation in rates among Toronto Central LHIN hospitals:

- “Prefer not to answer + Do not know + Missing data” ranged from 0.7% to 34.6%
- Proportion of White (North American) + White (European) ranged from 37.7% to 85.4%

Figure 2.
Toronto Central LHIN CHC data on racial/ethnic group from 25,500 clients



Variation in rates among Toronto Central LHIN CHCs:

- “Prefer not to answer + Do not know + Missing data” ranged from 2.8% to 22.3%

Next steps will include:

- Continuing demographic data collection, and improvements in data quality
- Using equity information to identify high needs populations
- Collaborating with other stakeholders on using the data to improve care and patient and client outcomes
- Guiding the use of demographic data on organizational, clinical levels
- Sharing best practices in addressing health equity disparities
- Scaling successful local innovations to improve health equity

For the first time, hospitals know who they serve. Streamlining the questions and methods will continue to improve results for both CHCs and hospitals and allow access to individual-level data that can be used to track treatment and outcomes for patients/clients, develop organization-specific analyses, and monitor the impact of policy or program changes. Previously this data had been available only through secondary sources (e.g., census) or research (e.g., geocoding). Comprehensive access to individual-level data can be used to inform care at the bedside/clinical level and develop more customized programming. Using the same set of questions both within and across sectors provides planners such as the Toronto Central LHIN with the ability to aggregate data and minimize the need to re-code data collected using multiple methods and approaches.



INTRODUCTION

Health equity allows people to reach their full health potential and receive high-quality care that is fair and appropriate to them and their needs, no matter where they live, what they have or who they are (HQO, 2016). Health inequities are differences in health outcomes that are avoidable, unfair and systematically related to social inequities (Braveman, 2014). Collecting patient and client demographic data identifies the gaps and inequities in health-care access and enables health-care organizations to develop and track interventions. Patient/client demographic data collection is recognized as a gold standard in understanding patients/clients being served and addressing health inequities (Siegel, Regenstein, & Jones, 2007; Weineck, Flaherty & Bristol, 2008).

The Toronto Central LHIN serves a population of 1.3 million (2015 estimates). It has the most diverse patient/client population in the province. Within the Toronto Central LHIN there are 17 hospitals (16 public and 1 private), 17 CHCs, 36 long-term care homes, 1 community care access centre (CCAC), 63 community support services, 73 community mental health and addictions agencies, and 1 regional geriatric program. Toronto Central LHIN hospitals and CHCs participating in the Measuring Health Equity Project are listed in Appendix D.

The Toronto Central LHIN's 16 public hospitals include acute care, continuing complex care, ambulatory care, and mental health facilities serving adult and pediatric populations. These organizations are also a mix of large academic centres, community hospitals, and smaller organizations focused on palliative care. Seven of the hospitals have emergency departments.

CHCs provide primary care, health promotion, education and illness prevention services using a community development approach. In addition to promoting the health of individuals and families, CHCs mount initiatives that address social, economic and environmental problems negatively impacting people's health. Governed by community members, and working hand in hand with those they serve, CHCs also prioritize improving the health and wellbeing of populations who have traditionally faced barriers accessing health services. The 17 CHCs in the Toronto Central region provide services to specific catchment areas, marginalized populations, and range in size and populations served.

The Toronto Central LHIN has a strong focus on health equity and equity has been included as priority in the LHIN's Integrated Health Service Delivery plans (IHSP). It is committed to ensuring that all residents have equitable, quality-driven care while maintaining a focus on a sustainable health-care system. Equity has gained more prominence with the establishment of the *Excellent Care for All* legislation and the *Patients First Act* that is emphasizing a population health and equity approach across the province. The Toronto Central LHIN has established an Equity Working Group under the Population Health and Equity Leadership table, which is tasked with guiding equity related work including demographic data collection.

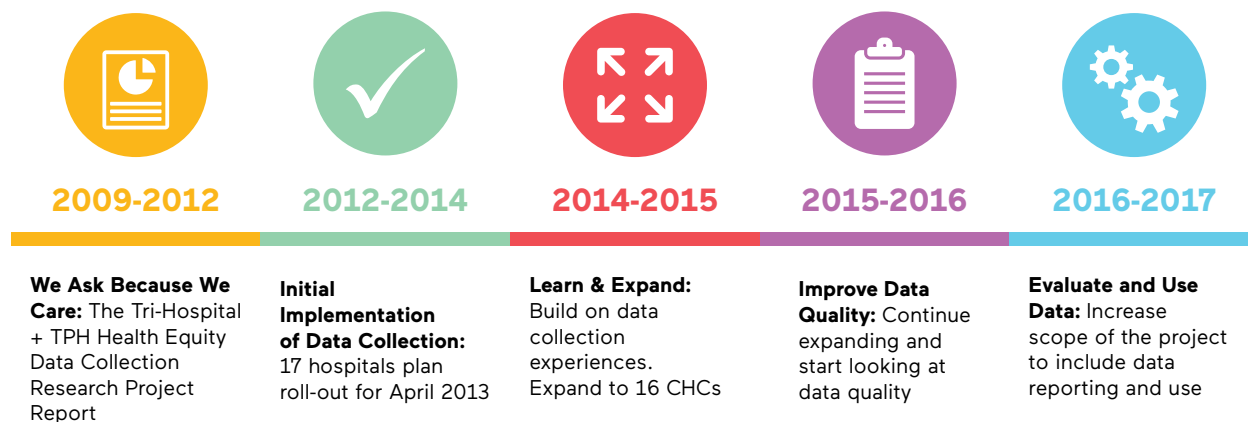
Standardized patient and client level demographic data collection started in 2013 in central Toronto hospitals and CHCs following the "Measuring Health Equity in Toronto Central LHIN" mandate. The demographic questions were developed through the Tri-Hospital + TPH (Toronto Public Health) Health Equity Data Collection Research Project, a collaboration between the Centre for Addictions and Mental Health (CAMH), Mount Sinai Hospital and St. Michael's Hospital. This project was led by Mount Sinai Hospital (MSH), now part of Sinai Health System, and aimed to develop a set of patient demographic questions that would enable health-care organizations to identify and track health inequities. Committee members interviewed key informants who were collecting or using demographic data, and met with the Toronto District School Board (TDSB) which had been collecting demographic data on their students and their families for many years.

The research project tested methods for data collection, data collection training models, and information technology (IT) solutions. The results were released in *We Ask Because We Care: The Tri-Hospital + TPH Health Equity Data Collection Research Project Report*¹ and included a recommended set of eight demographic questions that include: preferred language, whether born in Canada, racial/ethnic group, disabilities, gender, sexual orientation, income, and number of people supported by income (see Appendix A). The Toronto Central LHIN adopted the report’s recommendations and mandated the collection of patient demographic data using these eight questions, introducing a standardized data collection effort that would secure access to patient/client demographic data and promote a system-level approach to health equity.

MEASURING HEALTH EQUITY IN TORONTO CENTRAL LHIN

The Toronto Central LHIN asked Mount Sinai Hospital’s Human Rights & Health Equity Office to lead the Measuring Health Equity Project, the collection of patient and client demographic data in its hospitals and Community Health Centres. Planning was key in implementing standardized demographic data collection given the wide array of organizations, departments, staff, administrators, resources and functions that the project involved. It required identifying the essential elements needed for success, ways to secure these elements and deliberate action based on evidence. The main elements were leadership buy-in, data collection workflows, staff training and education, and information technology (IT) solutions.

Figure 3: History of the “Measuring Health Equity in Toronto Central LHIN” mandate



¹ Available at: http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity

LAYING THE GROUNDWORK

Hospitals

The Mount Sinai Hospital team visited all 16 Toronto Central LHIN hospitals for one-on-one meetings with CEOs and senior leadership to acquaint them with the mandate and secure buy-in (see Appendix D). The initial meetings were followed up with discussions on how to embed data collection into existing workflows, on-site staff training for data collection, individual consultations, and the development of a range of tools and resources including a comprehensive online demographic data collection guide. Special attention was given to exploring IT solutions for building demographic data into existing systems and designing alternative solutions for hospitals that had limited IT capacities.

As a first step in planning for demographic data collection, each hospital assigned a project lead and established a working group that included a range of roles such as IT, privacy, researchers, decision support, front line staff, and others.

Community Health Centres (CHCs)

Community Health Centres (CHCs) have been collecting a range of socio-demographic data from their clients for over 20 years. These data collection efforts fit with their focus on vulnerable population groups and the social determinants of health and facilitated tracking of service to their mandated populations. In an effort to standardize data collection across the system, the Toronto Central LHIN mandated that CHCs start collecting client demographic data using the eight standardized questions. Four of the questions had previously been collected by the CHC sector²: spoken language, born in Canada, income, and number of people that income supports.

Recognizing that CHCs have a unique environment, the Mount Sinai Hospital team coordinated a pilot project in five CHCs to adapt the questions and process to a CHC setting.³ Through the pilot project, they developed IT solutions, tested training materials, and identified workflows for data collection. A Technical Working Group was formed during the pilot project with the mandate to identify IT and data migration solutions that would support the adoption of the eight demographic questions across the Toronto Central LHIN CHCs. CHCs were in the midst of transitioning Electronic Medical Record software from Purkinje to Nightingale On Demand (NOD) which created challenges in the roll-out of the pilot project. The findings of the pilot were released in the *Measuring Health Equity in Toronto Central LHIN Community Health Centres Pilot Project* report and the lessons it contained were used to inform a wide rollout across 16 sites (see Appendix D). The recommendations included breaking down the income brackets to provide more granular data for low-income categories that aligned with existing categories and adding “two-spirit” to the gender question (see Appendix B). IT solutions focused on building demographic fields into NOD, and developing guidelines and queries to pull client demographic data. Many of the IT issues were resolved through the creation of the NOD Guidelines and NOD Data Entry Notes documents, while issues remained with extracting data from the eight Toronto Central LHIN questions consistently and accurately from NOD.

As had been the case with hospitals, the Mount Sinai team met with Executive Directors and senior leadership across the CHCs and worked closely with the project leads on the various aspects of planning and implementing demographic data collection.

Towards the end of 2015, a CHC Advisory Group (see Appendix E) was formed to help guide the Measuring Health Equity work in Toronto Central LHIN CHCs. At monthly meetings, members addressed IT and

2 The CHC questions differed in wording and answer options.

3 Access Alliance Multicultural Health and Community Services, Central Toronto Community Health Centres, Parkdale Community Health Centre, Planned Parenthood of Toronto, South Riverdale Community Health Centre

other issues and discussed ways to support the collection, analysis and use of the Toronto Central LHIN mandated demographic questions.

As of publication of this report, one CHC, Centre francophone de Toronto (CFT), has still not rolled out the demographic data collection due to ongoing IT issues.

Recognizing that data collection in pediatric settings may differ from others, the Toronto Central LHIN supported a pilot by the Hospital for Sick Children (SickKids) and Holland Bloorview Kids Rehabilitation Hospital to understand how the demographic questions and methods of collection can be adapted to the pediatric population (see Appendix C). Following the pilot, the two participating hospitals expanded data collection to include caregivers. The findings were also used to develop data collection guidelines for hospitals that serve patients and clients from all age groups and children and youth who visit CHCs.

Hospitals and CHCs collect data from children and youth using the original Toronto Central LHIN questions and incorporate the guidelines adapted from the pediatric pilot. The guidelines include that patients/clients over a certain age directly respond to the questions (13 years or over in CHCs, 14 years or over in hospitals). For those under that age, the primary caregiver provides information about the patient/client on all questions except for gender and sexual orientation (these two questions are not asked). In all cases, family income reflects the total income supporting the child/youth.

AREAS OF SUPPORT

Training, workshops, communications and engagement, visits and consultations, and the [Measuring Health Equity website](#) were developed to support data collection. Over 700 data collectors and staff of hospitals and CHCs were provided customized training that took into account their workflow, the physical environment where data would be collected and the nature of the patients’ and clients’ visits. Forms and brochures were produced in French and 11 languages that were most frequently requested for interpretation in the Toronto Central LHIN. The website provides an online data collection guide, tools, training modules, online learning module, references and research, event presentations, and all project materials. The Mount Sinai Hospital team provided a comprehensive suite of training modules and supports.

Figure 4: Supports provided by Mount Sinai Hospital Team

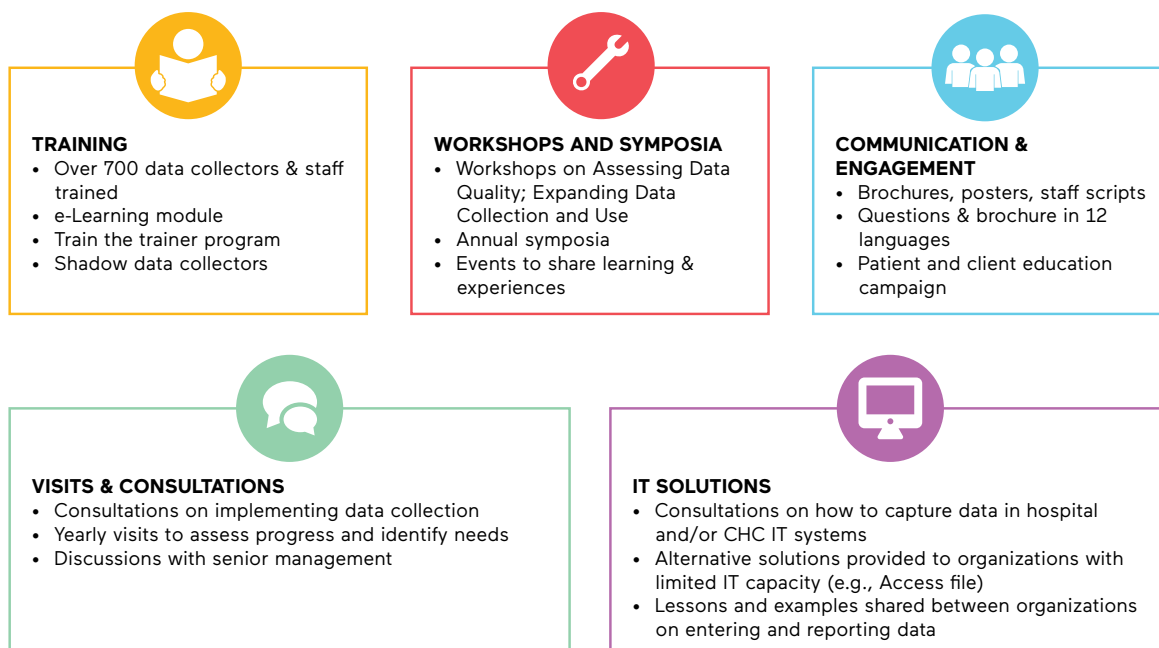
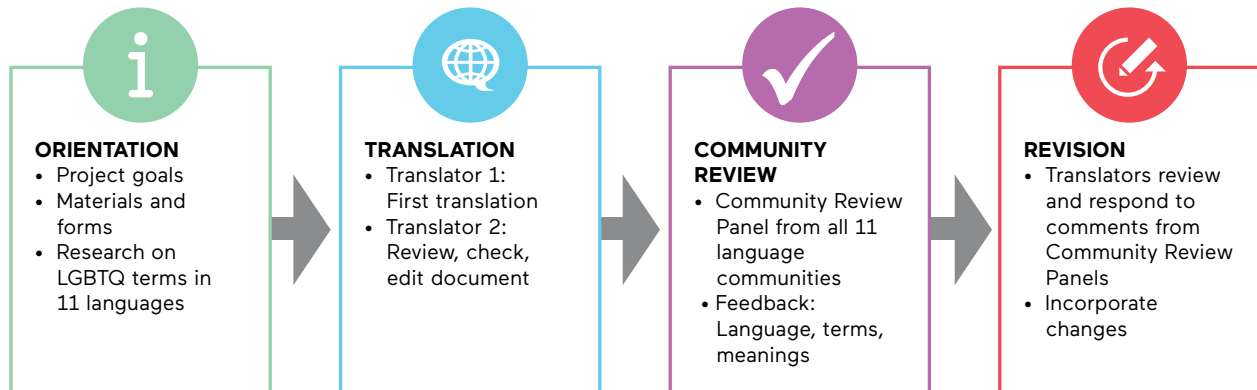


Figure 5: Process for Translating Toronto Central LHIN Questions



Language list: Arabic, French, Hungarian, Italian, Korean, Portuguese, Russian, Simplified Chinese, Spanish, Tamil, Vietnamese

INITIAL IMPLEMENTATION OF DATA COLLECTION

Demographic data collection started in hospitals and CHCs on a small scale, with the understanding that they would build on early lessons and expand toward the goal of collecting data from 75% of their patients/clients. The strategy for rolling out data collection focused on adapting best practices to fit with existing workflows. However, specific principles around data collection held across settings and informed decisions on how to collect data. Those principles of data collection included, but were not limited to, highlighting the importance of staff training, checking for missing data, and ensuring patients and clients are providing informed consent (why we ask, who has access to their information and that their response is voluntary).

Hospitals

Given the differences in patient volumes, admission procedures, areas of specialty, and workflows, the patterns of data collection in acute care differed slightly from collection in the Rehabilitation (Rehab) and Complex Continuing Care (CCC) facilities. In acute care, hospitals focus on collection at time of registration or admission through volunteer or administrative staff, using paper forms or in interviews while registering patients. For Rehab/CCCs, the predominant method was to interview patients at the bedside and collect the demographic data through a conversation with a social worker, another health-care provider or an admission clerk.

Figure 6: Summary of the data collection methods in hospitals



Note: 5 of the 16 hospitals use more than one data collection method to accommodate workflows in different areas (e.g., outpatient area vs. admitting)

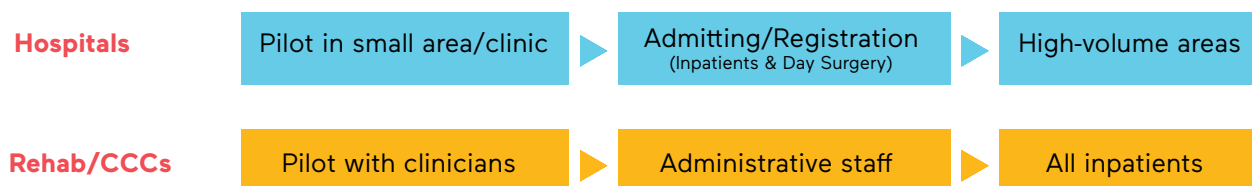
Community Health Centres (CHCs)

Data collection in CHCs primarily happens at the point that clients join the centre (i.e., new clients) or when they are attending an appointment. Since CHCs provide a multitude of services including primary care, health promotion, education and illness prevention, there were challenges in collecting the data from group clients, and clients seeking services offsite at other facilities (i.e., outreach services). The method for data collection is mainly by paper; the client is handed the demographic form to fill out on their own and staff check to ensure the form is returned and answer any questions from clients. In some CHCs, new clients are interviewed by staff and the questions are asked in person.

LEARN AND EXPAND

Following initial implementation of data collection, hospitals expanded data collection using processes that worked. For example, hospitals that had relied on volunteers as primary data collectors had staff collect data. Expansion often involved changes to data collection strategies and the methods for expanding collection in acute care hospitals differed from those in Rehab/CCCs. While not all hospitals had the same trajectory, the majority followed the pattern outlined below.

Figure 7: Evolution of data collection practices in hospitals and Rehab/CCCs



CHCs expanded their collection efforts without significant changes to their methodology as they had a history of collecting client data and had standardized the tool and workflow through the CHC pilot project.

There were five key lessons from rolling out data collection at hospitals and CHCs.

1. Build a respectful and inclusive environment.
2. Identify data reporting goals and embed them in early planning.
3. Standardize data entry practices to improve the quality of data recorded.
4. As changing an existing data collection practice can be more challenging than introducing new practices to an organization, provide more support when implementing changes.
5. Provide education and materials to project leads on difference between equal care vs. equitable care.

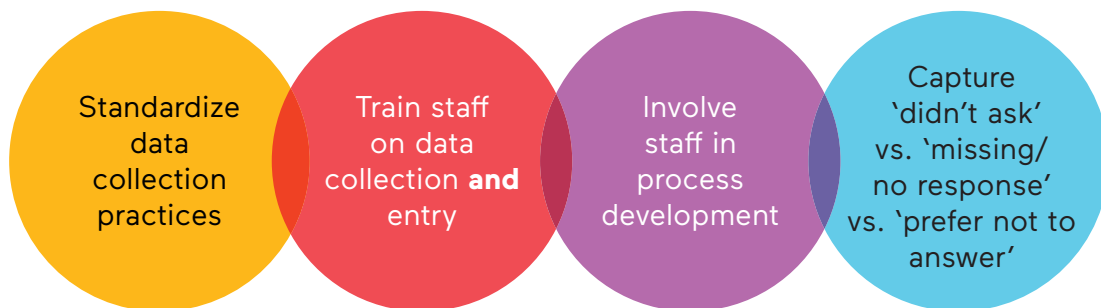
IMPROVE DATA QUALITY

Project leads within organizations did not necessarily have previous experience working with data. To increase familiarity with practices that would ensure high quality data, the MSH team developed a data collection guide, a workshop, and multiple presentations on data quality. Education and training focused on:

- Familiarizing leads with concepts of data quality such as reliability and validity.
- Emphasizing the importance of monitoring data quality.
- Developing dashboards and data audit templates to evaluate progress and share analysis of the data.
- Consulting on strategies to address gaps.

The Mount Sinai Hospital team provided guidance on building structures to ensure high quality data. This included workshops and consulting with organizations on missing data rates, participation rates and for hospitals, contact rates (who is being asked the questions). This required regular follow up with hospitals and CHCs that have high “missing data” rates. For CHCs, a specific data entry training post-pilot was delivered to ensure high quality data was entered into the Electronic Medical Record.

Figure 8: Planning for High Quality Data: Building “Good” Structures



FINDINGS AND DISCOVERIES

Community Health Centres (CHCs)

In Q1 and Q2 of 2016-2017, CHCs have seen a significant increase in the number of clients with demographic data. As the data in Table 1 shows, the first six months has seen significant increase in the number of demographic records. As illustrated, Q1-Q2 of 2016-2017 has nearly as many responses as the total for 2015-2016.

Table 1: Summary of data collection for the four new questions in CHCs

Total Responses 2015/2016	Total Responses Q1-Q2 2016/2017	% of Clients with Demographic Data 2015/2016	% of Clients with Demographic Data Q1-Q2 2016/2017
25,443	22,782	39%	49.1%*

* scores range between 28.1% to 92.8%

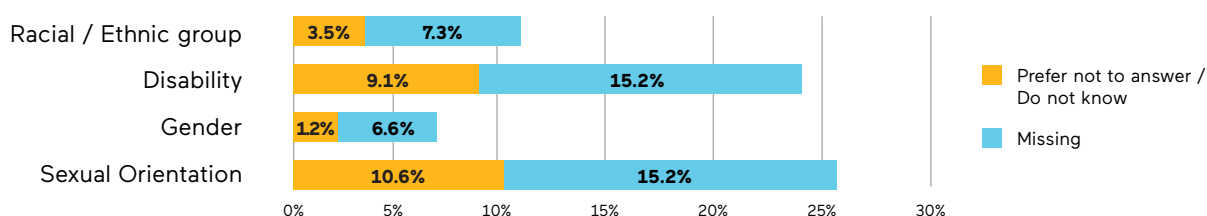
A closer look at individual CHC Q1-Q2 2016/2017 reports shows that out of 16 CHCs collecting data:

- 9 CHCs have demographic data on 25%-50% of clients.
- 5 CHCs have demographic data on 51%-75% of clients.
- 2 CHCs have demographic data on 76%-100% of clients.

CHCs reported 10 client complaints related to the data collection, i.e., 0.04% of clients who were asked the questions. The complaints were also reported to have been resolved after explaining the purpose of data collection and mandate information. This is consistent with other feedback from staff about patient/client openness to responding to the questions.

A look at Figure 9 (below) also highlights the percentage of Missing/Prefer not to answer/Do not know percentages for 4 out of the 8 questions.⁴

Figure 9: Summary of data collection in CHCs, 2016



Hospitals⁵

As of November 2015, over **261,000 patients** had been approached for data collection in 12 Toronto Central LHIN hospitals⁶ and the average participation rate over a two year period was 48%. A closer look at that average reveals a significant variation in participation rates, with the lowest being 13.5% in one hospital while 6 hospitals (i.e., half) reported participation rates of 90% or more.

In addition to looking at participation rates, hospitals were asked to report on “contact rate,” i.e., the percentage of patients who were approached for data collection in targeted areas. As with participation rates, there was a wide variation across hospitals. The average was 94% with rates ranging from 9.7% to the majority being at 100%.

In 2015, hospitals reported 12 patient complaints related to the data collection, i.e., 0.009% of patients who were asked the questions. These complaints were also reported to have been resolved after explaining

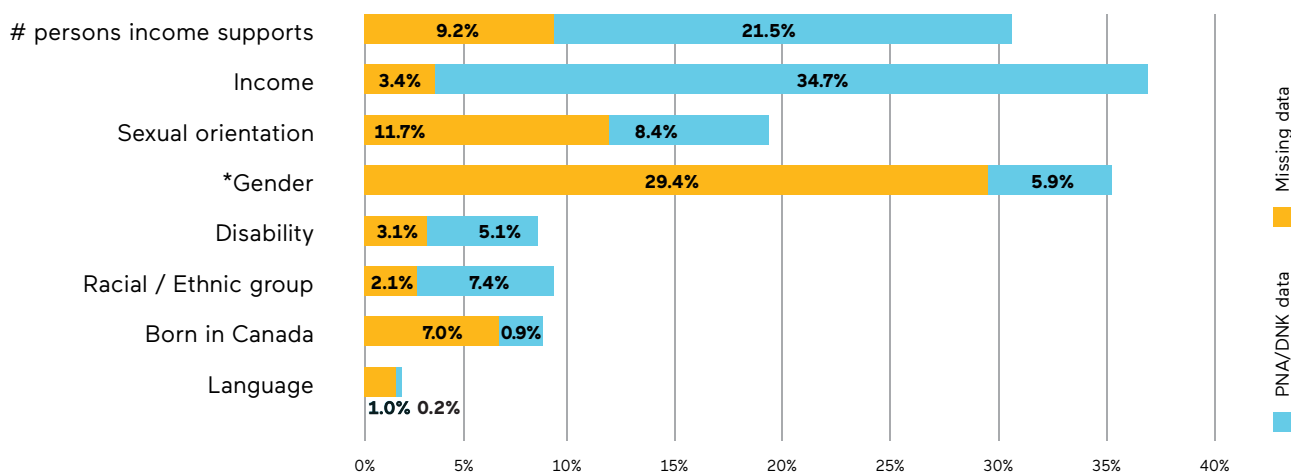
⁴ CHCs are still building the reports for pulling demographic data on the remaining 4 demographic questions.

⁵ Based on “Progress Report on Equity Data Collection by Toronto Central LHIN Hospitals: Results as of November 2015” Report

⁶ 4 out of 16 hospitals were excluded from this data summary: 2 pediatric facilities were exempt from submitting a data summary because they had a later start date for data collection, 2 hospitals had IT difficulties with pulling reliable reports.

the purpose of data collection and the Toronto Central LHIN mandate. This correlates with feedback from staff about general patient openness to responding to the questions. Figure 10 (below) also revealed that “Missing/Prefer not to answer (PNA)/Do not know (DNK)” accounts for only 10% or less of the data for six out of the eight questions. The higher number for PNA/DNK for income is in line with previous research on response rates for income (*We Ask Because We Care*, 2013) and a consistent pattern across hospitals. Given the low rates for PNA/DNK for the majority of questions, the MSH team focused on reducing missing data and understanding how data collection practices contributed to it. More specifically, they looked at how missing data rates were affected when staff followed up with patients who had completed the demographic questions.

Figure 10: Summary of data collection in hospitals, 2015



**Gender: High missing data rates are largely explained by issues with pulling the data reports from one hospital with a large sample size.*

REFLECTING ON THE FINDINGS AND DISCOVERIES

A look into the data in Figure 10 reveals that reported missing data, participation rates, contact rates, and “Prefer not to answer/Do not know” vary significantly within the hospital and CHC sectors. Those differences are still evident even after considering organizations comparable in terms of size, services, and staff roles.

When it comes to participation and missing data, a closer look suggests that data collection practices have a significant impact on patient/client participation. Hospitals and CHCs that have high participation rates share a number of characteristics:

- Staff training is a priority
- Workflow includes staff following up with the patient/client to ensure completion
- Patients/Clients have access to a staff person for questions
- Regular reporting that identifies which clients have not answered the questions (CHCs)
- Leadership buy-in (CHCs)

The elements needed to ensure high “contact rate” are:

- Leadership buy-in

- Trained and engaged staff
- Built-in accountability on data collection performance
- A respectful work environment with a focus on equity

Data collection experiences in hospitals and CHCs emphasize that *how we ask* is as important as *what we ask*.

USING THE DATA

Hospitals and CHCs are using the data in a variety of ways: to profile who is being served, to stratify health service utilization and outcome data, to build into quality improvement plans, and to inform clinical care. The table below expands on how data is used.

Table 2: Examples of how hospitals and CHCs are using the data

Profile who is being served	<ul style="list-style-type: none"> – Share demographic dashboards with boards, senior management, and data collectors – Identify the racial/ethnic profile of clients and tailor or develop programs to meet their needs – Identify language needs – for interpretation and translation – Identify characteristics of service users who access Emergency Departments more frequently
Stratify health service use and outcome indicators	<ul style="list-style-type: none"> – Stratify breast cancer screening rates by racial/ethnic groups to identify missed screening targets – Stratify FIM (Functional Independence Measure) scores at admission and discharge by language and racial/ethnic group
Build into Quality Improvement Plans (QIPs)	<ul style="list-style-type: none"> – Include demographic data collection target in organization’s QIPs – Include stratification of clinical indicator by demographic data in organization’s QIPs
Inform Clinical Care	<ul style="list-style-type: none"> – Provide clinicians, including physicians, nurses, social workers, physiotherapists and others with access to demographic data on electronic charts – Use racial/ethnic response to discuss nutrition with pregnant patients – Identify language/interpretation needs – Use “income” to consult on nutritional need and provide tokens for clients to access services

The collection of this demographic data is a very powerful tool for the Toronto Central LHIN, CHCs and hospitals. Collecting demographic data at the individual level allows organizations to link patients/clients with health utilization and outcomes, inform and transform care, and know who is being served. As a result, organizations can now benchmark and track health inequities, and develop programs and services to address those gaps thereby addressing the needs of patients and clients from marginalized groups.

LHIN's population health and health equity strategies

The patient and client level demographic data will be invaluable to Toronto Central LHIN health planning, funding and evaluation of the health system. From a population perspective, the data can be linked to ICES (The Institute for Clinical Evaluative Sciences) databases for health status, health service use and outcomes and CHC, community mental health and addictions and community support services use. This will help to understand who is being served by Health Service Providers and who is not; determine if some groups are over or under represented; and the socio-demographic profile of high users of the health-care system. The data can be analyzed at Sub-Region and neighborhood level to understand if there are geographic differences in use of hospital, CHC and community services based on selected equity variables and where the high needs areas are.

UNDERSTANDING DATA USE: THREE CASE STUDIES

CASE STUDY 1: Flemington Health Centre

Using demographic data for training, planning, and services

Identify the population served to inform training protocols:

- Flemington Health Centre pulled demographic data from two fiscal quarters and were surprised to see that none of their clients had identified as LGBTQ (lesbian, gay, bisexual, trans, queer). They were concerned about these findings and began to ask themselves why this might be. Did clients feel uncomfortable disclosing their sexual orientation and/or gender identity, and if so, why? In response to these findings, management implemented LGBTQ training for all staff at the CHC. The clinical care team staff participated in additional two-day training on providing care to trans clients. When the data was re-pulled in the following quarter, several clients were identifying as LGBTQ.

Inform language services and communication materials:

- Flemington Health Centre regularly pulls and analyzes client demographic data to identify the top languages spoken by their clients. They translate client communication materials, including the annual Client Experience Survey, into their top 10 languages. Increasing the accessibility of the Client Experience Survey means that Flemington is able to hear from more of their clients and receive feedback on how to provide the best possible care.

CASE STUDY 2: West Park Healthcare Centre

Using demographic data to stratify indicators

West Park Healthcare Centre is a complex continuing care facility with a range of services including rehabilitation. The West Park team decided to stratify Functional Independence Measures⁷ (FIM scores) that are collected from stroke patients at the time of their admission, at discharge and often during post-discharge follow-ups. The Research and Evaluation team stratified both intake and discharge FIM scores of all the stroke patients by three key demographic data variables.

Health Equity Variables

1. Spoken language (comparison: English vs. non-English)
2. Born in Canada (comparison: Born in Canada vs. Immigrant)
3. Racial/Ethnic Group (comparison: White vs. non-White)

⁷ This standardized tool assesses motor and cognitive abilities of patients and produces an overall FIM score.

Results pointed to statistically significant differences in FIM scores at the time of intake. Patients who preferred to speak a language other than English, were not born in Canada, or belonged to a racial/ethnic group other than 'White' had lower FIM scores than their counterparts. On a more positive note, a comparison of FIM scores at discharge revealed no statistically significant differences between groups. In other words, patients were admitted to West Park with differences in FIM scores but those differences were no longer there at the point of discharge. The next exploration will be to identify factors that can explain the improvement in patient outcomes and build on any lessons that emerge. The West Park team emphasized the importance of bringing together data collectors, clinicians, and data analysts/researchers to share and contextualize findings and plan for the next steps.

CASE STUDY 3: St. Michael's Hospital Academic Family Health Team

Using demographic data to have a full picture of patients' needs

Dr. Fok Han Leung at St. Michael's Hospital shared three clinical examples of how the availability of this patient demographic data promoted more questions about the care the patient needs.

- In the first example, a woman contemplating pregnancy agrees to routine bloodwork (Ministry of Health form has Hepatitis B, Rubella, Syphilis, HIV). But, the patient was not born in Canada, which prompted additional questions. The answer that she was born in Egypt led the provider to consider screening for Hepatitis C.
- In the second clinical example, a patient was diagnosed with migraines. The patient had stable employment, but was supporting more people than assumed. Therefore, the physician needed to consider cost in the choice of medication.
- In the third clinical example, a teen patient was feeling down. This led to a diagnosis of depression. However, once the sexual orientation question was answered, the provider then considered a more intensive screening regarding substances and suicide risk.

BEYOND THE TORONTO CENTRAL LHIN

With the increasing recognition of health equity and need for demographic data collection in the province, nationally and internationally, the Measuring Health Equity in Toronto Central LHIN Project is becoming more recognized and resources developed are being used and shared widely.

- Several organizations/areas have adapted some or all of the demographic questions. These include: Mississauga Halton LHIN and Central West LHIN which started pilots to collect the data within community services. Toronto Public Health, Saskatoon Public Health, Algoma Public Health (Sudbury region) and the Scarborough Hospital have also begun planning for limited equity data collection.
- Several other organizations have made inquiries regarding equity data collection, including William Osler Health System, Vancouver Coastal Health and Ontario Shores Centre for Health Sciences.

MOVING FORWARD: EMBEDDING THE COLLECTION AND USE OF DEMOGRAPHIC DATA

What should the Toronto Central LHIN's priorities be for the use of patient/client demographic data? What is needed to continue to advance the collection of patient/client demographic data in hospitals and CHCs in the Toronto Central LHIN? And, how can the Toronto Central LHIN increase accountability within health-care organizations for collecting and using patient/client demographic data?

Embedding the collection and use of this data is important to ensure that hospitals and CHCs use patient/client demographic data to improve access, experiences and outcomes for all patients/clients. While some organizations have embedded data collection into their practices, steps must be taken to improve accountability to ensure data collection is a priority in hospitals and CHCs. The LHINs and the Ministry of Health and Long Term Care can support accountability for data collection through funding and service agreement mechanisms.

The current collection target of 75% of patient/clients is difficult for hospitals to track and measure. Determining the total number of patients is difficult due to the differences in patient registration and a lack of integration of information between outpatient clinics and inpatients. In most hospitals, there are more outpatients than inpatients.

Embedding the collection and use of demographic data can be supported in three key ways:

1. Improve and expand data collection

- 1.1 Require hospitals and CHCs to develop plans and be accountable for achieving targets for collection, data quality and use.
- 1.2 Assign targets that hospitals can track more easily (i.e., Collect in Admitting, ED and 2-3 high volume areas).
- 1.3 When the questions are reviewed, ensure the process also considers how the data is collected; what training data collectors receive; whether data collectors review forms and are available for questions; and gather input from data collectors, patients, clinicians, project leads and hospital and CHC administrators.
- 1.4 Ensure the submission of hospital patient demographic data to ICES for use in planning and research.
- 1.5 Leverage data submission to ICES as a first step in identifying high needs populations.
- 1.6 Communicate widely (media, website, conferences) to increase patient/client/community awareness of the importance of collecting patient/client demographic data to improve health equity.

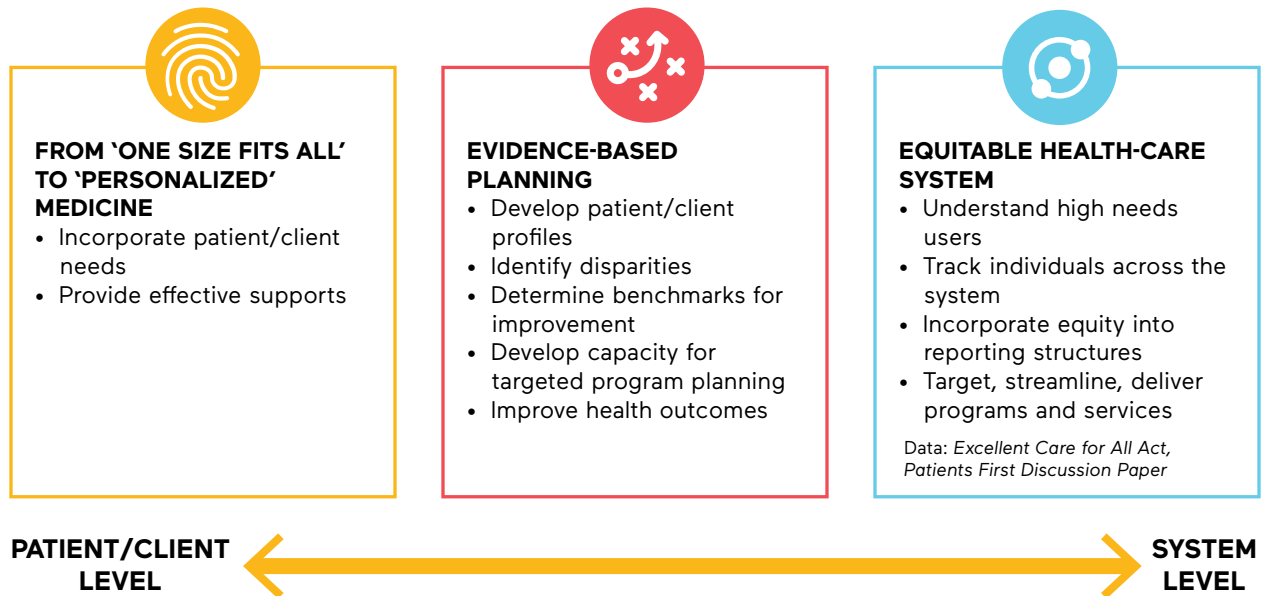
2. Share the benefits of using demographic data

- 2.1 Educate clinicians on the potential for using data to inform and improve care. Provide education and support to include demographic data on patient/client charts.
- 2.2 Provide training and education on successful data stratification, developing health equity dashboards, and including data collection and use in quality improvement plans.
- 2.3 Share best practices in addressing health inequities and successful innovations.

3. Foster a respectful and caring environment for collecting and using data

- 3.1 Promote and educate around equity organizational change within health-care settings that create a respectful environment for collecting and using data.
- 3.2 Provide training to support a safe environment for data collection that includes training on being an ally and cultural safety. Organization-wide campaigns, like the *Are You an ALLY?* campaign at Sinai Health System, LGBTQ training with The 519 at Michael Garron Hospital, or St. Michael Hospital’s creating inclusive environments for Indigenous and LGBTQI patients are examples of training for a respectful health-care environment.

Figure 11: Levels of demographic data use



CONCLUSION

Sinai Health System has learned from the Measuring Health Equity Project that health-care organizations can collect large amounts of data with support to ensure standards of process, data quality, and use. We also have learned that patients/clients are open to responding to the demographic questions, especially when delivered with respect and care. From our experiences across the Toronto Central LHIN, there are proven methods and approaches that show data collection has minimum impact on workflows, that staff are engaged in this work, and that patients and clients will provide us with answers when we ask them. The early focus had been on patient/client concerns and the eight standardized questions, but as the project progressed, we saw more emphasis on staff comfort, data collection methods, and creating safe and comfortable places for patients and clients to ask questions about why this information is important.

The Ontario Anti-Racism Directorate has mandated the collection of demographic data on race which signals significant momentum for this work. We have already made the case that demographic data collection has the capacity to improve health and health equity. The next step is to move it into broad use with a focus on how to best collect and use data to improve care for marginalized populations, address health inequities and improve the quality of care for all.

REFERENCES

Braveman, Paula A., Kumanyika, S., Fielding, J., LaViest, T., Borrell, L.N., Manderscheid, R & Troutman, A. (2011). *Health Disparities and Health Equity: The Issue Is Justice*. American Journal of Public Health. Available at: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3222512/>

Health Quality Ontario. (2016). Health Equity and Quality. Retrieved online: <http://www.hqontario.ca/What-is-Health-Quality/Health-Equity-and-Quality>

Siegel, B., Regenstein, M & Jones, K. (2007). *Enhancing public hospitals' reporting of data on racial and ethnic disparities' in care*. Commonwealth Fund.

Retrieved online: http://www.commonwealthfund.org/-/media/files/publications/fund-report/2007/jan/enhancing-public-hospitals-reporting-of-data-on-racial-and-ethnic-disparities-in-care/998_siegel_enhancing_pub_hosp_reporting_data_racia-pdf.pdf

Wray, R., Agic, B., Bennett-AbuAyyash, C., Kanee, M., Tuck, A., Lam, R., & Hyman, I. (2013). *We ask because we care: The Tri-Hospital + TPH health equity data collection research project: Summary Report*. Centre for Addiction and Mental Health, Mount Sinai Hospital, St. Michael's Hospital, and Toronto Public Health. Available at: <http://torontohealthequity.ca/wp-content/uploads/2014/10/FINAL-Full-Report-September-2013.pdf>

Weinick, R.M., Flaherty, K., Bristol, S.J. (2008). *Creating equity reports: a guide for hospitals*. Massachusetts General Hospital. The Disparities Solutions Center (DSC). Retrieved online: <http://www.rwjf.org/content/dam/farm/toolkits/toolkits/2008/rwjf24722>

APPENDIX A: EIGHT STANDARDIZED QUESTIONS FOR HOSPITALS

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 health-care 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."

1. What language would you feel most comfortable speaking in with your health-care provider? Check ONE only.

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

2. Were you born in Canada?

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

If no, what year did you arrive in Canada? _____

3. Which of the following best describes your racial or ethnic group? Check ONE only.

- Asian - East (e.g., Chinese, Japanese, Korean)
 Asian - South (e.g., Indian, Pakistani, Sri Lankan)
 Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
 Black - African (e.g., Ghanaian, Kenyan, Somali)
 Black - Caribbean (e.g., Barbadian, Jamaican)
 Black - North American (e.g., Canadian, American)
 First Nations
 Indian - Caribbean (e.g., Guyanese with origins in India)
 Indigenous/Aboriginal *not included elsewhere*
 Inuit
 Latin American (e.g., Argentinean, Chilean, Salvadorian)
 Métis
 Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
 White - European (e.g., English, Italian, Portuguese, Russian)
 White - North American (e.g., Canadian, American)
 Mixed heritage (e.g., Black - African and White - North American)
 (Please specify) _____
 Other(s) (Please specify) _____
 Prefer not to answer
 Do not know
-

4. Do you have any of the following? Check ALL that apply.

- | | |
|---|--|
| <input type="checkbox"/> Chronic illness | <input type="checkbox"/> Sensory disability (i.e., hearing or vision loss) |
| <input type="checkbox"/> Developmental disability | <input type="checkbox"/> None |
| <input type="checkbox"/> Drug or alcohol dependence | <input type="checkbox"/> Other (Please specify) _____ |
| <input type="checkbox"/> Learning disability | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Mental illness | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Physical disability | |
-

5. What is your gender? Check ONE only.

- | | | |
|-----------------------------------|---|---|
| <input type="checkbox"/> Female | <input type="checkbox"/> Trans – Female to Male | <input type="checkbox"/> Other (Please specify) _____ |
| <input type="checkbox"/> Male | <input type="checkbox"/> Trans – Male to Female | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Intersex | | <input type="checkbox"/> Do not know |
-

6. What is your sexual orientation? Check ONE only.

- | | | |
|--|-------------------------------------|---|
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Lesbian | <input type="checkbox"/> Other (Please specify) _____ |
| <input type="checkbox"/> Gay | <input type="checkbox"/> Queer | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Heterosexual (“straight”) | <input type="checkbox"/> Two-Spirit | <input type="checkbox"/> Do not know |

7. What was your total family income before taxes last year? Check ONE only.

- | | | |
|---|---|---|
| <input type="checkbox"/> \$0 to \$29,999 | <input type="checkbox"/> \$90,000 to \$119,999 | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> \$30,000 to \$59,999 | <input type="checkbox"/> \$120,000 to \$149,999 | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> \$60,000 to \$89,999 | <input type="checkbox"/> \$150,000 or more | |

8. How many people does this income support? _____ person(s)

- Prefer not to answer Do not know

APPENDIX B: EIGHT STANDARDIZED QUESTIONS FOR CHCs

We are collecting social information from clients to find out who we serve and what unique needs our clients have. We will also use this information to understand client 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 health-care team and protected like all your other health information. If used in research, this information will be combined with data from all other clients and no one will be able to identify any of the clients.

1. What language would you feel most comfortable speaking in with your health-care provider? Check ONE only.

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

2. Were you born in Canada?

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

If no, what year did you arrive in Canada? _____

If no, what country were you born in? _____

3. Which of the following best describes your racial or ethnic group? Check ONE only.

- Asian - East (e.g., Chinese, Japanese, Korean)
 Asian - South (e.g., Indian, Pakistani, Sri Lankan)
 Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
 Black - African (e.g., Ghanaian, Kenyan, Somali)
 Black - Caribbean (e.g., Barbadian, Jamaican)
 Black - North American (e.g., Canadian, American)
 First Nations
 Indian - Caribbean (e.g., Guyanese with origins in India)
 Indigenous/Aboriginal *not included elsewhere*
 Inuit
 Latin American (e.g., Argentinean, Chilean, Salvadorian)
 Métis
 Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
 White - European (e.g., English, Italian, Portuguese, Russian)
 White - North American (e.g., Canadian, American)
 Mixed heritage (e.g., Black - African and White - North American)
 (Please specify) _____
 Other(s) (Please specify) _____
 Prefer not to answer
 Do not know
-

4. Do you have any of the following? Check ALL that apply.

- Chronic illness
 Developmental disability
 Drug or alcohol dependence
 Learning disability
 Mental illness
 Physical disability
 Sensory disability (i.e., hearing or vision loss)
 None
 Other (Please specify) _____
 Prefer not to answer
 Do not know
-

5. What is your gender? Check ONE only.

- Female
 Intersex
 Male
 Trans – Female to Male
 Trans – Male to Female
 Two-Spirit
 Other (Please specify) _____
 Prefer not to answer
 Do not know
-

6. What is your sexual orientation? Check ONE only.

- Bisexual
 Gay
 Heterosexual ("straight")
 Lesbian
 Queer
 Two-Spirit
 Other (Please specify) _____
 Prefer not to answer
 Do not know

7. What was your total family income before taxes last year? Check ONE only.

- \$0 to \$14,999 \$25,000 to \$29,999 \$40,000 to \$59,999 Prefer not to answer
 \$15,000 to \$19,999 \$30,000 to \$34,999 \$60,000 or more Do not know
 \$20,000 to \$24,999 \$35,000 to \$39,999

8. How many people does this income support? _____ person(s)

- Prefer not to answer Do not know

APPENDIX C: PEDIATRIC HEALTH EQUITY DATA COLLECTION INSTRUMENT¹

Caregiver Health Equity Survey

This set of demographic questions is for primary caregivers of patients under 14 years of age or older patients who do not have the cognitive capacity to complete the youth survey.

Information about you

1. What is your relationship to the child you are here with today? (OPTIONAL)

- Parent (e.g., mother, father, step-parent, foster-parent)
- Grandparent
- Relative (e.g., aunt, uncle, sibling)
- Other (*please specify*): _____
- Prefer not to answer

2. Were you born in Canada?

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

If no, what year did you arrive in Canada? _____

3. What type of housing do you live in? Check ONE only. (OPTIONAL)

- Purchased house/condo
- Rental house/apartment/condo
- Geared-to-income rental
- Relative's home
- Friend's home
- Boarding home
- Group home
- Supportive/assisted housing
- Shelter/hostel
- Homeless/on the street
- Correctional facility
- Other (*Please specify*) _____
- Do not know
- Prefer not to answer

¹ Full report available online: <http://www.torontocentralhin.on.ca/~media/sites/tc/New%20media%20folder/Resources/Development%20of%20Paediatric%20Health%20Equity%20Data%20Collection%20Report.pdf?la=en>

4. What language would you feel most comfortable speaking in with your health-care provider? Check ONE only.

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

5. Which of the following best describes your racial or ethnic group? Check ONE only.

- Asian - East (e.g., Chinese, Japanese, Korean)
 - Asian - South (e.g., Indian, Pakistani, Sri Lankan)
 - Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
 - Black - African (e.g., Ghanaian, Kenyan, Somali)
 - Black - Caribbean (e.g., Barbadian, Jamaican)
 - Black - North American (e.g., Canadian, American)
 - First Nations
 - Indian - Caribbean (e.g., Guyanese with origins in India)
 - Indigenous/Aboriginal *not included elsewhere*
 - Inuit
 - Latin American (e.g., Argentinean, Chilean, Salvadorian)
 - Métis
 - Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
 - White - European (e.g., English, Italian, Portuguese, Russian)
 - White - North American (e.g., Canadian, American)
 - Mixed heritage (e.g., Black - African and White - North American)
(*Please specify*) _____
 - Other(s) (*Please specify*) _____
 - Prefer not to answer
 - Do not know
-

6. What is your religious or spiritual affiliation? Check ONE only. (OPTIONAL)

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

7. What is your highest level of education? Check ONE only.

- | | |
|--|---|
| <input type="checkbox"/> No education | <input type="checkbox"/> College degree or diploma |
| <input type="checkbox"/> Some elementary school | <input type="checkbox"/> University undergraduate degree (e.g., BA, BSc, BEd) |
| <input type="checkbox"/> Completed elementary school | <input type="checkbox"/> University graduate degree (e.g., MA, PhD) |
| <input type="checkbox"/> Some high school | <input type="checkbox"/> Professional degree (e.g., JD, MD, PEng) |
| <input type="checkbox"/> Completed high school | <input type="checkbox"/> Other (<i>Please specify</i>) _____ |
| <input type="checkbox"/> Trade school/Apprenticeship (e.g., carpentry, plumbing) | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Some college or university | <input type="checkbox"/> Prefer not to answer |

8. What is your gender? Check ONE only.

- | | | |
|-----------------------------------|---|--|
| <input type="checkbox"/> Female | <input type="checkbox"/> Trans – Female to Male | <input type="checkbox"/> Other (<i>Please specify</i>) _____ |
| <input type="checkbox"/> Male | <input type="checkbox"/> Trans – Male to Female | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Intersex | | <input type="checkbox"/> Do not know |

9. What is your sexual orientation? Check ONE only.

- | | | |
|--|-------------------------------------|--|
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Lesbian | <input type="checkbox"/> Other (<i>Please specify</i>) _____ |
| <input type="checkbox"/> Gay | <input type="checkbox"/> Queer | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Heterosexual ("straight") | <input type="checkbox"/> Two-Spirit | <input type="checkbox"/> Do not know |
-

10. Do you have any of the following? Check ALL that apply.

- | | |
|---|--|
| <input type="checkbox"/> Chronic illness | <input type="checkbox"/> Sensory disability (e.g., hearing or vision loss) |
| <input type="checkbox"/> Developmental disability | <input type="checkbox"/> Other (Please specify) _____ |
| <input type="checkbox"/> Drug or alcohol dependence | <input type="checkbox"/> None |
| <input type="checkbox"/> Learning disability | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Mental illness | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Physical disability | |

11. Last year, what was the total household income before taxes that supported the child? Check ONE only.

- | | | |
|---|---|---|
| <input type="checkbox"/> \$0 to \$29,999 | <input type="checkbox"/> \$90,000 to \$119,999 | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> \$30,000 to \$59,999 | <input type="checkbox"/> \$120,000 to \$149,999 | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> \$60,000 to \$89,999 | <input type="checkbox"/> \$150,000 or more | |

12. How many people does this income support? _____ person(s)

- Prefer not to answer Do not know

Information about your child**13. Was the child born in Canada?**

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

If no, what year did the child arrive in Canada? _____

14. What language would your child feel MOST comfortable speaking in with his/her healthcare provider? Check ONE only.

- | | | | |
|---|------------------------------------|-------------------------------------|---|
| <input type="checkbox"/> The child does not yet speak | <input type="checkbox"/> English | <input type="checkbox"/> Polish | <input type="checkbox"/> Tigrinya |
| <input type="checkbox"/> The child is non-verbal | <input type="checkbox"/> Farsi | <input type="checkbox"/> Portuguese | <input type="checkbox"/> Turkish |
| <input type="checkbox"/> Amharic | <input type="checkbox"/> French | <input type="checkbox"/> Punjabi | <input type="checkbox"/> Twi |
| <input type="checkbox"/> Arabic | <input type="checkbox"/> Greek | <input type="checkbox"/> Russian | <input type="checkbox"/> Ukrainian |
| <input type="checkbox"/> American Sign Language (ASL) | <input type="checkbox"/> Hindi | <input type="checkbox"/> Serbian | <input type="checkbox"/> Urdu |
| <input type="checkbox"/> Bengali | <input type="checkbox"/> Hungarian | <input type="checkbox"/> Slovak | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Chinese (Cantonese) | <input type="checkbox"/> Italian | <input type="checkbox"/> Somali | <input type="checkbox"/> Other (Please specify) _____ |
| <input type="checkbox"/> Chinese (Mandarin) | <input type="checkbox"/> Karen | <input type="checkbox"/> Spanish | |
| <input type="checkbox"/> Czech | <input type="checkbox"/> Korean | <input type="checkbox"/> Tagalog | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Dari | <input type="checkbox"/> Nepali | <input type="checkbox"/> Tamil | <input type="checkbox"/> Do not know |

**15. Which of the following BEST describes your child's racial or ethnic group?
Check ONE only.**

- Asian - East (e.g., Chinese, Japanese, Korean)
- Asian - South (e.g., Indian, Pakistani, Sri Lankan)
- Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
- Black - African (e.g., Ghanaian, Kenyan, Somali)
- Black - Caribbean (e.g., Barbadian, Jamaican)
- Black - North American (e.g., Canadian, American)
- First Nations
- Indian - Caribbean (e.g., Guyanese with origins in India)
- Indigenous/Aboriginal, *not included elsewhere*
- Inuit
- Latin American (e.g., Argentinean, Chilean, Salvadorian)
- Métis
- Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
- White - European (e.g., English, Italian, Portuguese, Russian)
- White - North American (e.g., Canadian, American)
- Mixed heritage (e.g., Black - African and White - North American)
(Please specify) _____
- Other(s) (Please specify) _____
- Prefer not to answer
- Do not know

16. Does the child have any of the following? Check ALL that apply.

- Chronic (long-term) illness (e.g., asthma, diabetes, cancer, arthritis)
- Developmental disability (e.g., intellectual disability, autism)
- Drug or alcohol dependence
- Learning disability
- Emotional health disorder (e.g., anxiety, depression)
- Behavioural disorder (e.g., attention deficit hyperactivity disorder)
- Physical disability
- Sensory disability (e.g., hearing or vision)
- Other (Please specify) _____
- None
- Do not know
- Prefer not to answer

Youth Health Equity Survey

This set of questions is for patients between the ages of 14 and 18. The primary caregiver completes the two income questions and the youth complete the rest of the questions on their own.

Information About Your Family

Before filling out this survey, please have your caregiver answer questions #1 and #2. If you do not have a caregiver with you today, please select 'Not Applicable'.

1. Last year, what was the total household income before taxes that supported your child? Check ONE only.

- | | | |
|---|---|---|
| <input type="checkbox"/> \$0 to \$29,999 | <input type="checkbox"/> \$90,000 to \$119,999 | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> \$30,000 to \$59,999 | <input type="checkbox"/> \$120,000 to \$149,999 | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> \$60,000 to \$89,999 | <input type="checkbox"/> \$150,000 or more | |

2. How many people does this income support (include yourself, your partner, and all dependents) _____ # person(s)

- Prefer not to answer Do not know

Information About You

3. Which caregiver did you come here with today?

- | | |
|--|--|
| <input type="checkbox"/> I did not come with a caregiver | <input type="checkbox"/> Relative (e.g., aunt, uncle, sibling) |
| <input type="checkbox"/> Parent (e.g., mother, father, step-parent, foster-parent) | <input type="checkbox"/> Other (<i>Please specify</i>) _____ |
| <input type="checkbox"/> Grandparent | <input type="checkbox"/> Prefer not to answer |

4. Were you born in Canada?

- Yes Prefer not to answer
 No Do not know

If no, what year did you arrive in Canada? _____

5. What type of housing do you live in? Check ONE only. (OPTIONAL)

- | | |
|--|---|
| <input type="checkbox"/> My own place (with roommate(s)/a partner) | <input type="checkbox"/> Boarding home |
| <input type="checkbox"/> Parent/guardian's home | <input type="checkbox"/> Shelter/hostel |

- | | |
|--|--|
| <input type="checkbox"/> Relative's home | <input type="checkbox"/> Homeless/on the street |
| <input type="checkbox"/> Foster home | <input type="checkbox"/> Correctional facility |
| <input type="checkbox"/> Friend's home | <input type="checkbox"/> Other (<i>Please specify</i>) _____ |
| <input type="checkbox"/> School residence | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Supportive/assisted housing | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Group home | |

6. What language would you feel most comfortable speaking in with your health-care provider? Check ONE only.

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

7. Which of the following BEST describes your racial or ethnic group? Check ONE only.

- Asian - East (e.g., Chinese, Japanese, Korean)
- Asian - South (e.g., Indian, Pakistani, Sri Lankan)
- Asian - South East (e.g., Malaysian, Filipino, Vietnamese)
- Black - African (e.g., Ghanaian, Kenyan, Somali)
- Black - Caribbean (e.g., Barbadian, Jamaican)
- Black - North American (e.g., Canadian, American)
- First Nations
- Indian - Caribbean (e.g., Guyanese with origins in India)
- Indigenous/Aboriginal *not included elsewhere*
- Inuit
- Latin American (e.g., Argentinean, Chilean, Salvadorian)
- Métis
- Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
- White - European (e.g., English, Italian, Portuguese, Russian)
- White - North American (e.g., Canadian, American)
- Mixed heritage (e.g., Black - African and White - North American)
- (*Please specify*) _____
- Other(s) (*Please specify*) _____
- Prefer not to answer
- Do not know

8. What is your religious or spiritual affiliation? Check ONE only. (OPTIONAL)

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

9. What is your gender? Check ONE only.

- | | |
|---|---|
| <input type="checkbox"/> Female | <input type="checkbox"/> Trans – Male to Female |
| <input type="checkbox"/> Intersex – female | <input type="checkbox"/> Trans, do not identify as totally female or male |
| <input type="checkbox"/> Intersex – male | <input type="checkbox"/> Other (<i>Please specify</i>) _____ |
| <input type="checkbox"/> Intersex, do not identify as either female or male | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Male | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Trans – Female to Male | |

10. How do you identify? Check ONE only.

- | | |
|--|--|
| <input type="checkbox"/> Asexual | <input type="checkbox"/> Questioning |
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Two-spirit |
| <input type="checkbox"/> Gay | <input type="checkbox"/> Other (<i>Please specify</i>) _____ |
| <input type="checkbox"/> Heterosexual ("straight") | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Lesbian | <input type="checkbox"/> Do not know |
| <input type="checkbox"/> Queer | |
-

11. Do you have any of the following? Check ALL that apply.

- Chronic (long-term) illness (e.g., asthma, diabetes, cancer, arthritis)
- Developmental disability (e.g., intellectual disability, autism)
- Drug or alcohol dependence
- Learning disability
- Emotional health disorder (e.g., anxiety, depression)
- Behavioural disorder (e.g., attention deficit hyperactivity disorder)
- Physical disability
- Sensory disability (e.g., hearing or vision)
- Other (*Please specify*) _____
- None
- Do not know
- Prefer not to answer



APPENDIX D: LIST OF PARTICIPATING HOSPITALS AND COMMUNITY HEALTH CENTRES

HOSPITALS

Baycrest Centre for Geriatric Care	St. Joseph's Health Centre
Bridgpoint Active Healthcare site - Sinai Health System	St. Michael's Hospital
Centre for Addictions and Mental Health	Sunnybrook Health Sciences Centre
Casey House	Toronto Grace Hospital
Michael Garron Hospital	University Health Network
Mount Sinai Hospital site - Sinai Health System	West Park Healthcare Centre
Providence Healthcare	Women's College Hospital
Runnymede Healthcare Centre	Hospital for Sick Children
	Holland Bloorview Kids Rehabilitation Hospital

COMMUNITY HEALTH CENTRES (CHCs)

Access Alliance Multicultural Health and Community Services	Parkdale Site - Parkdale Queen West Community Health Centre
Anishnawbe Health Toronto	Planned Parenthood of Toronto
Anne Johnston Health Station	Queen West Site - Parkdale Queen West Community Health Centre
Centre francophone de Toronto	Regent Park Community Health Centre
Davenport Perth Neighbourhood and Community Health Centre	South Riverdale Community Health Centre
East End Community Health Centre	Stonegate Community Health Centre
Flemingdon Health Centre	Unison Health and Community Services
Four Villages Community Health Centre	Women's Health in Women's Hands
Lakeshore Area Multi-Service Project	



APPENDIX E: CHC ADVISORY GROUP⁹

Cynthia Damba
Toronto Central LHIN
Senior Planner/Epidemiologist

Marylin Kanee
Sinai Health System
Director, Human Rights & Health Equity

Nancy LaPlante
Ontario's Community Health Centres
Regional Decision Support Specialist, Central Region

Bev Leaver
Stonegate CHC
Executive Director

Narina Nagra
Sinai Health System
Human Rights & Health Equity Specialist

⁹ As of March 2017

Measuring Health Equity

Demographic Data Collection
and Use in Toronto Central LHIN
Hospitals and Community
Health Centres



**Sinai
Health
System**

**Human Rights & Health Equity
Sinai Health System**

60 Murray Street, Room L2-403
Toronto, ON M5T 3L9

416-586-4800 ext. 7519

humanrights@sinaihealthsystem.ca

www.torontohealthequity.ca