# Evaluating robust sociodemographic data collection within a primary care setting

## Final Report and Recommendations

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**EXECUTIVE SUMMARY**

For the last four years, hospitals, primary care organizations, and other institutions in the Toronto Central LHIN have been collecting robust sociodemographic data from patients using a standardized set of Health Equity Questions (HEQ) developed through a consensus process. We undertook a study at the St. Michael's Hospital Academic Family Health Team (SMHAFHT) to understand how the Health Equity Questions have been integrated into workflows, the quality of the data collected, the perspectives of patients responding to the questions, and the perspectives of clinicians and health care administrators using the data. The study was funded by the Toronto Central LHIN and the results and recommendations are meant to inform the Toronto Central LHIN and other stakeholders as they move forward with robust sociodemographic data collection.

SMHAFHT is a large interprofessional primary care organization serving more than 40,000 enrolled patients at six clinics geographically dispersed in the eastern edge of downtown Toronto. SMHAFHT piloted the questions in the summer of 2012[1] and implemented routine use of the questions in December 2013.

This study had both quantitative and qualitative components. The quantitative component included data from any patient who registered for a visit at the FHT between December 1, 2013 and March 31, 2016, including both those who did and did not answer the HEQ. The qualitative component included semi-structured individual interviews with 27 patients, 7 clerical staff, and 7 members of the FHT leadership team as well as a focus group with 9 clinicians (i.e. physicians and/or nurse practitioners). The study was overseen by an advisory group that included representatives from the TC LHIN, TC LHIN hospitals, organizations involved with data collection and reporting in the health sector, and SMHAFHT patients. The study findings were discussed at a roundtable held on December 8, 2016 attended by over 60 health care providers and health system administrators from a variety of sectors across Ontario.

Our study noted significant non-response bias among those who did and did not respond to the questions at SMHAFHT. Patients who visited the FHT more often were more likely to have responses to the HEQ in their medical chart. Some populations, such as children, were much less likely to have responses to the HEQ. Interviews with clerical staff and the leadership team at SMHAFHT highlighted that although there was a plan and commitment to educate all staff about the HEQ, in practice this became difficult to sustain over the years, particularly with staff turnover. At the roundtable, participants agreed that staff at all institutions would benefit from standard initial orientation as well as ongoing retraining to mitigate the potential for non-response bias.

Interviews with patients, clinicians, and the leadership team at SMHAFHT revealed the significant potential of the HEQ, including understanding inequities in care and outcomes and developing programs to meet the unique needs of the population served. Some patients particularly appreciated the inclusiveness of the HEQ, particularly the questions related to gender identity and sexual orientation. Some patients, however, raised concerns that some of the questions were uncomfortable to answer and could be stigmatizing. Patients revealed specific challenges with answering some of the questions, often due to a lack of clarity of the terms used

in the question or responses. Clinicians and health system administrators raised concerns that the data could be used to discriminate against patients or that the data may underrepresent minority populations, with implications for funding. Many patients assumed that the data would be used at the point-of-care by their clinician.

Members of the advisory committee and roundtable noted some domains were missing from the HEQ such as education, employment, and whether a patient had insurance for prescription medications. Providers noted that many of the questions are not asked in a way that would be useful at the point-of-care. The purpose – or purposes – of robust sociodemographic data collection should determine the domains covered, the wording of each question, and how data was collected. Purposes are not mutually exclusive, and could include action at the point-of-care, organization change, health system planning and research.

This study is limited by drawing only on the experience of one organization in the Toronto Central LHIN. Further, although our quantitative findings are based on a large sample, these patients may not be representative of the whole patient population in the Toronto Central LHIN. Nevertheless, our findings and recommendations will likely be useful to other organizations as they embark on similar efforts.

The Toronto Central LHIN is now considering two streams of data collection: provincial collection of immutable sociodemographic characteristics at time of health card registration and collection at the health care organization of data useful to organizations and clinicians. This two-pronged approach offers the potential to address some of the challenges raised in our study. There is interest provincially, nationally, and internationally to learn from and build on the experiences in the Toronto Central LHIN to collect this data to advance health equity.


**RECOMMENDATIONS**

1. **Health institutions, regional and provincial health authorities, together with stakeholders, including patients and community members, should identify the purpose(s) of engaging in the collection of robust sociodemographic data from patients. The purpose(s) should be communicated to patients at the time of data collection.**

2. **At an early stage, institutions involved in collecting robust sociodemographic data should identify how to use the data to improve care, and should develop plans to share lessons learned with others.**

3. **As with any personal health information, the data collected is subject to PHIPA and other privacy legislation. Health organizations should indicate to patients the steps taken to keep their data secure and under what circumstances it will be used.**

4. **Institutions should inform patients about ways to report any concerns about discrimination that could arise based on answers to the HEQ.**

5. **In its current form, the HEQ collection tool is missing key domains that could improve its utility, particularly for point-of-care use. There should be a clear process to develop additional questions and evaluate their impact, at an institutional and system level.**

6. **A number of best practices for collecting the HEQ have been developed by staff at Sinai Health System. Health institutions should use these to reduce non-response bias. Staff training should convey that the questions should be offered to all eligible patients. Non-response bias should be measured and addressed, within each institution separately and also across institutions.**

7. **Using training materials developed by staff at Sinai Health system, health institutions should orient all staff – including leadership, management, administrative and clinical staff – to the purpose of robust sociodemographic data collection. For new staff, this should be included in staff orientation. Refresher training should be provided every 6-12 months.**

8. **Following best practices developed by staff at Sinai Health System, each health institution should establish a central point of coordination at each organization, responsible for both <u>data collection</u> and <u>analysis</u>. This person or small team would be the main point of contact for the organization and the TC LHIN and other stakeholders.**

9. **Reword the question about <u>spoken language</u> to reflect the intended purpose and clarify this purpose for patients when asking the question. For example, it would be helpful to clarify for patients whether their response will be used by their health care provider to determine what language should be used to deliver health care services (i.e. pragmatic interpretation) or whether the purpose is to understand the sociodemographic diversity among the population for health planning.**

10. **Retain the questions related to <u>immigration status</u>, but consider changing response options to be fixed year categories (e.g. 1980-1985) along with the year when the data is collected to minimize errors associated with free-text entry.**

11. **Regarding the question on <u>race/ethnicity</u>:**
a. **Develop a guide on how organizations can aggregate responses to the question related to race/ethnic group. Response options should strike a balance between the need for people to find themselves but also allow options to be aggregated.**
b. **Clarify the purpose of the race/ethnicity question and modify the question and/or instructions accordingly. For example, are institutions interested in self-identity, country of origin, parents' country of origin, or place of birth?**
c. **The TC LHIN should complete the development of a data sharing agreement, in consultation with the Toronto Indigenous Health Advisory Circle and other stakeholders.**

12. **Clarify the purpose of asking the question related to <u>disability</u> and whether it relates to *perception* of disability or *identifying diagnoses* or whether it should be repurposed to focus on *disability accommodation*. Consider that other data sources, such as the medical chart, may provide more accurate information on patient diagnoses.**

13. **Consider explaining and updating terms used in the question on <u>gender</u>, including clarifying that this question is asking about gender identity. As the language to describe gender identity is evolving, there should be a process to adapt or update options, and could include a broad option of gender queer or gender non-binary.**

14. **Consider explaining and updating terms used in the question on <u>sexual orientation</u>. As the language to describe sexual orientation is evolving, there should be a process to adapt or update options.**

15. **Further work is necessary to understand how to address patient concerns and discomfort with the question related to <u>income</u>, and how to format this question to make it easier to analyze (e.g. to identify low-income individuals or income gradients). The question "How many people does this support?" should be modified. Consider changing this question to one designed to be useful at the point-of-care.**

16. **Consider moving the question on <u>language preferred for written information</u> directly after the question related to spoken language and potentially highlighting with formatting the difference between the two questions.**

17. **Clarify the purpose of the question on <u>religion</u> (e.g. identifying practicing religion versus religious affiliation). For example, if used to identify dietary preferences, a question on religious or spiritual affiliation is not an adequate proxy. Finally, consider including Agnostic as a response option.**

18. **Clearly define the response options for the question related to <u>housing</u>. Clarify an option for people living with family. Consider using "house or apartment" instead of the term "home".**

## 1. BACKGROUND AND RATIONALE

Substantial evidence now exists that an individual's health is influenced by the social, economic and political context in which she lives. These have been referred to as the "social determinants of health", the conditions in which people are born, grow, live, work and age.[2] The Public Health Agency of Canada identifies income, social status, education, the social and physical environment, gender and culture, as key determinants of health.[3] Governments around the world have recognized the importance of addressing these social determinants, particularly in order to reduce health inequities. These are those differences, variations and disparities in the health achievements of individuals and groups that are deemed to be unjust or unfair.[4] Part of the causal mechanism that underlies the social determinants of health may lie within the health care system. Low-income and low-education attainment patients are less likely to be referred to specialists.[5] They may be less likely to access diagnostic and therapeutic services in a timely fashion.[6] Patients from low-income neighbourhoods may be more likely to be hospitalized for conditions that could have been prevented by optimal care in ambulatory settings.[7]

One barrier to understanding and addressing health inequities is the lack of sociodemographic data at the individual level. While information on gender and age is available, few Canadian institutions routinely collect data on other characteristics of patients. There is a substantial body of evidence from the United States that suggests collecting such data is feasible and acceptable, particularly if it is part of improving the quality of care. The *Tri-Hospital Plus TPH Health Equity Data Collection Collaborative* was an initiative supported by the Toronto Central Local Health Integration Network (TC LHIN) and engaged St. Michael's Hospital, Mount Sinai Hospital, the Centre for Addiction and Mental Health and Toronto Public Health.[8] Through a number of meetings, consultations and by conducting a literature review, the *Collaborative* reached consensus on a set of questions to be administered by each institution in the form of pilot projects. These included questions about language, immigration, race/ethnicity, religion, disability, gender identity, sexual orientation, income and housing. During June 2012 to August 2012, each institution collected data in a different location on approximately 400 patients. Based on this experience, collecting such data was deemed to be feasible and acceptable. TC LHIN health institutions were encouraged to routinely collect this data using the Health Equity Questions (HEQ), supported by tools, training and resources developed and delivered by staff at the Office of Human Rights and Health Equity at Mount Sinai Hospital.[9]

Our Family Health Team (FHT) participated in the initial pilot of the HEQ[1] and has been routinely collecting data using the HEQ since December 2013. Early attempts at using the data reinforced its importance as a method for understanding and addressing health inequities but also revealed challenges with using the data.[10] These experiences prompted us to conduct the current study to assess the quality of the HEQ as well as patient and provider perspectives on collecting and using the data.

### STUDY OBJECTIVES

1. Assess the response rate to the HEQ and potential non-response bias.
2. Explore how data from the HEQ compares to other similar data documented in the patient chart.

3. Understand the perspectives of patients, clinicians, clerical staff, and Family Health Team leadership on i) implementation of the HEQ data collection at the FHT and ii) the potential use of the data and related considerations.
4. Understand patient comfort with and cognitive understanding of each of the HEQ.


## 2. <u>METHODS</u>

### *Study setting*

The SMHAFHT is a large provider of primary care in south-east Toronto. With over 40,000 patients, it is Ontario's largest academic Family Health Team. The SMHAFHT was one of the four pilot sites for the Tri-Hospital + TPH project.[1] Initially, patients were asked to respond to the questions using a tablet provided to them when they checked-in for their scheduled appointment. The HEQ were implemented at four clinic sites in 2013. Implementation at a fifth site was delayed due to inconsistent wireless internet access, which was required for the HEQ to be administered on a tablet. A sixth clinic site for SMHAFHT was opened in 2015 and the HEQ was implemented from its inception. Clerical staff were trained on the purpose of the HEQ and on how to offer tablets to patients. Over time, both tablet and paper versions of the HEQ were offered to patients at all six sites. If the HEQ were answered using a tablet the responses were automatically uploaded to the patient's electronic medical record (EMR). If the HEQ were answered on paper the answers were later manually inputted by staff on a tablet, with the responses automatically uploaded to the patient's EMR.

### *Quantitative data collection and analysis*

This cross-sectional analysis was formally reviewed by institutional authorities at St. Michael's Hospital and deemed to neither require Research Ethics Board approval nor written informed consent from participants. We analyzed data from patient charts, examining information entered between December 1, 2013 and March 31, 2016. Data was extracted in spring 2016 and analyzed from April to November 2016. We included all patients who had at least one physician visit at SMHAFHT during the study period. These patients should all have registered at the front desk of their clinic and therefore could potentially have been offered the HEQ. Our outcome of interest was whether a patient completed at least one HEQ as documented in the EMR. We also assessed who was offered the survey and among those who were offered the survey, who completed at least one question versus who declined.

We obtained data on physician visits from the Admissions/Discharges/Transfers system of the hospital. We collected a number of explanatory variables from the EMR including patient's year of birth, sex, postal code, and roster status. We assessed whether a patient was on Ontario Works (OW) or Ontario Disability Support Program (ODSP) by whether billing codes K050, K051, K052, K053, K054, K055 were submitted. This method is highly specific as these bills can only be submitted for patients on OW or ODSP, however its sensitivity is unknown. We also attempted to assess whether patients were living in poverty using the presence of a referral form to or a note from an internal Income Security Health Promoter Service. Although we had initially planned on also using data from annual health exam forms that indicated that a patient was living

in poverty (checkbox on forms), a separate study had found this data was difficult to extract accurately, was completed inconsistently by providers and that providers were moving away from conducting annual health exams on patients. We determined the presence of specific chronic diseases using internal patient registries for HIV, diabetes, and gender dysphoria. We determined the presence of a mental health condition using billing codes per a previously validated algorithm.[11]

We calculated descriptive statistics to compare those who were offered the HEQ to those who were not offered, and to compare those who completed the HEQ (i.e. data is available) to those who declined or were not offered (i.e. data is not available). We examined the distribution of answers provided for each of the HEQ. We examined each question and evaluated whether there are significant differences in the characteristics of those who provided an answer to the question and those who did not. We used logistic regression to examine which patient characteristics were associated with completing at least one HEQ versus not. We estimated the association between data on income provided (by itself and also divided by the number of people supported) and neighbourhood income quintile as determined by postal code (using ANOVA or Kruskal-Wallis test). We also compared income reported to other identifiers of low-income (bills submitted for the completion of Ministry of Community and Social Service forms, referral form to an internal Income Security Health Promoter Service present or a note present by an income security health promoter). We estimated the percent agreement between answers to the question about gender identity and the gender listed in chart and presence of a Gender Dysphoria diagnosis. We also estimated the agreement (percent agreement between responses to evidence of mental illness, HIV and type II diabetes and medical diagnoses noted in the chart. We assumed that self-reported data on the HEQ is the gold standard.

### *Qualitative data collection and analysis*

The qualitative component of the study focused on the experience and perspectives of patients, staff in leadership and clerical roles, as well as FHT clinicians. Approval for this aspect of the project was received from the St. Michael's Hospital Research Ethics Board. Qualitative data was collected from May to July 2016. Patients, clerical staff and HEQ leaders (e.g. executive staff, HEQ implementation leads) were interviewed throughout this study period, and a focus group was held with health care providers in June 2016.

Patients were recruited to be interviewed shortly after they completed the HEQ in the waiting room of clinics where they presented for routine care. Patients were approached by a research team member and their participation was voluntary. Maximum sampling variation was used to ensure the sample represents a diversity of patients in terms of gender identity and age category. Interviews lasted approximately 20 minutes and occurred in a private room. Patients were asked about their overall impression of the HEQ, their level of comfort with questions and their understanding of what each question was asking. Patients were also asked about their feelings about data security and the use of the data. These interviews were audio-recorded and transcribed verbatim and a $20 gift card was offered to the patient as an honorarium. Clerical staff involved in distributing and collecting the HES, along with departmental and institution leaders, were also interviewed to understand their perspective on the process of collecting data through the HEQ. We explored changes to process that have happened and how obstacles have been identified and

addressed. These interviews were audio-recorded and transcribed verbatim. Finally, SMHAFHT physicians and nurse practitioners were invited to participate in a focus group. During the focus group, we examined a) general impressions around the HEQ, b) potential uses of the data, c) concerns about the data, including data quality, d) perspectives on how data is collected at each site, e) suggestions for improvement. Altogether 50 people participated in the qualitative component of the study. All transcripts were analyzed in NVivo by a team of coders. Most codes emerged from the data and a small subset of codes was pre-determined based on the interview guides and methodology used. After the codebook was developed based on a subset of interviews, two rounds of coding were done by a team of five coders. A high value inter-rater reliability was achieved (95.3%).  Smaller teams of coders then did a sub-theme analysis of individual codes.

### *Advisory Group and Roundtable*

To inform the design, analysis and interpretation of findings, we established an Advisory Group for this study at its inception. This Advisory Group included representatives from institutions using the HEQ and actively collecting and analyzing the data (St. Michael's Hospital, Mount Sinai Hospital, University Health Network, , Stonegate Community Health Centre), organizations interested in supporting the use of the HEQ to identify health inequities (Association of Family Health Teams of Ontario, Health Quality Ontario, Canadian Institute for Health Information), the office supporting multiple institutions in the implementation of the HEQ, the regional health authority (Toronto Central LHIN), and two patients of the SMHAFHT. This Advisory Group met four times (Table 1).

*Table 1: Advisory Group meeting schedule and agenda items.*

| Meeting | Date | Agenda |
|---|---|---|
| 1 | April 7, 2016 | • Introductions<br>• History of the Health Equity Survey and Rationale for Current Project<br>• Role of the Advisory Group<br>• Health Equity Data Project Part 1: Plan for Analysis of Medical Record Data<br>• Health Equity Data Project Part 2: Interviewing patients, health care providers and other staff within the SMHAFHT<br>• Open Discussion |
| 2 | June 9, 2016 | • Introductions<br>• Brief review of the project<br>• Presentation and discussion of early results on Part 1: Quality of the sociodemographic data<br>• Using health equity data to understand patients overdue for cancer screening: lessons learned<br>• Using and interpreting income data<br>• Progress on Part 2: Interviewing patients, health care providers and other staff within the SMHAFHT |

| | | |
|---|---|---|
| | | • Update on planning of Roundtable December 2016<br>• Open discussion<br>• Next steps |
| 3 | September 29, 2016 | • Introductions<br>• Review of project and updates<br>• Presentation and discussion of results on Part 1: Quality of the sociodemographic data<br>• Presentation and discussion of other tools and measurements<br>• Discussion and next steps |
| 4 | November 3, 2016 | • Introduction and project recap<br>• Qualitative findings<br>• Study recommendations<br>• December roundtable |

In addition, we organized a Roundtable meeting on December 8, 2016 for a half-day, hosted at the Li Ka Shing Knowledge Institute, St. Michael's Hospital. Over 60 individuals attended, including several patients from SMHAFHT. The objectives were:

1) To **share findings** from a set of research studies that assessed the quality of data, the implementation process, and patient and provider perspectives on the Health Equity Data collection initiative.
2) To **generate discussion** on how these findings compare to the experiences of other organizations.
3) To **advance action** on how data can be used to improve health equity.

Results and draft recommendations developed through this study were presented and feedback was received through oral reports from small groups and written comments and suggestions. Notes were taken throughout the Roundtable and all written comments and suggestions were compiled and reviewed by Drs. Pinto and Kiran.


### 3.  RESULTS AND RECOMMENDATIONS

Our recommendations are based on both quantitative and qualitative results. Quantitative results are drawn from an analysis of the charts of 42,396 patients who had at least one physician visit during the 28-month study period. Of these, 14,247 (33.6%) were categorized as "completers" with at least one question answered on the survey (Figure 1). Qualitative results are drawn from interviews with 27 patients, seven clerical staff and seven leadership staff, and a focus group with nine health care providers.

Where appropriate, we have provided representative quotes, figures or statistics to support the recommendation. However, several recommendations emerged from a synthesis of data collected, discussions at meetings of the Advisory Group and from participants at the Roundtable and are not based on any single statistic or set of quotes.

*Figure 1. Patients who visited the Family Health Team and were offered and completed the Health Equity Questions.*
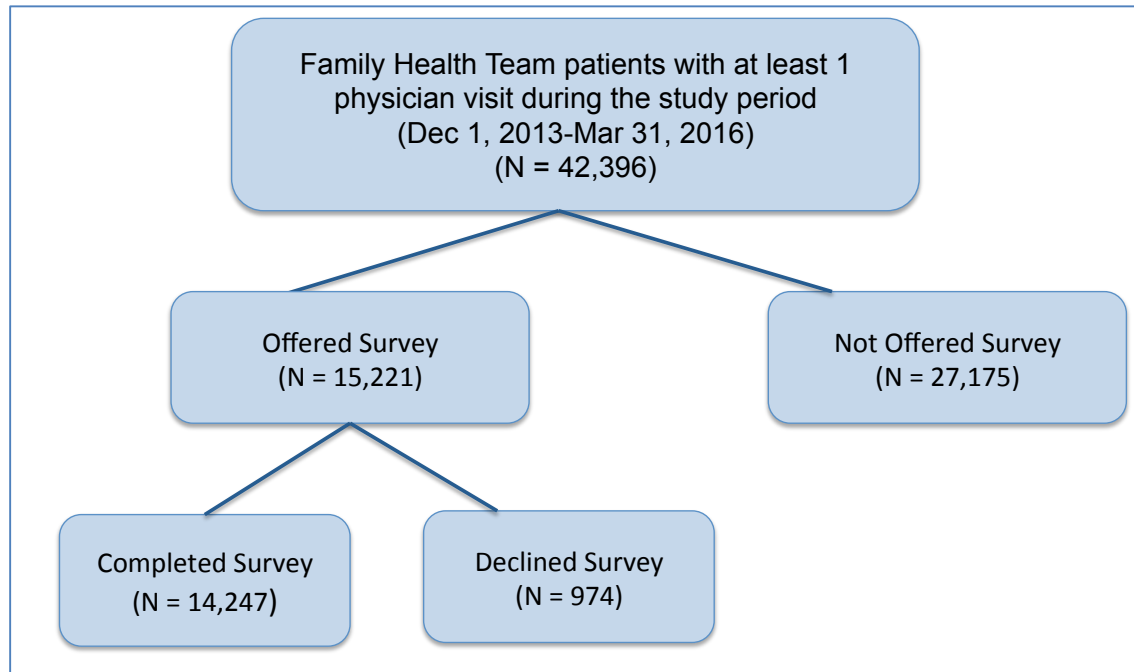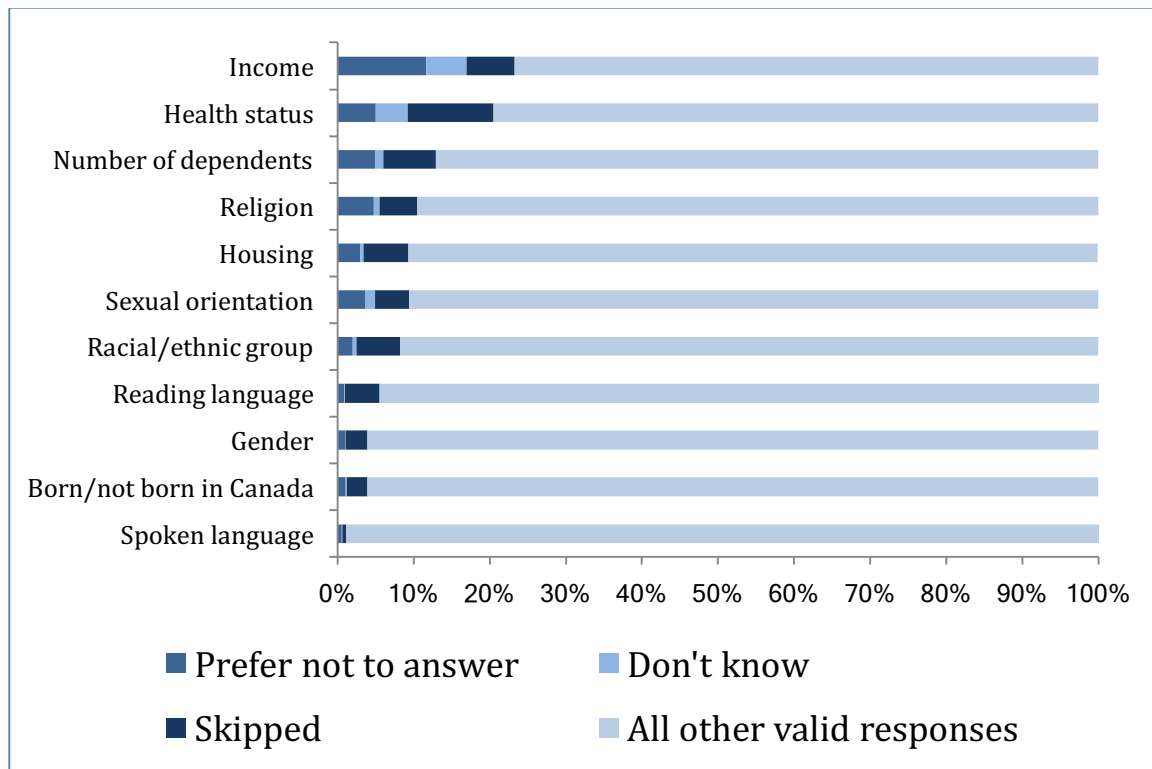


*Figure 2. Response rates to the Health Equity Questions.*

**Recommendation 1. Health institutions, regional and provincial health authorities, together with stakeholders, including patients and community members, should identify the purpose(s) of engaging in the collection of robust sociodemographic data from patients. The purpose(s) should be communicated to patients at the time of data collection.**

Four broad purposes that are not mutually exclusive, include: 1) improving care for individuals and families at the *point-of-care*, 2) supporting *quality improvement* initiatives and program planning to address health inequities in a health care institution, 3) informing *health system planning and regional initiatives* and 4) conducting a variety of *research* studies (Table 2).

The intended purpose influences how the data is collected, the domains that are included and the format of the questions. For example, for the data to be used for health system planning and research, data collection must be standardized across institutions. In contrast, for the data to be used effectively at the point-of-care, institutions can choose to customize how they collect data (e.g. through one-on-one interview, paper surveys, tablets etc.). Where possible, questions should be informed by local, provincial/territorial and national data collection and reporting initiatives. The purpose(s) of data collection and intended uses(s) of the data should be clearly stated in the preamble to the questions to assist patients, caregivers and staff. Consideration should be given as to whether consent is required from patients to use the data (e.g. for research).

*Table 2. Four main purposes to collect robust sociodemographic data from patients.*

|  | **Types of questions** | **Use considerations** | **Implementation considerations and alternative data sources** |
|---|---|---|---|
| **Point-of-care** (individual-level knowledge and action) | Should be actionable at point-of-care, and should focus on identifying social needs that impact health and access to healthcare. | Data should be available in a user-friendly format in the medical record to ensure providers can take action. | Screening for social needs should be integrated into routine care. Institutions may benefit from including domains that are important for providers. Institutions can have flexibility on how the questions are delivered (e.g. paper or tablet, and who is asking the questions). If social needs are identified, providers must be trained in how to address these (e.g. referral to appropriate resource). |
| **Quality improvement and program planning** (organization-level knowledge and action) | Should be actionable by an organization through change or through advocacy initiatives. Should | Should be able to be easily analyzed by an institution with minimal data support. Should be linked to other | Institutions may benefit from including custom questions that meet their need. Institutions can have flexibility on how the questions are delivered (e.g. |

| | not include questions where the data can be obtained by the institution through other means. | institutional data to identify non-response bias. | paper or tablet, and who is asking the questions) but should be educated on best practices to minimize non-response bias. |
|---|---|---|---|
| **Regional health system planning** (regional-level knowledge and action) | Should not include questions where data can be obtained elsewhere. Should be actionable by health region or partners | Should be linkable to other administrative data. Should be able to estimate non-response bias. | Questions and implementation process must be standardized for comparability across organizations. |
| **Research** (system-level knowledge and action) | Should not include questions where data can be obtained elsewhere. | Should be linkable to other administrative data. Should be able to estimate non-response bias. | Questions and implementation process must be standardized for comparability across organizations. |

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**Using data for point-of-care:**

*"So, for example if a person, if their gender on their OHIP card was male but they identified as female we wouldn't… they would never have an opportunity to say that until this time, right. Or if they felt they had a mental illness or a disability that wasn't listed in the record, they might not have ever said that, right, kind of thing. So the hope was that a) physicians would then - physicians and other providers would then be able to provide more patient-centred care." (provider)*

*"It's a… yeah because my family doctor I think she's the one who can…who can really know my health, yeah so it's better… it's better to know everything about me." (patient)*

**Using data for quality improvement and program planning:**

*"I think everyone, you know in order to deliver services everyone says 'Oh our patients are different, our clients are different, they have different needs, they are all unique.' But we really didn't know. We knew anecdotally you know that our patients might be from different backgrounds, requiring different levels of service, maybe more culturally, more sensitive services. But you know until you actually have that good data, you really don't know. You are guessing. So we really wanted to better understand who our patients were in order to better deliver our services and care." (leadership)*

*"So there is some rich personal information in there for patients that physicians and others can use to improve care. I think that they can learn as well what they need to improve on. So I think the opportunities are there for... for individual practice, as well as the site clinic practice." (leadership)*

*"I would assume that you're using it to determine the need for various cases of health information in different languages, what the demand is you know for different things, probably just to get a sense of you know, the demographic makeup of the you're population base or the patient base" (patient)*

*"So, well if it increases the possibilities so say you have a very large population of one ethnicity, one particular language or sexual orientation, there is opportunity to provide more specialized services. Then I think that's a great opportunity. Like if a certain area that demands a certain focus then that's a nice thing to know and if that then be provided to those people in that area, then that's great" (patient)*

*"we've been planning on using this data in evaluation of risk factors for breastfeeding practice within our family health team. So looking at demographics of women who are and are not, so we previously did this as a chart review looking at the PSS data, but looking at the Health Equity Survey data it allows us to mine this information a little bit better or more efficiently actually." (provider)*

**Using data for regional health system planning:**

*"This is a growing area of interest, there isn't a lot of data currently available and so I think it could help at a systems level, sort of speaking with the interest of the Toronto Central LHIN, just to look at how's the health system is performing in relation to health equity."*
*(leadership)*

*"It would be good to also collect information and then on a system's level better understand for the various populations that are hard to reach, how to better reach them"* *(provider)*

*"I guess my main thing out of this is just making sure that we use the data in a relevant way. That really does – especially at a systems level, so not only individually but at a system's level where we can use it appropriately to advocate for broader services within the system to help our patients."* *(provider)*

*"I guess the only thing would be to kind of compare hospitals to see if you know, if this data helps, if what kind of... what types of population are you servicing, just in general to see... to see how you guys could improve."* *(patient)*

*"We could advocate to the LHIN or the ministry or partner with organizations to meet those needs, so that's like at kind of a higher, system's level, to advocate more effectively for our patients if we knew we needed certain translation, or Saturday or evening clinics. Like whatever it was, knowing the needs at a more complete and comprehensive way would help us to advocate for services."* *(provider)*

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**Using data for research:**

*"Well for example if you find, let's say just let's go back to Latin American, if there is a large proportion of Latin Americans who are prone to have diabetes or cancer and all that, maybe those doctors would opt to do studies, can concentrate and study why is this? Why are these Latin Americans having pancreatic cancer? Or liver cancer, no? It can help studies but if they don't have the information, how can they do the studies, right?"* *(patient)*

*"I'll give you an example with our cancer screening. We are looking at income quintile and cancer screening and we looked at the fact that there was definitely differences that people, again, who are better educated and higher incomes had better screening, so again what do WE need to do? Like it's not our patients' fault. It's up to us then to target, you know, they deserve, in my mind, everyone deserves the same care"* *(leadership)*

**Recommendation 2. At an early stage, institutions involved in collecting robust sociodemographic data should identify how to use the data to improve care, and should develop plans to share lessons learned with others.**

Health institutions should be aware that collecting such data from patients implies the data will be used. If patients and communities do not see that the data are used, this could lead to a loss of trust in data collection and negatively impact on response rates in the future. If the purpose of data collection includes point-of-care, health providers must be trained on how to respond to social needs that are identified. Patients generally assumed, by the nature of their responses, that the data would be used by providers at the point-of-care. In some cases, completing the questions elicited psychological distress for patients as they recalled difficult experiences in their past (see section below on question about sexual orientation). Training should include how to respond to patient distress as needed.

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**Patient and provider views on the importance of using data collected:**

*"We were talking about what the different hospitals are doing to address health equity … someone at another institution said, 'Yeah, we're addressing health equity also. We did the Health Equity Survey.' Uh, period. Like that was the approach to health equity…that file is closed."* (provider)

*"Perhaps by answering some of these questions, saying that 'Oh I speak Hungarian' and then an expectation like 'Oh, because I answered this then there may be resources that come to me in this language.' So setting up those expectations: I'm contributing this so I should get something in return. But that might not be feasible."* (provider)

On answering the question about <u>spoken language</u>: *"I guess I felt most likely there wouldn't be a doctor who would speak Punjabi here anyway, so it was just like English was like the default thing to do."* (patient)

On answering the question about <u>religion</u>: *"I mean, for me, I'm vegetarian and my vegetarian practice is linked with my religion, but then I just wonder whether it would be more appropriate to have some more direct questions that would be more helpful for the healthcare provider."* (patient)

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**Recommendation 3. As with any personal health information, the data collected is subject to PHIPA and other privacy legislation. Health organizations should indicate to patients the steps taken to keep their data secure and under what circumstances it will be used.**

All health providers and organizations are subject to PHIPA and other privacy legislation, and hence are obligated to store and manage all data from patients in an appropriate manner. Health institutions must decide on where the data will be stored and how it will be managed, in consultation with institutional privacy officers. The approach to data storage and management likely differs by institution. Institutions should verify that data storage processes are operationalized appropriately. As with other personal health information, data that is collected may be shared within the "circle of care" as appropriate.

> *"Someone who comes to Toronto for care, may feel very comfortable telling a Toronto doctor about whether or not they're gay, but then they might not feel so comfortable with their Thunder Bay doctor, but the Thunder Bay doctor now has access to the full medical record. So that's where there's, might be a potential for discrimination, or vice versa, so they might be more comfortable telling the Thunder Bay doctor but not the Toronto doctor for whatever reason."* (leadership)

**Recommendation 4. Institutions should inform patients about ways to report any concerns about discrimination that could arise based on answers to the HEQ.**

Patients interviewed reflected concerns that some people could be discriminated against based on their responses to the HEQ. Institutions should consider this serious concern and mitigate any harms by clearly identifying to patients the steps that they should take if they feel they have been discriminated against.

> *"I think it is probably true that some people may be discriminated against because of the information that is collected. Because of conscious or unconscious biases related to things like ethnicity, income, religion. So I think that THAT patient was actually right to worry about being discriminated against and there's a reason that people are reluctant to provide that information."* (*provider*)

**Recommendation 5. In its current form, the HEQ collection tool is missing key domains that could improve its utility, particularly for point-of-care use. There should be a clear process to develop additional questions and evaluate their impact, at an institutional and system level.**

A number of additional domains were identified through this study, particularly when considering using the tool at point-of-care to identify social needs (e.g. ability to afford medications, social isolation, access to a telephone or the internet, access to childcare, access to transit, educational attainment, employment status, food security).[12–14] Existing questions, as well as new questions, should undergo further validation (i.e. compare answers provided to other sources of data) and further cognitive testing after question purpose(s) are defined and before a new version is released for on-going data collection. Further cognitive testing samples should account for the location of data collection (e.g. primary care, emergency), the location of the health institution (e.g. rural, small communities), and variability in terms of all demographic questions included in the questions. Special consideration should be given to language if instrument is translated. Usability testing should also be done for all modes of data collection (e.g. tablets, paper).

## Implementation

**Recommendation 6. A number of best practices for collecting the HEQ have been developed by staff at Sinai Health System. Health institutions should use these to reduce non-response bias. Staff training should convey that the questions should be offered to all eligible patients. Non-response bias should be measured and addressed, within each institution separately and also across institutions.**

In our setting, more than 90% of patients who were offered the opportunity to answer the HEQ completed at least one HEQ. However, only about one-third of patients who visited the practice were offered the survey. We examined which patient characteristics were associated with completion of at least one HEQ. We found that patients with more visits to the clinic were more likely to complete at least one HEQ (Table 3). Even after adjusting for the number of visits, some patients appear to be less likely to complete the HEQ (Table 3). The very young and the very old (80+) were much less likely, males were less likely, and those who did not have certain chronic diseases (HIV, diabetes, developmental delay or mental illness) were less likely. Health institutions should implement minimum data collection quality assurance processes (e.g. observations of how the questions are offered, examination of why some patients are not offered the questions). There should be a focus on monitoring missing data and "Prefer not to answer".

*"but... even if it's only a half or 40%, there is a lot of patients who are missing and the question is: are we missing the patients who we're most concerned about?" (leadership)*

*"just from my experience and my practice, I saw this in many more of my... you know, as I said University educated or college educated, higher functioning patients." (leadership)*

*"I would caution us around you know utilizing this data as 'end all be all' for sure, knowing that it's not really capturing our full, it's not giving us a full picture. So until we are able to address those equity issues, we should really approach the data with caution because in a certain form it may not be clean, like it would be difficult to clean it." (leadership)*

*"there's some selection bias in who fills it out and who doesn't [noted agreement in focus group]. So we're not finding socio-economic gradients in screening in those who fill it out, and we ARE in our whole practice. So there are some limitations because not everybody has filled it out, and maybe the more motivated or the more literate or the more English-speaking have, so there are some barriers for using it for program planning." (provider)*

*"If only the literate, English-speaking, healthier, wealthier, more health engaged people are the ones filling it out, we're going to say 'oh we have these characteristics in our department that aren't so bad. We don't have a lot of this kind of problem or that kind of problem by virtue of who is filling it out.' We may quite dramatically underestimate the nature of the problems." (provider)*

**Table 3. Association between patient characteristics and completion of at least one Health Equity Question**

| | Unadjusted (Odds Ratio, 95% CI) | Adjusted for number of visits only (Odds Ratio, 95% CI) | Adjusted for age, gender, clinic attended and number of visits (Odds Ratio, 95% CI) |
|---|---|---|---|
| **Gender (reference: female)** | | | |
| Male | **0.80 (0.77, 0.84)** | **0.83 (0.80, 0.87)** | **0.87 (0.83, 0.91)** |
| Transgender | **1.78 (1.44, 2.20)** | **1.60 (1.29, 1.99)** | 1.08 (0.87, 1.36) |
| **Age (reference: 50-64 yrs.)** | | | |
| 0-5 yrs. | **0.08 (0.07, 0.09)** | **0.08 (0.07, 0.10)** | **0.08 (0.07, 0.10)** |
| 6-18 yrs. | **0.08 (0.07, 0.10)** | **0.11 (0.10, 0.13)** | **0.12 (0.11, 0.15)** |
| 19-49 yrs. | 1.04 (0.99, 1.09) | **1.17 (1.11, 1.23)** | **1.23 (1.16, 1.30)** |
| 65-79 yrs. | **0.90 (0.84, 0.97)** | **0.82 (0.76, 0.88)** | **0.79 (0.73, 0.85)** |
| 80+ yrs. | **0.52 (0.46, 0.59)** | **0.44 (0.39, 0.50)** | **0.40 (0.36, 0.46)** |
| **Income quintile (reference: Q5)** | | | -- |
| Q1 | **0.90 (0.85, 0.96)** | **0.86 (0.81, 0.91)** | -- |
| Q2 | 1.02 (0.95, 1.10) | 1.00 (0.93, 1.07) | -- |
| Q3 | **0.90 (0.84, 0.97)** | **0.87 (0.81, 0.94)** | -- |
| Q4 | 1.01 (0.94, 1.09) | 0.99 (0.92, 1.06) | -- |
| **One or more of HIV, DM, mental illness, developmental disability (reference: none)** | **1.68 (1.61, 1.75)** | **1.35 (1.29, 1.41)** | -- |
| **Number of visits (reference: 2-4)** | | ----- | |
| 1 | **0.58 (0.54, 0.63)** | ----- | **0.54 (0.50, 0.58)** |
| 5-9 | **1.60 (1.52, 1.68)** | ----- | **1.72 (1.62, 1.82)** |
| 10+ | **2.55 (2.42, 2.69)** | ----- | **2.94(2.77, 3.12)** |

**Recommendation 7. Using training materials developed by staff at Sinai Health system, health institutions should orient all staff – including leadership, management, administrative and clinical staff – to the purpose of robust sociodemographic data collection. For new staff, this should be included in staff orientation. Refresher training should be provided every 6-12 months.**

Training should include strategies that staff can use to offer the questions to all eligible patients particularly those at risk of not being offered (e.g. older patients, parents on behalf of their children, patients who do not speak English, patients with cognitive health issues). Best practices related to offering the questions in non-English languages should be shared across the region and a common approach developed. All staff should receive training on the concept of health equity, the role of data and on related aspects of providing cultural safe, anti-oppressive care to patients.

> *"I was actually on maternity leave when it was implemented so when I came back it was...Truthfully it was "every patient that comes in needs to fill one of these out. You need to give it to them and you need to make sure that they fill it out". I'm like "OK" and they sort of explained to me what the questions were but not...there was not really giving an understanding of why this was happening, and so it's sort, it's up to you to sort of dig and find out if you choose to, but..." (clerical)*

**Recommendation 8. Following best practices developed by staff at Sinai Health system, each health institution should establish a central point of coordination at each organization, responsible for both <u>data collection</u> and <u>analysis</u>. This person or small team would be the main point of contact for the organization and the TC LHIN and other stakeholders.**

Patients, health providers, organization leaders and health authorities, such as the TC LHIN, will find it helpful to know who is responsible for both the collection of data and its analysis. Standards for the analysis and reporting on this data – including a standard approach to combining categories, or adjusting for non-response bias (e.g. weighting) – need to be developed.

> *"I think that we rely on our researchers of the department to clean it up, identify where the gaps are and help to lead us in terms of how to make things better. So that we can actually get to the point where we can actually use the data to make informed decision making." (leadership)*

What language would you feel most comfortable speaking in with your healthcare provider? Choose **ONE**.

| Choose one | Greek | Punjabi | Vietnamese |
|---|---|---|---|
| English | Hebrew | Russian | Other |
| Amharic | Hindi | Serbian | Prefer not to answer |
| Arabic | Hungarian | Slovak | Do not know |
| ASL | Inuktitut | Somali | Prefer not to answer |
| Bengali | Italian | Spanish | Do not know |
| Chinese (Cantonese) | Karen | Tagalog | |
| Chinese (Mandarin) | Korean | Tamil | |
| Cree | Nepali | Tigrinya | |
| Czech | Ojibwe | Turkish | |
| Dari | Oji-Cree | Twi | |
| Farsi | Polish | Ukrainian | |
| French | Portuguese | Urdu | |

**Recommendation 9: Reword the question about <u>spoken language</u> to reflect the intended purpose and clarify this purpose for patients when asking the question. For example, it would be helpful to clarify for patients whether their response will be used by their health care provider to determine what language should be used to deliver health care services (i.e. pragmatic interpretation) or whether the purpose is to understand the sociodemographic diversity among the population for health planning.**

We found that this question had a very high completion rate (99%). The vast majority of respondents in our setting (92%) answered "English". In our setting, the question was the first on the survey and the survey was only offered in English. Interviews with patients suggest that patients interpreted the term "most comfortable" as encompassing their ability and ease in speaking the language, understanding when others spoke, and what language they preferred to speak with their health care provider. Preference for a language seemed to be influenced by the perceived feasibility of being able to communicate with their health care provider in the language. Patients considered, for example, whether there was a provider in the clinic who spoke their language or whether the language they spoke at home was reflected in the response choices.

Some patients commented positively on the breadth of responses to the language questions. Others remarked that they could not find their native language in the list of responses. Clerical staff commented that patients would approach them because their language of choice was not reflected in the list of responses. Providers commented that knowing the language was helpful because it could trigger them to use the language line during an encounter. Leadership reflected on why English was the most common language and wondered if patients selected it for pragmatic reasons.

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**Patients who speak a non-English language explaining their rationale for selecting English as their spoken language**

*"I guess I felt most likely there wouldn't be a doctor who would speak Punjabi here anyway, so it was just like English was like the default thing to do." (patient)*

*"Because if the person doesn't have a good grasp of the language and tries to speak in Spanish to explain something to me, I might not understand, even though Spanish is my language." (patient)*

*"My first language back home it's not here, ... I pick English because that's the language I can speak here ... I'm not comfortable with English because I'm not perfect and some grammar, like I'm not perfect but I can, I can talk and I can listen." (patient)*

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**Patient and provider quotes conveying the benefits of the language question**

*"I think you know the questions that were in there were very appropriate to a place like Toronto because there are lots of languages. Language seems to be a big component of the questions, you know. In terms of 'are you receiving the information the way you understand' that's really important and it's hard to do because you know we have such a diversity of languages and cultures in Toronto that it's hard to produce one brochure in 150 languages. So you know I think it's a very useful survey given the context of the city of Toronto." (patient)*

*"Whether someone comes from India or from Scarborough it doesn't really matter to me you know because we're Canadian; and that's what I see. So I think for me, that's most important, the ethnicity. I think in terms of language, that's a totally different thing; that's a communication thing. But unless there is a specific reason to know someone's ethnicity for a very specific reason, it shouldn't be a consideration, you know." (patient)*

*"So then you can either utilize the services of Language Line to make them more comfortable speaking a different language other than English – make sure they understand or are able to express themselves and then are able to understand the recommendations as well." (provider)*

---

> Were you born in Canada?
>
> ☐ Yes
>
> ☐ No
>
> ☐ Prefer not to answer
>
> ☐ Do not know
>
> If no, what year did you arrive in Canada?  _____

**Recommendation 10: Retain the questions related to <u>immigration status</u>, but consider changing response options to be fixed year categories (e.g. 1980-1985) along with the year when the data is collected to minimize errors associated with free-text entry.**

In our setting, this was the second question asked and approximately 96% of patients provided a complete response. However, of the patients who said they were not born in Canada (41%), only 81% provided the year of arrival. In our setting, patients entered their year of arrival using free-text and some of the responses were nonsensical (so were not included as a complete response) Patients did not express any difficulty or discomfort with this question. [Please note that our interviewers did not probe to understand how patients retrieved information to answer the question and the potential accuracy of the year that the respondent selected.] Providers mentioned that the answer to this question would remain the same over time so unlike a question about income, this question would not need to be repeated in future data collection efforts.

| Which of the following best describes your racial or ethnic group?  Choose **ONE**. |
| :--- |
| ☐ 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. American, Canadian) |
| ☐ Mixed Heritage (e.g. Black – African and White-North American) |
| ☐ Other (s) |
| ☐ Prefer not to answer |
| ☐ Do not know |

**Recommendation 11: Regarding the question on <u>race/ethnicity</u>:**
**a. Develop a guide on how organizations can aggregate responses to the question related to race/ethnic group. Response options should strike a balance between the need for people to find themselves but also allow options to be aggregated.**
**b. Clarify the purpose of the race/ethnicity question and modify the question and/or instructions accordingly. For example, are institutions interested in self-identity, country of origin, parents' country of origin, or place of birth?**
**c. The TC LHIN should complete the development of a data sharing agreement, in consultation with the Toronto Indigenous Health Advisory Circle and other stakeholders.**

The large number of response options make it difficult to analyze the data to identify trends and health inequities. Organizations likely need to roll-up response categories to allow sufficient numbers in various groups to enable comparisons. However, it is unclear which categories could be combined in analyses. Response options should strike a balance between the need for people

to find themselves but also allow options to be aggregated. Specific suggestions include changing the question to state "check all that apply", removing the mixed heritage option, not using "e.g." and including open-text after "other". Our advisory committee and roundtable participants reminded us that this question should be aligned with national initiatives underway in this area.

Patients made different assumptions as to what the question was asking about. The majority of patients thought that the question was interested in their heritage or ancestry. Some patients thought that the question was asking about what culture they identify with. Others felt the question related to the country where they were born and/or raised. Some patients thought the question related primarily to the colour of their skin.

Many patients found the question difficult to answer or confusing. Many patients whose parents had immigrated to Canada from elsewhere were confused about how to respond (e.g. whether their response should reflect one or both of their parents' birth country or how they identify currently). Some patients did not understand the meaning of "e.g." used in the response option; they thought that the response was limited to the countries specified after "e.g.". Some patients did not see the mixed heritage option.

Some patients and providers commented on the potential benefits of the question. Other patients were uncomfortable with the question because they felt it was asking about their skin colour and others questioned why it needed to be asked.

This question generates data on Indigenous peoples and communities including persons who identify as "First Nations", "Inuit", Metis" and "Indigenous/Aboriginal not included elsewhere". If the data will be included in a research study or distributed publicly, the researchers must follow the Tri-Council Policy on Research Involving the First Nations, Inuit and Métis Peoples of Canada. Relevant data sharing agreements have not been developed which means currently the data specific to Indigenous peoples and communities cannot be used.

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**Patients express confusion about the purpose of the question and difficulty answering it:**

*"My parents are from India but we lived most of our lives in Hong Kong before I moved to Canada… it's confusing if it's asking about racial group or ethnic group like. Because I think ethnic group is like very specific to like language and like the food whereas, racial group tends to have, is more focused on the color of the skin. So it's like grouping a lot of different things. But then in the actual answers its listing up countries and continents." (patient)*

*"I didn't really know exactly if they wanted where I was born or like what my background was." (patient)*

*"My father was English and my mother was Ukrainian. I am white you know, Caucasian but you know they were European. Then I saw the next 'English' category that said 'Canadian-North American' which is what I am you know — I've come from that — but you know I am born and bred in Canada. So that was just a little bit confusing. It's like "what kinda white person am I?" (patient)*

> *"Well it says chose one, and my mom's family is from Britain like my grandparents are from Northern Ireland and England but dad he's part native and his real father is Scottish. And I was like, okay well you know like I'm not fully European but like I'm not Native enough that I would like just check off that one"* (patient)

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**Some patients do not see their own race/ethnicity included in the responses:**

*"I'm mixed-race but I'm Caribbean mixed-race (…) I'm mixed heritage I guess, but see you have 'Black-African and White-North American', so there are other mixed heritages that are not included in this group that are common (…) I just put 'other'."* (patient)

*"There is white but it's European and says white North American which I'm not. American means U.S, right. So I'm neither of them, although I consider myself white because my background is Italian and Spanish. My grandparents and before that they came from Europe, so I could be White Latin American but here they just have it like that."* (patient)

*"I didn't find my country (…) I wrote other. (…) I'm black African but not Ghana and Kenya, Somalia, I'm not from there."* (patient)

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**Patients and providers discuss how the race/ethnicity data could be used:**

*"Yeah, I mean basically is asking, 'what your skin colour is and where you are from'. So [very long pause] and like I think in terms of like health equity like it's helpful to know that because like sometimes we face a lot of discrimination…"* (patient)

*"I find that, sorry, with language, so if there is sort of a cultural or language barrier or a cultural… sort of specificity, some of our dieticians can speak certain languages or have a cultural background that may work with a patient, in terms of diet and counseling advice. So I would refer to one instead versus another one to maintain that, in order to provide that background and cultural context for a patient."* (provider)

*"From the ethnic group and the gender group, it allows me to try to like stratify, in terms of medicine. So the transgender group, the different needs in terms of screening tools you utilize, as well as your ethnicities, helps you assess, in terms of what medical illnesses they are at risk for."* (provider)

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**Some patients express discomfort with the question:**

*"I think it's trying to be polite, but it's not polite. (…) I mean basically is asking, 'what your skin colour is and where you are from'."* (patient)

*"I don't know why that question was there. I think that the fact that I am white or you know and you're of a different ethnicity, I don't think it makes a big difference, certainly doesn't to me. And you know I think unless there is a medical reason to determine someone's colour I think – I'm not sure how necessary that is…. I think if you are gonna to ask it, there should be a specific reason and you know…that should be explained..."* (patient)

> Do you have any of the following? (Circle **ALL** that apply)
>
> | None | | Chronic illness | | Developmental Disability | | Learning disability |
>
> | Mental illness | | Physical disability | | Sensory disability (i.e. hearing or vision loss) |
>
> | Drug or alcohol dependence | | Other | | Prefer not to answer | | Do not know |

**Recommendation 12: Clarify the purpose of asking the question related to <u>disability</u> and whether it relates to *perception* of disability or *identifying diagnoses* or whether it should be repurposed to focus on *disability accommodation*. Consider that other data sources, such as the medical chart, may provide more accurate information on patient diagnoses.**

There was a significant lack of concurrence between data on disabilities found in the electronic medical record and the answers provided by patients. In general, it appears that patients chose not to disclose disabilities. Of those who had a mental health-related visit, 74% did not report that they had a mental illness on the survey. Of those who did not have a mental health-related visit during the study period 6% reported that they had a mental illness on the survey. Of those who had a visit for psychotic disorders, 32% did not report that they had a mental illness on the survey. Of those who did not have a visit for psychotic disorders, 10% reported that they had a mental illness on the survey. Of those who had a visit for substance use disorders, 58% did not report that they had drug or alcohol dependence issues on the survey. Of those who did not have a visit for substance use disorders, 2% reported that they had drug or alcohol dependence issues on the survey. Of those with Diabetes or HIV, 55% reported that they did not have a chronic illness on the survey. Of those without Diabetes or HIV, 10% reported that they had a chronic illness on the survey.

Patients interviewed identified concerns with this question, including that it stood out as only one about health. While the list of options appeared comprehensive, some patients expressed difficulty understanding what should be included under each response option and figuring out where a condition fit or if it was considered a disability (e.g. physical disability vs. chronic illness) and in some cases resulted in participants not checking an option or leaving the question blank.

Members of the advisory committee and roundtable suggested that clarifying the purpose of the survey may be of particular importance if patients are being assessed by other organizations (e.g. MCSS, WSIB or private insurance) to see if they have a disability. Some stakeholders suggested this question could be repurposed to focus on accessibility for patients who have a disability or disabilities, and could include a follow-up question if a patient reports a disability e.g. "Did you receive the services you needed/were your needs met? Do you require assistance to do …"? (i.e. accommodation)"

> **Patients express difficulty with classifying their health concerns as disabilities:**
>
> *"...I have macular degeneration so like I am not driving, you know what I mean? So I wasn't sure whether you'd consider that a disability because I am not blind. But I don't know, like I guess it is a disability...but you know I just thought when you say 'disability' you think it's a more serious problem than I have."* (patient)
>
> *"Yes, one was a physical disability because I have tendonitis and bursitis which is chronic in the right shoulder and so to me it's presenting to be a physical disability. It's a challenge. So I don't know whether or not it can translate into what the medical profession considers a physical disability."* (patient)

> **Drug or alcohol dependence and mental illness:**
>
> *"...about the dependence thing, I don't know how to define that.*
> *Like I'm not a drug addict like selling things I own to buy drugs and stuff. I'm a drug user...so I wasn't sure what to put. I had no idea."* (patient)
>
> *"...I mean the drug or alcohol dependence was a tough one to...it's hard to know if you're dependent on something. You know, if you can consume a drug, most days, is that a dependence? I didn't circle it..."* (patient)
>
> *"...I knew exactly where I fit. I just didn't want to. That's part of it as well, is when you see it in writing. It's REALLY difficult to circle it...there's that stigma. It's me, confessing to me, that my brain is like that."* (patient)
>
> *"I'm still figuring it — figuring out my own disability and my mental health — like things have been unstable so like it was hard for me to figure out what really is happening for me. And then some of it says disabilities, some of it says illness, and like I feel hesitant with chronic illness and mental illness...because I don't know what it is and [pause] yeah, and like I don't want to be like labeled with it like for the rest of my life. If it's temporary or like, yeah."* (patient)

> What is your gender?  (Circle **ALL** that apply)
>
> Female   Male   Trans – Female to Male   Trans – Male to Female
>
> Intersex   Prefer not to answer   Do not know   Other

**Recommendation 13: Consider explaining and updating terms used in the question on gender, including clarifying that this question is asking about gender identity. As the**

**language to describe gender identity is evolving, there should be a process to adapt or update options, and could include a broad option of gender queer or gender non-binary.**

There was an appreciation for its inclusivity and that there were a number of choices provided. The terms used in this question were unclear for a number of patients interviewed. Although patients may not recognize or understand all of the terms, there was a sense that this led to learning about something new and sparked curiosity.

Of those whose gender was listed as female in their chart (which was based on their OHIP card data stored in the ADT system), 99.5% reported their gender as female in the survey. Similarly, of those whose gender was listed as male in their chart, 98.6% reported their gender as male in the survey. In contrast, of those whose chart had a medical diagnosis of gender dysphoria, only 57.1% reported their gender as transgender in the survey.

The advisory committee and roundtable participants raised a number of specific recommendations to consider. For example, stakeholders recommended including a short explanation of what gender means and also providing definitions for response options (e.g. definition appears when patient hovers over option or as glossary). Regarding the options "trans – female to male" and "trans – male to female", consider making the response options more specific (e.g. gender assigned at birth and current gender identity). Given that the language to describe gender identity is evolving, there should be a process to adapt or update options. Include two-spirited as a response as it relates to both gender identity and sexual orientation. An open ended option was available in other HES sites but not at SMH and should be included in future versions of the survey. Further research is required to explore how transgender individuals respond to this question. Of note, gender identify may change over time for an individual patient. Ethical and privacy considerations should be explored relating to having parents respond to this question on their children's behalf.

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**Patient views of gender identity question:**

*"it's super great that it's[the HES questionnaire], it's very inclusive in that people are like acknowledging that trans people exist. Like not just people who have medically transitioned or any of that. That's pretty cool, it's pretty cool." (patient)*

*"So like for me like it's, there are multiple things happening but then I also wasn't sure like, I didn't want to make myself vulnerable and write 'trans' and I wasn't sure – and I realized after I had put trans that within a medical setting it tends to see trans identity as a, as a very medical phenomena. In terms of the physical attributes of like and the sexual reproduction aspects and that's not like really my kind of association with terms. So then I considered 'other' but, ya. I didn't really fully figure that out. And it was a difficult conversation to have with my doctor and I think my doctor looked at it and then my doctor got confused. It was very uncomfortable, I felt like if the questionnaire had gotten like had some more options open, that I would feel more comfortable with, then the doctor would understand me a bit more." (patient)*

What is your sexual orientation?  Choose **ONE**.

- ☐ Heterosexual ("Straight", male/female relationships)
- ☐ Gay
- ☐ Lesbian
- ☐ Bisexual
- ☐ Two-Spirit
- ☐ Queer
- ☐ Prefer not to answer
- ☐ Do not know
- ☐ Other

**Recommendation 14: Consider explaining and updating terms used in the question on <u>sexual orientation</u>. As the language to describe sexual orientation is evolving, there should be a process to adapt or update options.**

Overall, patients were very positive about this question as they felt asking the question helped create a more inclusive space. Anecdotal reports were received that some patients were not familiar with the term "heterosexual", and hence the explanation "straight" and "male/female relationships" was added at SMHAFHT. Several patients were unclear about the term "two-spirit". Some patients described how psychologically difficult it was to answer the question given discriminatory attitudes they faced in the past.

> **Patient views of question on sexual orientation:**
>
> *"I'm trying to break free from what I've dealt with my whole life from my family, because of the stipulations and you know, the generations back on the persecution of gays, and that whole history… It's had me hide part of myself my whole life. And so it was difficult just for me personally to answer it, but I you know, I made it through it; and answered it as honestly I could. But still difficult, just because of what I've gone through and what I've had to hide in a sense. And not been able to speak about it, you know?"* (patient)
>
> *"I am gay and I also come from a time when you know gay people used to get beat up quite routinely. And you know we weren't allowed to come out and caused a lot of angst when I was a young man and you know that kinda thing. If we can do anything to avoid kids going through those things you know that we had to go through, I'm all for it, you know, and I don't care how they identify that's up to them. But they have to be comfortable themselves and to be able to express themselves. So yeah give them as many options as they can and make sure that you know, that they are comfortable enough to say 'This is how I identify' whatever it is."* (patient)

What was your total family income before taxes last year? Choose **ONE**.

- [ ] $0 to $29,999
- [ ] $30,000 to $59,999
- [ ] $60,000 to $89,999
- [ ] $90,000 to $119,999
- [ ] $120,000 to $149,999
- [ ] $150,000 or more
- [ ] Prefer not to answer
- [ ] Do not know

How many people does your income support? Choose **ONE**.

- [ ] 0
- [ ] 1
- [ ] 2
- [ ] 3
- [ ] 4
- [ ] 5
- [ ] 6
- [ ] 7
- [ ] 8
- [ ] 9
- [ ] 10+
- [ ] Prefer not to answer
- [ ] Do not know

**Recommendation 15: Further work is necessary to understand how to address patient concerns and discomfort with the question related to income, and how to format this question to make it easier to analyze (e.g. to identify low-income individuals or income gradients). The question "How many people does this support?" should be modified. Consider changing this question to one designed to be useful at the point-of-care.**

In our setting, this question had a response rate of 77%, the lowest of any Health Equity Question. Many patients entered "0" in response to "How many people does this income support?" which suggests that question was interpreted differently by different respondents. It was difficult to know how to analyze the two questions to estimate which respondents were living in poverty. We used a method our team developed previously[10], categorizing patients as above or below the Low-Income Cut-Off (LICO). However, this approach is approximate and has not been validated.

In our analysis of medical record data, we found that those who reported income below the LICO, 44.2% were living in the lowest neighbourhood income quintile. Of those who reported income above the poverty line, 21.5% were living in the lowest neighbourhood income quintile. If we assume that patient-reported income is relatively accurate, these findings suggest that neighbourhood income quintile is a poor proxy for individual income in Toronto. Specifically, more than half of the individuals who reported living below the poverty line did not reside in the lowest neighbourhood income quintile.

Our interview findings suggest that patients experienced the greatest discomfort with answering this question. Clerical staff noted that some patients stopped answering the questions at this point. Some patients reported that their income after taxes would have been more accurate. Roundtable participants also agreed that after tax income likely better reflects disposable income. Patients noted that changes in income – unemployment, change in marital status, benefits – can alter their income year-to-year, i.e. reporting last year's income before taxes would not be useful today. Patients also noted the differences in tenses between the two parts of the question. Patients

asked how this data is useful to their provider, some expressed discomfort elicited by the question, and some conveyed the fear that this would be used to discriminate against them.

Advisory group members and roundtable participants suggested modifying the question "how many people does this support?" Some reflected that patients living on low incomes often do not feel "supported". In addition, not all patients may interpret "support" as including not only household members, but others (e.g. family members abroad). Participants discussed that it might be less threatening and more useful for providers and organizations to have an income-related question designed for use at the point-of-care. An example of a potential point-of-care question is, "Do you have difficulty making ends meet at the end of the month?" or "Do you have difficulty affording medications?"[15]

> **Patient perspectives on question about income:**
>
> *"The only thing that would be different would be that income question, so I don't know how relevant that is to, for a doctor to know, but the rest of the information's OK, I'm just a little unsure about the income question." (patient)*
>
> *"… I am flat broke; my husband is the sole income earner. My income is covering not even me, I don't have an income. So it was a bit uncomfortable… difficult to answer." (patient)*
>
> *"I had a really strange year last year where I got laid off and I got a year's severance pay. So because I was laid off because of my inabilities to work because of my mental health. So they gave me a really good package and so I felt like if I said like over 100,000 dollars it would be very misleading as...especially since now my doctors are helping me with trying to secure ODSP. So it's like that would be bizarre... I didn't make 100,000 a year but I made like 30,000 or 40,000 dollars last year and then got like a 57,000 dollar payout so it all totals to like 100." (patient)*
>
> *"... my fear is that maybe I would lose some services or that it would affect my quality of care in one way or another... that my salary is too low or too high, regardless my income... sometimes I also don't have a job, right? So that changes and that's not necessarily... like that's not an option in here...my concern is always like it's going to have some kind of negative repercussion for me that I can't necessarily anticipate." (patient)*

## Optional questions

| In what language would you prefer to read healthcare information? Choose **ONE**. | | | |
|---|---|---|---|
| English | Hindi | Slovak | Do not know |
| Amharic | Hungarian | Somali | |
| Arabic | Inuktitut | Spanish | |
| Bengali | Italian | Serbian | |
| Braille | Karen | Tagalog | |
| Chinese (Simplified) | Korean | Tamil | |
| Chinese (Traditional) | Nepali | Tigrinya | |
| Cree | Ojibwe | Turkish | |
| Czech | Oji-Cree | Twi | |
| Dari | Polish | Ukrainian | |
| Farsi | Portuguese | Urdu | |
| French | Punjabi | Vietnamese | |
| Greek | Russian | Other | |
| Hebrew | Serbian | Prefer not to answer | |

**Recommendation 16: Consider moving the question on <u>language preferred for written information</u> directly after the question related to spoken language and potentially highlighting with formatting the difference between the two questions.**

The vast majority of respondents in our setting (89%) answered "English". In our setting, the survey was only offered in English.

Some patients selected a different response for speaking and reading, for example preferring to speak to their health provider in English but wanting written information in a different language. Some patients explained that their ability to speak and read are different. Patients also mentioned that when speaking English as a non-native speaker, they have the advantage of being able to use gestures or can have the help of informal interpreters. Some patients thought that the two language questions were the same and were confused why it was repeated and why the second question was at the end of the survey.

**Patients explaining why they chose a different language for speaking with their health care provider versus reading health care information:**

*"I think reading is most difficult just like no explanation, just you have to read exactly what you read and it's gonna be like everything. So then I comfortable with my first language. So that's why I put the 'other'"* (patient)

*"A lot of friend of mine who are children of immigrants for example who speak the language but they don't read it. You know or they read the language and they can barely speak it. So you know there's various levels of competency may vary."* (patient)

What is your religious or spiritual affiliation?  Check **ONE** only.

☐ I do not have an religious or spiritual affiliation

☐ Christian Orthodox

☐ Protestant

☐ Roman Catholic

☐ Christian, not included elsewhere on this list

☐ Animism or Shamanism

☐ Atheism

☐ Baha'i Faith

☐ Buddhism

☐ Confucianism

☐ Hinduism

☐ Islam

☐ Jainism

☐ Jehovah's Witness

☐ Judaism

☐ Native Spirituality

☐ Pagan

☐ Rastafarianism

☐ Sikhism

☐ Spiritualism

☐ Unitarianism

☐ Zoroastrianism

☐ Other

☐ Prefer not to answer

☐ Do not know

**Recommendation 17: Clarify the purpose of the question on religion (e.g. identifying practicing religion versus religious affiliation). For example, if used to identify dietary preferences, a question on religious or spiritual affiliation is not an adequate proxy. Finally, consider including Agnostic as a response option.**

Patients were unclear about the intent of the question. Some were not sure if they should check off a religion if they were not practicing that religion. Some were not sure if they should select the religion they were raised with OR the one they currently follow. Some patients would like to have the option to select more than one religion. Patients also mentioned that response options were missing.

> *"So I put my non-practicing religious affiliation in terms of like what I was… what my family… you know like getting baptized as a Lutheran and confirmation, but none of that matters to me really. I mean, what I practice is Buddhism more than anything." (patient)*
>
> *"So the one that I felt that I was having a problem was here. They have Atheism but they don't have Agnosticism…yeah that was my only thing because I had to say I don't have any religious or spiritual affiliation and that so it left Agnostic out. Which I felt was, where I would have landed."*

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What type of housing do you live in? Choose **ONE.**

☐ Own Home

☐ Renting Home

☐ Boarding Home

☐ Correctional Facility

☐ Homeless/on Street

☐ Group Home

☐ Shelter/Hostel

☐ Supportive Housing

☐ Other

☐ Prefer not to answer

☐ Do not know

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**Recommendation 18: Clearly define the response options for the question related to <u>housing</u>. Clarify an option for people living with family. Consider using "house or apartment" instead of the term "home".**

Besides 'own home', 'renting home' and 'homeless/on the street', patients were mostly unfamiliar with the meaning of the response options, regardless if it applied to them or not to them. One patient was unsure if he was living in supportive housing or subsidized housing. Patients tended to equate the term "home" with the term "house". This was particularly problematic for patients residing in apartment buildings and apartments inside a house. Patients

living with family members (e.g. parents, children) were unsure about what response option to select. This was an uncomfortable question for some patients to answer.

> *"I was actually looking for apartment, I wasn't looking for, you know, home. Well does that mean a house? Cause I don't rent a whole house." (patient)*

## 4. **CONCLUSION**

In summary, this study found that there was support from health providers and patients to collect this data and it holds significant potential. The data can be used for at least four purposes: (a) at the point-of-care, (b) for organizational change and quality improvement, (c) for health system planning and (d) for research. In general, it was feasible to implement the HEQ, administer to thousands of patients and extract the data from the EMR. Our study also revealed some of the key challenges, including the importance of clarifying the main purpose or purposes, non-response bias (which could be addressed by training and workplaces processed that track and address it), and the need to edit some of the questions.

Our recommendations can assist the TC LHIN and health institutions as they decide on the next steps to advance the collection and use of robust sociodemographic data from patients. Such data is vital to understanding who an organization serves and who is potentially being missed. This may allow an organization to report publicly on equity in access to services, to develop innovative programs for hard-to-reach populations and to evaluate the impact of such programs over time.[16]

# REFERENCES

1   Pinto AD, Glattstein-Young G, Mohamed A, Bloch G, Leung F-H, Glazier RH. Building a Foundation to Reduce Health Inequities: Routine Collection of Sociodemographic Data in Primary Care. *J Am Board Fam Med* 2016; **29**: 348–55.

2   World Health Organization. Commission on Social Determinants of Health. Geneva, 2008.

3   Canada PHA of. What determines health? 2011. http://www.phac-aspc.gc.ca/ph-sp/determinants/index-eng.php (accessed April 10, 2017).

4   Kawachi I, Subramanian S V, Almeida-Filho N. A glossary for health inequalities. *J Epidemiol Community Health* 2002; **56**: 647–52.

5   Dunlop S, Coyte P, McIsaac W. Socio-economic status and the utilisation of physicians' services: results from the Canadian National Population Health Survey. *Soc Sci Med* 2000; **51**: 123–33.

6   Alter DA, Naylor CD, Austin P, Tu J V. Effects of socioeconomic status on access to invasive cardiac procedures and on mortality after acute myocardial infarction. *N Engl J Med* 1999; **341**: 1359–67.

7   Information CI for H. Health Indicators 2008. Ottawa, 2008 https://secure.cihi.ca/free_products/HealthIndicators2008_ENGweb.pdf.

8   Toronto Public Health, St. Michael's, CAMH, Mount Sinai Hospital. We Ask Because We Care: The Tri-Hospital + TPH Health Equity Data Collection Research Project Report. Toronto, 2013.

9   Hospital MS. Measuring Health Equity: Demographic Data Collection in Health Care. 2017. http://torontohealthequity.ca/ (accessed April 10, 2017).

10  Lofters A, Schuler A, Slater M, *et al.* Using self-reported data on the social determinants of health in primary care to identify cancer screening disparities: opportunities and challenges. *BMC Fam Pract* 2017.

11  Steele LSLS, Glazier RHRH, Lin EE, Evans MM. Using administrative data to measure ambulatory mental health service provision in primary care. *Med Care* 2004; **42**: 960–5.

12  Gottlieb LM, Hessler D, Long D, *et al.* Effects of Social Needs Screening and In-Person Service Navigation on Child Health. *JAMA Pediatr* 2016; **124**: e162521.

13  Garg A, Marino M, Vikani AR, Solomon BS. Addressing Families' Unmet Social Needs Within Pediatric Primary Care. *Clin Pediatr (Phila)* 2012; **51**: 1191–3.

14  Garg A, Butz AM, Dworkin PH, Lewis RA, Thompson RE, Serwint JR. Improving the management of family psychosocial problems at low-income children's well-child care visits: the WE CARE Project. Pediatrics. 2007; **120**: 547–58.

15  Brcic V, Eberdt C, Kaczorowski J. Development of a tool to identify poverty in a family practice setting: a pilot study. Int. J. Family Med. 2011; : 1–7.

16  Kiran T, Pinto AD. Swimming ' upstream ' to tackle the social determinants of health. *BMJ Qual Saf* 2016; **25**: 138–140.