REPORT
SEPTEMBER
2013

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## The Tri-Hospital + TPH Health Equity Data Collection Research Project Report

Toronto Public Health

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The Steering Committee would like to acknowledge the Toronto Central Local Health Integration Network's (TC LHIN) financial support toward the production of this document.

The Steering Committee would also like to acknowledge the significant contributions made by our extended group of data collectors, IT support, front-line staff, data analysts, and members of our hospitals' internal committees. Their efforts were vital for the success of this project.

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The full research project report is available at:

- http:// www.mountsinai.ca
- http://knowledgex.camh.net/health_equity/Pages/default.aspx
- http:// www.stmichaelshospital.com
- http://www.toronto.ca/health

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# Introduction

Toronto has undergone a massive transformation over the last three decades. From the force of immigration, the demographics of the city have dramatically changed. No less transformative is the concerted community push for greater recognition of all forms of diversity and social exclusion related to factors such as disability, sexual orientation and gender. While Toronto has experienced deep-rooted change, it remains unclear whether our health care system has evolved at the same pace. Such a question becomes all the more relevant in light of changes to the Ontario Human Rights Code and the Excellent Care for All Act (2010), along with an evolving health care system that has come to recognize patient-centred care as a pillar of quality care.

With the introduction of the Hospital Insurance and Diagnostic Services Act (1957) and the Medical Care Act (1966), Canada sought to eliminate one of the major barriers to health care services – affordability. Further enshrined in the Canada Health Act (1984), the principles of universal health care reflected the policy target of maxmizing access to 'medically necessary services'. Despite the far-reaching and positive effects of Canadian health care legislation and policy, the traditional concepts of affordability and access reflect a constricted perspective on modern health care equity and little on the issue of quality.

> Population health survey data has helped us identify many forms of inequities in health and health care, yet the lack of standardized and routinely collected socio-demographic data hinders our ability to assess organizational performance and identify improvements for reducing the identified inequities.

Affordability does not address barriers in relation to other factors such as racialized status and ethnicity, language, immigration status, gender, sexual orientation, religion or housing status. We know that there is a significant decline in the physical and mental health status of recent immigrants within a two to five year period following settlement (Beiser, 2005; DeMaio, 2010; Hyman, 2007; Ng, Wilkins, Gendron, & Berthelot, 2005; Pahwa, Karunanayake, McCrosky, & Thorpe, 2012). Research also tells us social stigma and discrimination affect access and usage of health care services by persons from lesbian, gay, bisexual, transgender and intersex populations (Coker, Austin, & Schuster, 2010; Eliason & Schope, 2001; Jillson, 2002; Kenagy, 2005; Kerith, Conron, Mimiaga, & Landers, 2010; Scherzer, 2000; Sears, 2009; Smith & Mathews, 2007).

Why are socio-demographic data important? Over four decades of research has generated a large and compelling body of literature on socio-demographic differences in health care access, experiences and outcomes, drawing attention to other barriers beyond the issue of affordability. While a focus on health equity has pushed the boundaries of identifying exclusion, there has not been a parallel expansion in the type of data that is routinely collected and used to improve the health care system. Currently in Canada, most information on health equity is derived from population level data such as the Canadian Community Health Survey and/or linked databases, which can signal important variations in health outcomes. While that data can provide insight into diverse social and geographic population groups, characteristics such as sexual orientation or gender identity are often missed.

Population health survey data are not routinely linked to specific health care organizations, limiting organizational capacity to assess performance improvements in relation to the observed risk and prevalence of differences in health.

From a comparative standpoint, Canada is a laggard. The evolution of mandatory and standardized data collection of socio-demographic variables by health care organizations, particularly race/ethnicity and language data, is evident in places like the US, England, Wales and Scotland. At the same time, many of these jurisdictions are building on the initial movement of health equity measurement to capture information on other critical dimensions such as sexual orientation and gender identity (e.g., transgender). The lack of this data within Canada is amplified in a complex urban centre such as Toronto.

As the old saying goes, "you cannot manage what you don't measure". Administrative records have traditionally focused on limited patient factors such as age and geographic location along with medical outputs like diagnosis and length of stay. All critical information, yet insufficient when viewed against the new imperatives of health care management. The lack of demographic information hinders the growth of patient-centred care that captures diversity in multiple forms, and presents a barrier to investigating whether past and on-going change initiatives have produced positive outcomes.

The following report provides an overview of a four year process among these four organizations:

- Centre for Addiction and Mental Health (CAMH)
- Mount Sinai Hospital (MSH)
- St. Michael's Hospital (SMH)
- Toronto Public Health (TPH)

Through the development and pilot project trial of a socio-demographic questionnaire, a set of eight questions and three optional questions have been recommended for wide-scale implementation. Research on the equity of health and health care compels action on the collection of socio-demographic data. The results of the Tri-Hospital + TPH Health Equity Data Collection Research Project provide evidence that it is "doable".

## Getting Started

In 2009, a group of equity practitioners from CAMH, MSH, and SMH convened a meeting to establish a partnership to further equity in health through the collection of socio-demographic data. All participants had deep experience in the theory and practice of health equity principles, yet recognized that the current system of health data collection did not capture variables that are essential for understanding health care access, experience and outcomes within their organizations and on a system-wide level. At a later point, TPH asked to join the process, providing a population health perspective as well as another unique pilot project setting. The commitment to move forward on this critical issue was made in the absence of external funding to support the research coordination efforts, and without , at the outset, specific organizational resources to off-set the day-to-day responsibilities and workload of the steering committee members.

The project objectives of the partnership were decided to be the following:

- Develop and pilot test evidence-based data collection methods and a survey tool
- Analyze patient responses and feedback from data collectors to improve the methodology and tool
- Explore the relation between demographic variables and self-rated health
- Ensure knowledge exchange with other institutions in the Toronto Central LHIN around the findings of the project

## Moving Along the Learning Curve

The definition of 'mission critical' was acquiring the best evidence on a range of questions and employing the appropriate expertise - policy researchers, data experts, information technology specialists - at each stage of development. The questions from the first phase of development were:

1) Which socio-demographic variables should be collected?
2) Who is best suited to ask patients for personal information?
3) What formats maximize response rates?
4) How best to inform patients and staff about socio-demographic data collection?

Answering these research questions was a multi-stage process of collecting evidence on existing local, provincial and international approaches to gathering socio-demographic data; establishing an evidence-informed consensus on the variables and appropriate questions; implementing the questions on a pilot project basis at each organization; and, lastly, adopting a final standardized set of questions for on-going use.

### LITERATURE REVIEW:
Who is Collecting Socio-Demographic Information? A Story of Fragmentation and Inconsistency

The first step along the learning curve was to undertake a literature review of international studies to identify which socio-demographic variables are being collected on a standardized basis, the health equity research underlying these variables, and the methods of collection. The search was conducted on PubMed, Google Scholar and Scopus for only-English publications between 2000 and 2012, and was further augmented by existing literature reviews.

In response to the expanding recognition of the social determinants of health and an increasing focus on health equity, a number of jurisdictions have set a regulatory requirement that health care organizations (often only hospitals) collect socio-demographic data, most often on racialized status and/or ethnicity. Over the last two decades, it has been increasingly recognized that monitoring and taking action on health inequities is significantly limited in the absence of data or lack of standardized data.

Research indicates that health care organizations collecting race, ethnicity and language are more likely to focus on inequities and improve quality of care (Hasnain-Wynia & Baker, 2006; Institute of Medicine [IOM], 2009).

Despite growing recognition that demographic information is key to health equity planning, the collection of socio-demographic data on race and ethnicity is scattered, fragmented, and in most jurisdictions, often not standardized. Data remains relatively unknown for other categories of population equity such as lesbian, gay, bisexual and trans (LGBT) or disabled persons.

In 1995, it became government policy in England and Wales that racial/ethnic data be recorded in Hospital Episode Statistics (Iqbal, Gumber, Johnson, Szczepura, Wilson, & Dunn, 2009). Despite a mandatory requirement, the initial rate of compliance was weak (Aspinall, 2000). While all hospitals collected the data as required, the number of responses marked 'not known' or 'not stated' was nearly 90% before a concerted policy push to improve compliance (Fulton, 2010). Later attempts to push race/ethnicity data collection into primary health care have been inconsistent, with nearly 40% of practices failing to report on race and ethnicity, thus sustaining the lack of systematic data collection within the National Health Service (Fulton). Experiences in neighbouring Scotland have been similar; the commitment toward the collection of data on race and ethnicity varies greatly from organization to organization (National Health Service Scotland [NHS Scotland], 2012). The general consensus suggests the problem is less about the feasibility of data collection and more about a lack of commitment on the part of organizations. As a result, there have been increased calls for stronger mandates and mechanisms to be put in place to ensure higher levels of compliance and commitment (Fulton).

The US might be the most advanced jurisdiction in the systematic collection of socio-demographic data on ethnicity and racialized groups. It was estimated that in 2009 almost 90% of US hospitals were collecting race data in some format using different approaches (IOM, 2009). Much of this growth was stimulated by 1960s civil rights legislation, whereby data collection was designed to demonstate access rather than improve quality. With increased reliance on this data for planning and quality improvement, several challenges remain around how the data is being collected, catergorized, and standardized. For example, a large number of health plans have continued the practice of identifying client ethnicity by last name rather than client self-report (IOM).

> Encouraging the collection of socio-demographic data is not enough – the critical success factors are the standardization of data collection and the use of 'best practices' to ensure reliability.

The Insitute of Medicine's "Unequal Treatment: Confronting Racial and Ethnic Disparities in Health Care" (Smedley, Stith, & Nelson, 2003) represented a clarion call and shift from concern with differential health care access to inequities in health care quality for marginalized groups. However, the US process of data collection continued to be fragmented and inconsistent, reflecting a "smorgasboard" of policies, initiatives and requirements and mirroring the highly fragmented character of the US health care system and government. More recently, there are signs of consolidation, with emerging evidence of greater consistency in standards and implementation. The most striking example of consolidation is at the state level in Massachusetts. Initial steps were taken when the Massachusetts Department of Public Health began work on developing an improved and standardized approach for data collection (Hawkins, Torres, Simpson, & Cohen, 2011). The standards were then subjected to pilot project trials to refine the tool and applications. With a consensus on evidence-based standards, the Massachusetts Division of Health Care Finance & Policy required all acute care hospitals to collect race and ethnicity data starting in 2007, including the adoption of the standardized data collection tool created by the Department of Public Health. Along with the standards, there has been a program fostering recommended practices and training materials (Hawkins et al., 2011; Jorgensen, Thorlby, Weinick, & Ayanian, 2010).

While previously focused on collecting race, ethnicity, and language data ("REaL data"), US hospitals have now started expanding the list of demographic paramters in pursuit of a more comprehensive picture of health equity. The Affordable Care Act requires the mandatory collection of data on disability status (Office of Minority Health [OMH], 2011). More recently, the US Department of Health and Human Services (HHS) stated that it would begin a plan to collect LGBT data (OMH).

## PUBLIC PERCEPTIONS OF SOCIO-DEMOGRAPHIC DATA COLLECTION

While the value and importance of collecting socio-demographic data is recognized by most in the health equity field, research into how the average person perceives data collection is relatively limited and the findings are somewhat mixed.

The first Canadian study (conducted in Calgary through a telephone survey) investigating public opinion on the collection of race and ethnicity data found approximately 85% of study participants were comfortable with the collection of data about ethnicity, with the level of support holding across age, gender and ethnic origin (Quan, Wong, & Johnson, 2006). The findings were remarkably similar to those from similar studies in the US (Baker et al., 2005; Baker, Hasnain-Wynia, Kandula, Thompson, & Brown, 2007).

More recently, a national telephone survey of Canadians was conducted exploring public perceptions of the collection of socio-demographic data including income, sexual orientation, education, ethnicity, immigration status and language (Lofters, Shankardass, Kirst, & Quiñonez, 2011). The conclusions suggested a lower level of support in comparison to the Calgary or US studies cited earlier. More specifically, 50% of respondents agreed with the question "It is important for hospitals to collect information from patients about personal characteristics like ethnic background, family income, and language of preference" while only 41% disagreed. Like the Calgary study, the results pointed to a '*gradient of comfort*' around *what* information is being collected and *who* is collecting it. Lofters et al. found that 65% of respondents stated being most uncomfortable with disclosing income (highest rate), followed by sexual orientation (38%), education (37%), citizenship (27%), and language (7%). They also found a '*gradient of comfort*' around data collection methods. Respondents reported being most comfortable sharing this information with a family physician (68%), followed by filling out a form (49%), a face-to-face interaction with a clerk (48%), through mail or internet/email (29%), access to their government records (29%), or none of these options (6%).

From the data collector perspective, a number of articles cite health care provider concern around time constraints and patient willingness to share demographic data (Iqbal, Johnson, Szczepura, Wilson, Gumber, & Dunn, 2012; Jorgensen et al., 2010; Ramos, Davis, Ross, Grant, & Green, 2012). In response to these types of challenges around staff reluctance, leading experts in demographic data collection indicate that education and training are essential to not only addressing those challenges, but maintaining effective and successful data collection.

Ensuring successful demographic data collection is therefore about ensuring that patients understand the "why" behind data collection and preparing staff to be able to articulate that "why", in addition to being comfortable with answering related questions. In a later section, the report describes the process undertaken to develop and implement an evidence-based strategy to foster understanding, acceptance and comfort.

## "BEST" METHODS IN STANDARDIZED SOCIO-DEMOGRAPHIC DATA COLLECTION

### "Best" Method: Self-Reporting

The *'gold standard'* is self-reporting by patient (Bierman, Lurie, Collins, & Eisenberg, 2002; Dorsey & Graham, 2011; IOM, 2009; National Alliance on Mental Illness, 2009; Weinick, Zuvekas & Cohen, 2000). In the early days of socio-demographic data collection, the most frequent method of data collection consisted of staff guessing a patient's race or ethnicity. However, the evidence is quite clear that judging one's race by appearance is semi-reliable and only for distinguishing between black and white. For ethnicity, the past staff method was scrutinizing the last name of the patient. Research suggests that this technique leads to 50% or more of patients/clients being misclassified and generates extremely high rates of missing data using this method (Andrews, 2011; Baker et al., 2005; Escarce, Carreon, Veselovskiy, & Lawson, 2011). Even more problematically, these errors in classification tend to occur in relation to the most marginalized populations (Buescher, Gizlice, & Jones-Vessey, 2005; West et al., 2005; Zaslavsky, Ayanian & Zaborski, 2012).

### "Best" Method: Data Collection at Registration

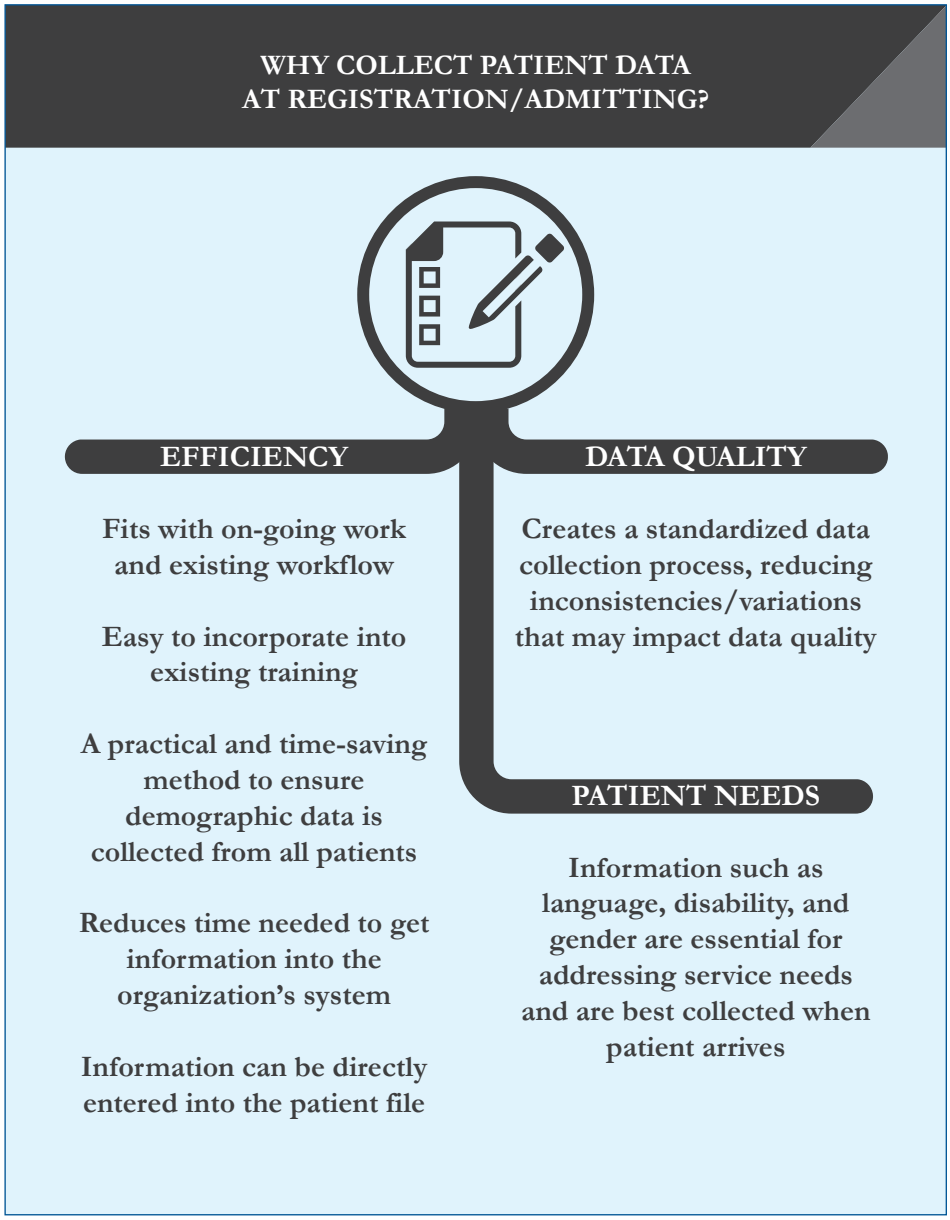
An important step in planning for demographic data collection is identifying when to ask questions. Data collection at registration/admitting has been strongly recommended by researchers and practitioners alike (Agency for Healthcare Research and Quality [AHRQ], 2010; Health Research and Educational Trust, 2012; Wynia, Hasnain-Wynia, Hotze, & Ivey, 2011). An extensive environmental scan of data collection practices in the US and the UK hospitals and health clinics confirmed registration/admitting as the most widely-adopted standard in demographic data collection. Key informant interviews with US leaders in demographic data collection included several health care networks and health equity experts in Massachusetts (*Nancy Conner*, Director of Admitting and Registration Services, Health Partners Network[i]), Texas (*Guwan Jones*, Director of Office of Diversity Management and Health Equity, Baylor Health Care System[ii]), and Illinois (*Romana Hasnain-Wynia*, Director of Centre for Health Equity at Northwestern University School of Medicine). The research and interviews provided several rationales for why demographic data collection at registration/admitting continues to be strongly advocated as a best practice (Please see inforgraphic on p. 7).

While public survey research suggests that the preferred point of contact is a physician, experience in health care settings indicates this is not the most practical approach. Rather than focusing on the type of provider, the key factor appears to be trust in that individual. The research and environmental scan that identified registration/admitting as the best standard in data collection also provided consensus that patient participation is heavily dependent on staff training and patient awareness/education. Such training should first emphasize the importance of the data collection process to ensure buy-in at all organizational levels – leadership, administration and clinical – as low rates of organizational compliance or poor completion rates are associated with lack of staff acceptance and comfort (Iqbal et al., 2012; Jorgensen et al., 2010; Ramos et al., 2012). Second, training should provide strong guidelines on the approach, as well as maintaining privacy and confidentiality (IOM, 2009; Iqbal et al., 2012; Jorgensen et al, 2010; Weinick et al., 2000). Third, training will not be effective without staff engagement and meaningful involvement around demographic data collection; one

*i Health Partners Network: The largest health care provider in Massachusetts with 10 hospitals and a network of 8 rehabilitation medical centres, 3 continuing care facilities, and over 25 outpatient clinics.*

*ii Baylor Health Care System: A not-for-profit healthcare system in Texas that includes 30 owned and affiliated hospitals, ambulatory surgical centres, outpatient clinics, and senior centres.*

*Rationale for data collection at registration/admitting*




successful engagement strategy used by Baylor Health Care System has been to provide staff with updates around data collection findings (G. Jones, personal communication, September 2012).

### "Best" Method: Integrate data collection into standard workflows

In applying best practices, health care organizations must stay committed to applying data collection methods that easily integrate into existing workflows and physical spaces. Health care organizations often have diverse and complex structures, with many patient pathways and trajectories marked by different settings, workflows and physical spaces. Settings include departments and programs ranging from emergency, medical inpatient beds, outpatient procedures, diagnostics, specialty clinics and beyond (IOM, 2009). From a health system perspective, these differences are further expanded with organizations such as Public Health or community

mental health agencies. With each organization and setting there are also patient factors which may facilitate or hinder data collection. When thinking of best practices, it is important to consider their applicability within the workflow and physical space. As examples, think of the cognitive well-being of older adults attending a gerontology program or the level of trust for persons with serious mental illness using a psychiatric hospital service (IOM).

### "Best" Method: Electronic integration

Lastly, it is important to recognize that the future of health care information lies in the electronic health record and the evolution of integrated systems of accurate data capture, storage and retrieval. It is widely believed that the collection of socio-demographic data would be strengthened by the use of digital methods (Weinick et al., 2000). Digital information capture reduces the need for labour intensive data entry and would enable the integration of socio-demographic data with other patient information.

## IDENTIFICATION OF CRITICAL SOCIO-DEMOGRAPHIC QUESTIONS

Research on social exclusion and health equity provides strong evidence of what is relevant to inequities in health status, access, quality and outcomes. Moreover, this research provides a firm evidence base for identifying what groups are most vulnerable to inequities in health. Accordingly, evidence has driven this project's process of selecting critical socio-demographic factors. Given the depth of health equity research and the multiplicity of factors driving the social determinants of health, it is not possible to list all the studies and systematic reviews forming the research base; instead, an empirical snap-shot lays out the rationale and evidence that helped identify 'what is most relevant'.

As shown in the upcoming table, this research project focuses on nine core demographic variables. Other factors that influence access and utilization of health care such as immigration status, education, and employment were considered but did not make the final list due to difficulty with data collection and/or weak reliability in Toronto. Common fears around disclosing legal status (Immigration Legal Committee, 2008) and Toronto's unique demographic profile of a majority foreign-born population that is highly educated but struggling with long-term underemployment (Li, Gervais, & Duval, 2006) are two such examples of why immigration status and education were respectively excluded.

## EVIDENCE-BASED RATIONALE FOR SOCIO-DEMOGRAPHIC MEASURES OF HEALTH EQUITY

| Socio-Demographic Factors | Rationale |
|---|---|
| Income | The evidence that income levels and income inequalities create health inequalities is wide and deep (Lightman, Mitchell & Wilson, 2008; Phipps, 2003; Ross et al., 2006). There is a large consensus that low income is the single most powerful predictor of poor health status and treatment outcomes. This is largely due to factors ranging from the deprivation of material factors to psychosocial mechanisms amplified by hierarchical differences in socio-economic position. While access to primary care and inpatient hospital care is not strongly associated with low income in most Canadian studies, a small number of studies indicate that low income affects differential access to specialty care (Alter, Naylor, Austin, & Tu, 1999; Murphy et al., 2012; Singh et al., 2004; Williamson et al., 2006).<br><br>There is a less robust research base exploring income-related stigma, discrimination and other inequities in health care experiences affecting quality of care. A recent Toronto based study reported that those with high income receive preferential access in finding a regular provider (Olah, Gaisano & Hwang, 2013), while research in Australia suggests that more affluent primary care patients receive preferential access to care regardless of the level of need (Johar, Jones, Keane, Savage, & Stavrunova, 2012). |
| Immigration Health | While it is recognized that most immigrants arrive with a higher health status than those born in Canada (the "healthy immigrant effect"), nearly two decades of research provides compelling empirical evidence that immigrants experience significant decline in health in terms of physical and mental health status within a two to five year period of arrival (Beiser, 2003; DeMaio, 2010; Hyman, 2007; Ng et al., 2005; Pahwa et al., 2012). In other words, immigrants are healthier than the average Canadian when they first arrive but start exhibiting worsening health outcomes after settlement; the original "healthy immigrant effect" pattern diminishes over time and immigrant health inequities start emerging (Zhao, Xue, & Gilkinson, 2010).<br><br>Due to the lack of health care organization socio-demographic data, Canadian research exploring immigrant related differences in access, experience and quality is less explored. Much of the research tends to focus on race and ethnicity (see below) so that it is difficult to ascertain whether it is immigrant status or race and/or ethnicity affecting access and experience. Few studies use quantitative methods or use strong, rigorous, qualitative research designs (Pollock et al., 2012). There is a small body of research examining how immigrant status and length of residence affect access to mental health services (Beiser, 2003; Hansson et al., 2009; Tiwari & Wang, 2008; Whitley, Kirmayer & Groleau, 2006). It is unclear whether reduced rates of mental health service utilization reflect immigrant status per se, or influential variables such as language proficiency (or preference) or cultural attitudes (both providers and residents). What is clear is that there is a strong and consistent association between immigration status and lower rates of mental health access (which is not fully explained by differences in need). |

## EVIDENCE-BASED RATIONALE FOR SOCIO-DEMOGRAPHIC MEASURES OF HEALTH EQUITY cont'd

| | |
|---|---|
| Race/Ethnicity (including Aboriginal status) | There is strong US evidence that race and ethnicity have an independent effect on health status, health care access and experiences and health outcomes (AHRQ, 2009; Laditka & Laditka, 2006; Macinko & Elo, 2009; Mayberry, Mili, & Ofili, 2000; Shavers et al., 2012; Weinick et al., 2000; Williams, 2012; Williams & Mohammed, 2009). A smaller body of research provides the same pattern of evidence in the UK (Nazroo, 2003; Nazroo, Jackson, Karlsen, & Torres, 2007).<br><br>While the amount of Canadian research is significantly smaller in comparison to the US, there is an emerging base of Canadian empirical research drawing attention to the critical variable of race and ethnicity as a health risk (Nestel, 2012; Wray & Hyman, 2013). A number of studies have concluded that the rate of health decline among immigrants is stronger among racialized groups than non-racialized immigrants (DeMaio & Kemp, 2010; Ng et al., 2005). Veenstra (2009) recently found evidence of significant differences in health status between racialized groups and White Canadians even after controlling for gender, age, immigrant status, income, and educational attainment. More recently, a number of small investigations point to an over-representation of Blacks in some types of mental health services, which would be consistent with studies in the US and UK (Barnes, 2004; King et al., 2005). Forensic psychiatric units in Southwestern Ontario "seem to have a disproportionately high number of men of colour, including African-Canadian men" compared to Whites (Annoual, Bibeau, Marshall, & Sterlin, 2007, p. 13), while an Ontario Early Intervention Program found that a high proportion of admissions were Black youth, representing 25% of the subsample from Toronto in comparison with Black persons comprising 6.7% of the population in Toronto (Archie et al., 2010).<br><br>Whereas the US has a deep research base examining racial and/or ethnic discrimination in health care (Shavers et al., 2012), Canada has few strong well designed empirical studies (Carrasco, Gillespie, & Goodluck, 2009; Pollock et al., 2012). One quantitative study observed significant differences between White and non-White groups in Canada with regard to their "satisfaction with health care received", a level of dissatisfaction comparable with US racialized variations (Lasser, Himmelstein, & Woolhandler, 2006). A small number of qualitative studies in the Greater Toronto Area (GTA) suggest up to 30% of persons of racialized status report discriminatory encounters in health care (Black Health Alliance, 2005; Hamilton Urban Core Community Health Centre, 2010; Pollock et al., 2012; Women's Health in Women's Hands, 2003).<br><br>Aboriginal Health<br><br>Canada's Aboriginal people in both rural communities and urban environments have significantly lower life expectancy (Tjepkema, Wilkins, Senecal, Guimond, & Penney, 2009; Tjepkema, Wilkins, Senecal, Guimond, & Penney, 2010). Almost regardless of the health indicator used – self-rated health, diabetes, cardiac health, infant mortality – Aboriginal populations typically have the greatest risk and experience the worst outcomes (Adelson, 2005; Health Canada, 2001; Lix, Bruce, Sarkar, & Young, 2009; Myers, 2002; Reading & Wien, 2009). Other research suggests Aboriginal people are more likely to receive a diagnosis at a later point in a disease progress (Morrisseau, 2009).<br><br>A number of studies have explored differences in access and utilization of health care services (Marrone, 2007; National Collaborating Centre for Aboriginal Health, 2011; Shah, Gunraj, & Hux, 2003). For those in urban centres, rates of primary care utilization are not significantly differentiated in comparison with non-Aboriginals, but there are variations in the utilization of specialists and specialty care. Moreover, Aboriginal communities speak about their fear of using impersonal medical services and wish for more culturally appropriate care in relation to their beliefs and traditions (Health Council of Canada, 2012). |

## EVIDENCE-BASED RATIONALE FOR SOCIO-DEMOGRAPHIC MEASURES OF HEALTH EQUITY cont'd

| | |
|---|---|
| Gender | The last two decades have seen an increasing recognition of the need to differentiate our understanding of sex and gender. Sex refers to a person's biological status, usually assigned at birth and typically categorized as male or female. Gender relates to gender identity and is linked to a person's sense of self, particularly the sense of being male, female, both, or neither; a person's gender identity may be different from their birth-assigned sex and is separate from their sexual orientation.<br><br>Historically the research on gender and health has focused on the health inequities faced by women in comparison to men, both in terms of health status (e.g., the higher prevalence of chronic disease and depression) and variations in access to and quality of health care. A slowly growing research base has started pointing to significant gender variations in use of cardiac defibrillators, coronary revascularization procedures, and likelihood of admission to an intensive care unit (and increased odds of dying in an ICU) (Birnie, Sambell, & Johansen, 2007; Fowler, Sabur, & Li, 2007; Kaul, Chang, & Westerhout, 2007). More recently, Ontario's POWER study has illustrated distinct variations in health care ranging from primary care to tertiary/quaternary care (Bierman et al., 2012).<br><br>With an increasing emphasis on gender there has slowly emerged a growing recognition of diverse forms of gender identities such as trans and intersex individuals. With such recognition has come acknowledgement that the health care system is lacking appropriate responses to ensure access and quality of care (IOM, 1999; Kaufman, 2007). "Trans" is an abbreviation, which includes but is not limited to, transgender, transsexual, gender non-conforming, and gender questioning persons. "Trans" can mean transcending beyond, existing between, or crossing over the gender spectrum. It is an umbrella term used to describe individuals who, to varying degrees, do not conform to what society usually defines as a man or a woman. Intersexuality refers to a physical and/or chromosomal set of possibilities in which the features usually understood as belonging distinctly to either the male or female sex are combined in a single body (Holmes, 2008). Issues of stigma and discrimination can affect health care utilization by individuals who identify as trans and intersex, such as research showing that 21% of trans people reported having avoided the emergency room when they needed it because they were trans (Trans Pulse Project, 2012). Trans and intersex individuals can also be vulnerable to specific health risks that need to be addressed, such as Frasier Syndrome among intersex people, a condition that affects skin development and poses a cancer risk that can run as high as 60% (Cools, Drop, Wolffenbuttel, Ooosterhuis, & Looijenga, 2006). |
| Language | Language is considered one of the greatest barriers in access to quality of care for people of non-English-speaking backgrounds. The US research on language and health is deep and points to the detrimental impact of language barriers on treatment, patient satisfaction, patient understanding and compliance, standards of ethical care (e.g., agreement to treatment), effectiveness, and cost (Flores, Laws & Mayo, 2003; Timmins, 2002; Yeo, 2004). Research linking language and quality of care through the use of interpreters is similarly robust. In a systematic review, Flores (2005) concluded that quality of care is compromised when Limited English Proficiency patients are not provided with interpreters.<br><br>In Canada, language barriers have been linked to variations in diagnostic testing, patient follow-up, pain management, medication prescription and chronic disease management such as diabetes (Bowen, 2001; Hyman, 2009). Similarly, Canadian evidence has linked language barriers with both higher and lower rates of service utilization (Bowen, 2000). Recent research by the POWER study (Project for an Ontario Women's Health Evidence-based Report) observed a significant relationship between poor access to primary care and having a first language other than English or French. Although this gap declines over time, it remains significant even up to 10 years after initial settlement (Bierman et al., 2012). Taken together, research findings on interpreter use suggest that communication, patient satisfaction, and health care outcomes are optimal when trained professional interpreters are available. |

## EVIDENCE-BASED RATIONALE FOR SOCIO-DEMOGRAPHIC MEASURES OF HEALTH EQUITY cont'd

| | |
|---|---|
| Lesbian, Gay, Bisexual Persons | Long a socially marginalized and excluded group, over the past few decades clinicians, public health researchers, and officials have become increasingly aware that lesbian, gay, and bisexual (LGB) persons face multiple barriers to quality care based on their unique health care needs (Mayer et al., 2008). Such recognition led the Institute of Medicine [IOM] (2011) to prepare and release a report on the known barriers to quality care while calling for better data collection and research. With local initiatives demonstrating that the collection of LGB data is feasible (Dilley, Simmons, Boysun, Pizacani, & Stark, 2010), the US Department of Health and Human Services has started developing standardized data collection plans suited for LGB populations.<br><br>Existing research points toward the distorting effects of social stigma on health status and health care access and quality (Coker et al., 2010; Kerith et al., 2010; Ryan, Brotman & Rowe, 2000).US research suggests LGB individuals do not disclose their sexual orientation due to fear of provider bias, while other studies report discriminatory behaviour such as refusal of treatment by health care staff, verbal abuse, and disrespectful behaviour affecting access to appropriate care and compromising health care experiences (Eliason & Schope, 2001; Jillson, 2002; Kenagy, 2005; Scherzer, 2000; Sears, 2009; Smith & Mathews, 2007). In Canada, research has found that gay, lesbian and bisexual Canadians have different health care-seeking behaviour than do other Canadians, and that there are differences within the larger category of LGB (Mathieson, Bailey, & Gurevich, 2002; Tjepkema, 2008). For example, lesbians are less likely to have a family doctor, have a primary health care consultation or receive a Pap test than heterosexual women. While not fully understood, the findings are suggestive of stigma avoidance as some research suggests increased health care use by lesbians who have told their doctor about their sexual orientation (Bergeron & Senn, 2003). Conversely, having a regular doctor and primary care utilization was not significantly different for gay, bisexual or heterosexual men. Health care-seeking behaviour can further be distinguished in relation to bisexual persons who, unlike gays or lesbians, are more likely to report an unmet health care need (Tjepkema, 2008). |
| Disability | Persons with disabilities encounter frequent barriers that generate inequities in health (Lezzoni, 2011). In recognition of these challenges, the US Patient Protection and Affordable Care Act requires health care organizations to collect data on the use of services by those with a disability. Yet persons with disabilities are not a homogenous group, and there are significant differences in the type and severity of disability, further diversified by age, gender, socioeconomic status and other factors (Alborz, McNally, & Glendinning, 2005; Sullivan, Heng, & Cameron, 2006). In addition to the disabling condition, there is often a strong association with secondary and co-morbid conditions (Alborz et al., 2005; Krahn, Hammond, & Turner, 2006; Sullivan et al., 2006; Wei, Findley, & Sambamoorthi, 2006). The presence of a disability may impact access to care and the health care experience, but not necessarily in a uniform way. For example, persons who are pre-linguistically deaf have been found to under-utilize health care services, while persons who are post-linguistically deaf over-utilize services (O'Hearn, 2006). Generally speaking, even though the evidence is mixed, persons with disabilities are more likely to under-utilize preventive services (O'Day, Killeen, Sutton, & Iezzoni, 2005; O'Hearn, 2006; Rurangirwa, Van Naarden Braun, Schendel, & Yeargin-Allsopp, 2006). Moreover, patterns of utilization appear to follow an inverse gradient such that those persons with less severe disabilities are more likely to use health care services and those with greater limitations less likely to access care (Wei et al., 2006).<br><br>Dissatisfaction with health care among persons with disabilities is well-documented. For example, in a study conducted in Toronto, one-in-five persons with a disability (21.9%) felt that their disability prevented them from receiving adequate health care (Veltman, Stewart, Gaetan, Tardif, & Branigan, 2001). Satisfaction and experience is affected not only by provider attitude and behaviour, but also by the health care environment. The key components required to ensure high quality care for a disabled population is well-documented in the research including: 1) Accessible environments; 2) Procedural accommodation (e.g., amount of time allocated for appointment, sign language interpretation); and 3) Health information in accessible formats (Mele, Archer, & Pusch, 2005; Smeltzer, Sharts-Hopko, Ott, & Zimmerman, 2007; Ubido, Huntington, & Warburton, 2002; Veltman et al., 2001). |

| EVIDENCE-BASED RATIONALE FOR SOCIO-DEMOGRAPHIC MEASURES OF HEALTH EQUITY cont'd | |
|---|---|
| Housing Status | Homelessness is a significant health risk and health equity issue (Frankish, Hwang & Quantz, 2005; Hwang, 2000; Hwang, 2001; Research Alliance for Canadian Homelessness, Housing, and Health [REACH], 2010). There is strong evidence indicating that persons of no permanent residence (e.g., couch surfing) are more likely to be in poor health, yet less likely to be able to obtain adequate and appropriate health care (REACH). Moreover, homeless persons are at a higher risk of encountering discrimination in the care process ranging from staff attitudes and behaviours to inequitably differentiated treatment pathways (Hwang & Henderson, 2010; Kushel, Vittinghoff & Haas, 2001; Wen, Hudak & Hwang, 2007). |
| Religion | It is well documented that persons who maintain strong religious and spiritual beliefs and/or have strong connections to faith- based communities experience better health outcomes than their counterparts (Williams & Sternthal, 2007). However, certain faith communities may experience discrimination that the health care system is not immune to. One example from the UK points to a gap in faith-based services for Muslims and insufficient research on conditions affecting Muslims' health (Sheikh, 2007). First Nations in Canada have made similar calls for the need to accommodate their traditional spiritual and cultural beliefs as part of a holistic approach to health care (First Nations Health Council, 2011).<br><br>There is a growing research base pointing toward the need to consider religious beliefs and needs as a critical aspect of quality processes and assessments (Clark, Drain & Malone, 2003; Flannelly, Galek, & Handzo, 2005). Recognition of unique beliefs toward quality of life and end-of-life are among the more obvious, although not exclusive examples (Balboni, Vanderwerker & Block, 2007; Curlin, Chin, Sellergren, Roach, & Lantos, 2006; Ehman, Ott, Short, Ciampa, & Hansen-Flaschen, 1999; Koenig, 2007). Overall, the accommodation of diverse religious and spiritual beliefs in the health care system is becoming an important criterion of patient satisfaction, and a subject of exploration in relation to access and outcomes. |

## IDENTIFYING THE FORMAT FOR SOCIO-DEMOGRAPHIC QUESTIONS

Once the key socio-demographic concepts were identified, the next step (or challenge) was to identify the format and instructions for asking socio-demographic questions.

The processes of survey question development aimed to format and create questions that were both useful for the purposes of collection, aggregation and analysis, while being meaningful for survey respondents.

Sociology research suggested that the "best" method for defining ethnicity is open-ended selection by the individual on the basis of "identity", defined as an individual's self-understanding of their racialized status and/or ethnicity. This is distinguishable from "identification", which refers to how people categorize themselves on surveys (Brunsma, 2005; Brunsma, 2006). The option of creating questions with open-ended formats created several challenges to the steering committee's survey goals. First and foremost, the lack of defined categorization meant that the data would be impossible to aggregate and would not satisfy the requirements for comparative utility. Secondly, the open ended approach would introduce unmeasured influences and factors such as social norms, socialization, neighbourhood composition, age, and socio-economic status that could affect responses and confound any aggregation and comparison (Khanna, 2012).

Although the "check all that apply" structure has been commonly used in surveys, research has shown that it can compromise data quality and pose challenges to data analysis. Using "check all that apply" is associated with respondents' failure to carefully consider all other options once the first selection is made (Safir, 2007). In contrast, "check one only" instructions lead to a more careful consideration of options when responding (Safir). Using "check all that apply" also poses challenges from a data usage perspective since multiple responses require complex statistical analyses that continue to be debated in the research methods field, and lead to restrictions around aggregating, comparing, and understanding data (Lavassani, Movahedi, & Kumar, 2009).

Given the various limitations and restrictions raised above, the steering committee chose to collect demographic information using closed-ended questions and ask patients to "check one only" (except when not applicable).

## ENVIRONMENTAL SCAN – LOCAL ORGANIZATIONS COLLECTING SOCIO-DEMOGRAPHIC DATA

The environmental scan was the next step in building an evidence base of the critical issues, challenges and promising practices related to the collection of socio-demographic patient data. The purpose of the scan was to explore the practical and on-going experiences among 11 local organizations (and one US agency) that have engaged in collecting demographic data[iii]. Accordingly, the scan queried each organization in relation to critical barriers and success factors, the type of socio-demographic data currently collected, the instruments and methods of collection, staff and/or patient compliance rates, and materials used to support these efforts.

[iii] *Client Access to Integrated Services and Information (CAISI); Centre for Addiction and Mental Health – Problem Gambling Services; Centre for Addiction and Mental Health – Rainbow Services; Centre for Health Equity and Social Justice (Boston); Committee for Accessible AIDS Treatment; Mount Sinai Hospital – Neonatology; South Riverdale Community Health Centre; Thorncliffe Neighbourhood Office/Public Interest; Toronto Community Housing Corporation; Toronto District School Board; and, United Way Toronto.*

The first level of findings from the environmental scan of key informants confirmed many of the findings in the literature review. Taken together, the key findings on survey design and implementation were:

- **'Keep it short and sweet'** – While there is a high temptation to ask for all possible types of relevant information, the longer the questionnaire and time required for completion and the higher the degree of complexity, the lower response rates will be. Knowing less but knowing it reliably is a better outcome than knowing more but less reliably. Research evidence suggests it is the most marginalized groups and those most at risk of inequitable access, quality, and outcomes who are the most likely to fall off in the response rate.
- **'From least to most sensitive'** – Consistent with surveys of public perception, there is a 'gradient of comfort' in terms of the socio-demographic factors. Public sensitivity regarding questions on income was confirmed by organizations implementing this question. Rather than substituting or avoiding sensitive questions, the preferred strategy for organizations is to order the sequence of question from least sensitive (language) to most sensitive (income).
- **Practice, Practice, Practice'** – All organizations emphasized the vital importance of training and education for staff. The staff acceptance of the need for collecting socio-demographic information will be reflected in acceptance by patients/clients. Consequently, staff resistance and discomfort would be projected. For example, high rates of 'unknown' or 'prefer not to answer' might be more an indicator of staff discomfort and avoidance of asking the questions than patient willingness (as was the case in the UK). The key to effective training are the following:
  - Emphasize the rationale and importance of asking socio-demographic questions to build awareness, including education on the social determinants of health and health equity. Education will increase 'buy in' as well as help staff explain to, and support the patient
  - Design education and training processes in a manner that consults and builds consensus
  - Use a hands-on approach with ample opportunities for practice – or in the words of one informant – "practice, practice, practice"
  - Create expectations but within a supportive, flexible learning environment
  - Allow for re-training and follow-up questions
- **'Take from what works'** – Materials developed by the various organizations and sources of relevant quality reports were identified for use in the development process. For example, the questionnaire preamble used by the Boston Disparities Project was viewed as an excellent means of initiating contact with patients/clients, while the concise plain language approach for question development by the Toronto District School Board provided a good example for ensuring understanding.

Secondary findings included a clear gap in data collection on sexual orientation and consensus that data collection should happen through patient self-identification instead of other proxies (e.g. staff guessing from last name or appearance). In addition, it was emphasized that the categorization of race and ethnicity should be developed with sufficient detail to enable robust and nuanced analysis, while also layered in a format that enables aggregation. All informants emphasized that it is important the categories be developed in a way in which people can 'recognize themselves' and yet retain analytical validity and utility. As one informant stated it, one can fall into a trap of definitional paralysis so the guiding principle of survey development should be: "don't let perfect get in the way of good enough".

# Gearing Up

## SURVEY DEVELOPMENT

The final 14 pilot questions (see Appendix A) followed 23 distinct iterations of the survey over a two-year period; the changes included language use, categorizations, and answer formats. The foundations for the questions were the evidence-based socio-demographic factors and the next step was to translate these factors into meaningful and useful questions and selection categories. Moreover, the categorization and choices underwent frequent revisions that were driven by the goals of practical application and stakeholder feedback. The key ingredients in this developmental process were research evidence and practical experience shaped via collegial negotiations, debates, and consensus building (Please see *Bringing It All Together* section on p. 30 for more details on each item).

## AWARENESS, TRAINING AND PROMOTION

The next phase of development was the creation of education and training tools, promotional materials and standardized scripts to be used in the collection process. Much of the material was identified during the environmental scan and key informant interviews before being adapted and standardized for use across the Tri-Hospital + TPH sites.

A training phase was launched for each organization including cross-organizational learning sessions for senior leaders and front-line staff. Up to 12 hours of training and preparation was implemented by the pilot sites prior to data collectors entering the field. The key source of training information was derived from the NHS Scotland's "Happy to Ask" DVDs and manual. These materials had been developed, implemented and evaluated as part of Scotland's strategy to improve the low rates of collecting data on race/ethnicity, religion and other factors from people using the health care system. Materials were also developed to assist the trainers in setting up and facilitating their training session.

## PILOT PROJECT SITES

As noted earlier, the health care system is obviously not a singular system. There are a wide variety of settings and types of programs, posing potential differences in the application and receptiveness of patients/clients. To account for this heterogeneity in form and function, a variety of health care settings and programs were carefully selected.

This step required the negotiation and support of medical and research staff, as well as the stringent process of obtaining Research Ethics Board (REB) approval and discussions with privacy officers. As well, moving forward required the activation and participation of information technology specialists involving the formation of special committees to guide implementation. There was no single process for internal hospital engagement and each pathway was reflective of the unique organizational structure and cultures. However, it is essential to note that establishing an internal process represented a time intensive process of engagement and complicated negotiation/agreement.

Settings included family medicine at two organizations, a geriatrics program, a general internal medicine program (the only in-patient program), an outpatient schizophrenia program and a public health program (Healthiest Babies Possible Program). Below is a brief overview of each site:

## Mount Sinai

### Family Medicine and General Internal Medicine

With the strong support and championing by medical leadership, the data collection pilot project was implemented in two diverse settings. The first setting was in General Internal Medicine (GIM); a particularly unique challenge given the acute illness, age and cognitive competency of many of the patients. With admissions through the emergency department, the inpatient program cuts across three hospitals units with a diverse range of conditions and multi-disciplinary care ranging from simple pneumonia to complex medical conditions with multiple comorbidities. GIM also has a partnership with the Geriatrics Program reflecting the age and fragility of many GIM patients.

> The survey question and categorizations for race/ethnicity were adopted from the Toronto District School Board, a census survey that has been validated through repeated successful implementations.

The second setting was the Family Medicine clinic, a fast-paced clinic with a mixed population of age groups, medical conditions, and complexity of care. The Mount Sinai Academic Family Health Team (MSAFHT) is in downtown Toronto, with patients who are from all over the GTA. MSAFHT has just over 9,600 rostered patients and has approximately 33,000 patient visits a year. MSAFHT provides multi-disciplinary care for families at any age including preventive and acute care, as well as maternity care (including prenatal, birth and postpartum), pediatric, adult, and geriatric care. The MSAFHT has special programs devoted to diabetes, mental health and maternity care. The team includes family physicians, family medicine residents, nurse practitioners, social workers, dieticians, registered nurses, a mental health nurse, a diabetes nurse educator, a maternity care nurse, and a pharmacist.

## St. Michael's

### Family Medicine Outpatient Clinic (80 Bond Street)

St. Michael's Hospital provides care in the heart of downtown Toronto. The pilot project setting was the Family Practice Outpatient Clinic at 80 Bond Street which to a great degree reflects the urban environment within which it sits regarding race, language, sexual orientation, gender identity, faith, disability, age, income, and housing status.

## CAMH

### Schizophrenia Outpatient Program

The CAMH Outpatient Schizophrenia program constitutes a particularly unique population of patients with serious mental illness, many of whom are long time users of the services.

This off-site service provides a coordinated and comprehensive treatment program for people who have chronic schizophrenia or related disorders and are living in the community. The approach is recovery-oriented, interdisciplinary, and holistic. Assessment, individual, family and group counselling, medication monitoring, case management, peer support and education are also provided.

## TPH

### Healthiest Babies Possible Program

Due to the nature of the 'public health' mandate, many TPH programs are specially designed to pro-actively address the social conditions known to contribute to health risk and compromised health status. Moreover, unlike hospitals, access and use of the TPH services is not dependent on OHIP status, and a number of programs operate on the principle of anonymity (e.g., sexual health, AIDS). This has the dual effect of drawing a population of service users who are more likely to be economically marginalized and socially excluded.

Specifically, the Healthiest Babies Possible (HBP) program was selected as the pilot project site. HBP is a prenatal nutrition support intervention for pregnant women at risk of having a low weight baby. Services are delivered by 16 Registered Dieticians (RDs) in over 50 locations across the City of Toronto (beyond formal TC LHIN boundaries). On an annual basis, approximately 650 program clients receive on-going assessment, nutrition counselling, education and intensive support. Additional instrumental resources such as food certificates, prenatal vitamins and public transit tokens are provided when necessary support the mother's well being (and future health of the baby), as well as referrals when necessary to other human service providers to address issues ranging from domestic violence, settlement, housing or smoking.

# The Pilot Project

This section provides information on *What We Did*- the methods and approaches to data collection, and *What We Found*- a summary of data analysis from Tri-Hospital + TPH sites. This pilot, along with the follow up data analyses, addressed these three objectives:

- Develop and pilot test evidence-based data collection methods and a survey tool
- Analyze patient responses and feedback from data collectors to improve the methodology and survey tool
- Explore the relation between demographic variables and self-rated health

The data used in the final analyses came from these two sources:

1) *Data from patients across four health institutions*. This data, predominantly in quantitative form, was collected from patients through survey administration. The findings (reviewed below) were used to determine differences in response rate to each question, and how those differences related to methods of data collection. The analyses also tested associations between socio-demographic variables and self-rated health.

2) *Data from data collectors*. This information was captured through focus groups, one-on-one interviews with data collectors, and an online feedback survey. The data was predominantly qualitative in nature and provided insightful information about the data collection experience.

## WHAT WE DID – DATA COLLECTION METHODS

Data collection methods were developed with the intention of expanding those practices beyond the survey pilot stage and into system-wide data collection, meaning they were developed with long-term use in mind. While flexibility was allowed and encouraged when adapting methods to each specific setting, the 'gold standard' of having patients directly supply information rather than using secondary sources was applied across all sites.

TABLE 1

*Information on location, method, and data collectors across all sites*

| LOCATION | METHOD | ADMINISTRATION |
|---|---|---|
| MSH – General Internal Medicine – bedside | Paper | Volunteers (Internationally educated health professionals) |
| MSH – Granovsky Gluskin Family Medicine Centre – waiting room | Paper | Self with assistance of volunteers (internationally educated health professionals) |
| SMH – Family Practice Outpatient Clinic – waiting room | iPad Tablet | Self with assistance of two multi-lingual post-graduate students |
| CAMH – Outpatient Schizophrenia Program | Paper | Volunteers, research staff and health care providers |
| TPH – Healthiest Babies Possible Program – 2nd visit | Paper | Health Providers |

The variation in data collection methods paved the way for comparisons on the impact of various methods on response validity, and provided sites with the ability to adopt a data collection approach that fits with their ongoing work. Data collectors were asked to complete an "Office Only" section for each survey; this section provided information on the following data collection methods:

1) Who provided the information?
2) What method was used?
3) Who administered the survey?
4) How was the survey completed?
5) Where was the survey completed?

## WHAT WE LEARNED – DATA FROM THE PILOT PROJECT

A total of 2,242 patients were approached in five pilot sites during the summer of 2012. Of these, 86.6% of patients ($n$ = 1,942) answered the survey and 13.4% ($n$ = 300) declined to answer[V]. Therefore the first finding was that patients were willing to share their information. It is also important to note that the statistical data and data collectors' feedback from each site were aggregated to ensure participants' anonymity.

In order to meet the objectives of the Tri-Hospital + TPH pilot project, a number of follow-up data analyses were carried out on the survey data, the data collection methods, and self-rated health. These analyses ranged from calculation of percentages to more complex tests such as Chi-Square tests of associations. Once completed, the analyses provided a number of insightful findings on:

1) Data collection methodologies
2) Survey tool analysis
3) Tests of association
    a. Association between data collection methods and valid responses
    b. Association between survey items and self-rated health
    c. Summary of findings
4) Follow-up: Feedback from data collectors

[V] *Please note that one site did not report the number of refusals to participate. The revised participation rate after removing that site is 82.5%.*

## Data Collection Methodologies – Summary

In order to provide a summary of the methods that were used to collect data in the Tri-Hospital + TPH pilot project, data collectors were asked six questions on data collection practices (refer to *What We Did-Data Collection Methods*).

Responses are summarized in graphs below, with each graph laying out the various methods and the frequency of their use.

**FIGURE 1**

*Summary of who provided responses to the demographic questions across all sites*

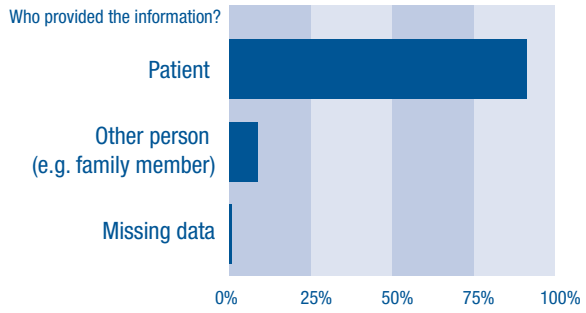



**FIGURE 2**

*Summary of methods used to capture patient demographic data*

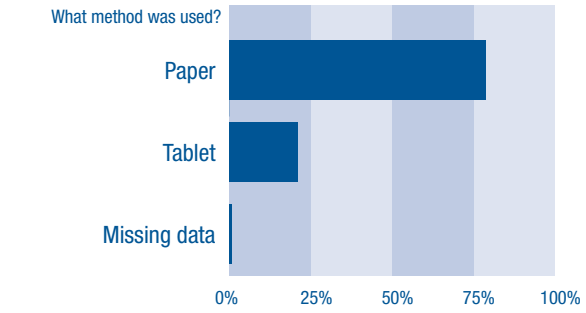



**FIGURE 3**

*Summary of who administered the survey to patients*

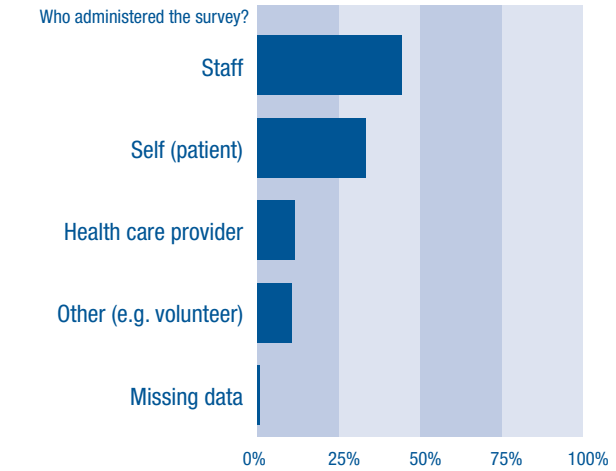



**FIGURE 4**

*Summary of the proportion of patients who completed the survey in English and other languages*

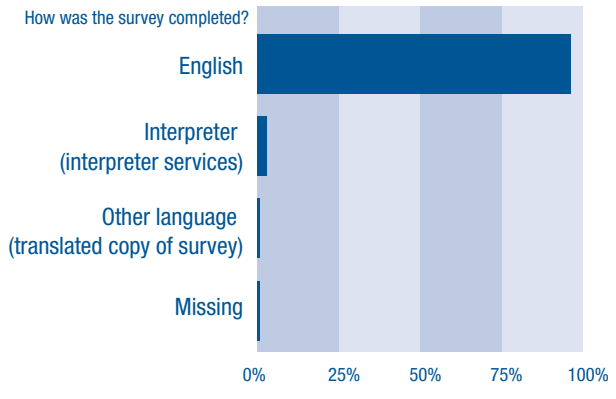
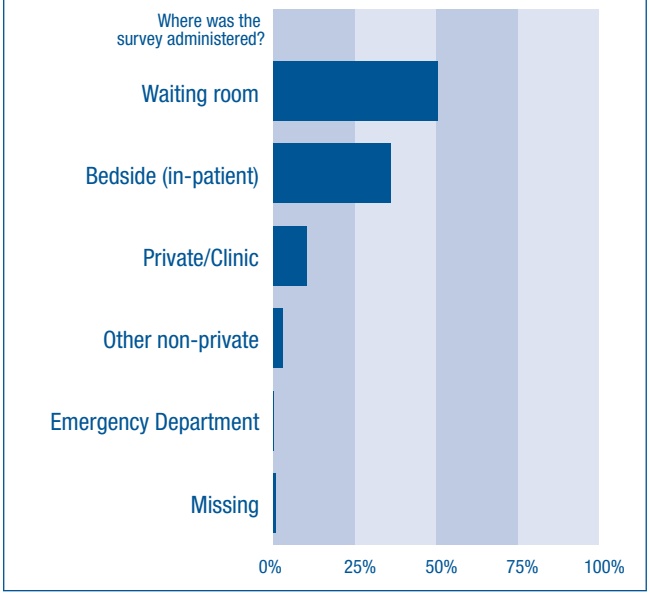


FIGURE 5

*Summary of where demographic data was collected*




## Analysis of the Survey Tool

### Response Validity

Response validity was calculated for each item by looking at the proportion of 'valid' responses (versus 'invalid'). A response was considered to be 'valid' if the respondent selected any one of the available response options (responses of 'don't know' and 'prefer not to answer' are considered valid).

As Table 2 shows, the majority of questions had response validity exceeding 95% with the exception of two items: "If not born in Canada, what year did you arrive?" (85.5%) and "How many people does this income support?" (84.6%). Both of those questions were follow-up questions rather than stand-alone items.

TABLE 2

*Percentage of valid responses per survey item*

| QUESTION<br>* FOLLOW UP ITEM | VALID RESPONSES |
|---|---|
| In what language would you feel most comfortable speaking in with your healthcare provider? ($n$ = 1942) | 97.6% |
| How would you rate your ability to speak and understand English? ($n$ = 1942) | 98.3% |
| In what language would you prefer to read healthcare information? ($n$ = 1942) | 97.3% |
| Were you born in Canada ($n$ = 1942) | 98.6% |
| *If not born in Canada, what year did you arrive? ($n$ = 876) | 85.5% |
| Which of the following best describes your race? ($n$ = 1942) | 97.6% |
| What is your religious or spiritual affiliation? ($n$ = 1727)[vi] | 94.6% |
| What is your gender? ($n$ = 1942) | 97.9% |
| What is your sexual orientation? ($n$ = 1942) | 97.1% |
| What was your total family income before taxes last year? ($n$ = 1942) | 96.4% |
| *How many people does this income support? ($n$ = 1942) | 84.6% |
| What type of housing do you live in? ($n$ = 1942) | 97.2% |
| In what year were you born? ($n$ = 1232)[vii] | 96.1% |
| Do you have any of the following disabilities? ($n$ = 1942) | 94.2% |

[Vi] *Note: the sample size is smaller because some respondents were asked this question as two separate questions. These individuals could not be grouped appropriately with the other respondents.*

[Vii] *Note: the sample size is smaller because for some respondents their date of birth was taken from their health record, not as it was reported on the survey.*

### Frequency of Don't Know and Prefer Not to Answer Responses by Question

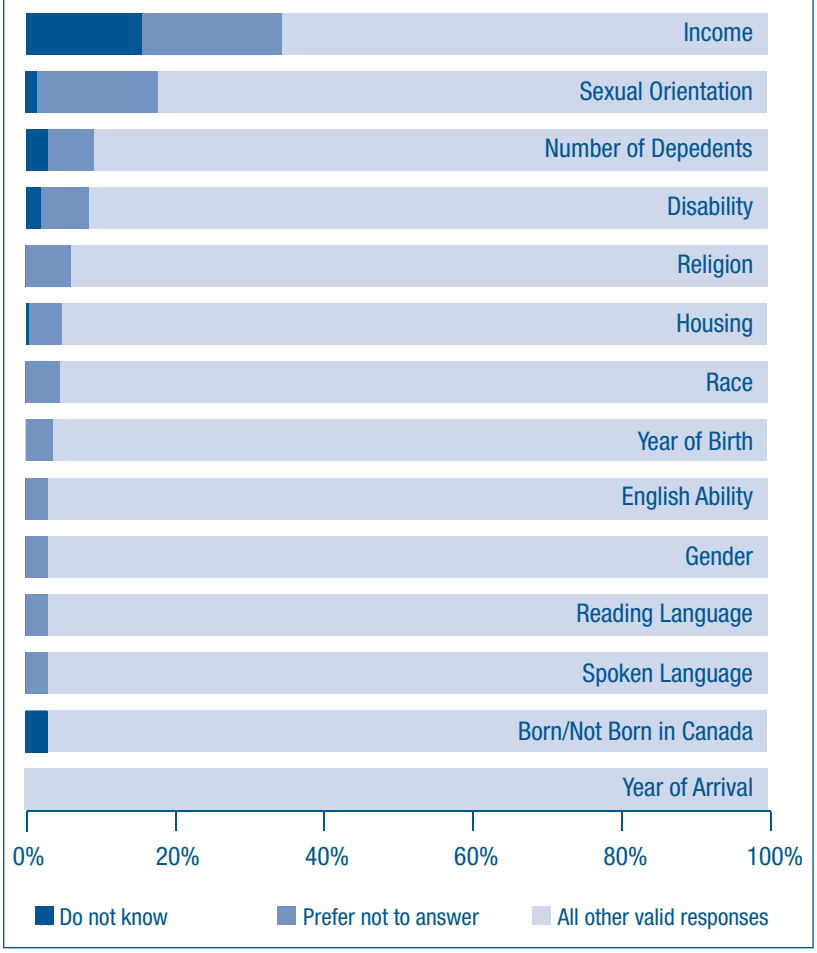
The frequency of 'don't know' and 'prefer not to answer' responses for the survey questions is presented in Figure 6. Most of the questions had very low proportions of 'don't know' and 'prefer not to answer' responses. Not surprisingly, the highest proportion of either response was for income.

Highlights:

- The valid response rate for the Income item was 96.4%. Out of those valid responses, 65.5% indicated a specific income range, with 18.9% of all valid responses being "prefer not to answer"
- The highest "do not know" rate was for Income
- Of those who agree to participate, over 90% of patients were willing to identify with responses for Race (94%), Gender (97%) and Sexual Orientation (92%)

FIGURE 6

*Frequency of 'don't know' and 'prefer not to answer' responses for each survey question*




### Tests of Association

#### Association between *Data Collection Methods and Response Validity*

The next step after the calculation of valid response rates was to test for significant associations between the proportion of valid responses for each survey item and the data collection methods. In other words, is there a connection between the methods used to collect data and the rate of valid responses that patients provide? A Pearson Chi Square was identified as the appropriate statistic for testing these potential associations.

With cells of five or more, (i.e. > 5), the Pearson Chi Square test was used and results were considered significant if $p < .05$. In 2X2 cases of smaller cell counts with expected cells < 5, the Fischer exact test statistic was used to identify significant associations. The results are highlighted in Table 3 below, with '*ns*' indicating that there was no significant association.

TABLE 3

*Chi-square associations between four data collection methods and valid response rates* [viii]

| Question | % Valid | Data Collection Methods and p-value | | | |
|---|---|---|---|---|---|
| | | **Factor:** Who provided information? [Patient/Other person] | **Factor:** Method used? [Paper/Tablet] | **Factor**: Who administered? [Self/Other] | **Factor**: Where administered? [Waiting Room/In-patient/ Outpatient] |
| 1. Preferred spoken lang. | 97.7% | *ns* | *ns* | *ns* | *ns* |
| 2. English ability | 98.3% | .018* | .006 | *ns* | *ns* |
| 3. Preferred reading language | 97.4% | *ns* | .000 | *ns* | .001 |
| 4. Born in Canada | 98.7% | .022* | *ns* | .019* | *ns* |
| 5. Year of arrival | 85.5% | *ns* | .000 | .013 | .000 |
| 6. Year of birth | 96.1% | *ns* | .002 | *ns* ($p < .1$) | *ns* |
| 7. Racial affiliation | 97.6% | *ns* | *ns* | *ns* | *ns* |
| 8. Religious affiliation | 94.6% | *ns* | *ns* | .002* | .000 |
| 9. Disability status | 94.2% | *ns* | .000 | *ns* | .000 |
| 10. Gender | 98.0% | *ns* | .001 | *ns* | *ns* ($p < .1$) |
| 11. Sexual orientation | 97.1% | *ns* | .000 | *ns* | .001 |
| 12. Income | 96.4% | *ns* | .000 | *ns* | .000 |
| 13. No. of dependents | 84.6% | .000* | .000 | .000 | .000 |
| 14. Housing | 97.3% | *ns* | .000 | *ns* | .001 |
| 15. Self-rated health | 97.2% | *ns* | .000 | *ns* | .015 |

* $p<0.05$, ** $p<0.01$, *** $p<0.001$; *ns* = not significant

A closer look at the significant associations reveals a number of patterns, a few of which are highlighted below:

"Who provided the information?"

**FIGURE 7**

**Ability to speak and understand English**

*Pattern of findings for the significant association between 'who provided information?' and 'rate your ability to speak and understand English' ($x^2 = 7.00$, $p < .01$)*

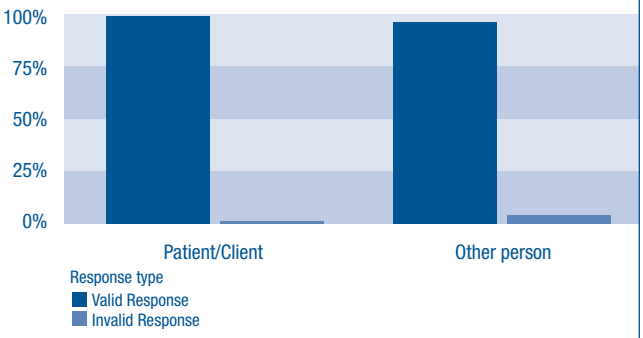



**FIGURE 8**

**Born in Canada**

*Pattern of findings for the significant association between 'who provided information?' and 'born in Canada?' ($x^2 = 6.76$, $p < .01$)*

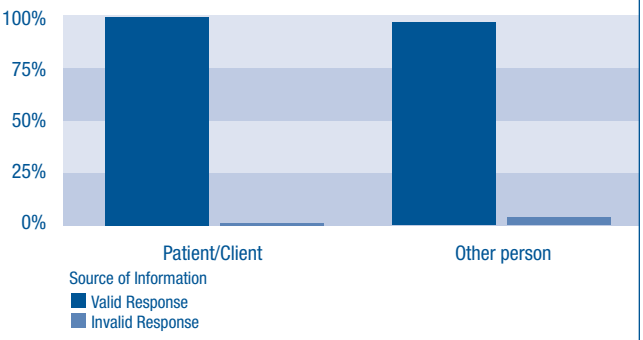
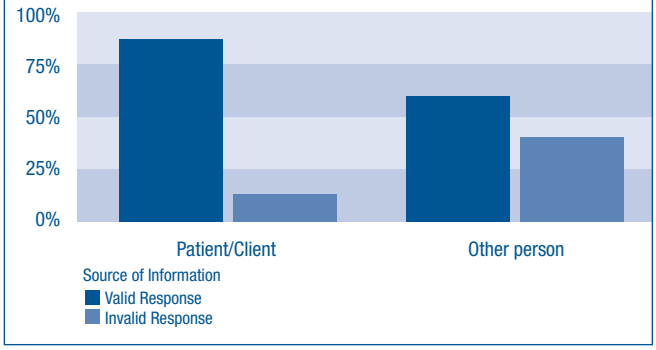



**FIGURE 9**

**Number of People income supports**

*Pattern of findings for the significant association between 'who provided information?' and 'number of people this income supports' ($x^2 = 87.14$, $p < .001$)*




[viii] *Due to small sample sizes in for those who completed the survey in a language other than English, the method, data looking at "How was the survey completed?" was not analyzed.*

## “How was the information collected?”

FIGURE 10

**Do you have any of the following disabilities**

*Pattern of findings for the significant association between ‘How was the information collected?’ and ‘Do you have any of the following disabilities?’ ($x^2 = 83.83$, $p < .001$)*

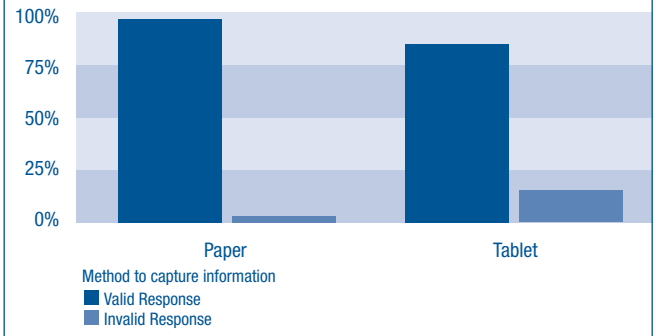



FIGURE 11

**What is your sexual orientation**

*Pattern of findings for the significant association between ‘How was the information collected?’ and ‘What is your sexual orientation?’ ($x^2 = 14.60$, $p < .001$)*

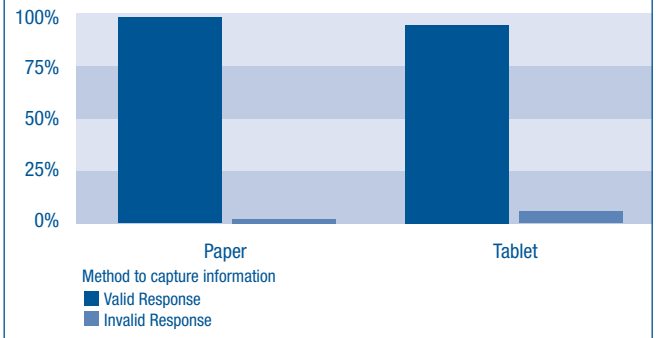
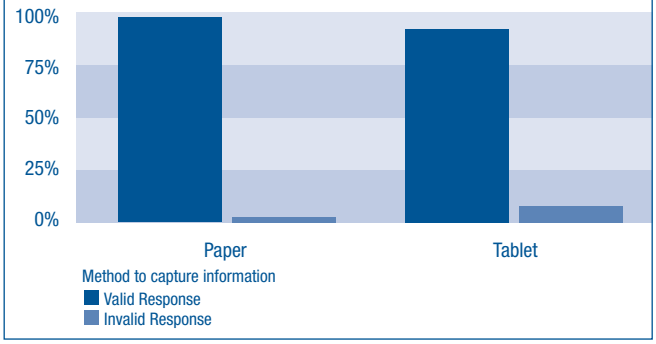



FIGURE 12

**What was your total family income before taxes last year**

*Pattern of findings for the significant association between ‘How was the information collected?’ and ‘what was your total family income before taxes last year?’ ($x^2 = 26.44$, $p < .001$)*




## "Who administered the survey?"

FIGURE 13

**Were you born in Canada**

*Pattern of findings for the significant association between ‘who administered the survey?’ and ‘were you born in Canada?’ ($x^2 = 5.69$, $p < .05$)*

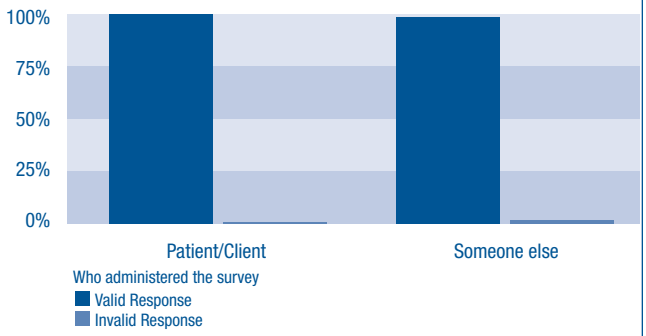
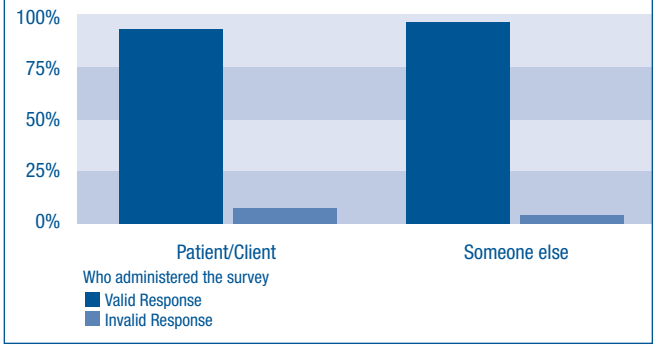



FIGURE 14

**What is your religious affiliation**

*Pattern of findings for the significant association between ‘who administered the survey?’ and ‘what is your religious or spiritual affiliation?’ ($x^2 = 10.11$, $p < .001$)*



"Where was the survey administered?"

FIGURE 15

**Do you have any of the following disabilities**

*Pattern for the association between 'where was survey administered?' and 'do you have any of the following disabilities?' ($x^2 = 53.39$, $p < .001$)*

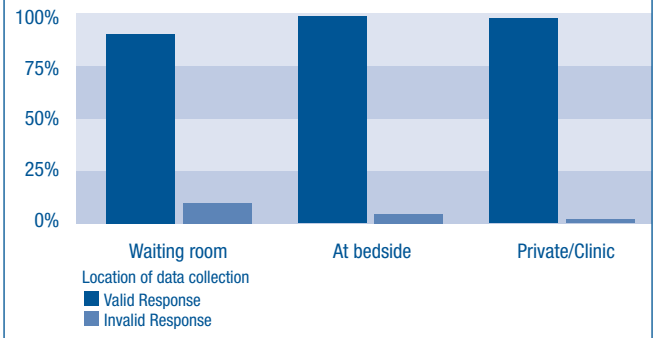



FIGURE 16

**What is your sexual orientation**

*Pattern for the association between 'where was survey administered?' and 'what is your sexual orientation?' ($x^2 = 13.58$, $p < .001$)*

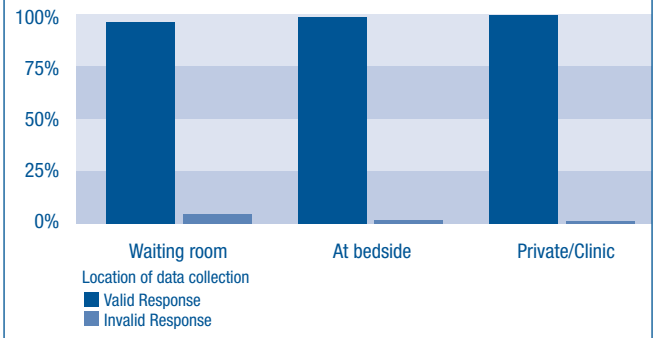
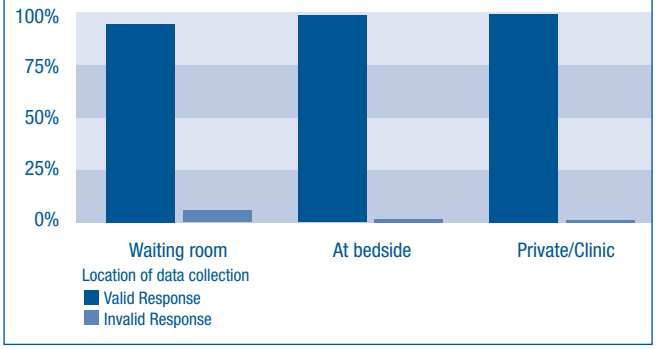



FIGURE 17

**What was your total family income before taxes last year**

*Pattern for the association between 'where was survey administered?' and 'what was your total family income before taxes last year?' ($x^2 = 23.63$, $p < .001$)*




## Associations between Survey Questions and Self-Rated Health

One of the stated objectives was to explore the relation between the survey's demographic variables and self-rated health (SRH). Self-rated health is a measure of how an individual perceives his or her health—rating it as "excellent", "very good", 'good", "fair", or "poor". SRH has been validated as a useful indicator of health for a variety of populations and allows for broad comparisons across different populations.

### Self-Rated Health Question

In general, would you say your health is:

- ❍ Excellent
- ❍ Very good
- ❍ Good
- ❍ Fair
- ❍ Poor
- ❍ Prefer not to answer
- ❍ Do not know

To test the association between each demographic item and SRH, a Chi Square test was used to examine associations between categorical data and SRH. ANOVA was used to examine associations between continuous variables (i.e., age and length of stay in Canada) and SRH. In both cases results were considered significant if $p$ <.05.

Note: For most questions, due to a small cell size, several response categories were combined into one to enable statistical testing (e.g. preferred spoken language response categories were collapsed into two: English and Non-English).

All demographic items, with the exception of sexual orientation, exhibit a significant association with self-rated health. A number of interesting patterns are highlighted below:

**FIGURE 18**

*Significant association between preferred spoken language and SRH*
*($x^2 = 34.50$, $p < .001$)*

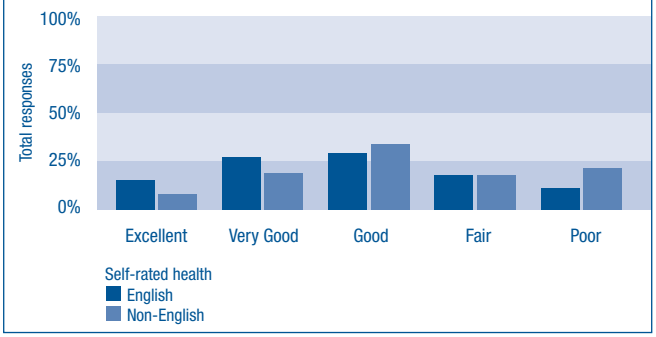



**FIGURE 19**

*Significant association between born/not born in Canada and SRH*
*($x^2 = 12.09$, $p < .05$)*

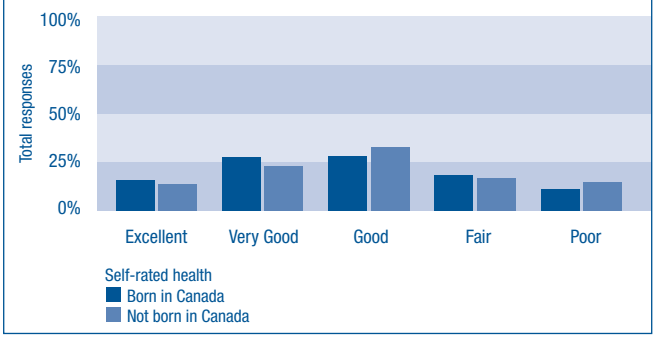



**FIGURE 20**

*Significant association between Race/Ethnicity and SRH*
*($x^2 = 18.58$, $p < .001$)*

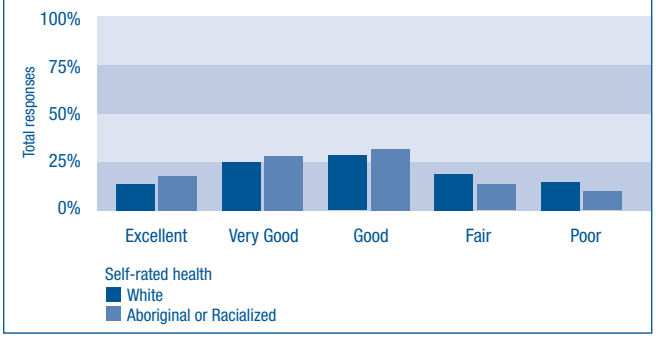



**FIGURE 21**

*Significant association between disability and SRH*
*($x^2 = 400.60$, $p < .001$)*

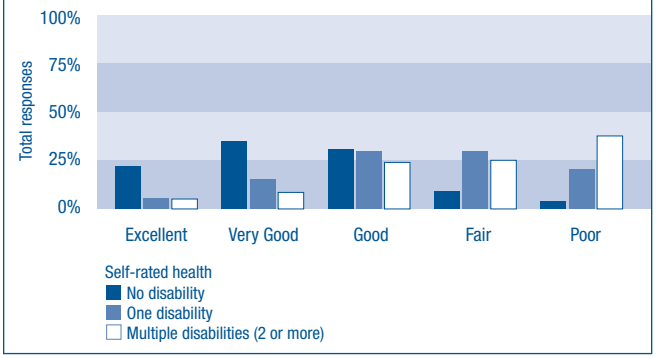



**FIGURE 22**

*Significant association between gender and SRH*
*($x^2 = 22.08$, $p < .001$)*

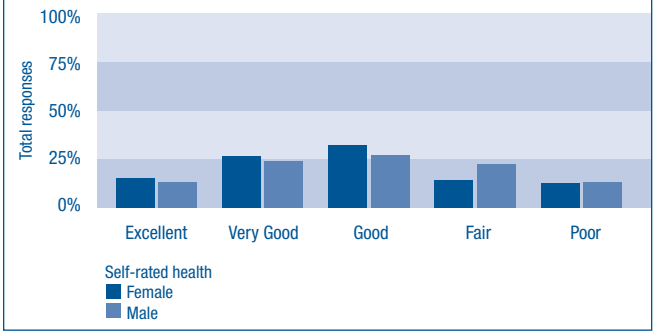
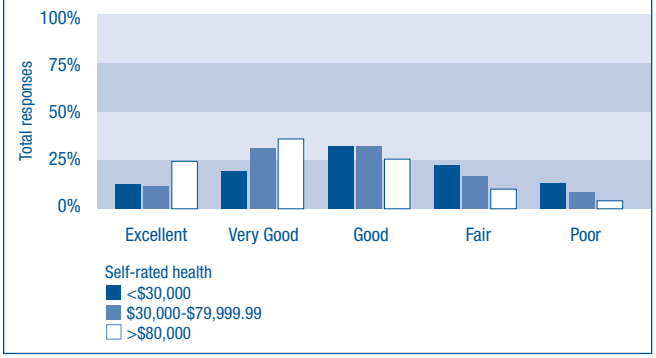



**FIGURE 23**

**Demographic variable: Income**

*Significant association between income and SRH ($x^2 = 88$, $p < .001$)*




Two ANOVAs were used to examine associations between continuous variables: length of stay in Canada, age, and SRH. Both ANOVAs produced significant results (see Figures 24 and 25).

FIGURE 24

*Significant association between length of stay in Canada (for non-Canadian born) and SRH (F (4) = 19.06, p <.001)*

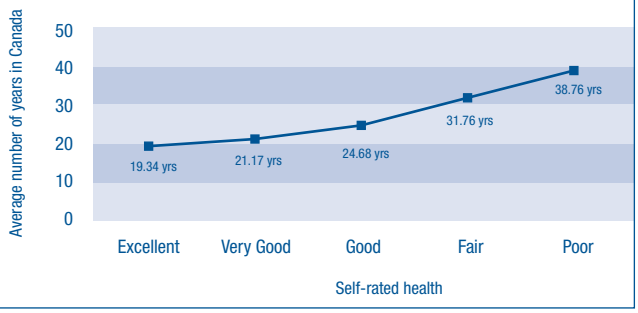
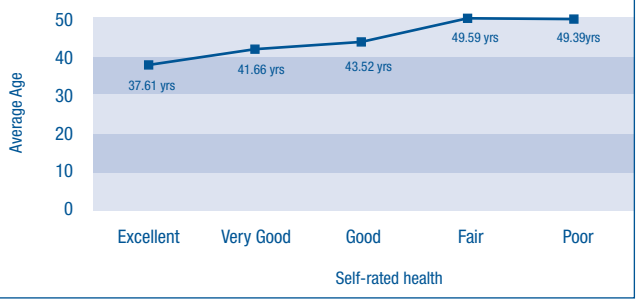



FIGURE 25

*Significant association between average age and SRH (F (4) = 13.21, p <.001)*




## Summary of findings on significant associations with self-rated health

- A greater proportion of individuals who rated their ability to speak and understand English as "Not Well" or "Not at All" reported "Poor" perceived health (29.7%) compared to those who said they spoke and understood English "Very Well" Or "Well" (11.1%).
- The average length of residency in Canada was significantly longer for immigrants who rated their health as "Poor" (38.76 ± 19.46 years) compared to immigrants who rated it as "Excellent" (19.34 ± 20.149 years), "Very Good" (21.17 ± 18.97 years), or "Good" (24.68 ± 19.39 years).
- A greater proportion of the Aboriginal and Racialized group (17.6%) rated their health as "Excellent" than the "White" group (13.7%), and a lower proportion rated their health as "Poor" (9.7%) compared to the "White" population (14.4%).
- A greater proportion of males (35.6%) reported their health as "Fair" or "Poor" compared to females (26.7%).

## Follow-up: Feedback from data collectors

Responses from the focus groups and one-to-one interviews with data collectors varied from site to site. Feedback has been aggregated into four primary themes: Patient/ Client Response & Comfort; Staff Acceptance; Implementation Challenges; and Technology.

**Comfort** – The diversity of settings and patient population generated, as anticipated, a diversity of responses. Overall, the reception of patients/ clients was positive and most people were willing to provide the necessary information. Initial fears that people would be unwilling to provide confidential and sensitive socio-demographic information were relatively unfounded. There was variation across the sites in regard to rates of agreement to participate and replies on all questions. For one site, the refusal rate was higher when patients were approached by the research team (volunteers and staff) compared to clinical staff. In some cases, people could not understand the purpose of the survey and were therefore reluctant to answer questions.

Consistent with public surveys of perception, evidence of reluctance to share information was the greatest for the income question (although in many cases it was because the respondent was unsure of their income). A number of patients expressed scepticism that the data would remain private and anonymous. Many patients did not ask questions at the start, but queried about the survey at the end and asked about how the information would be used – a sign of curiosity rather than resistance. In other cases, people would pause for an explanation

of a category – again, curiosity as to the importance and relevance of the question rather than resistance. In a few cases, patients shared their interest and enthusiasm for the data collection with their physician or nurse during their clinical appointment.

The general conclusion from focus group feedback is that the survey questions are "doable" and patient resistance suggested by some public perception surveys is exaggerated when the data is collected by well trained, knowledgeable individuals.

**Staff Acceptance** – Overall, the data collectors commented positively on the education and training received prior to moving the questions into the field. For some, it was an opportunity to simply learn more about the social determinants of health and health equity – a reminder to not assume high levels of knowledge and acceptance. Similarly, there was an appreciation for the glossary of terms and other supporting material. A consistent message from the data collectors was the need to stress the importance of data collection and, equally important, connect the ground level process of data collection to the 'big picture' of why the data is required and how it will be used. There appears to be a strong preference for small group training sessions versus larger meeting settings. This preference seems to be influenced by the opportunity to talk and ask questions more freely, as well as the more practical hands-on aspect of training. Several data collectors suggested the opportunity to shadow someone collecting data first or, alternatively, having someone with them the first couple of times they were in the field.

The general conclusion of data collectors was that the training was of high quality and helpful in a way that made the process of collection relatively easy. There were no indications on the part of data collectors that this data should not be collected or is unfeasible.

> The reception of patients/clients was positive and most people were willing to provide the necessary information. The general conclusion from focus group feedback is that the survey questions are reasonable and patient resistance is minimal.

**Implementation Challenges** – If there was a problem of significance in implementation it was the issue of time and workflow. In some of the trial settings, staff felt time-pressed in establishing a comfort level with patients.. Similarly, the work flow of some settings was such that it was difficult to complete the questions before patients were called for their appointment. However, in a number of cases, patients asked if the data collector could come back if they were interrupted for their clinical appointment. Many of the data collectors felt the problems of time diminished with increased experience making contact and/or after making 'learning curve' adjustments.

**Technology** – The greatest challenge was for those unfamiliar with tablet based technologies, specifically some elderly patients and patients living with mental illness. The functional lay out was identified as challenging with patients expressing trouble finding the English language screen button, seeing/reading the questions due to font size, difficulty seeing the options, scrolling and other program issues. In addition to these challenges, some non-English scripts could not be easily loaded onto the iPad or were loaded in a way that changed the meaning of the questions. As a result, two non-English language translations[ix] had to be removed from the pilot phase at one site. Moreover, some patients found the actual device to be physically challenging due to weight, inability to click with long finger nails

[ix] *Arabic and Tamil*

and other physical limitations. In addition to lack of familiarity with digital devices and the experience of technological 'fear', some issues arose with data entry accuracy (difficulties using a drop-down menu).

Even with these challenges, the majority of staff and patients found a self-completed tablet with direct connections to the patient's Electronic Medical Record (EMR) the easiest method to gather this data from those able to use it correctly. However, it was advised that the completed information should be checked again during follow-up.

# Bringing it All Together

## UPDATED QUESTIONS - SEE APPENDIX B

Findings from the Pilot Project were used to update the original survey questions. The final list was shortened to 8 core items that focus on priority health equity variables, while the reduction in the number of questions takes into account time constraints faced by data collectors. An additional 3 optional items were refined and recommended, providing data collectors with an expanded health equity data list and supplying information on possible patient service needs (e.g. religion).

The final list of 8 core items and 3 optional items were derived from the original survey before being updated to reflect data analyses and feedback. Below is a brief explanation of each item and when applicable, an explanation of the changes that were made:

### Born in Canada

As questions about immigration status can be met with reluctance and fear, the survey asked patients whether they are born in Canada. If the patient responded "no" they were asked for their year of arrival. This information allows hospitals to track who has come to Canada and the impact on their health over time, as well as identifying newcomer patients who may benefit from further support.

### Disability

In order to provide consistency with existing language around disability, category definitions in the survey adopted the terminology currently used by the Ontario Human Rights Commission (2009).

### Gender

Following the findings of the pilot study, the category of trans was divided into trans-male and trans-female to increase clarity and an "other" category was added to increase specificity.

### Housing

The final recommended housing item was a product of research on data collected on types of housing across the province. This was further refined following the pilot study to reflect the most cited types of housing identified in the "other" category.

### Income

Patients were provided with salary range options rather than being asked for a specific income, a strategy that is used to increase response rates for income questions (Taylor-Powell, 1998). Asking for the number of individuals supported by that income is essential as this number affects household costs and available disposable income. Statistics Canada (2012) also uses the number of dependants in the calculation of the Canadian 'low income cut-off' (poverty), where "adjusted" indicates that increasing family needs are taken into account.

### Language

The language categories in the final survey were updated to reflect the top 30 language requests among Toronto Central LHIN area hospitals.

## Race/Ethnicity

For race/ethnicity, it was important to recognize that there is no single way of categorizing race or ethnicity. Despite the viewpoints of some, there is a clear consensus that race is not a scientific construct, but rather, a social construct (Krieger, 2003; Williams, 2012). While there are phenotype differences, these do not neatly fit a singular set of definitions; moreover, social research has clearly demonstrated that it is the social response to phenotype in terms of hierarchy, social position, attitudes and beliefs that form the essential context of the experience of racialized status. Ultimately, most categorizations reflect an uneasy blend of racial phenotype or colour, along with the identification of geographic regions associated with characteristics of "race" (e.g., Asian) (Fernando, 1991). Ethnicity was equally, if not more so, difficult to quantify and categorize given that people experience and express their ethnicity in many different and inconsistent ways – origin, ancestry and identity being the three dominant forms (Statistics Canada, 2003).

Existing definitions and categorizations on race and ethnicity were reviewed. A sample of US examples were analyzed, but viewed as demographically misaligned with Toronto/Canada demographics. The race/ethnicity categorization of the Canadian Census was also reviewed, but found to be limited and inconsistent (a viewpoint reflected in health equity literature). Instead, the focus shifted to existing and on-going socio-demographic data collection by local organizations and a decision was made to adapt and trial the question and blended categorizations utilized by the 2011 Toronto District School Board [TDSB][iv]. Along with matching the demographic mix of Toronto and creating the desired layered effect for aggregation, the critical rationale was the 'real world' validation of the TDSB survey in a local context through repeated implementation and validation.

The next level of difficulty was identifying the menu of choices in terms of examples of source countries, as well as a list of languages and religions. For source countries, as was discovered in the trial project, some individuals wanted to know why their country or region was not listed as an example (e.g., Ghana and not Uganda). In response to similar feedback the TDSB chose to use examples based on volume in Toronto (largest numbers) and we followed suit. The intent was to identify a useful number of fixed choices to assist in aggregation, while retaining sufficient flexibility for alternative selection.

Following the pilot study, Aboriginal health care leaders provided feedback on the importance of differentiating between Inuit, Métis and First Nations when collecting demographic data.

## Religion

The categories falling under religion were chosen based on the most commonly identified religious and spiritual groups in Canada (Statistics Canada, 2011) and groups whose religious affiliation can impact medical treatments (e.g. Restrictions on blood transfusion for Jehovah's Witnesses).

## Sexual Orientation

The category options were developed with LGB health equity experts and reflect the current standards in collecting information on sexual orientation (e.g. Rainbow Health Ontario, 2012).

Following the pilot, all items were updated to include "other (please specify)" for patients who do not identify with listed categories.

[iv] *For copy of the 2011 TDSB census please visit http://www.tdsb.on.ca/_site/ViewItem.asp?siteid=310&menuid=39563&pageid=33197*

## CONCLUSIONS AND LESSONS

The success of the Tri-Hospital + TPH project is now moving from a small collaborative initiative to a system-wide application. The TC LHIN identified the collection of socio-demographic as a key pillar in its health equity strategy. The questions and categorizations were assessed to work well, and a final set of eight core questions with three optional – but recommended – questions has been adopted as the preferred survey approach for wide scale implementation as directed by the TC LHIN (See Appendix B).

The following are lessons learned from the Tri-Hospital + TPH project:

**Lesson #1:** With a participation rate of over 80%, the pilot project demonstrated that the collection of socio-demographic data from patients/clients is "doable".

**Lesson #2**: A strong commitment by senior leadership to the value and importance of socio-demographic data collection is necessary.

**Lesson #3**: The training of data collectors is the key step in successful implementation. Education on health equity (the 'big picture') is important in moving attitudes and acceptance toward buy-in and interest.

**Lesson #4**: The use of technology is challenging for some patients. For certain populations such as the elderly or people with some disabilities, there is the potential for a steeper learning curve.

**Lesson #5:** When introducing a demographic data collection model and coordinating data collection across multiple sites, it is essential to continually monitor progress and engage staff and management around that progress. This can include monitoring participation rates for data quality and addressing issues that arise early on**.**

**Lesson #6**: All hospitals should implement their own process of learning and adaptation to align the data collection method with technology, setting, and program population. While standardizing definitions, categories of the questions, and self-reporting is necessary to ensure quality data, the method of data collection for each setting can be flexible.

The Tri-Hospital + TPH project was able to meet its objectives after years of discussions, consultations, and research. The extensive work leading up to those objectives makes it easy to forget that demographic data collection is only a means to a bolder end: equity in health, represented in "the absence of systematic disparities in health between groups with different levels of underlying social advantage/ disadvantage- that is, wealth, power, or prestige" (Braveman & Gruskin, 2003, p. 254). The lessons laid out in this report are key to the ambitious work ahead of us, and provide much-needed direction on the long journey to providing equitable health care.

# References


Adelson, N. (2005). The embodiment of inequity, health disparities in aboriginal Canada. *Canadian Journal of Public Health, 96*, S45-S61.

Agency for Healthcare Research and Quality [AHRQ]. (2009). *National healthcare disparities report*. Washington, DC.

Agency for Healthcare Research and Quality [AHRQ]. (2010). *Improving data collection across the health care system: race, ethnicity, and language data: standardization for health care quality improvement*. Rockville, MD.

Alborz, A., McNally, R., & Glendinning, C. (2005). Access to health care for people with learning disabilities in the UK: mapping the issues and reviewing the evidence. *Journal of Health Services Research and Policy, 10*, 173-182.

Alter D., Naylor, C., Austin P., & Tu, J. (1999). Effects of socioeconomic status on access to invasive cardiac procedures and on mortality after acute myocardial infarction. *New England Journal of Medicine, 341,* 1359–1367.

Andrews, R. (2011). Race and ethnicity reporting in statewide hospital data: progress and future challenges in a key resource for local and state monitoring of health disparities. *Journal of Public Health Management, 17,* 167-173.

Annoual, P. C., Bibeau, G., Marshall, C., & Sterlin, C. (2007, November). *Developing a new service model for Canadians of African descent*. Centre for Addiction and Mental Health. Retrieved from *http://www.camhx.ca/Publications/Resources_for_Professionals/EACRIMH/eacrimh_report1107.pdf*

Archie, S., Akhtar-Danesh, N., Norman, R., Malla, A., Roy, P., & Zipursky, R. B. (2010). Ethnic diversity and pathways to care for a first episode of psychosis in Ontario. *Schizophrenia Bulletin, 36,* 688-701.

Aspinall, P. (2000). The mandatory collection of data on ethnic group of inpatients: experience of NHS trusts in England in the first reporting years. *Public Health, 114,* 254–259.

Baker, D., Cameron, K., Feinglass, J., Georgas, P., Foster, S., Pierce, D., Thompson, J., & Hasnain-Wynia, R. (2005). Patients' attitudes toward health care providers collecting information about their race and ethnicity. *Journal of General Internal Medicine, 20,* 895-900.

Baker, D., Hasnain-Wynia, R., Kandula, N., Thompson, J., & Brown, E. (2007). Attitudes toward health care providers, collecting information about patients' race, ethnicity, and language. *Medical Care, 45,* 1034-42.

Balboni, T.,Vanderwerker, L., & Block, S. (2007). Religiousness and spiritual support among advanced cancer patients and associations with end-of-life treatment preferences and quality of life. *Journal of Clinical Oncology,* 25, 555-560.

Barnes, A. (2004). Race, schizophrenia, and admission to state psychiatric hospitals. *Administration and Policy in Mental Health, 31*, 241-252.

Beiser, M. (2003). Community in distress: mental health needs and help-seeking in the Tamil community in Toronto. *International Migration, 41,* 233-245.

Beiser, M. (2005). The health of immigrants and refugees in Canada. *Canadian Journal of Public Health, 96,* 30-44.

Bergeron, S., & Senn, C. (2003). Health care utilization in a sample of Canadian lesbian women: predictors of risk and resilience. *Women & Health, 37,* 19-35.

Bierman, A. S., Johns, A., Hyndman, B., Mitchell, C., Degani, N., Shack, A. R., Creatore, M. I., Lofters, A. K., Urquia, M. L., Ahmad, F., Khanlou, N., & Parlette, V. (2012). Social determinants of health and populations at risk. In A. Bierman (Ed.), *Project for an Ontario Women's Health Evidence-Based Report,* Toronto.

Bierman, A. S., Lurie, N., Collins, K., & Eisenberg, J. (2002). Addressing racial and ethnic barriers to effective health care: the need for better data. *Health Affairs, 21,* 91-102.

Birnie,,D., Sambell, C., & Johansen, H. (2007). Use of implantable cardioverter defibrillators in Canadian and US survivors of out-of-hospital cardiac arrest. *Canadian Medical Association Journal, 177,* 41-46.

Black Health Alliance. (2005). *How do Scarborough's black youth access the health care system?* Toronto.

Bowen, S. (2000). Access to health services for under-deserved populations in Canada. In Health Canada (Ed.), *Certain Circumstances: Issues in equity and responsiveness in access to health care in Canada.*

Bowen, S. (2001). *Language barriers in access to health care*. Ottawa: Health Canada.

Braveman, P., & Gruskin, S. (2003). Defining equity in health. *Journal of Epedimiology and Community Health, 57,* 254-258.

Brunsma, D. (2005). Interracial families and the racial identification of mixed race children: evidence from the early childhood longitudinal study. *Social Forces, 84,* 1131-1157.

Brunsma, D. (2006). Public categories, private identities: exploring regional differences in the biracial experience. *Social Science, 35*, 555-576.

Buescher, P., Gizlice, Z., & Jones-Vessey, K. (2005). Discrepancies between published data on racial classification and self-reported race: evidence from the 2002 North Carolina live birth records. *Public Health Reports, 120,* 393-398.

Carrasco, C., Gillespie, M., & Goodluck, M. (2009). Accessing primary care in Canada: giving voice to the perceptions and experiences of racialized immigrants. *Ethnic and Pluralism Studies Student Conference,* January 29-30.

Clark, P., Drain, M., & Malone, M. (2003). Addressing patients emotional and spiritual needs. *Joint Commission Journal on Quality and Safety,* 29, 659-670.

Coker, R., Austin, S., & Schuster, M. (2010). The health and health care of lesbian, gay, and bisexual adolescents. *Annual Review of Public Health, 31,* 457-477.

Cools, M., Drop, S., Wolffenbuttel, K., Oosterhuis, J., & Looijenga, L. (2006). Germ cell tumors in the intersex gonad: old paths, new directions, moving frontiers. *Endocrine Reviews*, 27, 468-484.

Curlin, F., Chin, M., Sellergren, S., Roach, C., & Lantos, J. (2006). Religious characteristics with their attitudes and self-reported behaviors regarding religion and spirituality in the clinical encounter. *Medical Care,* 44, 446-453.

DeMaio, F. (2010). Immigration as pathogenic: a systematic review of the health of immigrants to Canada, *International Journal for Equity in Health, 9.* doi:10.1186/1475-9276-9-27

DeMaio, F., & Kemp, E. (2010). The deterioration of health status among immigrants to Canada. *Global Public Health*, 5, 462-478.

Dilley, J., Simmons, K., Boysun, M., Pizacani, B., & Stark, M. (2010). Demonstrating the importance and feasibility of including sexual orientation in public health surveys: health disparities in the Pacific Northwest. *American Journal of Public Health, 100,* 460-467.

Dorsey, R., & Graham, G. (2011). New HHS Data Standards for race, ethnicity, sex, primary language and disability status. *Journal of American Medical Association, 306,* 2378-2379.

Ehman, J., Ott, B., Short, T., Ciampa, R., & Hansen-Flaschen, J. (1999). Do patients want physicians to inquire about their spiritual or religious beliefs if they become gravely ill? *Archives of Internal Medicine*, *159,* 1803-1806.

Eliason, M., & Schope, R. (2001). Does "don't ask don't tell" apply to health care? Lesbian, gay, and bisexual people's disclosure to health care providers. *Journal of the Gay and Lesbian Medical Association, 5*, 125–134.

Escarce, J., Carreon, R., Veselovskiy, G., & Lawson, E. (2011). Collection of race and ethnicity data by health plans has grown substantially, but opportunities remain to expand efforts. *Health Affairs, 30,* 1984-1991.

Fernando, S. (1991). *Mental health, race and culture*, London: Macmillan.

First Nations Health Council. (2011). *Implementing the vision: BC First Nations health governance*. West Vancouver, British Columbia.

Flannelly, K., Galek, K., & Handzo, G. (2005). To what extent are the spiritual needs of hospital patients being met? *International Journal of Psychiatry in Medicine*, *35,* 319-323.

Flores, G., Laws, M., & Mayo, S. (2003). Errors in medical interpretation and their potential clinical consequences in pediatric encounters. *Pediatrics, 111,* 6-14.

Flores, G. (2005). The impact of medical interpreter on the quality of healthcare: a systematic review. *Medical Care Research and Review, 62,* 255-299.

Fowler, R., Sabur, N., & Li, P. (2007). Sex- and age-based differences in the delivery and outcomes of critical care. *Canadian Medical Association Journal, 177,* 1513-1519.

Frankish, J., Hwang, S., & Quantz, D. (2005). Homelessness and health in Canada: research lessons and priorities, *Canadian Journal of Public Health, 96,* 23-29.

Fulton, R. (2010). *Ethnic monitoring: is health equality possible without it?* London: Race Equality Foundation.

Hamilton Urban Core Community Health Centre. (2010). *Inner city health experiences of racialization & health inequity*. Hamilton.

Hansson, E., Tuck, A., Lo, T., Lurie, S., Pendakur, S., & McKenzie, K. (2009). *Improving mental health services for immigrant, refugee, ethno-cultural and racialized groups: issues and options for service improvement*. Mental Health Commission of Canada Diversity Task Group.

Hasnain-Wynia, R., & Baker, D. (2006). Obtaining data on patient, ethnicity and primary language in health care organizations: current challenges and proposed solutions. *Health Services Research, 41,* 1501-1518.

Hawkins, S., Torres, B., Simpson, G., & Cohen, B. (2011). Setting the standards for collecting ethnicity data in the Commonwealth of Massachusetts. *Journal of Public Health Management Practice, 17,* 550-563.

Health Canada. (2001). *Diabetes among aboriginal (First Nations, Inuit and Métis) people in Canada: the evidence*. Ottawa: Health Canada.

Health Council of Canada. (2012). *Empathy, dignity, and respect: creating cultural safety for aboriginal people in urban health care*, Toronto: Health Council of Canada.

Health Research and Educational Trust. (2011). *HRET toolkit: a toolkit for collecting race, ethnicity and primary language information from patients*. Retrieved from *http://www.hretdisparities.org/WhoSRegi-4151.php*

Holmes, M. (2008). I*ntersex: a perilous difference*. Selinsgrove, PA: Susquehanna University Press.

Hwang, S. (2000). Mortality among men using homeless shelters in Toronto, Ontario. *Journal of American Medical Association, 283,* 2152-2157.

Hwang, S. (2001). Homelessness and health. *Canadian Medical Association Journal, 164,* 229-232.

Hwang, S., & Henderson, M. (2010). *Health care utilization in homeless people: translating research into policy and practice*. Agency for Healthcare Research and Quality, Working Paper No. 10002.

Hyman, I. (2007). *Immigration and health: reviewing evidence of the healthy immigrant effect in Canada*. CERIS Working Paper No. 55.

Hyman, I. (2009). *Racism as a Determinant of Immigrant Health*. Toronto: Metropolis and Public Health Agency of Canada.

Immigration Legal Committee. (2008, May). *Police service: Safe access of all.* Report presented to the Toronto Police Services Board.

Institute of Medicine [IOM]. (1999). *Lesbian health: current assessment and directions for the future*. Washington, DC: National Academies Press.

Institute of Medicine [IOM]. (2009). *Race, ethnicity, and language data: standardization for health care quality improvement*. Washington, DC: National Academies Press.

Institute of Medicine [IOM]. (2011). *The health of lesbian, gay, bisexual, and transgender people: building a foundation for better understanding.* Washington, DC: The National Academies Press.

Iqbal, G., Gumber, A., Johnson, M., Szczepura, A., Wilson, S., & Dunn, J. (2009). Improving ethnicity data collection for health statistics in the U.K.. *Diversity in Health and Care, 6*. doi:10.1186/1471-2458-12-243

Iqbal, G., Johnson, M., Szczepura, A., Wilson, S., Gumber, A., & Dunn, J. (2012). UK ethnicity data collection for healthcare statistics: the South Asian perspective. *BMC Public Health, 12*. doi:10.1186/1471-2458-12-243

Jillson, I. (2002). Opening closed doors: improving access to quality health services for LGBT populations. *Clinical Research and Regulatory Affairs, 19,* 153–190.

Johar, M., Jones, G., Keane, M., Savage, E., & Stavrunova, O. (2012). Discrimination in a universal health system: explaining socioeconomic waiting time gaps, *Journal of Health Economics, 32*, 181-194.

Jorgensen, S., Thorlby, R., Weinick, R., & Ayanian, J. (2010). Responses of Massachusetts hospitals to a state mandate to collect race, ethnicity and language data from patients: a qualitative study, *BMC Health Services Research, 10.* doi:10.1186/1472-6963-10-352

Kaufman, R. (2007) Introduction to transgender identity and health. In H. Mukadon, K. Mayer, J. Potter, H. Goldhammer (Ed.) *The Fenway Guide to Lesbian, Gay, Bisexual, and Transgender Health,* Philadelphia. PA: American College of Physicians.

Kaul, P., Chang, W., & Westerhout. C., (2007). Differences in admission rates and outcomes between men and women presenting to emergency departments with coronary syndromes. *Canadian Medical Association Journal, 177*, 1193-1199.

Kenagy, G. (2005). Transgender health: findings from two needs assessment studies in Philadelphia. *Health & Social Work, 30*, 19–26.

Kerith, J., Conron, J., Mimiaga, S., & Landers, L. (2010). A population-based study of sexual orientation identity and gender differences in adult health. *American Journal of Public Health, 100,* 1953-1960.

Khanna, N. (2012). Multiracial Americans: racial identity choices and implications for the collection of race data. *Sociology Compass*, *6*, 316-331.

King, M., Nazroo, J., Weich, S., McKenzie, K., Bhui, K., Karlsen, S., Stansfeld, S., Tyrer, S., Blanchard, M., Lloyd, K., McManus, S., Sproston, K., & Erens, B. (2005). Psychotic symptoms in the general population of England – a comparison of ethnic groups, *Social Psychiatry & Psychiatric Epidemiology*, *40*, 375-381.

Koenig, H. (2007) *Spirituality in patient care*. Philadelphia, PA: Templeton Foundation Press.

Krahn, G., Hammond, L. & Turner, A. (2006) A cascade of disparities: Health and health care access for people with intellectual disabilities, *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 70-82.

Krieger, N. (2003). Does racism harm health? did child abuse exist before 1962? On explicit questions, critical science, and current controversies: an eco-social perspective. *American Journal of Public Health, 93,* 194-199.

Kushel, M., Vittinghoff, E., & Haas, J. (2001). Factors associated with health care utilization of homeless persons. *Journal of American Medication Association, 285*, 200-206.

Laditka, J., & Laditka, S. (2006). Race, ethnicity and hospitalization for six chronic ambulatory care sensitive conditions in the USA. *Ethnicity and Health, 11*, 247-263.

Lasser, K., Himmelstein, D., & Woolhandler, S. (2006). Access to care, health status, and health disparities in the United States and Canada: results of a cross-national population-based survey. *American Journal of Public Health, 96,* 1300-1307.

Lavassani, K. M., Movahedi, B, & Kumar, V. (2009). Developments in analysis of multiple response survey data in categorical data analysis: The case of enterprise system implementation in large North American firms. *Journal of Applied Quantitative Methods, 4,* 45-53.

Lezzoni, L. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs, 30,* 1947-1954.

Li, C., Gervais, G., & Duval, A. (2006). *The dynamics of over-qualification: Canada's underemployed university graduates*. Statistics Canada Catalogue no. 11-621-MIE. Ottawa. Analytical Paper. No. 039.

Lightman, E, Mitchell, A., & Wilson, B. (2008). *Poverty is making us sick: a comprehensive survey of income and health in Canada*. Toronto: The Wellesley Institute.

Lix, L., Bruce, S., Sarkar, J., & Young, T. (2009). Risk factors and chronic conditions among aboriginal and non-aboriginal populations. *Health Reports, 20,* 21-29.

Lofters, A., Shankardass,K., Kirst, M., & Quiñonez,C. (2011). Socio-demographic data collection in healthcare settings: an examination of public opinions. *Medical Care, 49*, 193-199.

Macinko, J., & Elo, I. (2009). Black–white differences in avoidable mortality in the USA, 1980–2005. *Journal of Epidemiology and Community Health, 63,* 715-721.

Marrone, S. (2007). Understanding barriers to health care: a review of disparities in health care services among indigenous populations. *International Journal of Circumpolar Health, 66*, 188-98.

Mathieson, C., Bailey, N., & Gurevich, M. (2002). Health care services for lesbian and bisexual women: some Canadian data. *Health Care for Women International, 23,* 188-96.

Mayberry, R., Mili, F., & Ofili, E. (2000). Racial and ethnic differences in access to medical care. *Medical Care Research and Review, 57,* 108-145.

Mayer, K., Bradford, J., Makadon, H., Stall, R., Goldhammer, H., & Landers, S. (2008). Sexual and gender minority health: what we know and what needs to be done. *American Journal of Public Health, 98,* 989-995.

Mele, N., Archer, J., & Pusch, B. (2005). Access to breast cancer screening services for women with disabilities. *Journal of Obstetric, Gynecologic, and Neonatal Nursing*, *34*, 453-64.

Morrisseau, K. (2009). *Aboriginal cancer control progress report*. Aboriginal services. Retrieved from *http://www.cancercare.mb.ca/resource/File/Aboriginal_CancerControlProgressReport_07-08.pdf*

Murphy K., Glazier, R., Wang, X., Holton, E., Fazli, G., & Ho, M. (2012). *Hospital care for all: an equity report on differences in household income among patients at Toronto central local health integration network hospitals, 2008-2010*. Toronto.

Myers, K. (2002). Cardiovascular disease and risk in the aboriginal population. *Canadian Medical Association Journal, 166*, 355.

National Alliance on Mental Illness. (2009). *Collecting race and ethnicity data: guidance for NAMI state organizations and affiliates*. Arlington, VA.

National Collaborating Centre for Aboriginal Health. (2011). *Access to health services as a social determinant of First Nations, Inuit, and Métis health.* Prince George, BC.

National Health Service Scotland. (2012). *Review of equality health data needs in Scotland*. Edinburgh: National Health Service of Scotland.

Nazroo, J. (2003). The structuring of ethnic inequalities in health: economic position, racial discrimination, and racism. *American Journal of Public Health, 93,* 277-284.

Nazroo, J., Jackson, J., Karlsen, S., & Torres, M. (2007). The Black diaspora and health inequalities in the US and England: does where you go and how you get there make a difference? *Sociology of Health & Illness, 29,* 811–830.

Nestel, S. (2012). *Colour coded health care: the impact of race and racism on Canadians' health*. Toronto: Wellesley Institute.

Ng, E., Wilkins, R., Gendron, F., & Berthelot, J-M. (2005). The changing health of immigrants. *Canadian Social Trends*, Statistics Canada: Ottawa.

O'Day, B., Killeen, M., Sutton, J., & Iezzoni, L. (2005). Primary care experiences of people with psychiatric disabilities: barriers to care and potential solutions. *Psychiatric Rehabilitation Journal*, *28*, 339-345.

Office of Minority Health. (2011). *Reducing health disparities with improved data collection: new refined data standards for race, ethnicity, sex, primary language, and disability status*. Retrieved from *http://minorityhealth.hhs.gov/templates/content.aspx?ID=9232*

O'Hearn, A. (2006). Deaf women's experiences and satisfaction with prenatal care: a comparative study. *Family Medicine*, 38, 712-716.

Olah, M., Gaisano, G., & Hwang, S. (2013). The effect of socioeconomic status on access to primary care: an audit study. *Canadian Medical Association Journal, 185*. doi: 10.1503/cmaj.121383

Ontario Human Rights Commission. (2009, December). *Policy and guidelines on disability and the duty to accommodate*. Retrieved from *http://www.ohrc.on.ca/en/policy-and-guidelines-disability-and-duty-accommodate*

Pahwa, P., Karunanayake, C., McCrosky, J., & Thorpe, L. (2012). Longitudinal trends in mental health among ethnic groups in Canada. *Chronic Diseases and Injuries in Canada, 32,* 164-176.

Phipps, S. (2003). *The impact of poverty on health: a scan of research literature*. Ottawa: Canadian Institute for Health Information.

Pollock, G., Newbold, B., Lafrenière, G., & Edge, S. (2012). *Perceptions of discrimination in health services experienced by immigrant minorities in Ontario*. Ottawa: Citizenship and Immigration Canada.

Quan, H., Wong, A., & Johnson, D. (2006). The public endorses collection of ethnicity information in hospital: implications for routine data capture in Canadian health systems. *Healthcare Policy, l,* 55– 64.

Rainbow Health Ontario. (2012, August). Fact sheet: Designing surveys and questionnaires. Retrieved from *http://www.rainbowhealthontario.ca/admin/contentEngine/contentDocuments/Designing_Surveys_and_Questionnaires.pdf*

Ramos, R., Davis, J., Ross, T., Grant, C., & Green, B. (2012). Measuring health disparities and health inequities: do you have REGAL data? *Quality Management in Health Care, 21*, 176-187.

Reading, C. & Wien, F. (2009). *Health inequalities and social determinants of aboriginal peoples' health.* Prince George, BC, National Collaborating Centre for Aboriginal Health.

Research Alliance for Canadian Homelessness, Housing and Health. (2010). *Housing vulnerability and health: Canada's hidden emergency, a report on the reach health and housing in transition study*. Toronto.

Ross, N., Wolfson, M., Kaplan, G., Dunn, J., Lynch, J., & Sanmartin, C. (2006). Income inequality as a determinant of health. In J. Heymann, C. Hertzman, M. Barer & R. Evans (Ed.). Healthier Societies: From Analysis to Action. New York: Oxford University Press.

Rurangirwa, J., Van Naarden Braun, K., Schendel, K., & Yeargin-Allsopp, M. (2006). Healthy behaviours and lifestyles in young adults with a history of developmental disabilities. *Research in Developmental Disabilities, 27,* 381-399.

Ryan, B., Brotman, S., & Rowe, B. (2000). Access to care: exploring the health and well-being of gay, lesbian, bisexual and two-spirit people in Canada. Montreal: McGill Centre for Applied Family Studies.

Safir, A. (2007). Check all that apply. In *Encyclopedia of Survey Research Methods* (Vol. 2, pp. 94-95). Thousand Oaks, California: Sage Publications.

Scherzer, T. (2000). Negotiating health care: the experiences of young lesbian and bisexual women. *Culture, Health & Sexuality, 2,* 87–102.

Sears, B. (2009). *Delaware—sexual orientation and gender identity law and documentation of discrimination*. Los Angeles, CA: The Williams Institute.

Shavers, V., Fagan, P., Jones, D., Klein, W., Boyington, J., Moten, C., & Rorie, E. (2012). The state of research on racial/ethnic discrimination in the receipt of health care. *American Journal of Public Health, 102*, 953-966.

Shah, B., Gunraj, N., & Hux, J. (2003). Markers of access to and quality of primary care for aboriginal people in Ontario, Canada. *American Journal of Public Health*, *93*, 798–802.

Sheikh, A. (2007). Should Muslims have faith based health services? *British Medical Journal, 334,* 75.

Singh, S., Paszat, L., Li, C., He, J., Vinden, C., & Rabeneck, L. (2004). Association of socioeconomic status and receipt of colorectal cancer investigations: a population-based retrospective cohort study. *Canadian Medical Association Journal*, *171*, 461-465.

Smedley, B. D., Stith, A. Y., & Nelson, A. R. (Eds.) (2003). *Unequal treatment: Confronting racial and ethnic disparities in health care*. Washington, D.C.: National Academies Press.

Smeltzer, S., Sharts-Hopko, N., Ott, B., Zimmerman, V., & Duffin, J. (2007). Perspectives of women with disabilities on reaching those who are hard to reach. *Journal of Neuroscience Nursing*, *39*, 163-171.

Smith, D., & Mathews, W. (2007). Physicians' attitudes toward homosexuality and HIV: survey of a California medical society-revisited. *Journal of Homosexuality, 52*, 1–9.

Statistics Canada. (2003). *Ethnic diversity survey: a portrait of a multicultural society*. Ottawa: Statistics Canada.

Statistics Canada. (2011). Religion. Retrieved from *http://www.statcan.gc.ca/search-recherche/bb/info/3000017-eng.htm*

Statistics Canada. (2012). *Low income cut-offs*. Retrieved from *http://www.statcan.gc.ca/pub/75f0002m/2012002/lico-sfr-eng.htm*

Sullivan, W., Heng, J., & Cameron, D. (2006). Consensus guidelines for primary health care of adults with developmental disabilities. *Canadian Family Physician, 52*, 1410-1418.

Taylor-Powell, E. (1998). *Questionnaire design: Asking questions with a purpose*. University of Wisconsin. Madison, Wisconsin.

Timmins, C. (2002). The impact of language barriers on the health care of Latinos in the United States: a review of the literature and guidelines for practice. *Journal of Midwifery and Women's Health, 47*, 80-95.

Tiwari, S., & Wang, J. (2008). Ethnic differences in mental health service use among white, Chinese, South Asian and South East Asian populations living in Canada. *Social Psychiatry and Psychiatric Epidemiology, 43*, 866-871.

Tjepkema, M. (2008). Health care use among gay, lesbian and bisexual Canadians. *Health Reports, 19*, 53-64.

Tjepkema, M., Wilkins, R., Senécal, S., Guimond, E., & Penney, C. (2009). Mortality of Métis and registered Indian adults in Canada: an 11-year follow-up study. *Health Reports, 20*, 31-51.

Tjepkema, M., Wilkins, R., Senécal, S., Guimond, E., & Penney, C. (2010). Mortality of urban aboriginal adults in Canada, 1991–2001. *Chronic Diseases in Canada, 31*, 4-21

Trans Pulse Project. (2012). *Research and study results*. Retrieved from *http://transpulseproject.ca/research/*

Ubido, J., Huntington, J., & Warburton, D. (2002). Inequalities in access to healthcare faced by women who are deaf. *Health and Social Care in the Community, 10*, 247-253.

Veenstra, G. (2009). Racialized identity and health in Canada: Results from a nationally representative survey. *Social Science & Medicine*, 69, 538-542.

Veltman, A., Stewart, D., Gaetan, E., Tardif, S., & Branigan, M. (2001). Perceptions of primary healthcare services among people with physical disabilities. part 1 access issues. *Medscape General Medicine, 3*, 18-22.

Wei, W., Findley, P., & Sambamoorthi, S. (2006). Disability and receipt of clinical preventive services among women. *Women's Health Issues, 16*, 286-296.

Weinick, R., Zuvekas, S., & Cohen J. (2000). Racial and ethnic differences in access to and use of health care services, 1977 to 1996. *Medical Care Research and Review, 57,* 36-54.

Wen, C., Hudak, P., & Hwang, S. (2007). Homeless people's perceptions of welcomeness and unwelcomeness in healthcare encounters. *Journal of General Internal Medicine, 22*, 1011-1017.

West, C., Geiger, A., Greene, M., Harris, E., Liu, L., Barton, M., Elmore, J., Rolnick, S., Nekhlyudov, L., Altschuler, A., Herrinton, L., Fletcher, S., & Emmons, K. (2005). Race and ethnicity: comparing medical records to self-reports. *Journal of the National Cancer Institute, 35*, 72-74.

Whitley, R., Kirmayer, L., & Groleau, D. (2006). Understanding immigrants' reluctance to use mental health services: a qualitative study from Montréal. *Canadian Journal of Psychiatry, 51*, 205-209.

Williams, D. (2012). Miles to go before we sleep: racial inequalities in health. *Journal of Health and Social Behaviour, 53,* 279-95.

Williams, D., & Mohammed, S. (2009). Discrimination and racial disparities in health: evidence and needed research. *Journal of Behavioural Medicine, 32,* 20 – 47.

Williams, D. R., & Sternthal, M. J. (2007). Spirituality, religion, and health: Evidence and research directions. *Medical Journal of Australia, 186,* 547-558.

Williamson, D., Stewart, M., Hayward, K., Letourneau, N., Makwarimba, E., Masuda, J., Raine, K., Reutter, L., Rootman, I., & Wilson, D. (2006). Low-income Canadians' experiences with health-related services: implications for health care reform. *Health Policy, 76,* 106–121.

Women's Health in Women's Hands Community Health Centre. (2003). *Racial discrimination as a health risk for female youth: implications for policy and healthcare delivery in Canada*. Toronto: Canadian Race Relations Foundation.

Wray, R., & Hyman, I. (2013). *Health inequalities and racialized groups: a literature review*. Toronto Public Health.

Wynia, M., Hasnain-Wynia, R., Hotze, T., & Ivey, S. (2011). *Collecting and using race, ethnicity and language data in ambulatory settings: a white paper with recommendations from the commission to end health care disparities*. Chicago: American Medical Association.

Yeo, S. (2004). Language barrier and access to health care. *Annual Review of Nursing Research*, *22*, 59-73.

Zaslavsky, A., Ayanian, J., &Zaborski, L. (2012). The validity of race and ethnicity in enrollment data for medicare beneficiaries. *Health Services Research, 10*, 1300-1321.

Zhao, J., Xue, L., & Gilkinson, T. (2010, March). Health status and social capital of recent immigrants in Canada: Evidence from the longitudinal survey of immigrants to Canada. Citizenship and Immigration Canada. Retrieved from *http://www.cic.gc.ca/english/pdf/research-stats/immigrant-survey.pdf*

# Appendix A

## Pilot Project Survey

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

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

2. How would you rate your ability to speak and understand English? **CHECK ONE ONLY.**

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

3. In what language would you prefer to read healthcare information? **CHECK ONE ONLY.**

| | | |
|---|---|---|
| ❍ Arabic | ❍ Greek | ❍ Polish |
| ❍ Bengali | ❍ Gujarati | ❍ Portuguese |
| ❍ Braille | ❍ Hebrew | ❍ Punjabi |
| ❍ Chinese (Traditional) | ❍ Hindi | ❍ Russian |
| ❍ Chinese (Modern) | ❍ Hungarian | ❍ Spanish |
| ❍ Cree | ❍ Italian | ❍ Somali |
| ❍ Dari | ❍ Korean | ❍ Tagalog |
| ❍ English | ❍ Ojibwe | ❍ Tamil |
| ❍ French | ❍ Oji-Cree | ❍ Urdu |
| ❍ German | ❍ Farsi (Persian) | ❍ 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 (e.g., Inuit, First Nations, Non-status Indian, Métis, Aboriginal person from outside Canada) | ❍ Latin American (e.g., Argentinean, Chilean, Salvadoran) |
| ❍ Asian - East (e.g., Chinese, Japanese, Korean) | ❍ Middle Eastern (e.g., Egyptian, Iranian, Lebanese) |
| ❍ Asian - South (e.g., Indian, Pakistani, Sri Lankan, Indo-Caribbean) | ❍ Mixed heritage (Please specify) _____ |
| ❍ Asian - South East (e.g., Malaysian, Filipino, Vietnamese) | ❍ White/ European (e.g., English, Italian, Portuguese, Russian) |
| ❍ Black - Africa (e.g., Ghanaian, Kenyan, Somali) | ❍ Other(s) (Please specify) _____ |
| ❍ Black – North America | ❍ Prefer not to answer |
| ❍ Black - Caribbean Region (e.g., Barbadian, Jamaican) | ❍ Do not know |

7. What is your religious or spiritual affiliation? CHECK **ONE** ONLY.

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

8. Do you have any of the following disabilities? CHECK **ALL** THAT APPLY.

| | |
|---|---|
| ❍ No disabilities | ❍ Sensory disability (i.e. hearing or vision loss) |
| ❍ Chronic illness | ❍ Drug or alcohol dependence |
| ❍ Developmental disability | ❍ Other (Please specify) |
| ❍ Learning disability | _____ |
| ❍ Mental health disability | ❍ Prefer not to answer |
| ❍ Physical disability | ❍ 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”) | ❍ Queer |
| ❍ Gay | ❍ Questioning |
| ❍ Lesbian | ❍ Prefer not to answer |
| ❍ Bisexual | ❍ Do not know |
| ❍ Two-Spirit | |

11. What was your total family income before taxes last year? CHECK **ONE** ONLY.

| | |
|---|---|
| ❍ Less than $10,000 | ❍ $60,000 to $79,999 |
| ❍ $10,000 to $19,999 | ❍ $80,000 to $99,999 |
| ❍ $20,000 to $29,999 | ❍ $100,000 to $150,000 |
| ❍ $30,000 to $39,999 | ❍ $150,000 or more |
| ❍ $40,000 to $49,999 | ❍ Prefer not to answer |
| ❍ $50,000 to $59,999 | ❍ Do not know |

12. How many people does this income support? _____
CHECK **ONE** ONLY.

| | |
|---|---|
| ❍ Prefer not to answer | ❍ Do not know |

13. What type of housing do you live in? **CHECK ONE ONLY.**

| | |
|---|---|
| ❍ Renting | ❍ Correctional facility |
| ❍ Own | ❍ Other (specify): _____ |
| ❍ Living with family or friends | ❍ Prefer not to answer |
| ❍ Temporary housing (e.g. shelter, hostel) or homeless | ❍ Do not know |

14. In general, would you say your health is:
**CHECK ONE ONLY.**

| | |
|---|---|
| ❍ Excellent | ❍ Poor |
| ❍ Very good | ❍ Prefer not to answer |
| ❍ Good | ❍ Do not know |
| ❍ Fair | |

# Appendix B

## 8 Final Core Questions

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

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

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

4. Do you have any of the following disabilities? **CHECK ALL THAT APPLY.**

| | |
|---|---|
| ❍ No disabilities | ❍ Physical disability |
| ❍ Chronic illness | ❍ Sensory disability (i.e. hearing or vision loss) |
| ❍ Developmental disability | ❍ Other (Please specify) _____ |
| ❍ Drug or alcohol dependence | |
| ❍ Learning disability | ❍ Prefer not to answer |
| ❍ Mental illness | ❍ Do not know |

5. What is your gender? **CHECK ONE ONLY.**

| | | | |
|---|---|---|---|
| ❍ Female | ❍ Intersex | ❍ Male | ❍ Trans- Female to Male |
| ❍ Trans-Male to Female | ❍ Other (Please specify) _____ | ❍ Prefer not to answer | ❍ Do not know |

6. What is your sexual orientation? **CHECK ONE ONLY.**

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

7. What was your total family income before taxes last year? **CHECK ONE ONLY.**

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

8. How many people does this income support? _____

| | |
|---|---|
| ❍ Prefer not to answer | ❍ Do not know |

## Optional Questions
(Recommended but not required by the TC LHIN)

1. In what language would you prefer to read healthcare information? **CHECK ONE ONLY.**

| | | |
|---|---|---|
| ❍ Amharic | ❍ Hindi | ❍ Somali |
| ❍ Arabic | ❍ Hungarian | ❍ Spanish |
| ❍ Bengali | ❍ Italian | ❍ Tagalog |
| ❍ Braille | ❍ Karen | ❍ Tamil |
| ❍ Chinese (Simplified) | ❍ Korean | ❍ Tigrinya |
| ❍ Chinese (Traditional) | ❍ Nepali | ❍ Turkish |
| ❍ Czech | ❍ Polish | ❍ Twi |
| ❍ Dari | ❍ Portuguese | ❍ Ukrainian |
| ❍ Farsi | ❍ Punjabi | ❍ Urdu |
| ❍ English | ❍ Russian | ❍ Vietnamese |
| ❍ French | ❍ Serbian | ❍ Prefer not to answer |
| ❍ Greek | ❍ Slovak | ❍ Do not know |
| ❍ Other (Please specify) _____ | | |

2. What is your religious or spiritual affiliation? **CHECK ONE ONLY.**

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

3. What type of housing do you live in? **CHECK ONE ONLY.**

| | | | |
|---|---|---|---|
| ❍ Boarding Home | ❍ Homeless/on street | ❍ Shelter/Hostel | ❍ Prefer not to answer |
| ❍ Correctional Facility | ❍ Own home | ❍ Supportive Housing | ❍ Do not know |
| ❍ Group Home | ❍ Renting | ❍ Other (Please specify) _____ | |

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