Understanding Health Inequities and Access to Primary Health Care in Southeastern Ontario
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The Belleville Quinte West Community Health Centre and the Southeast Local Health Integration Network funded the study. The results and recommendations of the study are those of the Project Team and no official endorsement of either agency is intended or should be inferred.
### Abbreviations

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<td>CCAC</td>
<td>Community Care Access Centre</td>
<td>NACRS</td>
<td>National Ambulatory Care Reporting System</td>
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<td>CHC</td>
<td>Community Health Centre</td>
<td>ODB</td>
<td>Ontario Drug Benefit</td>
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<td>CIHI</td>
<td>Canadian Institute for Health Information</td>
<td>PCA</td>
<td>Principal Components Analysis</td>
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<td>CTAS</td>
<td>Canadian Triage Acuity Scale</td>
<td>REB</td>
<td>Research Ethics Board</td>
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<td>DA</td>
<td>Dissemination Area</td>
<td>SELHIN</td>
<td>Southeast Local Health Integration Network</td>
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<td>DAD</td>
<td>Discharge Abstract Database</td>
<td>SES</td>
<td>Socioeconomic Status</td>
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<td>DI</td>
<td>Deprivation Index</td>
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<td>ED</td>
<td>Emergency Department</td>
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<td>GIS</td>
<td>Geographic Information System</td>
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<td>ICD</td>
<td>International Classification of Diseases</td>
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The Challenge

This report of the primary health care needs of the population of the South East Region was initiated by the Belleville & Quinte West Community Health Centre (BQWCHC) to support utilizing a social determinants of health lens to provide a solid basis in evidence and in valid, local data to illuminate the needs of individuals facing multiple barriers to health in Southeastern Ontario.

In its Integrated Health Services Plan (IHSP), the Southeastern Ontario Local Health Integration Network (SELHIN) listed “the development of a primary health care system” as a priority. A key first step in the implementation of a coordinated, integrated and holistic primary healthcare system is a more comprehensive understanding of the needs of the population it intends to serve. Recognising the influence of the social determinants of health, a particular focus of this report is to comprehend the needs of those facing multiple barriers to health in the SELHIN.

In order to best understand primary health care needs, it is also necessary to comprehend the challenges and barriers that form the context of those needs. Well-being hinges on a number of different, inter-related factors. Health equity “implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that none should be disadvantaged from achieving this potential, if it can be avoided.” (Whitehead, 1992: 433)

Health care equity means, “equal access to available care for equal need, equal utilization for equal need, equal quality of care for all.” (Whitehead, 1992: 424) Whitehead’s definition is clear, but almost twenty years on, there remains difficulty measuring the concept of “health inequity” and greater difficulty relaying the real life experiences of those that experience barriers to primary health care services.

“Health for All” declared at the International Conference on Primary Health Care at Alma Ata in 1978 marked a watershed of the world’s governments orienting toward equity in health; yet today the gap in health gains between disadvantaged and advantaged groups of people continues to widen (Tugwell et al., 2006).

“Health for All” is an elusive concept in its own right, but the persistent difficulty measuring and researching health inequities as they relate to primary health care is perpetuated by a lack of definitional consensus in the literature.

For the purposes of the current research, it was important to outline the working definitions for primary health care versus primary care and the shades of nuance associated with the concept of access.
Primary health care (PHC)—incorporates personal care with health promotion, the prevention of illness and community development. The philosophy of PHC includes the interconnecting principles of equity, access, empowerment, community self-determination and inter-sectoral collaboration. It encompasses an understanding of the social, economic, cultural and political determinants of health.

Primary care—is more clinically focused, and can be considered a sub-component of the broader PHC system. Primary care is considered to be health care provided by a medical professional that is a patient’s first point of entry into the health system. Primary care is practiced widely in nursing and allied health, but predominately in general practice.

(Kelaher, Dunt, Day & Feldman, 2006)
A comprehensive definition developed by the Australian Primary Health Care Research Institute (APHCRI) expands the former definition to include a focus prioritizing those most in need as well as explicit inclusion of health promotion, illness prevention, community development and advocacy.

Primary health care is socially appropriate, universally accessible, scientifically sound first level care provided by health services and systems with a suitably trained workforce comprised of multi-disciplinary teams supported by integrated referral systems in a way that: gives priority to those most in need and addresses health inequalities; maximizes community and individual self-reliance, participation and control; and involves collaboration and partnership with other sectors to promote public health.

Comprehensive primary health care includes health promotion, illness prevention, treatment and care of the sick, community development, and advocacy and rehabilitation.

"Primary Health Care Reform in Australia: Report to support Australia's First National Primary Health Care Strategy," 2009)
Access to primary health care services follows similar conceptual, methodological and measurement variations that make defining ‘access’ onerous. Health service research is split between diverse approaches. On one side, medical (health services) research has investigated access as a formal entry point to the health system; correspondingly measurements include demand, availability, utilization, service provision, quality, health outcomes and need for services that are professionally defined (Kovandžić et al., 2011). On the other side, social science and behavioural research pivots around health seeking behaviors that occur prior to the formal point of entry to the health system such as individual, interpersonal and/or societal influences on health service access (Kovandžić et al., 2011). There has been some effort to integrate these divergent perspectives but empirical research remains scarce (Dixon-Woods et al., 2006). In an environment of universal healthcare such as Canada’s, the conviction that prompt and affordable healthcare ensures equal health outcomes is unfounded. There are serious shortcomings. Health inequities continue to worsen (Welch et al., 2010). For many Canadians, living conditions, food security, employment security, poverty and social exclusion continue to worsen with deleterious and direct effects on health (Raphael, Curry-Stevens & Bryant, 2008). Also, disadvantaged people use the healthcare system more often, yet they still have worse health outcomes (Alter, Stukel, Chong & Henry, 2011). Moreover, inequalities in health status may not be fully explained by differences in health behaviours (Marmot et al., 2010). The contribution of medicine and health care is limited compared to the influencing factors of social determinants on population health (Marmot et al., 2010). People with lower socio-economic status have more behavioral risk factors such as increased tobacco use, poor diet and reduced physical activity; increased rates of chronic disease; and worse health outcomes (Brennan Ramirez, Baker & Metzler, 2008; Phipps, 2003; Raphael, 2004).
Understanding how persons with chronic diseases or risk factors access and use health services is equally challenging. Often data cannot be disaggregated to a regional or local level. Nor is it sufficiently granular such that deeper contextual comprehension emerges. It is problematic considering population level trends such as age and chronic disease rates compared with community and individual levels where health system disadvantages are exacerbated (Wong & Regan, 2009).

Population based surveys capture self-reported health conditions and behavioural risk factors for illness, but it is difficult to capture similar data from administrative databases (Iron, 2006). A suitable measure of socio-economic status is equally challenging to distill. Many studies investigating poverty employ a measure of income as a predictor of health inequalities in a population, but income measures often overlook important factors such as social deprivation or social capital (Patychuk & Smith, 2010; Raphael, 2004). Canadian administrative databases do not contain socio-economic information (Pampalon, Hamel, Gamache & Raymond, 2009).

An all-encompassing tool for measuring equitable access to primary health care doesn’t exist. Complicated and interconnecting factors influence health outcomes. Bound by the availability of statistical data and constrained timelines for systematically gathering qualitative information, solutions for unraveling the intertwined nature of health inequities must be equally creative.

It is essential that understanding primary health care needs be explored using multiple perspectives. Only by uniting divergent approaches for evidence gathering, research that incorporates both medical and social sciences, will a comprehensive, multi-dimensional picture of need be revealed.

This report outlines the mixed methodological approach that was done to better understand the scope, scale, and distribution of populations facing complex barriers to health in the SELHIN. Equally important, by documenting their lived experiences accessing primary healthcare, this research provides the very necessary context to best understand the story behind the numbers in order to optimally support the development of a primary healthcare system in the SELHIN.
As illustrated in Figure 7-1, this report documents the mixed methodological approach and findings of our research to better understand the scope, scale, and distribution of populations facing complex barriers to health in the SELHIN. We commence with a comprehensive review of both the peer-reviewed and grey literature on health inequities. Amongst important substantive findings about access barriers and health inequities, that review simultaneously reveals methodological challenges in how health analytics research has operationalized the social determinants of health. We carefully review some options and offer a rationale for our selection of a well-known deprivation index. The subsequent quantitative analyses of two key administrative databases (inpatient stays and emergency department visits) enable us both to test the robustness of the deprivation index to discriminate differential health outcomes and to also analytically demonstrate some forms of health inequity.

Equally important, by documenting the lived experiences of SELHIN residents as they access primary healthcare, this research provides the very necessary context to best understand the story behind the numbers in order to optimally support the development of a primary healthcare system in the SELHIN.

We do so by first conducting a series of key informant interviews with healthcare service providers to identify and better understand what they believe are the more salient themes and issues in the delivery of primary healthcare services. These are supplemented with a series of focus group discussions with residents to explore for similar or divergent themes in their perceptions of primary healthcare delivery. Though we find the themes and issues are congruent, we field a more complete survey to a larger, more representative sample of SELHIN residents to understand how stable and pervasive these themes are. The report concludes with a more integrated synthesis of the key empirical findings that illuminate primary healthcare inequities and access barriers in the SELHIN. Several strategic and pragmatic recommendations are offered towards the improvement of access to primary healthcare and closing the health inequity gap. Within the literature, the definition of health equity lacks conceptual clarity (Welch et al., 2010).

Figure 7-1: Research Design
Though health equity dialogue is well established and accepted as health differences between groups, equity oriented objectives and plans are often unobserved (Tugwell et al., 2006). Tugwell et al. (2006) provide a succinct definition: “inequalities are termed inequities when these inequalities are deemed to be unfair and avoidable.” There are challenges teasing out and measuring unfair inequalities which are done in a variety of ways:

The measurement of equity is an area not as well-developed as measurement of morbidity, mortality or health care needs. Primarily, it consists of dissemination of these measures of morbidity, mortality, and health care needs by sectors (i.e., rural vs. urban, or remote vs. central areas, racial groups, socio-economic categories). In addition, it may also include measures of inputs (i.e., doctor; population ratio in rural vs. urban areas). (WHO Collaborating Center for Knowledge Translation and Health Technology Assessment in Health Equity)

Similarly, the designation “priority populations” has acquired broad usage as a term for distinct populations that are hard to reach, vulnerable, or otherwise grouped for purposes of description, no one term adequately characterizing people. This project designated priority populations as “those facing multiple barriers to health”. Abiding by well-established patterns of association between greater social and material disadvantage with poorer health, it follows that people facing multiple barriers to health are more often deprived populations (Braveman, Egerter & Williams, 2011). Other sections of this report explore specific sub-populations to provide a regionally-specific description of priority populations in the SELHIN.

Two distinct literature reviews were conducted to inform different knowledge acquisition objectives. First, to research the extent to which social and health disadvantage affects different groups, it is important to understand and know which factors most often influence health disparities related to getting the primary health care services that people need. Secondly, exploring evidence based operational frameworks adopted by other researchers best informs the development of research tools, strategies, methods and techniques for understanding the primary health care needs of people in the SELHIN.
The two literature reviews conducted considered existing research regarding:

1. access and barriers to primary health care, with a focus on priority populations and
2. how priority populations are identified and engaged in primary health care research.

8.1 Methodology

We conducted a rigorous and extensive review of the grey and peer-reviewed international literature. The method used to review the literature closely mirrored the interpretive strategy outlined by Dixon-Woods et al. that uses emergent and exploratory methods to uncover relevant material (Dixon-Woods et al., 2006).

We sought indicators applicable to the social determinants of health or improving health equity; as well as methodological processes associated with identifying priority populations and successful practices for working with and engaging priority populations. Several broad questions guided the search strategy:

1. What are the barriers to primary health care?
2. How are priority populations identified?
3. How are priority populations engaged in primary health care research?
4. What methods are used to gather information and data from priority populations?

The following databases were searched, restricted to English language documents:

- MEDLINE (1996 – March 2011),
- CINAHL (1981 to March 2011),
- HealthSTAR (1999 – February 2011),
- PsycINFO (2001 – March week 1 2011),
- all EBM Reviews (includes Cochrane database of systematic reviews, 2005 – February 2011),
Specific search terms were:

- Primary and Health and Care; Access; Barrier*;
- Medic*;
- socioeconomic, - status, - factor
- inequalit*
- inequit*
- poverty
- priority population
- vulnerable population

As well as a variety of terms to capture primary health care service models such as:

- community health service
- comprehensive health care
- health behavior
- health seeking behavior
- community mental health
- health service availability

In addition, we performed a review of grey literature sources recommended or monitored by health organizations and/or by governing associations/societies for relevant primary health care research in Canada, and elsewhere, as well as identifying priority populations (e.g., Statistics Canada, Canadian Institute for Health Information, Institute for Clinical Evaluative Sciences, Public Health Agency of Canada, Canadian Public Health Association, Canadian Council on Social Development, Canadian Health Services Research Foundation, Ontario Ministry of Health and Long Term Care, Ontario Public Health Libraries Association, Ontario Public Health Association, Association of Ontario Health Centres, Centers for Disease Control and Prevention, National Health Service).

Literature included for further consideration was based on the following criteria:

1. provision of sufficient descriptive information for its practical use; and
2. evidence of its relevance or importance to primary health care and priority populations.

In order to cast as wide a net as possible, the quality of the specific evidence behind a given study—with respect to study design, bias, confounding, or outcome measurement—was not a determinant of selection at this stage. Moreover, a formal analysis of the psychometric and/or statistical properties was beyond the scope of this project. Literature resulting from this review was then organized

8.2 Findings

Four main barriers to accessing primary health care were identified.
8. Poverty

The burdening effects of poverty on health have been well studied in Canada (Alter, Stukel, Chong & Henry, 2011; Kramer et al., 2001; Mustard & Roos, 1994; Sword, 2003; Wilkinson & Marmot, 2003). Poverty influences health through a variety of mechanisms including material deprivation, increased stress, and unhealthy behaviours (Alter et al., 2011; Braveman et al., 2011). Low income Canadians consistently experience poorer health and are more likely to experience chronic health conditions and cognition challenges compared with higher income adults (Alter et al., 2011; Fang, Kmetic, Millar & Drasic, 2009). People living in poverty tend to under-use preventive services such as prenatal care, cancer screening, non-publically funded services such as vision-correction services, alternative healthcare and dental services (Alter et al., 2011; Mustard & Roos, 1994; Stewart et al., 2005; Sword, 2003). Publically funded services, on the other hand, such as acute care services, home care services, general practitioners and some mental health services, are more likely to be utilized by low income Canadians compared to other Canadians (Booth & Hux, 2003; Hay, Pacey, Bains & Ardal, 2010; Sword, 2003).

An individual’s ability to access services to maintain or improve their health is dependent on a variety of factors in addition to income (Alter et al., 2011; Stewart et al., 2005; Wilkinson & Marmot, 2003; Williamson et al., 2006). For instance, a study by Williamson et al. (2006), investigated the use of health related services by low income Canadians living in Toronto and Edmonton. The study revealed that programs and policies relating to income, food and housing security, as well as the manner health services are delivered, all play a role in low-income individuals’ decision to use services.

The importance of maintaining physical health is well-established, yet extracurricular activities and recreation programs are sometimes cost prohibitive (Williamson et al., 2006). People with lower incomes are stuck in a repeating cycle, whereby they lack the funds to ensure sufficient life necessities (such as food and housing), experience challenges having to pay for certain medical services or health improvement activities (including certain medications, dental services, or joining a gym), and have poor utilization of illness prevention services, all contributing to poorer health (Aved, Irwin, Cummings & Findeisen, 1993; Tough, Siever & Johnston, 2007; Williamson et al., 2006; Vozoris & Tarasuk, 2003). Once their health has deteriorated, people in poverty lack the funds necessary to access the services that may improve their functionality and well-being (i.e., chiropractor, physiotherapy, or eye and dental services). It is understandable then, that many low-income individuals suffer depression and stress. Federal and provincial cuts to social income security spending over the past two decades increase stress levels for people experiencing financial issues (Stewart et al., 2005). Once again, many of these individuals simply lack the financial capacity for services not covered by provincial health care plans that may help with stress conditions (such as a psychologist).
8.22 Geography

Geography remains a key determinant of health in Canada, as rural populations generally experience poorer health compared to more urban populations (Hutten-Czapski, 1999; Primary Health Care: People, Practice, Place, 2009). Canadian life expectancy is amongst the world’s highest at 79 years but falls to below 75 years in some rural communities (Primary Health Care: People, Practice, Place, 2009). Close to one third of Canadian seniors live in rural areas and small towns (Jennissen, 1992). As Canada’s population ages, there will be increasing pressure to effectively care for these individuals. Rural areas also tend to be undersupplied by health professionals and primary health care services, which contributes to the relative inaccessibility many rural residents experience (Primary Health Care: People, Practice, Place, 2009).

Unique to rural communities is the need to travel larger distances to urban centres in order to access many forms of health care (Boydell et al., 2006). Access to out-of-town services can be hindered, however, by adverse weather conditions, lost wages, lack of public or private transportation, and travel costs (e.g., gas, car maintenance, parking, meals, and hotel accommodation) (Boydell et al., 2006; Arcury, Preisser, Gesler & Powers, 2005; Barer & Stoddart, 1999; Brual et al., 2010; Chalifoux, Neese, Buckwalter, Litwak & Abraham, 1996; McDonald & Conde, 2010; Jennissen, 1992). The small size of rural communities reduces anonymity and may cause stigma associated with seeking mental health services that can often delay or prevent access (Boydell et al., 2006). In urban areas, geography and transportation were also barriers for many low-income individuals (Stewart et al., 2005). Stewart et al. (2005) found that poor Canadians were more restricted to services offered in their neighbourhood, as services in other communities were considered too far, and too costly to get to (i.e., transportation costs).
Poor Health Literacy

The Canadian Public Health Association defines health literacy as the “skills to enable access, understanding, and use of information for health” (‘Health Literacy in Canada: A Healthy Understanding,’ 2008). Poor health literacy influences the degree to which people are able to navigate a complex health system. Alarmingly, nearly half of all Canadian adults have inadequate health literacy skills, which can result in poorer health (Beiser & Stewart, 2005). Canadians with the lowest health literacy skills are 2.5 times more likely to report being in fair or poor health as those with the highest skills, even after accounting for age, education and gender (‘Health Literacy in Canada: A Healthy Understanding,’ 2008).

Health literacy encompasses more than functional verbal skills, with social and cultural aspects of communication being equally important (Quan et al., 2006). Clients may have different expectations of care, cultural preferences, and preferences for a particular service provider (i.e., female over male) (Ng & Newbold, 2011). Health service providers should be aware of the relationship between cultural values and the health seeking behaviour of their clients (Quan et al., 2006). A report by the Public Health Agency of Canada (2009), noted that 32% of foreign-born women have extreme difficulty with printed materials, compared with 24% of foreign men. Immigrant women with low literacy scores and limited English skills may be less aware of preventive services or the importance of them (Woloshin, Schwartz, Katz & Welch, 1997). A study examining the relationship between language barriers and preventive services in Ontario, found that women whose first language was not English were less likely to obtain a breast examination, mammography or a pap test (Woloshin et al., 1997). Electronic communication and information, especially for online health resources, has increased exponentially over the last decade. Yet many seniors tend to experience more challenges with internet access compared with other age groups (Alpay et al., 2004; Becker, 2004).

Physiological factors associated with aging affect seniors’ usage of the internet, where vision, cognition and physical impairments may impede web utilization (Becker, 2004). Web design issues such as fonts (size and type), colours, graphics, background images, navigation tools, and search mechanisms may also contribute to low utilization. Web sites that do not meet the online needs of seniors can create virtual barriers to accessing services and information (Becker, 2004).

Other important barriers to accessing primary health care include knowing what services are available, as well as familiarity with staff and services (Stewart et al., 2005). Finally, poor health literacy prevents Canadians from attaining proper chronic disease management services and following medication regimes (Simich, 2009). Simich (2009) noted that self-management and decision-making requires a patient be fully understanding of their health options, of concepts of risk, their treatment options and how to access care.
Poor Relationships with Health Care Providers

Canadians prefer providers who treat them with respect, compassion, and care (Stewart et al., 2005). A provider’s ability to listen, understand, and empathize with people from low-income groups reinforces engagement and utilization of services (Williamson et al., 2006). However, some service providers can be disablers, reducing client health-seeking behaviors because of poor attitudes, aggressive interaction styles, a desire to control clients, and an inability to build relationships (Sword, 2003).

Vulnerable subgroups often experience multiple stresses such as personal and family problems, depression, fatigue, and a lack of motivation, as they are often concerned with challenges around food and housing security (Morton & Loos, 1995; Sword, 2003). A common factor limiting utilization of services by low income Canadians include the behaviour of the health care provider and the service environment (Williamson et al., 2006).

Other service environments such as health care facilities or community organizations such as food banks and social assistance offices that harbour rude, critical, and condescending service providers equally deter clients (Stewart et al., 2005). Also, stigmatization and discrimination based on gender, ethnicity, appearance, income, or location of residence may contribute to the quality of care received (Stewart et al., 2005). Providers should ensure that their interaction style and terminology resonate with each individual client. People are more likely to use services if providers are welcoming, friendly, respectful, compassionate, and sensitive to the unique situation of people in poverty (Stewart et al., 2005).

The SELHIN comprises a large, mostly rural territory. The literature review strongly suggests that rural communities are undersupplied with primary health care services, which subsequently forces individuals to travel long distances for services that incur transportation costs (in both money and time). Regional demographics reveal that the SE LHIN has a higher proportion of elderly people compared to other LHINs. Studies show that rural seniors utilize services less than urban seniors, suffer poorer health literacy, and have reduced social supports. Additionally, the proportion of lone parent families in the SE LHIN is higher than the provincial level. It is expected that the four access barriers exist to some degree in the SELHIN and may be influenced by both age and geographic factors.

The second comprehensive review of studies done to investigate how priority populations are identified and engaged in primary health care research revealed a range of study designs and outcome measures. Much of the evidence was drawn from observational studies making clear comparisons very difficult. The complexity of research definitional frameworks, sampling and recruitment strategies, methodology, and outcome measures makes it very difficult to state with confidence how different techniques are successful or how they work with different groups. Consequently, much of the evidence may only be regarded as promising practice rather than proof of effectiveness. One systematic review, one scoping review, one description of a research protocol and twenty-six studies were reviewed.

Challenges of access are often studied within individual vulnerable groups or tend to focus on between group differences rather than similarities across groups (Kovandžić et al., 2011). Studies looking at specific subgroups within “disadvantaged groups” included subgroups of: adults with intellectual, physical or developmental disabilities, immigrants, homeless youth, women with low family income, war veterans, and Latino parents (Clark et al., 2009; Lebrun & Dubay, 2010; Ward, Nichols & Freedman, 2010; Harrington, 2009; Bauer, Willford, McBride, McBride & Shea, 2005; Kurtz Landy, Sword & Valaitis, 2009; Flores, Abreu, Olivar & Kastner, 1998). The remaining studies investigated disadvantaged population groups as a measure of income, education or employment, either as composite or individual measures to define and sample for “low socioeconomic status” and/or geographic boundaries for “socioeconomically deprived regions” using census data. Many studies represented targeted research approaches rather than investigating gaps between the most and least advantaged groups or approaches investigating a gradient between the most disadvantaged to the least disadvantaged groups.

Measurements of access to primary health care included: having a regular physician, consultation with a health professional in the last 12 months, having a dentist visit in the last 12 months, various screening
tests (PAP, mammogram), median wait time between referral from a primary health care provider to being seen by a specialist, how long patients wait for their clinical encounter, whether patients are taken on time for their scheduled appointment, how long they spend with a physician, overall satisfaction with the physician-patient encounter, difficulty getting after-hours medical treatment, and medical insurance coverage (Lebrun & Dubay, 2010; Mercer & Watt, 2007; Kisely & Chisholm, 2009; Kelaher, Dunt, Day & Feldman, 2006; Guendelman & Pearl, 2001).

The social behavioural research offers different interpretations of access. Kovandžić et al. (2011), in their study of equitable access to primary care for people with mental health problems, listed a number of access concepts that are common across hard to reach groups: knowledge about available services; adequate and timely information about services; availability of social networks to assist a pathway to care (diabetes support network, for example); time available for engagement with those services; affordability in terms of time (employment hours or lack of childcare may prevent access); affordability in terms of finances; transportation; readiness to pursue health care; personal perception of diagnosis; care need or disease progression; distance from home; unpleasant physical surroundings or design of health facilities; services responding to the rhythms of life; receptivity of services; compliance with disease management; health literacy and communication (ability to articulate a health issue); availability of therapeutic options; and the ability to integrate different aspects of care (Kovandžić et al., 2011).

Other barriers such as fear of failure or fear of being judged are also common among disadvantaged groups (Murray, Bauld, Hackshaw & McNeill, 2009). Concepts of cultural capital in the form of perceptions, health values, health knowledge, behavioral norms, the ability to use appropriate language and communication styles, influence of social networks and resilience are equally influential to differential health outcomes (Abel, 2008).
The division between social and medical science continues around methodological approaches. Population health surveys and epidemiological techniques are often employed in the health services literature, while qualitative techniques such as focus groups and key informant interviews are often used in social research. Survey methodology overlaps both domains. Large population health surveys dominate the epidemiological literature while smaller, author developed specific surveys command social research.

Recruitment strategies for disadvantaged groups or priority populations employ snowball sampling, purposeful sampling, convenience sampling, complex multi-stage sampling and random sampling. A review of literature regarding smoking cessation strategies among disadvantaged groups showed evidence that social marketing for delivering client-centered approaches for cessation strategies was successful: community outreach, media campaigns, cessation materials, and quiz nights (Murray et al., 2009). Other studies used recruitment flyers sent to web site members, phone calls, emails, flyers dropped at relevant agencies, faxes, recruitment at clinics or hospitals, introduction letter followed by a telephone survey, random seat selection at study site, consumer group meetings, at employment skills classes, church groups, at a public school health fair, through consultations with community centres or neighbourhood organisations (Ward et al., 2010; Mercer 2007; Harrington 2009; Whitford & Chan, 2007; Kelaher et al., 2006; Flores et al., 1998; Johnston, 2001; Trevena, Simpson & Ntbeam, 2003). Two studies provided participants incentives for study participation (Ward et al., 2010; Kurtz Landy et al., 2009). In the review of smoking cessation interventions, larger incentives were more effective for recruiting disadvantaged groups to programs (Murray et al., 2009).

In recent years, there has been an increase in available internet based health information. The use of electronic survey collection methods has also increased. However, the use of computers with disadvantaged populations continues to be prohibitive. The digital divide experienced by disadvantaged people, is defined by both inaccessibility to computers (and the internet), as well as by computer skill limitations (Beacon & Newman, 2010).

Specific data collection methods included telephone surveys, (Lebrun & Dubay, 2010; Wong & Regan, 2009); face-to-face interviews (Clark et al., 2009); Jatrana 2009; Trevena et al., 2003); self-administered surveys (Abbott & Hobby, 2005; Flores et al., 1998; Harrington, Hirsch, Hammond, Norton & Bockenek, 2009; Mercer & Watt, 2007); focus group sessions (Higgs, Bayne & Murphy, 2001; Johnston, 2001; Mykota & Muhajarine, 2005); mailed questionnaires (Adamson, Ben-Schlomo, Chaturvedi & Donovan, 2003; Higgs et al., 2001); and national population health surveys (Alter et al., 2011; Lebrun & Dubay, 2010; Grossman, Legedza & Wee, 2008; Jatrana & Crampton, 2009; Shi & Stevens, 2007; Kelaher et al., 2006; Lorant, Boland, Humblet & Deliege, 2002; Guendelman & Pearl, 2001; Fouts, Anderson & Hagglund, 2000).

The complexity of research definitional frameworks, sampling and recruitment strategies, methodology, and outcome measures make it difficult to state with confidence how different techniques may be more successful or how they work with different groups. It is clear that a combination of research methodologies yield the best contextual evidence in a given population and/or region. Quantitative methods are useful for identifying deprivation areas using census data or geographic information systems (GIS). Disease rates and distributions—the traditional measurements used in epidemiological studies and utilization-based reporting (costs of services and numbers) are insufficient to support an integrated population health approach (Barnard & Hu, 2005). Pairing GIS with administrative data produces cogent representations of health needs of people in the context of health influences, services and outcomes (Barnard & Hu, 2005).

GIS can be a useful tool for revealing health inequities (Tugwell et al., 2006). Qualitative methodology, on the other hand, allows people to tell their stories, identify dimensions of primary health care that are important to them, and to suggest solutions from a patient perspective towards improving the system (Wong & Regan, 2009). These methods, paired with traditional health service data, may better capture the complex realities of communities and allow for a sharper focus on health inequities than by relying on a single approach (Tugwell et al., 2006).
There are broad methodological steps consistent across studies we reviewed and these informed the methodological approach of the current research:

1. identify priority populations using demographic information and/or regional boundaries;
2. data collection;
3. data analysis; and
4. information synthesis and recommendations for incorporation into health service planning.
That social forces, composition, and status are, at least in part, determinants of health outcomes and health seeking behaviours is well-established in the research literature. The challenge, however, is that as ample as the evidence is that health outcomes are driven in part by social determinants, there is no consensus in the literature on how to operationalize and measure these social determinants. To be sure, the suite of approaches is diverse and range from more simplistic univariate measures such as personal income or social class to more multidimensional, composite metrics that simultaneously consider multiple variables.

Prior to these multidimensional techniques gaining currency, health analytics research would often profile health outcomes against several socioeconomic variables individually. Mortality, for example, would be profiled separately against income, occupational class, net wealth, family status, marital status, or ethnicity. Health outcomes might be well-discriminated against some socioeconomic status (hereafter, SES) variables but not others while other health outcomes might be correlated against the latter SES variables but not the former. The number of combinations and interaction effects can sometimes frustrate and mask insights about the social drivers of health outcomes.

As data reduction techniques, principal components (PCA) and factor analysis enable us to control for the often considerable collinearity inherent in socioeconomic variables (income, for example, is highly correlated with educational attainment). PCA enables us to distill such duplicative variance into notably fewer variables that still account for the majority of the variance in the original variables. Analytically, PCA is efficient and, as an organizing framework, is parsimonious in capturing the multidimensionality of what we understand when we speak of “social determinants.”

The technique has become more conventional and has been employed to develop a number of area-based SES scoring frameworks, including the Ontario Marginalization Index\(^1\) and the related Canada Marginalization Index\(^2\) (ON-Marg and CAN-Marg, respectively), a Distress Index\(^3\), a Deprivation Index\(^4\), and the Carstairs and Morris Index\(^5\) and Townsend Index\(^6\) used in the UK.

We concur with the thrust of these approaches and, as such, adopt Pampalon et al.’s Deprivation Index (hereafter, DI) not only for these reasons of statistical efficiency but also because the DI—like all PCA solutions—reduce the complexity of individually examining health outcomes against numerous SES-type variables. In short, the DI offers a conceptually parsimonious framework for thinking about the social determinants of health. The DI, like all area-based measures, is geographically-anchored and is scored at the smallest unit of Canadian census geography, the dissemination area (hereafter, DA) and, thus, has a fine spatial resolution and is actionable in that specific neighbourhoods could be targeted in the development of subsequent on-the-ground interventions.

Pampalon et al. identify two principal components that they term a ‘material’ deprivation component\(^7\) and a ‘social’ deprivation component. Three (3) of the six (6) SES, census-based variables used in the PCA load highly on the ‘material’ deprivation component (i.e., the proportion aged 15 and older with no high school diploma; the employment to population ratio of those aged 15 and older; and the average income of people aged 15 years and older) while the other three variables (3) load highly on the ‘social’ deprivation component (i.e., the proportion of those aged 15 and older living alone; the proportion of those aged 15 and older who are separated, divorced, or widowed; and the proportion of single-parent families). Each component summarizes roughly one-third of the variance in the original six indicators.

While a principal components analysis yields continuous, dimensionless component scores for each unit of analysis (being census DAs...
in the case of the DI), many analysts prefer to rank-order the component scores into discrete quantiles to ease interpretation. We have, thus, ranked all DAs in the SELHIN from least to most materially deprived into quintiles of equal population. Figure 9-1 depicts spatial patterns of material deprivation in the SELHIN by these census dissemination areas. For the purposes of this report, urban areas refer to the cities of Belleville, Kingston, Brockville and they are shown at larger scales in the inset maps since they are relatively densely populated and constitute the majority of the SELHIN’s population. Northern areas show predominantly greater material deprivation compared to communities along and south of the 401 corridor. Along the 401 corridor there is considerable variation of deprivation across quintiles.

1. [http://www.crunch.mcmaster.ca/ontario-marginalization-index](http://www.crunch.mcmaster.ca/ontario-marginalization-index)
2. [http://www.crunch.mcmaster.ca/canadian-marginalization-index](http://www.crunch.mcmaster.ca/canadian-marginalization-index)
Figure 9-1: SELHIN Material Deprivation
Likewise, the DAs are ranked into quintiles of social deprivation and Figure 9-2 illustrates the spatial distribution of the social deprivation component. While there are seemingly no regional patterns to social deprivation, it is useful to note the clusters of high social deprivation in the urban areas of Belleville, Kingston, and Brockville.

Notwithstanding the data reduction already afforded by the DI, health analysts have sought even more thrift by cross-tabulating social and material deprivation into a single composite metric. As such, we borrow the approach developed by the Canadian Institute for Health Information (hereafter, CIHI) and illustrated in Table 9-1.
Table 9-1: Combined Material and Social Deprivation

<table>
<thead>
<tr>
<th>Material Deprivation Quintile</th>
<th>Q1</th>
<th>Q2</th>
<th>Q3</th>
<th>Q4</th>
<th>Q5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Deprivation Quintile</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Q1</td>
<td>1 - Least</td>
<td>1 - Least</td>
<td>1 - Least</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Q2</td>
<td>1 - Least</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Q3</td>
<td>1 - Least</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5 - Most</td>
</tr>
<tr>
<td>Q4</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>5 - Most</td>
</tr>
<tr>
<td>Q5</td>
<td>3</td>
<td>4</td>
<td>5 - Most</td>
<td>5 - Most</td>
<td>5 - Most</td>
</tr>
</tbody>
</table>

Having assigned a ‘combined’ deprivation rank to each DA in the SELHIN using the cross-tabulation shown in Table 9-1, Figure 9-3 then illustrates the spatial distribution of the combined rank. Areas shaded in the darkest red represent neighbourhoods and communities of the SELHIN that are simultaneously the most materially and socially deprived; that is, these areas have lower incomes, higher unemployment, less educational achievement, more single parent families, and have higher proportions of residents who live alone, or are separated, divorced, or widowed.
Figure 9-3: SELHIN Combined Material and Social Deprivation
Geographic access is arguably amongst the most fundamental of all potential barriers to primary health care. Absent the in-home visits of a bygone era, contemporary service delivery is overwhelmingly predicated on patients, usually by their own means, visiting the place of practice of their primary care provider. As illustrated in the previous chapter, there exists considerable variation in the spatial distribution of the SELHIN’s population across the DI quintiles. We seek in the present chapter to explore for inequities in simple geographic accessibility to primary care providers experienced by more deprived populations.

We have geocoded the locations of the approximately 453 primary care physicians in the SELHIN and, simultaneously, know the residential population counts of SELHIN residents from the 2006 census at the fine geographic resolution of the census dissemination block of which there are approximately 8100 in the SELHIN. Using a standard gravity modeling approach we can generate a unitless Index of Accessibility (A) for each dissemination block.

Formulaically,

\[ A_i = \sum_{i=1}^{n} \frac{S_j}{d_{ij}^\beta} \]

where

- \( i \) represents the \( i \)th dissemination block,
- \( j \) represents the \( j \)th primary care physician,
- \( d_{ij} \) represents the distance between the \( i \)th dissemination block and the \( j \)th primary care physician,
- \( \beta \) is the friction of distance (set to the gravity constant 2.0), and
- \( S \) is some measure of the attractiveness or capacity of \( j \) (set to 1.0)
Lower values represent comparatively poor access while higher index values suggest, in general, that those neighbourhoods enjoy relatively easier access to primary care physicians.

As illustrated in Figure 10-1 geographic accessibility to primary care physicians in the SELHIN is characterized by an urban-rural cleavage where the urban residents of Belleville, Kingston, Brockville, Perth, and Smith Falls enjoy relatively good geographic access to primary care physicians while more rural residents in the northern extremes of Frontenac and Hastings counties, for example, experience less choice of primary care physicians over longer distances.

As described above, the deprivation index developed by Pampanol et al. is scored on census dissemination areas and, since dissemination blocks nest within dissemination areas, we can ascribe the DI ranks of the DAs to the individual dissemination blocks. As such, we can compute mean geographic accessibility by social, material, and combined deprivation ranks.
Figure 10-2 illustrates, as depicted in blue, that access to a primary care physician is inversely related to deprivation; that is, areas of higher deprivation in the SELHIN have commensurately poorer access to primary care. Decomposing combined deprivation into its material and social components reveals more pronounced relationships. Material deprivation and geographic accessibility (as shown in red) are inversely related while social deprivation (in green) covaries directly with geographic accessibility. Said differently, our most materially deprived populations have the least access to primary care physicians while our most socially deprived populations have relatively superior geographic access to primary care physicians. The 95% confidence intervals indicate same significant inter-quartile accessibility differences.
Figure 10-3 assists to visually corroborate that the SELHIN’s most deprived communities are confronted with the least accessibility to primary care physicians. Notice that the areas shaded red (the SELHIN’s most deprived populations) are overwhelmingly co-located in areas with the lowest accessibility to primary care physicians.

While the preceding analysis offers some evidence of the inequities faced by the SELHIN’s more deprived populations in accessing primary care physicians, there exist some caveats. First, the analysis is limited to primary care physicians and does not include other primary care providers such as nurse practitioners, for example. Additionally, each physician is treated as an equal destination for primary care yet no account is taken of physicians who may not be accepting new patients or differentiating between physicians who practice full-time versus those that may be semi-retired or otherwise have limited hours.
While we have selected the Deprivation Index as an organizing principle for thinking about social determinants, we need next to test the DI as a tool for operationalizing socioeconomic status and discriminating health behaviours and outcomes. Theoretically compelling as the DI may be, it is of limited utility in the design and execution of on-the-ground interventions if it is a weak discriminator of differential health outcomes. The preceding chapter suggests some evidence that the DI is useful in identifying inequitable geographic access to primary care physicians but a more complete understanding of the social determinants of health requires that the DI be profiled against a variety of health outcomes and metrics. In the present chapter, we seek to reveal health disparities using the DI that may be evident in two key administrative databases.
11 Disparities in Hospital Inpatient Stays

The information for this analysis was obtained from the Discharge Abstract Database (hereafter, DAD) maintained at the Canadian Institute for Health Information. The DAD is a standardized source for inpatient hospital care, and reports on completed cases or discharges. As noted earlier, it is instructive to empirically understand health outcomes as a function of social and material deprivation that are geographically-anchored. Doing so requires that we characterize inpatient stays in terms of the social and material deprivation of the communities in which inpatients reside.

11.1 Methodology

Amongst the host of variables that describe an inpatient stay is the residential postal code of the patient. Through standard geocoding, we can approximately map the area in which every patient resides. However, since the deprivation index is a product of census data, it is scored on census dissemination areas. Statistics Canada’s Postal Code Conversion File (or PCCF) offers a linkage between the postal geography used by Canada Post and the census geography used by Statistics Canada. Using the PCCF, each inpatient’s residential postal code can be mapped to the DA most representative of that postal code. While the two geographies are not commensurate, postal codes generally nest well within DAs, especially in more urban areas (the former are geographically smaller than the latter).

All inpatient visits at SELHIN hospitals between April 1st, 2005 and March 31st, 2010 (N = 235,508) were geocoded and transposed onto standard census geography, such that inpatient utilization metrics are made commensurate with census-driven social determinants of health as measured by the deprivation index. Specifically, we examined the ability of the DI to discriminate differences in inpatient utilization and frequency rates, utilization rates by age cohorts, lengths of stay, the resource intensity of each stay, and the presence of comorbidities. Additional analyses were performed for selected diagnosed conditions (ICD-10 coded), including: respiratory conditions (J00-J99), ischaemic heart disease (I20-I25), diabetes (E10-E14), depression (F32-F33), and injury (S00-T98).

![Figure 11-1: Five-Year Inpatient Utilization Rate](chart.png)
11.12 Findings

Figure 11-1 depicts inpatient utilization rates in the general population across the combined DI quintiles. The least deprived populations have the lowest rates of inpatient service utilization at 350 stays per 1000 residents while our most deprived communities utilize inpatient services at over 500 stays per 1000 residents, almost 50% higher. Canada’s universal approach to health care assumes equal utilization and health outcomes for its citizens despite socioeconomic variations. In an environment of equal health care little variation across deprivation quintiles would be shown. Contrary to this expectation, the figure below shows greater inpatient utilization rates amongst the more deprived quintiles. Strongly supported within the literature, these numbers corroborate evidence showing people of lower socioeconomic status have worse health outcomes.

While the preceding chart illustrates the utilization rate in the general population (i.e., the number of unique residents using inpatient services relative to the population), it is also useful to explore for differences in how frequently a given inpatient uses inpatient services by the DI.

Figure 11-2 illustrates that the average five-year inpatient usage rate (shown horizontally in red) is 1.61 stays but is well differentiated by DI. The SELHIN’s most deprived inpatients, on average, have 1.68 stays while the least deprived inpatients have an average of 1.53 stays over the five-year window, or 10% more.

![Figure 11-2: Inpatient Usage Rate]
Figure 11-3 extends the prior finding by disaggregating inpatient stays by age cohort and deprivation index. The age cohorts are 0-19 years, 20-44 years, 45-64 years, 65-74 years, and greater than 75 years of age. Note that because the inpatient stay frequencies are vastly different when age cohorts are intersected with the DI, the resulting graphs render the visual detection of age-DI differences very difficult. We have, thus, standardized the reported values as indices of the actual number of stays over the expected number of stays. If DI made no difference, the actual number of stays would equal the expected number of stays and all bars would equal 1.0. Values below 1.0 indicate that those DI populations are experiencing stays less than would be expected while values greater than 1.0 indicate that those DI populations are experiencing stays greater than we would expect.

Figure 11-3 agrees with normative expectations that more senior populations will have disproportionately higher utilization of hospital inpatient services. And note that deprivation is positively related to inpatient utilization across all age cohorts, save for the two eldest.
Figure 11-3 illustrates somewhat more prominently the importance of controlling for age. Universally, we see that inpatient utilization rates increase with age, regardless of socio-economic status.

Figure 11-4 illustrates DI differentials in the median length of inpatient stays. The length of stay of the most deprived quintile is approximately twelve (12) days compared to just seven (7) days for those in the least deprived quintile. The 95% confidence intervals suggest a significant difference and the graph further reveals that the relationship remains stable when the combined DI is disaggregated into its material and social components.

However, notwithstanding our use of the median instead of the mean, we observed that some patients are recorded as continuous inpatients in the hospital for a number of years and therefore thought it prudent to trim the top and bottom 1% of the population from the analysis to remove the confounding effects of these particular outliers.
Figure 11-5 reveals an attenuated relationship. A modest difference between the least and most deprived quintiles remains, showing, on average, an extra day’s stay for people in the most deprived quintile compared to the least.

Resource Intensity Weights (RIW) are a measure determining the resource usage for similar clinical conditions. They are currently “under review” by the Ministry of Health and Long Term Care because of wide variations in the weighting has been found in the groupings for what seem to be similar cases. Without an alternative measure for hospital resource use in this preliminary analysis, the RIWs were analysed.

Figure 11-6 shows the most deprived quintile commands greater hospital resources for similar clinical conditions. This may be attributed to a number of different factors. The co-morbidity rate may be greater for people who are more deprived. Knowing health literacy rates are lower in lower socioeconomic groups, treatment adherence is likely to be lessened, explanations may command more time, and/or treatments may become more complicated. Additionally, unlike less deprived groups, there may be fewer family members to provide support, for a myriad of reasons.

Figure 11-7 illustrates that comorbidity rates vary directly with deprivation. Clinically significant comorbidity reflects the cumulative impact of comorbid conditions. As noted earlier, this may at least partially explain why more deprived populations have higher resource intensity weights.
Figure 11-8 illustrates the total number of inpatient stays by the most responsible diagnosis (hereafter, MRD), using ICD10 coding summarized earlier. MRDs reflect the condition or diagnosis attributed to being the most responsible for an individual patient’s stay in hospital. Clearly there are more respiratory, heart and injury diagnoses compared with diabetes, depression and femur injuries. Again because of large variations in the absolute case counts, we present in Figure 11-9 a standardized representation of differentials by DI.

We note that more deprived populations have disproportionately higher inpatient stays related to a respiratory condition, diabetes, and depression. For ischaemic heart, all injuries and femur injuries, the trends are reversed, with more deprived populations actually experiencing lower than expected rates.
Figure 11-10 illustrates the relationship between age and DI for inpatient stays whose MRD was respiratory related. Individuals aged 0-19 in the least deprived populations have a higher rate of respiratory diagnosis compared with other age groups, and quintiles. Interestingly, those aged 75+ in the most deprived populations have a lower than expected rate of respiratory diagnosis compared with other senior populations, from all other quintiles.

Figure 11-11, depicting the age-DI relationship across ischemic heart inpatient stays, shows that the rate is highest for those aged 20-44, in the most deprived quintile. The 0-19 age groups was removed from the chart because of low sample size (N≤5).

The age-DI relationship of diabetes-related inpatient stays is illustrated in Figure 11-12. Despite smaller numbers of hospitalizations related to diabetes—compared with other diagnoses—youth (i.e., 0-19 year olds) of the least deprived populations show disproportionately high inpatient stays stemming from diabetes. Like diabetes, the number of
inpatient stays with depression-related MRDs (Figure 11-13) is much lower than other hospital diagnosis yet we see some evidence of differential rates across the DI and age cohorts. The saddle of Q2 is problematic as is the lack of clearly discernable patterns by age or DI.

Figure 11-14 depicts age-DI differentials in inpatient stays stemming from injury. The chart shows that those aged 0-19 in the least deprived quintiles have relatively higher diagnoses for injuries compared to those in the more deprived quintiles. This may suggest that those in higher quintiles may have obtained injuries through activities that require increased resources (such as time and money). For instance, least deprived children may have obtained hockey injuries, and children from more deprived families simply do not have the money participate in this activity.

Figure 11-15 replicates Figure 11-14 but focuses on femur injuries only. Like Figure 11-14 those aged 0-19 in the least deprived quintile had disproportionately more inpatient stays stemming from injuries to the femur compared with 0-19 year olds in the most deprived quintile. This may reflect the injury related to sports hypothesis suggested above.
11. Summary

From the foregoing analysis, there would appear to be some evidence that key characteristics of hospital inpatient stays can be differentiated by the deprivation index. More deprived populations show greater utilization rates and more repeat usage, for example, and this empirical evidence dovetails well with extant research on the social determinants of health finding that people of lower socioeconomic status tend to experience worse health outcomes (Phipps, 2003; Patychuk and Smith, 2010). It also supports Alter et al.'s. findings that more deprived populations use health services more often (Alter et al., 2011).

Yet some of the evidence is decidedly more complex and warrants deeper investigation. A myriad of questions are raised but the graphs do collectively suggest that more deprived populations have higher rates of utilization of inpatient services in the general population, have more frequent and repeat usage, have longer stays, and have more resource intensive stays. We are unable, given the scope of the present study, to quantify these incremental costs but the magnitudes of several of the differentials suggest that they would be considerable.

This alone may pique the interests of health economists to entertain strategies that support increased community based prevention and interventions, particularly for more vulnerable populations.

We next explore for similar kinds of differences in the utilization of emergency departments in the SELHIN.
11.2 Disparities in Emergency Department Visits

11.2.1 Methodology
A complementary analysis was undertaken to explore for health disparities in emergency department (hereafter, ED) visits. The analysis was limited to the 315,222 visits at EDs in the SELHIN in the 2009 fiscal year (i.e., from April 1st, 2008 to March 31, 2009). We examined disparities by level and type of deprivation in case acuity, ambulance arrivals, visit type (unplanned new, unplanned repeat, etc.), wait time, utilization frequency, diagnosis, and other key variables.

11.2.2 Findings
Figure 11-16 illustrates the utilization rate of emergency departments by DI within the general population. We see across all three forms of the deprivation index, a relatively stable pattern of increasing utilization with increasing deprivation. The SELHIN’s most deprived populations have utilization rates approximately three times that of the least deprived populations. It may be that EDs are being somewhat used as a substitute for primary health care or more deprived populations simply have more frequent acute health conditions that require ED visits; more likely, the disproportionate utilization of EDs by more deprived populations is some combination of these factors.)
Figure 11-17 depicts visit acuity by DI. Note that less deprived populations have disproportionately fewer life threatening visits that may require resuscitation while more deprived populations have disproportionately more.

Figure 11-18 illustrates two interesting trends. First, patient referrals to the ED by non-ED service providers is inversely related to deprivation. That is, more deprived populations may be less often under the care and counsel of non-ED service providers such that when acute conditions are present they have less (or an absence) of guidance to visit the ED. Secondly, the figure illustrates that unplanned returns to the ED for the same clinical condition varies directly with deprivation. This may suggest more complex conditions, less follow-up, and/or challenges adhering to a treatment regimen or filling and completing prescriptions.
Figure 11-19 demonstrates that more deprived populations more frequently arrive at EDs by ambulance while less deprived populations do less so. This may reflect access to private transportation, more or less acute conditions, or some combination thereof.

Figure 11-20 shows the average proportion of each ED visit that is consumed by wait time (i.e., the amount of time prior to being seen for the first assessment). To some extent, this should reflect and be a surrogate or corroborating metric of case acuity. That is, ceteris paribus, more acute cases should have proportionately less wait time (which, by extension, means proportionately more treatment time). The figure reveals good discrimination by DI, as less deprived populations wait less than more deprived populations, ostensibly because the former use the ED for generally more acute conditions than the latter.
Figure 11-21 depicts ED usage by condition (or most responsible diagnosis). Several trends are apparent. Cases involving respiratory conditions vary directly—though modestly—with increasing deprivation. Diabetes is highly differentiated between less and more deprived populations and depression-related visits vary directly somewhat steeply with deprivation. Injuries vary indirectly with deprivation and this may, in part, reflect more active, outdoor lifestyles of less deprived populations than perhaps less active lifestyles of more deprived populations.
Figure 11-22 reveals that 45% of the SELHIN’s most deprived population who have used an ED have done so more than once compared to only 34% of the least deprived population. This may be suggestive of more complex health conditions requiring more frequent usage of EDs and/or it may suggest that multiple ED visits are, to some extent, substituting for primary care consultations (owing to real or perceived access barriers to the latter).

Figure 11-23 similarly explores for the ‘super user’ phenomenon by examining the proportion of patients by DI that have used an ED at least once, twice, three times, four times, and up to five times. We see, for example, that of all the patients who utilized any SELHIN ED five or more times, the most deprived accounted for approximately 38% of them compared to only 7% for the least deprived patients.

Figure 11-24 depicts the relationship between multiple ED visits and access to primary care physicians that was developed in chapter 11.

Here we see that not only do more deprived populations have poorer accessibility to primary care physicians but also that they have higher repeat usage of ED services. This might suggest that ED services are substituting for primary care visit because of more challenging access.
Understanding Health Inequities and Access to Primary Health Care

11.2.3 Summary

Compatible with and complementary to the earlier analysis of inpatient stays, the preceding analysis of ED visits illustrates that the deprivation index is a robust discriminator of key acute care metrics. More deprived populations are much more likely to utilize EDs and to do so with greater frequency. However, the evidence that the services of ED are necessary is less compelling. Case acuities do not present a clear picture, though wait times suggest that more deprived populations may be presenting with less acute conditions. And more deprived populations are more likely to make unplanned return visits to the ED for the same clinical condition. More deprived populations comprise the heaviest users of EDs and comprise the majority of ‘super users.’ We note also that more deprived populations are more likely to not only have multiple visits but that these same populations have the least geographic accessibility to primary care physicians.

One would not conclude from this analysis that EDs are substituting for primary healthcare services but we would suggest that further exploration is warranted. In any event, we see that the deprivation index is a useful tool and conceptual framework for better illuminating how the social determinants of health may be manifested in the utilization of ED services.

11.3 Conclusion

The preceding analysis illustrates that DI, for the most part, is robust in detecting and discriminating differential health outcomes in both hospital inpatient stays and ED visits in the SELHIN. The analysis reveals that more deprived populations of the SELHIN have higher utilization of inpatient services, are more frequent users, have longer stays, and those stays are generally more resource intensive. Similarly, more deprived populations are more frequent users of the SELHIN’s emergency departments and there is some evidence that more deprived populations use EDs more frequently and for lower acuity conditions that could perhaps be treated through primary care interventions.

The graphs are compelling evidence for improving primary health care delivery opportunities for people in the most deprived populations. The foregoing evidence is a powerful springboard to deeper inquiry and layering to substantiate the broader experience of primary health care in a context of deprivation. Analytically robust and conceptually straightforward, we continue to employ the deprivation index as our social determinants lens in how we design the qualitative phase of the study, including key informant interviews, focus groups, and a major survey.
The experiences of people facing multiple barriers to health offer important insights into barriers to accessing care. An essential first step for learning about those challenges is to identify who those people are. Evidence from the literature review and counsel provided by the project Advisory Committee agreed that priority populations be approached with sensitivity and in a spirit of participatory research. It was necessary to talk with those who work closely with more deprived people, to be able to get closer to learning about their experiences before engaging them directly. There was also the possibility that the SELHIN comprise several different groups of people who face multiple barriers to health and we wanted to be able to canvass as many of those stories as we could. A variety of front-line health service providers were approached to provide key informant interviews to satisfy four broad objectives:

1. To understand and/or gain knowledge, from the provider perspective, the challenges and barriers their clients face when accessing health services in the community.

2. To learn what contexts or situations typically influence or affect the way service providers engage more deprived clients in their health services.

3. To engage health service providers in both rural and urban communities to facilitate participant identification and recruitment for focus groups (people who experience multiple barriers to health).
12.1 Participant Recruitment

Ten front-line health service providers from the SELHIN, working in areas identified as having higher material and social deprivation, were recruited between June 2011 and August 2011. Introduction to key informants was facilitated using existing connections/relationships with members of the Project Advisory Committee. Front line health service providers were first contacted via telephone. Following verbal agreement to participate in the project, telephone interviews were scheduled and information letters and a consent form were sent via email. Signed consent forms were collected via fax prior to interview times. Front line health service providers were selected to satisfy a variety of front line primary health care professions, both medical and social, in both urban and rural settings. For this project urban referred to Belleville, Kingston and Brockville; rural referred to all other areas in the SELHIN catchment area. Criteria for inclusion in the study considered employment in the field for at least one year, employment in the community for at least one year, and provision of front line health services, as necessary. Also, health service providers who demonstrated involvement in outreach services for deprived populations, or support group facilitation, or knowledge of community groups, were also considered. Inclusion criteria were relaxed for two of the ten participants to obtain information from regionally isolated areas (see figure # [HSP summary chart]). Physicians were selected to be representative of either an independent practice or a Family Health Team.

“When asked about specific people who “fall through the cracks”, participant answers were more reflective of either a social or medical profession context.”
12.2 Data Collection

To explore health service provider perspectives, a semi-structured interview guide was developed to address two distinct objectives: to understand health service provider knowledge about difficulties their clients experience in getting the health care they need, and to engage health service providers in both rural and urban communities to facilitate participant identification and recruitment for focus groups.

Prior to fielding, the interview guide was revised several times using a cognitive interviewing process with two, non-affiliated, front line public health staff to improve the content and focus of each question. The interview guide was comprised of demographic questions followed by open-ended questions to address specific key topics. The guide may be found in Appendix II. Interviews were conducted over the telephone.

At the beginning of each interview, a general introduction, including a brief description of the project goals, and a reminder regarding the audio recording, was read to each participant. The semi-structured interview was conducted and audio recorded by the research associate. Interviews were between 20 and 50 minutes in length. A research assistant later transcribed the recording, verbatim.

Credibility and trustworthiness of the raw data were enhanced by the following means: interviews were transcribed verbatim, with field notes taken during the interview to supplement accuracy of data interpretation, and the research associate listened to each interview while reading corresponding transcripts prior to analysis. A second research associate listened and read transcript interviews independently. Both associates met to discuss concepts prior to analysis to ensure agreement.

12.3 Data Analysis

One researcher used NVivo 9 software to conduct thematic analysis and coding. In order to address the two distinct objectives of the research, two methods of data interpretation were employed. Key questions relating to facilitating subsequent phases of the research project (focus groups and survey) did not require in depth analysis or interpretation. These questions correspond to numbers 7, 8, 9 and 10 of the interview guide. The responses to these questions were separated from the interview transcripts and reviewed simply for information content. Transcript responses to key questions 1 to 6 in the interview guide underwent review and identification of central concepts using inductive analysis and synthesis. Initial analysis involved immersion in the details and specifics of the interview transcripts to reveal coding categories. Beginning with broad coding categories, specific observations moved toward general patterns. Ongoing review and memo writing during analysis was employed to discover important patterns, themes and inter-relationships as the researcher came to understand the phenomenon of health service providers’ views regarding the difficulties their clients experience getting the health care they need. Cross transcript analysis of the emerging themes was done to synthesize and present the findings in this report. With this iterative approach, the researcher believed saturation of themes was achieved after analyzing 5 interviews and was confident after a further 2 interviews revealed no new themes or disconfirming data.
Overall, participants viewed people who experience challenges getting the healthcare they need as those with: lower income, mental health and anxiety issues, less education, poor communication or self advocacy skills, addiction issues, complex health issues, transient or unstable housing and immigrants. In particular, specific vulnerable populations discussed were seniors, young families, people with disability and the working poor. Sub-analyses confirmed that both social (mental health counselor and social worker) and medical (physician, nurse practitioner, dietician), as well as urban versus rural participants, viewed people who experience challenges the same way. When asked about specific people who “fall through the cracks,” participant answers were more reflective of either a social or medical profession context. For example, social participants cited people with addiction, shift workers, people with unstable housing, people who aren’t comfortable with services, and people with schizophrenia. In contrast, medical participants cited people who are healthy, people who don’t pay attention to their health until it is needed, people who don’t prioritize health screening, people caught up in day to day living and people without a physician as those who “fall through the cracks.”

Participants consistently discussed client experiences and challenges that comprised difficulties with the health system, and navigating it in particular; the relationships between individuals and their primary health care providers; regional service variations; and client financial limitations. These were five key themes revealed through analyses.
12.31 Health System Issues

Participants recognized an on-going challenge related to physician attachment; there are still a number of people who do not have a regular family physician.

“there are people we are definitely missing because they are still walking in the door stating that they don’t have a health care provider and haven’t had for years”

“we are reporting a number that has been reported to us through some statistical data gathering right. They have asked people about this but they haven’t asked everybody, they have only asked a sample. And who responds to those questions? Not the patients with severe mental illness, not the hearing impaired, not the illiterate. Right? So we are missing a huge chunk of the population that we think is connected to primary care”

Participants described the health system as lacking warmth or human feeling, which was seen as a barrier for clients, especially those who are more vulnerable to begin with.

“the way the health care system currently works um you know it’s so cold let’s say and it’s not welcoming”

“They [clients] don’t feel so comfortable going through a system that isn’t going to support them”

“there are gaps in terms of our connections with all the inter-systems within the larger health care systems. Like our connections with the hospitals, our connections with nursing homes, our connections with retirement agencies, connections of care along the continuum. There have been some challenges there.”
Extending further, the health system for both health service providers and clients was described as lacking integration or coordination.

“the context that I’m actually working in is quite a complex network”

“other agencies don’t always play well with other agencies”

“we all tend to work individually or in silos. So maybe um some organizations don’t know what the other organization does. So that kind of prevents…sometimes you know individuals in the community from getting the best health care that they possibly can because we are not able to, you know, refer clients onto other organizations, maybe simply because we don’t know they exist, we don’t know what they do. We don’t have a really good understanding of each other’s, um you know, missions or mandates.”

“general understanding of the health care system I think is another um, we have done a really good job of keeping things secret in terms of how it works because I find patients asking questions all the time”

Some participants proposed opposing views of the health system.

“my sense is that it was a pretty accessible system and that um that the people of all educations and backgrounds get a pretty reasonable opportunity to get the same care.”

Several participants expressed concerns with the health system’s punitive nature. For example, clients may be charged a fee for asking their health care provider for a sick note for missed employment hours.

“Our system has been set up to be punitive and not set up to understand the realities of our patients.”

“linking people to other resources and that’s a huge role in primary care and there is just so many other resources.”
12.3.2 Navigating the Health System

In a health system related, but distinct concept, participants expressed strong support for helping clients to move through the health system. They viewed the practice of primary health care as evolving away from traditional, passive encounters, where clients come to the health provider, to more progressive and active advocating on behalf of clients to facilitate linking people to other resources in the community.

“we make things happen for people, it’s our responsibility to kind of collaborate and make sure the client gets what they need, the services they need, of the sort they need where and when they need it.”

“linking people to other resources and that’s a huge role in primary care and there is just so many other resources.”

“the system needs to become coherent and well connected and coordinated so that the client doesn’t have to worry about which door they go through, every door is the right door.”

This skill is directly connected to health providers’ knowledge about which community services exist.

“It’s complex doing that linking. First of all knowing that the resource is there, secondly when you’re seeing a patient, connecting that they have a need that might be met by a resource – it’s not always that obvious you know.”

Predictably, this knowledge varies across the region and the level to which providers are themselves engaged in their community.

“when you refer them to those other resources we do it often in a very personalized way. So if we were referring to one of the other counselors then we make a direct connection with the counselor and with the patient’s permission, to get the counselor to call them to make an appointment.”
Another challenge navigating the health system included the variability of service delivery models that comprise different eligibility for allied health services. For example, a community health centre or family health team may include the services of a dietician or social worker whereas a client who is not attached to a provider in these models may be asked to pay a fee for the same service. Similarly, referrals between health services varies between health service delivery models; community health centres and family health teams were cited as having more efficient referrals and communications between providers. Participants noted that providing allied health services in one location or building was beneficial for enhancing communication and referral practices.

“our philosophy is a little bit different from the mainstream you know we make it more of a welcoming community or a welcoming facility for them and um you know, it’s their centre, it’s client focused, it’s um a team approach, you know they can get so many services in one building. You know rather than having them have to try to navigate through you know four or five different facilities to get services that they could actually get under one roof.”

“because we are in the same building- referrals- and we get to know each other, we get to do whole week consults; we have referral back and forth very easily. It’s one stop shopping for the client.”

“they don’t have to pay for [mental health counseling], or like you say, foot care or OT [occupational therapy]. So they have access to that once they have a doctor here.”
Different models of care delivery also affect the amount of time allotted to client appointments.

“there is a lot of upfront investment of time but our agencies have seen the benefits so they’re willing to invest the upfront time in order to have the collaborative model working.”

“It takes more time to look after these types of patients [more vulnerable] and I’ve been very grateful that I do not have to push patients through in 15 minute schedules. That’s not how we run things here; it’s as long as it takes.”

“[a presentation about] dual diagnosis patients and sort of saying what they felt was required for those people to get proper care and it was incredibly challenging. The amount of time one would have to spend per visit [!] to do the things per visit they were suggesting would need to be done, to manage those people equally well.”

Finally, participants discussed the challenges associated with hours of operation that are often not accommodating for clients who do not work regular hours or who work shift hours.

“they [working poor] work all these horrible hours and a lot of our services they wouldn’t necessarily access because they are sleeping during the day because they work nights”
12.3.3 Relationship with the Health Care Provider

Overall, participants felt that it is essential health providers understand the client’s lived experience.

“we have to start thinking out of the box, we have to identify with the realities of our patients and give them the care that they need when they need it”

“I do think that if you have meaningful contact with them, that you’ll relate well to them and understand what true poverty is and how hard their life is. Which is difficult when you have a middle class professional right? …. There is a disconnect, so though I try and try to understand, but it’s still a disconnect”

“I think the quality of the visit is quite variable depending on the personality and nature of the patient as well as [the] personality and nature of the provider.”

Participants discussed the necessity of taking time to establish relationships with clients.

“you spend a lot of time with them, and, I’m maybe more in favour of the one on one, what we can do when we [are] in the moments when we’re with a patient and the ability of the relationship to be therapeutic”

But there were also concerns voiced about the challenge taking the time to establish relationships, which can upset the efficiency of day-to-day operations.

“doctors or counselors, you know, we are kind of punished for taking the time to establish a relationship with somebody.”

just by treating them with decency and respect…
dignity and respect and that’s it.”
When considering the implications of relationships with health care providers, it was generally agreed that sensitivity and respect were essential for supporting ongoing communication.

“just by treating them with decency and respect ...dignity and respect and that’s it.”

“when they don’t feel listened to, they don’t want to go back”

“simply having people that can communicate in a way that makes people feel supported and feel better is huge. So our therapies in terms of medications and other approaches I think has a fairly marginal impact on the symptoms that we’re trying to manage. I think the therapeutic relationship can even have more impact on whether people feel better or cope better with their illness or their symptoms or whether they engage in healthy activities.”

Some participants voiced worries that clients experience fears about the care they receive.

“sometimes they are afraid that they are going to let their doctor down if they disclose something or they don’t really believe what their doctor said. I get a sense of that – people have a lot of loyalty to their doctors.”

“she said, “no what if...he might not treat me if somebody complained.” So there was a fear of even voicing concern.”

“I don’t really know what that’s about. I don’t know that a doctor would refuse treatment, maybe they would. But I guess I hear of doctors firing patients. You know I have heard that a few times and it seems like the more severe the problem therefore the more specialized the treatment, the greater the fear. I [the client] can’t lose a specialist right?”
The notion of “firing a patient” was considered further through text querying of the data, leading the researcher to conclude some frontline health care providers believe this practice may be occurring.

“I don’t ever fire anybody, they can fire me, but I don’t fire anybody and you know if they miss an appointment if I don’t see them for six months um they can call me up and I’ll get them in as soon as I can – I’m not going to stand on my head you know if it has to be in two weeks then fine, but I’m not going to make them feel bad.”

12.34 Regional Service Variation

Outside the realm of the health care provider relationship, another set of barriers related to geographical service variations across the SEL-HIN. Both urban and rural participants viewed service variation equally. Namely, specialists were cited as rarely traveling outside urban centres, which necessitating clients travel to them. Distance, whether comprised of large rural areas or beyond urban neighbourhood boundaries, is prohibitive for accessing primary health care services.

“the biggest barrier is the driving.”

“the main one for rural health care is the driving; the long drive for anywhere.”

“there is a barrier around transport [in urban centres] … that is out of their geographical neighbourhood.”

Interestingly, analysis revealed participants sense that rural communities have better community connectivity, both from the perspective of health providers being more aware of the availability of allied health services, as well as better communication between people in the community.
“in the small towns we do tend to hear about a lot of people that probably would be missed in a larger setting.”

“There’s a huge network and a very connected network …. Nothing to compare in the cities absolutely nothing.”

“[they] were very resourceful as community grass roots organizations often are in rural areas.”

One participant described how rural settings must be understood in a different context.

“I think rural life is hard. It’s beautiful but it has its own stresses that are different than city life and you have to [be] mindful of the differences.”

12.3.5 Individual Client Financial Challenges

Participants consistently raised the issue of client financial means as directly influencing the ability to access health services, particularly the ability to travel distances to services that are further away. After considering distance in a geographical sense, the related but more limiting barrier, whether due to rural isolation or anything outside a client’s neighbourhood, is lower incomes. Financial resources influence the ability of clients to be able to afford public transportation or gas money to get to health services.

“the cost of gas is much on everybody’s mind”

“people will book an appointment for someone out of town and may not end up showing up because they just can’t afford to get there.”
“they can’t afford a car, or the car isn’t in good repair, you know they are often always at risk of … accidents because the cars are in poor shape and they can’t afford to maintain them.”

“taxis [are] certainly an issue. So you know if I want to refer someone to somewhere they may not want to go because they don’t want to pay the taxi.”

“I think I just need transport money. Really it’s that simple, but it’s that expensive too.”

Lower incomes also affect clients’ utilization of resources to be able to live a healthy lifestyle (exercise, housing and food).

“The economy currently hit people so hard that those with the least disposable income available are the ones who struggle to really lead healthy lifestyles.”

“The vast majority of my patients are on ODSP [Ontario disability support program] and they have to think about whether they can afford their prescriptions versus whether they can eat.”

Another financial-related concern for participants is the compensation variability for different support program allowances.

“If you’re on ODSP of course they will pay for medical travel but then there are a lot of people that are perhaps the working poor or are on say Canada Disability Pension they don’t make those kind of allowances for medical travel.”

“ODSP will pay 18 cents a kilometer for medical travel; Canada pension disability doesn’t pay anything”

“we do a dental program here but it is not for the working poor… you know you give it to people on OW [Ontario Works] or ODSP”

“clients who don’t have access to I guess some private insurance like medical coverage for services like dental health, physiotherapy, occupational therapy, that certainly becomes a barrier”

Some participants noted that even with some financial support programs providing compensation for dental services, few dentists (and possibly none) will conduct dental services in advance of payment or pro bono.
12.4 Key Informant Recommendations for Focus Groups and Survey

The interview guide included key questions aimed to explore opinions and suggestions for facilitating subsequent phases of the research project. Frontline health service providers were asked to recommend facilitators of existing support groups who might be willing to donate some of their support group time to conduct focus group interviews. This was to ensure the researchers would access, through snowball sampling, a group of people with established relationships as well as a trusted facilitator. It enabled the researchers to choose groups that represented a cross section of ages as well as those in areas of deprivation. Please see the corresponding focus group methodology, analysis and results (Appendix I).

Participants were also asked about what methods would be helpful for conducting surveys of more deprived groups. Overwhelmingly, participants were in favour of in-person, one-on-one interview surveys. This method, they suggested, would bypass the low literacy challenges associated with these groups and enable a better response rate compared with mail out or paper and pencil surveys.

All participants showed strong opposition to telephone surveys, mostly due to the difficulties and inconsistencies associated with housing and changing phone numbers. Also, many clients use cell phones, as opposed to land-lines, with inconsistent plans and limited minutes. Similarly, computer access is variable across the region and, in particular in more rural areas, people do not have computer access at all. Although participants recognized in-person interviews to be resource intensive, with higher potential for introducing biased sampling, they steadfastly supported one-on-one interview methodology as the only way to be able to access people who are experiencing the most challenges getting the primary health care they need.

Some participants counseled against surveys, favouring focus group methodology as superior for examining the experiences, attitudes and needs of more vulnerable people to “get a true reflection of those patients who are really challenged to get primary health care.”

In terms of questionnaire design, participants advocated for low reading level scores for questions. Additionally, the questions, most said, should be designed to be meaningful to priority populations.

“If it’s relevant to their life, like if questions...resonate with the person then they will go, “hey, you know yeah, I have something to say about that.”

For more deprived populations, participants recommended an intermediary facilitate introduction of the researcher because there is a need to have a degree of trust. Many participants encouraged the use of an incentive or remuneration such as grocery store gift certificates or cinema tickets.

Finally, participants cautioned the researcher to be wary of weather and time of year, particularly in rural areas where driving in the winter is difficult. Following this, the researcher was advised to go to where the people are, not necessarily a primary health care setting, but grocery stores, pharmacies, or other community services, to be able to meet with more deprived people.

“to get a true reflection of those patients who are really challenged to get primary health care.”
12.5 Discussion

These front line health care provider interviews provide an initial understanding of the challenges and barriers people, particularly those with higher levels of deprivation, encounter trying to get the primary health care services they need. There was consensus among participants, consistent with the literature, that vulnerable people are more often people with co-morbidities, particularly those with mental health issues, less financial resources, and fewer self-advocacy skills.

It was widely recognized that the health care system is complex and that services could be better integrated. Also, navigating through the system is more difficult for people with higher deprivation and/or complex health needs; often they do not have the skills, knowledge, time (working poor) or resilience to be able to negotiate the complexity. Participants believed that primary health care providers should act as the link and advocate on the client’s behalf to be able to enhance access to primary health care services. Provider advocacy skills depend on knowledge regarding eligibility and availability of services in the community and the region, a complexity that can be equally difficult to negotiate at the provider level. Additionally, participants perceived provider sensitivity and attentiveness as an integral component for enhancing consistent utilization of primary health care services. Some participants discussed some of the fears that their clients have voiced about receiving worse care if they complain about how they are treated.

Though the SELHIN is comprised of a vast geography, client financial resources were cited as a greater determinant of access to health services compared with geographical distance. Health services located beyond neighborhood boundaries, regardless of whether the locations are in urban or rural areas, were seen to prohibit service access. Interestingly, some participants noted that for clients who are experiencing significant challenges with employment and income as well as the stresses of daily living, it is possible that accessing health services is not a priority, thereby limiting the potential for prevention and early screening interventions.

12.6 Study Limitations

A key limitation of this study is that the participants were all from south eastern Ontario, and this factor might limit the transferability of the findings to other regions. Though the sampling was targeted to particularly deprived regions, the scope of front line health service professions was restricted to mental health counselors, dieticians, social workers, nurse practitioners and physicians. There is no doubt that other professionals were overlooked in this selection process, particularly those who focus care with paediatric, First Nations, Metis or disability populations. The subsequent phases of study that roll forward from the key informant interviews follow this limitation. Future studies should aim to include these groups to best enhance any plan for integrating primary health care services in the region.

12.7 Conclusion

These findings set the stage for subsequent phases of the research, including focus groups and the fielding of a questionnaire, to better understand the challenges and barriers people experience trying to get the health care they need.
At the very heart of this project are the lived experiences of people who face multiple barriers to health. Often, the challenges encountered trying to get health care are a manifestation of the difficulties and stress people cope with in other facets of their daily lives. Focus groups were conducted to be able to understand the challenges and barriers people with higher deprivation experience with primary health care. Depth of emotion cannot be translated easily using written words; the research could not sufficiently incorporate intonation or gesticulation, those necessary tools of linguistic emphasis. However, it is our hope that the quotations in this section, offered freely by the participants, resonate to provide the voice and context to best understand their needs.

131 Participant Recruitment

Front line health service providers, who participated in the study as key informants, were asked to recommend community support group facilitators in their areas. Following that key informants were selected within regions of higher deprivation, community facilitators work in areas identified as having higher material and social deprivation.

This snowball sampling method enabled the research team to recruit focus group participants through a trusted intermediary (a support group facilitator) as well as conduct focus group sessions in pre-established group settings where, it was hoped, participants would feel comfortable, or at least used to, speaking in front of their support group peers. Through introductions from key informants, the researcher contacted five group facilitators to request cooperation and help recruiting clients to participate in focus group sessions. Support groups that were selected for recruitment were those that would provide both urban and rural representation, as well as a range of ages from youth through seniors. It should be noted that all support group facilitators were enthusiastic and eager to promote focus group sessions, greatly enhancing the recruitment process. Facilitators were emailed a copy of the project information letter and consent form, as well as a copy of the focus group interview guide to review. Facilitators were requested to ask their support group clients if they would be interested in participating in an hour long, audio taped, focus group session. In all cases, support groups agreed to be part of the focus group sessions. Sessions were planned for regularly scheduled support group times and locations. Group facilitators were asked to remain in the room during the focus group sessions. Five focus group sessions were conducted between August and October 2011 with a total of 42 participants (see Table 13-1).
13.2 Data Collection

Two researchers attended all focus group sessions. One researcher conducted the interview guide and moderated group discussion and a second researcher recorded hand written notes. At the beginning of each session, both researchers introduced themselves to the group and briefly reviewed the project. Information letters and consent forms were distributed to group participants. Researchers offered to read letters and consents for people as well. Signed consents were collected prior to initiating the focus group guide. The researchers provided coffee and tea and homemade cookies or muffins as part of each session. Participants were reminded that the session would be audio recorded before the recorder was turned on.

The semi-structured interview comprised introductory and closing remarks as well as open-ended key questions to understand participant experiences getting primary health care they need. The focus group guide, letter of information, consent form and a demographic questionnaire were written to be consistent with a grade six readability level as measured by the Flesch-Kincaid grade level readability test. The focus group questions were pre-tested with two students on summer placement with the KFL&A Health Unit prior to fielding. Demographic questions were designed to provide consistent information related to the census variables used for calculating the Deprivation Index. Focus group sessions ranged between 55 minutes and 1 hour and 17 minutes. Each session was audio-recorded.

A research assistant later transcribed the recordings, verbatim. Immediately following the focus group discussions, participants were asked to complete a brief, 9-item demographic questionnaire. Both researchers offered to record answers for participants who preferred the questionnaire be read to them.

Credibility and trustworthiness of the raw data were enhanced by the following means: interviews were transcribed verbatim, field notes were taken during the sessions to supplement the accuracy of data interpretation, and the research associate listened to each interview while reading corresponding transcripts prior to analysis. One research associate interpreted data for analysis.

Table 13-1: Focus Group Participant Demographic Summary

<table>
<thead>
<tr>
<th>Occupation</th>
<th>Count</th>
</tr>
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<tbody>
<tr>
<td>Divorced</td>
<td>2</td>
</tr>
<tr>
<td>Widowed</td>
<td>7</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
</tr>
<tr>
<td>Never been married</td>
<td>11</td>
</tr>
<tr>
<td>Member of unmarried couple</td>
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</table>

<table>
<thead>
<tr>
<th>Annual Income</th>
<th></th>
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</thead>
<tbody>
<tr>
<td>Above $28,000</td>
<td>2</td>
</tr>
<tr>
<td>Below $28,000</td>
<td>32</td>
</tr>
</tbody>
</table>

| Grade 9 to 11                     | 12    |
| Grade 12 (graduate)              | 8     |
| Some College                     | 6     |
| College Graduate                 | 5     |
| Some University                  | 3     |
| University Graduate              | 0     |
13.3 Data Analysis

Thematic analysis and coding using Nvivo 9 software was interpreted by the research associate through review and identification of the key concepts using inductive analysis and synthesis. Initial analysis involved immersion in the details and specifics of the interview transcripts to reveal coding categories. Beginning with broad coding categories, specific observations moved toward general patterns. Ongoing review and memo writing during analysis was employed to discover important patterns, themes and inter-relationships as the researcher came to understand the phenomenon of participant views regarding the difficulties they experience getting the health care they need. Cross transcript analysis of the emerging themes was done to synthesize and present the findings in this report.

With this iterative approach, the researcher believed saturation of themes was achieved after analyzing 4 interviews and was confident after the final interview revealed no new themes or disconfirming data.

A phenomenological approach was chosen to explore and understand the challenges more vulnerable people experience trying to get the primary health care they need. Four themes are discussed: health system issues, client-health care provider relationship, financial challenges and emotional perceptions. The themes provide insights into notions underlying the barriers accessing primary health care services in the SELHIN.

13.3.1 Health System Issues

Participants consistently raised concerns about the difficulties associated with having a regular family physician, particularly after moving to the region from a different community. Some participants spoke about the need to drive long distances to maintain their doctor because changing to a new one is difficult and requires relationship building.

“another thing with finding a doctor, if you don’t have a family doctor first, like they give you a number, a toll-free number you can call, and like when I call you get a machine. I find that really difficult to deal with.”

“we were driving to [place, 2 hour drive away] for a family doctor when we moved here for over three years. Because we couldn’t find one closer.”

“I know when we moved into [urban place] we were still going to [rural place] to our doctor out there and we put our name on a list here and it took us two years to get a nurse practitioner here. So in those two years, four times a year we had to drive out to [rural place] and back again.”

Several participants spoke about how hard it is to change physicians, illustrating confusion about the process and a belief that it relates more to who you know, rather than a systematic transition. One participant described physicians as “picky” about the patients they will accept. Also, the transition process is believed to be lengthy and complicated.
“they really discourage changing doctors. It’s always very difficult changing doctors.”

certain family doctors you can get your spouse or friend to see if you can get in with them or something, right.”

“you have to be a family member of some sort to get in with a doctor. It’s hard.”

“you know you have to have somebody and it’s such a hassle to try and change doctors even if there is somebody who has a practice that is available that you could sign up with.”

“if you don’t like your doctor, if you have a conflict you can’t just…. I’ve called [place] and they’ve said, ‘oh you have a doctor … we can’t take you as long as you have a family doctor that you are assigned to’ you cannot get another doctor to take you.”

“you can’t leave your own doctor and go to another doctor without going through all the process of withdrawing from his practice and getting a form. You have to wait six weeks before you can sign on with another doctor.”

Some female participants expressed strong concerns about the challenges associated with preferences for female doctors. The preference was discussed in a context of history with sexual abuse. Participants believed that past history was ignored.

“From my opinion I would go for a female than a male just because I’ve had too many issues with males in my life so that’s like an actual personal issue. That’s not me like, oh I don’t like you. I’ve got to go to a girl.”
"especially as women a lot of us have been in abusive situation. So if you have been beaten or whatever...it’s hard to go to a male doctor if that’s the only doctor you can get and especially if you don’t feel comfortable and say ‘but there’s a female in your office can you just transfer me to her?’… ‘nope you’ve got a doctor’"

Some participants mentioned service restrictions related to catchment areas and clinics that influence the ease with which care is sought.

“What I think the problem here is that we have to be the [specific neighbourhood region], am I right, to get a doctor’s appointment. Is that right? It used to be. I don’t know if they changed the rules.”

“The only thing I find about the doctors here is that they are only working certain days and you have to go almost a month before you get the next appointment made.”

“They want you to sign into their group and then they don’t want you to see anybody in a walk in clinic or an emergency room. Unless you absolutely have to because they are not in their, you know, little group of membership kind of thing.”

Participants would like more information about how to find a doctor.

“If there could be some sort of more information on that it would be really great because I have a hard time looking for a doctor, especially new ones. I’m trying to switch from my old doctor because of all the issues that I have had before and I can’t seem to find any.”

“My family doctor just retired from practice and I would like to see the doctor here but I don’t know how.”
Several participants discussed challenges with making appointments within clinics. These challenges caused considerable frustration that, in some cases, influenced whether participants seek the care they need.

“It takes me a long time to get in to her because she is so busy. Sometimes she is booked for 6 weeks.”

“I can only get in once a month to see her.”

“You can only do one problem at a time you know, ‘we don’t do more than one problem per visit. So I will deal with this issue today, make an appointment for next week for your second issue’.”

“the …system that we have right now at the doctor’s office is ridiculous also (it doesn’t work) it doesn’t. It works if you don’t have a problem that’s an ongoing thing but if you have like a real …. They’re saying now that it’s a walk in clinic type of thing. So that morning when the office opens you are to call the office and they will book you for the doctor to see you that day or within 24 hours whatever it is. But it doesn’t work all the time and it doesn’t work very well.”

“you call the doctor’s office and I need to see the doctor and she says well he is booked up you will have to call back tomorrow. …or you will have to wait three or whatever weeks…..so the choice is to either keep calling every day and getting really pissed off, because you do. Because you need to see a doctor or waiting the three weeks but in that three week’s time….especially in our case because we have chronic pain issues that’s not stuff that can really wait.”

“I had an appointment for 12:15, she saw me at ten minutes to three. Not one person came out and said, sorry we’re delayed, we are behind. You know it’s just your time is not valuable. Their time is valuable I understand they are overloaded…very overloaded but that shouldn’t be the case.”

“They won’t make the appointment when you are leaving the office, you will have to call the office. I’m right here, why do I have to call the office?...‘I’m not making appointments that way’”

“I thought that was the stupidest arrangement ever and all that it did was keep me away from my doctor.”

“now there are times when I just feel like I don’t need to go through all this crap to get to my doctor. Screw it I’m not going to bother with him.”

“we are almost self-treating at home because we can’t get access to the doctor.”

Extending from the lack of physician availability, accessing specialist services was a particular concern, especially psychiatric services outside of urban centres. Dental services, specifically for people who do not have dental insurance or coverage through financial support programs, were also difficult to access. Wait times in the emergency room were also cited as problematic for getting the care needed at the time it is needed. Some participants expressed strong concerns about the unfair nature of missed specialist appointments.
“if you don’t give your specialist enough notice to change your appointment it’s a 100 dollar fee. But I’ve got half way to [place] to my specialist who then phoned me and said ‘oh by the way I am not coming into the office today so we’ve rescheduled.’ And I have said, ‘I’m already an hour and a half into the three hour drive’ and I didn’t get paid 100 dollars because he didn’t show up for my appointment.”

“you know they are very cavalier about changing our appointment but we don’t get 100 dollars if they don’t give us 48 hours notice.”

Many participants were in agreement that the health system “is on overload” and “a salient point, one has to advocate all the way through the system.” The language used by some participants demonstrates the perceived need of having to leverage health services or fight to get necessary care.

“she doesn’t know what avenues to threaten them with. She doesn’t know who to go to or who to call you know.”

“the better you are, the nicer you are, the more they kick you in the head. They figure that they can push you around because we want to be nice. We don’t want to yell with anybody. We don’t want to push anybody we just want to be well, that’s all we ask is to be well.”
13.3.2 Client Health Care Provider Relationship

Relationships with health care providers were described both positively and negatively. Providers who take the time to establish a relationship, to focus and listen to the client and provide genuine care and concern, were preferred over providers who disregard clients, view themselves as superior, or do not attend to their clients. Most negative comments were in relation to physicians.

“well first of all I’m not going to my doctor because he doesn’t give a shit.”

“he was useless. He doesn’t listen to you. He doesn’t make eye contact with you.”

“I don’t like my doctor. My doctor is a jerk.”

One participant voiced an opposing opinion.

“the doctor there is not only friendly but he is also very serious and he always has really good advice as well. If there is something you need specifically he can refer you to other places.”

Comments about allied health professionals tended to be more favourable, specifically those related to nurse practitioners and social workers.

“I have a nurse practitioner now too and actually she is a lot kinder, more interested in my well-being than the doctor.”

“They tend to be much more personable and actually try and deal with what your issue is and work together to try and figure it out than just not look you in the eye and send you on your way.”

“the nurse practitioner sent me to [social worker] and she’s amazing she’s very thoughtful.”

“she um has great efficacy in her work and in her approach with clients is inordinately kind and compassionate”

“They’re all very supporting. They don’t judge you. They don’t look at you any different. You can be straight forward with them about your life and they don’t judge you in any way.”

One participant voiced reluctance to see a nurse practitioner, believing that, compared with a physician, the skill level and knowledge is not as good.

“I really think there is too much going on with nurse practitioners instead of doctors…. I knew it was a bad infection of some kind and she didn’t have a clue….like how much responsibility now nurse practitioners are given instead of doctors”

Health service provider demeanor was seen as important for enhancing the patient-provider relationship.

“How comfortable you feel with them, yeah. It all depends on the body language you get from the other person.”

“If one is accessing a care giver who is …who has empathy and compassion and is hearing what you are saying, even if it is at a subconscious level, one realizes that one knows. And if one is with a health care professional who is frankly doing the job almost rote or for the societal accolades or high salary or whatever and doesn’t really give a damn i.e. talking into a machine or looking at a computer screen
whilst prescribing (really impersonal) that is detrimental for the individual...(it’s cold) it’s very cold.”

“everything is very impersonal”

Overall, participants were discouraged by a health system that inhibits the time necessary to build and maintain relationships with health care providers. There was a degree of understanding evident amidst displeasures.

“I um personally believe that there are many very caring… individuals within the health care system they are not all there just to career build or what have you. There are many caring individuals but um they tend to be over worked um which is counter productive to giving good health care.”

“our medical people are not listening they are lacking the compassion because they seem to be so desensitized and that’s a real big issue.”

“if you have two thousand patients, how could you be warm to a person?”

“it is with the in and out diagnosis and the quick checks and the long waiting. It’s just like I feel we’re just numbers to them because with no follow-up and forgetting to put your referral in and everything, we’re just numbers.”

Many participants felt their own opinions were not valued among health care professionals.

“Gosh I think the most important thing is to bloody well listen to people (yeah have some compassion) like I think that has to be the number one thing is people know their own bodies better than you know.”

“I have heard people say that before, you don’t know what you’re talking about.”

“one of the things that in the system once one is ill one ceases to be a human being, one becomes a patient… and so you have the kind of, have the unequal professional health care giver - doctor, nurse, whatever – here, and you are here, and there is this disconnect and we need to be working on a level of human being to human being.

Finally, some participants voiced another difficulty related to seeing different health care providers each time they visit their clinic. Longer-term, positive relationships with one primary health care provider were preferred.

“they keep switching them all the time here so you don’t know who you are going to have.”
13.3 Final Challenges

For many participants, issues arising out of poverty influenced their ability to lead healthy lifestyles and to heal from illness. The concepts emerging out of the focus group discussions mirrored well-recognized determinants of health: employment, income, housing, nutrition, education and support networks. The most salient factor, however, influencing health seeking behaviors and lifestyle choices boiled down to financial resilience. One participant, suffering from long-term mental health issues, described the challenges associated with getting well when there is restricted eligibility for financial support programs.

“the whole point is that the health system should be there to assist healing. And with compassion and wisdom and no matter how compassionate the care giver may or may not be, if there isn’t that other support, you really are challenged not to go down.”

Other participants echoed the importance of tackling issues of poverty as integral to issues of health.

“I think there is something fundamentally wrong with this system that treats issues of poverty like that as simply acting on issues. These are health issues. These affect people’s lives, their ability to not just eat healthy but their ability to live in a healthy environment, in an apartment that is not full of mould or cockroaches or whatever and if affects people’s health in terms of stress levels.”

“The idea is to maintain health not to simply treat sickness and I think that the economic system that we have that treats issues of inequality and issues of poverty as if they are simply social problems or sometimes just people blame or scapegoats and not as actual health problem to solve ev-

ery bit as much as people solve smallpox and polio. We’re actually not going to get anywhere.”

“you know to be really healthy is unobtainable for people in our situation because it’s just too darn expensive”

Some participants spoke about difficulties getting employment with little educational experience. Many participants discussed the experience of living on restricted retirement incomes. Some highlighted the challenges living with chronic health issues that prevent steady employment. Often participants spoke about the stigma and judgments associated with applications for financial support programs such as Ontario Works and the Ontario Disability Support Program.

“Well very condescending…like total disregard…I have never met her before, she doesn’t know who I am, she doesn’t know what I have accomplished, she doesn’t know what I am about to accomplish. What I intend to do, it was just total disregard.”

“and this lady that I am facing right now, you can see it in my face I am quite upset with it…she talks down to me, she’s condescending”

“I was so ill at the time and the level of bullshit that they weigh you down with I couldn’t cope with it, I couldn’t fill out all those forms….weekly stuff comes in. I should be running an empire with the amount of bloody paper work I have sent to me for ten dollars and seventy cents a month. It’s an insult.”
Participants discussed how many costs needed to maintain health, such as prescriptions, dental care, healthy foods and fitness activities, are simply not feasible. Seniors also cited the prohibitive cost of hearing aids.

“I’m finding that some of them [prescriptions] are not covered that you really need. I had an infection and I had to pay $67.00 just for one little pill and a little thing of cream…not many people can just pull out $70…and it was hard that month when I had to do that.”

“I can’t afford my supplement for example; there is a list of supplements, vitamin D being one …I haven’t been able to purchase it for a month. Um, I simply can’t afford to. It is either pay my lease and so on and in terms of diet, my diet is not as healthy as I would like it to be because I simply can’t afford it. And I know there is a food bank but I have to leave myself with some pride, I refuse to use it. I was not always in these financial circumstances; quite the reverse for most of my life.”

“it all costs money. You know we can’t even do physiotherapy because it costs money and all of us should most likely being doing some sort of physiotherapy but we can’t afford it.”

“95% of us are on low income and we just can’t afford the dentist fees”

“When I went to the dentist it was a free visit, thank heaven, and he just checked it out and he said it’s going to cost you $3000.00 … I’m on a pension, where am I supposed to get $3000.00? And that was it.”

“sometimes parents can’t afford all that healthy food. Junk food seems actually a lot cheaper.”

“Oh, it’s hard. When you’re limited to money and half of it goes towards like your hydro and rent and all that, it sucks because then you’re down to like $150 towards groceries and then baby supplies and then winter stuff on top. It’s hard and a struggle”

“Electricity, heat and mortgage have to come first so if food gets sacrificed then food gets sacrificed.”

“being in healthy active programs like sports and stuff is really expensive … a lot of this stuff is just too expensive.”

“50 bucks that’s a lot of money for people that don’t have the money in the first place and a lot of people say ‘oh this activity it’s only 50 dollars’ but if you have two kids who want to participate and only 50 dollars – you know like it’s hard in a lot of ways”

Extending from the lack of money for maintaining health, the costs for transportation were a specific issue that participants described as particularly problematic. These issues held regardless of urban or rural regions because money for gas or public transportation is prohibitive.

“who can afford the gas?”

“so you know it was a major drive and a major expense you know just to see even a family physician.”

“it’s nearly $5.00 every time I got it [bus]. Like even that because I’m on just my senior citizen pension I find it difficult.”
Several participants spoke about challenges associated with the access bus service which they believed was never on time, restricted only for those who met eligibility criteria, difficult to book and often unreliable.

A further difficulty for people relying on financial support programs is the way travel money is compensated. Some support programs cover medically related travel expenses while others don’t. Compensation is only provided after travel, such that initial travel expenses are required up front, usually out of pocket. One participant noted that there is a significant delay between receipt submissions and money compensated.

“the money if you need for transport because some people won’t just drive for free no more. You’ve got to have the money up front to give to them to go and that’s always my problem not having the money to be able to give it to them to take me.”

“with social services you have to submit your receipts in after”

“then you fight with disability to pay the traveling”

Similarly, reduced incomes impact living situations and contribute to anxiety and stress for several participants. One participant described her living situation:

“My front door in my apartment, and my balcony door didn’t even lock at all. There was just a door and it had like a skeleton key hole and my water would like run all the time so I never had hot water and they never came to fix it and all the pot smoke would come in my apartment and all the trafficking and all that, and then I took my kids outside to play and I didn’t really know what was going on but we had the paramedics come up this way in front of the building and I guess the back of the building was just swarmed with cops and cars and stuff. I didn’t really see it. These guys were yelling at me to get your kids, get your kids. There was me and my girlfriend we have six kids altogether, and also this big bang went off and all the smoke came out of the side of the building. They were doing a raid right. So me and the kids can’t go in the building and we’re stuck on the front lawn under the balcony hiding. So we really didn’t know what was going on, all these cops swarming the building. It was crazy.”

Many participants talked about their struggle to make ends meet in an environment of crises and anxiety.

“[you] have so much shit on your mind with your daily stuff with living and then your finances and trying to survive”
Emotional Perceptions

Though aspects of emotional perceptions emerging from the analysis integrate well with the previous three themes already discussed, it is important to explore the negative feelings experienced by participants as a separate and distinct theme. Many of the emotional experiences of focus group participants provide an understanding of feelings of disempowerment, frustrations, helplessness, fears and anxiety that contribute either directly or indirectly to health and health seeking behaviors.

Participants were frustrated with the perceived difference in value placed on physician time over client time.

“I get upset when you get an appointment, get someone to drive you down and they cancel it. This has happened three times. We’ve got one for tomorrow let’s hope. It’s inconvenient for your son to take the day off to be at the clinic with me. Do they realize that if they expect to have someone with you, my son can’t take three days off work.”

Frustrations also arose out of experiences with disconnections between what participants are asked to do to be healthy and the realities of what is feasible, given restricted finances.

“I get to the doctors and she says... ‘what are you eating in 24 hours?’ A boiled egg and applesauce. ‘you can’t survive on it you need to eat more’ well where do I buy it from? What am I supposed to do, take leaves off the trees? Like you can’t eat what isn’t there!”

Several participants spoke openly about feeling judged by health care providers as well as by people in their community, which undermined their confidence and self-esteem.

“It’s hard to trust somebody. It’s hard to call on someone if you need something. It’s really hard when everybody is putting your self-esteem down. It’s hard to look at somebody and be like don’t say anything but I need your trust, you know what I mean”

“They [medical people] treat you like a two year old”

“I go for my medications and there is one individual in the pharmacy and I feel judgment on this individual’s face.”

“You have no credit they don’t want to rent to you, right and they’re just so judgmental and everything. I spent my whole summer trying to find a place and nobody would rent to me, just because you have no credit, or got three kids and you’re a single mother.”

“I have had someone like a psychiatrist kind of social worker who I didn’t know if she really took her job seriously but to me kind of seemed like she judged each person as they came in, like she was cold to talk to, she didn’t make you feel comfortable in the area, more like she was judging you for what had happened or what your problems were.”

In addition to feelings of frustration and judgment, there was an underlying fear relating to prescribing practices. Initially, the researcher believed the fear to be restricted to one focus group with younger participants, however, deeper analysis revealed the fear to be prevalent across all five focus groups. Several participants were concerned that they were “getting pills pushed on me” and “felt they were just throwing pills at you.” Many participants believed that people are regularly prescribed wrong medications and incorrect dosages.

“She took eight [medications], all of them at once, no weaning off of them, no nothing”
“they [medical people] didn’t know what the heck they were doing with her and now they conclude that she’s so weak and so worn because of all the drugs and all the antibiotics she was taking. And you have no idea what something like that does to a person in our situation with chronic pain. Because that just sends you into such a depression it sends you flying back so much further.”

“you would think they would have me talk to a doctor first before she [nurse practitioner] would give me anything off the shelf or whatever. They call them samples is what they call them. She had enough to do me two weeks, right. Well, then what?”

“a lot of them are after getting you on pills…they don’t address the root cause and of course pharmaceuticals are behind that.”

“if they [medical people] were like more educated about making prescriptions in terms of those sorts of drugs and if they knew more about it [mental health] then they would be able to make those types of calls. I know a number of people that have gotten the wrong dosage or whatever, they’ve gotten the wrong prescription.”

Some participants were mistrustful of their health care providers as a result of prescribing practices.
“she gave me these pills, they’re anti-depressants, right … and then told me that, I don’t know, if you are getting into taking them and stop you could have heart attacks or whatever so I never did take them. I never did go back to see her.”

One participant suspected kickbacks exist in the health system.

“the more pills they sell the more money they make. They get a percentage of those pills they make money on them”

Underlying fears and mistrust contribute to anxiety. Most participants believed stress and anxiety was detrimental to health and well-being. Many participants openly discussed their feelings of stress.

“you see his stress, her stress, our stress is caused by the situations we are facing right now and the situation, they [medical people] are actually making things worse and making everybody sicker. By stressing these people.”

“I possibly have a mental break down because of the anxiety is so high and the stress is so high and I can’t handle the noise and the traffic and the and and people you knowing living within touching distance of my side door.”

“it’s all interconnected it’s that ripple effect one little thing ripples down into everything else.”

“if we don’t address the underlying causal factors for disease in our society then disease is going to occur and increase. Stress reduces the efficacy of the immune system and the stressors in our society today are many.”
Focus Group Participant Suggestions for Improving Health Services

Overall, participants were appreciative of having been asked their thoughts and opinions about their experiences getting the health care they need. Participants in four of the five focus group sessions provided suggestions for improving health services. Interestingly, the remaining focus group was comprised predominantly of seniors who described themselves as “too independent I think to even ask for help.”

Some suggestions put forth by other participants were:

“they don’t have a psychiatrist on staff or anything like that. They should have more support for that. They should have more people working on a team versus like if you go there you don’t get necessarily the help that you need. There should be more access to psychiatrists.”

“they should have like a separate section [in emergency departments] for just those types of people that you know are just quick-ins but still so that the doctor can sit with them…a separate section where they have separate doctors to keep track of that and then for more serious patients they have other ones and so that way everyone would have a time with someone and so that there is no waiting for so long.”

“I don’t know whether there is or not but like maybe having something that is like one step between family doctor and the hospital.”

“you need a place … where you can just walk into a health centre and they can help you get a doctor and all that”

“there’s different types of patients and they should be categorized. So say that is his um what do you say diagnose illness he may need two hours … break it down … it isn’t balanced, there is no balance in your practice so that should be broken down [between healthy and unhealthy patients who need more time]”

“that video link for that five minute appointment [with a specialist] would be a huge, huge progress because then you are not spending five hours [driving] each way.”

“I think there definitely needs to be better focus on rural medicine because I find that health service in the cities is far, far better than the health service in the country.”

“I guess my biggest thought would be that people in power positions that deal with the public so much need to be screened to see if they have people skills. Because there is too much disregard going on.”

Other suggestions, related to health care provider demeanor and listening skills, have been discussed in previous sections.
Discussion

The focus group discussions provide ample evidence to better understand the challenges and barriers more deprived people experience getting the health care they need. Broad based systemic barriers influence the ease with which people are able to access health services. Problems with attachment to health care providers persist within the groups of people interviewed for this study. Prescribed service catchment areas, restrictive appointment processes and variable hours of operation were also factors that caused challenges and considerable frustration. Though several participants sympathized with a system they believe to be overloaded or broken, many perceived these barriers as unfair. Moreover, these issues highlight clinic operations that are not conducive to dealing with people who have multi-morbidities. There is a fair amount of confusion and lack of knowledge about maneuvering through barriers that are inconsistent across the region.

Specific service or health related needs mirrored those that are not covered through OHIP. For example, dental services, prescription and non-prescription medications and physiotherapy. A shortage of psychiatrists was noted as a particular specialist need in the region. Long wait times in clinics, followed by quick consultations, as well as having to pay for missed appointments, contributed to feelings of inequity between clients and their care providers and reinforced a perceived hierarchy in the relationship. It is clear that participants value health care providers who are compassionate, attentive, and who listen to their clients. Dismissive, curt and condescending provider behaviors inhibited, and even prevented, people from seeking the health care they needed. Implicit in provider sensitivity is a corresponding consultation time required to develop and maintain a positive relationship that enhances health-seeking behaviors.

A distinct vein of mistrust ran beneath the surface of discussions related to client-health care provider relationships and different theories emerged from the analysis that might explain its presence. At the highest level, the challenges associated with living in poverty, such as lack of affordable and safe housing, lack of affordable transportation and an inability to access or purchase healthy food, contribute to feelings of powerlessness in the face of demands from health care providers disconnected from the realities and struggles of daily living. Adhering to care plans and suggestions for leading healthier lifestyles are more complicated and often more difficult for more deprived people.

Health issues are very personal. Probing more deeply, discourse between clients and providers about private concerns, involves opening up and becoming vulnerable. This is especially true when discussing emotional and/or mental health issues with strong stigma associations. If that vulnerability is not matched with corresponding concern or empathy in the demeanor of a health care provider, it creates friction. The resulting tension and feelings of frustration contribute to a perception that providers have an inability to provide proper care. Knowing the time constraints and patient loads plaguing health care providers, it is difficult to know whether the expectations of clients are beyond what may reasonably be expected within consultation times. Regardless, this second disconnect, contributed to feelings of mistrust among focus group participants.

Thirdly, feelings of mistrust, rather than actual experiences, may be the reason for the fear of prescribing practices. This question warrants deeper investigation to better understand whether this influences adherence to care plans, but this is beyond the scope of the current study.

Mistrust, when considered in context with disempowering experiences trying to access other community and social supports, enhances our understanding of how provider sensitivity, and the ease with which clients can see their providers, influence health-seeking behaviors.

Stress associated with living in poverty has direct, often negative, consequences on health and well being. Anxieties arising out of just trying to make ends meet amidst the chaos of daily living prevented some participants from considering health care a priority - unless it related to an emergency or treating a more chronic condition that required prescriptions.
It is imperative that access to primary health care be considered within these contexts to devise strategies to empower and ultimately improve the health of more deprived people. Issues of poverty and health are inextricably linked.

13.6 Limitations

A key limitation of this study is that the participants were all from southeastern Ontario, and this factor might limit the transferability of the findings to other regions. Though focus groups were targeted to regions of deprivation as defined by the deprivation map, some participants did not “fit” the “most deprived” profile, though the majority of participants did. It is not expected that this would influence questions for a survey tool designed for a wider population.

With the exception of one group, focus groups were conducted within existing community support groups where participants were familiar with one another. This may have enhanced the degree to which participants were willing to share their experiences. However, the one group comprised of clients related to a single social worker, appeared comfortable and easy during discussions, despite being strangers to one another.

Two of the five focus groups were comprised of too many participants (over 14 people). Discussion within the larger groups was restricted to surface commentary. To ensure everyone had a chance to voice their opinions within the prescribed time, researchers were unable to probe responses for deeper meaning. It is quite possible more meaningful responses would have emerged had those groups been smaller (4-6 people, as the remaining three groups were).

One focus group session was conducted in a room where the heating system was not functioning properly. The room was unbearably hot making it difficult for people to sit for the length of time set aside for discussion.

The homogenous nature of support groups, though enhancing communication within each session, narrowed the scope of participants selected for inclusion in the study. Many people, outside these specific support groups, will have been neglected using this sampling process. Most notably people with disability and Aboriginal people, regrettably, are missed. Future studies should endeavor to include their voices.

13.7 Conclusion

Understanding the context within which more deprived people struggle to live is integral to enhancing access, in every shade of meaning, to primary health care services in the SELHIN. Respect, compassion and attentiveness are key aspects of health-provider-client relationships that sustain health-seeking behaviors and adherence to care plans. These findings set the foundation for developing a survey tool that resonates with people who experience multiple barriers getting the health care they need. Indeed, they provide the lived experience and the voice to best understand the story.
The final phase of the research project involved the creation of a regionally relevant survey tool that incorporated the information gathered from previous phases of the project: literature reviews; key informant interviews; and focus group interviews. The specific survey tool domains and questions were designed to encompass the challenges and barriers people spoke about, and to support utilizing a social determinants of health lens, to reveal inequalities. In this way, the results of the survey provide measures of the extent and scope of the primary health care needs of individuals in the SELHIN. Additionally, by investigating the response intersections of Deprivation Index quintiles, urban/rural, and age group differentials, the sub-analyses illuminate the distribution of challenges and barriers people experience with particular attention to those facing multiple barriers to health. More simply, this final phase of research sought to provide an estimate for how widespread challenges and barriers accessing primary healthcare in the region are, and whether or not those experiences are more often attributed to: more deprived groups of people; whether people live further away from centralized services in urban centres; whether age affects the degree to which people encounter access issues; and finally, whether responses are a composite of all three, or fewer, interactions.
14.1 Questionnaire Design

Survey content was developed to reflect 5 dimensions of challenges and barriers accessing primary health care services as identified by front line health care providers and participants with higher deprivation in the qualitative phases of instrument design. These were: health systems issues; navigating the health system; relationship with the health care provider; regional service variation; and individual financial challenges. Additional items were included in order to gather socio-demographic information congruent with census variables associated with calculating the deprivation index. Several validated surveys were used to select specific questions that were modified to correspond to particular aspects of each dimension. Established instruments included: Primary Care Access Survey, (Ontario) 2011 version; Canadian Community Health Survey, 2010 version; Canadian Survey of Experiences with Primary Health Care, 2008 version; Saskatchewan Patient First Review, 2009; and the Consumer Assessment of Healthcare Providers and Systems, United States Department of Health and Human Services 2008 version. Where conceptual themes were not covered by existing questions from established survey instruments, we designed questions by following the templates of existing surveys and adapting the wording and context to best fit the necessary concept. This draft was tested with two members of the KFL&A Health Unit to meet a timing target of 15 to 18 minutes and reduce individual question ambiguities.

Following this, the project advisory committee, consisting of several expert individuals involved with community and primary health care delivery and research, provided insight and refinement for survey questions. Based on input from the advisory group an initial survey instrument was developed. CCI Research Inc. (CCI), a telephone survey company based in Toronto, Ontario, was engaged to refine the draft survey, to develop a computer assisted telephone interview (CATI) program, and administer the survey. The 65 item, 15 page questionnaire asked respondents to provide information on the following: the overall quality of healthcare in the community, health system issues, relationship with the healthcare provider, dental health, navigating the health system, individual financial challenges and demographic questions. Lastly, for a sub-sample of respondents (n = 59), an additional open-ended question was administered at the end of the survey, specifically, “And finally, what would help you to get the healthcare or help you need?” A survey flow chart was created to map branching question responses (see Appendix III).

Sample and Sampling Procedures

In a small pilot study, the prototype questionnaire was given to 50 respondents. Modifications were made as deemed appropriate. The average time to complete the questionnaire was 15 minutes.

The survey population was defined by the geographical boundaries of the South East Local Health Integrated Network that comprises close to 500,000 people. Sub analyses of the data included levels of deprivation (as defined by the Deprivation Index quintiles (Q) used in earlier phases of this study); urban and rural differences; as well as three age cohorts (18-39, 40-59, and 60+). To ensure representative estimates within each strata, the sample size was calculated to account for the population size, expected percentages as well as a 90% degree of confidence for the estimates. The completed sample target was 1211.

The survey sampling frame was generated using the Postal Code Conversion File (PCCF), available from Statistics Canada, which provided a link between census geographic areas and the six-character postal code (version 2010). All postal codes corresponding to the six target geographies were used to purchase residential phone numbers in those geographies. The list of phone numbers did not include numbers registered with the national Do Not Disturb/Do Not Call list or business numbers. The postal code related phone lists were pooled together according to the quintile groups noted above. The survey sample consisted of a list of phone numbers randomly selected from within each of the six target geography groups. As the survey was executed, each of the six groups were further sub-divided into three age cohorts (18-39, 40-59, and 60+) to provide 18 sub-quotas for subsequent analysis.

Efforts to reduce coverage error included evening, day and weekend calling, as well as call backs to unanswered calls (up to a maximum of 10 times). Initial contact was made with prospective participants using a standard telephone script that described the study and screened participants for eligibility. In order to be eligible, participants had to: 1) a Canadian citizen, 2) be aged 18 years or older, 3) be English-speaking. All data were collected between December 2011 and February 2012. Interviewers entered telephone survey data directly into the CATI program.

As the list included telephone numbers for residents by postal code, it is possible that people who did not have a fixed permanent address were excluded from this group. To account for this potential bias, an additional recruitment of 60 more deprived participants was done using a two-step selection process: a targeted approach for specific site selection (6 sites; 3 urban and 3 rural), and a systematized approach for participant selection at each site. Site selection was chosen in collaboration with the Project Advisory Committee such that organizations selected were those that serve more vulnerable clients and were situated within deprived locations as defined by the Deprivation Index. Through established relationships with Project Advisory Committee members, organizations were contacted to request whether they would support face-to-face interviews with their clients to conduct surveys on location. Six site locations agreed to be part of the project. CCI conducted survey interviews at three urban sites, while members of the research team conducted survey interviews in three rural locations. At each site, organization coordinators were asked to divide the total number of clients (in all other age groups)
their client list) by ten and contact every nth person to request participation in a face-to-face interview (for example, if the client list totaled 30 people, 30/10 = 3, contacted every third person to an n = 10 per site). Surveys were administered, one on one, verbally, and in a private area. A letter of information and signed consent was obtained prior to administering the survey (see Appendix III). To ensure participants understand the project in the event of challenges with literacy, the interviewers asked each participant if they would prefer the letter of information and consent form be read out loud. Participants were able to view their answers. The open-ended question at the end of the survey was transcribed in situ. The interviewers read the responses back to participants to ensure the correct information was recorded. Following completion of the survey, these participants were provided with a $25.00 gift voucher for groceries (checked to be available in specific interview locations) as a thank you for participating in the survey process. The gift voucher was accompanied by a thank you letter (see Appendix IV).

Interviewers entered face to face interview survey data directly into the CATI program, with the exception of 29 interviews in rural regions of the SELHIN. For this sub-sample, data was recorded manually on paper surveys and later entered into an excel spreadsheet and appended to the original data file containing the majority of survey respondents.
14.3 Survey Representativeness of the SELHIN

The sampling design aimed for a pool of survey respondents drawn distributed along key characteristics approximately proportional to their size in the general population. The characteristics of interest were three-fold: age cohorts, level of deprivation, and geographic locale. Target sub-quotas and fill rates are given in Table 14-1 below.

We see that 50% or higher fill rates were achieved in a majority of the 54 sub-quotas. Coverage is particularly problematic in four (4) of the sub-quotas, shown in yellow in Table 14-1. Aggregating over each of the three key variables of interest (i.e., age, DI, and locale), we see that the survey response pool largely reflects distributions in the general population.

### Table 14-1: Sample Targets and Respondents

<table>
<thead>
<tr>
<th>Survey Sub-Quotas</th>
<th>Young Adults</th>
<th>Adults</th>
<th>Seniors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Q1/Q2</td>
<td>Q3</td>
<td>Q4/Q5</td>
</tr>
<tr>
<td>North - Central (A1)</td>
<td>10</td>
<td>15</td>
<td>25</td>
</tr>
<tr>
<td>North - Central (A2)</td>
<td>35</td>
<td>30</td>
<td>16</td>
</tr>
<tr>
<td>Perth - Smiths Falls (A3)</td>
<td>22</td>
<td>23</td>
<td>28</td>
</tr>
<tr>
<td>South - West (A4)</td>
<td>27</td>
<td>31</td>
<td>30</td>
</tr>
<tr>
<td>Kingston - Islands (A5)</td>
<td>27</td>
<td>25</td>
<td>25</td>
</tr>
<tr>
<td>South - Leeds Grenville (A6)</td>
<td>13</td>
<td>10</td>
<td>13</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Survey Respondents</th>
<th>Young Adults</th>
<th>Adults</th>
<th>Seniors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Q1/Q2</td>
<td>Q3</td>
<td>Q4/Q5</td>
</tr>
<tr>
<td>North - Central (A1)</td>
<td>0</td>
<td>10</td>
<td>12</td>
</tr>
<tr>
<td>North - Central (A2)</td>
<td>25</td>
<td>18</td>
<td>1</td>
</tr>
<tr>
<td>Perth - Smiths Falls (A3)</td>
<td>12</td>
<td>15</td>
<td>19</td>
</tr>
<tr>
<td>South - West (A4)</td>
<td>21</td>
<td>25</td>
<td>28</td>
</tr>
<tr>
<td>Kingston - Islands (A5)</td>
<td>28</td>
<td>16</td>
<td>26</td>
</tr>
<tr>
<td>South - Leeds Grenville (A6)</td>
<td>7</td>
<td>7</td>
<td>14</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Fill Rates</th>
<th>Young Adults</th>
<th>Adults</th>
<th>Seniors</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Q1/Q2</td>
<td>Q3</td>
<td>Q4/Q5</td>
</tr>
<tr>
<td>North - Central (A1)</td>
<td>0%</td>
<td>67%</td>
<td>52%</td>
</tr>
<tr>
<td>North - Central (A2)</td>
<td>71%</td>
<td>60%</td>
<td>6%</td>
</tr>
<tr>
<td>Perth - Smiths Falls (A3)</td>
<td>55%</td>
<td>65%</td>
<td>68%</td>
</tr>
<tr>
<td>South - West (A4)</td>
<td>78%</td>
<td>81%</td>
<td>93%</td>
</tr>
<tr>
<td>Kingston - Islands (A5)</td>
<td>104%</td>
<td>64%</td>
<td>104%</td>
</tr>
<tr>
<td>South - Leeds Grenville (A6)</td>
<td>54%</td>
<td>70%</td>
<td>108%</td>
</tr>
</tbody>
</table>
Figure 14-1 illustrates that, in aggregate, the age distribution of survey respondents reasonably reflects that of the general population. The proportion of adults is comparable and the overrepresentation of seniors amongst respondents (relative to the population) is approximately equal to the underrepresentation of youth amongst respondents (relative to the population).
Figure 14-2 likewise illustrates that, in the aggregate, the distribution of survey respondents by DI is well-balanced. Note that, for cost efficiency reasons, Q1 and Q2 were collapsed together as were Q4 and Q5. The aggregate quota for the middle quintile, Q3, had to remain as large it is for statistical analysis and hypothesis testing.

Figure 14-3 depicts the geographical distribution of survey respondents relative to the population distribution in the SELHIN. Note that while the relative distribution is stable, the absolute differences are attenuated. This is by design so that each locale would yield a sufficient number of respondents to enable the testing of various hypotheses. Mapping the sample size by respondents’ residential postal code (see Figure 14-4) likewise demonstrates good geographic representation.
Figure 14-4: Geographic Distribution of Survey Respondents
14.4 Findings

We present below a comprehensive analysis of the survey responses, both the structured questions and the single open-ended question that was asked of the face-to-face interviewees. In total, 1212 interviews were conducted (59 in-person and 1153 by telephone). Of the 1212, 43 people did not provide a valid postal code (15 from the in-person interviews and 28 from the telephone interviews). For the 15 in-person interviews for which the postal code was missing, these persons were assigned to the highest deprivation group (Q4/Q5). The remaining 28 were excluded from all analyses involving deprivation. In total 1184 participants were classified as belonging to a specific deprivation group.

14.4.1 Findings from the Questionnaire

14.4.1.1 Statistical Analysis

The analysis approach was consistent across all the outcomes that were studied. First, the percentage of respondents that had the outcome under investigation is reported across the 3 deprivation groups (Q1/Q2, Q3, Q4/Q5) for each of material, social and combined deprivation. Of primary focus was combined deprivation. In cases where the deprivation components were deemed to be potentially influential the social and/or material deprivation groups were then explored in a similar way to what had already been done with the combined deprivation groups. For each question, the primary unit of analysis was the proportion (or percentage) of individuals having the outcome of interest. This is reflected in the figure at the beginning of each section describing the percentage of persons with the outcome across the three broad groups of deprivation. Then, multivariate analyses were done using a log-binomial model (generalized linear model for the binomial distribution employing a log link function). The interested reader is referred to McCullagh and Nelder’s text on generalized linear models for a careful detailing of the generalized linear model framework.

A backwards elimination modeling strategy was adopted and each model began assessing whether the 54 age-geographical area-deprivation groups were different from one another with respect to the outcome under consideration. Where evidence of this was absent, the model was progressively simplified until the simplest model that still captured all of the important information was obtained.

The results presented below represent that simplified model and present only the most relevant information for that particular outcome. All analyses were done using Stata statistical software version 11.2.
The most fundamental concept in statistics is taking the results from a sample and inferring similar results in the larger population. In order for this to be reasonable, more than just a large sample is required. The way that participants are included in the study has implications for the analysis and results.

In this study, investigating the health equity in the SELHIN, individuals were selected for inclusion by stratifying the sample into 3 groups: 1) those in the most deprived quintiles (Q1/Q2); 2) those in the middle of the deprivation scale (Q3); and 3) those least deprived (Q4/Q5). To ensure that the sample included participants from each of these groups samples were drawn from within each strata. Consequently, the inclusion probabilities was not the same for all participants in the sampling frame. One possible way to account for this is to use sampling weights in the analysis. This method assigns the appropriate influence to each sample observation to account for the fact that some observations represent greater or fewer individuals in the population. The use of sample weights ensures that the results are representative of the entire population.

An alternative to using sampling weights in the analysis is to use a multivariate statistical model for the analysis and to include design variables in the model. As the intention of the study was always to examine differences across the deprivation groups, it was natural to simply account for the design characteristics in model rather than adding sampling weights and thus this was the method chosen for this investigation.

One might criticize the analysis for not employing sampling weights. However, the choice to not use sample weights was influenced by a number of factors. One of the most notable being the fact that our sample included in-person interviews as well as telephone interviews. With the telephone interviews the sampling weights would be calculated from the sampling frame (the list of all phone numbers). For the in-person interviews no such list exists. Without reasonable sampling weights these persons would be excluded from the analysis. Conversely, the model based approach could make use of this data as well as examine whether there is evidence to suggest that in-person responses were systematically different from telephone responses.

Another advantage of the model based approach rather than the weight based approach is that by design the sampling frame is likely to have a different coverage rate across the strata. Ideally, any sampling frame would be a comprehensive list of all potential participants for the population. In this study, we used a telephone directory. Practically speaking, this is highly unlikely to be comprehensive. However, if the coverage rate (the proportion of coverage by this sampling frame) is similar across the strata then it is less concerning. However, this is quite unlikely. Potential participants from the most deprived quintiles are going to be less likely to have a phone than those that are least deprived. Further, those that are least deprived are more likely to have multiple phone lines further invalidating the sampling weights drawn from this sampling frame.
14.4.1.2 Section 1: Overall Quality of Healthcare in the Community

How would you describe the overall quality of health care available in your community within the last 12 months? Is it excellent / good OR poor / very poor?

Relative to those in the least deprived quintiles, those in the most deprived quintiles were 1.4 times as likely to indicate that they felt the overall quality of health in their community in the last 12 months was poor to very poor (RR=1.39; 95% CI: 0.97 to 2.00; p=0.071). Also, older adults were 0.6 times as likely as other adults to indicate that health care in their community was poor (R=0.56; 95% CI: 0.40 to 0.78; p=0.001). Further, patients in geographical area number 5 were much less likely to indicate that the overall health care in their community was poor or very poor (RR=0.41; 95% CI: 0.24 to 0.69; p=0.001).

14.4.1.3 Section 2: Health Systems Issues

Can you please tell me where you PRIMARILY go for your day-to-day health care needs? Specifically, if you needed to see a health care provider to get a regular check up, a medical exam, or because you were not feeling well, where would you go for help?

Obviously, the majority of patients receive their care at their doctor’s office (64%). However, for completeness the proportion of patients indicating that their primary source of care was a family medicine centre such as a family health team (17%), a community health centre (5%), a walk-in clinic (5%), or the emergency department (4%) was explored in relationship to geographical area, patient age group and their deprivation group (combined, social, and material).
There is no evidence to suggest that there is an association between deprivation (combined, social, or material) or age group and indicating that you primarily go to a family medicine centre for care. However, there is geographical effect. Those in geographical areas 3, 4 and 5 are the least likely to report primarily going to a family medicine centre (13%). Those in areas 2 and 6 are 1.6 times as likely, as those in areas 3, 4, and 5, to report primarily going to a family medicine centre (RR=1.62; 95% CI: 1.21 to 2.17; p=0.001). Those in geographical area 1 were the most likely to report using a family medicine centre as their primary source of primary care (36%). They were 2.8 times as likely to report this as those in areas 3, 4 and 5 (RR=2.82; 95% CI: 2.10 to 3.79; p<0.001).

Those in geographical area 3 were 3 times as likely to report using a CHC relative to other respondents (RR=2.99; 95% CI: 1.82 to 4.90; p<0.001). There is no evidence to suggest that there is an association with deprivation (combined, social, or material) or age group.

Those in geographical area 5 were more likely to indicate that they primarily go to a walk-in or after hours clinic relative to all other respondents (RR=2.34; 95% CI: 1.40 to 3.92; p=0.001). Additionally, those with the highest combined deprivation (Q4/Q5) were twice as likely to report primarily going to a walk-in or after hours clinic (RR=2.14; 95% CI: 1.30 to 3.53; p=0.003).

There is certainly a trend that suggests that those in higher deprivation groups are more likely to give the emergency department as their primary source of primary care. However, it was not significant. Also, there is no evidence to suggest an association between age group and primarily using the emergency room for care. There is, however, evidence to support the fact that those in geographical area 3 are 3.5 times more likely to use the emergency department as their primary source of care than those form the rest of the LHIN (RR=3.55; 95% CI: 1.98 to 6.39; p<0.001).
Do you have a primary health care provider such as a family doctor, general practitioner, or nurse practitioner? The analysis below describes the proportion of respondents who indicated that they do not have a primary care provider.

Nearly all of the respondents (96%) indicated that they have a primary care provider. However, in this section the investigation centers around the respondents that indicated that they do not have a primary care provider.

There does not seem to be statistical relationship between combined deprivation group and indicating that you do not have a primary care provider. Not surprisingly, older adults were much less likely to report that they do not have a primary care provider than other adults (RR=0.31; 95% CI: 0.14 to 0.69; p=0.004). Also, those in geographical area 3 (Perth - Smiths Falls) were twice as likely as those in the other geographical regions to indicate that they did not have a primary care provider (RR=2.05; 95% CI: 1.12 to 3.74; p=0.019).

From the above figure, it appears that there is a relationship with social deprivation and not having a regular primary care provider. If the analysis is repeated using the social deprivation groups, the message changes. The geographical area affect shown above is attenuated and replaced by a strong association with being in the most deprived social group (Q4/Q5 social deprivation). The age effect is almost identical after removing the geographical area component. Ultimately, it seems that those that are in the highest social deprivation quintiles are 2.8 times as likely to indicate that they do not have a primary care provider as all other respondents.

Clearly there is an interdependence of geographical area 3 and social deprivation. As it turns out, 58% of the respondents from geographical area 3 are among the most deprived socially (Q4/Q5) - the highest proportionally of any of the geographic areas. Yet, with respect to material deprivation they have the second lowest proportion of Q4/Q5 respondents at only 25%.
Of the 47 people that indicated that they do not have a regular primary care provider 45 (96%) indicated that they had had a provider previously but they no longer had a provider for various reasons. There most two commonly given reasons for no longer having a primary care provider. The most common reason was that the patient had moved and had not yet found a new doctor (14 respondents). These respondents came predominantly from areas 3 and 5. Twenty nine percent of those from area 3 and 40% of those from area 5 gave this as a reason for no longer having a primary care provider. The second most common reason given for no longer having a primary care provider was that the provider stopped practicing for some reason (e.g. retired, deceased, changed practice type, sick, pregnant, etc.) (12 respondents). Again, 29% of those from area 3 and 45% of those from area 4 gave this as their reason for no longer having a primary care provider.

Most of those that indicated that they do not have a primary care provider indicated that they have not had one for years (87%). The average time amount of time that these people have been without a primary care provider is 6.76 years with the range being from 1 month to 35 years.

Thirty nine of the 47 respondents (83%) that do not have a primary care provider (45 that used to and 2 that never have) indicated that they would like to have a primary care provider. Of those thirty nine, 25 (64%) reported that they have tried to find a primary care provider. Eight respondents (32%) indicated that they had contacted doctor’s offices to see if they were taking new patients, 6 (24%) contacted a hospital, CCAC, or public health program to see who was accepting new patients and 4 (16%) indicated that they registered with health care connect.
What type of health care provider is this - a family doctor, general practitioner, or nurse practitioner?

Ninety four percent of respondents indicated that their primary care provider was a family physician. Five of the remaining six percent identified a nurse practitioner as their primary care provider and consequently, this section will focus on those that indicated that their primary care provider was a nurse practitioner. There was no association with combined deprivation index; however, there was a very strong association between geographical area and identifying a nurse practitioner as your primary care provider. Those in geographical area 2 (RR=0.37; 95% CI: 0.16 to 0.87; p=0.022), area 4 (RR=0.42; 95% CI: 0.22 to 0.81; p=0.010) and area 5 (RR=0.22; 95% CI: 0.08 to 0.60; p=0.003) were much less likely than the rest of the LHIN to list a nurse practitioner as their provider.

Also, those in the highest level of social deprivation deprivation were much less likely to report having a nurse practitioner as their provider compared to those in the less deprived groups (RR=0.55; 95% CI: 0.31 to 1.00; p=0.049).

Five percent of respondents had had their primary care provider for less than 1 year. Yet, one respondent had had the same primary care provider for 47 years. The average (mean) time being 12.9 years.

Could you please tell me approximately when you had your last appointment with your [“Doctor” OR “”][“General Practitioner” OR “”][“Nurse Practitioner” OR “”]?

Most patients have seen their primary care provider within the last year (87% overall). Interestingly, this seems to be less likely as social deprivation increases and more likely as material deprivation increases. However, none of these minor variations were found to be statistically significant.

In all, none of the 3 deprivation measures manifest a group effect. However, both age and geographical area were important contributors to whether a respondent indicated that they had seen their health care provider in the last year. In fact, there is evidence to suggest that there is a potentially differential effect between the areas with respect to whether or not respondent over 60 had seen their provider in the last year. When looking at persons over 60, it seems that there are 3 geographical areas where respondents are not visiting their provider yearly: area 1 (90%), area 3 (90%) and area 6 (84%). The average yearly attendance rate was 96% for those over 60 in the other areas of the LHIN. That is geographical area modifies the influence of being over 60 on whether you had seen your provider in the last year. For those that are in areas 1, 3, or 6, older adults are not more likely to have visited their primary care provider (RR=1.04; 95% CI: 0.97 to 1.11; p=0.281). However, for those in geographical areas 2, 4, or 5 being over 60 is associated with an increased likelihood of having visited your doctor in the last year (RR=1.16; 95% CI: 1.11 to 1.22; p<0.001). This result could be phrased another way. Suppose that we expressed the relationship in terms of the probability of having seen your doctor in the last year with respect to geographical region. This result suggests that the relationship between geographical region and the likelihood of having seen your doctor in the last year is different for those that are over 60 than those that are under 60. In an truly equitable system we would not expect to see older persons having a different relative yearly attendance rate in different geographical regions.

There were a number of reasons given for challenges encountered by the respondent in making the appointments. However, in the interest of time, and for brevity, these are given in the report from CCI and the reader is referred there. If that is of interest it can be added later.
Were you ever asked to pay a fee by your ["Doctor" OR ""] ["General Practitioner" OR ""] ["Nurse Practitioner" OR ""]'s office?

Twenty percent (n=229) of respondents indicated that at some time they had been asked to pay a fee by their primary care provider’s office. The most commonly given reason (50%) for this fee was obtaining a note or something similar. Investigation of the combined deprivation groups rendered nothing noteworthy. However, inspecting the figure below it seems that there may be an association between social deprivation and the likelihood of having to pay a fee, with decreasing probability of paying fees with increasing social deprivation.

This was further evidenced by the subsequent log-binomial model. This model suggests that the most important factors are social deprivation (specifically those that are most socially deprived) and being a middle aged adult. Interestingly, being a middle aged adult status modifies the relationship between being in the highest social deprivation group and expressing that you have had to pay fees at your doctor’s office. Among those that are not middle aged adults (meaning the young adults and the older adults) being in the highest social deprivation group (Q4/Q5) was associated with half the likelihood of fee paying (RR=0.50; 95% CI: 0.32 to 0.76; p=0.002). However, among the middle aged adults being socially deprived was not associated with a difference in the likelihood of reporting fee paying (RR=1.13; 95% CI: 0.82 to 1.57; p=0.448).
Did you have difficulty paying this fee?

Twenty five (11%) of those that indicated that they had paid fees in the past at primary care offices. An initial look at the proportions that indicated that paying the fee was difficult, as presented in the figure below, seems to suggest that there might be an association with social deprivation but on analysis none of the variables under investigation seemed to be statistically associated with having difficulty paying the fee.

Does your [“Doctor” OR “”][“General Practitioner” OR “”][“Nurse Practitioner” OR “”] limit the number of health problems you can discuss during an appointment?

Two hundred and twenty five (20%) of respondents indicated that their provider limits the number of problems they can discuss during an appointment. Those with the highest combined deprivation (Q4/Q5) were less likely to report that their provider limited the number of problems they could discuss per visit (RR=0.71; 95% CI: 0.54 to 0.92; p=0.011).

Also, those in geographical area 5 were more likely to indicate that their provider limits the number of problems they can discuss than those in the other areas (RR=1.33; 95% CI: 1.02 to 1.73; p=0.036) while those in geographical area 6 were less likely than those in other geographical areas to indicate a problem limit (RR=0.54; 95% CI: 0.31 to 0.91; p=0.020).
Is your [“Doctor” OR “”][“General Practitioner” OR “”] [“Nurse Practitioner” OR “”] part of a larger health care team that includes access to other health care professionals at no charge?

Seven hundred and eighty respondents (77%) identified as belonging to a practice that includes access to other health care professionals at no charge. Each of geographical area, age category and combined deprivation groups were associated with whether your provider was part of a team. Relative to those with lower combined deprivation, those in the highest deprivation quintiles were less likely to have a provider who was part of a team (RR=0.92; 95% CI: 0.85 to 0.98; p=0.018). Also, younger adults were much more likely to have a provider that was part of a team than those that were over 40 (RR=1.09; 95% CI: 1.01 to 1.16; p=0.019). Also, those in geographical areas 2, 3 and 4 were less likely to report that their provider was part of a team than those in the other geographical areas (RR=0.89; 95% CI: 0.84 to 0.95; p=0.001).

What type of other health care professionals are part of this team: Other Doctors or Physicians?

There was no evidence of an association between any of the factors of interest and the likelihood of reporting that the other team members included other doctors.
### What type of other health care professionals are part of this team: Nurse Practitioner?

Indicating that your primary care provider team includes a nurse practitioner is associated with being in the highest combined deprivation group and being from geographical area 6. As has been seen in other analyses, the geographical area modifies the relationship between combined deprivation group and the outcome. In this case, for those not in geographical area 6 there is not an association between membership in the highest combined deprivation group and reporting that the team included a nurse practitioner. (RR=0.98; 95% CI: 0.88 to 1.09; p=0.718). However, for those in geographical area 6, being in the highest combined deprivation group is associated with a much higher probability of indicating that your primary care team includes a nurse practitioner (RR=1.28; 95% CI: 1.13 to 1.46; p<0.001).

### What type of other health care professionals are part of this team: Nurse?

There is no evidence of an association between combined deprivation group and indicating that there was a nurse as part of the primary care team. However, there is evidence to suggest that respondents in area 4 were much less likely to indicate that there was a nurse in their primary care office than other respondents (RR=0.83; 95% CI: 0.75 to 0.92; p=0.001).
What type of other health care professionals are part of this team: Nutritionist?

There is no evidence that deprivation group is associated with indicating that there is a nutritionist as part of the primary care team where you attend. However, it was clear that those in geographical area 4 were much less likely to respond that a nutritionist was part of the team (RR=0.74; 95% CI: 0.60 to 0.92; p=0.006).

What type of other health care professionals are part of this team: Dietician?

There is modest (but not significant) evidence to suggest that being in the highest material deprivation group is associated with more frequently reporting that a dietician is included in their primary care team (RR=1.19; 95% CI: 1.00 to 1.41; p=0.051). In addition there is strong evidence that those in geographical area 4 are less likely, than the rest of the LHIN, to report that a dietician is available to them as part of the primary care team at their primary care providers office (RR=0.75; 95% CI: 0.63 to 0.89; p=0.001).
What type of other health care professionals are part of this team: Social Worker?

There is no evidence of an association between deprivation and a social worker being identified as a team member. However, those in geographical areas 1 and 3 were 1.75 times as likely to report that a social worker was part of the primary care team at their providers office (RR=1.75; 95% CI: 1.40 to 2.18; p<0.001).

What type of other health care professionals are part of this team: Psychiatrist?

There is no evidence of any statistical association between indicating that there is a psychiatrist as part of the primary care team where your provider is and any of the factors of interest.
What type of other health care professionals are part of this team: Counselor?

There is no association between combined deprivation group and indicating that there is a counselor as part of the primary care team where your provider is. However, this is evidence that those who are the least materially deprived were less likely to indicate that a counselor was included in their primary care providers team (RR=0.70; 95% CI: 0.53 to 0.94; p=0.016). and those that were in the youngest age category were more likely to indicate the same (RR=1.30; 95% CI: 1.00 to 1.68; p=0.048). Respondents in geographical areas 2, 4 and 6 were less likely than respondents from the other areas to report a counselor as being part of the team as well (RR=0.70; 95% CI: 0.54 to 0.89; p=0.004).

What type of other health care professionals are part of this team: Occupational Therapist?

There is no association between with age category or geographical area. Those that are in the least deprived group with respect to material deprivation are less likely than others to report that an occupational therapist was a member of the team at their provider’s office (RR=0.69; 95% CI: 0.48 to 0.99; p=0.045).
What type of other health care professionals are part of this team: Medical Residents?

Those that in the group with the highest combined deprivation were more likely to attend a clinic where they identified medical residents as being part of the team (RR=1.24; 95% CI: 1.03 to 1.49; p=0.021). Middle aged adults were less likely to identify as having medical residents as part of the team (RR=0.80; 95% CI: 0.66 to 0.98; p=0.029). Also, those in geographical area 5 were more likely than every other part of the LHIN to indicate that there were medical residents as part of the health care team at their provider’s office (RR=1.38; 95% CI: 1.14 to 1.67; p=0.001). All of these observations are multiplicative, that is a person from the most deprived group and area 5 would be approximately 1.71 times (1.24 x 1.38 = 1.71) as likely to have residents in their practice.

What type of other health care professionals are part of this team: Physiotherapist?

There is no evidence of an association between deprivation or age category with having a physiotherapist in the clinic. However, those in geographical areas 3, 4, and 5 were much more likely to report that a physiotherapist was a member of the primary care team that included their provider (RR=1.44; 95% CI: 1.08 to 1.92; p=0.014).
What type of other health care professionals are part of this team: Pharmacist?

There are two factors that are associated with the having a pharmacist as part of the team. Those that are the least deprived, with respect to the combined deprivation index, are much less likely to have a pharmacist included in their provider’s team (RR=0.76; 95% CI: 0.58 to 0.99; p=0.045). Also, those that are in geographical area 1 are much more likely to have a pharmacist included in the team (RR=1.88; 95% CI: 1.49 to 2.38; p<0.001).

What type of other health care professionals are part of this team: Chiropodist?

Not surprisingly, those that are over 60 were much more likely to indicate that their provider’s team included a chiropodist (RR=1.55; 95% CI: 1.15 to 2.10; p=0.004). Also, those that are from geographical areas 1 and 3 were more likely to indicate that there was a chiropodist in their provider’s team (RR=1.56; 95% CI: 1.15 to 2.12; p=0.004).
Would you strongly agree, agree, disagree, or strongly disagree that your [“Doctor” OR “”][“General Practitioner” OR “”][“Nurse Practitioner” OR “”] delivers a range of services or referrals that meet your health needs?

The analysis below describes the proportion of respondents who indicated that they disagreed or strongly disagreed.

Those most likely to disagree or strongly disagree that their provider delivers a range of services that meet their health needs are the middle aged adults. They were more than twice as likely as others to disagree or strongly disagree (RR=2.05; 95% CI: 1.16 to 3.62; p=0.014). No other statistical associations were observed. However, in geographical areas 1 and 2 the disagreement rate was observed to be lower than elsewhere in the LHIN but not that could sufficiently to rule out random variation (RR=0.54; 95% CI: 0.25 to 1.14; p=0.107).
Thinking back to your last appointment with your ["Doctor" OR ""] ["General Practitioner" OR ""] ["Nurse Practitioner" OR ""], please answer yes or no if you have encountered any of the following issues.

**Long Distances**

There is no evidence of a deprivation index effect for either the combined or social deprivation groups. However, there is modest evidence that those that are least deprived materially were less likely than all others to indicate that traveling long distances was an issue they encountered (RR=0.72; 95% CI: 0.51 to 1.02; p=0.067). Independently of this result, it appears that relative to those in other geographical areas, respondents in area 3 were 1.5 times as likely to indicate that they had encountered this issue (RR=1.54; 95% CI: 1.07 to 2.20; p=0.019) and those in area 1 were 2.4 times as likely as respondents from elsewhere to report this issue (RR=2.41; 95% CI: 1.73 to 3.36; p<0.001).

**Transportation Problems**

Neither social or material deprivation scores alone show an association with reporting transportation problems. Those that are least deprived according to the combined deprivation index however, were half as likely as others to indicate that transportation problems were an issue in their last physician visit (RR=0.54; 95% CI: 0.35 to 0.83; p=0.005). Independently of this, those in the youngest age category were 1.6 times as likely as those in older age categories to express transportation problems (RR=1.60; 95% CI: 1.14 to 2.25; p=0.007). Also, those in geographical area 1 were 1.7 times more likely than all others to indicate transportation problems (RR=1.69; 95% CI: 1.13 to 2.54; p=0.011).
Section 3: Relationship with Healthcare Provider

Overall, how often does your [“Doctor” OR “”][“General Practitioner” OR “”] [“Nurse Practitioner” OR “”] allow you enough time to discuss your feelings, fears or concerns about your health? Would you say always, usually, rarely, or never?

Most respondents indicated that their provider usually or always allows enough time to discuss feelings and fears about the patient’s health (93%). This analysis examines the proportion of persons who indicated that their provider rarely or never allows enough time for discussion. There is no evidence to suggest that responding in this way is associated with any of the deprivation measures or the geographical area that the respondent resides in. The strongest association is with the respondents age. Respondents that are young adults (under 40) were 1.7 times as likely to indicate that their provider does not allow enough time for discussion (RR=1.71; 95% CI: 1.09 to 2.69; p=0.019).

How often does your [“Doctor” OR “”][“General Practitioner” OR “”] [“Nurse Practitioner” OR “”] show respect for what you have to say? Would you say always, usually, rarely, or never?

Most respondents felt that their provider shows respect for what they have to say (96%). There was modest evidence to suggest that older adults were less likely to indicate that their provider rarely or never shows respect for what they have to say (RR=0.49; 95% CI: 0.24 to 1.03; p=0.059).
How often does your [“Doctor” OR “”][“General Practitioner” OR “”] [“Nurse Practitioner” OR “”] explain things in a way that is easy to understand? Would you say always, usually, rarely, or never?

Most respondents felt that their provider explains things is a way that is easy to understand (96%). As can been seen from the above figure, those that are in the middle combined DI group appear less likely to feel that their provider explains things in a way that is rarely or never easy to understand. This was observed to be only modestly significant (RR=46; 95% CI: 0.20 to 1.03; p=0.058). No other factors were associated with the outcome.

I have experienced unacceptable conduct from health care workers such as rude or dismissive behaviour.

Overall 22% of respondents agreed or strongly agreed that they had experienced unacceptable conduct from a health care worker. As can been seen from the above figure, those that are in the middle combined DI group appear less likely to feel that their provider explains things in a way that is rarely or never easy to understand. This was observed to be only modestly significant (RR=46; 95% CI: 0.20 to 1.03; p=0.058). No other factors were associated with the outcome.
I worry that my care would not be as good if I complained about how I am treated.

Overall 21% of respondents agreed or strongly agreed that they worry that their care would be worse if they complained about the way they are treated. This is not associated with deprivation but is associated with age and geographical location. Older adults were much less likely to strongly agree or agree that they were worried that their care would be worse if they complained about the way they are treated (RR=0.52; 95% CI: 0.39 to 0.69; p<0.001). Also, those in geographical area 2 were more likely than people from geographical regions 1, 3, 4, and 5 to indicate that they were worried about how complaining would negatively affect their care (R=1.42; 95% CI: 1.09 to 1.85; p=0.010) while those in geographical area 6 were less likely to agree with that statement relative to the other areas (1, 3, 4, and 5) (RR=0.60; 95% CI: 0.36 to 0.98; p=0.041).

I like to do my own research before I take my [“Doctor” OR “”] [“General Practitioner” OR “”] [“Nurse Practitioner” OR “”]’s advice.

Nearly half of all participants agreed or strongly agreed that they like to do their own research before taking their providers advice (47%). Those that were most likely to do express this were young adults in the least deprivation group (Q1/Q2) from geographical area 6. Each of these factors was independently associated with an agreement to this statement. Those in the least combined deprivation group (Q1/Q2) were 1.1 times as likely as those in the higher deprivation groups to agree that they do their own research (RR=1.14; 95% CI: 1.00 to 1.29; p=0.046). Young adults were 1.2 times as likely as other adults to do their own research (RR=1.22; 95% CI: 1.07 to 1.39; p=0.004) and those on geographical area 6 1.3 times as likely to do their own research compared to those in other areas (RR=1.28; 95% CI: 1.08 to 1.50; p=0.003).
Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied with your [“Doctor” OR “”] [“General Practitioner” OR “”] [“Nurse Practitioner” OR “”]? Most of the respondents were either somewhat satisfied or very satisfied with their provider (94%). Those that were over 60 were much less likely than those under 40 to indicate that they were somewhat / very dissatisfied with their provider (RR=0.48; 95% CI: 0.25 to 0.92; p=0.026).
Section 4: Dental Health

Do you have insurance that covers all or part of your dental expenses?

The majority of respondents had dental insurance of some nature (61%). However, there are many strong messages coming through in this section. First, there is a strong age effect. Compared to young adults, middle aged adults were 1.5 times as likely to not have dental insurance (RR=1.45; 95% CI: 1.14 to 1.86; p=0.002) and older adults are more than twice as likely to not have dental insurance as younger adults (RR=2.36; 95% CI: 1.88 to 2.96; p<0.001). Also, those in geographical area 1 were much more likely to not have dental insurance than respondents from elsewhere in the LHIN (RR=1.29; 95% CI: 1.10 to 1.52; p=0.002). Note that these effects are independent, that is they are multiplicative.

Have you been to a dentist in the past 3 years?

There is a marked discrepancy across the deprivation groups with respect to the percentage who have visited the dentist in the last 3 years. Not surprisingly, those that are most deprived, as measured by either material or combined deprivation, are much more likely to not have visited the dentist in the last 3 years.

When exploring this from a modeling perspective the message gets even more complicated. There is a very strong interaction between geographical area 1 and combined deprivation group with respect to indicating that you have not visited the dentist in the last 3 years. However, in addition to that, age is playing an independent role. Ultimately, the relative probability of attending the dentist in the last 3 years comparing those that have the least combined deprivation (Q1/Q2) relative to those with higher combined deprivation is modified by whether we are speaking about those in geographical area 1 or not. In geographical area 1, those that are in combined deprivation Q1/Q2 are 2.2 times as likely to report not having been to the
dentist in the last 3 years compared to those in the other quintiles (RR=2.21; 95% CI: 1.34 to 3.65; p=0.002). However, everywhere else in the LHIN the opposite is the case; those in the least combined deprivation quintiles (Q1/Q2) are approximately half as likely to have not attended the dentist in the last 3 years (RR=0.49; 95% CI: 0.35 to 0.68; p<0.001). But that’s not all. In addition to this, there is a uniform age effect. Regardless of deprivation or geographical location, adults less than 40 years old are less likely to have visited the dentist in the last 3 years (RR=0.73; 95% CI: 0.54 to 0.99; p=0.041).

There were 238 persons who indicated that they had not been to the dentist in the last 3 years. These 238 persons were then asked to identify the reasons why they haven’t been to the dentist (multiple reasons were allowed). The most commonly given reasons for not attending the dentist are (in decreasing order of frequency): cost (80; 34%), wears dentures (76; 32%), respondent did not think it was necessary (33; 14%), and no insurance (23; 10%). There were a wide range of other reasons why the respondent hadn’t sought dental care in the last 3 years, however, these were the most common. There was no evidence to suggest that patients in different deprivation groups have a different proportion that identified cost as one of the reasons why they haven’t been to the dentist. In fact, those with the highest combined deprivation had only 30% list cost as one of the barriers while 37% of the respondents who had not been to the dentist in the last 3 years in the less deprived groups included cost as one of the reasons they hadn’t been to the dentist.

The only association that was found with including cost as a barrier for visiting the dentist was among the older adults who were less likely than those under 60 to include cost as one of the reasons they hadn’t been to the dentist in the last 3 years (RR=0.56; 95% CI: 0.37 to 0.85; p=0.007).
Not surprisingly, the proportion of respondents that wear dentures is dramatically higher as age increases. Middle aged adults (i.e. those between the ages of 40 and 60) were used as the reference group. Adult respondents that were younger were much less likely to indicate that they wear dentures (RR=0.10; 95% CI: 0.01 to 0.77; p=0.026), while those that were over 60 were more likely to wear dentures (RR=2.76; 95% CI: 1.83 to 4.16; p<0.001).

Also, combined deprivation was associated with reporting denture wearing. Those in the higher deprivation group (Q4/Q5) are twice as likely to report wearing dentures than those in the least deprived group (Q1/Q2) (RR=1.96; 95% CI: 1.13 to 3.40; p=0.016). Note that this result is independent of the age effect. That is, regardless of age the deprivation effect is manifest.

With respect to combined deprivation groups, there is no evidence of any difference. This was maintained when looking at each of material and social deprivation as well.

The only thing associated with reporting no insurance as a barrier to seeking dental care in the last 3 years is age category, with a decreasing rate with increasing age. Middle aged adults were less likely than young adults to indicate that no insurance was a barrier to obtaining dental care in the last 3 years (RR=0.40; 95% CI: 0.18 to 0.92; p=0.032). Also, older adults were less likely than young adults to indicate that lack of insurance was a barrier to seeking dental care in the last 3 years (RR=0.18; 95% CI: 0.06 to 0.55; p=0.003).
14.4.1.6. Navigating the Health Care System

The only thing associated with reporting no insurance as a barrier to seeking dental care in the last 3 years is age category, with those over 60 being less likely, than those those under 60, to indicate that they had difficulty obtaining the specialist care they needed (RR=0.60; 95% CI: 0.48 to 0.74; p<0.001).

Of the people that indicated that they did have difficulties getting the specialist care they required, there were a number of reasons that were given for this difficulty. In fact, 74 respondents of the 331 (22%) that expressed having difficulty getting specialist care gave a reason that was not included in the list on the questionnaire (i.e. the classified it as 'other').

The most commonly given reasons for expressing that they had difficulty in obtaining specialist care are (in decreasing order of frequency): waited to long to get an appointment (171; 52%), difficulty getting an appointment (65; 20%), waiting too long to see the specialist (i.e. in-office waiting) (47; 14%), and difficulty getting a referral from their physician (44; 13%).

This is the most frequently given barrier to specialist care given by the respondents by a significant margin with more than half of the respondents reporting this barrier. Those that were in the middle combined deprivation group (Q3) were more likely to report this than others (RR=1.24; 95% CI: 1.00 to 1.53; p=0.045). Also, adults under 40 were less likely than adults over 40 to report this as a barrier (RR=0.76; 95% CI: 0.59 to 0.99; p=0.044).

The only thing associated with indicating that getting an appointment was a barrier to specialist care was age. There was modest evidence to suggest that young adults were more likely to indicate that this was a barrier for them although this was not significant (RR=1.54; 95% CI: 0.99 to 2.40; p=0.054).
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The variation in responding that in-office waiting was one of the barriers seems to be random variation. Nothing that was tested was associated with the outcome.

Again, the variation in responding that getting a referral from their physician was a barrier to specialist care seems to be random variation. Nothing that was tested was associated with the outcome.

My personal health care records such as lab results, x-rays, or referral requests seem to get lost in the system.

There is no association between deprivation and responding that your records seem to get lost in the system. However, those that are middle aged adults were more likely than all others to feel this way (RR=1.43; 95% CI: 1.09 to 1.88; p=0.011).

I am confident that if I had a medical problem I would receive the treatment I needed.

Approximately 11% of respondents expressed that they disagreed or strongly disagreed that they were confident that they would get the care they needed if they were to have a medical problem. Middle aged patients are twice as likely to indicate this feeling relative to a combined group of the older adults and younger adults (who had similar rates for this question) (RR=2.00; 95% CI: 1.46 to 2.77; p<0.001).
I am confident that if I had a medical problem I would receive treatment AS SOON AS I needed it.

Many more respondents indicated that they disagreed or strongly disagreed that if they were in need of medical care that they would get that care as soon as they needed than patients who respondents who were concerned about getting the care (30% vs 11%). Those that had the lowest combined deprivation (Q1/Q2) were more likely to disagree or strongly disagree that they felt confident in getting the care they needed as soon as they needed it (RR=1.23; 95% CI: 1.03 to 1.47; p=0.022). Also, older adults were less likely to indicate a lack of confidence in getting care they need as soon as they needed it relative to adults less than 60 (RR=0.72; 95% CI: 0.59 to 0.88; p=0.001).

The health care system is so complex, I worry that if I become seriously ill I will not be able to find the help I need.

Approximately one third of all participants either agreed or strongly agreed with the statement that they were concerned about navigating the health care system (31%). There was no observed association with combined deprivation or material or social deprivation. Also, there was no geographical association with the outcome. However, middle aged persons were more likely to agree or strongly agree that they were worried about being able to find the help that was needed (RR=1.41; 95% CI: 1.19 to 1.67; p<0.001).
If I had a health condition, I am confident that I could find information about the medical treatment options available for my condition.

Younger patients were less likely than middle aged or older adults to disagree or strongly disagree with this statement (RR=0.63; 95% CI: 0.41 to 0.96; p=0.032). Also, patients in the middle quintile (Q3) of social deprivation were less likely than people that were both less deprived and more deprived to disagree or strongly disagree that they felt confident that they would be able to find information about the medical treatment options available (RR=0.59; 95% CI: 0.36 to 0.96; p=0.035).

In the past 12 months, I was encouraged to attend programs in the community that could help me, such as support groups or exercise classes?

There is modest evidence to suggest that those that are in the higher deprivation group are more likely to have been encouraged to participate in a community program; however, this was not significant (RR=1.16; 95% CI: 1.00 to 1.34; p=0.052).
During the past 12 months, was there a time when you skipped a medical test, treatment, or follow-up that was recommended because of the cost?

Fifty one respondents (5%) indicated that they had skipped a medical test, treatment, or follow-up because of the cost. However, these results are not what you might expect. There were two factors that were associated with the outcome. Those in geographical area 1 were almost 3 times as likely as respondents from elsewhere in the LHIN to indicate they had skipped a recommended medical treatment, test or follow-up because of cost (RR=2.77; 95% CI: 1.35 to 5.67; p=0.005). Additionally, regardless of geographical area, patients that were the group with the least material deprivation were about twice as likely to indicate skipping a treatment, test of follow-up because of cost (RR=1.90; 95% CI: 1.03 to 3.48; p=0.039).

During the past 12 months, was there a time when you did not fill a prescription for medicine, or you skipped doses of your medicine because of the cost?

One hundred and thirty two respondents (11%) indicated not filling a prescription in the last 12 months because of cost. Older adults were less likely to have this be the case than persons who were less than 60 (RR=0.36; 95% CI: 0.23 to 0.55; p<0.001). There was no evidence of an association with deprivation.
In the past 12 months, has any long-term health condition interfered with your normal daily activities?

More than one third of sample respondents (36%) felt that a long-term health condition interfered with their normal daily activity. This was not found to be associated with deprivation or geographical area. However, middle aged adults were more likely to respond in affirmation of this question than either the younger or older adults (RR=1.22; 95% CI: 1.05 to 1.42; p=0.010).

In the past 12 months, how much work have you missed because of a long-term health condition?

There was a strong geographical effect for this outcome. There was no evidence of an association with either deprivation or age; however, those in geographical areas 1 and 6 combined were 2.5 times as likely to have missed more than 3 months work because of long-term health condition.

The specific condition that caused this time off was extremely variable. While the survey intentionally attempted to capture the most prevalent chronic conditions there more than half (55%) of respondents gave a reason that did not fit the options given by the questionnaire. Common answers were injuries or arthritis in its varying forms.
In the past 12 months, were you or others in your household ever hungry but didn’t eat because you couldn’t afford enough food?

Sixty eight respondents (6%) indicated that in the last year there was time when they were hungry but didn’t eat because they couldn’t afford food. There is evidence to suggest that, independent of other factors, patients in the most deprived groups are more than twice as likely to report that in the last 12 months they were unable to buy enough food even though they were hungry (RR=2.38; 95% CI: 1.45 to 3.92; p=0.001). Also, younger adults were more likely than middle aged or older adults to declare that they were unable to buy enough food (RR=2.42; 95% CI: 1.49 to 3.94; p<0.001). Last, if the LHIN is divided in 2 groups where geographical areas 1, 4 and 5 are one group and areas 2, 3, and 6 are the other group, then those in the second group are half as likely to report not having enough money to buy food (RR=0.53; 95% CI: 0.30 to 0.92; p0.024).

During the past month, how often did you feel: ... hopeless? Would you say, all of the time, most of the time, some of the time, or none of the time?

Two hundred and ninety nine respondents (25%) expressed feeling hopeless at least some of the time. There is a relationship between combined deprivation and feeling hopeless and it is modified by age category. Among those that are middle aged or older adults, being in the group with the least combined deprivation (Q1/Q2) is associated with a lower likelihood of reporting feeling hopeless relative to those in higher deprivation groups (RR=0.63; 95% CI: 0.48 to 0.84; p=0.001). However, among younger adults, deprivation group is not associated with increased likelihood of feeling hopeless (RR=1.38; 95% CI: 0.92 to 2.09; p=0.123).
During the past month, how often did you feel: ... nervous or anxious?

More than half of the respondents reported having feelings of nervousness or anxiety (672; 56%). It seems that these feelings decrease with increasing age. Relative to middle aged adults, younger adults were more likely to express feelings of nervousness or anxiety (RR=1.13; 95% CI: 1.01 to 1.25; p=0.029) while older adults were less likely than middle aged adults to express feelings of nervousness or anxiety (RR=0.69; 95% CI: 0.60 to 0.79; p<0.001). There is no evidence of a deprivation or geographical effect.

During the past month, how often did you feel: ... sad or depressed?

Again, approximately half of respondents indicated that they felt sad or depressed in the last month (49%). Regardless of a persons age group or geographical location, persons in the highest combined deprivation group were more likely to indicate that they felt sad or depressed in the last month (RR=1.16; 95% CI: 1.03 to 1.30; p=0.012). In addition, older adults (those over 60) were less likely than adults under 60 to indicate that they felt sad or depressed (RR=0.73; 95% CI: 0.64 to 0.84; p<0.001), this was again independent of the other factors. Last, respondents in geographical areas 2, 3 and 5 were more likely than respondents from elsewhere in the LHIN to report being sad or depressed (RR=1.22; 95% CI: 1.08 to 1.37; p=0.001).
During the past month, how much did these feelings usually interfere with your life or activities? Would you say a lot, some, a little, or not at all?

Approximately 61% of respondents felt that these feelings interfere with their daily activities. Older adults were less likely to indicate that these feelings interfere with daily life or activities (RR=0.76; 95% CI: 0.66 to 0.88; p<0.001). Also, those in geographical area 1 were more likely to indicate that their feelings interfered with their life or activities than people from other regions (RR=1.23; 95% CI: 1.06 to 1.42; p=0.006). Note that these results are independent. That is, regardless of age, persons in area 1 are more likely to respond that their feelings interfere with daily life and regardless of area older people are less likely to feel this way.

At or near your residence, do you have access to a place where you can exercise or be physically active?

About one fifth of respondents indicated that they do not have a place where they can exercise or be physically active (19%). There was no association between age group or combined, social, or material deprivation. However, there was a substantial geographical effect. Those in areas 3 and 5 were the least likely to indicate that there is not a place near their residence where they could exercise or be physically active (12%). Relative to these respondents, those from geographical areas 2, 4 and 6 were 1.7 times as likely to express no place where they could exercise or be physically active (RR=1.71; 95% CI: 1.26 to 2.33; p=0.001). Those in geographical area 1 were even more likely to feel that there was not a place where they could exercise or be active relative to those in areas 3 and 5 (RR=3.18; 95% CI: 2.26 to 4.47; p<0.001).
14.2 Analysis of the Open-Ended Face-to-Face Question

Responses to the open-ended question for 59 face-to-face survey interview respondents, “what would help you to get the healthcare or help you need?” provided insight for the specific needs of more deprived people in the SELHIN. Table 14-2 below presents the frequency of “mentions” or references in respondents’ open-ended answers.

At more than one-third, the most frequently cited single challenge were those associated with transportation, both in relation to costs as well as distance. Roughly one quarter of respondents indicated they were pleased with the care they receive, saying they did not have any needs. Overwhelmingly, financial pressures and stress related to eligibility for social assistance, housing, access to fitness programs, medication, physiotherapy and dental services, were most often referenced. To a lesser degree, clinic wait times, referrals, continuity of care, health service provider availability and hours of operation, continue to be issues. Physician sensitivity, their ability to listen and respect clients to thoroughly attend to individual client needs, were additional healthcare needs cited. These comments mirror the experiences of focus group participants; specifically, needs align with improving health system issues, enhanced relationships with healthcare providers, and reducing the stress and exclusions related to financial limitations.

<table>
<thead>
<tr>
<th>Response Type</th>
<th>Number of References (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A place to live</td>
<td>4 (7%)</td>
</tr>
<tr>
<td>Access to exercise facility</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Better continuity of care</td>
<td>6 (10%)</td>
</tr>
<tr>
<td>Better hours of operation</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Counselling</td>
<td>1 (2%)</td>
</tr>
<tr>
<td>Dental coverage</td>
<td>8 (14%)</td>
</tr>
<tr>
<td>Doctors take time to listen and be thorough</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>Financial pressures affect utilization of health services</td>
<td>10 (17%)</td>
</tr>
<tr>
<td>Health service office too busy</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Improved wait times in clinic and/or referrals</td>
<td>11 (19%)</td>
</tr>
<tr>
<td>Lack of services in the area</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>Money for prescriptions</td>
<td>5 (8%)</td>
</tr>
<tr>
<td>More doctors or nurses</td>
<td>10 (17%)</td>
</tr>
<tr>
<td>No needs cited - happy with care</td>
<td>14 (24%)</td>
</tr>
<tr>
<td>Physiotherapy and occupational therapy</td>
<td>2 (3%)</td>
</tr>
<tr>
<td>Transportation issues (distance and cost)</td>
<td>20 (34%)</td>
</tr>
</tbody>
</table>

Table 14-2: What Would Help Getting Healthcare
14.5 Conclusions

In total, 1212 people were surveyed (1153 over the phone and 59 in-person). By design, the sample targeted individuals from a range of social contexts from those that were among the most deprived to those that were among the least deprived with the LHIN. The sample included respondents that were young adults (18-39), middle aged adults (40-59), and older adults (60+). The sample included individuals from six (6) geographical areas within the LHIN.

The interview includes questions on a number of topics including overall quality of health care to issues with the health system to dental health, relationships with primary care providers and individual financial concerns. Throughout the investigation, the principle objective was to detect and understand health inequity in the SELHIN.

In general, there were a number of results that seemed to confound what could be called the generally held perceptions of health inequity. In some circumstances the geographical area plays a bigger role than the deprivation metrics, while in others the outcome is most certainly tied to the deprivation groups, and in others still both play a complementary role.

One of the most obvious themes emerging from the survey relates to whether or not respondents have a primary care provider. There is evidence to suggest that in Smiths Falls – Perth (geographical area 3) respondents were more likely to indicate that they do not have a primary care provider. A number of reasons were given by those surveyed for the underlying reason they did not have a primary care provider. Almost all had previously had a provider but no longer did. This will almost certainly result in accessing other sources of primary care. The most frequently identified principle sources of primary care, after doctor’s offices, are in decreasing order: family medicine centres (such as family health teams), community health centres, walk-in or after hours clinics and emergency departments. Those in Smiths Falls - Perth were 3.5 times a likely to report using the emergency department as their principle source of primary care as respondents from the rest of the LHIN.

Another issue that was plainly manifest was geographical discrepancy with respect to accessing the services offered by allied health care providers. There were many participants who indicated that their primary care provider worked in a team that included access to other health care providers at no charge. However, there was considerable discrepancy among the geographical regions with respect to who that team includes. Those in area 4 were less likely to report that the other team members included a nurse practitioner, a nurse, a dietician, a nutritionist, a counsellor, or a physiotherapist as an example. While in areas 1 and 3 there was a higher rate of social workers and chiropodists being part of the team.

The section on dental health offered some very interesting results. One might expect that those with higher social or material deprivation would be less likely to have dental insurance; however, this was not found to be the case in this sample. Instead, age group was found to influence the rate of dental insurance coverage with the probability of having dental insurance dramatically deceasing with increasing age. Not surprisingly, those that had the highest deprivation were more likely to have not been to the dentist in the last years; however, for persons that have not been to the dentist in the last 3 years it was actually those that were least deprived who most frequently gave cost as a reason for not attending.

There were 68 respondents (6%) that indicated that at some time in the last 12 months there was a time where they were hungry but did not have enough money to buy food. Similarly, there was a small proportion (5%) that indicated they had skipped a recommended medical test treatment, or follow-up for reasons of cost. While one might assume that this would be entirely related to material deprivation it was found that geographical area played an equally, and in some cases more, important role in this. Typically, it was geographical area 1 that rendered a higher proportion of persons skipping treatments, prescriptions, or meals because of cost.
The mixed methods approach and analyses above are rich and varied, at once with persistent themes and with subtleties and nuance. Given the extent and intensity of the foregoing analysis, we summarize here the more salient findings of the report.

The guiding research question is to illuminate and elucidate the primary health care needs of the population of Southeastern Ontario and to do so utilizing a social determinants of health lens. The charge was to provide a solid basis of evidence, using locally-germane data—from both primary and secondary sources—that would shed insights into the needs of individuals facing multiple barriers to health in Southeastern Ontario. Ours is a deliberately mixed methods approach; on the one hand we profitably leverage key administrative databases that provide a largely compelling story of inequities in health outcomes through our social determinants of health lens. However, these administrative databases are not designed to capture population needs and in only the most superficial of ways can they capture the lived experiences of SELHIN residents. We, thus, employ key informant interviews, focus groups, and a larger population-based sample to implicitly tease out significant challenges to accessing primary healthcare.

From a review of the health inequities and social determinants literature emerges key and arguably pervasive themes that situate and provide context for the present study. We find also that there exists little consensus in the literature on how to operationalize the “social determinants of health.” Techniques range from simple self-reported univariate metrics (such as, say, household income), to bivariate cross-tabulations of census-generated socioeconomic variables, to more advanced multivariate techniques such as principal components analysis that attempt to capture and distill the several dimensions of what we understand about the “social determinants of health.” We review and adopt a widely used deprivation index in Canada.

We commence by first exploring for inequities in simple geographic access to primary care. From a roster of primary care physicians (our proxy for primary healthcare in general), we geocode their locations and compute geographic accessibility by the deprivation index. Notwithstanding several methodological limitations we find that access to primary care is inversely related to material deprivation. By superimposing the locales of the most deprived populations of the SELHIN on a map of primary care accessibility, we find that in very few cases are the two coincident.

A more detailed examination of hospital inpatient stays and emergency department visits in the SELHIN reveals not only that more deprived populations experience and confront inequities in myriad ways but also demonstrates that the deprivation index provides good analytical traction for detecting differential health outcomes. We find that more deprived populations have higher penetration (i.e., as a proportion of the general population), higher utilization (i.e., repeat usage), longer and more resource intensive stays, and higher comorbidities. We also find significant differentiation of conditions/MRDs by the deprivation index. Likewise, for emergency department visits, we find higher penetration amongst more deprived populations and acute differences in utilization by the deprivation index. Case acuity is less well discriminated though wait times are longer amongst more deprived populations and that, coupled with much higher repeat usage rates, may suggest some substitution of ED services for primary healthcare. We find also that higher ED usage covaries with poorer geographic access to primary care, and both covary with level of deprivation.

The more quantitative analysis of these administrative databases collectively illustrate that more deprived populations of the SELHIN do, in fact, experience and interact with the healthcare system in disproportionately ways in the best case and in ostensibly inequitable ways.
in the worst. However, as interesting and novel as these findings may be, they do not provide a basis on which to better understand the lived experiences of SELHIN residents.

Towards a more intensive, granular understanding of these access barriers to primary healthcare, we commence with a series of key informant interviews with health service providers in the SELHIN. The interviews are semi-structured and afford providers the freedom, confidentiality, and opportunity to articulate in their own words what challenges they see and believe that SELHIN residents—and in particular those more deprived populations—experience in getting the healthcare they need. These front-line health service providers recognize the same priority populations gleaned from the literature and from the quantitative analysis. Though the language and expressiveness vary from interviewee to interviewee, they also identify what are five (5) main barriers that they see from the provider side: (1) systemic health system issues; (2) navigating the healthcare system; (3) maintaining the patient-provider relationship; (4) coping with geographic service variations; and (5) managing one’s health in the face of considerable financial challenges.

Facilitated focus groups with SELHIN residents generated largely compatible and complementary findings. As in the key informant interviews, focus groups participants recounted numerous stories and instances of how systemic health system issues impede their ability to get the healthcare they need.

Likewise, discussion around the patient-service provider relationship elicited strong feelings and important learning. Financial challenges were a persistent and pervasive theme in all focus group discussions. Somewhat dissimilar to the key informant interviews, there emerges from the qualitative analysis a theme that revolves around emotional perceptions of healthcare and the healthcare system, a theme that hones in on trust and mistrust, disempowerment, anxiety, and in some cases a cynicism and scepticism significant enough to condition healthcare choices and health-seeking behaviours. Participants also volunteered a number of means and ways that access to primary healthcare could be improved, ranging from more pragmatic suggestions such as supporting videoconferencing and web-based interactions with providers (so as to obviate five-hour drives) to more complex system-level changes that would see less emphasis on practice-based care and rostering with more emphasis on open, walk-in, clinic-type service delivery.

As we note, the key informant interviews and the focus group discussions for the most part yielded complementary themes and both align well with the literature review and our distillation of differential health outcomes and health system usage from the analysis of inpatient stays and emergency department visits. Collectively, they offer guidance and direction in the design of the survey tool developed to systematically capture and measure the prevalence of these themes in the SELHIN. The survey was then tested, slightly modified, and then fielded against a sampling frame straddling a representative mix of the age cohorts, the deprivation index, and geographic locale in the SELHIN. For the most part, the sample provided good coverage over most of the 54 sub-quotas though four (4) of target cells are poorly covered. Aggregated up to the three key axes, the sample is conformant and well-distributed relative to the general population. Chapter 15 provides a more exhaustive analysis of every question in the survey but we here note several of the more salient, important, and potentially actionable findings.

Whether it stems from personal experience, anecdotes of friends, or from media coverage, the SELHIN’s most deprived populations are more likely than the least deprived populations to report that the overall quality of health care in the SELHIN is poor or very poor. That that may reflect first-hand experience is problematic but that that perception of poor quality care may ill-condition and otherwise deter more deprived populations from more fully engaging healthcare services and realizing their full health potential.

More deprived populations are much more likely to utilize walk-in and after clinics than are the SELHIN’s least deprived populations. This is somewhat akin to our earlier finding of disproportionately higher usage of emergency departments for lower acuity conditions. In fact, the survey buttresses that finding as more deprived populations report using emergency departments as their primary source of primary care. While this destination is not statistically significant,
it is telling that the question was self-reported and fully 47 respondents volunteered emergency departments as their primary source of day-to-day healthcare needs.

Higher deprivation populations were also much more likely to report that they do not have a regular healthcare provider but, still, 96% of survey respondents report having a regular primary care provider. More deprived populations are also less likely to report having a provider who is part of a healthcare team that includes access to allied healthcare professionals at no charge.

The survey questions around dental health and mental health yield some important findings. While having insurance to cover dental expenses is surprisingly not well-discriminated by the deprivation index, there is a pronounced effect between the deprivation index and those having not been to a dentist in the last three years. There is a strong geographic mediating effect that either amplifies or attenuates this relationship. In terms of mental health, more deprived populations were more likely to report feeling hopeless during the last month at least some of the time. The relationship, however, is conditional and exists only in the adult and senior cohorts. Regardless of age or locale, more deprived populations were more likely to report that they felt sad or depressed during the last month.

Financial challenges are apparent throughout the survey results but are perhaps most epitomized in the question regarding food security where the most deprived populations were well over twice as likely to report that they or others in their household were hungry but did not eat because they could not afford enough food. Strong variations are also apparent by age and locale. The deprivation index also discriminates around health literacy and self-advocacy in that those in the least deprived quintiles are significantly more likely to do their own research than are more deprived populations before taking their health providers’ advice. There is also a strong age effect wherein youth are more likely to supplement their provider recommendations with their own learning and knowledge.

A few findings, however, are somewhat counter-intuitive. For example, less deprived populations more often report that their primary care provider limits the number of problems that can be discussed during a single visit. Given higher rates of comorbidity, one might expect that more deprived populations would meet with these kinds of limits. Also, it is less deprived populations who are more likely to agree that they will not get the care they need as soon as they need it.

In terms of the overarching themes evident through the study, we find that the social determinants of health (SDOH) lens is not always of significant import. There would appear to be a SDOH lens to overall perceptions of healthcare quality, health system issues, relationships with health service providers, and dental care but the survey results suggest only a weak SDOH lens to how residents of the SELHIN navigate the healthcare system.

The survey findings are quite nuanced as age, deprivation, and locale intersect in complex ways that demand careful interpretation. These cell-specific subgroup findings are perhaps less prescriptive about population-level interventions and suggest more tailored, customized healthcare that are place- and population-specific. We explore some potential policy implications, strategic directions, and recommendations stemming from these finds in the final chapter.
The foregoing analysis portends a transformative vision of primary health care and its achievement in Ontario. A reorientation towards more integrated, customized, and patient-centric service delivery figures centrally in that vision and will require a multifaceted approach to effect meaningful change, including:

- following strategic directions about where to place primary health care services to meet community needs (Drummond, 2012) using a determinants of health lens;
- health services should be community and needs based and encompass a variety of services that coordinate and communicate together;
- promote effective system leadership to create accountability agreements between variable models of primary health care, public health and locally-integrated health networks to meet specific, measurable, agreed upon, realistic and timely population health goals;
- align the right primary health care model with the right population;
- focus on chronic disease prevention and management instead of acute care that is characterized by reactive and more resource intensive interventions;
- align funding and billing strategies to enhance communication, collaboration and coordination to enable increased emphasis on disease prevention;
- ongoing measurement of health outcomes that align with resources and incentives to provide accountability;
- identify priority populations and use a determinants of health focus and tools such as the deprivation index;
- use spatial analytics for mapping higher needs populations and measuring accessibility;
- explore creative solutions to enhance the care for the minority of the population that experience complex health issues and access barriers (Glazier et al., 2008);
- improve health information system management and technology; and
- partner with public health to identify population based health needs and integrate with them for solutions and ongoing evaluation.
Next Steps

It is necessary to transform primary health care and decrease acute care utilization. Interdisciplinary health care teams may be tailored to community needs and disease prevalence; accessible and available; and placed directly in communities based on geospatial analysis and need. Encouraging self help, group interaction; adopting innovative care delivery models; and focusing on health as opposed to disease care can allow primary health care transformation. A coordinated and proactive primary health care system integrates public health services and programs; community support services; and primary care to best enhance personal skill development.

This study proposes a framework to reduce health inequity and inequalities to improve primary health care services in South Eastern Ontario, comprised of:

- improving population health by having a proactive, not reactive, approach for promoting health, preventing illness and ensuring equal access and enhanced availability to health and health care services;
- enhancing the experience of health care by improving the quality of health services and focusing on patient-centered care;
- integrating primary health care services into a coherent system to improve efficiency, accountability and value for money;
- identifying all individuals with the highest acute care utilization rates for each hospital in southeastern Ontario and immediately linking them into an accessible, available, primary health care team model to demonstrate the cost effectiveness of this approach longitudinally; and
- consistent recognition that place and time are important: we must understand that some neighborhoods and communities need primary health care services they can walk to or are delivered in the home, and at hours that they can access, and we must reorient to their needs to save acute care sector utilization and costs.

By following the proposed framework, primary health care services will be sustainable, proactive and, most importantly, benefit the lives and health of all members of the community.


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Understanding Health Inequities and Access to Primary Health Care


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Research Protocol - Understanding Health Inequities in the South East Local Health Integration Network (SELHIN): A Quantitative Analysis

Introduction

In an environment of universal healthcare such as Canada’s, the conviction that prompt and affordable health care ensures equal health outcomes is unfounded. There are serious shortcomings, and health inequities continue to worsen (Welch et al., 2010). For many Canadians, living conditions, food security, employment security, poverty, and social exclusion continue to worsen with deleterious and direct effects on health (Raphael, Curry-Stevens and Bryant, 2008). Also, disadvantaged people use the health care system more often, yet they still have worse health outcomes (Alter et al., 2011). Moreover, inequalities in health status may not be fully explained by differences in health behaviours (Marmot et al., 2010).

The contribution of medicine and health care is limited compared to the influencing factors of social determinants on population health (Marmot et al., 2010). People of lower socioeconomic status have more behavioural risk factors such as increased tobacco use, poor diet, reduced physical activity, increased rates of chronic disease, and worse health outcomes (Phipps, 2003; Raphael, 2004; Brennan Ramirez, Baker and Metzler, 2008). It is also problematic considering population-level trends such as age and chronic disease rates compared with community and individual levels where health system disadvantages are exacerbated (Wong and Regan, 2009). An all-encompassing tool for measuring equitable access to primary health care does not exist.

Research Question and Hypothesis

Social and economic factors play a complex role in determining the health outcomes of individuals. The purpose of this study is to conduct research and analysis on the primary health care needs of the population of the South-East Local Health Integration Network (SELHIN) utilizing a social determinants of health lens. The primary outcome is to determine the relationship between social deprivation, as measured by a ‘deprivation index’ developed by Pampalon et al. (2009), and use of both hospital and primary care services. The results of this study will reveal gaps in health services, and identify whether socioeconomic factors play a role in such access to care.

It is hypothesized that those with higher material and social deprivation use emergency services proportionately more often, and primary care services proportionately less often, than those with less deprivation. The goal would be to shift the health care utilization by those in the most deprived populations in the SELHIN from emergency services to primary care. Information gathered by this study will assist the government and health administrators in developing policies designed to reorient the primary care system to prevention, health promotion, and service accessibility for those of low socioeconomic status. This in turn will help alleviate the pressure that is placed on emergency services.
Methods: Data Retrieval

This is a retrospective review of data gathered in from six databases, each described in full in the paragraphs to follow. The study population includes any residents of the SELHIN that make use of the services described below. Data will be extracted from the databases by the Kingston, Frontenac and Lennox & Addington GIS Manager (Paul Belanger). There will be no specific subject identification, no subject participation, and no subject follow-up. All data collection processes used will follow strict principles of privacy and consent.

The Discharge Abstract Database (DAD) reports detailed patient level “abstracts” for all types of hospital care in one standardized source. This includes acute care, general and special rehabilitation, chronic and various inpatient psychiatric units, and day procedures/surgery. Data from DAD will be pulled during the period from 2005 to 2010.

The National Ambulatory Care Reporting System (NACRS) was developed by the Canadian Institute for Health Information (CIHI) and the Ministry Of Health And Long-Term Care of Ontario. The NACRS system collects patient level data on visits to a hospital’s ambulatory services. Emergency Departments were the first areas or visit functional centres to report to NACRS, and was expanded in 2003/2004 to include other major ambulatory visit functional centres within the hospital (day surgery, medical day/night care, for example). Data from NACRS will be pulled during the period from 2009 to 2010.

The Discharge Abstract Database (DAD) reports detailed patient level “abstracts” for all types of hospital care in one standardized source. This includes acute care, general and special rehabilitation, chronic and various inpatient psychiatric units, and day procedures/surgery. Data from DAD will be pulled during the period from 2005 to 2010.

The Emergency Department Syndromic Surveillance System (EDSS) monitors visits to emergency departments (ED) at nine hospitals; three in the Kingston, Frontenac, and Lennox & Addington Public Health region, four hospitals in the Hastings And Prince Edward Counties Health Unit Catchments and two hospitals in Leeds, Grenville And Lennox area. The nine sites have approximately 275,000 visits per year within a catchment area population of approximately 425,000. The EDSS System captures approximately 90% Of the ED Visits by this population. Information From each of these visits is captured at triage when the patient is registered in the ED. The Information is entered in the hospital computer system in ‘real–time’ – within minutes of speaking with the triage nurse. Data Elements required by the EDSS System include the date and time of visit, patient demographics (age and sex), a geographic identifier, and the patient’s chief complaint. No personal identifiers are included or required. Similar information is collected for hospital admissions. Data from EDSS will be pulled during the period from 2004 to 2011.

The Medical Services Database contains OHIP-approved claims files regarding service and payment information for both fee-for-service claims submitted by physicians and other licensed health professionals and some of the “shadow billings” by providers in organizations covered by alternate payment arrangements (such as Community Health Centres). Included in a typical claim is information about the patient, provider, fee schedule code/procedure performed, number of services/units delivered and some diagnostic information. Data from the Medical Services Database will be pulled during the period from 2007 to 2008.

The Mortality Surveillance Database contains information regarding death statistics in the SELHIN. Data from the Mortality Surveillance Database will be pulled during the period from 2002 to 2007.

The Physicians Database contains the locations of the approximately 453 primary care physicians in the SELHIN. Data from the Physicians Database will be pulled during the period from 2011, to reflect up-to-date location of primary care physicians.
Methods: Statistical Analysis

Kingston, Frontenac and Lennox & Addington will perform the statistical analysis. Much of the collected data set will be placed into respective social and material deprivation indices through a postal code-to-deprivation index conversion file. Specific patient information will not be included in the results. The patient’s postal code will be used to derive a deprivation index for each patient. This will be used as an approximation for socio-economic status.

Data Analysis and Review

Data collected in will be analyzed to further understand the barriers to healthcare which exist within the study area. The importance of providing adequate healthcare across diverse populations is not to reduce attention from existing healthcare at the cost of equalizing the system. Instead, a levelling up approach is required to bring populations experiencing difficulty accessing healthcare up to the highest level within the population. This objective will be at the forefront of the project team as data are analyzed. Initially, a spatial deprivation analysis will be conducted for the study area. This will spatially delineate the social and material deprivation conditions under which the project populations are living. Once the general deprivation index has been delineated, a spatial analysis of specific populations will be undertaken. This will include those over 65 years of age, those living with co-morbidities, chronic diseases, mental health issues and addictions. In addition, disease specific conditions will be analyzed at the levels available with existing data. Once the social and material deprivation index, along with specific identified vulnerable populations have been spatially analyzed, specific regional features will be analyzed to help understand the issues associated with levelling up access to healthcare across the project population. For instance, the location of all stakeholder organizations and facilities (hospitals, community health centres, family health teams, family health networks, walk-in clinics and other health service organizations) will be mapped and added as an electronic layer to the maps of the deprivation indices and vulnerable populations. In addition, the location of group homes, long-term care facilities and retirement homes will be mapped as additional layers.
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QUALITATIVE PHASE

Research Protocol

Title: Development of a survey tool to understand barriers to accessing primary health care for people with greater material and social deprivation in the South East Local Health Integrated Network (hereafter, SELHIN)

Summary:

The project proposes a three-phase research process to develop a survey tool to understand barriers accessing primary health care. This study will focus on access for those with greater material and social deprivation in the SELHIN. The initial phenomenological inquiry, Phase 1, seeks to understand the experiences of front-line primary health care service providers (key informants). We will gain insight into their knowledge of the difficulties their clients face in accessing the health care they need. The second phenomenological inquiry, Phase 2, seeks to understand the experiences of people who have difficulties getting the health care they need. Methods of inquiry for Phase 1 and Phase 2 include telephone interviews, focus groups, and phenomenological reflection on data elicited from interview and focus group participants. The final research component, Phase 3, involves developing a survey tool using the phenomenological information as the framework for constructing survey domains and questions. The survey will be disseminated to respondents in the SELHIN to determine the extent and distribution of the challenges and barriers to accessing primary health care.

Aims and Objectives:

The aim of the study is:
To survey people with higher levels of material and social deprivation in the SELHIN to better understand the challenges and barriers they experience in accessing primary health care.

*Populations of people with higher levels of deprivation, relative to other, less deprived populations within the SELHIN as defined by a Deprivation Index (1).

The objectives of the study are to engage in a three phase survey tool development process:

Phase 1

1. Conduct ten (10) key informant interviews with health service providers located in more materially and socially deprived areas of the SELHIN, to identify and understand clients with greater material and social deprivation.

   Analyze key informant interview data to develop discussion guides for Phase 2.

Phase 2

3. Conduct five (5) focus groups with residents of the SELHIN’s more materially and socially deprived areas to more fully understand their experiences with primary health care, to develop a conceptual framework for specific domains for a survey tool.
4. Analyze focus group data to develop domains for a survey tool, by incorporating the information gathered from literature reviews, key informants, and focus group participants.

Phase 3

5. Create a draft survey tool.

6. Assess survey tool readability through a cognitive interviewing process.

7. Disseminate survey tool to materially and socially deprived people in the SELHIN (more precisely, disseminate to any number of people to achieve N=300).

8. Analyze survey data.

9. Write a report incorporating all levels of evidence and survey results.

Background:

Health equity “implies that ideally everyone should have a fair opportunity to attain their full health potential and, more pragmatically, that none should be disadvantaged from achieving this potential, if it can be avoided.” (2)(p. 433) Health care equity means, “equal access to available care for equal need, equal utilization for equal need, equal quality of care for all.” (2)(p.424) Whitehead’s definition is clear, but almost twenty years on, there remains difficulty measuring the concept of “health inequity” and greater difficulty relaying the real life experiences of those that experience barriers to primary health care services.

In an environment of universal healthcare such as Canada’s, the conviction that prompt and affordable healthcare ensures equal health outcomes is unfounded. There are serious shortcomings. Health inequities continue to worsen (3). For many Canadians, living conditions, food security, employment security, poverty and social exclusion continue to worsen with deleterious and direct effects on health (4). Also, disadvantaged people use the healthcare system more often, yet they still have worse health outcomes Alter 2011.

Moreover, inequalities in health status may not be fully explained by differences in health behaviours (5). The contribution of medicine and health care is limited compared to the influencing factors of social determinants on population health (5). People with lower socio-economic status have more behavioral risk factors such as increased tobacco use, poor diet and reduced physical activity; increased rates of chronic disease; and worse health outcomes (6,7) (8). It is also problematic considering population level trends such as age and chronic disease rates compared with community and individual levels where health system disadvantages are exacerbated (9).

An all-encompassing tool for measuring equitable access to primary health care doesn’t exist. Complicated and interconnecting factors influence health outcomes. Bound by the availability of statistical data and constrained timelines for systematically gathering qualitative information, solutions for unraveling the intertwined nature of health inequities must be equally creative.

Population based surveys capture self-reported health conditions and behavioural risk factors for illness, but it is difficult to capture similar data from administrative databases (10). Understanding how persons with chronic diseases or risk factors access and use health services is equally challenging. Often data cannot be disaggregated to a regional or local level. Nor is it sufficiently granular such that deeper contextual comprehension emerges. A suitable measure of socio-economic status is equally challenging to distill. Many studies investigating poverty employ a measure of income as a predictor of health inequalities in a population, but income measures often overlook important factors such as social deprivation or social capital (6,11). Canadian administrative databases do not contain socio-economic information (12).
A deprivation index developed by Pampalon et al. (2009) and adopted by the Institute National de Santé Publique Quebec (INSPQ)/ Canadian Institute for Health Information (CIHI) offers a comprehensive measure (1). The deprivation index (DI) uses a compilation of six markers of social and material deprivation, which have been shown through principal component analysis to be most indicative of an individual's socioeconomic conditions. These markers include: education, employment, income, marital status, living alone and single-parent family. The six factors are used to classify an individual into one of five quintiles, from one being the most advantaged, to five being the most deprived. The quintiles are applied geographically, at the smallest statistically significant census area, the, ‘dissemination area’ (1). Geographically, the dissemination areas cover neighbourhoods of approximately 400 to 700 residents. The average of the five quintiles for each dissemination area can be used to gain an overall level of deprivation for a specific geographic area (1). There is a presumed homogeneity of population factors within the dissemination area. The index is intended to serve as a proxy for individual level measures and can be generalized to the people living in that area. It is not an individual measure of socioeconomic conditions, but rather a measure of conditions seen at the neighborhood level (1). There are advantages to using area-based indicators in that they are statistically reliable and consistent with individual factors; they comprise a socio-economic spectrum of the entire population; and they discern significant inequalities between groups (13).

Shifting from a biomedical perspective to a social determinants of health paradigm requires health researchers use ethnographic and qualitative approaches to provide rich sources of contextual information and hear the voices of the most vulnerable (4). Using deprivation index methods employed by Philibert, Pampalon et al., the current research maps regions with greater deprivation; inquiry will employ qualitative and quantitative techniques targeting these areas to collect and present stories about barriers and challenges accessing primary health care in the SELHIN (14).

A broad initial literature review was undertaken to investigate existing research regarding access and barriers to primary health care, with a focus on priority populations. One systematic review, one scoping review, one description of a research protocol and twenty-six studies were reviewed.

Assessment of equity in systematic reviews is uncommon (3). The reviewed studies employed a range of designs as well as outcome measures. Much of the evidence was drawn from observational studies making clear comparisons very difficult.

Challenges of access are often studied within individual vulnerable groups or tend to focus on between group differences rather than similarities across groups (15). Studies looking at specific subgroups within “disadvantaged groups,” included subgroups of: adults with intellectual, physical or developmental disabilities, immigrants, homeless youth, women with low family income, war veterans, and Latino parents (16-18) Harrington 2009 (19,20) (21). The remaining studies investigated disadvantaged population groups as a measure of income, education or employment, either as composite or individual measures to define and sample for “low socioeconomic status” and/or geographic boundaries for “socioeconomically deprived regions” using census data. Many studies represented targeted research approaches rather than investigating gaps between the most and least advantaged groups or approaches investigating a gradient between the most disadvantaged to the least disadvantaged groups.

Measurements of access to primary health care included: having a regular physician, consultation with a health professional in the last 12 months, having a dentist visit in the last 12 months, various screening tests (PAP, mammogram), median wait time between referral from a primary health care provider to being seen by a specialist, how long patients wait for their clinical encounter, whether patients are taken on time for their scheduled appointment, how long they spend with a physician, overall satisfaction with the physician-patient encounter, difficulty getting after-hours medical treatment, and medical insurance coverage (17,22) (23) (24) (25).

The social behavioural research offered different interpretations of access. Kovandžič et al. (2011) in their study of equitable access to primary care for people with mental health problems, listed a number of access concepts that are common across hard to reach
groups: knowledge about available services; adequate and timely information about services; availability of social networks to assist a pathway to care (diabetes support network for example); time available for engagement with services; affordability in terms of time (employment hours or lack of childcare may prevent access); affordability in terms of finances; transportation; readiness to pursue health care; personal perception of diagnosis, care need or disease progression; distance from home; unpleasant physical surroundings or design of health facilities; services responding to the rhythms of life; receptivity of services; compliance with disease management; health literacy and communication (ability to articulate a health issue); availability of therapeutic options; and the ability to integrate different aspects of care (15). Other barriers such as fear of failure or fear of being judged are also common among disadvantaged groups (26). Concepts of cultural capital in the form of perceptions, health values, health knowledge, behavioral norms, the ability to use appropriate language and communication styles, influence of social networks and resilience are equally influential to differential health outcomes (27).

The division between social and medical science continues between methodological approaches. Population health surveys and epidemiological techniques were employed in the health services literature, while qualitative techniques such as focus groups and key informant interviews were used in social research. Survey methodology overlapped both domains. Large population health surveys dominated the epidemiological literature while smaller, author developed specific surveys commanded social research.

Recruitment strategies for disadvantaged groups or priority populations employed snowball sampling, purposeful sampling, convenience sampling, complex multi-stage sampling and random sampling. Specific data collection methods included telephone surveys, (9,17); face-to-face interviews (16); Jatrana 2009 (28); self-administered surveys (21,22,29,30); focus group sessions (31-33); mailed questionnaires (31,34); and national population health surveys (17,35) (36-38) (24) (39) (25) (40).

The complexity of research definitional frameworks, sampling and recruitment strategies, methodology, and outcome measures makes it very difficult to state with confidence how different techniques are successful or how they work with different groups. Consequently, much of the evidence may be seen only as promising practice rather than proof of effectiveness.

It is clear that a combination of research methodologies will yield the best contextual evidence in a given population and/or region. Quantitative methods are useful for identifying deprivation areas using census data or geographic information systems (GIS). Disease rates and distributions, the traditional measurements used in epidemiological studies and utilization-based reporting (costs of services and numbers) are insufficient to support an integrated population health approach (41). Qualitative methodology allows people to tell their stories, identify dimensions of primary health care that are important to them and suggest solutions for improving the system (9). These methods, paired with survey methodology will capture the complex realities of communities and allows a sharper focus on health inequities (42).

There were broad methodological steps consistent across studies:

1. identify priority populations using demographic information and/or regional boundaries*
2. data collection
3. data analysis
4. information synthesis and recommendations for incorporation into health service planning

*Note: using census data regarding income and or education. Also, some studies added an extra step: engage health service stakeholders familiar with the populations of interest for consultation and/or development of survey tools.
To develop an appropriate survey tool relevant to the regional populations of people with greater material and social deprivation, the current project will employ a postpositivist paradigm (43). Using a phenomenological approach, the study will be comprised of three consecutive phases to understand several individuals’ common or shared experiences of challenges and barriers accessing primary health care (44). Each phase of research will use an inductive approach to provide evidence and inform the subsequent phases of data gathering. The current survey tool development study is a sub-component of a larger project seeking to understand health inequities and access to primary health care in the SELHIN. The larger project seeks regular advice and guidance from an Advisory Committee comprised of a range of community primary health care service providers and policy makers.

Methods:

The current project is divided into three phases: the first two are exploratory, to gather information about the nature of challenges and barriers to accessing primary health care. The third will be a descriptive phase, to provide information regarding the extent and distribution of the challenges and barriers to accessing primary health care in the SELHIN. Without an all-encompassing tool for measuring equitable access to primary health care, it is necessary to develop a questionnaire that resonates with the identified regional priority population (those with higher material and social deprivation). Following the broad outline provided by the literature review, this project will use a step-wise process to develop relationships with health service intermediaries to help identify and engage individuals with higher deprivation. In this way, a final survey tool will be commensurate with experiential challenges and barriers to accessing primary health care for deprived populations in the SELHIN.

The project is guided by an Advisory Committee comprised of regional health service stakeholders: community health centre executive directors; community health centre program managers; physicians; a nurse practitioner; the Kingston coordinator for the round table on poverty reduction; a representative from the Ministry of Health and Long Term Care; and representatives from the SELHIN. As each phase involves an inductive process that precedes subsequent phases. The current protocol and ethics application refers only to the data gathering and analysis relating to Phase 1. Subsequent phases are briefly described, however, specific methodology, data gathering instruments, and consent forms will be submitted for ethics review through the amendments process. Research for subsequent phases will not be conducted without the express permission of the Health Sciences Research Ethics Board.

Statistics Canada’s Postal Code Conversion File (or PCCF) offers a linkage between the postal geography used by Canada Post and the census geography used by Statistics Canada. The deprivation index developed by Pampalon et al. is scored on every census dissemination area in Canada. Using the PCCF, a geographic reference (Figure 1) illustrates the spatial distribution of a combined social and material deprivation rank by census deprivation area. Areas shaded in the darkest red represent communities of the SELHIN that are simultaneously the most materially and socially deprived; that is, these areas have lower incomes, higher unemployment, and a greater proportion of people who live alone.

Figure 1: Combined material and social deprivation for the SELHIN by census dissemination area.

For this project, Belleville, Kingston and Brockville will be considered “urban”, while the rest of the SELHIN area will be considered “rural”. Priority populations, for the present study, refer to more deprived populations as defined by quintile 4 and quintile 5. In figure 1, these regions are shown as darkest red and darkest orange.
Phase 1 Methodology:

Phase 1 Aim and Objectives:

There are two aims for Phase 1:

1. To understand front-line health service providers’ knowledge about difficulties their clients experience in getting the health care they need.

2. To engage health service providers in both rural and urban communities to facilitate participant identification and recruitment for Phase 2.

The objectives for Phase 1 are:

1. Conduct ten (10) key informant interviews with front-line health service providers located in more materially and socially deprived areas of the SELHIN, to identify and understand clients with greater material and social deprivation.

2. Analyze key informant interview data.

3. Develop methodology for Phase 2 of the study (understand the challenges and barriers to accessing primary health care for people with higher material and social deprivation).

Phase 1 Design:

As evidenced by the literature review and information provided by the project Advisory Committee, it is clear that engaging priority populations in a research process is challenging. For this reason, this phase of the project involves conducting key informant interviews with health service providers in the SELHIN, to ask four broad questions:

1. What are health service providers’ understanding and/or knowledge of challenges and barriers that their clients face when accessing health services in the community?

2. What contexts or situations have typically influenced or affected the key informants’ knowledge or understanding [of their clients who have difficulties accessing their services]?

3. What are health service providers’ experiences with engaging more deprived clients in their health services?

4. What contexts or situations have typically influenced or affected the way key informants engage more deprived clients in their health services?
Sample Size, Participants & Recruitment:

Key informants will be front-line health service providers in the SELHIN that work in regions of higher material and social deprivation (Figure 1, regions Q4 and Q5). Permission to access key informants will be obtained through introductions using existing connections/relationships with the project Advisory Committee. A call for nominations of health service providers for identified regional deprivation areas was put forth at a recent Advisory Committee meeting. To develop the possibilities of experience, it is recommended researchers interview 5 to 25 individuals (45). In order to gain a variety of perspectives, as well as ensure rural and urban representativeness, 10 front-line health service providers will be selected using the following parameter matrix:

<table>
<thead>
<tr>
<th>Recruitment Matrix</th>
<th>RN/Nurse Practitioner</th>
<th>Independent Physician</th>
<th>Addictions/Mental Health Counselor/Street Nurse</th>
<th>Dietitian</th>
<th>Social Worker</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rural</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Urban</td>
<td>X</td>
<td>X</td>
<td>X</td>
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Inclusion criteria:
- Informed written consent obtained, AND
- Employed in their field/position for at least one year, AND
- Worked in specific community for at least one year, AND
- Provides front-line service As well as one of the following:
  - Involved in outreach services specific for deprived populations, OR
  - Facilitates a support group specific to a dimension of our research, OR
  - Knowledge of community groups outside the field of health services.

Exclusion criteria
- Did not provide written consent to participate, OR
- Worked in field/current position less than one year, OR
- Has not worked in the specific community more than one year.

Key informants will be recruited through health service agencies nominated by the Advisory Committee and/or according to whether service agencies are located in geographical areas demarcated as having higher deprivation (Figure 1, regions Q4 and Q5). Permission from organizational directors/managers will be sought prior to contact with specific key informants. Potential key informants will be contacted by the researcher, via telephone, to ask if they are willing to participate as a key informant in the study. Positive respondents will be asked for contact email and information and to schedule a telephone interview time. Consent forms will be emailed to each Key Informant for signature and faxed back to the researcher (appendix).
Phase 1 Data Collection Tools:

The study will use a semi-structured interview guide that includes basic demographic information, key questions with specific objectives, introductory and closing remarks, transitions and bridges, as well as supplementary questions to gain more complete responses (appendix). A semi-structured interview style will permit freedom to alter the order of key questions and broaden the scope of the interview to include emergent sub-topics.

Interviews will be conducted via telephone and tape-recorded for transcription and analysis purposes. Four types of field notes will be generated:

- Interview Transcription Notes – verbal discourse transcribed to Microsoft Word (speech variations, pauses etc. excluded)
- Theoretical Notes - attempts to derive meaning as the researcher reflects on experiences
- Methodological Notes - reminders, instructions or critiques regarding the process
- Analytical Memos/Journaling – thematic and coding definitions, text and context examples, as well as decisions regarding the analytical process
- All field notes will be managed using NVIVO 9 software.

Phase 1 Data Analysis:

Key informant interview data will be transcribed verbatim, by a research assistant into a Microsoft Word document. The data will be imported to NVIVO 9 software. Data analysis will be conducted by one researcher. To begin, data will be assigned to broad themes relating to information provided by a literature review investigating barriers and challenges to accessing primary health care. This initial partial structure provides a starting framework for assigning themes. As coding progresses, new, emergent themes will be added. Using a phenomenological approach, front-line health service provider qualitative data will be assigned to themes and sub-theme codes; examples of knowledge of client difficulties getting the health care they need, as well as the contexts for this knowledge and understanding will be built upon an emerging framework. As theme development and coding ensues, the researcher will record analytical memos and theoretical notes to provide a methodological audit as a platform for “trustworthiness”. During the process of analysis, discussions between the researcher and other project team members will enable coding ambiguities to be settled and queries to be thoroughly explored.

Phase 1 Study Process:

Please find the Phase 1: Key Informant Interview Flowchart

Phase 1 Data Management:

All information obtained for the study is confidential. The voice file of the interview will be stored at the Kingston, Frontenac, Lennox & Addington (hereafter, KFL&A) Public Health Unit, and managed in compliance with the organization’s record retention guidelines. Interviews will be transcribed verbatim. If any names are provided during the interview, they will not be transcribed but simply replaced with the word “name” or “place” (e.g.: John = “name”). All electronic files will be encrypted and password protected, including voice files and transcripts. All hard copy forms and transcripts will be stored in a locked filing cabinet for security. Information in this study is for research purposes only. When the study results are presented or published, no names will never be used.

The research team is based at the Kingston, Frontenac, Lennox & Addington Public Health Unit, as well as at the Queen’s University Department of Family Medicine. Information gathered for this project will not be shared with other project staff.
Phase 1 Ethical Considerations:

All information will maintain confidentiality and will be anonymized through the use of key informant study identification numbers. Categorization and paraphrasing of responses in written reports will further maintain anonymity.

For reporting purposes, to maintain consistency and minimize recognition of the key informant respondents, the descriptive term “patients” will be changed to “clients”.

Any area identification information will be removed and changed to a generic format to maintain anonymity for reporting purposes. For example, the town of “Bancroft” would be renamed as “rural town”.

Phase 2 Methodology:

The following paragraphs regarding methodology are restricted to current knowledge regarding how the process will unfold. Complete methodology will be generated following analysis and integration of Phase 1 information. Health Science Research Ethics Board approval will be obtained through an amendments process before proceeding with this phase of the study.

Phase 2 Objectives:

Phase 2 Design:

This phase of the study will use focus groups to be able to understand the challenges and barriers people with higher deprivation experience with primary health care. Focus group format will enable investigation of several participants sharing common geographical areas.
Phase 2 Participants:

Focus group participants will be recruited through key informant suggestions of facilitated community groups using a snowball sampling process. Criteria for more deprived participants will be defined in relation to aspects of the Deprivation Index; material variables are education, employment and income, while social variables are marital status, living alone and single-parent family. Criteria for participant selection may be satisfied by having: two low level material variables as well as one low level social variable. The selection criteria for focus group participants will be refined over the course of key informant interviews. In order to capture the experiences of priority populations, it may be necessary to broaden the definition of “deprived populations” in order to recruit and engage people with the research process.

Study information and rights of the participant to withdraw or refrain from answering any part of the research process will be verbally explained for each focus group participant. Written informed consent will be obtained prior to focus group participation.

Phase 2 Data Collection Tools:

The study will use a semi-structured interview guide that includes key questions with specific objectives, introductory and closing remarks, transitions and bridges, as well as supplementary questions to gain more complete responses. In order to capitalize on the unique knowledge or experiences of respondents, a semi-structured interview style will permit some freedom to alter the order of key questions and broaden the scope of the focus group interview to include unforeseen sub-topics, should the opportunity arise. The researcher will act as moderator for focus group sessions. Five focus group sessions will be conducted.

Focus groups will be conducted face-to-face, and will be tape-recorded for transcription and analysis purposes. A research assistant will hand write notes during focus group sessions. Five types of field notes will be generated:

- Focus Group Transcription Notes – verbal discourse transcribed to Microsoft Word (speech variations, pauses etc. excluded) and checked against research assistant written notes regarding focus group sessions
- Post-Interview Summary Notes – the researcher will record thoughts, insights, interpretations regarding the overall atmosphere of each focus group session
- Theoretical Notes - attempts to derive meaning as the researcher thinks or reflects on experiences
- Methodological Notes - reminders, instructions or critiques regarding the process
- Analytical Memos/Journaling – thematic and coding definitions, text and context examples, as well as decisions regarding the analytical process
- All field notes will be managed using NVIVO 9 software.

In addition, a brief demographic and health questionnaire will be disseminated to each participant at the close of each focus group session. No identifying information will be collected on the questionnaire.

Phase 2 Study Process:

A flow chart will be provided with the future amendment process.

Phase 2 Data Collection Management:

No identifying information. Questionnaires will be kept in a locked filing cabinet located at Kingston, Frontenac and Lennox & Addington Public Health. Demographic information will be entered into a Microsoft Excel spreadsheet and managed in compliance with KFL&A Public Health record and retention guidelines.
Phase 2 Ethical Considerations:
All information will maintain confidentiality and anonymity.

Phase 3 Methodology:
The following paragraphs regarding methodology are restricted to current knowledge regarding how the process will unfold. Complete methodology will be generated following analysis and integration of Phase 1 and Phase 2 information. Health Science Research Ethics Board approval will be obtained through an amendments process before proceeding with this phase of the study.

The methodology for this aspect of the study is divided into three steps:
1. Developing the survey items
2. Refining the survey through a series of cognitive interviewing sessions
3. Disseminating the survey

Phase 3 Objectives:

Phase 3 Design: The survey sampling frame will be determined through discourse with key informants in phase 1.

Phase 3 Participants: Recruitment/Sampling
This aspect of the project is currently under theoretical development and will integrate information from previous phases of the research process to best inform this section.
Epi-info power calculation for sample size will estimate the number of responses to achieve statistically significant effects according to the sampling frame population number.
The following sections will be completed and submitted for ethics review prior to moving forward:

Data Collection Tools:

Study Process:

Data Management:

Data Analysis and sample size:

Ethical considerations:

Dissemination: Findings from the study will be submitted to peer review journals, presented at primary health care conferences and regional meetings with key stakeholders in the SELHIN, and others in Ontario.
References


44. Creswell, Hanson, Plano Clark, Morales. Qualitative research designs: Selection and implementation. The Counselling Psychologist 2007, Mar;35(2):236-64.

You are invited to participate in an interview as part of a project to better understand the challenges and barriers accessing primary health care for people in the South East Local Health Integrated Network (hereafter, SELHIN). This letter has been designed to provide you with the information necessary to make an informed decision about whether to participate in the research. If you have any questions, please do not hesitate to contact our project team.

**Purpose:**

The main goals of the project are to understand health inequities and access to primary health care in the SELHIN. As part of this research, the project team is developing a survey tool to assess difficulties people experience getting the health care they need. To best tailor survey domains and questions that resonate with people in our region, the project is using a step-wise information gathering process. Key informant interviews with front-line health service providers are the first step in the survey development process.

**Procedures:**

Ten front-line health services providers will be interviewed. Health service providers are comprised of a variety of front-line professionals: nurse practitioners, dieticians, social workers, physicians and mental health counsellors. In the interview, you will be asked to describe your experiences and knowledge regarding people who have difficulty getting the health care they need; your thoughts and opinions regarding how best to engage people who experience difficulties getting the health care they need; and your knowledge regarding other services in your community.

The telephone interview will take place at a time that is convenient for you and will take approximately one half to three quarters of an hour (30–45 minutes). The interview will be tape recorded. This allows for a more fluid discussion such that the interviewer does not have to stop you to take notes.

**Risks and Discomforts:**

There are no known risks related to being in this study. You may not benefit directly from being in this study. The information from this study may be used to improve future projects to help enhance the delivery of primary health care in the SELHIN.
Voluntary Participation:
Participation in this study is voluntary. You may refuse to participate and you may refuse to answer any questions or withdraw from the study at any time. No one will be informed by our research team about your part in the study. You will be asked to sign a consent form prior to beginning the interview.

Confidentiality and Privacy:
All information obtained for the study is confidential. The voice file of the interview will be stored at the Kingston, Frontenac, Lennox & Addington Public Health Unit and managed in compliance with the organization’s record retention guidelines. Interviews will be transcribed verbatim. If you use any names during the interview, they will not be transcribed but simply replaced with the word “name” or “place” (e.g.: John = “name”). All electronic files will be encrypted and password protected, including voice files and transcripts. All hard copy forms and transcripts will be stored in a locked filing cabinet for security. Information in this study is for research only. When the study results are presented or published your name will never be used.

The research team is based at the Kingston, Frontenac, Lennox & Addington Public Health Unit, as well as at Queen’s University Department of Family Medicine. Information gathered for this project will not be shared with other project staff.

Contact Persons for Questions
If you have any questions regarding your participation in the study, please contact Dr. Kieran Moore (Principal Investigator) at (613) 549-1232 ext. 1121 or Ms. Suzanne Biro (Research Associate) at (613) 549-1232 ext. 1588 or (613) 533-9300 ext. 79567; or Dr. Paul Belanger (Principal Investigator) at (613) 549-1232 ext. 1602.

If you have any questions regarding your rights as a research participant, or the conduct of the study, you may contact Dr. Albert Clark, Chair of Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081. These people are not involved in the study and contacting them will not affect your participation in the study.
Consent Form

I have read and understand the Letter of Information for this study, have had the nature (purposes, procedures and technical language) of this study explained to me and I agree to participate. I have been given sufficient time to consider the above information and to seek advice if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will keep the Letter of Information for my reference.

If at any time I have further questions, problems or adverse events, I can contact Dr. Kieran Moore (Principal Investigator) at (613) 549-1232, ext. 1121 or Ms. Suzanne Biro (Research Associate) at (613) 549-1232, ext. 1588 or (613) 533-9300, ext. 79567; or Dr. Paul Belanger (Principal Investigator) at (613) 549-1232, ext. 1602.

If I have questions regarding my rights as a research subject I can contact Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.

Participant’s Name: _______________________________________________________________
(print)
Participant’s Signature: __________________________________________________________
Date:  ____________________________________________________________
Key Informant Interview Guide

Introduction

Introduction of the researcher/interviewer – name, where work, involvement in the project.

The main goals of the project are to understand health inequities and access to primary health care in the SELHIN. As part of this research, the project team is developing a survey tool to assess difficulties people experience getting the health care they need. To best tailor survey domains and questions that resonate with people in our region, the project is using a step-wise information gathering process. Key informant interviews with front-line health service providers are the first step in the survey development process. The interview will be tape-recorded and will take approximately half to three quarters of an hour (30 – 45 minutes). All information obtained for the study is confidential.

Brief Demographics

1) What is your job title?
2) Please describe your role and responsibilities as a _________(answer above)_.
3) How long have you worked in your current position?

Key Questions

1) Based on your day-to-day work, who are the people who experience difficulties getting the health care they need?
   PROBE (if needed)

2) What are the difficulties people have getting the health care they need?
   PROBES (if needed)
   a. Can you describe particular challenges or barriers people have getting the health care they need?
   b. Can you provide an example of a particular difficulty your clients encounter trying to get the healthcare they need?
   c. For example, distance, public transit, operating hours, making an appointment

* For interviewer: make sure to round out structural, organizational, physical, cultural etc. issues if these are cited…

3) What do you feel might improve health services for people in your community, particularly people who experience challenges or barriers to health care?

4) For the health services that you provide, are there people that you sense you are missing? Who? How come?
   PROBE
   a. Are there people who “fall through the cracks”?

5) [For people who experience difficulties with health care or for those who fall through the cracks] Can you suggest effective ways to engage people in their primary health care?
6) Can you suggest effective outreach strategies for those hard to reach populations?
   
   PROBE
   a. What are effective ways to communicate information about existing services, or getting people involved in managing their own healthcare [with people who experience difficulties with health care]?

7) What support groups for particular health conditions are there in your community?
   
   PROBE
   a. Examples: mental health, COPD or Diabetes etc.

8) In this project we want to understand health inequities, particularly for people who are more vulnerable - those people who have lower levels of material and social resources (education, income and fewer social networks to draw on). What other services in your community provide programs for more vulnerable people?
   
   PROBE
   a. Can you give me some examples of programs?
   b. Early years programs? Soup kitchen programs?

9) In the next phase of our study, we would like to speak with people who experience difficulties getting the health care they need. Would you be comfortable giving me the name of a group facilitator so that I can contact them?
   
   a. This may be a paid or a volunteer facilitator

10) The final part of our project will be a survey. Do you have an opinion about what method to use for disseminating a survey to more vulnerable people?

11) [In our discussion] Is there anything else that you feel we missed, or that you would like to add?
   
   a. A message or relevant point, or “take-away” statement

Thank you very much for your time. The information you have provided has been extremely helpful.
Dear Dr. Moore

Study Title: EMED-156-11 Development of a survey tool to understand barriers to accessing primary health care for people with greater material and social deprivation in the South East Local Health Integrated Network (SE LHIN)

File # 6006025

Co-Investigators: Paul Belanger, Suzanne Biro, Amit Sehdev

I am writing to acknowledge receipt of your recent ethics submission. We have examined the protocol (May 31, 2011), Key Informant Interview Guide (May 30, 2011), Key Informant Consent Form (May 29, 2011) for your project (as stated above) and consider it to be ethically acceptable. This approval is valid for one year from the date of the Chair's signature below. This approval will be reported to the Research Ethics Board. Please attend carefully to the following listing of ethics requirements you must fulfill over the course of your study:

- **Reporting of Amendments**: If there are any changes to your study (e.g. consent, protocol, study procedures, etc.), you must submit an amendment to the Research Ethics Board for approval. Please use event form: HSREB Multi-Use Amendment/Full Board Renewal Form associated with your post review file # 6006025 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

- **Reporting of Serious Adverse Events**: Any unexpected serious adverse event occurring locally must be reported within 2 working days or earlier if required by the study sponsor. All other serious adverse events must be reported within 15 days after becoming aware of the information. Serious Adverse Event forms are located with your post-review file 6006025 in your Researcher Portal (https://eservices.queensu.ca/romeo_researcher/)

- **Reporting of Complaints**: Any complaints made by participants or persons acting on behalf of participants must be reported to the Research Ethics Board within 7 days of becoming aware of the complaint. Note: All documents supplied to participants must have the contact information for the Research Ethics Board.

- **Annual Renewal**: Prior to the expiration of your approval (which is one year from the date of the Chair's signature below), you will be reminded to submit your renewal form along with any new changes or amendments you wish to make to your study. If there have been no major changes to your protocol, your approval may be renewed for another year.

Yours sincerely,

Chair, Research Ethics Board
June 15, 2011

Investigators please note that if your trial is registered by the sponsor, you must take responsibility to ensure that the registration information is accurate and complete.
The membership of this Research Ethics Board complies with the membership requirements for Research Ethics Boards as defined by the Tri-Council Policy Statement, Part C Division 5 of the Food and Drug Regulations, OHRP, and U.S DHHS Code of Federal Regulations Title 45, Part 46 and carries out its functions in a manner consistent with Good Clinical Practices.

Federalwide Assurance Number: #FWA00004184, #IRB00001173

Current 2011 membership of the Queen's University Health Sciences & Affiliated Teaching Hospitals Research Ethics Board:

Dr. A.F. Clark, Emeritus Professor, Department of Biochemistry, Faculty of Health Sciences, Queen's University (Chair)

Dr. H. Abdollah, Professor, Department of Medicine, Queen's University

Dr. R. Brison, Professor, Department of Emergency Medicine, Queen's University

Dr. M. Evans, Community Member

Dr. S. Horgan, Manager, Program Evaluation & Health Services Development, Geriatric Psychiatry Service, Providence Care, Mental Health Services, Assistant Professor, Department of Psychiatry

Ms. D. Morales, Community Member

Dr. W. Racz, Emeritus Professor, Department of Pharmacology & Toxicology, Queen's University

Dr. B. Simchison, Assistant Professor, Department of Anesthesiology, Queen's University

Dr. A.N. Singh, WHO Professor in Psychosomatic Medicine and Psychopharmacology Professor of Psychiatry and Pharmacology, Chair and Head, Division of Psychopharmacology, Queen's University, Director & Chief of Psychiatry, Academic Unit, Quinte Health Care, Belleville General Hospital

Dr. E. Tsai, Associate Professor, Department of Paediatrics and Office of Bioethics, Queen's University

Rev. J. Warren, Community Member

Ms. K. Weisbaum, L.L.B. and Adjunct Instructor, Department of Family Medicine (Bioethics)
Study Title: EMED-156-11 Development of a survey tool to understand barriers to accessing primary health care for people with greater material and social deprivation in the South East Local Health Integrated Network (SE LHIN)

File # 6006025
Principle Investigator: Dr. Kieran M Moore
Co-Investigators: Paul Belanger, Suzanne Biro, Amrit Sehdev

Protocol Phase 2

Phase 2 Objectives:
1. Conduct five (5) focus groups with residents of the SELHIN’s more materially and socially deprived areas to more fully understand their experiences with primary health care, to develop a conceptual framework for specific domains for a survey tool.

2. Analyze focus group data to develop domains for a survey tool, by incorporating the information gathered from literature reviews, key informants, and focus group participants.

Phase 2 Design:
This phase of the study will use focus groups to be able to understand the challenges and barriers people with higher deprivation experience with primary health care. Focus group format will enable investigation of several participants sharing common geographical areas.

This phase of the project involves conducting focus group sessions with vulnerable (more deprived) people in the SELHIN, to ask three broad questions:

1. What are the difficulties or challenges vulnerable people experience when accessing health services in the community?

2. What contexts or situations have typically influenced difficulties or challenges accessing health services?

3. What would help vulnerable people to get the health care that they need?

Phase 2 Participants:
Focus group participants will be recruited through key informant suggestions of facilitated community groups using a snowball sampling process. Criteria for more deprived participants will be defined in relation to aspects of the Deprivation Index; material variables are education, employment and income, while social variables are marital status, living alone and single-parent family. Criteria for focus group selection may be satisfied by community program or support groups that are conducted within defined Q4 & Q5 deprivation areas (geographically). The selection criteria for focus group participants will attempt to capture a range of ages as well as people identified by Key Informants as more vulnerable. In order to capture the experiences of priority populations, it may be necessary to broaden the definition of “deprived populations” in order to recruit and engage people with the research process.
Study information and rights of the participant to withdraw or refrain from answering any part of the focus group interview, as well as the research process, will be verbally explained at the beginning of each focus group session for each focus group participant. Written informed consent will be obtained prior to focus group participation.

Phase 2 Data Collection Tools:

The study will use a semi-structured interview guide that includes key questions with specific objectives, introductory and closing remarks, transitions and bridges, as well as supplementary questions to gain more complete responses. In order to capitalize on the unique knowledge or experiences of respondents, a semi-structured interview style will permit some freedom to alter the order of key questions and broaden the scope of the focus group interview to include unforeseen sub-topics, should the opportunity arise. The researcher will act as moderator for focus group sessions. Five focus group sessions will be conducted.

Focus groups will be conducted face-to-face, and will be tape-recorded for transcription and analysis purposes. A research assistant will hand write notes during focus group sessions. Five types of field notes will be generated:

- Focus Group Transcription Notes – verbal discourse transcribed to Microsoft Word (speech variations, pauses etc. excluded) and checked against research assistant written notes regarding focus group sessions
- Post-Interview Summary Notes – the researcher will record thoughts, insights, interpretations regarding the overall atmosphere of each focus group session
- Theoretical Notes - attempts to derive meaning as the researcher thinks or reflects on experiences
- Methodological Notes - reminders, instructions or critiques regarding the process
- Analytical Memos/Journaling – thematic and coding definitions, text and context examples, as well as decisions regarding the analytical process

All field notes will be managed using NVIVO 9 software.

In addition, a brief demographic questionnaire will be disseminated to each participant at the close of each focus group session. No identifying information will be collected on the questionnaire.

Phase 2 Data Analysis:

Focus group data will be transcribed verbatim, by a research assistant into a Microsoft Word document. The data will be imported to NVIVO 9 software. Data analysis will be conducted by one researcher. To begin, data will be assigned to broad themes relating to information provided by a literature review investigating barriers and challenges to accessing primary health care, as well as those that emerged from the Key Informant interview data. This initial partial structure provides a starting framework for assigning themes. As coding progresses, new, emergent themes will be added. Using a phenomenological approach, focus group participant qualitative data will be assigned to themes and sub-theme codes; examples of difficulties people experience getting the health care they need, as well as the contexts for understanding will be built upon an emerging framework. As theme development and coding ensues, the researcher will record analytical memos and theoretical notes to provide a methodological audit as a platform for “trustworthiness.” During the process of analysis, discussions between the researcher and other project team members will enable coding ambiguities to be settled and queries to be thoroughly explored.
Phase 2 Study Process:

1. Review Key Informant Interview transcripts regarding programs and/or services in communities supporting people with lower levels of material and social resources.

2. Through suggestions and contacts provided by Key Informants (above), contact support service or program facilitators to relay information regarding the study and ask for co-operation recruiting focus group participants.

3. Recruit focus group participants using support service/program facilitators as intermediary for investigator introduction.

4. Schedule interview time and place.

5. Conduct focus groups face to face, interviews will be tape-recorded.

6. Transcribe interview data to Microsoft Word format.

7. Analyse Focus Group transcripts using NVivo 9 software.

8. Write summary report.
Phase 2 Data Collection Management:

All information obtained for the study is confidential. The voice files of the focus groups will be stored at the Kingston, Frontenac, Lennox & Addington (hereafter, KFL&A) Public Health Unit, and managed in compliance with the organization’s record retention guidelines. Interviews will be transcribed verbatim. If any names are provided during the interview, they will not be transcribed but simply replaced with the word “name” or “place” (e.g.: John = “name”). All electronic files will be encrypted and password protected, including voice files and transcripts. All hard copy forms, demographic questionnaires and transcripts will be stored in a locked filing cabinet for security. Information in this study is for research purposes only. When the study results are presented or published, no names will ever be used.

The research team is based at the Kingston, Frontenac, Lennox & Addington Public Health Unit, as well as at the Queen’s University Department of Family Medicine. Information gathered for this project will not be shared with other project staff.

No identifying information. Questionnaires will be kept in a locked filing cabinet located at Kingston, Frontenac and Lennox & Addington Public Health. Demographic information will be entered into a Microsoft Excel spreadsheet and managed in compliance with KFL&A Public Health record and retention guidelines.

Phase 2 Ethical Considerations:

All information will maintain confidentiality and will be anonymized through the use of focus group study identification numbers. Categorization and paraphrasing of responses in written reports will further maintain anonymity.

Any area identification information will be removed and changed to a generic format to maintain anonymity for reporting purposes. For example, the town of “Bancroft” would be renamed as “rural town”.

UNDERSTANDING HEALTH INEQUITIES AND ACCESS TO PRIMARY HEALTH CARE
Focus Group Interview Guide

**Introduction – Introduction of moderator (name, where work, brief background)**

We would like to know about the difficulties you experience getting the health care you need. The information we discuss today will be used to help develop a survey that will ask people about the challenges they experience getting the healthcare they need. By speaking with you, we hope to gain knowledge about some of the more important issues you face. The survey results will be used to improve health services in your community. All discussions will be kept confidential and any names or other identifying information will be removed.

**When we talk about health care services we mean a lot of different services: counseling, disability support, chronic disease management (such as diabetes) as well as services provided by a doctor or nurse practitioner.**

**Focus Group Questions**

1. What are services you need that you have trouble getting?
2. Can you describe some particular challenges or difficulties you experience getting the healthcare you need?
3. What would help you to get the healthcare or help you need?
4. Are there other challenges or situations you experience which influence how healthy you could be? (Probe: For example, do you have access to comfortable housing? Access to nutritious food? Do you have the ability to exercise regularly?)
5. Our last question is whether you have anything you want to add that you feel we haven’t covered or we may have missed?
   - Identify myself and other researcher
   - Invite participants to introduce themselves
   - Review letter of information – please sign
   - If there is a word or question you need to understand better please ask
   - Free to leave the room
   - Free not to answer a question
   - 3 ground rules
     - no right or wrong answers – you all have wisdom to contribute about your own experiences
     - one person talks at a time
     - confidentiality
   - acknowledge expertise – now can we hear from someone else?
   - That’s one point of view – are there others?
   - Does anyone feel differently?

**Probes:**

- Would you explain further
- Would you give me an example of what you mean?
- Is there anything else?
- Would you say more?
- Please describe what you mean...
- I don’t understand
- What experiences have you had that make you feel that way?
Focus Group Interview Guide

**Introduction**

Introduction of moderator (name, where work, brief background). We would like to know about the difficulties you experience getting the health care you need. The information we discuss today will be used to help develop a survey that will ask people about the challenges they experience getting the healthcare they need. By speaking with you, we hope to gain knowledge about some of the more important issues you face. The survey results will be used to improve health services in your community. All discussions will be kept confidential and any names or other identifying information will be removed.

When we talk about health care services we mean a lot of different services: counseling, disability support, chronic disease management (such as diabetes) as well as services provided by a doctor or nurse practitioner.

**Focus Group Questions**

1) What are services you need that you have trouble getting?

2) Can you describe some particular challenges or difficulties you experience getting the healthcare you need?

3) What would help you to get the healthcare or help you need?

4) Are there other challenges or situations you experience which influence how healthy you could be? (Probe: For example, do you have access to comfortable housing? Access to nutritious food? Do you have the ability to exercise regularly?)

5) Our last question is whether you have anything you want to add that you feel we haven’t covered or we may have missed?
Demographic Questionnaire
These questions help us to round out the information you have provided to us during our conversation. The answers you provide here do not include any information that will let us know who you are and will never be able to be linked back to you. Some of these questions might not apply to you, and we apologise for this, however it is important that we ask everyone the same things. Please try to be as accurate as possible when answering these questions and know that all answers you give will be kept confidential.

Question 1
What is your age? ________________ (years)

Question 2
Sex: □ Male □ Female

Question 3
Are you: (Check only one)
□ Married
□ Divorced
□ Widowed
□ Separated
□ Never been married
□ A member of an unmarried couple

Question 4
Do you live alone?
□ Yes □ No

Question 5
Are you a single parent?
□ Yes □ No

Question 6
What is your current primary occupational status? (Select the single best option)
□ Paid employment (full-time)
□ Paid employment (part-time)
□ Supported employment
□ Non-paid work such as voluntary/charity
□ Self-employed
□ Student
□ Home maker
□ Retired
□ Unemployed (health reasons)
□ Unemployed (other reason)
□ Other: (Specify) ________________

Question 7
What is the highest grade or year of school you completed? (Select the single best option)
□ Never attended school or only attended kindergarten
□ Grades 1 through 8 (Elementary)
□ Grades 9 through 11 (Some high school)
□ Grade 12 (High school graduate)
□ College 1 year to 3 years (Some college or technical school)
□ University 1 year to 4 years (Some university)
□ College Graduate
□ University Graduate
□ Graduate School (Advance Degree)

Question 8
Is your average personal income per year above or below $28 000?
□ Above $28 000 per year
□ Below $28 000 per year

Question 9
What is your postal code? ________________

Thank you so much for your time!
Development Of A Survey Tool To Understand Barriers To Accessing Primary Health Care For People In The South East Local Health Integrated Network

Focus Group Letter of Information/Consent Form

You are invited to participate in a group interview as part of a project to better understand the challenges and barriers people experience trying to get the health care they need. This letter provides you with the information necessary to make an informed decision about whether you would like to participate in the group interview. If you have any questions, please do not hesitate to ask our project team.

Purpose:
The main goals of the project are to understand unequal health outcomes and access to community health services. We are developing a survey to understand the health care needs in your community. We are speaking to people in the region to learn what issues are most important to help define the questions for the survey.

Procedures:
In the group interview, you will be asked to:
1) Talk about your experiences and challenges getting the health care you need
2) Talk about your thoughts and opinions about what services would help you to get the support you need
3) Talk about your experiences with other services in your community that influence your health

The face to face group interview will take place at a time that is convenient for your group and will take about three quarters of an hour (45 minutes to 1 hour). The group interview will be tape recorded. The discussion will flow more easily and the interviewer won’t have to stop you to take notes.

You will be asked to fill in a brief demographic questionnaire (9 questions) at the end of the group interview.

Risks and Discomforts:
There are no known risks related to being in this study. You may not benefit directly from being in this study. The information from this study may be used to improve future projects to help improve the community health services in our region (South East Local Health Integrated Network).

Voluntary Participation:
Participation in this study is voluntary. You may refuse to participate and you may refuse to answer any questions or withdraw from the study at any time. No one will be informed by our research team about your part in the study. You will be asked to sign a consent form prior to beginning the group interview.

Confidentiality and Privacy:
All information obtained for the study is confidential. All files (both electronic and hard copies) of the group interview will be stored at the Kingston, Frontenac, Lennox & Addington Public Health Unit and managed in compliance with the organization’s record retention guidelines. If you use any names during the interview, they will not be transcribed but simply replaced with the word “name” or “place” (e.g.: John = “name”). Information in this study is for research only. When the study results are presented or published your name will never be used.

The research team is based at the Kingston, Frontenac, Lennox & Addington Public Health Unit, as well as at Queen’s University Department of Family Medicine. Information gathered for this project will not be shared with other project staff.
Contact Persons for Questions

If you have any questions regarding your participation in the study, please contact Dr. Kieran Moore (Principal Investigator) at (613) 549-1232 ext. 1121 or Ms. Suzanne Biro (Research Associate) at (613) 549-1232 ext. 1588 or (613) 533-9300 ext. 79567; or Dr. Paul Belanger (Principal Investigator) at (613) 549-1232 ext. 1602.

If you have any questions regarding your rights as a research participant, or the conduct of the study, you may contact Dr. Albert Clark, Chair of Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081. These people are not involved in the study and contacting them will not affect your participation in the study.

This is your copy of the Letter of Information to keep for your records.

Development Of A Survey Tool To Understand Barriers To Accessing Primary Health Care For People In The South East Local Health Integrated Network

Focus group participant consent form

I have read and understand the Letter of Information for this study, have had the nature (purposes, procedures and technical language) of this study explained to me and I agree to participate. I have been given the time to review the above information and to ask for clarification if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will keep the Letter of Information for my reference.

If at any time I have further questions or problems, I can contact Dr. Kieran Moore (Principal Investigator) at (613) 549-1232 ext. 1121 or Ms. Suzanne Biro (Research Associate) at (613) 549-1232 ext. 1588 or (613) 533-9300 ext. 79567; or Dr. Paul Belanger (Principal Investigator) at (613) 549-1232 ext. 1602.

If I have questions regarding my rights as a research subject I can contact Dr. Albert Clark, Chair,

Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.

Participant’s Name:_______________________________________
(print)

Participant’s Signature:_____________________________________

Date:____________________________________________________
Amendment Acknowledgment/Approval Letter

August 12, 2011

Dr. Kieran M Moore
Department of Emergency Medicine
Queen's University

File #: 6006025EMED-156-11 Development of a survey tool to understand barriers to accessing primary health care for people with greater material and social deprivation in the South East Local Health Integrated Network (SE LHIN)

Dear Dr. Moore

I am writing to acknowledge receipt of the following:

- Request for approval of Phase 2 of the study
- Protocol – Phase 2
- Focus Group Demographic Questionnaire
- Focus Group Questions
- Information/Consent Form for Focus Groups

I have reviewed these materials and hereby give my approval. Receipt of these amendments will be reported to the Health Sciences Research Ethics Board.

Yours sincerely,

Albert Clark, Ph.D.
Chair
Research Ethics Board
Study Title: EMED-156-11 Development of a survey tool to understand barriers to accessing primary health care for people with greater material and social deprivation in the South East Local Health Integrated Network (SE LHIN)

File # 6006025

Principal Investigator: Dr. Kieran M Moore
Co-Investigators: Paul Belanger, Suzanne Biro, Amrit Sehdev

Phase 3 Protocol

Phase 3 Objectives:

1. Create a regionally relevant survey tool that incorporates the information gathered from literature reviews, key informant interviews and focus groups.

2. Refine the survey tool through input and expertise from the project advisory committee as well as through pilot cognitive interviewing sessions.

3. Design sampling frame

4. Disseminate survey

5. Analysis of Survey Data

Phase 3 Methodology:

Design/Participants/Recruitment and Sampling: The survey will be conducted using telephone interviews.

The survey population is defined by the geographical boundaries of the South East Local Health Integrated Network, that comprises close to 500,000 people. Sub analyses of the data will include levels of deprivation (as defined by the Deprivation Index quintiles used in earlier phases of this study); urban and rural differences; as well as three age cohorts (18-39, 40-59, and 60+). To ensure representative estimates within each strata, the sample size has been calculated to account for the population size, expected percentages as well as a 90% degree of confidence for the estimates. The completed sample target is 1211.

The survey sampling frame will be generated using the Postal Code Conversion File (PCCF), available from Statistics Canada, which provides a link between census geographic areas and the six-character postal code (version 2010). The sampling frame consists of six target geographies:

1. Q1/2 urban
2. Q1/2 rural
3. Q3 urban
4. Q3 rural
5. Q4/5 urban
6. Q4/5 rural

All postal codes corresponding to the six target geographies will be used to purchase residential phone numbers in those geographies. The list of phone numbers will not include numbers registered with the national Do Not Disturb/Do Not Call list or business numbers. The postal code related phone lists will be pooled together according to the quintile groups noted above. The survey sample consists of
a list of phone numbers randomly selected from within each of the six target geography groups. As the survey is executed, each of the six groups will be further sub-divided into three age cohorts (18-39, 40-59, and 60+) to provide 18 sub-quotas for subsequent analysis.

Efforts to reduce coverage error will include evening, day and weekend calling, as well as call back to unanswered calls (up to a maximum of 10 times). As the list includes telephone numbers for residents by postal code, it is possible that people who do not have a fixed permanent address may be excluded from this group. As the survey is executed, the researchers will assess if additional interview modes will be introduced to include people without telephones. An additional amendment will be submitted to address any methodological additions or changes.

**Data Collection Tools:**

Analysis of the key informant interviews (n=10) and the focus groups (five focus groups, n=42) identified conceptual themes to better understand the experience and challenges people have getting the primary health care services they need. The conceptual themes were used to guide the selection of specific survey questions to develop a final survey tool to understand the challenges and barriers accessing primary health care services in the SELHIN. In order to increase the validity of specific questions, existing, pre-validated, survey instruments were used to select questions referencing the qualitatively identified conceptual themes. Established instruments included: Primary Care Access Survey, (Ontario) 2011 version; Canadian Community Health Survey, 2010 version; Canadian Survey of Experiences with Primary Health Care, 2008 version; Saskatchewan Patient First Review, 2009; and the Consumer Assessment of Healthcare Providers and Systems, United States Department of Health and Human Services 2008 version.

Where conceptual themes were not covered by existing questions from established survey instruments, the researchers designed questions by following the templates of existing surveys and adapting the wording and context to best fit the necessary concept. The draft survey tool for the SELHIN was presented to the Project Advi-
sory Committee for comment and review (the committees is comprised of physicians, executive directors and directors of regional community health centres, a nurse practitioner, a representative from the Kingston roundtable on poverty reduction, an epidemiologist with the Ministry of Health and Long Term Care, and a statistician with the SELHIN). Question wording, context and consistency were improved through consultation with the Project Advisory Committee. The length of time for survey administration was tested with two members of KFL&A health unit staff and found to be approximately 15-20 minutes. A survey research company has been hired to field the survey. Additional refinements to wording, question order, and content were reviewed through several discussion meetings between the researchers and the company. Final testing of the survey estimates delivery of the survey requires approximately 15 minutes. The resulting survey tool, accompanied by a survey question flow chart, is attached.

Study Process:

Data Management:
The Survey Research Company will manage survey dissemination and data collection. Survey data will be compiled using Excel and SPSS statistical software. All data files are maintained in accordance with privacy and protection standards of the Survey Research Company, CCI Research Inc., (519) 938-9552, http://www.cci-research.com/index.htm. CCI Research Inc. is committed to the protection of all personal information, in compliance with Canada’s Personal Information Protection and Electronic Documents Act (PIPEDA). CCI Research Inc.’s own Corporate Privacy Policy outlines their responsibility to protect the personal information that they collect and manage. CCI Research collects only the information that is required for the purpose of the study. They follow strict ‘industry-standard’ safeguards and controls to protect all personal information (including scheduled shredding or deleting of data, encryption, data stripping, and password protection).

Data Analysis:
Analysis of the survey data will be conducted using SPSS statistical software. The survey analysis will investigate each of the six geographic groups (includes level of deprivation and rural/urban), as well as three age cohorts (18-39, 40-59, and 60+) to compare 18 sub-quotas.

Ethical considerations:
All information will maintain confidentiality.
Any individuals’ area identification information or personal identification will maintain anonymity through the use of aggregate information for reporting purposes and will be kept in accordance with privacy and protection standards of the KFL&A Public Health.
Telephone interview methodology has potential sampling limitations for people who are not part of the telephone list, for those unable to be contacted, as well as a high non-response rate. It is quite possible that coverage error will increase in areas of higher deprivation, lowering the overall representativeness of the sample. The researchers will assess survey progress to determine if the sampling methodology will need to expand to include alternative survey modes to capture groups that may be omitted as a result of simply using telephone interviewing.

Dissemination: Findings from the study will be submitted to peer review journals, presented at primary health care conferences and regional meetings with key stakeholders in the SELHIN, and others in Ontario.

1 http://www.statcan.gc.ca/bselc/olc-cel/olc-cel?catno=92F0153X&lang=eng
5 http://www.health.gov.sk.ca/patient-first-review
6 http://www.caahps.ahrq.gov
Introduction:
Hello, my name is ______ and I am calling from CCI Research on behalf of your local health care services. I would like to speak to a Canadian citizen who lives in the household and is 18 years of age or older. Would that be you?

(Interviewer Prompt: This is a survey being conducted as part of an initiative to understand health care in your region.)
(Interviewer Prompt: Canadian citizen would include permanent resident or refugee)
(Interviewer Prompt: If asked on behalf of which local health care services, respond with “your local health integration network. This network is responsible for funding, planning and coordinating local health services.”)

☐ Speaking Go to I3.
☐ Goes to get them Go to I2
☐ Not available Record Call Back
☐ Refused Thank you for your time.
Goodbye (Refused)

I2. Hello, my name is ____________and I am calling from CCI Research on behalf of your local health care services. I am told you are a Canadian citizen who lives in this household and is 18 years of age or older. Is this correct?

☐ Yes Go to I3
☐ No Go to I2b
☐ Not available Record Call Back
☐ Refused Thank you for your time.
Goodbye (Refused)

I2b. I am sorry, I was looking to speak with a person in this household who is 18 years of age or older. Is that person available?

☐ Yes Go to I2
☐ Not available Record Call Back
☐ Refused Thank you for your time.
Goodbye (Refused)

I3. Hi, We are contacting community residents to get their opinions regarding the way health care services are delivered, and to explore ways to improve patient experiences in the region. Your participation in this survey is completely voluntary and confidential and will take approximately 15 minutes of your time. You may refuse to answer any question or end the survey at any time. However, your participation is very important for us to gather residents’ opinions to help your local health integration network fund, plan and coordinate local health services. All of your responses will be kept strictly confidential. Would you be willing to participate in this survey with me now?

[For questions or concerns regarding the survey, contact Dr. Kieran Moore at KFL&A Public Health, (613) 549-1232 ext. 1121. For questions regarding your rights as a research participant contact Dr. Albert Clark, Chair of Queen’s University Health Sciences Research Ethics Board at (613) 533-6081.]

☐ Yes Go to W1
☐ No later Go to Call back screen
☐ No never Code as Refused (RF)
The first set of questions will be about general health care services and the availability of primary health care providers in your community.

**Warm Up**

W1. How would you describe the overall quality of health care available in your community within the last 12 months? Is it excellent, good, poor, or very poor?

- Excellent
- Good
- Poor
- Very Poor
- Have not used any health care services
- Don’t know
- Refused

**Health System Issues**

HS1. Can you please tell me where you PRIMARILY go for your day-to-day health care needs? Specifically, if you needed to see a health care provider to get a regular check up, a medical exam, or because you were not feeling well, where would you go for help?

[Interviewer: Do not read list. Select one.]

- Doctor’s office
- Your own primary care provider at a family medicine center (such as a family health team)
- Your own primary care provider at a Community health center, women’s health centre, centre at work, school, or university
- A doctor or clinic that specializes in alternative medicine such as a naturopath, herbalist, etc.
- A chiropractic clinic or office
- A walk-in or after-hours clinic
- A hospital outpatient department
- A hospital emergency department
- Call telehealth
- The family doctor of another household member or friend
- Other [Specify]
- Do not need help/would not need care
- Don’t know
- Refused

Now we would like to ask some questions about your primary health care provider. A primary health care provider may be a family doctor, general practitioner, or nurse practitioner. Your primary health care provider would be the person who you would normally call if you wanted a yearly check up, or if you had a non-emergency problem or illness. This would typically be a health care provider you saw before and would likely see again.

[Interviewer Prompt: We do not mean dentists, eye doctors, gynecologists, obstetricians or specialists that you might be seeing for chronic health problems or a sports type injury.]

HS1.b. Do you have a primary health care provider such as a family doctor, general practitioner, or nurse practitioner?

- Yes (Proceed to question HS3a)
- No (Proceed to question HS2)
- Don’t know (Proceed to question HS2a)
- Refused (Proceed to question HS2a)
HS2.a. Have you ever had a primary health care provider such as a family doctor, general practitioner, or nurse practitioner?

- Yes (Proceed to question HS2b)
- No (Proceed to question HS2d)
- Don’t know (Proceed to question DHS10a)
- Refused (Proceed to question DHS10a)

HS2.b. Why do you no longer have one?

[Interviewer prompt: Why do you no longer have a family doctor, general practitioner, or nurse practitioner?]

[Do not read. Select all that apply.]

- Respondent moved and it is no longer practical to see that doctor, have NOT found new doctor
- Respondent was not satisfied with family doctor, they decided not to see him/her again, doctor never available
- Switched to using some form of clinic/walk in clinic/clinic at hospital, other clinic, easier to use/get to clinic, better "service," etc.
- Doctor retired/deceased/changed practice type/sick/pregnant
- Doctor moved from area/cannot locate
- Did not see doctor often, did not see for long time, doctor dropped patient, etc.
- Negative experience with family/other doctor/health care system
- None available/hard to find
- Other (specify)
- Don’t know
- Refused

HS2.c. How long has it been since you last had one?

- Enter number of months
- Enter number of years
- Don’t know
- Refused

INTERVIEWER: Proceed to question HS2e.

HS2.d. Why have you never had one?

[Interviewer prompt: Why have you never had a family doctor, general practitioner, or nurse practitioner?]

[Do not read. Select all that apply.]

- No family doctors (or equivalent) available in the area
- Family doctors (or equivalent) in the area are not taking new patients
- Want family doctor to be the same sex (gender) as me, cannot/have not found one
- Have not tried to find/contact one
- Not covered by OHIP (wait listed)
- Use clinic (walk in or other clinic type)
- Do not need doctor/never sick
- Other, specify
- Don’t know
- Refused
HS2.e. Would you like to have a family doctor, general practitioner, or nurse practitioner?
- Yes (Proceed to HS2f)
- No (Proceed to DHS10a)
- Don’t know (Proceed to HS2f)
- Refused (Proceed to HS2f)

HS2.f. Have you tried to find a family doctor, general practitioner, or nurse practitioner?
- Yes (Proceed to HS2g)
- No (Proceed to DHS10)
- Don’t know (Proceed to DHS10a)
- Refused (Proceed to DHS10a)

HS2.g. What have you done, in the last 12 months, to find a family doctor, general practitioner, or nurse practitioner?
[Do not read. Select all that apply.]
- Contact a doctor/doctor’s office to see if they were taking new patients
- Contact an organization, such as the College of Physicians and Surgeons of Ontario to see if they could help you find a doctor
- Contact the Ontario Ministry of Health and Long Term Care to see if they could help you find a doctor
- Contact a hospital, Community Care Access Centre (CCAC), public health program, clinic, in person or via the web, telephone, etc.
- Asked family, friends, co-workers, etc. for names & information
- On waiting list (may have filled out application)
- Have registered for Health Care Connect (the new provincial program to help people find family doctors)
- Other, specify
- Nothing
- Don’t know
- Refused

INTERVIEWER: Proceed to DHS10a.
****The following questions are asked only to those respondents who have a provider****

HS3.a. What type of health care provider is this – a family doctor, general practitioner, or nurse practitioner?

[Prompt: If multiple providers are noted, ask to identify their main health care provider – who do they see the most.]

(1) Family physician/family doctor
(2) General Practitioner
(3) Nurse practitioner
(4) Other not on list - record response (Proceed to DHS10a)
(5) Don’t know
(6) Refused

[**Use the provider type for all other questions. Insert 1 = family doctor, 2 = general practitioner, 3 = nurse practitioner, 5 = primary health care provider, 6 = primary health care provider**.]

HS3.b. How many years have you had your current <primary care provider>?
- Never actually saw family doctor
- Less than one year
- Enter number of years
- Don’t know
- Refused
HS3.c. Could you please tell me approximately when you had your last appointment with your <primary care provider>?

[Read list. Select one.]
- Less than one year ago
- 1-3 years ago
- More than 3 years ago
- Don’t know
- Refused

HS4b. Thinking back to your last appointment with your <primary care provider>, please tell me if you encountered any of the following issues.

[Read list. Select all that apply Enter 1 for YES, and a blank cell otherwise.]
- Difficulty making the appointment
- Waited too long to get an appointment
- Had to travel a long distance to get to the doctor’s office
- Transportation problems such as car trouble, cost of gas or taxi, lack of public transportation
- Difficulty getting out of the house because of health problems
- Waited too long in the doctor’s office
- Doctor seemed rushed during appointment
- Doctor did not explain things in a way that was easy to understand

HS6. What was the fee for?

[Do not read list. Select all that apply.]
- Missed Appointment
- Getting a doctor’s note for work/school/government documents
- Changing an appointment
- A prescription form
- Obtaining advice from health care provider/health care provider office
- Annual fee for renewing registration/roster
- Fee for referral to a specialist
- Travel vaccinations
- Other, specify
- Don’t know
- Refused

HS6.c. Did you have difficulty paying this fee?

- Yes
- No
- Don’t know
- Refused

HS7. Does your <primary care provider> limit the number of health problems you can discuss during an appointment?

- Yes
- No
- Don’t know
- Refused
HS8.a. Is your <primary care provider> part of a larger health care team that includes access to other health care professionals at no charge?
- Yes (Proceed to HS8b)
- No (Proceed to HS9)
- Don’t know (Proceed to HS9)
- Refused (Proceed to HS9)

HS8.b. What type of other health care professionals are part of this team?
[Read list. Select all that apply.]
- Yes/No/Don’t know/Refused
- Other Doctors or Physicians
- Nurse Practitioner
- Nurse
- Nutritionist
- Dietician
- Social Worker
- Psychiatrist
- Counselor
- Occupational Therapist
- Medical Residents
- Physiotherapist
- Pharmacist
- Chiropodist (foot treatment/prevention of disease)  
  (Interviewer: pronounced shiropodist)
- Other (specify)
- Don’t know
- Refused

HS9. Would you strongly agree, agree, disagree, or strongly disagree that your <primary care provider> delivers a range of services or referrals that meet your health needs?
- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don’t know
- Refused

Relationship With Health Care Provider

R1. Overall, how often does your <primary care provider> allow you enough time to discuss your feelings, fears or concerns about your health? Would you say always, usually, rarely, or never?
- Always
- Usually
- Rarely
- Never
- Don’t know
- Refused

R2. How often does your <primary care provider> show respect for what you have to say? Would you say always, usually, rarely, or never?
- Always
- Usually
- Rarely
- Never
- Don’t know
- Refused
R3. How often does your <primary care provider> explain things in a way that is easy to understand? Would you say always, usually, rarely, or never?

- Always
- Usually
- Rarely
- Never
- Don’t know
- Refused

R4. For the following three statements please indicate whether you strongly agree, agree, disagree or strongly disagree.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don’t know
- Refused

R4a. I have experienced unacceptable conduct from health care workers such as rude or dismissive behaviour.

[Interviewer prompt: Do you strongly agree, agree, disagree or strongly disagree]

R4b. I worry that my care would not be as good if I complained about how I am treated.

[Interviewer prompt: Do you strongly agree, agree, disagree or strongly disagree]

R4c. I like to do my own research before I take my <primary care provider>’s advice.

[Interviewer prompt: Do you strongly agree, agree, disagree or strongly disagree]

R5. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied with your <primary care provider>?

- Very satisfied
- Somewhat satisfied
- Somewhat dissatisfied
- Very dissatisfied
- Don’t know
- Refused

DENTAL HEALTH  **Asked to ALL respondents**

DHS10.a Do you have insurance that covers all or part of your dental expenses?

- Yes (all or in part)
- No
- Don’t know
- Refused

DHS10.b. Have you been to a dentist in the past 3 years?

- Yes  (Proceed to NS1a)
- No  (Proceed to DHS10c)
- Don’t know  (Proceed to NS1a)
- Refused  (Proceed to NS1a)
DHS10c. What are the reasons that you have not been to a dentist in the past 3 years?

[Do not read list. Select all that apply.]

- Have not gotten around to it/don’t have time
- Respondent did not think it was necessary
- Doctor did not think it was necessary
- Personal or family responsibilities
- Not available - at time required
- Not available - at all in the area
- Waiting time was too long
- Language - problem
- Cost
- No insurance
- Had to travel a long distance to get to the dentist’s office
- Transportation problems such as car trouble, cost of gas or taxi, lack of public transportation
- Did not know where to go/uninformed
- Dislike going to dentist
- Fear (e.g., painful, embarrassing, find something wrong)
- Wears dentures
- Unable to leave the house because of a health problem
- Other
- Don’t know
- Refused
NAVIGATING THE HEALTH SYSTEM
**Asked to ALL respondents**

NS1.a. Did you ever experience any difficulties getting the specialist care you needed for a diagnosis or consultation?
- Yes (Proceed to NS1b)
- No (Proceed to NS2)
- Have never required specialist care (Proceed to NS2)
- Don’t know (Proceed to NS2)
- Refused (Proceed to NS2)

NS1b. What type of difficulties did you experience? [Do not read list. Select all that apply.]
- Difficulty getting a referral from physician
- Difficulty getting an appointment
- Appointment was cancelled by specialist
- Unable to leave the house because of a health problem
- Do not have personal/family physician
- Waited too long to get an appointment
- Waited too long to see the specialist (i.e., in-office waiting)
- Service not available at time required
- Service not available in the area
- Transportation problems
- Cost
- Language problems
- Did not know where to go (i.e., information problems)
- Other - Specify
- Don’t know
- Refused

NS2. For the following statements please indicate whether you strongly agree, agree, disagree, or strongly disagree.
- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don’t know
- Refused

NS2.a. My personal health care records such as lab results, x-rays, or referral requests seem to get lost in the system.
[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.b. I am confident that if I had a medical problem I would receive the treatment I needed.
[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.c. I am confident that if I had a medical problem I would receive treatment as soon as I needed it.
[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.d. The health care system is so complex, I worry that if I become seriously ill I will not be able to find the help I need.
[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]
Understanding Health Inequities and Access to Primary Health Care

NS2.e. If I had a health condition, I am confident that I could find information about the medical treatment options available for my condition.

[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.f. In the past 12 months, I was encouraged to attend programs in the community that could help me, such as support groups or exercise classes?

[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]  
[Prompt: This could be encouragement by anyone such as primary health care provider, family, friends]

INDIVIDUAL FINANCIAL CHALLENGES **Asked to ALL respondents**

IF2. During the past 12 months, was there a time when you skipped a medical test, treatment, or follow-up that was recommended because of the cost?

- Yes
- No
- Not Applicable (no medical test, treatment, etc. necessary in last 12 months)
- Don’t know
- Refused

IF3b. During the past 12 months, was there a time when you did not fill a prescription for medicine, or you skipped doses of your medicine because of the cost?

- Yes
- No
- Not Applicable (no prescriptions in last 12 months)
- Don’t know
- Refused

IF4.a. In the past 12 months, has any long-term health condition interfered with your normal daily activities?

- Yes (Proceed to IF4b)
- No (Proceed to IF6a)
- Not Applicable (no health conditions in past 12 months) (Proceed to IF6a)
- Don’t know (Proceed to IF6a)
- Refused (Proceed to IF6a)

IF4b. In the past 12 months, how much work have you missed because of a long-term health condition?

- Have not missed any work
- Less than 1 month
- 1 month
- 1-3 months
- More than 3 months
- I do not work
- Don’t know
- Refused
IF5. Which long-term health condition is this?
[Read list. Select One]

[INTERVIEWER prompt: If the respondent wants to report more than one condition, probe for the main reason or the one that has required the highest number of days of absence.]

☐ Injury
☐ Diabetes
☐ Cancer
☐ Depression
☐ Respiratory Disease
☐ Heart Disease
☐ Other - Specify
☐ Don’t know
☐ Refused

IF6a. The following question is about the food situation for your household over the past year. In the past 12 months, were you or others in your household ever hungry but didn’t eat because you couldn’t afford enough food?

☐ Yes
☐ No
☐ Don’t know
☐ Refused

IF7a. During the past month, how often did you feel: ... hopeless? Would you say, all of the time, most of the time, some of the time, or none of the time?

[INTERVIEWER prompt if necessary: From [date one month ago] to yesterday, how often did you feel . . . hopeless?]

☐ All of the time
☐ Most of the time
☐ Some of the time
☐ None of the time
☐ Don’t know
☐ Refused

IF7b. During the past month, how often did you feel: ... nervous or anxious?

[INTERVIEWER prompt if necessary: From [date one month ago] to yesterday, how often did you feel . . . anxious?]

☐ All of the time
☐ Most of the time
☐ Some of the time
☐ None of the time
☐ Don’t know
☐ Refused

IF7. The following questions are about any distress you may have experienced in the past month, that is, since [date one month ago] to yesterday. For each item, please tell me whether you have felt that way all of the time, most of the time, some of the time, or none of the time.
IF7c. During the past month, how often did you feel: ... sad or depressed?
[Interviewer prompt if necessary: From [date one month ago] to yesterday, how often did you feel ... sad or depressed?]
☐ All of the time
☐ Most of the time
☐ Some of the time
☐ None of the time
☐ Don’t know
☐ Refused

IF8. During the past month, how much did these feelings usually interfere with your life or activities? Would you say a lot, some, a little, or not at all?
☐ A lot
☐ Some
☐ A little
☐ Not at all
☐ Don’t know
☐ Refused

***If respondent answers “all of the time” to one or more of IF7a, IF7b, or IF7c, telephone number is provided at the end of survey for where they can get assistance***

DEMOGRAPHIC QUESTIONS **Asked to ALL respondents**
The next questions are asked to help us group answers and for classification purposes only. I would like to remind you that this information is completely confidential, and that no individual information will ever be reported or released.

SD1. What is your postal code?
☐ Record Postal Code
☐ Don’t know
☐ Refused

So just to confirm I’ve entered everything correctly, your postal code is: >CHECK_POSTAL<

Is that correct?
☐ Yes
☐ No
☐ Refused

SD2. INCLUDING yourself, how many people live in your household?
[INTERVIEWER: If required, includes all persons, whether or not they are family members, who usually live in the household, even if they are temporarily away on business, at school or on vacation. This does not include renters.]
Enter number of persons [Enter 1 if person lives alone]

Nineteen or more people [INTERVIEWER: if respondent provides this as an answer, please probe and confirm. If respondent lives in a retirement home, please record them as being “one person” or “2” if they live with their spouse.]

☐ Don’t know
☐ Refused

SD3.a. Are there any children under the age of 16 who live in your household?

☐ Yes (Proceed to SD3b)
☐ No (Proceed to SD4)
☐ Don’t know (Proceed to SD4)
☐ Refused (Proceed to SD4)

SD3.b. Are you a parent or guardian of any of these children?

☐ Yes
☐ No
☐ Don’t know
☐ Refused

SD4. What is your current marital status?

☐ Married
☐ Common Law/Living with partner
☐ Separated
☐ Divorced
☐ Widowed
☐ Single, never married
☐ Don’t know
☐ Refused

SD5. Are you an Aboriginal person, that is, North American Indian, Métis or Inuit?

☐ Yes
☐ No
☐ Don’t know
☐ Refused

SD6.a. Can you please tell me the year you were born?

☐ Enter year (Proceed to SD7)
☐ Don’t know (Proceed to SD6b)
☐ Refused (Proceed to SD6b)

SD6.b. Would you be able to tell me what age range you fall into?

[Read list. Select one.]

☐ 18-39
☐ 40-59
☐ 60+
SD7. What is the highest level of education you have completed? [Do not read list. Select one. Probe where necessary to clarify.]

- □ Less than high school
- □ Completed high school
- □ Some community college or technical school
- □ Completed community college or technical school
- □ Some University
- □ Completed Bachelor’s Degree (Arts, Science, Eng, etc.)
- □ Post graduate Training: Master’s - MA, MSc, MLS, MSW, MBA, etc.
- □ Post graduate Training: PhD, "doctorate"
- □ Professional Degree (Law, Medicine, Dentistry)
- □ Don’t know
- □ Refused

SD8.a. What is the best estimate of your total annual PERSONAL income for the year ending December 31st, 2011, before taxes and deductions, and NOT including income that other members of your household earn? [Read list. Select one.]

- □ Less than $28,000 (Proceed to SD9)
- □ $28,000 to less than $40,000 (Proceed to SD9)
- □ $40,000 to less than $50,000 (Proceed to SD9)
- □ $50,000 to less than $65,000 (Proceed to SD9)
- □ More than $65,000 (Proceed to SD9)
- □ Don’t know (Proceed to SD8b)
- □ Refused (Proceed to SD8b)

SD8.b. This is a critical question as part of our research on access to health care. All information will remain anonymous and non-identifiable. Would you be able to tell me more generally whether your annual PERSONAL income this year is less than $28,000 or more than $28,000?

- □ Less than (or equal to) $28,000
- □ More than $28,000
- □ Don’t know
- □ Refused

SD9. Record Gender [Do not ask unless necessary]

- □ Male
- □ Female

Thank you for your time today. Your answers will be used to help us improve the planning of health care services, and to understand the barriers to health care services experienced by those in your community. Goodbye.

***If respondent answers “all of the time” to one or more of IF7a, IF7b, or IF7c, telephone number is:

Telehealth Ontario – Free Access to a registered nurse – 24 hours a day, 7 days a week:
1-866-797-0000 TTY: 1-800-796-0007
Amendment Acknowledgment/Approval Letter

August 12, 2011

Dr. Kieran M Moore  
Department of Emergency Medicine  
Queen's University

File #: 6006025EMED-156-11 Development of a survey tool to understand barriers to accessing primary health care for people with greater material and social deprivation in the South East Local Health Integrated Network (SE LHIN)

Dear Dr. Moore

I am writing to acknowledge receipt of the following:

- Request for approval of Phase 2 of the study
- Protocol – Phase 2
- Focus Group Demographic Questionnaire
- Focus Group Questions
- Information/Consent Form for Focus Groups

I have reviewed these materials and hereby give my approval. Receipt of these amendments will be reported to the Health Sciences Research Ethics Board.

Yours sincerely,

Albert Clark, Ph.D.
Chair  
Research Ethics Board
Study Title: EMED-156-11 Development of a survey tool to understand barriers to accessing primary health care for people with greater material and social deprivation in the South East Local Health Integrated Network (SE LHIN)

File # 6006025

Principal Investigator: Dr. Kieran M Moore
Co-Investigators: Paul Belanger, Suzanne Biro, Amrit Sehdev

Phase 3 Protocol Addition

Phase 3 Objectives:

1. Create a regionally relevant survey tool that incorporates the information gathered from literature reviews, key informant interviews and focus groups.
2. Refine the survey tool through input and expertise from the project advisory committee as well as through pilot cognitive interviewing sessions.
3. Design sampling frame
4. Disseminate survey
5. Analysis of Survey Data

AMENDMENT Addition:

In an effort to enhance participant selection to include more deprived populations in the SE LHIN, the same survey will be administered using face to face interviews to a subset of the population.

Phase 3 Amendment Methodology:

The survey will be conducted using face-to-face interviews. These surveys are a subset of the original sample size and will be analyzed in accordance to the surveys conducted using telephone interviews, outlined in the approved Phase 3 Protocol (approval date: 12/13/11). Recruitment for 60 participants will use a two-step selection process: a targeted approach for specific site selection (6 sites; 3 urban and 3 rural), and a systemized approach for participant selection at each site. Site selection was chosen in collaboration with the Project Advisory Committee such that organizations selected are those that serve more vulnerable clients and are situated within deprived locations as defined by the Deprivation Index. Through established relationships with Project Advisory Committee members, organizations were contacted to request whether they would support face-to-face interviews with their clients to conduct surveys on location. Six site locations have agreed to be part of the project. They are:

- Partners in Mission Food Bank, Kingston
- Home Base Housing, Kingston
- Belleville & Quinte West Community Health Centre Good Food Box
- Guthrie House: Elgin
- Central Hastings Support Network, Madoc
- Northbrook Area

At each site, organization coordinators maintain client lists. Coordinators will be asked to divide the total number of clients by ten and contact every nth person to request participation in a face-to-face interview to complete the (for example, if the client list totals 30
people, \(30/10 = 3\), contact every third person to an \(n = 10\) per site). Surveys will be administered, one on one, verbally, and in a private area. A letter of information and signed consent will be obtained prior to administering the survey (attached). To ensure participants understand the project in the event of challenges with literacy, the interviewer will ask each participant if they would prefer the letter of information and consent form be read out loud. Survey answers will be recorded using both pen and paper and a laptop computer. Participants will be able to view the answers on the laptop and the answers with pen and paper. One open-ended question at the end of the survey will be transcribed in situ. The interviewer will read the response back to the participant to ensure the correct information has been recorded. Following completion of the survey, participants will be provided with a $25.00 gift voucher for groceries as a thank you for participating in the survey process. The gift voucher will be accompanied by a thank you letter (attached).

**Data Collection Tools:**
An identical survey tool to the approved telephone interview version will be used. It is revised and attached with track changes to show where the content was changed to reflect the face-to-face interview methodology (as opposed to telephone interview).

**Study Process: See chart**
Data Management:
Survey data will be compiled using Excel and SPSS statistical software. All information obtained for the study is confidential. The survey files will be stored at the Kingston, Frontenac, Lennox & Addington (hereafter, KFL&A) Public Health Unit, and managed in compliance with the organization’s record retention guidelines. All electronic files will be encrypted and password protected. All hard copy surveys will be stored in a locked filing cabinet for security. Information in this study is for research purposes only. When the study results are presented or published, no names will ever be used.

The research team is based at the Kingston, Frontenac, Lennox & Addington Public Health Unit, as well as at the Queen’s University Department of Family Medicine. Information gathered for this project will not be shared with other project staff.

Data Analysis:
Analysis of the survey data will be conducted using SPSS statistical software. The survey analysis will investigate each of the six geographic groups (includes level of deprivation and rural/urban), as well as three age cohorts (18-39, 40-59, and 60+) to compare 18 sub-quotas.

Ethical considerations:
All information will maintain confidentiality.
Any individuals’ area identification information or personal identification will maintain anonymity through the use of aggregate information for reporting purposes and will be kept in accordance with privacy and protection standards of the KFL&A Public Health Unit.

Dissemination:
Findings from the study will be submitted to peer review journals, presented at primary health care conferences and regional meetings with key stakeholders in the SELHIN, and others in Ontario.
A Survey To Understand Barriers To Accessing Primary Health Care For People In The South East Local Health Integrated Network

**Survey Letter of Information/Consent Form**

You are invited to participate in a survey interview as part of a project to better understand the challenges and barriers people experience trying to get the health care they need. This letter provides you with the information necessary to make an informed decision about whether you would like to participate in the survey interview. If you have any questions, please do not hesitate to ask our project team.

**Purpose:**
The main goals of the project are to understand unequal health outcomes and access to community health services.

**Procedures:**
In the survey interview, you will be asked to answer questions about your experiences and challenges getting the health care you need. The interviewer will ask you questions and will record your answers.

**Risks and Discomforts:**
There are no known risks related to being in this study. You may not benefit directly from being in this study. The information from this study may be used to help improve the community health services in our region (South East Local Health Integrated Network).

**Voluntary Participation:**
Participation in this study is voluntary. You may refuse to participate and you may refuse to answer any questions or withdraw from the study at any time. Our research team will not inform anyone about your participation in this study. You will be asked to sign a consent form prior to beginning the survey interview.

**Confidentiality and Privacy:**
All information obtained for the study is confidential. All files (both electronic and hard copies) of the survey interview will be stored at the Kingston, Frontenac, Lennox & Addington Public Health Unit and managed in compliance with the organization’s record retention guidelines. No identifying information will be recorded. Information in this study is for research only. When the study results are presented or published your name will never be used.

The research team is based at the Kingston, Frontenac, Lennox & Addington Public Health Unit, as well as at Queen’s University Department of Family Medicine. Information gathered for this project will not be shared with other project staff.

**Contact Persons for Questions**
If you have any questions regarding your participation in the study, please contact Dr. Kieran Moore (Principal Investigator) at (613) 549-1232, ext. 1121 or Ms. Suzanne Biro (Research Associate) at (613) 549-1232, ext. 1588 or (613) 533-9300, ext. 79567; or Dr. Paul Belanger (Principal Investigator) at (613) 549-1232, ext. 1602.

If you have any questions regarding your rights as a research participant, or the conduct of the study, you may contact Dr. Albert Clark, Chair of Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081. These people are not involved in the study and contacting them will not affect your participation in the study.

This is your copy of the Letter of Information to keep for your records.
Survey Participant Consent Form

I have read and understand the Letter of Information for this study, have had the nature (purposes, procedures and technical language) of this study explained to me and I agree to participate. I have been given the time to review the above information and to ask for clarification if I chose to do so. I have had the opportunity to ask questions which have been answered to my satisfaction. I am voluntarily signing this form. I will keep the Letter of Information for my reference.

If at any time I have further questions or problems, I can contact Dr. Kieran Moore (Principal Investigator) at (613) 549-1232, ext. 1121 or Ms. Suzanne Biro (Research Associate) at (613) 549-1232, ext. 1588 or (613) 533-9300, ext. 79567; or Dr. Paul Belanger (Principal Investigator) at (613) 549-1232, ext. 1602.

If I have questions regarding my rights as a research subject I can contact Dr. Albert Clark, Chair, Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board at (613) 533-6081.

Participant’s Name:_________________________________________
(print)
Participant’s Signature: _________________________________
Date: _________________________________
Introduction:

Hi, my name is ______ and I am here on behalf of your local health care services. We are talking to community residents to get their opinions regarding the way health care services are delivered, and to explore ways to improve patient experiences in the region.

Before we begin, there is an Information Letter to read, and a consent form for you to sign. Would you like me to read the information to you, or would you like a few minutes to read it yourself?

[Once letter is read and consent form is signed, begin interview.]

The first set of questions will be about general health care services and the availability of primary health care providers in your community.

Warm Up

W1. How would you describe the overall quality of health care available in your community within the last 12 months? Is it excellent, good, poor, or very poor?

- Excellent
- Good
- Poor
- Very Poor
- Have not used any health care services
- Don’t know
- Refused

Health System Issues

HS1. Can you please tell me where you PRIMARILY go for your day-to-day health care needs? Specifically, if you needed to see a health care provider to get a regular check up, a medical exam, or because you were not feeling well, where would you go for help?

[Interviewer: Do not read list. Select one.]

- Doctor’s office
- Your own primary care provider at a family medicine center (such as a family health team)
- Your own primary care provider at a Community health center, women’s health centre, centre at work, school, or university
- A doctor or clinic that specializes in alternative medicine such as a naturopath, herbalist, etc.
- A chiropractic clinic or office
- A walk-in or after-hours clinic
- A hospital outpatient department
- A hospital emergency department
- Call telehealth
- The family doctor of another household member or friend
- Other [Specify]
- Do not need help/would not need care
- Don’t know
- Refused
Now I would like to ask some questions about your primary health care provider. A primary health care provider may be a family doctor, general practitioner, or nurse practitioner. Your primary health care provider would be the person who you would normally call if you wanted a yearly check up, or if you had a non-emergency problem or illness. This would typically be a health care provider you saw before and would likely see again.

[Interviewer Prompt: We do not mean dentists, eye doctors, gynecologists, obstetricians or specialists that you might be seeing for chronic health problems or a sports type injury.]

HS1.b. Do you have a primary health care provider such as a family doctor, general practitioner, or nurse practitioner?

- Yes (Proceed to question HS3a)
- No (Proceed to question HS2a)
- Don’t know (Proceed to question HS2a)
- Refused (Proceed to question HS2a)

HS2.a. Have you ever had a primary health care provider such as a family doctor, general practitioner, or nurse practitioner?

- Yes (Proceed to question HS2b)
- No (Proceed to question HS2d)
- Don’t know (Proceed to question DHS10a)
- Refused (Proceed to question DHS10a)

HS2.b. Why do you no longer have one?
[Interviewer prompt: Why do you no longer have a family doctor, general practitioner, or nurse practitioner?]

[Do not read. Select all that apply.]

- Respondent moved and it is no longer practical to see that doctor, have NOT found new doctor
- Respondent was not satisfied with family doctor, they decided not to see him/her again, doctor never available
- Switched to using some form of clinic/walk in clinic/clinic at hospital, other clinic, easier to use/get to clinic, better "service," etc.
- Doctor retired/deceased/changed practice type/sick/pregnant
- Doctor moved from area/cannot locate
- Did not see doctor often, did not see for long time, doctor dropped patient, etc.
- Negative experience with family/other doctor/health care system
- None available/hard to find
- Other (specify)
- Don’t know
- Refused

HS2.c. How long has it been since you last had a family doctor, general practitioner, or nurse practitioner?

- Enter number of months
- Enter number of years
- Don’t know
- Refused

INTERVIEWER: Proceed to question HS2e.
HS2.d. Why have you never had one? [Interviewer prompt: Why have you never had a family doctor, general practitioner, or nurse practitioner?]

[Do not read. Select all that apply.]
- No family doctors (or equivalent) available in the area
- Family doctors (or equivalent) in the area are not taking new patients
- Want family doctor to be the same sex (gender) as me, cannot have not found one
- Have not tried to find/contact one
- Not covered by OHIP (wait listed)
- Use clinic (walk in or other clinic type)
- Do not need doctor/never sick
- Other, specify
- Don’t know
- Refused

HS2.e. Would you like to have a family doctor, general practitioner, or nurse practitioner?

[Interviewer note: For respondents who ask about finding a family doctor: “I can provide contact information for Health Care Connect. The telephone number is 1-800-445-1822, or you can look up Health Care Connect online.” If asked, “The website is http://www.health.gov.on.ca/en/ms/healthcareconnect/public/”]

- Yes (Proceed to HS2f)
- No (Proceed to DHS10a)
- Don’t know (Proceed to HS2f)
- Refused (Proceed to HS2f)

HS2.f. Have you tried to find a family doctor, general practitioner, or nurse practitioner?

- Yes (Proceed to HS2g)
- No (Proceed to DHS10)
- Don’t know (Proceed to DHS10a)
- Refused (Proceed to DHS10a)

HS2.g. What have you done, in the last 12 months, to find a family doctor, general practitioner, or nurse practitioner?

[Do not read. Select all that apply.]
- Contact a doctor/doctor’s office to see if they were taking new patients
- Contact an organization, such as the College of Physicians and Surgeons of Ontario to see if they could help you find a doctor
- Contact the Ontario Ministry of Health and Long Term Care to see if they could help you find a doctor
- Contact a hospital, Community Care Access Centre (CCAC), public health program, clinic, in person or via the web, telephone, etc.
- Asked family, friends, co-workers, etc. for names & information
- On waiting list (may have filled out application)

Have registered for Health Care Connect (the new provincial program to help people find family doctors)

- Other, specify
- Nothing
- Don’t know
- Refused

INTERVIEWER: Proceed to DHS10a.
****The following questions are asked only to those respondents who have a provider****

**HS3.a. What type of health care provider is this – a family doctor, general practitioner, or nurse practitioner?**

[Prompt: If multiple providers are noted, ask to identify their main health care provider – who do they see the most.]

[Prompt if asked about the difference between a nurse and a nurse practitioner: A nurse practitioner can prescribe some medicines whereas a nurse cannot.]

- (1) Family physician/family doctor/medical doctor/general practitioner
- (2) General Practitioner
- (3) Nurse practitioner
- (4) Other not on list - record response (Proceed to DHS10a)
- (5) Don’t know
- (6) Refused

[**Use the provider type for all other questions. Insert 1 = doctor, 2 = general practitioner, 3 = nurse practitioner, 5 = primary health care provider, 6 = primary health care provider**.]

**HS3.b. How many years have you had your current <primary care provider>?**

- Never actually saw family doctor
- Less than one year
- Enter number of years
- Don’t know
- Refused

**HS3.c. Could you please tell me approximately when you had your last appointment with your <primary care provider>?**

[Read list. Select one.]

- Less than one year ago
- 1-3 years ago
- More than 3 years ago
- Don’t know
- Refused

**HS4b. Thinking back to your last appointment with your <primary care provider>, please answer yes or no if you encountered any of the following issues.**

[Read list. Select all that apply Enter 1 for YES, and a blank cell otherwise.]

- Difficulty making the appointment
- Waited too long to get an appointment
- Had to travel a long distance to get to the doctor’s office
- Transportation problems such as car trouble, cost of gas or taxi, lack of public transportation
- Difficulty getting out of the house because of health problems
- Waited too long in the doctor’s office
- Doctor seemed rushed during appointment
- Doctor did not explain things in a way that was easy to understand
- None of the above
- Don’t know/Refused
HS6.a. Were you ever asked to pay a fee by your primary care provider’s office?

☐ Yes (Proceed to HS6b)
☐ No (Proceed to HS7)
☐ Don’t know (Proceed to HS7)
☐ Refused (Proceed to HS7)

HS6.b. What was the fee for?  
[Do not read list. Select all that apply.]

☐ Missed Appointment
☐ Getting a doctor’s note for work/school/government documents
☐ Changing an appointment
☐ A prescription form
☐ Obtaining advice from health care provider/health care provider office
☐ Annual fee for renewing registration/roster
☐ Fee for referral to a specialist
☐ Travel vaccinations
☐ Other, specify
☐ Don’t know
☐ Refused

HS6.c. Did you have difficulty paying this fee?

☐ Yes
☐ No
☐ Don’t know
☐ Refused

HS7. Does your primary care provider limit the number of health problems you can discuss during an appointment?

☐ Yes
☐ No
☐ Don’t know
☐ Refused

HS8.a. Is your primary care provider part of a larger health care team that includes access to other health care professionals at no charge?

☐ Yes (Proceed to HS8b)
☐ No (Proceed to HS9)
☐ Don’t know (Proceed to HS9)
☐ Refused (Proceed to HS9)

HS8.b. What type of other health care professionals are part of this team?

[Read list. Select all that apply.]

[Prompt if asked about the difference between a nurse and a nurse practitioner: A nurse practitioner can prescribe some medicines whereas a nurse cannot.]

[Interviewer note: The health professionals do not have to be located in the same building.]

[Interviewer Definitions]

Dietitian: A Dietitian is a health care professional who has a degree in food and nutrition and is registered with a Provincial Regulatory Body. A Dietitian provides advice and counseling regarding food and nutrition.
Nutritionist: A Nutritionist provides advice and counseling regarding food and nutrition but may not have a degree and does not hold any Registration.

Medical resident: A Medical Resident is a person who has achieved a medical degree and who is practicing medicine under the supervision of fully licensed physicians. A Resident is training to specialize in a particular medical field such as family medicine.

- Yes/No/Don’t know/Refused
- Other Doctors or Physicians
- Nurse Practitioner
- Nurse
- Nutritionist
- Dietician
- Social Worker
- Psychiatrist
- Counselor
- Occupational Therapist
- Medical Residents
- Physiotherapist
- Pharmacists
- Chiropodist (foot treatment/prevention of disease) (Interviewer: pronounced shiropodist)
- Other (specify)
- Don’t know
- Refused

HS9. Would you strongly agree, agree, disagree, or strongly disagree that your <primary care provider> delivers a range of services or referrals that meet your health needs?

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don’t know
- Refused

Relationship With Health Care Provider

R1. Overall, how often does your <primary care provider> allow you enough time to discuss your feelings, fears or concerns about your health? Would you say always, usually, rarely, or never?

- Always
- Usually
- Rarely
- Never
- Don’t know
- Refused

R2. How often does your <primary care provider> show respect for what you have to say? Would you say always, usually, rarely, or never?

- Always
- Usually
- Rarely
- Never
- Don’t know
- Refused
R3. How often does your <primary care provider> explain things in a way that is easy to understand? Would you say always, usually, rarely, or never?

☐ Always
☐ Usually
☐ Rarely
☐ Never
☐ Don’t know
☐ Refused

R4. For the following three statements please indicate whether you strongly agree, agree, disagree or strongly disagree.

☐ Strongly agree
☐ Agree
☐ Disagree
☐ Strongly disagree
☐ Don’t know
☐ Refused

R4a. I have experienced unacceptable conduct from health care workers such as rude or dismissive behaviour.

[Interviewer prompt: Do you strongly agree, agree, disagree or strongly disagree]

R4b. I worry that my care would not be as good if I complained about how I am treated.

[Interviewer prompt: Do you strongly agree, agree, disagree or strongly disagree]

R4c. I like to do my own research before I take my <primary care provider>’s advice.

[Interviewer prompt: Do you strongly agree, agree, disagree or strongly disagree]

R5. Overall, are you very satisfied, somewhat satisfied, somewhat dissatisfied or very dissatisfied with your <primary care provider>?

☐ Very satisfied
☐ Somewhat satisfied
☐ Somewhat dissatisfied
☐ Very dissatisfied
☐ Don’t know
☐ Refused

Dental Health **Asked To All Respondents**

And now I would like to ask you a few questions regarding dental health.

DHS10.a Do you have insurance that covers all or part of your dental expenses?

☐ Yes (all or in part)
☐ No
☐ Don’t know
☐ Refused

DHS10.b. Have you been to a dentist in the past 3 years?

☐ Yes (Proceed to NS1a)
☐ No (Proceed to DHS10c)
☐ Don’t know (Proceed to NS1a)
☐ Refused (Proceed to NS1a)
DHS10c. What are the reasons that you have not been to a dentist in the past 3 years?

[Do not read list. Select all that apply.]

- Have not gotten around to it/don’t have time
- Respondent did not think it was necessary
- Doctor did not think it was necessary
- Personal or family responsibilities
- Not available - at time required
- Not available - at all in the area
- Waiting time was too long
- Language - problem
- Cost
- No insurance

**Had to travel a long distance to get to the dentist’s office**

- Transportation problems such as car trouble, cost of gas or taxi, lack of public transportation
- Did not know where to go/uninformed
- Dislike going to dentist
- Fear (e.g., painful, embarrassing, find something wrong)
- Wears dentures
- Unable to leave the house because of a health problem
- Other (specify)
- Don’t know
- Refused

Navigating The Health System **Asked To All Respondents**

Now I would like to ask you a few questions regarding the health care system in general.

NS1.a. Did you ever experience any difficulties getting the specialist care you needed for a diagnosis or consultation?

- Yes (Proceed to NS1b)
- No (Proceed to NS2)
- Have never required specialist care (Proceed to NS2)
- Don’t know (Proceed to NS2)
- Refused (Proceed to NS2)

NS1b. What type of difficulties did you experience?

[Do not read list. Select all that apply.]

- Difficulty getting a referral from physician
- Difficulty getting an appointment
- Appointment was cancelled by specialist
- Unable to leave the house because of a health problem
- Do not have personal/family physician
- Waited too long to get an appointment
- Waited too long to see the specialist (i.e., in-office waiting)
- Service not available at time required
- Service not available in the area
- Transportation problems
- Cost
- Language problems
- Did not know where to go (i.e., information problems)
- Other - Specify
- Don’t know
- Refused
NS2. For the following statements please indicate whether you strongly agree, agree, disagree, or strongly disagree.

- Strongly agree
- Agree
- Disagree
- Strongly disagree
- Don’t know
- Refused

NS2.a. My personal health care records such as lab results, x-rays, or referral requests seem to get lost in the system.

[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.b. I am confident that if I had a medical problem I would receive the treatment I needed.

[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.c. I am confident that if I had a medical problem I would receive treatment as soon as I needed it.

[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.d. The health care system is so complex, I worry that if I become seriously ill I will not be able to find the help I need.

[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.e. If I had a health condition, I am confident that I could find information about the medical treatment options available for my condition.

[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

NS2.f. In the past 12 months, I was encouraged to attend programs in the community that could help me, such as support groups or exercise classes?

[Prompt: Do you strongly agree, agree, disagree, or strongly disagree?]

[Prompt: This could be encouragement by anyone such as primary health care provider, family, friends]

Individual Financial Challenges **Asked To All Respondents**

These next questions are about your personal health.

IF2. During the past 12 months, was there a time when you skipped a medical test, treatment, or follow-up that was recommended because of the cost?

- Yes
- No
- Not Applicable (no medical test, treatment, etc. necessary in last 12 months)
- Don’t know
- Refused
IF3b. During the past 12 months, was there a time when you did not fill a prescription for medicine, or you skipped doses of your medicine because of the cost?

- Yes
- No
- Not Applicable (no prescriptions in last 12 months)
- Don't know
- Refused

IF4.a. In the past 12 months, has any long-term health condition interfered with your normal daily activities?

- Yes (Proceed to IF4b)
- No (Proceed to IF6a)
- Not Applicable (no health conditions in past 12 months) (Proceed to IF6a)
- Don't know (Proceed to IF6a)
- Refused (Proceed to IF6a)

IF4b. In the past 12 months, how much work have you missed because of a long-term health condition?

- Have not missed any work
- Less than 1 month
- 1 month
- 1-3 months
- More than 3 months
- I do not work
- Don't know
- Refused

[INTERVIEWER prompt: If the respondent wants to report more than one condition, probe for the main reason or the one that has required the highest number of days of absence.]

- Injury
- Diabetes
- Cancer
- Depression
- Respiratory Disease
- Heart Disease
- Other - Specify
- Don’t know
- Refused

IF5. Which long-term health condition is this?

[Read list. Select One]

IF6a. The following question is about the food situation for your household over the past year. In the past 12 months, were you or others in your household ever hungry but didn’t eat because you couldn’t afford enough food?

- Yes
- No
- Don’t know
- Refused

IF7. The following questions are about any distress you may have experienced in the past month, that is, since [date one month ago] to yesterday. For each item, please tell me whether you have felt that way all of the time, most of the time, some of the time, or none of the time.
IF7a. During the past month, how often did you feel: ... hopeless? Would you say, all of the time, most of the time, some of the time, or none of the time?
[Interviewer prompt if necessary: From [date one month ago] to yesterday, how often did you feel . . . hopeless?]
- All of the time
- Most of the time
- Some of the time
- None of the time
- Don’t know
- Refused

IF7b. During the past month, how often did you feel: ... nervous or anxious?
[Interviewer prompt if necessary: From [date one month ago] to yesterday, how often did you feel . . . anxious?]
- All of the time
- Most of the time
- Some of the time
- None of the time
- Don’t know
- Refused

IF7c. During the past month, how often did you feel: ... sad or depressed?
[Interviewer prompt if necessary: From [date one month ago] to yesterday, how often did you feel . . . sad or depressed?]
- All of the time
- Most of the time
- Some of the time
- None of the time
- Don’t know
- Refused

[Skip IF8 if IF7a, IF7b, AND IF7c = None of the time.]

IF8. During the past month, how much did these feelings usually interfere with your life or activities? Would you say a lot, some, a little, or not at all?
- A lot
- Some
- A little
- Not at all
- Don’t know
- Refused

***If respondent answers “all of the time” to one or more of IF7a, IF7b, or IF7c telephone number is provided for where they can get assistance***

“You have indicated that you have experienced some distress in the past month. I have the number for Telehealth Ontario, where a registered nurse is available 24 hours a day, 7 days a week. Can I provide you with this number?” “The number is 1-866-797-0000 TTY: 1-800-796-0007”

IF9. At or near your residence, do you have access to a place where you can exercise or be physically active?
- Yes
- No
- Don’t know
- Refused
Demographic Questions **Asked To All Respondents**

The next questions are asked to help us group answers and for classification purposes only. I would like to remind you that this information is completely confidential, and that no individual information will ever be reported or released.

**SD1. What is your postal code?**
- Record Postal Code
- Don’t know
- Refused

So just to confirm I’ve entered everything correctly, your postal code is: >CHECK_POSTAL<
Is that correct?
- Yes
- No
- Refused

**SD2. INCLUDING yourself, how many people live in your household?**
[Interviewer prompt for any response over 1: And this includes yourself?]
[Interviewer: If required, includes all persons, whether or not they are family members, who usually live in the household, even if they are temporarily away on business, at school or on vacation. This does not include renters.]

Enter number of persons [Enter 1 if person lives alone]
Nineteen or more people [Interviewer: if respondent provides this as an answer, please probe and confirm. If respondent lives in a retirement home, please record them as being “1 person” or “2” if they live with their spouse.]
- Don’t know
- Refused

**SD3.a. Are there any children under the age of 16 who live in your household?**
- Yes (Proceed to SD3b)
- No (Proceed to SD4)
- Don’t know (Proceed to SD4)
- Refused (Proceed to SD4)

**SD3.b. Are you a parent or guardian of any of these children?**
- Yes
- No
- Don’t know
- Refused

**SD4. What is your current marital status?**
- Married
- Common Law/Living with partner
- Separated
- Divorced
- Widowed
- Single, never married
- Don’t know
- Refused

**SD5. Are you an Aboriginal person, that is, North American Indian, Métis or Inuit?**
- Yes
- No
- Don’t know
- Refused
SD6.a. Can you please tell me the year you were born?

- Enter year (Proceed to SD7)
- Don’t know (Proceed to SD6b)
- Refused (Proceed to SD6b)

SD6.b. I understand, but to help your local health integration network plan and coordinate local health services, would you be willing to tell me what broad age range you fall into? Would that be:

[Read list. Select one.]
- 18-39
- 40-59
- 60+
- Don’t know
- Refused

SD7. What is the highest level of education you have completed? [Do not read list. Select one. Probe where necessary to clarify.]

- Less than high school
- Completed high school
- Some community college or technical school
- Completed community college or technical school
- Some University
- Completed Bachelor’s Degree (Arts, Science, Eng, etc.)
- Post graduate Training: Master’s - MA, MSc, MLS, MSW, MBA, etc.
- Post graduate Training: PhD, “doctorate”
- Professional Degree (Law, Medicine, Dentistry)
- Don’t know
- Refused

SD8.a. What is the best estimate of your total annual PERSONAL income for the year ending December 31st, 2011, before taxes and deductions, and NOT including income that other members of your household earn?

[Read list. Select one.]

- Less than $28,000 (Proceed to SD9)
- $28,000 to less than $40,000 (Proceed to SD9)
- $40,000 to less than $50,000 (Proceed to SD9)
- $50,000 to less than $65,000 (Proceed to SD9)
- More than $65,000 (Proceed to SD9)
- Don’t know (Proceed to SD8b)
- Refused (Proceed to SD8b)

SD8.b. This is a critical question as part of our research on access to health care. All information will remain anonymous and non-identifiable. Would you be able to tell me more generally whether your annual PERSONAL income this year is less than $28,000 or more than $28,000?

- Less than (or equal to) $28,000
- More than $28,000
- Don’t know
- Refused

SD9. Record Gender [Do not ask unless necessary]

- Male
- Female

OE1. And finally, what would help you to get the healthcare or help you need?
Amendment Acknowledgment/Approval Letter

April 05, 2012

Dr. Kieran Moore
Department of Emergency Medicine
Queen's University

File #: 6006025 EMED-156-11 Development of a Survey Tool to Understand Barriers to Accessing Primary Health Care for People With Greater Material and Social Deprivation in the South East Local Health Integrated Network (SE LHIN)

Dear Dr. Moore

I am writing to acknowledge receipt of the following:

- Request for approval of the Phase 3 – Protocol Addition (January 16, 2012)
- Interview/Survey Questions
- Thank You Letter for Participants Who Completed the Interview/Survey
- Letter of information and Consent Form (January 16, 2012)

I have reviewed these materials and hereby give my approval. Receipt of these amendments will be reported to the Health Sciences Research Ethics Board.

Yours sincerely,

Albert Clark, Ph.D.
Chair
Research Ethics Board
Access to Health Care Study

Dear Study Participant,

CCI Research Inc., on behalf of the Kingston, Frontenac and Lennox & Addington Public Health Unit and the South East Local Health Integration Network (LHIN), would like to take this opportunity to thank you very much for the time you have taken to participate in this interview today.

Sharing your experiences will contribute toward the evaluation of access to health care in your region and will help your local health integration network plan and coordinate local health services.

In appreciation of your time, please accept an honourarium of a $25.00 gift certificate to your local grocery store.

Further information that may be helpful to you is provided below.

• If you or someone you know needs to find a primary health care provider such as a family doctor, you can contact Health Care Connect at 1-800-445-1822, or you can look up Health Care Connect online. The website is http://www.health.gov.on.ca/en/ms/healthcareconnect/public.

• If you or someone you know is experiencing distress, you can call Telehealth Ontario, where a registered nurse is available 24 hours a day, 7 days a week. The number is 1-866-797-0000 TTY: 1-800-796-0007.

• If you need or someone you know needs medical advice, you can call Telehealth Ontario, where a registered nurse is available 24 hours a day, 7 days a week. The number is 1-866-797-0000 TTY: 1-800-796-0007.

• If you or someone you know is having a medical emergency or needs immediate medical assistance, you should go to your local hospital’s emergency ward.

• For questions or concerns regarding the survey, you can contact Dr. Kieran Moore at KFL&A Public Health, (613) 549-1232 ext. 1121.

Thank you again for your participation in this important study.
Access to Healthcare