

PUBLIC ENGAGEMENT – WHY BOTHER?

**Public engagement - why bother? Exploring the
conditions under which public engagement
practices in local health care decision making
matters**

By

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ABSTRACT

Public engagement - why bother? Exploring the conditions under which public engagement practices in local health care decision making matters

Public engagement is increasingly becoming an important part of equitable decision-making in healthcare. In particular, it is important to ensure that minority populations can be involved in policy forming activities, given Canada's growing diverse population. Therefore this research examines the nature and scale of public engagement occurring with visible minority populations in terms of enhancing their awareness and access to health care resources. This was explored within the contexts of general health care services organised through Local Health Integration Networks (LHINs) in Ontario, Canada, as well as more specialised health care services, provided through Cancer Care Ontario (CCO). Key-informant interviews, focus groups and a document review were utilized to gain insight into institutional and community perceptions about engagement and its importance in accessing healthcare services. Findings highlight some of the barriers and facilitators for engagement of visible minority community members. The theoretical and policy contributions point to the need create opportunities to facilitate interrelationships between institutions existing at smaller spatial scales; therefore allowing community leaders, decision makers, activists and citizens to exchange skills and knowledge to aid in better understanding of the delivery of regional health care.

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CHAPTER 1 – INTRODUCTION

1.1 Research context

Public participation in health care stems from the early notions of health promotion. In 1986 the First International Conference for Health promotion, held in Ottawa, was instrumental in broadening our understanding of health to include more than just the biomedical model of health. Instead, the federal document of 1974; A New perspective on the health of Canadians, outlined the concept of health promotion. This emphasizes the importance of looking at the overall quality of life and highlights that citizens and communities should have the ability to make choices about their own health and define what health means to them (Epp, 1987). Therefore, to enable this citizen voice to be heard in decision making for health care, a strategy that is now in widespread use in health care decision making, is public participation.

The term public participation was first coined in the 1960s by Sherry Arnstein; her work provides valuable insights into the links between citizen engagement and citizen power (Arnstein, 1969). Past efforts in public engagement have been primarily utilized within the fields of environmental and planning policy and decision making (Beirele & Cayford, 2002). However, in recent decades there has been a drive towards incorporation of public values in health care decision making (Eyles & Litva, 1998; Charles & Demaio, 1993). This shift towards population-based health and a focus on the broader determinants of health has occurred due to an increased expectation by the public to have their individual preferences reflected in treatment choices and decisions (Abelson *et al.*, 2007; Frankish *et al.*, 2002,). Therefore, in order to be responsive to community based priorities, there has been a prominent trend towards decentralized health care systems and an increase in public participation in health care (Abelson & Eyles, 2002; Frankish *et al.*, 2002). Although there are differing conceptualisations of decentralised health care systems, all visions share the desire to shift decision making power to regional levels for the purpose of increased autonomy at the local level (Eyles & Litva, 1998).

Through the 1960s and 70s there have been attempts world-wide with public representation and catering to population based preferences in local health service provision (Checkoway, 1982). In Canada, there have been many government commissions, reports and publications advocating citizen participation in health care decision making (Charles & Demaio, 1993). Therefore, in 1975 this trend of public participation in health care decision making continued in Ontario, Canada, with the creation of the District Health Councils (DHC). The DHC were created to play the role of advisor to the Ontario Ministry of Health and Long-Term Care on the health requirements of the geographic communities they were set up to serve. More importantly, they also played an important role of relaying information on health care services to the community (MOHLTC, 2009). In 2005, the DHC were dissolved to form Ontario's new regionalised health care authorities, the Local Health Integration

Networks (LHINs). The LHINs have been set up to plan, integrate and fund local health services (LHIN, 2009).

Given that the population of visible minorities in Ontario is 22.8%, and immigrant population, 26%, it is important that the Canadian political arena be inclusive of these groups (Statistics Canada, 2006). Specifically, in line with a key piece of federal legislation, the Canada Health Act (CHA) of 1984, which states that all Canadians have equal access to medically necessary services regardless of their ability to pay (Health Canada, 2006). Acknowledging the high levels of diversity in the province creates a growing pressure on health care services to respond to the changing needs and expectations of these diverse groups in a culturally sensitive and efficient manner (Lawrence & Kearns, 2005).

1.2 Research question and objectives

Currently, the literature on public engagement is narrow in scope with regards to understanding the involvement of minority and newcomer populations in decision making. This is illustrated by the lack of direct proof of innovative engagement efforts with minority populations, despite the evidence of lacking knowledge and accessibility issues among minority populations and marginalised groups (Lawrence & Kearns, 2005; Raja-Jones, 1999; Watts *et al.*, 2004).

Therefore, the objectives of this research are to understand whether, how and under what conditions innovative public engagement practices in local health care decision making may occur and might be sustained for and with visible minority communities. Particularly, the research question to be examined is:

With respect to awareness of and access to healthcare resources, what is the nature and scale of public engagement for and with visible minority populations? This will be explored in the context of: general health care, Local Health Integration Networks (LHINs) and specific health care, Cancer Care Ontario (CCO).

1.3 The relevance of health geography

It is important early on in this thesis to set the stage for the health geography context utilized. The field of health geography has its roots in the older discipline of medical geography, which followed a more biomedical paradigm (Elliott, 1999). Since then, the definition of health has evolved to be more than simply the absence of disease, to complete physical social and emotional well-being (WHO, 1957). Therefore, in line with the evolving model of health, geographers altered the field of medical geography to the geography of health and health care, giving rise to a population health perspective (Elliott, 1999).

Traditionally, medical geographers studied the geographical distribution of disease and illness, using space as a passive container by which to examine the issues surrounding disease spread (Kearns, 1993). In the context of health geography, however, there is a 'sense of place concept', which has changed the

examination of disease within *space*, to instead observe how health is affected by *place*. Therefore the importance of place has been renewed by involving an interest in the context of an experienced place, with meaning and familiarity, as opposed to simply the characteristics of regional geography (Kearns, 1993).

Health geography lends itself to a more holistic approach to health and a move towards a community-based health care model by focusing attention on the social context of health (Dyck, 1999; Kearns 1993). An important aspect about the discipline health geography is we can critically study health disparities and systematic inequalities in the context of the factors that cause these disparities (Cutchin, 2007). More importantly for this research, the discipline allows us to recognise subjective experiences through the framing of relations and distributions of power (Dyck, 1999).

The concept of decentralisation is the “transfer of authority or dispersal of power” from a national or sub-national level to a lower level of government. Therefore, this concept of regional health care and public participation is inherently geographical; as we treat place as a key element in determining the nature and scope of public participation within the context of a regional health care setting (Eyles & Litva, 1998).

1.4 Chapter outline

This thesis is composed of five chapters. The second chapter provides a critical review of the literature providing a theoretical understanding of the relationship between public engagement activities and decision making in the local health care arena, specifically at a community level. This chapter explores the concept of citizen participation and discusses the trends of public engagement in Canada; additionally it addresses the importance of inclusion of immigrants and visible minorities in decision making. The chapter concludes by identifying some of the major gaps in the literature that cause the emergence of research objectives that form the basis of this thesis.

The third chapter sets the context for this research and discusses the methods used for the study. This chapter introduces the comparative nature of this study as well as the research setting. The qualitative nature of the study is justified, and the utilization of semi-structured interviews, focus groups and a document review are discussed as strategies used for data collection. A description of participant selection, data collection and analysis is provided. Finally, the chapter discusses the steps taken to maintain rigour throughout the research process.

The fourth chapter illustrates the results obtained through a policy document review, key-informant interviews and focus groups. The results are organized into four sections, beginning with the meaning and importance of public engagement, which sets the context for understanding the varying perceptions of the participants. The chapter then discusses the barriers and

accessibility to health care, the importance of culturally appropriate public engagement, challenges faced by institutions undertaking public engagement and finally, community beliefs and values on public engagement.

The final chapter discusses the significance of the research findings. After summarizing the key results, this chapter provides a discussion of the theoretical and policy implications of the findings. The chapter also provides limitations of the research conducted, and suggests areas for further exploration.

CHAPTER 2 – LITERATURE REVIEW

2.1 Introduction

This Chapter aims to provide a theoretical understanding of the relationship between public engagement activities and decision making in the local health care arena, specifically at a community level. The concept of public participation in the realm of health care stems from the early notions of health promotion. In 1986 the First International Conference for Health Promotion was held in Ottawa which was instrumental in broadening our understanding of health to include more than just the biomedical model of health as put forth by the federal document of 1974; *A New Perspective On the Health of Canadians*. The concept of health promotion emphasizes the importance of looking at the overall quality of life therefore implying that citizens should have the ability to make choices and manage their surroundings (Epp, 1987).

“This view of health recognizes freedom of choice and emphasises the role of individuals and communities in defining what health means to them” (Epp, 1987, pg. 420).

To enable this citizen voice in the arena of health care decision making and governance, a strategy that is now in widespread use is public participation.

This chapter is divided into four sections. To set the context, the first section provides a brief history of public participation, including some of the first experimentations with citizen representation and then moving onto some of the varying definitions and objectives of public participation. The second section explores the concept of “lay participation” and the ambiguous interpretations as well as the importance of citizen values. In the third section, trends of public engagement in Canada are discussed, along with the importance of the inclusion of immigrants and visible minorities in decision making. Finally the fourth section discusses the emergence of research objectives for this thesis. Additionally, the chapter identifies some of the major gaps within the current literature.

2.2 Public participation, an historical perspective

Over the past three decades, public participation has been important in determining how society will manage and protect the environment (Beirele & Cayford, 2002). The concept of public participation was first brought about in the 1960's, coined by Sherry Arnstein and used primarily in planning (Arnstein, 1969). Her research provided valuable insight into the link between citizen engagement and citizen power (Arnstein, 1969). Over the years, emphasis has been placed on engaging and empowering stakeholders and citizens to plan and deliver programs and services (Bruni *et al.*, 2008). However, the use of public participation in health did not come about until a decade later. Indeed, the increasing role of public engagement in environmental and planning policy making has spurred a flurry of activity aimed at incorporating public values in

health care decision making, especially within the context of decentralized decision making trends (Eyles & Litva, 1998, Charles & DeMaio, 1993).

The idea of public participation in health care decision making has been prevalent all over the world for the past four decades, and has been included as a part of health sector reform, often times in the form of regional health authorities. The drive towards this type of health care reform has been brought about by a variety of factors, including, most notably a structural shift towards population health and broader determinants of health frameworks (Frankish *et al.*, 2007). The public increasingly expects that individual preferences be reflected in treatment choices and decisions; that health professionals and decision makers be responsive to community based priorities; and that there is greater accountability with respect to the allocation of resources (Frankish *et al.*, 2002, Checkoway, 1982).

Health care reforms of the mid eighties and nineties in Canada have been the most recent drivers of public inclusion (Charles & DeMaio, 1993). Over the past few decades, the most prominent trend has been that of devolved health care and the creation of health regions (Frankish *et al.*, 2007). This devolution of authority has come about in efforts to curb health care spending, to better integrate services, empower citizens and make health providers more accountable to the communities they serve (Lomas, 1997, Church *et al.*, 2002, Abelson *et al.*, 1995). Unfortunately, with decentralized authority, these goals can never be pursued equally because there is a constant power struggle between the multiple levels of governments, health service providers and the local citizenry (Lomas, 1997). The following section describes some of the earliest attempts with public representation and catering to population based preferences in local health service provision.

2.2.1 Models of participation

A fundamental goal of public participation is to survey the needs and preferences of the citizenry with the aim of designing a responsive health system (Abelson & Eyles, 2002). This intent was the foundation for some of the earliest experiments with citizen representation in health authorities. In the United States, The National Health Planning and Resources Development Act of 1974 allowed for planning in health to employ public participation. This was to be facilitated by Health Systems Agencies (HSA's), which would allow citizenry to benefit from planning methods that would involve representation, improve communication and activate participation (Checkoway, 1982). HSA's were set up with the intentions of cutting health care expenses and improving access to high quality medical care. Each HSA would recognize their local health priorities and accordingly set community goals to obtain better health care (Morone & Marmor, 1981). A key feature of these HSA's is that they were presumed to offer representation of the health care consumers in the communities they served (Morone & Marmor, 1981). A nation-wide study in the US examined the objectives and methods used in public participation strategies within health policy and decision making settings.

The study was based on survey responses by agency officials and it was found that for the most part public engagement was carried out to satisfy minimum mandate requirements without enabling any transference of power (Checkoway, 1982).

Similarly, in the United Kingdom, population-based planning in health care began in the 1960's. The idea was formalised by the District General Hospitals (DGH's) to incorporate population-based preferences in the planning of health service provision. There was not yet a guaranteed role for patient participation, rather, this change came about in order to better manage the allocation of resources (Toth, 1996). In the 1970s and 80s there was more of an effort made on the part of the National Health Service (NHS) to include patient and public preferences in health care planning, however this was carried out without much success (Toth 1996). Similar to the HSA's in the US, there was a formation of Community Health Councils (CHC's) in the U.K. to represent the public's views to the NHS. The role of the CHC's was primarily that of a consultative body, and their value was largely dependent on the local health authority being represented (Toth, 1996). This attempt by the health care system in the U.K. was to fulfill the notion of consumer rights in health care, and the idea that the public should be involved in resource allocations and priority setting (Toth, 1996).

The concept of public participation in health care decision making in Canada also emerged in the early 1970's, stemming from early government publications such as the Lalonde Report. The idea addressed in this document was that in addition to simply looking at disease and treatment, the health care system ought to look at the overall quality of life, implying that citizens should have the ability to make choices and manage their surroundings (Lalonde, 1974). Consequently there have been many government commissions, reports and publications advocating increased citizen participation in health care decision making (Charles & Demaio, 1993). Akin to the creation of HSA's in the US and CHC's in the U.K. was the creation of District Health Council's (DHC's) in Ontario. These DHC's were created in 1975 to play the role of advisor to the Ontario Ministry of Health and Long-Term Care on the health requirements of the geographic communities they were set up to serve. Additionally, they also played an important role of relaying information on health care services to the community (MOHLTC, 2009). This notion of citizen representation in health care decision making and priority setting was a new and exciting style of governance; however, the ambiguous nature of the idea raised questions surrounding the definition and objectives of this undertaking.

2.2.2 Definitions and objectives of public participation

Collective participation and regional health care decision making did not become widespread in Canada until the 1990's. With a step away from regular bureaucracies, there was increased community control and a move towards new governance structures. Public consultation exercises were the traditional route

through which public opinion was gauged and this process is normally initiated by the government, be it at the federal, provincial or local level (Abelson & Eyles, 2002). Such public consultations generally provide the citizenry with a sense of ownership of and commitment to, the health care system. Regional health authorities are commonly run by a board of elected officials and through this electoral process it is believed that the health boards are then directly accountable to their communities (Abelson & Eyles, 2002). Unfortunately, the downside of this system is that the conflicting interests of and in the community may pose a barrier to participation. Therefore most communities have a low voter turnout with the exception of those communities comprised of concentrated political interests or those with financial stakes in the health system (Marmor & Morone, 1980).

Disputes over consumer roles in health care have been ongoing in the history of public participation (Morone & Marmor 1981). On the one hand, the terms ‘citizen involvement’ and ‘direct participation’ imply that everyone should have a say. However, on the other hand it is argued that political and technical elites, including medical practitioners or health administrators are simply better equipped to identify, prioritize and cater to consumer needs (Morone & Marmor 1981).

Therefore there remain many questions with respect to what exactly concepts such as ‘consumer needs’, ‘citizen & public engagement’ or ‘participation’ entail. One concise definition of public engagement is:

“the practice of involving members of the public in the agenda-setting, decision making and policy forming activities of priority setting in healthcare” (Bruni *et al.*, 2008, pg. 15).

However, it is widely accepted that public participation is a highly complex and relative term, using multiple methods and serving multiple purposes (Abelson *et al.*, 2007). For decades public policy analysts and participation advocates have argued about the worth and challenges of involving citizens in health care decision making. The concept of public participation is linked to the democratic notion of ‘government for the people, by the people’ (Abelson *et al.*, 2001). The ideals of democratic participation encourage power sharing between citizens, experts and elected officials; henceforth leading to citizen empowerment (Abelson *et al.*, 2001). Citizen empowerment means that citizens feel they are in control of the decisions that govern the delivery of their health care (Lomas, 1997). However, very few studies have been carried out to examine whether citizens indeed want this increased responsibility.

2.3 Lay participation and public values

While there is plenty of theoretical literature on the merits of “health care participation”, there is minimal empirical evidence on *actual* participation within health care decision making and related implications (Abelson *et al.*, 1995).

Abelson *et al.* carried out one such study, where randomly selected citizens, elected health officials and experts in health care were polled on their preferences on involvement in health care decision making (1995). It was found that there were significant differences in willingness to be involved between the groups polled. Aside from those who distinctly indicated an interest via their attendance at town-hall meetings, citizens in general, do not think their group is suitable for making decisions. Participants favoured the representation of elected officials, government or experts as an authority for decision making (Abelson *et al.*, 1995). Other works have questioned whether decentralized health care produces better results for citizen participation and empowerment in terms of outcomes, while also expressing scepticism about whether average citizens are even willing to be involved in health care decision making (Lomas, 1997).

There have been studies showing that despite utilizing inventive methods, certain groups of the citizenry remain unlikely to partake in health care decision making. For example, a study carried out in the US examined and analysed the methods employed by HSA's that were successfully able to influence and enhance citizen participation (Checkoway, 1981). It was found that these particular HSA's applied innovative methods that facilitated meaningful involvement of consumers and consumer organisations in order to involve them in planning, implementation and to build support and community organisation. However, this was not achieved uniformly across all HSA's because it was highly dependent on the diversity of the community in the area, the type of community leadership as well as staff and resources available at the particular agency (Checkoway, 1981).

The concept of "lay", "public", "citizen", or "community" participation is ambiguous (Charles & DeMaio, 1993). One way of thinking about the lay public could be anyone who has a financial stake in health care decision making outcomes (Checkoway, 1981). Alternatively, one could make the simple distinction between providers and non-providers (Charles & DeMaio, 1993). This interest in citizen participation indicates that the Canadian government is reacting to the increasingly common view that major institutions of health care are indifferent and unaccountable to citizens (Church *et al.*, 2002, Abelson & Eyles, 2002). Advocates of public participation propose that including citizenry in decision making will lead to more accountable and cost effective decisions. However, due to the elusive definition of public participation and the vague nature of what the government hopes to achieve by implementing this strategy, researchers have been investigating specific aspects of citizen participation to evaluate its contributions to decision making and consequent policies (Church *et al.*, 2002). Some of the aspects of citizen engagement undergoing examination included: who ought to participate; the level of input the public should have; and the types of decisions they should be involved in (Church *et al.*, 2002)?

Successful democracy involves understanding and representing public values and beliefs. However, despite the acknowledged importance of values in healthcare decision making, stakeholders and decision makers disagree on how values are actually defined and what they consist of (Giacomini *et al.*, 2004).

Values can be viewed as ethical principles such as autonomy or equity, but they could also be viewed as preferences. Due to this ambiguity in defining values, stakeholders and policy makers are uncertain about how to allow values to explicitly guide actions. To overcome this confusion, health reformers consider the term value as one that encompasses many definitions (Giacomini *et al.*, 2004). However, this lack of clarity has policy analysts and stakeholders arguing about their own value positions. Hence a more useful approach to integrate values into healthcare research might be to recognize the differences between different value positions and find a way in which they might fit together (Giacomini *et al.*, 2004).

Researchers have been grappling with the lack of clarity surrounding the issue of citizen participation in health care for decades. Despite the substantial theoretical, practical and political literature to support citizen involvement in health care decision making, there are still many practical challenges to address before regional health authorities and public participation can be seen as a pragmatic approach to health care reform and meaningful citizen engagement. For instance, there is still debate about whether there ought to be community participation at all; differing views on what level and through which processes citizens should be participating at; differences in perceptions about the roles and compositions of regional health authority board members and the lack of evaluation of the impact of public engagement on health care decision making (Frankish *et al.*, 2002). The next section will address some of the studies undertaken with the hopes of shedding some light on how citizen values might be incorporated and effectively utilized in the health care decision making arena.

2.4 Trends in public engagement in Canada

Despite clear attempts at involving citizens in health care decision making, it has proven to be an ominous task. The competing interests of politicians and health service providers leave limited scope for the lay public to have their voices heard, thus reducing opportunities for collaborative problem solving and discouraging the public from participatory activities (Frankish *et al.*, 2002).

While numerous studies in the past have been carried out to determine the significance of public engagement, researchers are now trying to decipher how to further understand the merit of its use in health care decision making. Therefore, the research conducted in the past decade has focussed more on understanding the role of civic participation in local health care decision making. A case study conducted in four separate geographic regions in Ontario explores the influences that shape public participation in health care decision making (Abelson, 2001). Several interesting findings emerged from this research. For example, communities with different social and structural attributes were more inclined to partake in varying styles of participation. This is in part due to differing community values, which could be shaped by education, culture and religion (Abelson, 2001). These results highlighted the importance of incorporating public views in the contextual fabric of a local community setting (Abelson, 2001).

One of the theoretical reasons behind the concept of citizen participation is the longing for local accountability (Litva *et al.*, 2002). Whose desire is it? A study was conducted to investigate the degree of involvement desired by the public. After identifying three levels of potential participation; (system, program and individual levels), it was found that there was a definite willingness to be involved in the system and program levels, but less on an individual level, which was correlated by the public, to a higher level of involvement in the decision making process. The main message that came across was that the public want their personal experiences and values to supplement the input from health care professionals when making final decisions, and consequently for decision makers to be transparent about the choices made (Litva *et al.*, 2002). These results also support the conclusion that Lomas came to; the public do not feel equipped to make decisions they feel they do not possess the knowledge for (Lomas, 1997).

Complimenting the work of Litva *et al.*, another study looked at the theoretical reasons why public engagement has gained popularity over the past few decades and what its contributions are to the health sector (Abelson *et al.*, 2003a). This too concluded that despite the obvious potential of citizen engagement, there are some key challenges to this method of decision making. For example, strong vested interests may try to influence the final verdict in the direction of their benefit. Conversely, citizens that shy away from participation remain under-represented on citizen panels and therefore decisions made are not necessarily reflective of the entire population. It is also difficult to ensure accountability to participants for the outcome of deliberation, when the actual decision might not be constituted until years later (Abelson *et al.*, 2003a).

Public demand for transparent and accountable decision making has led to experimentations with citizen consultations and engagement to greatly evolve over the decades (Abelson *et al.*, 2003b). In the early to mid 1990's the trend was to simply use traditional approaches of polling the public through surveys and focus groups intended to bring forth citizen views. Public consultation methods are now becoming more sophisticated as policy makers are more interested in value-laden priority setting processes. Increasingly, the methods are being designed to promote discussions with the hopes of obtaining carefully considered and well informed decisions (Abelson *et al.*, 2003b). A study was conducted to determine the effects of introducing different opportunities for deliberation to gather public input on compiling community health priorities. It was found that participants were more accepting to differing perspectives and more agreeable to change their views when exposed to deliberative methods. However, results also indicated that dominant views such as high ranking priorities were less amenable to change, and if anything, were more, rather than less embedded after deliberation (Abelson *et al.*, 2003b).

In addition to these studies, other works have created frameworks to aid in understanding the complexities of public participation in regionalized health governance. Thurston *et al.* conducted a qualitative study using five health regions as case studies to explore their public engagement initiatives and furthermore,

surveyed community agencies utilizing the grounded theory tradition (2005). Using the data obtained from the study, several themes emerged that were relevant to describing the processes of public participation initiatives. The conceptual framework emphasizes the following key factors: that public engagement initiatives are an on-going process and therefore require constant evaluation; the importance of transparent policy making processes *within* the specific health region and hence the need for accounting for the entire “political space”; the need to be cognisant about the impact that social factors have on public participation; the significance of inclusion of policy communities; and that the overall health of the population ought to be seen as the ultimate outcome of public participation (Thurston *et al.*, 2005).

In another study, researchers emphasized the importance of community development and capacity building and how these can contribute to the sustainability of the Canadian health system (Germann & Wilson, 2004). In a qualitative study conducted in Alberta, Canada, community development workers at five regional health authorities were interviewed. The results from the study contributed towards the development of a model for visualizing organisational capacity in community development. It was shown that organisational capacity is a multi-layered concept based on the values and beliefs of administrators and organisational leaders. Therefore success in community autonomy and capacity building is highly dependent on the principles and commitment of the staff involved at all levels of the organisation (Germann & Wilson, 2004).

While these empirical works have provided significant insight into the complex nature of public engagement for the purpose of health care decision making and the multi-faceted approaches through which this might be achieved sustainably, there are still many gaps in the literature. It has been identified that future studies will benefit from undertaking comparative analyses of public input into community decision making (Abelson, 2001). Although the conceptual model provided by Germann & Wilson is helpful in clarifying that enhanced community autonomy and participation is an essential component of health care reform, it can only be used as a guide for further innovations and action in community capacity building by health practitioners, researchers and decision makers (2004). Additionally, the framework provided by Thurston *et al.* solidifies the factors that ought to be considered in assessing the processes and outcomes of citizen participation. However this framework is in need of validation within other sectors of government as well as within non-governmental organisational settings (2004). Furthermore it is advised that this research would benefit from active engagement with stakeholders of regional health authorities to examine whether the key components are meaningful and feasible (Thurston *et al.*, 2004).

One of the fundamental reasons for the shift towards regionalized health care and public participation is to move towards a more population based approach. This implies incorporation of societal values and beliefs. One study conducted by Veenstra & Lomas explores the relationship between the civic nature of communities and effective political governance in regional health

authorities (1999). A community, whose citizens actively partake in community based activities in order to form effective collaborations, is thought to be one that is high in social capital (Putnam, 1993). The findings from this research show that in order for society to benefit from high social capital, provinces must incorporate collaborative problem solving in order to obtain trust and commitment between political organisations and community structures (Veenstra & Lomas, 1999).

Within the decentralized health governance models, a special effort is made to include minority groups to engage in collective action. However, although there is encouragement to share views, values and beliefs, there is often a lack of capacity to impose significant changes to policy outputs (Wayland, 2006). A report written by the Social Protection division of the World Bank, created a development framework to be applied at a local level, linking; community empowerment, decentralised governance and public service provision (Helling *et al.*, 2005). This framework points to three alternative approaches to local development; (decentralized sectoral, local government and community support) and that all three approaches highlight similar principles. Empowerment of socio-economically disadvantaged, as well as marginalized populations, receptiveness to the need for funding and resources and increased autonomy of local organisations leading to greater accountability and augmentation of local capacity. Unfortunately, regardless of congruent ideologies, integrating the three approaches at a local level remains a struggle. Local development requires a strong base of existing institutions that have heightened capacity and influence within their local space to appropriately link organisational processes (Helling *et al.*, 2005).

One of the most challenging issues when considering social capital and civic participation is the overall composition of society (Stolle & Howard, 2008). In the past three decades, global migration has been on the rise; with international migrants accounting for an increasing percentage of the population in many developed countries (United Nations, 2008). In Canada approximately 250,000 new immigrants arrive yearly, comprising 20% of the total population and contributing to two-thirds of the population growth (Asanin & Wilson, 2008). Due to this change in population over recent decades, Canadian society has become more ethnically and culturally diverse (Stolle & Howard, 2008). Hence there has been an interest by the international research community to explore and investigate policy maker, government and decision maker attitudes towards this diversity (Asanin & Wilson, 2008). The next section will address the barriers and challenges associated with the incorporation of the views of immigrants and minorities.

2.4.1 Engagement with the immigrant population and visible minorities

Inclusion of immigrants and visible minorities in the Canadian political arena has been an ongoing process. Initially these groups were barely granted any recognition from the federal government as valuable assets to Canadian society. However, this began to change in part due to post war economic expansion, and

also due to the rise of welfare state policies (Wayland, 2006). These policies and programs were put in place to reduce inequality, amplify freedom and promote democracy (Moscovitch, 2010). This desired equality was aided by the Multiculturalism Policy that came into effect in 1971. By confirming this as an official policy, Canada declared the value and dignity of all Canadian citizens as equal regardless of race, ethnicity and religion. Therefore all citizens were increasingly encouraged to integrate into their society and partake actively in social, cultural and political affairs (CIC, 2008a).

Prior to the 1950's, the majority of immigrants were mostly from European countries, however, starting in the 1970's successive waves of immigrants began arriving from Asian countries such as China, India, Pakistan, Hong Kong and Korea (Hyman, 2001). This influx of immigrants and the focus on population based health in the past few decades has led to increased investigation by researchers into the social determinants of immigrant health (Dunn & Dyck, 2000). In addition, an important factor to consider for host countries is accessibility to health care for newcomers and minority populations; as inaccessibility poses a barrier to participation in society (Asanin & Wilson, 2008).

A policy that governs health care delivery in all of Canada's provinces and territories is the Canada Health Act (CHA) of 1984 (Health Canada, 2006). The main goal of the CHA is to ensure medically necessary services for all Canadians regardless of their ability to pay. The provinces and territories must follow five key principles; universality, accessibility, comprehensiveness, portability and public administration (Health Canada, 2006). Despite this key federal legislation, a phenomenon gaining recognition in Canada over the past few years is the Healthy Immigrant Effect (HIE). This refers to the observation that recent waves of immigrants have better health as measured by higher self-reported health and reduced incidence of chronic conditions as well as disability, than their Canadian-born and previously immigrated counterparts (Dunn & Dyck, 2000; Newbold, 2005).

Particularly concerning is the subsequent decline in health status of immigrants after arrival in Canada. Not only has it been noted that these declining levels of health are on par with the Canadian population, in some cases, it is declining to a level that is below that of the Canadian population (Newbold & Danforth, 2003). A key question to ask therefore is why is this HIE being lost? Some researchers attribute this to an uptake of the host nation's life style, such as poor eating habits and increased alcohol intake (Newbold, 2005). It is also likely however, that this decline in health status could be amounted to unease with the new health care system due to a lack of culturally appropriate services. Another plausible link could be a loss of socioeconomic status, social networks and language barriers (Newbold, 2005). It would be logical to assume that once language skills improve and with an increased knowledge of the health care system, minority populations would face better prospects for better and more stable over-all health (Newbold, 2005). Hence to obtain equipoise in the health

care system, the system must try to cultivate social inclusion and empower minority communities and newcomers to the country.

2.4.2 Gaps and challenges identified

The barriers and challenges to public engagement that were identified in a review of the literature are likely exacerbated for visible minorities and immigrants, because ethnicity and culture affect health attitudes and perceptions (Newbold, 2005). Therefore, as western countries are becoming increasingly multicultural there is a growing pressure on health care services to respond to the changing needs and expectations of these diverse groups (Lawrence & Kearns, 2005). A qualitative study was carried out to reveal the barriers faced by immigrants in accessing health care services as well as the challenges that health service providers are up against in catering to the diverse needs in a culturally sensitive and efficient manner (Lawrence & Kearns, 2005). It was found that despite the difficulty in communication between health service providers and diverse populations as well as the clear differences in health beliefs and expectations, with increased capacity at the local level, new communities are more likely to have an impact on the policy environment. However, there still remain pertinent questions of sustainability of established local capacity due to inadequate funding and resources (Lawrence & Kearns, 2005). This work was conducted in New Zealand; therefore there remains a need to explore similar issues within the Canadian context, especially due to the growing immigrant populations.

2.5 Emergence of research objectives and summary

While the literature surrounding the topic of public engagement is broad, only the trends most relevant to understanding the Canadian context were discussed for the purpose of this review. Historical context provided on early attempts at citizen involvement in health care decision making highlight the ambiguous nature of public participation. Since the early 1960's when the term was first used, the definitions and objectives of this undertaking have become clearer. However, the literature in the field is still narrow in scope with regards to understanding the involvement of minority and newcomer populations. This is illustrated by the lack of direct proof of innovative engagement efforts with minority populations despite the expansive evidence of lacking knowledge and accessibility issues among minority populations and marginalized groups (Raja-Jones, 1999; Watts *et al.*, 2004; Lawrence & Kearns, 2005). Hence, the objectives of this research are to understand whether, how and under what conditions innovative public engagement practices in local health care decision making may occur and might be sustained for and with visible minority communities.

CHAPTER 3 – RESEARCH METHODS

3.1 Introduction

This chapter outlines the study design and methods used to address the following research objective: to understand whether, how and under what conditions innovative public engagement practices in local health care decision making may occur and might be sustained for and with visible minority populations.

To achieve this objective, this paper focuses on public engagement practices in the context of general health care as well as a specific health care resource in two specific regions of Ontario, Canada. As described in the previous chapter, there is relatively little research focussing on engagement efforts with visible minorities and newcomers (Hyman, 2001). Although there is literature indicating the lack of sustainability in participatory action in decision making, very few works have attempted to decipher how this might be achieved (Lawrence & Kearns, 2005).

Therefore the research question to be examined is: With respect to awareness of and access to healthcare resources, what is the nature and scale of public engagement for and with visible minority populations? This will be examined in the context of: general health care, Local Health Integration Networks (LHINs) and specific health care, Cancer Care Ontario (CCO).

This chapter is divided into four sections; the first sets the context of the research, rationalising the choice of region for study and also introduces the collaborative nature of the study. It also explains the methods for participant selection, data selection and analysis, including a description of key-informant interviews, focus groups and a policy document review. Finally, the chapter discusses the steps taken to maintain rigour throughout the research process.

3.2 Research setting and collaborative research

This research is designed as a multiple case study, specifically, a comparative case study (Yin, 2003). According to Yin, this is an appropriate research strategy because this study aims to deliberately examine contextual conditions believing that they are highly pertinent to the phenomenon being studied (2003). The phenomenon being explored in this thesis is public engagement; and the various contextual conditions include two regions which pose a comparison based upon their demographic differences in visible minority populations. Therefore, this comparative case study method may be used to explore these situations where the intervention, public engagement, is being evaluated (Yin, 2003).

3.2.1 Collaborative research

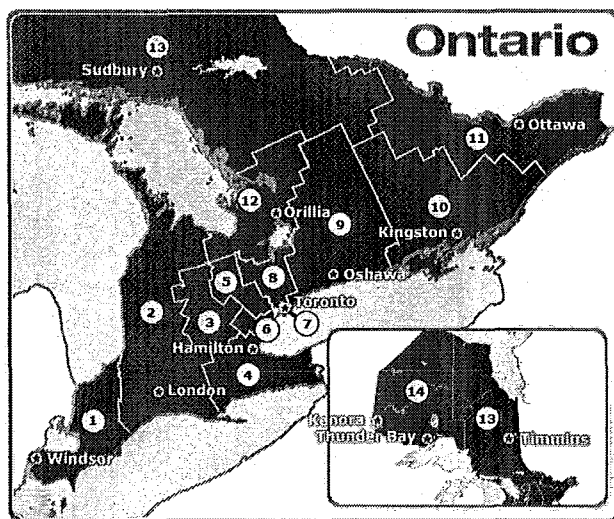
This thesis is a sub-section of a larger project being carried out by the Centre for Health Economics and Policy Analysis (CHEPA). This pan-Canadian public engagement project undertaken by CHEPA, is a follow up study to one done in 2001. Some of the findings from the past work highlight insights into pathways through which innovations in public engagement might be used within health systems. Additionally, the previous research emphasized important baseline information about early impacts of public engagement on organisational learning. Therefore, some of the next steps identified for further investigation were to examine whether public engagement actually generates a more active and informed citizenry as the theoretical literature suggests. Furthermore, if the health policy decision making process is enhanced by public participation, and how.

This thesis evaluates public engagement within the context of Ontario's regional health care arena; allowing investigation of public engagement efforts and the consequent effects on citizenry and decision making, at a local level. Particular attention will be paid to public engagement efforts with visible minority populations.

3.2.2 Setting the context

This research was conducted in two health regions within the province of Ontario, Canada. In March of 2006, Ontario implemented regional health care which created fourteen regions in Ontario (see figure 3.1), each with their own Local Health Integration Network (LHIN) (LHIN, 2009).

Figure 3.1: Local health integration networks in Ontario



The LHINs have been set up to plan, integrate and fund local health services. Health care reform was brought about by the Ontario government in an effort to place more decision-making power at the community-level and thus better meet local health care needs (LHIN, 2009). A part of the LHIN mandate is to:

“Engage the community of diverse persons and entities involved with the local health system about that system on an ongoing basis, including the integrated health service plan and while setting priorities” (Local Health System Integration Act, 2006).

Prior to 2006, Ontario had decentralized health care in the form of District Health Councils (DHC) which were created in 1975 (MOHLTC, 2009). The interpretation of decentralisation varies from country to country and province to province. One definition is:

“... the transfer of authority or dispersal of power in public planning, management, and decision making from national to subnational levels or from higher to lower levels of government” (Eyles & Litva, 1998, pg. 249).

The DHC were formed to play the role of advisor to the Ontario Ministry of Health and Long-Term Care on the health requirements of the geographic communities they were set up to serve. Additionally, they also played an important role in reflecting local autonomy and implying different avenues of accountability by relaying information on health care services to community (Eyles & Litva, 1998). These DHC were dissolved in 2005 which gave way to the formation of the LHINs (MOHLTC, 2009).

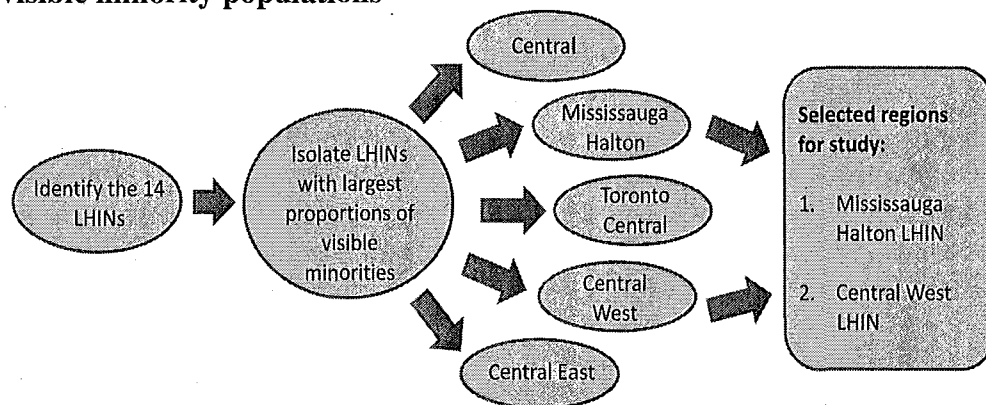
3.2.3 Selecting the research areas

Ontario is one of the most socially and culturally diverse provinces in Canada, with an immigrant population of approximately twenty-six percent (Statistics Canada, 2007). Almost ninety percent of newcomers to the country settle in the major cities: Toronto, Vancouver or Montreal, however the City of Toronto attracts the largest concentration of immigrants, comprising nearly fifty percent of its total population (CIC, 2007). Recent trends have indicated that immigrants are settling outside of the urban core into more suburban communities of the Greater Toronto Area, predominantly in Markham, Scarborough and Mississauga (Ray et al., 1997; Bauder & Sharpe, 2002).

In order to select which LHIN regions to study, a framework was created to aid in selection purposes, to identify areas of concentration (refer to figure 3.2). From the fourteen LHINs in Ontario, five LHINs with the highest percentages of visible minority populations compared to Ontario’s average visible minority population were chosen. The province’s average is twenty-two percent, in comparison, the remaining nine LHINs had lower percentages of visible minority

populations (below fifteen percent) (Statistics Canada, 2006). The LHINs with the largest proportions of visible minority populations were first isolated, finally two LHINs were chosen. The LHINs identified to have the greatest percentages of visible minority populations are all concentrated in the region of Southern Ontario: Mississauga-Halton, Central West, Toronto Central, Central and Central East (refer to figure 3.2).

Figure 3.2: Framework for selecting the LHINs with highest proportions of visible minority populations



These five LHINs were compared and contrasted based on the following characteristics: visible minority population, education levels, income levels, percentage of new immigrants and annual change in population (refer to table 3.1).

Table 3.1: Characteristics taken into account when selecting LHINs (Statistics Canada, 2006)¹

LHIN	Total population	Education level (%)	Visible minorities (%)	Income (\$)	Immigrant population (%)	Population change
Mississauga Halton	1,007,995	27.6	36.2	79,915	43.2	12.1
Toronto Central	1,090,301	35.8	32.6	66,363	40.8	-0.3
Central	1,532,649	26.9	42.1	70,978	47.9	13.3
Central West	739,965	16.8	50.3	65,562	45.6	18.1
Central East	1,432,695	16.6	34.5	65,712	33.3	6.3

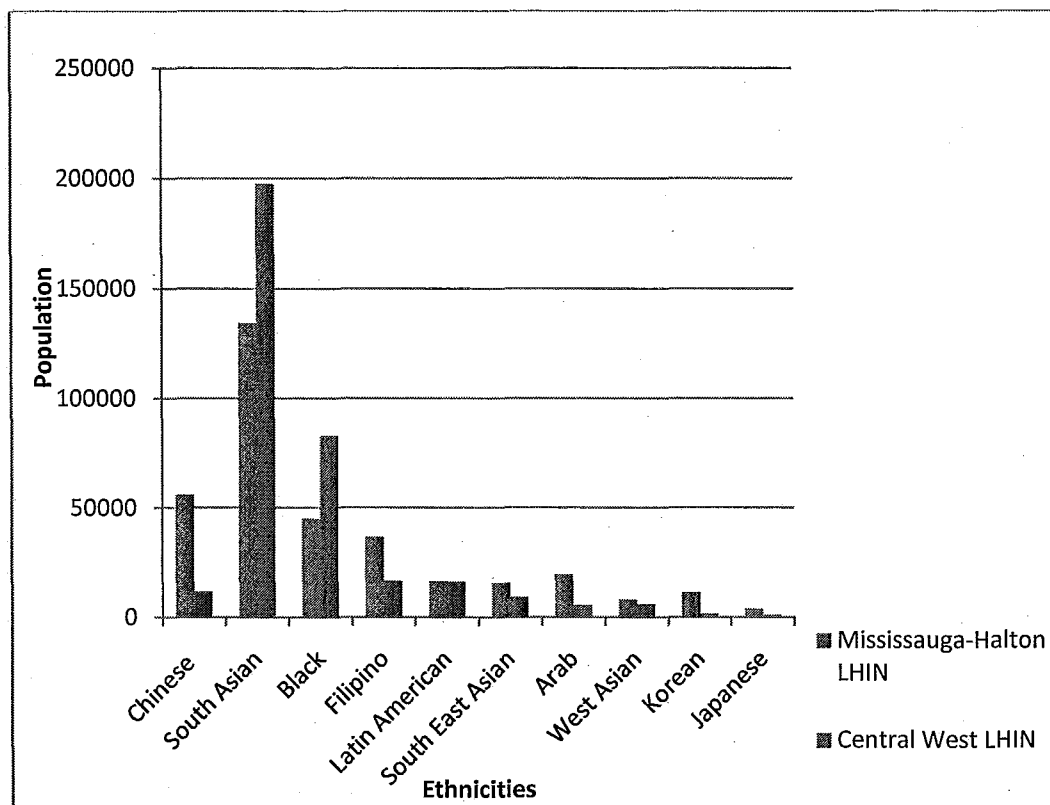
¹ - Education level: Percentage of total population in the region that is 15 years of age or older, with a post secondary certificate, diploma or degree

- Income: Median income recorded in 2005 for all census families

- Population change: Between 2001 and 2006

After comparing the five LHINs based on socioeconomic indicators as well as percentages of visible minority populations, the Central West LHIN and the Mississauga Halton LHINs were picked as areas of concentration. This was because, although they are not representative of the two highest percentages of visible minority populations, they are in fact most comparable in the distribution of visible minority populations. According to Citizenship and Immigration Canada, the percentage of immigrants from Asia and the Pacific (for countries in these regions, see Appendix 1) has grown even in the past 10 years (CIC, 2008b). Migrants from this part of the world, vastly outnumber those from other continents. In 2008, the percentage of immigrants in Ontario from Asia and the Pacific was fifty-one percent, the next big group of migrants originates from Europe and the United Kingdom, however the percentage of immigrants from that part of the world was just twenty-two percent in 2008 (CIC, 2008b). Hence, not surprisingly, these two LHINs have a large percentage of the population originating in Asia and the Pacific (refer to figure 3.3). Specifically however, South Asians comprise of a substantially large proportion of the population of these two health regions (refer to figure 3.3).

It is evident from the statistics presented in table 1, that the Central West LHIN has a lower socioeconomic level over all, when compared to the Mississauga Halton LHIN. The selection of the two LHINs, along with a specialised health care resource to be examined in this thesis, leads to the generation of some hypotheses. It is hypothesized that public engagement strategies may be different for institutions that oversee primary and secondary care, versus the institutions that carry out specialist care. Public engagement strategies might also vary between the two health regions, dependent on people's knowledge of and accessibility to health care programs and services.

Figure 3.3: Comparing visible minority populations

The two health regions chosen for study are comprised of a combination of municipalities (For maps illustrating the health region boundaries see Appendix 2). The Mississauga Halton LHIN is made up of the Halton, Peel and Toronto municipalities (MHLHIN, 2010). The Central West LHIN overlaps municipalities, and consists of a large part of the Peel as well as Dufferin (CWLHIN, 2010). Due to the large area boundaries of these health regions, there is a vast diversity among the residents (refer to table 3.2 & figure 3.3). This requires specialized health care accessibility and resources. The following section will survey the health care resources available to the residents in these two catchment areas, as well as those resources specifically for newcomers and visible minorities.

Table 3.2: Mississauga-Halton LHIN and Central West LHIN characteristics
(Statistics Canada, 2006)

	Mississauga-Halton LHIN	Central West LHIN
Total population		
	1,007,995	739,965
Age distribution		
0-14	19.7%	22.1%
15-29	19.7%	20.6%
30-59	45.4%	43.7%
60+	15.2%	13.6%
Citizenship status		
Canadian	88.3%	85.3%
Non-Canadian	11.1%	14.1%
Generation status		
1 st	413,605	321,615
2 nd	175,635	119,655
3 rd	214,355	130,270

3.2.4 Available health care resources in the selected areas of concentration

Cancer Care Ontario (CCO) was chosen as the institution to represent the specialised health care resource. Other options would have been Canadian Mental Health Association or Canadian Diabetes Association. However, Cancer Care Ontario was chosen based upon being a government funded agency. CCO was launched in 1997 by the provincial government, governed by an act of legislation called The Cancer Act (CCO, 2009). CCO is the provincial cancer agency responsible for improving cancer services (CCO, 2009). They oversee public healthcare dollars to hospitals and other cancer care providers to deliver high quality, timely and equitable access to cancer services. CCO implements provincial prevention and screening programs aiming to reduce cancer risks and raise rates of screening participation (CCO, 2009).

3.3 Research Design

This study utilizes qualitative methods; in the recent past, there has been more of an effort to include these methods in social science research and more specifically human geography research (Elliott, 1999; Winchester, 1999). Health geography has traditionally been more of a quantitative endeavour; however, this has been challenged by human and health geographers, to facilitate inclusion of views, perceptions and experiences of study participants (Dyck, 1999). This addition to the research strategy in health geography is to enable better understanding of place sensitive and subject centred dimensions of health and health care (Dyck, 1999).

Qualitative methods have become increasingly valuable to the emerging discipline of 'post-medical geography' (Dyck, 1999; Dyck & Kearns 1995; Elliott, 1999; Kearns, 1993; Kearns & Moon, 2002; Limb & Dwyer, 2001). This post-medical geography, or health geography, focuses on the broad definitions of health and the health care system. This holistic approach to examining health examines not only the physical factors that influence individual and community health, but also allows for the consideration of socio-cultural, political and economic positions (Dyck, 1999; Kearns & Moon, 2002).

The strengths of qualitative research lie in its ability to understand individual experiences of health by linking the relationship between an individual's place in the world and their experiences in this particular space (Elliot & Gillie, 1998). Qualitative research has also been the preferred method for use among marginalized populations, such as immigrants, whose voices have historically been unheard (Parr, 2001; Elliot & Gillie, 1998). Dyck highlights that qualitative research lends itself to investigate socio-political forces, thereby allowing for the study of relations and distributions of power (1999).

Health geographers therefore utilize qualitative methods to explore the feelings, perceptions and knowledge of others to gain insight into the complex processes that shape our social worlds (Dyck, 1999; Limb & Dwyer, 2001). For the purpose of this thesis, qualitative methods will be employed to allow for the exploration of institutional and community perceptions on public engagement practices.

There are a variety of strategies within qualitative methods and all have their own attributes and challenges. For the purpose of this research in-depth interviews, focus groups and document review will be utilized as a means of understanding how public engagement practices are helpful in health care decision making at a local level.

3.3.1 Interviews

The key-informant interviews provided the richest and most detailed information on the case. They allowed the researcher to obtain in-depth, detailed accounts of the social and policy context, governance responses and approaches to management. Additionally, they also suggested challenges inhibiting or opportunities advancing collaborative, integrative and participatory approaches to conceptualizing public engagement within the Mississauga Halton and Central West LHIN regions.

Interviews normally involve the interviewer asking open-ended questions of the interviewee that trigger discussion about the participant's views and experiences on a given topic. This interaction has been described as "a dialogue rather than an interrogation" by Valentine (2005) and "a conversation with a purpose" by Eyles and Smith (1988). With this methodology, it is the information gathered through the interview that is much more valuable than the number of

participants (Valentine, 2005). According to Goetz & LeCompte (1984) as quoted in Crabtree & Miller (1999):

“key informants are individuals who possess special knowledge, status, or communication skills, who are willing to share their knowledge and skills with the researcher, and who have access to perspectives or observations denied the researcher through other means” (pg. 73).

There are four main reasons for employing the use of interviews as a research method. Interviews narrow the gaps in knowledge that may not effectively be done by utilizing other methods such as observation or the use of census data; they highlight the diversity of viewpoints and experiences; they are also able to explore complex behaviours and motivations; and finally, interviews empower participants (Dunn, 2000). All four of these aspects are strengths of the interview strategy and are appropriate to the objectives of this study. For instance, the diverse perceptions of public engagement held by health care professionals and community based health care workers are varied. Furthermore, the nature of public engagement is ambiguous and complex, based on its multiple characteristics and definitions. Finally the act of allowing community health care workers to speak openly about their opinions and experiences allows them to feel empowered. Therefore, using interviews as a qualitative research strategy was most appropriate for the study design.

There are several different types of interview formats that can be used, some being more formal and structured than others. The design used for this research is a semi-structured interview (Dunn, 2000). The advantage of applying this design is that the respondent has flexibility in the way issues are addressed, hence allowing for a more conversational exchange between the interviewer and the interviewee (Dunn, 2000). In the semi-structured design used in this study, the first set of questions is standard biographical questions that require short and direct answers. These questions establish the interview style, jog the respondent's memory, build rapport between the interviewer and interviewee and provide context data for analysis (Crabtree & Miller, 1999). The main body of the interview script was guided by a check-list of topics informed by relevant literature on the topic of public engagement (Elliott & Gillie, 1998). These topics included definitions and objectives of public engagement, appropriateness of the strategies for public engagement and barriers and facilitators of this undertaking (for interview script, see Appendix 3). These key-informant interviews will be approximately forty minutes in length.

3.3.2 Focus groups

Focus groups are a form of group interview that benefits from the communication and interaction between research participants to generate data (Kitzinger, 1995). In the focus group methodology, the researcher does not have to individually speak to each participant; rather the participants are encouraged to

speak to one another, exchange experiences and perceptions. This allows the researcher to gain an understanding of what people's views are on a specific subject, and also why they hold this view (Cameron, 2000; Kitzinger, 1995). Geographers are interested in these interactive discussions because they aid in understanding collective ideas and help transfer and translate knowledge, thereby empowering the study participants (Cameron, 2000). Additionally, focus groups are an effective way to explore the nuances and complexities associated with people's relationships with place (Cameron, 2000).

Focus groups are a cost-effective and time-sensitive way of collecting data especially if the matter being discussed is not extremely private and confidential (Crabtree & Miller, 1999). A focus group consists of a small group of people (usually between six to twelve people) discussing a topic or issue defined by the investigator (Cameron, 2000). Focus groups differ from individual interviews because they gather information based on participant interactions, they can also often be therapeutic and educational for those involved (Crabtree & Miller, 1999). This method was used with citizens from the visible minority communities in the catchment areas of the two LHINs under study.

Focus group discussions were semi-structured, based on revised interview guides (see Appendix 4). The purpose of this type of discussion is to encourage the participants to speak freely and respond to the contributions of others facilitating a dynamic conversation (Cameron, 2000). However, if the discussion veered off topic, probing questions were asked to enhance the important themes that might otherwise be neglected (Crabtree & Miller, 1999). These discussions did not exceed an hour in length and were conducted in person.

3.3.3 Document review

The policy document review involved examining relevant government, NGO or community agency documents, policies, strategic plans, and websites that were chosen based on their ability to provide information on the organisational mandate, objectives and definitions of public engagement. The policy document analysis helped the investigator gain a better understanding of the context public engagement is utilized by the organisation, while also obtaining a grasp over the language and use of words. In addition, it helped with identifying some of the major governance players, organisations and agencies involved in addressing these concerns. Finally, the documents were also used to verify and elaborate upon information derived from key-informant interviews.

Eight documents were chosen for review; they were selected to depict the public engagement practices of some of the institutions involved in this study; Cancer Care Ontario, Canadian Cancer Society, Peel Public health, Mississauga Halton LHIN and the Central West LHIN (for list of documents reviewed, see Appendix 5). These documents were chosen based upon their relevance to the research topic as well as the dates they were written. If there were multiple documents available on the same topic, the most recently written version was the one utilized for the document review.

3.4 Participants and data collection

A purposeful sampling strategy was used to recruit the key-informants as well as the focus group participants for this study (Crabtree & Miller, 1999). This strategy will help obtain information rich sources of data with knowledge, experiences and stories that shed light on the research question (Patton, 2002).

3.4.1 Recruitment of key-informants

For the recruitment of key-informants, criterion sampling was used (Patton, 2002). This allowed for the “study of all cases that meet some predetermined criterion of importance” (Patton, 2002). Accordingly, a sample of health care professionals was chosen from Cancer Care Ontario, the Mississauga Halton LHIN, Central West LHIN and several community agencies (see table 3.3). The characteristics of people approached were the CEO, public engagement officer, knowledge translation officer, senior planner as well as policy analyst. As Valentine says, the aim in recruiting informants for qualitative research is not to choose a representative sample, it is to select an illustrative one (2005).

Table 3.3: Community agencies available in the catchment areas

Community agencies		
Mississauga Halton LHIN region	Central West LHIN region	Mississauga Halton & Central West LHIN regions
Mississauga Halton Community Care Access Centre	Brampton Multicultural Community Centre	Punjabi Community Health Services
	Brampton Neighbourhood Resource Centre	Aurat Health Services
	Central West Community Care Access Centre	Cross-Cultural Community Services Association
		India Rainbow Community Services of Peel

Knowing the appropriate person to contact in the organisations chosen is not an easy task, and requests for interviews are more effective when targeted at a named individual (Valentine, 2005). Therefore thorough searches were carried out by obtaining institutional publicity material and also through research on the websites. Gatekeepers were also used to access potential participants for research (Valentine, 2005). The selected potential participants were then sent an e-mail outlining the aims of the research, the issues to be discussed and an estimation of how long the interview would take (see Appendix 6). Often, there was no

response the first time round, and therefore a follow up e-mail or phone call was made (Valentine, 2005).

A total of seventeen participants were identified as potential interview participants, of which three indicated right away that they did not wish to participate, five others declined upon subsequent follow-up calls or e-mails. Although every effort was made to accommodate the participants, including daytime, evening, weekend and early morning interviews, in person or on the telephone, not all willing participants were able to take part due to scheduling conflicts and lack of availability. In the end, a total of nine participants; four from Cancer Care Ontario, one representative each from the two LHINs and one representative each from the three community agencies were interviewed.

The three community agencies willing to participate were Punjabi Community Health Services (PCHS), Brampton Neighbourhood Resource Centre (BNRC) and Aurat Health Services (AHS). PCHS, based in Brampton, providing health care services, specialising in aging, mental health and addictions. They primarily cater to the South Asian population living in the Greater Toronto Area, however, the agency also has clients from the Caribbean community as well as other ethnicities from the Indian Sub-continent (PCID, 2009). BNRC was created a few decades ago by Peel social service representatives who wanted to help provide information on social and health service programs as well as educational programs to meet the needs of families in Brampton in a culturally sensitive manner (BNRC, 2010). Aurat means 'woman' in the South Asian languages of Urdu and Hindi, hence Aurat health services has been set up to empower South Asian women. The main goal of this organisation is to focus on the health and well-being. Although based out of Brampton, Aurat health services provides support, health and social care to South Asian women across the Greater Toronto Area (AHS, 2010).

An additional method was used for recruitment for interviews. Respondents were asked if they knew other informants that might be helpful to speak, would enrich the data and might be interested in the research. This snowball method accounted for six additional interviewees (Valentine, 2005). These participants were health care professionals from a variety of national and regional institutions that serve communities in the two catchment areas; Peel Public Health, Heart and Stroke Foundation, Carlo Fidani Regional Cancer Centre (out of the fourteen regional cancer centres in Ontario, Carlo Fidani serves the Central West and Mississauga Halton LHINs) and Canadian Cancer Society. Hence, a total of fifteen key-informant interviews were carried out (see Appendix 7 for a list of pseudonyms used for the participants).

3.4.2 Recruitment of focus group members

The method used for recruitment of focus group participants was convenience sampling (Patton, 2002). This is a very common sampling strategy, however, very undesirable because the information obtained is too limited for

generalizations (Patton, 2002). Two of the three community agencies that agreed to partake in the research aided in the formation of the two focus groups.

A community agency representative from PCHS and BNRC played the role of gatekeeper, and granted access to the senior citizen's group for the purpose of focus group research. The two focus groups consisting of eight and ten participants respectively were created. They consisted of male and female community members between the ages of fifty and seventy, which frequently attend the senior's group community gatherings. These meetings are constructed as health care information sessions as well as various social events.

3.4.3 Collecting the data

Interviews with health care professionals took place in their own offices; however, the focus groups were conducted at a venue provided by the community agency that the participants were recruited from. Conducting the interviews and focus groups in settings familiar to the participants puts them at ease (Valentine, 2005). The interviews and focus groups were audio recorded and later transcribed verbatim for analysis. The benefit of taping is that it allows the researcher to focus on engaging the participant in conversation, capture the nuances of their responses and take notes to aid in further probing and questions (Valentine, 2005).

Qualitative methods often involve exploring sensitive issues; therefore the interviews were designed to ensure both anonymity and confidentiality of all participants and their responses (Dowling, 2000). Outside the confines of the focus group, responses were kept confidential and anonymous; however a limitation of this method is maintaining anonymity within the focus group. Participants were advised in a letter of information; the nature of the study, proposed use of data and confidentiality of their identity. It was mentioned in the invitation and reiterated again at the time of the interview or focus group, that participation was completely voluntary and that they may refuse to answer a question, stop the interview process or leave the focus group at any given time, without consequences. In accordance with ethical conduct, outlined by the McMaster Research Ethics Board, participants were asked to sign a form of informed consent, outlining their agreement to be involved in the study, prior to the start of the interview (see Appendix 6). This implies that they are aware of the research being conducted and the issues to be discussed (Dowling, 2000). Any questions and concerns were answered prior to the start of the interview or focus group. Ethics approval for this research was obtained prior to any contact with participants.

3.5 Data analysis

The method of analysis used in this study is a hybrid approach of thematic analysis; incorporating both the data driven inductive approach, but also a deductive a priori template of codes approach (Fereday & Muir-Cochrane, 2006). Codes were constructed a priori, based on prior research or theoretical

perspectives and also created with the help of preliminary scanning of available literature (Crabtree & Miller, 1999).

All the interviews and focus groups were digitally recorded, with the permission of participants. These were then transcribed as closely as possible to the actual conversations, including interactions during the focus groups. Grammar was not edited, and pauses and inaudible parts of the conversation were noted. Once all the data was transcribed, it was coded following an editing style of coding, adding to the codes and sub-codes created beforehand (Crabtree & Miller, 1999). This coding employed the use of computer-assisted qualitative data analysis software (CAQDAS) (Peace, 2000). Specifically, the software package used was NVivo 8, tailored for academic social science research. It is paramount to note that CAQDAS is only a tool for research that simplifies and speeds up the analysis process, as opposed to completing the analysis (Peace, 2000).

3.6 Ensuring rigour

Setting out a detailed research strategy and the consistent application of that strategy at all stages of the project is crucial in ensuring rigour in qualitative research (Crabtree & Miller, 1999). There has been a lot of debate in geography in the past decade about the evaluative criteria used to assess rigour of qualitative research (Mays & Pope, 2000). Particularly, the use of quantitative criteria (i.e. reliability, validity, objectivity, and generalisability) has been widely criticized (Baxter & Eyles, 1997). It is agreed however, that qualitative research must be assessed with the same broad concepts of validity, but these need to be applied in a different manner in order to reflect the distinctive nature and goals of qualitative research. Hence, using the word of Lincoln & Guba (1985), Baxter and Eyles (1997) propose four characteristics to determine 'rigour' of the research process. These four new criteria include credibility, transferability, dependability and confirmability (Lincoln & Guba, 1985).

The first of the four criteria is credibility, which means that the results must be valid and authentic representations of the population being studied. In this research, credibility was established through the use of purposeful sampling strategies proposed by Crabtree & Miller (1999). This ensured that a number of 'information rich cases' were interviewed, and that these individuals were able to provide authentic representations of their experiences, contributing to the credibility of the findings. A total of fifteen interviews and two focus groups were conducted which allowed for a range of authentic and information rich data.

The second criterion to ensure rigour in qualitative research is transferability, referring to the generalisability of a study to other similar research settings. To achieve transferability, the processes and strategies employed in the research methods must be clearly disclosed so that the findings can be replicated outside the specific research situation. In this chapter particularly, and throughout this thesis, every effort is made to be transparent and thorough about the research practices utilized.

Confirmability is the third test for evaluating rigour in qualitative research; it tests the objectivity of the investigator including how their personal biases, motivations and interests influence the research. It is integral that researcher exercise reflexivity, acknowledging their own subjectivities and perspectives (Crabtree & Miller, 1999).

Qualitative methodologies are characterized by a relational construction of knowledge between researcher and research subjects and emphasis is placed upon both developing empathy between researcher and researched as well as focussing upon the reflexivity of the research encounter (Limb & Dwyer, 2001).

As a South Asian immigrant being placed in the position of power as a researcher during the focus groups, I was confronted with the notion of positionality and the 'insider'/'outsider' boundary with regard to research methodology and knowledge production (Mohammad, 2001). When conducting focus groups, I was seen in a position of power due to my western demeanour and graduate level education. However, a shared commonality was our ethnicity which served as a suitable starting point to make participants feel more at ease. Additionally, this similarity helped me genuinely empathize with the experiences and perceptions they were willing to share. When carrying out interviews, I was well informed about Ontario's health care system and knowledgeable of the challenges it poses to visible minorities. Given the complex nature of the researcher's and participant's identities, claims of truth can be grounded only in a real recognition of the limitations of vision, knowledge and the acknowledgement of the existence of multiple truths (Mohammad, 2001).

The fourth and final criterion is dependability; this considers whether results are reliable and consistent. This can be achieved in several ways; triangulation, the acknowledgement of 'deviant' cases, consistency throughout the research process and finally, the use of an auditor or peer review (Crabtree & Miller, 1999). Triangulation is when multiple sources, methods, investigators and theories are incorporated to verify results (Farmer *et al.*, 2006). For this research, triangulation of methods and sources was used. The multiple methods used were; interviews, focus groups and document review. Source triangulation involved using multiple respondent groups, for example, professionals versus lay opinions (Farmer *et al.*, 2006). Hence, the data is corroborated with other data to ensure dependability (Winchester, 1999). Anomalous cases that contradict overall findings will be recognized, examined and explained thoroughly (Mays & Pope 2000). Dependability is also assured through consistency throughout the research process (i.e. one interviewer to conduct all data collection, use of audio recordings, verbatim transcription processes, use of same coding procedure). Finally, the use of an auditor or peer reviewer to monitor and advise decisions and supervise consistency, for this research, this role is filled by the supervisor (Baxter & Eyles, 1997). These criteria allow for a more appropriate evaluation of quality in qualitative research. All four have been discussed in relation to this study highlighting the rigour in this research.

3.7 Summary

The purpose of this chapter was to illustrate the context for this research and discuss the comparative case-study methods used for the study. Additionally, it introduced the collaborative nature of the study. The qualitative study design is justified and the utilization of key-informant interviews, focus groups and a document review are discussed as strategies used for data collection. A description of participant selection, data collection and analysis is provided. Finally, the chapter discusses the steps taken to maintain rigour throughout the research process. The study has been designed with the intent to best examine the public engagement practices of the institutions selected in the Mississauga-Halton and Central West LHIN regions. This chapter sets the context for chapter 4 which describes the findings derived from the research designed above.

CHAPTER 4 – RESULTS

4.1 Introduction

The purpose of this chapter is to provide an in depth description of the results of eight documents reviewed, fifteen key-informant interviews and two focus groups conducted (the list of reference codes for key-informant and focus group participants is provided in Appendix 6 and a list of documents reviewed is provided in Appendix 5). These results are organised around fundamental themes arising from the following objective; to understand whether, how and under what conditions innovative public engagement practices in local health care decision making may occur and might be sustained for and with visible minority communities. In this chapter, the results are discussed in four sections. The first section describes the perceptions portrayed by health care professionals, as well as community awareness regarding the meaning and importance of public engagement. The section also incorporates excerpts from the documents, representing institutional values on the topic. The second section examines the importance of culturally appropriate public engagement in alleviating barriers and enabling access to health care services for visible minority communities. This section is subdivided to discuss strategies by which culturally appropriate services may be utilized when exercising public engagement. The third section addresses the challenges faced when undertaking public engagement and the final section portrays the values and beliefs of community members. The results are presented using quotes from interviews and focus groups as well as excerpts from the policy documents to best depict the similarity in responses as well as the variety of perceptions held about public engagement.

4.2 Meaning and importance of public engagement

One of the fundamental concepts to be explored was institutional and lay interpretations of the term public engagement. Key-informant interview discussions captured the importance of public engagement and how this differs from institution to institution. Policy documents reviewed also mentioned the importance of public engagement; within each document the priorities of public engagement for the institutions were made clear, some examples are shown below:

Cancer Care Ontario

Ontario now has a system for measuring, managing and reporting on the performance of our cancer system. This knowledge is transforming our ability to plan and manage patients' treatment, and to keep the public informed about the quality of cancer services they rely on (Ontario Cancer Plan 2008-2011).

Central West LHIN

The Central West LHIN needs to recognize that community engagement leads to more effective decisions and a more sustainable system (Community Engagement Plan for Diverse Communities).

Mississauga Halton LHIN

Critical to improving health in our communities is the importance of an engaged population about their health. Providers need to ensure that programs and services are “patient/client driven” thereby giving them choices, empowering them with the necessary knowledge and helping them navigate the right services at the right time in the right settings (Integrated Health Service Plan 2010-2013).

Out of all the documents reviewed, only one of the documents from the Central West LHIN addresses the meaning of public engagement.

Community engagement is defined as the process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being (Community Engagement Plan for Diverse Communities).

It goes on to say:

Communities taking responsibility for and having control over their own health and health decisions is a fundamental goal of meaningful community engagement (Community Engagement Plan for Diverse Communities).

It appears through these excerpts from policy documents that the act of public engagement differs across institutions, dependent upon how the term ‘public’ is defined. It seems that Cancer Care Ontario being a specialized health care organisation with a specific goal in mind, approaches public engagement with a more patient centred approach; whereas the two LHINs are more inclined to address the general citizenry in their catchment areas.

None of Cancer Care Ontario’s documents addressed the meaning of public engagement; however, during interviews with key representatives, it was made apparent that all informants had a sound understanding of the meaning of public engagement as well as the importance of it to the institution.

One representative spoke of the meaning of public engagement as:

To engage in extraction from the citizenry their views in order to assist in decision making (CCO 4)

Cancer Care Ontario deems public engagement as important, however, highlighted the fact that it is not the only aspect to consider in making accurate policy decisions. One spokesperson of the organisation said:

It's an important ingredient, it's important for temperature taking, it's not the whole... otherwise you wouldn't need a bureaucracy with typical skills like the one we have here... It's often very meaningful to hear a narrated story by a person who has an experience, it's motivational for work for the rest of the day but it's not that common that we would have big town hall meetings with patients in attendance. Multiple methods are more sophisticated than just using one method; however, we cannot just rely on the patient voice (CCO 1)

CW LHIN representatives linked the importance of public engagement to the mandate of the organisation.

In order to plan services close to home, local services, you have to engage with your providers, you have to engage with your public, in order to really understand. It's part of the mandate (CW LHIN)

The CCS also associated public engagement to the mandate of the organisation.

Our mandate is essentially in two parts... the first part is we're interested in eradicating cancer through prevention, through research, by teaching people about healthy life styles, and advocating healthy living. And we're also interested in supporting people that are living with cancer. That's made possible through our support services that we have, our transportation service, our peer support, which does, emotional support, for people living with cancer, either over the phone, or in person, or in group settings. The acronym to remember what the CCS does is PARIS, which stands for Prevention, Advocacy, Research, Information and Support (CCS 1)

The two parts of the CCS mandate signify public education in the form of prevention and advocacy; as well as support, in the provision of relevant programs and services.

The CW LHIN also correlated the importance of public engagement with understanding the needs and values of the public.

If you don't engage them you won't know what their needs are, you won't know what their values are, you won't know what their backgrounds are... (CW LHIN)

This was illustrated by an example:

When we had sessions with seniors, we learned things like, they need transportation in order to go to a doctor's appointment, so transportation was a need for seniors. Another request that came up was that, they seem isolated, so we introduced a telecheck service. Where someone phones them once a day to speak to them, find out how they're doing – that helps them feel less isolated and also they can get help when they need it (CWLHIN)

A spokesperson of the Canadian Cancer Society, linked public engagement with the dissemination of knowledge and empowerment; allowing the public to make informed decisions about their health.

Looking at the areas that I serve and recognizing those ethnic diversities and understanding that it does play a huge role in understanding how people approach their own health care... because if they're not engaged they don't know who we are, they don't know what we do, they don't know what services we have to offer and therefore they're not taking advantage of it (CCS 2)

Although there is a consensus about the meaning of public engagement among all those interviewed, there was a participant who alluded to the notion of public engagement as an activity being ineffective as it only targets interested parties which have a stake in the matter. Therefore does not gauge the general view of the citizenry in question.

Going out to have a town hall meeting isn't public engagement because what happens is who shows up are interested parties, so, concentrated interest masquerading as the public (CCO 4)

Another perception of public engagement put forth by an informant was the idea that government themselves represent a form of public engagement.

The government themselves represent a form of public engagement called democracy and so we take instruction from government based on their public engagement with the electorate who genuinely are the public (CCO 4)

This quote implies that although public engagement may not explicitly be carried out by the organisation, indirectly public engagement practices are being undertaken because of reporting to the government, which is a democratic body.

These differing opinions reflect the ambiguous nature of the term ‘public engagement’ and also how it is a relatively new phenomenon in the Ontario health care arena. It is imperative to observe that public engagement has been defined as a two-way street. First, engaging the public by offering public education programs, therefore the public may be able to make knowledgeable decisions about their own health. Second, engaging with the public to understand better what their needs of the health care system are, hence when designing health care programs and services, an informed decision can be made.

When discussing the meaning and importance of public engagement with respondents, the term cultural sensitivity was mentioned numerous times. It is important to be cognisant of the fact that the catchment areas being examined have a high population of visible minorities and therefore it is crucial to be aware of different cultures, values and beliefs. The following section will discuss the importance of culturally appropriate public engagement.

4.3 Barriers and Accessibility

The importance of public engagement in healthcare was correlated by most participants affiliated with non-specialized health care with diversity; particularly, ethno-cultural diversity. Several of the documents reviewed emphasized alleviating barriers and enabling greater accessibility for visible minority communities through innovative public engagement strategies.

Cancer Care Ontario boasts technology and innovations to improve accessibility, but unlike the other institutions being looked at, it does not cater to diversity at all. Being a provincial head office of Cancer Care, CCO has a responsibility to monitor systemic, clinical and financial performance throughout the system. Although CCO is trying to take a turn towards more patient-centred care, they seem to have an indirect approach to public engagement.

Ontarians of the future will take more active roles in their cancer care. Through e-tools, patients will have easy access to personalized disease and treatment information, and support from a community of cancer patients, health professionals, caregivers and research scientists (Ontario Cancer Plan 2008-2011)

The Central West LHIN however recognizes that it is integral to acknowledge diversity in order to plan, fund and provide accessible services for the communities they serve.

To provide accessible health services in Central West LHIN, we believe it is vital for us to recognize, respect and value the diversity within our communities (Community Engagement Plan for Diverse Communities)

Similarly, Peel Public health's ten year strategic plan stresses that their programs will be barrier free and accessible to all ethno-culturally diverse groups within Peel.

We will build our capacity for identifying appropriate approaches for removing barriers and improving access. Applying an ethno-cultural lens to service planning will identify, at a program level, whether a specific targeted intervention is necessary or whether access can be improved by tackling the issues at the broader, population based level (PPH-10 year strategic plan 2009-2019)

The non-specialized health care organisations had a much more broad focus on public engagement. They see it as reaching out to the public or direct communities that they serve in a culturally appropriate manner. In order to disseminate information to enable citizens to make informed decisions about their health care and provide feedback to policy makers and health care providers about how the system may be improved.

4.3.1 Cultural Sensitivity

A major theme resonating throughout the data was the overarching concept of cultural sensitivity. It was addressed by the LHINs, Peel Public Health as well as the Canadian Cancer Society. However, although this notion was not covered in any of the Cancer Care Ontario documents, it was spoken about broadly by representatives of the organisation.

Both the Central West and Mississauga Halton LHINs state the fact that they are culturally diverse and therefore must cater programs and services in an appropriate way for its clientele.

Central West LHIN:

The central West LHIN is one of the most ethno-culturally diverse regions in Ontario. The majority of the population is a visible "minority". Over 45% are immigrants. This rich diversity requires health services designed to be sensitive to language barriers, respect cultural beliefs, and targeted to prevent and treat diseases frequently seen in these populations (Integrated Health Service Plan 2010-2013)

They go as far as to say:

It is critical for decision makers to be cognizant of the fact that there is "diversity within diversity" (Community Engagement Plan for Diverse Communities)

This term ‘diversity within diversity’ highlights that the populations being focused on are heterogeneous. Also that these varying populations cannot be reached out to with a cookie-cutter approach. Rather, each group should be treated exclusively with respect to their own values and beliefs.

Mississauga Halton LHIN:

The cultural and linguistic diversity we enjoy in our LHIN means that, to meet the needs of our residents, health service providers must plan and deliver services in a culturally competent and equitable way (Integrated Health Service Plan 2010-2013)

Similarly, Peel Public Health recognises the diversity in the communities they serve; they also recognize that in order to serve diverse populations, it is helpful to have a reflectively diverse workforce which makes it easier to be compliant to the needs of the community.

In order to be a leading public health unit and to meet the specific needs of the region of Peel, we require a workforce that is professionally competent, highly motivated, multilingual and culturally sensitive to the needs of many ethnic groups (PPH-10 year strategic plan 2009-2019)

All the respondents alluded to the importance of culturally appropriate public engagement. However, this was expressed to varying degrees. A respondent of the Central West LHIN particularly stressed this need:

We are very cognisant of the services and the planning, the cultural values, and the cultural background. Whenever we are planning projects, or services they are culturally and linguistically appropriate as much as possible. That is critical. (CW-LHIN)

It appeared to be less of a priority for the Mississauga Halton LHIN:

They have identified, that it is through good community engagement that you get them interested in the LHIN – also get people interested in sitting on the board; having a good diverse representation that reflects your communities on the board. (MH-LHIN)

The lack of a distinct focus on cultural sensitivity is likely because of the fact that MH LHIN’s definition of diversity is all encompassing:

We’ve now got a whole equity plan, it’s all equal access for everyone, diverse is in the broadest sense... beyond cultural, it’s everything from seniors, to low income, to blind, to lesbian-gay-bisexual-transgender... (MH-LHIN)

When discussing whether a particular institution had a mandate on public engagement, many interviewees spoke of institutional values and beliefs, and how this was in line with addressing diversity. Some respondents even spoke about how the current health care system was designed by an individual who is no longer a typical resident in the region of study any more.

A representative of the Canadian Cancer Society said:

The problem is we're a very Canadian brand, it's very white, middle aged, Anglo-Saxon brand, it's just we preach diversity and we have things available in other languages and we're trying to steer in that direction, but ultimately we're traditional. (CCS1)

By saying that the Canadian Cancer Society is ultimately traditional, the respondent was insinuating that the organisation is following along on the guidelines that were set for the Anglo-Saxon Canada of several decades ago. Since then, especially in Southern Ontario, the rates of immigration have drastically increased. However, the methods employed by the CCS to carry out health and policy advocacy, as well as public education programs for cancer screening and prevention have not been altered to cater to the changing public.

Community group leaders speak of the importance of focus on cultural diversity:

The system breaks down when culture comes into play and the client's language is not primarily English (CO1)

They also identified lacking cultural sensitivity in the health care system and a definite need for greater understanding of cultures. When asked about the positives and negatives of the health care system, a community group leader of a major South Asian group spoke about one of the biggest barriers to the Canadian health care system.

The system also breaks down because it assumes the client is the primary candidate for the intervention. That is because this culture, this society places heavy emphasis on the individual, the majority of the world cultures are not as individualistic as western civilization is. The majority of the world's cultures are family based, collective based; where confidentiality plays a minor role. (CO1)

This quote indicates the frustration faced by the respondent on the importance placed by the Ontario health care system on the individual user. The concept of confidentiality is a largely western concept and does not translate to eastern cultures, where decisions are often made as a family unit, not on an individual level.

4.3.2 Strategies to enhance accessibility

Several suggestions were made by respondents on how to alleviate barriers and encourage the development of more culturally appropriate programs and services. Some of these tactics are actually being exercised now by organisations, others are still in the planning stages. The documents reviewed as well as the informants discussed strategies to enhance accessibility for visible minority communities. However, enlightened propositions regarding increased accessibility to health care for visible minority populations were primarily brought forth by community group leaders and representatives of the Canadian Cancer Society.

Empowerment

The concept of knowledge translation leading to empowerment of the public through increased responsibility has been reflected in most of the documents reviewed. This enables the public to make informed decisions about their health.

Cancer Care Ontario

Contribute to better disease management by informing and engaging Ontarians and primary care practitioners through Ontario Cancer Facts, Cancer Care Ontario's new multi-format cancer prevention information service. Ontario Cancer Facts will deliver customized web-based and print information to help ensure healthy living strategies are based on reliable, up-to-date evidence (Ontario Cancer Plan 2008-2011)

As quoted earlier in the importance of public engagement section, the Mississauga Halton LHIN also sees the value of providing clients and patients with knowledge in order to navigate the system accurately.

“...empowering them with necessary knowledge...” (Integrated Health Service Plan 2010-2013)

The Central West LHIN

Before individuals and organisations can gain influence and become players and partners in community health decision-making and action, they may need additional resources, knowledge, and skills (Community Engagement Plan for Diverse Communities)

Peel Public Health

Our goals are to increase awareness and knowledge of public health issues, to inform others of the role of Peel Public Health and

to build out credibility as a respected authority on matters of public health. We will communicate in a coordinated strategic culturally sensitive manner congruent with the region's overall values and vision (10 year strategic plan)

Some participants also mentioned the concept of empowerment. A community group leader equated empowerment to informed decision making.

It's not just the responsibility of the system to keep your healthy. It's first and foremost your own responsibility. Which is part of my focus, to educate the public... if you're not going to get your cancer screening done, your mammograms done, if you're not going to look after your diet, these are all going to impact the health care system (CO2)

The role of media was also brought up as a way to ensure the dissemination of information to a variety of audiences.

I try to inform the community as to what are listened to, ie: radio programs and I try to educate the community as to what's different... it's all of that, it's access, resources and information, it's education also... educating our communities that it's ok for them to go and question the system (CO2)

A representative of the Canadian Cancer Society addressed the issue of targeting those populations that are most challenging and contemplated the potential barriers that they face in accessibility.

You kind of have to know why they're not being engaged, is it because we're not approaching them or is it because they don't have a desire or an interest to have anything to do with the community – low socioeconomic levels, low education levels, and I know from being in Malton that it's relatively young families that maybe don't have an interest in learning more about the community – they don't have a chance, they don't have the time... (CCS1)

Another representative verified this by talking about a number of reasons why engagement with visible minorities is a challenge.

... And in terms of visible minorities it could be for a number of reasons... being a new immigrant, just not being aware that these services are being offered, religious reasons... (CCS2)

The first respondent went on to talk about how although fundraising for cancer research was one of the main goals of the organisation, putting effort into health promotion and educating the public would be very beneficial for the future.

... We could be saving a ourselves a lot of trouble by helping to do prevention work before hand... (CCS1)

Public engagement is a two way street, it can be utilized to gauge public opinion on health care service and delivery issues so that policy makers can make more informed decisions. However, currently, it is only being applied by organisations to disseminate awareness about health care resources to the public.

Language as a barrier and translation

When considering health promotion and public education, it is important that organisations ensure this knowledge transfer is conducted in a linguistically competent manner, and hence accessible to everyone. Although this sensitivity to language is implicit in most of the documents, it was only explicitly mentioned in two of the documents cited below:

The Canadian Cancer Society annual report states that:

To serve the many diverse communities that make up Ontario, the society continues to distribute publications in languages other than English and French. To date, over 150 fact sheets and brochures have been translated and printed in 15 languages, including Chinese, Persian, Portuguese, Polish, Punjabi, Spanish, Tagalog, Tamil and Urdu. These materials are distributed in doctor's offices public health offices, cancer centres, community health centres and social service agencies around the province (Ontario division annual report 2007-2008)

The Central West LHIN also mentions:

The Central West LHIN is one of the most ethno-culturally diverse regions in Ontario. The majority of the population is a visible "minority". Over 45% are immigrants. This rich diversity requires health services designed to be sensitive to language barriers, respect cultural beliefs, and targeted to prevent and treat diseases frequently seen in these populations (CW LHIN IHSP 2010-2013)

This document also addresses that:and

Bridging the gap among the Central West LHIN, service providers, health care professionals, and diverse communities requires a multi-pronged approach in order to address the health needs of diverse populations, but more specifically, ethno-cultural/linguistic groups (CW LHIN Community Engagement plan for diverse communities)

During discussions with participants about cultural sensitivity in health care planning and delivery, an issue that everyone spoke about was language being a barrier to effective public engagement.

A representative of the Central West LHIN stressed the importance of culturally and linguistically appropriate engagement as a way of understanding the needs of the communities being served.

I spoke Punjabi with them; I spoke Gujarati with the people there. I had other colleagues who spoke Urdu with them... so we tried to engage by talking to them in all languages and understand what their needs are (CWLHIN)

Another informant mentioned that if a community was stigmatized, and additionally had language issues, it would be extremely difficult for them to cope with the stress of having to understand medical terminology.

I'm not even talking about understanding English, I'm talking about terminology, medical terminology... that cannot be translated (CCS3)

In order to overcome any type of language or auditory handicap, the Canadian Cancer Society has introduced not only an interpreter service, but also a teletypewriter or text telephone (TTY) system:

With the introduction of an interpreter service and access to over 100 languages, callers to the Peer Support program can now conduct an intake and assessment in their own language. As well, Peer Support intake for the deaf, deafened and hard of hearing has been enhanced with the use of TTY technology (CCS – ON division annual report 07-08)

It was acknowledged by several informants that although an effort was made to create linguistically appropriate documents and services, the population that was targeted is the section of the public that seeks the information; as opposed to the public that lacks education and therefore knowledge regarding health care accessibility.

We produce materials in multiple languages to reach the population... but again, often, even with culturally relevant materials we're giving it to educated people, not to poor uneducated people who are less likely to participate... (CCO 4)

There is an idea of preaching to the already converted. If you're attending an event, picking up a flyer, reading translated documents online, you're already connected. How do you then target those who are in tightly knit communities, not inclined to be engaged?

A key reason for undertaking culturally and linguistically appropriate public engagement is so that the needs of the communities being served can be fully understood. This would allow organisations to carry out prevention measures appropriately; hence not burden the health care system with treatment costs.

This is alluded to by some of the respondents:

...but we could be saving ourselves a lot of trouble by helping to do prevention work before hand... (CCS 1)

We get into community engagement because we want to find out from our local population, whether it's health care providers, whoever is out there, we get in touch with all of them, we engage with them to help us come up with priorities and what the real needs are for healthcare. Based on that, we create programs in order to fund specific projects (CW-LHIN)

An informant on the front lines of community engagement grappled with the issue of why some segments of the population were so hard to reach:

You have to know why they're not being engaged, is it because we're not approaching them or is it because they don't have a desire or an interest to have anything to do with the community? This could be due to low socioeconomic levels, low education levels, and I know from being in Malton that it's relatively young families that maybe don't have an interest in learning more about the community and what it has to offer. They don't have the chance, they don't have the time (CCS 2)

One way of targeting those who perhaps are less educated and not actively seeking information is by utilizing community ambassadors. According to multiple informants, a community ambassador, although not explicitly phrased in that way is one who embodies the capabilities to influence their respective communities. Therefore, a community ambassador could be a respected religious, business or community group leader.

Documents as well as some informants stressed that it was important to reflect ethno-cultural commonalities with community members who were not as aware or educated on their rights to the health care system. This was the idea of appearing accessible.

When dealing with visible minorities, you want to reflect your own diversity and your own understanding of those visible minorities, so we tried to attract volunteers from within the community (CCS 2)

We recognize the need to cultivate ethno-cultural diversity within our work force (PPH 10 yr strategic plan)

It's not necessary for us to be sitting in a large board room wearing a two piece suit and high heels, that's not what they're responsive to (CO 2)

Identify yourself as one of them (CW LHIN)

Another informant also mentioned how although organisations make an effort to portray information in a culturally appropriate manner, they were not engaging with the population that is less aware and therefore less likely to partake in engagement activities.

You need immediate leaders, and community health leaders in those communities, you have a better understanding of where the barriers are, where the differences are in the world view. What the kind of dietary and risk behaviour practices that need to be targeted (CCO 4)

Representation of diversity on the board of organisations was one way in which the LHINs were attempting to portray their solidarity with the communities they serve. An informant said:

...they have identified that it's through good community engagement that you get them interested in the LHIN and you get people interested in maybe sitting on the board, and have a good diverse representation that reflects your communities... (MH-LHIN)

An informant also spoke about targeting specific individuals in a household to deliver key messages; this person might be the woman of the house, a mother or grandmother. The purpose of this would be to deliver the knowledge that requires dissemination, to a respected individual in a household. This would therefore allow for relaying of this information in an appropriate manner to the rest of the family.

A lot of the times the mother-in-law is the decision maker with regards to health care because she is the one who knows the herbal medicines. Most of the time she'll decide if you'll go to the doctor... if she begins to understand her own responsibilities in terms of healthcare, and screening and prevention, she will begin to emulate these decisions at home which will spread to the whole family (CCS 2)

In order to facilitate these partnerships and foster relationships with community ambassadors and reach those individuals that will successfully be able to spread

the information, it was deemed essential that there is an effort to create community capacity.

Collaboration and capacity

Policy documents, in addition to most informants, spoke to the concept of community capacity. It was acknowledged that although it may be time consuming, capacity building will cultivate greater trust and communication within health districts and communities.

The Central West LHIN addressed that public engagement was absolutely necessary in order to build community capacity, but it was also seen as an arduous task. After primary research carried out by the LHIN itself, it was found that:

Preliminary findings suggest that the LHIN needs to move to a stronger community based model of care with improved access to all health care services and better care coordination across the entire health system (CE plan for diverse communities)

However the main problem identified was:

The crux of the challenge is how to engage communities to build community capacity; how to build resource capacity and integrate services and how to create culturally competent organisations to improve access and provide quality health services to the public (CE plan for diverse communities)

A document from Cancer Care Ontario alludes to the need for community collaboration. This was enabled by the regionalisation of cancer services. These regional districts had the same boundaries as the 14 local health integration networks created.

Cancer Care Ontario should continue to build capacity within regional cancer prevention and screening networks to help regions work towards achieving Cancer 2020 targets (Report on Cancer 2020)

Among some of the principles highlighted in this future vision, was a focus on population based health. The institution understood that in addition to sustained action, an evidence based approach and strategic use of resources, there was a need to concentrate on the public being served.

A population-based focus would utilize a variety of targeted strategies to increase knowledge among the public and health professionals and create a supportive public policy environment that reinforces behaviour change across the entire population (Report on Cancer 2020)

When speaking with most of the informants, the notion of enhanced capacity was intertwined with the idea of partnerships. A similar theme was found in the policy documents.

Cancer Care Ontario addressed the topic of partnerships in two key documents, the Ontario Cancer Plan 2008-2011 as well as the Report on Cancer 2020. Excerpts highlighted below, indicate a desire to move towards a more population and patient centred approach, rather than only clinical performance monitoring.

Cancer Care Ontario is forging partnerships with the Ontario government, associations, non-governmental organisations and local health system partners to undertake innovative approaches for reaching under-screened populations (Ontario Cancer Plan 2008-2011)

Collective action on common chronic disease risk factors should be enhanced through collaboration of government, health agencies and non-profit organisations on cancer-specific risk factors in order to reduce cancer incidence and mortality. Better linkages and mobilization of our efforts will lead to greater impact and changes through action (Report on Cancer 2020)

Terms such as collective action and mobilization of efforts imply joint efforts, and therefore partnerships.

An important relationship that ought to be described is the one between Cancer Care Ontario and the Canadian Cancer Society. Informants of both the CCS and CCO alluded to this partnership; however, it is explicitly quoted by a CCO researcher, in a CCS policy document.

“Insight represents an extraordinary partnership, we have the knowledge and access to data, while the Society knows how to get information out to those who need it.”

The researcher referred to *Insight on Cancer*, which is a joint initiative of the CCS and CCO. Each edition focuses on a specific topic area, allowing readers to get up to date on issues, guidelines and research. The collaboration between these two institutions has granted easier identification of relevant topics and therefore the creation of useful promotional materials for the public.

The Central West LHIN believes in collaboration and shared accountability. They maintain the standpoint that relationships play a vital role in establishing trust and commitment within the community.

Building effective health services for communities is deliberate, collaborative work requiring shared and measurable goals and a

clear plan for achieving them (CW LHIN Community Engagement Plan for Diverse Communities)

Partnership across the continuum of care is essential to transforming the health system... The CW LHIN is working in partnership with local health service providers to improve access to culturally competent health care services (Integrated Health Service Plan 2010-2013)

The Mississauga Halton LHIN also advocates for partnerships and an empowered public, as some of the key requirements to move forward and create increased community capacity.

Execution of the plan will also require partnerships with many of the non-LHIN funded providers including our physicians, public health departments, social service agencies and many others. It will also require an engaged and an empowered public that embraces personal responsibilities to improve one's own health and well-being (Integrated Health Service Plan 2010-2013)

There was consensus among the policy documents assessed that partnerships with other organisations, whether they be community-based, non-governmental or governmental, would enhance and facilitate capacity building. Most informants also shared the same opinion.

A key community group leader expressed a dire need for mainstream organisations to partner with community agencies to better understand ethnic communities resulting in more beneficial engagement strategies. There was a tone of frustration when this informant spoke about how much health care service delivery would benefit from such cooperation.

I think there has been an overwhelming amount of research available that demonstrates that if you work in partnerships with communities it will give the mainstream agencies some insights into how to penetrate these communities, some creative ideas about how things should be... I think that is what is lacking at this time (CO1)

This informant carried on to discuss some examples of how community relationships might prove extremely favourable for all stakeholders involved.

Another way in which community partnerships can be useful was mentioned by an informant of the Canadian Cancer Society. While referring to a community organisation that already has an established clientele and runs programs for children and youth as well as seniors, this informant said:

By having them distribute our flyers to all their clients there's going to be some showing of interest. Partnering with these groups that already have clients, they've already worked to generate interest by health promotion, why not use some of their power? In return I promised to them that they could use our volunteers to come out and teach their seniors groups about cancer prevention. A lot of partnerships like this should take place... (CCS1)

Similarly, when asked about how to target those individuals who perhaps have less education and awareness than other community members more willing to be engaged, an informant mentioned the constructive use of community partnerships.

It's a huge challenge... that's why partnering with community organisations such as India Rainbow, PCHS and Aurat really help us, because they have access to the individuals who we don't, right? (CCS 2)

A representative of a regional cancer centre referred to a partnership with patients. This was a unique idea not presented by other informants:

We'd like to see patients as our partners rather than the things that we do... understanding them can essentially provide what you may call a reverse knowledge transfer (RCC)

The respondent is essentially alluding to the concept of public engagement as a form of partnership.

Another type of partnership only mentioned by one informant was a partnership with sponsors. Charitable organisations that primarily obtain funding through fundraising rely greatly upon sponsors. Utilizing sponsors that also portray themselves as culturally sensitive are attractive to establishments that are aiming to portray a specific image to their public. For example, the Canadian Cancer Society would form a partnership with TD Canada Trust because they promote diversity in their advertisements, therefore appealing to an ethno-cultural public.

If we do fundraising events, we normally approach sponsors from our community. In terms of ethnic specific things, we will try to engage sponsors that can show that diversity element themselves (CCS2)

LHIN responses indicated that although they themselves do not form partnerships with other health care organisations, they encourage this by providing necessary funding and resources for the services required.

We do the planning, the funding and community engagement to plan services that are meeting the local needs. We encourage

integration and partnerships and collaboration, so we would encourage community groups to partner with mainstream organisations such as the H&S foundation to organise a special session for the SA seniors on knowledge on H&S problems (CWLHIN)

However, they do employ the use of community ambassadors to gain better access to their community:

We actually reach out to local leaders... so we use the experts, to get together people from the community, people that we don't have access to, people they think will benefit (MHLHIN)

This section has described the need for culturally appropriate public engagement and the various tactics that are being or will be applied by organisations to achieve success in this endeavour. There were several challenges associated with this undertaking that were identified over the course of data collection; these will be presented in the following section.

4.4 Challenges to Public Engagement

Participants in this study alluded to the challenges associated with employing culturally appropriate public engagement strategies. A review of the documents indicated that health care organisations undertaking public engagement were aware of the challenges they are up against. Participants were asked general questions pertaining to public engagement, but did not require probing to speak about the challenges associated with this undertaking. This was particularly mentioned with regards to engaging diverse communities.

One of the main issues mentioned was funding. This concern was voiced by the respondents from community and charity organisations. Informants from both the LHINs also spoke about funding issues, however, not with regards to obtaining it, rather with difficulties allocating the resources.

Informants were asked about culturally appropriate engagement and how this could be carried out with certain segments of the population that are harder to reach due to lower socioeconomic status and therefore awareness of health care services. This topic brought about a discussion on relationships and partnerships in order to build community capacity. However, when speaking with informants from community agencies, there was a sense of being constrained and feeling helpless due to limited resources. A general disconnect was identified between mainstream and community organisations causing frustration within agencies serving ethnic communities.

One, the program is not funded to do this, so we have to then somehow explain it to the ministry as to why I'm working on breast cancer, when the staff that they're paying to do something

else... So, it's not easy to, even if I wanted, my hands are tied. I think the decision makers need to look at how they are funded... Where is the majority of the funding? (CO 1)

It appeared that even if a need was identified within a community for patient education on breast cancer for example; community agencies are obligated to ignore this need and fulfil only the programs and services that they are funded for by the ministry, due to constrained budgets. It was found that unless a mainstream organisation offered to partner with them, sharing funding and resources; important needs within the community would remain unmet. A major impediment to this type of cooperative alliance is the unwillingness to share resources, and therefore an equal indisposition on the part of community organisations to offer their insights.

Another issue, related to funding, was the lack of sustainable programs. Many times niche communities were identified, targeted and consequently, successful pilot projects were designed to fulfil unmet needs in the community. The majority of the time however, these projects were deemed successful, but their funding was not sustained and therefore the service provided would be discontinued.

Lack of funding, lack of understanding, lack of support... everybody applauded that project, because it was focussed, specifically targeted to a minority group, but it just didn't go any further (H&S)

Another example of a potentially successful idea was spoken about by a spokesperson from CCO. However, this initiative too was not sustained.

There's a study I heard of was focused on immigrant population and the cancer system. The study was run at Toronto General Hospital and was looking at the use of interpreters or coaches, or navigators or something like that. Their whole purpose was to help those citizens of Ontario who don't speak English get through the system. It was a small study led by people from e-health innovations at Toronto General (CCO 2)

This lack in sustainability of viable projects demonstrated a need for greater awareness on the part of healthcare organisations to be sentient to the vulnerable populations served.

A point brought up by many informants, particularly from the LHINs as well as Cancer Care Ontario, was the notion of targeted funding. This term means, resources allocated towards a particular project, with a targeted goal in mind.

An informant of the LHIN equated public engagement with marketing in healthcare. The question raised by this informant was:

The LHIN has 1.1 million residents, how am I actually going to connect with them all? ... We don't really have a marketing budget in health care right? So the question is, how far do we go with public engagement? We need to do it and we want to do it, but how much time and effort do we put into it, and there's limited resources (MHLHIN)

This quote suggests that when there's an overwhelming amount of people, how does one reach everybody? Especially with limited resources; i.e.: manpower as well as funding. Therefore, the quotes below highlight the value of targeted programs and funding for specific communities.

When speaking about public engagement a respondent of CCO said: It's better for more discrete problem solving rather than perhaps here's how we're doing things, full of information. If there's something to kind of work on together actively then you have a goal, in relationship to a particular population, so that would be a targeted effort (CCO 1)

Similarly, illustrating what the quote above is implying, an informant of the LHIN said:

For example, some new money comes to the LHIN for the aging at home strategy, so focusing on seniors, but say that there's a pocket of Chinese seniors that have certain special needs, then we float the money to a long term care home that has a big population of Chinese residents, that would be specific programming for that group. We can do that for South Asian populations as well, we could target them if we needed to (MHLHIN)

A participant from the Regional Cancer Centre said:

We don't have a very good tool kit to use, although there are different approaches – I can't say there's one approach or any approach which is clearly beneficial. It would be helpful number 1, to develop those tool kits that work well. The second thing CCO could do is moderate and measure whether it has an impact or not. What we don't want to do is use things that don't really work that well. A third thing that they can do is something called targeted funding, because each region is a little bit different (RCC)

The last quote implies that the strategies currently employed by CCO for public engagement are not proving very useful. This informant was suggesting that if evaluation of current methods were undertaken, then the initiatives and approaches which were useful would be emphasized. Finally, this informant suggested, in accordance with other key-informants, that targeted funding for each

region might be useful, emphasizing the fact that diversity exists even within the diverse areas.

The extract taken from a document from the MHLHIN concurs with the statement above in mentioning the importance of monitoring and evaluation:

Along with provider funding, we hold the serious responsibility of monitoring their performance and engaging them to continuously improve while ensuring that most taxpayer dollars are spent providing direct patient care services to improve the health and health care of local residents (MHLHIN 07-08 Annual Report)

All these quotes and excerpts signify that there was a consensus in thinking that culturally appropriate public engagement can only be carried out by targeted funding. This means, efforts should be actively channelled towards an objective that has been designed with the aid of consultations with the broader community including affected cultural groups. Therefore targeted funding refers to having pre-designed outcome targets in mind, as opposed to blindly allotting a large amount of funding.

Targeted funding ties in with the concept of 'diversity within diversity', described earlier. It is important to reiterate that diversity within diversity highlights that even within diverse populations, variability exists, and therefore these groups need to be targeted differently in accordance with their own cultural values and beliefs. Therefore, targeted funding can be utilized here; for example, if it has been demonstrated that a particular segment of the population appears more vulnerable, organisations could start up a dialogue with that particular community. In order to then pursue an active goal, targeted projects could be designed as interventions.

This notion of 'diversity within diversity' was coined in a document from the CWLHIN:

It is imperative that the coordination of health services for diverse populations result in processes and mechanisms that are responsive to the diversity within diverse populations as "one size will not fit all". However, the real challenge for Central West LHIN, and health service agencies within the LHIN, is to design a comprehensive plan to address these complex and growing demands of diverse populations in the context of public spending on health services (CWLHIN Community Engagement Plan for Diverse Communities)

An informant of the Canadian Cancer Society spoke about an instance that captured the importance of the concept of 'diversity within diversity'.

One of the things we learned was that we couldn't even talk about smoking in that particular temple because it's against their religion to smoke. So, the assumption is that nobody smokes anyway, therefore we could not talk about the dangers of smoking. But we do know that there are people within that community that smoke and who need that necessary information (CCS 2)

It is imperative to note here that the informant is only speaking about one particular segment of the South Asian temple-going population. The prevention message was not catered in line with the values and beliefs of this community; therefore they were not responsive to this outreach effort.

Another major barrier recognized as a challenge to culturally appropriate public engagement was a lack of ethno-cultural data. Many participants insinuated this by mentioning it as an impediment to designing targeted programs; however, only one participant explicitly stated it as a challenge.

We need more rich ethno-cultural data, so, for example, you know there are issues that disease contours follow, ethno-cultural regions stock, biological stock, the population, so, if we were to say, let's take screening for example, if we were to take screening rates in ON, where do you think the lowest rates of breast screening are in ON? Because we don't know this, we are unable to ethically reach out to cultural groups (CCO 4)

This informant stated that until there was concrete evidence revealing significant statistical variations with regards to ethnicity or culture for screening, it would be ethically difficult to alter programs currently provided.

Funding and resources were identified as the primary limiting factor to carrying out culturally appropriate public engagement. A disconnect was demonstrated between mainstream and community organisations, stemming from lacking resources leading to an unwillingness to then share the wealth of knowledge that they have. The concept of diversity within diversity was also discussed, and finally the fact that there was a deficiency of ethno-cultural data. Clearly, there are many challenges associated with attempting culturally appropriate public engagement. The final section will address the community perceptions on public engagement as well as discuss the value of public engagement, is it worth it?

4.5 Community Beliefs and Values

Two focus groups were conducted, and although the participants do not represent the majority of the South Asian population in the catchment areas, they do offer insights into community views on public engagement. Community members were asked about their positive and negative experiences

with the health care system, whether they were aware of the health care resources available to them in their region, and finally if they felt engaged by the health care system.

For the most part, there was a sense of satisfaction with the health care services provided among the community members. When asked if they thought health care was provided in a culturally sensitive manner, participants of the focus group said:

We're happy with the care provided, although doctors have little time to give to us, they're very attentive (FG-BNRC participant)

Another participant described an experience with the cancer system. Despite not having a South Asian family doctor, she says her needs are definitely met by the health care system.

During a yearly check up and mammogram a lump was found, I was referred to a specialist. I have always had my mammograms done, the whole system was very easy to navigate, people helped all along the way (FG-BNRC participant)

There were some narratives describing negative experiences with the health care system as well, one participant said:

Well, the nurses can be pretty brutal, they really don't care to understand things from the patient's perspective. One patient was crying, and she just didn't care, she kept saying, no, go to bed, just go to bed... she didn't want to think about it and see what's really bothering her (FG-PCHS participant)

Another participant insinuated that there was a language barrier, and that health care professionals ought to better cater to what patients actually need.

I was at the emergency, I could see this man in pain, asking a nurse for some pain killers... she kept refusing him because she kept saying she didn't understand what he wanted. Finally I went in there and asked him what he wanted, he had just had knee surgery and couldn't get through to the nurse that he needed medicine. I then went and told the nurse what he was looking for... there's definitely a communication gap! (FG-BNRC participant)

With regards to knowledge about prevention and screening, most participants were aware of the common screening practices, such as mammograms. Slightly less familiar types of screening such as PET screening for prostate cancer for example, almost all the participants had not heard of. They had not been informed by their family doctor, through a mail out from a public health unit or any other form of public education outreach.

The PET test, we still have to pay for it, they said they were going to make it free mandatory testing (FG-BNRC participant)

Well, if it was free, we would definitely get it done, but if you charge for it, we'd have to think about it (FG-PCHS participant)

It is important to note that when speaking about health care services and programs offered, community members immediately thought about family doctors, hospitals, emergency services and OHIP. This implied that the public is perhaps only interested in knowing the bare basics of health care.

The focus groups revealed a complete lack of awareness of the existence of the LHINs as well as Cancer Care Ontario. Some of participants (20% of participants) asked if CCO was the same thing as the Canadian Cancer Society. Others said they knew of the Heart and Stroke Foundation, or Canadian Diabetes Association, even Peel Public Health was mentioned. Clearly these were the agencies that the community felt engaged by. The individuals involved in the focus groups were representative of the public that are willing to be engaged and involved in their health care system. The reason they were aware of the other health care organisations was due to their affiliation with their respective community agency. The participants were asked why they enjoyed coming to these community group meetings, one member answered:

Lots of reasons, I gain knowledge about my health, the Canadian Diabetes Association came in once and gave us a presentation, a nurse practitioner from Public health came in to talk about health and nutrition. I have made friends and it gives me something to do (FG-PCHS participant)

When asked how they discovered this group, one group member said:

Well, I heard about it from here only, I go to the Gurdwara next door and it's attached, so naturally I was curious (FG-PCHS participant)

It was evident from these discussions that community agencies play a big role in public education and facilitation of partnerships with other health care organisations in order to disseminate knowledge in areas that may not be within their range of expertise.

These focus group discussions illustrated that although there was a willingness to learn, the interest of the majority of the public is basic health care. This demonstrated a mismatch between the system's idea of engagement and the public's idea of engagement. A quote mentioned earlier in the meaning and importance of public engagement section states:

The government themselves represent a form of public engagement called democracy and so we take instruction from government based on their public engagement with the electorate who genuinely are the public (CCO 4)

This quote implies that by taking instruction from the government, an organisation is carrying out public engagement, because a democratic government caters to the needs and wants of its citizenry. This notion is somewhat in line with the beliefs of members in the focus groups; the impression obtained from conversation with participants was not that of dissatisfaction with the health care system. Rather, as verified by some of the quotes earlier in this section, for the most part there is a blind trust of the system, as long as the services are there and available when required, community members do not particularly care to be engaged. This ties in closely with what a spokesperson from the Mississauga Halton LHIN stated:

Do the public really need to know what the LHINs are? No, not really... So, the question is, how far do we go with public engagement? We still need to do it, we still want to do it, but how much effort do you put into it? (MHLHIN)

Evidently, even institutions such as the LHINs who are mandated to undertake public engagement, question the value of this activity and how far it will go in aiding decision making with regards to culturally sensitive care. This section has addressed the values and beliefs of the public involved in two focus groups conducted, therefore, representing the views of the community in the catchment areas of the Mississauga Halton (MH) and Central West (CW) LHINs. It was also revealed through the results that perhaps the majority of the citizenry was rather unconcerned with being engaged. This raises questions pertaining to the value of public engagement and the notion that perhaps simply having a democratic government is enough public engagement.

4.6 Summary

This chapter presented the results of eight documents reviewed, fifteen key-informant interviews and two focus groups conducted. These conversations complemented by evidence from the policy documents, highlighted the perceptions portrayed by health care professionals as well as community awareness regarding the meaning and importance of public engagement. Excerpts from policy documents were also used to represent institutional values on the topic. This was used to set the context to better understand the importance of culturally appropriate public engagement to alleviate barriers and enable access to healthcare services for visible minority communities. The results revealed strategies by which culturally appropriate services may be utilized, and highlighted the challenges faced when undertaking public engagement. With these results in mind, there are important theoretical implications and policy

recommendations that will benefit both decision makers as well as the broader public. These will be discussed at length in the next chapter.

CHAPTER 5 – DISCUSSION, RECOMENDATIONS AND CONCLUSIONS

5.1 Introduction

This chapter presents an interpretation of the findings presented in Chapter 4. The chapter is organised around fundamental themes arising from the primary research objective; which was to understand whether, how and under what conditions innovative public engagement practices in local health care decision making occur and how they might be sustained for and with visible minority communities. Particular attention was paid to the nature and scale of engagement occurring with visible minorities in terms of enhancing their awareness and access to healthcare resources. This was explored within the contexts of general health care services organised through Local Health Integration Networks (LHINs) as well as more specialized health care services, provided through Cancer Care Ontario (CCO).

Utilizing a review of eight documents, fifteen key-informant interviews and two focus groups, the research revealed varying perceptions and values held by health care professionals and community members on the meaning and importance of public engagement. Professional opinions differed and appeared to vary according to the institutional affiliation of the informants (e.g. whether they provided specialized care or not; whether the organisation was community based or not, and whether they were involved in advocacy campaigns). The review of policy documents from the institutions being studied, affirmed among other things, that views on public engagement varied based upon the organisation's definition of 'public' as well as the institutional mandate. The nature and implications of these differences are discussed below.

The importance of culturally appropriate public engagement was also a key theme discussed, as well as strategies by which this may be carried out. Consequently the challenges involved when attempting to meet this objective are revealed and described by respondents in the study, along with ways in which they feel these challenges could be addressed or overcome. The merits and challenges of citizen engagement discussed in the findings are similar to those that have been documented in the literature.

Overall, the majority of participants advocated citizen involvement in local health care decision making. However, an atypical viewpoint disclosed by an informant was one that pertained to government itself representing public engagement. Some citizen values corresponded with this perception of public engagement. This is in line with the literature, which suggests an apprehension on the part of citizens to partake in decisions that they do not feel equipped to make (Abelson & Eyles, 2002; Litva *et al.*, 2002; Lomas, 1997).

This chapter will identify the theoretical and policy implications of the research findings. Additionally, it will include limitations of the research

conducted, and also suggest directions for further exploration. Finally, a conclusion to the thesis will be presented.

5.2 Theoretical contributions

The results of this research point to three major theoretical contributions that relate to better understanding the relationship between public engagement activities and decision making in the local health care arena, specifically at a community level. Each of these will be discussed individually throughout this section.

5.2.1 Meaning, objectives and importance of public engagement

This research has demonstrated that although health professionals from the various organisations examined understand the importance of public engagement, the exact meaning and objectives of public engagement are often misinterpreted, poorly communicated and misconstrued.

It is generally acknowledged that citizen views cannot be the only “ingredient” in the decision making process. This view became particularly clear through the words of an informant from CCO, who highlighted that decision making requires a bureaucracy, with specific skills. When speaking about the importance of public engagement, another representative of CCO emphasized “extraction of information” as a fundamental goal of public engagement. These two definitions of the meaning and objectives of public engagement portray confusion over what the actual purpose or objectives are with respect to engaging the public. What also remains questionable here is what bureaucracies do (as opposed to what they might be expected to do) with the information and public desires that are communicated to them within public engagement processes. That is, discrepancies exist between the expectations and objectives of those with final decision making power, vs. those who are ‘consulted’ or ‘engaged’ with. Merely informing or legitimizing a decision maker is very different than having the power to shape the final decision yourself. The term ‘extraction’ also denotes a very calculated exercise, suggesting that specific anecdotal information may be collected to positively support medical evidence. Whereas the prior perception regarding citizen engagement as being an ingredient in the decision making process stresses that utilizing more than one method to inform decisions is a more effective and sophisticated approach.

In addition, the use of the word bureaucracy suggests a hierarchy of authority, with the citizen voice being the lowest tier. It is important to note that the informant referred to the citizen voice as being the patient voice. The term ‘extraction’ also implies medical terminology, which correlates to the idea that CCO sees their public as patients of the cancer system. Therefore the language used by spokespeople from CCO is indicative of CCO’s definition of ‘public’ as patients of the cancer system. Other institutions such as the CCS and the H&S foundation, despite being specialised health care resources are national; community based volunteer organisations, set up to serve Canadian communities through prevention, advocacy, education and support. These institutions therefore

seek to provide information and support to all members of the public (CCS, 2010; H&S, 2010). Therefore, an issue raised in the findings was confusion over 'who' or 'what' the public actually entails.

According to Eyles and Litva (1998), there are four different types of decentralization; one of them being devolution. The devolution of health care services in Ontario to the fourteen LHINs has ultimately resulted in the creation of sub-national levels of government that have substantial autonomy from the provincial government take on described functions. As quoted by Eyles & Litva (1998), Hurley *et al.*, (1993), explain that the restructuring of the health care system in Ontario occurred to ensure better overall management which:

... will produce and deliver services with improved efficiency in ways more flexible and responsive to community needs... Finally, there is to be a significant increase in community participation in planning decisions for health care (1998, pg 251)

Organisations such as the Mississauga Halton LHIN, Central West LHIN and Canadian Cancer Society explicitly incorporated the need to carry out public engagement into the mandate of their organisations. However, the respondents expressed a desire or need to be better equipped to create programs and services according to the needs and values of the community members that they serve. Some organisations do indeed focus on recognising the ethnic diversities present in their areas in order to better understand how people approach their health care, and access or face barriers to health care services. These institutional values correspond to secondary literature which states that successful democracy involves understanding and representing public values and beliefs (Giacomini *et al.*, 2004).

The meaning and importance of community engagement was also linked to the objective of knowledge dissemination and empowering the public to make knowledgeable decisions about their health care. Nevertheless, many respondents alluded to the importance of cultural sensitivity when discussing the challenges of knowledge transfer. This recognition was deemed as important to alleviating barriers and enabling greater accessibility for visible minority communities. Many participants posed viable strategies to ensure that engagement activities are carried out in a culturally appropriate manner. The minimum requirement for cultural sensitivity, agreed on by all key-informant participants, is the translation of health information and educational documents. Certain organisations, such as the CCS have adopted technology to cater to the needs of diverse and marginalized populations. They have introduced a teletypewriter or text telephone system (TTY system), enabling access to over one hundred languages as well as a support for those that are deaf or hard of hearing. This technological advancement allows marginalised populations such as deaf, blind as well as all those who do not speak English as a first language to effectively communicate with peer support workers, doctors and specialists. According to LHIN documents reviewed, this is the direction that they too intend to go in:

Bridging the gap among the Central West LHIN, service providers, health care professionals and diverse communities requires a multi-pronged approach in order to address the health needs of diverse populations, but more specifically, ethno-cultural/linguistic groups (CW LHIN Community Engagement plan for diverse communities).

Similarly, PPH documents also revealed initiatives promoting the use of an “ethno-cultural lens” to their future interventions, to enable targeting the broader population that they serve. Recent efforts and trends in citizen engagement in Canada have incorporated education, culture and religion (Abelson, 2001). This is an attempt to address disparities in self-reported health status of newcomers as compared to their Canadian-born counterparts (Dunn & Dyck, 2000; Newbold, 2005).

There is little way of effectively utilizing an “ethno-cultural lens” to incorporate culturally sensitive programs and practices without the aid of partnerships, collaboration and enhanced community capacity. Institutions require links within ethnically and culturally diverse communities to appropriately address health care service and delivery issues. This figurative lens will otherwise only serve as a window to view the communities, not a mechanism through which either party can be engaged. The next section allows some insights into the relationship between partnerships and effective public engagement.

5.2.2 Collaborative governance

A major theme depicted in the findings was the need to foster partnerships between organisations of varying levels. For example, institutions that follow a more bureaucratic approach to governing in health care, should be partnering with more community-based agencies in order to enhance the sustainability of civic engagement and the efficiency and effectiveness of collaborative efforts. Collaborative health care models are also purported to alleviate organisational challenges such as resource scarcity, polarized interests, uncoordinated policies and lack of trust resulting from hierarchical management systems (Edge & McAllister, 2009).

The importance of collaborative arrangements to sustainable resource allocation was emphasized by all the key informants. This was a particularly important issue for representatives of community agencies due to their programs being highly dependent on external funding. Resource allocation decisions affect the sustainability of programs because there is often insufficient funding to keep them going. If effective partnerships were created between, for example, the CCS and a community agency, then perhaps funds and resources could be shared, and programs and services required by the community could be sustained. However, this is not currently happening.

Indeed, one of the biggest challenges identified in the results of this study was the lack of community capacity. The policy documents reviewed and the discussions with key informants indicated that the words capacity, collaboration and partnerships were used interchangeably. All the institutions pointed towards a need to build capacity and facilitate partnerships within the various networks of the health care arena. There is agreement amongst informants that community engagement in governance leads to effective decisions and a more sustainable system. Therefore the support for collaboration amongst participants is in line with broader prescriptive recommendations to shift towards these types of governance arrangements in the wider literature. Governance itself has been defined as organisations *collaborating* to achieve goals that have been mutually agreed upon. Hence, governance as a concept, acknowledges the importance of the network of actors playing a role in community sustainability (Edge & McAllister, 2009; Veenstra & Lomas, 1999). Work on sustainable communities recognizes that both influential and marginalized actors within the system as well as other significant variables in the community must be understood in terms of their interactions and effects (Edge & McAllister, 2009; Veenstra & Lomas, 1999). The system in the context of this research would be Ontario's health care system and the regionalized governance context, specifically the LHINs. In this particular case, key actors involved include; CCO, the two LHINs, PPH, CCS, H&S foundation, RCC and the community agencies involved (BNRC, PCHS & AHS). Through acknowledging the different actors in the system it is easier to conceptualize the idea of community sustainability as a network that ought to work together. The findings highlighted certain limitations within the collaboration model, because some of the key actors do not form effective collaborations. This is surprising of the LHINs, especially given their mandate.

However, it is also important to understand why certain groups of the broader population are hesitant to be engaged. Existing literature suggests that this could be due to being too busy or that newcomers are preoccupied with trying to start their new life and/or that certain demographics do not have enough education or knowledge to be motivated to be involved (Lawrence & Kearns, 2005; Newbold, 2005). Raco & Flint (2001) argue that in order to carryout democratic action, it is important to instil interest in the pursuit of objectives to enable willing participation rather than forced engagement. It is also worthwhile for policy makers and planners to be aware of the fact that when mobilizing community, that they are creating place-space relations. Therefore by purposefully asking communities to partake in engagement activities, decision makers are reorganising community routines, rituals, procedures and institutional spaces that have been created in specific ways (Raco & Flint, 2001). Hence, it is important to note that civic responsibility is intrinsically linked to practical and emotional attachment to the local community (Raco & Flint, 2001).

Suggestions by several informants alluded to being cognisant of "diversity within diversity" or being cautious of prescribing "one size fits all" solutions. Representatives of community agencies spoke about this idea, and highlighted that even within the South Asian community in the catchment areas being studied;

there is a great deal of diversity and the need to target different sub-populations in unique and appropriate ways. Communities that are defined geographically or have shared needs are not necessarily alike and hence need to be engaged in varying ways that accommodate their language, religion, socio-economic status and community values (Abelson & Eyles, 2002). For example, the LHINs have been divided up geographically despite the fact that the populations they encompass are very disparate. As mentioned previously in chapter 3, the two LHIN areas being focussed on are particularly high in varying visible minority populations, hence requiring a need to focus on ethno-culturally specific public values when considering citizen consultation strategies.

Suggestions presented by participants to approach citizen participation are in line with some of the “preconditions” set out by Eyles and Litva (1998). A knowledgeable citizenry regarding health and health care issues is among other important precursors for a supportive local climate for citizen participation. One of the ways to obtain this might be through efficient media and communications systems. This was a viable solution proposed by community agency representatives as well as focus group participants to specifically target certain segments of the population.

When discussing collaborative governance, Lerner (2006) distinguishes between the different types of collaborative governance arrangements based on how and by whom the process is initiated. These factors are very important with respect to whether citizens decide to partake in, or reject the collaborative process. The three types of collaborative governance arrangements defined are “other-organised”, “self-organised” and a hybrid of the two. “Other organised” groups link the public sector, private sector, NGO, non-profit organisations and lay citizens in decision making. Projects stemming from these groups are normally, however, not always, initiated by governments that are not locally based, thereby effectively mobilizing local citizens and other stakeholders to address goals. In “self organised” governance arrangements (e.g. citizen advocacy groups, NGO, etc) the organisation of citizen involvement is carried out by the actors themselves, serving their own purposes, as opposed to being delegated to by an external actor such as government (Lerner, 2006). The differences in the two types can be significant in terms of what the public expects and their experiences with the activities they’re involved in.

Key informants spoke about the challenges of conducting public engagement due to hesitancy by the public to participate, and focus group members identified the lack of knowledge and involvement in civic engagement amongst their fellow citizenry. The introduction of civic engagement to aid in health care decision making was to expand accountability beyond the confines of government alone (Eyles & Litva, 1998; Litva *et al.*, 2002). However, a big challenge is getting a representation of all members of the public. Furthermore, it is difficult to demarcate the public from interested parties that are motivated by political agendas. A respondent referred to this as: “concentrated interest masquerading as the public”. In the past few decades, the relationship between

state and civil society has been changed, where citizens and communities play a more active role in the governance of society. However, these participatory governance processes remain vulnerable to control by a few active citizens and stakeholder interests who seek to initiate, sponsor and thereby control the information that influences decision making outcomes (Abelson & Eyles, 2002; Raco & Flint 2001).

Decentralization of health care was carried out in order to delegate authority and distribute autonomy, and therefore power, to local institutions as well as citizens (Eyles & Litva, 1998). However, due to the rigid nature of many institutions, there is a lack of willingness to share authority. Perrow (1977) discusses the paradoxical nature of bureaucracy in contemporary times, and how the delegation of authority goes hand in hand with centralized power. Once those with control; the institutions attempting to achieve citizen engagement, realize the authority they have and delegate it, the outcome of their goals will be much more likely to be met. The next section discusses the relations of power and the effect these have on public engagement.

5.2.3 Power relations

An important finding was the notion that the citizenry is in fact uninterested in being engaged, and therefore involved in the decision making process. Concurrently, a quote from one of the key informant interviews implies there is no need to incorporate public preferences:

The government themselves represent a form of public engagement called democracy and so we take instruction from government, based on their public engagement with the electorate who genuinely are the public (CCO 4).

This brings about the question, why do we then conduct public engagement? From an institutional perspective, it is evident that civic participation in decision making is beneficial because it can help promote goals, promote a sense of competence and responsibility, enhance community capacity and allow the citizenry to express political or civic identity (Litva *et al.*, 2002). The public's perspective however is yet unclear. There have been many studies to explore the views of lay civilians on their motivations or their perceptions towards participation; however, it is only apparent that so far, citizen engagement is skewed towards the educated and affluent (Eyles & Litva, 1998).

Some focus group participants expressed an interest in being engaged by the health care system; however their understanding of the health care system was poor. Many participants were unaware of how the health care system works. When speaking about health care, the ideas that came to mind were basic components, such as availability of family practitioners, emergency wait times, and the Ontario Health Insurance Program (OHIP). This gap in knowledge indicates that most lay citizens are not very well-informed of the issues being

dealt with by local health care services. Hence the majority of the citizenry is unable to provide knowledgeable input to aid in decision making. It can be deduced that the lay public simply wants knowledge and notification about the happenings of the health care system. They also want decisions to be transparent and reflective of their own personal experiences and values (Litva *et al.*, 2002). However, instead of doing this, institutions are publicizing citizen governance as a critical means of achieving more responsive decision making, while using these structures as cost-cutting instruments (Abelson & Eyles, 2002). This demonstrates a mismatch between the system's idea of engagement, and the public's idea of engagement. Participatory processes ought to be community focussed and educative (Eyles & Litva, 1998).

Citizen governance and empowerment in the regional health care system is linked to the selection of elected board members. The public must feel as though the board is representative, well intentioned and accountable to the entire community (Lomas, 1997). Popular control is the cornerstone of democracy, and hence, often, due to poor electoral turnout, accountability breaks down into representation and accountability to specific interest groups (Lomas, 1997).

The public are hesitant to participate due to a lack of knowledge about the issues being debated, and therefore do not feel equipped to make decisions (Litva *et al.*, 2002). It is therefore necessary that these lay citizens be accurately represented on electoral boards in regional health districts. In order to facilitate this, special efforts need to be undertaken to empower individuals with enough knowledge to minimally participate in community based civic activities and vote for regional health district board members. The next section poses some policy and applied contributions that may assist in empowering the public with some basic understanding of their health care system.

5.3 Policy & applied contributions

This research provides a case-specific set of findings for community participation activities and decision making in the local health care arena. It provides a set of descriptive and prescriptive principles and recommendations for understanding and responding to complex problems. These include recommendations about how local governance capacity might be strengthened and how participatory approaches might be adapted to be more culturally appropriate. The research exposes some of the structural and procedural inadequacies of governance systems and decision-making processes within the CW and MH-LHIN areas; but also highlights opportunities for building upon existing community capacity. It does so by providing recommendations for enhancing collaborative action and illustrating the challenges which impede this action. The recommendations in the following sections discuss strategies for promoting social and institutional learning and opportunities for knowledge exchange. Hence, this work will benefit civil society, as well as governmental and non-governmental institutions by providing insight into what is needed for building community capacity, social capital and harmonized advocacy efforts.

5.3.1 Cultural sensitivity

Organisations must be culturally sensitive, to openly represent the diversity of the organisation itself. This idea was mentioned by some of the participants in the focus groups, but also by several key informants. By designing culturally appropriate programs and services, organisations can illustrate solidarity with their community and therefore the public are likely to be more responsive to partake in civic activities. This was brought forward primarily by community agencies as they have a deeper understanding of what communities need. A representative of the CW-LHIN also advocated this strategy, highlighting that if you show the community that you are one and the same, they will be more inclined to believe that you understand their needs and inherently, their values.

Excerpts from the MH-LHIN policy documents indicate that they too, have honourable intentions, and want to depict diverse representation on their board to reflect the communities they serve. However, this was very vaguely alluded to and therefore gives way to suspicion. How will this reflection of diversity be accomplished, and will this positively affect community capacity? The lay public does not see the LHIN board, they have no association with the LHIN board, and therefore, it is essential that they see diversity reflected at the grassroots level. There will otherwise be an inability to trust, and hence a lack of knowledge will be transferred.

Another effective strategy to represent cultural appropriateness in public engagement is by using key family or community members to relay important information to the desired audience in a way that will be understood. The term used for this strategy is “community ambassadors”. To adequately utilize this method however, it is integral that these community ambassadors are strategically appointed and expertly trained to deliver the knowledge transfer. Unless institutions are well integrated among their community and are rich in social capital, these culturally appropriate strategies will not be easily obtained. Collaborations and partnerships need to be fostered to gain insight into communities and trust by the community members. The next section will address the valuable role community agencies can play in fostering these partnerships.

5.3.2 Value of community agencies

The political role of ethno-cultural associations remains largely undocumented, however, these agencies have been shown to play a positive part in the lives of visible minorities and immigrants in Canada (Wayland, 2006). The nature of the relationship between community agencies and federal and provincial governments however, is deemed problematic (Wallace & Frisken, 2003). Particularly, there is criticism surrounding the way in which funding and program agendas are decided provincially or nationally, but implemented locally. This is the process by which local municipalities and non-profit sector organisations implement programs and services which have been planned at the federal and provincial government levels (Wallace & Frisken, 2003).

The challenge faced by community agencies is the “lack of fit” between the needs of the visible minorities and newcomers utilizing the services of these organisations and the programs prescribed by government. Unfortunately, community agencies “have their hands tied behind their backs” when it comes to providing these services. This is largely because they have little or no control over the policies or allocation of funds and resources (Wallace & Frisken, 2003).

A way to alleviate this mismatch between the resource needs of these community agencies and the development of policies and programs at the federal and provincial levels is effective communication and collaboration. Currently, there is no conversation in place to discuss these issues; it is advantageous for regional and provincial governments to conduct consultations with community agencies to aid in constructing appropriate policies and programs to target health care needs of visible minorities and immigrants.

In the case of this research, the three community agencies looked at were BNRC, PCHS and AHS. All three have key insights into the large South Asian population in the CW & MH-LHIN areas. These organisations however, cannot share their wealth of knowledge without adequate funding and resources to then expand their services. Partnerships between these agencies and other mainstream organisations (CCS, H&S, CCO) and government entities (LHINs, provincial government) would facilitate a valuable knowledge transfer and allow for increased regional capacity.

5.4 Limitations and directions for future research

The findings from this study are significant in terms of their theoretical and policy implications, however, it is important to address the limitations of this research. Firstly, the findings are case-specific, and not readily generalized to other contexts. There is a need for testing the devised objectives within other empirical settings in order to provide further support to the validity of the findings. However, some of the findings are generalizable, as the case study reinforces the documented literature presented in chapter 2.

A small sample size of key informants was used during interviews and only two focus groups were conducted. This prevented the use of any quantitative analysis and testing of statistical significance of the findings. Additionally, all the participants in the focus groups were recruited through the seniors program of two community agencies, PCHS and BNRC. Therefore, these individuals are not representative of the broader population of the two catchment areas as they are already civically engaged individuals who are affiliated with a community agency and therefore integrated into wider social society. The focus group participants were all representative of only one demographic, that is, men and women over the age of fifty-five. Therefore research would be enhanced by further exploring the views on public engagement of other demographics such as youth, single parents, and women who have experienced pregnancy in the country. There is evidence in

the literature that reflects the need for greater awareness of health service provision among visible minority populations (Newbold & Willinsky, 2009).

Great effort was put into obtaining insights from a wide range of informants from each of the organisations, however, this goal was unattainable. Due to the preliminary and exploratory nature of this research, the study focused on key informants that were particularly knowledgeable about the subject area as opposed to trying to obtain a representative sample. Hence, although the key informants who were purposefully selected using a criterion sampling strategy from the institutions under examination were very knowledgeable about the subject area; it would have been fruitful to have a greater variety of insight. The interviewees were not entirely illustrative of local decision making in the two regions being studied. Therefore, future investigation would benefit from including greater representation from a more diverse range of NGO's, community agencies and politicians.

The aim of this thesis was to examine the nature and scale of public engagement for and with visible minority populations. However, this study focussed specifically on South Asians. It would be useful to carry out a similar study to look at immigrants and minorities from other parts of Asia and the Pacific, as these areas are the largest sources of migrants to Canada (CIC, 2008b). Furthermore, to obtain a broader view of perceptions on public health to aid in decision making, areas other than Southern Ontario which are hosts to a large proportion of visible minority populations could be examined.

While it is important to note these limitations, this research has provided explorations of institutional perceptions and values on undertaking citizen engagement with the broader public, and specifically, visible minority communities.

5.6 Conclusions

In conclusion, information derived from the findings of this research is in support of the documented theoretical and policy based literature. This literature states that public participation in decision making and a commitment to mutual social learning at the local level are essential to advancing a systemic and integrated approach to enhancing governance capacity for regional health care. Interview participants as well as focus group members understood the necessity and value of collaborative governing arrangements. The benefits of partnerships outlined by key-informants and policy documents included mutual learning, a clearer understanding of the importance of cultural sensitivity, better lines of communication, the sharing of resources and expertise, a greater harmonization of policies and finally, achievement of overlapping objectives. All these benefits will help reduce system fragmentation, mobilize untapped social capital, and therefore enhance the capacity of local governance. A few emerging initiatives were identified by health professionals during interviews that may have the potential to

promote such collaborations and hence create sustainable regional health programs and services.

Finally, to answer the research question posed at the beginning of this thesis; there is a demonstrated lack of knowledge pertaining to the health care system, amongst visible minority populations examined in this study. Although public engagement has been identified as a mechanism through which this knowledge transfer may take place, it is primarily important to create culturally appropriate avenues through which this can happen. The strategies and innovations in place, or under construction, vary based upon the specialized and general health care delivery. However, the one pertinent common factor prescribed is the need to create opportunities to facilitate interrelationships between institutions existing at smaller spatial scales; therefore allowing community leaders, decision makers, activists and citizens to exchange skills and knowledge to aid in better understanding of the delivery of regional health care.

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APPENDIX 1: Countries in regions of ‘Asia’ and ‘Pacific’**Asia**

Afghanistan	Macau, SAR
Bangladesh	Malaysia
Bhutan	Mongolia, People’s Republic of
Brunei	Myanmar (Burma)
Cambodia	Nepal
China, People’s Republic of	Oman
Hong Kong	Pakistan
India	Philippines
Indonesia, Republic of	Singapore
Japan	Sri Lanka
Korea, People’s Democratic Republic of	Taiwan
Korea, Republic of	Thailand
Laos	Tibet
Macao	Vietnam, Socialist Republic of

Pacific

Australia	Pacific Islands, US Trust Territory of
Fiji	the
French Polynesia	Papau New Guinea
Maldives, Republic of	Samoa, Western
Nauru	Tonga
New Zealand	Vanuatu

Mississauga Halton LHIN

Central West LHIN



APPENDIX 3: Interview script**Interview protocol for health care organisations – LHINs & Cancer Care Ontario*****Opening***

- Hello, my name is Sarah Ahmad, you might recall that I sent you a letter of consent informing you about the purpose of my research and this interview; as well as your rights as a participant
- As a reminder, I will review the purpose of the interview
- Outline of interview purpose - I am interested in learning about the institutional mandate regarding public participation and the initiatives you are working on to accomplish these goals. I want to understand what public participation means to you and how you plan on engaging all visible minorities in your catchment area.
- State confidentiality of the interview and remind participant of their rights and assure safety of participation

Interview - professionals

1. What does your organization do?
 - a. Why are you part of this organization?
2. What is your mandate on engagement with the public? Is there one? Why, why not?
 - a. If yes, do you think you fulfil this mandate?
 - b. If not, do you think this is something that will be considered in the future?
3. Background on public engagement
 - a. What is public engagement? What does public engagement mean to you?
 - b. In the past public engagement has been used mostly in environmental decision making and planning... So, what is the importance of public engagement? – in health care – in education - in environmental issues
 - c. Do you partake in public engagement at [insert institution name]
4. Is the PE focussed on
 - a. health conditions
 - b. diseases
 - c. populations
 - i. elderly
 - ii. Younger people
 - iii. What about visible minorities

5. Is it important to engage these communities? Why?
6. What are your CE plans for diverse populations? (central west LHIN)
 - a. “Identify and implement strategies to engage diverse communities”
– how do you propose doing this?
 - b. “Identify and address their current and future health needs” – plans
in place for this?
7. You have held seminars and workshops regarding diversity and inclusivity
– who are these intended to target?

APPENDIX 4: Focus group script**Interview protocol for community – visible minority citizens in focus group setting*****Opening***

- Hello, my name is Sarah Ahmad, you might recall that I sent you a letter of consent informing you about the purpose of my research and this interview; as well as your rights as a participant
- As a reminder, I will review the purpose of the interview
- Outline of interview purpose - I am interested in learning about your experience with the health care system, your access to it, and interactions with it.
- State confidentiality of the interview and remind participant of their rights and assure safety of participation

Interview - Citizens

First begin by introducing all participants...

1. I will start with asking you a few questions about yourself:
 - a. Are you first, second or third generation?
 - b. Is English your first language?
 - c. Which ethnic group do you think you belong in?
2. What are your experiences with the health care system?
 - a. Would you say they are positive or negative experiences? Why – what caused this viewpoint?
 - b. How accessible do you think it is?
 - i. Which characteristics enable this? Or make it difficult?
 - c. Why were you successful or unsuccessful in accessing health care?
 - d. Do you feel fully informed when dealing with the health care system?
3. Have you heard of the LHINs? If yes,
 - a. What do you see as their purpose?
 - b. Have you had any contact with them?
 - i. If yes, what for?
 - ii. Were they helpful or unhelpful?
4. Have you heard of Cancer Care Ontario? If yes,
 - a. What do you see as their purpose?
 - b. Have you had any contact with them?
 - i. If yes, what for?
 - ii. Were they helpful or unhelpful?

5. The LHINs and CCO are mandated to not only inform people about health care services in their community, but to interact fully with them.
 - a. Have you come across this activity?
 - b. If yes:
 - i. Opinion on this
 - ii. Is it important
 - iii. Does it raise awareness
 - iv. Does it help, yes/no, why?
 - v. Did you feel fully engaged with them in this process?

APPENDIX 5: List of documents reviewed

Cancer Care Ontario

- Report on Cancer 2020
- Ontario Cancer Plan 2008-2011

Canadian Cancer Society

- Ontario Division Annual Report 2007-2008

Central West LHIN

- 2007-2008 Annual Report
- Integrated Health Service Plan (IHSP) 2010-2013
- Community Engagement Plan for Diverse Communities

Mississauga Halton LHIN

- 2007-2008 Annual Report
- Integrated Health Service Plan (IHSP) 2010-2013

Peel Public Health

- Staying Ahead of the Curve: Peel Public Health's 10 Year Strategic Plan 2009-2019

APPENDIX 6: Letter of information and consent**Letter of Informed Consent**

“Awareness of and access to healthcare resources: Public engagement with visible minority communities”

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Objective of the Study

The objective of this study is to understand *whether, how* and under *what conditions* innovative public engagement practices in local healthcare decision making may occur and might be sustained, for and with visible minority communities. To achieve this objective, my research will focus on public engagement practices of institutions that oversee primary and secondary health care, namely the Local Health Integration Networks (LHINs) and also one that focuses on one type of specific healthcare, Cancer Care Ontario (CCO).

Procedures involved in the Research

If you choose to take part in the study, you will be interviewed and asked to answer a set of in-depth questions regarding engagement with the public for the purpose of bettering health care services provided. The interview will last approximately an hour and will take place at a time and location most convenient for you. If you consent, the interview will be audio-taped and notes will be taken.

Potential Harms, Risks or Discomfort

It is very unlikely that there will be any harm, risk or discomfort associated with your interview. However, if you feel that some questions are probing, embarrassing or upsetting, you do not have to answer them. You may also request to skip any of the questions at any point during the interview.

Potential Benefits

The study may benefit the visible minority community in the Central West and Mississauga Halton LHIN areas. These communities may gain knowledge and awareness about healthcare organizations and resources. Similarly, health care organizations such as yours may potentially benefit from community responses. This may enable health care organizations to improve their services or community engagement strategies to better shape service provision for these communities.

Confidentiality

Anything that you say during the interview will not be shared with anyone else with the exception of my supervisor. No identifying information about you will be published or told to anyone else unless I have your permission to do so. Your privacy will be respected and if you wish at any point to withdraw from the study, your information will be immediately destroyed. The information obtained during the interview will be kept confidential. Excerpts of the interview may be part of the final research report, but under no circumstances will your name be identified. It is a privilege for me to obtain the information you share with me and I will treat our conversation with the utmost respect. The audio-tapes, hand written notes and transcripts of the interview will be locked in a cabinet in my office and the tapes will be destroyed after the completion of the final project and my Master's thesis defense.

Participation

Your participation in this study is voluntary at all times. If you decide to participate, you have the right to stop the interview at any time. You do not have to answer all of the questions in the interview in order to take part in the study. If you decide to withdraw from the study, you can do so at any point and there will be no consequences to you. Any data you have provided will then be destroyed unless you indicate otherwise.

Information about the Study Results

If you wish to obtain a copy of the research summary, a copy of the findings will be e-mailed or mailed to you. Please provide your e-mail address or home/work address for these to be mailed to:

Contact:

Information about Participating as a Study Subject

If you have questions or require more information about the study, please feel free to contact me, Sarah Ahmad at any time, or my supervisor, Dr. John Eyles.

This study has been reviewed and approved by the McMaster Research Ethics Board. If you have any concerns or questions about your involvement and rights as a participant or about the way the study is conducted, you may contact:

McMaster Research Ethics Board Secretariat
Telephone: (905) 525-9140 ext. 23142
c/o Office of Research Services
E-mail: ethicsoffice@mcmaster.ca

CONSENT

I have read the information presented in the information letter about a study being conducted by Sarah Ahmad of McMaster University. I have had the opportunity to ask questions about my involvement in this study, and to receive any additional details I wanted to know about the study. I understand that I may withdraw from the study at any time if I choose to do so, and I agree to participate in this study. I have been given a copy of this form.

Name of Participant

Signature of Participant

APPENDIX 7: Reference codes for key-informant and focus group participants

Interview/focus group number	Affiliation	Area of expertise	Reference code
Interview 1	Community agency	Health care professional	CO1
2	Heart and Stroke Foundation	Health care professional	H&S
3	Cancer Care Ontario	Health care professional	CCO1
4	Peel Public Health	Health care professional	PPH
5	Canadian Cancer Society	Health care professional	CCS1
6	Mississauga Halton LHIN	Health care professional	MHLHIN
7	Cancer Care Ontario	Health care professional	CCO2
8	Central West LHIN	Health care professional	CWLHIN
9	Canadian Cancer Society	Health care professional	CCS2
10	Cancer Care Ontario	Health care professional	CCO3
11	Community agency	Health care professional	CO3
12	Community agency	Health care professional	CO2
13	Regional Cancer Centre	Health care professional	RCC
14	Cancer Care Ontario	Health care professional	CCO4
15	Canadian Cancer Society	Health care professional	CCS3
Focus group 1	Brampton Neighbourhood Resource Centre	Lay public	FG-BNRC participant
2	Punjabi Community Health Services	Lay public	FG-PCHS participant