ORIGINAL RESEARCH

Building a Foundation to Reduce Health Inequities: Routine Collection of Sociodemographic Data in Primary Care

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Introduction: **Detailed data on social determinants of health can facilitate the identification of inequities in access to health care. We report on a sociodemographic data collection tool used in a family medicine clinic.**

Methods: **Four major health organizations in Toronto collaborated to identify a set of 14 questions that covered a range of social determinants of health. These were translated into 13 languages. This survey was self-administered using an electronic tablet to a convenience sample of 407 patients in the waiting room of a primary care clinic. Data were uploaded directly to the electronic medical record.**

Results: **The rate of valid responses provided for each question was high, ranging from 84% to 100%. The questions with the highest number of patients selecting "do not know" and "prefer not to answer" pertained to disabilities and income. Patients reported finding the process acceptable. In subsequent implementation across 5 clinics, 10,536 patients have been surveyed; only 724 (6.9%) declined to participate.**

Conclusion: **Collecting data on social determinants of health through a self-administered survey, and linking them to a patient's chart, is feasible and acceptable. A modified survey is now administered to all patients. Such data are already being used to identify health inequities, develop novel interventions, and evaluate their impact on health outcomes. (J Am Board Fam Med 2016;29:348–355.)**

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Our health is influenced by the complex interaction of individual- and community-level social and economic factors. These are called "social determinants of health" (SDOHs) and include income, social status, education, the social and physical environments, gender, and culture.[1] Understanding the SDOHs—and addressing these factors to reduce health inequities—has steadily risen up the

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agenda of health professionals,[2,3] health organizations[4–6] and policymakers.[7,8]

How SDOHs are linked to better or worse health outcomes is becoming better understood. One link in the causal chain is access to health services.[8,9] Even in countries with publicly financed health insurance to cover the cost of physician visits and hospitalizations, not all individuals enjoy the same access to such health services. In Canada, for example, those with a low income have been found to have less access to specialists than the wealthy.[10–13] Those with lower educational attainment have less access to specialists than those with higher educational attainment.[14] Gay, lesbian, and bisexual Canadians report more negative experiences within the health system and greater unmet health needs.[15,16] Transgender patients report high rates of discrimination when seeking health care.[17] New immigrants to Canada access fewer primary care services than their Canadian-born counterparts.[18–20] Other factors that influence who receives service and who does not, and the quality of the service received, include housing status,[21] whether a patient has a disability,[22] the language a patient speaks,[23] and their race or ethnicity.[24]

Such evidence of disparities in access to health services and inequitable health outcomes is typically derived from the combination of administrative data and surveys. When patient demographic data exist, they are often not self-reported. Few health service organizations routinely collect data on a sociodemographic variables, and fewer still link such data to individual patient files.[25]

Studies to date[26,27] have identified several barriers to collecting sociodemographic data, including a lack of consensus about which questions to ask, how to word these questions, how best to survey patients, and concerns that asking such questions could disrupt the therapeutic relationship.[28–31] Some patients may question the utility of sociodemographic data collection and worry about discrimination.[25,32] Moreover, public awareness of health inequities remains low[33]—hence the need for clarity around the purpose behind any such data collection.[27,34]

This article reports lessons learned from the collection of sociodemographic data within a Canadian family medicine clinic. We examined whether it was feasible and acceptable to ask patients about sociodemographic variables through a tablet-based survey administered in the waiting room. We begin by outlining the development of the survey. We then present the findings from testing this survey at an outpatient primary care facility and discuss its subsequent implementation into the routine workflow across multiple clinic sites.

Methods

Setting

The Department of Family and Community Medicine at St. Michael's Hospital is a large, academic family practice unit in downtown Toronto, a city of approximately 2.6 million people. Over 200 health professionals, including over 60 full- and part-time physicians, serve 35,000 patients at 5 separate clinics. A broad cross section of the community is seen at St. Michael's Hospital, which has a particular mandate to provide care to marginalized populations.[35] This study received the approval of the St. Michael's Hospital Research Ethics Board.

In the fall of 2010 a number of physicians and staff of the Department of Family and Community Medicine expressed an interest in the routine collection of sociodemographic data. This led to involvement in a joint initiative with 3 other health organizations in Toronto: the Centre for Addiction and Mental Health, Mount Sinai Hospital, and Toronto Public Health. Two authors (ADP, AM) were members of the steering committee of that project. Representatives from these institutions had been meeting regularly since 2009 and had identified a need to collect sociodemographic data from their patient populations. Question domains were identified based on studies that identified variables that are consistently tied to differences in access to health services, the quality of health services, and health outcomes. Interviews were conducted with key informants from 11 local organizations that were already collecting sociodemographic information. The wording of questions was informed by a literature review and refined through an iterative process, with numerous meetings and consultations involving staff and physicians at all 4 organizations over 4 years (Online Appendix 1). To ensure accessibility, the survey was translated into Arabic, French, Spanish, Russian, Simplified Chinese, Tamil, Farsi, Korean, Portuguese, Punjabi, Traditional Chinese, and Vietnamese. These were the most commonly requested languages when interpreter services were sought at the 4 participating institutions. Translated versions were back-translated into English to ensure the quality of the translations.

Best practices in data collection methods were identified and incorporated into data collection. Self-reporting by patients was identified as being essential for all questions, particularly race or ethnicity.[36–38] Data collection was integrated into the standard workflow at registration, given that this is an entry point for all patients, who are available while waiting to be seen. Given that success is related to staff buy-in, ongoing engagement and meaningful involvement of staff was prioritized throughout the pilot study and implementation process.[27] Finally, we understood that it was important to integrate data into existing electronic data systems to eliminate the need to reenter data and to allow the collected data to be linked to a patient's electronic medical record (EMR).[39]

Population and Sampling

The survey (Online Appendix 2) was piloted with approximately 400 adult (≥16 years old) patients at each of the 4 participating sites during the summer of 2012. Each site used a different method to survey patients; St. Michael's Hospital was the only site to use an electronic tablet interface. Further details on the other collaborating sites are available elsewhere.[40] One clinic site at St. Michael's Hospital, the Health Centre at 80 Bond, was chosen for the pilot because it had wireless Internet and the staff had experience in supporting similar research activities. Posters advertising the project were displayed in the waiting room for all patients to see, and information pamphlets were available. A convenience sample of patients attending the clinic was created. Data collectors were 2 multilingual postgraduate students who received training before any data collection efforts. A scripted dialog was used to invite patients waiting for an appointment to participate in the study, and each was provided an information sheet in English. This was not translated into other languages. The number of patients who declined the survey was not tracked during this pilot phase. If a patient agreed to participate, his or her medical record number was used to link the survey responses to the patient's EMR. The patient was then provided with an iPad connected to the Internet using a secure, password-protected wireless network. No paper version of the survey was available in the case of failure of the tablet. The opening screen prompted participants to select a language; a subsequent screen took participants through the consent process, which was in the language that the participant had selected. Following this, the 14 survey questions were presented; the options "Prefer not to answer" and "Do not know" were available for each question. Each survey ended with questions to the participant about their experience responding to the survey. Data collectors were directed to encourage patients to complete the survey on their own, with assistance only provided upon request. Participants entered responses directly on the tablet, and their responses were visible only to themselves. Exclusion criteria included inability to provide informed consent and not registration as a patient of the family practice unit. Data were posted within 48 hours to the physician's EMR result inbox labeled "socio-demographic data." After the results were viewed and the physician acknowledged receipt, this information was posted into the patient's record as entered.

Data Analysis

All data were extracted from the EMR at the end of the study. Descriptive statistics were used to assess the overall response rate for each question. Data on the language chosen by participants to complete the survey was not collected because of how the tablets were programmed. For the purposes of this study, we defined a valid response as any of the available options, including "Do not know" and "Prefer not to answer." An invalid response was defined as either no data (patient skipped the question without choosing any available option) or an inappropriate response, such as stating their year of birth was before 1900. The tablets were not programmed to reject impossible answers for questions that required direct entry. Each participant could provide a comment at the end of the survey if they wished. Data collectors submitted a summary of their experience and were also interviewed; notes were taken during this conversation. Comments provided by patients and data collectors were independently analyzed by 2 members of the study team (ADP, GG-Y) using thematic analysis. Once key themes were agreed on, they were confirmed with the entire study team and representative quotes were identified.

Table 1. Responses to the Pilot of Sociodemographic Questions Answered by 407 Participants at the Department of Family and Community Medicine, St. Michael's Hospital (July–August, 2012)

Questions*	Appropriately Answered†	Prefer Not to Answer†	Do not Know†	Blank/Inappropriate Response	Valid Responses (%)
1. What language would you feel most comfortable speaking in with your health care provider?	405	0	2	0	100
2. How would you rate your ability to speak and understand English?	406	1	0	0	100
3. In what language would you prefer to read health care information?	381	2	1	23	94.3
4a. Were you born in Canada?	403	4	0	0	100
*4b. If no, what year did you arrive in Canada?	108	0	0	39	73.5
5. In what year were you born?	357	17	0	33	91.9
6. Which of the following best describes your race?	400	6	1	0	100
7. What is your religious or spiritual affiliation?	391	10	6	0	100
8. Do you have any of the following disabilities?	315	20	8	64	84.3
9. What is your gender?	405	1	1	0	100
10. What is your sexual orientation?	391	14	2	0	100
11. What was your total family income before taxes last year?	351	41	15	0	100
12. How many people does this income support?	343	25	8	30	92.4
13. What type of housing do you live in?	400	7	0	0	100
14. In general, would you say your health is…	404	3	0	0	100

Data are counts unless otherwise indicated.
*Follow-up item.
†Included in valid responses.

Results

The survey was tested with 407 patients within the family practice unit at St. Michael's Hospital. The rate of valid responses (any option chosen, including "Do not know" and "Prefer not to answer") provided for each question was high, ranging from 84% to 100% (Table 1). The lowest rate (73.5%) was for the follow-up to item 4a: "In what year did you arrive in Canada?" Blank or inappropriate responses occurred at the highest frequencies for questions about birth year (8.1%), number of dependents (7.4%), and preferred language in which to read health care information (5.7%). The frequency of "Do not know" and "Prefer not to answer" responses was >3% for the majority of questions. Questions with the highest frequency of "Prefer not to answer" responses were related to financial status, including income (10.1%) and the number of people supported by the income (6.1%). Less than 5% preferred not to answer questions about birth year (4.2%), sexual orientation (3.4%), religion (2.5%), and housing (1.7%), whereas <2% preferred not to answer questions regarding race (1.5%), gender (0.2%), and language abilities (≤0.7%). Stated another way, over 95% of participants were willing to answer such questions. The highest frequency of "Do not know" responses were attributed to questions on income (3.7%), the number of people supported by the income (2.0%), and religious affiliation (1.5%).

Feedback from Participants

Of 407 respondents, 50 (12.3%) provided a comment at the end of the survey. Of these, 18 respondents stated simply that they had no comment, 17 had a positive comment (eg, "It was fine," "Good survey," "Simple to understand"), and 8 made a suggestion for improvement (eg, "I do identify as queer and trans, but have not and do not plan to transition to male. So it would have been helpful to have a blank space under gender to explain that!"). Only 7 respondents provided comments that were negative, including 5 who reported feelings of discomfort in responding to the survey (eg, "Some questions are a bit too personal," "Income question made me uncomfortable. I would like to know that everyone would get the same standard of care no matter the income.") or a lack of clarity on the survey's purpose (eg, "Question clear. The purpose of the survey not so much!").

Regarding the survey question that asked about race, 2 respondents felt that there should have been a response that allowed for the selection of "Canadian." Two respondents pointed out the complexity of using terms like *race* when asking someone to self-identify with a racial/ethnic category: "I found some of your categories to be problematic. . . . Race, for instance, is a term that is a cultural construct, and therefore relatively meaningless in relation to biological health. It is also difficult to correlate it with geography. . . . Fundamentally, ethnicity would have been a more valuable category."

Feedback from Data Collectors

As noted, in this pilot study the patients who refused to participate in the survey were not counted. Data collectors anecdotally reported that non-English-speaking patients were more likely to refuse to participate, despite the availability of translated surveys. Older patients seemed to have the greatest difficulty when it came to viewing, zooming in, and selecting options on the tablet interface. Some patients reported that they had too many tasks to complete at the clinic already and reported this as a reason for survey refusal. Data collectors also reported that a reason patients did not complete the survey was they were called into an appointment midway through completion. Data collectors also reported that willingness to complete the survey depended on whether others in the waiting room had accepted or declined.

Discussion

In this study we found that asking questions about the sociodemographic characteristics of individual patients using a tablet was feasible and acceptable. Participants were willing to answer questions about sensitive subjects, including sexual orientation, gender, housing, religion, and race or ethnicity. As expected, the highest rate of "Do not know" and "Prefer not to answer" responses were for questions about income. By directly linking detailed sociodemographic data to the EMR, we are able to identify health inequities in real time, develop tailored interventions, and much more easily evaluate the impact of such interventions on health outcomes.

This study has a number of strengths, including that it examines the pragmatic use of a survey in the waiting room of a busy primary care setting, and questions include sensitive topics such as sexual orientation, income, and race/ethnicity. This is, to our knowledge, the first study of its kind in Canada, where the routine collection of sociodemographic data in health settings is rare. This study also has a number of limitations. One key limitation was that the precise number of patients who declined to participate was not tracked as part of the pilot phase.[40] The data collectors were not instructed to collect this information. While this is certainly an oversight for a pilot study of a survey, the decline rate with our small sample is not anticipated to be representative of the decline rate in actual practice. In the implementation of these questions across our department, of 10,536 patients surveyed between December 2013 and August 2015, only 724 declined (6.9%). Future research is planned to examine nonresponse bias and to interview patients about why they may not complete such a survey. Another limitation is that the language chosen by a participant was not tracked. This was not possible, based on how the tablets were programmed for this pilot. In addition, the information sheet provided to patients was only in English; hence some non-English-speaking patients may have declined to participate because they could not understand the rationale for the study. However, the consent process that patients completed on the tablet was available in all languages. Also, further information on how patients perceive such a survey could have been gathered through interviews or focus groups. Such work has already been conducted in Canada, however, including a survey of >1000 adults that found that most supported their family physician collecting such data (Miller L, personal communication, 2015).

Our experience is comparable to other studies of the collection of sociodemographic data. Studies from the United States have described that using a computer interface as part of the registration process is efficient and feasible.[32,41] Participants in other studies have also reported broad support for collecting sociodemographic data, with some reservations if it is unclear why the data are being collected.[28,29,42] Similar to our study, others have found that race and ethnicity questions can be controversial, something that can be ameliorated by allowing patients to self-identify in their own terms.[27,36,43]

Following this pilot, in December 2012 the Toronto Central Local Health Integration Network, the regional health authority, directed all hospitals in their catchment area to collect sociodemographic data. Other jurisdictions have mandated such data collection.[44] Eight questions were recommended.[45] Within the family medicine department at St. Michael's Hospital, the routine collection of sociodemographic data occurs at all 6 clinic locations. A third-party organization has been contracted to provide equipment and technical support. This includes programming the tablet interface, uploading responses to the patients' EMRs via a secure server, developing a flag at patient registration to alert staff of prior survey completion to reduce the number of times a patient may be asked to complete the questionnaire, and training staff to use the system. A clerical staff person at each site oversees day-to-day processes. They reported that patients are willing to complete the survey when they understand it is about improving the quality of their care and the care of others. For patients who are not comfortable with using a tablet, a paper version of the survey is available. Clerical staff then use the tablet interface at a later point to enter the patients' written answers.

A number of small changes were made to the questions based on the results of the pilot study and should be noted (Online Appendix 3). Eight additional languages were added to provide more options to patients. Based on reports of confusion about the term *race*, the question now asks about "racial or ethnic group." "Aboriginal" as a racial or ethnic category was expanded to 4 separate categories ("First Nations," "Inuit," "Métis," and "Indigenous not included elsewhere"). The question on gender was changed to "sex/gender" so that intersex could be included without adding to the total number of questions yet could continue to recognize the difference between these 2 terms. For the question on sexual orientation, "male-female relationships" was added in brackets after "heterosexual" because some patients were unfamiliar with the term. "Trans–Male to Female" and "Trans–Female to Male" were added as options under the question on sex/gender based on feedback to allow differentiation of experiences and outcomes between these groups. The financial ranges under the income question were expanded to make it easier for patients to feel comfortable answering (eg, making the lowest category <\$30,000). Further, the data are now entered directly into the electronic chart immediately after the survey is complete (ie, they do not enter physician's EMR inbox).

Plans for this data include using it to identify and reduce inequities in access to primary health care services (eg, identify racial or ethnic groups that have particularly low cancer screening rates and implement targeted screening efforts); to identify and reduce inequities in health outcomes (eg, identify the language preference of people with poorly controlled diabetes and ensure translation services are available and used); and to target health promotion interventions (eg, provide information on pre- and postexposure prophylaxis to men who have sex with other men who are human immunodeficiency virus negative).

A number of questions remain about collecting sociodemographic data within primary care settings. How should further changes to the wording of questions or the available answer options be implemented, and how will this affect the analysis of data already collected? How can data quality be assessed and what are benchmarks? How can missing data be addressed in a simple and practical way? How often should patients be asked these questions, and how can tools within the EMR be used to prompt a repeat survey? How can patients and communities be involved in the interpretation of data and trends? Each organization will need to develop an infrastructure to manage these concerns.

Collecting data on SDOHs is feasible in a primary health care setting. These data allow health organizations to see who is being served and who is not and to identify differences in outcomes across groups. In turn, these data can inspire new programs to reduce inequities, and if tracked over time, they can be used to evaluate the impact of such interventions. By implementing this survey, health system leaders have a new and powerful tool to use to improve individual and population health and achieve the "Triple Aim."[7]

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Appendix 1

Rationale for Questions Used in the Tri-Hospital + Toronto Public Health Equity Data Collection Research Project

Questions, by Topic	Evidence for Disparities in Access to Health Services	Evidence for Disparities in Health Outcomes	Rationale for Wording and Options Provided
Language			
1. What language would you feel most comfortable speaking in with your health care provider? Check one only. 2. How would you rate your ability to speak and understand English? Check one only. 3. In what language would you prefer to read health care information? Check one only.	A strong relationship has been found between poor access to primary care and having a first language other than English or French. In particular, women who do not speak English as a first language are less likely to receive preventive services, including breast exams, mammography and pap testing.[1–3]	Language is a key social determinant of health.[4,5] Recent immigrants with prolonged limited English language proficiency are more likely to experience a downward trend in self-reported health and higher rates of unmet health needs.[6] Ontarians who do not speak English are more likely to report poor health. [3] Limited English proficiency in Canada has been associated with reduced treatment comprehension and compliance, increased risk of adverse drug reactions, and increased likelihood of inadequate management for chronic disease.[7] Non-English-speaking patients are less likely to be satisfied with the care received when not speaking the same language as their provider.[7,8]	The options listed under the questions on language were based on the top 29 languages spoken across Toronto, plus ASL. To be inclusive from an equity perspective, other languages were added representing some of the most common nonofficial mother tongues in Toronto. This was important because certain groups who are fluent in English (and therefore do not request translation services) make up a sizeable group in the GTA (ie, Tagalog in the Filipino community).
Immigration status			
4a. Were you born in Canada? 4b. If no, what year did you arrive in Canada?	Approximately 25% of immigrants reporting a decline in health (from the time of arrival) experienced barriers to accessing health services. [9] Many Canadian newcomers report discrimination on the basis of immigration status as a significant obstacle to accessing primary care.[10]	New immigrants arrive to Canada with a better health status than Canadian-born persons but experience a reduction in physical and mental health within 2–5 years of settlement, measured not only by self-reported health status but also by physician visits.[11–13] Among immigrant women, stressful resettlement experiences contribute to an increased risk of preterm labor and low-birth-weight infants,[14] and cervical cancer is more likely to be detected later than in the general population.[15,16]	Questions about immigration status can be a source of fear for those residing in Canada without legal status.[17] The question was phrased purposefully to not require disclosure of immigration status. This may mitigate fear of reprisal while allowing the assessment of differential health access or health outcomes for those born outside Canada. Asking about time of arrival in Canada allows institutions to identify and potentially anticipate the health decline that many immigrants experience without adding complexity to the question.[9]
Age			
5. In what year were you born?	Age clearly influences the use of health services, with older persons typically using more services.[18,19]	Health and quality of life decline as we age, in part related to an increase in the number of chronic diseases.[20,21]	This question was phrased in a simple and direct fashion.
Race			
6. Which of the following best describes your race? Check one only.	African-Canadians are underrepresented in voluntary mental health services (eg, outpatient psychiatry clinics and addiction services) but are overrepresented in involuntary services such as medicolegal units in psychiatric hospitals.[22] In a study comparing health disparities between Canada and the United States, Canadian women of color were less likely to receive a Pap test in the past 3 years compared with white women.[23] The Canadian health system has numerous shortcomings for Aboriginal Canadians who often avoid using mainstream health care because of a lack trust and culturally inappropriate care. Many Aboriginal people therefore delay seeking care and often do not benefit from preventive services.[24,25]	Racialized groups are more likely to have worse health status than white Canadians after controlling for sex, age, education, immigration status, and income.[26,27] Nonwhite persons in Canada are more likely to have a lower perceived quality of care and satisfaction with services received.[23] Race is an independent predictor of in-hospital mortality and adverse outcomes for certain conditions.[28] Compared with nonaboriginals, urban Aboriginal men and woman in Canada have a significantly shorter life expectancy and are more likely to die prematurely from preventable diseases (including cervical cancer, pneumonia, and influenza), as well as from smoking and alcohol-related causes.[29,30] Canadian aboriginals are more likely to receive a cancer diagnosis at a more advanced stage of disease.[31]	The accuracy of ethnoracial data is enhanced by self-reporting[32] as well as the availability of options outside of fixed categories; this is particularly true for persons of multiracial/ethnic backgrounds. [33] These are important considerations for health systems data collection; self-identification with a certain subgroup often corresponds with beliefs and patterns of health care utilization that are shared within that subgroup.[34,35] However, open-ended questions on "ethnicity" may fail to provide useful information because of response heterogeneity and the inability to collate data. The formulation of this question therefore necessitated a balance between accuracy and utility, and respondents were asked to choose between categories. This pilot question also specifically used the term *race* as opposed to *ethnicity* in an effort to avoid the infinite number of ethnic categorizations and enhance data utility.

Continued

Appendix 1 Continued

Questions, by Topic	Evidence for Disparities in Access to Health Services	Evidence for Disparities in Health Outcomes	Rationale for Wording and Options Provided
Religion			
7. What is your religious or spiritual affiliation? Check one only.	Few Canadian studies have explored faith-based disparities in access to health care. One study from Newfoundland found that Muslim women identified providers' lack of awareness and insensitivity to religious differences as a reason for unmet maternal care needs.[36]	The capacity of health care providers to understand and accommodate a patient's spiritual and religious paradigms can affect routine care[24,36,37] and end-of-life care and is increasingly important for patient satisfaction within the health care system.[38–40]	Religion is a key social determinant of health.[4,5] The major religious denominations of people living in Ontario were included in the survey. To be inclusive from an equity perspective, other major world religions were included, such as Wicca, Zoroastrianism, and Jainism, as well as less common spiritual affiliations.
Disability			
8. Do you have any of the following disabilities? Check all that apply.	People with disabilities often require greater health care attention because of comorbid conditions that occur with higher frequencies or differ from those faced by the general population; however, there is a trend of service underutilization within this group that is inversely correlated with disability severity.[41–43] Factors making this population particularly vulnerable to disparities in access (and outcomes) include functional and communication limitations as well as systemic barriers such as inadequate facilities and insufficient training for health care professionals.[41,44]	There is considerable evidence that certain intellectual disabilities are associated with higher rates of morbidity and shorter life expectancies compared with people without disabilities.[44–46] The multiplicative effect of overlapping social determinants is shown strongly within this group. For example, Aboriginal people with epilepsy are less likely to see a neurologist but more likely to visit the emergency department or be hospitalized, whereas lower socioeconomic status is associated with poor medication compliance.[47] Also, nonwhite people with Down syndrome have a higher mortality rate than white persons with Down syndrome.[48] Psychotropic medications are prescribed with a high frequency for people with intellectual disabilities for behavioral or emotional problems; however, incorrect diagnoses often lead to misuse of these drugs, with significant adverse effects for cognition, mobility, and bone and metabolic health.[44]	All of the options provided under the question on disability were adopted from the OHRC definition of disability.[49] OHRC definitions for each type of disability were linked to the question and could be referenced while completing the survey. Acknowledging that often multiple disabilities coexist, participants were prompted to select "all that apply."
Gender			
9. What is your gender? Check one only.	Studies focusing on trans and intersex populations have identified stigma and discrimination as limiting access and quality of care.[50–53] Approximately half (52%) of trans people surveyed reported negative experiences in the emergency department on the basis of their gender, whereas 21% reported avoiding care in the emergency department because of fear of a negative encounter.[52]	Research focusing on differences in care between the male and female sexes has uncovered inexplicable disparities across all levels of health care after controlling for potentially disease-mitigating factors.[3,54,55] For instance, women with coronary syndromes are less likely to be admitted to acute care and receive revascularization procedures compared with men and more likely to die after a critical illness in hospital.[56]	There is a need to separate sex from gender in health research to understand and measure the impacts of gender relations, identity, and sex-linked biology.[53] Whereas sex refers to one's biological status, assigned at birth, gender is tied to a person's sense of self. Thus gender identity can be male, female, both, or neither; it differs from sex and is distinct from sexual orientation. Within the survey, "trans" was used an abbreviation and umbrella term to include transgender, transsexual, gender nonconforming, and gender questioning. "Intersexuality" was meant to include those with physical and/or chromosomal variations where features often considered either male or female are combined into one body.[57] Gender has been identified by the PHAC as a key social determinant of health.[58]
Lesbian, gay and bisexual persons			
10. What is your sexual orientation? Check one only.	LGB Canadians consistently report more negative experiences within the health system.[59,60] When encounters are not overtly discriminatory, LGB patients are treated "just like everybody else," with inattention to the unique health needs of this population.[61,62] Many LGB persons do not divulge sexual orientation for fear of provider bias,[63] and experiences of stigma leads to future avoidance or delay of care seeking.[59,64] Lesbians are less likely to see a family physician for a Pap test than heterosexual women.[64]	Canadian LGB youth are at higher risk of suffering from mental illness (including suicidal ideation, suicide attempts, and depression), physical and sexual abuse, homelessness, and exposure to human immunodeficiency virus.[65]	Categories selected for this question were formulated based on consensus among the steering committee, which consisted of multiple health equity experts and researchers. Once again, the options provided for this question were designed as a balance between inclusivity (creating categories that people can identify with) and the need for utility in measurement and analysis.

Continued

Appendix 1 Continued

Questions, by Topic	Evidence for Disparities in Access to Health Services	Evidence for Disparities in Health Outcomes	Rationale for Wording and Options Provided
Income			
11. What was your total family income before taxes last year? Check one only. 12. How many people does this income support?	Low-income persons have lower access to specialist[66–70] and primary care compared with high-income persons.[71]	Poverty in Canada is strongly correlated with the chronicity and severity of disease, with poorer treatment outcomes.[3,72] Canadians with a very low income experience as much as 9.8 years' difference in their life expectancy compared with the wealthy.[73] Low-income Canadians are >2 times as likely to die of conditions for which effective preventive measures and/or treatment options exist, including diabetes, cervical cancer, and suicide.[74]	Income has been identified by the PHAC as a key social determinant of health ("income and social status").[75] Income brackets were developed in $10,000 increments so that they would be narrow enough to capture the LICOs but broad enough that participants would feel comfortable selecting a category. Asking about the number of dependents supported by the income allows for a more accurate assessment of poverty and its effect on health as LICO vary by family size (ie, LICO in 2009 was $18,421 for an individual but $34,829 for a family of 4).[76]
Housing status			
13. What type of housing do you live in? Check one only.	People who are homeless often feel unwelcomed within the health system and cite discriminatory treatment as a reason for avoidance.[77]	Canada's homeless suffer from higher levels of disease are more likely to die prematurely.[78,79] Persons without a fixed address are more likely report poor health status and experience difficulty securing appropriate care.[80–82]	Categories selected for this question were formulated based on consensus among the steering committee, based on an understanding of options available in Toronto. Steering committee members had extensive experience working with patients who were homeless or underhoused.

ASL, American Sign Language; GTA, Greater Toronto Area; LGB, lesbian, gay, and bisexual; LICO, low-income cutoff; OHRC, Ontario Human Rights Commission; PHAC, Public Health Agency of Canada.

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Appendix 1 Continued

Questions, by Topic	Evidence for Disparities in Access to Health Services	Evidence for Disparities in Health Outcomes	Rationale for Wording and Options Provided

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Appendix 1 Continued

Questions, by Topic	Evidence for Disparities in Access to Health Services	Evidence for Disparities in Health Outcomes	Rationale for Wording and Options Provided

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Appendix 2

Survey Questions on Sociodemographic Variables Used in a Pilot Study in the Department of Family and Community Medicine, St. Michael's Hospital, During Summer 2012

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

American Sign Language
Arabic
Bengali
Chinese (Cantonese)
Chinese (Mandarin)
Cree
Dari
English
Farsi (Persian)
French
German
Greek
Gujarati
Hebrew
Hindi
Hungarian
Italian
Korean
Oji-Cree
Ojibwe
Polish
Portuguese
Punjabi
Russian
Somali
Spanish
Tagalog
Tamil
Urdu
Vietnamese
Other (Please specify) ___________
Do not know
Prefer not to answer

2. How would you rate your ability to speak and understand English? Check one only.

Very well
Well
Not well
Not at all
Unsure
Prefer not to answer
Do not know

3. In what language would you prefer to read health care information? Check one only.

Arabic
Bengali
Braille
Chinese (Modern)
Chinese (Traditional)
Cree
Dari
English
Farsi (Persian)
French
German
Greek
Gujarati
Hebrew
Hindi
Hungarian
Italian
Korean
Oji-Cree
Ojibwe
Polish
Portuguese
Punjabi
Russian
Somali
Spanish
Tagalog
Tamil
Urdu
Vietnamese
Other (Please specify) ___________
Prefer not to answer
Do not know

4. Were you born in Canada?

Yes
No
Prefer not to answer
Do not know
If no, what year did you arrive in Canada?

____

5. In what year were you born?

____

Prefer not to answer
Do not know

6. Which of the following best describes your race? Check one only.

Aboriginal (eg, Inuit, First Nations, Non-status Indian, Métis, Aboriginal person from outside Canada)

Asian–East (eg, Chinese, Japanese, Korean)
Asian–South (eg, Indian, Pakistani, Sri Lankan, Indo-Caribbean)
Asian–South East (eg, Malaysian, Filipino, Vietnamese)
Black–Africa (eg, Ghanaian, Kenyan, Somali)
Black–Caribbean region (eg, Barbadian, Jamaican)
Black–North America
Latin American (eg, Argentinean, Chilean, Salvadoran)
Middle Eastern (eg, Egyptian, Iranian, Lebanese)
Mixed heritage (Please specify) __________
White/European (eg, English, Italian, Portuguese, Russian)
Other(s) (Please specify) __________
Prefer not to answer
Do not know

7. What is your religious or spiritual affiliation? Check one only.

I do not have a religious or spiritual affiliation.
Animism or Shamanism
Atheism
Baha'i faith
Buddhism
Christian Orthodox
Christian, not included elsewhere on this list
Christianity
Confucianism
Hinduism
Islam
Jainism
Judaism
Native spirituality
Protestant
Rastafarianism
Roman Catholic
Sikhism
Spiritual
Unitarianism
Wicca
Zoroastrianism
Other (Please specify) __________
Prefer not to answer
Do not know

8. Do you have any of the following disabilities? Check all that apply.

No disabilities
Physical disability
Chronic illness
Sensory disability (ie, hearing or vision loss)
Developmental disability
Drug or alcohol dependence
Learning disability
Mental illness
Other (Please specify) __________
Prefer not to answer
Do not know

9. What is your gender? Check one only.

Female
Male
Trans
Intersex
Prefer not to answer
Do not know

10. What is your sexual orientation? Check one only.

Heterosexual ("straight")
Gay
Lesbian
Bisexual
Two-spirit
Queer
Questioning
Prefer not to answer
Do not know

11. What was your total family income before taxes last year? Check one only.

<$10,000
$10,000 to $19,999
$20,000 to $29,999
$30,000 to $39,999
$40,000 to $49,999
$50,000 to $59,999
$60,000 to $79,999
$80,000 to $99,999
$100,000 to $150,000 ≥$150,000
Prefer not to answer
Do not know

12. How many people does this income support? __________

Prefer not to answer
Do not know

13. What type of housing do you live in? Check one only.

Rent
Own
Living with family or friends
Temporary housing (eg, shelter, hostel) or homeless
Correctional facility

Other (specify): __________

Prefer not to answer

Do not know

14. In general, would you say your health is: (Check one only.)

Excellent

Very good

Good

Fair

Poor

Prefer not to answer

Do not know

Appendix 3

Survey Questions on Sociodemographic Variables Implemented within the Department of Family and Community Medicine, St. Michael's Hospital, as of December 2013

Preamble: Measuring Health Equity

Please tell us about yourself.

We want to ask you 11 brief questions as part of our ongoing work to improve access and quality of care for all patients and to identify health inequities. It should take approximately 2–5 minutes to complete.

Your participation is VOLUNTARY and you can stop at any time.

You do not have to complete the survey if you don't want to. You can skip questions.

The information you share with us will be safely kept with your medical file.

This will not affect your access to care.

1. What language would you feel most comfortable speaking in with your healthcare provider? Check one only.

English

Amharic

Arabic

ASL

Bengali

Chinese (Cantonese)

Chinese (Mandarin)

Cree

Czech

Dari

Farsi

French

Greek

Hebrew

Hindi

Hungarian

Inuktitut

Italian

Karen

Korean

Nepali

Ojibwe

Oji-Cree

Polish

Portuguese

Punjabi

Russian

Serbian

Slovak

Somali

Spanish

Tagalog

Tamil

Tigrinya

Turkish

Twi

Ukrainian

Urdu

Vietnamese

Other (Please specify) __________

Prefer not to answer

Do not know

2. Were you born in Canada?

Yes

No

Prefer not to answer

Do not know

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

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

Asian–East (eg, Chinese, Japanese, Korean)

Asian–South (eg, Indian, Pakistani, Sri Lankan)

Asian–South East (eg, Malaysian, Filipino, Vietnamese)

Black–African (eg, Ghanaian, Kenyan, Somali)

Black–Caribbean (eg, Barbadian, Jamaican)

Black–North American (eg, Canadian, American)

First Nations

Indian –Caribbean (eg, Guyanese with origins in India)

Indigenous/aboriginal not included elsewhere

Inuit

Latin American (eg, Argentinean, Chilean, Salvadorian)

Métis
Middle Eastern (eg, Egyptian, Iranian, Lebanese)
White–European (eg, English, Italian, Portuguese, Russian)
White–North American (eg, American, Canadian)
Mixed heritage (eg, black–African and white–North American)
Other(s) (Please specify) ___________
Prefer not to answer
Do not know

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

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

5. What is your sex/gender? Check one only.

Female
Male
Trans–Female to Male
Trans–Male to Female
Intersex
Other (Please specify) ___________
Prefer not to answer
Do not know

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

Heterosexual ("straight," male-female relationships)
Gay
Lesbian
Bisexual
Two-spirit
Queer
Other (Please specify) ___________
Prefer not to answer
Do not know

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

$0 to $29,999
$30,000 to $59,999
$60,000 to $89,999
$90,000 to $119,999
$120,000 to $149,999
≥$150,000
Prefer not to answer
Do not know

8. How many people does this income support?

____
Prefer not to answer
Do not know

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

English
Amharic
Arabic
Bengali
Braille
Chinese (Simplified)
Chinese (Traditional)
Cree
Czech
Dari
Farsi
French
Greek
Hebrew
Hindi
Hungarian
Inuktitut
Italian
Karen
Korean
Nepali
Ojibwe
Oji-Cree
Polish
Portuguese
Punjabi
Russian
Serbian
Slovak
Somali
Spanish
Serbian
Tagalog
Tamil
Tigrinya
Turkish
Twi
Ukrainian
Urdu
Vietnamese

Other (Please specify) __________

Prefer not to answer

Do not know

10. What is your religious or spiritual affiliation? Check one only.

I do not have a 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 (Please specify) __________

Prefer not to answer

Do not know

11. What type of housing do you live in? Check one only.

Own home

Renting home

Boarding home

Correctional facility

Homeless/on street

Group home

Shelter/hostel

Supportive housing

Other (Please specify) __________

Prefer not to answer

Do not know

Thank you for participating in this survey.