

WE ASK BECAUSE WE CARE
FEASIBILITY AND ACCEPTABILITY OF SOCIODEMOGRAPHIC DATA COLLECTION
IN SASKATOON

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ABSTRACT

The study assessed the feasibility and acceptability of sociodemographic data collection in one western Canadian urban centre. It also explored local facilitators and barriers to implementation in order to gain insight about how to support change and foster adoption of similar equity interventions across health regions in the province of Saskatchewan.

A multiple case study was used to evaluate the process of implementation of sociodemographic data collection across three acute and ambulatory care sites. The study draws on multiple qualitative and quantitative methods including individual and group interviews, chart reviews and surveys to understand the diverse participant perspectives and experiences. Cases were studied sequentially. Within cases an integrated approach to data collection and analysis was applied. Cross case synthesis was done to identify similarities and differences across health contexts.

Analysis revealed that it was feasible to collect selected sociodemographic information although there was a gradient of comfort depending on the question and context in which it was asked. High item non responses were observed for questions related to annual household income and year of arrival to Canada. Perceived importance of sociodemographic data collection varied by participant characteristics including age, race/ethnicity and gender identity. Patient participants who felt that data collection was important appreciated how it could be used to improve care, trusted institutional motives for collection and had positive experiences with the health care system. Common reasons for reservations about data collection included perceptions that it was inappropriate to ask or irrelevant to the provision of care, and concerns about the potential for misuse of the information. Preferences for mode of administration of questions varied depending on the participant characteristics. Structural, organizational, provider and patient factors influenced implementation across sites.

There is growing interest in upstream approaches to the delivery of care. The study demonstrated feasibility and acceptability for sociodemographic data collection, however more work is needed to support wider implementation of some determinants across local health care settings.

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I am indebted to the clients and patients across the three project sites who graciously agreed to participate and courageously shared their perspectives without reservation. It is my hope that this work will change the way that care is delivered and pave the way for mainstreaming equity-oriented care.

Many thanks to my peers who provided moral support and opportunities for thoughtful reflection during the many phases of this study. I learned many informal lessons as we reasoned about how best to confront challenges that seemed overwhelming at times.

DEDICATION

I dedicate this thesis to my wonderful family whose sacrifices did not go unnoticed.

My mother Eugenie

My sister Melissa

My princesses Syanna, Syrah, Syage

Ronald

Masaya

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LIST OF ABBREVIATIONS

ACT	Assertive community treatment
AHRQ	Agency for Healthcare Research and Quality
CASP	Critical Appraisal Skills Tool
CHIP	Children’s Health Insurance Program
CFIR	Consolidated Framework Implementation Research
CTI	Critical time intervention
EHR	Electronic health records
FACM	Family Advocates of Central Massachusetts
FNMHS	First Nations Métis Health Services
HITECH	Health Information Technology for Economic and Clinical Health
HFSS	Household Food Security Survey
HRET	Health Research Educational Trust
ICM	Intensive case management
IOM	Institute of Medicine
JCAHO	Joint Commission on Accreditation of Health care Organizations
LDLN	Learning disability liaison nurse
LEI	Language and ethnicity indicators
LEP	Limited English Proficiency
LGBTQ	Lesbian, gay, bisexual, transgender, queer
LHA	Lay Health Advisors
MASQ	Medical Legal Advocacy Screening Questionnaire
OMB	Federal Office of Management and Budget
PAP	Pharmaceutical Assistance Programme
QOF	Quality and Outcomes Framework
PCAM	Patient centred assessment method
RHA	Regional Health Authority
RWJF	Robert Wood Johnson Foundation
SCM	Standard case management
SIREN	Social Intervention Research & Evaluation Network
SOGI	Sexual orientation and gender identity
SURE	Supporting the Use of Research Evidence
TC LHIN	Toronto Central Local Health Integration Network

GLOSSARY

Cultural safety	Within an Indigenous context means that the educator/practitioner/professional whether Indigenous or not can communicate competently with a patient in that patient's social, political, linguistic, economic and spiritual realm. It moves beyond cultural sensitivity and extends to analysing power imbalances, institutional discrimination, colonization and colonial relations as they apply to health care. (1)
Health disparities	A particular type of health difference that is closely linked with economic, social or environmental disadvantage. Health disparities adversely affect groups of people who have systematically experienced greater social or economic obstacles to health based on their racial or ethnic group, religion, socioeconomic status, gender, age or mental health, cognitive, sensory or physical disability, sexual orientation, geographic location or other characteristics historically linked to discrimination or exclusion. (2)
Health equity	This is said to exist when all people have the opportunity to attain their full health potential and no one is disadvantaged from achieving this potential because of their social position or other socially determined circumstances. (3)
Health inequalities	Differences in health status or distribution of health determinants between different population groups. (2)
Health inequities	Differences in health outcomes between population groups that are systematic, avoidable and unjust. (3)
Intervention	A set of actions with a coherent objective to bring about change or produce identifiable outcomes. These actions may include policy, regulatory initiatives, single strategy projects or multicomponent programs.(4)
Patient centred care	Is about providing respectful, compassionate, culturally responsive care that meets the needs, values, cultural backgrounds, beliefs and preferences of patients and their family members in diverse backgrounds by working collaboratively with them.(5)
Social determinants of health	The conditions in which people are born, grow, live, work and age. These circumstances are shaped by the distribution of money, power and resources at global, national and local levels.(6)

Social stratification

A system in which a society ranks categories of people in a hierarchy according to economic class, social status and political power. (7)

CHAPTER ONE

GENERAL INTRODUCTION

1.0 Introduction

This chapter introduces the topic of social determinants of health and presents a context for understanding its significance in the delivery of health care. Following a description of the research problem and definition of objectives, the author explains how the study responds to the knowledge gap. It concludes with a roadmap of subsequent chapters that explore in detail important facets of the research.

The association between socioeconomic factors and health outcomes is well established in the extant literature. The evidence suggests that the social gradient in health is a manifestation of the circumstances in which people are ‘born, grow, live, work and age’.(6) While there are several theoretical expositions (8–11) of the social production of health and disease, views generally converge that social stratification maintains social hierarchies that produce differential exposures and vulnerabilities to health damaging conditions and result in unequal consequences of illness for more or less advantaged groups. (12) Based on this interpretation of an underlying social mechanism, policy frameworks have identified various approaches to tackling social determinants. These strategies range from social and macroeconomic policies directed at structural determinants to approaches that focus on the health care system and its role in mitigating the unequal consequences of illness across social groups. (12) The standardized collection of sociodemographic data is needed in health settings to advance efforts to identify and address non-medical determinants at the individual level as well as support more responsive community planning. This multiple case study examined the feasibility and acceptability of sociodemographic data collection across three diverse urban health care settings in a large health region of a western Canadian province. The research also explored the perceived facilitators and barriers to implementation of sociodemographic data collection and its integration into care delivery.

1.1 Statement of the problem

Despite increasing recognition of the importance of social determinants of health, ‘crucial social history details have often not been asked or acted upon during the medical encounter’.(13) Historically in Canada, only limited information such as age, sex and residence have been systematically collected by health care systems. However, Mikkonen et al. (14) have summarized a body of research that has shown that other factors such as ethnicity, language, disability and sexual orientation influence outcomes, care experiences and satisfaction. The omission of this information excludes important dimensions of the patient’s social context and represents a missed opportunity to deliver care that acknowledges and is responsive to patients’ holistic needs. A holistic approach addresses social needs alongside medical treatment to support patients to make the choices that improve health.

There is increasing concern that the health care system does not respond effectively to the needs of all patients. Escalating health care costs attributable to high service utilization by a fraction of patients with complex needs has prompted closer examination of care delivery pathways. (15) Often in these complex needs patients, there is a clustering of social determinants and vicious cycle of worsening health outcomes that result from the interplay of increased vulnerability and decreased opportunity to take measures needed to improve health and well-being. Efforts to screen for social determinants and address identified needs through responsive care and treatment plans have the potential to mitigate those social conditions that are barriers to the patient’s achievement of good health. (16) The health care system can facilitate access to needed patient supports such as interpreters, education materials that communicate information across diverse audiences and referral to social safety net and community programs.

Given renewed interest in addressing social causes of poor health, the Saskatoon Health Region in Saskatchewan, Canada developed an initiative called ‘We Ask Because We Care’ to support collection and application of sociodemographic data by local health care organizations. The initiative represents a major change in current practice and requires a cultural shift in attitudes to data collection in health care settings. It also seeks to improve responsiveness to non-medical determinants that adversely affect health outcomes.

The project architects had a broad vision that included standardized sociodemographic data collection and its application in the delivery of care. Although the ideal project site would

implement the initiative to its full scope including clinical application during the delivery of care, it was not practical to impose it as a condition of project participation. Consequently, the project team exercised flexibility to adapt to the site's context and prioritized their information needs during implementation. The following objectives were outlined for the initiative:

- a. To develop a tool/instrument to collect patient level sociodemographic information in local health settings.
- b. To increase staff capacity for enhanced sociodemographic data collection.
- c. To pilot the tool to screen at least 50% of patients/clients who presented for care at project sites during the study period.
- d. To assess the patient/client's acceptability and experience with sociodemographic data collection using the tool developed.
- e. To assess feasibility of clinical application of sociodemographic information in patient care and treatment pathways.
- f. To understand the factors that facilitate and hinder implementation of standardized sociodemographic data collection in local health care settings.

This study sought to understand how to collect sociodemographic data in local health care settings. There was an emphasis on identifying the perceived facilitators and barriers to implementation in order to gain insight about how to support change and foster adoption of similar equity interventions across a large health region in the western province of Saskatchewan. Multiple sources of data allowed for appreciation of complex interrelated facets that determined the activities in a given site. Patient perspectives were captured through interviews as well as analysis of the responses collected during administration of the sociodemographic data collection tool. Focus group discussions with health service personnel allowed for understanding their experiences with implementation. Interviews were conducted with a small number of key informants at each site to understand the context of project implementation.

1.2 Purpose of the study

The purpose of this multiple case study evaluation was to assess the feasibility and acceptability of standardized collection of selected sociodemographic data elements in diverse health settings. The research also sought to understand how organizational context shaped implementation in each of the project sites. An in-depth understanding of context allows researchers and decision makers to identify whether an intervention is a good fit and which

factors are critical to address to increase the chance of successful implementation. A variety of perspectives were needed to develop a comprehensive account of important aspects of the context in each site. Patients, providers and key informants who were knowledgeable and had experienced the initiative were interviewed and views were triangulated with available documentary evidence.

1.3 Research questions

This formative evaluation examined the feasibility and acceptability of collecting selected sociodemographic information in three urban health care settings in a large health region in Saskatchewan. The study also assessed the perceived facilitators and barriers to implementation of data collection and its application to improve the quality of care. Research questions focused on the implementation process and understanding the ideal conditions for standardized sociodemographic data collection from multiple perspectives. The following questions were addressed:

1 How feasible and acceptable is standardized sociodemographic data collection in health care settings in Saskatoon?

(a) How did implementation proceed across the various settings?

- (i) To what extent was the initiative implemented as designed?
- (ii) How well did training activities prepare staff for project implementation?
- (iii) How can the implementation process be improved from the perspective of various participants?

(b) How did participants respond to sociodemographic data collection?

- (i) What were the response rates for the various sociodemographic questions?
- (ii) How did item response rates vary by any characteristics (e.g. site, ethnicity)?
- (iii) How did patients/clients perceive sociodemographic data collection?
- (iv) How did health service personnel perceive sociodemographic data collection?

2 How did the organizational context influence implementation of the initiative across health care organizations?

- (i) What were the conditions that facilitated or hindered standardized collection of sociodemographic data and its clinical application to improve delivery of care?
- (ii) How can health care organizations be supported to implement similar equity initiatives in the Saskatoon Health Region?

1.4 Significance of the study

Despite local advocacy for enhanced sociodemographic data collection in clinical settings, momentum has been slow. There is limited experience in the Canadian context with sociodemographic data collection and its clinical application in care delivery pathways. This study is uniquely positioned to contribute to the body of knowledge in a relatively unexplored area, advance the local health equity agenda and reorient clinical practice. The novelty of the initiative within the health region offered the opportunity to examine organizational contextual factors that were important for implementation across three different urban health care settings.

There is a body of related work across multiple disciplines that focuses on organizational behavior, change management and implementation science. While there is some research about critical conditions that one should consider, it is not known whether all factors are necessary for all interventions. Consequently, there was a need to explore which contextual factors were more important and how they actualized during implementation. A better understanding of resistance to change/barriers to implementation of sociodemographic data collection was also needed to enhance our ability to modify organizational context in order to increase receptivity to new initiatives.

Now that the context and scope for the study have been clarified, chapter 2 will further explore the relevant literature to demarcate where knowledge gaps exist. Chapter 3 discusses key theoretical and conceptual assumptions related to the research in order to facilitate understanding of the initiative. This is followed by a discussion of epistemological and methodological considerations that underpin the study in chapter four. Chapter 5 describes the results of the study while interpretations are explored in the sixth chapter. The study concludes with implications for future research and recommendations to advance local work.

CHAPTER 2

LITERATURE REVIEW

2.0 Introduction

The overwhelming global evidence of health disparities and concerns about social injustice establish social determinants of health as an important area for scholarly inquiry. This chapter presents a literature review of key advances in the collection and application of sociodemographic data in health care settings. It begins with an account of the main historical international and national developments that anchor this research. This is followed by a description of tools/instruments that have been developed to collect sociodemographic data in health care settings in Canada and selected developed countries. In order to support sites interested in clinical application of sociodemographic information, research related to clinical interventions to address social determinants has also been examined. The feasibility and acceptability of sociodemographic data collection was likely to be related to the presence of enabling factors as well as barriers in a given site. Consequently, we sought to understand and anticipate facilitators and barriers to implementation of sociodemographic data collection by reviewing the literature related to factors affecting implementation of similar projects. Finally, the chapter concludes with a critical reflection of the extant literature that summarizes trends, gaps and offers insights for future directions.

The general approach to identifying relevant studies focussed on a search of the academic and grey literature. Although the various sections are related, it was more efficient to develop search strategies for each main area. The background historical narrative pertaining to global health equity developments was informed by general content knowledge acquired through seminars and readings.

With regard to literature pertaining to clinical screening tools and targeted approaches, peer reviewed publications were searched in selected electronic databases including PubMed, MEDLINE, Cumulative Index to Nursing and Allied Health Literature (CINAHL) and Scopus. All searches were conducted using the OVID interface. Google scholar was used to search the web based literature to identify additional articles of relevance such as dissertations, reports and conference presentations. The reference lists of all included papers were examined for additional articles not discovered through the primary search.

Specific terms used for searches were derived from the subject headings in MeSH list, free text and review studies related to the specific subject(s). Search strategies were built in MEDLINE and adapted for different databases. Searches were limited to papers published in the English language during the period 2006 to 2016. This ensured that the most recent evidence was considered in a rapidly evolving field. There was no restriction on type of study designs considered. Both empirical research and reviews were included in order to cover the breadth of the subject. The methodological quality of studies was not systematically evaluated although there was an effort to comment on the predominant designs, methods used and their inherent limitations.

Studies were screened initially using titles and abstracts. All articles that were potentially relevant were subjected to a detailed assessment of the full text. Studies selected were required to meet the following inclusion criteria: 1) described a tool/instrument/indicators related to one or more social determinants of health or 2) explicitly referenced an intervention based on a social determinant of health that was applied in a clinical setting; and 3) conducted in Canada, USA, Western Europe, Australia or New Zealand. The following exclusion criteria were applied to the search results: 1) the article was an opinion, editorial or audit; 2) employed only qualitative methods. The heterogeneity of interventions, study designs and outcomes precluded quantitative synthesis. A qualitative approach with narrative synthesis of the evidence has been presented.

2.1 Global action to achieve health equity

There has been growing global interest in health equity fuelled by ethical and moral concerns about social inequalities in health within and between countries. (17) Over time the health equity movement has ebbed and flowed through many re-incarnations. The foundational definition of health enshrined by the WHO Constitution in 1946 established health as a

multidimensional, positive concept that is inextricably linked with social well-being. (18) This paved the way for global solidarity and recognition of health as an inalienable right in the Declaration of Human Rights in 1948. (19) Translation of these early commitments has always implied action to address social determinants of health.

The Lalonde Report (20) is etched in Canadian history and is credited with ushering in a new era where the role of other non-medical determinants of health was recognized. It asserted that further improvements in health would require attention to environmental risks, behavioural risk factors and biology. (20) Some scholars have argued that any revolutionary value of decreased emphasis on health care was neutralized by ‘blaming victims’ for unhealthy behaviours that were in fact socially conditioned. Nevertheless, this new perspective shifted the traditional focus and created opportunities to look upstream of the health care system. In 1978, the Alma Ata Declaration (21) called for universal access to primary health care as a strategy for achievement of ‘health for all’. While still situating responsibility for health within the health care system, it embraced principles of equity, intersectoral collaboration and participation of communities as an integral part of social and economic development of communities. (21)

The Health Promotion movement emerged from the recommendations in the Lalonde Report and sought to address lifestyle factors through health education, social marketing, community development and healthy public policies. The work of proponents was crystallised in the Ottawa Charter for Health Promotion that clearly articulated the prerequisites for health including peace, shelter, education, food, income, stable ecosystems, sustainable resources, social justice and equity. (22) This global policy positioned health promotion as necessary for achieving health goals and championed the view that individuals must be provided with the necessary economic and environmental supports in order to achieve health. The strategies recommended by the charter also reflected the need to move beyond clinical and curative services and to embrace an expanded mandate that considered the broader political, social, economic and physical environment. (22) Additionally, although these strategies fostered intersectoral collaboration to advance health, they also challenged the health care system to reorient the way that it delivered services to refocus on the holistic needs of individuals.

The Black Report (23), published in the United Kingdom in 1980, was also influential in calling attention to the contribution of social conditions to poor population health. The document provided compelling evidence of the link between material deprivation, ill health and death. It

also concluded that ‘people’s behavior is constrained by structural and environmental factors over which they have no control’. (23) The report’s architects made several recommendations to tackle health inequalities including setting national health goals. Although the advice was not heeded by the incoming Conservative government, it had an impact on policies developed in other countries such as Sweden and Ireland. (23)

Despite the growing interest in prevention, health promotion and population health approaches, the expected gains in health did not occur in the 1990s. Some reports such as the Acheson Report (24) provided evidence of widening health inequalities between social classes. The analysis pointed once more to the role of social factors such as income, employment, education, material deprivation and lifestyle in poor health outcomes. The report’s recommendations (24) urged that priority be given to improvement in the standard of living for poor households and increasing efforts to promote health of families and children particularly those who bear a disproportionate burden of ill-health. Among the actions focused on the health care system were calls for more equitable distribution of resources to match need and burden of illness, targeted programs to improve access and utilization particularly of preventive health services among those underserved and improved capacity to routinely capture information on social class that could be used to stratify service statistics and health outcomes. (24)

During the 21st century, world leaders have renewed their commitment to the pursuit of ‘Health for All’ through many declarations including the Millennium Declaration (2000) (25), Beijing Platform and Declaration for Action (26), UN Declaration on Rights of Indigenous Peoples (2007)(27) and Rio Political Declaration on Social Determinants of Health (2011) (28). The unifying thread in these declarations reflects concern for social determinants of health although shifting global priorities are evident. This period has also been marked by health care reform as countries struggle to meet the challenges of population aging as well as dual epidemics posed by communicable and chronic non communicable diseases. (29)

In 2004, global concern for growing health inequities prompted the establishment of a Commission on Social Determinants of Health (6) to review evidence for action to reduce health inequities. A foundational component of the Commission’s work was the development of a conceptual framework that explicitly linked structural determinants to social conditions of daily living and health outcomes. Among the actions proposed to ‘close the gap in a generation’ were: 1) improvement in the daily conditions of living; 2) tackle the inequitable distribution of power,

money and resources (structural drivers of conditions of daily living) and 3) measure and understand the impact of action. (6) In consideration of these recommendations, the Rio Political Declaration on Social Determinants of Health operationalized actions needed at various levels and committed to monitor progress and increase accountability for the global vision.

The platform for health equity action continues to be guided by the Rio Declaration and the preceding evidence informed work of the Commission on Social Determinants of Health. Specific reference has been made to establishment of global surveillance systems for health equity and social determinants of health and research on effectiveness of interventions to reduce health inequities. There has been progress towards measurement of health inequalities although a global surveillance system remains elusive. (30)

2.2 Health equity agenda in Canada

Consistent with the global equity agenda, there is growing national support for establishing indicators and baselines that can be used to measure progress towards the reduction of health inequities. (31) This is a formidable challenge because conventional sources of information on socioeconomic determinants are separate and independent of those that contain morbidity and mortality data. Much of the work to measure social gradient in health outcomes has relied on complex analyses that relate administrative health care utilization databases and survey data derived from Census or Community Health Surveys. (32) The latter are often the most available sources of information on socioeconomic variables. A common approach has been to assign area-based measures of socioeconomic status and aggregate individual morbidity and mortality data for similar geographic areas. While imperfect, as there are assumptions vulnerable to ecological fallacy that individual lived experiences are reduced to their community geography, such studies (33,34) have been invaluable in advancing the field. Admittedly, there is also limited access to individual identifying data that can be linked to outcomes based on confidentiality considerations resulting in the continued use of area based measures.

Population health surveys, such as the Canadian Community Health Survey, offer an opportunity to explore higher level analyses of socioeconomic inequalities in health. These studies demonstrate the utility of individual level measures of socioeconomic status and advance our understanding of its relationship to morbidity, disability and access to health services. Despite large sample sizes, population health surveys are not well suited to sub-regional small area analyses because of small cell sizes and unreliable estimates for some health indicators. (35)

Data collected in these surveys often cannot be used to monitor the impact of quality improvement initiatives in health care organizations seeking to reduce health inequalities for vulnerable groups that access care in these settings. (35) This argument supports the adaptation of existing information systems to capture data on social determinants that can be applied locally as well as at the population level to resolve challenges related to measuring health inequalities.

In recent times, we have seen the suspension of the long form of the Census (36,37) that has been a longstanding repository for researchers to facilitate linkage of sociodemographic data to health outcomes. Although it was reinstated, this unprecedented event serves as reminder of the uncertainty of the future availability of current sources of comprehensive sociodemographic information. This development has also fuelled interest in augmenting the collection of critical information on social determinants during medical encounters in health care delivery settings. This could be an enduring source for locally relevant information that can also be aggregated at the population level and used to measure health inequalities.

The availability of micro level data on social determinants also has implications for the provision of client/patient-centred care. Historically only limited information such as age, sex and residence have been systematically captured although research has shown that other factors such as ethnicity, immigration status, primary language, disability and sexual orientation influence outcomes, care experiences and satisfaction. (14) The omission of this information excludes important patient social dimensions and represents a missed opportunity to deliver care that acknowledges and is responsive to patients' holistic needs.

Patient centered care is a recognised tenet of high quality care and an explicit expectation of service delivery in high performing health care organizations. Studies (5,38–41) have shown numerous benefits associated with patient centred care approaches including decreased emergency return visits and hospital admissions; higher functional status, improved clinical care, health outcomes and patient satisfaction. The desire to maintain a patient centred focus and increase the capacity to identify and respond to patients' holistic needs was the primary driver for the introduction of an initiative to screen for social determinants. It was proposed that increased access to micro level data on social determinants would create opportunities for the clinical care team to leverage the information to deliver more patient focused care that better addresses complex needs and potentially improves health outcomes. (16) There is a paucity of evidence in the Canadian context about how to collect and apply sociodemographic data in clinical settings.

Organizational context is likely to influence uptake and process of implementation of this type of initiative. An understanding of critical factors that influence the implementation of sociodemographic data collection contributes to the body of knowledge and informs policy solutions about how to support health service organizations who want to collect and apply sociodemographic data in patient care.

2.3 Sociodemographic data collection in health care settings in Canada

Empirical evidence of the feasibility of standardized collection of sociodemographic data has mostly been reported from the United States, United Kingdom and Australia. (42) In these countries, data collection elements have almost exclusively been limited to race, ethnicity and preferred language and are often backed by a legislative mandate for reporting equal access to care for racialized groups. (42) Although there is growing interest in collection of data related to sexual orientation and gender identity, it still remains an elusive issue. (43–45)

There are relatively few published reports with mixed experiences with implementation in Canada which suggests that context specific enablers may be important in the introduction of standardized sociodemographic data collection in clinical settings. Of the six initiatives that were identified, one was implemented in Manitoba (46), four (47–50) were implemented in the province of Ontario and one in British Columbia. The initiative in British Columbia collected information about Indigenous self-identity in the interior communities of Thompson Cariboo, Okanagan and Kootenay. Efforts to secure additional information about the initiative's evaluation were unsuccessful hence no further elaboration is possible. Additionally, very limited contextual information was available about the CLEAR toolkit (49) and the clinical poverty tool (50). Hence these tools have been reviewed in latter sections as part of the general literature.

The following sections describe three of the projects based on published reports but also draw on conversations with key informants including two program managers and a program evaluation consultant who were knowledgeable about these programs. This provided critical information about potential contextual factors that may have influenced the implementation of these projects.

2.3.1 Language and ethnicity indicators in the Winnipeg Health Region

A Language Access Initiative (46) began in 2004 as a response to address language barriers faced by an increasingly diverse patient population who access services in Winnipeg health

facilities. This initiative paved the way for other equity efforts including the introduction of language and ethnicity indicators into the health information system.

The introduction of language and ethnicity indicators (LEI) was serendipitous. The development of a new electronic health record offered the opportunity to develop modules to accommodate the ethnicity and language indicators. Prior to the introduction of LEI, only one hospital was collecting language and ethnicity data and only selected patients were asked the questions. With the Language Access Initiative, there was now a compelling reason to ask all persons as the appropriate resources were in place to address the barriers.

A steering committee (46) was formed to advance the project and guide planning and implementation. At the outset, a number of pertinent issues were recognized including ethical/legal implications, feasibility of collecting the information and whether there would be support from front line staff. Three subcommittees were established to address these concerns. (46) An ad hoc committee comprised of individuals who were responsible for ethics, privacy and legal counsel agreed to act as a resource as needed. The other two committees provided IT expertise and included managers and staff in departments that would be responsible for implementing the changes. This process ensured that relevant stakeholders were engaged in the initiative.

In the Winnipeg project, there was legitimate uneasiness about collecting ethnicity data at the outset. This was related to the fact that the intent was solely to use this for equity research. This was in contrast to the language indicator where resources were already available through the Language Access Initiative to address any needs identified. There was particular concern that providers were not well educated about ethnicity, consequently the propensity to stereotype may be greater.

It was difficult to determine the appropriate categories for the ethnicity indicator. The team ultimately used the Statistics Canada classification largely to simplify the coding for analysis. These categories were thought to be easily understood and represent the standard way of asking about ethnicity within the Canadian context.

There was careful consideration of the site for data collection. While it may have been ideal to include the questions at the point of care where there is a therapeutic relationship, it was more

practical to integrate the questions during the registration process. Training was provided for registration personnel to ensure a standardised approach to asking the questions. Training sessions incorporated didactic presentations, small group discussions and role play scenarios. Components of the training emphasized the rationale for asking the questions, how to collect the information and respond to patient concerns. The evaluation of the initiative reported more positive experiences with the collection of data on preferred language of communication with providers while the ethnicity indicator was discontinued after a few months (personal communication). Although a script was developed, there were instances when questions were reworded with loss of clarity and intent. There was high acceptance among patients including racialized groups to provide the information. Despite high acceptance, some patients registered concerns about the legality of asking the questions and others questioned whether screening should be universal since ‘the problem’ affected clearly recognized groups. The report concluded that while data collection on ethnicity and preferred language was feasible, additional support and resources are needed.

2.3.2 Tri-hospital and Toronto Public Health Equity Data Collection

In 2009, four ‘equity practitioners’ formed a partnership to advance equity through standardized collection of sociodemographic data collection.(47) All partners had experience and content expertise in the area of equity. Although there was no external funding at the time the project was initiated, the partnership was committed, exercising creativity and mobilizing resources to achieve their goal.

The partners employed an evidence-based approach to identify best practices for who, when, where and how the data should be collected.(47) The researchers were particularly interested in critical factors for success as well as barriers to standardized sociodemographic data collection. They searched the academic and grey literature as well as consulted content experts. The selection of sociodemographic questions was rationalised based on relevance, feasibility and or reliability in the local context. Over a two year period, there was also extensive consultation with local stakeholders to select the final 14 pilot questions. (47)

The training activities were an important part of the preparation for data collection.(47) Targeted audiences for training included senior management in addition to front line staff. It was thought that high quality training increased staff confidence and ability to collect sociodemographic data. When health service personnel understood the rationale for asking the

questions and uses of the data, they were able to respond appropriately when challenged by patients who expressed concerns. Training materials were adapted from Scotland's 'Happy To Ask' training manual and DVDs. Materials were also developed to assist trainers in the facilitation of training sessions.

In the summer of 2012, the Tri-Hospital and Toronto Public Health (TPH) Health Equity Data Collection Research Project (47) collected data on socioeconomic factors in five sites reflecting both in-patient and outpatient hospital settings. The survey was available in paper format for the majority of respondents although 25% used a tablet.(47) All responses were self-reported although the questionnaire was self-administered in some sites or assistance was provided by providers or volunteers in other sites. High overall response rates (86.6%) were achieved which suggests general acceptability of the methods of administration.(47) The highest non-response rates occurred for the question enquiring about income.

Feedback obtained during focus group discussions with data collectors suggested that the training prepared them adequately for field work. Staff concerns about patient reluctance to provide the information were largely unfounded. (47) Although patients asked questions about the uses of the data and expressed privacy and confidentiality concerns, the experiences were largely positive. Time pressure to complete the questionnaire prior to being seen by providers was a challenge however this improved with experience over the duration of the project. (47) The results of the study were applied to refine the questions. The number of questions was reduced to eight core items and three optional (but recommended) items. The pilot was strategic and timely and paved the way for wide scale implementation in Toronto as directed by the Toronto Central Local Health Integration Network (TC LHIN). The information has not been applied at the individual level to tailor care and treatment although it currently supports program planning and understanding the population who access services.

2.3.3 Pediatric health equity data collection instrument

Following the encouraging results of the pilot project, TC LHIN mandated hospitals to collect sociodemographic data using the standardized tool that had been previously developed. The tool had been developed in adult populations and there were concerns about its use in pediatric populations. (48) The SickKids Hospital and Holland Bloorview Rehabilitation Hospital (48) partnered to develop a pediatric tool. The project was implemented in two diverse sites reflecting inpatient and outpatient settings. There were two instruments that were developed – a

Youth Health Equity Survey and a Caregiver Health Equity Survey. (48) The latter was developed for caregivers of youth under the age of 14 years or older who did not have the cognitive capacity to complete the Youth Survey. The tool included sociodemographic questions about the primary care giver and four questions about the youth (country of birth, spoken language, race/ethnicity and disability). The Youth Equity Survey (48) was completed by youth between ages 14 and 18 years. This survey included two questions for the caregiver about the income that supported the youth's household and the remaining sociodemographic questions were completed by the youth.

Similar to the TPH project, a working group (48) was established in April 2013 to guide the process of development of the instruments. The process included a search of the literature to identify sociodemographic factors related to health inequities in children and established instruments that had been used to collect data in pediatric populations. The group also consulted with key stakeholders such as patients, family members, providers, senior management, quality leaders and privacy officers. (48) The questions were designed to be comparable with those of TPH Equity Project, however additional questions about the relationship between the caregiver and the child, income supporting the child and highest education of the primary caregiver were included. Registration was selected as the most optimal point for data collection. Registration personnel were prepared during three hour training sessions that covered health equity concepts as well as sociodemographic data collection. Three methods of data collection were tested in the project including paper survey, computer survey and verbal interview. Surveys were completed anonymously in all sites. Measures were instituted to track number of eligible patients, number who were unable to complete a survey in English and the number who decline to participate.

There was a high compliance rate (81%) for completion of the survey. (48) Although staff were apprehensive about data collection during the training, the post implementation assessment showed that they were comfortable administering the surveys. Follow up interviews with patients and care givers also indicated that they were comfortable and willing to provide sociodemographic information. (48) Paper survey administration yielded high participation rates in outpatient settings while interview administration generated higher rates in inpatient sites. Computer administration yielded low rates in outpatient settings where it was piloted. (48) The impact on registration staff workload was minimal with paper or computer administration however interview administration added significantly to participant and staff burden.

High response rates (>90%) were achieved across items except for year of arrival for patients who were not born in Canada and primary caregiver's education, employment and occupation. (48) Questions related to household income, number of persons supported by that income and child disability also yielded lower response rates. (48) The final survey did not include relationship of caregiver to the patient as available data revealed the majority of patients were accompanied to health visits by primary care giver. The proposed question to capture cost of care for children with chronic conditions was also excluded as it was felt that it lacked face validity. The project advanced the health equity agenda by developing a tool that considered the unique needs of the pediatric population. It is not known how the information has been used and specifically whether there are plans to apply the information at the individual level to improve quality of care.

Summary. There were common themes that were evident across the three Canadian projects. All initiatives established coordination structures to guide planning and implementation. The composition of committees varied, however there were efforts to consult with persons who would be affected and who would be involved with implementing the proposed change. Evidence based approaches to selection of sociodemographic questions were employed. The identification of a location and data collectors was guided by practical considerations as well as best practices from other sites. Training for data collectors was conducted in each project prior to implementation of data collection.

Contextual factors shaped motivation for each project. The Pediatric Equity Project occurred as a result of TC LHIN mandate to collect sociodemographic data in all hospitals. In Manitoba, the Language Access Initiative created a supportive environment for asking language and ethnicity questions during patient care. The Tri-Hospital and TPH Equity Project was driven by equity champions whose work was strategic and advanced the region's equity agenda. Staff apprehension about sociodemographic data collection was perceived to be a barrier across all sites. It was also assumed that patients/clients would be reluctant to disclose their personal information.

The unique features of each initiative influenced implementation activities. In some projects, multiple modes of administration were tested across various sites while in others a single method was employed. Provisions were made for translation of the questionnaire in some projects. Communication strategies also varied but leaflets and posters were common media for

disseminating information to patients. This might be a reflection of resources available to support projects.

Projects were implemented successfully across diverse organizational contexts which makes it difficult to identify specific factors that are necessary for any initiative. In these projects, clinical application of the sociodemographic data and incorporation into the health record only occurred in the Winnipeg project for the language indicator. It is difficult to predict whether patients/clients would be comfortable with clinical application across a full complement of questions. The provider's perspective of clinical application would also need to be explored.

2.4 Tools for sociodemographic data collection in health settings

This section synthesizes the literature about available tools that screen for social determinants. It also describes, how or if, they have been clinically applied to mitigate the impact of patients' adverse social circumstances in an effort to improve health outcomes. There are two broad approaches to addressing social determinants in health care settings. There is a nascent but growing body of research related to screening tools for social determinants of health that have been applied to identify individual social needs and tailor care and treatment during clinical practice. A second approach relates to targeted initiatives that have been designed to address the needs of specific socially disadvantaged groups usually within the context of a particular disease (e.g. diabetes, HIV). The latter initiatives have often been developed to address health disparities in these populations.

The rationale for collection of sociodemographic data includes (16): 1) understanding the social needs of patients who access services; 2) identification of health disparities in care processes and health outcomes; 3) informing the development of interventions to reduce health disparities and 4) tailoring care holistically to address medical and social needs. In this project, it was uncertain at the beginning how pilot sites would use sociodemographic data. In order to plan for these varied information needs, the literature was reviewed in three areas relating to experiences with implementation of social screening tools and their clinical application, targeted clinical interventions to address social determinants and facilitators and barriers to standardized collection of sociodemographic information. Table 2-1 provides a summary of the screening tools that were identified.

Table 2-1: Summary of sociodemographic data collection tools

Author	Tool	Settings	Clinical application	Major findings of evaluations
Bowen et al., 2011 (46)	<u>Language and ethnicity indicators</u> (LEI) Two language questions and 1 ethnicity question	Acute care hospital setting, Winnipeg, Manitoba	Information about limited English language proficiency was used to address language barriers Ethnicity indicator used for equity measurement only.	High acceptance of collection of information on preferred language of communication by patients. Ethnicity indicator discontinued.
DGL Consulting et al., 2013 (47)	<u>Tri-Hospital and TPH Health Equity Tool</u> 8 core and three optional questions: Preferred language of communication Place of birth Race/ethnicity Disability Gender Sexual orientation Annual family household income Number of persons supported by income (Optional: Preferred language for reading, religious affiliation, housing)	Acute and ambulatory care settings in Toronto, Ontario	At the time of reporting, the information is being used for descriptive purposes to map the sociodemographic profile of patients who access services at particular facilities.	High overall participation rate (86.6% of persons approached completed the survey). Most persons completed the paper format of survey (25% used a tablet) Generally high item response rates (>90%). Highest non-response rates for follow up questions to year of arrival in Canada (85.5%) and number of persons supported by family income (84.6%).
Bloch et al., 2013 (50)	<u>Clinical Poverty Tool</u> Single poverty screening question	Target: Adults Primary Care, British Columbia, Canada	Three step approach 1. Screening question 2. Adjust risk 3. Intervene by assessing for eligibility for specific benefits and connect to resources	The sensitivity (98%) and specificity (40%) of this primary screening question have been established.(51) This single question was best predictor of LICO status (OR 32.3, 95% CI 5.4 – 191.5).

Author	Tool	Setting	Clinical application	Major evaluation findings
Pratt et al., 2015 (52)	<u>Patient Centred Assessment Method (PCAM)</u> 11 items covering 3 domains including health, wellness, social environment and health literacy and communication	Target: Adults Primary care – Wellness Clinic, Scotland	Nurses integrated the assessment into the clinical encounter. Provisions were made to record specific actions taken in relation to the needs identified.	1) No differences in patient satisfaction or perceived provider empathy pre and post intervention. 2) The pattern of referrals changed post intervention with fewer medical referrals but an increase in psychological, social and lifestyle referrals. 3) Nurses found the tool acceptable and applicable to their patients.
Colvin et al., 2015 (53)	<u>I-HELP</u> (54) screens for unmet needs related to: I ncome H ousing/utilities E ducation L egal (Immigration status) P ersonal and family stability	Target: Families with children Hospitals and health centres, Boston, USA	The tool empowers clinicians to screen for specific unmet needs. Care is delivered in a multidisciplinary model with legal providers who intervene for violation of rights related to benefits eligibility, termination or denial. Social workers are also important members of the health care team.	Pediatric residents who were exposed to a multifaceted behaviour change intervention improved screening and referral for I-HELP domains. The tool had fair sensitivity (0.63), high specificity (0.96) and positive predictive values (0.94).
Manchanda Gottlieb, 2015 (55)	<u>HealthBegins Tool</u> -Education -Employment -Social connection and isolation -Immigration -Financial strain -Housing insecurity -Food insecurity -Transportation -Exposure to violence -Stress -Physical activity and dietary patterns	Target: Adults Not specified, USA	The tool included recommendations for intervals for screening for each domain, scores responses (0 – 2) and provides for documentation of plans to address identified needs. The authors do not offer recommendations about who should apply the screening tool.	The authors report that the domains were adapted from the recommendations issued by the Institute of Medicine. However no information has been provided about assessments of the tool in practice.

Author	Tool	Settings	Clinical application	Major evaluation findings
NHS Health Scotland, 2011 (56)	<u>Happy To Ask, Happy To Tell</u> offers a resource to support standardized data collection related to: -Disability -Gender -Sexual orientation -Race/ethnicity -Religion	Target: ?Adults Health settings (not specified); Scotland, UK No particular mode of administration is privileged.	The tool provides guidance on standardized questions, how to ask the questions and rationale for data collection. A DVD has been developed in addition to trainer and trainee manuals.	There were plans to evaluate the toolkit in 2009 however it is uncertain whether they were carried out.
Cahill et al., 2014 (57)	<u>Do Ask, Do Tell</u> The instrument includes one question about sexual orientation and a two-step gender identity and birth sex question	Target: Adults 4 Community Health Centres (USA)	There was no clinical application based on participant responses. In the majority of sites, research staff approached potential participants in the waiting area and administered the short survey.	1) The majority of participants thought that it was important to ask about sexual orientation (74%) and gender identity (82%). 2) Most found the questions easy to understand and included response options that allowed them to accurately document their SOGI. 3) Sexual minorities were more likely than heterosexual counterparts to perceive that it was important to ask about sexual orientation (p=0.007)

Author	Tool	Settings	Clinical application	Major evaluation findings
Berkowitz et al., 2016 (58)	<u>Health Leads Social Needs Screening Tool</u> (59) includes core and optional items -Food security -Housing instability -Utility needs -Financial resource strain -Transportation -Exposure to violence -(Optional: Child care, education, employment, social isolation and supports, general health and mental health behaviors)	Target: Adults 3 academic primary care practices in Boston, USA	A standardized form was used to screen patients for unmet social needs. Those who screened positive were offered brief information or meeting with an advocate to obtain resources. Participants were followed up to see whether intervention with the Health Leads Program had an effect on blood pressure, glycosylated hemoglobin and cholesterol.	Among those who enrolled in Health Leads Program (compared to those who opted out), there were greater improvements in systolic and (differential change -2.6 mm Hg; 95% CI, -3.5 to -1.7) diastolic blood pressure (differential change -1.4, 95% CI -1.9 to -0.9) and LDL cholesterol (differential change, -6.3 mg/dL; 95% CI, -9.7 to -2.8). Glycosylated hemoglobin did not improve in patients with diabetes who were part of the Health Leads group (58).
Garg et al., 2012 (60)		Target: Families Urban hospital based pediatric clinic (Baltimore MD)	Integrated care model with screening for social needs, referral by providers to the health desk where patients are connected with services	The model successfully linked families to community resources. At 6 months follow up, 50% of those who had used the HL desk had accessed at least 1 community based resource. 85% of providers who made referrals had received an update about their patient.

Author	Tool	Settings	Clinical application	Major evaluation findings
<p>Naz et al., 2016 (61)</p>	<p><u>CLEAR Tool Kit</u> (49) includes discussion aids related to: -Access to food, clean water -Stable income -Quality housing -Child care -Education and literacy -Freedom from violence -Support from families and friends</p>	<p>Target: Adults/Families Primary care setting; developed for middle and low income countries</p>	<p>The kit advocates four steps: 1) Treat the acute health problem 2) Ask about underlying social problems; 3) 3) Refer to social supports 4) Advocate for a healthier community</p>	<p>-Most participants understood the importance of social determinants of health and were engaged in caring for vulnerable persons. However, there were gaps in knowledge of how to ask and appropriate resources. -Health workers who had specific ways of asking about social challenges reported being able to help them address any identified needs (93% vs 52.9% p=0.003) -Most participants found the toolkit clear and relevant to their work. Almost half (48 %) agreed that it would change the way they practised.</p>
<p>Page-Reeves et al., 2016 (62)</p>	<p><u>WellRx</u> 11 items to assess -Food insecurity -Housing -Utilities -Income -Employment -Transportation -Education -Substance abuse -Childcare -Safety -Abuse</p>	<p>Three family medicine clinics, Albuquerque, New Mexico</p>	<p>Patients who screened positive for social needs were offered assistance with connecting to appropriate services and resources.</p>	<p>3048 patients were screened over 90 day period. 46% screened for at least 1 area of social need. Most of the needs identified were not previously recognized by clinicians. Face to face administration by medical assistants had higher yield than self-administration</p>

Author	Tool	Settings	Clinical application	Major evaluation findings
PEDIATRIC TOOLS				
Gee et al., 2013 (48)	<u>Pediatric equity tool</u> <u>Youth Equity Survey</u> Place of birth Spoken language Race/ethnicity Disability + Caregiver income <u>Caregiver equity survey</u> Income, education, employment of caregiver +questions in youth survey	Acute and ambulatory care pediatric settings, Ontario	Clinical application of information unknown	High compliance rate (81%) Lower response rates for questions pertaining to year of arrival among immigrants, caregiver education, employment, occupation and income
Garg et al., 2007 (63)	<u>WE CARE:</u> 10 item self-administered screening tool that included: -Education -Employment -Homelessness -Child care need -Smoking, substance abuse, depression, intimate partner violence	Target: Families of children attending well child visits Urban hospital-based pediatric clinic (Boston, USA)	Pediatric resident physicians reviewed the completed survey and made referrals to address identified needs.	-The WE CARE intervention had a positive impact on provider discussion of psychosocial issues and referral to community resources. -It was not burdensome to staff and added less than 5 minutes to screen for the ten items.

Author	Tool	Settings	Clinical application	Major evaluation findings
Garg et al., 2016 (64)	<u>WE CARE:</u> 10 item self-administered screening tool that included: -Education -Employment -Homelessness -Child care need -Smoking, substance abuse, depression, intimate partner violence	Target: Families with infants < 6 months old attending well child care visits at 8 urban community centres (Boston, MA)	Mothers in the WE CARE arm completed a screening tool that was reviewed by clinicians. Clinicians were provided with a resource book that had detachable pages. If the patient indicated that she needed help with a particular need, the appropriate information was removed and provided from the resource book. Participants at control clinics received standard care	Cluster RCT found that more participants in the WE CARE intervention arm received ≥ 1 referral at the index visit (AOR 29.6, 95% CI 14.7 -59.6). At 12 month follow up, mothers in the intervention group were more likely to be accessing a new resource (aOR 2.1, 95% CI 1.2 – 3.7) as well as be enrolled in employment training (aOR 44.4, 95% CI 9.8 – 201.4), child care program (aOR 6.3, 95%CI 1.5 -26), receiving fuel assistance (aOR 11.9, 95% CI 1.7-82.9) and lower odds of being homeless or in shelter (aOR 0.20, 95% CI 0.1-0.9)
Fleegler et al., 2007 (65)	<u>Online Advocate</u> Computer-based questionnaire that included 5 domains: -Access to health care -Housing -Food security -Income security -Intimate partner violence	Target: Parents of children 2 Urban pediatric child wellness clinics (Boston, USA)	Research assistants approached families in the waiting room and invited them to participate in the study. Participants completed the survey using a laptop. Participant responses generated a unique list of agencies that offered services to address an identified need.	1) The majority of families (82%) had at least one health related social problem. 2) Screening for health related social problems was desirable and acceptable (92%) among study participants. 3) Almost two thirds (63%) of families who received referrals contacted the agency. The majority (82%) of families reported satisfaction with agencies contacted.

Author	Tool	Settings	Clinical application	Major evaluation findings
Hassan et al., 2015 (66)	<u>Online Advocate</u> Computer-based questionnaire that included 5 domains: -Access to health care -Housing -Food security -Income security -Intimate partner violence	Target: adolescent/young adults attending an urban hospital adolescent/young adult clinic	Self-administered web based tool that provided feedback about health related social needs and allowed for patient selection of referrals.	76% of youth who were screened had ≥ 1 social need. 83% of participants were reached for follow up. Forty percent had contacted a resource that they had been referred to and 50% had either completely or mostly resolved their top problem.
Gottlieb et al., 2014 (67)	<u>iScreen Questionnaire</u> included 23 items in 16 psychosocial domains related to: -Income -Housing stability and habitability -Household violence -Substance use -Child care access	Target: Adult caregivers seeking care for a child at a pediatric emergency department of larger urban children's hospital (California, USA)	Participants were randomized to either computerized self-administration of the questionnaire or face to face interviews by fully bilingual research assistants.	There was no significant differences by mode of administration for most items however participants in the computer based group were more likely to report stress related to interpersonal violence ($p=0.03$) and substance abuse ($p=0.05$) as well as disclose annual household income ($p=0.02$).
Gottlieb et al., 2016 (68)		Target: Caregivers of children seeking services at pediatric primary and urgent care clinics in 2 safety net hospitals (California, USA)	After standardized screening, participants either received written information on resources (control group) or in-person assistance to navigate services and telephone follow up telephone calls for further assistance as needed.	Caregivers in the navigator arm experienced a reduction in mean number of social needs while those in the control arm saw an increase ($p<0.001$). Similarly, caregivers in the navigator intervention arm reported improved global child health status compared with those in the control arm ($p<0.001$).

Author	Tool	Settings	Clinical application	Major evaluation findings
Keller et al., 2008 (69)	<u>Medical Legal Advocacy Screening Questionnaire (MASQ)</u> Ten items covering four domains: -Access to services -Dignity and safety -Housing -Financial stability	Target: Parents of children attending 5 pediatric and family practices caring for children living in poverty (Massachusetts, USA)	Research assistants recruited participants in the waiting area and administered the survey. The responses were discussed with the participants who then decided whether they would accept a referral for legal consultation.	The MASQ was more sensitive (0.81) but less specific (0.75) than physician judgment resulting in a lower PPV (0.35) in the population screened. The low specificity may overestimate need for legal services in high risk populations or indicate the family is not ready to seek legal counsel at the time of screening.
Kleinman et al., 2007 (70)	<u>Single item</u> about hunger	Target: Caregivers attending primary care pediatric clinic in MA, USA	Subset of participants who agreed to follow up interviews were provided with information about community resources. No specific interventions were delivered during this pilot project	Sensitivity for the single item screen was 0.83 and specificity was 0.80. Time to time stability was 77% and kappa was 0.62. Hungry families were more likely to be using food assistance programs.
Hager et al., 2010 (71)	<u>2 item screen</u> -Worry about food access -Adequacy of food supplies	Target: Caregivers of children (0-3 years) attending 7 urban medical centres (Primary care and hospital ED settings) in USA	No clinical application. The purpose was to develop a clinical screen based on the Household Food Security Scale	Sensitivity for 2 items screen was 0.97 and specificity 0.83. Food insecurity was associated with increased odds of child health fair/poor (aOR 1.56, 95%CI 1.44-1.68) hospitalization during the lifetime (aOR 1.17, 95% CI 1.10-1.24) and developmental risk (aOR 1.60, 95%CI 1.42-1.80).

Settings. The literature review identified eighteen tools that were designed to screen for social risks/determinants in health care settings.(46–50,52,53,55–57,59,62,63,65,67,69–71) Most of the tools originated in the USA, however two were developed in the United Kingdom (52,56) and six in Canada (46–50). Outpatient settings were the most common sites for implementation across tools. Almost half of the tools identified were intended for application in pediatric populations with families being the target for intervention. (63,65,67,69–71)

Comprehensiveness of tools. Although few tools screened comprehensively, most of those identified assessed for financial need/income and housing security. (47,49,53,55,62,65,67,69) Fewer tools (49,53,59,62) assessed food security, education and access to services (health). There were two tools that screened exclusively for food security (70,71). Only two tools (47,56) asked about disability status, race/ethnicity and religion. Screening for gender identity and sexual orientation was also uncommon.(47,56,57) Among the tools intended for pediatric settings, several assessed other psychosocial needs such as depression, intimate partner violence, smoking/substance abuse, transportation and need for child care services.

Evaluation of tools. The majority of studies that evaluated screening tools tracked success by the number and satisfaction with referrals to social service and other community organizations. This is probably related to the relatively short duration of follow up of study participants that precluded assessment of health outcomes. However, two studies examined different health outcomes such as clinical endpoints (58) and self-reported overall child health (68). Screening characteristics were assessed for five tools that reported high sensitivity and variable specificity. (50,53,69–71) Three of the tools had low specificity. (50,53,69) While not ideal, an argument can be advanced for casting a wide net in order to rule out the presence of a health related social problem than can have costly consequences if unaddressed.

A few studies described the feasibility and acceptability of screening tools or questions.(49,52,57,62,63,67) In these studies, feasibility and acceptability were often not explicitly defined, however could be operationalized as determination of whether the intervention/project components could be implemented and how it was received by either those individuals who delivered or received it. Common measures of feasibility and acceptability included social screening response rates as well as perceptions and experiences with implementation captured using qualitative methods. The perspectives of providers were assessed in four of the six studies. (49,52,62,63) Two studies gauged acceptability only based on patient

response rates.(57,67) Only one study examined the perspective of administrators in order to understand institutional factors affecting implementation.(61) The results of these studies suggested that there was support from providers and patients for asking about social circumstances in health care settings however it is still likely that variation exists across questions and settings since comprehensive screening was uncommon.

Although these studies pointed to a variety of factors implicated in successful implementation, none of these influences were tested empirically. These factors include buy in from staff and appropriate training (52,57), identification of resources which could serve as sources of referral (52,61–63) and strong organizational support to facilitate integration of social determinants approaches in clinical care. (52,61) One study (61) identified the presence of role models as important for supporting residents to ask about social causes of poor health. In a few studies (61,63,67), the related issues of time constraints and efficiency of data collection were also identified as important considerations in approaches to sociodemographic data collection. In general, structural factors and the broader context were relatively neglected. Based on these studies, our understanding remains limited about the factors that facilitate or hinder sociodemographic data collection.

Some social determinants have been relatively neglected in sociodemographic screening tools. Hence, more work is needed with respect to comprehensive screening approaches in health care settings. The majority of studies described self-administered tools that employed either paper-based or electronic formats. In many instances, tools were also available in other languages. Mechanisms for connecting patients with resources to address prioritized social needs were variable. This may have implications for adaptation of screening in real life settings with limited human, technological and other resources. More studies are needed using existing staff models to demonstrate how well implementation occurs under pragmatic conditions. Studies were mostly conducted in high need outpatient settings (e.g. low income participants, sexual minorities) where screening may be more desirable. It is difficult to extrapolate the findings to settings with different patient characteristics and or acute care settings.

Screening and intervention are depicted as static and following discrete algorithmic solutions. Few screening approaches emphasized interventions that are possible within the care encounter such as friendly and inclusive practice environment, culturally sensitive communication and integration of knowledge of social determinants to adjust patient risk, as well

as care and treatment strategies. While it is important to assess uptake and satisfaction with referrals for social determinants, it would also be useful to explore the effect on the patient's care experience since screening invites disclosure of more sensitive information and potentially requires more rapport and trust. Further the influence of context on implementation as well as facilitators and barriers have seldom been critically examined.

There are many provider barriers to the implementation of screening and surveillance for psychosocial issues such as lack of time, training and knowledge of community resources. However, there is limited evidence that the challenges can be addressed through innovative models that provide benefits for families who struggle with non-medical determinants that impact the family's health. (72) This case study contributes to the existing body of knowledge and guides local practice related to implementation of sociodemographic data collection in urban health care settings. An evaluation of the feasibility and acceptability of a comprehensive sociodemographic data collection tool is the first step to increasing capacity for individual level intervention and development of targeted interventions that better address community needs.

2.5 Targeted clinical approaches to address social determinants of health

Another approach to social determinants in health care settings incorporates targeted interventions for subgroups defined by specific social characteristics. In this project, the vision was for clinical application of sociodemographic information in each of the three project sites. Consequently, there was a review of the literature to identify interventions to address each social determinant explored by the project. This was part of the preparatory work that informed the identification of potential clinical interventions that could be considered in the local context. The extent to which information was clinically applied was limited to one specialised ambulatory care site. As a result, several of the clinical interventions were not applicable. This related review of clinical interventions has been presented in Appendix E.

2.6 Facilitators and barriers of implementation of sociodemographic data collection

The previous sections explored social screening tools that have been applied in clinical settings as well as the clinical interventions to address social determinants. This research informed the identification of potential sociodemographic questions and selection of practical actions that could be employed by health care organizations.

A key research objective was to understand the facilitators and barriers to implementation of standardized sociodemographic data collection in order to identify appropriate strategies to support wider local implementation. The prior review of social screening tools suggested that comprehensive screening was underutilized in the studies identified. Further, some factors such as race, ethnicity, language, gender identity and sexual orientation had seldom been included. This selected group was identified for further exploration as it was possible that data was captured by health care organizations but not necessarily for clinical application. A review of the relevant literature focussed on the experiences of health care organizations with implementation of data collection for these selected determinants. This information helped the project team to anticipate challenges and create a supportive and enabling environment in local project sites.

There is limited and mixed experience with the implementation of sociodemographic data collection in the Canadian context.(46–48) This suggests that context specific enablers are critical to success. The systematic collation of studies exploring the barriers and facilitators of sociodemographic data collection could contribute to the evidence base and guide implementation strategies. To the best of the author's knowledge, there has not been a systematic review of factors affecting implementation of sociodemographic data collection related to race, ethnicity, language, gender identity and sexual orientation in health care settings. These factors may be perceived as particularly sensitive by both patients and providers and presents an opportunity for greater understanding in a relatively underexplored area. This subsection identifies, appraises and synthesizes the literature pertaining to facilitators and barriers of collection of sociodemographic data related to these selected factors by health care organizations.

Criteria for included studies. There was no restriction on the types of studies included in the review although it was anticipated that the majority of studies would employ designs that apply qualitative methods such as interviews and focus group discussions. Articles that were comments, editorials or opinion pieces were excluded. Articles that only described the

development of a standard or provided guidelines for sociodemographic data collection were excluded unless they also included empirical information about the stakeholders' experiences with implementation.

The review emphasized and reported on the perceptions and experiences of a variety of stakeholders including patients or clients, health service personnel, administrators and policy makers who were involved with implementation of sociodemographic data collection. Geographical settings were restricted to USA, Canada, Europe, Australia and New Zealand to maximise relevance of studies to the local context.

The term 'sociodemographic data collection' was operationalised to refer to capturing standardized self-reported patient data related to language proficiency or preferred language of communication, race, ethnicity, Indigenous identity, gender identity and sexual orientation in health care settings. Additionally, health care setting was defined as any health care organization that provides health care services either acute or ambulatory whether public or privately administered. Studies based on experiences of health plans with sociodemographic data collection were also included as they were seen as extensions of health care settings.

Any study in which patient sociodemographic data was obtained through linkage of administrative databases to the census or population health surveys was excluded. This was consistent with the focus on understanding how to collect sociodemographic data through patient self-reports during a health care visit. Only studies in the English language were included. A study was included once it satisfied the criteria outlined whether or not factors influencing implementation were the main focus or a secondary objective of the study.

Search strategy and identification of relevant articles. The search strategy incorporated key words, their synonyms and MeSH terms. Searches clustered sociodemographic terms by associated groups that experience suggested might occur together. For example, studies might explore sociodemographic data collection pertaining to race, ethnicity and language together. This search included key words 'sociodemographic data' OR data collection (MeSH) AND 'ethnicit*' OR 'race' OR 'primary language OR preferred language OR language proficiency OR language barrier'. The search strategy for Medline is shown below and illustrates these principles. (Table 2-2). The electronic databases searched included PubMed, MEDLINE, CINAHL and Scopus. The search was limited to the years from 2000 – 2016 to reflect the evolution of work in this field. The search strategy was developed in MEDLINE and adapted for other databases.

Table 2-2: Search strategy for MEDLINE

Data collection	1. Data collection[MeSH:no exp]
	2. Collecting data[tiab]
	3. Collect data[tiab]
	4. Sociodemographic Data [tiab]
	5. Socioeconomic factors[MeSH]
Ethnicity	6.Ethnicit*[mp]
	7.Indigenous[mp]
	8.Aborigin*[mp]
	9. First adj (Nation or Nations)[mp]
	10.Métis[mp]
	11.(American adj2 indian*)[mp]
	12.(Native adj2 American*)[mp]
	13.Torres Strait[mp]
	14.Oceanic Ancestry Group[MeSH]
	15.American Native Continental Ancestry Group[exp]
	16.Inuit*[mp]
	17.(Alaska adj2 native*)[mp]
	18.Eskimo*[mp]
Race	19.Race (mp)
Language	20.Language*(mp)
	21.Primary language [mp]
	22.Preferred language[mp]
	23.Language proficien*[mp]
	24.Primary spoken language[mp]
	25.Bilingual[mp]
	26.Mother tongue[mp]
Gender	27.Gender identity [MeSH:no exp]
	28.Gender[tiab] AND identity[tiab]
Sexual orientation	29.Sexual orientation[MeSH]
	30.Sexual[tiab] AND behavior[tiab]
	31.Sexual behavior[tiab]
32.1 OR 2 OR 3 OR 4 OR 5	
33.6 OR 7 OR 8 OR 9 OR 10 OR 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18	
34. 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26	
35. 27 OR 28	36. 29 OR 30 OR 31
37. 32 AND 33 AND 34	
38 32 AND 35 OR 36	
[mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	

The grey literature was searched using Google Scholar (first 25 frames due to volume) as well as websites of governmental and non-governmental organizations such as Social Interventions Research and Evaluation Network (SIREN), Robert Wood Johnson Foundation (RWJF), Health Education Research Trust (HRET), Agency for Healthcare Research Quality (AHRQ) and the Institute of Medicine (IOM). Articles identified during the search were screened using titles and abstracts. Those articles that appeared to be relevant were retrieved and their full texts assessed for eligibility. All articles that satisfied the inclusion criteria were included in the synthesis. The reference lists of included studies were also searched for related articles that might have been missed in the primary search. The search results have been reported in Figure 2-1 as recommended by the Preferred Reporting Items from Systematic reviews and Meta-Analyses (PRISMA) guidelines.

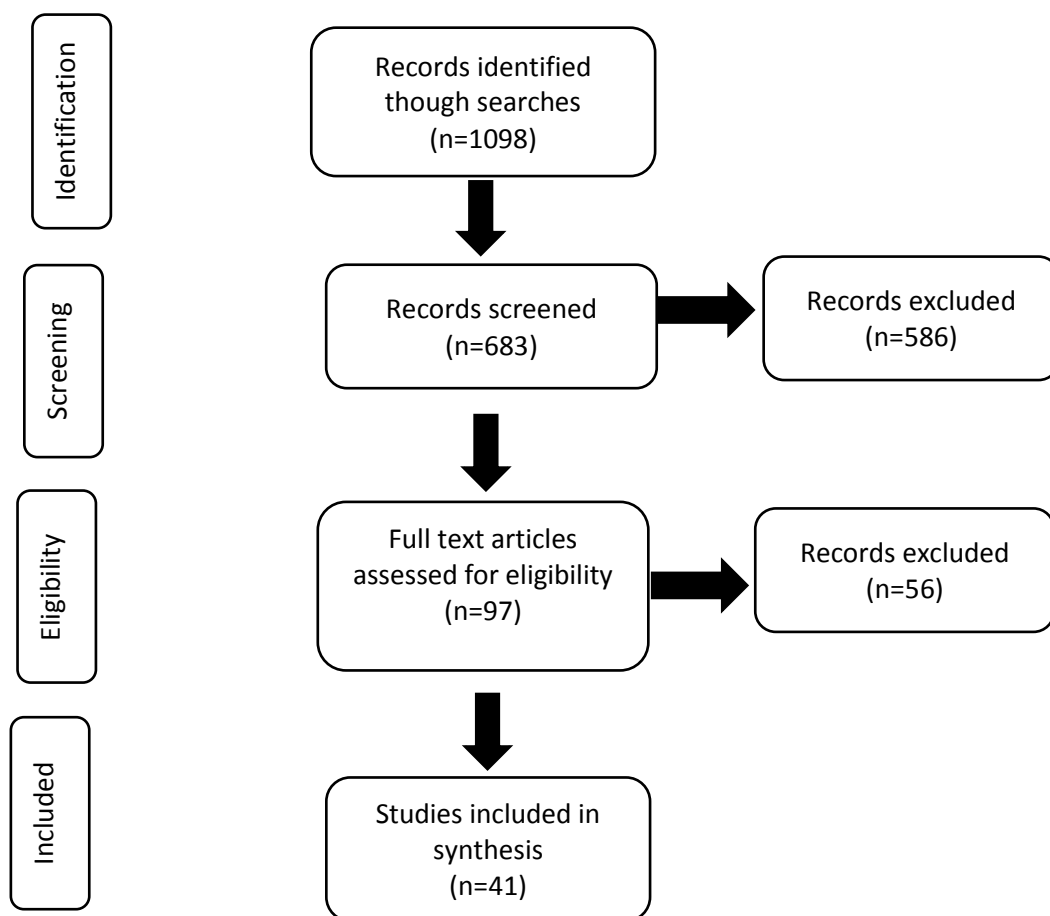


Figure 2-1: PRISMA diagram showing study results

Data extraction. A standardised data extraction form was developed based on Supporting the Use of Research Evidence (SURE) framework.(73) The SURE framework includes a checklist of potential enablers and barriers to implementing health system interventions. The elements considered by the checklist include attitudes, knowledge and skills of providers of care and recipient of care, health system constraints (e.g. financial resources, leadership and information systems), social and political constraints (e.g. legislation or regulations). The data extraction form was piloted on three potential articles from the list. Data was abstracted about the authors, year of publication, setting (i.e. country, urban or rural, type of facility), stakeholder group (e.g. provider, patient), sociodemographic question(s), research methods and barriers/enablers reported.

Assessment of quality. The Critical Appraisal Skills Tool (CASP) for qualitative studies was used to assess the quality of qualitative studies. (74) This tool does not incorporate a summary score and response options to criteria include ‘yes’, ‘no’ or ‘not clear’. Quantitative descriptive studies such as surveys were assessed using the NIH Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies. (75) Similar to the CASP, this tool also does not create a tally based on responses to the various questions in order to arrive at an overall assessment of quality. However, it assists the assessor to systematically evaluate the potential for bias in the study and draw conclusions about the overall quality rating of the study. Studies were not excluded based on their quality. The quality of included studies informed the author’s assessment of confidence in the review findings. An overall assessment was based on methodological limitations, relevance of studies, adequacy and coherence of the review findings.

Synthesis. The results were synthesized using a thematic framework analysis approach. (76) This was thought to be most appropriate as the information was expected to be largely descriptive and provided insight about stakeholders’ experiences and reactions to the implementation of sociodemographic data collection. The extracted information about facilitators and barriers was read repeatedly to allow for familiarity. Through this process, codes were assigned based on the SURE framework. The codes were sorted into themes that represented patterns in the data. The potential themes were reviewed for coherence and a thematic map was created with the final themes. A narrative was created that described and explained the various themes.

2.6.1 Results

The search identified 683 articles in English after the removal of duplicates. Based on titles and abstracts, 97 articles were retrieved for full text review. Forty one studies met the inclusion criteria and had the relevant information abstracted and synthesized. Table 2-3 presents a summary of the results clustered by sociodemographic questions.

2.6.1.1 Race, ethnicity and language

The majority of studies were conducted in the USA and pertained to the collection of race and or ethnicity and language (REL) data.(77–98) One Oregon study that had recently introduced legislation in 2013 also required collection of data about disability (REAL+D data).(95) The exploration of barriers and or enablers of sociodemographic data collection was seldom the main objective of studies. (92,99) Often studies focused on addressing health disparities but described implementation of standardized data collection as a foundational component of their research. This is consistent with one of the common reasons for collection of sociodemographic data in health care settings.(16)

There was marked variation in the emphasis of data collection across countries represented in the review. In the United States, studies explored the collection of data related to race, ethnicity and language although the former elements have been more consistently collected than the latter by health care organizations. (100) In the United Kingdom, the focus has been on collection of ethnicity data as opposed to race or language. In New Zealand, the focus has also been on collecting general ethnicity data although there is an acknowledgement of the social disadvantage of Maori peoples. (100) In contrast to the other countries, the Australian approach has been less inclusive in its narrowed focus on collection of information related to identity as either Indigenous or Torres Strait Islander, both or neither.(100)

In each of the respective countries, standards for data collection have been established over time.(42,101–103) These were intended to facilitate ‘roll up’ of categories into the broader national race or ethnic groups used in the census or population health surveys. The consistency of application of these standards by health care organizations has been variable and affects the comparability, quality and utility of data for planning and quality improvement.

Table 2-3: Summary of studies that were included in the review

Author	Setting	Stakeholder(s)	Research methods	Facilitator/Barrier	Quality Assessment
Race or ethnicity or language					
Hasnain-Wynia et al., 2004 (77)	1000 US hospitals nationwide Six leading US health consortiums (Consortium for Eliminating Disparities Through Communities and Hospital Partnerships)	Survey respondents' info not provided Clinical, research and operational staff	Survey Direct observation on site visits	Structural State mandate to collect race/ethnicity data (F) Organizational Leadership support (F) Education/training for staff (F) Resource limitations (B) Perceived legal barriers (B) Individual Staff discomfort (B) Perceived patient discomfort (B) Privacy and confidentiality concerns (B) Fear of misuse of information (B)	27% Response rate Patient perspective not captured. Validation of the results by comparison with another national survey.
Hasnain-Wynia et al., 2010 (78)	20 medical practices with ≤ 5 physicians in US (5 urban, 6 rural, remaining suburban)	Practice managers, nurse managers and physicians	Semi-structured telephone interviews	Organizational IT infrastructure (having an EMR) (F) Perceived legal barriers (B) Individual Patient discomfort (B) Privacy concerns (B) Staff discomfort (B) Uncertainty whether data collection is useful (B)	Physicians randomly selected to be invited to participate however those who accepted might have been more motivated.

Author	Setting	Stakeholder(s)	Research method	Facilitators/Barriers	Quality assessment
Regenstein & Sickler, 2006 (79)	Non-federal acute care hospitals in US (American Hospital Association members) Over half (52.7%) of these hospitals have an average daily census below 20.	501 Chief financial officers	Survey	<p><u>Organizational</u> Lack of consensus from executive leadership on need to collect data (B) Size and type (larger and teaching status) (F) IT infrastructure limited to accommodate data (B) Lack of funding to support data collection (B)</p> <p><u>Individual</u> Staff reluctance to ask (B) Patient reluctance to provide information (B) Concerns about legality of data collection (B) Perceived time constraints (B) No demonstrated need for data collection (B)</p>	Response rate of 45.5% Survey findings weighted to reflect distribution of non-Federal acute care hospitals
	64 National Association of Public Hospitals and Health Systems (NAPH) Member safety net hospitals in USA Most public entities with teaching programs	Principal respondent was an individual who was knowledgeable about registration and data collection processes (hospital CEOs, director of patient relations, medical directors)	Telephone survey	<p><u>Organizational</u> Staff training (F) Perceived low priority of data collection (B) Requirement for registration to complete race field (F)</p>	Response rate of 60%, Patient population diverse with high proportions of racial minorities Accuracy of the data was not verified

Author	Setting	Stakeholder(s)	Research method	Facilitator/Barrier	Quality assessment
Berry & Kaplan, 2014 (80)	Ten diverse US hospitals varied in size and payer mix (Eight urban and three major teaching facilities) All had substantial proportion of cardiac patients who were racial and ethnic minorities	Hospital administrators Registration supervisors Quality management Line staff Program staff	Two day site visits (12- 19 interviews per site) at two points in the study (early and later) Telephone interviews with key informants (4-7 per site) of sites that were not visited	<u>Organizational</u> Staff training and implementation aids (F) Adaptation of information technology infrastructure (B) Use of data to examine health disparities (F) <u>Individual</u> Perceived patient discomfort (B) Appropriateness of coding categories (B)	Sites were not representative of all US hospitals (substantial minority populations) Staff were highly motivated. Data was reviewed only for patients with re-admissions who were likely sicker and older.
Gomez et al., 2014(81)	367 non-Federal general acute care hospitals (GAC) in California 80% were private, urban and not academic centres	Chief administrators QI personnel Registrars Fiscal personnel	Surveys (sent via both US post and online)	<u>Organizational</u> Collecting data at first visit (F) Staff training and implementation aids (F) Incorporating questions into routine admission forms (F) Enforcement of hospital policies regarding data collection (F) Auditing processes (F)	Response rate 56% but no significant differences between those who did or did not respond. Survey focused on GAC hospitals in California and may not generalise to other types of hospitals. Discrepancies between survey responses for multiple respondents not reconciled.

Author	Setting	Stakeholder(s)	Research method	Facilitators/Barriers	Quality Assessment
Weinick et al., 2007 (82)	All hospitals, Massachusetts	Researchers Policy makers	Report Participant observation (?)	<p><u>Organizational</u> Leadership support (F) Staff training (F) Timing of implementation (B) Fidelity to existing national models vs adaptation (B/F) Lack of understanding the rationale for data collection (B) Appropriate and meaningful categories (B) Need to reprogram information systems (B)</p>	No details about how studies were identified and results synthesized
Jorgensen et al., 2010 (83)	Sample of hospitals (stratified by number of beds, location and teaching/non-teaching status), Massachusetts	Senior executives from the following areas: Patient access and registration (n=8); community, diversity and disparities (n=7); quality, safety and performance (n=6); information technology systems (n=4); and finance (n=3)	Semi-structured interviews conducted via telephone with participants from 28 hospitals	<p><u>Structural</u> State mandate for data collection in hospitals (F) <u>Organizational</u> Resources for modifying IT systems (B) Staff training (F) Determining how best to ask about Hispanic/Latino ethnicity (B) <u>Individual</u> Concerns regarding importance of data collection and how it will be used (B) Perceived lack of direction from the state (B)</p>	Only 45% of hospitals participated and they were more likely to have resident training programs, be located in Boston or Metrowest and had been involved in pilot prior to implementation

Author	Setting	Stakeholder(s)	Research method	Facilitator/Barrier	Quality assessment
Thorlby et al., 2011(84)	Three US hospitals, two community health centres and three health plans	Senior managers, senior clinicians and data analysts (up to 5 per site)	In person semi-structured interviews	<p><u>Structural</u> State mandate for data collection</p> <p><u>Organizational</u> Staff training and implementation aids (F) Need to modify IT systems to accommodate categories Staff time constraints (B)</p> <p><u>Individual</u> Staff discomfort due to perceived negative patient reactions (B) Ethnic categories that fit patient self-descriptions (B)</p>	Cases studies examined the experiences of organizations that were likely more to be engaged in data collection and hence were atypical.
Hasnain-Wynia et al., 2011 (85)	Massachusetts (various locations)	Persons privately insured or covered under Medicaid/Medicare plans	Six focus group discussions (each homogeneous for participant race, ethnic or language background)	<p><u>Individual</u> Gradient of comfort (language least worrisome) (B) Concerns about misuse and adverse effects on premiums and services (B) Perceptions that information is not relevant for plan (B) Recognition of potential benefits (F) Providing an explanation about why the information was being collected (F) Timing of data collection (B)</p>	Single state, perceptions of plan members may differ by geography. Participants were engaged and had some knowledge about the topic prior to participation. Focus group findings are specific to a particular group

Author	Setting	Stakeholders	Research method	Facilitators/Barriers	Quality Assessment
Escarce et al., 2011(86)	US Health plans offering commercial, Medicaid, or Medicare Advantage products	Respondents from health plans	Surveys of health plans conducted in 2003, 2006, 2008 by America's Health Insurance Plans Foundation	<p><u>Organizational</u> Large commercial, Medicare and Medicaid plans were more likely to collect race and ethnicity data (F) Limited human and IT resources (B) Absence of race/ethnicity fields in transaction forms or enrollment systems (B) Costs of collection and maintenance (B)</p> <p><u>Individual</u> Perceived patient concerns (B) Privacy concerns (B)</p>	<p>Response rates varied across years (40%, 60% 50% respectively in 2003, 2006, 2008)</p> <p>Unable to verify accuracy of data collected.</p>
Lawson et al., 2011 (87)	245 US health plans offering commercial, Medicaid or Medicare Advantage products listed in the Atlantic Information Services Directory of Health Plans for 2007	Health plan representatives (e.g. chief medical officers, directors of quality improvement)	<p>Excel based survey completed by 123 plans</p> <p>Follow up interviews with staff from 15 plans representing both 'collecting' and 'non collecting plans'</p>	<p><u>Organizational</u> Larger commercial and Medicaid plans were more likely to capture language data (F) Majority of commercial plans used direct methods to collect language data (F)</p> <p><u>Individual</u> Perceived negative reactions from patient (B) Inadequate information technology systems (B)</p>	<p>50% response rate in 2008</p> <p>Methodological differences between 2008 survey and earlier surveys</p> <p>Earlier surveys asked about primary language only while 2008 surveys asked about primary and or preferred language</p>

Author	Setting	Stakeholders	Research method	Facilitators/Barriers	Quality Assessment
Gazmararian et al., 2013 (88)	AHIP member plan Varied (region, plan type, enrolment size, health plan type, stage of work)	Representatives from 15 health plans - 10 plans from those who indicated that they collect and use data and 5 plans that did not	In-depth interviews	<p><u>Structural</u> Regulatory hurdles that prevent employers from sharing enrollee data (B) Requirements from compliance organizations (B)</p> <p><u>Organizational</u> Support from senior leadership (F) IT system capacity to store and reconcile multiple data categories (B) Ability to share information across plan and health care system (B) Legal issues (real and perceived)(B) Limited resources and competing priorities (B) Homogeneous member population (B)</p> <p><u>Individual</u> Member privacy concerns (B) Lack of provider understanding about importance of data collection (B)</p>	Small number of health plans that may not represent the experiences of plans who do or do not collect REL data

Author	Setting	Stakeholders	Research method	Facilitators/Barriers	Quality Assessment
Nerenz et al.,2013 (89)	250 Health plans nationwide listed in the Atlantic Information Services Directory of Health Plans, USA	Representatives of health plan	Excel-based electronic survey	<p><u>Organizational</u> Verification of physician proficiency in non-English Language (B)</p> <p><u>Individual</u> Physician concerns about information may be used to exclude them or adversely affect patient selection of their practice (B) Physician acceptance or understanding of ethnic categories (B)</p>	<p>51% response rate Possible non-responding plans were less engaged with respect to REL data collection.</p> <p>Sample size too small for detailed analysis of relationship between REL data collection and service area characteristics</p> <p>Unable to explore why a subset of plans discontinued data collection between 2006 and 2010.</p>

Author	Setting	Stakeholders	Research method	Facilitators/Barriers	Quality assessment
Bierman et al., 2002 (90)	US Managed Care health plans	Representatives of managed care (commercial, Medicaid, and Medicare), purchasers (CMS, state agencies, and employers) and federal agencies	Report presents an overview and reports dialogue of meeting in June 1999 with stakeholders indicated	<p><u>Organizational</u> Costs of data collection (B) Perceived legal barriers (B) Concerns about public reporting and accountability (B) Timing of data collection with respect to enrollment (B)</p> <p><u>Individual</u> Privacy and confidentiality concerns (B) Patient concerns about misuse of data (B) Education of public, insurers, purchasers and providers about the benefits and appropriate use of data (F)</p>	Unable to determine whether or how information was synthesized from primary sources, discussions in other fora among providers, purchasers, government and other health services
Baker et al., 2005 (91)	General Internal Medicine clinic of the Northwestern Medical Faculty Foundation in Chicago, Illinois	Patients who had completed their visit and who were fluent in English	Semi-structured interview (N=220)	<p><u>Individual</u> Patient willingness to disclose REL data (F) Rationale provided for data collection affects patient comfort (B/F) Concerns about discrimination (B)</p>	Convenience sample in a single clinic Participants were middle and upper income hence views may not be representative. All native English speakers.

Author	Setting	Stakeholder(s)	Research method	<u>Facilitators/Barriers</u>	Quality assessment
Hasnain-Wynia et al., 2006 (92)	?US health care settings (hospitals, medical group practices, health plans)	Multiple perspectives considered (provider, patient, administrator)	Review and synthesis	<p><u>Organizational</u> Staff Training (F) Categories that do not match patient self-perceptions (B) Cost of data collection (B) Time constraints (B)</p> <p><u>Individual</u> Negative reactions from patients (B) Staff discomfort (B)</p>	Overview has been provided of several key areas however approaches to identification of relevant studies and synthesis have not been described.
Hasnain-Wynia et al., 2012 (93)	14 Aligning Forces for Quality (AF4A) Alliances	AF4Q alliance leaders, project directors, and disparities/equity staff leads;	<p>Semi structured interviews (n=51) with key informants during two day site visits to AF4Q communities.</p> <p>Data supplemented by regular 6 month telephone interviews (n=28) with program directors on progress on disparity related activities</p>	<p><u>Organizational</u> Systematic collection of REL as starting point for disparities work (F) Low priority in communities with minimal REL diversity (B) REL data collection seen as an ineffective use of resources (B) Hospitals more willing to be engaged (F) Varied work cultures in physician practices and data management systems.(B)</p> <p><u>Individual</u> Provider beliefs that they already provided high quality care without REL(B)</p>	Patient perspective not directly captured although projects work closely with communities and are familiar with the issues.

Author	Setting	Stakeholders	Research method	Facilitators/ Barriers	Quality assessment
Wilson et al., 2013 (94)	Institute for Family Health operates 17 community health centers providing primary, mental health and dental care in cities and rural settings New York, USA	Program developers	Program monitoring reports (comparison for % race filed completed pre and post implementation)	<p><u>Organizational</u> Leadership commitment (F) Electronic reminders to collect data (F) Adapted EHR field created by vendor for another client (F) Staff training and implementation aids (F) On-site refresher training on REL data collection (F) Communication with all staff (F)</p> <p><u>Individual</u> Patient willingness (F) Staff discomfort (B) Multiple modalities offered for data collection (paper or verbally) (F) Limited literacy (B)</p>	<p>Single network Centre may have been more engaged and motivated to collect REL data</p> <p>No control group</p>
Oregon Department of Health Services, 2014 (95)	Oregon, USA	Managers of sixty five Oregon Health Authority and Oregon Department of Human Services datasets	Survey	<p><u>Structural</u> Legislation (F)</p> <p><u>Organizational</u> Funding (B) Nationally defined standards(B) Rigid and external data systems (B)</p> <p><u>Individual</u> Staff discomfort (B) Patient concerns (B)</p>	Baseline assessment of compliance verified for a subset of 15 datasets

Author	Setting	Stakeholders	Research method	Facilitators/Barriers	Quality assessment
Voices for Racial Justice, 2014 (96)	RESO (diverse communities by race, ethnicity, language and other socio-demographic factors) communities in Minnesota	Community members from American Indian/Native American; Black-African American, African Immigrant, Asian Pacific Islander, Latino/Hispanic, Lesbian Gay Bisexual Transgender Queer (LGBTQ) Two-Spirits ⁸ , and People with Disabilities.	Interviews (85 with community members)	<p><u>Organizational</u> Trained staff (F) Community engagement in planning (F) Knowing that information will be shared with the communities (F) <u>Individual</u> Patient comfort (F) Mistrust of health care and government systems (B) Lack of knowledge about how the information would be used (B) Confusion around definitions of race and ethnicity (B)</p>	Some constituents would have been excluded due to financial and time constraints Difficulty recruiting an interviewer from West African community Some interviewees including those with disabilities expressed difficulty understanding the questions
Voices for Racial Justice, 2014 (96)	Safety net clinics (six) in Minnesota	Community-based non-profit safety net health care providers (Safety Net Coalition)	Interviews (9 with providers)	<p><u>Structural</u> State mandate, financial incentives or grant funding (F) <u>Organizational</u> Time constraints (B) Cost (B) Need for standardisation of processes and definitions (B) All options not accommodated in EHR (B) Collection of information for new patients (F) <u>Individual</u> Patient willingness to disclose (B)</p>	Uncertainty regarding how the participants were selected. Approaches to data analysis not explained. Ethical considerations not described.

Author	Setting	Stakeholder(s)	Research method	Facilitators/Barriers	Quality assessment
Bhalla et al., 2012 (97)	Urban academic medical centre in Bronx, New York	Program developers/ implementers	Program report - Proportion of inpatient discharges with unknown race, ethnicity and preferred language	<p><u>Organizational</u> Senior executive stewardship (F) Staff engagement in planning (F) Staff training and use of implementation aids (F) IT expertise (F) Access to content experts through quality improvement initiative (F)</p> <p><u>Individual</u> Lack of categories that fit the patients' self-description (B)</p>	<p>Single centre Predominantly African American/ Black /Hispanic population</p> <p>No control group</p> <p>No formal mechanism for verification of the accuracy of registrar's data collection</p>
Lee et al., 2016 (98)	Academic health centre, Galveston County, Texas	Programme implementers	Report – Pre and post implementation comparisons of the proportion of patients with unknown REL status	<p><u>Structural</u> Meaningful use of EHR incentives (F)</p> <p><u>Organizational</u> Staff training (F) Inadequate financial and human resources (B) Need to reprogram EHR (B)</p> <p><u>Individual</u> Patient discomfort (B) Categories do not accommodate patient's self-description (B)</p>	<p>Single centre that serves predominantly minority populations</p>

Author	Setting	Stakeholder (s)	Research methods	<u>Facilitators/Barriers</u>	Quality Assessment
Aspinall, 2000 (104)	Acute and non-acute NHS Trusts in South Thames region	Front line admission staff Information managers	Self-administered questionnaires Review of finished consultant episode counts	<p><u>Structural</u> Mandate for data collection by hospitals (F)</p> <p><u>Organizational</u> Indirect methods of assignment used (B) Limitations in categories (B) Staff training (B)</p> <p><u>Individual</u> Staff concerns about relevance (B) Perceived patient discomfort (B) Perceived homogeneity of patient population (B) More difficult in some service areas (emergency services and mental health) (B) Perception that information should be collected by GP and shared with hospital.</p>	<p>40 of 60 eligible trusts returned the questionnaires.</p> <p>Ethical considerations were not described.</p> <p>Approaches to analysis of qualitative data not described.</p>
Sangowawa & Bhopal, 2000 (105)	Eight practices in the Teeside area, UK Two primary care practices, Teeside, UK	General practitioner Practice manager	Semi-structured interviews Audit of GP referral letters	<p><u>Structural</u> Lack of incentives (B)</p> <p><u>Organizational</u> Staff training (F) Cost not considered a barrier Ethnicity field created in referral letter template (F)</p> <p><u>Individual</u> Patient awareness about why data is needed (B)</p>	<p>Participants selected randomly.</p> <p>Unable to verify reasons provided by participants for missing information on patient ethnicity.</p>

Author	Setting	Stakeholder(s)	Research method	Facilitators/Barriers	Quality Assessment
Jones and Kai, 2007 (106)	<p>Eight primary care practices in Birmingham, UK that use EMIS computer systems</p> <p>Information include ethnicity, religion, preferred written and spoken language</p>	<p>Practice manager Receptionists Practice nurse</p>	<p>Extracts of data collected for 6 – 12 months on patient ethnicity</p> <p>Site visits to practices</p>	<p><u>Organizational</u> Staff training (F) Staff shortages (B) Flags on arrival screen (F) Form not translated (B) <u>Individual</u> Patient comfort with data collection (F) Staff morale (B)</p>	<p>No ethics review as project thought to be exempt on grounds of local service development.</p> <p>Populations served by practices varied in diversity</p>
Iqbal et al., 2012 (107)	<p>Primary care trusts in England and Wales Members of Race for Health mailing list National Cancer Research Network</p>	<p>30 participants including clinicians, nurses, managers, information scientist and other staff</p>	<p>Survey (questionnaire could be returned via post or email)</p>	<p><u>Organizational</u> Availability of staff training materials (F) Lack of resources (B) Not required to collect ethnicity data (B) Ethnicity categories are not appropriate (B) Time constraints (B) <u>Individual</u> Lack of understanding by staff and patients of the need for data collection (B) Staff reluctance (B) Perceived patient discomfort (B) Concerns about privacy and legality of data collection (B)</p>	<p>Unable to determine response rate as questionnaire was distributed as a link through websites, forums, newsletters and mailing lists</p> <p>Adapted a questionnaire that has been validated in the target population.</p>

Author	Setting	Stakeholder(s)	Research method	<u>Facilitators/Barriers</u>	Quality Assessment
Iqbal et al., 2012 (108)	Local community centre and places of worship Manchester, UK	South Asian participants from India, Pakistan, Bangladesh	Five focus group discussions (4-10 per group) in native language of participants. Total =36	<p><u>Individual</u> Staff comfort (F) Patient discomfort if the reason for data collection not explained (B) Inappropriate ethnic categories (B) Concerns that information although collected would not be utilized (B)</p>	Research focused on largest minority group Results pertained to specific groups. Difficulty recruiting facilitators of particular ethnicity for gender segregated focus groups
Morrison et al., 2014 (109)	Diverse health settings in UK (England, Scotland, Wales, Ireland) including hospitals, general practice, research institutes	Managers and administrators involved in processes of collection and utilisation of patient ethnicity data in general practices and hospitals	Qualitative case study drawing on interviews (n=14 with 16 participants) and document review (n=50)	<p><u>Structural</u> Incentives under the QOF were discontinued in 2011 (B) <u>Organizational</u> Data collection not supported by existing forms (B) Lack of training (B) Resource constraints (B) <u>Individual</u> Staff discomfort and fear of offending patients (B) Perceived irrelevance in the context of particular services (e.g. Emergency care) (B)</p>	Patient perspective not captured Singular focus on ethnicity Medical record not examined for documentation of ethnicity within the clinic narrative

Author	Setting	Stakeholder(s)	Research method	Facilitators/Barriers	Quality Assessment
Kehoe & Lovett, 2008 (99)	General practices in Australia Capital Territory Division of General Practice (ACTDGPs) catchment area	General practitioners Practice nurses and division staff (N=145)	Survey mailed to general practices but also distributed at 145 general practitioners) Semi structured interviews with 16 staff members from 9 practices	<u>Organizational</u> Absence of routine identification processes (B) Support for staff training (B) Lack of support for identification and use of Aboriginal and Torres Islander specific health interventions(B) <u>Individual</u> Perceptions that patients would be offended (B) Perceived legal barriers (B) Perceptions that identification was not beneficial for either practice or patient (B)	Response rate estimated at 25% and views may be unrepresentative of target population. Study captured views of practice staff who influence whether and quality of data about Indigenous identity
Scotney et al., 2010 (110)	Indigenous Australians residing in the Australian Capital Territory who were recruited through a range of Indigenous organisations	Indigenous Australians who had been asked about their identity in GP practices (N=28, 12 men; 18 Aboriginal and 5 both Torres Strait Islander and Aboriginal)	In person interviews	<u>Individual</u> Patient willingness to disclose their identity if provided with an explanation (F) Staff trained who know how to ask in culturally sensitive way (F) Prior experiences with racism (B) Perception that disclosure of identity would lengthen consultation time (B)	Ethical considerations not described. Approaches to sampling and analysis were not described

Author	Setting	Stakeholder(s)	Research method	Facilitators/Barriers	Quality Assessment
Kelaher et al.,2010 (111)	General practice network in Australia	General Practice Networks Information technology Cultural safety informants Public Health Medical Officers Area Health Services Persons with prior experience with identification	Semi-structured interviews with key informants (n=31) from range of organizations and General Practice Networks Focus groups with general practitioners, GP educators and practice nurse	<p><u>Organizational</u> Involvement of Indigenous people and organizations in developing solutions and processes (F) Preserve Indigenous peoples' privacy and autonomy to determine to whom and under what circumstances they want to disclose their identity. (F) Staff education (F) IT infrastructure improvements (F) Broader ethnicity question (F)</p> <p><u>Individual</u> Staff discomfort (B) Perceived patient discomfort (B) Fear of misuse of the information and adverse consequences (B) Clear explanations about why the information is being collected.(F) Increasing community awareness (F) Provider perceptions that all patients should be treated equally hence identity is not important (B)</p>	Multiple perspectives captured through case studies. Limited information about approaches to analysis.

Author	Setting	Stakeholder(s)	Research method	<u>Facilitators/Barriers</u>	Quality Assessment
Schutze et al., 2017(112)	Eastern (ESML) and South-eastern Sydney Medical Local (SESML) Three practices from ESML and four from SESML, Australia	8 General practitioners 4 Practice managers 2 Nursing staff 16 Receptionists 1 Allied health professional 1 Unannounced standardised patient	30 Semi structured interviews (in person or via telephone) 2 Focus group discussions each with 5-6 members of Aboriginal and Torres Island Strait communities 1 visit per clinic by the unannounced standardised patient Medical record audits of reporting practices Self-completed mail questionnaires (practice staff)	<u>Structural</u> National standards and health reform (F) <u>Organizational</u> Lack of effective routine identification processes (B) Software does not permit recording of status by National Best Practice guidelines (B) No materials in practice environment encouraging disclosure (B) <u>Individual</u> Perceived homogeneity of the population (B) Perceptions that Indigenous status can be determined by physical appearance (B) Lack of awareness of the rationale for data collection (B) Perceived patient reluctance (B) Lack of awareness of disparities and health needs of Indigenous peoples (B)	Participants were self-selected and may have been more motivated than non-participants. Practices were in urban areas although reflected a mix of other practice characteristics Only women were interviewed as part of the community focus groups. Multiple perspectives captured Member checking with focus group participant Prolonged engagement in field Investigator and data triangulation

Author	Setting	Stakeholder(s)	Research method	Facilitators/Barriers	Quality assessment
Ethnicity					
Mc Leod et al., 2000(113)	Sixty-eight general practices and three After Hours Medical Centres, in the greater Wellington area including Porirua, the Hutt Valley and Wainuiomata, New Zealand	Practice personnel, patients and researchers/users of health data (Statistics New Zealand, The Ministry of Health, New Zealand Health Information Service, Te Puni Kokiri, Te Ropu Rangahau Hauora a Eru Pomare, RNZCGP and the Wellington Independent Practitioners Association)	Survey of current practices Interviews with practice personnel Interviews with fourteen patients and ethnic group representatives, including Maori and Pacific people, Asian, Indian, Chinese and different European groups, all living in Wellington	<u>Organizational</u> Cost of data collection (B) IT systems (B) Staff education (B) <u>Individual</u> Perceived benefits to data collection (F) Perceived patient reluctance (B) Patient perceptions that data is not relevant to delivery of care (B) Fear of negative consequences (B)	Multiple perspectives captured.
Health Utilisation Research Alliance (HURA), 2006(114)	37 Wellington Independent Association general practices (WIPA) using electronic patient management software	25 WIPA general practices	Data abstracted from practice computing systems	<u>Organizational</u> IT infrastructure (B) Time constraints (B) Competing priorities (B) Implementation aids (patient pamphlet and staff card) (F)	No systematic difference between practices who participated and those who declined. Study period coincided with the introduction of a new incentive for collection of data in primary care

Author	Setting	Stakeholders	Research method	Facilitators/Barriers	Quality Assessment
Cormack and McLeod, 2010 (100)	Health and disability sector in New Zealand	Researchers	Discussion paper	<p><u>Structural</u> Incentives (F) <u>Organizational</u> Leadership support (F) IT infrastructure (B) Cost (B) Appropriateness of ethnic codes (B) Staff training (F) <u>Individual</u> Understanding the relevance and meaning of ethnicity (B) Perceived patient discomfort (B)</p>	Process for identification and synthesis were not described.
Neuwelt al., 2014 (115)	Eight general practices - six in north and two in west of Auckland New Zealand; two were solo practices	General practitioners Practice managers Receptionists	<p>Questionnaire (self-completed or via structured interview with evaluator)</p> <p>Face to face interviews also conducted to clarify findings from the questionnaire</p>	<p><u>Structural</u> Lack of incentives (B) <u>Organizational</u> Appropriateness of categories (B) Lack of training (B) Time constraints (B) Practice management systems that facilitate accurate recording (B) <u>Individual</u> Staff discomfort (B) Lack of understanding of relevance and meaning of ethnicity data collection (B)</p>	<p>Small number of practices from particular regions hence findings were not be generalizable.</p> <p>No demographic data was audited (e.g. number and ethnicity of patients enrolled)</p>

Author	Setting	Stakeholders	Research methods	Facilitators/Barriers	Quality assessment
Gender Identity and Sexual orientation					
German et al., 2017 (116)	Emergency departments (ED) of three community and 2 academic medical centres in Baltimore, Washington and Maryland	ED health care professionals ED Patients	In-depth interviews (twenty six ED health care providers, fifty three patients) National online survey	<p><u>Organizational</u> Staff training in SGM health and cultural competency (B) Lack of guidance on collection and use of SOGI data (B) Protection against discrimination (F) Provisions to allow in person disclosure but opt out of storage (F) SGM inclusive signs and brochures (F) Community awareness campaigns (F)</p> <p><u>Individual</u> Patient willingness to disclose (F) Patient perception that SO data was medically relevant (F) Perceived patient reluctance by providers (B) Provider perception that SO was irrelevant to care (B) Fear of negative consequences and maltreatment (B) Assurances of privacy and confidentiality of data (F) Implications for insurance coverage (B)</p>	Patient survey response rate =70% Clinical survey response rate=86% Patient and provider perspectives were captured.

Author	Settings	Stakeholders	Research method	Facilitators/Barriers	Quality Assessment
Maragh-Bass et al., 2017 (117)	Self-identified transgender persons (adults, residing in the USA) recruited by marketing firm	Self-identified Transgender patients	Online survey	<p><u>Structural</u> National policies impacting LGBT rights (F) Institutional policies to protect against discrimination (e.g. insurance) (F)</p> <p><u>Organizational</u> Access to known LGBT-identified providers (F) LGBT friendly site (F) Trained and knowledgeable staff (F) Assurances of privacy and confidentiality (F) Inclusive signs and art (F) Routine collection of SOGI from all patients (F) Perceived cultural acceptance (F) Inclusion of partners/spouse (F)</p> <p><u>Individual</u> Perceived need for disclosure (F)</p>	<p>Small sample size 89.4% of those eligible participated</p> <p>Most participants has high educational attainment.</p> <p>Unadjusted analyses.</p> <p>Gender queer or non-binary were excluded</p>

Author	Setting	Stakeholders	Research method	Facilitators/Barriers	Quality assessment
Maragh-Bass et al., 2017 (118)	National sample recruited with assistance of marketing firm	Providers working in ED settings (N=429) LGBT/Heterosexual patients (N=1516)	National online survey of ED providers Patients	<p>Individual</p> <p>Perceived benefits of SOGI collection differed between patients and providers</p> <p>Concerns that data collection could engender bias (B)</p> <p>Providers perceived patients would be uncomfortable (B)</p> <p>Concerns about privacy (B)</p>	<p>Patient and provider perspectives captured.</p> <p>Majority of providers self-identified as heterosexual.</p> <p>Transgender participants excluded in analysis</p> <p>Results pertain to particular healthcare settings explored (ED and primary care)</p> <p>Study did not explore prior experiences with discrimination and the implications for perceptions of SOGI data collection</p>

Author	Setting	Stakeholders	Research method	Facilitators/Barriers	Quality Assessment
Callahan et al., 2015 (119)	University of California, Davis Health Care System (619-bed academic medical center and includes hospital-based primary care and specialty clinics, 14 regional primary care centers, 3 affiliated cancer centers, and several affiliated hospitals)	Leaders across the organizations	Interviews with 30 key informants	<p><u>Organizational</u> Leadership commitment (F) HRC Recognition of the organization as a leader in LGBT health care equality (F) Staff and leader education (F) Provider and patient educational resources (F) Updated institutional policies and procedures related to LGBT care (F) List of self-identified LGBT friendly providers (F) Multiple modalities for disclosure (F)</p> <p><u>Individual</u> Provider discomfort (B)</p>	<p>No details provided about participants characteristics or approaches to analysis</p> <p>Patient perspective not captured</p>
Dunne et al., 2015 (120)	Community health centre, Oregon, USA	Health care providers (five) Self-identified transgender/gender non-conforming patients (seven)	Semi-structured interviews (in-person, phone, video conferencing)	<p><u>Organizational</u> EHR does not readily accommodate GI (B)</p> <p><u>Individual</u> Patient perceptions re disclosure of that birth assigned sex (B) Providers perceived that patient sex assigned at birth was necessary (B) Patient preference to disclose to person with medical or social work training (F)</p>	Small sample size due to difficulties in recruitment of participants

Hospitals accounted for the majority of study settings reported in the USA while primary care settings were more common in United Kingdom, Australia and New Zealand. The majority of studies examined the perspectives of providers of care, managers and administrators using either surveys or interviews. There were a few studies that evaluated change in data collection practices by assessing patterns of reporting pre and post implementation of sociodemographic data collection. (94,97,98,114)

A closer examination of the facilitators and barriers reported by studies pointed to a hierarchical order of influences on implementation. There were structural factors such as legal mandates that required the collection of sociodemographic data, accreditation criteria and voluntary quality standards. (42) Collection of sociodemographic data was also facilitated by incentives that increased health care organizations' motivations. (42) There were factors within a health care organization (labelled 'organizational factors') that influenced the collection of sociodemographic information such as access to financial and human resources, leadership support and commitment, information systems and patient flow processes. Within a given organization, the attitudes, knowledge and skills of individuals (providers, patients) also affected willingness to collect sociodemographic data. Figure 2-3 shows the various factors that are also described in the following sections.

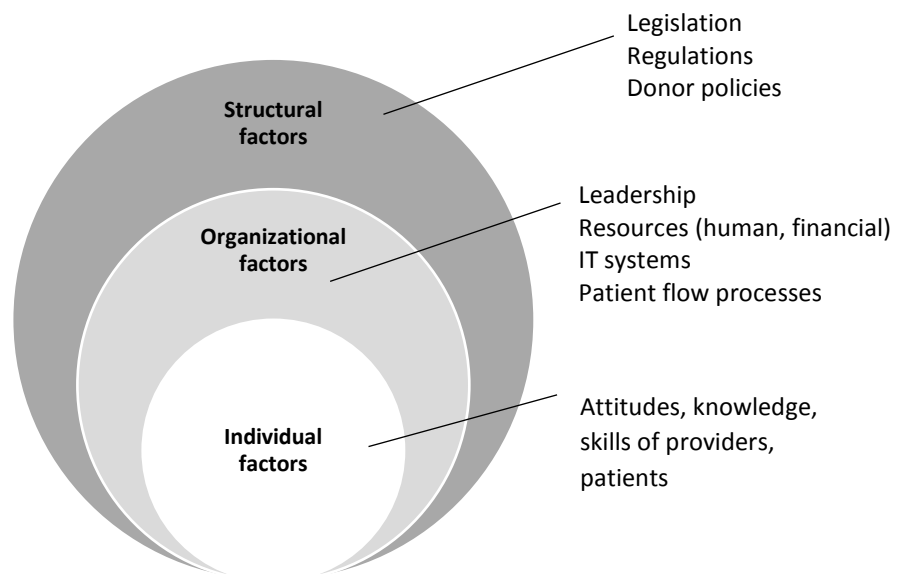


Figure 2-3: Facilitators and barriers of sociodemographic data collection

Structural factors

Most studies described factors at the level of the organization and or individuals. Structural factors were the least commonly acknowledged although cited by several studies mostly in the USA. (77,83,84,95,96,98,100,104,105,109,115) Ulmer and colleagues described several structural factors that can create an enabling environment for the collection of sociodemographic data within health care organizations.(42) These factors included: 1) state mandates or regulations that impose a duty on the health care organization to collect sociodemographic data; 2) accreditation and voluntary quality standards that require data collection as a criteria and 4) financial or other incentives for good performance and compliance. The influence of these factors will be illustrated in the following section with examples.

There are several legal mandates in the USA that support the collection of data pertaining to race, ethnicity and language. Title VI of the Civil Rights Act is the broadest mandate imposed by the federal government that requires the collection and or reporting of data on race, ethnicity and primary language. (121) The Act prohibits discrimination on the basis of race or national origin in the provision of any services that are supported with federal funds. Collection of data pertaining to race and ethnicity provides the basis for demonstrating compliance with the law.

The 2010 Affordable Care Act (ACA) makes provision for collection and reporting of race, ethnicity, language, disability and gender data in federal programs such as population surveys, Medicaid and Children's Health Insurance Program (CHIP) in order to track health disparities on a national level.(122,123) Additionally, the Health Information Technology for Economic and Clinical Health (HITECH) Act provides incentives to physicians to record the race or ethnicity for at least half of their patients as part of implementing the 'meaningful use' of electronic health record.(122)

The exemplar of Massachusetts' implementation of standardized collection of race, ethnicity and language data in response to a state mandate for all hospitals has been well described and illustrates the effect of structural factors. (83) In 2006, the Massachusetts Division of Health Care Finance and Policy (DHCFP) issued new regulations requiring all acute-care hospitals to collect patients' self-reported race, ethnicity and preferred language with a standardized approach. The Massachusetts Hospital Association (MHA) provided training and support materials and sponsored four regional training sessions for hospitals in the fall of 2006 to

explain the requirements. The project was piloted in order to anticipate likely problems with wide spread implementation. A study by Jorgensen et al. (83) assessed the impact of the state regulation after two years post implementation. The study found that the regulation facilitated standardization of data collection. Additionally, almost all hospitals (except for one) reported using data for equity monitoring and to improve quality of care. Study participants also felt that implementation had been relatively uneventful which was contrary to their expectations given apprehension of staff. (83)

Another study (84) clarified the beneficial effects of regulation of sociodemographic data collection. In this study, among organizations where data collection was imposed as a result of regulations, there was a perception that it added legitimacy and facilitated making a case for investment in training and information technology. (84) Despite positive sentiments, other organizations felt that regulations encroached on their autonomy. There was also concern that mandates or regulations were often not adequately funded to foster organizational compliance.

There are other recent successful exemplars including TC LHIN mandate for collection of a core set of sociodemographic data in hospitals in Toronto (47) and HB 2134 legislation in Oregon that required collection of standardized data related to race, ethnicity, language and disability status in all Oregon Health Authority (OHA) datasets. (95)

Accreditation bodies and other professional standards-setting bodies can also play a role in fostering collection of race, ethnicity and primary language data. (92) Joint Commission on Accreditation of Healthcare Organizations (JCAHO) encourages the collection of race, ethnicity, and language data as part of its guidance to hospitals in the *Advancing Effective Communication, Cultural Competence, and Patient- and Family-Centered Care: A Roadmap for Hospitals*.

Incentives can also motivate health organizations to collect sociodemographic data. The American Recovery and Reinvestment Act of 2009 urges the “use of electronic systems to ensure the comprehensive collection of patient demographic data, including, at a minimum, REL and gender information”. In a study (98) conducted in Texas, the REAL Data Project received funds through an EHR incentive program to strengthen the health information system to reduce health disparities. In New Zealand, two studies (100,115) also reported benefits from incentives for capturing patient self-reported ethnicity as part of the enrolment data. Through this initiative,

general practices receive funding adjusted for ethnicity as part of the population-based formula for funding in primary care.

Despite the benefits of financial incentives, they may not always be sustainable. Further while they may increase completeness, they do not necessarily guarantee quality of the data collected.(109) In the United Kingdom, collection of demographic data relating to patient ethnicity in general practice has been encouraged within the Quality and Outcomes Framework (QOF). (107) This is a national pay for performance scheme that was introduced in 2004. Under the initiative, practices received one point (of a possible 1000) for recording ethnicity of new patients. The specific incentive was discontinued in 2011, ostensibly because it was thought that data collection was sufficiently embedded in general practices and would be self-sustaining. In two studies conducted in the United Kingdom, participants cited the lack of financial incentives as a barrier to data collection. (107,109)

Health Plans. There has been growing interest in the collection of REL data by health plans in the USA. (86) Health plans have a unique opportunity to capture data for a larger proportion of the population than health services as they also include persons who may not have regular contact with health care services. An important context for collection of REL data for physicians by health plans originates from a requirement in the Patient Protection and Affordable Care Act (ACA) that health plans certified for participation in federal and state insurance exchanges include “essential community providers” in order to serve low-income or medically underserved individuals (Section 1311).(89) Although the legislation and associated regulations did not specify race, ethnicity, and language competence as defining characteristics of essential community providers, the law encourages health plans to improve healthcare access for a population of patients who generally access care in medically underserved areas.(89)

Since 2003, the Atlantic Hospital Insurance Plan Foundation (AHIPF) has collaborated with the Robert Wood Johnson Foundation to monitor the progress of health plans in the collection and use of REL to reduce health disparities and improve quality of healthcare. Assessments of progress have mostly been conducted using a series of national health plan surveys in 2003, 2006, 2008, 2010. (86,87,90) In-depth interviews have also been used to understand the experiences and challenges of health plans who have and have not initiated REL data collection.(88) These studies provide insight into the range of factors that influence sociodemographic data collection.(85–89)

Organizational level

Leadership support. At the organizational level, several facilitators and barriers of implementation of sociodemographic data collection were described. The need for commitment and leadership support at all levels to champion efforts to implement sociodemographic data collection was emphasized. (77,79,82,88,97,100) In a study by Regenstein and Sickler (79), among peer health care organizations that had not initiated sociodemographic data collection, key informants cited a lack of support from executive leadership as for a contributor to inaction.

Resources. Despite the availability of financial incentives, some health care organizations cited a lack of funding to mitigate the anticipated costs of data collection and its application in quality improvement. (79,96,100) The Institute of Medicine (IOM) has recognized the role of incentives in facilitating the collection of data on race, ethnicity and language. They recommend that incentives be tied to accreditation or other mechanisms that support ongoing collection of high quality data. (42) Limited human resources particularly in solo and small physician practices also hampered collection of patient sociodemographic data. (78,98,115) It was a prominent barrier among health plans that was compounded by competing priorities. (86,88,89)

Time constraints were also reported as a barrier to collection of race, ethnicity and language data by staff. (79,92,96,106,107,114) This concern was expressed even when the potential benefits of data collection were acknowledged. Although a valid concern particularly in organizations plagued by staff shortages and high turnover, it was demonstrated in two studies (92,115) that data collection did not add substantial to routine processes.

IT infrastructure. Information technology infrastructure was both a facilitator and barrier to data collection in health care organizations and health plans. (79,83,84,96,98,113,114) The need to adapt information technology systems to accommodate multiple response options to sociodemographic questions was a challenge especially when it required negotiations with software vendors and additional costs. (80,82,97) Some health care organizations with electronic health records with the appropriate fields were empowered to begin the process of data collection once management had committed to implementation.(78,94,111) Another related issue concerns the inability of systems to communicate with each other to share information, thus necessitating collection of data repeatedly for the same individuals.

Workflow processes. Some studies reported how patient flow processes positively influenced data collection. The timing of data collection was critical. Collection of data at the first visit from new patients was perceived to be easier. (81,114) Additionally, incorporation of sociodemographic questions into routine admission forms also worked well. (81) The timing of data collection (whether at or after enrolment) was a challenge for health plans. Although at the time of enrolment with the health plan appeared to be a convenient point, there were enrollee concerns that information about race, ethnicity and language would be used to exclude racial minorities.(85,88,90)

The process of stakeholder engagement in planning for sociodemographic data collection was also important. In two studies (96,111) that reported engagement of representatives from socially disadvantaged and Indigenous communities, this was viewed positively as a contributor to creating an inclusive and participatory planning process for sociodemographic data collection and reduction of health disparities. Additionally, it was felt that the information should be shared with communities to foster their empowerment and closer collaboration in program development. (96)

Individual level factors.

Staff and patient comfort. Individual level factors relate to a person's attitudes, beliefs and practices as they pertain to the collection of sociodemographic information. Two critical actors in the process of data collection are the patient who is being requested to disclose and the health service personnel who is requesting the information. The interaction may be fraught with conflict if supportive conditions are not present to foster the exchange of information. Staff and patient comfort with data collection were important considerations across all studies. Frontline staff expressed discomfort with data collection because of perceptions that it would provoke negative reactions from patients. (77,80,82–84,100,111,112,115) Consistent with this view, some patients felt uncomfortable however several studies (91,110,111) also suggested that patients were willing to disclose particularly if they were provided with a clear explanation of the reasons for data collection and how it would be used. Among some care providers, there was uncertainty about whether the information was relevant or useful in the delivery of care. An argument was advanced that all patients should be treated equally and provided with high quality care.(111)

Training of data collectors was endorsed across studies as an important strategy to increase staff knowledge, skills and confidence in requesting the information.

Training. A cross cutting factor that supported implementation of sociodemographic data collection was training for staff. (79–82,84,97,98) Some studies emphasized the need for training at all levels to ensure that the importance of data collection was appreciated. Approaches to training varied but almost invariably focused on explaining the rationale for data collection and providing scripts for data collectors about how to request information in a culturally sensitive way as well as suggestions about how to respond to patient concerns. (84,94,114)

Patient education. A few studies also pointed to the importance of patient education to increase public awareness about the benefits of data collection and its role in improving the quality of care. (78,83,85,88,111) This strategy recognised patient discomfort originating from lack of knowledge about why the information was being requested. Issues related to trust in organizational motives for data collection particularly among racialized groups were also identified as barriers.(77,78,85,96,111)

Perceived legal barriers. In some studies, the legality of sociodemographic data collection was disputed. (77–79,90) There was a misunderstanding that health care organizations were prohibited from collecting sociodemographic information when legal statutes actually supported data collection. (121) Participants also expressed concerns about privacy and confidentiality of information.

In several studies, patient confusion about the definition of race and ethnicity affected data collection. (80,97) In the USA, the standards established for collection of race/ethnicity data by the Federal Office of Management and Budget (OMB) recommend a single ethnicity question that ascertains whether an individual identifies as Hispanic/Latino, followed by another question pertaining to their racial group. Some persons who identify primarily as Hispanic do not appreciate why the second question is needed and may refuse to answer.(124) This conflict may arise because the individuals identify with multiple racial groups or primarily identify as Hispanic rather than belonging to any racial group. (124) This begs consideration about the options provided in a data collection effort and whether they will be perceived as acceptable and appropriate by the individuals from whom data is being requested.

Studies were fairly consistent in demonstrating a pattern of multilevel influences on sociodemographic data collection. An overview of sociodemographic data collection challenges in 2004 pointed to similar factors.(92) Patient and provider factors were a common denominator across studies. The need for nimble information technology systems that can accommodate the standardized response options was also noted. Although requiring greater advocacy and political will, enacting structural levers to support the collection of sociodemographic data is a strategy that can be effective.in acute and ambulatory settings.

The majority of studies in this section were designed for quality improvement including organizational development and learning about what works in a particular context. Consequently, they were descriptive in nature and sometimes lacked methodological rigor. Most studies had a clear description of the research objective. Both qualitative and quantitative studies often described the participants and approach to sampling and data collection. However, details of analytical techniques were often scant. The two reviews (82,92) that were included did not provide details about the identification of studies, methods of data abstraction and analysis. While neither claimed to be a systematic review, it would have been helpful for more details to better assess the study's quality.

Among qualitative studies, the relationship between the researcher and participants was not adequately considered. For example, information about the researcher's role and potential for bias was not critically examined. Additionally, few studies provided information about measures to promote credibility and trustworthiness of results.

Quantitative studies often applied surveys of health care organizations. Response rates were invariably low and affects generalizability of the results to the target settings. In some instances, the study was conducted at a single site that may not have been representative of others with the same characteristics. Small sample sizes also made it difficult to conduct subgroup analyses. The information provided by survey participants about their data collection practices was not verified for accuracy in most cases. In studies with pre- post implementation designs, there were no comparative controls to allow for an assessment of whether any changes could be attributable to the project.

The majority of studies were descriptive and imbued a low level of confidence in findings based on the methodological quality. However, the consistency among studies conducted in

various countries using different methods provides valuable insight into factors that enable or hinder collection of data pertaining to race, ethnicity and primary language.

2.6.1.2 Gender identity and sexual orientation

There is a growing body of research that points to health disparities among sexual and gender minorities.(125) Mayer and colleagues (126) purport that health disparities experienced by sexual and gender minorities may be related to the following factors: 1) delayed care seeking due to fears of discrimination; 2) inadequate numbers of providers who are trained to provide competent LGBT care; 3) structural barriers that impede access to health insurance and 4) lack of culturally appropriate prevention services. In recent years, there has been increasing interest in the collection of gender identity and sexual orientation (SOGI) data. The Institute of Medicine (IOM) has recommended the collection of data pertaining to gender identity and sexual orientation in all federally funded population health surveys as well as documented in the electronic health record. (127) Federal guidelines require that all meaningful use certified electronic health records include provisions for collection of gender identity and sexual orientation data and is consistent with policy recommendations of the Joint Commission on Accreditation (JCAHO).(128) These structural levers provide support and foster collection of SOGI data in health care settings.

There were five studies (116–120) that explicitly explored barriers and facilitators of collection of SOGI data. Although a recent integrative review (129) was identified that examined patient perceptions of being asked about sexual orientation in health care settings, it did not address barriers and facilitators. All of the studies had been conducted within the past five years and incorporated patient perspectives in all but one study. Methods applied across studies included either interviews, surveys or a combination of both methods.

Similar to studies exploring REL data collection, most identified factors at the organizational or individual levels One study (117) affirmed the existence of multilevel facilitators that were described as ‘personal’, ‘environmental’, contextual/interactional’ and ‘political’ factors. In this study, transgender participants endorsed the importance of national and institutional policies that protect privacy and penalise discrimination against sexual and gender minorities.

At the organizational level, the importance of leadership support and commitment was underscored.(119) In a study by Callahan and colleagues, a task force was established to chart the course for planning the inclusion of SOGI data in EHR. One of the activities that galvanized efforts of the task force was navigating the process to be recognized by the Human Rights Campaign as the first leader in LGBT health care equality. In this initiative although there was initial resistance, over time it gave way to support and spawned several complementary initiatives.

The need for education and training to prepare clinical providers and other staff for their respective roles was endorsed across studies. (116,117,119) The availability of educational resources for both providers and patients was also thought to facilitate data collection.

Consistent with other studies, information technology infrastructure was either a facilitator or barrier to SOGI data collection. In one study, the EHR did not have the capacity to include provisions for preferred pronouns and gender identity.(120)

It was also noted that the availability of self-identified LGBT-friendly providers added to the comfort of gender and sexual minority patients. (117,119) This feature contributed to a LGBT-friendly environment that also had inclusive signage and brochures.

Another factor that encouraged disclosure was a universal approach to SOGI collection.(117) Participants felt that data collection should be normalized as other sociodemographic information. This is consistent with perceptions that LGBT did not want to be singled out for data collection as this was seen as a stigmatizing experience. Despite welcoming data collection, participants also wanted assurances of privacy and confidentiality of their responses. It was also recommended that multiple modalities for data collection be allowed including the option to disclose SOGI but opt out of having it entered into the records.(119)

At the individual level, factors were similar to those explored for collection of REL data. Patients who understood the reason for data collection and perceived that the information was relevant to medical care were more inclined to favour SOGI collection.(116,117) It was anticipated by providers that patients would be reluctant to disclose SOGI data. This was in stark contrast to patient perceptions. Some providers also expressed discomfort with requesting SOGI

data. This was partly based on concerns about causing offense however some providers argued that high quality care was delivered to all patients hence it was irrelevant. (116,119)

Some patients expressed concerns about protection of privacy for SOGI data.(116) Other patients feared negative consequences of data collection including discrimination and implications for health insurance coverage. (117)

In terms of quality assessment, the majority of studies satisfied the criteria and documented a clear aim, described approaches to sampling, methods of data collection and data analysis. The notable exception was the study by Callahan and colleagues where these aspects of the study were not explored.(119) Limitations in sample size and response rates affected generalizability of findings. (117,120) Further, participants' responses reflect the context in which they were obtained. Hence it may not be wise to expand to vastly different settings It was also noted that studies did not consider prior experience with discrimination and how that influenced perceptions of SOGI data.

There were similarities between studies that described implementation of REL and SOGI data. Both confirmed multilevel influences and captured patient and provider perspectives in order to fully understand concerns and preferences. The review points to particular strategies such as staff training, patient education and strengthening information technology infrastructure that increase chances of successful implementation. This information is useful to guide program developers to a plan that responds to local needs.

This chapter has reviewed global developments that ground work related to social determinants of health. It has also examined social screening tools that have been developed to capture sociodemographic data. Clinical interventions to address social determinants have been explored to guide practical actions. Finally studies that described enablers and barriers to collection of REL and SOGI data were assessed in order to understand the salient conditions that support institutional change. Together, the chapter establishes the foundation for decisions pertaining to design as well as signposts approaches to data collection and analysis.

CHAPTER THREE

CONCEPTUAL AND THEORETICAL FRAMEWORKS

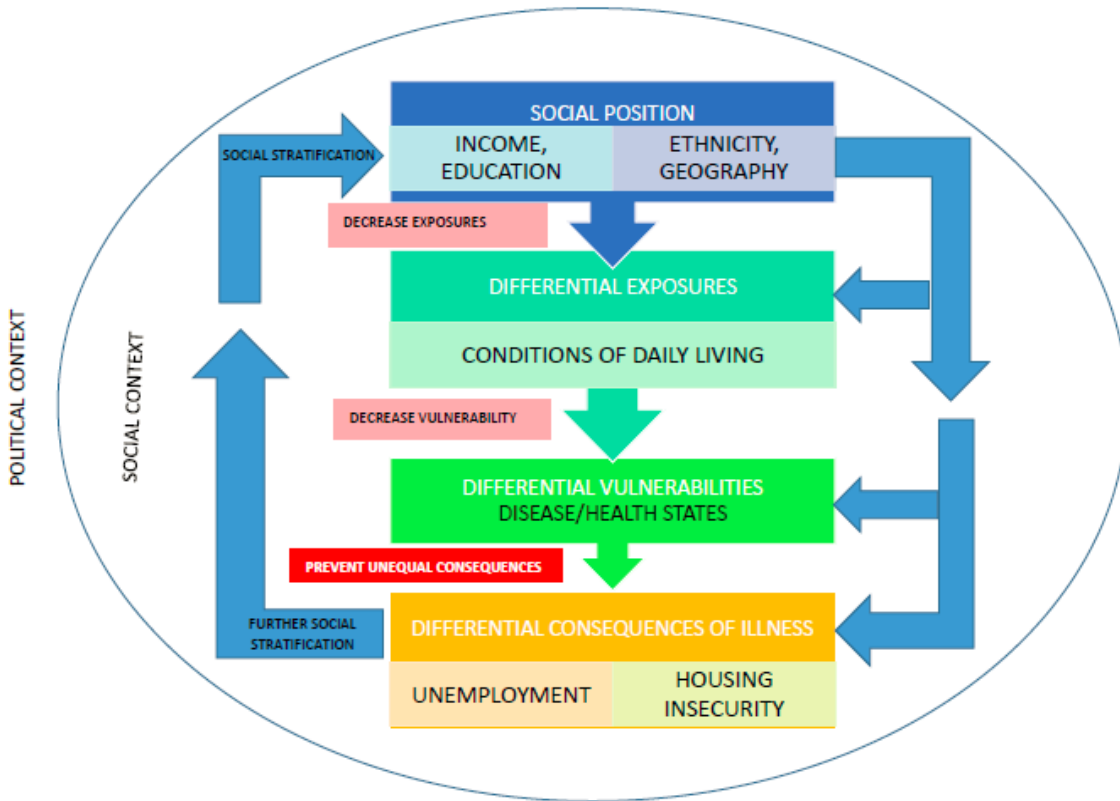
3.0 Introduction

This chapter focuses on the theoretical and conceptual approaches that underpin the study. This includes a description of the project's logic and theory of change in order to facilitate understanding of the mechanisms that were expected to be activated during implementation. Relevant theories of implementation are also discussed to explore potential contextual factors that facilitate and hinder sociodemographic data collection in local health care settings.

3.1 Theories of social causation of poor health

The collection of sociodemographic information and its application in social risk assessment and intervention is undergirded by multiple theoretical perspectives that are reinforcing and complementary. Available theories of social causation explore the mechanisms and complex pathways that manifest downstream as poor health in individuals and communities and suggest opportunities for multilevel interventions. The central tenet is that conditions of daily living and the structures that give rise to and perpetuate these conditions are the fundamental causes of differences in health status between groups characterized by variations in social status.(6) As a corollary, action to reduce health inequities must tackle social determinants in order to achieve optimal health for all.

The ecosocial theory of disease causation (8) posits that social inequalities in health are biological expressions of unequal social relations. Further explication of the underlying pathways in the production of health inequalities also considers the role of social stratification. Social stratification (130) engenders differential exposure and vulnerability to health damaging conditions and results in differential consequences of ill health for more or less advantaged social groups (Figure 3-1). The sociodemographic questions (proxies for social determinants) assessed were therefore key social stratifiers in accordance with this framework.



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Figure 3-1: Diagram showing relationship between social stratification and health outcomes.

Figure 3-1 suggests multiple points of interventions to reduce health disparities by decreasing exposures, vulnerability and preventing unequal consequences of illness. The evaluand had two main components that included: 1) collection of information about selected social stratifiers (study's proxies for social determinants of health) and 2) application of information at individual or aggregate level to improve care. These components when viewed and operationalized according to this framework reflect the pathway from identification of social stratifiers, assessment of implications for exposures and vulnerability and determination of opportunities to intervene either through decreasing vulnerability or the consequences of poor health. In this study, each case (health care setting) identified primarily with a particular application of the sociodemographic information. The various types of health interventions to address social determinants are explored in the next section.

3.2 Conceptual frameworks for interventions to address social determinants in health care settings

Gottlieb and colleagues (16) have proposed a concept map to guide health care organizations in three tiers of intervention to mitigate the effects of social determinants of health. In this framework, there are individual level interventions that directly impact patient’s social circumstances; institutional interventions that target populations served by health care organizations and community or societal level interventions including political advocacy and research. The collection of sociodemographic information is an important precursor for social risk assessment and application in delivery of care.

Several examples of how data on social determinants can be applied are illustrated in Table 3-1. Sociodemographic information can be used to adjust risk in traditional calculators or clinical screening recommendations/algorithms. (16) It can also inform patient referral to needed support services. Targeted programs informed by knowledge of the sociodemographic profile and needs of the patient population are an example of institutional level interventions. (16) At the community level, health care organizations can advocate for healthy public policy that transforms community social conditions.(16)

Table 3-1: Examples of potential interventions to mitigate the impact of social determinants

Level	Examples of interventions
Patient (Individual)	<ul style="list-style-type: none"> • Address language access barriers through medical interpreters • Appropriate use of gender neutral language. • Adjustment of risk in clinical calculators/algorithms. • Referral to support services (e.g. social safety net and income support services)
Institutional	<ul style="list-style-type: none"> • Identify health disparities by stratifying process and health outcomes by sociodemographic characteristics. • Develop targeted programs to address unique needs of specific populations
Community	<ul style="list-style-type: none"> • Health care organizations can be agents of change through advocacy for policy reform and community needs assessment.

3.3 The initiative - We Ask Because We Care

Increasing recognition of the paucity of sociodemographic information being captured in local health information systems and missed opportunities to deliver patient centred and equity – oriented care stimulated interest in implementation of an initiative to enhance the collection and application of sociodemographic data. A small team within the Public Health Observatory of the Saskatoon Health Region worked to plan and implement the initiative in three pilot sites throughout the regional health authority.

The project architects had a broad vision that included enhanced standardized sociodemographic data collection and its application in the delivery of care. Two main components of work required the development of a tool/instrument to capture sociodemographic data during health care encounters and provisions to incorporate the sociodemographic information into social risk assessment and intervention. An ideal pilot site would implement the initiative to its full scope with clinical application in patient care to mitigate underlying social determinants that are barriers to the patient’s achievement of personal health goals.

This section presents a detailed description of the initiative and its respective components as it was intended to be implemented. The rationale for project activities is explained and the relationships between the various phases are visually represented. It also advances the argument for why particular outputs and outcomes were measured.

A theory was developed that conveyed the project’s logic and clarified the mechanism by which the activities should produce the expected results. The project theory is an invaluable tool for guiding the design of an evaluation and serves to focus research questions and identify plausible performance measures.(131) The following section describes the sequence and rationale for the project activities as well as anticipated outputs and outcomes. It represents the ideal process model against which all site implementations were compared.

The initiative’s underlying premise was that patients/clients had unmet social needs and the medical encounter was an appropriate setting to identify and address those needs. The designers posited that collection of patient level information on social determinants was a catalyst and precursor for inclusion in patient assessment by providers who then instituted the appropriate measures as an integral part of the patient’s care and treatment plan. Professional bodies such as the Canadian Nurses Association (132) and Canadian Medical Association (133) support the provider in this expanded role.

Further, a better understanding of patient social context potentially allows for the delivery of care that is safe, effective as well as patient centered and equity-oriented. However, these service related outcomes are only possible if sociodemographic data collection is feasible and acceptable in the local context. Hence implementation outcomes must precede service-related outcomes.

There were two critical assumptions implicit in the project design. The first was that it was feasible in the local context to collect sociodemographic data in health care settings. Secondly, clinical application would require that providers be willing to integrate sociodemographic information into patient care and treatment pathways. The body of research on sociodemographic data collection and clinical application pointed to a number of potential obstacles that challenged these assumptions.

Public opinion of sociodemographic data collection. Research related to public opinion about data collection in Canada presents a mixed picture. The culture of information sharing in health settings has traditionally excluded more ‘sensitive’ sociodemographic questions. A few studies (134,135) suggest that there is a gradient of respondent comfort depending on the social determinant. Additionally, while the benefits of data collection on social determinants are somewhat appreciated by providers, patients may share disparate views. (134) Some patients may perceive that sociodemographic data collection has no bearing on clinical care, therefore has little relevance. For these individuals, data collection represents an invasion of privacy. In racialized groups, requests for information about social determinants may be met with resistance because of fear that the information once collected will be used to discriminate against them and adversely affect receipt of care. (135)

Health service personnel attitudes to sociodemographic data collection. Patient reluctance is also compounded by staff apprehension about collection of information of this nature. Providers’ knowledge of the impact of social determinants of health and appropriate interventions is important for clinical integration of sociodemographic data. There is limited evidence that providers acknowledge that they have a role to play in tackling social determinants. However, barriers such as the time to explore these complex issues and confidence that they have the resources to address any needs that are identified during the visit often deter them from engaging patients in these domains. (136,137)

These two factors that pertained to patient/client willingness to disclose personal information and health service personnel attitudes to data collection and application were the major foci for project activities as they represented key outputs needed to achieve the implementation outcomes. Patients/clients needed to appreciate why the information was being collected and how it would be beneficial to their care. Similarly, health service personnel needed to understand the rationale for data collection, have the inclination and knowledge to appropriately incorporate the information into patient assessment and possess the ability to overcome perceived barriers to adoption of the target behavior. Injunctive norms such as patient expectations that health service personnel will ask about sociodemographic information also contribute to a supportive environment that fosters positive change.

Training. The Canadian experience with sociodemographic data collection in health care settings is limited. However, two projects with varied degrees of success with sociodemographic data collection confirmed that high quality training of data collectors was critical to successful implementation.(46,47) In these projects, data collectors who were knowledgeable about the rationale and patient benefits associated with data collection were able to overcome their apprehension and successfully engage the client/patient.

Training was an important activity in the program theory. Through training, data collectors develop the skills and confidence to persuade the patient to share sociodemographic information. Training directed at care providers also needed to address barriers related to knowledge of local community resources for identified social needs. The project team developed appropriate education and training materials to respond to these different needs in the various project sites.

Patient education/awareness. The project developed posters and brochures that were adapted to each project site. These were the main information, education and communication materials that were employed to increase patient/client awareness about why they were being requested to provide sociodemographic information. There was skepticism by health service personnel that these communication strategies would be effective in their patient populations.

Education materials were designed to support patient disclosure by providing information about benefits of sociodemographic data collection and addressing concerns about any associated risks. It also addressed specific myths such as the legality of collecting sociodemographic information in health care settings. These materials were intended to support trained and knowledgeable health service personnel who were adequately prepared to respond when

patients/clients requested further information about data collection. The intent was also to influence salient beliefs surrounding the norms of data collection in health care settings. (138)

Discussions with stakeholders also raised concerns about the fact that registration was not considered value added by the patient/client. Hence, the current trend has been to reduce the time spent in this activity. The addition of new fields would in theory lengthen the process, however consideration was given to inclusion of a minimum number of questions that would allow for meaningful needs assessment and not impose a heavy participant response burden. It was also considered whether to reserve more sensitive questions for providers who have a therapeutic relationship with the patient and who are more likely to be successful in eliciting a response. (139)

The full scope of project implementation considers clinical application of sociodemographic information. However, in one project site, sociodemographic information was not applied at the individual level at the point of care. The aggregate data was used to inform program planning for immunization services. Despite this variation, the mechanisms discussed previously for increasing staff capacity to collect sociodemographic information as well as patient/client engagement to increase awareness were equally relevant. Improvements in service and patient outcomes at the level of the population can also result from application of sociodemographic data.

Social determinants influence health outcomes through multiple pathways. More distal outcomes require a longer time to be achieved than the pilot project's life span. It is anticipated that other types of evaluation will be conducted as the initiative matures. These studies would be better positioned to assess more distal service and patient outcomes. This research focused specifically on the process of implementation including the outputs of project activities and early implementation outcomes related to feasibility and acceptability of standardized sociodemographic data collection across diverse health settings. This was commensurate with the maturity of the initiative as well as considered the resources that were available (time, funding and personnel).

The project's logic model illustrates the inputs, activities, outputs and outcomes that link the goals and objectives of the initiative to the intended results (Figure 3-2)

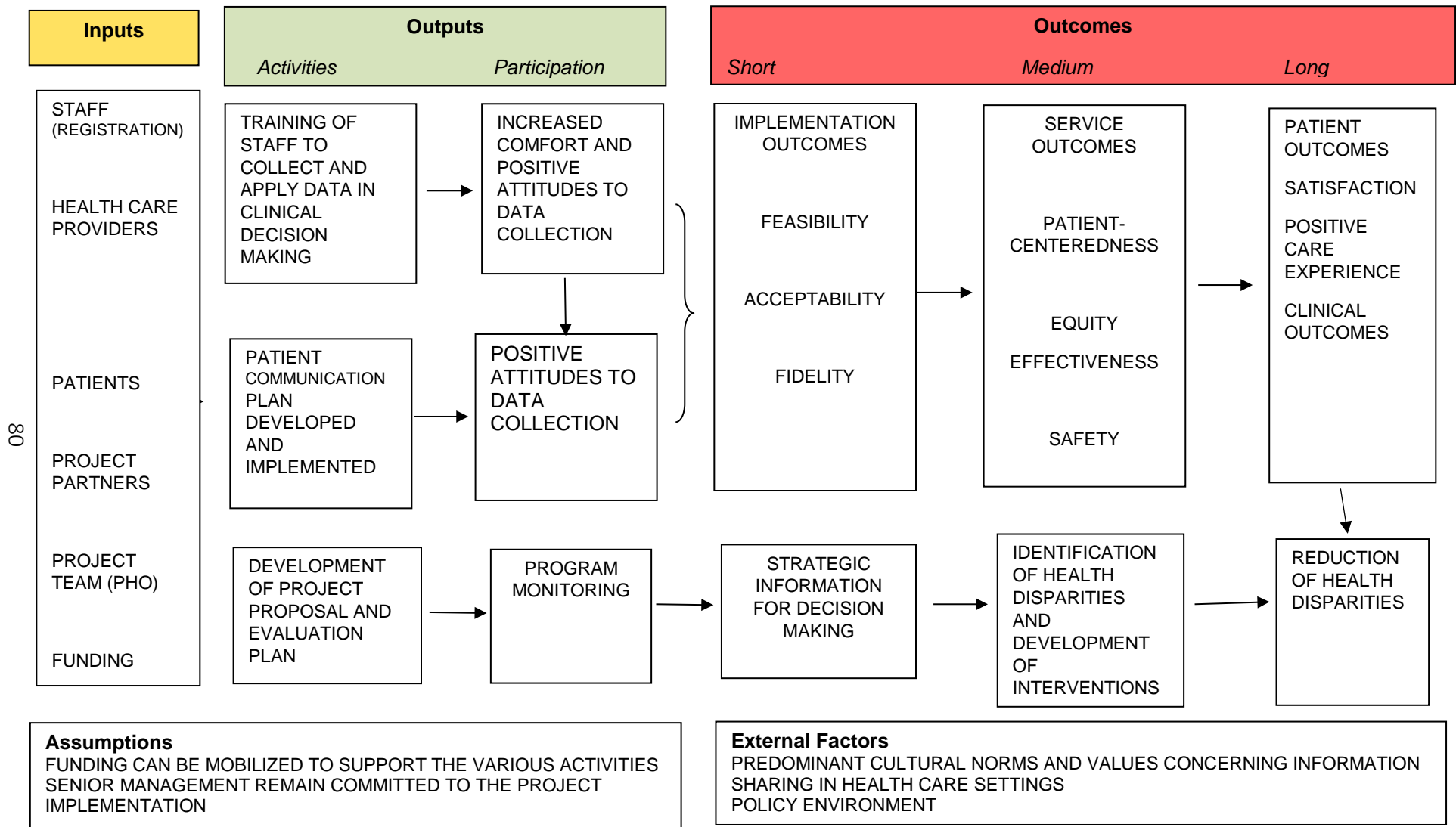


Figure 3-2: We Ask Because We Care Logic Model

3.3.1 Theories of implementation

The project team hypothesised that implementation of the initiative would be context dependent. Consequently, we sought to understand the contextual factors that facilitated or hindered implementation of standardized sociodemographic data collection across three urban health care settings. This provided insight about salient conditions that are necessary to foster standardized sociodemographic data collection across similar health care settings. We recognized that perspectives of various persons at different levels of the health service organizations were critical for understanding an inherently complex process; however we needed to ground our exploration of these factors in the appropriate theoretical frameworks. This section describes relevant theories related to processes of implementation as applied to the study. Key constructs are defined and operationalized as well as the implications for measurement are discussed.

The literature related to implementation science as well as organizational change were potential sources for appropriate theoretical frameworks that could be applied to the study. A recent review (140) of change management literature in health care identified common elements across theories including environmental circumstances, organizational harmony, power dynamics and organizational capacity. In addition to these components, the review also proposed that two additional factors, namely the nature of the change and process of change were also important in any change initiative.(140) However, the authors cautioned against prescriptive approaches to change management and emphasized that no single or combination of elements are sufficient to achieve change. Further, they called for more research about most appropriate models of change and the nature of resistance to change in Canadian health care. (140) Given the review's assessment of the organizational change literature related to change management in healthcare, its focus on system-level factors and considerably more familiarity with the implementation science literature, it was decided to focus on applicable theories available in the latter area.

In this study, implementation was operationalized as any concrete actions taken by the organization to actualize the proposed change – standardized sociodemographic data collection. The study applied concepts in implementation science to understand how to successfully collect sociodemographic information and use it to improve patient care. Implementation science is defined as 'the scientific study of methods to promote the systematic uptake of research findings and other evidence based practices into routine use to improve the quality and effectiveness of health services and care'.(141) In the field of implementation science, implementation is viewed

as part of a continuum that also includes diffusion and dissemination. It focuses on how to use an innovation to produce the desired results. The application of implementation science was appropriate to pursue the objectives of this study and gain insight about the process of implementation and associated barriers and facilitators.

This formative evaluation assessed the process of implementation across different contexts to identify effective approaches to sociodemographic data collection. Under real-life conditions, participant characteristics and perceptions as well as organizational contexts will vary between institutions. Although limited Canadian experience suggests that sociodemographic data collection is feasible, it is important to understand which implementation strategies work, for whom and under what conditions in the local context.

Several theoretical approaches (142) have been applied to understand implementation outcomes. Nilsen (142) has reviewed the body of implementation research and proposed a broad classification of approaches into five categories that include process models, determinant frameworks, classic theories, implementation theories and evaluation frameworks. These categories are not always easily distinguishable and approaches have been borrowed from many other disciplines. (142) Among the subgroup of determinant frameworks, the Consolidated Framework for Implementation Research (CFIR) offers a comprehensive taxonomy of constructs that have been applied to study implementation of complex programs. (143) The framework has five domains including characteristics of the intervention, outer setting, inner setting, characteristics of individuals and the process of implementation. (143) In this study, the framework was treated as a 'menu of constructs' to systematically identify potential influences for consideration in the study. The use of previously defined and operationalized constructs was practical and also allowed for framing the results in a way that enabled comparison with other studies. (144)

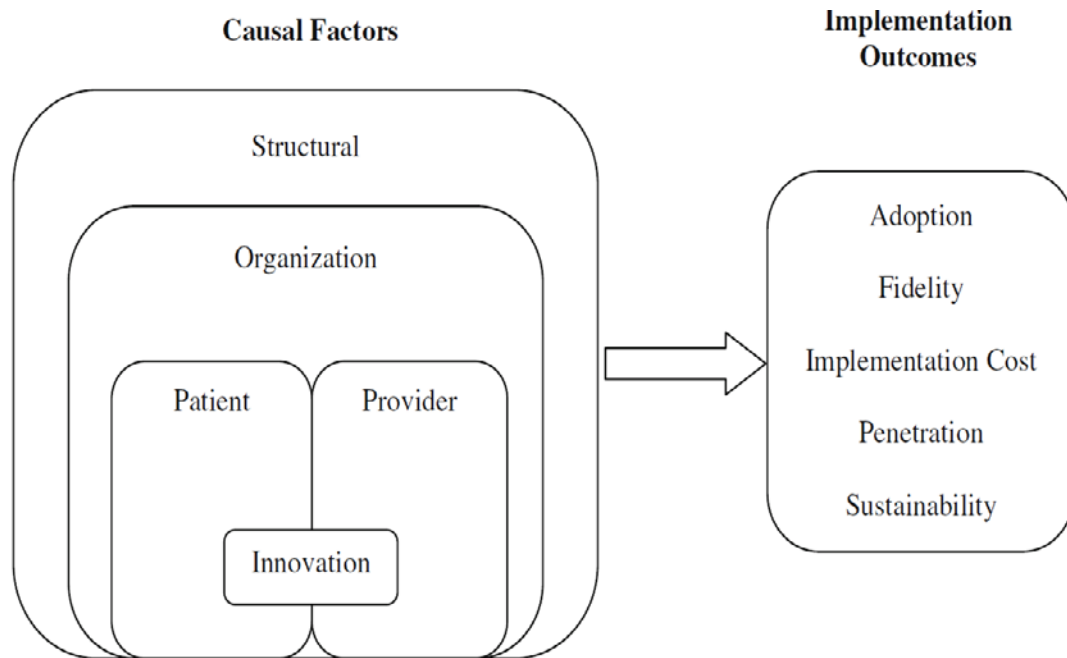
The five domains of the Consolidated Framework for Implementation Research cover multiple levels of influences although it does not offer causal mechanisms or specific implementation outcomes. (145) The authors of the framework have applied a rating process to reflect the valence and strength of the CFIR constructs. This approach has often been used to differentiate between facilities with different implementation success. (145)

Each domain of CFIR is briefly described. The characteristics of the intervention refer to the specific qualities that make it desirable including adaptability, trialability, cost, relative

advantage conferred by implementation and evidence that the intervention can result in the desired outcomes. (145) The outer setting relates to factors external to the organization including any policy directives or incentives, peer pressure to implement due to competitive advantage and awareness and concern for patient needs and the barriers and facilitators to meeting those needs. (145) The inner setting focuses on the organization and considers its structural characteristics, norms and values (culture), implementation climate, learning climate and readiness for implementation. Within the latter, leadership engagement and resources for implementation are considered. (145) The domain related to characteristics of individuals pertains to individuals' knowledge and beliefs about the intervention, their self-efficacy, their individual stage of change and other personal attributes. (145) The final domain explores the process of implementation and includes planning, engagement of appropriate individuals, executing the implementation plan and reflection and evaluation.

In a recent systematic review, Chaudoir et al. (146) also outlined a multilevel conceptual framework that identified many overlapping constructs in addition to patient level factors that are hypothesised to result in implementation outcomes. This framework offered additional elements that were thought to be important for the study. (Figure 3-3) The nesting of factors within broader levels is significant as it reminds us of the interconnectedness of the different factors. The intention was not to collapse an inherently complex process into fixed attributes that 'work everywhere' but to show how these attributes operate in different environments to facilitate or hinder implementation.

Chaudoir et al. (146) also described measures that had been used by included studies for various factors and the implementation outcomes that had been assessed. The implementation outcomes were based on a typology by Proctor and colleagues (147) that includes acceptability, adoption, appropriateness, cost, feasibility, fidelity, penetration and sustainability. The most common implementation outcome assessed in studies was adoption. Only a few studies assessed fidelity and none of the included studies explored implementation cost, penetration or sustainability. Although, the specific implementation outcomes of interest in this study were not necessarily those commonly assessed by other studies in the Chaudoir review, the tendency to assess early implementation outcomes was equally relevant to this study. Consequently, the factors identified in the conceptual framework were explored in this study. Figure 3-3 illustrates the framework components.



Reproduced with permission from Chaudoir et al. 2013 (146)

Figure 3-3: Multilevel framework predicting implementation outcomes

This chapter describes key theoretical and conceptual frameworks that have been applied to the study. Important constructs have been defined and their relationships explored in the context of the program that was implemented. With an understanding of theoretical foundations for the study, the reader can appreciate the methodological decisions that will be discussed in the next chapter.

CHAPTER FOUR

METHODOLOGY

4.0 Introduction

The thesis is an evaluation of the implementation of an initiative to collect standardized sociodemographic data across three urban health care settings in Saskatoon, Saskatchewan, Canada. This chapter explains the rationale for the methodology and design strategies that were used as well as provides a brief discussion of their application to the field of evaluation. There is an exposition of the methods and procedures that were employed including data collection tools and participants. This is followed by a detailed discussion of analytical approaches within and across cases. The strengths and limitations of the study are discussed as well as ethical considerations.

4.1 Project coordination

The scope of project activities required a project team to oversee and coordinate the various activities. Team members and their roles and responsibilities included:

- Principal Investigator (CN): Chief Medical Officer and Associate Professor in the Department of Community Health and Epidemiology who provided overall project supervision, advice about research design and project advocacy.
- Project Coordinator (LM): Manager/Epidemiologist who served multiple roles including project coordination, logistical support, project advocacy and stakeholder engagement, content expertise related to equity and social determinants of health and advice on tool development.
- Policy Advisor/Knowledge Translator (EB): She provided support with advocacy and stakeholder engagement, training, design of implementation aids (posters/brochures/training materials), advice about tool development and project implementation. This team member has experience with social science research and qualitative research methods but also has content expertise related to clinical interventions to address social determinants of health.

- Research Officer (MB): This team member has experience with social sciences research and has applied both qualitative and quantitative research methods. She provided advice about evaluation design, data collection tools as well as assisted with data collection, data entry, analysis and case report writing in selected sites.
- Student Researcher (HWR): Thesis author who was involved from the inception of the project. She performed multiple roles including designing tools and assisting with stakeholder engagement. HWR also prepared ethics applications for approval by the Research Ethics Board. Her main contribution was project evaluation with responsibility for planning and implementation of data collection, analysis and report writing.

The team met regularly throughout the project to make critical decisions. In each site, there was also an implementation team or focal point person who collaborated with the project team to plan logistics and ensure smooth implementation.

4.2 Philosophical orientation

A researcher is encouraged to develop an awareness of his/her epistemological position as part of the ‘distinct hierarchical levels of decision making within the research process’. (148) This foundation influences the motivation and expectations of the researcher and facilitates congruence with choice of methodology and methods. (148–150) The author’s epistemological orientation was motivated by commitment to congruence between the research questions and data collection methods. Based on this overarching consideration, the research was positioned within the philosophical assumptions of pragmatism. Pragmatism (151) rationalizes the choice of methods based on ‘what works’ given the research question and the purpose of the research. It averts tension created by attempts to integrate diametrically opposed paradigms based on fundamentally different assumptions about the nature of knowledge. Consequently, it represents a practical and applied research philosophy.

The annals of history describe three epistemological positions that represent a continuum in the spectrum from objectivity to subjectivity.(148) In more recent times, pragmatism has emerged as a contested fourth position and the underlying philosophy for mixed methods research. (151) While the research community remains divided by ‘paradigm purists’ who insist that that the vastly different paradigms that underlie qualitative and quantitative methods preclude compatibility, the pragmatist position arose as a counterargument to the incompatibility thesis.(152) Denzin’s introduction of the concept of triangulation also paved the way for

acceptance of mixed methods research The utility of mixed methods research is one of its greatest appeals. When strategically combined, qualitative and quantitative methods are complementary and exploit the strengths and overcome the limitations inherent in each approach. In this research, multiple sources and methods of data collection were employed including patient/client and key informant interviews, focus group discussions with service delivery personnel and chart reviews of provider practices depending on the project site. The complexity of the phenomena demanded a variety of methods to fully comprehend the observed patterns and multiple contexts. The use of mixed methods was aligned with the pragmatist view that places the research question(s) as the central focus and selects methods that best address the problem.

Among pragmatists, there are different views (151) about whether the mixture of methods also reflects a similar blending of the underlying philosophical assumptions of each method. There are those who adopt an ‘a-paradigmatic’ stance and ignore underlying philosophies. Their research is driven only by the methods that are deemed most appropriate without loyalty to a particular epistemology. Other scholars advocate for a single paradigmatic stance that supports the use of qualitative and quantitative data collection methods but rejects the forced dichotomy of post-positivism and constructivism instead embracing both or an intermediate position. While others propose a dialectic stance that considers the value of all paradigms but see them as only partial world views. Another group of scholars hold the view that multiple paradigms may be applied to diverse mixed methods designs. This author most readily identifies with the moderate view of a single paradigmatic thesis that harmonises world views and intentionally engages quantitative and qualitative methods in an effort to provide meaningful answers to perplexing problems.

The author identifies with the sentiments expressed by Tashakkori and Teddlie (151), ‘Study what interests and is of value to you, study it in the different ways that you deem appropriate, and utilize the results in ways that can bring about positive consequences within your value system’. Ultimately her penchant for equity research is inextricably linked with a desire to contribute to the development of meaningful solutions to vexing public and population health problems. Her values prioritize the flexibility to address the research question with the techniques that are appropriate without being constrained by a prior intellectual commitment to a philosophical position. Both subjective and objective knowledge are useful and the choice should

be dependent on the question as well as the competence of the team to execute particular approaches.

Morgan (153) advances an argument for the legitimacy of pragmatism beyond the practicality that has become associated with its use in mixed methods research. He clarifies that pragmatism is also about ‘why we do’ and not merely the ‘how we do’ aspects of the research design. Drawing on Dewey’s concept of inquiry, he constructs a process-based philosophy of knowledge with inquiry as the defining process. (118) He drifts away from a metaphysical emphasis on abstract concepts of ontology and epistemology, an idea that this author finds very convincing. According to Morgan (153), pragmatism is able to reconcile the differences between the various approaches to research. It treats the differences as ‘social contexts for inquiry and as a form of social action rather than abstract philosophical systems’. (153)

4.3 Research strategy

A pragmatic orientation paved the way for selection of a flexible strategy that addressed the research objectives. It was recognized that implementation of sociodemographic data collection was context-sensitive. In order to understand how and why events occurred, multiple sources were required to capture the varied perspectives. Several of these requirements pointed to a case study as an appropriate strategy.

There is controversy about the classification of case study as methodology, meta-method or research strategy. (154–156) The author wrestled with these notions and wondered whether it was more a matter of semantics than diametrically opposed concepts. In this research, ‘case study’ was most aptly considered an overarching research strategy that allowed for examination of a complex process that was inextricably linked to the context of implementation. In this regard, the perspective of Yin was embraced as case study does not propose a specific approach consistent with a methodology and it is more than a tool/instrument for data collection.

4.3.1 Why case study?

According to Yin (156), it is appropriate to consider a case study research strategy when ‘how and why’ questions are posed about processes and outcomes of an intervention. This study sought to explore two early implementation outcomes (feasibility and acceptability) of an initiative to collect standardized sociodemographic information across three local urban health care settings. The evaluation focussed on the process of implementation as it was most appropriate given the maturity of the initiative. It was important to understand how and why

implementation of the initiative proceeded in each site through an examination of the perceptions and experiences of different groups of participants. The rich detailed accounts from multiple perspectives provided a contextualized understanding of the project in each site. This approach offered the opportunity to examine similarities and differences across project sites and appreciate implications for future adaptation. Finally, there was limited control over events at project sites as a result of the real world context of implementation hence an experimental design was not practical.

The utility of case studies in program evaluation has long since been recognized. (156,157) Appreciation for case studies has also grown because of the need to understand increasingly complex social interventions in their real-life contexts. The implementation of sociodemographic data collection was context sensitive. The form of the initiative was adapted to the site with standardization of the function. This diversity increased complexity and required a flexible evaluation approach that could address the research questions. There has been interest from other sites and it is anticipated that work will continue. This approach can serve as a scaffold for other applications of the tools developed. Whatever the specific application, case studies make a distinctive contribution as a research strategy for empirical inquiry.

Robert Stake and Robert Yin (154,156) are two seminal writers on the subject of case studies. While there are similarities, each author's perspective is influenced by their epistemological orientation and motivation for their works. Both authors acknowledge that the focus of inquiry may be a single case or multiple cases. Yin (156) however uses the unit of analysis to further subdivide each type into holistic or embedded cases. In the holistic case, the analysis focuses on a macro level entity such as the program as a whole in contrast to embedded cases where subunits are emphasized. In contrast, Stake (154) identifies case studies by the 'intent' or motivation for the case study. In his typology there are intrinsic, instrumental and collective case studies. The intrinsic case study is one in which the case is of primary interest for its own sake because of some unique or interesting quality and the researcher is less concerned about generalization to other cases. With the instrumental variety, the case is secondary and its selection illustrates the issue of interest. The collective case study is an extension of the single instrumental case because multiple cases are selected that illuminate the issue. (154) As a novice to case study, the author sees value in Yin and Stake's perspectives as motivation drives the design phase when an appropriate case is identified for exploration. The type of analysis supports

the researcher's intent and translates design logic into meaningful understanding of the case. Elements of both authors' perspectives were used to give a comprehensive description of the approach in this study. A descriptive multiple-case study research strategy was particularly well suited to address the evaluation research questions about how and why events unfurled as observed.

4.3.2 Case selection

A case in this study referred to the process of implementation of sociodemographic data collection in a particular setting. There was an instrumental intent in the use of collective case studies. Different sites reflected variation in context and processes of implementation of sociodemographic data collection. All existing cases were studied. Within cases, an embedded analysis of subunits was used to describe the perceptions and experiences of various groups of participants who were either recipients or providers of services or key decision makers who presided over administration of the project.

There were three cases in this study comprised of implementation at West Winds Primary Health Centre (urban, public sector); Sexual Health Centre Saskatoon (urban, community based organization) and St Paul's Hospital (urban, independently affiliated hospital). While representing vastly different contexts, the potential for transferability of results to other similar settings was a motivating factor for case selection.

The next section orients the reader to the broader regional health context for the research. A detailed description follows of each project site and provides a context for understanding decisions related to the design and methods that were applied.

4.3.3 Case study contexts

Regional Health Authority Overview. Saskatoon Health Region is the largest Regional Health Authority (RHA) in Saskatchewan. (83) The region is accountable for services and programs delivered through 74 facilities including nine hospitals, 33 long term care homes and several primary care centres, mental health and addiction centres.(158) There are three tertiary care hospitals that serve as provincial referral sites for residents with advanced health care needs from across Saskatchewan. The construction of the Children's Hospital of Saskatchewan is scheduled to be completed in 2019. It will also be a referral site and support high quality care for the province's children. The Saskatoon Health Region has been accredited by Accreditation Canada. (159) This is a continuous quality improvement process with the organization working

towards its milestones over a four year cycle that culminates with an external visit by the accrediting entity.

Demography. The demographic profile of the Saskatoon Health Region mirrors that of the province with continued growth as a result of migration and natural increase. (160) The health region now accounts for over 30% of the total population of the province. Newcomers (immigrants and refugees) comprised almost 10% of the total population of the region in 2011. (161) Among recent immigrants, over one third (37%) were from the Philippines followed by China (7.9%) and India (5.3%). (161) Increasing cultural diversity has implications for provision of culturally competent care that respects patient values, beliefs and preferences.

The province of Saskatchewan was originally inhabited by many Indigenous Peoples. As increasing numbers of European settlers arrived throughout the 18th and 19th century, treaties were entered into between First Peoples and the Crown that established rights to settle and develop the land in exchange for health and other benefits for Indigenous peoples.(162) The Saskatoon Health Region is located within Treaty 6 territory and traditional homeland of the Métis people and is obliged to respect the historic treaties and entitlements of First Peoples. (162)

Indigenous peoples. Indigenous peoples account for 16% of the total population of Saskatchewan compared to 4% of the overall Canadian population. (87) Within the Saskatoon Health Region, Indigenous peoples comprise 10% of the population. (163) Among this group, there is an almost equal distribution of the proportion who identify as First Nations or Métis.(163) With respect to health and wellbeing of Indigenous peoples, there have been several memoranda of understanding between Indigenous stakeholders and the Saskatoon Regional Health Authority. Further, an Aboriginal Health Strategy (2010 – 2015) (164) was developed to guide priorities and actions to improve health outcomes for Indigenous peoples in the health region. There have been efforts to work closely with Indigenous communities and stakeholders to develop culturally appropriate programs that are more responsive to the specific needs of Indigenous peoples. The Saskatoon Health Region has also articulated its commitment to reconciliation and to implementation of the health related Calls to Action of the Truth and Reconciliation Commission. (165)

West Winds Primary Health Centre. The West Winds Primary Health Centre, a publically owned and operated community facility was established in 2007.(166) It serves a population of about 63,000 persons who reside in neighborhoods in the west and north of the city

of Saskatoon. This catchment area includes several inner-city/core neighborhoods that are among the most socioeconomically deprived in the health region. Despite a generally higher proportion of low income residents, gentrification of some areas have attracted a more diverse group of residents including seniors. (167) Increasingly, there are also many immigrant families who settle in the locale because of close proximity to amenities and more affordable housing costs. (167) In 2015, Canada's Liberal government committed to resettlement of 25,000 refugees by the end of 2016 as part of its humanitarian response to the Syrian crisis. The Saskatoon RHA also has welcomed an increasing number of Syrian refugees as part of the national resettlement commitment. The demographic and cultural mosaicism of the catchment area affects service needs and programs for the population. The full complement of primary health services are offered at the centre including maternal and child health, oral health, home visits, chronic disease management and health promotion. The Department of Academic and Family Medicine of the University of Saskatchewan also operates from the facility and provides primary care services for persons throughout the lifecycle. (166)

In this site, the project was implemented across immunization clinics. The centre offers both drop-in and booked appointments for immunization. The drop-in clinic has been offered since 2011 and over time has increased in popularity. The clinic manager approached the Public Health Observatory (Saskatoon Health Region) for support to conduct a survey among clients to understand their service related needs and preferences. The serendipitous opportunity presented to include a subset of sociodemographic questions to provide a context for service-related results. This project site therefore served as a pilot for testing a subset of questions as well as field procedures. Although the information was not integrated at the point of care, the survey results were intended to inform service planning and assist management to deliver immunization services in a more responsive way that meets community needs and preferences.

Sexual Health Centre. The Sexual Health Centre Saskatoon, formerly known as Planned Parenthood Saskatoon has been operating for more than forty years. The centre is a community based organization that envisions 'a society where sexual and reproductive health and rights are celebrated and accessible to all'.(168) To achieve this goal, the centre provides sexual and reproductive health services with an emphasis on 'safe, inclusive, empowering clinical care and education'.(168) A small multidisciplinary team provides counseling and testing for sexually

transmitted infections, pregnancy tests, cervical cancer screening, contraception counselling as well as counselling about various pregnancy options. A wide variety of information and education materials are available as well as a resource library. Various contraception methods are available at reduced costs including emergency contraception and free condoms. Sex toys can also be purchased from the centre.

The centre is conveniently located in the heart of downtown Saskatoon and offers both drop-in and booked visits on various week days and evenings. Occasionally services are offered on the weekend subject to the availability of a physician. The clinical team composition includes a nurse practitioner, physician (rotational basis) and a laboratory/phlebotomy support person. Volunteers are an integral part of the institutional model and social work students provide options counselling during their practicum. There are also volunteers who perform administrative/reception duties and assist at fund raising events. There is a full time youth education counsellor who delivers outreach to youth at various institutions. The daily operations of the centre are managed by an executive director with support from one full time office manager. The director is accountable to a board that provides oversight, strategic direction and financing for the centre's programs. Funding for the centre's operations is obtained through grants, fund raising events and donations.

The Sexual Health Centre Saskatoon has an active partnership with OUT Saskatoon. The latter is a queer and transgender friendly centre that provides support, information and education as well as sexual health services. A care provider from the Sexual Health Centre delivers screening and treatment for sexually transmitted infections at a weekly evening clinic. The two organizations also work together on community outreach and advocacy events. Each facility accepts referrals from the other centre to best meet the unique needs of their clients.

Increasingly, potential donors to the Sexual Health Centre Saskatoon have requested additional information to characterize the needs of clients who access services. Only limited information was collected with service statistics including age, gender identity and sexual behavior. The centre was motivated to participate in the project to better identify the social needs of its clients and improve the delivery of care.

St Paul's Hospital. The St Paul's Hospital was established in 1907 by the Grey Nuns. (169) In 1999, ownership was transferred to Emmanuel Care (formerly Catholic Health Ministry

of Saskatchewan). The institution has a unique governance structure as a result of its affiliation agreement with the Saskatoon Health Region.(169) Accountability for the institution's performance is shared between the institution's board and that of the Saskatoon Health Region. This arrangement allows the board to exercise its compassionate and religious mandate while delivering high quality care.

The hospital offers acute and ambulatory care services including laboratory, diagnostic imaging, emergency care, and specialty outpatient clinics. The institution has a capacity of 230 acute beds. It is recognized in the province as a centre of academic and teaching excellence and has established a local niche in the areas of chronic renal disease management, provincial transplant services and palliative care and hospice services.(169)

The St Paul's Hospital is located in Saskatoon's core neighbourhood. (167) The facility is surrounded by several communities that are among the most socioeconomically deprived in the health region. There is a higher concentration of Indigenous peoples who reside in the communities surrounding the hospital. Consequently, the location of the facility may influence patterns of utilization by some socially disadvantaged residents. There are several other community facilities including White Buffalo Youth Lodge, Friendship Inn and Station 20 West that offer a wide range of health and social programs. Several stakeholders including Saskatoon Tribal Council (STC) and Central Urban Métis Federation Incorporated (CUMFI) collaborate to advocate for Indigenous peoples and strengthening of programming to address their unique health and social needs. The Aboriginal Health Strategy (2010-2015)(164) presented a situation analysis and identified a unified vision for Indigenous health, and strategies to improve health and care experience of the target population.

The First Nations and Métis Health Service (FNMHS) operationalizes the plans articulated in the Aboriginal Health Strategy. The First Nations and Métis Health Council is the mechanism for shared accountability among Indigenous health stakeholders/partners for implementation of the Aboriginal Health Strategy. Under the leadership of its director, the FNMHS offers cultural support, interpretation and navigation to patients/families at the three tertiary care hospitals. The project team who supported implementation of sociodemographic data collection worked closely with FNMHS to plan and conduct the study.

In December 2014, the Canadian Institute for Health Information (CIHI) issued a public release of hospital standardized mortality ratios for acute care institutions across Canada.(170) The hospital standardized mortality ratio (HSMR) is a key indicator of patient safety and quality of care. The metric considers the observed number of hospital deaths to that expected for a given hospital. In the 2013-2014 reporting period, the St Paul's Hospital was the only hospital with a ratio above the national average (111 vs 100). (170) This finding caused much concern and prompted management to explore underlying reasons for the variation.

In 2015, a Safety hoshin (Safer Every Day) was one of the initiatives designed to improve quality of care through reduction of preventable harm to patients and staff. (84) At St Paul's Hospital, Lean processes and tools including rapid process improvement workshops (RPIW) were employed by frontline staff to address safety priorities. Sepsis was identified as one of the main contributors to inpatient mortality. Consequently, teams worked to improve early identification and management for patients at risk. While it was important to address clinical aspects of delivery of care, it was recognized that only limited information was available about patient social context that allowed for appreciation of events that led to their acute presentation. One of the recommendations of the safety initiative was to advance enhanced sociodemographic data collection to better understand the factors that affect access and presentation to care.

The implementation of data collection related to Indigenous identity at St Paul's Hospital supported First Nations and Métis Health Services in the delivery of cultural support and navigation services. The unit relies on surname and home community analysis of the daily hospital census to identify patients who are First Nations or Métis. Cultural support services are then offered to these individuals in an effort to provide culturally appropriate care. The limitations and opportunities for misclassification with this method were recognized. It was thought that facilitating patients to self-identify as First Nations or Métis at registration would increase the yield, preserve patient right to choose whether they disclose their identity and provided valuable information to support program planning.

The detailed descriptions of the project site contexts lay the foundation for understanding site motivations for participation and subsequent methodological considerations. Figure 4-1 shows the case study research strategy and summarizes the defining features for each case study site.

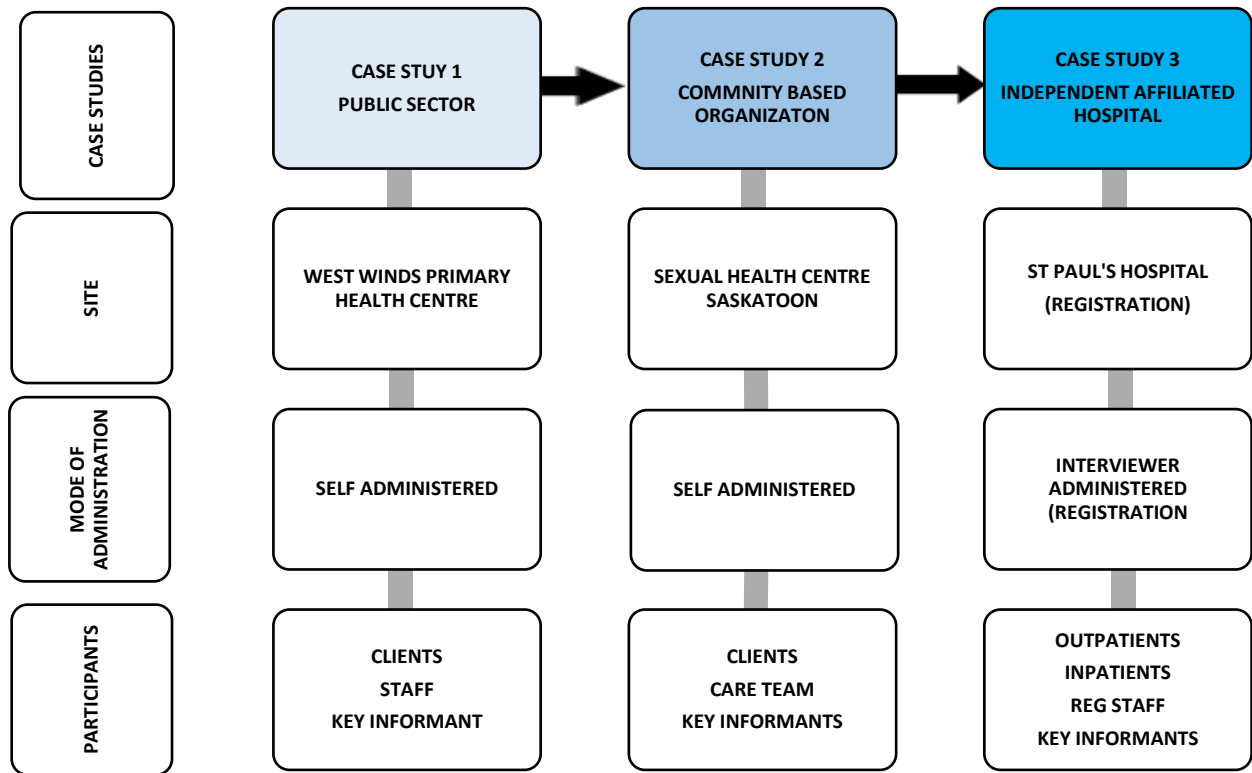


Figure 4-1: Diagram of multiple case study strategy

4.4 Research design

The research design is the ‘logical sequence that connects the empirical data to the study’s initial research questions and ultimately its conclusions’. (156) As previously mentioned in this chapter in subsection 4.2, a pragmatic orientation to selection of methods underpinned this study. In this multiple case study, mixed methods were applied in order to adequately address the research questions. The methods were selected to be complementary and greatly facilitated understanding of different perspectives of multiple sources. (171)

Creswell et al. (172) have proposed a typology of mixed method designs based on the priority assigned to each method, sequence of implementation of the methods and integration of methods. The priority refers to the importance assigned to a particular method and reflects whether the emphasis is on either the quantitative or qualitative strand or shared equally among methods. The sequence refers to the timing of application of the respective methods. Methods

may be applied concurrently, sequentially or in multiphase combinations. Finally, the approach to mixing of methods within the design determines level of integration. Methods can be mixed at the design, data collection, data analysis and interpretation phases. Based on the various combinations, there are six main designs including the convergent parallel design, explanatory sequential design, exploratory sequential design, embedded design, transformative and multiphase design. (172)

This multiple case study employed a multiphase design with cases examined sequentially in three phases. Higher priority was accorded to qualitative methods compared to quantitative methods. Both concurrent and sequential timing of data collection was employed. Integration occurred at the level of design and analysis. While some methods were common across particular phases of all case studies, there was also variation in order to address the research question in a given site. Quantitative data derived from the analysis of responses to self or interviewer-administration of sociodemographic questions was collected in all cases. This established a pattern of item responses that needed to be further explored. Qualitative data sources allowed for deeper exploration of participant experiences with implementation and included: (a) semi-structured or intercept interviews with patients/clients and (b) focus group discussions with care providers/care team. Key informant interviews with managers provided critical information about the context of implementation and suggested facilitators and barriers to implementation. Other types of quantitative data were collected during various phases of project implementation. At one site, pre and post training surveys were used to assess changes in knowledge and attitudes of registration participants as a result of training activities. Although predominantly quantitative, qualitative responses were collected for open ended questions about the training content and areas for improvement. In one site, review of medical records for a comparable period prior to study implementation provided a baseline to measure changes in provider care practices. Figure 4-2 illustrates the various designs employed in cases.

This multiphase design was particularly useful for program evaluation and arose because of the need to conduct case studies sequentially and adapt methods for each case. Both strands enabled comprehensive understanding of the cases. However it also presented a number of challenges. Multiple methods over various phases demanded adequate resources. Sequential case studies allowed for rationalization of available human and material resources and optimization of

organizational readiness. There was also a need to submit multiple amendments to the ethics application to accommodate each of the case studies. Although this requirement was anticipated, it called for toleration of uncertainty as the application could only be prepared after site selection, engagement and consensus on critical decisions about project implementation. In one site, this occurred one year after initial engagement and approval. One of the most formidable challenges of this design related to integration of various methods across phases within a case but also across multiple cases. This was necessary to bring a cohesive thread between what might otherwise remain silos of information about different cases/sites.

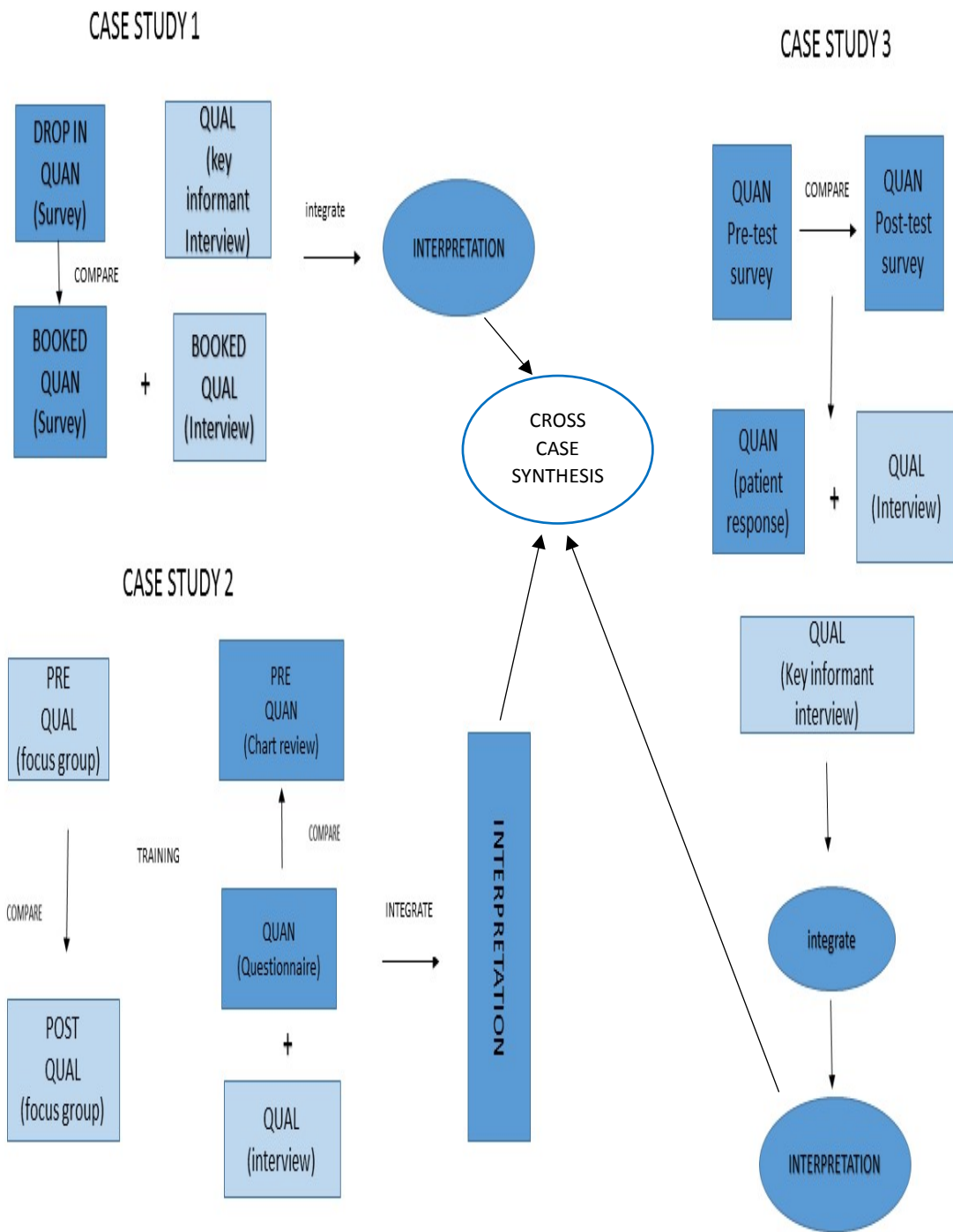


Figure 4-2: Diagram of mixed method design for case studies

4.5 Strategies for data collection

It has been recommended (92) that the most reliable means for sociodemographic data collection is through self-reports. Observer reporting, particularly of race/ethnicity is fraught with error and is discouraged. (86,173–175) It was emphasized to relevant health service and study personnel during the project that all sociodemographic data collection should be through patient/client self-report of the information.

In case studies, pragmatic considerations influenced the location within a site for data collection. Research suggests that patients may be most comfortable disclosing sociodemographic information to their physicians; however this was not feasible or practical given their competing responsibilities. (139) A few Canadian projects (47,48,176) have successfully integrated sociodemographic data collection during the registration process. The project was flexible and considered what worked best in each site. There were several advantages to integration at registration in that the information systems for data collection and reporting were often present, clerical staff were used to collecting sociodemographic data and the organization culture was familiar with tools of quality improvement. While staff may have been well positioned to collect demographic data, additional efforts were required to increase patient comfort including training for staff and patient education about the purpose and importance of data collection.

Electronic integration (42) has been recommended as an ideal practice as it has the potential to streamline collection processes and facilitate information reporting and sharing across health encounters. High functionality and interoperability was challenging given legacy IT systems. Despite engagement and support from the appropriate IT personnel, sociodemographic data could only be collected electronically at one of the three project sites. This necessitated parallel administration of a paper-based screening tool alongside routine registration procedures in the other two sites. There were also implications for sharing the information among members of the care team.

In discussions with partners, there was a strong preference for self-administration of the screening tool by patients/clients. This strategy offered its pros and cons however in low literacy sub populations, the team expressed concerns about low rates of completion. Some studies have also suggested that clients may prefer interviewer-administered data collection by a physician or

registration over self-completion. (48,139) The project was guided by preferences of the project site and tailored the implementation accordingly.

Data was collected from multiple sources at each project site in order to address the evaluation questions. Consistent with the initiative's logic model (See Figure 3-2), data collection focused on key activities and their outputs. This included training/preparation of staff for implementation, number of participants screened and their characteristics as well as perceptions and experiences of various types of participants with implementation.

In each site, multiple sources were also employed to uncover different understandings within the case. Triangulation of data sources is a common feature and has been touted as a strength of case studies. (156,171) Credibility of findings is achieved through triangulation when converging lines of inquiry provide support for data collected from different sources and in different ways. The alternative concept of crystallization has been advanced as a more desirable approach to understanding how various methods relate and inform the research process. Further, proponents of crystallization proffer that the goal of the research process should not be to establish a singular truth but to allow the multiple truths to emerge through engagement of multiple realities and methods. (177) This is consistent with the project's rationale for its selection of methods and participants.

The two main types of data collected in case studies were participant responses from application of sociodemographic data collection questionnaire or question and interviews, although other types of data were captured depending on the particular case. The following sections discuss the purpose and processes for each data collection method. Table 4-1 summarizes the data collection methods that were employed at each site.

Table 4-1: Summary of data collection methods used at each project site

Research objective	Site	Phase	Participants	Method
To assess uptake of screening for selected social determinants among patients at project sites	All sites	Post implementation	Clients	Primary analysis of participant responses
To assess perceptions and experiences with sociodemographic data collection	All sites	During implementation	Clients	Intercept interviews
	West Winds	Post implementation	Nurse Providers	Group discussion
To understand the institutional context as well as facilitators and barriers to implementation	All sites	Post implementation	Key informants	Semi-structured interviews
Training evaluation				
To assess fidelity of the training implementation	Sexual Health Centre Saskatoon St Paul's Hospital	Pre-Implementation	Care team Registration clerks	Review -Training attendance logs and training materials used -Participant observation
To assess any changes in knowledge, and attitudes to sociodemographic data collection	St Paul's Hospital	Pre and post training/education session	Registration clerks	Pre and post training surveys
To assess baseline knowledge about social determinants and community resources, attitudes and practices related to sociodemographic data collection.	Sexual Health Centre Saskatoon	Pre-implementation	Providers/ Interdisciplinary team	Focus group discussion
To assess changes in knowledge of community resources and attitudes as well as experiences with data collection	Sexual Health Centre Saskatoon	Post implementation	Interdisciplinary care team	Focus group discussion
To assess whether provider care practices change post intervention	Sexual Health Centre Saskatoon	Post implementation	Care team	Retrospective chart review of subset of medical records for pre and post intervention periods

4.5.1 Questionnaires

A major component of the initiative was the development of a sociodemographic data collection tool that could be applied at the individual patient level during the medical encounter. The following section describes the project's process to identify appropriate questions and engage stakeholders to ensure that the tool was relevant, easy to understand and appropriate for a broad array of settings. The process unfurled over several months and several iterations of the tool were produced as stakeholder feedback was incorporated.

Development of the sociodemographic data collection tool. The process to develop a local tool began with the identification of criteria to guide the selection of appropriate sociodemographic questions. The criteria considered were similar to those of other organizations who have engaged in a similar process during priority setting exercises. (127) Two main criteria were established by the team for selection of candidate sociodemographic questions for inclusion in the tool. Firstly, there had to be compelling evidence for existence of health disparities related to a particular determinant in the local and or broader Canadian context. A review of the evidence of health disparities was conducted to support the team's decisions based on this criteria. It was most appropriate to focus on determinants that were likely to pose barriers for patients/clients in a given local setting.

The second criteria was feasibility to collect data related to the particular question. This was assessed by a combination of factors including prior experience with collection in other settings (e.g. Census, Population health surveys), availability of information from alternate sources and potential sensitivity and willingness to disclose the information by patients/clients. There was a consensus that preference should be given to previously validated questions where available. The following areas were considered based on these two established criteria:

- Ability to speak English
- Preferred language of communication with health care provider
- Need for an interpreter
- Country of birth
- Indigenous identity
- Disability
- Gender identity
- Housing security
- Annual household income
- Year of arrival in Canada
- Race/ethnicity
- Highest educational attainment
- Sexual orientation
- Food security
- Number of persons that the income supports

There are no single standard instruments for the collection of sociodemographic information in health care settings although socioeconomic factors are often measured as potential confounding covariates in many studies. A review of existing sociodemographic data collection tools that have been used to capture social factors in clinical settings has previously been discussed in Chapter 2. This review informed the identification of potential questions to be included in tool. We also sought advice from content experts with respect to questions pertaining to language and food security. The Tri-Hospital and Toronto Public Health Equity Tool (47) included the broadest complement of questions that had been successfully applied in a Canadian context. The team agreed that these features made it an ideal model for this study which derives its name from that parent initiative. The project team examined each question against the established criteria and justified any additions by group consensus. A summary matrix was developed that captured each question and the rationale for its inclusion in the draft tool.

Once a set of candidate questions had been identified, the team embarked on a process of consultation with health care managers as well as community-based organizations that work with vulnerable populations. A list of local organizations was created to reflect the spectrum of candidate sociodemographic questions. (Table 4-2)

Stakeholder comments and concerns were summarized in the respective meeting notes or minutes. Table 4-3 summarizes this feedback. The team considered and incorporated the changes to the extent possible. Based on these suggestions, questions pertaining to immigration status, diagnosis with an intersex condition, preferred name and pronoun were added. This process was an important component of establishing face and content validity of the tool and ensuring that it was locally adapted to each of the settings. In general, this was an iterative process that required several revisions to the draft sociodemographic data collection tool.

The draft tool was also pretested among five staff members (not part of the project team) in the Public Health Observatory for clarity and comprehension, flow of questions and time required for self-administration. Although staff reported ease with administration, it was recommended that the readability of the tool be assessed.

The team maintained flexibility in negotiations with project sites and prioritized their information needs. This meant that sites could select a subset of the available questions for

application in their site. While it was desirable to include the comprehensive list, considerations related to relevance and utility influenced final decisions.

Table 4-2: List of external stakeholders consulted during the development of the tool

Question	Stakeholder category	Name
Language	Non-profit community based organization that provides re-settlement services for immigrants and refugees.	Global Gathering Place
Place of birth		Newcomer Centre
Race/ethnicity	Community based organization funded by Immigration, Refugees and Citizenship Canada that provides information and assistance to new immigrants to connect to services.	Newcomer Information Centre
Indigenous identity	Council established to monitor implementation of the Aboriginal Health Strategy	First Nations and Métis Health Council
	Individual First Nations communities	One Arrow First Nation Beardy's & Okemasis
	Group of volunteers who collaborate with the health region to identify opportunities to improve patient and family experience.	Aboriginal Patient and Family Advisory Committee
	Community centre that provides free breakfast and lunch to persons in need in core neighborhood.	Saskatoon Indian and Métis Friendship Centre
Disability	Non-profit community based organization that works on behalf of people living with mental health disabilities	Crocus Co-op
	Community based organization that advocates for persons with intellectual disabilities	Saskatchewan Association for Community Living
	Mental Health and Addiction Services include community crisis intervention for persons with mental health conditions	Mental Health and Addictions
Gender	Community based organization that delivers sexual and reproductive health services	Sexual Health Centre Saskatoon
Sexual orientation	Community based organization that supports sexual minorities	OUT Saskatoon
Housing security	Medical Health Officer	Dr Michael Schwandt
Food security Income	Population and Public Health - Nutrition	Public Health Nutritionist
	Community based organization that provides food and learning programs for persons affected by poverty and hunger	Saskatoon Food Bank & Learning Centre

Table 4-3: Summary of stakeholder suggestions to improve the draft sociodemographic tool

Sociodemographic domain	Suggestions
Language	<ul style="list-style-type: none"> ➤ Consider an additional question about literacy and reading ability ➤ Add options for ‘non-verbal and lip reading’ ➤ Consider inclusion of more language options. ➤ Consider implications for availability of interpreter services
Place of birth	<ul style="list-style-type: none"> ➤ Consider alternative question that asks about ancestry ➤ Consider addition of a question about immigration status
Race/ethnicity	<ul style="list-style-type: none"> ➤ Too many options provided
Indigenous identity	<ul style="list-style-type: none"> ➤ Consider a separate question for Indigenous identity
Disability	<ul style="list-style-type: none"> ➤ Confirmed that it is acceptable to use the term ‘mental illness’ ➤ Consider re-wording of question to improve clarity. Suggested ‘Do you have any condition that impacts you daily?’ ➤ Suggestions regarding wording of terms (e.g. use of the word impairment) ➤ Consider addition of option for acquired brain injury. ➤ Consider addition of an option for sensory issues. ➤ Consider re-wording of chronic illness to reflect illness and or pain.
Education	<ul style="list-style-type: none"> ➤ Consider collapsing into fewer categories
Gender	<ul style="list-style-type: none"> ➤ Consider addition of question about intersex diagnosis. ➤ Consider additional question about preferred pronoun
Sexual orientation	<ul style="list-style-type: none"> ➤ Consider order of the response options ➤ Objection to inclusion of this question by some stakeholders
Housing	<ul style="list-style-type: none"> ➤ Add an option for ‘approved home’ ➤ Consider formatting so that most common option appears first ➤ Consider question about housing hazards (e.g. pests, mold, repairs)
Food security	<ul style="list-style-type: none"> ➤ Consider improving the wording of the question ➤ De-emphasize access to money as it does not consider traditional ways of acquiring food such as hunting and farming
Income	<ul style="list-style-type: none"> ➤ Consider changing to monthly income as persons new to the province may not have been resident for year at the time of asking ➤ Consider different categories
Other suggestions/concerns	<ul style="list-style-type: none"> ➤ Consider additional question about employment status ➤ Consider additional questions about frequency and location of access to health services, contact with family physician, use of government services such as income assistance

Sociodemographic domain	Suggestions
Other suggestions	<ul style="list-style-type: none"> ➤ Concerns about whether services were available to address all determinants. ➤ Include more information in the introductory preamble in order to convey benefits of disclosure ➤ For the gender identity question, it is necessary to define unfamiliar/technical terms ➤ Inclusion of information about quality of nutritional intake. ➤ The question pertaining to income may cause discomfort among patients with low income who identify as First Nations and serve to stigmatize and profile the community. ➤ Consider consistent formatting of response options (e.g. either listed alphabetically or frequency of occurrence)

The final sociodemographic data collection tool included 11 themes (mapped to 20 items) that covered ability to speak English, preferred language of communication with provider and need for interpreter services, country of birth and immigration status, Indigenous identity, race/ethnicity, disabilities, gender, sexual orientation, highest level of education completed, housing security, food security and annual family income. The majority of response choices were closed ended and requested the patient/client to give one option. Where an open response choice such as ‘other’ was indicated, provisions were made for the patient to specify. One of the research objectives of the study was to assess acceptability hence valid response choices also included ‘prefer not to answer’ and ‘I don’t know’. This provided valuable information about differential comfort with data collection for various questions. The questions and themes are displayed in Figure 4-3.

The cumulative experience with administration of the sociodemographic data collection tool provided insight to the project team about questions that lacked clarity. Consequently, modifications to the tool were permitted based on feedback received from pilot site stakeholders and results obtained in earlier projects.

Language	<ul style="list-style-type: none"> •How well do you speak English? •What language would you feel most comfortable communicating in with your doctor/nurse? •Do you need an interpreter?
Place of birth	<ul style="list-style-type: none"> •Were you born in Canada? •If NO, What year did you come to Canada to live? •What is your current immigration status?
Indigenous identity	<ul style="list-style-type: none"> •Do you self-identify as an Indigenous/Aboriginal person? •If YES, please select from the following
Race/ethnicity	<ul style="list-style-type: none"> •Which of the following best describes your racial/ethnic group?
Disabilities	<ul style="list-style-type: none"> •Do you have any conditions that limit your activities of daily living? •If YES, is this condition....?
Gender	<ul style="list-style-type: none"> •What is your gender? •Have you ever been diagnosed with an intersex disorder? •What pronouns do you use?
Sexual orientation	<ul style="list-style-type: none"> •What is your sexual orientation?
Education	<ul style="list-style-type: none"> •What is the highest level of education that you have completed?
Housing	<ul style="list-style-type: none"> •Which of the following options best describes your housing situation?
Food security	<ul style="list-style-type: none"> •In the past month, how often did you or others in your household worry that food would run out? •In the past month, how often did you and others in your household run out of food and you could not get more?
Income	<ul style="list-style-type: none"> •What was your total family income before taxes last year? •How many people does this income support?

Figure 4-3: Sociodemographic questions in data collection tool

Administration procedures. Sociodemographic questions were self-administered using a paper questionnaire in two project sites. A questionnaire offered several advantages over alternate methods. (178) It allowed for standardized application of the screening tool to a large number of people in a short time. The privacy offered by self-administration potentially increased participant comfort in responding to sensitive questions. While a questionnaire can inquire about multiple issues, depth of inquiry is often limited. It also required that participants have the ability to read and comprehend questions. In multicultural settings, availability of the questionnaire in other languages is needed to support participation by populations with limited English language proficiency. Resources were not available to translate the questionnaire.

West Winds Health Centre. In immunization clinics at West Winds Health Centre, the sociodemographic questions were incorporated into a survey of client service needs and preferences. Designated non-clinical personnel (HWR, community development officer) distributed the questionnaire to prospective participants in the waiting room. Using a brief script, they explained the purpose of the survey and any related procedures and obtained verbal consent for participation. After informed consent was obtained, the questionnaire was presented to participants on a clipboard with a pencil. All questionnaires were completed anonymously. Only one questionnaire was completed per family even if multiple persons were being immunized. Personnel were available to provide clarification as needed. Completed forms were returned to these designated persons and placed in an envelope. The envelope was secured by the nurse manager at the end of a clinic session. Tracking of the persons who were approached was only systematically done for booked participants. Data collection occurred over the period October 13th to November 6th 2015 at drop-in clinics and January 18th to February 11th 2016 at booked clinics.

Sexual Health Centre Saskatoon. At this site, the questionnaire was distributed by the office manager or reception clerks. She explained the purpose of the questionnaire as well as related procedures to prospective participants. After verbal consent for participation was obtained, the questionnaire was distributed as part of the routine medical intake process for new clients to the centre. Recruitment focused on new clients to reflect the usual intake process. Revisiting clients did not complete an intake form unless the chart could not be located. Completed forms were returned to reception and were compiled into the medical record. Care

providers reviewed the record prior to the consultation. The client’s clinical management considered any identified social needs based on responses from the questionnaire. Project activities at this site occurred during the period 9th March to 14th June 2016.

St Paul’s Hospital. At the only acute care site, a single question was asked by registration clerks. The question was incorporated into the demographic tab of the Enovation registration program. (Fig 4-3) All patients presenting to registration/admitting were asked ‘Would you like to self-identify as First Nation or Métis?’ Response options were limited to ‘yes’ or ‘no’. The field was left blank if the question was not asked. If the patient declined to answer, this was recorded as ‘no’ so that the question was not asked on a subsequent occasion. Completion of the Indigenous identity field was not a mandatory requirement during the registration process hence the clerk could omit the field without asking the question.

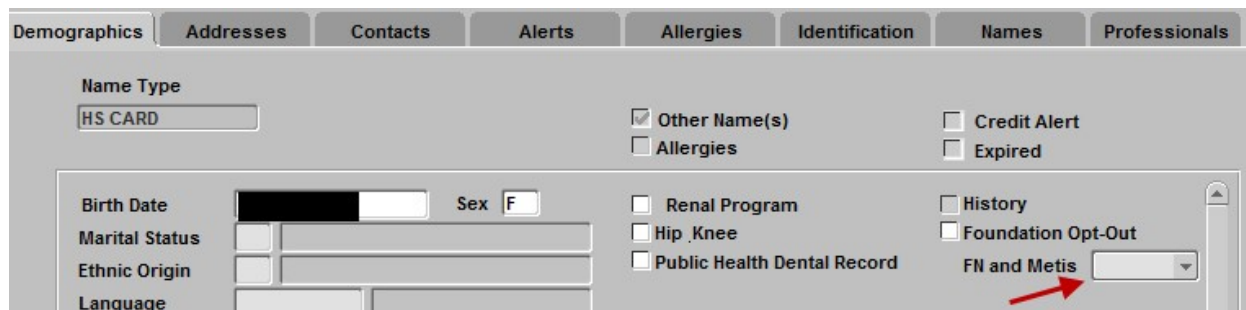
The image shows a screenshot of a software interface for patient registration. At the top, there are several tabs: Demographics, Addresses, Contacts, Alerts, Allergies, Identification, Names, and Professionals. The 'Demographics' tab is active. Below the tabs, there are several input fields and checkboxes. On the left, there are fields for 'Name Type' (containing 'HS CARD'), 'Birth Date' (with a redacted date), 'Sex' (containing 'F'), 'Marital Status', 'Ethnic Origin', and 'Language'. On the right, there are checkboxes for 'Other Name(s)', 'Allergies', 'Credit Alert', 'Expired', 'Renal Program', 'Hip_Knee', 'Public Health Dental Record', 'History', and 'Foundation Opt-Out'. A dropdown menu labeled 'FN and Metis' is located at the bottom right, and a red arrow points to it.

Figure 4-4: Snap shot of Demographic tab of Enovation showing question field

Registration personnel were requested to ask all patients who presented for services about their identity without regard for physical appearance, personal knowledge of the patient or their family background. It was integrated alongside other questions that are routinely asked/verified such as date of birth, address, emergency contact person and family physician. Patients were asked once during the study although it was acknowledged that willingness to disclose one’s identity could change with time.

There was no preamble before directly asking patients the Indigenous identity question. Registration clerks were encouraged to view the question as no more sensitive than other personal information that is routinely collected. They responded to patient requests for explanations about why the information was being collected. The registration manager addressed any unresolved patient concerns that were escalated from clerical staff. A brochure was

developed that provided additional context about the project. Posters were also displayed in the registration area as well as general areas of the hospital. (Appendix C)

Although the information pertaining to Indigenous self-identity was stored in Enovation, it was not included on the registration output that comprised the medical chart inset. Special reports were generated for First Nations and Métis Health Service (FNMHS) that comprised of extracts using information collected about self-identified First Nation or Métis status. The information facilitated outreach by First Nations and Métis navigators to inpatients who self-identified as First Nations or Métis to offer cultural support and navigation services.

Data from application of the sociodemographic data collection tool/question was collected for all consenting adult clients/patients (defined as at least 18 years) who received services at project sites during the study period. The number of clients/patients varied across project sites. Each client/patient was represented once even if there were multiple visits during the study period. Data was entered into a database and descriptive and inferential analyses performed using SPSS version 24.

Pre and post-training surveys were conducted among registration personnel at St Paul's Hospital in order to assess the effect of education/training activities. This method was ideal for efficient and timely collection of feedback. Questions focused on participants' knowledge, attitudes and behaviors related to sociodemographic data collection. Items also assessed the perceived relevance and utility of training content. The proximity of survey administration to the training activity facilitated participant recall and completion of the questionnaires. Question format was varied with multiple choice items, Likert scales for rating and open ended questions. Response options allowed participants to indicate that they 'did not know' or 'preferred not to answer'. Limited sociodemographic information was also collected about participants at the end of the pre-training questionnaire. (Appendix C)

Written consent was obtained for participation in the evaluation component of training. (Appendix C) All questionnaires were self-administered and clarification was provided by the author (HWR) as necessary. Completed forms were returned to the researcher after completion of each pre and post-tests. Data was entered into an Excel database and imported into SPSS version 24 for analysis. Data was summarized using descriptive statistics with frequencies and percentages for categorical data and median and interquartile range for non-normally distributed

continuous data. Pre and post training responses were compared using McNemar test for categorical data and Wilcoxon sign rank for attitudinal scores.

All registration clerks were targeted for training/orientation. Clerks with casual appointments are deployed across hospital sites. During the study, some shifts were covered by individuals who had not participated in the orientation sessions. It was agreed that the manager would assume responsibility for providing orientation and ensure that the clerk was apprised of the procedures.

4.5.2 Chart reviews

A retrospective review of medical records for clients seen at Sexual Health Centre Saskatoon during the same three month (pre-initiative) period (March 14, 2015 – June 14, 2015) in the previous year was undertaken. The objective of the review was to assess whether there was evidence of a change in provider practices that might be due to project activities. Similar times of year were selected to minimize any effects of seasonal trends in clinic attendance.

The centre relies on paper records for documentation of clinical encounters. Medical records were selected for clients seen on similar days and types of appointment as during the project's implementation. Although some of these clients also had visits during the study period in 2016, there was no overlap as clients recruited were predominantly new to the centre at the time they were considered for inclusion. Consequently, the pre and study cohorts comprised of different clients. Only clients who were at least 18 years were eligible to be included.

The sample size per group was estimated to detect at least 20% difference in proportion of charts with documentation of any sociodemographic data elements and interventions. Epitools online calculator was used to calculate the sample size for a dichotomous outcome (presence of at least one sociodemographic data element) where p_1 is the proportion of charts with the outcome of interest in the pre-initiative period while p_2 represents the proportion with the outcome during the study period. For type-I error = 0.05 and power = 0.80, for pre-specified values of p_1 (estimated at 0.20), a sample of size $n=91$ per period (total $N=182$) was required. (179)

Assessments and endpoints. Data pertinent to the study objectives was abstracted from the original paper medical records and recorded on a paper case report form. A standardized approach to data abstraction was employed. A data abstraction tool was developed that identified

and defined key elements. (Appendix B) All data collected were de-identified and participants were assigned a unique study identifier. Study variables included documentation of client sociodemographic factors and efforts to mitigate the impact of adverse social factors. These factors were age, gender identity, racial/ethnic origin, Indigenous identity, English language ability and need for interpretation services, sexual orientation, presence of a disability, highest level of education, housing status, food security and income. The types of interventions that were anticipated were use of interpreters, referral to social workers or community resources and adjustment of disease risk based on knowledge of social factors. This information was most likely to be located either on client intake forms or clinical assessments for a given visit. The primary outcome was the proportion of charts that documented each of the sociodemographic factors of interest. Additionally, the proportion of charts that addressed an identified social risk was also assessed.

Analysis. Study data collected for primary outcomes both pre and during implementation were compared. Descriptive characteristics for both groups of clients were also compared. There was no imputation or replacement of missing values and all analyses related to observed cases. Results are presented as frequencies and percentages as well as median (interquartile range) where appropriate. Differences between groups were assessed for statistical significance using chi squared tests (or Fisher's Exact Test) and Mann Whitney test depending on the type of variable. A two tailed p value of ≤ 0.05 was used as the significance level in all analyses.

4.5.3 Interviews

Several types of interviews were used in the case studies. There were semi-structured interviews, intercept interviews and focus group discussions. This method allowed for greater exploration of perceptions and experiences with the project at the respective sites. (180) Interviews also provided rich detailed information for understanding the context for implementation as well as elucidating the perceived facilitators and barriers to change in the various settings. The timing of interviews varied depending on the function. Except for focus groups, interviews were a single event and occurred at strategic times during implementation.

Semi-structured individual interviews. At the Sexual Health Centre, semi-structured interviews were conducted with 25 clients who had registered and were seated in the waiting area. The participants were selected purposively using criterion sampling. Eligible participants

included adult clients (≥ 18 years) who had completed a sociodemographic data questionnaire as part of their intake and who were willing to be interviewed. Participants also had to be fluent in English as access to interpretation services was limited. Although the purpose of qualitative sampling is not to achieve generalization, participants were identified who were thought to reflect a wide range of opinions (age, gender and ethnicity) that shape perceptions of sociodemographic data collection. (139,180) The interviews explored client perceptions about the need to collect sociodemographic information, who should be asked and preferences for timing and location of data collection. Participant's level of comfort and experience with the study were also subjects of inquiry. The interviews allowed for deeper understanding of the pattern of client responses to the sociodemographic questions as well as insight about how the process could be improved. Interviews were structured according to an interview guide that focused conversations while maintaining flexibility for participants to express new ideas and freely share experiences. Participant consent was obtained for audiotaping of interviews. Transcripts were transcribed verbatim and analysed using thematic analysis. (181)

During the analysis of semi-structured interviews, all transcripts were printed. Segments of texts were highlighted and assigned codes in the margins. Data that were similar were assigned the same code. Codes were refined as the process was repeated with each transcript. Codes were sorted into potential themes in an iterative process. Themes were reviewed at the level of codes as well as broader theme to ensure coherence. Final themes were named and described with a brief narrative. Exemplary excerpts of the data were presented to capture a particular theme.

Key informant interviews. Key informant interviews with the focal point (e.g. manager) were also conducted at all sites. All individuals were in positions of authority and were knowledgeable about the institution's operations, policies, culture and project implementation. As with the client interviews a guide was developed. Informed consent was obtained for participation and recording of the interview. While some topics overlapped with the client/patient participant guide, it was the main source of information about implementation and perceived facilitators and barriers to the project. The face-to-face interview was the ideal forum to explore the meanings assigned by the participant to events and obtain clarification about decisions that were made in relation to the project.

Intercept interviews. Intercept interviews were used at both hospital and community clinic sites to capture selected client perceptions of the importance of collection of sociodemographic data in health settings, the appropriate target population for screening for social needs as well as enquire about preferences for who should collect the data. This was essential for extending the quantitative results and gaining insight about why participants responded in the manner that was observed.

The intercept interview or ‘person on the street’ interview is commonly used in marketing research. (182) In this method, an interviewer intercepts a sample of patients or consumers who pass by to ascertain if they would like to participate in a study. Those who agree are either interviewed on the spot or taken to a facility/designated area for the interview. While often conceptualized as a survey, the intercept process can accommodate rich exchange between interviewer and participant. Both quantitative and qualitative data can be generated in these encounters.

At St Paul’s Hospital, prospective participants were intercepted by the researcher (HWR) after they had registered and were en route to their appointment or while waiting to be seen in the various departments. There are separate registration areas for emergency services, urological services and other services (diagnostic imaging, laboratory, day surgery, outpatient specialist clinics). It was not possible for a single researcher to cover all areas so the focus was on main registration where the majority of patients are captured. The hours of operation are 6.15am until 4pm during weekdays. Interviews were conducted over a six week period during the hours of 8am to 4pm. All weekdays were represented. The schedule for data collection included alternate days. One in five patients on a given day were approached to participate. An imaginary line was used to count patients as they were leaving registration. Eligible patients had to be registered, at least 18 years and asked by the clerk whether they wished to self-identify as First Nations or Métis. Reasons for refusal to participate were noted. Perceived sociodemographic characteristics (age, sex and race) were noted for those who declined.

An intercept tracking form was developed that standardized the interview questions and facilitated ease and speed of documentation. The form was secured with a clipboard while in the field. The date of the interview was noted and information about age, gender and ethnicity was also requested from participants. (Appendix C) The researcher (HWR) approached outpatients

after they had registered, introduced herself and briefly explained the objectives of the study. She subsequently inquired whether they were willing to answer a few optional and anonymous questions. The questions were presented in a standardized way using an open question format. The researcher classified responses using pre-determined 'codes' and made notes and quotations in the adjacent space. Descriptive summaries were created to display frequencies and percentages for each response choice. Chi-squared tests were used to assess the relationship between each of the questions and sociodemographic characteristics. The qualitative data was coded and analyzed manually by thematic analysis. (181)

Thematic analysis is a generic approach to identifying, analysing and reporting patterns in qualitative data. (181) The participant responses from the intercept tracking form were entered in an Excel database. Comments for each participant were systematically coded. Codes were assigned to segments of text until the entire data corpus was completed. The various codes were then sorted into potential themes. These potential themes were reviewed for coherence at the level of the code as well as theme. Final themes were named and explained with a short narrative. Excerpts of the data were selected to capture the essence of a particular theme.

There were several advantages (136) to the intercept interview that made it particularly suitable for these two sites. Both sites had high traffic areas and allowed for efficient recruitment and contact with the target population. Similar to other types of interviews, it offered the opportunity to ask follow up questions to clarify or probe a response. Another advantage related to the fact that the context for the situation being examined was foremost in the mind of the participant. This made it easy to inquire about the experience with data collection during the project.

There were also disadvantages of this method. (136) Often convenience sampling is employed consequently the participants may not be representative of the target population. In this study, an effort was made to document perceived sociodemographic characteristics as well as reason for refusal. This allowed for calculation of the response rate for those who were approached to be interviewed. Due to the nature of the encounter, patients may have been more reluctant to participate. This might have been because of preoccupation about health concerns as well as limited privacy particularly as interviews were conducted on the spot. The interview must

also be kept brief to minimize inconvenience for the participant. This necessarily limited the breadth of subjects that could be covered.

The opportunities to interview patients who identified as First Nations or Métis were limited during outpatient encounters. It was important to accurately reflect the experiences of all persons particularly those who self-identified as First Nations or Métis because of potential implications for asking under culturally unsafe conditions. Intercept interviews were also conducted with 37 inpatients who identified as First Nations or Métis during visits by navigators from First Nations Métis Health Services. Eligible participants included adults (at least 18 years of age) whose condition was stable and who consented to the interview. Common reasons for exclusion were inability to consent, unstable condition or critically ill and unavailable at time of visit. Similar to other intercept interviews, the information was captured on a tracking form and quotes were recorded. No audiotaping was done. Interactions were brief as patients tired quickly and rooms were often shared with limited privacy.

Focus group discussions. Focus group discussions were conducted with care providers in two sites. Both sites were community clinic settings. Provider complement and involvement varied at project sites. In the context of a small private community facility with an interdisciplinary care team, focus group discussions at two time points (pre and post implementation) were the main method of data collection with care providers. A single focus group was also convened post implementation with care providers at the community health centre to understand their perspectives and any concerns about sociodemographic data collection at the centre.

This method offered a number of advantages particularly as staff worked collaboratively in client care. (183,184) The focus group promoted exchange among participants and allowed for validation of ideas. It also provided the opportunity to get a balanced view and to clarify similarities and differences between the perspectives of participants. It was an efficient use of time as providers had limited availability during working hours for individual engagement. There were disadvantages associated with this method. Participants did not contribute to the same extent to discussions. It was possible that dissenting views were suppressed or that participants were swayed by the prevailing opinions of the group.

Topics explored with the clinical care team included knowledge about social determinants, attitudes to screening for social determinants and current care practices. Barriers and facilitators to addressing social needs as an integral component of care were also examined. In the post implementation discussions, participant experiences with the project were covered as well as areas for improvement of training and service delivery. As with individual interviews, sessions were recorded when possible. The interviewer completed field notes and observations that were relevant to research questions. All interviews and field notes were transcribed and subjected to a thematic analysis. (181) During analysis, transcripts were printed and read repeatedly in order to encourage general familiarity with content. ‘Memos’ were developed to capture initial impressions as well as begin to define specific codes. Segments of text were labelled with codes based on a priori (derived from interview guide or guiding theories) or emergent ideas that were refined through an iterative process. The data were interpreted by formulating a coherent thematic map that accurately represented the meanings and relationships between participants and events. Quotations from the text were used to highlight exemplary perspectives on each theme and constituted the specific supporting evidence.

4.6 Case analytical approaches

The general analytic approach to the case study revolved around dual use of qualitative and quantitative data. (156) Methods were complementary with qualitative methods enriching or explaining quantitative results in some instances. In other cases, qualitative methods were used exclusively for selected evaluation questions. An integrated analysis was employed. This was facilitated by highlighting common themes across multiple sources within and across cases. The incorporation of mixed methods of data from embedded units was the most useful way to address the complex research questions about project implementation.

Within case analysis. The data for each case/site was analysed and used to produce a case description of project implementation. A case report was prepared that described the context, activities, results and provided recommendations for future work in each site. Within each case, qualitative and quantitative data were analysed separately in accordance with their individual traditions. This has been described in the previous sections. Data from different methods for a given source (e.g. patients/clients) were compared using joint displays (Table 4-4) in order to identify similarities and differences. For example, patterns in the responses to sociodemographic questions were compared with patient interviews to understand the possible reasons for lower

response rates to particular questions. A similar procedure was applied for different sources within a case. Mixing of the data during the interpretation allowed for understanding of feasibility and acceptability of sociodemographic data collection from varied perspectives.

Table 4-4: Example of joint display used to visualize the results within a single case study

Cross cutting domains of inquiry	Participants (sources)			Research questions
	Patients	Health service personnel	Managers/administrators	
	Method(s)			
	Intercept or semi-structured interview	Group interview	Key informant interviews	
Comfort with data collection	+/- (Item response rates)	+/-	+/-	Acceptability
Perceived importance of data collection	+/-	+/-	+	Acceptability
Appropriate target for sociodemographic data collection	Universal vs targeted	Universal vs targeted	Universal vs targeted	Acceptability
Preferred mode of administration	Self/provider/registration	Patient administered/provider/registration	Patient administered/provider/registration	Feasibility/acceptability
Facilitators	Structural/ Organizational/ Individual	Structural/ Organizational/ Individual	Structural/ Organizational/ Individual	Feasibility
Barriers				

Cross case analysis. A cross case synthesis was done in order to draw out similarities and differences across implementation contexts and inform recommendations about successful approaches to collect sociodemographic data in the local context. (185) The perspectives of the different sources were compared across cases with respect to common themes. In this regard, there were elements of pattern matching across cases. Table 4-5 is a matrix that illustrates how this process was applied in the study. The results were also examined with respect to the relationships outlined in the logic model (Figure 3-2). This allowed for determination of the extent to which the anticipated relationships applied within and across cases.

Table 4-5: Multilevel thematic matrix showing cross case synthesis

Domains of inquiry	Codes	Theme	Case 1	Case 2	Case 3
Level of comfort	Sensitivity of question	Gradient of comfort (Item response rates)	+ (§Δ)	+ (§)	+ (§†Δ)
	Participant personal characteristics			+ (§)	+ (§)
Perceived importance of data collection	Tailor care	Understanding benefits of data collection	+ (§†)	+ (§†Δ)	+ (§†Δ)
	Describe patient population social profile		+ (§†Δ)	+ (§)	+ (§)
	Advocacy for funding			+ (§Δ)	
	Low relevance to delivery of care		+ (§)	+ (§†)	+ (§†)
	Inappropriate to ask		+ (§)	+ (§Δ)	+ (§)
	Safe space	Trust in institutional motives	+ (§)	+ (§)	+ (§)
	Privacy and confidentiality			+ (§†Δ)	+ (§)
	Fear of negative consequences				+ (§)
	Pride in cultural identity	Personal relevance			+ (§)
	Purpose of the visit	Service context	+ (§Δ)	+ (§)	+ (§)
Appropriate target for data collection	Limitations of physical appearance	Universal approach		+ (§)	+ (§)
	Avoidance of profiling		+ (§)	+ (§†Δ)	+ (§Δ)
	Screen most vulnerable and likely to benefit	Targeted approach		+ (§)	+ (§)
Preference for mode of administration	Time constraints	Practical considerations	+ (§†Δ)	+ (§†)	+ (§†)
	Collection with usual demographic data			+ (§†)	+ (§†)
	Collection and use by care provider	Role expectations	+ (§†)	+ (§†)	+ (§†)
	Multiple locations for collection	Sensitivity of question		+ (§†)	

§=Patient, †=Staff, Δ=Administration

Quantitative and qualitative research use different terms to express quality of the study. Validity is used in quantitative research to convey the extent to which the results are deemed to reflect 'truth'(internal) and extend beyond the sample to larger population (external).(178) In qualitative research, parallel concepts of credibility, dependability, transferability and confirmability are important to establish trustworthiness of the results. (186) In this study, appropriate details are provided to allow the reader to judge credibility including strategies for sampling, statistical tests and analytical approaches.

Many of the principles of case study research support the establishment of credibility. Multiple sources and methods ensured that diverse perspectives were explored. Member checking was used to determine the accuracy of the findings. (187) The results were discussed with participants to ensure that it was representative of their views as expressed during the study. During the various phases of implementation, the project team met weekly to discuss activities and resolve challenges. It was also an important arena to explore feelings, uncover implicit biases and question assumptions about things that the student researcher thought and or observed. The regular exchanges with others encouraged transparency in decision making and reflection about the interpretation of the data.

4.7 Ethical considerations

The project received ethics approval from the Behavioral Research Ethics Board at the University of Saskatchewan as well as operational approval from the Saskatoon Health Region. The ethics application was amended to accommodate the specific adaptations required for project implementation in each of the sites.

It was also important to ensure that sociodemographic data collection was linked to commitment to address any identified needs whether at individual or community levels. The project team felt that it was unethical to detect problems without adequate provisions to link people to services or resources to improve their health. (188) A critical barrier (136) to screening for social determinants among providers is lack of knowledge of community resources and feelings of powerlessness to address complex social and structural issues. The project mapped specific sociodemographic questions to practical actions that could be taken during the medical encounter. It was also recognized that in the absence of concerted efforts to address social needs, screening could inadvertently result in reinforcement of misconceptions and stereotypes about already stigmatized and socially disadvantaged groups.

Informed consent was obtained for data collection in all sites. Patients/clients were recruited during their medical encounters hence it was important to emphasize the voluntary nature of participation. Given the asymmetry of information in health care and imbalance in power, the potential existed for patients to feel obligated to respond. It was necessary to ensure that patient autonomy was preserved and refusal was not associated with adverse effects on care.

In the hospital site where a single question about Indigenous identity was introduced, there were additional implications. Persons with Registered Indian Status (RIS) can be identified by their health card. Consequently, it was possible to complete the field without asking the question for this subset of patients. It was emphasized in training that each patient should be given the opportunity to decide whether or not they want to disclose their identity. Asking each person without regard for physical appearance, treaty status or personal knowledge of the patient's ancestry – is the only way to preserve the patient's right to disclose. It was possible because the question was interviewer-administered that some fields were completed based on observation rather than self-report. It is not possible to verify the extent to which this happened during the project. However, future efforts to expand data collection will continue to emphasize the duty of data collector to obtain information only by patient self-report.

There were staff concerns about privacy and the legitimacy of asking sociodemographic questions in health settings. On two occasions, these concerns were brought to the attention of the Privacy Office. The issues were successfully addressed and the project activities continued with endorsement from the relevant authorities. There is limited awareness among staff and management that the Human Rights Code 'permits and encourages sociodemographic data collection in order to monitor discrimination and remove systemic barriers, ameliorate disadvantage and promote equality'.(189)

4.7.1 Special considerations related to collection of Indigenous identity data

The research process for this study respected Ownership Control Access and Possession (OCAP) principles as it relates to research, data or information that involves First Nations peoples.(190) There was an ethical requirement to engage Indigenous communities as the research would involve asking an Indigenous self-identification question and interpretations would broadly refer to group membership. (191) It was important and desirable for the project team to engage stakeholders in order to be transparent about the project goals, design, benefits and potential risks. We wanted to identify their priorities, address any concerns and gain trust for

a successful endeavour. The goal was meaningful engagement and partnership that would extend beyond the project.

The relevant Indigenous health stakeholders including community leaders and patient/family advisory councils were engaged prior to and during project implementation at the acute care site. There were initial concerns about the implications of yet another research project that focused on perceived deficits in Indigenous peoples. The project team included an Indigenous researcher (TL) who ensured that the appropriate processes were followed to consult with Indigenous communities. The study protocol was reviewed and approved by the relevant Indigenous health authorities/custodians. This is consistent with OCAP principles that maintain the locus of control over ‘whether research should happen and how it should be done’ with Indigenous peoples.(190)

There was respect for Indigenous ways of knowing and cultural traditions. A pipe ceremony was performed by the respective elders to symbolize partnership, seek spiritual guidance for the project and favour to reach its objective. This set high expectations for the research process and established a platform for mutual trust and reciprocity.

Throughout the project, there were opportunities to provide feedback and seek guidance from the Indigenous health stakeholders including First Nations Métis Health Council. The project in the acute care site prioritized a single question on Indigenous identity based on its relevance to program goals and information needs. Staff from the First Nations and Health Service (FNMHS) were integrally involved in the development and delivery of training of staff in preparation for implementation of data collection. Project preliminary results were also shared with Indigenous community leaders who assisted with its interpretation and offered recommendations to advance research and local practice.

The data collected in two project sites resided within the health information system. In the case of the acute care site, data was stored in the registration system and in the paper medical record of the community based site. This has implications for ownership and control by Indigenous communities over use of the data for research and quality improvement purposes. Although the current regional health policy has maintained exemption to the provisions of OCAP for administration data, there is an agreement to consult Indigenous communities with regard to use and release of data. This maintains the spirit of OCAP and considers the right to self-

determination and control over the data so that it is used for the benefit of Indigenous communities.

CHAPTER FIVE

RESULTS

5.0 Introduction

The collection of patient sociodemographic data is important for equity measurement and increases clinical opportunities to provide more holistic and patient-centered care.(16) This evaluation assessed the implementation of sociodemographic data collection across three urban health care settings in Saskatoon, Saskatchewan. The institutional contexts of the settings reflect the diversity of the urban health care system and include public and private acute and ambulatory care sites.

The chapter is organized into five sections to distil the project results and articulate a response to the evaluation questions. In section one, the author compares implementation across the three sites to the proposed model and discusses the implications of any departures. Section 2 considers education/training activities and participants' knowledge and attitudes to sociodemographic data collection. Section 3 focuses on the key project screening outputs and examines participant perceptions and experiences with implementation of sociodemographic data collection. This contributes to understanding the feasibility and acceptability of data collection from multiple perspectives. Gaps and opportunities for improvement in the process of implementation are also described. In section 4, the author explores how sociodemographic data was applied and the extent to which it has influenced provider approaches to care. Finally, the perceived facilitators and barriers to sociodemographic data implementation are described across the three settings and insights offered about common elements that fostered implementation.

5.1 Fidelity of implementation

The project was designed to support collection of individual level patient sociodemographic data and its application during the medical encounter to tailor care to address unmet social needs. Consistent with this vision, a broad range of social determinants were identified that were mapped to sociodemographic questions. The questions were incorporated into a sociodemographic data collection tool that considered local relevance, ease of comprehension, logical format and order of items and breadth of response options. The tool was presented to stakeholders as the ideal complement however the final decision about which questions would be asked was left to the site implementation teams. The project team recognized that it was critical to be responsive to the information needs, capacity and preferences of the sites. This flexibility resulted in marked variation across the sites. Only one community site collected the full complement of sociodemographic questions. Among the other sites, one site implemented data collection for six questions and the only acute care site a single question related to Indigenous identity.

5.1.1 Sociodemographic questions

The plan was to have standardized questions in all of the sites regardless of the actual number of questions that were implemented. The project team identified validated questions from the literature and engaged internal and external stakeholders to obtain feedback on these proposed questions. The final complement reflected the input from stakeholders and pre-testing among departmental staff members. In two project sites, two different questions (need for interpreter and Indigenous identity) were modified.

The community health centre requested a modification of the question pertaining to need for an interpreter. There was concern that in its current framing, it implied that an interpreter would be provided by the centre in the future. So the question was modified to ask ‘If it were available, would an interpreter be helpful?’ The intent was to focus on the conditionality of ‘if available’. There were two iterations of the question. In the first round, response options were limited to ‘yes’ and ‘no’. In the second round among booked clients, we expanded the response options to include ‘prefer not to answer’ and ‘do not know’. Both iterations appeared to lack clarity and returned high rates of missing data and ‘do not know’. This occurred among persons who were Canadian-born and self-identified their race/ethnic group as White or Indigenous.

Without information about English language proficiency and preferred language of communication, it was difficult to fully realize the significance of the finding. However, it validated the project wisdom of adopting standardized questions and applying themed clusters at future project sites.

The question related to Indigenous identity was modified in the acute care/hospital setting. In the modified version, the phrase was asked ‘Would you like to self-identify as First Nations or Métis?’ This question had a more local focus and excluded response options for Inuit and Indigenous peoples from outside of Canada. Response options were limited to ‘yes’ and ‘no’. The rationale for truncation of response options pertained to the legacy registration system that had limited capacity to accommodate an expanded field list. There was also little inclination to make extensive modifications because the registration system would be upgraded in the near future. The semantical modifications had an impact on interpretation of the question and responses. In this site, those who declined as well as who did not identify as First Nation or Métis were subsumed under the ‘no’ response option. If the question was not asked, the field was left blank. Despite the limitations imposed, the information was still useful for its primary purpose that was to flag individuals who could be linked to cultural support and navigation services.

5.1.2 Mode of administration

Interviewer-administration was the proposed ideal mode for asking clients/patients about social needs. It was thought that it would overcome literacy barriers, minimize non-response and provide a platform for clarification/explanation of items. It was recognized that given the sensitivity of questions, adequate provisions to ensure privacy would be paramount. Time for administration by alternate modes was also considered. The project was encouraged by another Canadian project that had been successful with varied modes of administration for an expanded list of questions. (47)

The project team advocated for distribution of the questionnaire by reception personnel at immunization clinics. This suggestion was rejected by the site as it was thought that it would impose a burden on registration. There was also concern that time was limited to allow for adequate staff preparation. An alternative strategy was devised and a member of the project team (HWR) distributed the questionnaire along with the community development officer. Even with

this strategy, it was only possible to cover three quarters of booked clinics. This is an example of how key decisions pertaining to various aspects of the project were negotiated with site teams.

Only one site employed an interviewer-mode of question administration. This was the natural choice for integration into that site's registration process and work flow. Participants completed self-administered questionnaires in the other two sites. A unique plan for implementation was developed in conjunction with each site. The logistics of implementation including the mode of administration and specific location within a given site were guided by the evidence as well as pragmatic considerations.

5.1.3 Patient education/awareness

Based on the We Ask Because We Care logic model (Figure 3-2) and project theory, patient awareness of the rationale for collection of sociodemographic information was important for increasing willingness and comfort with disclosure. The main information and education materials developed to support implementation were brochures and posters. The posters were displayed at registration and in general patient areas such as waiting rooms and corridors. There was limited availability of brochures across sites and these were distributed when patients requested additional information. At the acute care site, the materials played an even more critical role as there was no preamble for the question and it was the default response to patient concerns about the project. In this site, patient concerns could also be escalated to the manager or client representative services. The effectiveness of these materials in communicating project information was not formally assessed. However, participant perceptions about the importance of collection of sociodemographic information provided insight about general awareness of related issues. Based on the author's observations, clients/patients relied on the questionnaire or interaction with study personnel for project related information. Very few brochures were distributed at any of the sites. Although it was anticipated, consideration should be given to how best to support patient awareness in future projects.

5.1.4 Application of sociodemographic data

The underlying philosophical tenet of the project was grounded in the principle of equity that dictated application of the information to improve client care. This was often couched in the rhetoric of quality improvement and cultural safety. In each site, the application of data took one

of several forms including supporting program planning for more responsive immunization services; provision of patient-centred care through individual clinical accommodations to mitigate the impact of social determinants and referral to culturally safe navigation services. This flexibility was required to advance the project. It also had implications for which research questions could be answered in a particular site. There was one common function of the initiative across sites – the collection of sociodemographic data collection. This will be revisited as the other evaluation questions are addressed.

5.2 Staff education/training activities

West Winds Primary Health Centre. Consistent with the project’s logic model, preparation of staff for implementation of data collection was a priority for the project and site implementation teams. At West Winds Primary Health Centre, a member of the project team (HWR) and the community development officer distributed the questionnaire and responded to any participant concerns. The researcher received capacity building and coaching as part of the project team and a brief orientation was provided to the community development officer. A script was used by these two personnel who supported the project. There was no formal training for other staff members at that site.

Training/education activities were implemented in the other two sites. Training content was different for both sites to respond to various needs. Across all sites, it was important for staff to understand the rationale for data collection and be confident responding to patients/clients who challenged their request for information. Time allocated for training was limited across all sites. Ongoing support was provided by the project team throughout implementation.

Sexual Health Centre. Preparation of staff for implementation at the Sexual Health Centre occurred during a one hour team orientation to the study. A power point presentation guided the interaction between trainer (EB), co-facilitator (HWR) and the care team. Topics covered included key definitions, rationale for the project, screening tool questions and study procedures including how to respond to client questions. A provider resource manual was developed as an implementation aid. It explained the rationale for each sociodemographic question as well as offered potential clinical interventions to address unmet social needs identified from the screening tool. (Appendix B) The care team was also oriented to the resource manual. Other implementation aids including a poster, client brochure and client referral cards

were also shared with the team. A separate session was arranged for the lead physician to receive an orientation to the resource manual. The resource manual was downloaded to computers in the provider consultation rooms where it could readily be accessed as needed.

Participants' knowledge. The care team's knowledge and attitudes to sociodemographic data collection was assessed during a pre-training focus group discussion. Clinical staff had been exposed to information about social determinants of health during their clinical training. Most participants were recent additions to the staff and had not been exposed during their brief tenure at the centre. All had experiential knowledge of how social circumstances affected people's ability and opportunities to make healthy decisions. For example, one participant noted reading difficulties and repeated adverse outcomes among some socially disadvantaged clients.

I have not received formal training about social determinants but I have been noticing [some] factors frontline. Like we had a patient yesterday that has a problem with reading comprehension. So being able to address those kind of issues would be really beneficial for me. Because I need more experience in how to deal with those [issues] without being insensitive but providing better care for the patient in the long run. So mostly that is where I come in. I see firsthand all of the different comprehension levels or social problems. Like we have lots of young women that have repeated issues with pregnancy or repeated issues with sexually transmitted infections and a lot of that is due to socioeconomic status. (P4_SHC)

Another participant shared her experience of working in rural areas where geographic barriers pose challenges to access to services and commodities that are crucial for health and disease management.

Certainly I was exposed to the concept of social determinants of health in nursing school a couple of years ago. Certainly something I have experienced in my professional life, the different barriers that people experience. Before I came here, I was working in the north on a reserve so geographical location was definitely a big barrier. And then also like on reserve, status - Indians status versus non-status makes a big difference in terms of access to medication and stuff like that. I have seen some different stuff now that I am here in terms of income and other social barriers people experience. (P2_SHC)

A social work student on her practicum placement with the centre was very familiar with concepts and implications of social determinants of health as a result of her educational experiences. She stated, 'With my social work education, a lot of it is

grounded in social determinants of health. So I have gotten to see how that affects a person pretty in depth'. (P3_SHC)

Care team attitudes to sociodemographic data collection. There was consensus by the care team that sociodemographic data collection was important. A care provider expressed her views about the anticipated benefits of identification of patients' unmet social needs during clinical encounters and opportunities to tailor their care to address identified needs.

From a provider perspective, I think it would be really excellent to have like a brief and consistent tool for recognizing and acknowledging social determinants of health and how they might affect care and how it could be incorporated in the plan. (P2_SHC)

Another participant highlighted the need for better sociodemographic information to guide development of more responsive programs and services. These additional data elements were also needed to justify requests for funding on grant applications.

I really see the importance of this work. I think it is really relevant to the work that we are doing and it helps us to expand on some of the programs and services that we are currently offering. Also selfishly as the person also responsible for the grant writing and the fund development, it really helps me in terms of the demographic data and knowing who our clients are and knowing what their needs are. (P1_SHC)

Providers felt that they already considered social factors in client care and shared several examples of how they supported clients to meet their needs. There was generally little apprehension and much optimism about client willingness to participate during the pre-implementation period. Two participants reported,

So I also do options counselling. I have done all kinds of things like walking people up to the community clinic, trying to arrange for translation, begged, borrowed and done things that are outside of our scope to try to get people's needs met. I have helped people with things like getting ID and provincial health cards. If there is a barrier to accessing one of our services and it is also a barrier to accessing other services, I will try to help people and connect them to other places. And in terms of our HIV testing work, we are also in the process of having more of a relationship with Westside. So if we have a positive test, we have a structure in place to ensure that person gets linked into care with a physician. I think part of it is trying to figure out basically, sometimes on the fly, what we can best do to meet people's needs. And also in a more structured way figuring things out and building those relationships with other organizations that we are not currently working with. (P1_SHC)

Sometimes we get patients that we know already are at risk because they come from group housing centres such as Bethany Home or Calder Centre. So if you know that someone is coming from Calder Centre then you know that it is a short term program and they are only going to be there for a short time so we have to do everything more quickly to make sure that when they get back to their community, they have the information they need .We have lots of girls from Calder Centre that need IUDs like the next week. So that’s something we consider. (P4_SHC)

There was no assessment immediately post training session with the team because of time constraints. The activity’s focus was to explain the rationale for the project and to build capacity to address patient concerns about sociodemographic data collection. It was also important for staff to be familiar with the community resources to address any social needs identified by the screening tool. The post implementation focus group discussion assessed the team’s experience with the project.

St Paul’s Hospital. Training for registration clerks at St Paul’s Hospital was held on 18th May 2016. There were two sessions (same content) that each lasted two hours. A total of 10 clerks attended in addition to registration manager, trainers and project team. All registration clerks self-identified as female. Descriptive characteristics of training participants are shown in Table 5-1. Just under half of participants had been working for fewer than five years.

Table 5-1: Descriptive characteristics of training participants at St Paul’s Hospital

Characteristic	No (%)
<u>Age (years)</u>	
18 – 30	1 (9.1%)
31 – 40	5 (45.5%)
41 – 50	1 (9.1%)
≥51	4 (36.4%)
<u>Years of experience</u>	
≤5 years	5 (45.5%)
6 – 10 years	3 (27.3%)
>10 years	3 (27.3%)
<u>Hospital deployed</u>	
One only	6 (54.5%)
Two hospitals	2 (18.2%)
All three hospitals	3 (27.3%)

Participants' knowledge. Baseline knowledge of two key terms was poor among registration personnel. Only one participant had heard of the terms 'social determinants of health' or 'cultural competence' prior to the training. There was a significant increase in the proportion of participants who were familiar with these two terms post training. (Figure 5-1A, B) Among those participants who had heard the term social determinants (n=8) during the session, 50% were able to identify the correct answer. In contrast, of those who had heard the term cultural competence (n=10), 90% were able to provide the correct definition.

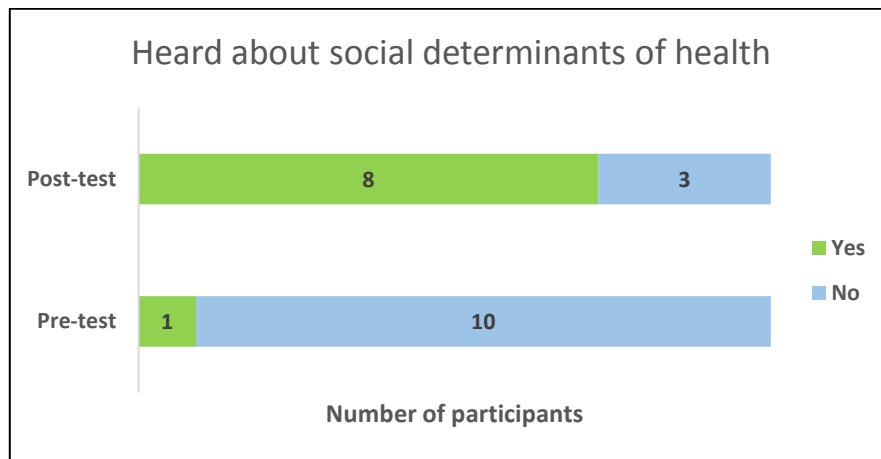


Figure 5-1A: Number of participants who had heard of social determinants pre and post training

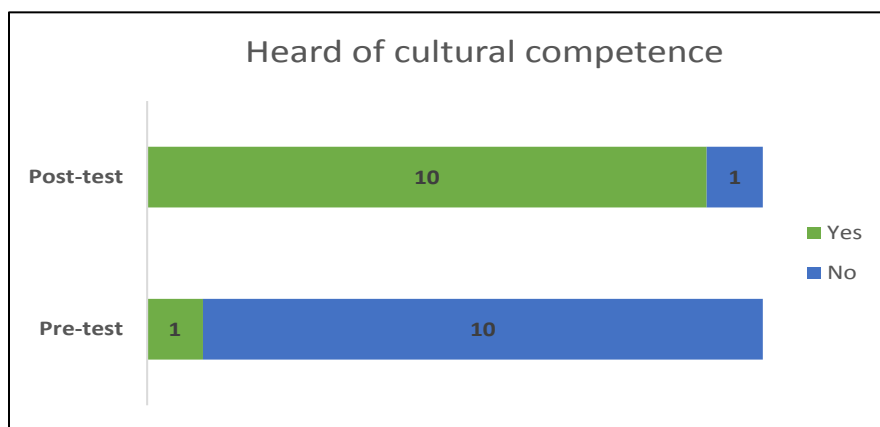


Figure 5-1B: Number of participants who had heard of cultural competence pre and post training

Attitudes to sociodemographic data collection. Participants harboured unfavourable attitudes toward sociodemographic data collection. In general, attitudes varied little from baseline training assessment. (Figure 5-2) Almost half of participants did not think it was necessary to screen patients for social circumstances. This remained stable although the number who felt that patients should be screened increased from three to five post training.

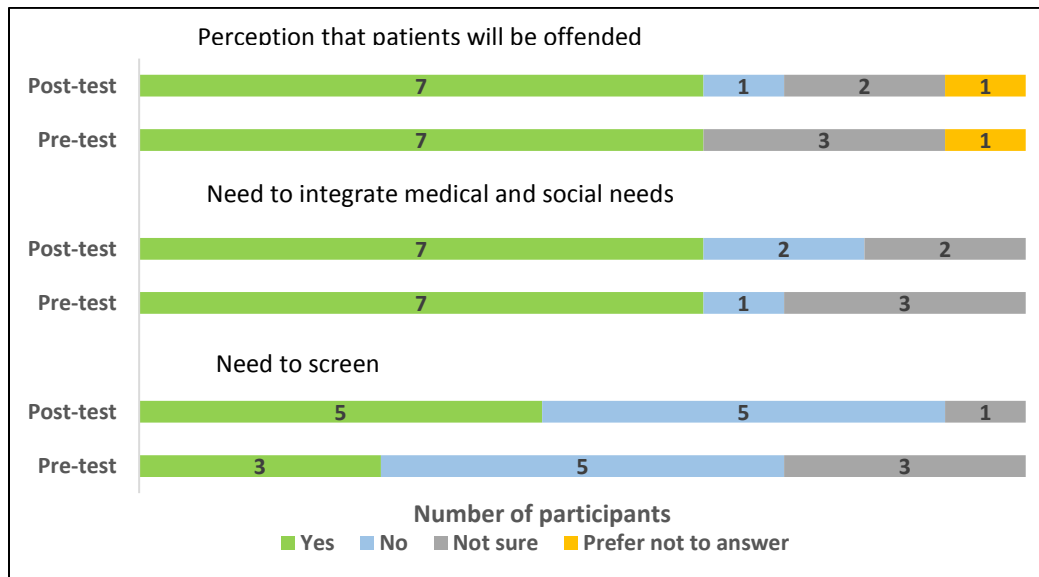


Figure 5-2: Attitudes to sociodemographic data collection

Most participants agreed that patient care and treatment plans should address both medical and social needs (n=7). There was little change of opinions on post training assessments. An equal number of participants either disagreed or were not sure about this statement.

Participants felt strongly that patients would be offended if asked about social circumstances during registration. This did not change in post training assessments.

Information was captured about perceived challenges faced by registration clerks in requesting patient sociodemographic data. Almost three quarters of participants expressed concern that it was outside their scope of practice to request information on social needs. This was compounded by fear of offending patients if they asked about social circumstances. Patient reluctance to disclose was also identified as a potential barrier to data collection. Just over a third

(36%) of participants reported that they lacked knowledge and skills about how to ask in a sensitive way. (Figure 5-3)

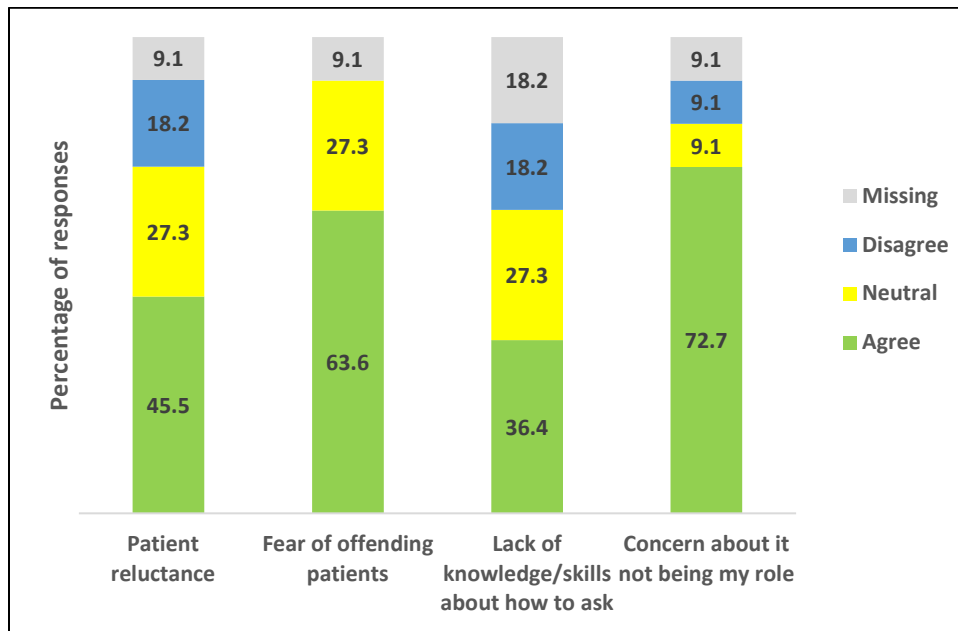


Figure 5-3: Challenges encountered by staff in sociodemographic data collection

Participants were asked about their level of comfort with asking about a wide range of social needs. (Figure 5-4) There was a low level of comfort with asking about any of the social determinants. There was little change between pre and post-training assessments. One participant selected prefer not to answer for almost all items. There was most comfort with asking about language needs, although an equal proportion of participants also felt uncomfortable. Information about religious affiliation is currently captured during registration as well as biological sex. The latter is obtained from the health card. Only 27.3% of participants were comfortable asking about religious affiliation at baseline. This was virtually unchanged in post training assessment. The pattern of responses was similar for asking about gender identity. In addition to the 27.3% who were comfortable, an additional 18.2% were neutral at baseline. Although 45.5% of participants were either neutral or comfortable with asking about disability, only 27.3% shared the same opinion on post-test assessments.

Although no participant was comfortable asking about ethnicity either at baseline or post training, 27.3% (n=3) reported being neutral post training. Most (63.6%, n=7) remained

uncomfortable asking about ethnicity. The vast majority expressed discomfort with asking about sexual orientation, income, educational needs, food and housing insecurity.

During the training sessions, participants expressed concerns about the proposed change to include an additional question related to self-identified Indigenous status. It was anticipated that patients would be reluctant to answer the question. Clerks shared a few of their experiences with patients who had been disgruntled with requests for routine information. While it was agreed that the majority of patients were cooperative, there still was apprehension.

One participant expressed her view that, 'it's just gonna slow me down'. She recounted departmental efforts to reduce patient time spent at registration. Her concern was motivated by lengthening of an optimized process and whether that would reflect negatively on her performance. She was reassured that the additional question was not expected to increase registration time drastically based on experiences in other provinces.

Another participant thought that asking about Indigenous identity would increase the burden on registration personnel and fuel conflicts with patients. She voiced her concern to the group stating, 'I feel this will put us in the line of fire'.

It was difficult to allay participants' fears about perceived patient reluctance to disclose sociodemographic data. The rationale for data collection was emphasized as well as the benefits from being linked to cultural support and navigation services. Despite these efforts, one participant admitted that she does not collect information about religious affiliation and was not inclined to support collection of ethnicity data as a matter of principle.

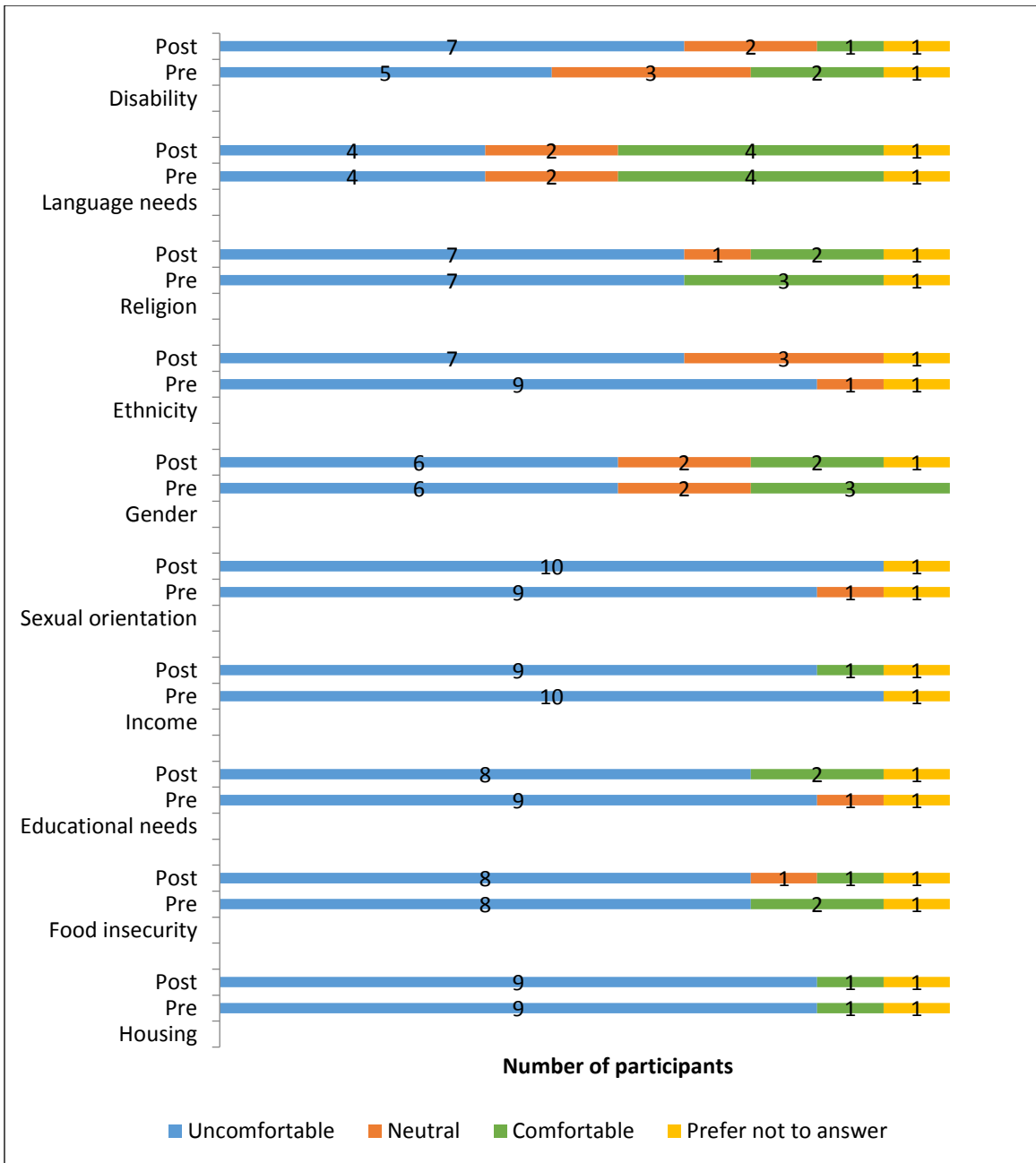


Figure 5-4: Staff attitudes to sociodemographic data collection

Training content. Just over half (54.5%) of participants expressed a neutral view about the relevance of the training topics. Only 27% either strongly or somewhat agreed that the content was relevant. Training time allocated was assessed as adequate by 63.6% (n=7) of participants while two (18%) participants thought that more time was needed.

Participants were asked about the components of the training that were most helpful. Responses varied but included an appreciation for the cultural awareness component, understanding the role of First Nations and Métis Health Service, history of First Nations peoples in Canada, rationale of the project and health equity concepts.

Participants provided several suggestions for improving future trainings and implementation. It was felt that support from the project coordinator would be needed during the initial phase of implementation. Another participant thought that the training example illustrated from Toronto was not relevant to the local context and she would have preferred a more specific example for the project. One participant felt that the training should have been longer and the information presented was too much to assimilate in the time allocated. Another participant felt strongly that the question was too narrow and that the project should also ask about other race/ethnicities. One participant felt that the balance of the training components should be adjusted. She wanted even more information about the project in order to feel comfortable with asking about indigenous identity.

Summary. Participants' knowledge of two key terms was limited at baseline but improved post training. Attitudes to sociodemographic data collection were unfavourable among participants. There was little change in participants' attitudes with training. Most participants expressed high levels of discomfort with asking about social needs. There seemed to be some receptiveness to asking about language needs however even those questions that were routinely captured such as religious affiliation and biological sex caused most participants to be uncomfortable. This was consistent with challenges encountered by clerks in performance of their duties. There seemed to be a mismatch in organizational expectations compared to those of participants. The majority of participants felt that information about social determinants was not necessary for their role. This suggested that participants perceived that enhanced data collection was outside of their scope of practice. Most participants also thought that patients would be offended if asked about social circumstances or would be reluctant to answer questions.

Participants did not indicate a greater need for capacity building to improve comfort with sociodemographic data collection.

Time allocated for training was limited which meant that the scope had to be focused to support implementation needs. The intensity of the training was likely inadequate to change deeply entrenched attitudes about sociodemographic data collection. It was noted that most participants were neutral about relevance of the training content while concurrently holding the view that the time allocated for training was adequate. This suggested ambivalence on the part of participants and potential for implementation challenges. In the future, training about social determinants and how to ask sociodemographic questions should be integrated into orientation for registration personnel. It might also be useful to expand competencies to include ability to ask and respond to patient requests for information.

5.3 Acceptability of sociodemographic data collection

Each site explored the feasibility and acceptability of collecting patient sociodemographic data within a specific context bounded by a particular service, client population and intended application of the information. Information was collected from multiple perspectives including patients/clients, providers, administrative staff and management to understand their perceptions and experiences with data collection. Analysis of missing data and distribution of item responses was one indicator of participant willingness to answer sociodemographic questions. Comparisons were only possible where sites collected data for similar questions. Table 5-2 shows the distribution of questions across project sites. The detailed results for all questions at each site are summarized in supplementary Tables F-1 and F-2 located in the Appendix F.

Table 5-2: Sociodemographic questions across project sites

<u>St Paul’s Hospital</u> (1 question)	<u>West Winds Primary Health Centre</u>	<u>Sexual Health Centre Saskatoon</u>
Indigenous identity	(6 questions) Need for interpreter Place of birth Indigenous identity Race/ethnicity Gender Housing	(11 questions) Language, need for interpreter Place of birth Immigration status Indigenous identity Race/ethnicity Disability Gender Sexual orientation Food security Housing Annual household income

5.3.1 West Winds Health Centre and Sexual Health Centre (Common questions)

A subset of five questions were common to the West Winds Primary Health Centre and the Sexual Health Centre Saskatoon including need for interpreter, place of birth (and year of arrival in Canada), Indigenous identity, race/ethnicity, gender and housing circumstances. At West Winds Primary Health Centre, information was only available to track participation at booked clinics. Among those approached by study personnel, 79% completed the survey. The majority of participants were female caregivers attending with their children (73% and 81.4% respectively). At Sexual Health Centre Saskatoon, only 59.4% of those who visited during the study period completed the sociodemographic questionnaire. The majority of participants were also female (76.9%). Participant responses across the two sites are displayed in Figure 5-5. Variations in patterns of response by sociodemographic characteristics are examined in following sections. In the figures, the designation ‘other’ refers to selection of a valid response option besides ‘prefer not to answer’, ‘do not know’.

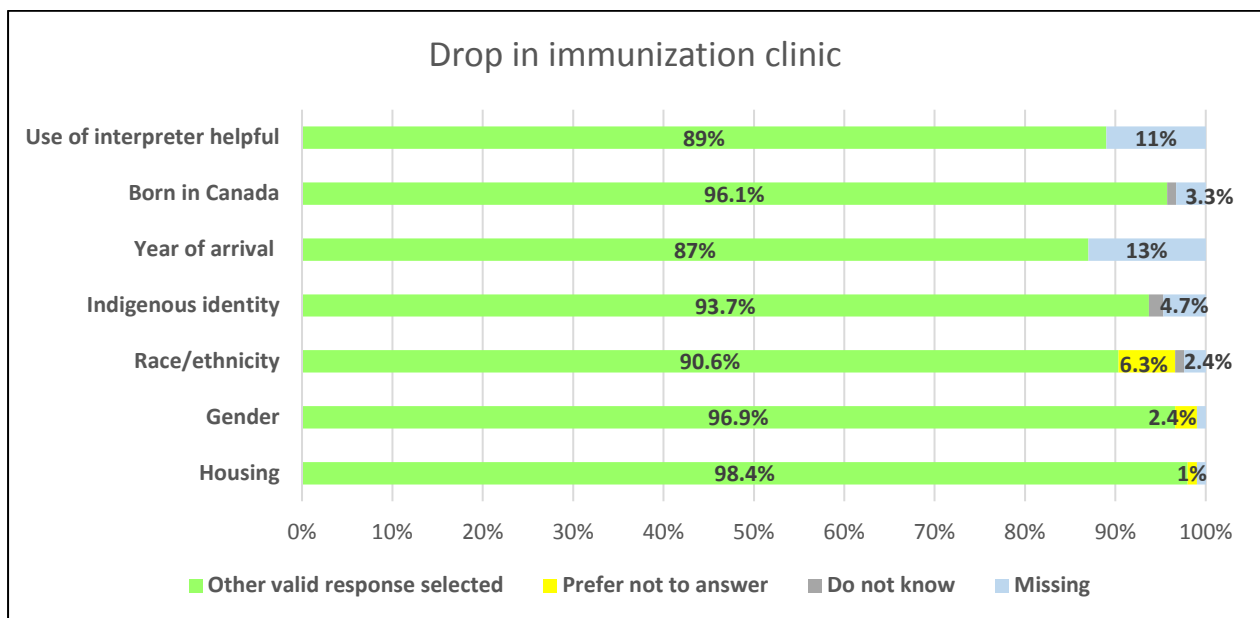


Fig 5-5(A): Distribution of participant responses to sociodemographic questions

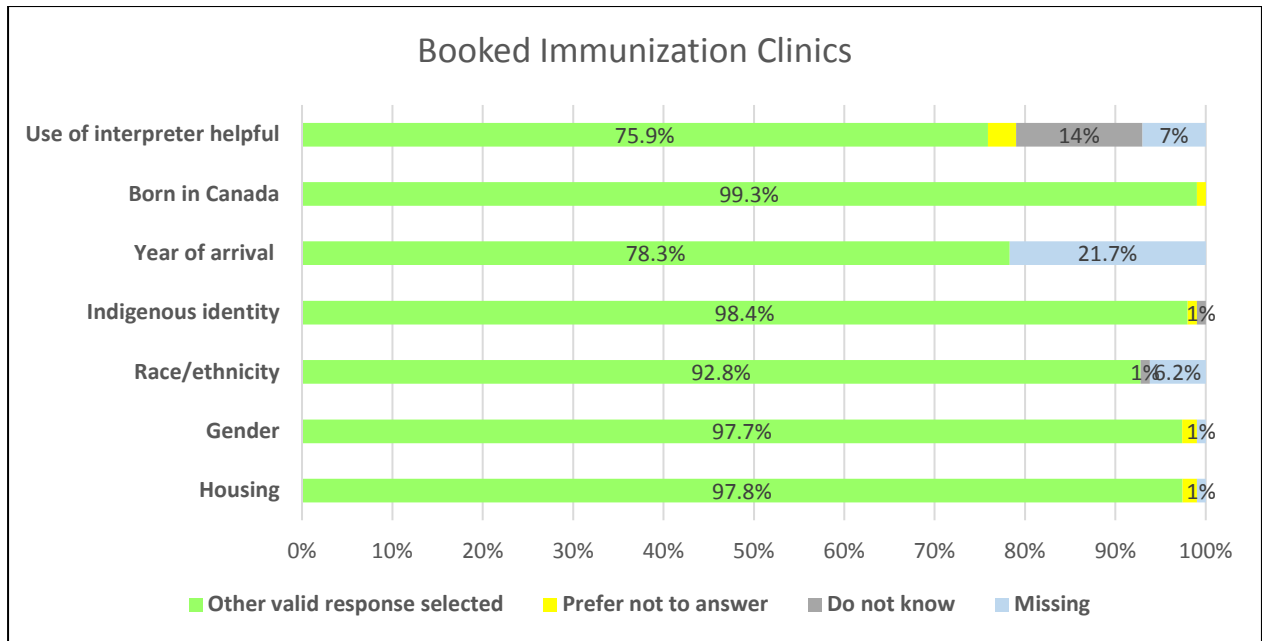


Figure 5-5(B): Distribution of participant responses to sociodemographic questions

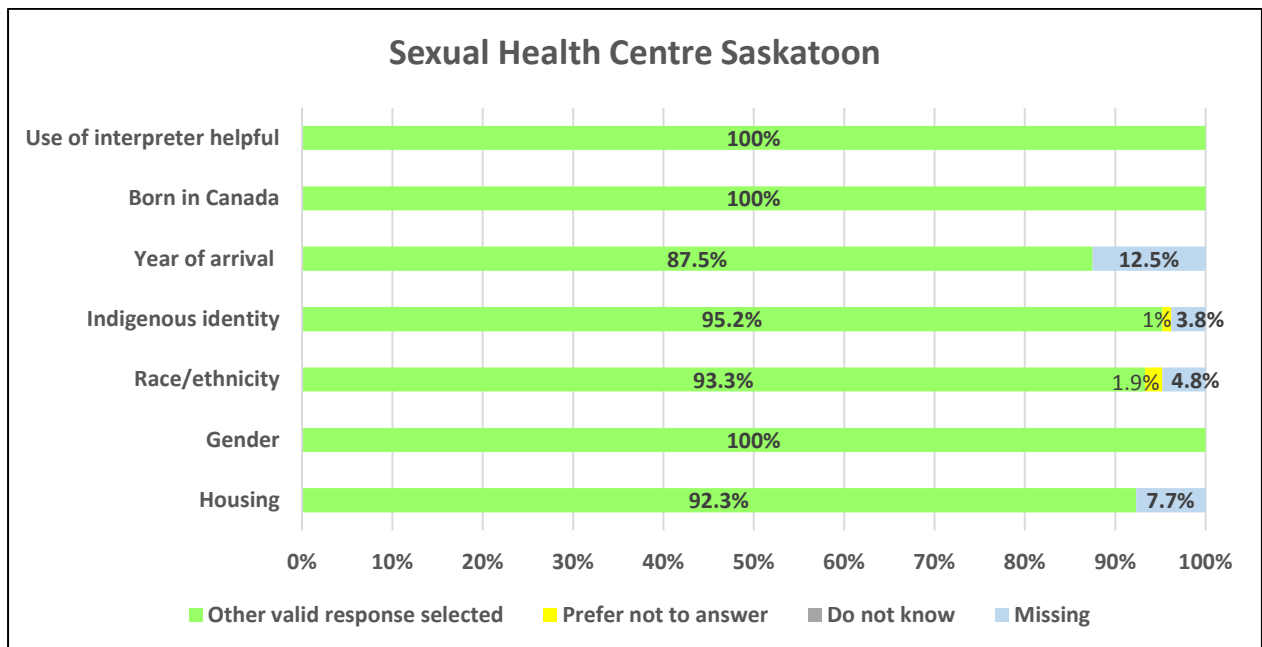


Figure 5-5 (C): Distribution of participant responses to sociodemographic questions

Whether an interpreter would be helpful. As previously explained, two iterations of the modified question pertaining to need for an interpreter performed poorly among booked and drop-in participants. There were high rates of missing responses and even with an expanded response set, 14% of booked participants ‘did not know’ whether an interpreter would be helpful for them. Further analysis revealed that it was more problematic for participants who had been born in Canada and self-identified as White or Indigenous. (Figure 5-6)

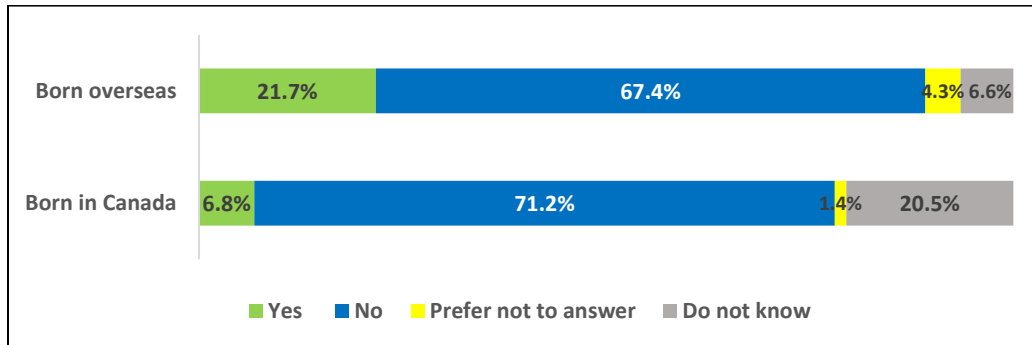


Figure 5-6: Percentage of booked participants who would find an interpreter helpful disaggregated by place of birth

The standard question was included in the questionnaire at the Sexual Health Centre. There were no missing responses to this question. No one selected the response options ‘prefer not to answer’ or ‘do not know’. This may suggest that the standard version had more clarity and conveyed the intent better. The majority of participants in this site were Canadian-born (84.6%) and 57% self-identified as White. This group had similar characteristics to the subset of the population who had difficulty with the question at drop-in clinics. Additional information was also collected about their English language ability and preferred language of communication. This further strengthens the assertion that the question was easier to understand particularly for those who probably had no language barriers.

Place of birth (year of arrival). The nativity question returned low rates of missing responses across sites where it was asked. Among booked clients, all participants (n=7) who had missing data for this question also had missing responses for all other questions except gender. This was likely the result of missing the second page of the questionnaire where the majority of sociodemographic questions were located. These participants were excluded from the analysis.

In contrast, the follow up question related to year of arrival in Canada had high rates of missing data across both sites (12.5% – 21.7%). This question was open-ended and required the participant to state the year when they arrived in Canada. The purpose of the question was to identify participants who had arrived less than 5 years ago (newcomers). New immigrants may be vulnerable as they adjust to living conditions in another country. The exact reasons for the observed pattern of responses to this question were not clear. They may relate to perceptions that the information is not relevant to care or poor recall of the exact year. It might be helpful to examine whether the expansion of response options to include ‘prefer not to answer’ and ‘do not know’ for this question improve responses. Another option would be to ask directly whether participants had arrived in the past 5 years.

Indigenous identity. This question was captured by all sites however each site had a different phrasing. Response options were only similar for the community health centres. The chronology of changes to the format of the questions is important and will be emphasized. Across the two community sites, there were relatively low rates of missing responses. Generally $\leq 1\%$ of participants either ‘preferred not to answer’ or ‘did not know’.

In the first iteration among drop-in clients, the question asked whether the participant had an ‘Aboriginal background’. This question was asked before race/ethnicity and it was not linked to the latter by a skip pattern. The second part of the question then required the participant to specify a particular identity. It was plausible that participants interpreted that the question was asking about ancestry however most went on to specify either First Nations or Métis. Among the 23 participants who self-identified as Indigenous, ten subsequently selected White North American as their race/ethnicity. Six selected ‘other’ and identified as either Aboriginal/First Nations/Métis while five preferred not to answer. Two selected South Asian. This pattern may be partly explained by differences between the participant’s ancestry and social identity.

In the second iteration among booked clients, the question inquired about self-identity as an Aboriginal/Indigenous person and was now signposted through a skip pattern to the following question about race/ethnicity. It is noteworthy that the word ‘Indigenous’ was included in the phrasing as there was now dialogue about the appropriate/preferred terminology for the question. This was also the preferred term for the questionnaire at the Sexual Health Centre. The linkage of the Indigenous identity and race/ethnicity questions improved the performance of question. It was

intended that participants who self-identified as Indigenous would skip the race/ethnicity question. This result was observed in responses from the booked survey and Sexual Health Centre.

Race/ethnicity. The race/ethnicity question included compounded elements of racial origin as well as global geographic regions. While race and ethnicity are two different constructs, this classification had practical value for coding responses and had been used previously in the Canadian context.(47) This question had low rates of missing responses except for participants at booked immunization clinics. Among the booked participants with missing data (n=8), almost all had been born in Canada, none self-identified as Indigenous and almost all reported that they were homeowners. Based on this information, it seemed likely that the pattern of missing responses was not random. The potential for lower acceptability for asking about race/ethnicity in this subpopulation cannot be excluded.

Among drop-in participants, 6.3% (n=8) preferred not to respond however five of these participants self-identified as Indigenous on the previous Indigenous identity question. The remaining three participants were foreign-born and two indicated that an interpreter would be helpful. The concordance of responses may suggest that participants who self-identified as Indigenous did not see a response option that represented their distinct identity in the race/ethnicity question. As previously explained, the intention was to capture Indigenous and non-Indigenous identities separately.

When the question was asked at the Sexual Health Centre, there were five participants who had a missing response. Similar to participants at booked immunization clinics, they were Canadian-born females but there was also no information about Indigenous identity. Four of the participants had information about educational attainment (3 had post-secondary education and 1 less than high school). The two participants who preferred not to answer this question had also been born in Canada (1 male, non-Indigenous and 1 female). While the numbers are small, the pattern needs to be explored. Interviews with clients at the centre hinted at the potential for lower acceptability particularly if there was no further consideration of why the information was requested. One participant explained her reactions to the question,

A little surprised yeah when it said my ethnicity like I wonder why they would need that and made me stop and think for a second. That kind of makes sense

from a health perspective. If there are health concerns that might be related to a specific ethnicity then I would want my doctor to know that so they would be able to look out for that for me. Other than that it was a brief second ‘well oh that’s weird and then ok’. (SHC_P10)

Gender. There were high item response rates to the question that asked about gender identity. Less than 1% of participants had a missing response. Few (n=5) participants preferred not to answer. No participant self-identified as transgender. Among participants who preferred not to answer, four were immigrants who identified their race/ethnic origin as Asian. The majority of participants self-identified as female across both sites. This is probably related to social roles of women and the nature of the services (immunization and sexual and reproductive health) that were being accessed. Caution should be exercised in extrapolating the results to male participants.

In some instances, it was observed that two parents/care givers and children presented for clinic. It is assumed that the responses describe the participant who completed the questionnaire on behalf of family members. Figure 5-7 shows that a greater proportion of foreign-born participants were male compared to Canadian-born participants across both immunization clinic surveys. It is possible that foreign-born males who accompanied their partners/spouses were more likely to complete the questionnaire on behalf of the family. Unfortunately, no information was captured about the number of couples who attended the clinic and the extent to which this occurred cannot be verified. Also we do not know whether English language proficiency determined who completed the questionnaire.

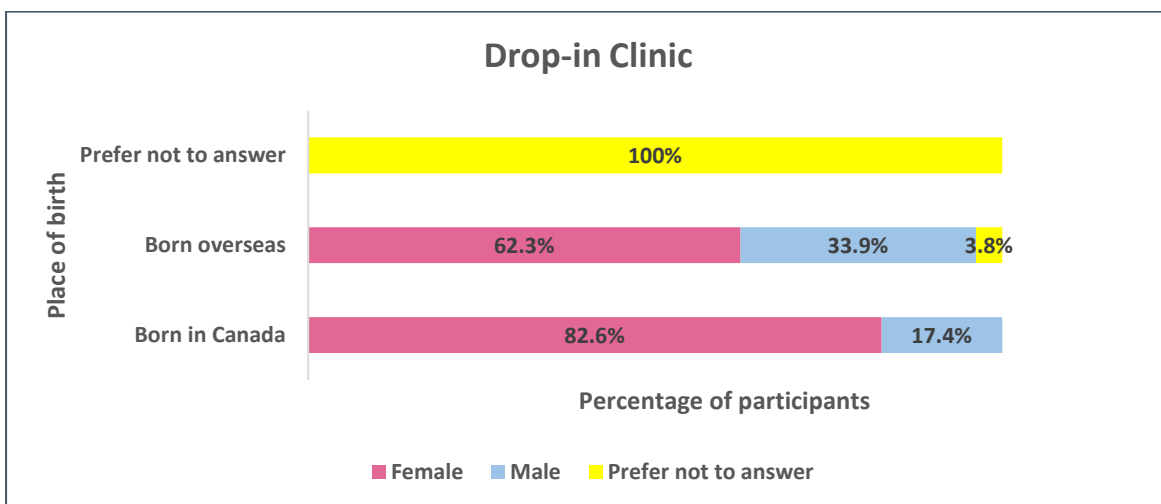


Figure 5-7 A: Participants’ place of birth disaggregated by gender identity (Drop in)

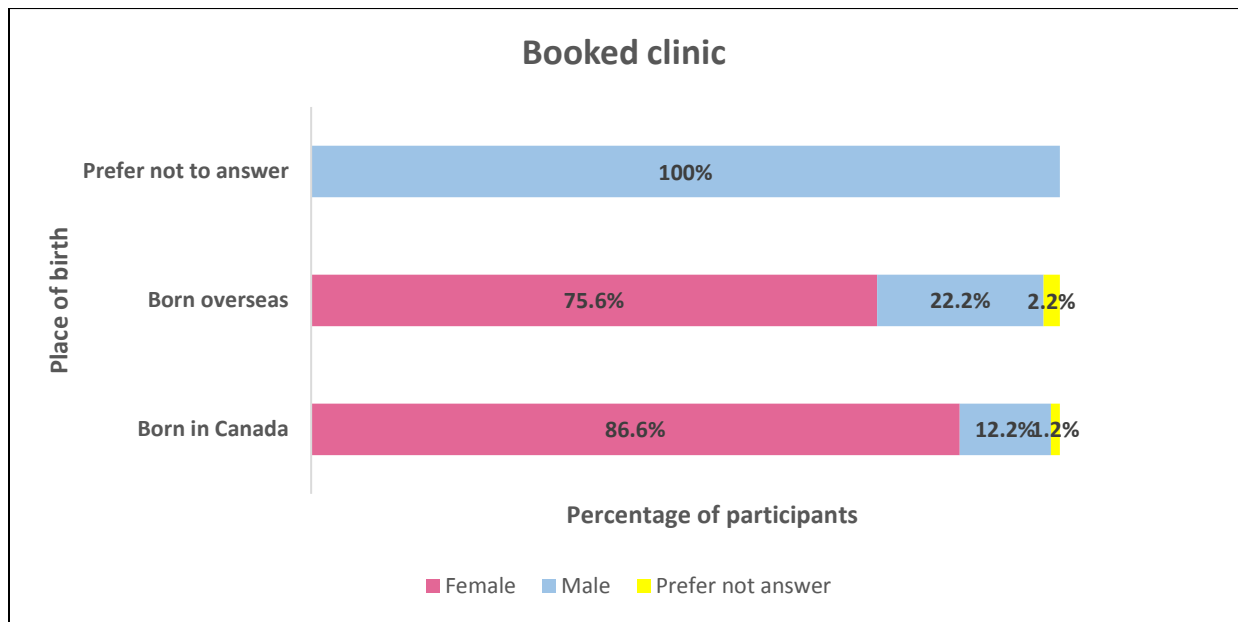


Figure 5-7(B): Participants’ place of birth disaggregated by gender identity (Booked immunization clinics)

A different pattern was found among participants at the Sexual Health Centre where foreign-born male participants were relatively few (2/16) compared to those who were born in Canada (22/88). This suggested that the service context influenced the gender distribution of the responses but could not be explored further with the available data.

Housing security. The housing question had variable non-response rates across the two sites. The lowest rate of missing responses occurred among drop-in participants (<1%). Less than 2% of participants across sites selected ‘prefer not to answer’. This suggests that there was little sensitivity among those who responded to the question.

The participant housing profiles were different across project sites. Almost two thirds of booked participants owned their home (65.9%) compared with 52.7% of drop-in participants. The majority of participants at the Sexual Health Centre were residing in rented accommodations (60.5%). No participant reported being homeless at any of the sites. A higher percentage of participants at the Sexual Health Centre were staying with family/friends (20%) compared with immunization clinic participants (4%). At immunization clinics only, a small percentage of participants reported living in supportive housing (1%).

5.3.2 Sexual Health Centre Saskatoon

The following sections describe the response rates for questions that were *only* included at the Sexual Health Centre Saskatoon. This subset of questions included English language ability and preferred language of communication with provider, immigration status, disability, intersex condition, preferred pronoun, sexual orientation, education, food security and annual household income.

The study sample (N=104) had a median age of 25 years (range 18 – 59 years). The majority (89.4%) of participants were between the ages of 18 and 35 years. This is consistent with the profile of the general clinic population. Although ineligible for the study, clients as young as 13 years were seen at the centre during the study period. The overall participation rate was 59.4%. This likely reflects inconsistent recruitment particularly by volunteer reception personnel. The preponderance of youth accessing these services is consistent with national surveillance estimates that report the highest rates of sexually transmitted infections among young Canadians. (192)

Language. All participants responded to the question related to self-reported English Language proficiency. All participants spoke English either ‘very well’ or ‘well’. However participants who had been born overseas were less likely to rate their ability as ‘very well’ (75%) compared to those who were born in Canada (99%) ($p=0.02$, Fisher’s Exact test). These results were consistent with the majority (97.1%) of participants also expressing a preference to communicate with their provider in English. No participant felt that they needed an interpreter during their consultation.

Immigration status. There was also a high response rate to this question. No participant selected ‘prefer not to answer’ or ‘do not know’. The majority of participants (84.6%) were born in Canada and 90.4% identified their legal immigration status as Canadian citizens. Only 4.8% of respondents were permanent residents while 2% had a work permit or were visiting and 1% were international students.

It is important to note that participants at this site were not as linguistically diverse as those at drop-in clinics. No participant reported needing an interpreter compared to 21% of drop-in

clients and 11% of booked participants. These differences in the participant profile make it difficult to anticipate whether the response would be similar in more diverse populations.

Disability. There was a high response rate to the question related to presence of disabilities. Only 4.8% (n=5) of responses were missing and 1% of respondents ‘did not know’ or ‘preferred not to answer’. Seventeen percent of respondents reported having a disability. The most common disability reported was mental illness (7.6%) followed by chronic illness (3.9%) and physical impairment (1.9%). More females than males reported having a disability (18.8% vs. 12.5%).

Intersex condition (and preferred pronoun). Although there was a high response rate to the question related to gender identity, there was a small percentage (2.9%) of participants who preferred not to disclose whether they had ever been diagnosed with an intersex condition. One participant ‘did not know’ and three did not respond. It was anticipated that some persons would be unfamiliar with this more technical term and this was confirmed during participant interviews. One participant noted, ‘there was one question [intersex] I wasn’t entirely sure about. I guess I don’t have it so I didn’t know’ (SHC_P23). It was included because of its clinical significance and it was thought that persons with the diagnosis would be able respond appropriately.

Similarly, there were a small number of participants (3.8%) who did not understand the meaning of the word ‘pronoun’. One participant stated that, ‘the only one that I had trouble with was the pronoun that I use’ (SHC_P5). This might also have influenced their response to the question. One participant who self-identified as female reported the preferred pronoun ‘he’. Another participant who self-identified as male also selected ‘they’ as their preferred pronoun.

Sexual orientation. There was a higher rate of missing responses (5.8%) for the question related to sexual orientation when compared to gender identity. Four percent (3.8%) of respondents selected ‘prefer not to answer’. More females than males either preferred not to answer (3/4) or did not respond (5/6). One female respondent selected ‘did not know’ and another described her identity as ‘questioning’. The majority of participants (64%) described their sexual identity as heterosexual while 11.5% were bisexual, 5.8% were gay and 3.8% were pansexual. A greater percentage of participants who identified as either bisexual (11/12) or pansexual (4/4) also identified as female. One participant described her sexual identity as queer while another selected

two-spirit. Among the subset of participants who self-identified as sexual minorities, there were no participants who were also racial/ethnic minorities.

During client interviews, it was suggested that discomfort with disclosure of their sexual orientation may be related to uncertainty about sexual identity. A client shared her views about the issue.

Definitely probably the sexual orientation question especially if people are not sure themselves. Whether it is that they are dealing with their own issues or their expectations of others probably or something like that. (SHC_P7)

Another participant speculated that social norms surrounding discussion of particular topics such as sexual identity might also explain participant discomfort with sharing this information. A client participant provided the following explanation,

I am assuming sexual orientation or if someone was diagnosed with an intersex condition, they may feel a little bit uncomfortable as I know these subjects tend to be a bit more touchy or taboo in our society. (SHC_P5)

However, it was also suggested by both patients and providers that sexual orientation may be perceived to have low clinical relevance. One client expressed strong views about this,

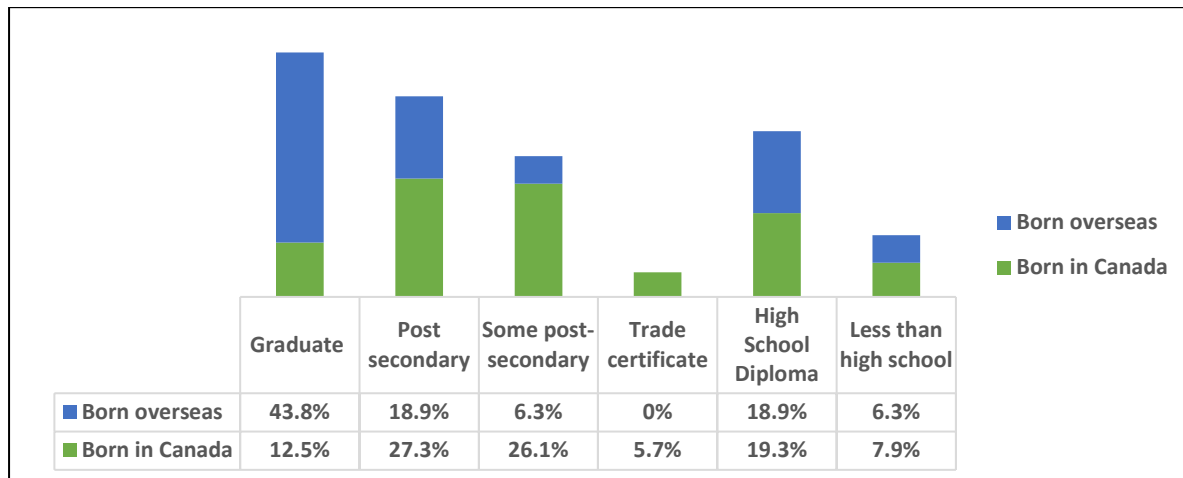
The only one that I was kind of questioning was the one question about who do you like, are you bi [bisexual] or straight. I thought that one was a little personal like why did they need to know that. That is kind of my thing. Only I need to know that. (SHC_P16)

A provider/manager expressed her views that information about sexual identity was not essential for delivery of immunization services. Hence, there was little inclination to advocate for inclusion in the survey. She indicated,

Yeah that [sexual orientation] doesn't affect how we provide service to that client so I didn't feel it was necessary. If it was strictly about social determinants of health it would have been relevant. For our services, it really isn't relevant. It doesn't matter what their sexual orientation is because we are going to provide them the same care regardless. (KI_WPC)

Education. There was a very low non-response rate (1.9%) to the question that pertained to the highest level of education completed. No participants selected 'prefer not answer'. Just over a quarter (25.9%) of participants had completed post-secondary education while slightly fewer (23.1%) participants had not completed their post-secondary studies. Nineteen percent of respondents had only completed high school while 17.3% had a graduate or professional

qualification. There were significant differences ($p=0.041$) between the pattern of educational achievement according to place of birth. Participants who were foreign-born were more likely to have completed graduate training compared to their Canadian born counterparts (43.8% vs. 12.5%) and no immigrants in the study reported trade certification. See Figure 5-8 below.



(*NB 1 participant from both groups had a missing response so percentage does not add up to 100%)

Figure 5-8: Bar chart showing educational attainment by place of birth

Food security. There were two questions pertaining to food security or access. The first question inquired whether the respondent worried about their food supply and the second assessed the frequency with which food shortage occurred in the previous month. Eight percent of respondents had a missing response to both questions. Only one participant preferred not to answer. Most participants (69.2%) never worried about their food supply while 13.5% rarely were concerned and 7.7% were sometimes concerned. An even higher percentage had never experienced food shortage (82.7%). A small percentage of participants had experienced food shortage ‘rarely’ or ‘sometimes’ during the previous month. Two participants who indicated worrying about their food supply also ‘sometimes’ experienced actual shortage in the prior month.

It was suggested by a few participants that there was sensitivity to being asked about food security. This seemed to originate from concerns about relevance to care. However other participants expressed support for data collection and perceived that persons identified could be linked to needed supports. This participant explained, ‘you would want to know if people don’t have food. Like it would be good to get a program for people like that’ (SHC_P6).

Annual household income. Just over 10% of respondents had a missing response for their annual household income. Another 13.5% of participants did not know their household income and 8.7% preferred not to respond. Eight participants had missing responses for the cluster of questions pertaining to housing, food security and income. It was noted that these questions were on the last page of the questionnaire hence the risk of not being completed was higher than preceding questions.

Almost a quarter (20.5%) of participants who responded had an annual household income of less than \$20,000 while 7.7% had earnings of at least \$100,000. Over a third (39.4%) of participants lived in single person households while the maximum household size was five. The annual household income is interpreted in the context of the number of persons that it supports. Information was only available for 61 participants. Using the low income cut offs (LICO) thresholds, 23 (38%) participants could be classified as having income below cut offs for family size. All participants who had an annual income below LICO thresholds were either renting or staying with friends/family. All participants who had experienced food shortage either rarely or sometimes also had annual household incomes below LICO thresholds.

Participant interviews confirmed that there was reluctance to disclose annual household income. One client explained, 'I don't see why a place like this would need to know my annual income. I can understand the food part but not my income' (SHC_P14).

Additionally, even if clients were inclined to disclose they did not necessarily know the income of other members of the household. This is one of the limitations of directly requesting family household income. A client noted,

No I felt ok answering all of them but I couldn't answer it because I didn't know the answer to family income. Even if I did know it, I just prefer not to answer my specific family income. I feel that's kind of private. (SHC_P22)

It was suggested by one participant that a better approach might be to ask about the adequacy of the income to meet basic needs. More detailed questioning could then follow to determine how best to intervene. She stated,

On socioeconomic questions, you know I don't know so much as monetary as it puts people on the spot. I didn't get the tax return question. Off the top of my head questions like that but whether your income is a comfortable income for you, whether you feel that you are meeting your medical needs to its best on

this income, can you afford like the medicine that you need (the prescriptions that you need, the birth control that you need). Do you feel living in a certain area of town where you don't have access to public transit or you don't have access to these sort of things? Do you feel that you are getting the kind of medical access that you need? And like what else would you ask? I think like with terms of housing, people can tell that in their own way. I think that it is more like do you feel you have the access that you need and if you do not feel like you are not being accommodated why. That could bring an array of answers maybe that people didn't think about. If you do not feel that your needs are being met then why and that could open a whole new door. (SHC_P7)

5.3.3 St Paul's Hospital – Indigenous identity

The results for the Indigenous identity question at St Paul's Hospital are discussed separately in this section. This is appropriate because the context in which the question was asked was different. A single (isolated) question may be perceived differently than when presented alongside other sociodemographic questions. The response options were also different so it was difficult to determine when participants preferred not to answer the question. The rationale for the decisions about the response options has already been explained.

De-identified data for patients who were registered at St Paul's Hospital was abstracted for the period July 18th to December 9th 2016. All patients were counted once even if there were multiple visits during the period. Data was obtained for all patient visitors combined as well as those visitors to the Emergency Department. The analysis is restricted to patients who were at least 18 years of age. Only patient sex (derived from the health card) and age were included in addition to response recorded in Enovation to the Indigenous identity question.

The descriptive characteristics of the sample are shown in Figure 5-9. A total of 25,559 patients were registered during the study period and 23,567 were 18 years or older. Among those patients who were at least 18 years, 7,874 were seen in the Emergency Department (ED). Almost equal proportions of males and females were registered during the study period. Thirty one percent of patients were not asked about their identity in the ED compared to 28.4% of all visits combined. Further, a higher percentage of patients self-identified as First Nations or Métis in the ED compared to all types of visits (23% vs 13.8%).

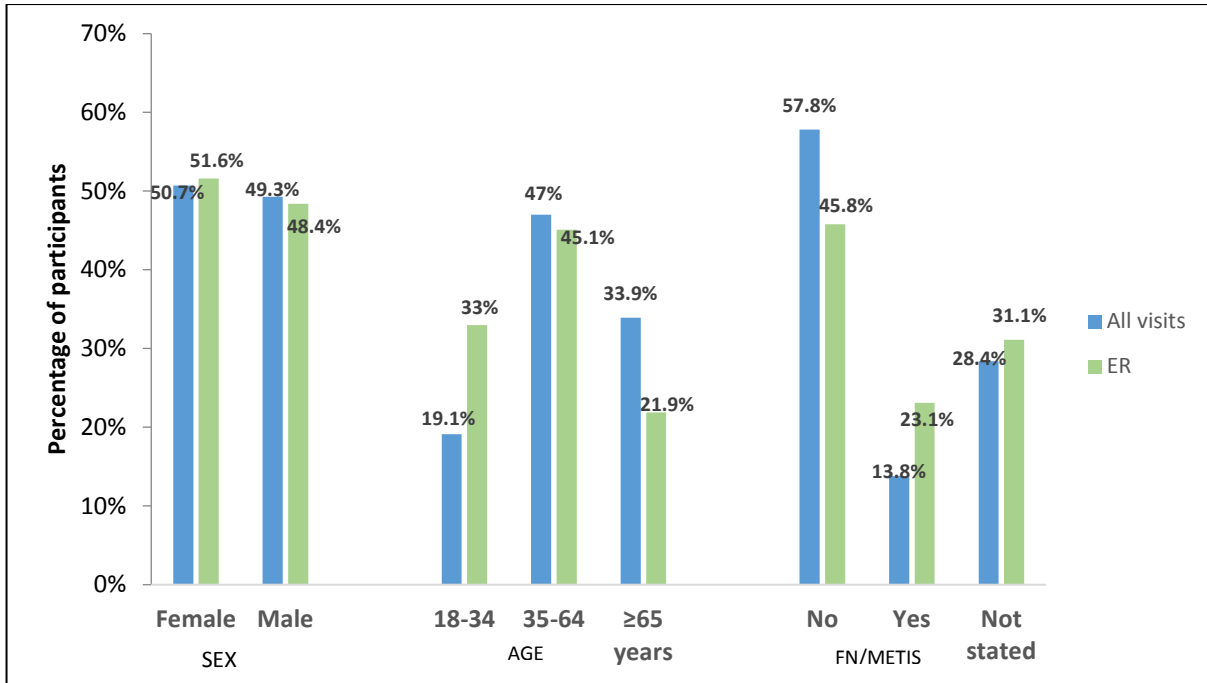


Figure 5-9: Characteristics of registered patients at St Paul's Hospital

There was an association between Indigenous identity and patient sex and age that was observed across all combined visits as well as ED visits. Participants who self-identified as First Nations or Métis were younger and a greater percentage were female. (Figures 5-10, 5-11) This is consistent with population projections for the region and province. (193,194)

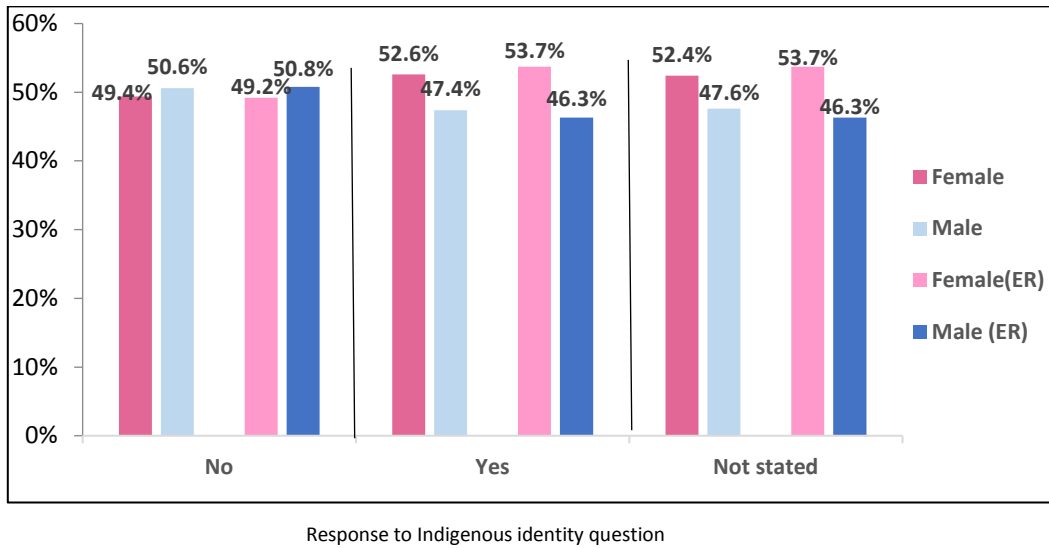


Figure 5-10: Percentage of responses for Indigenous identity disaggregated by patient sex

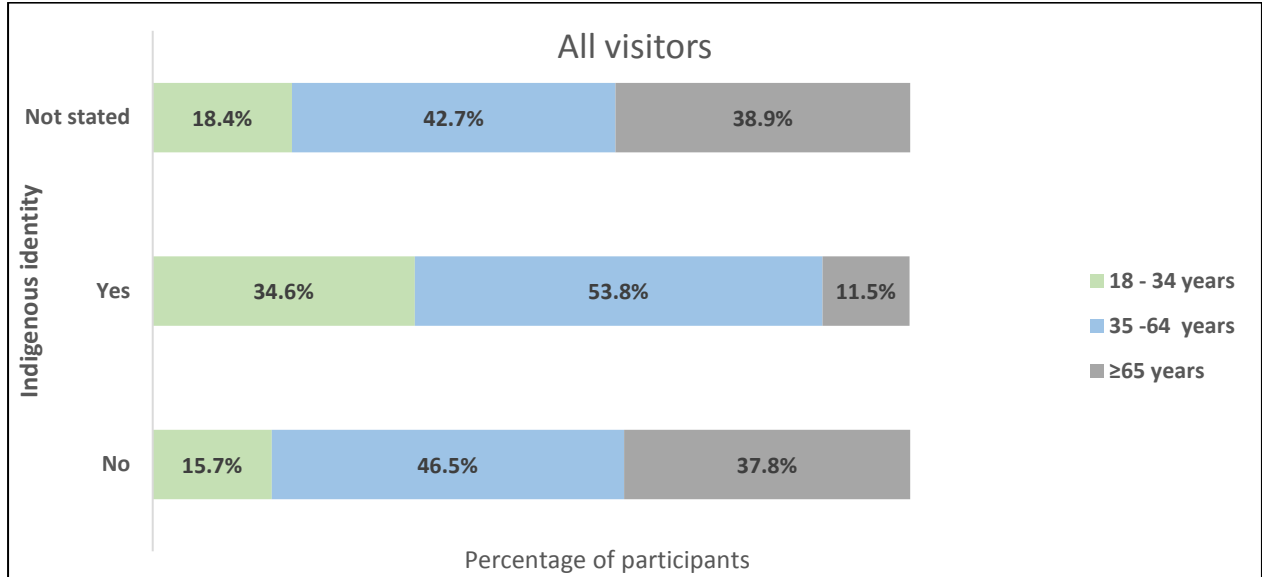


Figure 5-11A: Bar chart showing responses for Indigenous identity disaggregated by age group (All visitors)

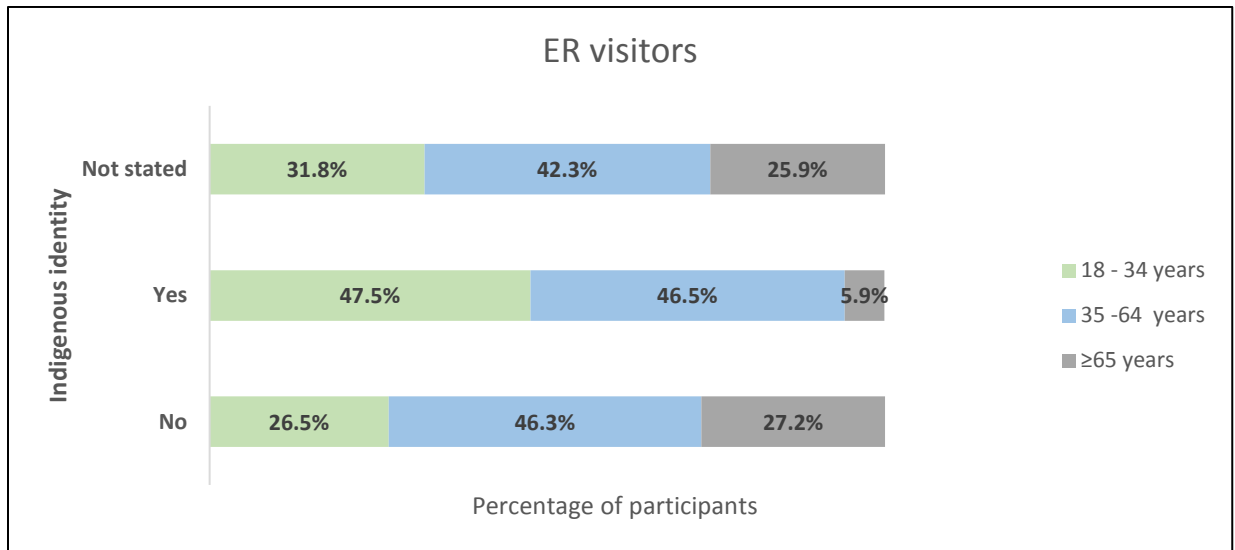


Figure 5-11B: Bar chart showing responses for Indigenous identity disaggregated by age group (ER visitors)

A multivariable logistic regression model was fitted with ‘response=yes’ as the dependent variable and age group and sex as independent variables. Patient’s sex was not associated with responding ‘yes’ to the Indigenous identity question ($p=0.490$, $OR=1.03$ 95% CI 0.95 – 1.11) in these adjusted analyses. However, younger patients were more likely to identify as First Nations or Métis than elderly patients (≥ 65 years). Patients who were 18 – 34 years had 6.1 times greater odds (95% CI 5.4 – 6.8) of identifying as First Nations or Métis compared to those who were elderly (≥ 65 years). Similarly, participants who were 35 – 64 years also had greater odds of responding ‘yes’ than elderly participants ($OR\ 3.3$, 95% CI 2.9 – 3.7). (Table F-3) From the available information, non-Indigenous participants were more likely to be older. It is plausible that clerks were less likely to ask persons who they perceived were non-Indigenous. The author was unable to confirm whether this practice occurred despite several attempts to investigate this result.

There were limited opportunities to explore the reasons why patients were not asked about their identity. Those who were not asked (“not stated”) were more similar in sociodemographic characteristics to those who did not identify as First Nations or Métis. It was suggested by key informants that patients who were too ill or distressed may not be asked. Information about the severity of illness was unavailable to examine this hypothesis. The author observed that unaccompanied patient transfers by ambulance were registered by attendants hence there was no direct patient interaction with the clerk. It is unlikely that this group of patients accounted for the large number of blank/not stated fields. It is more plausible that clerks exercised more subjective judgments about whether to ask patients about their identity based on a combination of factors including patient volume, comfort with asking and observable characteristics.

5.3.4 Participant perceptions of sociodemographic data collection

The pattern of responses to sociodemographic questions provided limited information about the acceptability of data collection. It was necessary to explore the underlying reasons for the responses during interviews. The perceptions of other actors such as providers and management were also needed for a comprehensive understanding of acceptability from multiple perspectives. The following section presents an integrated narrative that compares participant perceptions across sites with respect to perceived importance of sociodemographic data

collection, appropriate target audience to screen for social risks and preferred mode of administration of questions.

Interviews were the main source of information about participant perceptions and experiences with sociodemographic data collection. Demographic characteristics of interview participants are summarized in Table 5-3. The number of participants varied across sites and was largest for the hospital site. Most participants were outpatients at the time of the interview except for those interviews with inpatients who identified as First Nations or Métis. Across all sites the majority of participants were White North American/Caucasian except at booked immunization clinics. A higher percentage of interview participants self-identified as First Nations or Métis at St Paul’s Hospital than the other two project sites. The majority of participants were female except at St Paul’s Hospital where the proportion of males and females was almost equal. As anticipated, age distribution of participants was different with younger persons at the Sexual Health Clinic and immunization clinics.

Table 5-3: Descriptive characteristics of interview participants across sites

Characteristic	Booked immunization clinic N=17 (%)	Sexual Health Centre N=25 (%)	St Paul’s Hospital Outpatients	St Paul’s Hospital Inpatients
			N=222 (%)	N=37 (%)
Gender				
Female	12 (71)	19 (76)	113 (50.9)	21 (56.8)
Male	5 (29)	6 (24)	109 (49.1)	16 (43.2)
Age (years)				
18 – 34	15 (88.2)	17 (68)	29 (13.1)	4 (10.8)
35 – 64	2 (11.8)	2 (8)	124 (55.9)	28 (75.7)
≥65	0	0	65 (29.3)	5 (13.5)
Missing	0	6 (24)	3 (1.4)	
Race/Ethnicity				
Caucasian	7 (41.2)	23 (92)	192 (86.5)	37 (100)
FN/Métis	1 (5.9)	1 (4)	23 (10.4)	
Asian	7 (41.2)	0	4 (1.8)	
African	2 (11.8)	1 (4)	2 (0.9)	
Hispanic	0	0	1 (0.5)	

Level of comfort. During interviews, only the participants at the Sexual Health Centre and St Paul’s Hospital were asked about their level of comfort with the collection of sociodemographic information. Most participants felt comfortable but were often surprised that the information was requested during their medical encounter. One participant said, ‘I was surprised that they asked but I wasn’t offended’ (STP_P55). Participant perceptions of comfort

were best appreciated in context. At St Paul's Hospital, although Indigenous and non-Indigenous participants were comfortable with providing the information, the underlying reasons given were different.

Non-Indigenous participants perceived that the question had less relevance for them. A participant noted, 'It didn't bother me because I am not First Nations' (STP_P1). Among some participants who self-identified as First Nations or Métis, their identity was an embodiment of self and source of cultural pride. For example, one participant shared her views, 'I was very comfortable because I am secure in my identity. If it bothered me I would have told them' (STPI_5).

There were also assumptions by some participants that the question was asked in order to appropriate benefits (Non-insured Health Benefits). An Indigenous participant noted, 'I was ok with it. I thought they asked because of the treaty benefits for our people' (STPI_7).

Those persons who expressed discomfort perceived that it was inappropriate to ask and unnecessary for the delivery of care. This was consistent with limited appreciation of the importance of asking about Indigenous identity. One participant explained, 'I don't think that they should ask because that is not important' (STP_P107). Another Indigenous participant shared his concern about being asked about his identity. 'I was kind of uncomfortable because I didn't know whether it was appropriate and if they needed the information for my care. I wanted to be respectful so I answered' (STPI_P2).

While participants at the Sexual Health Centre were also comfortable with data collection, this varied depending on the specific question. This has been discussed previously with regard to income, sexual orientation and race/ethnicity. In contrast to outpatient participants at St Paul's Hospital, there seemed to be greater appreciation of the importance of sociodemographic data collection and this will be discussed further in the next section. A participant shared his perspective on the issue.

It didn't bother me at all because I understand that it is necessary for them to have that information to help you in general. It is not there to be intrusive but to help everybody. Honestly, I was quite pleased because it was very gender friendly for LBGTT people. I had no problem with it and I thought it was good and quite important (SHC_P25).

However participants who were uncomfortable also felt that it was either inappropriate to ask or deemed it unrelated to the care that was provided. As one participant noted, ‘I don’t think that it is appropriate to ask’ (SHC_P14).

Perceived importance of sociodemographic data collection. Management assigned high priority and importance to the collection of sociodemographic data to understand the needs of clients who accessed care at the sites. This varied little across project sites even though the expressed purpose for collection of sociodemographic information was different. A manager explained,

We can’t really just think of the health of a person as a specific issue that we are dealing with because there are all kinds of social factors and other things going on in their life that determine their ability to make health decisions or healthy choices. So I guess for me, it is something that I feel is very important and contributes to health equity. I see sexual and reproductive health as a fundamental part of that whole piece because it really determines a lot of the choices that people are able to make and I think that the choices that people are able to make are really impacted by their other social circumstances that are going on in their life. (K1_2)

Another manager discussed her motivation for participating in the project,

So I was really curious to see exactly what the clientele need that come here and use that service and it has changed drastically in the past five years. So just getting a better feel for who is using the services and who is coming here and why they are coming here. (K1_1)

Yet a different manager shared her hopes for the project’s impact on health of Indigenous peoples. She said,

Recently I saw this quote ‘without data we cannot empower the people’. People need the data to be empowered and that is how we will be able to get the community to really understand why we need to ask certain questions. And why it is that we need to deliver the services and supports that we provide. Sometimes services don’t work based on the way that they have been developed. (KI_3)

Providers also perceived that it was important to understand the social context of clients although it was not a common practice across all types of visits. This was illustrated by primary care nurses who explained that social needs assessment was an integral part of the care for postnatal clients but not during immunization visits. One primary care nurse provider explained,

‘we always ask our postnatals about their financial needs such as whether they have employment insurance (EI) and if they have applied for child tax benefit’ (N_WPC).

Clients’ perceptions of the importance of asking about social circumstances varied across the project sites. The context in which the question was asked as well as participant awareness of related issues seemed to influence perceptions. At St Paul’s Hospital, perception of importance of asking about Indigenous identity was associated with self-identifying as First Nations or Métis, gender identity and age group. (Figure 5-12, 5-13, 5-14)



Figure 5-12: Perceived importance of asking about Indigenous identity disaggregated by Indigenous identity

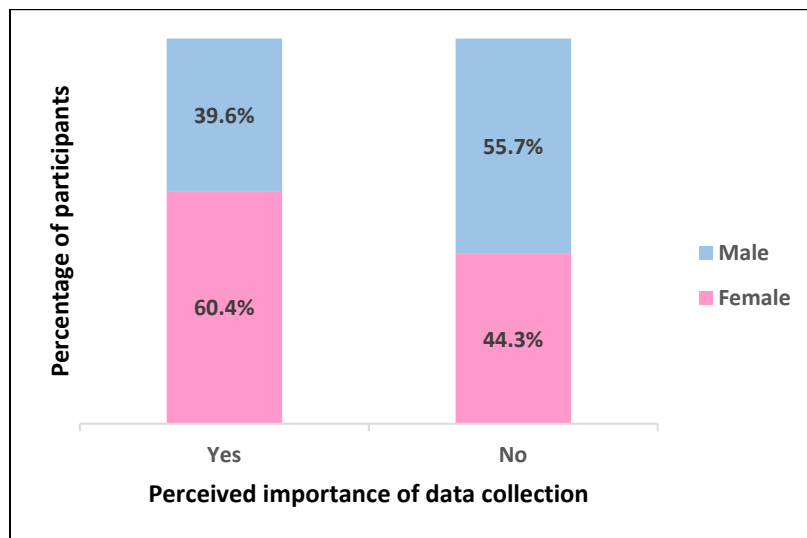


Figure 5-13: Perceived importance of asking disaggregated by gender identity

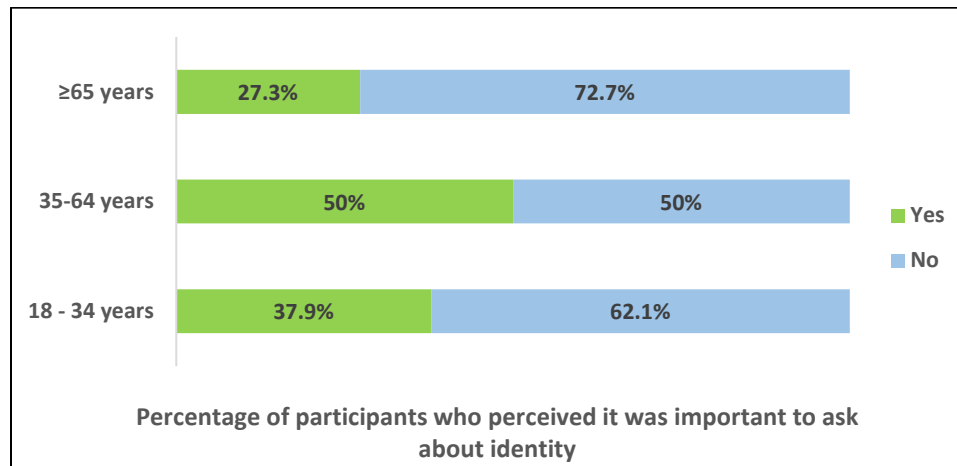


Figure 5-14: Age disaggregated by perceived importance of asking about identity

Factors that favoured patient disclosure of sociodemographic data

Interviews with participants pointed to several factors that encouraged patients to share sociodemographic information. These perceived factors will be discussed in this section.

Understanding the rationale for data collection. Participants who felt that it was important and beneficial to ask clients about their social circumstances shared examples or experiences of how the information could be used to improve care. Reasons offered included:

Surveillance and understanding of clients social needs. A client compared sociodemographic data collection to other population based efforts to capture data such as the census. She stated, ‘Important like a census. I guess it is important to understand the society that we live in. Very important for the future to assess the needs of clients’ (SHC_P5).

Adjustment of clinical care to address unmet social needs. Another participant explained how information could be used in care, ‘I think it is important to ask clients about those situations in order to tailor health care treatment based on their need’ (SHC_P21).

Advocacy to funding agencies for resources and to demonstrate need. This was illustrated by the following two clients who said,

No because if I take just a second to think about it. It makes sense why you would want to find out about how much you make. This is a service that a lot of people use and it is not only for people who have a lot of income coming in, it is for everybody. And I think if you had something like this you would be able to show the government if they were ever to question should this be something that we should charge for, you will actually have some documentation that says no these are the people that we are here to support and help and not everybody is able to pay. (SHC_P10)

..And then if you are looking for funding, you need data so that you can approach people for the funding. And it is like we need more information to say that we need more resources in particular areas of the city. (SHC_P24)

Provision of culturally competent care. Some participants thought that it was important to acknowledge a person's cultural identity during the delivery of care. One participant said, 'I believe in equality and fairness and I treat everyone with dignity and respect. Understanding who we are is part of achieving this goal' (STP_P17). Another participant was aware of the disproportionate burden from chronic diseases among Indigenous peoples and felt that it was important to adjust risk for screening based on Indigenous identity. He explained that, 'People who are First Nations have a higher rate of diabetes and some other conditions so it is important to know so that you can check for those diseases and treat them' (STPI_P3, inpatient).

Other participants referred to the importance of asking about Indigenous identity in order to determine eligibility for treaty entitlements and benefits. A participant reported, 'there are many First Nations peoples and there are different regulations for them so I think that it is important to ask' (STP_P160). Another participant shared her views about being asked at registration, 'I was surprised but so glad that they asked. I used to spend \$400 per month on medications and I couldn't afford it. Now I can get help because of the benefits' (STPI_P15).

Trust in organization's motives for data collection. Support for collection of sociodemographic information was expressed by some participants based on a genuine trust about the institutional motives of sociodemographic data collection. This occurred among participants who had prior positive experiences with the health care system. One

client stated, 'As long as it is for improvement, it is ok' (M_WPC). Another participant was willing to disclose her Indigenous identity although she wasn't completely certain of the reason for asking. She explained, 'If they want to know who I am, I will tell them who I am. They must have a reason for asking that question' (STP_P181).

Safe space for disclosure. For others, perception that the Sexual Health Centre was a safe space to discuss and receive help for sensitive health issues eased the burden of disclosure. One participant explained, 'I come here because I feel comfortable talking with the people here about my sexual health. So I just think it is a really good atmosphere and no one is really judgey [judgmental] and anything so that is very good' (SHC_P23).

Another participant emphasized the importance of ensuring confidentiality of the information in supporting client disclosure. She reported, 'When I was told that it was confidential, I believed that it was and trusted that. I felt quite safe to include anything' (SHC_P15).

Factors that discouraged patient disclosure of sociodemographic data

Low priority. Although some participants agreed that it was 'somewhat important' to collect sociodemographic data, it was perceived to be low priority in the context of particular services such as immunization. The participants viewed the visit as focused with respect to its purpose and perceived that opportunities to discuss other issues were limited. A participant shared this view, 'When we come to the clinic, we are here for immunization and to talk about how [the] baby is doing' (F_WPC).

Time constraints. This service expectation was also shared by primary care nurses who also felt that the scope of the immunization service was limited. Nurses expressed that service design features made it difficult to accomplish other tasks such as screening for social needs in the available time. A nurse was supportive however shared her concerns about integrating sociodemographic data collection. 'If patients want the nurse to ask them about social factors then I will do it but give me more time. I can't do it within the normal clinic session' (N_WPC).

Low relevance to delivery of care. Among participants who felt that it was not important to ask about social circumstances, the reason most commonly cited was that it was not relevant to the purpose of the visit. One elderly participant said, 'I don't think that it affects my care'

(M_WPC). Another participant felt that it was inappropriate in health care settings. She explained, 'I think that it would be more appropriate for like a bank or social services or something that. That is what I think' (SHC_P14)

A subset of participants who were not socially disadvantaged also perceived data collection to be of low personal relevance. One male participant explained.

Well you know it probably is important. Myself I don't give it much thought because I am not socially or economically disadvantaged. I am a professional and I make a good living so I don't even think about stuff like that. But I suppose when somebody is not in a situation like that, it is probably very important. If I go back 30 years when I was a university student maybe it was a concern but I always had good family and emotional support so I never gave it much thought then either. So I didn't worry about it but I suppose that it is very important. If somebody needs some help, you have to find out why they need the help. So that is about all I can think about that one. (SHC_P11)

Among non-Indigenous participants at St Paul's Hospital, this sentiment was also expressed. One participant stated, 'I don't think that it is important for me because I am not First Nations' (STP_P32).

Fear of misuse of information. An Indigenous participant also expressed concern about the potential for misuse of the information. She had prior negative experiences with the health care system. She shared her perspective, 'Not important to me especially if it will affect how you are treated in a bad way' (STPI_P15).

Perceptions that sociodemographic data collection was contrary to principles of equality. A few participants were vehemently opposed to the collection of information about Indigenous identity. They felt that it perpetuated or magnified historical tensions between Indigenous and non-Indigenous peoples and that everyone should be treated the same thus negating need for additional information about personal characteristics. A non-Indigenous participant offered this comment, 'Do we want to be one or not? We can't have it both ways. Time for healing and coming together. When we have to single people out, we reinforce stereotypes and stay stuck in the past' (STP_138). Another participant said, 'I am opposed to special treatment for people who are First Nations so I don't think that it is important' (STP_P25).

Other participants argued that the practice of asking about one particular ethnic group was contrary to principles of equality. Views tended to be more polarized in the acute care site compared to other sites. A non-Indigenous patient suggested, ‘We shouldn’t single out one group for support but we should be concerned about the needs of all ethnic groups’ (STP_P19). A participant asked, ‘Why can’t we all be treated the same? Aren’t we all equal?’ (STP_P180). One participant asserted that it was discrimination against the majority to offer cultural supports for only one group. He argued, ‘Isn’t it discrimination to ask the question and treat people differently?’ (STP_P175).

Perceptions about who should be screened

All participants were asked about their perceptions of the appropriate target population for collection of sociodemographic information. Across all sites, there was overwhelming support for a universal screening approach. This would avoid subjectivity and profiling some clients. A participant noted,

If you started to single people out, for instance I might be struggling desperately and financially with drugs and addiction. I don’t think that I present myself as someone who is struggling financially and with substance abuse. I just think that singling people out could harm the accuracy of the data collected. Again depending on why you are collecting it, I think that asking everybody is the safest way to collect accurate information. (SHC_P15)

Another participant shared similar views and stated, ‘I think you should ask everyone or no one in order to be fair’ (STP_P15).

There was an appreciation among participants at the hospital that it could be difficult to distinguish some identities based on their physical appearance. A participant explained, ‘[You] can’t tell by appearance alone. Some are Aboriginal but don’t look it, so best to ask’ (STP_P1).

However, a few clients thought that only selected persons who they perceived as vulnerable, for example those who had low income, other risk factors (e.g. lack insurance or chronic conditions) or who could benefit were appropriate to ask. A male participant offered this explanation,

I think that it isn’t always a necessary question. When it comes to medication that you may have to pay for or when it comes to certain illnesses and ailments,

I think that it can be valuable to know about someone's social circumstances so that you can give them the best advice possible and best recommendation. And also so that as the doctor, you can understand where your patient is coming from and learn what works within the community. (SHC_P12)

I think it should be based on whether or not you have say insurance, whether or not it is a chronic illness, whether or not it is an illness or ailment that most likely affects those living in poverty; say someone with AIDS for example who may not be able to afford the medicine necessary from day to day. It would be important that the doctor know in that case. External appearances I don't think should be the qualifier but personal information definitely should be and what they are dealing with. (SHC_P12)

Another participant thought that a targeted approach was also complimentary as sometimes people who are the most vulnerable could be missed. She explained,

I think everybody like a universal approach is good because then you get to know what services are needed. I do think though in communities that are facing poverty and stuff, you sometimes need to have that targeted approach because there are a lot of people who are being missed or whether it is a transient community, people living in poverty and if there are language barriers as well. Well they might be hesitant to answer or straight out not answer and you might get all the straight up like white affluent males answering that particular survey. So I think both are important. Just in considering if you are doing a universal approach, you need to look at who might be being missed. (SHC_P24)

One participant at the booked immunization clinic felt that the onus was on the client to engage the nurse for assistance if there were social factors that were affecting the health of the child/family. She did not believe that the health care system should intrude but be invited to intervene in these matters.

Despite the fact that most participants appreciated the limitations of physical appearance as an arbiter of racial/ethnic origin, a few participants argued that 'common sense should prevail'. They reasoned that it was unnecessary to ask patients who appeared non-Indigenous. A non-Indigenous participant argued, 'Do I look First Nations? I think common sense should apply in some cases you can see that the person is not native [Indigenous]' (STP_P105).

Preferred mode of data collection

There was marked variation across sites in preferred modes for data collection. It was evident that multiple factors were at play including role expectations for providers, pragmatic considerations and sensitive nature of the questions. There were some similarities between client perceptions at immunization and sexual reproductive health clinics although it was apparent that ‘one size didn’t fit all needs’.

Role expectations. Some clients would be most comfortable with the doctor/nurse collecting sociodemographic data because of privacy and confidentiality concerns. Participants also felt that the doctor/nurse was in a unique position to help the patient to address unmet social needs. A client attending immunization clinic shared his views, ‘I think maybe that it would be good if the nurse asks because then she is able to help you to find support for the problem’ (M_WPC). Another participant explained her preference, ‘I think it would be better if the doctor brought it up in a verbal conversation because that way you are dealing face to face and you get the opportunity to elaborate on your own needs’ (SHC_P7).

In contrast, other participants felt that it was not appropriate for the physician to ask about sociodemographic information because they were engaged in more important aspects of clinical care. A participant reported, ‘I feel maybe the nurse or administration. I feel like doctors are little bit less involved with that but nurses are little bit more personal’ (SHC_P22). Another participant explained, ‘I definitely would not want my doctor asking me about that. The time is too short and I prefer to spend it talking about my care’ (STP_P173). Yet another client felt that neither physicians nor nurses should inquire about sociodemographic information. He stated, ‘Doctors and nurses have other things to do’ (STP_P206).

For other participants, the specific designation of the individual was less important than whether they possessed the skills to engage the client in a sensitive and appropriate way. One participant explained, ‘As long as the person is someone in authority who won’t disclose what is being said. So a professional who keeps it confidential’ (SHC_P6).

Sensitivity of questions. However, some participants at the Sexual Health Centre expressed a preference for self-administration as they felt that it could be more

intimidating being asked the questions by a provider. One participant shared her concerns, ‘My preference was a self-administered survey and I felt more comfortable answering those questions on paper than I would if a nurse or doctor were asking those questions’ (SHC_P21).

Another participant shared a similar view,

I like this for me personally because I felt awkward like face to face. This way I don’t have to face anyone so I can subtly circle my answer without having to say it out loud if I was uncomfortable. I was comfortable with it but I am just thinking for other people if they didn’t like to talk about their sexuality or things like that they don’t have to. They can just circle or check mark. (SHC_P8)

Practical considerations. Other participants considered that it was more efficient to complete the form while waiting so that the limited consultation time could be spent on clinical care. A participant shared her perspective,

I think it is a better idea just filling it out before your appointment and giving it back to them with the forms. Because then it is not taking time from the doctor when you could be discussing the things that you came here for. You can get it done over and dealt with before your appointment and they can grab your file, read it, take a look and know what’s up and get going with all the important stuff. (SHC_P23)

An outpatient participant at St Paul’s Hospital expressed support for data collection at registration. He explained, ‘I think that the point of first contact is the best place to collect the information’ (STP_P156).

A participant preferred to complete the form because she wanted to be sure that her needs were correctly identified and accurately documented. She stated,

It would feel more comfortable always with a written question. I feel that sometimes even with doctors and nurses you can feel whether or not it is actually there, a sense of judgement or even interpretation of your answer that is going into filling out the form. Someone is always giving you signals of their reaction to it. So I would always prefer especially personal information writing it. I would also be certain that I have written exactly what I mean whereas sometimes when someone is listening to you if there is a longer answer form or even shorter answer form, you don’t necessarily know what it is that they are filling out and if it is exactly representative of the answer that you wanted to have. (SHC_17)

A few participants thought that clients should be offered the option of self or provider administration and there was no one right way to collect the information. One participant shared her views about multiple points of data collection,

I think even if a doctor or nurse were able to ask, some of those questions like the financial one could be answered personally. (Pauses to think) No you know what? I would prefer to answer it on my own as I did today. I think it is important in regular intake to ask about sexuality too. I would prefer to fill out the financial and eating stuff on my own. The other stuff I think could be asked by a doctor or nurse. (SHC_P24)

Figure 5-15 shows preferences for mode of data collection among outpatients at St Paul’s Hospital. Most participants felt that it was appropriate to ask at registration because it was the first point of contact and information was already being captured here. A minority of participants (8.6%) interviewed felt that it was consistent with the role expectations of doctors and nurses. However, self-administration was not a common preferred mode of data collection for the single question on Indigenous identity.

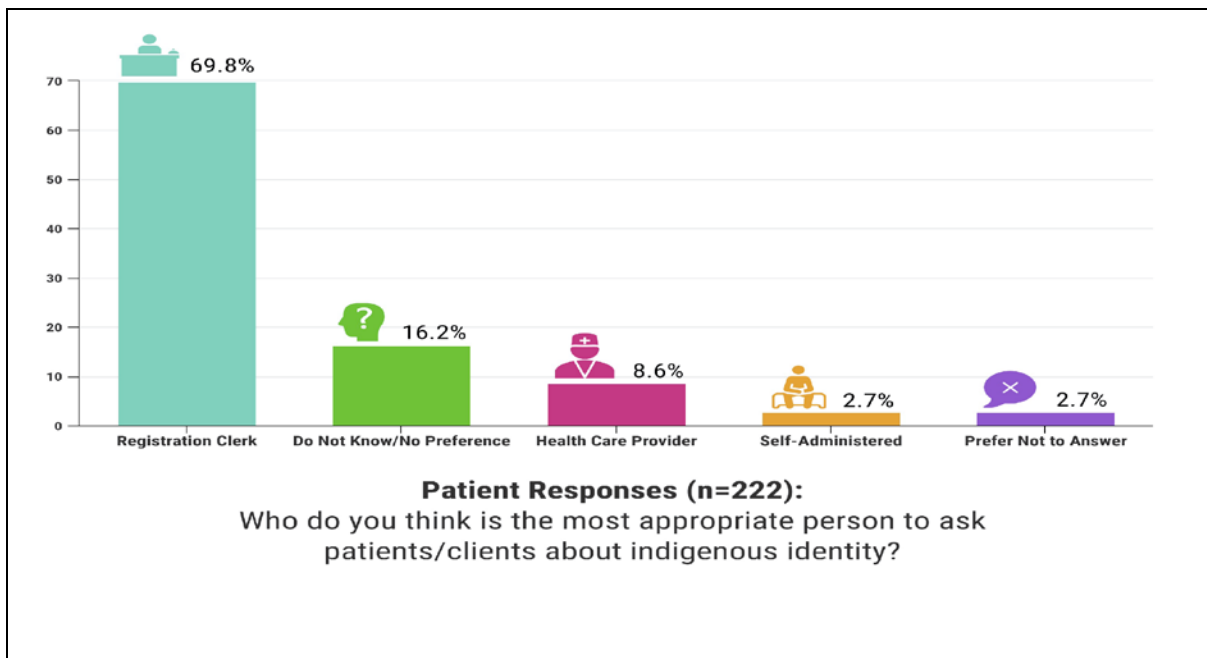


Figure 5-15: Responses to most appropriate person to collect sociodemographic information (Outpatients St Paul’s Hospital)

Inpatients at St Paul’s Hospital reported more variation in their preferences than outpatients. While participants agreed that it was ideal to collect information at the first point of contact, others perceived that it would be better for those involved in care to obtain the

information. One participant explained, 'I prefer the doctor because they are the ones taking care of you. They know if that is important to your care' (STPI_P33). Another participant shared a similar view, 'The nurse is best because they get to know you and care about you as a person' (STPI_P34). Some participants did not have a preference however no one offered self-administration as their option of choice.

Management and providers prioritized similar considerations as patients with respect to determination of who should collect sociodemographic information. Within outpatient settings, it was felt that nurses were well placed to collect and act on the information. Several advantages of provider administration were discussed. There is a therapeutic alliance with the provider who is seen by clients as being trustworthy. Also the privacy of the consultation room and minimization of distractions were felt to be advantageous over self-administration in the waiting area. One provider explained,

I definitely think that you could do a frontline survey but I feel like the questions are a lot more personal and confidential. Patients would feel more comfortable in a private setting, either with a counsellor or a nurse answering those questions, rather than a waiting room with two or three other people and they have a question on how to answer a question. It kind of negates some of their privacy so I feel like that is something to consider. (P4_SHC)

Additionally low literacy and language access barriers could be better mitigated through nurse-administration. There was also recognition of pragmatic considerations related to time available for clinical tasks and the priority accorded to their achievement. One manager commented,

I think ideally if we had all the time in the world, I would choose to have the nurse deliver it within the clinic room. If they have never met that client then they can establish a bit of a relationship and start asking those questions [...] But I think as a second option which would definitely work would be to deliver the questionnaire and have the nurse review it and go over any key points within the clinic consultation. (KI_1)

For institutionalization of sociodemographic data collection in primary care settings, it was felt that a dual approach would be feasible with completion of the self-administered questionnaire while waiting and follow up with the provider for positive screens. A manager explained how this could be achieved,

From an administrative perspective, it is really difficult because you want to balance all of these different needs, wants and desires in that kind of short clinical visit. So yeah, I think in the best world situation, an organization like ours would have funding for a full time counsellor or some role like that would be able to do some of that frontline work. But unfortunately that is not the model that is available to us right now. So I think, in the model that we are working with right now, the best option for us is the questionnaire. However if there was another model of funding where you actually were able to do much more full spectrum work that incorporated the clinical visit with some kind of other services going on. That would be more generative but yeah it is the way that we are trying to balance the time spent clinically and the time spent doing other stuff is a real challenge. (KI_2)

At St Paul's Hospital, there was support from key informants for asking about identity at registration. However, this did not extend to an expanded list of questions. This suggested that future efforts to include more questions at registration may require greater advocacy. A manager clarified her views,

I don't think registration is the appropriate place to ask the full list of questions, I think that should be part of the intake on the ward if it is going to be done. With that said, I think it is ok to ask the Indigenous identity question at registration. While I don't that the staff understands in detail all the things [services] that First Nations Metis Health offers, they can direct/refer patients there if they identify and there is a need for support. (KI_3)

In contrast, another manager emphasized practical considerations and adapting current options to collect sociodemographic information. She explained,

It has to be through registration. It has to be where we can actually capture the data. We already have that system in place so we have to be able to work with them. It is not a matter of making something different. It is a matter of using the tools that we already have and re-evaluating the way that we use them and take a step back and see how else we can better serve the people. (KI_4)

Summary. It was feasible to collect selected sociodemographic information across three urban health care sites although there was a gradient of comfort depending on the question and the context in which it was asked. The number of questions evaluated, participant characteristics and mode of administration varied across sites. This imposes limitations on the transferability of results to vastly different health contexts.

There were high response rates for questions related to English language ability, preferred language of communication, immigration status and place of birth in the site(s) where they were

assessed. A modified version of the question about need for an interpreter seemed to lack clarity and had higher rates of missing responses than the original version.

Despite high acceptability of asking about place of birth, year of arrival had one of the higher rates of missing responses. Within the Saskatoon Health Region, it is estimated that newcomers account for 10% of population. (161) Although the absolute numbers were small, the consistency of this finding across sites requires further investigation.

The question related to race/ethnicity had good response rates although results also suggested that there was sensitivity to asking among subgroups of participants. Once the issue related to signposting was resolved, there were few participants who preferred not to answer. However, the profile of participants who had missing responses reflected persons who were female, Canadian-born and non-Indigenous. This is likely to include persons who belong to the dominant cultural heritage who may perceive little relevance to asking about their race/ethnicity.

Various questions inquired about Indigenous ancestry and identity across sites. Response rates were lower when an isolated question was asked by registration. This may suggest that there is higher acceptability for asking a subset of ethnicity questions that include Indigenous identity. The fact that the mode of administration allowed the interviewer to assess observable characteristics of the respondent and their reaction to the question complicated the disentanglement of self-reported and observer ascribed identities. Despite the problems encountered, majority of participants who were interviewed were willing to disclose their identity at registration. System supports to improve the IT platform to accommodate the expanded list of response options and increased capacity among registration would be required to increase the quality of data collection.

Asking about the presence of disabilities and highest education completed were assessed at one site. This adds to the literature as the other Canadian project that examined sociodemographic data collection did not include a question about education.(47) Among study participants, the percentage that did not have a high school education was lower than the regional average for Saskatoon (7.7% vs. 11%). (195) This may have influenced acceptability as study participants may have been more likely to understand the questions. A different mode of survey administration may be more conducive for client populations with lower literacy level.

There were high response rates to the gender identity question. All sites currently capture information about biological sex. The distinction may not be appreciable for some persons whose gender identity is concordant with their sex assigned at birth. The majority of participants self-identified as female in the two sites where the question was evaluated. Further, there are gender differences in the pattern of health care seeking behaviour that is further compounded by sexual and reproductive health needs. (196–198) Traditionally, women have been the central focus for sexual and reproductive health services as they are primary targets for screening and contraceptive products. Although this is gradually changing, it is not uncommon for females to account for the majority of clients especially in primary health care settings. Consequently, caution must be exercised in extending the results to male participants.

The response rate to questions pertaining to sexual orientation was high. This suggested that participants were willing to answer questions about their sexual orientation in the context of the delivery of sexual and reproductive health services. In addition, sexual minorities accounted for a higher proportion of study participants compared to regional estimates which was reassuring given the mission of the centre. (199) Several factors may contribute to client comfort with self-disclosure of sexual orientation including non-judgmental attitudes of staff and clients, LGBTTQ positive posters and signage, use of inclusive language, confidentiality and staff who are knowledgeable about LGBTTQ specific issues. (126) The centre has a close collaboration with another queer friendly CBO and shares a provider who delivers outreach clinical services at their facility. It is likely that the centre is perceived by sexual minorities as a safe space where high quality sexual and reproductive health services are available. Among study participants, there were no racial/ethnic minorities who also self-identified as sexual minorities. It is possible that patterns of responses would differ among this subgroup.

The possible reasons for the pattern of responses to the housing question across sites has already been explored. A combination of factors likely affected the response including context in which the question had been asked, order and response options of the question. The housing status profiles of participants at various sites were different. There is increasing concern about the affordability of housing in Saskatoon as demand and prices have increased steadily since 2007. (200) This is an example of an issue that is invisible unless specifically broached in a clinical context.

The lowest acceptability was found for questions related to income. This is a consistent finding among surveys with income questions. (201) This question was placed last and presented close-ended options because it was anticipated that it would be the most sensitive. It is noteworthy that some participants did not know their annual household income. The difficulty is appreciable as estimation requires consideration of different sources of income and different contributors in the household. This raises concerns about the accuracy and utility of this question for screening purposes. The most common social risk to health in this sample was low income. Clustering of social disadvantage also occurred among low income participants with coexistence of food shortage and residing in rental accommodation. This illustrates how the information could be applied if it could be successfully collected.

There was support for universal screening for social determinants across sites. Even when perceived importance of asking was low, participants agreed that if the information were to be collected, all persons should have the opportunity to choose whether or not they wanted to respond. Most respondents had a mode of administration preference however context likely influenced the choice. It may be desirable to offer respondents a choice in order to have the flexibility to meet diverse needs.

5.3.5 Suggested improvements to sociodemographic data collection

Although it was feasible to collect sociodemographic data, there were several suggestions from patients and providers about how it could be improved. These suggestions will be discussed in two general groups according to whether they pertained to the question and its format or the process of data collection. The majority of participants at the Sexual Health Centre found it easy to understand the questions and thought that the response options were adequate for self-description. One participant commented,

I thought that there was a great breadth of response choices. My view is probably skewed. My answer choices were always right at the beginning. I have no problem with English and I didn't have to read very far to find that applies to me or that's my box to tick. So for me personally that was very easy to fill out. (SHC_17).

Participants also welcomed the inclusion of an option for 'prefer not to answer'. One participant explained, 'No I thought it was good and it gave the option if someone was uncomfortable that they could check that they didn't want to answer the question'. (SHC_20)

There was a suggestion to improve the question pertaining to presence of disabilities to reflect the daily variation in functional capacities. The client's suggestion was to identify specific tasks perhaps self-care and decision making that may be easier to answer. She noted,

I think there was one question there where it asked if it affected your daily activities. And I have ADHD [attention deficit hyperactivity disorder] so not every single day does it affect my daily activities but you know if I don't take my medication or if it is really bad one day, I struggle with certain things more than I do other days. I don't think that question should be daily activities but certain life tasks you know. (SHC_P4)

There was also a suggestion to modify the income question to inquire about general adequacy to meet basic needs. The care team proposed that the format of the questionnaire should be altered. The number of pages should be reduced and questions arranged in columns on each page. This would reduce the likelihood that clients would miss questions located on the back pages of questionnaires. A care team member outlined these suggestions,

I would say that maybe if the format were different then it would have made people answer the questions faster. I feel like you know how our medical history form is – really condensed and small with a series of checks? I feel like if it had been more questions on a page then they would have gotten through it faster. (P4_SHC)

I don't think that it was too long. People didn't mind filling it out. I just think that some questions got missed because of the last page. It could be solved by placing more questions on a page. Or to print the survey single sided so that it is like I fill this out, I fill this out then I fill this out. (P4_SHC)

Especially when participants felt comfortable putting prefer not to answer for sexual orientation and then didn't put answers for those questions on the back. This indicates that they probably didn't even see that page. (P4_SHC)

There was limited understanding of the rationale for data collection particularly at St Paul's Hospital. It was suggested by some participants that it would be helpful to have a better understanding of why they were being asked about their identity. As one participant noted, 'Explaining why the information is being requested can go a long way to encouraging people to answer' (STP_P76). Another participant agreed and shared a similar opinion, 'It can be uncomfortable if you don't know the reason that they are asking' (STP_P99).

It appeared that most persons did not see the posters or request additional information from registration. One participant stated, 'Signage is needed so that patients are not taken aback by the question' (STP_P53). Consequently there were assumptions about why the question was asked.

Some patient participants also suggested that more consideration should be given to privacy of the environment. A few participants suggested that the question should be asked more discreetly by registration. One participant commented, 'The registration clerks should try to ask more discreetly' (STP_P157). Another participant suggested that a silent process may afford a modicum of privacy in the current hospital environment. He said, 'Privacy may be an issue. There should be a silent process' (STP_P151).

5.4 Application of sociodemographic data collection

In one site, there was clinical application of sociodemographic information in individual care. Information was collected that assessed the effect of the project activities on the provider practices. At the Sexual Health Centre, a pre-post implementation comparison of documentation of unmet social needs and provider care interventions was conducted. During the post implementation focus group discussion, the care team was also asked about their experiences and any perceived impact on the way that they provided care. The author (HWR) planned to assess the effect of data collection on patient care pathways however it was not feasible to interview clients after their consultation. This limited the ability to examine client perceptions of how their care experience was impacted by the collection of sociodemographic information.

5.4.1 Chart review of provider practices

A total of 118 records were reviewed for the period 14th March to 14th June 2015. This time period was of similar duration to the study implementation in 2016. The centre modified their intake forms and introduced collection of data about ethnicity in June 2015. The information about race/ethnic origin was captured by an open-ended field. There was no prompting and each client could use any term(s) to describe their ethnic origin. Over the same period there were also other changes to the intake including an open ended field for gender identity in addition to the closed ended field that requested sex on health registration card.

The descriptive characteristics of the sample are presented in Table 5-4. The median age of clients was 26 years and ranged from 18 to 68 years. The majority (89%) of clients were between the ages of 18 and 35 years. Gender identity was missing in five (4.2%) clients. Over two thirds (67.8%) of clients self-identified as female while 28% identified as male. Ethnic origin was allocated for nineteen (16.1%) clients. Within this subgroup of participants, 47.4% were

White while 15.8% self-identified as Indigenous, 22% Asian and 11% African. One client self-identified as mixed. More details were not consistently recorded to allow for more granular classification of race/ethnicity.

The information documented in the medical record pertained to sexual behavior (i.e. number of new and existing partners, type of sex acts). There was no record of sexual identity. A distinction is important because a person’s sexual behavior and attraction may be different to their sexual identity. In just over half of clients (55.9%), records did not have any information about sexual partners. In 20.3% of records, there was limited information about sexual partners such as number of partners or whether there was a new partner. Among the remaining clients, 18.6% had a sexual partner of the opposite sex, 3.4% same sex partner and 1.7% had partners of both sexes.

Very little information was available about other sociodemographic data elements. One client was accompanied by a friend who served as an interpreter during the visit. Another client had documentation of financial need. There were two instances where clients had an out of province health card.

Table 5-4: Descriptive characteristics for pre-implementation study participants

Variable	Options	N (%)
Age (years)	Median (IQR)	26 (23, 29.3)
Gender	Female	80 (67.8%)
	Male	33 (28%)
	Missing	5 (4.2%)
Race/Ethnicity	White	9 (7.6%)
	Asian	4 (3.4%)
	Indigenous	3 (2.5%)
	African	2 (1.7%)
	Mixed	1 (<1%)
	Missing	99 (83.9%)
Sexual behavior/attraction	Opposite sex partner(s)	22 (18.6%)
	Same sex partner(s)	4 (3.4%)
	Both sex partners	2 (1.7%)
	Sexual behavior	24 (20.3%)
	Missing	66 (55.9%)

There was no difference between the two groups of clients with respect to documentation of gender identity. (Table 5-5) However, there were marked differences in documentation of all other factors including race/ethnicity, English language ability, place of birth, immigration status, presence of disability, educational attainment, housing status, food security and income.

Table 5-5: Comparison of documentation of social determinants in medical records

Sociodemographic variable	Pre-implementation N=118 (%)	Implementation N=104 (%)
Language proficiency/need for interpreter	1 (<1%)	104 (100%)
Place of birth	1 (<1%)	104 (100%)
Immigration status	0	104 (100%)
Race/ethnicity	19 (16.1%)	99 (95.2%)
Disability	0	99 (95.2%)
Gender	113 (95.8%)	104 (100%)
Sexual orientation	*	98 (94.2%)
Education	0	102 (98.1%)
Housing	0	96 (92.3%)
Food security	0	95 (91.3%)
Income	1(<1%)	92 (88.4%)

*Information recorded does not strictly reflect identity but sexual behavior

There was little documentation of interventions to mitigate the impact of unmet social needs. This may be partly related to relatively few social needs among the client population. In the pre-implementation group, there was one client who needed interpretation services. In the intervention group, all participants reported good English language proficiency and likely had few language access barriers. The centre currently does not have access to the health region's language line for interpretation services. With the growing diversity of the region's population, the centre anticipates the need for greater access to interpretation services in order to better serve those who may have language barriers. The main social needs related to low income and ability to access the contraceptive method of choice due to cost barriers. Although the author expected to find documentation of use of medication assistance schemes, none of the records that were reviewed had any such notations.

From the available information, it was evident that standardization of the collection of sociodemographic data increased rates of documentation in the medical records. All new elements had higher rates of inclusion within the records during the study period. The information was too sparse to appreciate whether there was a gradient by social determinant.

There was no evidence to suggest that provider care practices differed between the two periods studied. This was consistent with the views shared by the care team during the post intervention focus group interview. One provider admitted,

Well I honestly didn't feel that it changed my practice very much. I didn't get many flags and the basic thing for most people is low income which we do already address. We are offering low cost birth control and we have ways to get people what they need. I was working with that before. That's why it didn't change my practice very much. However, I feel that the information would be really useful on an organizational and population level. (P3_SHC)

The provider resource manual was not utilized by the providers after the initial review. It was most useful to reception staff and the executive director to identify resources for clients as well as potential partners. It was thought that utility could be improved by inclusion of additional content to reflect common emerging concerns for the population accessing services. She explained,

I think if we included a section on trauma because we refer people all the time to the assault centre. So I think it is just a matter of finding out what we need. We might just need to include what we need in the manual. (P4_SHC)

There were few social needs among clients and when present they were well managed. The same participant also stated,

I was really excited about the disability resources but most of the people coming in with disabilities are coming with their care workers or they have got their condition managed. Or they are with their social workers and guardians. Everything is being managed that way. I think that it is just a matter of finding what resources we need. (P4_SHC)

It was difficult to identify interventions for social needs based on documentation in medical records. This may be partly due to low levels of risks for some factors (e.g. language barriers) and therefore an appropriate absence. It is possible that clients were referred but it was not documented in the medical record. It is important to note that charts reviewed were for both new clients and re-visits to the centre. It is plausible that providers who had prior knowledge of clients didn't necessarily document their social context. As previously mentioned, different providers delivered care during the pre and implementation periods, consequently personal preferences and other nuances may have influenced styles of documentation.

One of the disadvantages of chart reviews relates to the fact that the information is not collected primarily to satisfy the research objective. It is not uncommon to find gaps in documentation that make it difficult to identify the variables of interest. (202) Another limitation related to dual roles of the researcher as data abstractor. As a result there was no blinding to the research objectives or group assignment of clients. Use of a standardized data abstraction form to guide data collection and clear definition of variables were measures used to minimize information bias.

5.5 Facilitators and barriers to implementation

5.5.1 Facilitators of implementation

One of the research objectives was to identify facilitators and barriers to implementation in the various health care settings. An understanding of the salient conditions that support implementation would contribute to recommendations to support institutions who have an interest to pursue similar projects. Qualitative data sources were mainly employed to address this evaluation question. This section identifies these themes as perceived by key informants at each site.

Project satisfied an important information need. The key informant interviews explored the context for data collection in a given site. Several factors motivated immunization clinics to participate in the project. There was a gap in knowledge about the service-related needs of the clients who accessed care at the centre. It was also perceived that the sociodemographic profile of the surrounding catchment area had changed and needed to be described. It was thought that services could be made more responsive if client needs and preferences were better understood. The manager explained,

So I was really curious to see exactly what the clientele need who come here and use that service and it has changed drastically in the past five years. So just getting a better feel for who is using the services and who is coming here and why they are coming here. I think the needs of individuals have changed in the last year. There are more working parents, more parents that have more than one job and even the sociodemographics of the area surrounding West Winds has changed significantly. (K1_1)

The Sexual Health Centre also had a similar motivation for participation. The project would meet a critical need for information about the client profile as well as support advocacy for funding. The manager shared her reasons for participation,

The data provides us with significant information that enables us to actually seek out funding to address client needs. Currently we don't have a lot of demographic data. We have very basic data on gender, age and a little bit on sexuality as well. But that does not really provide us with any evidence base or doesn't really tell us who it is that we are serving and what kinds of other needs they are experiencing. And too having that information gives us the ability to seek out funding opportunities to provide better supports and to enhance the clinical stuff that we are doing. And that gives us a stronger case when asking the health region, Ministry of Health and other levels of government for more targeted funding. So I think from that perspective, it is really important and I think it also enables us to tailor our services and make changes to our schedule or whatever that could better suit whoever it is that we are seeing what their needs are. So I think in terms of that it is really valuable and it is also something that our funders are asking for that we are currently not collecting. (P1_SHC)

Team members also were interested in data collection for specific reasons related to planning for complex needs and forecasting need for subsidized birth control. One participant expressed her needs for the initiative,

I would also find it useful on the frontline knowing what struggles a person has before they even make it to the nurse. It would be helpful for me to be able to determine how long of an appointment they might need or if their care requires services with the doctor. I feel like that would be very helpful if I was just getting that information right away to be able to use it to better know the person and know how I should help them. (P4_SHC)

Another provider was concerned about unmet needs for contraception due to financial barriers. She explained,

I just have a specific thing that I am interested in. A few people who I have seen have talked about even the subsidized birth control here is too much for them. So I am curious how many people are not using birth control or sporadically using birth control because of cost. (P2_SHC)

At St Paul's Hospital, the project supported the efforts of First Nations Métis Health Services to reach persons who identified as First Nations or Métis and who could benefit from cultural support and navigation services. The current procedures were unreliable particularly for

identification of individuals who were Métis. A key informant explained the process of identification,

We don't go by treaty status for our programme. We go by last name so that is how we identify persons through the daily census. The problem is that we are missing a lot of Métis. With the question being asked at registration, it has increased especially the Métis that we have been able to see. A lot of times we miss them based on last name. (KI_3)

Organizational imperative to address social determinants. Although the survey at immunization clinics was an institution specific initiative, it was supported by district-level priorities. The survey provided an opportunity to satisfy dual objectives of understanding service related needs and preferences as well as focusing on equity and social needs of clients. The manager clarified,

I think it was a little bit of both. There were two needs that were running parallel to each other at the time. Last year at district review, we did identify that we want to hone in on the sociodemographic aspects of client care and really meet the needs of clients from that perspective because I don't know that we feel that we are doing a good job in that area any more. So that occurred at the same time as our clinic was focussed on especially meeting the needs of our clients. So because of the fact that those two concerns were out there and they are very much related, they kind of merged. So that was the rationale behind it because there was talk about looking more in-depth about the sociodemographic factors for clients and the proportionate universalism that we can provide to clients. (KI_1)

The project was consistent with the Sexual Health Centre's institutional mandate and concern for social justice and equity. The manager shared her views,

I think on a broader perspective, it resonated with me because I really believe so strongly that the social determinants of health are a factor in our clients' lives and that we are not necessarily addressing that in the best way possible. I think that we are health equity seeking and we really believe in social justice, eliminating poverty and helping people to be their best selves and be able to make the choices that are right for them. For me, having a belief in reproductive justice, the social determinants and all that kind of stuff made me feel that this is something that was going to be challenging but was important for us to do. (P1_SHC)

It also coincided with re-visioning of the organization and strategic planning to better accommodate changing needs of the clients. A care team member explained,

I feel like we are in a rebirth of the organization with [name] so knowing now what our patients want and need is really helpful so we can start planning for the future. We have new life, new breadth, and new people so that means that we also need to find out what things we need to do. (P4_SHC)

The First Nations and Métis Health Service operationalizes the goals of the Aboriginal Health Strategy that call for integration of holistic and traditional approaches in hospital settings. It advocates for increased access to interpreters, cultural experts and healers to complement western approaches and enhance the care experience. (164) Increased capacity to identify the target group is necessary for engagement and service delivery. The project in this site supported the department's functions. It also aligned with Truth and Reconciliation Commission's Calls For Action that also advocate for greater integration of Indigenous healing practices when requested by patients and cultural competency training for health service personnel. (165)

Leadership support. Timing of the project at West Winds also occurred under the leadership of a new interim manager who was an equity champion. This individual had been re-deployed from the Public Health Observatory where efforts to mainstream equity across programs were a central focus. The familiarity with the observatory's work made it easy to recognize synergies and opportunities for advancing the equity agenda and meet the clinic's information needs. The key informant commented,

I think it was just the right time in terms of readiness for other departments to be involved and for other people to be involved and support it. So [name] and the PHO for sure. [Name of manager] had a huge part in it. She looked at it from a very different lens as well because of her work in the PHO. So really honing in on this as an opportunity where we can use the survey to maximise the information that we want to get from the clients rather than having two separate surveys where you are basically asking similar questions. Yeah so definitely there was readiness within our department, the PHO and then we had an opportunity to utilize other supports to make it happen which was really, really great.

The support of key leaders in the organization also facilitated implementation of the project at St Paul's Hospital. This was confirmed in the key informant interview and examples were provided of activities that board members participated in. The project was positioned as another example of the good will and receptiveness to advancing systems change and inclusiveness of First Nations and Métis peoples. The manager explained,

We are making big strides with the TRC [Truth and Reconciliation Commission] Calls for Action and the flag raising ceremony that occurred. And big strides in our leadership. The CEO here for St Paul's and the VPs have started to receive some training on cultural competence and safety awareness protocols. They are starting to appreciate the world view of First Nations and Metis peoples (because we have our own ways of knowing). We have a long way to go but by the leadership acknowledging that was needed is huge towards creating that systems change. This is a small but mighty step – We ask because we care- into understanding that because it gives that data that the people need to be empowered. (KI_3)

Availability of additional resources to support implementation. The timing of the project at immunization clinics was instrumental in that it aligned with departmental readiness and availability of personnel to support survey administration. It was felt that availability of dedicated persons to explain the purpose of the study and respond to questions and concerns contributed to the feasibility of the survey. The manager noted,

Yeah I think it would have been a lot more difficult to have facilitated that though because everybody is just so stretched to find help to provide the survey to clients and to explain the survey to clients was just so helpful. It was helpful to have [names] available to do those surveys. It would have been really hard to make that happen. We probably would have made it happen but it would have been difficult for sure. Maybe it would not have been as effective. (K1_1)

Need for a resource of community services. There was recognition that the Sexual Health Centre needed a resource of community services and programs where clients could be referred. This would increase capacity of staff to identify appropriate relevant resources in a timely manner. A care team member shared her experience,

I am also interested in being able to have a flow chart of resources or other organizations that we can refer people to easily. Because right now if somebody says they have LGBTQ questions and issues, I say call OUT Saskatoon. They have counsellors, support, a great library and they can help you. Or I got drunk last night and I think I was assaulted, do you want counselling or do you just want testing? So I feel that is easier for me to do if I have a list of resources and community organizations that we can touch. There are just so many small organizations in the city that we are not using. (P4_SHC)

5.5.2 Barriers to implementation

Availability of human resources. The main challenge posed by the project at immunization clinics related to the availability of human resources to distribute the questionnaire and respond to participant concerns. Financial costs were not substantial and related to

reproduction of copies of the questionnaire. A community program builder was released to assist with the survey along with HWR. It was thought that it would not be feasible or desirable to assign either the reception personnel or clinical staff to collect the information. The manager reflected,

I think just knowing that we have someone like a community program builder to be able to facilitate that. I think if we were going forward into other sites to implement the survey we would need to have some supports in place or a plan so that we could take the person out, implement the survey and have the nurse follow up with it. If we did it that way, it would be difficult for the nurses to find that time but I think that would be ideal. But if not then we definitely need help from another department like PHO or like immunization with a community program builder in place just to provide that information and feedback to the clients about why we are doing the survey. I just think it is so much more meaningful when you have someone attached to that rather than just a piece of paper handed to somebody. So I definitely think we would need some type of support for that. (K1_1)

The staff was informed about the survey at the departmental huddle meetings. However, there was very little interaction with clinical staff during the survey. An effort was made to minimize disruption to clinic process and to complete research related activities prior to clients being called by nurse providers.

Perception of relevance to service delivery. The rationale for selection of sociodemographic questions that were finally incorporated was explained. It was perceived that only a subset of questions was relevant to the survey. The manager explained, ‘There were a few questions that I just didn’t know with what we were using the survey for if they were relevant so we didn’t include them’ (K1_1). It was reasoned that additional information, for example sexual orientation would not affect service delivery. This suggested that there was lower acceptability for asking about some determinants in the context of delivery of immunization services.

Yeah that [sexual orientation] doesn’t affect how we provide service to clients so I didn’t feel it was necessary. If it was strictly about social determinants of health that would have been relevant. For our services, it really isn’t relevant. It doesn’t matter what their sexual orientation is because we are going to provide them the same care regardless. (K1_1)

Staff comfort with sociodemographic data collection. Although it was agreed by providers that understanding of client/family social context has a place in the provision of care, it is likely that staff capacity and comfort with collection of the information were variable. A nurse

stated, 'I think that we know it is important but I don't think that everyone would be comfortable with it' (N_WPC). This could be a barrier to implementation.

During training sessions, registration clerks expressed unfavourable attitudes to data collection and shared concerns that patients would be offended and reluctant to disclose their identity. A manager recollected her experience,

The main challenge was staff concerns about singling out one group for consideration. It made it seem as if there was less concern for others who were experiencing similar hardships. When we started the project, there was a member of staff who is First Nations and she was uncomfortable being asked the question. It made me wonder if they don't want to be asked then what is the point. (KI_4)

Despite the fact that implementation was relatively uneventful with few complaints reported, the prevailing sentiment throughout the project remained one of reticence. Another key informant noted,

This project needed to be absorbed and bought into by the registration clerks because they are the ones that are asking and need to champion the questions. We do want to ask other questions like they do in Ontario and other provinces so that we can better deliver service and really make patient centred care. I think that is where I saw a lot of push back. Even when we were doing the training. Even our own First Nation and Métis clerks were some of the biggest opponents that threw up the barrier saying 'I don't feel comfortable asking and this is not right. This is against what we should be doing'. To me it was a misunderstanding of what this kind of project means to the whole community of Saskatchewan. (KI_3)

Client comfort with data collection. Client comfort and willingness to disclose is the Achilles heel of sociodemographic data collection. Adequate knowledge about the rationale for data collection and how it will be used by the facility may improve client comfort. One Indigenous participant expressed his dissatisfaction, 'I felt uncomfortable. I didn't know why they were asking and whether they needed the information. I wanted to be respectful so I answered' (STPI_P). In contrast, other participants who had more information were more comfortable with disclosure. One participant stated, 'I saw the poster and I understood why they were asking if I was First Nations' (STP_P129). Another participant shared his experience, 'I asked them about that and they gave me a pamphlet that explained it. If there are services then it is ok to ask if it allows you to offer people better care' (STP_P88).

One Indigenous participant reported that although she could see the relevance, she felt uncomfortable with the process. She suggested, 'They should mention cultural services so that you don't feel singled out' (STP_P15). Another participant shared similar views and she explained, 'It is a sensitive issue and when you ask that question, it is really out of context. It would be better to announce that there are cultural support services available if you need them' (STP_P27). These perceptions further emphasized that clients needed to understand why the information was being collected in order to feel comfortable with disclosure.

Time constraints. One of the perceived barriers to implementation was added time required by providers and clients. It was perceived that clients would need more time to complete the questionnaire and providers would also require longer appointments to accommodate clients with complex needs. A care team participant explained,

I do think that time is also a factor for the patients as well. I feel like the longer it takes to fill out a form, the longer an appointment is or the more they have to wait for that appointment to finish, I feel that makes a huge difference. Not just with this project but currently so it definitely something that we need to consider. (P4_SHC)

The same participant also rationalized how she could better anticipate and accommodate clients with complex needs through longer appointments. She further explained,

And I think that is something, knowing that I can make more time for the doctors and the nurses and I can do a bit more screening on the phone. Not just you need testing, you don't want birth control too and a pap as well? You have some symptoms, I can do a bit more screening so that you know what kind of things that they are going to need once they get to the centre. Right now I am just asking if you need a nurse or a doctor. (P4_SHC)

The benefits of the project to the institution and clients were thought to outweigh any challenges associated with implementation in some sites. A manager shared her perspective, 'I think the time was certainly something that I considered when I was signing on but I also think that I just decided that it was worth the investment' (P1_SHC).

Limited funding. The Sexual Health Centre Saskatoon is a small non-profit enterprise that depends on grants and donations to fund its activities. This limits its ability to undertake extensive projects including research activities. The manager noted,

Well I think for us one of the biggest challenges is funding. The current models funding are not great and they don't allow us to plan long term. We are often

asking for more money and often told 'no'. It is not really allowing us to do things that are innovative and evidence based and kind of exist over the long term. We are sort of piece meal putting things together and constantly in the cycle of writing small grants and not being able to do things that are interesting or kind of impactful. It is kind of what we can do with what we have in the moment. So I think that is the biggest challenge that we face. People and time and money. (KI_1)

Although the general economic climate was one of fiscal prudence, financial resources were mobilized in each site as needed.

This chapter described the process of implementation and results of key activities in each of the three project sites. Consistent with the project's focus on two implementation outcomes (feasibility and acceptability), perceptions and experiences of three main groups of participants (patients/clients, providers, managers) have been examined by cross cutting themes related to levels of comfort, importance of sociodemographic data collection, perceptions of the appropriate target population for data collection and preference for mode of administration. Variations in results that occurred by selected sociodemographic characteristics have been described. The perceived facilitators and barriers to implementation in each of the sites have also been explored. These results will be further examined in the next chapter to produce a comprehensive understanding of conditions needed to facilitate implementation and processes that are likely to work to implement sociodemographic data collection in the local context. Recommendations are also proposed to support next steps for advancing the work.

CHAPTER 6

DISCUSSION

6.0 Introduction

This chapter discusses the evaluation results in the context of the existing body of knowledge. The gaps in the literature and opportunities for further work are highlighted. It also explains the implications for local efforts to collect sociodemographic data in urban health care settings and provides recommendations to support wider implementation.

Data on selected sociodemographic factors was collected successfully across three urban health care settings in Saskatoon, Saskatchewan. The number of questions implemented, patient/client characteristics, mode of administration, service context and extent to which the information was clinically applied varied across sites. The adaptation of the project to the needs and capacities of the various sites was critical to canvass support for implementation of the initiative. Despite the constraints imposed by the context sensitive nature of implementation, several common facilitators and barriers were identified that advance our understanding about the salient conditions that fostered change and may be important for scale up to other local sites.

6.1 Feasibility and acceptability of sociodemographic data collection

Proctor et al. (147) define feasibility as ‘the extent to which a new treatment, or an innovation, can be successfully used or carried out within a given agency or setting’. In this study, determination of feasibility was assessed retrospectively based on participation rates and item response rates. Three sites were successfully engaged to pilot standardized sociodemographic data collection. However, sites varied in their receptiveness to include the full complement of sociodemographic questions that were developed. The factors implicated by participants in influencing these patterns of implementation have been explored in the context of three case studies.

6.1.1 Participation rates

The participation rate (percentage of those who completed the questionnaire among the eligible population) was variable across pilot sites ranging from 59.4% to 79%. Although this is lower than has been observed in some studies (47,48,203), it is promising that there is interest and willingness to engage in sociodemographic data collection. Among the studies identified, information was limited about the demographic characteristics of study participants to enable comparison with our local settings. Within the local context, there also was heterogeneity in participant characteristics across sites that likely affected participation rates.

6.1.2 Item response rates

In sites where multiple questions were evaluated, there was a gradient of comfort depending on the question and context in which it was asked. Lowest item response rates were noted for questions related to annual family household income and year of arrival in Canada. This pattern of response is consistent with findings of other Canadian studies. (47,176) The potential explanations are explored in respective sections.

Language. There were high response rates to the cluster of language related questions. It is plausible that clients intuitively understood the reason for asking about English language proficiency and preferred spoken language in order to facilitate effective communication with providers. Similar findings have been noted in other Canadian studies. (47,176) In these studies, resources were available for translation of the questionnaire in multiple languages. A few studies (91,139) have also reported general public support for collection of information related to preferred language. These results suggest high feasibility for asking about language needs in the local context.

All sites did not collect data about English language proficiency and preferred spoken language. A question about ‘need for an interpreter’ was included as a proxy to identify language need. A modified version of this question that inquired ‘whether an interpreter would be helpful’ had high rates of missing responses among study participants. The original version appeared to have greater clarity and was answered by all participants. It is suggested that questions should be applied in their standard form to ensure clarity. Based on existing research and these results, the language cluster of questions is unlikely to pose a challenge for clients if introduced. The availability of the telephone interpreter services in the public sector also paves the way for

systematically asking about language access barriers. This would ensure that patients with limited English proficiency are identified and accommodated.

Education. A question pertaining to highest education level attained had high response rates and no one selected either prefer not to answer or do not know. Other Canadian studies have not examined this particular question (47,176) or reported lower response rates (48). Hence the study adds to the literature in this area. Two prior Canadian studies (134,139) that assessed public perceptions of sociodemographic data collection suggested that there was lower acceptability for being asked about race/ethnicity, sexual orientation and education. Although these results should be confirmed in more diverse populations, the study suggests that there is low sensitivity to collection of information about education in a local clinical context.

Immigration status. Immigration status was evaluated in one community site in addition to other questions about place of birth and year of arrival in Canada. This is potentially a sensitive issue as entitlement for provincial health services is based on the legal status of an individual. There were high response rates, however this may have been related to the fact that the majority of participants were Canadian citizens by birth or naturalization. This question may have been perceived as non-threatening by these participants.(204,205) This is consistent with limited Canadian research (134) that suggests that there is lower acceptability for data collection about immigration status among immigrants compared to Canadian born counterparts . While this result is promising, further work is need to confirm whether it equally obtains in larger diverse populations.

There are multiple reasons for sensitivity of survey questions. (201) A question may be sensitive because it relates to a taboo subject. In this sense, the question is perceived as intrusive and an invasion of privacy.(201) The nature and content of sociodemographic questions risk offending clients regardless of the specific response to the question. Clients may also worry about the threat of disclosure of their information to third parties because of fear about the consequences if their answers are known by these individuals. (201) Some sociodemographic characteristics including being a member of a racial/ethnic, gender and sexual minority are associated with stigma and discrimination which also affects willingness to self-report.

Year of arrival. The rate of missing responses for year of arrival to Canada was also high compared to other questions. A similar response was also observed in three Canadian studies

(47,48,176) conducted among patients/caregivers attending acute and ambulatory care services in Toronto. Two studies (47,176) did not provide an explanation for this finding and marginalized its importance because it was a follow up question. Another study (48) noted that participants often responded with their country of origin instead of year of arrival. It is possible that there is lower acceptability for asking about year of arrival as response rates for the nativity question were high. It is also possible that participants considered the question too personal and unrelated to service provision. It has been suggested that immigrants may be more tolerant of immigration-related questions because of their familiarity and experience with being asked in other contexts. This may not extend to health settings. In addition, non-status immigrants are likely to be fearful of disclosure of their status to third party agencies. (205) Provision was not made for additional response options such as 'prefer not to answer' or 'do not know'. This would have been helpful to confirm the reason for the missing responses. An alternative question format that requests specific information about whether clients had arrived within the past 5 years may have better success.

Race/ethnicity. There was variation in response rates across sites for questions related to race/ethnicity. This suggested that there may be sensitivity to asking in subpopulations. The sensitivity of asking about race/ethnicity in Canadian health care settings has been acknowledged. (134,135) These studies have described concerns about data collection that arise from evoking anxiety among racialized persons who have experienced racism and insinuations that racial inequities are widespread. In this study, the observed pattern points to multiple explanations, some likely related to the format of the question. Those participants who preferred not to answer or had missing responses were Canadian-born. In the first survey among drop-in immunization clients, response options that related to Indigenous identity were not included in the general race/ethnicity question hence it was not surprising that participants who self-identified as Indigenous selected 'prefer not to answer'. In the second survey, this issue was rectified and there were no participants who preferred not to answer. However, unexplained missing responses were identified for participants who were Canadian-born but non-Indigenous. It is not known whether this group of participants were racial/ethnic minorities. There is the perception by some patients and providers that racial inequities are non-existent in Canada and by extension negates efforts to increase data collection. (206) This is a plausible explanation however alternative explanations cannot be excluded.

Indigenous identity. Health disparities between Indigenous and non-Indigenous Canadians have been well documented. (207–209) Community concerns about the role of systemic racism and discrimination and the need for cultural safety have increasingly become part of health system discourse. Intergenerational trauma and distrust of institutions because of historical human rights violations plague relations between the state and Indigenous peoples. (210,211) In this context, it is to be anticipated that questions about Indigenous identity may be met with resistance and cause discomfort particularly if motivations for asking are not explicit. Response rates were higher ($\geq 95\%$) in sites with multiple sociodemographic questions compared with a single Indigenous identity question (71%). There were low rates of participants who selected ‘prefer not to answer’ in these sites suggesting that clients were willing to disclose their identity. As previously explained, the proportion of patients who preferred not to respond could not be disaggregated for acute care participants because of limited capacity to include all response options. It was also noted that while absolute numbers were smaller in community sites, the percentage of participants who identified as Indigenous was higher (20%) when compared with the acute care site (13.8%). This pattern of responses suggested that the context in which the question was asked influenced participant responses. A closer examination of participant perceptions during interviews provided further insight to this issue.

Sexual orientation. Information about sexual orientation was collected from participants in one private community site. Response rates were high with few participants (3.8%, $n=4$) who preferred not to answer. This suggested that it was acceptable in the context of delivery of sexual and reproductive health services to ask about sexual identity. Other Canadian studies (47,48,176) have found similar or higher percentages of participants who preferred not to disclose their sexual orientation in acute and ambulatory care settings. However, a US-based study (57) conducted in four primary care settings found that participants with diverse sexual identities were willing to answer questions about their sexual orientation and thought it was important for their provider to know about their gender and sexual identity. In this US study (57), perceived importance was not associated with ethnicity, gender identity or location of the centre. However, sexual minorities were more likely than heterosexuals to think that it was important to ask about sexual identity.

The nature of services as well as participant and site characteristics provided a unique context for the responses to this question. Level of comfort with disclosure among clients is

likely to be variable. Based on responses from other groups of study participants, perceived low clinical relevance, staff capacity and comfort with asking about sexual orientation are likely to pose challenges to implementation in other sites. Nonetheless this is an emerging area that should be carefully considered along with necessary supports for health service providers to ensure that patients feel safe to disclose if they wish to do so.

Income. Low income is a marker of socioeconomic status and affects health in several ways.(14,212) It influences access to material resources such as food, clothing and shelter. Although persons with low income have access to publicly funded health care through provincial health coverage, they may struggle to access some services that may not be covered through other supplementary plans. This includes vision and dental care as well as prescription medications, podiatry, chiropractic care, physiotherapy and counselling from psychologists. (213) Screening for poverty has been widely promoted among family practitioners across Canada.(214–216) This approach has solicited information from a general question but has not advocated for the disclosure of specific income earned. The results for this study were similar to two other Canadian studies (47,176). Given the challenges encountered, it might be useful to screen using the standardised poverty question and follow up only those persons with positive screens by requesting information about their family income in order to link them to appropriate income security supports.

6.2 Participant perceptions of sociodemographic data collection

Proctor et al. (147) define acceptability as ‘the perception among implementation stakeholders that a given practice, service or innovation is agreeable, palatable or satisfactory’. Implementation of sociodemographic data collection depends on participant willingness to share their information. Consequently, acceptability is an important implementation outcome that needs to be assessed. In this study, acceptability was assessed based on perceptions and experiences of participants with the process of implementation. Domains of inquiry considered comfort with content, perceived importance of data collection, perceptions about who should be asked about social needs and preferences for mode of administration. Multiple perspectives including patients/clients, providers and administration were examined using individual and group interviews. The results will be further explored in this section.

Interviews confirmed that there was a gradient of comfort depending on the question and the context in which it was asked. Patient/client comfort with sociodemographic content was assessed in two sites (Sexual Health Centre and St Paul's Hospital). It was suggested by client participants at the Sexual Health Centre that questions about sexual orientation and income caused more discomfort with disclosure. Canadian studies (134,139) that have assessed public perceptions of sociodemographic data collection also suggest that there is lower acceptability for asking about these subjects. In addition to the personal nature of the question, collection of data about annual household income in multiple occupant households poses additional challenges. Primary intended uses of the information should determine the most appropriate question in a given setting. It might be more helpful to ask a general poverty question for clinical application.

Perceptions of some categories of staff towards sociodemographic data collection were unfavourable. Management was also less supportive of data collection for more sensitive issues such as sexual orientation in some sites. This is consistent with the literature that points to staff attitudes and apprehension as a major challenge for implementation. (217) The quality of training for staff in preparation for implementation has been identified as an important ingredient for success.(46,47) It will need to be accorded higher priority in order to scale up implementation to include an expanded set of questions.

It is interesting that although year of arrival had lower item response rates across the two sites where it was assessed, it was not mentioned as a cause for concern by any of the participants. There remains uncertainty about the interpretation of the pattern of responses to this question. Changes to the format of the question to include additional response options such as 'prefer not answer' may provide more insight.

A race/ethnicity question did not elicit an adverse response among participants who were interviewed. Despite predictions in the literature (134,139) that suggest lower acceptability for sociodemographic data collection among racialized groups, it was not borne out in this study. An interesting pattern emerged among participants with missing data to this question that remains unexplored. These participants were Canadian born and non-Indigenous with various other characteristics including homeownership and postsecondary education. It is not possible to determine whether these individuals belong to a racial/ethnic minority group.

Information about Indigenous ancestry or identity was captured at all study settings although the question varied. Other studies (47,176) have integrated response options into a single race/ethnicity question and achieved high response rates. In the two community sites, clients did not express concern. The context was different in that questions were self-administered compared to the acute care site where a single question was asked by registration personnel. The conditions of administration likely influenced the response.

At the hospital site, participants interviewed were generally comfortable with being asked about Indigenous identity. This stood in stark contrast to staff who expressed concerns that patients would be offended and reluctant to answer. Despite being comfortable, perceptions of importance of data collection varied by sociodemographic characteristics. Further, several other factors influenced participant support for collection of information about Indigenous identity.

6.2.1 Factors influencing support for sociodemographic data collection

Race/ethnicity. In this study, perceived importance of collection of information about Indigenous identity varied by identity and age. A significantly higher proportion of Indigenous participants felt that it was important to ask about Indigenous identity compared to non-Indigenous participants. A study by Varcoe et al. (135) also found that individuals who identified as ‘White’, ‘Euro-Canadian’ or Caucasian tended to see little benefit to collection of ethnicity data for themselves. This is an important observation in the study’s context as it points to the larger issue of understanding privilege and levelling up among those most disadvantaged to achieve equity.

Age. A Canadian study (139) that examined public perceptions of sociodemographic data among urban dwelling Ontarians found that younger persons (18 – 34 years) were more supportive (less likely to disagree) of data collection for equity monitoring than individuals older than 55 years. In this study, a higher percentage (62% and 73% respectively) of those who were younger (18-34 years) and older (≥ 65 years) felt that it was not important to ask about Indigenous identity compared to those individuals 35-64 years (50%). These findings may be a reflection of the underlying distribution of race/ethnic groups in the sample however the explanation remains uncertain.

Understanding why data is being collected. Generally, among the subset of participants who assigned high priority to asking about social factors, there was lived or vicarious experience of the benefits of data collection. For example, clients/patients cited how care could be tailored based on knowledge of social factors or programs could achieve better understanding of the needs of clients who access care. This is consistent with studies (47,48,110,176) that suggest understanding the rationale for data collection supports patient disclosure of sociodemographic information. Further, it strengthens the argument for increasing public awareness about the need and benefits of data collection in order to support wider implementation of data collection.

Trust in organization's motives. Even when participants were not entirely certain about why the sociodemographic information was being requested, those individuals who had prior positive experiences with the health care system and trusted the institutional motives for asking were willing to share their information. Kandula et al. (219) found that individuals who had experienced racism and discrimination were less trusting of institutions. This is important in the historical context of relations between Indigenous and non-Indigenous Canadians. It also suggests a broader role for fostering supportive environments that are welcoming to individuals from culturally diverse backgrounds.

Concern regarding relevance of data collection. Two of the most common reasons for lack of support for sociodemographic data collection relate to perceptions that the information has low relevance to the delivery of care or is inappropriate to share in health care settings. The importance of clear explanations of the purpose for data collection was alluded to earlier. These two factors may be addressed through increased awareness of the benefits of sociodemographic data collection in equity monitoring and tailoring individual care.

Concern for misuse/adverse effects. A more insidious concern pertains to the few participants who expressed fears of misuse of sociodemographic information and adverse effects of disclosure on quality of care. Several studies (134,135,139) have identified potential harms of collecting sociodemographic information in health care settings. These harms (135) arise from potential for reinforcing stereotypes about racialized groups when individuals are assigned labels, subjecting individuals to a racializing process by requesting disclosure of ethnicity and increased participant burden as a result of fear and stress at the consequences of disclosure. The value of

an enabling and supportive environment cannot be underestimated where staff are adequately prepared and skilled to deliver high quality care to all persons.

In the context of a single question related to Indigenous identity in the acute care site, the problem was magnified. The limitations of Indigenous identity as the single marker of vulnerability must be acknowledged.(220) Additional information about social context is important for further risk stratification. Further, although individuals in theory can choose whether they would like to disclose their identity, some may argue that their identity is obvious based on their physical appearance. This makes it difficult to disentangle race/ethnicity assigned by an observer and self-identification. For this reason, it might still be important to confirm that an individual identifies as First Nations or Métis before offering cultural services as it is impossible to know whether the recorded status was based on alternative means of identification such as physical appearance or Registered Indian status as indicated on health card.

Service context. Client and provider perceptions of importance of collection of sociodemographic information appeared to be influenced by the context in which the information was requested. Client participants at immunization clinics assigned lower priority to sociodemographic data collection because they perceived that the visit was focused with limited opportunity to explore other issues. This was consistent with the provider's perspective and experience that time was a limiting factor. In contrast, most providers and client participants at the Sexual Health Centre perceived that it was important to ask about social factors in order to receive support for any identified needs.

Reason for sociodemographic data collection. The extent to which sociodemographic data was applied clinically varied across project sites. In two sites, responses to sociodemographic questions were used to tailor care and link patients to appropriate cultural supports respectively. At immunization clinics, the information was used to identify needs and plan for service improvement. It was the opinion of a key informant that clients would be more comfortable with data collection for general quality improvement. However, some clients shared a disparate view and welcomed a personalized approach to care. Lofters et al. (134) suggest that patients more readily grasp clinical application of sociodemographic data collection in the delivery of care to individuals compared to monitoring of equitable access to care at the population level. It is difficult to speculate with any degree of certainty whether clients would be

equally comfortable with varied uses of their sociodemographic information based on this study. However, it seems reasonable that participants would have considered the particular context in which data was collected at a given site as their point of reference.

Previous research (221) has found that the rationale provided for data collection affects client comfort levels. Baker et al. (221) reported greater patient comfort with reporting race and ethnicity if information was used for quality monitoring when compared to other reasons including government recommendation, needs assessment or for tailoring personal care. A Toronto Tri-Hospital Health Equity project (47) also found high acceptability for collection of a wide range of sociodemographic information from patients in acute and ambulatory care settings. The rationale provided could best be classified as ‘quality improvement’. Although regional variation in support for sociodemographic data collection exists, the study’s results and literature lend support for collection of sociodemographic information in the local context for both quality improvement and clinical application purposes.

6.2.2 Acceptable modes of administration

Participants were also asked about their preferences for collection of sociodemographic information during interviews. There was marked variation in preferences across project sites. Role expectations of various categories of health service personnel, sensitivity of the question and practical considerations appeared to be the main drivers of participant preferences.

Role expectations. At immunization clinics, most participants would prefer that the nurse asks about their social circumstances. This finding is not surprising and has been noted in other studies. (134,139) Management also agreed that under ideal conditions, nurse providers were well placed to ask and intervene on individual social factors. However concerns about time constraints outweighed perceived benefits during this service. Despite the preference for nurse provider, high response rates to questions suggest that self-administration is a viable option for data collection in this setting. Potential concerns about privacy and confidentiality would need to be addressed along with preparation of reception staff to respond to challenges to the request for information.

Sensitivity of questions. At the Sexual Health Centre Saskatoon, there was more comfort with self-administration although participants also expressed preferences for other modalities. Some client participants preferred the privacy of answering sensitive question discreetly

compared to provider-administration. A prior Canadian study (47) suggested that method (paper or tablet) as well as who and where data was collection was associated with the proportion of valid responses. More private settings facilitated disclosure and paper (compared to tablet) was better for collecting more sensitive information such as disability status, sexual orientation and total annual family income. Some participants at this site also explained that completion of the questionnaire while waiting to be seen was a means to actively pass the time.

Practical considerations. The majority of outpatient participants at St Paul’s Hospital preferred to be asked about their identity at registration. Participants expressed that demographic information was already being collected at this point, hence it was practical to also include information about Indigenous self-identity. From a management perspective, this mode of administration was also least disruptive for work flow hence it was the best choice for data collection.

Among inpatient participants at St Paul’s Hospital, more variation was noted with mixed views recommending either provider or registration. Participants explained that it was more comfortable for a provider to ask about identity as they were best placed to determine whether the information was necessary for their care. This view is consistent with another Canadian study (48) that also found a similar preference among inpatients in pediatric setting.

The mode for data collection in each site was determined by practical considerations including work flow, time for administration and staff capacity. Data collection was integrated into routine registration processes wherever possible. Multiple modalities are likely to be required to meet diverse needs in various settings. The two modes of administration that were tested were feasible in the given study contexts and offer local proof-of-concept. Whatever the primary mode selected, efforts should be made to follow up with persons who have not had the opportunity for data collection.

6.2.3 Perceptions about appropriate population for sociodemographic data collection

Most participants across all sites felt that ‘everyone’ should be asked about their social circumstances. However a few participants advocated for selective screening of clients most likely to have adverse social needs. Universal offer ensures that patient/client’s right to choose

whether or not to respond is preserved. Raising awareness of the rationale for data collection among all stakeholders would dispel myths and also support wider implementation.

6.3 Facilitators and barriers to implementation of sociodemographic data collection

The collection of sociodemographic data in the Canadian context is limited with mixed experiences. (46–48,176) This suggests that context specific enablers may be important in implementation success. The Consolidated Framework for Implementation Research (CFIR) (143) and Chaudoir et al. (146) offer useful multilevel frameworks for assessing factors that affect the implementation of health innovations. Based on these overlapping frameworks, a number of perceived factors have been identified through key informant interviews at each site including structural, organizational, provider, patient and characteristics of the initiative. This section frames discussion related to facilitators and barriers using these operationalized constructs.

There were several perceived facilitators and barriers to collection and use of sociodemographic data in the local context. These were similar in many regards to those identified by the literature including other Canadian projects (46–48) that collected sociodemographic data for health equity purposes.

Structural factors. While there is increasing recognition of the importance of social determinants of health, there is no overarching local mandate for collection and use of this information to support equity measurement and quality improvement. The Public Health Observatory, Saskatoon Health Region has charted the course and developed a regional equity position statement that establishes equity as a central health region organizational imperative. (222) The collection of sociodemographic data has been championed as a strategic activity that is required to advance the equity agenda and improve the quality of care for all. This is a meaningful development and may pave the way for stronger dictates and widespread implementation. In 2006, Massachusetts publically mandated standardized data collection of race and ethnicity in all acute care hospitals. (82) While not without its challenges, it was a positive step towards identification of health disparities. A similar TC LHIN mandate to institute standardized data collection in all hospitals in Ontario has continued to be an impetus for work in

this area. (47) These examples of successful policy drivers of standardized sociodemographic data collection offer a model for consideration in the local context.

Across pilot sites where there was an institutional mandate or compatible vision for equity, it was easier to build the project around these goals. The desire to collaborate and to work through challenges of implementation was present in all project sites. The need for information to understand client sociodemographic characteristics and service related preferences was a key driver of implementation at immunization clinics. The project was a good fit with the centre's priority and facilitated a common understanding of shared goals. Added impetus for centre participation also came from district-level support for efforts to improve sociodemographic data collection. Since the completion of the surveys at this centre, other primary care sites have conducted similar surveys.

In a similar manner in the other two sites, the project satisfied an important need for information to improve care delivery. This suggests that opportunities exist for expansion of this work in its current form. It is likely that a mandate to collect information in a standardized way in addition to the necessary supports to prepare staff for expanded roles and IT systems to capture and share information across providers will be needed to support wider implementation.(217,218)

The social context of the health care organization was also relevant to understanding implementation decisions. The St Paul's Hospital is located in close proximity to inner city neighborhoods where a disproportionate number of residents live in poverty and experience social and economic marginalization. (167) A key demographic feature of the neighborhoods is the high proportion of Indigenous peoples who reside there, largely because of availability of more affordable or social housing than other areas of the city. Given this unique geographical context and the existing work to provide culturally appropriate care for First Nations and Métis peoples, stakeholders prioritized a single Indigenous identity question for the project.

The Sexual Health Centre Saskatoon (168) occupies a unique niche as a private provider of sexual and reproductive health services. As an organization, it espouses values of inclusiveness and accessibility for all persons especially the most vulnerable. The history of the organization is inextricably linked to the local advocacy for sexual and reproductive health rights. As the organization is pro-choice, it was not desirable to incorporate a question about religious affiliation into the sociodemographic data collection tool. The organization supports women in

their reproductive choice and offers options counselling without moral judgements. The scope of services provided by the organization fit squarely with interest in capturing information about gender and sexual identity. This naturally influenced willingness to incorporate related questions in the sociodemographic data collection tool. There was also some experience with data collection. In contrast, there was reluctance to incorporate questions related to sexual identity in less specialised context of immunization clinics.

Although all pilot sites were keenly interested and motivated to implement sociodemographic data collection, the lack of an overarching mandate resulting in a fragmented approach that was dependent on the organization's initiative. The importance of an enabling environment that embodies commitment and support for health equity actions through the appropriate system level mandates has been acknowledged. (223–225) The results of the study demonstrate the potential local effects that could be multiplied with the right policy directives. However, these high level system factors were not necessarily explicitly mentioned by key informants.

Resources. The feasibility of the project was influenced by the availability of resources. A key facilitator was the availability of support from dedicated persons to administer the survey to consenting clients at immunization clinics. The general sentiment was that integration of the survey into the routine registration process was not desirable as it would adversely affect work load. The concerns from providers about the limited time for additional tasks also suggested that service design elements needed to be reoriented to support any future clinical application in this site despite immense possibilities for application with such as captive population.

There were financial resource constraints at the private sector community site as a result of their existing funding model. Projects at this site were often driven by external funding priorities consequently support was critical for implementation. While there continues to be willingness to capture all project related elements, the organization's reality may relegate this to a lower priority and jeopardize its ability to sustain project efforts.

One of the three pilot sites in this study relied on the project team to support distribution of questionnaires to potential participants. While other Canadian projects (47,48) have relied on external support of research personnel during the pilot phase to perform various roles, all transitioned to sustainable models embedded in routine medical health information systems. In

the case of Toronto (47), building capacity of registration service personnel enabled smooth integration of sociodemographic data collection into routine work flows and processes. In this study, resources were more influential at community project sites compared to the acute care site. This suggests that future efforts to scale up implementation will need to be adequately resourced.

Organizational factors. At the organizational level, leadership support facilitated implementation in all sites. The governance structures of the three institutions varied and this had implications for autonomy to make project decisions. In smaller organizations, managers had greater autonomy and latitude to make decisions. When there was a flat structure and leadership was committed, project implementation followed expeditiously. In larger organizations such as the hospital site, the support of leadership at all levels was required. Although there was early engagement of leadership at the highest levels, interest ebbed and flowed with competing organizational priorities. The enduring commitment, determination and advocacy of a middle manager eventually propelled the project to a higher priority where it was more visible and the need for action perceived as more acute.

Leadership has been identified in the literature as an important catalyst for health equity action. (223,226) Support from leaders at all levels (system, organization, individual) is needed to advance health equity and in particular the implementation of sociodemographic data collection. The concept of an equity champion has been applied to describe individual leaders who create a vision and engage others to promote positive change and momentum to achieve the desired goal. (226) In the acute care site, the project team engaged with focal points who were recognized as equity champions and who were empowered to implement the project activities. In all project sites, the role of leaders in facilitating the project was acknowledged.

Information technology infrastructure was identified as both a facilitator and barrier to implementation. In the only acute care site, a question pertaining to Indigenous identity was introduced within the registration system. This resulted in a smooth almost imperceptible integration alongside other questions. However, capacity to include the expanded list of response options was limited. Despite the limitations inherent in the legacy system, it facilitated sharing of the information collected with First Nations and Métis Health Services to support provision of culturally appropriate care. At all other sites, data collection utilized parallel tools and procedures which had implications for ease of data sharing and integration into patient care pathways.

Appropriate IT infrastructure offers a comparative advantage over paper based systems with institutionalization of sociodemographic data collection.

The Institute of Medicine has recommended the incorporation of social and behavioural factors into electronic health records in order to increase provider access to critical information to assess and address identified social needs.(227) Since 2009, as part of regulations to support the ‘meaningful use of electronic health records (EHRs)’, physician practices and hospitals in the USA receive incentives for installation of certified EHR systems and reporting of quality measures to demonstrate improved population health outcomes.(227) This examples illustrates a vision for effective integration and clinical application of standardized sociodemographic information similar to this project.

Process of engagement. There was a desire and ethical requirement for engagement of the First Nations and Métis community and leadership in order to canvass support for the project’s implementation. (191) During the preparatory phase in the acute site, the First Nations and Métis Health Service facilitated meetings with the First Nations and Métis Health Council. The rationale for the project was explained and concerns were addressed. There were also meetings with individual First Nations to allow for additional time to address questions. The Aboriginal Patient and Family Advisory Committee also provided input about the sociodemographic data collection tool. Finally, the Saskatoon Tribal Council was also engaged as not all First Nations and Métis constituents were represented on the First Nations and Métis Health Council. Although community engagement lengthened the planning process by more than a year, it was important to ensure that community preferences were considered and provisions to ensure that participants felt safe to disclose in health care settings were instituted.

In other sociodemographic data collection projects (46–48), engagement of relevant stakeholders has been an important part of the planning process and contributed to successful implementation. In this project, the team sought to establish a partnership with stakeholders that built bridges for broader health equity work. Specifically with regard to First Nations and Métis stakeholders, there was acknowledgement of the four Rs including respect, reciprocity, responsibility and relevance.(228) In keeping with these principles, the team was respectful of Indigenous knowledge and traditions. Efforts to ensure reciprocity included sharing information and providing opportunities for feedback. In addition the team was responsible and accountable

for agreed actions and considered the project's relevance to Indigenous health needs and priorities.

Provider factors. Provider level factors also affected project implementation. Provider is used as a general term for health service professionals who interact with the patient in the course of the health encounter. Several studies (78,217,229) describe multiple concerns of health care providers with regard to sociodemographic data collection. These included time constraints, perceived patient and staff discomfort, cost and perceived legal barriers. Health service personnel in the study expressed many of these same concerns.

Although in theory there was consensus by nurse providers about the importance of social determinants, time constraints and perceived relevance within specific services (such as immunization) pose a challenge to data collection. There is a need for re-orientation of service design in order to support integration of the sociodemographic information during child health visits. Given the coverage of immunization and child health/wellness clinics, this program offers immense potential and opportunity for collection and application of sociodemographic data.

There was apprehension and reluctance by registration personnel to collect sociodemographic data except at the private sector site. The pre-post education assessment showed that registration participants at the acute care site gained specific knowledge however attitudes remained unfavourable. During implementation, there were higher rates of blank/not stated fields as a result of some patients not being asked the Indigenous identity question. This likely reflects a combination of factors including leadership and poor compliance by registration personnel with asking all patients as well as inability of some patients to answer because of their health condition or other barriers.

Other projects (47,48,176,230) have urged that quality education for staff is critical for successful data collection. Although the two hour education session was not expected to produce culturally competent staff after a single encounter, it was designed to equip staff with the cultural awareness and understanding to engage others respectfully and respond to patient requests about why the information was being collected. A recent systematic review (231) assessed the evidence for effectiveness of interventions for improving cultural competence in health care for Indigenous peoples. Few education/training interventions for health professionals improved

knowledge however most found improved confidence to deliver care for Indigenous peoples. This suggests that education and or training may not be sufficient to change behavior.

Staff comfort and support remained a challenge at the acute care site during the project. Laminated cards outlining the procedures for asking and recording responses were provided for each registration station. The project team also tried to find creative ways to share stories about how patient care was being improved by the collection of identity information. The registration team was also recognized for their efforts with a Bravo award during the study. These strategies did not increase coverage for Indigenous self-identification.

At immunization clinics, the questionnaire was administered by designated non-clinical staff as it was thought to be the most efficient way to collect the information while not burdening staff with additional tasks. Improved staff capacity would be required to support ongoing data collection. Integration of training into orientation for service personnel as well as inclusion of specific competencies that require acquisition of skills to ask and respond to patient concerns about sociodemographic questions may facilitate sustained data collection efforts.

Client/patient factors. Studies (91,108,221) suggest that there is variable support among patients for sociodemographic data collection. In this study, clients had high acceptability for a subset of sociodemographic questions across two modes of administration. A gradient of comfort was observed depending on the context and specific question that was evaluated. Patient/client willingness to disclose personal information is the Achilles heel for successful data collection through self-reports. Consistent with findings of other studies (47,108,110), patient understanding of why the information is being collected and how it will be used for their benefit is necessary to foster acceptance. This strengthens the argument for effective information and communication strategies to increase patient awareness of benefits. It is also hoped that over time patient willingness to disclose may allay staff fears that any requests for data collection will be met with anger and conflict.

Intervention characteristics. The nature of the initiative conferred a relative advantage at all sites where it was implemented. The intervention satisfied an existing need for sociodemographic information that would inform the way care was delivered. Further, the experience of implementation in other provinces such as Ontario and Winnipeg provided support for feasibility and efficacy of the project in the local context.

6.4 We Ask Because We Care Logic Model revisited

The original logic model appropriately focused on three main activities including capacity building for staff involved in delivering various aspects of the initiative, development of a plan for project communication and monitoring and evaluation. The intensity of the training was too low to achieve the anticipated level of staff comfort needed for implementation in the acute care site. In other Canadian projects (47,48), the length of training sessions was variable but longer than 3 hours and often consisted of multiple sessions. It is interesting that although the project team perceived that the session was too short, registration personnel expressed a different view. The mismatch in expectations between trainer and trainee calls for exploration of other modalities. Further, the combination of time constraints (in sequestering staff for training) and low interest among some staff in the subject of equity and social determinants of health offer challenges to finding the right balance for learning opportunities.

Given the experience with this project, the importance of high quality training and preparation of staff was affirmed. The team has started to develop content to be delivered using an online platform. In future, it has also been recommended that training related to social determinants of health and how to ask the questions should be integrated into structured opportunities such as orientation and ongoing staff development for registration personnel. It would also be helpful to expand competencies to include ability to ask and respond appropriately to patient requests for information.

The other area of concern related to dissemination of information and education materials for patients/clients about the project. Similar to other projects (47,48), we developed posters and brochures that explained the rationale for sociodemographic data collection, uses of the information, voluntary nature of disclosure and assurances of confidentiality. During interviews, it was apparent that patients were often preoccupied with other concerns and did not see the posters that were displayed. Very few patients requested additional information from registration or research personnel. This presents a dilemma for future efforts to increase patient awareness about the importance and benefits of sociodemographic data collection. The experience further confirmed the central role of staff who collect sociodemographic information and the need for them to be adequately prepared to respond to questions and concerns as the first point of patient contact. It is likely that posters and brochures will continue to be secondary sources of

information however efforts should be made to translate these materials into other commonly spoken languages to increase access among persons with limited English language proficiency.

The influence of structural factors on implementation is not prominent or well explored by the model. Legal and policy mandates for sociodemographic data collection particularly when enforced are powerful levers that create a supportive environment that facilitate data collection. There is a vague acknowledgement in the diagram (Figure 3-2) that factors external to the institution are important however their role needs to be better defined. In the local context, a mandate does not exist and the work is in its infancy, hence this may explain the absence in the model. Nonetheless, future efforts to achieve wider implementation may be accelerated by advocacy for provincial mandates for sociodemographic data collection in health care settings.

Another important factor that emerged during the project related to the process of implementation. Engagement of stakeholders was a critical part of preparation for implementation. A participatory process ensured that the needs and concerns of persons who would be affected by data collection were adequately considered. Key lessons learned from other projects included the benefits of establishing coordination structures with key stakeholders and grounding the process in institutional realities and needs. (47,48,119) The model identifies project partners as a critical project input but is silent regarding the activities of project partners that contribute to successful implementation.

Although the model affirmed the importance of local factors (mostly at the individual level), it is limited in embracing the complexity of factors that operate at multiple levels. This needs to be improved to account for a broader range of factors that may be implicated in a particular project's success with sociodemographic data collection. A comprehensive model of implementation of sociodemographic data collection is an important contribution to the literature that will enable other researchers to identify facilitators and develop strategies to mitigate against barriers. More work is needed to empirically test the utility of the model in diverse contexts.

Although all sites improved collection of sociodemographic data and identification of social needs through the project, there was little evidence to support its clinical utility in this study. With the exception of First Nations and Métis Health Service who increased the identification of underserved clients, there are still barriers to clinical application despite its intuitive appeal. There are indications of system readiness locally with the introduction of

electronic health records and increased capacity to share information across providers. These IT infrastructural developments could pave the way for standardized sociodemographic data collection.(227) Currently, there is a need for more research engaging clinical providers to further examine the best ways to integrate sociodemographic data into patient care and treatment pathways. However, there appears to be adequate support for use of sociodemographic information for health equity purposes. This suggests that an incremental approach to application may be indicated at this time until the evidence becomes available to guide clinical application.

From a research and evaluation perspective, rapid cycle evaluation approaches are ideal for ongoing assessment of local efforts to collect and apply sociodemographic data.(232) In all project sites, decision makers committed to a relatively short period to implement and assess effects of sociodemographic data collection. In the typical research design, data is often collected and only analyzed at the end of the study. Rapid cycle research employs a process that can be achieved over a relatively short period by implementing and assessing small tests of change to address a problem. The process is applied early in the project and often in multiple cycles with the results used to adapt/improve the initiative. Despite the success in the three project sites, contexts are likely to be different even in the same type of health care organization. Hence, other health care settings that embark on implementation should employ an appropriate process to test incrementally what works best under their local conditions.

Rapid cycle research offers a rigorous process where problems are identified and addressed using incremental approaches that are contextually informed. (232) Through an iterative process, teams move through six phases including preparation, exploration of the problem, knowledge exploration, solution development, solution testing and implementation and dissemination.(232) There are several open access tools that are available for each of the six phases that help teams to successfully navigate the process.

6.5 Strengths and limitations of study

The evaluation employed both qualitative and quantitative methods of data collection. While more resource intense, it allowed deeper understanding of the pattern of participant responses and experiences with project implementation. The study tapped into multiple perspectives at various levels and was able to offer solutions grounded in the organizational reality and informed by intimate knowledge of intersections with other work.

Cases were studied sequentially which allowed for lessons to be carried forward throughout the study of subsequent sites. This experience with other sites brought currency to the project and increased interest about the project among stakeholders. Data collection and analysis was mostly conducted by a single researcher. While this allowed for immersion in sites and building relationships with partners, a singular etic vantage point likely limits complete understanding of all contextual facets of the sites/events.

The study explored multiple settings in the local Saskatoon context however no rural sites were included. It is likely that the results may have limited application in these settings particularly if patient/client characteristics and perceptions differ. Implementation was extremely context sensitive hence questions, mode of administration and application of information varied across settings. While it was necessary to adapt the form of the intervention for successful implementation, it is unlikely that experiences can be transplanted across sites.

The reliability of the sociodemographic data questionnaire was not assessed as part of the current project. Although the questions had been adapted, it would have been desirable to test the psychometric properties of the complete tool in the local context. There currently is no gold standard for sociodemographic questions. While several questions are included in population health surveys or census, the clinical context may elicit more nuanced responses. This is an issue that should be resolved. Cognitive interviews may be helpful to understand the underlying thought process of the few questions that posed difficulty for participants.

The tool and questions were only available in English. All interviews and interactions with patient participants also occurred in English. This necessarily limited participation to persons who were fluent in English and had the capacity to understand the questions. The perceptions of individuals with limited English language proficiency may be different to those expressed by language concordant participants. It will be important to access resources for translation in order to support more inclusive participation.

Sample sizes and participant characteristics varied at project sites. Particularly in instances where participation rates were lower, the sample may not have been representative of the study population. Consequently, it is difficult to determine whether patterns of responses reflect those of the source population. For example, there were relatively fewer male participants across sites except the acute care site where only a single question was evaluated. Similarly there were fewer older participants at community sites compared to acute care sites. This affects the types of

inferences that can be made with certainty. Larger samples with diverse participant characteristics would be needed to test the full complement of sociodemographic questions in a clinical context.

6.6 The way forward

The collection of individual level patient sociodemographic data in health care settings is needed to understand the social needs of patients who access services, identify health disparities in care process and health outcomes, inform the development of targeted community health interventions and tailor individual care to holistically address medical and social needs. (16) The project represents an important milestone in advancing the local health equity agenda. It potentially ushers in a shift in cultural attitudes to data collection in health care settings, although receptiveness to the initiative likely varies across settings.

Since the project has been implemented, there has been keen interest from providers in clinical application of sociodemographic data. There is currently a pilot project exploring feasibility and acceptability of sociodemographic data collection and its application in a primary care setting. The tools employed during this evaluation were adapted for the current primary care project. When completed, the results will extend the local research about how to successfully apply the information in care and treatment pathways.

As sociodemographic information becomes more available in health information systems, demands for its application in research will also increase. The risks and benefits of sociodemographic data collection must always be acknowledged (220) The issue of capacity building for staff at all levels needs to be prioritized to ensure responsible use. Privacy concerns and protections are also of paramount importance as the sensitivity of the health information increases.

The phased implementation of electronic health records in the health region also presents an unprecedented opportunity to systematically capture comprehensive sociodemographic data and enhanced capacity to share information across providers to increase coordination and effectiveness of care. (227) During the project, electronic integration of a sociodemographic question facilitated its embedding within the routine work processes.

Finally, work to develop Pan Canadian health system performance measures for health inequity intersects with local efforts to collect sociodemographic data. (31) In 2016, the Canadian Institute for Health Information (CIHI) convened stakeholders to identify core stratifiers for use in measuring health inequalities. Based on consensus building exercises, the following elements

have been prioritized for data collection: age, sex, geographic location, Indigenous identity, education and income. Although work is ongoing, local and national efforts pave the way for systematic collection of sociodemographic data and signal positive change towards advancing health equity.

6.6.1 Recommendations

The following recommendations were suggested for consideration by the relevant authorities. They reflect the collective wisdom and experience with the project in the local context as well as information available about other similar initiatives.

- 1) Adopt a core set of standardized questions for wider urban implementation based on the regional priorities, availability of resources to address identified needs and capacity for data collection.
- 2) Consideration should be given to multiple locations and modes for data collection (e.g. more sensitive questions such as sexual orientation and household income may have better success if collected at points other than registration where care is delivered).
- 3) Further work is needed in rural contexts to adapt questions that will be appropriate and sensitive to their unique circumstances.
- 4) Build on existing provisions for collection of sociodemographic information as it is easier to integrate new elements than develop entirely new systems.
- 5) Include appropriate provisions into any upgrades of IT infrastructure to facilitate future data collection in all health care settings.
- 6) Develop a mechanism to follow up with patients/clients who have not had the opportunity to be asked/complete the sociodemographic data collection tool. This would improve quality and completeness of information.
- 7) Build capacity for cultural competence of all levels of staff to facilitate data collection and application of sociodemographic information. This is likely to require investment of time to allow for the internal reflective processes and skill building that is required. It may be best accomplished through enhancement of structured opportunities such as orientation of new staff members, staff development sessions for existing staff and embed requisite core competencies into job descriptions for frontline staff.
- 8) Invest in decision supports for staff whether through prompts/reminders as appropriate to encourage data collection.

- 9) There is a need to increase awareness of patients/clients about the importance of sociodemographic data collection and how the information can be used to improve the quality of care. This would help to change prevailing norms and culture of information sharing in health care settings.
- 10) Explore strengthening the organizational imperative for data collection and application through the health region's equity agenda. This has been an important ingredient for success in other provinces such as Ontario that have scaled up implementation of sociodemographic data in health care settings.
- 11) Continue to engage stakeholders in meaningful partnerships to canvass ongoing support for data collection and other interventions to promote equity oriented care.

6.7 Conclusion

It was feasible to collect selected sociodemographic data in three urban health care settings. There was a gradient of comfort depending on the question and the context in which it was asked. Consistent with other studies, lowest item response rates occurred for questions related to annual household income and year of arrival to Canada. A universal approach to screening was endorsed by most participants although a minority contended that targeted approaches may be more appropriate. Preferences for mode of administration varied across sites and suggested that availability of multiple options may be required, Preparation of staff for implementation was challenging and more capacity building is needed to increase comfort with data collection. Across sites, multilevel factors including structural, organizational, as well as individual level patient and provider factors influenced project implementation. More research is needed to assess whether findings are applicable to the full complement of questions in more diverse settings.

REFERENCES

1. Brascoupé S. Cultural Safety. Exploring the applicability of the concept of cultural safety to Aboriginal health and community wellness. *J Aborig Health* [Internet]. 2009 Nov [cited 2017 Jan 24]; 5(1): 6-41. Available from: http://www.naho.ca/jah/english/jah05_02/V5_I2_Cultural_01.pdf.
2. Braveman P. Health disparities and health equity: concepts and measurement. *Annu. Rev. Public Health*[Internet]. 2006 Apr 21[cited 2017 Apr 12];27:167-94. Available from: <http://annualreviews.org/doi/abs/10.1146/annurev.publhealth.27.021405.102103>
3. Braveman P, Gruskin S. Defining equity in health. *J Epidemiol Community Health* [Internet]. 2003 Apr [cited 2017 Feb 12];57(4):254–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12646539>
4. Rychetnik L, Hawe P, Waters E, Barratt A, Frommer M. A glossary for evidence based public health. *J Epidemiol Community Health* [Internet]. 2004;58(7):538–45. Available from: http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=PubMed&dopt=Citation&list_uids=15194712%5Cnhttp://www.ncbi.nlm.nih.gov/pmc/articles/PMC1732833/pdf/v058p00538.pdf
5. Bertakis KD, Azari R. Patient-centered care is associated with decreased health care utilization. *J Am Board Fam Med* [Internet]. 2011 [cited 2017 Feb 12];24(3):229–39. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21551394>
6. Marmot M, Friel S, Bole R, Houweling TA, Taylor S .Closing the gap in a generation: health equity through action on the social determinants of health. *Lancet* [Internet]. 2008 [cited 2017 Feb 11]; Available from: <http://www.sciencedirect.com/science/article/pii/S0140673608616906>
7. Weber M, Parsons T, Henderson AM, Alexander M. *The theory of social and economic organization*. New York:Free Press; 1967.
8. Krieger N. Theories for social epidemiology in the 21st century: an ecosocial perspective. *Int J Epidemiol* [Internet]. 2001;30(4):668–77. Available from: <http://ije.oxfordjournals.org/content/30/4/668.short>
9. Minkler M, Wallace SP, McDonald M. The political economy of health: A useful theoretical tool for health education practice. *Int Q Community Health Educ* [Internet]. 1994 Jul [cited 2017 Mar 20];15(2):111–25. Available from: <http://journals.sagepub.com/doi/10.2190/T1Y0-8ARU-RL96-LPDU>
10. Cassel J. The contribution of the social environment to host resistance. *Am J Epidemiol* [Internet]. 1976 Aug [cited 2017 Mar 20];104(2):107–23. Available from: <https://academic.oup.com/aje/article/101648/THE>

11. McEwen BS, Seeman T. Protective and damaging effects of mediators of stress: Elaborating and testing the concepts of allostasis and allostaticLoad. *Ann N Y Acad Sci* [Internet]. 1999 Dec [cited 2017 Mar 20];896(1):30–47. Available from: <http://doi.wiley.com/10.1111/j.1749-6632.1999.tb08103.x>
12. Mindell J, Ison E, Joffe M. A glossary for health impact assessment. *J Epidemiol Community Health* [Internet]. 2003 [cited 2017 Feb 11];57:647-51 Available from: <http://jech.bmj.com/content/57/9/647>
13. Behforouz H, Drain P. Rethinking the social history. *New Engl J Med*[Internet]. 2014 Oct [cited 2017 Feb 11]; 371(14):1277-9Available from: <http://www.nejm.org/doi/full/10.1056/NEJMp1404846>
14. Mikkonen J, Raphael D. *Social Determinants of Health: The Canadian Facts* [Internet]. Toronto: York University School of Health Policy and Management; 2010 [cited 2014 Oct 12]. Available from: http://www.the_canadianfacts.org/the_canadian_facts.pdf.
15. Stone C, Rosella L, Goel V. Population health perspective on high users of health care Role of family physicians. *Can Fam Physician* [Internet]. 2014 [cited 2017 Feb 11];60(9):781-3 Available from: <http://www.cfp.ca/content/60/9/781.short>
16. Gottlieb L, Sandel M, Adler N. Collecting and applying data on social determinants of health in health care settings. *JAMA Intern Med* [Internet]. 2013 Jun [cited 2017 Feb 11];173(11):1017-20 Available from: <http://jamanetwork.com/journals/jamainternalmedicine/fullarticle/1682357>
17. Marmot MG. Closing the gap in a generation. *Bull World Health Organ*. 2011;89(11):702. Available from: <http://www.who.int/bulletin/volumes/89/10/11-094862.pdf>
18. World Health Organization. *Constitution of the World Health Organization* [Internet]. Geneva: WHO; 1946 [cited 2016 Mar 6]. Available from: <http://apps.who.int/gb/bd/PDF/bd47/EN/constitution-en.pdf?ua=1>
19. United Nations General Assembly. *Universal Declaration of Human Rights* [Internet]. Paris: United Nations; 1948 Dec [cited 2016 Mar 6]. Available from: http://www.ohchr.org/EN/UDHR/Documents/UDHR_Translations/eng.pdf.
20. Lalonde M. *A new perspective on the health of Canadians*[Internet]. Ottawa: Ministry of National Health and Welfare. 1981;76. Available from: <http://www.phac-aspc.gc.ca/ph-sp/pdf/perspect-eng.pdf>
21. World Health Organization. *Declaration of Alma-Ata* [Internet]. 1978 [cited 2017 Feb 12]. p. 6–12. Available from: http://www.who.int/publications/almaata_declaration_en.pdf?ua=1

22. World Health Organization. The Ottawa Charter for Health Promotion [Internet]. World Health Organization; 1986 [cited 2017 Feb 12]. Available from: <http://www.phac-aspc.gc.ca/ph-sp/docs/charter-chartre/pdf/charter.pdf>
23. Gray AM. Inequalities in health, Black Report: A summary and comment. *Int J Health Serv*[Internet]. 1982 Jul [cited 2016 Mar 4];12(3):349-80.
24. Acheson D. Independent Inquiry into Inequalities in Health [Internet]. London:The Stationary Office; 1980 [cited 2017 Feb 12]. Available from: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/265503/ih.pdf
25. United Nations. United Nations Millennium Declaration[Internet]. Geneva: United Nations; 2000 [cited 2017 Feb 12]. Available from: <http://www.un.org/millennium/declaration/ares552e.pdf>
26. United Nations. Beijing Declaration and Platform for Action [Internet]. Beijing:United Nations; 1995 Sep 15 [cited 2017 Feb 12]. Available from: <http://www.un.org/womenwatch/daw/beijing/pdf/BDPfA E.pdf>
27. United Nations. United Nations Declaration on the Rights of Indigenous Peoples [Internet]. Geneva: United Nations; 2007 [cited 2017 Feb 12]. Available from: http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf
28. World Health Organization. Rio Political Declaration on Social Determinants of Health [Internet]. Rio de Janeiro, Brazil:World Health Organization; 2011 Oct[cited 2016 Mar 6]. Available from: http://www.who.int/sdhconference/declaration/Rio_political_declaration.pdf
29. Pan American Health Organization. A century of public health in the Americas [Internet]. Washington, DC; 2013 [cited 2017 Feb 12]. Available from: http://www.paho.org/saluden-las-americas-2012./index.php?option=com_docman&task=doc_view&gid=155&Itemid=
30. Jackson B, Huston P. Advancing health equity to improve health: The time is now. *CCDR Suppl* [Internet]. 2016 [cited 2017 Feb 20];42(Suppl 1):S1-6. Available from: http://www.phac-aspc.gc.ca/publicat/ccdr-rmtc/16vol42/dr-rm42s-1/assets/pdf/16vol42s-1_ar-01-eng.pdf
31. Pan-Canadian Public Health Network. Indicators of health inequalities[Internet]. 2009 [cited 2016 Mar 6]. Available from: <http://www.phn-rsp.ca/pubs/ih-idps/pdf/Indicators-of-Health-Inequalities-Report-PHPEG-Feb-2010-EN.pdf>

32. Pampalon R, Hamel D, Gamache P. A comparison of individual and area-based socio-economic data for monitoring social inequalities in health. *Stat Canada* [Internet]. 2009 [cited 2017 Feb 12];20(4):82-003-X. Available from: <http://search.proquest.com.cyber.usask.ca/docview/207495271/fulltextPDF/B8F0D987EB13485EPQ/1?accountid=14739>
33. Geronimus AT. Using Area-based Socioeconomic Measures--Think Conceptually, Act Cautiously. *Am J Epidemiol* [Internet]. 2006 Sep 12 [cited 2017 Feb 12];164(9):835–40. Available from: <https://academic.oup.com/aje/article-lookup/doi/10.1093/aje/kwj314>
34. Schuurman N, Bell N, Dunn JR, Oliver L. Deprivation Indices, Population Health and Geography: An Evaluation of the Spatial Effectiveness of Indices at Multiple Scales. *J Urban Health* [Internet]. 2007 Jul 13 [cited 2017 Feb 12];84(4):591–603. Available from: <http://link.springer.com/10.1007/s11524-007-9193-3>
35. Denny K, Davidson MJ. Area-based socio-economic measures as tools for health disparities research, policy and planning. *Can J Public Health*. 2012;103(Suppl.2):4–6.
36. Deonandan RS. The mandatory census: Tension between individual rights and the public good. *Can J Public Health*. 2011;102(6):4–16.
37. Collier R. Long-form census change worries health researchers. *Can Med J* [Internet]. 2010 [cited 2017 Feb 12];182(12):1293. Available from: <http://go.galegroup.com.cyber.usask.ca/ps/i.do?&id=GALE%7CA237134719&v=2.1&u=usaskmain&it=r&p=CPI&sw=w&authCount=1>
38. Flach SD, McCoy KD, Vaughn TE, Ward MM, BootsMiller BJ, Doebbeling BN. Does patient-centered care improve provision of preventive services? *J Gen Intern Med* [Internet]. 2004 Oct [cited 2017 Feb 12];19(10):1019–26. Available from: <http://link.springer.com/10.1111/j.1525-1497.2004.30395.x>
39. Mead N, Bower P, Hann M. The impact of general practitioners' patient-centredness on patients' post-consultation satisfaction and enablement. *Soc Sci Med*[Internet]. 2002 Jul;55(2):283–99.
40. Meterko M, Wright S, Lin H, Lowy E, Cleary PD. Mortality among patients with acute myocardial infarction: The influences of patient-centered care and evidence-based medicine. *Health Serv Res* [Internet]. 2010 Oct [cited 2017 Feb 12];45(5p1):1188–204. Available from: <http://doi.wiley.com/10.1111/j.1475-6773.2010.01138.x>
41. Stewart M, Brown JB, Donner A, McWhinney I, Oates J, Weston W, et al. The impact of patient-centered care on outcomes. *J Fam Pract* [Internet]. 2000 [cited 2017 Feb 12];49(9):796–804. Available from: <http://www.mdedge.com/jfponline/article/60893/impact-patient-centered-care-outcomes>

42. Ulmer C, Mcfadden B, Nerenz DR. Race, ethnicity, and language data standardization for health care quality improvement [Internet]. Washington, DC; 2009 [cited 2017 Feb 12]. Available from:
<https://www.ahrq.gov/sites/default/files/publications/files/iomracereport.pdf>
43. Joloza T, Evans J, O'Brien R, Potts-Collins A. Measuring sexual identity: An evaluation report. 2010 [Last updated 2011 Mar 31; cited 2017 Jan 21]. London, UK: Office of National Statistics. Available from:
<http://webarchive.nationalarchives.gov.uk/20160105160709/http://www.ons.gov.uk/ons/rel/ethnicity/measuring-sexual-identity---evaluation-report/2010/index.html>
44. Taylor T. Developing survey questions in sexual orientation: Review of international organizations' experiences of administering questions on sexual orientation. 2008. London, UK: Office for National Statistics. Available from:
http://internationalexperiencesonsexualidentity_tcm77-181187.pdf
45. Pega F, Gray A, Veale JF, Binson D, Sell RL. Toward global comparability of sexual orientation data in official statistics: A conceptual framework of sexual orientation for health data collection in New Zealand's official statistics system. *J Environ Public Health* [Internet]. 2013 [cited 2017 Jan 21]; 47351. Available from:
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3694548/>
46. Bowens S, Botting I, Roy J. Promoting action on equity issues: A knowledge-to-action handbook. Edmonton, Alberta: School of Public Health, University of Alberta; 2011. Available from: <http://www.wrha.mb.ca/professionals/language/files/equityissues-handbook.pdf>
47. Wray R, Hyman I, (DGLConsulting), Agic B, Bennett-Abuayyash C, Kanee M, Lam R et al. We ask because we care. The Tri-Hospital + TPH Health Equity Data Collection Research Project Report [Internet]. Toronto, ON: Steering Committee. 2013 Sep [cited 2017 Feb 11]. Available from: <http://torontohealthequity.ca/wp-content/uploads/2014/10/FINAL-Full-Report-September-2013.pdf>
48. Gee S. The development of a pediatric health equity demographic data collection instrument. Project Summary Report. 2014 Dec. Toronto, ON: Hospital for Sick Kids Steering Committee. Available from:
www.torontocentrallhin.on.ca/.../Development%20of%20Paediatric%20Health%20Eq
49. The CLEAR Collaborative. The CLEAR Toolkit. 2013. Available from:
https://www.mcgill.ca/clear/files/clear/clear_toolkit_2015_-_english_1.pdf
50. Centre for Effective Practice. Poverty: A Clinical Tool for Primary Care Providers [Internet]. Toronto, ON: Centre for Effective Practice; 2016 [cited 2017 Feb 13]. Available from: https://thewellhealth.ca/wp-content/uploads/2016/05/Poverty_-_A_Clinical_Tool_for_Primary_Care_ProvidersMay-1.pdf

51. Bric V, Eberdt C, Kaczorowski J. Development of a tool to identify poverty in a family practice setting: A pilot study. *Int J Family Med* [Internet]. 2011 May [cited 2017 Feb 13];2011:812182. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/22312547>
52. Pratt R, Hibberd C, Cameron I, Maxwell M. The Patient Centered Assessment Method (PCAM): Integrating the social dimensions of health into primary care. *J Comorbidity* [Internet]. 2015;5(1):110–9. Available from: <http://www.jcomorbidity.com/index.php/test/article/view/35>
53. Colvin JD, Bettenhausen JL, Anderson-Carpenter KD, Collie-Akers V, Plencner L, Krager M, et al. Multiple behavior change intervention to improve detection of unmet social needs and resulting resource referrals. *Acad Pediatr* [Internet]. 2016;16(2):168–74. Available from: <http://dx.doi.org/10.1016/j.acap.2015.06.001>
54. Tames EP. *Clinical Partners in Advocacy : How Can I-HELP ?* [Internet]. Boston: Medical Legal Partnership; 2009. Available from: <http://www.dfccguide.org/docs/IHELPGuide.pdf>
55. Manchanda R, Gottlieb L. *Upstream Risks Screening Tool & Guide* [Internet]. Los Angeles, CA: Health Begins; 2015. Available from: <https://www.aamc.org/download/442878/data/chahandout1.pdf>
56. NHS Health Scotland and ISD Scotland. *Equalities monitoring guidance. Guidance and recommended questions for NHS Scotland* [Internet]. Edinburgh: NHS Health Scotland; 2012. Available from: <http://www.isdscotland.org/Health-Topics/Equality-and-Diversity/Training-Materials/EqualitiesMonitoringGuidance3403WEB.pdf>
57. Cahill S, Singal R, Grasso C, King D, Mayer K, Baker K, Makadon H. Do Ask, Do Tell: High levels of acceptability by patients of routine collection of sexual orientation and gender identity data in four diverse American Community Health Centers. *PLoS ONE* [Internet]. 2014 [cited 2016 Mar 22]; 9(9):e107104. Available from: <http://journals.plos.org/plosone/article?id=10.1371/journal.pone.010710475>.
58. Berkowitz SA, Hulberg AC, Standish S, Reznor G, Atlas SJ, D M, et al. Addressing unmet Basic resource needs as part of chronic cardiometabolic disease management. *JAMA Intern Med*. 2017;177(2):244-52. Available from: <http://jamanetwork.com/journals/jamainternalmedicine/fullarticle/2592698>
59. Health Leads. *Health Leads Toolkit*. 2016 [Last updated October 2016, cited 2016 Dec 31]. Available from: <https://healthleadsusa.org/wp-content/uploads/2016/07/Health-Leads-Screening-Toolkit-October-2016.pdf>.
60. Garg A, Marino M, Vikani AR, Solomon BS. Addressing families' unmet social needs within pediatric primary care. *Clin Pediatr (Phila)* [Internet]. 2012;51(12):1191–3. Available from: <http://journals.sagepub.com/doi/10.1177/0009922812437930>

61. Naz A, Rosenberg E, Labonté R, Andermann A. Health workers who ask about social determinants of health are more likely to report helping patients. Mixed-methods study. *Can Fam Physician* [Internet]. 2016 Nov;62(11):e684–93. Available from: <http://www.cfp.ca/content/62/11/e684.full.pdf+html>
62. Page-Reeves J, Kaufman W, Bleecker M, Norris J, McCalmont K, Ianakieva V, et al. Addressing Social Determinants of Health in a Clinic Setting: The WellRx Pilot in Albuquerque, New Mexico. *J Am Board Fam Med* [Internet]. 2016 [cited 2017 Apr 4];29(3):414–8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/27170801>
63. Garg A, Butz AM, Dworkin PH, Lewis RA, Thompson RE, Serwint JR. Improving the management of family psychosocial problems at low-income children’s well-child care visits: the WE CARE Project. *Pediatrics* [Internet]. 2007;120(3):547–58. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=17766528&site=ehost-live>
64. Garg A, Toy S, Tripodis Y, Silverstein M, Freeman E. Addressing social determinants of health at well child care visits: A cluster RCT. *Pediatrics* [Internet]. 2015;135(2):e296-304. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25560448><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC4306802><http://www.scopus.com/inward/record.url?eid=2-s2.0-84922611404&partnerID=tZOtx3y1>
65. Fleegler EW, Lieu TA, Wise PH, Muret-Wagstaff S. Families’ health-related social problems and missed referral opportunities. *Pediatrics* [Internet]. 2007;119(6):e1332–41. Available from: <http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.2006-1505>
66. Hassan A, Scherer EA, Pikcilingis A, Krull E, McNickles L, Marmon G, et al. Improving social determinants of health: Effectiveness of a web-based intervention. *Am J Prev Med* [Internet]. 2015;49(6):822–31. Available from: <http://dx.doi.org/10.1016/j.amepre.2015.04.023>
67. Gottlieb L, Hessler D, Long D, Amaya A, Adler N. A randomized trial on screening for social determinants of health: the iScreen study. *Pediatrics* [Internet]. 2014;134(6):e1611–8. Available from: <http://search.ebscohost.com/login.aspx?direct=true&db=cmedm&AN=25367545&site=ehost-live>
68. Gottlieb LM, Hessler D, Long D, Laves E, Burns AR, Amaya A, et al. Effects of social needs screening and in-person service navigation on child health: A randomized clinical trial. *JAMA Pediatr* [Internet]. 2016;94118(11):e162521. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/27599265>
69. Keller D, Jones N, Savageau JA, Cashman SB. Development of a brief questionnaire to identify families in need of legal advocacy to improve child health. *Ambul Pediatr* [Internet]. 2008;8(4):266–9. Available from: <http://www.sciencedirect.com.cyber.usask.ca/science/article/pii/S1530156708000877>

70. Kleinman RE, Murphy JM, Wieneke KM, Desmond MS, Schiff A, Gapinski JA. Use of a single-question screening tool to detect hunger in families attending a neighborhood H health center. *Ambul Pediatr* [Internet]. 2007;7(4):278–84. Available from: <http://www.sciencedirect.com.cyber.usask.ca/science/article/pii/S1530156707000536>
71. Hager ER, Quigg AM, Black MM, Coleman SM, Heeren T, Rose-Jacobs R, et al. Development and validity of a 2-item screen to identify families at risk for food insecurity. *Pediatrics* [Internet]; 2010 [cited 2017 Jan 30]; 126:e26–e32. <http://pediatrics.aappublications.org/content/126/1/e26>.
72. Garg A, Dworkin PH. Applying surveillance and screening to family psychosocial issues: implications for the medical home. *J Dev Behav Pediatr*[Internet]. 2011 Jun;32(5):418–26. Available from Medline.
73. The SURE Collaboration. SURE guides for preparing and using evidence-based policy briefs [Internet]. 2011. Available from: <http://global.evipnet.org/SURE-Guides/>
74. Critical Skills Programme. CASP [Internet]. Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist. 2017 [cited 2017 Jul 14]. Available from: http://docs.wixstatic.com/ugd/dded87_25658615020e427da194a325e7773d42.pdf
75. National Heart Lung and Blood Institute. Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies [Internet]. 2014 [cited 2017 Jul 15]. Available from: <https://www.nhlbi.nih.gov/health-pro/guidelines/in-develop/cardiovascular-risk-reduction/tools/cohort>
76. Booth A, Noyes J, Flemming K, Gerhardus A, Wahlster P, Van Der Wilt GJ, et al. Guidance on choosing qualitative evidence synthesis methods for use in health technology assessments of complex interventions [Internet]. 2016 [cited 2017 Jul 15]. Available from: <http://www.integrate-hta.eu/downloads/>
77. Hasnain-Wynia R, Pierce D, Pittman MA. Who, when and how: The current state of race, ethnicity and primary language data collection in hospitals [Internet]. 2004 [cited 2017 Jul 15]. Available from: <http://www.commonwealthfund.org/publications/fund-reports/2004/may/who--when--and-how--the-current-state-of-race--ethnicity--and-primary-language-data-collection-in-ho>
78. Hasnain-Wynia R, Van Dyke K, Youdelman M, Krautkramer C, Ivey SL, Gilchick R, et al. Barriers to collecting patient race, ethnicity, and primary language data in physician practices: An exploratory study. *J Natl Med Assoc* [Internet]. 2010 Sep [cited 2017 Apr 11];102(9):769–75. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0027968415306738>

79. Regenstein M, Sickler D. Race, ethnicity, and language of patients: Hospital practices regarding collection of information to address disparities in health care[Internet]. Washington, DC:National Public Health and Hospital Institute. 2006 Jan[cited 2017 Jul 18]. Available from: http://hsrc.himmelfarb.gwu.edu/cgi/viewcontent.cgi?article=1203&context=sphhs_policy_facpubs
80. Berry C, Kaplan SA, Mijanovich T, Mayer A. Moving to patient reported collection of race and ethnicity data: implementation and impact in ten hospitals. *Int J Health Care Qual Assur*. 2014[cited 2017 Jul 18];27(4):271–83. Available from: <http://www.emeraldinsight.com/doi/full/10.1108/IJHCQA-05-2012-0043>
81. Gomez SL, Lichtensztajn DY, Parikh P, Hasnain-Wynia R, Ponce N, Zingmond D. Hospital practices in the collection of patient race, ethnicity, and language data: a statewide survey, California, 2011. *J Health Care Poor Underserved* [Internet]. 2014[cited 2017 Jul 18];25(3):1384–96. Available from: <https://muse.jhu.edu/article/552207/pdf>
82. Weinick RM, Caglia JM, Friedman E, Flaherty K. Measuring racial and ethnic health care disparities in Massachusetts. *Health Aff (Millwood)* [Internet]. 2007 [cited 2017 Feb 20];26(5):1293–302. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17848439>
83. Jorgensen S, Thorlby R, Weinick RM, Ayanian JZ. Responses of Massachusetts hospitals to a state mandate to collect race, ethnicity and language data from patients: A qualitative study. 2010 [cited 2017 Jul 13]; Available from: <https://bmchealthservres.biomedcentral.com/track/pdf/10.1186/1472-6963-10-352?site=bmchealthservres.biomedcentral.com>
84. Thorlby R, Jorgensen S, Siegel B, Ayanian JZ. How health care organizations are using data on patients' race and ethnicity to improve quality of care. *Milbank Q* [Internet]. 2011[cited 2017 Jul 18];89(2):226–55. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3142338&tool=pmcentrez&rendertype=abstract>
85. Hasnain-Wynia R, Taylor-Clark K, Anise A. Collecting race, ethnicity, and language data to identify and reduce health disparities: Perceptions of health plan enrollees. *Med Care Res Rev* [Internet]. 2011 Jun 1 [cited 2017 Jul 13];68(3):367–81. Available from: <http://journals.sagepub.com/doi/10.1177/1077558710382549>
86. Escarce JJ, Carreón R, Veselovskiy G, Lawson EH. Collection of race and ethnicity data by health plans has grown substantially, but opportunities remain to expand efforts. *Health Aff (Millwood)* [Internet]. 2011 Oct [cited 2017 Feb 16];30(10):1984–91. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21976343>
87. Lawson E, Carreao R, Veselovsky G, Escarce J. Collection of language data and services provided by health plans. *Am J Manag Care* [Internet]. 2011 [cited 2017 Jul 15];17(12):e479–87. Available from: http://www.rwjf.org/content/dam/farm/articles/journal_articles/2011/rwjf71963

88. Gazmararian J, Carreon Ri, Olson N, Lardy B. Exploring health plan perspectives in collecting and using data on race, ethnicity and language. *Am J Manag Care*[Internet]. 2012;18(7):254–61. Available from: <http://www.ajmc.com/journals/issue/2012/2012-7-vol18-n7/Exploring-Health-Plan-Perspectives-in-Collecting-and-Using-Data-on-Race-Ethnicity-and-Language>
89. Nerenz DR, Carreón R, Veselovskiy G, Perrin E. Race, Ethnicity, and Language Data Collection by Health Plans: Findings from 2010 AHIPF-RWJF Survey. *J Health Care Poor Underserved* [Internet]. 2013 [cited 2017 Jul 13];24(4):1769–83. Available from: http://muse.jhu.edu/content/crossref/journals/journal_of_health_care_for_the_poor_and_underserved/v024/24.4.nerenz.html
90. Bierman AS, Lurie N, Collins KS, Eisenberg JM. Addressing racial and ethnic barriers to effective health care: The need for better data. *Health Aff.* 2002 May[cited 2017 Jul 18];21(3):91–102. Available from: <http://content.healthaffairs.org/content/21/3/91>
91. Baker DW, Cameron KA, Feinglass J, Georgas P, Foster S, Pierce D, et al. Patients' attitudes toward health care providers collecting information about their race and ethnicity. *J Gen Intern Med.* 2005 Oct[cited 2017 Jul 18];20(10):895–900. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1490236/>
92. Hasnain-Wynia R, Baker DW. Obtaining data on patient race, ethnicity, and primary language in health care organizations: current challenges and proposed solutions. *Health Serv Res* [Internet]. 2006 Aug [cited 2017 Apr 11];41(4 Pt 1):1501–18. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16899021>
93. Romana Hasnain-Wynia P, Deidre M. Weber B, Julie C. Yonek M, Javiera Pumarino B, and Jessica N. Mittler P. Community-level interventions to collect race/ethnicity and language data to reduce disparities. *Am J Manag Care* [Internet]. 2012 Sep 22 [cited 2017 Jul 16];18:S141-47. Available from: https://www.researchgate.net/profile/Jessica_Mittler/publication/268516933_Community-Level_Interventions_to_Collect_RaceEthnicity_and_Language_Data_to_Reduce_Disparities/links/546ec54d0cf2b5fc17607c60.pdf
94. Wilson G, Hasnain-Wynia R, Hauser D, Calman N. Implementing Institute of Medicine recommendations on collection of patient race, ethnicity, and language data in a community health center. *J Health Care Poor Underserved* [Internet]. 2013 [cited 2017 Jul 13];24(2):875–84. Available from: http://muse.jhu.edu/content/crossref/journals/journal_of_health_care_for_the_poor_and_underserved/v024/24.2.wilson.html
95. Oregon Health Authority and Oregon Department of Human Services. Report to the Oregon legislature: Race, ethnicity, language, and disability (REAL + D) Data: House Bill 2134 Baseline Assessment[Internet]. 2014 July. Available from: <https://reportstothelegislature.wordpress.com/2015/01/02/report-to-the-oregon-legislature-race-ethnicity-language-and-disability-reald-data/>

96. Voices for racial justice. Advancing health equity by making racial, ethnic and socio-demographic disparities visible in Minnesota's health care quality measurement system[Internet]. 2014 Dec[cited 2017 Jul 18]. Available from: <http://voicesforracialjustice.org/wp-content/uploads/2014/10/RES-D-Report-VRJ-01-26-15.pdf>
97. Bhalla R, Yongue BG, Currie BP. Standardizing race, ethnicity, and preferred language data collection in hospital information systems: Results and implications for healthcare delivery and policy. *J Healthc Qual* [Internet]. 2012 Mar [cited 2017 Jul 13];34(2):44–52. Available from: <http://content.wkhealth.com/linkback/openurl?sid=WKPTLP:landingpage&an=01445442-201203000-00006>
98. Lee WC, Veeranki SP, Serag H, Eschbach K, Smith KD. Improving the collection of race, ethnicity, and language data to reduce healthcare disparities: A case study from an academic medical center. *Perspect Health Inf Manag* [Internet]. 2016;13(Fall):1g. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/27843424>
99. Kehoe H, Lovett RW. Aboriginal and Torres Strait Islander health assessments - Barriers to improving uptake. *Aust Fam Physician* [Internet]. 2008 [cited 2017 Jul 16];37(12). Available from: <http://www.racgp.org.au/afpbackissues/2008/200812/200812kehoe.pdf>
100. Cormack D, McLeod M. Improving and maintaining quality in ethnicity data collections in the health and disability sector[Internet]. Wellington: Te Rōpū Rangahau Hauora a Eru Pōmare; 2010[cited 2017 Jul 18]. Available from: <http://www.otago.ac.nz/wellington/otago600098.pdf>
101. Department of Health. A practical guide to ethnic monitoring in the NHS and social care : Department of Health[Internet]. 2007 [cited 2017 Jul 17]. Available from: http://webarchive.nationalarchives.gov.uk/+http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/Browsable/DH_4116927
102. Australian Institute of Health and Welfare. National best practice guidelines for collecting Indigenous status in health data sets[Internet]. Canberra:AIHW;2010[cited 2017 Jul 18]. Available from: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442458760>
103. Ministry of Health. Ethnicity data protocols for the health and disability sector [Internet]. Wellington: Ministry of Health; 2004 [cited 2017 Jul 17]. Available from: <https://www.fmhs.auckland.ac.nz/assets/fmhs/faculty/tkhn/tumuaki/docs/ethnicity-data-protocols.pdf>
104. Aspinall P. The mandatory collection of data on ethnic group of inpatients. *Public Health* [Internet]. 2000 Jul [cited 2017 Jul 16];114(4):254–9. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S0033350600003401>

105. Sangowawa O, Bhopal R. Can we implement ethnic monitoring in primary health care and use the data? A feasibility study and staff attitudes in North East. *J Public Health Med*[Internet]. 2000[cited 2017 Jul 18];2(3):106–8. Available from: <https://www.era.lib.ed.ac.uk/handle/1842/2765>
106. Jones M, Kai J. Capturing ethnicity data in primary care: challenges and feasibility in a diverse metropolitan population. *Divers Equal Heal Care* [Internet]. 2007 [cited 2017 Jul 16];4(3). Available from: <http://diversityhealthcare.imedpub.com/capturing-ethnicity-data-in-primary-care-challenges-and-feasibility-in-a-diverse-metropolitan-population.php?aid=2280>
107. Johnson MR, Szczepura A, Iqbal G, Dunn JA, Gumber A, Wilson S. Ethnicity data collection in the UK: the healthcare professional's perspective. *Divers Equal Heal Care* [Internet]. 2012 [cited 2017 Jul 16];9(4). Available from: <http://diversityhealthcare.imedpub.com/ethnicity-data-collection-in-the-uk-the-healthcare-professionals-perspective.php?aid=1778>
108. Iqbal G, Johnson MR, Szczepura A, Wilson S, Gumber A, Dunn JA. UK ethnicity data collection for healthcare statistics: the South Asian perspective. *BMC Public Health* [Internet]. 2012 Dec 27 [cited 2017 Apr 11];12(1):243. Available from: <http://bmcpublichealth.biomedcentral.com/articles/10.1186/1471-2458-12-243>
109. Morrison Z, Fernando B, Kalra D, Cresswell K, Robertson A, Sheikh A. The collection and utilisation of patient ethnicity data in general practices and hospitals in the United Kingdom: A qualitative case study. *Inform Prim Care*. 2014;21(3):118–31. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/25207615>
110. Scotney A, Guthrie JA, Lokuge K, Kelly PM. “Just ask!” Identifying as indigenous in mainstream general practice settings: A consumer perspective. *Med J Aust*. 2010 may[cited 2017 Jul 18];192(10):609. Available from: https://www.mja.com.au/system/files/issues/192_10_170510/sco10157_fm.pdf
111. Kelaher M, Parry A, Day S, Paradies Y, Lawlor J, Solomon L. Improving the identification of Aboriginal and Torres Strait Islander People in the mainstream general practice[Internet]. Melbourne:Lowitja Institute; 2010 [cited 2017 Jul 16]. Available from: http://files.aphcri.anu.edu.au/research/kelaher_indigenous_identification_report_pdf_13237.pdf
112. Schütze H, Jackson Pulver L, Harris M. What factors contribute to the continued low rates of Indigenous status identification in urban general practice? - A mixed-methods multiple site case study. *BMC Health Serv Res* [Internet]. 2017 Dec 31 [cited 2017 Apr 11];17(1):95. Available from: <http://bmchealthservres.biomedcentral.com/articles/10.1186/s12913-017-2017-6>

113. Mcleod D, Mansell J, Harris R, Bailey, T, Dowell A, Robson B et al . The collection of patient ethnicity data: A challenge for general practice . NZ Fam Physician [Internet]. 2000 [cited 2017 Jul 17];27(3):51–7. Available from: <http://www.otago.ac.nz/wellington/otago019133.pdf>
114. Health Utilisation Research Alliance (HURA). Ethnicity data and primary care in New Zealand: lessons from the Health Utilisation Research Alliance (HURA) study. N Z Med J [Internet]. 2006 Mar 31 [cited 2017 Jul 17];119(1231):U1917. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/16582977>
115. Neuwelt P, Crengle S, Cormack D, McLeod M, Bramley D. General practice ethnicity data: Evaluation of a tool. J Prim Health Care[Internet]. 2014 Mar [cited 2017 Jul 18];6(1):49–55. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/24624411>
116. German D, Kodadek L, Shields R, Peterson S, Snyder C, Schneider E, et al. Implementing sexual orientation and gender identity data collection in emergency departments: Patient and staff perspectives. LGBT Health[Internet].2016 Dec [cited 2017 Jul 18];3(6):416-23 Available from: <http://online.liebertpub.com/doi/pdf/10.1089/lgbt.2016.0069>
117. Maragh-Bass AC, Torain M, Adler R, Ranjit A, Schneider E, Shields RY, et al. Is It Okay To Ask: Transgender patient perspectives on sexual orientation and gender identity collection in healthcare. Acad Emerg Med[Internet]. 2017[cited 2017 Jul 18];24(6):655–67. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/acem.13182/full>
118. Maragh-Bass AC, Torain M, Adler R, Schneider E, Ranjit A, Kodadek LM, et al. Risks, benefits, and importance of collecting sexual orientation and gender identity data in healthcare settings: A multi-method analysis of patient and provider perspectives. LGBT Health. 2017 Apr[cited 2017 Jul 18];4(2):141-152 Available from: <http://online.liebertpub.com/doi/pdf/10.1089/lgbt.2016.0107>
119. Callahan EJ, Sitkin N, Hendry T, Eidson-Ton W, Weckstein S, latimore J et al . Introducing sexual orientation and gender identity into the electronic health record: One academic health center’s experience. Acad Med. 2015;90(2):154–60. Available from Medline.
120. Dunne MJ, Raynor LA, Cottrell EK, Pinnock WJA. Interviews with patients and providers on transgender and gender nonconforming health data collection in the electronic health record. Transgender Health [Internet]. 2017 Feb [cited 2017 Jul 18];2(1):1–7. Available from: <http://online.liebertpub.com/doi/10.1089/trgh.2016.0041>
121. Youdelman M, Hitov S. Race, ethnici and primary language data collection: An assessment of federal policies, practices and perceptions Volume 2 [Internet]. Washington, D.C: Summit Health Institute for Research and Education Inc; 2001 [cited 2017 Jul 17]. Available from: <https://minorityhealth.hhs.gov/assets/pdf/checked/shire.report.pdf>

122. Weissman JS, Hasnain-Wynia R. Advancing Health Care Equity through Improved Data Collection. *N Engl J Med* [Internet]. 2011 Jun 16 [cited 2017 Jul 13];364(24):2276–7. Available from: <http://www.nejm.org/doi/abs/10.1056/NEJMp1103069>
123. Dorsey R, Graham G, Glied S, Meyers D, Clancy C, Koh H. Implementing health reform: improved data collection and the monitoring of health disparities. *Annu Rev Public Health* [Internet]. 2014[cited 2017 Jul 18];35:123–38. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/24365094>
124. Weinick RM. Researching disparities: Strategies for primary data collection. *Acad Emerg Med*[Internet]. 2003 Nov;10(11):1161–8. Available from: [http://onlinelibrary.wiley.com/doi/10.1197/S1069-6563\(03\)00484-6/abstract](http://onlinelibrary.wiley.com/doi/10.1197/S1069-6563(03)00484-6/abstract)
125. Daniel H, Butkus R. Lesbian, gay, bisexual, and transgender health disparities: Executive Summary of a policy position paper from the American College of Physicians. *Ann Intern Med* [Internet]. 2015 Jul;163(2):135–7. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25961598>
126. Mayer KH, Bradford JB, Makadon HJ, Stall R, Goldhammer H, Landers S. Sexual and gender minority health: What we know and what needs to be done. *Am J Public Health*[Internet]. 2008 Jun;98(6):989–95. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2377288/>
127. Institute of Medicine. Collecting sexual orientation and gender identity data in electronic health records Workshop Summary [Internet]. Washington, DC: Institute of Medicine; 2013 [cited 2017 Feb 13]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK132859/pdf/Bookshelf_NBK132859.pdf
128. Office of the National Coordinator for Health Technology, Department of Health and Human Services. 2015 Edition Final Rule [Internet]. 2016 [cited 2017 Jul 18]. Available from: <https://www.federalregister.gov/documents/2015/10/16/2015-25597/2015-edition-health-information-technology-health-it-certification-criteria-2015-edition-base>
129. Bjarnadottir RI, Bockting W, Dowding DW. Patient perspectives on answering questions about sexual orientation and gender identity: an integrative review. *J Clin Nurs* [Internet]. 2017 Jul [cited 2017 Jul 17];26(13–14):1814–33. Available from: <http://doi.wiley.com/10.1111/jocn.13612>
130. Braveman P, Barclay C. Health disparities beginning in childhood: A life-course perspective. *Pediatrics* [Internet]. 2009;124(Supplement):S163–75. Available from: <http://pediatrics.aappublications.org/cgi/doi/10.1542/peds.2009-1100D>
131. Issel L. Health program planning and evaluation: A practical, systematic approach for community health. 3rd ed. Burlington, MA; 2014. 206 p.
132. Canadian Nurses Association. Social determinants of health and nursing: A summary of the issues [Internet]. 2005 [cited 2017 Feb 11]. Available from: <http://www.cna-aic>

133. Canadian Medical Association. Health equity and the social determinants of health: A role for the medical profession [Internet]. Ottawa, ON; 2013 [cited 2017 Feb 11]. Available from: <https://www.cma.ca/Assets/assets-library/document/en/advocacy/PD13-03-e.pdf>
134. Lofters A, Shankardass K, Kirst M, Quiñonez C. Sociodemographic data collection in healthcare settings: an examination of public opinions. *Med Care* [Internet]. 2011 [cited 2017 Feb 11];49(2):193-9. Available from: http://journals.lww.com/lww-medicalcare/Abstract/2011/02000/Sociodemographic_Data_Collection_in_Healthcare.12.aspx
135. Varcoe C, Browne AJ, Wong S, Smye VL. Harms and benefits: Collecting ethnicity data in a clinical context. *Soc Sci Med* [Internet]. 2009;68(9):1659–66. Available from: <http://dx.doi.org/10.1016/j.socscimed.2009.02.034>
136. Canadian Medical Association. Health care transformation in Canada physicians and health equity: Opportunities in practice [Internet]. Ottawa, ON: Canadian Medical Association; 2013 [cited 2017 Feb 11]. Available from: <https://www.cma.ca/Assets/assets-library/document/en/advocacy/Health-Equity-Opportunities-in-Practice-Final-e.pdf>
137. Klein MD, Alcamo AM, Beck AF, O’Toole JK, McLinden D, Henize A, et al. Can a video curriculum on the social determinants of health affect residents’ practice and families’ perceptions of care? *Acad Pediatr* [Internet]. 2014 Mar [cited 2017 Feb 11];14(2):159–66. Available from: <http://linkinghub.elsevier.com/retrieve/pii/S1876285913003161>
138. Simons-Morton B, McLeroy K, Wendel M. Behavior theory in health promotion practice and research. Burlington, MA: Jones & Bartlett Learning; 2012.
139. Kirst M, Shankardass K, Bomze S, Lofters A, Quiñonez C. Sociodemographic data collection for health equity measurement: a mixed methods study examining public opinions. *Int J Equity Health*[Internet]. 2013;12(75):1–10.
140. Antwi M, Kale M. Change management in health care [Internet]. [Place unknown]: [The Monieson Centre, Queens School of Business]. 2014 Jan [cited 2016 Mar 2]; 1 -23. Available from: https://smith.queensu.ca/centres/monieson/knowledge_articles/files/Change%20Management%20in%20Healthcare%20-%20Lit%20Review%20-%20AP%20FINAL.pdf.
141. Eccles MP, Armstrong D, Baker R, Cleary K, Davies S, Glasziou P et al. An implementation research agenda. *Implement Sci* [Internet]. 2006 [cited 2017 Jan 24]; 4:18. Available from: <https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-4-18>.
142. Nilsen P. Making sense of implementation theories, models and frameworks. *Implement Sci* [Internet]. 2015;10(1):53. Available from: <http://www.implementationscience.com/content/pdf/s13012-015-0242-0.pdf%5Cnhttp://www.implementationscience.com/content/10/1/53>

143. Damschroder LJ, Aron DC, Keith RE, Kirsh SR, Alexander J a, Lowery JC. Fostering implementation of health services research findings into practice: a consolidated framework for advancing implementation science. *Implement Sci.* 2009;4(50):40–55.
144. Powell BJ, Proctor EK, Glisson CA, Kohl PL, Raghavan R, Brownson RC, et al. A mixed methods multiple case study of implementation as usual in children’s social service organizations: study protocol. *Implement Sci [Internet]*. 2013 Aug 20 [cited 2017 Feb 11];8:92. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23961701>
145. Damschroder LJ, Lowery JC. Evaluation of a large-scale weight management program using the consolidated framework for implementation research (CFIR). *Implement Sci [Internet]*. 2013;8(1):51. Available from: <http://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-8-51>
146. Chaudoir SR, Dugan AG, Barr CH. Measuring factors affecting implementation of health innovations: a systematic review of structural, organizational, provider, patient, and innovation level measures. *Implement Sci [Internet]*. 2013;8(22):20. Available from: <https://implementationscience.biomedcentral.com/articles/10.1186/1748-5908-8-22>
147. Proctor E, Silmere H, Raghavan R, Hovmand P, Aarons G, Bunger A, et al. Outcomes for implementation research: Conceptual distinctions, measurement challenges, and research agenda. *Adm Policy Ment Heal Ment Heal Serv Res.* 2011;38(2):65–76.
148. Carter SM, Little M. Justifying Knowledge, Justifying Method, Taking Action: Epistemologies, Methodologies, and Methods in Qualitative Research. *Qual Health Res [Internet]*. 2007 Dec [cited 2017 Feb 11];17(10):1316–28. Available from: <http://journals.sagepub.com/doi/10.1177/1049732307306927>
149. Watson C. Living the life of the social inquirer: Beginning educational research. *Forum Qualitative Social Research [Internet]*. 2005 May;6(2). Available from: <https://doaj.org/article/3344943dd15d4c668ff25fb78497b743>
150. Creswell JW, Plano Clark VL. *Designing and conducting mixed methods research.* Thousand Oaks, CA:Sage Publications; 2011. 457 p.
151. Tashakkori A, Teddlie C. *Sage handbook of mixed methods in social & behavioral research.* Thousand Oaks, CA: Sage Publications; 2003. 893 p.
152. Howe KR. Against the quantitative and qualitative incompatibility thesis or dogmas die hard. *Educ Res [Internet]*. 1988 [cited 2016 Mar 8]; 17 (8): 10 -16. Available from: http://www.jstor.org.cyber.usask.ca/stable/1175845?seq=1#page_scan_tab_content
153. Morgan DL. Pragmatism as a paradigm for social research. *Qual Inq [Internet]*. 2014 Oct [cited 2017 Feb 12];20(8):1045–53. Available from: <http://journals.sagepub.com/doi/10.1177/1077800413513733>

154. Stake R. The art of case study research. Thousand Oaks, CA: Sage Publications; 1995. 49-68 p.
155. Johansson R. Case study methodology. In: Methodologies in housing research [Internet]. Stockholm:Publisher unknown; 2003 [cited 2017 Feb 15]. Available from: http://www.psyking.net/htmlobj-3839/case_study_methodology-_rolf_johansson_ver_2.pdf
156. Yin RK. Case study research : Design and methods. Thousand Oaks, CA: Sage Publications; 2009.
157. Balbach E. Using case studies to do program evaluation [Internet]. 1999 [cited 2017 Feb 15]. Available from: <https://case.edu/affil/healthpromotion/ProgramEvaluation.pdf>
158. Saskatoon Health Region. Annual Report 2015-2016. Saskatoon; 2016 [cited 2017 April 11] Available from: https://www.saskatoonhealthregion.ca/news/media-centre/Documents/Reports-Publications/shr_annual_report_2015_2016.pdf.
159. Nicklin W. Accreditation Report Saskatoon Health Region [Internet]. Saskatoon; 2015. Available from: https://www.saskatoonhealthregion.ca/news/media-centre/Documents/Reports-Publications/2013Accreditation_Report.pdf
160. Saskatchewan Bureau of Statistics. Saskatchewan Population Report 2016 [Internet]. 2017. Available from: http://www.stats.gov.sk.ca/stats/pop/2016_census_population_counts.pdf
161. Sakatoon Health Region. Newcomer Population. 2014 [cited 2017 Apr 2]. Available from: http://www.communityview.ca/pdfs/2014_SHR_newcomers.pdf
162. Pitawanakwat B. The Encyclopedia of Saskatchewan [Internet]. Aboriginal Treaty Rights. [cited 2017 Apr 6]. Available from: http://esask.uregina.ca/entry/aboriginal_treaty_rights.html
163. Saskatoon Health Region. First Nations and Métis Population [Internet]. Saskatoon; 2000. Available from: http://www.collectionscanada.gc.ca/eppp-archive/100/205/301/ic/cdc/www.abheritage.ca/alberta/fn_metis/treaty_map.html
164. Saskatoon Health Region, Strengthening the circle partnership. Aboriginal Health Strategy 2010-2015[Internet]. Saskatoon: Saskatoon Health Region. 2010 [cited 2017 April 13]. Available from: https://www.saskatoonhealthregion.ca/locations_services/Services/fnmh/representative-workforce/Documents/Aboriginal-Health-Stragety-full.pdf
165. Truth and Reconciliation Commission. Truth and Reconciliation Commission: Calls to Action[Internet]. 2015[cited 2017 April 12]. Available from: http://www.trc.ca/websites/trcinstitution/File/2015/Findings/Calls_to_Action_English2.pdf

166. Saskatoon Health Region. West Winds Primary Health Centre [Internet]. Saskatoon Health Region; [cited 2017 Feb 16]. Available from:
http://www.usask.ca/medicine/family/wwphc/WWPHC_fact_sheet.pdf
167. City of Saskatoon. City of Saskatoon Neighborhood Profiles [Internet]. Saskatoon; 2014. Available from: https://www.saskatoon.ca/sites/default/files/neighbourhood_profiles.pdf
168. Sexual Health Centre Saskatoon. Sexual Health Centre Saskatoon [Internet]. 2016 [cited 2017 Feb 16]. Available from: <http://sexualhealthcentresaskatoon.ca/ab/mission.php>
169. St Paul's Hospital Foundation. St Paul's Hospital [Internet]. [cited 2017 Feb 16]. Available from: <http://www.stpaulshospital.org/about/index.php>
170. Craig M. Deaths at St. Paul's Hospital higher than national average.Saskatoon | Globalnews.ca [Internet]. 2014 Dec [cited 2017 Apr 2]. Available from:
<http://globalnews.ca/news/1704823/hospital-deaths-at-st-pauls-hospital-higher-than-the-national-average/>
171. Bryman A. Integrating quantitative and qualitative research: how is it done? Qual Res [Internet]. 2006 Feb 1 [cited 2017 Feb 16];6(1):97–113. Available from:
<http://qrj.sagepub.com/cgi/doi/10.1177/1468794106058877>
172. Creswell J, Plano-Clark VL. Choosing a mixed methods design. In: Designing and conducting mixed methods research [Internet]. Thousand Oaks, CA: Sage Publications; 2011 [cited 2017 Feb 16]. p. 58–89. Available from:
http://www.antle.iat.sfu.ca/courses/iat834/resources/Creswell&Clark_Chap4&5.pdf
173. Andrews RM. Race and ethnicity reporting in statewide hospital data: Progress and future challenges in a key resource for local and state monitoring of health disparities. J Public Health Manag Pract [Internet]. 2011 [cited 2017 Feb 16];17(2):167–73. Available from Medline
174. Buescher PA, Gizlice Z, Jones-Vessey KA. Discrepancies between published data on racial classification and self-reported race: Evidence from the 2002 North Carolina live birth records. Public Health Rep [Internet]. 1974 [cited 2017 Feb 16];120(4):393–8. Available from: <http://www.jstor.org/stable/20056812>
175. Huggins P, Taylor E. Measuring racial and ethnic disparities in health care: Efforts to improve data collection [Internet]. Princeton, NJ:Mathematica Policy Research Inc; 2009 May [cited 2017 Feb 16]. Available from:
http://search.proquest.com.cyber.usask.ca/docview/1698796247?rfr_id=info%3Axri%2Fsid%3Aprimo

176. Pinto AD, Glattstein-Young G, Mohamed A, Bloch G, Leung F-H, Glazier RH. Building a foundation to reduce health inequities: Routine collection of sociodemographic data in primary Care. *J Am Board Fam Med* [Internet]. 2016 [cited 2017 Feb 19];29(3):348–55. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/27170792>
177. Richardson L, St Pierre E. Writing: A method of inquiry. In: Denzin N, Lincoln Y, editors. *The Sage Handbook of Qualitative Research* [Internet]. Fourth. Thousand Oaks, CA: Sage Publications; 2011. p. 659–68.
178. Bowling A. Techniques of questionnaire design. In: Bowling A, Ebrahim S, editors. *Handbook of health research methods: Investigation, measurement and analysis* [Internet]. England: Open University Press; 2005 [cited 2017 Feb 16]. p. 394.
179. Sergeant E. EpiTools epidemiological calculators [Internet]. Australia: Ausvet Pty Ltd; 2016 [cited 2017 Feb 16]. Available from: <http://epitools.ausvet.com.au/>
180. Patton MQ. *Qualitative evaluation and research methods*. Thousand Oaks, CA: Sage Publications; 1990. 168-186 p.
181. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol* [Internet]. 2006 [cited 2017 Feb 16];3(2):77–101. Available from: <http://eprints.uwe.ac.uk/11735>
182. Rice R, Hancock L. The Mall Intercept: A social norms marketing research tool. *Rep Soc Norms* [Internet]. 2005;4:4–7. Available from: <http://www.socialnormsresources.org/pdf/mallintercept.pdf>
183. Krueger RA, Casey MA. *Focus groups: a practical guide for applied research*. Thousand Oaks, CA: Sage Publications; 2009.
184. Cyr J. The Pitfalls and Promise of Focus Groups as a Data Collection Method. *Sociol Methods Res* [Internet]. 2016 May [cited 2017 Feb 16];45(2):231–59. Available from: <http://journals.sagepub.com/doi/10.1177/0049124115570065>
185. Stake RE. *Multiple case study analysis*. New York: Guildford Press; 2006.
186. Lincoln YS, Guba EG. *Naturalistic inquiry*. Newbury Park, CA: Sage Publications; 1985.
187. Morse JM, Barrett M, Mayan M, Olson K, Spiers J. Verification strategies for establishing reliability and validity in qualitative research. *Int J Qual Methods* [Internet]. 2002 [cited 2017 Feb 16];1(2):13–22. Available from: <http://journals.sagepub.com.cyber.usask.ca/doi/pdf/10.1177/160940690200100202>
188. Garg A, Boynton-Jarrett R, Dworkin PH. Avoiding the unintended consequences of screening for social determinants of health. *JAMA* [Internet]. 2016;316(8):813. Available from: <http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.2016.9282>

189. Ontario Human Rights Commission. Guidelines for collection data on enumerated grounds under the Code [Internet]. 2009 Nov [cited 2017 Jan 27]. Available from: <http://www.ohrc.on.ca/sites/default/files/guidelines%20for%20collecting%20data%20on%20enumerated%20grounds%20under%20the%20code.pdf>
190. First Nations Centre. OCAP: Ownership, Control Access and Possession [Internet]. Ottawa: National Aboriginal Health Organization; 2007 [cited 2017 Jul 19]. Available from: <http://cahr.uvic.ca/nearbc/documents/2009/FNC-OCAP.pdf>
191. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans [Internet]. 2014 [cited 2017 Feb 18]. Available from: http://www.pre.ethics.gc.ca/pdf/eng/tcps2-2014/TCPS_2_FINAL_Web.pdf
192. Public Health Agency of Canada. Report on Sexually Transmitted Infections in Canada: 2012 of Canada [Internet]. [cited 2017 Feb 18]. Available from: <http://www.phac-aspc.gc.ca/sti-its-surv-epi/rep-rap-2012/index-eng.php>
193. Statistics Canada. Aboriginal Peoples in Canada: First Nations People, Métis and Inuit [Internet]. Ottawa, ON:Statistics Canada; 2011 [cited 2017 Feb 18]. Available from: <http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/99-011-x2011001-eng.pdf>
194. Rosenberg MW, Wilson K, Abonyi S, Wiebe A, Beach K, Lovelace R. Older Aboriginal Peoples in Canada demographics, health status and access to health care [Internet]. SEDAP Research Paper No. 249. 2009 Jul[cited 2017 Feb 18]. Available from: <http://socserv.mcmaster.ca/sedap/p/sedap249.pdf>
195. Saskatoon Health Region. Better Health for All. Health Status Reporting Series One [Internet]. Saskatoon:Saskatoon Health Region; 2014 [cited 2017 Feb 19]. Available from: https://www.saskatoonhealthregion.ca/locations_services/Services/Health-Observatory/Documents/Reports-Publications/2014_SHR_HSRFull_phase1.pdf
196. Kazanjian A, Morettin D, Cho R. Health Care Utilization by Canadian Women. *BMC Womens Health* [Internet]. 2004 [cited 2017 Feb 19];4(Suppl 1):S33. Available from: <http://bmcwomenshealth.biomedcentral.com/articles/10.1186/1472-6874-4-S1-S33>
197. Kalmuss D, Tatum C. Patterns of Men's Use of Sexual and Reproductive Health Services. *Perspect Sex Reprod Health* [Internet]. 2007 Jun [cited 2017 Feb 19];39(2):74–81. Available from: <http://doi.wiley.com/10.1363/3907407>
198. Thompson AE, Anisimowicz Y, Miedema B, Hogg W, Wodchis WP, Aubrey-Bassler K. The influence of gender and other patient characteristics on health care-seeking behaviour: a QUALICOPC study. *BMC Fam Pract* [Internet]. 2016 Dec 31 [cited 2017 Feb 19];17(1):38. Available from: <http://bmcfampract.biomedcentral.com/articles/10.1186/s12875-016-0440-0>

199. Banks C. The cost of homophobia: Literature review on the impact of homophobia on Canada [Internet]. Saskatoon, SK: Community-University Institute for social research; 2003 [cited 2017 Jan 27]. Available from: <http://www.usask.ca/cuisr/sites/default/files/BanksHumanCostFINAL.pdf>
200. Saskatoon Health Region. Housing Affordability [Internet]. Saskatoon:Saskatoon Health Region; 2014 [cited 2017 Feb 19]. Available from: http://www.communityview.ca/pdfs/2014_SHR_housing_affordability.pdf
201. Tourangeau R, Yan T. Sensitive questions in surveys. *Psychol Bull* [Internet]. 2007 Sep [cited 2017 Feb 19];133(5):859–83. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17723033>
202. Gearing RE, Mian IA, Barber J, Ickowicz A. A methodology for conducting retrospective chart review research in child and adolescent psychiatry. *J Can Acad Child Adolesc Psychiatry* [Internet]. 2006 Aug [cited 2017 Feb 19];15(3):126–34. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/18392182>
203. Australian Institute of Health and Welfare. Taking the next steps: Identification of Aboriginal and Torres Strait Islander status in general practice [Internet]. Canberra:AIHW;2013. Available from: <http://www.aihw.gov.au/publication-detail/?id=60129543899>
204. Carter-Pokras O, Zambrana RE. Collection of legal status information: Caution! *Am J Pub Health* [Internet]. 2006; 96(3):399 Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1470510/pdf/0960399.pdf>.
205. Sidhu N. Acknowledgments Accessing community programs and services for non-status immigrants in Toronto: Organizational challenges and responses [Internet]. Toronto, On:Social Planning Toronto; 2013 [cited 2017 Feb 20]. Available from: www.socialplanningtoronto.org.
206. Nestel S. Colour coded health care The Impact of Race and Racism on Canadians' Health [Internet]. Toronto, ON: Wellesley Institute; 2012 [cited 2017 Feb 20]. Available from: <http://www.wellesleyinstitute.com/wp-content/uploads/2012/02/Colour-Coded-Health-Care-Sheryl-Nestel.pdf>
207. Adelson N. The embodiment of inequity: Health disparities in Aboriginal Canada. *CJPH* [Internet]. 2005; 96 (Suppl 2):S45-61. Available from: <http://pubs.cpha.ca/pdf/p24/22247.pdf>.
208. Reading CL, Wein F. Health inequalities and social determinants of Aboriginal Peoples' health[Internet]. National Collaborating Centre for Aboriginal Health; 2009. Available from: http://www.nccah-ccnsa.ca/docs/social_determinates/nccah-loppie-wien_report.pdf

209. National Collaborating Centre for Aboriginal health in Canada. An overview of Aboriginal health in Canada [Internet]. [Date unknown; cited Nov 23 2016]. Available from: http://www.nccah-cnsa.ca/Publications/Lists/Publications/Attachments/101/abororiginal_health_web.pdf
210. McCaskill D. Discrimination and public perceptions of Aboriginal Peoples in Canadian cities. UAKN Research Paper Series. 2012 Available from: http://uakn.org/wp-content/uploads/2014/08/2012-UAKN-Research-Paper-Series_Discrimination-and-Public-Perceptions-of-Aboriginal-People-in-Canadian-Cities_Dr.-Don-McCaskill.pdf
211. Allan B, Smylie J. First Peoples, second class treatment: The role of racism in the health and wellbeing of Indigenous peoples in Canada. Toronto, ON: The Wellesley Institute; 2015. Available from: <http://www.wellesleyinstitute.com/wp-content/uploads/2015/02/Summary-First-Peoples-Second-Class-Treatment-Final.pdf>.
212. Lemstra M, Neudorf C. Health disparity in Saskatoon: analysis to intervention [Internet]. Saskatoon: Saskatoon Health Region; 2008 [cited 2017 Jan 28]. Available from: <http://www.caledoninst.org/Special%20Projects/CG-COP/Docs/HealthDisparityRept-complete.pdf>
213. Williamson DL, Stewart MJ, Hayward K, Letourneau N, Makwarimba E, Masuda J, et al. Low-income Canadians' experiences with health-related services: Implications for health care reform. *Health Policy (New York)* [Internet]. 2006 [cited 2017 Feb 20];76(76):106–21. Available from: <http://homelesshub.ca/sites/default/files/LOW-IN~1.pdf>.
214. Ontario College of Family Physicians. Child poverty: A practical tool for primary care. 2016 [cited 2017 Feb 11]. Available from: <http://>
215. Sharma S, Ford-Jones E. Child poverty. Ways forward for the paediatrician: A comprehensive overview of poverty reduction strategies requiring paediatrician support. *Paediatr Child Health* [Internet]. 2015 May; 20(4):203-207. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4443829/pdf/pch-20-203.pdf>
216. Knorr L. Advancing health equity through benefits screening. *The Philanthropist* [Internet]. 2016. Available from: <http://thephilanthropist.ca/2016/09/advancing-health-equity-through-benefits-screening/>.
217. Hasnain-Wynia R, Pierce D, Hedges Greising C, Hague A, Prince C, Reiter J. Health Research and Educational Trust (HRET) Disparities Toolkit. 2005. Available from: <http://www.hretdisparities.org/>
218. Hasnain-Wynia R, Taylor-Clark K, Anise A. Collecting race, ethnicity, and language data to identify and reduce health disparities: Perceptions of health plan enrollees. *Med Care Res Rev* [Internet]. 2011 Jun 1 [cited 2017 Apr 11];68(3):367–81. Available from: <http://mcr.sagepub.com/cgi/doi/10.1177/1077558710382549>

219. Kandula NR, Hasnain-Wynia R, Thompson JA, Brown ER, Baker DW. Association between prior experiences of discrimination and patients' attitudes towards health care providers collecting information about race and ethnicity. *J Gen Intern Med* [Internet]. 2009 Jul 5 [cited 2017 Apr 11];24(7):789–94. Available from: <http://link.springer.com/10.1007/s11606-009-0991-z>
220. Browne AJ, Varcoe CM, Wong ST, Smye VL, Khan KB. Can ethnicity data collected at an organizational level be useful in addressing health and healthcare inequities? *Ethn Health* [Internet]. 2014 Mar 4 [cited 2017 Feb 20];19(2):240–54. Available from: <http://www.tandfonline.com/doi/abs/10.1080/13557858.2013.814766>
221. Baker DW, Hasnain-Wynia R, Kandula NR, Thompson JA, Brown E. Attitudes toward health care providers collecting information about patients' race ethnicity and language. *Med Care* [Internet]. 2007 [cited 2017 Feb 20];45(11):1034–42. Available from: <http://www.jstor.org.cyber.usask.ca/stable/pdf/40221578.pdf>
222. Saskatoon Health Region. Health Equity Position Statement [Internet]. Saskatoon:Saskatoon Health Region; 2016 [cited 2017 Feb 20]. Available from: [https://www.saskatoonhealthregion.ca/locations_services/Services/fnmh/Documents/Health Equity Position Statement FINAL_20160728.pdf](https://www.saskatoonhealthregion.ca/locations_services/Services/fnmh/Documents/Health%20Equity%20Position%20Statement%20FINAL_20160728.pdf)
223. Cohen BE, Schultz A, McGibbon E, Vanderplaat M, Bassett R, GermAnn K, et al. Can J Public Health [Internet]. 2013 [cited 2017 Apr 11];104(3):262–6. Available from: <http://journal.cpha.ca/index.php/cjph/article/view/3735/2787>.
224. Whitehead M, Povall S, Loring B. The equity action spectrum: taking a comprehensive approach guidance for addressing inequities in health [Internet]. Copenhagen: World Health Organization; 2014 [cited 2017 Apr 11]. Available from: http://www.euro.who.int/__data/assets/pdf_file/0005/247631/equity-action-090514.pdf?ua=1.
225. Brown C, Harrison D, Burns H, Ziglio E. Governance for health equity taking forward the equity values and goals of Health 2020 in the WHO European Region [Internet]. Copenhagen:World Health Organization; 2013 [cited 2017 Apr 11]. Available from: http://www.euro.who.int/__data/assets/pdf_file/0020/235712/e96954.pdf.
226. National Collaborating Centre for Determinants of Health. Toward Health Equity Canadian approaches to the health sector role [Internet]. Ottawa:NCCDH; 2014 [cited 2017 Apr 11]. Available from: http://publications.gc.ca/collections/collection_2014/aspc-phac/HP35-44-2014-eng.pdf.
227. Institute of Medicine. Capturing social and behavioral domains and measures in electronic health records phase 2 [Internet]. Washington, DC:National Academies Press; 2014 [cited 2017 Apr 11]. Available from: https://www.ncbi.nlm.nih.gov/books/NBK268995/pdf/Bookshelf_NBK268995.pdf.

228. Kirkness VJ, Barnhardt R. First Nations and Higher Education: The Four R's-- Respect, Relevance, Reciprocity and Responsibility. *J Am Indian Educ* [Internet]. 1991 [cited 2017 Apr 11];30(3):1–15. Available from: <http://web.b.ebscohost.com.cyber.usask.ca/ehost/pdfviewer/pdfviewer?sid=ae6158fb-1bdf-40b5-b21b-09f2db96368d%40sessionmgr120&vid=1&hid=124>.
229. Baker DW, Cameron KA, Feinglass J, Thompson JA, Georgas P, Foster S et al. A system for rapidly and accurately collecting patients' race and ethnicity. *Am J Public Health*[Internet]. 2006 Mar;96(3):532–7. Available from: <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1470520/>
230. Australian Institute of Health and Welfare. Indigenous identification in hospital separations data: quality report [Internet]. Canberra: AIHW; 2013 [cited 2017 Feb 19]. Available from: <http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=60129543213>
231. Clifford A, McCalman J, Bainbridge R, Tsey K. Interventions to improve cultural competency in health care for Indigenous peoples of Australia, New Zealand, Canada and the USA: A systematic review. *Int J Qual Health Care* [Internet]. 2015 Mar 10 [cited 2017 Feb 14];27(2):89–98. Available from: <https://academic.oup.com/intqhc/article/27/2/89/1788185/Interventions-to-improve-cultural-competency-in>
232. Johnson K, Gustafson D, Ewigman B, Provost L, Roper R. Using Rapid-Cycle Research to Reach Goals: Awareness, Assessment, Adaptation, Acceleration [Internet]. Rockville, Maryland: Agency for Health Research and Quality; 2015 [cited 2017 Apr 12]. Available from: <https://pbrn.ahrq.gov/sites/default/files/docs/page/AHRQPBRNFinalRapidCycleResearchGuidanceDocument.pdf>
233. Klein MD, Kahn RS, Baker RC, Fink EE, Parrish DS, White DC. Training in social determinants of health in primary care: does it change resident behavior? *Acad Pediatr* [Internet]. 2011 [cited 2017 Feb 11];11(5):387–93. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/21640683>.
234. Garg A, Sarkar S, Marino M, Onie R, Solomon BS. Linking urban families to community resources in the context of pediatric primary care. *Patient Educ Couns*[Internet]. 2010;79(2):251–4. Available from: <http://www.sciencedirect.com/science/article/pii/S0738399109005011>
235. Andermann A. THE CLEAR Toolkit: Helping health workers tackle the social causes of poor health [Internet]. Montreal, Canada: Department of Family Medicine, McGill University; 2013. Available from: <http://www.who.int/workforcealliance/forum/2013/SE7-Handout.pdf>

236. Sandel M, Suther E, Brown C, Wise M, Hansen M. The MLP Vital Sign: Assessing and managing legal needs in the healthcare setting. *J Leg Med* [Internet]. 2014 Jan 2 [cited 2017 Feb 21];35(1):41–56. Available from: <http://www.tandfonline.com/doi/abs/10.1080/01947648.2014.884431>.
237. McCabe HA, Kinney ED. Medical Legal Partnerships: A Key strategy for addressing social determinants of health. *J Gen Intern Med* [Internet]. 2010 May 30 [cited 2017 Feb 21];25(S2):200–1. Available from: <http://link.springer.com/10.1007/s11606-010-1298-9>
238. Sandel M, Hansen M, Kahn R, Lawton E, Paul E, Parker V, et al. Medical-legal partnerships: Transforming primary care by addressing the legal needs of vulnerable populations. *Health Aff* [Internet]. 2010 Sep [cited 2017 Feb 21];29(9):1697–705. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20820029>
239. Weintraub D. Pilot study of medical legal partnership to address social and legal needs of patients. *J Health Care Poor Underserved* [Internet]. 2010 Jan [cited 2015 Oct 11]; 21:157-168. Available from: <http://medical-legalpartnership.org/wp-content/uploads/2014/03/pilot-Study-of-Medical-legal-partnership-to-address-Social-and-legal-needs-of-patients.pdf>.
240. Reading R. Medical-legal partnership: impact on patients with sickle cell disease. *Child Care Health Dev* [Internet]. 2012 Mar [cited 2017 Feb 21];38(2):303–4. Available from: http://doi.wiley.com/10.1111/j.1365-2214.2011.01363_7.x.
241. Pettignano R, Bliss LR, Caley SB, McLaren S. Can access to a medical-legal partnership benefit patients with asthma who live in an urban community? *J Health Care Poor Underserved* [Internet]. 2013 [cited 2017 Feb 21];24(2):706–17. Available from: http://muse.jhu.edu/content/crossref/journals/journal_of_health_care_for_the_poor_and_underserved/v024/24.2.pettignano.html
242. Butler M, McCreedy E, Schwer N, Burgess D, Call K, Przedworski J, Rosser S, Larson S, Allen M, Fu S, Kane RL. Improving cultural competence to reduce health disparities. Comparative Effectiveness Review No. 170. AHRQ Publication No. 16-EHC006-EF. Rockville, MD: Agency for Healthcare Research and Quality; March 2016. Available from: www.effectivehealthcare.ahrq.gov/reports/final.cfm
243. Flores G. The impact of medical interpreter services on the quality of care: A systematic review. *Med Care Res Rev* [Internet]. 2005 Jun [cited 2015 Oct 11]; 62(3):255-99. Available from: <http://mcr.sagepub.com/content/62/3/255>
244. Karliner LS, Jacobs EA, Chen AH, Mutha S. Do professional interpreters improve clinical care for patients with limited English proficiency? A systematic review of the literature. *HSR* [Internet]. 2007 Apr [cited 2015 Oct 11]; 42(2):727-754. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1955368/>

245. Horvat L, Horey D, Romios P, Kis-Rigo J. Cultural competence education for health professionals. *Cochrane Database Syst Rev* [Internet]. 2014 Jan [Cited 2017 Jan 18]; 5:CD009405. Available from: <http://onlinelibrary.wiley.com/doi/10.1002/14651858.CD009405.pub2/pdf>
246. Truong M, Paradies Y, Priest N. Interventions to improve cultural competency in healthcare: a systematic review of reviews. *BMC Health Serv Res* [Internet]. 2014;14(1):99. Available from: <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-14-99>
247. Berkman ND, Stacey Sheridan ML, Katrina Donahue ME, David Halpern MJ, Anthony Viera M, Karen Crotty M, et al. Health Literacy Interventions and Outcomes: An updated systematic review [Internet]. Rockville, MD; 2011 [cited 2017 Feb 14]. Available from: https://effectivehealthcare.ahrq.gov/ehc/products/151/671/Health_Literacy_Update_FinalT echBrief_20110502.pdf
248. Aspinall PJ. Inclusive practice. Vulnerable migrants, gypsies and travellers, people who are homeless and sex workers: A review and synthesis of interventions/service models that improve access to primary care and reduce risk of avoidable admission to hospital.[Internet] [Place unknown]: University of Kent; 2014 [cited 2015 Oct 14]. Available from https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/305912/Inclusive_Practice.pdf.
249. Social Planning P and PA. Hospital discharge: Safe and effective models for people experiencing homelessness [Internet]. Waterloo, ON; 2013 [cited 2017 Feb 14]. Available from: http://homelesshub.ca/sites/default/files/Hospital_Discharge_Report_Final.pdf.
250. Hewett N, Buchman P, Musariri J, Sargeant C, Johnson P, Abeysekera K, et al. Randomised controlled trial of GP-led in-hospital management of homeless people ('Pathway'). *Clin Med J R Coll Physicians London*[Internet]. 2016;16(3):223–9. Available from: <https://www.ncbi.nlm.nih.gov/pubmed/27251910>
251. Doran, Kelly M M, Ragins KT, Gross, Cary P M, Zerger, Suzanne P. Medical Respite Programs for homeless patients: A Systematic Review. *J Heal Care Poor Underserved* [Internet]. 2013;24(203):499–524. Available from: <http://search.proquest.com.huaryu.kl.oakland.edu/docview/1373219053/9E2BA6AC67E34CD2PQ/2?accountid=12924>
252. Reilly S, Graham-Jones S, Gaulton E, Davidson E. Can a health advocate for homeless families reduce workload for the primary care team: A controlled trial. *Health Soc Care Community* [Internet]. 2004;129(10):63–74. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2004.00469.x/full>

261. Trompeter JM, Havrda DE. Impact of obtaining medications from pharmaceutical company assistance programs on therapeutic Goals. *Ann Pharmacother* [Internet]. 2009 Mar [cited 2017 Feb 15];43(3):469–77. Available from: <http://journals.sagepub.com/doi/10.1345/aph.1L420>
262. Sauvageot J, Kirkpatrick MAF, Spray JW. Pharmacist-implemented pharmaceutical manufacturers' assistance Programs: Effects on health outcomes for seniors. *Consult Pharm* [Internet]. 2008 Oct 1 [cited 2017 Feb 15];23(10):809–12. Available from: <http://www.ingentaconnect.com/content/ascp/tcp/2008/00000023/00000010/art00006>
263. Felder TM, Palmer NR, Lai LS, Mulen PD. What is the evidence for pharmaceutical assistance programs? A systematic review. *J Health Care Poor Underserved* [Internet]. 2011 [cited 2016 Apr 3]. 22(1):24-49. Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3065996/>
264. Bowen S. The impact of language barriers on patient safety and quality of care [Internet]. [Place unknown]: Société Santé en Français; 2015 August [cited 2017 Jan 18]. Available from: <https://santefrancais.ca/wp-content/uploads/SSF-Bowen-S.-Language-Barriers-Study.pdf>.
265. Ku L, Flores G. Pay now or later: Providing interpreter services in health care. *Health Aff* [Internet]. 2005 Mar [cited 2015 Oct 11]; 24(2):435-44. Available from: <http://content.healthaffairs.org/content/24/2/435.full>
266. Flores G, Abreu M, Barone CP, Bachur R, Lin H. Errors of medical interpretation and their potential clinical consequences: A comparison of professional versus ad hoc versus no interpreters. *Ann Emerg Med* [Internet]. 2012;60(5):545–53. Available from: <http://dx.doi.org/10.1016/j.annemergmed.2012.01.025>
267. Kelley L, Chou CL, Dibble SL, Robertson PA. A critical intervention in lesbian, gay, bisexual, and transgender health: Knowledge and attitude outcomes among second-year medical students. *Teach Learn Med* [Internet]. 2008;20(3):248–53. Available from: <http://dx.doi.org/10.1080/10401330802199567>
268. McGarry KA, Clarke JG, Cyr MG, Landau C. Evaluating a lesbian and gay health care curriculum. *Teach Learn Med* [Internet]. 2002 Oct [cited 2017 Feb 14];14(4):244–8. Available from: http://www.tandfonline.com/doi/abs/10.1207/S15328015TLM1404_8
269. Beagan BL. Teaching social and cultural awareness to medical students: It's all very nice to talk about it in theory, but ultimately it makes no difference". *Acad Med* [Internet]. 2003;78(6):605–14. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/12805041>
270. Tervalon M, Murray-Garcia J. Cultural humility versus cultural competence: a critical distinction in defining physician training outcomes in multicultural education. *J Health Care Poor Underserved* [Internet]. 1998[cited 2018 Jan 30]; 9(2):117-25. Available from: <http://muse.jhu.edu.cyber.usask.ca/article/268076/pdf5..>

271. Shoptaw S, Reback CJ, Peck JA, Yang X, Rotheram-Fuller E, Larkins S, et al. Behavioral treatment approaches for methamphetamine dependence and HIV-related sexual risk behaviors among urban gay and bisexual men. *Drug Alcohol Depend.* 2005;78(2):125–34.
272. Fisher TL, Burnet DL, Huang ES, Chin MH, Cagney KA. Cultural leverage: interventions using culture to narrow racial disparities in health care. *Med Care Res Rev* [Internet]. 2007;64(5 Suppl):243S–82S. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/17881628><http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=PMC2505343>
273. Henderson S, Kendall E, See L. The effectiveness of culturally appropriate interventions to manage or prevent chronic disease in culturally and linguistically diverse communities: A systematic literature review. *Health Soc Care Community.* 2011;19(3):225–49.
274. Lantz PM, Golberstein E, House JS, Morenoff J. Socioeconomic and behavioral risk factors for mortality in a national 19-year prospective study of U.S. adults. *Soc Sci Med.* 2010;70:1558–66.
275. Tjepkema M, Wilkins R, Long A. Cause-specific mortality by education in Canada: A 16-year follow-up study. *Health Reports* [Internet]. 2012 [cited 2017 Feb 14];23(3). Available from: <http://www.statcan.gc.ca/pub/82-003-x/2012003/article/11700-eng.pdf>
276. Canadian Council on Learning. *Health Literacy in Canada: Initial Results from the International Adult Literacy and Skills Survey 2007* [Internet]. Ottawa: Canadian Council on Learning; 2007. Available from: <http://site.ebrary.com.cyber.usask.ca/lib/usask/reader.action?docID=10194968>
277. Statistics Canada. *Education and occupation of high-income Canadians* [Internet]. 2011 [cited 2017 Feb 14]. Available from: https://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-014-x/99-014-x2011003_2-eng.cfm
278. Frankish CJ, Hwang SW, Frankish J. Homelessness and health in Canada: Research lessons and priorities. *Can J Public Health* [Internet]. 2017 [cited 2017 Feb 14];96(2):23–9. Available from: <http://www.jstor.org/stable/41994457>
279. McGuire J, Gelberg L, Blue-Howells J, Rosenheck RA. Access to primary care for homeless veterans with serious mental illness or substance abuse: A follow-up evaluation of co-located primary care and homeless social services. *Adm Policy Ment Health* [Internet]. 2009 Jul 12 [cited 2017 Feb 14];36(4):255–64. Available from: <http://link.springer.com/10.1007/s10488-009-0210-6>
280. O’Toole TP, Johnson EE, Borgia ML, Rose J. Tailoring outreach efforts to increase primary care use among homeless veterans: Results of a randomized controlled trial. *J Gen Intern Med* [Internet]. 2015 Jul 12 [cited 2017 Feb 14];30(7):886–98. Available from: <http://link.springer.com/10.1007/s11606-015-3193-x>

281. Hwang SW, Ueng JJM, Chiu S, Kiss A, Tolomiczenko G, Cowan L, et al. Universal health insurance and health care access for homeless persons. *Am J Public Health*[Internet]. 2010;100(8):1454–61. Available from: Available from: <https://www.ncbi.nlm.nih.gov/cyber.usask.ca/pmc/articles/PMC2901287/>
282. Khandor E, Mason K, Chambers C, Rossiter K, Cowan L, Hwang SW. Access to primary health care among homeless adults in Toronto, Canada: Results from the Street Health survey. *Open Med*[Internet]. 2011[cited 2017 Jan 17]; 5(2):94-103. Available from: <https://www.ncbi.nlm.nih.gov/cyber.usask.ca/pmc/articles/PMC3148004/pdf/OpenMed-05-e94.pdf>.
283. Kushel M. The First Step is the Hardest: Overcoming barriers to primary care. *J Gen Intern Med* [Internet]. 2015;30(7):868–9. Available from: <http://dx.doi.org/10.1007/s11606-015-3279-5>
<http://link.springer.com/article/10.1007%2Fs11606-015-3279-5>
284. Hewitt N, Halligan A, Boyce T. A general practitioner and nurse led approach to improving hospital care for homeless people. *BMJ* [Internet]. 2012 [cited 2017 Feb 14];345:e5999. Available from: <http://www.bmj.com.cyber.usask.ca/content/bmj/345/bmj.e5999.full.pdf>
285. Batra P, Chertok JS, Fisher CE, Manseau MW, Manuelli VN, Spears J. The Columbia-Harlem Homeless Medical Partnership: A new model for learning in the service of those in medical need. *J Urban Health* [Internet]. 2009 Sep 8 [cited 2017 Feb 14];86(5):781–90. Available from: <http://link.springer.com/10.1007/s11524-009-9386-z>
286. Campbell DJ, Gibson K, O’Neill BG, Thurston WE. The role of a student-run clinic in providing primary care for Calgary’s homeless populations: a qualitative study. *BMC Health Serv Res* [Internet]. 2013 Dec 17 [cited 2017 Feb 14];13(1):277. Available from: <http://bmchealthservres.biomedcentral.com/articles/10.1186/1472-6963-13-277>
287. Hwang SW, Tolomiczenko G, Kouyoumdjian FG, Garner RE: Interventions to improve the health of the homeless: a systematic review. *Am J Prev Med* [Internet]. 2005 [cited 2015 Oct 11]; 29(4):311-319. Available from: <http://homelesshub.ca/resource/interventions-improve-health-homeless-systematic-review..>
288. Fitzpatrick-Lewis D, Ganann R, Krishnaratne S, Ciliska D, Kouyoumdjian F, Hwang SW. Effectiveness of interventions to improve the health and housing status of homeless people: a rapid systematic review. *BMC Public Health* [Internet]. 2011;11(1):638. Available from: <http://www.biomedcentral.com/1471-2458/11/638>
289. de Vet R, van Luijteleaer MJA, Brilleslijper-Kater SN, Vanderplasschen W, Beijersbergen MD, Wolf JRLM. Effectiveness of case management for homeless persons: a systematic review. *Am J Public Health* [Internet]. 2013 Oct [cited 2017 Feb 14];103(10):e13-26. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/23947309>

290. Anderson SA. Core indicators of nutritional state for difficult-to-sample populations. *J Nutr*. 1990;120 Suppl:1559–600. Available from: <http://agris.fao.org/agris-search/search.do?recordID=US9111600>
291. Rose-Jacobs R, Black MM, Casey PH, Cook JT, Cutts DB, Chilton M, et al. Household Food Insecurity: Associations With At-Risk Infant and Toddler Development. *Pediatrics* [Internet]. 2008 [cited 2017 Feb 14];121(1):65–72. Available from: <http://pediatrics.aappublications.org.cyber.usask.ca/content/pediatrics/121/1/65.full.pdf>
292. Cook J, Frank D. Food Security, Poverty, and Human Development in the United States. *Ann N Y Acad Sci* [Internet]. 2008 [cited 2017 Feb 14];1136:193–209. Available from: <http://web.a.ebscohost.com.cyber.usask.ca/ehost/pdfviewer/pdfviewer?sid=f592817d-1d03-44eb-b5e0-4c6210f70471%40sessionmgr4009&vid=1&hid=4109>
293. Ke J, Ford-Jones EL. Food insecurity and hunger: A review of the effects on children’s health and behaviour. *Paediatr Child Health* [Internet]. 2015 Mar [cited 2017 Feb 14];20(2):89–91. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/25838782>
294. Bales CW, Ritchie CS. *Handbook of Clinical Nutrition and Aging*. Humana Press; 2009. 668 p.
295. Seligman HK, Laraia BA, Kushel MB. Food Insecurity Is Associated with Chronic Disease among Low-Income NHANES Participants. *J Nutr* [Internet]. 2010 Feb 1 [cited 2017 Feb 15];140(2):304–10. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/20032485>
296. McLaughlin KA, Green JG, Alegría M, Jane Costello E, Gruber MJ, Sampson NA, et al. Food insecurity and mental disorders in a national sample of US adolescents. *J Am Acad Child Adolesc Psychiatry* [Internet]. 2012 [cited 2017 Feb 15];51(12):1293–303. Available from: <http://www.sciencedirect.com.cyber.usask.ca/science/article/pii/S0890856712007265>
297. Howard LL. Does food insecurity at home affect non-cognitive performance at school? A longitudinal analysis of elementary student classroom behavior. *Econ Educ Rev* [Internet]. 2011 [cited 2017 Feb 15];30(1):157–76. Available from: <http://www.sciencedirect.com.cyber.usask.ca/science/article/pii/S0272775710001093>
298. Council on Community Pediatrics, Committee on Nutrition. Promoting food security for all children. *Pediatrics* [Internet]. 2015;136(5):e1431-8. Available from: <http://www.ncbi.nlm.nih.gov/pubmed/26498462>.
299. McIntyre L, Musto R, Basualdo-Hammond C, Fleisch V, Farmer A, Galeslootb S. Scoping review: Addressing food security in health settings [Internet]. Calgary, AB: University of Calgary; 2015 [cited 2017 Feb 15]. Available from: <http://resources.cpha.ca/CPHA/Conf/Data/2015/A15-045ae.pdf>.

300. Lightman E, Mitchell A, Wilson B. Poverty is making us sick: A comprehensive survey of income and health in Canada. Toronto, ON: Wellesley Institute; 2008 Dec. Available from: <http://www.wellesleyinstitute.com/wp-content/uploads/2011/11/povertyismakingussick.pdf>
301. Raphael D. Poverty in Canada :Implications for health and quality of life. Canada: Canadian Scholars' Press Inc; 2011. 226-232 p.
302. Abbott S. Prescribing welfare benefits advice in primary care: Is it a health intervention, and if so, what sort? *J Public Health Med.* 2002;24(4):307–12. Available from: <https://academic.oup.com/jpubhealth/article/24/4/307/1551514/Prescribing-welfare-benefits-advice-in-primary>
303. Greasley P, Small N. Providing welfare advice in general practice: Referrals, issues and outcomes. *Health Soc Care Community.* 2005;13(3):249–58. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2005.00557.x/full>
304. Allmark P, Baxter S, Goyder E, Guillaume L, Crofton-Martin G. Assessing the health benefits of advice services: Using research evidence and logic model methods to explore complex pathways. *Health Soc Care Community.* 2013;21(1):59–68. Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1365-2524.2012.01087.x/full>
305. Safran D, Neuman P, Schoen C, Kitchman M. Prescription drug coverage and seniors: findings from a 2003 national survey. *Health Aff [Internet].* 2005 [cited 2017 Feb 15];105:152–66. Available from: <http://search.proquest.com.cyber.usask.ca/docview/204646270/fulltext/C85ABDC51BC467BPQ/1?accountid=14739>
306. Tseng C-W, Brook RH, Keeler E, Steers WN, Mangione CM. Cost-lowering strategies used by Medicare beneficiaries who exceed drug benefit caps and have a gap in drug coverage. *JAMA [Internet].* 2004 Aug 25 [cited 2017 Feb 15];292(8):952. Available from: <http://jama.jamanetwork.com/article.aspx?doi=10.1001/jama.292.8.952>
307. Schoen MD, DiDomenico RJ, Connor SE, Dischler JE, Bauman JL. Impact of the cost of prescription drugs on clinical outcomes in indigent patients with heart disease. *Pharmacotherapy [Internet].* 2001 Dec [cited 2017 Feb 15];21(12):1455–63. Available from: <http://doi.wiley.com/10.1592/phco.21.12.1455.34473>

APPENDIX A
STUDY MATERIALS FOR WEST WINDS PRIMARY HEALTH CENTRE

1. Survey Questionnaire (Drop-in and booked immunization clinics)
2. Consent forms
3. Intercept interview tracking form
4. Key informant interview guide



West Winds Primary Health Centre Survey

How can we serve you better?

We would appreciate it if you could answer the following questions so that we can better meet your needs. Your participation is voluntary and your responses will be kept confidential.

1. What was your reason for attending this child health clinic today? Check all that apply:

- I like the location of the clinic
I prefer drop-in clinics
Fridays work best for me
Afternoons work best for me
I like the clinic
I like the clinic staff
I don't have to wait to get an appointment
I couldn't get in to my preferred clinic.
My preferred clinic is:
Other reason (please specify):

2. Please circle the days/times that you would prefer to attend West Winds.

Table with 6 columns (Mon-Sat) and 3 rows (Morning, Afternoon, Evening)

3. What type of appointments do you prefer?

- Drop-in
Booked

4. Did you know that you have the option to book an immunization only appointment?

- Yes
No

5. Are booked immunization only appointments of interest to you?

- Yes
No

6. If it was available, would you check our wait times online?

- Yes
No

7. How did you get to West Winds today?

- Drove
Walked or cycled
Took the bus or a taxi
Other (please specify):

8. What is your postal code? 1?

9. Do you have a family doctor?

- Yes
No

10. What is your gender?

- Female
Male
Other
Prefer not to answer

Turn page over

1 Your postal code will help us determine how we might provide services closer to where you live. Nothing will be sent to your home or used in any way to identify you.

11. Were you born in Canada?

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

*If NO, what year did you arrive in Canada? _____

12. If it was available, would you find an interpreter helpful?

- Yes
- No

13. Are you of Aboriginal background? *Check ONE only:*

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

*If YES, please pick ONE of the following:

- First Nations (or Indian as defined by Indian Act)
- Non-Status Indian
- Métis
- Inuit
- Aboriginal from outside of Canada
- Other (please specify): _____
- Prefer not to answer
- Do not know

14. Which of the following best describes your housing situation? *Check ONE only:*

- Own home
- Renting
- Staying with friends/family
- Supportive housing
- Shelter/hostel
- Boarding home
- Group home

- Homeless on the street
- Other (please specify): _____
- Prefer not to answer
- Do not know

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

- White North American (e.g. Canadian, American)
- White European (e.g. English, Italian, Portuguese)
- Black North American (e.g. Canadian, American)
- Black African (e.g. Nigerian, Kenyan, Somali)
- Latin American (e.g. Argentinian, Chilean)
- Middle Eastern (e.g. Egyptian, Iranian, Lebanese)
- Asian – East (e.g. Chinese, Japanese, Korean)
- Asian – South (e.g. Indian, Pakistani, Sri Lankan)
- Asian – South East (e.g. Malaysian, Filipino)
- Mixed heritage (e.g. Black African and White – North American) (please specify): _____
- Other (please specify): _____
- Prefer not to answer
- Do not know

Thank you for taking the time to complete this survey!

Please hand the survey back to the clinic staff.



West Winds Primary Health Centre Survey
How can we serve you better?

We would appreciate it if you could answer the following questions so that we can better meet your needs. Your participation is voluntary and your responses will be kept confidential.

1. What was your reason for attending this child health clinic today? *Check all that apply:*

- I like the location of the clinic
- Booked appointments work best for me
- I like the clinic
- I like the clinic staff
- I don't have to wait to get an appointment
- I couldn't get in to my preferred clinic. My preferred clinic is: _____
- Other reason (please specify): _____

2. Please circle the days/times that you would prefer to attend West Winds.

Mon	Tue	Wed	Thu	Fri	Sat
Morning	Morning	Morning	Morning	Morning	Morning
After-noon	After-noon	After-noon	After-noon	After-noon	After-noon
Evening	Evening	Evening	Evening	Evening	Evening

3. What type of appointments do you prefer? *Check ONE only:*

- Drop-in
- Booked

4. Did you know that West Winds has drop-in immunization clinics?

- Yes
- No

5. Are drop-in immunization clinics of interest to you?

- Yes
- No

6. If it was available, would you check our wait times online?

- Yes
- No

7. How did you get to West Winds today?

- Drove
- Walked or cycled
- Took the bus or a taxi
- Other (please specify): _____

8. What is your postal code¹? _____

9. Do you have a family doctor?

- Yes
- No

10. What is your gender?

- Female
- Male
- Other
- Prefer not to answer

Turn page over

¹ Your postal code will help us determine how we might provide services closer to where you live. Nothing will be sent to your home or used in any way to identify you.

11. Were you born in Canada?

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

*If **NO**, what year did you arrive in Canada? _____

12. If it was available, would you find an interpreter helpful?

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

13. Do you self-identify as an Aboriginal/Indigenous person?

Check ONE only:

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

*If **YES**, please pick **ONE** of the following then skip to question 15:

- First Nations (or Indian as defined by Indian Act)
- Non-Status Indian
- Métis
- Inuit
- Aboriginal from outside of Canada
- Other (please specify): _____
- Prefer not to answer
- Do not know

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

- White North American (examples: Canadian, American)

- White European (examples: English, Italian, Portuguese)
- Black North American (examples: Canadian, American)
- Black African (examples: Nigerian, Kenyan, Somali)
- Latin American (examples: Argentinian, Chilean, Salvadorian)
- Middle Eastern (examples: Egyptian, Iranian, Lebanese)
- Asian – East (examples: Chinese, Japanese, Korean)
- Asian – South (examples: Indian, Pakistani, Sri Lankan)
- Asian – South East (examples: Malaysian, Filipino, Vietnamese)
- Mixed heritage (example: Black African and White – North American) (please specify):

- Other (please specify): _____
- Prefer not to answer
- Do not know

15. Which of the following best describes your housing situation? Check ONE only:

- Own home
- Renting
- Staying with friends/family
- Supportive housing
- Shelter/hostel
- Boarding home
- Group home
- Homeless on the street
- Other (please specify): _____
- Prefer not to answer
- Do not know

Thank you for taking the time to complete this survey!

Please hand the survey back to the clinic staff.



PARTICIPANT INTERVIEW CONSENT FORM (CLIENT)

Project Title: Better Health for All: One patient at a time. Evaluation of a clinical intervention to improve patient centred care.

Researcher:

Hazel Williams-Roberts, Graduate Student, Community Health and Epidemiology, University of Saskatchewan, 306-321-4848, haw778@mail.usask.ca

Supervisor: Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan 306-966-7920, cory.neudorf@usask.ca

Purpose(s) and Objective(s) of the Research:

The conditions where people live and work can influence their health. The collection of sociodemographic information in health care facilities may help health care providers to better understand and address patient needs. The purpose of this study is to evaluate the effects of a clinical intervention to improve patient care through screening for and addressing those identified social factors that are barriers to a client's achievement of good health.

Procedures:

Your participation will involve an interview of approximately 10 to 15 minutes. During the interview, I will sit with you in a comfortable place where we can speak privately. You will be asked questions about your care experience during this visit. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but me will be present unless you would like someone else to be there.

Potential Risks:

You will be asked to discuss some sensitive and personal information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give me any reason for not responding to any question, or for refusing to take part in the interview.

Potential Benefits:

Your participation will help us to understand how best to provide care that is responsive to the social and medical needs of our clients.

Compensation:

No reimbursement will be offered in exchange for your participation in this study.

Confidentiality:

All the information that you provide in the interview is completely confidential. It will not be shared with anyone outside of the research team. Your name will not appear on any report resulting from this study. However with your permission, anonymous quotations may be used.

Storage of data: The information collected in this study will be stored securely in a locked cabinet in my supervisor's office. Data will also be stored electronically on password protected computers. Information collected during the study will be retained for a period of six years before being destroyed.

Right to Withdraw:

Your participation is voluntary and you can withdraw from the study for any reason, at any time without penalty. If you withdraw from the research project, any data that you have contributed will be destroyed at your request. Your right to withdraw data from the study will apply until the data has been pooled. After this it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data. If any new information that could have a bearing on your decision to participate arises, you will be informed and given the opportunity to remove yourself from the study. At that time if you still consent, you will be asked to sign and date a consent form that includes any changes.

Whether you choose to participate or not will have no effect on your care, or how you will be treated. If you wish to withdraw, contact either Dr Cordell Neudorf (cory.neudorf@usask.ca), or the researcher (haw778@mail.usask.ca). If you choose to withdraw you will be given the option to also remove your data from the study.

Follow up:

To obtain results from the study, please contact the researcher (haw778@mail.usask.ca).

Questions or Concerns:

If you have any questions or would like additional information, you may contact me via email at haw778@mail.usask.ca. You can also contact my supervisor, Dr. Cordell Neudorf at 306-966-7920 or via email at cory.neudorf@usask.ca.

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office at ethics.office@usask.ca or via (306) 966-2975.

Signed Consent:

I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

Name of Participant

Signature

Date

Researcher's Signature

Date



KEY INFORMANT INTERVIEW CONSENT FORM

Project Title: Better Health for All: One patient at a time. Evaluation of a clinical intervention to improve patient centred care.

Researcher:

Hazel Williams-Roberts, Graduate Student, Community Health and Epidemiology, University of Saskatchewan, haw778@mail.usask.ca

Supervisor: Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan 306-966-7920, cory.neudorf@usask.ca

Purpose(s) and Objective(s) of the Research:

The conditions where people live and work can influence their health. The collection of information in health care facilities about people's social circumstances may help health care providers to better understand and address client holistic needs. The purpose of this study is to evaluate the effects of a project to improve client care through screening for and addressing those identified social factors that make it difficult for clients to achieve good health.

Procedures:

You will be interviewed for approximately 20 to 30 minutes. During the interview, I will sit with you in a comfortable place where we can speak privately. You will be asked questions about the factors that influenced the participation of your centre in the project. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but me will be present unless you would like someone else to be there. With your permission, the interview will be audiotaped to ensure accurate recording of responses and later transcribed for analysis. You will be given the opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

Potential Risks:

You will be asked to talk about the process of decision making and your experience with project implementation. The questions are not personal or particularly sensitive. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give me any reason for not responding to any question, or for refusing to take part in the interview.

Potential Benefits:

Your participation will also help us to understand how to best to support other institutions who are interested in enhanced sociodemographic data collection and its application to improve the quality of care given to our clients.

Compensation:

No reimbursement will be offered in exchange for your participation in this study.

Confidentiality:

All the information that you provide in the interview is completely confidential. It will not be shared with anyone outside of the research team. Your name will not appear on any report resulting from this study. However if you agree, anonymous quotations may be used.

Storage of data: The information collected in this study will be kept in a locked cabinet in my supervisor's office. Data will also be stored electronically on password protected computers. Information collected during the study will be retained for a period of six years before being destroyed.

Right to Withdraw:

You can choose whether you want to participate and you can leave the study for any reason, at any time without penalty. If you leave the study, your information will be destroyed at your request. However, you will only be able to remove your information from the study before it has been combined with that collected from other patients/clients. After this point, it may not be possible to withdraw your data. If any new information that could have a bearing on your decision to participate arises, you will be informed and given the opportunity to remove yourself from the study. At that time if you still consent, you will be asked to sign and date a consent form that includes any changes.

Whether you choose to participate or not will have no effect on your care, or how you will be treated. If you wish to withdraw, contact either Dr Cordell Neudorf (cory.neudorf@usask.ca), or the researcher (haw778@mail.usask.ca). If you choose to withdraw you will be given the option to also remove your data from the study.

Follow up:

To obtain results from the study, please contact the researcher (haw778@mail.usask.ca).

Questions or Concerns:

If you have any questions or would like additional information, you may contact me via email at haw778@mail.usask.ca. You can also contact my supervisor, Dr. Cordell Neudorf at 306-966-7920 or via email at cory.neudorf@usask.ca.

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office at ethics.office@usask.ca or via telephone at (306) 966-2975.

Signed Consent:

If you decide to take part in this study, there are some options for you to consider. Please place a check mark by the option that grants me permission to:

I grant permission to be audiotaped Yes No

You may use anonymized quotations Yes No

I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
_____	_____	
<i>Researcher's Signature</i>	<i>Date</i>	

WEST WINDS PRIMARY HEALTH CENTRE TRACKING FORM – INTERCEPT INTERVIEWS

ID	Item	Scale			Prefer not to answer	Do not know	Item	Item	Any comments	Age	Gender	Ethnicity
		VI	SI	NI								
		1	2	3	4	5						
1	How important do you think it is to collect information about social circumstances in health care settings?						Who do you think should be asked about their social circumstances?	Who do you think should collect this information from clients?				



PARTICIPANT INTERCEPT INTERVIEW GUIDE (CLIENT)

STUDY TITLE: Better health for all: We ask because we care. Evaluation of a clinical intervention to improve patient-centred care

SUPERVISOR:

Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan

STUDENT RESEARCHER:

Hazel Williams-Roberts, Department of Community Health and Epidemiology, University of Saskatchewan

Introduction:

Thank you for agreeing to meet with me today. My name is Hazel Williams-Roberts and I am a graduate student in the Department of Community Health and Epidemiology at the University of Saskatchewan. I am partnering with the Saskatoon Health Region to collect data for a study that will become part of my doctoral dissertation. I am interested in understanding your views about the collection and use of social information during the medical visit. I will ask you questions about your thoughts and experiences with the collection of social information during this visit and then we will talk about how you think the information was or was not used as part of your care.

You have been asked to give voluntary consent to this interview by reviewing and signing a consent form. You have been given the opportunity to ask any questions about the study. A copy of the form will also be left with you so that you can be reminded of what we discussed.

The information you share with me today is completely confidential. You will be assigned a false name (pseudonym) and your responses will not have any identifying information. Your responses will only be shared with members of the study team and will be compiled with other participants in the study. The information that I gather will be used to improve how information is collected and used to provide client-centred care.

It is helpful to know a little bit about you so that I have a context for your responses. This information helps to understand the backgrounds of study participants.

Age:

Gender:

Ethnicity:

First visit ever to facility:

- 1 **Importance of assessing social circumstances**
 - How important do you think that it is to gather information about clients' social circumstances in health care settings?

- 2 **Who should be asked about social circumstances?**
 - Who do you think should be asked about their social circumstances during a medical visit?
 - Can you explain why you feel that way?

- 3 **Who should ask questions about social circumstances in a health care setting?**
 - Why do you think that is the case?

- 4 **What aspects of the data collection need to be improved?**
 - What should be done to help clients feel comfortable about giving this information?
 - What needs to change from the current process?

CLOSURE: Thank you for taking the time to participate in this study. If you would like to receive a copy of the results upon completion of the study, my contact information is listed on the consent form.



KEY INFORMANT INTERVIEW GUIDE

STUDY TITLE: Better health for all: We ask because we care. Evaluation of a clinical intervention to improve patient centred care

SUPERVISOR:

Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan

STUDENT RESEARCHER:

Hazel Williams-Roberts, Department of Community Health and Epidemiology, University of Saskatchewan

Introduction:

Thank you for agreeing to meet with me today. My name is Hazel Williams-Roberts and I am a graduate student in the Department of Community Health and Epidemiology at the University of Saskatchewan. I am partnering with the Saskatoon Health Region to collect data for a study that will become part of my doctoral dissertation. I am interested in understanding your views about the collection and use of social information during the medical visit. I will you ask questions about how you came to participate in the project and your experiences with implementation in this centre.

You have been asked to give voluntary consent to this interview by reviewing and signing a consent form. You have been given the opportunity to ask any questions about the study. A copy of the form will also be left with you so that you can be reminded of what we discussed.

The information you share with me today is completely confidential. You will be assigned a false name (pseudonym) and your responses will not have any identifying information. Your responses will only be shared with members of the study team and will be compiled with other participants in the study. The information that I gather will be used to improve how information is collected and used to provide client-centred care.

To ensure that we are able to capture accurate and complete responses, I would like to audio-tape this interview. As previously mentioned, the recording will be transcribed and all names and places will be removed to protect your identity.

It is helpful to know a little bit about you so that I have a context for your responses. This information helps to understand the backgrounds of study participants.

Ethnicity:

Length of service:

- 1 **Importance of assessing social circumstances**
 - How important do you think that it is to gather information about clients' social circumstances in health care settings?

- 2 **Who should be asked about social circumstances?**
 - Who do you think should be asked about their social circumstances during a medical visit?
 - Can you explain why you feel that way?

- 3 **Who should ask questions about social circumstances in a health care setting?**
 - Why do you think that is the case?

- 4 **Feelings about being asked for sociodemographic information**
 - How do you think that patients feel about being asked questions related to their social circumstances?
 - Can you explain why you feel that way?

- 5 **Participation in the project**
 - Tell me about how you came to participate in the project:
 - What were the factors that encouraged you to consider the project for your centre?
 - What were some of the challenges that affected implementation of the project?

- 6 **How sociodemographic data should be collected**
 - How would you like to see social information collected in this centre?
 - What would be the best way to gather this information?

- 7 **What supports are needed for institutions who want to collect this information?**
 - How should we support other institutions who want to be involved in similar initiatives?

CLOSURE: Thank you for taking the time to participate in this study. If you would like to receive a copy of the results upon completion of the study, my contact information is listed on the consent form.

APPENDIX B

STUDY MATERIALS FOR SEXUAL HEALTH CENTRE

1. Sociodemographic data collection questionnaire
2. Consent forms
3. Interview guides (Patient and key informant)
4. Chart abstraction form
5. Information and education materials for patients
6. Resource manual for providers

WE ASK BECAUSE WE CARE

We are collecting social information from our clients to better understand and address your needs as well as find out who we serve. We will also use the information to plan our programs and services. It will only take 5 minutes to complete.

This information will be shared with your health care team and protected like your other health information. If used in research the information will be combined with that of other clients and no one will be able to identify any of the clients.

The questions are voluntary and you can choose 'prefer not to answer' for any question. This will not affect your care.

1a. How well do you speak English? Check ONE only:

- Very well Well Not well Not at all

1b. What language would you feel most comfortable communicating in with your doctor/nurse? Check ONE only:

- | | | | |
|------------------------------------|--------------------------------------|--|---|
| <input type="checkbox"/> Arabic | <input type="checkbox"/> English | <input type="checkbox"/> Michif | <input type="checkbox"/> Urdu |
| <input type="checkbox"/> Braille | <input type="checkbox"/> Farsi | <input type="checkbox"/> Punjabi | <input type="checkbox"/> Vietnamese |
| <input type="checkbox"/> Cantonese | <input type="checkbox"/> French | <input type="checkbox"/> Saulteaux | <input type="checkbox"/> Other(specify) _____ |
| <input type="checkbox"/> Chinese | <input type="checkbox"/> German | <input type="checkbox"/> Sign Language | <input type="checkbox"/> Prefer not to answer |
| <input type="checkbox"/> Cree | <input type="checkbox"/> Hindi | <input type="checkbox"/> Spanish | |
| <input type="checkbox"/> Déne | <input type="checkbox"/> Lip reading | <input type="checkbox"/> Tagalog | |
| <input type="checkbox"/> Dutch | <input type="checkbox"/> Mandarin | <input type="checkbox"/> Ukrainian | |

1c. Do you need an interpreter? Yes No Prefer not to answer Do not know

2. What name do you go by? _____

3a. Were you born in Canada? Check ONE only:

- Yes No* Prefer not to answer Do not know

If **NO***, what year did you come to Canada? _____

3b. What is your current immigration status? Check ONE only:

- | | | | |
|---|---------------------------------------|--------------------------------------|--|
| <input type="checkbox"/> Canadian citizen | <input type="checkbox"/> Refugee | <input type="checkbox"/> Work Permit | <input type="checkbox"/> Other (specify) _____ |
| <input type="checkbox"/> Permanent resident | <input type="checkbox"/> Study permit | <input type="checkbox"/> Visitor | <input type="checkbox"/> Prefer not to answer |
| | | | <input type="checkbox"/> Do not know |

Birth year: Age:

WE ASK BECAUSE WE CARE

4a. Are you an Aboriginal/Indigenous person? Check **ONE** only:

Yes* No* (**GO TO 4b**) Prefer not to answer Do not know

If **YES***, please pick **ONE** of the following:

First Nations (or Indian as defined by Indian Act) Other(specify) _____

Non-status Indian Prefer not to answer

Métis Do not know

Indigenous from outside of Canada

4b. Which of the following options best describes your racial or ethnic group?
Check **ONE** only:

<input type="checkbox"/> White North American (e.g. Canadian, American)	<input type="checkbox"/> Asian – East (e.g. Chinese, Japanese, Korean)
<input type="checkbox"/> White European (e.g. English, Italian, Portuguese, Russian)	<input type="checkbox"/> Asian – South (e.g. Indian, Pakistani, Sri Lankan)
<input type="checkbox"/> Black North American (e.g. Canadian, American)	<input type="checkbox"/> Asian – South East (e.g. Malaysian, Filipino, Vietnamese)
<input type="checkbox"/> Black African (e.g. Nigerian, Kenyan, Somali)	<input type="checkbox"/> Mixed heritage (e.g. Black African and White – North American)(specify) _____
<input type="checkbox"/> Black Caribbean (e.g. Jamaican, Barbadian, Trinidadian, Guyanese)	<input type="checkbox"/> Other (specify) _____
<input type="checkbox"/> Latin American (e.g. Argentinian, Chilean, Salvadorean)	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> Middle Eastern (e.g. Egyptian, Iranian, Lebanese)	<input type="checkbox"/> Do not know

5. Do you have any conditions that limit your activities of daily living?

Yes* No (**GO TO 6a**)

If **YES***, is this condition? Check **ALL** that apply:

<input type="checkbox"/> Chronic illness	<input type="checkbox"/> Learning disability	<input type="checkbox"/> Other(specify) _____
<input type="checkbox"/> Drug or alcohol dependence	<input type="checkbox"/> Mental illness	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> Hearing impairment	<input type="checkbox"/> Physical impairment	<input type="checkbox"/> Do not know
<input type="checkbox"/> Intellectual impairment	<input type="checkbox"/> Visual impairment	

Birth year: Age:

WE ASK BECAUSE WE CARE

6a. What is your gender? Check **ALL** that apply:

<input type="checkbox"/> Female	<input type="checkbox"/> Other(specify) _____
<input type="checkbox"/> Male	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> Transgender	<input type="checkbox"/> Do not know
<input type="checkbox"/> Two spirit	

6b. Have you ever been diagnosed with an intersex condition?

Yes (specify) _____ No Prefer not to answer

6c. What pronouns do you use?

<input type="checkbox"/> He/him/his	<input type="checkbox"/> Other(specify) _____
<input type="checkbox"/> She/her/hers	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> They/them/theirs	<input type="checkbox"/> Do not know

7. What is your sexual orientation? Check **ONE** only:

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

8. What is the highest level of education that you have completed?
Check **ONE** only:

<input type="checkbox"/> Less than high school	<input type="checkbox"/> Some post-secondary school	<input type="checkbox"/> Trade certificate or diploma	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> High school diploma or equivalent	<input type="checkbox"/> Post-secondary completion	<input type="checkbox"/> Graduate or professional degree	<input type="checkbox"/> Do not know

Birth year: Age:

WE ASK BECAUSE WE CARE

9. Which of the following options best describes your housing situation?
Check **ONE** only:

<input type="checkbox"/> Home owner	<input type="checkbox"/> Supportive housing	<input type="checkbox"/> Shelter/hostel	<input type="checkbox"/> Other(specify) _____
<input type="checkbox"/> Renting	<input type="checkbox"/> Approved home	<input type="checkbox"/> Boarding home	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> Staying with family/friends	<input type="checkbox"/> Group home	<input type="checkbox"/> Homeless	<input type="checkbox"/> Do not know

10a. In the past month, how often did you and others in your household worry that food would run out before you got more?

Most of the time Sometimes Rarely Never Prefer not to answer Do not know

10b. In the past month, how often did you and others in your household run out of food and you could not get more?

Most of the time Sometimes Rarely Never Prefer not to answer Do not know

11a. What was your total family income before taxes last year? Check **ONE only:**

<input type="checkbox"/> Less than \$20,000	<input type="checkbox"/> \$50,000 to less than \$60,000	<input type="checkbox"/> \$90,000 to less than \$100,000
<input type="checkbox"/> \$20,000 to less than \$30,000	<input type="checkbox"/> \$60,000 to less than \$70,000	<input type="checkbox"/> \$100,000 or more
<input type="checkbox"/> \$30,000 to less than \$40,000	<input type="checkbox"/> \$70,000 to less than \$80,000	<input type="checkbox"/> Prefer not to answer
<input type="checkbox"/> \$40,000 to less than \$50,000	<input type="checkbox"/> \$80,000 to less than \$90,000	<input type="checkbox"/> Do not know (GO to 11b)

11b. What was your monthly family income before taxes last year? _____

11c. How many people does this income support? _____

Prefer not to answer Do not know

**We thank you for taking time to complete the questionnaire.
This information will help us to improve the quality of care for all.**

Birth year: Age:



PARTICIPANT INTERVIEW CONSENT FORM

Project Title: Better Health for All: One patient at a time. Evaluation of a clinical intervention to improve patient centred care.

Researcher:

Hazel Williams-Roberts, Graduate Student, Community Health and Epidemiology, University of Saskatchewan, 306-321-4848, haw778@mail.usask.ca

Supervisor: Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan 306-966-7920, cory.neudorf@usask.ca

Purpose(s) and Objective(s) of the Research:

The conditions where people live and work can influence their health. The collection of sociodemographic information in health care facilities may help health care providers to better understand and address patient needs. The purpose of this study is to evaluate the effects of a clinical intervention to improve patient care through screening for and addressing those identified social factors that are barriers to a patient's achievement of good health.

Procedures:

Your participation will involve an interview of approximately 10 to 15 minutes. During the interview, I will sit with you in a comfortable place where we can speak privately. You will be asked questions about your care experience during this admission. If you do not wish to answer any of the questions during the interview, you may say so and I will move on to the next question. No one else but me will be present unless you would like someone else to be there. With your permission, the interview will be audiotaped to ensure accurate recording of responses and later transcribed for analysis. You will be given the opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

Potential Risks:

You will be asked to discuss some sensitive and personal information, and you may feel uncomfortable talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so, and that is also fine. You do not have to give me any reason for not responding to any question, or for refusing to take part in the interview.

Potential Benefits:

The social information requested during the study will be shared with your health care provider so that they can better assess your needs and provide more appropriate care. Your participation will also help us to understand how best to provide care that is responsive to the social and medical needs of our patients.

Compensation:

No reimbursement will be offered in exchange for your participation in this study.

Confidentiality:

All the information that you provide in the interview is completely confidential. It will not be shared with anyone outside of the research team. Your name will not appear on any report resulting from this study. However with your permission, anonymous quotations may be used.

Storage of data: The information collected in this study will be stored securely in a locked cabinet in my supervisor's office. Data will also be stored electronically on password protected computers. Information collected during the study will be retained for a period of six years before being destroyed.

Right to Withdraw:

Your participation is voluntary and you can withdraw from the study for any reason, at any time without penalty. If you withdraw from the research project, any data that you have contributed will be destroyed at your request. Your right to withdraw data from the study will apply until the data has been pooled. After this it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data. If any new information that could have a bearing on your decision to participate arises, you will be informed and given the opportunity to remove yourself from the study. At that time if you still consent, you will be asked to sign and date a consent form that includes any changes.

Whether you choose to participate or not will have no effect on your care, or how you will be treated. If you wish to withdraw, contact either Dr Cordell Neudorf (cory.neudorf@usask.ca), or the researcher (haw778@mail.usask.ca). If you choose to withdraw you will be given the option to also remove your data from the study.

Follow up:

To obtain results from the study, please contact the researcher (haw778@mail.usask.ca).

Questions or Concerns:

If you have any questions or would like additional information, you may contact me at 306 321 4848 or via email at haw778@mail.usask.ca. You can also contact my supervisor, Dr. Cordell Neudorf at 306-966-7920 or via email at cory.neudorf@usask.ca. This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975.

Signed Consent:

If you decide to take part in this study, there are some options for you to consider. Please place a check mark by the option that grants me permission to:

I grant permission to be audiotaped Yes No

You may use anonymized quotations Yes No

I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
_____	_____	
<i>Researcher's Signature</i>	<i>Date</i>	

Option for oral consent

I read and explained this Consent Form to the participant before receiving the participant's consent, and the participant had knowledge of its contents and appeared to understand it.

_____	_____	_____
<i>Name of Participant</i>	<i>Researcher's Signature</i>	<i>Date</i>



FOCUS GROUP PARTICIPANT CONSENT FORM

Project Title: Better Health for All: One patient at a time. Evaluation of a clinical intervention to improve patient centred care.

Researcher: Hazel Williams-Roberts, Graduate Student, Department of Community Health and Epidemiology, University of Saskatchewan, 306-321-4848, haw778@mail.usask.ca

Supervisor: Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan, 306-966-7920, cory.neudorf@usask.ca

Purpose(s) and Objective(s) of the Research:

The conditions where people live and work can influence their health. The collection of sociodemographic information in health care facilities may help health care providers to better understand and address patient needs. The purpose of this study is to evaluate the effects of a clinical intervention to improve patient-centred care through screening for and addressing those identified social factors that are barriers to patient's achievement of good health.

Procedures:

As a participant, you will be involved in a focus group discussion with 4 – 5 of your peers. The session is expected to last approximately 60 – 90 minutes. The discussion will take place in a comfortable space at the facility where participants can speak privately without interruptions. The session will be facilitated by a team comprised of myself and another researcher in order to effectively manage all aspects of the focus group discussion. No other persons except for the other participants and research team will be present during the discussion. You will be asked questions about your experience with the project's training activities and subsequent sociodemographic data collection as well as opinions about ways to improve the program. If you do not wish to answer a particular question during the interview, you may say so. You may contribute to the session as little or as much as you feel comfortable. With your permission, the interview will be audiotaped to ensure accurate recording of responses and later transcribed for analysis. You will be given the opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish.

Potential Risks:

The researcher will undertake to safeguard the confidentiality of the discussion, but cannot guarantee that other members of the group will do so. Please respect the confidentiality of the other members of the group by not disclosing the contents of this discussion outside the group, and be aware that others may not respect your confidentiality.

Because the participants for this research project have been selected from a small group of people, all of whom are known to each other; it is possible that you may be identifiable to other people on the basis of what you have said.

Potential Benefits:

You will not derive any personal benefits from this study.

Your participation will help us to understand how best to improve data collection so that the needs and preferences of all persons involved are accommodated.

Compensation:

No reimbursement will be offered in exchange for your participation in this study.

Confidentiality:

Confidentiality will be respected and no information that discloses the identity of a participant will be released or published. Any information that you provide will be grouped with the responses of other participants. It will not be shared with anyone outside of the research team. Your name will not appear on any report resulting from this study. However with your permission, anonymous quotations may be used.

Storage of data: The information collected in this session will be stored securely in a locked cabinet in my supervisor's office. Data will also be stored electronically on password protected computers. Information collected during the study will be retained for a period of six years before being destroyed.

Right to Withdraw:

Your participation is voluntary and you can withdraw from the study for any reason, at any time without penalty. If you withdraw from the research project at any time, any data that you have contributed will be destroyed at your request. Your right to withdraw data from the study will apply until the data have been pooled. After this it is possible that some form of research dissemination will have already occurred and it may not be possible to withdraw your data. If any new information that could have a bearing on your decision to participate arises, you will be informed and given the opportunity to remove yourself from the study. At that time if you still consent, you will be asked to sign and date a consent form that includes any changes.

Whether you choose to participate or not will have no effect on the terms of your employment or any job-related evaluations. If you wish to withdraw, contact either Dr. Cordell Neudorf (cory.neudorf@usask.ca), or the researcher (haw778@mail.usask.ca). If you choose to withdraw you will be given the option to also remove your data from the study.

Follow up:

To obtain results from the study, please contact the researcher (haw778@mail.usask.ca).

Questions or Concerns:

If you have any questions or would like additional information, you may contact me at 306 321 4848 or via email at haw778@mail.usask.ca. You can also contact my supervisor, Dr. Cordell Neudorf at 306-966-7920 or via email at cory.neudorf@usask.ca.

This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975.

Signed Consent:

If you decide to take part in this study, there are some options for you to consider. Please place a check mark by the option that grants me permission to:

I grant permission to be audiotaped Yes No

You may use anonymized quotations Yes No

I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records. I have had an opportunity to ask questions and my questions have been answered. I consent to participate in the research project. A copy of this Consent Form has been given to me for my records.

_____	_____	_____
<i>Name of Participant</i>	<i>Signature</i>	<i>Date</i>
_____	_____	
<i>Researcher's Signature</i>	<i>Date</i>	



FOCUS GROUP INTERVIEW GUIDE (PRE)

STUDY TITLE: Better health for all: We ask because we care. Evaluation of a clinical intervention to improve patient-centred care

SUPERVISOR:

Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan

STUDENT RESEARCHER:

Hazel Williams-Roberts, Department of Community Health and Epidemiology, University of Saskatchewan

INTRODUCTORY SCRIPT

Thank you for coming today. My name is Hazel Williams-Roberts and I am a graduate student in the Department of Community Health and Epidemiology at the University of Saskatchewan. I am partnering with the Saskatoon Health Region to collect data for a study that will become part of my doctoral dissertation. This is Y. She will observe and take notes while I will conduct the discussion. I am interested in understanding your views and experiences with the collection and application of social information in client care.

You have been asked to give voluntary consent to this interview by reviewing and signing a consent form. You have been given the opportunity to ask any questions about the study. A copy of the form will also be left with you so that you can be reminded of what we discussed.

In order to ensure that we have productive and meaningful discussions, I will outline the expectations for all participants in today's session. The session will be in the form of a discussion and group participants need not wait to be invited before they contribute. There are no right or wrong answers. The views and opinions of every participant are important. The aim is to hear as many different thoughts as possible. There are likely to be different views or experiences among the group and persons are free to say what they think and whether they agree or disagree with

other participants. We are not here to judge but to share our ideas and thoughts with each other. We ask that participants be respectful of each other and refrain from interrupting and talking over each other. Please place all mobile phones on silent mode if you need to keep them on during the session.

The views and comments shared during this discussion should be kept in the strictest confidence by all participants. Your responses will only be shared with members of the study team and will be compiled with other participants in the study. The information that I gather will be used to improve how information is collected and used to provide patient-centred care.

To ensure that we are able to capture accurate and complete responses, I would like to audio-tape this interview. As previously mentioned, the recording will be transcribed and all names and personal information will be removed to protect your identity. Do you have any questions about today's discussion?

I ask that each participant introduces himself/herself to the group so that we are all acquainted with each other. It would be helpful to know if you are part time or full time and the number of years that you have been working at the facility.

1 **Knowledge about social determinants of health**

- Can you tell me what you know about the term 'social determinants of health'?
 - How did you hear about social determinants of health?
- How comfortable are you addressing social needs of clients when they are identified during a consultation?

•

2 **Attitudes to screening for social determinants of health**

- How important do you think it is to obtain sociodemographic information during the medical visit?
- How do you think clients feel about being asked to give this information?
- Who do you think should ask about social circumstances during the medical visit?
 - Why do you feel that way?
- How do you think this information should be used in client care?

3 **Practices related to screening for social determinants of health**

- To what extent is information currently captured about client social circumstances?
 - Which ones are currently captured?
- To what extent is client care adapted to any social circumstances that are identified during a visit?

4 What if any challenges do you encounter in attempting to address the social needs of your clients?

CLOSURE: We are coming to the close of our discussion. I would like to thank you for your participation. Your contribution is valuable and will be used to improve the process so that we are better able to serve our clients. If you remember anything else later, you may contact me using the information that has been provided. Thanks for your time and enjoy the rest of your day.



FOCUS GROUP INTERVIEW GUIDE (POST)

STUDY TITLE: Better health for all: We ask because we care .Evaluation of a clinical intervention to improve patient centred care

SUPERVISOR:

Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan

STUDENT RESEARCHER:

Hazel Williams-Roberts, Department of Community Health and Epidemiology, University of Saskatchewan

INTRODUCTORY SCRIPT

Thank you for coming today. My name is Hazel Williams-Roberts and I am a graduate student in the Department of Community Health and Epidemiology at the University of Saskatchewan. I am partnering with the Saskatoon Health Region to collect data for a study that will become part of my doctoral dissertation. This is Y. She will observe and take notes while I will conduct the discussion. I am interested in understanding your views and experiences with the collection of social information during the pilot project.

You have been asked to give voluntary consent to this interview by reviewing and signing a consent form. You have been given the opportunity to ask any questions about the study. A copy of the form will also be left with you so that you can be reminded of what we discussed.

In order to ensure that we have productive and meaningful discussions, I will outline the expectations for all participants in today's session. The session will be in the form of a discussion and group participants need not wait to be invited before they contribute. There are no right or wrong answers. The views and opinions of every participant are important. The aim is to hear as many different thoughts as possible. There are likely to be different views or experiences among the group and persons are free to say what they think and whether they agree or disagree with other participants. We

are not here to judge but to share our ideas and thoughts with each other. We ask that participants be respectful of each other and refrain from interrupting and talking over each other. Please place all mobile phones on silent mode if you need to keep them on during the session.

The views and comments shared during this discussion should be kept in the strictest confidence by all participants. Your responses will only be shared with members of the study team and will be compiled with other participants in the study. The information that I gather will be used to improve how information is collected and used to provide patient-centred care.

To ensure that we are able to capture accurate and complete responses, I would like to audio-tape this interview. As previously mentioned, the recording will be transcribed and all names and personal information will be removed to protect your identity. Do you have any questions about today's discussion?

I believe that we all know each other however we can begin by each participant introducing himself/herself to the group so that we are all acquainted with each other. It would be helpful to know your role at the centre.

- 1 **Knowledge about social determinants of health**
 - How comfortable are you now in addressing the social needs of clients?

- 2 **Attitudes to screening for social determinants of health**
 - How important do you think it is to obtain sociodemographic information during the medical visit?
 - How do you think this information should be used in client care?

- 3 **Practices related to screening for social determinants of health**
 - To what extent is information currently captured about client social circumstances?
 - Which ones are currently captured?
 - To what extent is client care currently adapted to any social circumstances that are identified during a visit?

- 4 **Patient reactions to sociodemographic data collection**
 - How did clients react to being asked questions about their social circumstances?
 - How if at all, did the reactions differ according to various client characteristics?
 - Can you provide an example to illustrate each case?

- 5 **Expectations about sociodemographic data collection**
 - How did your expectations compare with the actual implementation of the project?

- 6 **Adequacy of training/preparation for implementation**
 - To what extent did the training activities prepare you for implementing the data collection?
 - What components were most useful?
 - What components were least useful?
 - What would you change if anything about the training now that you have had the experience in the field?

- 7 **Challenging experiences**
 - What were some of the challenges that you experienced with data collection?
 - How did you resolve these issues?

- 8 **Successful approaches to project implementation**
 - What aspects of data collection are going well?

- 9 **Areas for improvement**
 - How can the project improve data collection?

CLOSURE: We are coming to the close of our discussion. I would like to thank you for your participation. Your contribution is valuable and will be used to improve the process so that we are better able to serve our clients. If you remember anything else later, you may contact me using the information that has been provided. Thanks for your time and enjoy the rest of your day.



PARTICIPANT INTERVIEW GUIDE (CLIENT)

STUDY TITLE: Better health for all: We ask because we care. Evaluation of a clinical intervention to improve patient-centred care

SUPERVISOR:

Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan

STUDENT RESEARCHER:

Hazel Williams-Roberts, Department of Community Health and Epidemiology, University of Saskatchewan

Introduction:

Thank you for agreeing to meet with me today. My name is Hazel Williams-Roberts and I am a graduate student in the Department of Community Health and Epidemiology at the University of Saskatchewan. I am partnering with the Saskatoon Health Region to collect data for a study that will become part of my doctoral dissertation. I am interested in understanding your views about the collection and use of social information during the medical visit. I will ask you questions about your thoughts and experiences with the collection of social information during this visit and then we will talk about how you think the information was or was not used as part of your care.

You have been asked to give voluntary consent to this interview by reviewing and signing a consent form. You have been given the opportunity to ask any questions about the study. A copy of the form will also be left with you so that you can be reminded of what we discussed.

The information you share with me today is completely confidential. You will be assigned a false name (pseudonym) and your responses will not have any identifying information. Your responses will only be shared with members of the study team and will be compiled with other participants in the study. The information that I gather will be used to improve how information is collected and used to provide client-centred care.

To ensure that we are able to capture accurate and complete responses, I would like to audio-tape this interview. As previously mentioned, the recording will be transcribed and all names and places will be removed to protect your identity.

It is helpful to know a little bit about you so that I have a context for your responses. This information helps to understand the backgrounds of study participants.

Age:

Gender:

Ethnicity:

First visit ever to facility:

- 1 **Importance of assessing social circumstances**
 - How important do you think that it is to gather information about clients' social circumstances in health care settings?
 - How do you think this information might be useful in planning client care?

- 2 **Who should be asked about social circumstances?**
 - Who do you think should be asked about their social circumstances during a medical visit?
 - Can you explain why you feel that way?

- 3 **Who should ask questions about social circumstances in a health care setting?**
 - Why do you think that is the case?

- 4 **Feelings about being asked for sociodemographic information**
 - How did you feel about being asked those questions?
 - Can you explain what made you feel that way?

- 5 **Sources of discomfort**
 - Were there particular questions that made you feel more uncomfortable than others?

- 6 **How sociodemographic data should be collected**
 - How would you like to see social information collected in this centre?
 - What would be the best way to gather this information?

- 7 **What aspects of the data collection need to be improved?**
 - What should be done to help clients feel comfortable about giving this information?
 - What needs to change from the current process?

CLOSURE: Thank you for taking the time to participate in this study. If you would like to receive a copy of the results upon completion of the study, my contact information is listed on the consent form.

CHART ID: _____

DATA ABTRACTOR: _____

DATE (YYYY/MMM/DD): _____

DATE ENTERED (YYYY/MMM/DD): _____

BETTER HEALTH FOR ALL: WE ASK BECAUSE WE CARE

DATA ABSTRACTION FORM

SCREENING QUESTION: Did the date of service occur between --/--/-- and --/--/--/?	1= Yes 2= No If No then DO NOT PROCEED AS PATIENT IS NOT ELIGIBLE	SCQ <input type="checkbox"/>
DATE OF VISIT	YYYY/MMM/DD (E.g. 2015/May/05)	DISC _____
DATA ITEM	INSTRUCTIONS FOR ABSTRACTION	DATA ENTRY FIELD
CHART ID		
SITE	Name of project site	EXP <input type="text"/>
DATE OF BIRTH (YYYY/MMM/DD)	1= Yes 99= Not documented	DOB _____
GENDER	1= Male 2= Female 3= Other (Specify) 99= Not documented	GEN _____ <input type="checkbox"/>
MEDICAL DIAGNOSIS	This refers to the primary diagnosis of the patient	DIAG _____
Social determinants documented		
PLACE OF BIRTH	1= Canada 2= Other 99= Not documented	POB <input type="checkbox"/>
YEAR OF ARRIVAL	Year person arrived in Canada	YOA _____
ETHNICITY	1= Yes then specify 99= Not documented	RACE _____ <input type="checkbox"/>
LANGUAGE MOST COMFORTABLE SPEAKING	1= Yes then specify 99= Not documented	LAN _____ <input type="checkbox"/>
DISABILITY	1= Yes then specify 2= No disability 99= Not documented	DIL _____ <input type="checkbox"/>

APPENDIX J_ DATA ABSTRACTION FORM

LEVEL OF EDUCATION	1= Yes then specify 99= Not documented	EDUC _____	<input type="checkbox"/>
FOOD SECURITY OF HOUSEHOLD	1= Yes then specify 99= Not documented	FOS _____	<input type="checkbox"/>
HOUSING SITUATION	1= Yes then specify 99=Not documented	HOS _____	<input type="checkbox"/>
HOUSEHOLD INCOME	1= Yes then specify 99= Not documented	INC _____	<input type="checkbox"/>
Types of interventions			
USE OF AN INTERPRETER	1= Yes	INT _____	<input type="checkbox"/>
REFERRAL TO SOCIAL WORKER	1= Yes	SOW _____	<input type="checkbox"/>
REFERRAL TO OTHER COMMUNITY RESOURCES (E.G FOOD BANK)	1= Yes and specify	COR _____	<input type="checkbox"/>
ADJUSTMENT OF RISK	1=Yes	ADR _____	<input type="checkbox"/>

WHY ALL THE QUESTIONS?



The social aspects of your life impact your health.

By asking about you and your life, our goal is to make sure every person has access to the highest quality of health care that we can provide. The information you provide will:

- tell us more about you and your needs
- help us plan for services
- help us improve the quality of care for all

You can choose not to answer any or all questions. Please ask your care provider if you have additional questions or concerns.



Population and Public Health

WE ASK BECAUSE WE CARE.

Will you please provide us with information about yourself?

The information you share with us will be treated with respect and used to help us understand **who** you are, **what** needs you may have, and **how** we can provide you with the best care possible.

You can choose to participate or not.

You can refuse to answer any question.



QUESTIONS?

Ask your care provider if you have any questions or concerns.



WHY ALL THE QUESTIONS?



We ask because we care.

Why is the hospital asking these questions?

Our goal is to make sure every person has access to the highest quality of healthcare that we can provide. The information you give us will 1) Tell us more about you; 2) Help us plan for services; 3) Help us improve the quality of care for all.

Isn't it illegal to ask these questions?

No. The Saskatchewan Human Rights Code encourages the collection of this kind of information when the goal is to learn about discrimination and promote fair treatment and better care.

What are you going to do with my information?

Your answers will be used by the Sexual Health Centre to help us understand who you are, what needs you may have, and how we can provide you with the best care. We will also use this information to get a picture of who our clients are, plan for services, and ensure we are providing the best care for all. For example:

1. We will be able to look at whether health is affected by things like language, disability, gender, etc.
2. We will review the information and use it for program development and training.

Who can see my information?

Your information can be seen by people in your 'circle of care' – your doctors, nurses, counsellor, and others involved in your direct care – and will be treated with the same respect and confidentiality as all the other information you share as part of your care and treatment.

For research, program planning, and training, the information will only be available in 'aggregate' form; this means that your answers will be grouped with other answers and there will be no way to identify you (no name, address, or other identifying information).

Why are you asking me about my sexual orientation (or disability, or race...)?

Your answers will help us provide you with the best care that meets your needs. For example, we can use that information to link you with services or programs.

We also know that sometimes people experience discrimination in healthcare. We want to make sure that is not happening here – and, if it is, we want to correct that.

Why are you asking me about my place of birth? Do you think I'm here illegally?

No, that is not why we're asking. We just want to make sure that no matter where you come

from, or what your immigration status is, you get the best care possible.

Why do you need to know how much money I earn? Do you report this to any agency?

No – we don't give your information to anyone. For many people, knowing about income will help us inform you about services you may be eligible for and provide support for any unique needs. Research also tells us that different income groups, especially low income individuals, may experience poorer health or receive a different level of care than higher income people. We don't want this to happen here and we want to know if it is.

Do I have to participate? What if there are questions I don't want to answer?

No – it is your choice to participate or not. You can choose not to answer any or all questions.

QUESTIONS?

Ask your care provider if you have additional questions or concerns.



APPENDIX C

STUDY MATERIALS FOR ST PAULS HOSPITAL

- 1 Pre –test training questionnaire
- 2 Post-test training questionnaire
- 3 Consent forms
- 4 Intercept interview tracking sheet
- 5 Interview guides
- 6 Information and education materials (Poster, brochure)

WE ASK BECAUSE WE CARE

SECTION A: KNOWLEDGE OF SOCIAL DETERMINANTS OF HEALTH

(Please choose only **one** response for each question)

Q1. Have you ever heard the term 'social determinants of health'?

1. Yes → Please skip to Q2
2. No → Please skip to Q3
3. Not sure → Please skip to Q3
4. Prefer not to answer → Please skip to Q3

Q2. What do you understand by the term social determinants of health?

1. Non-medical factors that affect a person's risk and opportunity to make healthy
2. choices.
3. Behavioral factors (e.g. smoking, excessive drinking of alcohol, poor dietary practices)
4. that increase risk for disease.
5. Access to social support of family and or community members.
6. Social policies introduced by government to protect the welfare of its residents.

Q3. Have you ever heard the term 'cultural competence'?

1. Yes → Please skip to Q4
2. No → Please skip to Q5
3. Not sure → Please skip to Q5
4. Prefer not to answer → Please skip to Q5

Q4. What do you understand by the term 'cultural competence'?

1. Provision of similar care to all patients in need.
2. The ability of an individual to understand and respect values, beliefs and attitudes of people across cultures and to consider and respond appropriately to these differences in the delivery of care.
3. Reflection on one's values and beliefs about others who are culturally different.
4. Ensuring that the workforce is culturally diverse.

SECTION B: ATTITUDES TO SCREENING FOR SOCIAL DETERMINANTS

(Please choose only **one** response for each question)

Q5. In your opinion, is it necessary to screen all patients for social determinants that affect health during the medical assessment?

1. Yes 2. No 3. Not sure 88. Prefer not to answer

Q6. In your opinion, should the patient’s care and treatment plan address both medical and social needs?

1. Yes 2. No 3. Not sure 88. Prefer not to answer

Q7. In your opinion will patients be offended if they are asked questions about social circumstances during the medical visit?

1. Yes 2. No 3. Not sure 88. Prefer not to answer

Q8. How comfortable do you feel asking patients about each of the following issues? (Please choose the number that represents how you feel about the issue.)

	1 Very comfortable	2	3 Neutral	4	5 Very uncomfortable	88 Prefer not to answer
Housing needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Food insecurity	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Unmet educational needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Social assistance benefits/income	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Sexual orientation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Gender	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Ethnicity/race	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Religion	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Language needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Disability	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>

Q9. What, if any challenges have you encountered when asking patients about social needs? (Please choose the number that represents your degree of agreement with the statement)

	1 Strongly agree	2 Mildly agree	3 Neither agree nor disagree	4 Mildly disagree	5 Strongly disagree
Patient reluctance to answer questions	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Fear of offending the patient	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Lack of knowledge and skills about how to ask the questions in a sensitive way	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
Concern that the information is not necessary for my role	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>
<input type="checkbox"/> Other (Please specify) _____					

SECTION D: CHARACTERISTICS OF PARTICIPANTS

There are just a few questions left. (Please choose **the most appropriate** response for each question)

Q10. Which hospital(s) do you work at?

- 1. St Paul's Hospital
- 2. City Hospital
- 3. Royal University Hospital
- 4. Prefer not to answer

Q11. How many years have you been working in this job? _____ (no of years)

- 88. Prefer not to answer

Q12. What is your gender?

- 1. Male
- 2. Female
- 3. Other _____
- 88. Prefer not to answer

Q13. How old were you at your last birthday?

- 1. 18 – 30 years
- 2. 31 – 40 years
- 3. 41 – 50 years
- 4. 51 or more years
- 88. Prefer not to answer

Q14. Which, if any of the following hardships did you experience during childhood?

No hardships experienced → Please skip to the end.

- | Yes | No | |
|-----------------------------|-----------------------------|---------------------------------------|
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | Housing needs |
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | Food insecurity |
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | Receipt of social assistance benefits |
| 1 <input type="checkbox"/> | 2 <input type="checkbox"/> | Discrimination due to race/ethnicity |
| 88 <input type="checkbox"/> | 88 <input type="checkbox"/> | Prefer not answer |

We thank you for taking the time to complete this questionnaire.

We welcome any comments or suggestions to improve this tool.

WE ASK BECAUSE WE CARE

SECTION A: KNOWLEDGE OF SOCIAL DETERMINANTS OF HEALTH

(Please choose only **one** response for each question)

Q1. Have you ever heard the term 'social determinants of health'?

1. Yes ➡ Please skip to Q2
2. No ➡ Please skip to Q3
3. Not sure ➡ Please skip to Q3
4. Prefer not to answer ➡ Please skip to Q3

Q2. What do you understand by the term social determinants of health?

1. Non-medical factors that affect a person's risk and opportunity to make healthy choices.
2. Behavioral factors (e.g. smoking, excessive drinking of alcohol, poor dietary practices) that increase risk for disease.
3. Access to social support of family and or community members.
4. Social policies introduced by government to protect the welfare of its residents.

Q3. Have you ever heard the term 'cultural competence'?

1. Yes ➡ Please skip to Q4
2. No ➡ Please skip to Q5
3. Not sure ➡ Please skip to Q5
4. Prefer not to answer ➡ Please skip to Q5

Q4. What do you understand by the term 'cultural competence'?

1. Provision of similar care to all patients in need.
2. The ability of an individual to understand and respect values, beliefs and attitudes of people across cultures and to consider and respond appropriately to these differences in the delivery of care.
3. Reflection on one's values and beliefs about others who are culturally different.
4. Ensuring that the workforce is culturally diverse.

SECTION B: ATTITUDES TO SCREENING FOR SOCIAL DETERMINANTS

(Please choose only **one** response for each question)

Q5. In your opinion, is it necessary to screen all patients for social determinants that affect health during the medical assessment?

1. Yes 2. No 3. Not sure 88. Prefer not to answer

Q6. In your opinion, should the patient’s care and treatment plan address both medical and social needs?

1. Yes 2. No 3. Not sure 88. Prefer not to answer

Q7. In your opinion will patients be offended if they are asked questions about social circumstances during the medical visit?

1. Yes 2. No 3. Not sure 88. Prefer not to answer

Q8. How comfortable do you feel asking patients about each of the following issues? (Please choose the number that represents how you feel about the issue.)

	1 Very comfortable	2	3 Neutral	4	5 Very uncomfortable	88 Prefer not to answer
Housing needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Food insecurity	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Unmet educational needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Social assistance benefits/income	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Sexual orientation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Gender	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Ethnicity/race	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Religion	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Language needs	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>
Disability	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	88 <input type="checkbox"/>

SECTION C: TRAINING WORKSHOP

Please choose **one** response for each question

Q9. The topics discussed were relevant to me

- Strongly agree Somewhat agree Neutral Somewhat disagree Strongly disagree Prefer not to answer

Q10. What components of the training were the most helpful?

Q11. What components of the training could be improved?

Q12. The time allocated for the training was adequate.

- Strongly agree Somewhat agree Neutral Somewhat disagree Strongly disagree Prefer not to answer

SECTION D: CHARACTERISTICS OF PARTICIPANTS

There are just a few questions left. (Please choose **the most appropriate** response for each question)

Q10. Which hospital(s) do you work at?

- 1. St Paul's Hospital
- 2. City Hospital
- 3. Royal University Hospital
- 4. Prefer not to answer

Q11. How many years have you been working in this job? _____ (no of years)

- 88. Prefer not to answer

Q12. What is your gender?

- 1. Male
- 2. Female
- 3. Other _____
- 88. Prefer not to answer

Q13. How old were you at your last birthday?

- 1. 18 – 30 years
- 2. 31 – 40 years
- 3. 41 – 50 years
- 4. 51 or more years
- 88. Prefer not to answer

Q14. Which, if any of the following hardships did you experience during childhood?

No hardships experienced ➡ Please skip to the end.

Yes No

- 1 2 Housing needs
- 1 2 Food insecurity
- 1 2 Receipt of social assistance benefits
- 1 2 Discrimination due to race/ethnicity
- 88 88 Prefer not answer

We thank you for taking the time to complete this questionnaire.

We welcome any comments or suggestions to improve this tool.

ID	How comfortable did you feel being asked about Aboriginal/Indigenous background?	How important do you think that it is to ask patients about Aboriginal/Indigenous identity in the hospital?	Who do you think should be asked about their identity?	Who do you think is the most appropriate person to ask about Aboriginal/Indigenous identity?	Age	Gender	Ethnicity
	Very unconf Smwh unconf Neut comf Smwht comf Very comf	Very imp Smwh imp Not imp Pref not Don't know	Every One Some ppl No one Pref not Don't know	Reg Provider Self Adm Pref not Don't know			
	Very unconf Smwh unconf Neut comf Smwht comf Very comf	Very imp Smwh imp Not imp Pref not Don't know	Every One Some ppl No one Pref not Don't know	Reg Provider Self Adm Pref not Don't know			
	Very unconf Smwh unconf Neut comf Smwht comf Very comf	Very imp Smwh imp Not imp Pref not Don't know	Every One Some ppl No one Pref not Don't know	Reg Provider Self Adm Pref not Don't know			

PARTICIPANT INTERVIEW GUIDE (PATIENT)

It is helpful to know a little bit about you so that I have a context for your responses. This information helps to understand the backgrounds of study participants.

Age:

Gender:

Ethnicity:

First visit ever to facility:

- 1 **Importance of assessing social circumstances**
 - How important do you think that it is to gather information about patient's social circumstances in health care settings?
 - How important do you think that it is for your health care provider to know about your indigenous ancestry?

- 2 **Who should be asked about social circumstances?**
 - Who do you think should be asked about their social circumstances during a medical visit?
 - Can you explain why you feel that way?

- 3 **Who should ask questions about social circumstances in a health care setting?**
 - Who do you think is the most appropriate person to ask questions about indigenous identity? Why do you think that is the case?

- 4 **Feelings about being asked for sociodemographic information**
 - How did you feel about being asked about your indigenous identity?
 - Can you explain what made you feel that way?

- 5 **What aspects of the data collection need to be improved?**
 - What should be done to help clients feel comfortable about giving this information?
 - What needs to change from the current process?

- 6 **Application of sociodemographic data to inform client care plan**
 - How do you think the information was used in planning your care?
 - How has this made a difference to you in being able to follow your care and treatment plan?

CLOSURE: Thank you for taking the time to participate in this study. If you would like to receive a copy of the results upon completion of the study, my contact information is listed on the consent form.



KEY INFORMANT INTERVIEW GUIDE

STUDY TITLE: Better health for all: We ask because we care. Evaluation of a clinical intervention to improve patient centred care

SUPERVISOR:

Dr. Cordell Neudorf, Department of Community Health and Epidemiology, University of Saskatchewan

STUDENT RESEARCHER:

Hazel Williams-Roberts, Department of Community Health and Epidemiology, University of Saskatchewan

Introduction:

Thank you for agreeing to meet with me today. My name is Hazel Williams-Roberts and I am a graduate student in the Department of Community Health and Epidemiology at the University of Saskatchewan. I am partnering with the Saskatoon Health Region to collect data for a study that will become part of my doctoral dissertation. I am interested in understanding your views about the collection and use of social information during the medical visit. I will ask you questions about how you came to participate in the project and your experiences with implementation in this centre.

You have been asked to give voluntary consent to this interview by reviewing and signing a consent form. You have been given the opportunity to ask any questions about the study. A copy of the form will also be left with you so that you can be reminded of what we discussed.

The information you share with me today is completely confidential. You will be assigned a false name (pseudonym) and your responses will not have any identifying information. Your responses will only be shared with members of the study team and will be compiled with other participants in the study. The information that I gather will be used to improve how information is collected and used to provide client-centred care.

To ensure that we are able to capture accurate and complete responses, I would like to audio-tape this interview. As previously mentioned, the recording will be transcribed and all names and places will be removed to protect your identity.

It is helpful to know a little bit about you so that I have a context for your responses. This information helps to understand the backgrounds of study participants.

Ethnicity:

Length of service:

- 1 **Importance of assessing social circumstances**
 - How important do you think that it is to gather information about clients' social circumstances in health care settings?
- 2 **Who should be asked about social circumstances?**
 - Who do you think should be asked about their social circumstances during a medical visit?
 - Can you explain why you feel that way?
- 3 **Who should ask questions about social circumstances in a health care setting?**
 - Why do you think that is the case?
- 4 **Feelings about being asked for sociodemographic information**
 - How did you think that patients feel about being asked questions related to their social circumstances?
 - Can you explain why you feel that way?
- 5 **Participation in the project**
 - Tell me about how you came to participate in the project:
 - What were the factors that encouraged you to consider the project for your centre?
 - What were some of the challenges that affected implementation of the project?
- 6 **How sociodemographic data should be collected**
 - How would you like to see social information collected in this centre?
 - What would be the best way to gather this information?
- 7 **What supports are needed for institutions who want to collect this information?**
 - How should we support other institutions who want to be involved in similar initiatives?

CLOSURE: Thank you for taking the time to participate in this study. If you would like to receive a copy of the results upon completion of the study, my contact information is listed on the consent form.

WE ASK BECAUSE WE CARE.



What are we asking you?

We are asking all patients who register at this hospital whether they self-identify as First Nations or Métis.

You can choose not to answer this question.

Why are we asking you?



Our goal is to make sure you have access to the highest quality of health care that we can provide. The information you provide will:

- Help us connect you with services, such as First Nations and Métis Health Navigators and Cultural Advisors
- Help us plan for services
- Help us improve the quality of care for all.



Who will ask me this question? When? Where?

This question will be asked when you register for your appointment or hospital stay at Registration Services. You will be asked this question when the Registration Clerk verifies and updates your personal information, such as your address, phone number, next of kin and family physician.

What are you going to do with my information?



Your information may be seen by people in your circle of care – your doctors, nurses, health navigator and others involved in your care – and will be treated with the same respect and confidentiality as all the other information you share as part of your care and treatment. For research, program planning and staff training purposes, the information will only be available in aggregate form; this means that your answers will be grouped with other answers, and there will be no way to identify you (no name, address or other identifying



What impact will my response have on the care I receive?

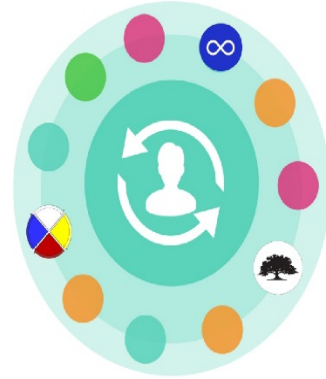
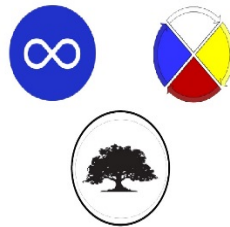
Your choice not to participate will not have a negative impact on the quality of care you receive. By choosing to participate, you can help us improve your care – and your health. Knowing how you self-identify will help us to connect you to services such as First Nations and Métis Health Navigators and Cultural Support Workers. We also know that sometimes people experience discrimination in health care. We want to make sure that is not happening here – and, if it is, we want to correct it.



You can choose not to participate in this research.

However, the information you share with us will be treated with respect and used to help us understand **who** you are, **what** needs you may have and **how** we can provide you with the best care possible.

You can choose not to answer this question.



WHY ALL THE QUESTIONS?



© Saskatoon Health Region, 2016



WE ASK BECAUSE WE CARE.

Why are you asking me if I self-identify as First Nations or Métis?

Your answers will help us provide you with the best care that meets your needs. For example, we can use this information to link you with services or programs.

We also know that sometimes people experience discrimination in health care. We want to make sure that is not happening here – and, if it is, we want to correct it.

Isn't it illegal to ask these types of questions?

No. The Saskatchewan Human Rights Code encourages the collection of this kind of information when the goal is to learn about discrimination and to promote fair treatment and better care.

What are you going to do with my information?

Your answers will be used by Saskatoon Health Region to help us understand who you are, what needs you may have and how we can provide you with the best care possible.

By choosing to participate, you can help us improve your care – and your health. Knowing how you self-identify will help us connect you with services such as connections to First Nations and Métis Health Navigators and Cultural Advisors.

Your participation will help us to understand if health is affected by ethnic identity and other social factors.

Your information will be kept confidential and will be used for program development and staff training.

Who can see my information?

Your information may be seen by people in your circle of care – your doctors, nurses, health navigator and others involved in your care – and will be treated with the same respect and confidentiality as all the other information you share as part of your care and treatment.

For research, program planning, and staff training purposes, the information will only be available in aggregate form; this means that your answers will be grouped with other answers, and there will be no way to identify you (no name, address or other identifying information).

Why are we asking these kinds of questions?

Our goal is to make sure every person has access to the highest quality of health care that we can provide. The information you give us will 1) help us connect you with services, such as First Nations and Métis Health Navigators and Cultural Advisors; 2) help us plan for services; 3) help us improve quality of care for all.

Do I have to participate? What if I don't want to answer?

It is your choice to participate. You can choose not to answer the question.

QUESTIONS?

Please ask to speak with the Registration Manager or contact Client Representative Services at 306-655-0250 if you have any questions or concerns.



APPENDIX D

CLINICAL TOOLS FOR ASSESSMENT OF SOCIAL RISKS

D1: Clinical Poverty Tool

Within the primary care literature in Canada, a Clinical Poverty Tool was identified that was developed by Bloch and colleagues for individual screening and intervention. (50) The tool screens with a single question ‘Do you ever have difficulty making ends meet at the end of the month?’ that has high sensitivity (98%) but low specificity (40%) for identifying those living below the poverty line. (51)

The tool advocates a three step approach beginning with a single poverty screening question. (50) A positive screen triggers ‘adjustment of risk’ which refers to integration of knowledge of the effects of poverty on disease risk to inform decisions about screening or other aspects of management. An example of this may be illustrated when a primary care physician increases frequency of screening for diabetes in low income patients. In the third step, providers develop treatment plans that are tailored to mitigate the patient’s lived experience of poverty. The tool also includes seven follow on questions that aim to prompt patients to explore entitlement for specific income benefits. The authors concede that while the provider is uniquely placed to facilitate patient access to income support and other resources, this role may not be equally embraced by all physicians. They recommend a team based approach to comprehensively address poverty in clinical practice. While the tool is available and its use is being promoted by the Ontario College of Family Physicians, evidence of its effectiveness in improving patient outcomes and care experience has not been studied.

The Toronto Poverty Tool has been adapted in other provinces such as British Columbia and Manitoba. Using the same general approach, a single screening question is asked of all patients, followed by adjustment of risk and eight questions that assess access to health care and eligibility for specific benefits such as First Nations Health Benefit and Disability Assistance. It is unclear whether the tool has been evaluated despite both a BC-wide and Kootenay Boundary versions.

D2: Patient-centred Assessment Method (PCAM)

The Patient-Centred Assessment Method (PCAM) was adapted for a UK context from similar tools that had been validated in the United States. (52) It was developed to provide a comprehensive assessment of psychosocial needs and to facilitate intervention by providers to any identified needs based on severity and urgency of these needs. The method was intended to be used by a range of providers including physicians and nurses. A study was conducted to assess the implementation of the PCAM and its effects on patient satisfaction, patient experience and referral patterns.

The PCAM was implemented in the public sector, primary care setting of a wellness clinic that targeted persons at risk for cardiovascular disease based on age and location. The program was implemented by nurses who in addition to their general wellness and mental health training also received training to integrate the PCAM into care and address any needs that were identified. The PCAM is an 11-item instrument that covers three domains including health and wellbeing, social environment and health literacy and communication. The tool includes a section to document the plan for intervention for each of the items assessed as well as a score for the level of need and urgency.

There were no differences found in patient satisfaction or perceived provider empathy pre and post intervention. This was attributed to a ceiling effect where already high ratings at baseline left little room for improvement in the post intervention assessment. The pattern of referrals changed in the post intervention assessment with fewer medical referrals but an increase in psychological, social and lifestyle referrals. It was difficult to attribute the change to the intervention as population characteristics were different and possibly also documentation of referrals.

Nurses found that the PCAM was easy to incorporate into their practice and fostered a holistic assessment of needs. Administration of the tool required an additional 10 – 15 minutes however they suggested that with more experience the efficiency could be improved. Initial concerns about the capacity to address needs identified were allayed during the program. Nurses found that they were able to cope with the range of problems identified and found appropriate resources available. They also perceived that patients were willing to discuss their problems and viewed it as a collaborative tool to inform provider-patient conversation.

D3: I-HELP

The I-HELP Tool was developed by a Medical Legal Partnership (MLP) in Boston, Massachusetts. (54) It was designed to assist clinicians to identify social circumstances that affect child health and are amenable to direct intervention. I-HELP is a mnemonic that refers to unmet needs related to income supports, housing and utilities, education, legal (immigration) status and personal and family stability. The tool empowers clinicians to diagnose these specific unmet needs and to mobilize resources to assist the patient. This may require referral to a social worker, consultation with a legal provider about the family's service or benefits eligibility, denial or termination and referral to the legal clinic for intake with the legal provider.

Clinicians who are interested in becoming advocates receive training in accredited Medical-Legal Partnership (MLP) education sessions. Training content focuses on naming and understanding social determinants of health, using the tool to screen patients for social determinants, learning about the laws and systems that govern the barriers identified by the tool, diagnosing in consultation or by referral to legal provider and treating patients with effective advocacy interventions.

The tool has been evaluated in a recent study among pediatric residents who were exposed to a multifaceted behavior change intervention to improve social risk screening in a pediatric hospital. (233) The sensitivity, specificity, positive and negative predictive values were established by comparing with social work evaluations. The intervention increased documentation of screening in I-HELP domains and referral to social work ($p < 0.001$). The sensitivity, specificity and positive predictive values were 0.63, 0.96 and 0.94 respectively. Residents who had been trained continued to practice screening 8 months post intervention.

D4: HealthBegins

HealthBegins is described as 'think-and-do tank comprised of doctors and public health innovators who are committed to demonstrating how a smarter health care system can improve health where it begins – where we live, work, learn and play'.(55) The group engages in a number of different activities including training and designing clinical tools that enable providers to practice care differently and address upstream factors in care.

The team has developed a screening tool that includes items related to education, employment, social connection and isolation, immigration concerns, nutrition, physical activity, financial strain, food security, housing security, transportation, exposure to violence (community and intimate partner violence) and stress. The guide recommends the appropriate screening interval for each question (first visit or annually) and has a section for scoring the patient's response. A positive screen on an item is allocated a score of one (1) hence higher scores signal more health-related social determinants. The tool also includes a section to record the referral plan. (55)

The authors reported that some domains were derived from 2014 Institute of Medicine recommendations for measures that should be incorporated into electronic health records. Training materials were not available on the website. No information was provided about validation of the tool or how it performs in clinical practice.

D5: Happy To Ask, Happy To Tell

'Happy To Ask, Happy to Tell' is a toolkit that was developed by the NHS Health Scotland and the Information Services Division of NHS National Services Scotland to support equity and diversity monitoring in health care settings. (56) The resource includes a standardized sociodemographic questionnaire, trainer and trainee manuals and DVDs. No single mode of collection (self or interviewer administered) is privileged by the toolkit. Although there were plans for a formal evaluation of the toolkit, it is uncertain whether it was implemented. Consequently, information is limited about the process for development of the questionnaire or experience with the toolkit (e.g. acceptability, effect on patient care experience or other health outcomes).

The questionnaire includes recommended items about disability, gender, sexual orientation, race/ethnic group and religion. Questions are closed ended with multiple choice options. Provisions are made to record 'other' responses not included among the listed options. The majority of questions require the respondent to select only one choice. There are response options for 'prefer not to answer' or 'do not know'.

The training manual introduces each domain with a definition. This is followed by the screening question and 'points to consider' around asking the question. The rationale is presented

with reference to key legal regulations and laws that support data collection. The trainee is also encouraged to reflect on how they would feel about sharing their information and how they would like to be treated. There are sample scripts for asking the questions and for inclusion in patient information materials.

There is also a trainer's manual that describes the rationale for equality and diversity monitoring, intended training audiences and provides a suggested sequence of activities. The resource is a step by step guide for the training that demonstrates how to use the supplementary materials such as the DVD. An evaluation form is also provided at the end to assess whether the learning objectives have been achieved.

D6: Do Ask, Do Tell

A growing body of research has reported health disparities among LGBT persons. The reasons for disparities are multiple. One of the reasons may be discriminatory treatment that LGBT persons receive in health care settings. As a result of prejudicial attitudes, many LGBT persons either avoid visiting health care facilities or receive substandard care from culturally incompetent providers. While training is needed for providers to improve interactions with LGBT persons, the collection of data about sexual orientation and gender identity (SOGI) will create the opportunity for meaningful discussions and provision of more appropriate care.

In 2013, the Fenway Institute and the Centre for American Progress conducted a study to assess the feasibility and acceptability of asking standardized SOGI questions at four community health centres in Chicago, Boston, Baltimore and South Carolina. (57) All four centres served ethnically diverse populations. The study enrolled persons who were transgender, lesbian, gay, bisexual and heterosexual to gather information. The questions were pre-tested with staff from the two institutions who conducted the survey. Amendments were made based on suggestions received. The survey was administered by a dedicated staff member in three of the four sites. All potential study participants were approached in the waiting room, asked if they were interested in completing a questionnaire and provided with an information sheet. If the person agreed to participate, they completed the questionnaire and received a \$10 gift card. When the participant was unable to complete the questionnaire before being seen, they continued after they were finished.

The SOGI questions comprised of a single item related to sexual orientation that had previously been tested by the Fenway Institute and incorporated into their electronic record. Gender identity was assessed with a two-step question that enquired about current gender identity and sex assigned at birth. (57) The questionnaire also included clarifying questions about ease with which questions were understood and whether the response choices allowed them to accurately document their sexual orientation and gender identity. Participant perception of the importance of sharing this information with their provider and willingness to answer the questions on a registration form were also explored.

Just over half (51%) of study participants self-identified as heterosexual while 25% were lesbian or gay. (57) Ten percent of participants reported their sexual orientation as ‘something else’ and 7% as bisexual. Missing responses occurred for only 1% of participants. There was variation across sites. The study population was diverse with 41% self-identifying as Black/African/American, 44% Caucasian, 5% multiracial and 2% Native American. Seven percent of participants were 65 years or older.(57)

The majority of participants supported the collection of SOGI data. Seventy four percent agreed that it was important to ask about sexual orientation on registration forms.(57) There was no difference in perceived importance by ethnicity, gender, age or site. However participants who self-identified as lesbian, gay or homosexual were more likely to perceive that asking about sexual orientation was important. (57)

A slightly higher percentage (82%) of participants thought that it was important to ask about gender identity. (57) There was no difference by ethnicity, sexual orientation or site however older persons were less likely to think that it was important to ask about gender.

Most participants agreed that “the question was easy for me to answer” and “I would answer this question on a registration form at this centre”. In addition, the majority of participants felt that the questions accurately reflected their sexual orientation and gender identity. Missing responses were noted for 1% – 3% of questions.

This study provided support for policy makers to introduce standardized SOGI data collection in electronic health records. The results suggested that it is feasible and acceptable to include questions across diverse populations. Despite overwhelming support for SOGI data

collection, participants expressed concerns about privacy, whether the questions should be asked at registration and the need for training staff to understand why the data is being collected and how it can be used to provide more affirming care for LGBT. The study protocol used research assistants for survey administration at the majority of sites. This is a departure from the circumstances that are likely to occur in clinical settings. It might be useful to test the questions under conditions that are more similar to practice. It is difficult to predict whether participant behaviour would be as reported with normal clinic procedures.

D7: Health Leads

Health Leads is a nonprofit organization that facilitates placement of volunteers (undergraduate students) at help desks in urban medical homes across the United States. (59) Parents complete a brief survey about social needs prior to the child health visit and this is shared with providers who then make referrals to the helpdesk where families are linked to appropriate services. Feedback is also given to providers about the progress made.

Two descriptive studies (60,234) explored the benefits of the Health Leads model in mobilization of support for families. The results indicated that the model successfully linked families to community based resources. In the earlier evaluation, 64% of patients who used the service contacted at least one of the community resources and 32% enrolled in at least one community program. The majority (90%) of patients who enrolled in a community program reported being satisfied with the community resource. The second study also found that 50% of persons who accessed the desk had enrolled in at least one community based resource within six months.

A recent study (58) extended the process results and demonstrated the effects of the model on clinical outcomes among adults with chronic diseases. This study was conducted in three primary internal medicine practices in Boston and employed a pre-post intervention design.(58) Patients who were screened positive and referred to Health Leads were compared with those who had screened negative. There was also a subgroup analysis with comparison of those who screened positive and were referred but declined assistance with those who accepted. (58) Among those who screened positive, 57.6% accepted referral to Health Leads program and most common needs included medication affordability, utilities and food.

There was a significant differential change in systolic blood pressure that favoured the Health Leads group in adjusted analyses (-1.6mmHg; 95% CI, -2.5 to -0.6 mm Hg; differential

change in DBP -1.1 mm Hg; 95% CI -1.6 to -0.6 mm Hg). (58) With regard to LDL-C, in adjusted analyses, there was also a significant change in difference of differences results that favoured the Health Leads group. (58) In contrast, no differential improvement was noted among those with diabetes (0.03%; 95% CI, -0.12 to 0.17) (58). In secondary analyses, enrollment in Health Leads program was also associated with reduction in systolic and diastolic blood pressure and LDL cholesterol compared to only screening positive. (58) While the investigators were uncertain why benefits did not extend to diabetes, they speculated that it may have been related to dietary supports that is also required in self-management of chronic diseases. Although the authors tried to adjust for multiple confounding factors, it is still possible that other factors contributed to the improvements that were observed. The small reductions in blood pressure may also not be clinically relevant at the individual level although meaningful at the population level. It would be helpful to explore effects of the Health Leads Model with randomized controlled trials and consider measurement of other types of outcomes such as quality of life.

D8: CLEAR Toolkit

The CLEAR Toolkit (49) is a clinical decision aid that assists health care providers to engage their patients/clients about social determinants of health. The toolkit was developed for use in middle and low income countries but is being piloted in specific populations in high income countries such as Canada. The toolkit has been translated in 10 languages that makes it widely applicable. A training manual outlines the steps for local adaptation and implementation.

The toolkit outlines for a four step process that includes treating acute medical problems, asking about underlying social problems and refer to appropriate services. (235) Advocacy is the final step in the process and encourages frontline workers to become part of a larger process of community change. The kit provides suggestions for asking about nine social needs including employment, childcare, nutrition, education, housing, domestic violence and child maltreatment. Examples of potential referrals are also provided to illustrate the principles espoused by the toolkit.

Naz et al. (61) assessed the feasibility of implementing the toolkit in a large university teaching centre in Montreal that serves an inner city neighbourhood. A multimethod study was devised that drew on online surveys, in-depth interviews and focus group discussions with health care workers and key informant interviews with senior administrators. Survey participants were

already engaged in caring for vulnerable patients and felt that it was part of their role to address social determinants of health. (61) The study found that health care workers who had specific ways of asking about social needs reported being able to help their patients compared to those without specific approaches (93.8% vs 52.9%, $p=0.003$). (61) The main barriers to address patient's health related social needs include time constraints, uncertainty about whether it was part of their mandate, lack of training and role models. (61) Participants expressed interest in the toolkit although they thought that it needed to be more concise and provide specific referral resources mapped to each social issue.

The authors were encouraged by the interest and willingness to use the toolkit however barriers encountered need to be addressed. This study provided information related to feasibility but more research is needed to establish whether providers use the toolkit and if patients who have the appropriate social interventions experience improved health outcomes.

Paediatric Clinical Tools

The importance of screening for social determinants in families with children has long been recognized. A small but growing body of research continues to demonstrate the impact of screening for multiple psychosocial issues at pediatric visits. The following sections describe the tools that were identified and any evidence of impact on patient health outcomes.

D9: We Care (Well-Child Care Visit, Evaluation, Community Resources, Advocacy Referral)

The *WE CARE* project developed a screening tool based on the Pediatrics Bright Futures pediatric intake form that screened for ten family psychosocial needs (lack of high school education, unemployment, smoking, drug abuse, substance abuse, alcohol abuse, depression, intimate partner violence, child care need and homelessness) for which there were community resources. (63) Parents in the intervention group completed the tool while waiting to see their provider. The tool also allowed for an indication of the client's motivation for addressing a particular factor. Providers also had access to a family resource book containing information sheets listing available community resources for each of the psychosocial factors.

The intervention was delivered by pediatric resident physicians who received a 20 minute teaching session prior to study implementation. (63) The session provided an introduction to the intervention materials. Residents were expected to review the survey responses with the client

during the consultation and make a referral if the client indicated that they needed assistance with any particular problem. A 10 minute refresher session was held with residents 1 month after the project was implemented.

The family resource book was also made available to residents in the control group however they were introduced to the resource by reading a standardized one paragraph script. (63) Prior to the study, a one page information sheet with resources was already available to providers. Consequently it was determined that the resource should be made available in order to be consistent with existing standard of care.

The majority of parents who participated were mothers, black and unemployed. (63) The majority of the index children were under 2 years old and insured by Medicaid. The researchers found that parents in the intervention group had fewer unmet needs to discuss psychosocial issues. A greater percentage (51%) had received at least one referral most often for employment services compared to parents in control group (12%).(63) In the post study survey among residents, the majority indicated that they felt comfortable being handed the WE CARE survey by patients. The impact on the duration of the visit was minimal as the majority (90.9%) reported that the survey added less than 5 minutes to the visit.

The WE CARE approach to screening and referral was also evaluated in a cluster randomized controlled trial of 8 urban community centres in Boston Massachusetts. (64) Mothers of healthy infants were recruited to participate. In the WE CARE arm, mothers were screened for needs pertaining to employment, child care, education, food security, housing and household heat. Providers made referrals to address the unmet health related social needs. Assistance was also provided to complete the necessary application forms for the referral agencies. Participants in the control group received usual care. Higher rates of referral occurred at the index visit among the WE CARE participants compared to control participants (70% vs 8%). At the 12 month follow up, there was higher engagement with community resources among the WE CARE group. Participants in the WE CARE arm had greater odds of being employed (aOR = 44.4; 95% CI, 9.8–201.4). Children of WE CARE participants had greater odds of being in child care (aOR = 6.3; 95% CI, 1.5–26.0). WE CARE families had greater odds of receiving fuel assistance (aOR = 11.9; 95% CI, 1.7–82.9) and lower odds of being in a homeless shelter (aOR = 0.2; 95% CI, 0.1–0.9).

Although it is possible that other programs also contributed to the improved engagement with community agencies, there was no reason to believe that the effects would have been differential among the groups. Participants' contact and enrollment at community agencies was assessed by self-reports which may have been biased. Study investigators did verify contact with agencies by a small percentage of participants and found high reliability. The study results are promising and suggested that screening and referral for unmet needs in families can increase access to needed supports.

D10: HELPSTEPS/The Online Advocate

HelpSteps is a web-based tool that was conceived by Dr. Eric Flegler in 2004. The tool is maintained by the Online Advocate team at the Boston Children's Hospital. (65) It was designed to screen individuals and families for health-related social problems, identify areas where assistance is needed or desired and provide targeted referral to nearby health and social service agencies. It can be used in various settings including primary care, specialty clinics, emergency rooms, social services offices and schools. The web-based platform allows service organizations to expand screening and take advantage of waiting room time. It can also be used as a research and tracking tool to assess social needs of the community. This latter function is made available through fee for service to interested organizations.

The tool originally assessed five domains but has been expanded to include new domains. Versions are available for screening adults and adolescents. The questionnaire can also be modified to accommodate the needs of specific populations. Several question formats are used in the questionnaire including drop down menus, Likert scales, multiple choice, yes/no, number and text entry. A bar at the bottom indicates the percentage of survey completed and tracks the progress of the user. The tool utilizes a pre-programmed logic to determine skip patterns based on previous responses of the user.

<u>Original Domains</u>	<u>New Domains</u>
1. Access to health care (medical, dental, insurance, prescriptions)	1. Safety equipment use (car seats, helmets, smoke alarms)
2. Housing (availability, utilities, structural problems)	2. Substance use/abuse (tobacco, alcohol, drugs)
3. Food security	3. Exercise/Nutrition
4. Income security (job, income, education)	4. Education/After-schools programs
5. Violence (intimate partner and violence risk factors)	5. Sexual activity/Birth control/Sexually transmitted infections testing

The tool prompts the individual to enter their address and follows with a series of questions to determine an individual's need and eligibility for services. The responses generate two unique lists that indicate the social domains where the individual is doing well and where services are need. The list of recommended domains makes provisions for the user to select those areas they would like to explore with a referral. Once the selections have been made, the agency selection page appears. The program presents a list of agencies that are most likely to be beneficial to the user. The formula selects agencies based on the number of relevant services provided and the distance of the agency from the user's address. When the user clicks on the name of an agency, its location is displayed on a map as well as a detailed description. The services offered by the agency that address the needs identified by the user are also highlighted. Finally the tool allows the user to print the list of agencies as a PDF document.

Fleegler et al. demonstrated the feasibility of the computer based screening tool in a high need urban pediatric outpatient setting. (65) Eighty two percent of families had at least one health related social need although only one third had been asked about social needs in the past 12 months. (65) The majority (92%) of participants who completed the tool found that screening was acceptable. Among those referred, 63% contacted the agency. Of those who contacted an agency, 82% found it beneficial.(65) This study provided early evidence that screening for social needs could increase uptake of referrals to community agencies.

A recent study examined whether the adolescent version of the web based tool would connect youth to services to address specific problems. (66) Potential participants received information about the study from a resource specialist and those who consented completed the questionnaire using a laptop that was provided. Participants met briefly with the resource specialist to review referrals and received a print out of the selected agencies. Seventy-six percent of participants had at least one health-related problem.(66) Eighty three percent of participants were reached at follow up, 40% of them had contacted an agency and 50% of those who contacted an agency had resolved their priority issue.(66) It was also observed that 45% who had not contacted a selected agency reported resolution of their problem through other resources. There was a mismatch between problems identified by the tool and those selected by the participant to be addressed. Participants were more likely to accept referrals for system identified needs related to income and education compared to other domains. The authors suggested that

there may be value in bypassing screening and allowing individuals to select resources directly. This is also supported by the fact that a large percentage of those who did not contact a selected agency reported that the process ‘helped them to figure out how to help themselves’.

Another study has been registered that explores the utility of an adapted version of the Online Advocate to resolve health related social problems in families with children. The results have not been published to date.

Other Tools

D11: iSCREEN

Gottlieb and colleagues (67) conducted a randomized controlled trial that compared face to face interviewer and computer-based administration of a social risk assessment tool to adult care givers of children who sought services at a large urban children’s hospital. Similar to the earlier study, a large proportion (66%) of participants was below the federal poverty level. The computer based group was more likely to disclose their annual household income although no differences were found in the other 18 items that were evaluated. While the study offered valuable information about the best ways to collect potentially stigmatizing information in low income families, it did not assess the impact of the application of the information on clinical management.

Another recent study (68) was conducted to assess the effectiveness of a navigation intervention on care-giver reported child health status. Parents and care givers of children attending 2 safety net hospitals in California were recruited. All participants were screened for social needs related to housing stability and habitability, food and income security, child care and transportation needs, employment, legal concerns, medical insurance and other public benefits enrollment, and concerns about any adult household member’s mental health. Participants were randomly allocated to receive in person-navigation for unmet social needs or written information about community resources.

At baseline, caregivers in the navigation arm had more social needs than in the control group but there were no significant differences in rates of follow up. At four month follow up, there was a statistically significant difference in mean number of social needs between groups (0.61 standard error 0.18, $p < 0.001$). (68) There was also a significant difference between groups

in mean child global health score (-0.24 standard error 0.07, $p < 0.001$). A subgroup analysis confirmed that improvements were not attributable to referral to social worker.

Navigators were trained volunteers and reduced costs associated with the intervention. Scale up and sustainability would be dependent on availability of volunteers. Navigators had fewer than 2 contacts with each patient but still had positive effects. The authors suggested that dose response effects should be investigated. The study contributes to the body of research by demonstrating an effect of social intervention on health outcomes.

Medical-Legal Partnerships

Increasing advocacy from the legal fraternity and public health agencies (mostly in the United States) has promulgated patient screening for material hardships and their legal underpinnings. (236) Medical-legal partnerships (MLP) (237) are a health care delivery model that serves to improve health and well-being by addressing unmet legal needs that impede health. A number of observational studies suggest that MLP assist families to access necessary food and income supports and decrease avoidance of health care due to lack of insurance or concerns about cost. (238,239) A few studies have also tried to estimate benefits of MLP services in families with children who have specific disorders such as asthma and sickle cell disease. (240,241)

A study by Klein and colleagues explored the establishment of a medical legal partnership coupled with an educational intervention with providers. (233) The study found that pediatric residents improved their self-assessed screening competence, parental perception of screening as well as referrals to the medical legal partnership and formula distribution programs. While the study's context exemplifies a well-resourced setting with physician providers who were previously sensitized through advocacy training related to social determinants and community resources, it also suggests that both screening and individual level intervention on social determinants can change provider practices. Patient health outcomes were not assessed in the study.

D12: Medical Legal Advocacy Questionnaire (MASQ)

The Medical Legal Advocacy Questionnaire was developed by Family Advocates of Central Massachusetts (FACM) to screen families with social needs that were amenable to legal intervention. (69) The FACM was a medical legal partnership between the Department of Pediatrics at the University of Massachusetts Medical School and Legal Assistance Corporation of Central Massachusetts. The questionnaire contained 10 items that covered 4 domains (housing,

financial stability, dignity and safety and access to services). The response options employed a 4 point Likert scale (no, not really, sort of, yes). (69) The questions were pretested for clarity and comprehension. The questionnaire was available in both English and Spanish.

The questionnaire was implemented across five partner sites of FACM. (69) A researcher approached parents of children in the waiting area and requested their participation in the study. Participants completed the MASQ and another questionnaire that included information about the parent and child's age, race and ethnicity, family size and family income. The provider's impression of whether or not a family needed to be referred for legal consultation was documented. The results of the MASQ were discussed with study participants who then decided whether they would like to be referred to FACM.

Scores were assigned to the responses in the MASQ.(69) A score of 1 was given for positive response (potential legal issue) and zero for a negative response. The MASQ score was the sum for responses to all ten questions. The study assessed the sensitivity, specificity, positive predictive value of the MASQ compared to clinical judgement in predicting families who would accept a referral to legal provider.(69)

There were high response rates with 95.5% (n=255) of parents who were approached participating in the study. (69) The average family size was 4.1 and 48% of participants reported an annual family income of less than \$30,000 per year. Twenty five percent of participants declined to complete questions about their race and ethnicity. A total of 37 participants accepted a referral to FACM. The sensitivity and specificity of the MASQ was assessed at different cut off scores. A cut off ≥ 2 had a sensitivity and specificity of 0.81 and 0.75 respectively. Clinical judgment had a sensitivity of 0.65 and specificity of 0.95. (69)The MASQ was more sensitive, less specific and had a lower PPV than clinical judgement. This might be explained by the fact that not all identified needs result in a legal referral. Further, some of the needs identified (e.g. immigration, domestic violence) often will never be discussed outside of the family. Although the low specificity of MASQ may overestimate the need for legal services in high risk families, the study suggested that formal screening may be useful. Without a gold standard to identify the presence of unmet legal needs, it is possible that some needs were undetected. More work is also needed to identify families that are ready to accept referral.

D13: Single-item hunger screen

Kleinman et al. assessed the sensitivity, specificity and accuracy of a single item question to screen for hunger in a single primary care setting. (70) Parents attending a pediatric primary care clinic were invited by the receptionist to complete the simple screening tool when they arrived for their appointment. A subset of 122 families were also interviewed about hunger and participation in food assistance programs.(70) The accuracy of the screening question was assessed against the 18 item USDA HFSS (Household Food Security Scale) that is considered the gold standard for classification of food insecurity with and without hunger. Eleven percent of the 1705 participants screened positive for hunger. The single question had a sensitivity of 83% and specificity of 80% compared to the HFSS.(70) Participants were re-screened six months later and 77% of participants provided the same answer (kappa 0.54). Participants who were classified as hungry based on the screening question as well as the HFSS were more likely to use food assistance programs than persons who were not hungry. However, there was underutilization of programs.

The study was conducted in a single centre among a predominantly Hispanic, low income population. (70) This may affect the generalizability of the findings. Less than half of the potential participants were screened and fewer persons than anticipated consented to be interviewed. This also increases the propensity for differences in characteristics between the sample and the general clinic population. The sensitivity and specificity of the question should not be affected by characteristics of the sample. The concordance of findings with the HFSS shows promise of this single question as a screening tool for hunger.

D14: Two item screen for food insecurity

Hager and colleagues (71) developed and validated a two-item screen for food security among at risk families with young children. The questions were identified from the full 18-item HFSS and maximized sensitivity, specificity and convergent validity with demographic and health related factors. The sample included low income families from 7 cities in the USA.

The majority (90.1%) of eligible participants agreed to be interviewed. About 60% of participants were caregivers of a child under the age of 12 months.(71) A higher percentage of children were breastfed among food insecure families compared to food secure families. Among food insecure families, a higher proportion identified as Hispanic compared to other ethnic

groups.(71) There were differences between caregivers based on food security status with regard to caregiver and child self-reported health outcomes. Children in food insecure households were more likely to have been hospitalized during their lifetime compared to food secure households.

The sensitivity and specificity of either question 1 and or 2 of the HFSS was 97% and 83% respectively.(71) When analyses were restricted to those who were food secure based on the full 18-item HFSS screen, attenuated associations with caregiver and child health outcomes were found based on FI status classified by the 2-item screen.(71) There was no association between child anthropometry and food security status suggesting that risk may be present prior to any changes in nutritional status. The 2-item screen was brief and had good properties that would be feasible in clinical settings.

APPENDIX E

TARGETED APPROACHES TO ADDRESS SOCIAL DETERMINANTS OF HEALTH IN CLINICAL SETTINGS

The following sections present a synopsis of interventions for selected social determinants considered in this study. All social characteristics assessed by the screening tool were not represented because of considerable overlap between identities and needs. The interventions described are by no means exhaustive but reflect contemporary scholarship in this area. The focus was on interventions delivered in health care settings. Although primary interest also revolved around identifying studies that reported an effect on health outcomes, in many studies only intermediate outcomes were measured. This section informed the identification of potential interventions that could be considered in the local context. The results are summarized in Table E-1.

In general within the literature, it is difficult to distinguish clinical interventions from related concepts such as patient centred care. Common themes within the literature include disease specific interventions (e.g. diabetes, cardiovascular diseases, HIV), cross cutting interventions such as cultural competency training (e.g. provider education) and culturally tailored approaches. However, there is no single typology for classification of interventions to address health disparities.

There are areas of overlap between determinants, for example provision of information in multiple languages or use of language concordant providers as part of cultural competency interventions that also consider unique beliefs and values of a particular group. The multiple intersecting identities of individuals also present a challenge for partitioning of interventions across single characteristics. For example, it is not uncommon for clustering of social disadvantage to occur such that racial/ethnic minorities may also be gender and sexual minorities who are living in poverty. While the ultimate goal is to identify interventions that are effective in reduction of health disparities, studies have seldom been designed to address questions about effectiveness of interventions. This would require comparisons between minority and majority groups to produce this direct evidence.

The literature is patchy with great heterogeneity across interventions, study designs and participant characteristics. Lack of uniformity in how intervention components and concepts are

operationalized also makes comparability difficult across studies. Cultural competency occupies an important focus among interventions to address disparities among racial/ethnic minorities, gender and sexual minorities and persons with disabilities. Among these three groups, most of the studies pertained to interventions targeted to racial/ethnic minorities. A recent systematic review (242) commissioned by the Agency for Healthcare Research and Quality (AHRQ) was a good resource for literature in this area despite its search for interventions that would be applicable to US settings. This occupied a substantial emphasis in discussions about these groups and commanded a sizeable focus in the review.

Table E-1: Summary of targeted interventions to address health disparities

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
Language barriers	Interpreters (Medical, Ad hoc) Language concordant providers	Flores et al., 2005 (243)	Limited English Proficiency (LEP) mostly Spanish speaking in outpatient settings in USA.	Systematic review (36 studies)	<p>Professional interpreters or bilingual health staff improve quality of care for LEP patients.</p> <p>LEP patients with interpreters report high satisfaction with care and experience similar clinical outcomes for diabetes and hypertension as English proficient patients.</p> <p>Improved uptake of preventive screening services.</p>
		Karliner et al., 2007 (244)	LEP mostly in outpatient and ED settings in USA. (Switzerland, Australia, South Africa, Saudi Arabia)	Systematic review (28 studies)	<p>Professional interpreters were better than ad hoc interpreters.</p> <p>Use of professional interpreters decreased communication errors, improved comprehension, reduced utilization disparities, improved clinical outcomes and satisfaction among LEP patients.</p>

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
Race/ethnicity	Provider cultural competency training	Horvat et al., 2014 (245) Truong et al., 2014 (246)	Students (nursing) Health care professionals (Mental health, primary care)	Systematic reviews (24 studies mostly from US)	Mixed effects on intermediate outcomes and no effects on patient health outcomes. Positive effects on provider knowledge/attitudes in observational studies but not RCTs.
	Interventions to improve patient provider interaction	Butler et al., 2016 (242)	African Americans Latino Americans (mental health and primary care)	Systematic review (6 studies in USA)	Increased patient activation and self-management, satisfaction and receipt of colorectal screening in some studies. Mixed effects on retention in care, patient engagement and empowerment.
	Cultural tailoring of clinical treatment	Butler et al., 2016 (242)	Various (including African, Latino, Korean, American Native, East Asian Americans)	Systematic review (12 studies in USA)	Positive effects of cultural tailored approaches on multiple health outcomes. Few interventions equally effective but demonstrate additional benefits in some outcomes. Few long term studies show mixed effects.

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
Sexual orientation	Provider education/training	Butler et al., 2016 (242)	Medical students, Medical residents	Systematic review (3 studies)	Few education interventions resulted in positive changes in providers' knowledge and attitudes but sustained gains and impact on patient care experience and satisfaction are unknown.
	Foster interaction between patient and provider/health care system	Butler et al., 2016 (242)	Adult men who have sex with men (MSM) Adult lesbian and bisexual women	2 Randomized controlled trials (Peru and USA)	Differential effects of intervention among subgroups. Screening intervention was more effective among women who were more 'out'. Among non-gay identified MSM, the video was more effective than text in increasing intention to test for HIV.
	Interventions involving providers in behavior risk reduction	Butler et al., 2016 (242)	MSM Women who have sex with women (WSW)	2 cohort studies and 2 RCTs	Most interventions showed change in risk behaviors. In one study effects were not sustained in longer term.

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
Disability	Provider educational interventions	Butler et al., 2016 (242)	Various (students including medical, nursing, pharmacy and physical therapy) -Primary care nurses -Mental health providers	Systematic review (16 studies in US, Canada, UK, Australia, Spain)	Mixed effects on participants' attitudes/reduction of stigma, knowledge, treatment confidence and intended social proximity.
	Interventions to improve interaction between patient and provider/health care system	Butler et al., 2016 (242)	Women with mobility impairment, adults with intellectual disabilities (ID), students with attention deficit hyperactivity disorder (ADHD)	Systematic review (5 studies) in US, UK, Netherlands, Australia)	Mixed effects with one comprehensive health assessment program showing improved health promotion and disease outcomes among people with ID. No effects on level of cooperation in dental visits or verbal/written communication between physicians and teachers.
	Interventions to increase virtual access to care among persons with selected disabilities	Butler et al., 2016 (242)	People with multiple sclerosis People with rheumatoid arthritis People with PTSD	Systematic review (4 RCTs)	Heterogeneous interventions showed some improvement in PTSD symptoms and fatigue impact but no change in depression severity/remission rate. Three studies showed sustained effects at 6-18 months but no difference in physical health domain.

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
Education	Specific design features (e.g. alternative document design, numerical presentation, media, readability)	Berkman et al., 2011 (247)	Various (Medicaid recipients, parents of children in Head Start programs, adults from primary care practices, adult men attending hospital)	20 studies (17 RCTs, 3 quasi-experimental studies)	Mixed results with few studies reporting improvements in comprehension for low literacy groups with specific features (e.g. limiting essential information, multimedia)
	Physician notification of health literacy status		Low literacy adults (74% low functional literacy)	1 cluster RCT	No improvement in self-efficacy or glycosylated hemoglobin
	Mixed strategies		Patients with asthma, congestive heart failure, diabetes, depression)	21 studies	Adherence and self-management intervention reduced hospitalizations and ED visits. Few studies assessed preventive health screening but not all stratified by health literacy levels. Mixed results related to knowledge, self-efficacy and skill.

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
Housing security	Hospital admission and discharge protocols	Aspinall et al., 2014 (248) Coleman 2013 (249)	Homeless adults (various criteria including mental illness) Aging adults who were unable to return to housing after discharge	Review – 10 models (3 from US, 7 from UK)	Studies reported cost savings as a result of safe discharge, decreased hospital re-admissions and mixed effects on length of stay. There was also increased networking and care coordination. Increased knowledge and awareness among hospital staff about effects of homelessness.
	Integrated health services (Pathway Model)	Hewitt et al., 2016 (250)	Adults hospitalized who were previously homeless	Randomized controlled trial (Two centres in UK)	No significant difference in duration of stay or readmissions to hospital between groups. Significant improvement in accommodation and quality of life after discharge among participants who received enhanced care compared to standard care.
	Intermediate or medical respite care	Doran et al., 2013 (251)	Homeless adults with medical illness (various criteria) Mostly men in mid 40s Majority with mental health and substance abuse disorders	Systematic review (13 studies mostly in USA)	Medical respite programs reduced future hospital admissions, inpatient days and hospital readmissions. Improved housing status Mixed results for costs and emergency department use.

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
	Outreach services	Reilly et al., 2004 (252)	All homeless persons registering at one GP practice	Pre-post design (UK)	When peer advocates interacted with participants prior to registration, there was a change in health care seeking behavior.
Food security	Screening for food insecurity and referral to community resources	Smith et al., 2017 (253)	Participants were uninsured and not eligible for other safety net programs	Cross sectional study	High uptake of screening among target population (92.5%). High rates of food insecurity. 201 diabetics received food boxes, 66 accessed community resources and 64 received benefits through SNAP.
	Pilot food bank intervention using community pantries	Seligman et al., 2015 (254)	Persons with diabetes	Pre-post design	Participants improved glycemic control, dietary intake of fruits and vegetables, self-efficacy and medication adherence

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
Poverty (Low income)	Welfare Advice Services	Wiggan et al., 2006 (255)	Elderly persons Persons with disabilities Families with small children	Systematic review (observational studies from UK)	Improved benefits uptake and financial gain for recipients Improved psychosocial and mental health Few studies report improved physical health.
		Adams et al., 2006 (256)	Various (all patients, subgroups defined by age, specific medical condition, persons who needed specific benefits such as disability living allowance and attendance allowance)	Systematic review (55 studies majority from UK, only 7 included comparison group)	Welfare rights advice services delivered in health care settings increased financial benefits however little evidence of health benefits.
		Mackintosh et al., 2006 (257)	Random sample of patients ≥ 60 years from 4 practices	Randomized controlled trial (UK)	58% of participants received a welfare benefit. No difference between groups in mean scores at 6 months (except financial vulnerability) Very little variation in scores at 6, 12 and 24 months except that in intervention group sleep quality and social interaction improved between 6 and 12 months then declined between 12 and 24 months.

Social risks	Intervention (s)	Author(s)	Participants	Design	Main Findings
Poverty (low income)	Medication Access schemes	White et al., 2016 (258)	Elderly ≥ 60 years who were socioeconomically disadvantaged	RCT (England)	No difference in CASP-19 scores between intervention and control groups. Intervention participants reported receiving more homecare at 24 months. Qualitative data suggested improved QOL among those receiving benefits.
		Chisholm et al. 2007 (259) Strum et al., 2005 (260) Trompeter et al., 2009 (261) Sauvageot et al., 2008 (262)	Patients with diabetes, hypertension, dyslipidemia, renal transplant recipients	Single group pre-post design Two group comparison design	Mixed effects on clinical outcomes (e.g. glycemic control, lipid levels and mean blood pressure)
		Felder et al., 2011 (263)	Various (persons with diabetes, hypertension, dyslipidemia, metabolic syndrome, heart disease, renal disease, transplant recipients)	Review (33 studies with 10 exploring patient outcomes) All from outpatient settings in US)	Positive effects on clinical indicators for diabetes, dyslipidemia and hypertension. Mixed perceptions of PAP noted in surveys. Economic evaluations showed that cancer drugs and immunosuppressants accounted for majority of cost savings.

Language. Language barriers impede effective communication with providers during health encounters and may result in dissatisfaction with care, medical errors and avoidable hospitalizations. (264,265) Two systematic reviews (243,244) have examined the evidence for effectiveness of interpreters in improving health outcomes of patients with limited English proficiency. Overall studies found a positive impact of use of professional interpreters on clinical care. The utilization studies in particular demonstrated that use of trained professional interpreters was associated with decreased disparities between patients with a language barrier as compared with patients receiving care from language concordant clinicians. A positive association was also found between use of interpreters and satisfaction. Five of six studies showed higher patient satisfaction with professional interpreters compared with ad hoc interpreters and one study reported higher satisfaction after clinician training in the use of professional interpreters. (244)

There were many limitations among studies including small sample sizes, less rigorous designs (only 1 randomized controlled trial), infrequent use of comparison groups and control for confounding factors. The earlier review (243) noted that various types of interpreters were often combined however this was addressed by the latter review where effects of different types of interpreters were compared. It was also noted that a standardized measure to assess need for an interpreter was not used. This likely resulted in variability of language proficiency among study participants and diluted the impact on outcomes. It was also difficult to determine whether all professional interpreters were trained. This is important because quality of training of professional interpreters affects competence. (266) More research is needed that assesses impact on health outcomes as well as cost effectiveness of provision of medical interpretation services.

E1 Cultural competency training

Race/ethnicity. Cultural competency training for health care providers was developed to increase knowledge, encourage positive attitudes and develop cultural skills as part of enhancing capacity for delivery of culturally competent care. Two high quality systematic reviews (245,246) that examined the effect of provider education/training interventions targeting improved care for racial/ethnic minorities found mixed effects on intermediate outcomes (e.g. health behaviors and patient evaluations of care) and no effects on patient health outcomes. Observational studies in the Truong review (246) consistently reported positive effects on providers' knowledge and attitudes using self-reported measures. However, scant evidence from randomized controlled trials has not confirmed these findings.

Clifford et al. (231) reviewed cultural competence interventions to improve care among Indigenous peoples in Australia, New Zealand, Canada and USA. Most of the studies addressed provider education and training interventions and focused on the subpopulation of Native Americans. Few studies in the review reported significantly improved levels of provider knowledge although four of five studies found improved self-reported provider confidence for delivery of care.(231) Methodological limitations were common among identified studies and authors suggested that more work was needed to strengthen the evidence base.

Sexual minorities. Similar to provider educational interventions for racial/ethnic disparities, the few studies (267–269) targeted at care for sexual minorities reported gains in provider knowledge and attitudes. However, one study (269) did not demonstrate any effect on medical students’ beliefs about the effect of social factors or the way they practiced. These observational studies (267–269) employed a pre-post design and were assessed as high risk for bias.

Disabilities. The AHRQ review (242) also explored the evidence for effectiveness of provider educational interventions to improve care for persons with disabilities. The majority of interventions identified were related to provider training and attempted to reduce stigma and foster positive attitudes to persons living with mental illness. Most of the studies were designed for students rather than practising professionals. A common approach to interventions involved cultural encounters with an individual with a disability. Results were mixed with half of the studies reporting improved attitudes; a third found no significant change and two studies both positive and negatives effects.(242) Only half of studies that assessed providers’ knowledge found improvements and there were also mixed effects on treatment confidence and intended social proximity. Studies were generally not designed to measure patient outcomes and would require clinical application of students’ knowledge to demonstrate effects. Most studies also did not examine long term effects. This is important because cultural competence is not a single event but part of an ongoing process. (270)

While it is possible that cultural competency training has no effect as a solitary intervention, standardized approaches and objective measures of cultural competency would assist with comparability across interventions. Patient perceptions of their provider post competency training should also be assessed. Given the risk of bias and paucity of studies related to some subgroups, authors suggest that more work is needed. The current evidence for

effectiveness of provider education/training is inadequate to determine its impact on health disparities. (242)

E2 Patient-provider/health system interaction interventions

Other broad types of interventions include approaches that seek to influence interactions between the patient and provider or health care system. (242) These types of interventions were identified by studies across all three minority populations. Diverse approaches were used including education for the patient to facilitate activation and collaborative decision making, encourage utilization of services such as preventive health screening and testing and prompt physician behavior at the point of care. There were also interventions that matched patients and providers in medical encounters or enhanced sense of common-in-group identity in racially discordant medical encounters.

Marked heterogeneity across studies and interventions precluded direct comparisons. (242) Mixed effects were found across interventions related to uptake of preventive screening and HIV testing. Two interventions for racial/ethnic minorities with mental illness reported increased patient activation and self-management although mixed results were found for retention in care and patient empowerment. (242) Some subpopulations were not represented among the identified studies. This constrains extension of results to subgroups more frequently studied if appropriate given heterogeneity of interventions.

E3 Cultural tailoring interventions

Race/Ethnicity. Culturally tailored treatment approaches were also encountered especially among interventions targeted at racial/ethnic minorities. These interventions addressed clinical outcomes related to diabetes, mental health and substance abuse as well as smoking cessation and alcohol abuse. Most studies found positive effects with cultural tailoring compared to non-tailored approaches (242). Two studies found improvements in both groups with one study showing additional benefit in mental health for the culturally tailored group at 24 months. A clinic-based mental health and substance abuse intervention tailored for gay and bisexual men also found a reduction in the number of unprotected receptive anal sex encounters among the tailored group although behavior effects were not sustained (271).

E4 Other types of cultural competence interventions

Sexual minorities. The AHRQ review also described a group of interventions targeted at LGBT populations that involved interaction with health providers for behavioral risk reduction.

(242) In these interventions, providers (in one study MSM peers) received training to enhance communication skills related to sexual risk assessment and behavior change. These studies reported positive changes in risk behaviors although these effects were not sustained in one study with longitudinal follow up of participants. Although promising, there is a need for more rigorous evaluation of interventions to confirm their effectiveness.

Virtual access to care for persons with disabilities. Among persons living with disabilities, interventions designed to increase virtual access to care offer potential to reduce health disparities. (242) Four randomized controlled trials were identified among people living with multiple sclerosis and rheumatoid arthritis. The interventions used multiple modalities to reach participants including teleconferences, emails and small number of in person visits. Studies reported improvement in some primary outcomes (e.g. symptoms of post-traumatic stress, fatigue impact severity) although no effects on physical health were observed. The intervention that targeted patients with rheumatoid arthritis also found that gains in self-efficacy and quality of life were sustained at 9 months post intervention.

There are many challenges with linking cultural competency interventions with improvement in health outcomes and reduction of health disparities. A common understanding of cultural competency is needed. Additionally, operationalization of cultural competence into testable components would advance current efforts. The AHRQ review described several cultural competence models but noted that most were developed for racial/ethnic interventions. (242) Most models had been developed to support provider training and is consistent with a focus on characteristics associated with particular cultural groups. Cultural competence does not map equally well with the needs of all groups. Traditionally, the concept has not been applied to disability populations although they share a common experience of stigma and discrimination with racial/ethnic and gender and sexual minorities. It required more framing to map disabilities interventions and cultural competence literature. (242)

One of the fundamental issues relates to the conventional designs of studies. Studies to assess the effectiveness of interventions on reduction of health disparities must compare minority and majority populations. This has seldom occurred and most studies explored single groups. Among identified studies, some subgroups were underrepresented in the literature (e.g. American Natives/Indigenous peoples, transgender individuals and individuals with physical and sensory disabilities) hence gaps exist about whether some interventions would offer benefit among all

groups. Another important design-related issue pertains to the nature of the comparator. The ideal design would evaluate a culturally tailored and non-tailored version of the intervention. Several prior studies (272,273) pertaining to areas of active research about the effectiveness of community health workers and patient navigation were excluded from the AHRQ review because they failed to compare culturally tailored and non-tailored versions of these interventions. Without isolation of the cultural competence component, it is not possible to assess its contribution. Until these issues are addressed the evidence base for the effectiveness of cultural competency interventions will not strengthened.

Education. The relationship between level of education and health is complex. Compared to people with higher levels of educational attainment, lower levels of education are associated with higher rates of mortality and disease. (274,275). There are multiple mechanisms through which education can affect health. Health literacy is one such pathway. (276) Higher educational attainment may increase opportunities for health through better access to health promotion and protection resources and ability to navigate the health system as well as increased earnings from better paying jobs. (277) Research has already established that an income gradient exists in health and also indirectly links educational attainment and health.

The critical role of health literacy and opportunity for health care settings to mitigate the effects of low education through health literacy interventions is the narrowed focus of this section. Berkman et al. (247) reviewed the evidence for effectiveness of health literacy interventions on health outcomes. The review encountered several challenges because many studies did not disaggregate findings by literacy levels. Interventions were grouped according to whether they employed a single strategy or mixed strategies and results were organized by common outcomes assessed including comprehension, knowledge, adherence, self-efficacy and health care utilization.

Twenty one studies utilized single strategies including alternative readability and document redesign. (247) There was limited evidence for the effect of specific design features such as presenting essential information first, use of symbols and multimedia on comprehension among low literacy participants in one or few studies. One cluster randomized trial found no effect of physician notification of literacy status on patient self-efficacy or glycosylated hemoglobin. (247)

A similar number (twenty one) of studies assessed mixed strategies across a wide range of participants with chronic diseases (e.g. asthma, congestive heart failure, diabetes). Intensive self-management and adherence interventions reduced ED visits and hospitalizations among low literacy participants. (247) Mixed results were found with respect to knowledge, self-efficacy and quality of life. Only two studies examined costs and reported a non-significant trend towards reduced costs.

Studies in the review were generally not designed to address health disparities.(247) A major challenge related to assessment of literacy/numeracy among participants and stratification of results by literacy levels. This would have allowed for assessment of differential effects. Other methodological problems related to small sample sizes to allow for subgroup analyses and absence of an appropriate comparison group. Heterogeneity among interventions and participants also limits comparability. Use of mixed strategies also made it difficult to isolate the effective component of the intervention.(247) The evidence base needs to be strengthened with more rigorous high quality studies that address current limitations.

Housing security. Homelessness is associated with a greater burden of health problems including premature mortality and higher rates of comorbidities with mental ill health and substance abuse. (278) Despite the disproportionate burden, chronically homeless persons with dual diagnosis of mental illness and substance abuse are less likely to receive care. (279) Among homeless persons who access services, there are higher rates of emergency department visits, more frequent hospitalizations and lower uptake of preventive care compared to those with stable housing. (280) Many barriers also reduce access to care among the homeless or vulnerably housed including lack of a permanent address to facilitate registration for health insurance, poor engagement skills and late presentation for care. (281–283) There are other challenges that homeless persons often encounter post discharge such as access to nutritious food, funding transportation costs, adherence to medications and attending follow up appointments. (281–283) Interaction of homeless persons with the health care system offers the opportunity to intervene and potentially to improve health outcomes. There is limited but growing evidence of the impact of clinical interventions to improve the health of homeless persons. The majority of studies are program evaluations that often focus on outputs achieved during the short term and employ non-experimental study designs.

Three kinds of interventions have been commonly described in the literature: 1) hospital discharge planning, 2) integrated models of care and 3) outreach services. (248) The interventions may be seen as a continuum with early identification of homeless persons when they are admitted to hospital, needs assessment and preparation for safe discharge to appropriate levels of care. Outreach services may engage persons who are homeless in places where they frequent and provide information /services to increase activation or reduce access barriers to care.

Discharge planning is critical for homeless persons. It offers an opportunity for engagement, motivation of behavior change and establishment of supports for housing and continuity of care to sustain recovery. Often this is accomplished by a team or through collaborative efforts to identify needs, preferences and available options. A recent scan identified ten discharge models for people experiencing homelessness. (249) Most of the models were developed in the United Kingdom and reported cost savings as a result of safe discharge of homeless persons, decreased readmissions and mixed effects on length of hospital stay. Evaluations employed less rigorous designs with small sample sizes and often without a comparison group.

The Pathway Model is an integrated health service based on a primary care team that provided in-reach to homeless persons during their admission. (250,284) The evaluation found no significant difference between intervention groups in length of stay or readmissions. (250) However, there was improvement in accommodation and quality of life among those who received enhanced care using the Pathway approach. The intervention was also cost effective using conservative estimates. There were challenges with recruitment and follow up of participants, however authors suggested that results were unlikely to have differed with a larger sample given similarities in outcomes assessed. It is also possible that given the severity of conditions on admission, change in the primary outcome was unlikely to occur. More intervention research is needed to increase evidence for effectiveness of integrated health care service models.

Intermediate or medical respite care is an alternative to discharging homeless persons to unstable housing conditions. Respite care allows homeless persons recovering from acute medical illnesses to rest and is often combined with housing placement services and effective case management. These provisions allow persons with complex medical and psycho-social

needs to recover in a stable environment. A systematic review (251) of the effectiveness of medical respite programs found that participants had reduced hospital admissions, inpatient days, and readmissions. Housing outcomes also improved. There were mixed results for reductions in cost and emergency department use. There was marked heterogeneity among studies in quality, outcomes assessed and use of a comparison group. Gaps remain in the literature about impact of medical respite programs and more studies of cost effectiveness are needed.

Outreach service models engage homeless persons to provide information or care in non-traditional health settings. Within the literature, student led service learning models (285,286) are an important source of primary care for homeless persons however the available information is primarily descriptive and does not allow for assessment of patient health outcomes. Outreach to homeless persons by peer advocates can also be helpful for establishing relationships, giving advice and providing support to reduce barriers to access to care. One UK study that evaluated the benefits of peer advocacy found an effect on the pattern of health seeking behavior if it was provided on outreach visits prior to registration. (252) More evidence of peer advocacy interventions is needed to confirm its effectiveness in improving health outcomes.

Most of the interventions to address homelessness have been studied among subgroups with mental illness and or substance abuse and probably reflects the high prevalence of these comorbid conditions. The available evidence suggests that housing interventions improve housing stability and reduce health care utilization. (287,288) Case management is often provided as a support for homeless persons who receive housing placement. Different case management models have been tested among different subpopulations with the least evidence found for intensive case management (ICM). (289) In general, case management improved housing tenure although studies reported mixed results with regard to effects on psychiatric symptoms and substance abuse. More research is needed on different subgroups of homeless persons across multiple settings that employ standardized measurement of health outcomes in order to more clearly establish health benefits.

Food security. Food insecurity is defined as ‘limited or uncertain availability of nutritionally adequate and safe foods or limited or uncertain ability to access acceptable food in a socially acceptable way’. (290) The relationship between food security and health is complex. Adverse effects of inadequate resources for food occur across the life cycle. In children, food

insecurity affects cognitive, academic and psychosocial development .(291–293) Among adults, food insecurity contributes to chronic disease occurrence and affects self-management of diet sensitive chronic diseases. (294,295) Food insecurity also had deleterious effects on mental health and likely has a bidirectional relationship with mental health problems. (296,297) The opportunity to screen for food insecurity in clinical settings is often underutilized despite advocacy from professional medical association and disease support organizations. (298)

There is a paucity of research pertaining to clinical interventions to address food insecurity in health care settings. Validated tools exist including clinical adaptations of the longer 18 item USDA Household Food Security Scale (HFSS) that would support wider use. (70,71) A recent scoping review (299) confirmed the availability of several screening tools however none of the four interventions targeted at adults with chronic diseases assessed food insecurity as a study outcome. Interventions identified included screening and referral to community resources and food pantries in health facilities. There is a significant overlap with evaluations of social determinants screening tools described in the previous section.

One study assessed the implementation of screening for food security and referrals in three student-run clinics in California. (253) All participants completed the 6-item version of the USDA HFSS and were provided with information about food pantries in close proximity to their addresses. Assistance was also provided to navigate applications for food assistance programs such as Supplemental Nutrition Assistance Program (SNAP). Residents, faculty and medical students were supported to document information related to food security status and the plan for referral in the electronic health record. Screening was feasible with high rates of uptake (92.5%). There were also high rates of food insecurity among participants (74%). Patients with diabetes had a higher prevalence of food insecurity compared to those who did not. The number of patients who accessed referrals was documented. Although the study used a validated tool for screening, no health outcomes were assessed. There was no control group or adjustment for confounding factors. While the results are promising, more rigorous evaluation is required to demonstrate effectiveness.

A multifaceted food security intervention for persons living with diabetes was carried out across multiple sites in three US states (Texas, Ohio and California).(254) Participants were recruited at food pantries and offered screening for diabetes (if the diagnosis was unknown) and

measurement of glycosylated hemoglobin among those who were known to be diabetic. Food security status was also assessed. Diabetes prepacked food boxes (that included fresh produce) were provided regularly to support participants with self-management of their disease. At 6 month follow up assessment compared to baseline, participants improved glycemic control, intake of fruit and vegetables, self-efficacy and medication adherence. (254) Satisfaction with food boxes was also high (88%). (254) Although authors adjusted for clustering and important confounding factors, the lack of a control group precluded assessment of effectiveness of the intervention. It was also not possible to determine individual contributions of the various components to the improved outcomes. Testing of the intervention is needed with more rigorous designs.

Poverty. The relationship between poverty and poor health is well established in the literature. (300,301) In the past five years, screening for adult and child poverty in Canada has been widely advocated. (215,216) Screening for poverty presents an opportunity for ‘social prescribing’ by providers to link patients to the social safety net and income supports that are available. Two of the clinical interventions that have been studied include welfare advice services and medication access schemes. The evidence for impact on health outcomes will be discussed in the following sections.

Welfare advice services. There is limited evidence to suggest that individual level poverty interventions in clinical settings can improve patients’ social circumstances. Several studies from the United Kingdom examining the financial, social and health outcomes of welfare advice services suggest that they improve uptake and result in financial gains for clients. (257,302) Few statistically significant health associations have been found but when present related to psychological aspects rather than physical health. (302,303) This might be related to methodological challenges such as small sample sizes, short duration of follow up and study designs. While the emphasis of measurement in studies was related to calculating income supplements received through welfare benefits, it was noted that resources provided also addressed other issues including housing, utilities and food security. (303)

A recent study has illuminated the complexities of linking welfare advice to improve health outcomes and developed a logic model that maps various elements in a causal pathway. (304) The authors suggest that further research should consider economic modelling of

financial outcomes in relation to intervention costs and further explore those associations as indicated by the model.

Medication access schemes. The cost of medications can be a health care barrier with uninsured individuals being twice as likely to exhibit non adherence behaviors such as not filling prescriptions, cutting tablets and skipping doses due to costs. (305,306) Poor access to affordable medications can result in difficulty with chronic disease management, increased utilization of emergency services and hospitalizations. (259,307) There are several ways that physicians can assist individuals who are not eligible for federal or provincial assistance with medication costs. Physicians may prescribe less expensive drugs, provide prescription samples or recommend over the counter substitutes where possible. Manufacturer medication assistance programs may also help patients gain much needed access to affordable medications. This section explores the evidence for the impact of these strategies on patient health outcomes.

Several studies (260–262) have examined the impact of medication assistance programs for financially vulnerable patients. Mixed results have been found with some studies showing improved glycemic control and lipid profile components. (260–262) Only one of the three studies found improvement in mean blood pressure but no change in triglycerides or glycosylated hemoglobin. (262) Two of the studies employed a single group before and after design while the other study compared outcomes for a group of patients who had enrolled in a pharmaceutical company assistance program with patients who had insurance for prescription coverage. Alternative explanations could not be excluded in these studies and future rigorous studies are required that accommodate longer duration of follow up in order to confirm benefits.

A systematic review (263) examined the impact of pharmaceutical assistance programs (PAP) on improving medication access and health outcomes. Although the results also suggested a positive effect on clinical indicators, the authors urged cautious interpretation because of heterogeneity and low rigor of study designs. (263) It has also been noted that the independent effect of PAP may be difficult to isolate as programs are often delivered with other medication services such as counselling and reminders. More economic evaluations are also needed to compare benefits of PAP with other cost minimization programs.

Summary. While the extant literature is replete with examples of interventions to address single social determinants in subgroups of individuals who present for health care services, a systematic approach to screening and mitigation has often not been applied. Social determinants

often cluster due to the underlying pathways and create multiple social identities. This adds complexity but also solidifies the rationale for a comprehensive approach to screening and intervention.

Improvements in population health have been framed as reduction in health disparities. However, most studies have not employed designs that would successfully address effectiveness of interventions targeted at health disparities. This is a cross cutting issue across determinants that needs to be remediated if it remains a health system priority.

A common language to describe interventions and components would be helpful to translate the literature across health disparities. A good example relates to cultural competency interventions. Multiple models and different ways of operationalizing concepts makes it difficult to understand the most effective components.

Although the rigor of intervention studies has improved, weak methodological designs are not uncommon, with inconsistent use of comparison groups and adjustment for confounding factors. Adequate sample sizes to detect meaningful change across multiple health outcomes are needed. More studies that assess long term effects are also needed as longer periods of observation may be necessary to demonstrate benefits.

Most of the studies were conducted among adults in the United States or Europe with little experience from Canada. Given the difference in health systems, participant characteristics and contexts, it is difficult to determine the extent to which many are applicable to the local settings. More local research is needed to identify health disparities and effectiveness of appropriate interventions.

APPENDIX F
SUPPLEMENTARY TABLES

Table F-1: Descriptive statistics for survey responses at drop-in and booked clinics

Sociodemographic Question	Response options	Drop-in N (%)	Missing	Booked N (%)	Missing
Gender	Female	93 (73%)	1 (<1%)	105 (81.4%)	1 (<1%)
	Male	30 (23.6%)		23 (16.3%)	
	Prefer not to answer	3 (2.4%)		2 (1.6%)	
	Do not know	0		0	
Born in Canada	Yes	69 (54.3%)	4 (3.1%)	82 (60.3%)	7 (5.1%)
	No	53 (41.7%)		46 (33.8%)	
	Prefer not to answer	0		1 (<1%)	
	Do not know	1 (<1%)		0	
Year of entry in Canada	Before 2010	22(40.7%)	7 (13%)	12† (26.1%)	10 (21.7%)
	2010 – 2015 (newcomer)	25 (46.3%)		24† (52.2%)	
Use of interpreter	Yes	27 (21.3%)	14 (11%)	15 (11%)	9 (7%)
	No	86 (67.7%)		83 (61%)	
	Prefer not to answer	*		4 (3.1%)	
	Do not know	*		18 (14%)	
Indigenous ancestry	Yes	26 (20.5%)	6 (4.7%)	11 (8.1%)	0
	No	93 (73.2%)		116 (85.3%)	
	Prefer not to answer	0		1 (<1%)	
	Do not know	2 (1.6%)		1 (<1%)	
	First Nations	16 (61.5%)	1 (<1%)	7 (58.3%)	0
	Métis	6 (23%)		4 (33.3%)	
	Non-status Indian Aboriginal outside Canada	1 (3.8%) 2 (7.7%)		1 (<1%) 0	
Race/ethnicity	White North American	51 (40.2%)	3 (2.4%)	57 (41.9%)	8 (6.2%)
	White European	5 (3.9%)		11 (8.1%)	
	Black North American	2 (1.6%)		1 (<1%)	
	Black African	4 (3.1%)		3 (2.2%)	
	Latin American	1 (<1%)		2 (1.5)	
	Middle Eastern	0		1 (<1%)	
	South Asian	20 (15.7%)		8 (5.9%)	
	South East Asian	15 (11.8%)		19 (14%)	
	East Asian	5 (3.9%)		3 (2.2%)	
	Other	12 (9.4%)		1 (<1%)	
	Mixed heritage	0		2 (1.5%)	
	Prefer not to answer	8 (6.3%)		0	
	Do not know	1 (<1%)		1 (<1%)	
Housing	Own home	67 (52.7%)	1 (<1%)	85 (65.9%)	1 (<1%)
	Renting	51 (40.2%)		33 (25.6%)	
	Staying with friends/fam	6 (4.7%)		6 (4.7%)	
	Supportive housing	1 (<1%)		2 (1.6%)	
	Prefer not to answer	1 (<1%)		2 (1.6%)	
	Do not know	0		0	

*Options were not available on the questionnaire †Intervals were different

Table F-2: Summary of participant responses at Sexual Health Centre

Question	Response options	N (%)	Missing (N/%)
Language proficiency	Very well	99 (95.2%)	0
	Well	5 (4.8%)	
Preferred language	English	101 (97.1%)	0
	Spanish	2 (1.9%)	
	Cree	1 (1.0%)	
Need for interpreter	No	104 (100%)	0
Born in Canada	Yes	88 (84.6%)	0
	No	16 (15.4%)	
Year of arrival	>5 years ago	7 (43.8%)	2 (12.5%)
	≤ 5 years ago	7 (43.8%)	
Immigration status	Canadian citizen	94 (90.4%)	0
	Permanent resident	5 (4.8%)	
	Work permit	2 (1.9%)	
	Study permit	1 (1.0%)	
	Visitor	2 (1.9%)	
	Prefer not to answer	0	
	Do not know	0	
Indigenous identity	Yes	21 (20.2%)	4 (3.8%)
	No	78 (75%)	
	Prefer not to answer	1 (1.0%)	
	Do not know	0	
	First Nations	17 (80.9%)	1 (4.8%)
	Métis	3 (14.3%)	
	Prefer not to answer	0	
Race/ethnicity	White North American	58 (55.8%)	5 (4.8%)
	White European	2 (1.9%)	
	Black African	4 (3.8%)	
	Latin American	1 (1.0%)	
	Asian-East	2 (1.9%)	
	Asian-South	1 (1.0%)	
	Asian-South East	3 (2.9%)	
	Mixed	1 (1.0%)	
	Other	4 (3.8%)	
	Prefer not answer	2 (1.9%)	
	Do not know	0	
Disability	Yes	18 (17.3%)	5 (4.8%)
	No	79 (76%)	
	Prefer not to answer	1 (1.0%)	
	Do not know	1 (1.0%)	
	Chronic illness	3	0
	Chronic pain	1	
	Epilepsy	1	
	ADHD	1	
	Intellectual Impairment	1	
	Mental Illness	8	
	Physical impairment	2	
	Other	1	

Question	Response options	N (%)	Missing (%)
Gender	Female Male	80 (76.9%) 24 (23.1%)	0
Intersex condition	Yes No Prefer not to answer Do not know	0 97 (93.3%) 3 (2.9%) 1 (1.0%)	3 (2.9%)
Preferred pronoun	She He They Prefer not to answer Do not know	71 (68.3%) 22 (21.2%) 1 (1.0%) 2 (1.9%) 4 (3.8%)	4 (3.8%)
Sexual orientation	Gay Heterosexual Bisexual Pansexual Lesbian Two spirit Questioning Queer Prefer not to answer Do not know	6 (5.8%) 67 (64.4%) 12 (11.5%) 4 (3.8%) 1 (1.0%) 1 (1.0%) 1 (1.0%) 1 (1.0%) 1 (1.0%) 4 (3.8%) 1 (1.0%)	6 (5.8%)
Highest level of education	Less than high school High School Diploma Some post-secondary PS completion Trade certificate/ diploma Graduate or professional degree Prefer not answer Do not know	8 (7.7%) 20 (19.2%) 24 (23.1) 27 (25.9%) 5 (4.8%) 18 (17.3%) 0 0	2 (1.9%)
Housing situation	Homeowner Renting Staying with friends/family Prefer not to answer Do not know	12 (11.5%) 63 (60.5%) 21 (20.2%) 0 0	8 (7.7%)
Food security (worry that food would run out)	Sometimes Rarely Never Prefer not to answer Do not know	8 (7.7%) 14 (13.5%) 72 (69.2%) 1 (1.0%) 0	9 (8.7%)
Food security (ran out of food)	Sometimes Rarely Never	2 (1.9%) 7 (6.7%) 86 (82.7%)	9 (8.7%)

Question	Response options	N (%)	Missing (%)
Annual household income	Less than 20K	21 (20.5%)	12 (11.5%)
	20K – less than 30K	2 (1.9%)	
	30K – less than 40K	9 (8.7%)	
	40K – less than 50K	9 (8.7%)	
	50K – less than 60K	8 (7.7%)	
	60K – less than 70K	4 (3.8%)	
	70K – less than 80K	6 (5.8%)	
	80K – less than 90K	1 (1.0%)	
	90K –less than 100K	2 (1.9%)	
	100K or more	8 (7.7%)	
	Prefer not to answer	9 (8.7%)	
Do not know	13 (12.5%)		
Monthly family income	\$800	1 (7.7%)	9 (69.2%)
	\$3500	1 (7.7%)	
	Prefer not to answer	1 (7.7%)	
	Do not know	1 (7.7%)	
Number of people supported by income	1	41 (39.4%)	24 (23.1%)
	2	10 (9.6%)	
	3	9 (8.7%)	
	4	7 (6.7%)	
	5	1 (1.0%)	
	Prefer not to answer	6 (5.8%)	
	Do not know	6 (5.8%)	
No of persons with low income based on LICO cut offs	Low income	23 (22.1%)	43 (41.3%)
	Other	38 (36.5%)	

Table F-3: Results of multivariable logistic regression model for ‘identity =yes’, sex and age showing odd ratios, 95% confidence intervals and p values

Model	OR	95% Confidence Intervals		P value
		Lower	Upper	
Sex				0.49
Male	1.000 (reference)			
Female	1.03	0.95	1.11	
Age				<0.001
18 -34 years	6.1	5.39	6.84	
35 – 64 years	3.3	2.92	3.66	
≥65 years	1.000 (reference)			<0.001

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