MEASURING HEALTH EQUITY IN TC LHIN COMMUNITY HEALTH CENTRES PILOT PROJECT
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Executive Summary

This report provides an overview of the *Measuring Health Equity in TC LHIN CHCs Pilot Project*, which consisted of a process evaluation of demographic data collection in Community Health Centres (CHCs) using a standardized set of eight Toronto Central Local Health Integration Network (TC LHIN) questions. The pilot project ran from January to June 2014 and involved five CHCs: Access Alliance Multicultural Health and Community Services, Central Toronto Community Health Centres, Parkdale Community Health Centre, Planned Parenthood of Toronto, and South Riverdale Community Health Centre.

Findings from this evaluation resulted in 20 recommendations for the promotion of evidence-based demographic data collection in TC LHIN CHCs:

**Communication and Engagement**
1) CHC project leads and senior management work together to ensure that all staff are made aware of the project and understand their responsibilities in the roll-out of the TC LHIN questions and changes in data management practices.
2) CHC project leads work with their teams to ensure appropriate time is allotted for planning prior to project launch.
3) Staff would benefit from having handy resources and scripts that would enable them to quickly and efficiently address client inquiries.

**Data Collection Procedures and Workflow**
1) Mount Sinai Hospital (MSH) team works with each CHC to adapt training and implementation to individual CHC needs (i.e. consult on best practices and help address issues of privacy, workload, data quality, etc.).
2) MSH team shares translations of the eight TC LHIN questions once they are available. The questions are being translated into the top 10 languages spoken in the Toronto Central Region plus French: Arabic, Chinese (simplified), Hungarian, Italian, Korean, Portuguese, Russian, Spanish, Tamil and Vietnamese.
3) Directly asking the TC LHIN questions to clients (as opposed to handing the questions to clients to complete on their own) is recommended as the ideal method of data collection due to its ability to significantly reduce missing data rates.
4) Client intake is recommended as the ideal location for data collection.
5) CHC project leads work with their teams to formulate a plan for capturing data on existing clients.
6) Strategies and procedures for collecting client demographic data should focus on reducing missing data rates.
7) The CHC Evaluation Framework adopt a clear guideline on how to collect demographic data from clients under 18 years of age.
8) CHCs update clients’ TC LHIN demographic data every 1 to 3 years.
Staff Training

1) CHC project leads work with their teams to ensure appropriate time is allotted for scheduling and running training sessions.

2) CHC project leads ensure that every staff member who will be asking and/or administering the TC LHIN questions is provided with training (such as intake workers, medical secretaries, reception staff, relief staff, etc.).

3) MSH team updates training curriculum to address staff concerns with asking questions on racial/ethnic group, disabilities and sexual orientation.

4) MSH team updates training curriculum to further highlight the differences between the eight TC LHIN questions and what is currently collected.

5) MSH team includes CHC content in the Measuring Health Equity eLearning module currently in development.

IT Solutions

1) CHC Data Management Coordinators (DMC) use the Nightingale On Demand (NOD) Guidelines to add the four new TC LHIN demographic questions to NOD prior to project launch. For quality assurance purposes, each DMC ensures a second staff member verifies that the four new TC LHIN questions are added to NOD correctly.

2) MSH team and the DMC hold a separate training session for data entry staff to focus on how to enter the demographic data accurately and consistently.

3) Data entry be limited to select staff member(s) who are trained on data collection/entry to reduce errors and improve data quality.

4) BIRT (Business Intelligence Reporting Tool), the CHC sector data warehouse, be used to aggregate and report on the eight TC LHIN demographic questions.
Background: Measuring Health Equity in Toronto Central LHIN

In 2009, four organizations (Mount Sinai Hospital, St. Michael’s Hospital, Centre for Addiction and Mental Health and Toronto Public Health) established a partnership to discuss the current limitations of health-care data collection where social determinants of health, such as income, are not collected yet influence health-care experiences, access and outcomes. The project objectives included: developing and testing demographic questions; analyzing patient and staff responses to improve the questions and methodology; exploring the relationships between self-rated health and demographic variables; and sharing knowledge and project findings with other institutions. The result was the “We Ask Because We Care: The Tri-Hospital plus TPH Health Equity Data Collection Research Project Report”.

The findings from this report were adopted by the Toronto Central LHIN (TC LHIN) through the Measuring Health Equity in TC LHIN Project, which mandated the collection of patient demographic data in 17 TC LHIN hospitals by April 2013. Mount Sinai Hospital (MSH) was asked to lead data collection efforts and support hospitals in planning and implementing a demographic data collection plan. Out of 17 hospitals in the TC LHIN, 15 have started collecting patient demographic data using a standardized set of eight patient demographic questions; two pediatric hospitals are finalizing a pilot study on how to adapt those eight demographic questions to a pediatric population.

In an effort to standardize health equity data collection across the health system in the Toronto Central Region, the TC LHIN expanded its Measuring Health Equity mandate to Community Health Centres (CHCs) in September 2013. Although CHCs have been collecting socio-demographic data for the past 20 years, it is not collected in a standardized manner, and does not allow for comparability across sectors. A standardized set of equity variables adopted within all TC LHIN sectors will allow the TC LHIN to have comprehensive data to measure and monitor equity within and across all health-care sectors under its jurisdiction, and thus develop a comprehensive system response to address identified inequities.

This expansion into CHCs started with a pilot of the eight demographic questions at five CHC sites (see TC LHIN demographic questions for CHCs in Appendix A) where data collection of the eight questions was trialed.

The purpose of this pilot was to implement a process evaluation of demographic data collection in CHCs using the eight TC LHIN questions, paving the way for an evidence-based and CHC-focused approach for collecting client demographic data.

1 For full report, please visit http://www.mountsinai.on.ca/about_us/human-rights/measuring-health-equity
Demographic Data Collection in CHCs

Currently, CHCs collect socio-demographic information of clients through an Evaluation Framework. The CHC Evaluation Framework is intended to support ongoing assessment and evaluation of the programs and services by providing a common starting point for more focused investigations. The framework consists of a Results-Based Logic Model which is based upon the CHC Model of Health and Well-Being (MoHWB). The MoHWB (see Figure 1) includes the principles of health equity and social justice which guide the programming and provision of services to the communities with which CHCs work\(^2\). In order to ensure CHCs are serving priority populations and that the services and outcomes are carried out in an equitable way, the collection of socio-demographic data on clients, including spoken language, religion, country of birth, household income, and household composition, has been carried out in the CHC sector for 20 years. The opportunity to standardize some of these questions alongside other health sectors is one step towards aligning CHCs health equity and people-centeredness work with the larger health-care community.

Figure 1. CHC Model of Health and Well-Being

The TC LHIN demographic questions consist of eight questions which are either the same as the existing questions, vary slightly or are new to CHCs. Please refer to Table 1 on page 7 for an overview of differences between these two sets of questions.

\(^2\) The CHC Evaluation Framework can be accessed in the AOHC member portal.
Table 1. Comparison of TC LHIN and CHC Demographic Questions

<table>
<thead>
<tr>
<th>TC LHIN Core Questions</th>
<th>Answer Option (*all answers where appropriate include “Prefer not to answer” and “Do not know” options)</th>
<th>CHC Demographic Questions</th>
</tr>
</thead>
</table>
| 1. What language do you feel most comfortable speaking in with your health-care provider? Check one only. | ➢ 34 choices  
➢ Includes American Sign Language  
➢ PLUS “Other (Please Specify)” option | ➢ Preferred Language of Service  
➢ Over 400 language choices |
| 2. Were you born in Canada?                                                             | ➢ Yes/No options  
➢ If no, what year did you arrive in Canada?                                                   | ➢ Country of Origin and if not Canada, the year of arrival (if applicable) |
| 3. Which of the following would best describe your racial or ethnic group? Check one only. | ➢ 15 choices  
➢ PLUS “Mixed Heritage (Please specify)”  
➢ PLUS “Other (Please Specify)”               | ➢ Cultural background (includes ethnic origin and/or religion) |
| 4. Do you have any of the following? Check all that apply.                              | ➢ Question about disabilities  
➢ 8 choices  
➢ INCLUDES “None”  
➢ PLUS “Other (Please Specify)”               | Currently not a question in the Evaluation Framework |
| 5. What is your gender? Check one only.                                                  | ➢ 5 choices (Female, Male, Trans Female to Male, Trans Male to Female, Intersex)³  
➢ PLUS “Other (Please Specify)”               | ➢ 3 options (Female, Male, Other) |
| 6. What is your sexual orientation? Check one only.                                      | ➢ 6 choices (Heterosexual, Gay, Lesbian, Bisexual, Two-spirit, Queer)  
➢ PLUS “Other (Please Specify)”               | Currently not a question in the Evaluation Framework |
| 7. What was your total family income before taxes last year?                             | ➢ 6 choices  
➢ Categories of income ranges high (e.g. lowest range is $0 to $29,999) so were changed to CHC groupings | ➢ Use term “household”, not “family”  
➢ Income ranges are lower and smaller |
| 8. How many people does your income support?                                            | ➢ Open field for numeric data                                                                  | ➢ Same question |

³ The CHC Performance Management Committee approved the inclusion of a sixth answer option “Two-spirit” for the gender question post-pilot.
Pilot Process and Evaluation Framework

As previously stated, the goal of the *Measuring Health Equity in TC LHIN CHCs Pilot Project* was to implement demographic data collection using a standardized set of eight TC LHIN questions and conduct a process evaluation. The pilot project ran from January to June 2014 and involved five Community Health Centres. These five sites volunteered to participate:

**Access Alliance Multicultural Health and Community Services**
Improves health outcomes for the most vulnerable immigrants, refugees, and their communities, by facilitating access to services and addressing systemic inequities. They provide accessible, community-governed, inter-professional, primary health care services including health promotion, illness prevention and treatment, chronic disease management, and individual and community capacity building. Access Alliance has three locations: downtown (College and Spadina), AccessPoint on Danforth at Danforth and Victoria Park and AccessPoint on Jane at Jane and St. Clair.

**Central Toronto Community Health Centres (CTCHC)** is a non-profit, community-based health organization committed to improving the health of community members, particularly those at risk for poverty and discrimination. Their multi-disciplinary approach includes the provision of primary health/dental care, counselling, harm reduction, community development, advocacy, and innovative partnerships with other organizations. CTCHC is a leader in the development of inner-city health services focusing on adults, families, and youth in the local area.

**Parkdale Community Health Centre** is situated in the multicultural, inner-city neighbourhood of Parkdale in downtown west Toronto. They work with the community to address health-related needs through the delivery of primary health care, health promotion, counselling, advocacy, community development and action. Parkdale CHC gives priority to individuals and groups who traditionally encounter barriers to high quality health care services, including marginalized or vulnerable populations such as newcomers, racialized communities, people who are homeless or living near the street, people with mental health challenges and addictions, people living with visible and invisible disabilities, isolated seniors, LGBTQ communities and people living in poverty.
Planned Parenthood of Toronto (PPT) is a community-based, pro-choice agency committed to the principles of equity and to providing accessible and inclusive services which promote healthy sexuality and informed decision-making to the people of the City of Toronto. PPT aims to be accessible to LGBTQ communities, newcomer communities, women, and youth. Services include primary health care, anonymous HIV testing, STI testing and treatment, pregnancy and birth control options, emergency contraception, prenatal care, counseling, nutrition, workshops, anti-homophobia / anti-transphobia initiatives, and community-based research.

South Riverdale Community Health Centre (SRCHC) is a community-based organization that offers primary health care services and health promotion programs to a diverse community. Priority is given to people who face barriers to services such as low literacy or income; homelessness, substance use and/or mental health issues; gender and sexual orientation; language, race and culture. They strive to respond to local issues and provide services in active partnership with clients, patients, neighbours, community groups and professional organizations.

A Technical Working Group was formed with the mandate to identify IT and data migration solutions that would support the adoption of the eight demographic questions across the TC LHIN CHCs.

Each CHC adopted their own unique approach to collecting client demographic information based on their current data collection practices, workflow, and logistical considerations.

Table 2. Breakdown of demographic data collection methodologies employed at pilot CHCs

<table>
<thead>
<tr>
<th>Target Sample</th>
<th>Who collects data?</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 All clients</td>
<td>Reception staff</td>
<td>Forms given to clients. Staff available to clarify and answer questions.</td>
</tr>
<tr>
<td>2 All clients</td>
<td>Administrative staff</td>
<td>Forms given to clients to complete.</td>
</tr>
<tr>
<td>3 Group clients</td>
<td>Group staff</td>
<td>Forms given to clients. Data management staff available to assist.</td>
</tr>
<tr>
<td>4 New clients</td>
<td>Medical secretary</td>
<td>Forms given to clients. Staff review forms and follow up with clients to answer questions or if information is missing.</td>
</tr>
<tr>
<td>5 New clients</td>
<td>Intake worker</td>
<td>Staff ask clients the questions in a private setting.</td>
</tr>
</tbody>
</table>
This report will document the implementation and evaluation of the pilot, followed by recommendations for demographic data collection using the eight TC LHIN demographic questions.

The pilot and evaluation framework focused on four areas that significantly impact the development, implementation, and evaluation of a demographic data collection plan.
Pilot Implementation

The pilot implementation focused on the four areas identified under the ‘Pilot and Process Evaluation Framework’ on page 10.

1. Communication and Engagement

- Introductory, planning and support meetings were held between individual pilot sites and the MSH team throughout the duration of the pilot.
- Communication materials such as posters, brochures and form templates were shared with all pilot sites by the MSH team.

2. Data Collection Procedures and Workflow

- A workplan template was developed by the MSH team and shared with pilot sites to help guide the implementation of a demographic data collection plan.
- Pilot sites updated registration forms to include the new demographic questions where appropriate, with support of the MSH team.
- The MSH team worked with individual pilot sites to identify ideal locations for data collection implementation.
- “We Ask Because We Care” posters were displayed in key locations.
- The TC LHIN questions were available in English only. Interpretation was provided as needed by CHC staff.

3. Staff Training

- MSH staff facilitated six training sessions (two group sessions and four site-specific sessions) with a total of 28 participants.
- The training focused on health equity concepts and messaging when asking clients the TC LHIN questions. Interactive training exercises including videos and role-playing were central to increasing staff confidence and comfort with the TC LHIN questions.
- In the training workshops, staff practiced asking the TC LHIN questions on Standardized Patients.
- The training module was tailored according to each individual CHC’s staff composition, workflow and data collection practices.
- The following adaptations were made to the training over the course of the pilot, based on participant feedback:
  - The training was condensed from a 3-hour to a 2-hour session in the interest of time and resources.
  - CHC specific material such as the CHC Model of Health and Well-Being and practice scenarios that reflected the CHC experience were incorporated into the training.
  - Key points from the NOD Guidelines and NOD Data Entry Notes were added to the training to familiarize staff with the changes to NOD and data entry procedures.

Standardized patients are individuals who are professionally trained to act as clients and patients in a health-care setting. They have been successfully used in health-care education and evaluation.
4. **IT Solutions**

- A small working group (Measuring Health Equity CHC Technical Working Group) was formed with data management coordinators (DMCs), project leads, the MSH team and Association of Ontario Health Centres (AOHC) subject matter experts to identify IT issues and solutions impacting the collection of quality client demographic data.
- 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 Technical Working Group recommended that the pilot be launched first in CHCs where the Electronic Medical Record transition from Purkinje to NOD was complete (Access Alliance, Parkdale and South Riverdale). Planned Parenthood and Central Toronto began collecting the TC LHIN demographic data once they had transitioned to NOD.
- The TC LHIN questions that varied slightly or were completely new to CHCs involved discussion and troubleshooting to determine how best to capture the data in NOD.
- The Technical Working Group developed NOD Guidelines and NOD Data Entry Notes outlining step-by-step instructions on how to capture information using the eight TC LHIN questions. These documents were shared with all CHC pilot sites.
- Data collected during the pilot project was extracted using Data Miner (in NOD) and analyzed using Excel. There were challenges with creating queries in Data Miner, leading to data inconsistency and with accurately pulling the correct data set for analysis between CHCs.
Process Evaluation

Data for the process evaluation was collected through a combination of quantitative and qualitative data sources (see original materials and questions in the appendices):

**Focus group feedback [open ended questions] (Appendix B)**
A focus group with six participants with representatives from each pilot CHC was conducted in May 2014 to gather feedback on the training and implementation of the pilot project. The focus group was facilitated by CHC Regional Decision Support Specialist (RDSS) Nancy LaPlante, and the main groups represented were data managers, front line staff, and clinical lead/manager/director. The responses were grouped into the following categories: training, staff experiences, the TC LHIN questions, and data and technology.

**Training session feedback [closed + open ended questions] (Appendix C)**
MSH led six training sessions (two group sessions and four site-specific sessions) with a total of 28 participants. The sessions were attended by CHC staff from across the pilot organizations including directors, managers, health planners, DMCs, intake workers, medical secretaries, reception staff and relief staff.

**Online survey responses [closed + open ended questions] (Appendix D)**
10 participants responded to an online survey administered through SurveyMonkey. CHC project leads and data management coordinators were asked to forward the survey to staff that participated in the pilot. The survey asked for feedback on data collection training and comfort with administering the TC LHIN questions. It is important to note that similar themes emerged between the survey results and the focus group.

**Client responses to the eight TC LHIN questions [closed ended questions]**
A meeting was convened among the data management coordinators and the MSH team to discuss and agree on how best to undertake extracting client responses to TC LHIN questions from NOD. It was agreed that common queries be developed and the instructions on how to run the queries be shared among the pilot centres. Once shared, each pilot participant pulled the data and shared it with the Regional Decision Support Specialist and MSH team for aggregation and analysis.

Findings from the multiple data sources listed above were grouped within each of the four areas of data collection and are summarized below:

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5 For one training session, feedback was received post-training.
1. Communication and Engagement

How to communicate with and engage staff around collecting client demographic information emerged as a key theme. Staff identified that internal meetings on data collection are useful for moving forward with this work. In addition, although not all staff members will be actively involved in the data collection processes, there was agreement that all CHC staff need to become familiarized with the rationale and process for collecting client demographic data using the TC LHIN questions.

Feedback on improving communication to clients highlighted two points:
- A need for translated versions of the demographic questions in order to provide non-English speaking clients with the opportunity to participate
- A need to address clarification requests around “racial/ethnic group” (highest volume), “income”, “disabilities” and “sexual orientation”

2. Data Collection Procedures and Workflow

One of the major points that came up around demographic data collection is staff comfort with asking the TC LHIN demographic questions. The online survey included the following question “Overall, how comfortable were you collecting this data?”. While sample size was limited to 10 people, the pattern indicated that over half reported feeling comfortable/very comfortable with collecting client demographic data using the TC LHIN questions, with 20% saying they were ‘neither comfortable nor uncomfortable’ and 20% indicating that ‘they were uncomfortable’ asking.

We also used a number of open ended survey questions to ask about comfort levels and strategies for improving them; comments included (direct quote indicated by “”):
- “it is easier to administer than expected”
- “the sexual orientation question is awkward for first time clients”
- “some questions were too personal”
- Suggestion to ask questions after the appointment since rapport with the client would have been strengthened.

A second theme around workflow and data collection procedures was client privacy when answering questions. Feedback from staff and data collectors covered a number of issues and recommendations (direct quote indicated by “”):
- Privacy is an issue when questions are asked at the front desk. An alternative would be to have another provider ask the questions in a more private space.
- “More privacy is needed to ask sensitive questions”

Guidance around how to ask younger populations under 18 came up at a number of CHCs. More specifically, staff expressed:
- A need for policy on how to collect demographic data from children/babies, particularly on sexual orientation.
- A need for a tool for collecting data from all clients under 18.
One of the major goals of the CHC pilot was to assess factors that can influence data quality and client responses. A total of 2011 clients participated in the pilot. Data analysis from all pilot CHCs showed that the majority of clients are willing to respond to demographic questions, with the (relatively) highest ‘prefer not to answer’ and ‘do not know’ provided for the income question.

The major challenge to data quality was ‘missing data’ in client responses. An examination of data patterns indicates that missing or poor quality data (particularly in open text box) are linked to a number of factors:

- Inability to follow up with client to ensure all questions are complete, particularly when client independently completes paper form
- Inconsistent data entry practices, leading to increased errors
- Ambiguity of practices around clients under 18
- Client not aware of the purpose of demographic data collection

3. Staff Training

The consensus from post-training evaluation, the focus group discussions, and the online survey was that providing data collectors with training was important for successful demographic data collection. In addition, the focus group discussed the importance of providing training on demographic data collection to relevant CHC staff (and volunteers) as a means of communicating the significance of demographic data collection using the TC LHIN questions.

Post-training feedback from staff is summarized in the figures below:

**Figure 2. Preparedness to collect (or train others) to collect client demographic data**

(source: training session evaluation)
Figure 3. Preparedness to administer demographic questions (source: online survey)

How well did the training prepare your centre to administer the questions?

- Not at all well, 0.0%
- Adequate, 30.0%
- Very Well, 70.0%

Figure 4. Prepared to Train Others (source: training session evaluation)

How prepared do you now feel to train others to carry out the collection of demographic data?

- Very prepared
- Prepared
- Somewhat prepared
- Not prepared

Figure 5. Evaluation of facilitator performance (source: training session evaluation)

Overall, how would you rate the performance of the session facilitators?

- Excellent
- Good
- Mediocre
- Poor
Additional information about the facilitator performances included (direct quote indicated by ""):
- “The facilitator did a great job, she was very engaging and answered questions.”
- “She did a very good job facilitating and explaining the info.”
- “...Timing of PowerPoint materials, participation and videos were excellent.”
- “Need more CHC context in presentation.”
- “Allow an extra 30 minutes so there isn’t a rush.”
- “Need more time to do the practice.”

When asked which topics and materials were useful, staff provided a wide range of responses:
- Videos and discussion
- Role playing and practice session
- Overview of project
- Data collection materials and resources (e.g. manual, glossary, laminated questions)
- Different approaches to address client questions
- Specific reasons why this project is needed

Staff were also asked to provide suggestions for improving the overall training and facilitator performances. Below are a number of representative responses:
- More time to practice and role play different scenarios
- How to handle diverse clientele (e.g. children, mental health clients, irate clients)
- More examples of how the data collected can help clients/patients
- More content specific to the CHC sector including scenarios and videos that are representative of the CHC environment and procedures

Given the variation in demographic data collection processes, feedback also indicated a need for tailoring training sessions to CHC-specific data collection methods.

4. IT Solutions

IT solutions focused on building demographic fields into NOD and developing queries to pull client demographic data, with each component posing unique challenges.

Demographic data fields were built or adapted into NOD using the NOD Guidelines developed by the Technical Working Group. The main challenge was articulated by one of the online survey participants:
- “I feel that the questions are not difficult for a CHC to incorporate into client registration however it is a challenge finding the correct (and consistent) place in NOD to record this data.”

Input from staff indicated success on two points:
- The NOD Guidelines provided clear instructions on how to build identifiers into the system
- Listing identifiers within NOD in the same order as the forms facilitated data entry
However, the data extracted from the pilot sites also indicated that not all sites had entered the new fields correctly into NOD, resulting in errors in the data set.

Following the integration of client demographic fields into NOD, the pilot focused on strategies to pull the data into summary reports of client data. The main challenges were:

- Pulling data that accurately captures participant response rates - the percentage of clients who responded to demographic data questions out of the total number of clients approached
- Pulling and organizing text-based data due to spelling mistakes and unclear text responses
- Comparing data between pilot CHCs due to limitations in Data Miner’s (in NOD) ability to extract data in a consistent manner
Overall Findings of the Pilot Project

The pilot project identified key findings and recommendations for the roll-out across TC LHIN Community Health Centres. In particular, the following successes and challenges were highlighted:

Successes
- Excellent collaboration between CHC and MSH teams
- Training provided necessary preparation to collect data
- General level of comfort increased through training and practice
- Client openness to answering TC LHIN demographic questions
- Challenges identified within pilot were addressed

Challenges
- Delays due to unexpected hurdles with IT and communication
- Scheduling training for key staff within the project’s relatively short timeframe
- Changes to long-standing data collection practices
- Questions not yet translated into languages other than English

Focus group participants and survey respondents were mainly comprised of administrative staff/front line workers, data management coordinators and clinical managers. There was a general comfort level in asking the questions, but some CHC staff found the sexual orientation question more difficult to ask due to privacy concerns (Survey, 50%, n=5). It was also noted that the racial/ethnic group question (Survey - 80%, n=8) and to a certain extent the income question (Survey 60%, n=6) required further explanation from staff.

Change management and internal communication within CHCs emerged from the pilot as two key areas that are vital to the successful implementation of the eight TC LHIN questions in the CHC sector. Challenges with these areas resulted in difficulties when scheduling training sessions and support meetings. For example, those who attended the training were not always the ideal staff to be trained; as well, fewer attended than was needed for each CHC to implement the project. Additional issues to consider for continued implementation into other CHCs include greater explanation of the changes to current CHC demographic questions and the rationale for the new questions that CHCs have not been collecting from clients (e.g. sexual orientation and disabilities).

IT challenges were experienced throughout the pilot project. Although many of them were resolved through the creation of the NOD Guidelines and NOD Data Entry Notes documents, issues remain with extracting data from the eight TC LHIN questions consistently and accurately from NOD.

Although the evaluation of the pilot project comprised a small number of individuals, the feedback received highlighted key themes that need to be considered in the implementation of the Measuring Health Equity in TC LHIN CHCs Project.
Recommendations

Based on the findings of the pilot project, it is recommended that:

1. **Communication and Engagement**
   1) CHC project leads and senior management work together to ensure that all staff are made aware of the project and understand their responsibilities in the roll-out of the TC LHIN questions and changes in data management practices.
   2) CHC project leads work with their teams to ensure appropriate time is allotted for planning prior to project launch.
   3) Staff would benefit from having handy resources and scripts that would enable them to quickly and efficiently address client inquiries.

2. **Data Collection Procedures and Workflow**
   1) MSH team works with each CHC to adapt training and implementation to individual CHC needs (i.e. consult on best practices and help address issues of privacy, workload, data quality, etc.).
   2) MSH team shares translations of the eight TC LHIN questions once they are available. The questions are being translated into the top 10 languages spoken in the Toronto Central Region plus French: Arabic, Chinese (simplified), Hungarian, Italian, Korean, Portuguese, Russian, Spanish, Tamil and Vietnamese.
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   7) The CHC Evaluation Framework adopt a clear guideline on how to collect demographic data from clients under 18 years of age.
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3. **Staff Training**
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1) CHC Data Management Coordinators (DMC) use the Nightingale On Demand (NOD) Guidelines to add the four new TC LHIN demographic questions to NOD prior to project launch. For quality assurance purposes, each DMC ensures a second staff member verifies that the four new TC LHIN questions are added to NOD correctly.

2) MSH team and the DMC hold a separate training session for data entry staff to focus on how to enter the demographic data accurately and consistently.

3) Data entry be limited to select staff member(s) who are trained on data collection/entry to reduce errors and improve data quality.

4) BIRT (Business Intelligence Reporting Tool), the CHC sector data warehouse, be used to aggregate and report on the eight TC LHIN demographic questions.

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**DATA QUALITY**

Ensuring data quality is critical for the validity, reliability, and usability of client demographic data collection.

Below is a list of best practices that are being used by TC LHIN CHCs (from the pilot and beyond) and leading health-care organizations to monitor and address data quality:

1. Pulling demographic data summary reports periodically (e.g. monthly for first six months, and quarterly thereafter) to identify critical issues with data quality
2. Setting targets for missing data (recommendation: 10%) to use as a benchmark for performance
3. Monitor “other” rates of responses to identify whether:
   a. Responses should be captured by existing categories
   b. Significant client population is not being captured by existing categories
4. Include data collection team (data entry staff, data coordinators) when addressing ongoing issues and developing standards for addressing unexpected challenges
5. Using the Data Quality Assessment Tool (DQAT)\(^6\) to understand critical areas for ongoing data quality improvement with socio-demographic data.

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\(^6\) DQAT is a tool currently available in BIRT that measures usability, accuracy, relevance, timeliness, and comparability. It is in the process of being updated and will be available in the near future for use by CHCs.
**Provincial Considerations**

The Performance Management Committee, a CHC provincial committee, has approved the TC LHIN client demographic questions for use at all CHCs in Ontario. As this pilot project is rolled out to all TC LHIN CHCs, plans are simultaneously underway to expand to all CHCs across Ontario. The adoption of the TC LHIN demographic questions by the entire provincial sector is a demonstration of the commitment by CHCs to health equity with the first step being the collection and use of high quality socio-demographic data.

**Acknowledgements**

This pilot project was comprised of a strong collaboration between the Community Health Centres and the Mount Sinai Hospital project team on behalf of the Toronto Central LHIN. Nancy LaPlante, Regional Decision Support Specialist on behalf of the CHCs, and the Mount Sinai Hospital project team, including Marylin Kanee, Caroline Bennett-Abuayyash, Mutiat Enikanolaiye and Narina Nagra, were supportive of the unique needs to ensure successful roll-out of the TC LHIN demographic questions in the participating pilot sites. Among the CHCs (Access Alliance, Central Toronto, Parkdale, Planned Parenthood, and South Riverdale), the staff not only participated and provided feedback but owned this work with enthusiasm. Their commitment to this project was vital to its implementation and the resulting evaluation. We would also like to thank the members of the Measuring Health Equity CHC Technical Working Group who were integral to the project’s success.
List of Appendices

Appendix A. TC LHIN Demographic Questions for CHCs

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

- [ ] 1. Amharic
- [ ] 2. Arabic
- [ ] 3. ASL
- [ ] 4. Bengali
- [ ] 5. Chinese (Cantonese)
- [ ] 6. Chinese (Mandarin)
- [ ] 7. Czech
- [ ] 8. Dari
- [ ] 9. English
- [ ] 10. Farsi
- [ ] 11. French
- [ ] 12. Greek
- [ ] 13. Hindi
- [ ] 14. Hungarian
- [ ] 15. Italian
- [ ] 16. Karen
- [ ] 17. Korean
- [ ] 18. Nepali
- [ ] 19. Polish
- [ ] 20. Portuguese
- [ ] 21. Punjabi
- [ ] 22. Russian
- [ ] 23. Serbian
- [ ] 24. Slovak
- [ ] 25. Somali
- [ ] 26. Spanish
- [ ] 27. Tagalog
- [ ] 28. Tamil
- [ ] 29. Tigrinya
- [ ] 30. Turkish
- [ ] 31. Twi
- [ ] 32. Ukrainian
- [ ] 33. Urdu
- [ ] 34. Vietnamese
- [ ] 35. Other (please specify):
- [ ] 98. Do not know
- [ ] 99. Prefer not to answer

2. Were you born in Canada?  

- [ ] 1. Yes
- [ ] 2. No
- [ ] 98. Do not know
- [ ] 99. Prefer Not to Answer

If NO, what year did you arrive in Canada?  _____________________

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

- [ ] 1. Asian-East (e.g., Chinese, Japanese, Korean)
- [ ] 2. Asian-South (e.g., Indian, Pakistani, Sri Lankan)
- [ ] 3. Asian-South East (e.g., Malaysian, Filipino, Vietnamese)
- [ ] 4. Black-African (e.g., Ghanaian, Kenyan, Somali)
- [ ] 5. Black-Caribbean (e.g., Barbadian, Jamaican)
- [ ] 6. Black-North American (e.g., Canadian, American)
- [ ] 7. First Nations
- [ ] 8. Indian-Caribbean (e.g., Guyanese with origins in India)
- [ ] 9. Indigenous/Aboriginal - not included elsewhere
- [ ] 10. Inuit
- [ ] 11. Latin American (e.g., Argentinian, Chilean, Salvadoran)
- [ ] 12. Metis
- [ ] 13. Middle Eastern (e.g., Egyptian, Iranian, Lebanese)
- [ ] 14. White-European (e.g., English, Italian, Portuguese, Russian)
- [ ] 15. White-North American (e.g., Canadian, American)
- [ ] 16. Mixed heritage (e.g., Black-African & White–North American)
  Please specify:  _____________________
- [ ] 17. Other(s): Please specify:  _____________________
- [ ] 98. Do not know
- [ ] 99. Prefer not to answer

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

- [ ] 1. Chronic Illness
- [ ] 2. Developmental Disability
- [ ] 3. Drug or Alcohol Dependence
- [ ] 4. Learning Disability
- [ ] 5. Mental Illness
- [ ] 6. Physical Disability
- [ ] 7. Sensory Disability (i.e. hearing or vision loss)
- [ ] 8. Other (Please specify):
  - [ ] 9. None
  - [ ] 98. Do not know
  - [ ] 99. Prefer not to answer

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7 The coding for answer options “do not know” and “prefer not to answer” were changed post-pilot for all questions.
5. **What is your gender?** Check ONE only.

- □ 1. Female
- □ 2. Intersex
- □ 3. Male
- □ 4. Trans-Female to Male
- □ 5. Trans-Male to Female
- □ 6. Two-Spirit
- □ 7. Other (Please specify): ____________________
- □ 8. Do not know
- □ 9. Prefer not to answer

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

- □ 1. Bisexual
- □ 2. Gay
- □ 3. Heterosexual (“straight”)
- □ 4. Lesbian
- □ 5. Queer
- □ 6. Two-Spirit
- □ 7. Other (Please specify): ____________________
- □ 8. Do not know
- □ 9. Prefer not to answer

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

- □ 1. $0 - $14,999
- □ 2. $15,000 – $19,999
- □ 3. $20,000 – $24,999
- □ 4. $25,000 – $29,999
- □ 5. $30,000 – $34,999
- □ 6. $35,000 – $39,999
- □ 7. $40,000 – $59,999
- □ 8. $60,000 or more
- □ 9. Do not know
- □ 99. Prefer not to answer

8. **How many people does this income support?**

____________________ person(s)  □ 98. Do not know  □ 99. Prefer Not to Answer

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8 The CHC Performance Management Committee approved the inclusion of a sixth answer option “Two-spirit” for the gender question post-pilot.
Appendix B. Focus group questions

1. Did you receive any questions or comments from clients?

2. Were there any unexpected issues that arose?

3. Did you have a chance to review the form after the client filled it out and ask the client any follow-up questions?

4. For those who attended the training, what did you find helpful? What could be improved? How can it be adapted to reflect the CHC environment?

5. With respect to IT and data entry, how did entering the data go? What were some challenges with technology? Have the initial challenges been resolved?

6. Any other comments or suggestions about the project?

7. Since community health centres are already asking demographic questions, don’t staff already know why we collect the information?

8. Any other comments?
Appendix C. Training Evaluation Form

1) Overall, how helpful was this training session in preparing you to collect or train others to collect demographic data in the healthcare setting?
   - Very helpful
   - Helpful
   - Somewhat helpful
   - Not very helpful

2) Overall, how would you rate the performance of the session facilitators?
   - Excellent
   - Good
   - Mediocre
   - Poor

3) What suggestions do you have for improving the facilitators’ performances?

4) Please list the topics/materials that were most useful to you:

5) What additional activities or topics would you like to see added to this training session?

6) How prepared do you now feel to train others to carry out the collection of demographic data?
   - Very prepared
   - Prepared
   - Somewhat prepared
   - Not prepared

7) Is there anything else you would like us to know?
Appendix D. Survey Questions

1. Please indicate the name of your CHC: __________________________

2. What is your role at the centre?
   - Data Management
   - Administration (front line worker)
   - Clinical Lead/Manager/Director
   - Administrative Supervisor
   - Other (please specify): __________________________

3. How well did the training prepare your centre to administer the questions?
   - Not at all well
   - Adequate
   - Very Well
   - Other (please specify): __________________________

4. How could the training be improved for the CHC environment?

5. On average, how much time did it take to...

<table>
<thead>
<tr>
<th>Activity</th>
<th>Less than 5 minutes</th>
<th>Five to 10 minutes</th>
<th>Ten to 15 minutes</th>
<th>More than 15 minutes</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Administer the 8 core questions to each client?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Record/tally the response rates?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do the data entry?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Other (please specify): __________________________

6. Our clients needed clarification of the questions... (please select all that apply)
   - What language would you feel most comfortable speaking in with your healthcare provider?
   - Were you born in Canada?
   - Which of the following best describes your racial or ethnic group?
   - Do you have any of the following?
   - What is your gender?
   - What is your sexual orientation?
   - What was your total family (household) income before taxes last year?
   - How many people does this income support?
   - Other (please specify): __________________________
7. Overall, how comfortable were you collecting this data?
   - Very comfortable
   - Comfortable
   - Neither comfortable nor uncomfortable
   - Uncomfortable
   - Very Uncomfortable
   - Not applicable, I did not ask the questions

8. If you were not comfortable at any time in asking these questions, can you please describe the reason(s) for your discomfort?

9. Do you have any other comments about the training and/or the process of collecting this information?
Appendix E. Resources and Supports Available

**CHC-specific materials**

The following materials were developed during the pilot for the CHC sector:

- The core eight questions created into a numbered form with the income question reflecting CHC appropriate income brackets.
- NOD Guidelines to help prepare NOD to accept the new questions
- NOD Data Entry Notes to guide data entry for the existing questions in NOD
- Training videos reflecting CHC settings and scenarios which are available on the website
- Training revised and condensed into a 2 hour session to better suit CHCs
- Workplan to help CHCs prepare and put all the pieces in place for implementation

**Other resources available from the MSH team**

- Individual meetings with each CHC
- One-hour Online E-learning module (soon to be available)
- Demographic questions are currently being translated into 11 languages
- Training sessions
- Support with IT changes
- Website [http://torontohealthequity.ca](http://torontohealthequity.ca)
- Communication and training materials
- Onsite support during data collection
- Ongoing support as needed
- Support with data analysis plan