THE PARTICIPATION OF MARGINALIZED POPULATIONS IN HEALTH SERVICES PLANNING AND DECISION MAKING

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By

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Abstract

Community participation has been identified as a key facilitator of community health among marginalized populations in international health statements. However, knowledge gaps in the community participation literature regarding marginalized populations has been attributed to the lack of consistent definitions of community participation, ambiguity about the features of community participation initiatives (e.g., methods and strategies) that are appropriate for marginalized populations, and limitations of existing community participation frameworks in specifying the ways and means in which different marginalized populations might effectively participate, as well as in recognizing that community participation is highly contextual and situational. All of these factors have made it difficult to draw broader conclusions about the impact of participation methods and strategies for marginalized populations from evaluations of participation initiatives.

The overall purpose of this thesis is to better understand how to involve marginalized populations in the planning and decision-making for local health services. First, a critical interpretive synthesis (CIS) was conducted to better understand the role of community development principles used in community participation initiatives with marginalized populations and the factors contributing to the influence of the principles in enabling the participation of these populations. Second, an in-depth comparative case study of four community participation initiatives in Ontario Community Health Centres (CHCs)—which are primary health care organizations serving 74 high-risk communities

throughout the Province of Ontario—was conducted to identify the core features of participation initiatives with marginalized populations, and reflect on the particular challenges of engaging marginalized populations. Third, four focus groups were held at four Ontario CHCs to examine the role of frameworks as mechanisms for knowledge translation about community participation practice with marginalized populations. Overall, this thesis broadens our understanding of community participation with marginalized populations in the context of local health services planning and decision making. Specifically, this thesis contributes a theoretical basis for future research and provides practical knowledge for planning and evaluating community participation initiatives with marginalized populations.

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Preface

This sandwich thesis presents the findings of three qualitative studies that explored community participation with marginalized populations in local health services planning and decision making. The research was based on a critical interpretive synthesis (CIS) of the community participation literature, an in-depth case study of community participation initiatives in four Ontario Community Health Centers (CHCs), and four focus groups held at four Ontario CHCs to examine the role of a conceptual framework for community participation with marginalized populations in health services planning within CHCs. Taken together, the findings from the three studies that comprise this thesis provide an in-depth exploration of how marginalized populations have been engaged in local health service planning and decision making, and, specifically, how the principles of community development have guided these initiatives. While I led each of the three studies that are described in the following chapters of this thesis (i.e., development of the study protocol, implementation of the research, analysis, interpretation of findings and manuscript preparation) I would like to acknowledge the contributions of my PhD supervisory committee (Dr. Julia Abelson, Dr. John N. Lavis, and Dr. James R. Dunn) who are co-authors on each chapter. In particular, Dr. Abelson helped with the development and planning of each study, assisted with data analysis, and provided constructive feedback and review of each chapter. Dr. Lavis and Dr. Dunn provided comments and suggested revisions for each chapter, which I incorporated. Dr. Lavis helped with the development and design of the third study (Chapter 4). Overall, this thesis represents an original scientific contribution to the field of community participation with

a focus on marginalized populations that I led with the support and contributions of my PhD supervisory committee.

Chapter 1:

Introduction

This doctoral dissertation follows a "sandwich thesis" format, and is composed of an introductory chapter, a series of three qualitative studies to be submitted for publication in scholarly journals, and a concluding chapter. This introductory chapter includes a discussion of key concepts and terms related to the main topic of interest—*community participation with marginalized populations*—as well as some reflections on the social and political influences that have shaped developments in the field, and a problem statement for the thesis. It will also briefly outline the key knowledge gaps and research objectives, which are addressed in the thesis, and lay out the methods used for each of the studies.

Definition of Core Terms and Concepts

The literature on community participation is diverse and spans several disciplines. Within this broad field, *community participation* with marginalized populations has been used interchangeably with other labels such as community development, community participatory-action, collaborative decision making, community empowerment, community capacity-building, community organizing, and community governance (Butterfoss, 2006; El Ansari, 2005; Jurkowski, Jovanovic, & Rowitz, 2002; Kegler, Norton, & Aronson, 2008; Rapport, Snooks, Evans, & Tee, 2008; 2008; Rifkin & Kangere, 2001; Roussos & Fawcett, 2000).

There has been considerable analysis and discussion among scholars and practitioners of community participation regarding the meaning of the term *participation*. According to Kahssay and Oalkey (1999) and Rifkin (1996) there are two distinct interpretations of *participation* apparent in the health literature. The first views participation as a means or intervention to achieve a specific outcome, such as local cooperation with a proposed health program. The other form views participation as an end through which people or individuals are empowered as they develop their skills, knowledge, and confidence to improve and gain control over the conditions that affect their lives (Morgan, 2001; Rifkin, 1996; Rifkin & Draper, 2007). Community participation with marginalized populations is often described in the scholarly literature according to the latter view, as involving a social process that empowers marginalized people to take responsibility for diagnosing problems, identifying opportunities and strategies for change, and taking collective action to improve health and social well-being (Rifkin & Kangere, 2001; De Vos et al., 2009; Wallerstein, 2006). In this thesis, I expand on the view of participation as "empowerment" to define community participation as a process that enables marginalized populations to recognize their own capabilities and skills to participate through personal and collective reflection on the root causes that impact their health and capacity-building activities, to enhance their capabilities and skills to participate and promote their views and experiences in the planning of and decision-making about health services (which includes primary health care services, health promotion and prevention services and/or programs, and broader population health programs).

Integral to a discussion of community participation is an examination of the concept of *community*. The centrality of community and its importance for health were reflected in prominent international statements such as the Ottawa Charter for Health Promotion (World Health Organization, 1986). However, there is little agreement on what community means. Typically, community is understood in geographic terms with relationships and identity based on a sense of place, and is tied closely to other sources of community identification, such as race/ethnicity, culture, sexual orientation, or occupation (Fellin, 2001; Rothman, 2001; Warren, 1963). More recently, definitions of community have been broadened to view communities as a social system where people with common ties or social interaction come together politically to affect change (Eng & Parker, 1994). Rubin and Rubin (2007) further suggest that there are nongeographic entities called "communities of interest" (e.g., advocacy groups, social movement participation, professional associations, and political affiliations). The recognition of these "communities of interest" has marked an important shift in how we conceptualize community and community participation practice.

Like community, *marginalization* also has several meanings. In this thesis, I use the term "marginalized populations" (as opposed to the broader conceptualization of marginalized "communities"). As described above, the conceptual ambiguity with the term "community" denotes a culturally and politically homogenous social system, or one that is internally cohesive, and obscures the social and cultural diversity within and among marginalized populations. For this thesis, then, I define marginalized populations to include individuals who are socially and economically excluded from the society in

which they live by race, class, gender, socio-economic status, ethno-cultural identity, age, or other stigmatized identities (Jenson, 2000; Lyman & Cowley, 2007) that are enforced by mechanisms of oppression, patriarchy, or stigmatization (Hall, 1999; Vasas, 2005; Lyman & Cowley, 2007). Marginalized populations are usually identified as those who are poor, the least educated, homeless, newcomers or immigrants, Indigenous groups, seniors, people with disabilities, some ethnic minority groups, cultural groups (such as Mennonites), women (in some ethnic-cultural groups), single mothers, low-income people (with unstable employment and at risk of poverty) and individuals with mental health and addiction problems (Jenson, 2000; Vasas, 2005). Individuals in these populations may experience barriers to participation because of complex social, cultural, and political processes that shape their capacity to articulate their needs, values, or concerns (Laverack & Labonte, 2000).

The term marginalization has been used interchangeably with the term social exclusion within different disciplines. The concept of marginalization has also been the subject of scholarly critique (Vasas, 2005); however, it is beyond the scope of this thesis to discuss these critiques. Although it is important to acknowledge the limitations of using the term marginalization, it is also inevitable that any term used to categorize or label people who are socially and economically excluded from mainstream society will be scrutinized. The term marginalization was chosen to refer to these populations because of its widespread use in the health fields of nursing, population health, community health, and primary care (Lyman & Cowley, 2007; Vasas, 2005).

Social and Political Trends in the History of Community Participation in Health with Marginalized Populations

Major social and political trends in the 1970s and 1980s, both in Canada and internationally, have influenced the demand for community participation with marginalized populations. These trends have been driven largely by public demands for greater responsiveness of health professionals and policy makers to the health needs of marginalized populations (Zakus & Lysack, 1998), the growing inequalities in population health (Ritchie, 2004), and interest in the role of community-level factors in shaping health (Veenstra & Lomas, 1999).

One major influence on the demand for marginalized populations' involvement in health service planning and decision making occurred in the 1970s with the recognition of the limits of medical care in achieving improvements in global health (Konner, 1993; Rifkin, 1996). The emergence of new diseases and the rise of chronic illnesses among the poor (such as heart disease and diabetes) (World Health Organization, 2002) influenced the notion of health as being determined by a number of complex interactions between social and economic factors, many of which fall outside the control of the health sector (such as income and social status) (Konner, 1993). The influence of non-medical determinants of health raised questions about the medical professions' ability to tackle all health-related issues. It also raised doubts about their legitimacy in making health care decisions on behalf of the communities they served (Charles & DeMaio, 1993; Zakus & Lysack, 1998).

In Canada and internationally, this new view about health gained prominence with *The Lalonde Report, New Perspective on the Health of Canadians* published in 1974. The

report identified four major sources of influence on an individual's health: human biology (all aspects of health, including physical and mental); the environment (physical and social environment); lifestyle (self-imposed risks created by unhealthy lifestyle choices); and the organization of health care (the quantity, quality, arrangement, nature and relationships of people and resources in the provision of health care). These early 'determinants of health' were influential in demonstrating the wide array of factors outside the health care system that influence health, including adequate income, healthy lifestyle practices, social relationships, respect for diversity based on gender and culture, and community involvement in decision making. This new discourse on health, in turn, advocated for the involvement of marginalized populations in the planning and decision-making for health services, as marginalized individuals were viewed to possess direct knowledge of their own concerns, needs, and values, the particularities of their local context and cultures, and the ways that problems contributed by these factors and solutions (in the form of plans, policies, programs, and services) affect their health (Lasker & Guidry, 2008, p. 7).

A second influential factor was the need for a response to persistent global inequalities in health among marginalized populations. In order for populations to receive basic health services and primary care, the World Health Organization (WHO) declared that radical changes needed to be made to the ways in which health services are delivered (WHO, 1978, Declaration of Alma-Ata). In the Alma Alta Declaration on Primary Health Care in 1978, Primary Health Care (PHC) was proposed as a new model of health care delivery that stressed health over illness, disease prevention over cure, and the needs of

the people over the needs of health professionals (WHO, 1978; Kahssay & Oakley, 1999). The Declaration identified participation as a guiding principle in improving people's health, embedding the concept in the definition of primary health care (WHO, 1978). In this definition, the WHO posited that people have both a right and a duty to participate individually and collectively in planning and implementing programs and services that affect their health (Kahssay & Oakley, 1999, p. 4).

While the Alma Alta Declaration influenced the aspirations for community participation, it did not specify the ways in which populations can be involved in community participation processes in health service planning and decision making. Almost a decade later, the Ottawa Charter for Health Promotion (WHO, 1986) was introduced, which expanded the view in the Alma Alta Declaration by identifying the conditions to support the participation of marginalized populations. This statement advocated for *strengthening capacities* and *empowerment* of marginalized populations as enablers to their participation in health service planning and decision making. The Ottawa Charter promoted a particular approach to the design of community participation initiatives that would specifically address the barriers to participation for marginalized populations. Fundamental to this 'community development approach' to participation is the following set of core principles: (1) building and strengthening the capacity and skills of individuals; (2) empowering individuals by supporting their control and ownership over decisions; (3) building relationships; and (4) promoting collaborative action.

The community development principles outlined in the Ottawa Charter (1986) posited several health and social benefits from enabling marginalized people to

participate in the planning and decisions that affect their health (Rifkin, 1986; 1996; Ritchie, 2004). First, the principles specified that the input from marginalized populations would capture the needs and concerns of marginalized populations that are important to the delivery of culturally appropriate and contextually relevant health services intended for them. Second, as marginalized people participate in the planning and decision-making for health services, they "develop their capabilities and skills to negotiate for and seek the resources and the changes they require to improve their lives" (Ritchie, 2004). This, in turn, would empower marginalized individuals to gain increased control over the factors affecting their lives, which research has shown, enhances peoples' health, well-being, and quality of life (Israel, Checkoway, Schultz, & Zimmerman, 1994; Wallerstein, 1992). Third, as marginalized people work together, they build social networks and social capital that help combat exclusion, counter prejudice and discrimination, as well as reduce conflict and build trust, which are all actions that can lower mortality, morbidity, and disease (Campbell & McLean, 2002; Frankish, Kwan, Ratner, Higgins, & Larsen, 2002; Maloff, Bilan, & Thurston, 2000; Veenstra & Lomas, 1999).

Several developments have been critical in shaping community participation practice in the quarter century since the Ottawa Charter: the development of the global healthy cities/communities movement (O'Neill & Simard, 2006); the growth of participation in research and evaluation, with action research, participatory action research, and community-based participatory research (CBPR); and the recognition of the social determinants of health (WHO, 2008), which focused on community participation to improve health outcomes and promote policy change (Wallerstein, 2006). Furthermore,

the principles and benefits of participation that have been promulgated in the international statements described above have not been critically examined or evaluated for their effectiveness in engaging marginalized populations, yet they are widely accepted within health service organizations and shape their motivation for carrying out community participation initiatives with these populations (Jewkes & Murcott, 1998; Kahssay & Oakley, 1999; Morgan, 2001; Zakus & Lysack, 1998).

Problem Statement

While the international health promotion statements described in the previous section detail the benefits of and need for community participation in health services planning and decision making, they provide less specificity about how community participation is to be operationalized for marginalized populations in particular. The result had been a myriad of interpretations of, approaches to, and methods for community participation. The meaning of community participation in health services planning and decision making has therefore evolved over the decades in response to scholarly critique, as well as to the social and political influences, that have shaped related developments in primary health care, health promotion, and health equity (Carlisle, 2010; Church et al., 2002; Morgan, 1991).

Furthermore, the lack of evaluation of existing community participation initiatives with marginalized populations has resulted in little systematic knowledge about how to design participation processes with marginalized populations, the influence of the community development principles used in the processes to enable the participation of marginalized populations, and how these processes are shaped and constructed by

different marginalized populations and the contexts within which they are implemented. There is also limited knowledge regarding the influence of participatory processes on broad policy-level changes that improve the health of marginalized populations, and that results in marginalized people feeling ineffectual in their ability to influence major policy decisions affecting their health (Blackwell et al., 2010). Lastly, to date, community participation studies have not involved an analysis of larger institutional and political structures that have shaped local determinants of health and well-being (Cleaver, 2001; Labonte, 2009). This paucity of evaluation research has provided scant practical guidance to health system managers and practitioners in local health service organizations regarding how best to implement their community participation initiatives (Butterfoss, 2006; Dressendorfer et al., 2005; Laverack & Labonte, 2000).

Knowledge Gaps, Research Questions and Objectives

This dissertation addresses the following four knowledge gaps: (1) the limited evidence underpinning the community development principles included in WHO health statements for enabling the participation of marginalized populations; (2) the limited empirical evidence about the core features that characterize community participation processes involving marginalized populations; (3) an incomplete conceptualization of the assumptions underlying the reasons why marginalized people take part in community participation initiatives and the processes involved in their decision to participate; and (4) the limitations of existing community participation frameworks in specifying the ways and means in which different marginalized populations might effectively participate, as well as in recognizing that community

participation is highly contextual and situational (Abelson, 2001; Barnes, Newman, & Sullivan, 2006; Cornwall, 2008; Draper, 2010; Tritter & McCallum, 2006).

I will address these gaps through a series of three original scientific contributions that collectively use a mix of qualitative approaches and methods to: (1) examine the evidence underpinning the arguments for the influence of community development principles in enabling the participation of marginalized populations; (2) improve our understanding of the participation methods and approaches that are appropriate for marginalized populations; (3) improve our understanding of the barriers that shape the participation of marginalized populations; and (4) examine the role of frameworks as one type of resource for guiding local health service organizations—especially Community Health Centres (CHCs) that are of particular interest to this thesis—in their community participation practices by identifying appropriate resources or tools to assist with their design and implementation of community participation initiatives with marginalized populations. This thesis addresses these knowledge gaps by deepening our understanding of community participation with marginalized populations in the context of health services planning and decision making.

Research Procedures

The following section provides a brief summary of the research procedures that I followed to address my research questions and objectives for each study.

Chapter 2 – Understanding the Role of Community Development Principles in Enabling the Participation of Marginalized Populations: A Critical Interpretative Synthesis

The second chapter describes the findings from a critical interpretive synthesis (CIS) to: (1) examine how community development principles are used in community participation initiatives with marginalized populations; and (2) identify the factors contributing to their influence. The main purpose of this chapter is to improve our conceptual understanding of community participation processes with marginalized populations by exploring the role of community development principles in enabling the participation of marginalized populations, and identify how the principles are used in the methods and approaches to engage marginalized populations. A diverse set of literature was searched using a purposive sampling strategy to select papers concerned with community participation processes that involve marginalized populations. A total of 61 papers were included in the final analysis and were used to identify key themes relevant to the question of interest. In this study, I identified that the influence of community development principles in enabling the involvement of marginalized populations in community participation initiatives was undermined by social structures that play a significant role in shaping the decisions of marginalized populations to participate. Despite the limited influence of community development principles documented to date, the synthesis results suggest ways in which these principles might be more effectively applied to the design of community participation methods and approaches to address the structural barriers of marginalized populations in the future.

Chapter 3 – Enabling the Participation of Marginalized Populations through Community Development: A Case Study Analysis of Community Participation Initiatives in Ontario, Canada

To further investigate community participation processes with marginalized populations, this third thesis chapter involves a qualitative comparative analysis of four-in-depth case studies of community participation initiatives in Ontario Community Health Centres (CHCs), which are primary health care organizations serving 74 high-risk communities throughout the Province of Ontario. In order to strengthen the capacity of CHCs to engage marginalized populations, this chapter seeks to address knowledge gaps related to the ambiguity surrounding the core features of participation initiatives (e.g., methods and approaches) that are appropriate to marginalized populations, and the factors that shape the decisions of marginalized people to participate. To address these knowledge gaps this study has three main objectives: (1) to describe how participation with marginalized populations differs from engagement with other types of publics; (2) to identify the specific features of participation initiatives with marginalized populations (e.g., the methods and approaches); and (3) to identify the challenges of engaging marginalized populations. The analysis drew on three sources of data to promote an in-depth understanding of community participation within CHCs that included: 28 key informant interviews with CHC staff, a document analysis of publicly available and internal documents from each participating CHC, and site visits to each CHC prior to conducting the key informant interviews. The study findings identify: (1) a more nuanced view of how the community development principles can be applied to the methods and approaches for enabling the participation of marginalized populations; and (2) the

influence of community development principles in the context of a population's cultural values and beliefs that shape their willingness to participate. In addition, the study builds on previous research related to the motivations of those who take part in participation initiatives (Barnes, Harrison & Murray, 2012; Barnes, Newman, Knops & Sullivan, 2003).

Chapter 4 – The Value of Frameworks as Knowledge Translation Mechanisms to Guide Community Participation Practice in Ontario CHCs

The fourth chapter of the thesis examines the value of community participation frameworks as knowledge translation mechanisms within Ontario CHCs. The frameworks that have guided community participation processes with marginalized populations have been critiqued for being generic and ignoring that community participation is highly contextual and situational. The purpose of this chapter, then, is to examine the role of frameworks as mechanisms for knowledge translation about community participation practice. The specific objectives of this study were: (1) to examine the factors that would influence the use of a generic framework for community participation with marginalized populations by CHCs; and (2) to improve the "context-specificity" of this framework, to enhance its relevance to CHC staff involved in the planning and design of community participation initiatives. In this study, I recommend the use of toolkits or guidebooks as a more appropriate resource for guiding CHCs with their community participation initiatives (instead of community participation frameworks) that are adapted to the local context of the CHC and reflect the marginalized population(s) they engage. I also identify areas for further research on how CHCs can be supported to use research evidence in their community participation practices.

As a whole, the thesis is comprised of three interconnected studies such that the insights from the first study subsequently informed the second and third study. Preliminary findings from the CIS study (Chapter 2) provided insights into how the community development principles might be used to engage marginalized populations within CHCs and the circumstances under which they may be more or less suitable. Findings from the synthesis of the literature were also used to develop a generic framework to describe the core features of community participation, which was presented to participants in the focus group study reported on in the third study (Chapter 4). Furthermore, the focus group findings enriched the findings from key informant interviews carried out for the multiple case study analysis of CHC community participation initiatives (Chapter 3).

Summary

Overall, the following chapters comprise a thesis that contributes new scientific knowledge about: (1) the role of community development principles as enablers of community participation with marginalized populations; (2) the social and cultural factors and experiences with marginalization that differentially shape the participation of marginalized groups, and how community development principles might be suited to address some barriers compared to others; (3) the core features of a community participation process (e.g., methods, approach, and strategies of participation) with marginalized populations; and (4) how to support health services organizations, and CHCs in particular, in their use of evidence to inform their community participation initiatives, and evaluations of these initiatives, with marginalized populations.

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Chapter 2:

Understanding the role of community development principles in enabling the participation of marginalized populations: A critical interpretive synthesis

Abstract

Community development principles are promoted in international policies such as the Alma Ata Declaration on Primary Health Care of 1976 and the Ottawa Charter for Health Promotion of 1986 as an approach to supporting the participation of marginalized populations. The principles outlined in these policies have been the subject of scholarly examination and debate, which has largely emphasized their conceptual ambiguity, limited knowledge of how to apply these principles in community participation processes with marginalized populations, and how effective these principles are in enabling the participation of these populations. We undertook a critical interpretive synthesis (CIS)—a type of systematic review that combines traditional systematic review methodology with interpretive inquiry—to: (1) examine how community development principles are used in community participation initiatives with marginalized populations; and (2) identify the factors contributing to their influence. Our strategy focused on findings from published and unpublished papers covering a wide range of topics from theoretical discussions to practice considerations, and some that included both. Our search process included searching electronic databases, websites, reference lists and consulting with key experts in the community participation field. Purposive sampling was used to select papers that were clearly concerned with participation processes that involve marginalized populations,

and papers were selected for inclusion based on relevance to our topic rather than on particular study type or methodological quality. We identified 61 papers from the 15 databases searched for the 2000-2011 period, which were analyzed using the constant comparative method. Our synthesis findings demonstrate the limited influence of community development principles in enabling the involvement of marginalized populations in community participation initiatives. Structural factors related to the social-cultural, organizational and political contexts within which participation takes place were found to constrain the participation of marginalized populations. These factors include local power relations, social norms, experiences with marginalization, power inequalities between marginalized individuals and community participation facilitators, and organizational capacity. Despite the role of structural factors in undermining the influence of community development principles, our findings also identified a range of possible methods and approaches where these principles can play a role in addressing structural barriers to enable the participation of marginalized populations. Developing a clearer understanding of how the structural factors constrain the agency of marginalized populations to participate, and the social theories that underpin them, is a key step towards enabling participation and knowing how to effectively apply the community development principles in methods and strategies for engaging these populations.

Background

Despite a broad consensus about the importance of engaging marginalized populations in health services decision making to ensure the development of appropriate and contextualized health services, implementing participatory initiatives with these populations has proven to be difficult (Carlisle, 2010; Church et al., 2006; Zakus & Lysack, 1998). A particular challenge is how best to translate the underlying normative beliefs about community participation, which have formed the basis of major international health statements, into practice. International statements such as the Alma Ata Declaration on Primary Health Care (WHO, 1978) and the Ottawa Charter for Health Promotion (WHO, 1986), stipulate that people are entitled to have control over the factors that affect their lives. To achieve this control, the capacities and skills of marginalized populations need to be recognized and further developed. Community participation is conceptualized in these statements as a process to *enable* or *strengthen community action* in the planning and implementation of health services. For marginalized populations, however, their social and economic exclusion from society influences the amount of control they have over their lives and the resources available to them. In some cases, marginalized people are not able to fully develop the skills necessary to assume ownership of decisions that affect their health.

Emerging from these WHO statements, several health promotion strategies have advocated for community development as an approach to address the barriers to participation that marginalized populations experience, and to support them to identify important health concerns or health service issues and develop the strategies to resolve

them (Ritchie, 2004; Scott & Thurston, 1997). Fundamental to this approach is a set of core principles for community development that include: (1) capacity-building (by ensuring that participants are actively involved in project planning and implementation or through formal (or informal) training and consciousness-raising activities); (2) empowerment (by encouraging marginalized populations to take ownership and control in planning and decision making for health services and/or programs); (3) building relationships (by fostering trust and respect for cultural diversity); and (4) collaboration (by sharing knowledge, experience, and resources between facilitators and the marginalized population) (Ritchie, Parry, Gnich, & Platt, 2004).

The community development principles outlined in the statements described above have been the subject of considerable scholarly examination and debate, which has largely focused on their conceptual ambiguity, limited knowledge of how to apply these principles in community participation processes with marginalized populations, and how effective these principles are in enabling the participation of these populations. For example, some scholars have argued that there has been an overemphasis on establishing best practice models and benchmarks for successful community participation in the absence of a strong theoretical foundation to support these best practice models (Burton, 2004; Cooke & Kothari, 2001; Cornwall & Shankland, 2008; Ramella & de la Cruz, 2000).

In this paper, we address these knowledge gaps by examining the influence of community development principles in enabling the participation of marginalized populations in community participation initiatives. We used the qualitative systematic

review method of critical interpretive synthesis (CIS) to address our main objectives which were to: (1) examine how community development principles are used in community participation initiatives with marginalized populations; and (2) identify the factors contributing to their influence.

Our review focuses on *marginalized populations*, as opposed to the broader conceptualization of marginalized "communities." Most of the literature on participation uses the term "community" without much qualification to denote a culturally and politically homogenous social system or one that is internally cohesive. Defining the community according to geographic boundaries obscures the diversity within and among marginalized populations, and obfuscates the local structures of economic and social power that are likely to influence participation initiatives. For this study, then, we define marginalized populations to include individuals who are excluded from their society by race, class, gender, socio-economic status, ethno-cultural identity, age, or other stigmatized identities (Jenson, 2000; Lyman & Cowley, 2007) that are enforced by mechanisms of oppression, patriarchy, or stigmatization (Hall, 1999; Vasas, 2005; Lyman & Cowley, 2007). Marginalized populations are usually identified as those who are poor, least educated, homeless, newcomers or immigrants, Indigenous groups, seniors, people with disabilities, ethnic minority groups, cultural groups (such as Mennonites), women (in some ethnic-cultural groups), single mothers, and individuals with mental health and addiction problems (Jenson, 2000; Vasas, 2005).

Approach and Methods

Our approach to reviewing the literature adopted the features of the critical interpretive synthesis (CIS) method. This method allows for the synthesis of diverse literatures and the conceptual translation of a range of evidentiary sources with the goal of developing new concepts and theories that move beyond the findings of any individual study included in the synthesis (Dixon-Woods et al., 2006; Pope, Mays, & Popay, 2007; Flemming, 2010). CIS is more suited to research questions that are broad and cross-cutting in terms of the literature from which they draw and where there is conceptual complexity or ambiguity—all distinguishing features of the community participation literature.

We applied the following key features of the CIS method to our synthesis:

- a search process that includes: searching electronic databases, websites, and reference lists; contacts with experts; or other strategies that suit the emergent and exploratory nature of the review question;
- the purposive selection of papers (i.e., as themes emerge in our review, more papers were selected to understand the emerging themes);
- modifying the question in response to search results and findings from retrieved papers; and
- selecting studies for inclusion based on relevance than on particular study types or papers that meet particular methodological standards.

Review Question

Our initial review question was: "What is known about participation strategies involving marginalized populations in local health service planning and decision making?" As we began our review, however, we observed a significant emphasis in the literature on discussions and critiques of the use of community development principles to enable the participation of marginalized populations. Therefore, we re-framed and narrowed our research question to focus on the following:

What is the influence of community development principles in enabling the participation of marginalized populations?

Sources and Literature Searched

We developed a list of search terms through a preliminary review of the literature, through consultations with members of the research team and with a research librarian (Appendix 1). Different combinations of terms were used to carry out several searches within each database. Thesaurus terms (terms relating to participation and marginalized populations formally indexed on databases) were used. We searched the following electronic databases: Applied Social Sciences Index & Abstracts (ASSIA); CINHAL; Communications & Mass Media Index; CSA Sociological Abstracts; CSA Worldwide Political Science Abstracts; EconLit; ERIC; International Bibliography of the Social Sciences (IBBS); OVID HealthStar; OVID/Medline; PAIS International; PsychInfo; Science Citation Index Expanded; Social Science Abstracts; and Social Sciences Citation Index. These databases include both health and non-health content. Systematic reviews or other types of syntheses were searched in Health System Evidence (HSE). Given the size and scope of the community participation literature and its long history, we limited our

search to articles published in English since 2000 to focus our examination on recent scholarly evidence. This search was complemented by existing literature databases created through a recent synthesis study (Abelson, Montesanti, Li, Gauvin, & Martin, 2010) and hand-searches of the reference lists of retrieved articles. We also consulted with three key experts in the community participation field to identify any recent work that was not yet published, or to identify potential papers that were missed in our search.

Article Selection

Our sampling of papers was driven primarily by conceptual relevance. Purposive sampling was used to select papers that were clearly concerned with community participation processes that involve marginalized populations. This allowed the principal investigator (SM) to identify papers that appeared to be relevant to the topic of interest. Articles were selected that: (a) included a definition or description of community participation in the area of health services planning and/or decision making (including broader population health policies and programs, health promotion and prevention services and/or programs, and primary health care services); (b) included a description of the marginalized population(s) engaged; (c) included a description of the methods, strategies and approaches that are used to engage marginalized populations; and (d) a description of how the community development principles were applied in the methods and strategies to enable the participation of marginalized populations. Our strategy focused on findings from published and non-published papers (i.e., grey literature such as government reports, conference presentations, and reports from health services and policy

research organizations). The articles included covered a wide range of topics from theoretical discussions to practice considerations, and some that included both.

Relevance and Quality of Papers

We considered the relevance of papers in relation to our research question throughout the coding and synthesis process. The quality of the included papers was assessed by one reviewer (SM) according to a set of reflective questions that are similar to those used elsewhere (Kuper, Reeves, & Levinson, 2008) (see Box 1 below).

Box 1. Quality Assessment Criteria
Empirical papers

a) Were the aims and objectives of the research clearly stated?
b) Was the research design clearly described and appropriate given the aims and objectives of the research?
c) Was the process by which findings were produced clearly described?
d) Were the data provided sufficient to propose interpretations and conclusions?
e) Was the analytical approach appropriate and adequately explained?

Non-empirical papers

a) Was a clear statement of the purpose of the paper provided?
b) Was the rationale for the paper provided?
c) Does the paper include enough information or argumentation to support claims or conclusions?

(Source: Kuper, Reeves, & Levinson, 2008)

Analysis and Synthesis

We began with a full-text review of the empirical and non-empirical papers. One author (SM) recorded descriptive information from the papers (where possible) on the methods, contextual factors (e.g., geographical location, community and cultural characteristics), characteristics of participants (e.g., types of marginalized groups

involved), the type of health service planning or decision making examined, the methods or approach to participation, and outcomes from the community participation process (positive or negative) reported and demonstrated. One author (SM) also reviewed the individual studies contained in the systematic reviews for relevant information on the outcomes from community participation processes.

Synthesis process

Our synthesis process was carried out in consultation with members of the research team, and was comprised of four interrelated steps using the constant comparative method (Leech & Onwuegbuzie, 2007; Leech & Onwuegbuzie, 2011). First, we coded concepts directly from individual papers using NVivo 9 Qualitative software to sort, classify and arrange information for the purpose of identifying patterns and themes. Second, we grouped similar concepts together across the papers and compared them for similarities, differences, and contradictions. Third, we identified themes that emerged from integrating and comparing the concepts (Dixon-Woods et al., 2006). Fourth, reflective comments forming a critique of each paper were written as "memos" to capture the patterns and contradictions in empirical and conceptual papers, and gaps in the research findings, noting where further theory might help to interpret the empirical findings.

Findings

In total, we retrieved 2,696 documents from the 15 databases searched for the 2000-2011 period (Appendix 2). We excluded 2,334 documents (including commentaries, editorials, book reviews and book chapters) based on irrelevant titles and/or abstracts and

duplicates. Of these papers, eight could not be located and based on a review of the publication title and abstract, they were excluded. One author (SM) reviewed the full-text of 362 papers. We excluded 319 papers that did not closely meet our inclusion criteria. After a more detailed review of health-related articles, a further 11 were excluded that were limited in relevance to our research question. We included 29 additional papers identified from a hand search of the reference lists of retrieved articles and from key experts in the field. A total of 61 papers were included in our analysis. Our core set of documents (n=61) included systematic reviews (n=10), published empirical papers (n=40) and published non-empirical papers (n=2), published conceptual papers (n=6), and grey literature (n=3). Descriptive details for the papers are provided in Appendix 3.

Our synthesis demonstrated that the influence of community development principles in enabling the involvement of marginalized populations in community participation initiatives is explained by social structures that constrain the agency of marginalized people and ultimately shape their decisions to participate. Developing a clearer understanding of how these structural factors constrain the agency of marginalized populations to participate, and the social theories that underpin them (Bourdieu, 1977; 1990; Giddens', 1984; Parsons, 1937), is a key step towards enabling their participation and knowing how to effectively apply the community development principles in the methods and strategies for engaging these populations. These themes are explored in the following sections.

Social-cultural context

In the following sections, we discuss three key factors within the social-cultural context that constrain the agency of marginalized populations to participate in health services planning and decision making. These include local power relations within a marginalized population, the social norms of a marginalized group, and social and economic constraints from marginalization.

Local power relations within marginalized populations

Community development principles emphasize the ownership and control of marginalized populations in participatory initiatives by *promoting their local knowledge* in planning for the health system (Larson, Schlundt, Patel, Goldzweig & Hargreaves, 2009). The knowledge that "local people" or "community members" acquire from their lived experiences allows them to see and understand the connections and interrelationships of problems within their community differently from other professionals or planners (Stern & Green, 2008; Boneham & Sixsmith, 2006; Rapport, Snooks, Evans, & Tee, 2008).

The benefits described from incorporating local knowledge, however, have been critiqued for failing to understand that knowledge is constructed differently within various categories of marginalized groups such as those defined by ethnicity, social class, gender, culture, and age. Some scholars have argued that privileging "local knowledge" in health service planning and decision making assumes there is unanimity among groups in a population on their values, interests, and beliefs towards health (Champion, Franks, & Taylor 2008; Kilpatrick, 2009; Boneham & Sixsmith, 2006; Zapata, 2009). The

differentiation of knowledge among groups can result in power inequalities among them, as one group attempts to exert their views and opinions over other groups (Callaghan & Wistow, 2006; Champion et al., 2008; Zapata, 2009). Unequal power relations, for instance, are reported among different Indigenous-speaking groups residing in the same community (as each group holds diverging conceptions of health and illness) that pose challenges to bringing the groups together in community participation initiatives (Champion et al., 2008). The principle supporting the benefits of incorporating the knowledge of marginalized populations, therefore, is challenged by a comprehensive understanding of how knowledge is produced and shaped by local relations of power within a marginalized population.

Social norms

The participation of marginalized individuals can also be constrained by the norms of their cultural group (Boneham & Sixsmith, 2006). Social norms influence the expected behaviours of members within a group that might devalue their involvement (Basu & Dutta, 2009; Campbell & McLean, 2002; Hongseok, Clung, Myung-Ho & Labianca, 2004; Maalim, 2006). The extent to which an individual is constrained or enabled by social norms is shaped by their own recognition of their power and capabilities, and their reflection on the structural factors that hinder their participation (Archer, 2003; Archer & Tritter, 2000). Social theories have conceptualized individuals as agents who are consciously and unconsciously reflexive of their own power and capabilities to intervene within the structures they live in (Giddens, 1984; Parson, 1937; Mansbridge, 2001). For instance, sex workers in India were motivated to participate in

health communication strategies for HIV/AIDS prevention by their personal and collective reflection on being socially excluded and stigmatized for defying cultural norms and gendered practices. Through participation, the sex workers gained a greater understanding of the cultural norms and gendered practices that constrain their agency.

Social and economic constraints from marginalization

Lastly, the social and economic exclusion of marginalized people both within their own populations and from other "mainstream" groups (Campbell & McLean, 2002; Majeed, Banarsee, & Molokhia, 2009) is often shaped by negative stereotypes, stigmatization and discrimination towards them. Social and economic exclusion may result in low self-confidence and self-esteem in a person's capabilities that influence their motivation to participate. Cornwall (2008) uses the term "self-exclusion" to explain how marginalization can discourage some marginalized people from participating. She describes the results of this as

> […] a lack of confidence, with the experience of being silenced by more powerful voices or fear of reprisals. It can be because people feel that they have nothing to contribute, that their knowledge and ideas are more likely to be laughed at than taken seriously (p. 279).

Stereotypes, for instance, have been shown to influence the recruitment of newcomer immigrants and Indigenous populations in community participation initiatives (Basu & Dutta, 2009; Kegler, Norton, & Aronson, 2008; Quantz & Thurston, 2006; Preston, Waugh, Taylor, & Larkins, 2005). Strategies for strengthening the capacities and skills of marginalized populations (which is a core principle of community development) are challenged by their perceptions that their views and opinions will be unwelcomed by

experts or professionals (Liberato, Birmblecombe, Ritchie, Ferguson, & Coveney, 2011; Wallernstein, 2006).

Community development principles also assume that individuals want to participate because of the benefits they gain from participating (e.g., increased social capital, improved knowledge, strengthened capacities and skills, etc.), and because they perceive it to be a social responsibility or right that they have as citizens or as members of a community (Boneham & Sixsmith, 2006; De Vos et al., 2009). Contrary to optimistic assertions about the benefits of community participation, there are examples of situations where marginalized people find it easier not to participate (Boyce, 2001; Cornwall, 2008; Dukeshire & Thurlow, 2002; Kegler, Painter, Twiss, Aronson, & Norton, 2009; Zapata, 2009). The social or economic circumstances of marginalized individuals, for instance, can influence their motivation to participate (Boyce, 2001). Marginalized populations tend to view their opportunity to participate as limited because of their life circumstances—which include a lack of economic resources, low education, or cultural norms and practices—that influence the motivation and ability of some individuals. Individuals in these circumstances usually face barriers related to competing family and work demands, language barriers, and transportation needs (Campbell & McLean, 2002; Dukeshire & Thurlow, 2002; Kegler et al., 2009; Zapata, 2009). Due to these life circumstances, individuals are more likely to focus their attention on getting by each day, rather than on committing time to join in any participatory opportunities (Zapata, 2009). The opportunities that are available to marginalized populations to participate, therefore, are shaped by social and economic constraints from their marginalization.

Organization and political context

Factors related to the organizational and political context are also reported to constrain the agency of marginalized populations to participate. These can include power inequalities between the organizers of participation initiatives and marginalized individuals, which poses challenges to working in partnership as well as to the organization's capacity to fully enable the participation of marginalized populations.

Power inequalities between organizers and marginalized populations

Working in partnerships is an essential community development approach for identifying solutions to the complex health issues among marginalized populations (Cornwall, 2000; Liberato et al., 2011; Roussos & Fawcett, 2000; Rummery, 2009). Despite the well-defined advantages of collaborative approaches to engaging with marginalized populations, others have articulated the limitations of partnerships that are contributed to by power imbalances between organizers and the marginalized people involved. Political and institutional systems have historically provided greater decision making power to experts and professionals (Carlisle, 2010). Theories of power argue that power relations reinforce dominant values, beliefs, and political institutions (e.g., "rules of the game") (Bachrach & Baratz, 1963). Bachrach and Baratz have described how power operates systematically and consistently to the benefit of certain persons and groups at the expense of others. Cornwall (2008, p. 275) makes a useful distinction between "invited spaces" for participation that, no matter how participatory they seek to be, are "still structured and owned by those who provide them" as compared with "opportunities [for participation] that people create for themselves."

Many community participation initiatives claim that simply identifying different stakeholders and working collaboratively to identify health issues and the solutions to resolve them (a defining principle of community development) will result in a consensus being reached that reflects the needs of the marginalized population (El Ansari & Phillips, 2001; Zapata, 2009). However, organizers and marginalized populations can have different perspectives, knowledge and values on the issue being addressed (Carlisle, 2010; El Ansari & Phillips, 2001; Zapata, 2009). For instance, a partnership initiative in England that involved a deprived South Asian community and health promotion planners identified several limitations with the partnership contributed by: unequal power relations between the South Asian community and the planners, cultural insensitivity of the planners towards South Asian culture, and different perceptions by the community and the planners on participation and its associated health benefits (Bandesha & Litva, 2005). Alternatively, other scholars have commented that groups within partnerships may agree on a common value, such as achieving improvements in health, but their perspectives on the solutions may differ (Downey, Ireson, & Scutchfueld, 2009; Zapata, 2009). Some scholars have described power imbalances to be influenced by staff perceptions of the skills and knowledge of marginalized populations to make rational health service decisions (Boyce, 2001; Kegler, Norton, & Aronson, 2008; Nathan, Harris, Kemp & Harris-Roxas, 2006; Martin, 2008).

Organizational capacity to engage marginalized populations

The motivation to participate among marginalized populations is also based on their perception of the capacity that health service organizations have to respond to their

health concerns and act upon their suggestions for improving the delivery of health services and programs. Marginalized populations might perceive organizers to lack a clear understanding of the cultural beliefs and values that shape their health behaviours and practices (Basu & Dutta, 2009; Smith-Morris, 2006). Rather, the capacity of organizations to act on the issues that marginalized populations express can be compromised by their budgetary constraints, political commitments towards the participation of marginalized populations in health services and program planning, and mandates from external funders that stipulate how these populations should be involved (Boyce, 2001; Kegler et al., 2008). This in turn constrains an organization's capacity to address the health needs of the different marginalized populations they serve (Boyce, 2001).

In addition, the health issues identified by a marginalized population in a community participation initiative might not always be acted upon by the organization because of competing health needs of the population (Attree, French, Milton, & Povall, 2011; Boyce, 2001; Smith-Morris, 2006). For example, communities with concentrated poverty face several social and economic barriers (such as unemployment and inadequate housing) that might overshadow other individual concerns (such as substance abuse or chronic illness) (Downey et al., 2009). Sometimes organizations focus on a particular health issue, not because they want to reinforce their own agenda, but because they are responding to calls for proposals from funders, or to the political commitments or mandates of local government (Boyce, 2001; Halabi, 2009; Smith-Morris, 2006). Traditionally, the health promotion and prevention programs of organizations, for which

community participation is sought, are often underfunded; the limited resource support of these organizations affect their capacity to engage populations and sustain initiatives (Boyce, 2001; Kegler et al., 2008).

Applying Community Development Principles More Effectively to Enable the Participation of Marginalized Populations

An understanding of the factors that contribute to the influence of community development principles in enabling the participation of marginalized populations is essential to knowing *how* they might be more effectively applied in community participation initiatives with these populations. Findings from community participation initiatives with marginalized populations have identified a range of possible methods and approaches to address structural barriers in order to enable their participation.

Methods and approaches to address structural barriers to participation for marginalized populations

Supporting organizations to recognize and attend to structural constraints on participation

Our synthesis findings reveal that community participation planners must have substantial knowledge of the marginalized populations they are working with, specifically, their culture, values and the challenges of being socially and economically marginalized, prior to engaging them in planning and decision-making processes (Basu & Dutta, 2009; El Ansari, 2005; Kano, 2009; Kilpatrick, 2009; Larson et al., 2009; Smith-Morris, 2006; Quantz & Thurston, 2006; Zapata, 2009). According to Smith-Morris (2006):

> a substantial amount of information about a community is necessary before even the most fundamental project decisions can be made: local demographic and epidemiological information; political and social structures, alliances, and rivalries; environmental factors that influence health, nutrition, work seasons, and financial

> cycles; geography; and intercultural relations, just to name a few. These and more variables will have significant impact on the health needs of the community, the resources available and barriers to any health project. (p. 89)

Understanding the structure and function of a culture has been discussed substantially in the literature with engaging Indigenous populations (Champion et al., 2008; Kilpatrick, 2009). Scholars have described how kinship, relationships, responsibilities, and obligations are fundamental to Indigenous social life and, therefore, need to be considered when engaging this population. Culturally appropriate community participation initiatives for Indigenous populations are described to involve an understanding of their daily lives, comfort level, and experiences with the health system (Champion et al., 2008).

Understanding the cultural and social context of marginalized populations was described in the literature to have a number of benefits for organizations such as: (a) aligning health programs with community expectations, customs, values and norms; (b) identifying and incorporating relevant community assets, including social capital, skills, and local organizational contexts; and (c) improving knowledge of health needs and priorities through community experiences. Furthermore, adapting the engagement strategy to a local context can provide community participation planners and facilitators with a better understanding of the factors that have created and reinforced marginalization within a community (that lead to resistances or lack of motivation by individuals to participate in decision-making) (Dukeshire & Thurlow, 2002; Quantz & Thurston, 2006; Zapata, 2009).

Specific approaches have been used to facilitate community participation processes and assist organizations in understanding the social-cultural characteristics that

influence the participation of a marginalized population. For example, the appointment of *community representatives* on committees within the structure of a health service organization in a semi-rural area in Sydney, Australia, resulted in a positive change in staff attitudes towards involving community members in health services planning and decision making, and an improved understanding among staff on the social and cultural life of the community (Nathan et al., 2006). Having community members working alongside staff, rather than simply providing organizational supports for community participation, appears to be an important element in creating an organizational environment that embraces community participation (Nathan et al., 2006). The direct engagement of community representatives can also be an effective mechanism for ensuring that organizations are accountable and transparent in planning health services for marginalized populations.

The use of a *dedicated community participation facilitator* is also viewed as a key element for enabling the participation of marginalized populations and for establishing a relationship with the relevant population (Etowa, Bernard, Oyinsan & Clow, 2007). Salaried facilitators were found to possess a high degree of motivation and to have close ties to their communities; they worked collectively with the marginalized population to identify issues and participated in the effective exchange of ideas and information between the population, the organization and policy-makers (Etowa et al., 2007).

The use of unstructured and informal methods to enable the participation of marginalized populations

Our synthesis findings suggest that informal engagement processes can play important roles in enabling members of marginalized populations to talk to, learn from,

and work with each other over an extended period of time (Moulton, Miller, Offutt, & Gibbens, 2007; Nimegeer, Farmer, West & Currie, 2011; Zapata, 2009). In keeping with the principles of community development, an unstructured and informal method of participation allows marginalized individuals to contribute their own skills, capacities and knowledge in the planning of health services. Key features promoting success include meaningful discourse (i.e., enabling diverse participants to talk *with* each other rather than *at* each other) "by valuing listening as well as speaking, by honoring and respecting different kinds of knowledge and points of view, and by fostering the development of a jargon-free language that is widely understood." (Zapata, 2009, p. 198) This creates an environment in which participants feel comfortable raising questions, expressing different opinions, and voicing new ideas. In addition to giving people voice, the process also combines the complementary knowledge, skills, and resources of participants so they can collectively create new ideas and strategies (Downey et al., 2009; Nimegeer et al., 2011; Zapata, 2009).

Community development principles can also be used to adapt more traditional participation methods to the needs of marginalized populations. A *citizen's jury method*, for example, was adapted to a community participation initiative that engaged a population with growing health inequalities in Northern England (Kashefi & Mort, 2004). The generic design of a citizen's jury method involves a structured and formal process that brings together a random selection of individuals who participate as "jury members" in deliberating on an issue. The jury hears from expert witnesses that are knowledgeable on the topic and deliberate on a solution or recommendation to the public and official

decision-makers. In their adaptation of the method referred to as *grounded citizen's jury*, Kashefi and Mort (2004) emphasized the group's local knowledge and experience through informal and unstructured discussions of health issues. The knowledge and experience of the marginalized population was promoted by the supportive attitude of organizers who viewed marginalized individuals as agents of change and capable of contributing to the decisions that affect their health.

Tailored participation methods for marginalized populations

While adapted methods can be effective, there are also community participation methods that have been specifically designed with marginalized populations in mind (Appendix 4). *Scenario planning* is one such participation method used to engage marginalized populations (Zapata, 2009). Instead of emphasizing a specific policy selection through deliberation on the issues, scenario planning focuses on "future oriented plans" that involve identifying long-term solutions to health and health service problems in a population (i.e., creating a "vision"). For instance, individuals are asked, through informal dialogue meetings, what health services and/or health outcomes they might look for in their community over a specified time frame (e.g., 10-15 years) by adopting (or not) a particular solution.

Community development principles, which guide the capacity-building of marginalized individuals, are essential elements of the scenario planning method (Zapata, 2009). Zapata (2009) examined the scenario planning method used in community participation initiatives in the U.S., and identified that the incorporation of storytelling, which focuses on informal dialogue and emphatic listening, and a focus on dialogue

instead of deliberation for the broader planning for health programs or services, were key features in enabling the involvement of ethno-cultural groups by strengthening their capacities and skills to participate (Zapata, 2009).

A more recent method (with similar features to scenario planning) is the *Remote Service Futures Game* used with remote and rural populations (Nimegeer et al., 2011). As the name suggests, this method involves a simulation 'game' where participants are given the opportunity to plan how they would design future health services. Participants are divided into working groups, where each group discusses 5-10 of their most important health care needs, and devise plans for the delivery of health services (including primary health care and health promotion and prevention services). Participants are also given a set of cards that list the skills and competencies of health and social care workers and asked to prioritize which skills and competences of practitioners would best meet their community's health and social challenges. The groups then come together to debate the potential merits and disadvantages of each plan and attempt to reach a consensus. The method reflected on the community development principles for building relationships through the sharing of information, values, preferences and experiences, and by promoting the population's ownership in planning health services. Participants in the project described the method as educational and helped them to learn about the budgeting and decision-making process in the local health system. Despite these benefits, the authors noted that the study's findings were unclear about the method's influence in sustaining the long-term participation of the population.

Another popular participation method employed with marginalized populations is the *photovoice* method. This method emphasizes the community development principle of ownership and control by individuals in defining their own health needs. One example identified in the literature used this method to assess the health service needs of a rural population by involving members of the population in defining the problem to be addressed (Downey et al., 2009). The photovoice method encouraged individuals to identify, represent, and enhance their community's health through photography (Downey et al., 2009). The study found that members of the population were more easily able to identify solutions to local health service issues when local images and narratives informed discussions.

Despite the limited influence of community development principles in enabling the participation of marginalized populations, our findings illustrate they can play a role in overcoming structural barriers when applied more effectively to the methods and approaches to engaging these populations. The methods and approaches that were adapted or tailored to the marginalized population engaged were largely informed by the objective of addressing structural barriers to participation. Community development principles can be more effectively applied to enable the participation of marginalized populations by: i) supporting organizations to recognize and attend to the structural constraints on participation (i.e., identifying appropriate facilitators within the population, and changing the attitudes and perceptions of organizers to view marginalized individuals as capable and competent to participate); ii) promoting the use of informal and unstructured participation methods with marginalized populations that incorporate techniques such as,

storytelling that allows for the sharing of their experiences and concerns with other marginalized groups; and iii) tailoring participation methods to the social and cultural characteristics of marginalized populations (i.e., their customs, norms, and values, and their experiences with marginalization).

Discussion

Key findings

The objective of our synthesis was to explore the role of community development principles in enabling marginalized populations' involvement in community participation initiatives. Our synthesis demonstrated that the influence of community development principles in enabling the involvement of marginalized populations is limited by several structural factors such as, local power relations, social norms and social and economic constraints from marginalization that constrain the agency of marginalized populations to participate. In particular, community participation strategies guided by community development principles have tended to underemphasize key structural factors that shape the motivations, rationality, and values of marginalized people towards participating, and which contribute important insights into understanding *how* and *why* marginalized people participate. For example, a key assumption underlying the community development approach is that marginalized populations share similar knowledge, views and beliefs about health and illness. Incorporating "local knowledge," however, requires an understanding of the various ways in which knowledge is constructed within a population, which is key to identifying effective methods for gathering divergent perspectives on health and illness in health services planning and decision making.

Community development principles also claim that strengthening the capacities and skills of marginalized populations will enable their ownership and control of decisions to improve their health. However, the decision of marginalized populations to participate in capacity or skill-building activities to enhance their participation is often constrained by social norms, social relationships, and experiences with marginalization. Social and economic circumstances, for instance, have been shown to be influential in shaping the motivations, willingness and confidence of marginalized people to participate.

Another assumption embedded in the principles of community development is the emphasis on establishing partnerships as an effective approach for addressing the health issues of marginalized populations. This principle, however, requires a consideration of power imbalances between organizers and marginalized people, who possess diverging perspectives on addressing health service issues. Lastly, community development principles do not consider the barriers that constrain the capacity of a health organization to facilitate participation with marginalized populations. An organization's capacity to address the health needs of the different marginalized populations they serve is shaped by political commitments or resource constraints (that impact both the recruitment of marginalized populations and retaining their participation in the long-term).

By understanding the role that community development principles play in enabling the participation of marginalized populations, and the particular importance of structural influences, we can gain a better understanding of how to apply the principles more effectively in community participation initiatives. The methods and strategies to involve marginalized populations that are described in the literature reviewed provide

initial steps towards addressing these structural constraints and strengthening the influence of the community development principles in enabling the participation of marginalized populations. These methods were designed to more effectively enable the participation of marginalized populations by alleviating power inequalities, strengthening their self-esteem and confidence to participate, and shaping the attitudes and perceptions of staff to view marginalized populations as capable and competent to participate in health service planning and decision-making processes.

Contributions to the literature

Our findings support the work of other scholars who have applied social theories of structure and agency to study participation, both with marginalized populations specifically (Larson et al., 2009) and the public at large (Boyce, 2001; Contandriopoulos, 2004; Medee, 2008). Our findings reinforce the work of Boyce (2001) who reported on the relationship between various dimensions of structure (social-cultural, organizational, political–legal–economic) and the community participation process. He demonstrated that participation was influenced by structural factors such as bureaucratic rules and regulators, perceived minority group rights and relations, the reputations and responsibilities of health organizations, available resources, and organizational roles. However, to our knowledge there are no systematic reviews that have examined the robustness of community development principles used in participation approaches for engaging marginalized populations. Furthermore, we attempted to identify where further theory of structure and agency might be helpful to understand the effectiveness of these principles for engaging marginalized populations.

Implications for research

Our findings also demonstrate the necessity for further research to address remaining knowledge gaps about community participation with marginalized populations. For example, knowledge gaps remain about how to sustain the involvement of marginalized populations over the long-term, given the structural factors that constrain their participation; and whether the approaches or methods of participation identified in the literature can be captured across different marginalized groups (as the examples in the literature are typically single cases and usually involving a specific marginalized population and in a particular context). Our findings also suggest that participation methods should be tailored to specific marginalized populations, however, the methods we identified in the literature have not been subjected to rigorous evaluation or applied with different marginalized populations for comparisons. The paucity of evaluation research in the community participation literature has been attributed to the lack of consistent definitions of community participation, ambiguity about the processes for participation, and vague descriptions of how community development principles are applied to facilitate community participation, which make it difficult to draw wider conclusions on the impact of such methods and strategies for marginalized populations (Draper, Hewitt & Rifkin, 2010; Kegler et al., 2008). We can further our understanding of participatory processes through an approach that takes into account the relationship between the social structures that shape the social norms and practices of different marginalized populations and how these structures change and are negotiated by

marginalized groups in order to enact their agency for greater control and ownership of their health.

Strengths and limitations

A main strength of synthesizing different forms of research evidence allowed us to consider conceptual analyses of structural factors and individual agency as well as examples of their interactions in participation initiatives involving marginalized populations (Boeije, van Wesel, & Alisic, 2011). Structural factors within the social and cultural context and organizational context can be seen to have a significant influence over which marginalized individuals are able to exert their agency in community participation initiatives. By including these conceptual works, we were able to offer a more comprehensive understanding of why marginalized populations participate (or not) and how community development principles might more effectively enable their participation.

Despite these strengths, there are several limitations of this study. First, because of the interchangeable use of the term "community participation," with a variety of related terms, we may have overlooked other relevant terms in our search. We attempted to conduct a thorough search using all possible terms to capture articles about community participation such as "community involvement," "community capacity-building," "community engagement," "community initiated," "community-based," "community developed," or "community controlled." Thesaurus terms were also suggested for "community participation," which was applied in the search. Second, our focus on English language papers and a one-decade time period is a limitation, where potentially

relevant non-English language and older papers were excluded. Lastly, most empirical papers reviewed in the synthesis are single-case studies with one marginalized community, which do not allow for comparisons of approaches or methods across different marginalized populations or groups.

Conclusion

Our synthesis findings illustrate the limitations of the community development approach, and its underlying principles, in enabling the participation of marginalized populations and the important role played by structural factors such as local power relations, social norms and social and economic challenges of marginalization in constraining the agency of these populations to participate. Our findings also suggest several ways in which community development principles could be more effectively applied through the methods and approaches to participation that have been used to involve marginalized populations, which have attempted to address the structural barriers to their participation. Rigorous evaluation of these approaches to assess their effectiveness in eliminating the structural barriers to participation would be a fruitful avenue for future research to guide the design of community participation initiatives involving marginalized populations.

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Appendix 1: Search Strategy and Results

Database Searched	Search Terms and Strategies Used **Note: Results from each database search were combined using the term AND to capture only those publications containing all of the desired search terms**	Thesaurus Terms Used?
Applied Social Sciences Index & Abstract (ASSIA)	1. "Community participation" OR "citizen participation" 2. "Health policy" OR "decision-making" [DE] OR "primary health care" [DE] OR "health reforms" [DE] 3. "Marginal"* OR "disadvantage populations" OR social integration [DE]	Yes
CINHAL (via EBSCO)	1. "Public participation" OR "community participation" OR "community engagement" 2. "Health"* OR "health services" OR "health policy" OR "community health services" OR "Indigenous health services" [EXP] 3. "Vulnerable populations" OR special populations [suggested terms]	No
Communications & Mass Media Index@ Scholar Portal	1. "Citizen participation" OR "community participation" 2. "Health"* OR "health care" [MH] OR "health services" [MH] 3. "Marginalized population" [MH] marginality [DE]	No
CSA Sociological Abstracts	1. SU.exact ("CITIZEN PARTICIPATION") OR SU.exact ("COMMUNITY INVOLVEMENT") 2. "Health planning"* 3. All (Marginal Groups*)	Yes
CSA Worldwide Political Science Abstracts	1. Community participation OR citizen participation OR democracy [DE] 2. "Health"* OR "health care" 3. All (minority groups*)	Yes
EconLit	1. All(participation*) AND 2. All(minority groups*) AND 3. All(health care*)	Yes
ERIC	1. SU.EXACT("Community Involvement") AND 2. (SU.EXACT("Multiracial Persons") OR SU.EXACT("Minority Groups") OR SU.EXACT("Ethnic Groups")) AND	Yes

Database Searched	Search Terms and Strategies Used **Note: Results from each database search were combined using the term AND to capture only those publications containing all of the desired search terms**	Thesaurus Terms Used?
	3. (SU.EXACT("Health Programs") OR SU.EXACT("Health Services"))	
International Bibliography of the Social Sciences (IBBS)	1. SU.EXACT("Community participation") AND 2. SU.EXACT("Minority groups") OR SU.EXACT("Marginalized people") AND 3. (SU.EXACT("Health services") OR SU.EXACT("Health planning"))	Yes
Ovid HealthStar	1. "Consumer participation" 2. "Health planning" OR "community health planning" OR "medically underserved area" OR "health policy" or "health care service" 3. "Minority groups" OR "vulnerable populations"	No
OVID/Medline	1. "Community participation" OR "public participation" OR "community engagement" 2. "Health" OR "health service"* OR "health sector" OR "health planning" OR "program development" OR "community health planning" 3. "Marginal population" OR "disadvantaged population" OR "vulnerable" OR "remote" OR "rural"	Yes
PAIS International	1. SU.EXACT ("Community development Citizen participation") OR SU.EXACT ("Community centers Citizen participation") 2. SU.EXACT ("Health planning") 3. SU.EXACT ("Socially handicapped") OR "social marginality"	Yes
PsychInfo	1. SU.EXACT ("Community Development") OR SU.EXACT ("Community Involvement") 2. (SU.EXACT("Health Care Delivery") OR SU.EXACT("Health Care Services") OR SU.EXACT("Government Policy Making") OR SU.EXACT("Health Care Policy")) 3. (SU.EXACT("Social Integration") OR SU.EXACT("Marginalization")	Yes
Science Citation Index Expanded	1. "Community participation" OR "public participation" OR "citizen participation" 2. "health sector" OR "health services" OR "health"* 3. "Marginal populations" OR "disadvantaged people"	Yes

Database Searched	Search Terms and Strategies Used **Note: Results from each database search were combined using the term AND to capture only those publications containing all of the desired search terms**	Thesaurus Terms Used?
Social Science Abstracts	1. SU.exact ("Citizen participation") OR SU.exact ("Community involvement") 2. "Health planning"* 3. All (Marginal Groups*)	Yes
Social Science Citation Index	1. "Community participation" OR "citizen involvement" OR "public engagement" 2. "Health care" [MH] OR "health planning" 3. "Disadvantaged" OR "marginal population" [MH] OR "minority groups" OR "low-income areas" OR "low income groups"	Yes

Interpretations of abbreviations and asterisk symbols:

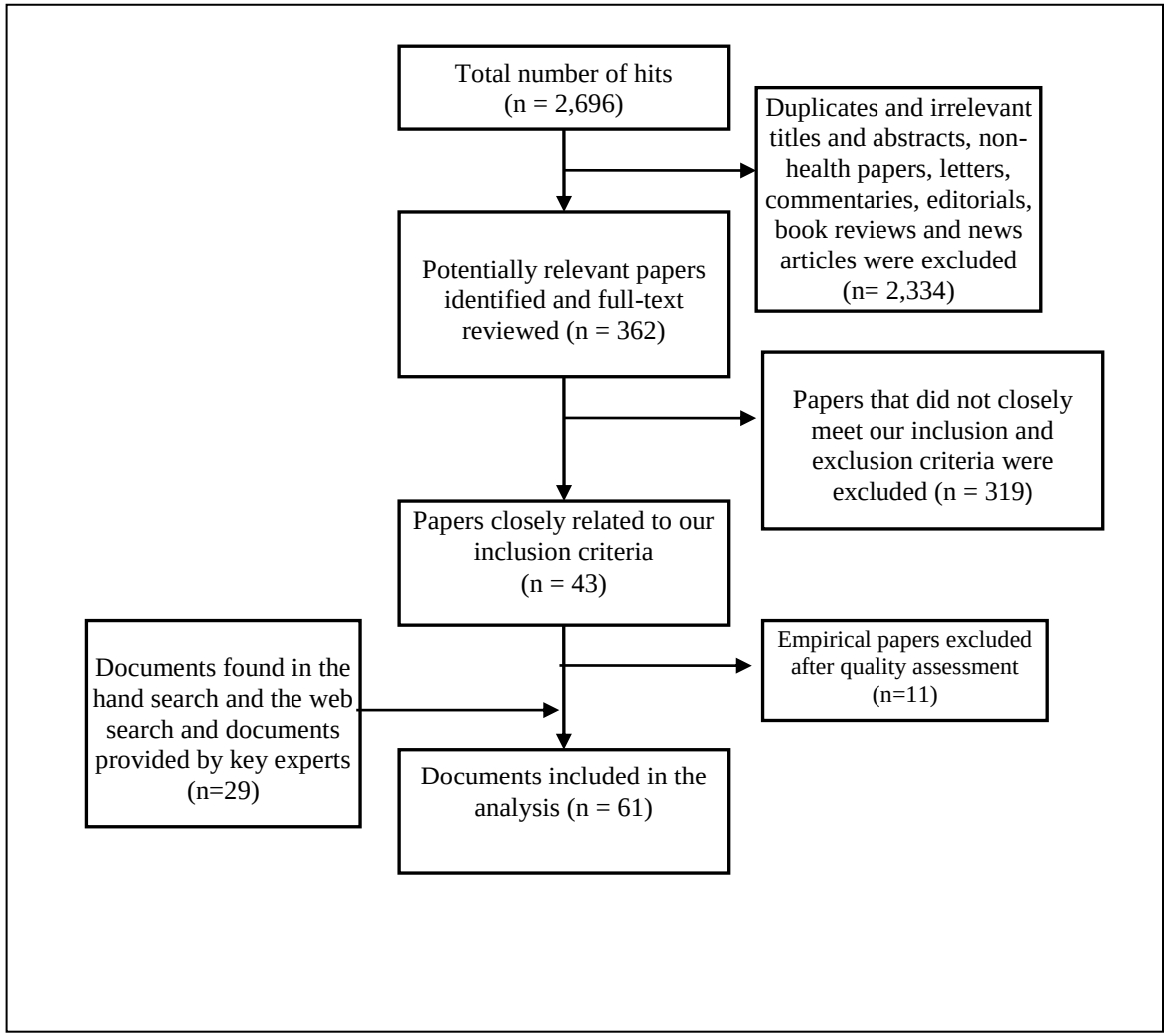
MEsH – Stands for Medical Subject Headings. It is the thesaurus developed by the National Libraries of America to index articles in the biomedical literature. MeSH terms were searched for similar terms used in the journal database.

DE – Stands for Descriptor terms. Terms assigned by compilers of a database to describe the subject content of a document. Descriptors are chosen so that all of the work on a particular topic can be found with a single word or phrase, even though there may be many different ways of expressing the same idea

SU – Stands for Subject heading

***** – Refers to wildcard search that enables the database to search for combinations of the word (e.g., marginal with the wildcard asterisk (*) can pull out different combinations of the word such as, marginalized, marginalization, marginal people etc.)

Appendix 2: Flow Diagram on screening process for articles searched



Appendix 3: Descriptive Summary of Each Paper Included in the Critical Interpretive Synthesis

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
Published reviews and syntheses							
Attree et al. (2011)	Not reported	Review	Three types of community participation initiatives were reviewed: (1) area-based initiatives, which target socially and economically deprived localities; (2) 'person-based' schemes, which seek to actively engage 'vulnerable' groups, such as low-income residents, older people, unemployed people, Black and minority ethnic communities, young people, persons with disabilities (PWD); and (3) initiatives which involve particular interest groups, such as poverty and environmental organizations. Types of community engagement described in the studies ranged from consultation, to delegated power for decision making in the planning and design of services, through to	Social determinants of health	Several marginalized populations were reported in the review, including: highly deprived communities, youth, seniors, and the unemployed.	Two studies in the review suggested three barriers to participation related to the social and economic constraints from marginalization for some marginalized populations: a) the physical and psychological demands of engagement (such as attending long meetings) were particularly burdensome for persons with disabilities (PWD); b) a lack of continuity in opportunities for involvement and some disadvantaged groups perceived their involvement was	Features of CP include: a) increasing mutual trust and understanding between different population groups; and b) greater community ownership/control over the participation processes and decision making.

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
			co-governance or co-production of services.			not valued; and c) 'tokenism' on the part of public organizations	
Liberato et al. (2011)	Not reported	Review	Aim of the review is to identify all domains used in systematically documented frameworks developed by other authors to assess the evidence on community capacity-building.	Health promotion	No specific marginalized population mentioned	No specific barriers were mentioned. There are multiple understandings of community capacity with multiple domains having been identified to describe the characteristics of community capacity. For this reason, community capacity has proven difficult to measure and its value often rendered invisible or underestimated.	Nine comprehensive domains for capacity-building were identified: a) learning opportunities and skills development; b) resource mobilization; c) partnership/linkages/ networking; d) leadership; e) participatory decision making; f) assets-based approach; g) sense of community; h) communication; and i) development pathway. In addition, six sub-domains were also identified: a) shared vision and clear goals; b) community needs assessment; c) process and outcome

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
							monitoring; e) sustainability; f) commitment to action; and h) dissemination
Loewenson (2000)	Zimbabwe	Review of health system reform and calls for greater community participation in Zimbabwe	Community participation/capacity-building broadly discussed	Local health system reform	Communities in rural and urban Zimbabwe	Barriers that influenced the participation in rural and urban communities were primarily related to the organization and political context that included: a) changes in health system reforms; b) exclusion of some key groups who play a role in health, including churches, other health providers, traditional, civic and social leaders; and c) reluctance of some health staff to give communities greater control over resources	Successful participation was described to involve a change in capacities within civic and elected groups, and in processes of information-sharing and decision making within health systems and local government. Also, changes in structures, from local (ward/health centre) level, through district level upwards. Enhanced community participation in health interventions demands more informed and active communities.
Majeed et al.	United	Review of	Examined the role of	Planning,	Communities with	Not specified	Different strategies

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
(2009)	Kingdom, England	community participation in England	Primary Care Trusts (PCTs) in England, who are initiated by the NHS, in implementing and motoring community participation to tackle health inequalities.	developing and evaluating health services	low socio-economic status and ethnic disparities		were discussed, but no mention of features of community participation or how to design or implement participation initiatives. Some examples discussed include: forums for communities, focus groups, community meetings, role of community groups, health panels and citizen juries have been used in the UK
Preston et al. (2010)	Not reported	Synthesis of peer reviewed published literature, in particular, empirical studies.	A research synthesis was conducted of 689 empirical studies in the literature linking rural community participation health outcomes. The 37 papers reviewed were grouped and analysed according to: contextual factors; the conceptual approach to community participation	Rural health service and/or planning or development	Rural and remote communities	Specific barriers to participation for the communities were not mentioned. However, methodological limitations to studying community participation were noted. A number of knowledge gaps were described from the	In some studies local people are recruited into health systems as employees and they act as "boundary crossers" where they draw on their community connections to create links between health systems and

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
			(using a modification of an existing typology); community participation process; and level of evidence and outcomes reported.			review, which include a lack of evaluation of community participation initiatives, and studies reported to improve health outcomes and extensive participation were not clearly described and quantified.	communities. The studies demonstrated a spread of approaches to community Participation: studies primarily conducted in developing countries used a contributions approach; an instrumental approach was reported in 12 studies using community participation as an intervention; four studies used an empowerment approach; and eleven studies used a developmental approach where community participation was conceived of as an evolutionary process with community members achieving

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
							community initiated goals as well as those of health systems
Rosato et al. (2008)	Multiple low-income countries	Review	Participatory initiatives into primary health care programmes	Primary health care	No specific marginalized population mentioned.	Partnerships between organizations were described to be essential to addressing health issues, but were also described to result in challenges contributed by differences in organizational cultures and values, competition for resources, and varying levels of capacity.	Features for a successful CP initiative were described to include: a) advocacy; b) strengthening community capacity; c) partnerships/new alliances with other sectors; d) must be culturally acceptable; and e) must be flexible enough to respond to variations between, and within communities and allow for adequate time for capacity-building. Specific organizational elements include: a) establish credibility in the community; b) cultural sensitivity; c)

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
							knowledge of community structures; and e) a clear communication infrastructure.
Roussos & Fawcett (2009)	Not reported	Review of literature	Aim of the review was to assess the evidence for partnerships to address inequalities in health, and particularly among marginalized populations who are at a greater risk of poor health	Population health	No specific marginalized population was mentioned.	Several challenges with partnerships between organizations and the public were reported: a) engaging marginalized populations whose social and economic circumstances hinder their participation; b) collaborating with community leaders in sectors outside the professional field of the leader organization in a partnerships; c) sharing resources and responsibilities among participating people and organizations; d) confronting and	Components and characteristics of successful community partnerships were described to include: a) a clear vision and mission; b) action planning for community and system change; c) developing and supporting leadership (e.g., engaging a broad group of members); d) ongoing feedback on progress; e) technical assistance and support; and f) securing financial resources.

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
						overcoming conflict within and outside the partnerships; and e) maintaining adequate resources	
Rummery (2009)	Australia USA UK Canada Sweden Northern Ireland Brazil Italy Finland Austria Netherlands Spain New Zealand	Review	Collaborative partnerships	Primary care, psychiatric care, and hospital services	Older people, mental health service users, children, vulnerable and hard to reach populations,	The review examined the international evidence base for the policy drivers behind health and social care partnerships, the effects the policy changes have had on the governance of health and social care, the results for service commissioners and practitioners, and particularly the results for patients and service users.	There is limited evidence for the link between collaborative partnership with vulnerable populations and improved health outcomes. There is also limited evidence on the long-term outcomes of partnerships with older people.
Smith-Morris (2006)	New Mexico	Review	Community-based health interventions	Heath programming (e.g., diabetes education)	Native Americans	Barriers for organizations in enabling the participation of Native Americans were described to involve funding for community	Core fundamentals for successful community participations were described to include: a) identifying the parameters of the community of

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
						participation with no financial support for project modification and change; and funds were also dispersed sporadically across an unreasonably large target population.	interest; b) the active involvement of community members in all phases of the project, from conceptualization to implementation and revision, where community members and outside advisers have equal roles; c) stressing an attention to and application of local culture and language; d) sustainability and co-learning; and e) collaboration among members, organizations, donors, and government so that widespread political support is mobilized.
Wallerstein (2006)	Not reported	Review (Health Evidence Network Synthesis	A review on the effectiveness of empowerment strategies in community participation initiatives	Health system planning	No specific marginalized population mentioned.	The review highlighted specific social, racial, political, and economic structures	Key messages about the effectiveness of empowerment strategies were described to include:

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
		Report)				that constrain the empowerment of marginalized populations.	a) adapting empowering strategies to the local context; and b) specific population programmes to overcome the larger political, social, racial and economic forces that produced and maintain inequities need to be development and further developed
Published empirical papers							
Bandesha & Litva (2005)	United Kingdom	Qualitative study	Community partnerships between health professionals and a South Asian community. The aim of the project was to understand and respond to the health needs of the community through participation initiatives.	Primary care delivery	Small town, underserved South Asian community	Social-cultural and organizational barriers to participation included: a) lack of time and financial resources among health professionals to engage the community; b) language and cultural diversity of the community	Features of CP were described to include: a) greater ownership by the community on setting health care priorities; b) attention to cultural and linguistic differences in the community; c) attention to power imbalances between professionals and

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
						described to be a challenge to engaging the community; and c) lack of time or willingness among community participants to be involved relating to specific life circumstances.	community participants; and d) assessment of the community's health needs, prior to participation in decision making.
Basu & Dutta (2009)	India	Case study	Participatory health communication models Emphasis on a bottom-up, culture-centered approach to participation	HIV/AIDS prevention	Sex workers	Barriers to the participation for sex workers were related to societal stereotypes towards them. These individuals participated in health communication strategies to challenge the social structures their lives are embedded in.	Features of the culture-centered approach to participation include: a) the agency of participants and dialogue in understanding health issues; b) increased control by the community on defining the issues that affect their health; c) communication and dialogue in these participatory

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
							processes should be informed by the context and structure that embody the lives of the participants; and d) sustain participation by maintaining connections between internal and external stakeholders, and allowing for feedback.
Boneham & Sixsmith (2006)	United Kingdom	Qualitative study	Sharing of ideas and voicing concerns through informal community participation initiatives that include residential associations or community groups	Health service planning	Disadvantaged women	Barriers to participation include: a) the low level of social cohesion and social capital among women (e.g., informal participation structures in the community, through neighbourhood associations, community groups, etc.); and b) the community's distrust of decision-makers and health	Features of CP were described to include: a) strengthening existing social networks and reciprocal relationships in the community; b) ensure diverse and inclusive representation; and c) build trust between the CP facilitator and the community; and d) gain an understanding of the

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
						professionals to adequately incorporate their values in the decision-making or planning process.	health experiences and concerns of the marginalized group involved
Boyce (2001)	Canada	Case study	The outcomes of community participation in five community projects in the Canadian Health Promotion Contribution Program (HPCP) were examined. The intention of the program was to provide financial resources to community groups for local projects to help them to identify and solve their own health problems.	Health promotion	Predominately, poor women, street youth, and disabled persons. Ethnic community members were evident in only two of five projects.	Barriers were described to relate to the social and economic constraints from marginalization and within the organizational context which is specifically shaped by the funder's policy agenda to support community participation with disadvantaged groups, and poorly resourced organizational practices (i.e., limited federal resource commitment to HPCP).	Features of CP were described to include: a) identifying key observable parameters (participant numbers, range, roles, influence) in the participation process; b) delineating major dimensions of structural factors which affect these parameters; and c) identifying the organizational dimension of structure.
Callaghan & Wistow	United Kingdom	Multi-method design,	Two rural communities were examined. In one	Primary health care governance	Rural communities.	Barriers were described to relate to	The exploratory research was

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
(2006)		including attendance at public and at three board meetings in each locality, analysis of documents and unstructured interviews	community, public opinion was solicited, and in the other community dialogues were used.	in the National Health Service (NHS) context, using insights from research in two Primary Care Groups/Trusts (PCG/Ts).	The two localities in which the fieldwork was conducted were purposively selected to provide similarities in organizational and other contexts for the implementation of a common policy initiative.	differential power relations in both rural communities. The PCG/T in both communities boards gave primacy to their own 'expert' knowledge	designed to examine how PCG/T boards understood and implemented their responsibilities for public engagement in the shift from government control to local governance models.
Campbell & McLean (2002)	United Kingdom	Qualitative study	This paper examines the impact of ethnic identity on the likelihood of peoples' participation in local community network.	Delivery of programs and services to address health inequalities	African-Caribbean residents of a deprived multi-ethnic area, from a town in south England.	Barriers were related to the social-cultural context. In particular, the construction of ethnic identities (e.g., stereotypes or historical forms of social exclusion) undermines the likelihood of local community participation advocated in policies that are concerned with reducing health inequalities.	Necessary pre-requisites for community participation were suggested: a) a sense of collective identity, and b) a sense of collective efficacy in the community.
Carlisle (2010)	Scotland	Ethnographic fieldwork	Multi-sectoral partnerships and community-led	Health policies aimed at	Reference to a disadvantaged	Barriers were described to relate to	Various contextual factors were

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
			approaches in the Social Inclusion Partnership (SIP) in Scotland.	addressing health inequalities	community	power imbalances contributed by disagreements on priorities and values between health authorities and marginalized groups that impacted consensus on identifying solutions.	described to be examined: a) a history of social exclusion in the community; b) facilitators should address the issues of poor previous engagement initiatives in the community, which might have left feelings of anger, and distrust in the community; and c) fair and legitimate representation in participation initiatives.
Champion et al. (2008)	Australia	Participatory action research (PAR)	Participatory action research with an Aboriginal community	Aboriginal health services planning and delivery	Aboriginal reserve	The social structure of the Aboriginal community (e.g., social norms, beliefs, and practices) shapes their participation and their views on health issues. There were 10 or more different Indigenous-speaking language groups on	Features of CP were described to include: a) forming relationships with the community; b) understanding of the community issues; c) cultural sensitivity; and d) valuing diversity in selection and representation of

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
						the reserve; they interact almost exclusively within their own groups causing segregation in this population.	participants.
Coelho (2006)	Brazil	Survey of 31 Local Health Councils (LHCs) and literature review	Local Health councils	Local health system reform	Critiqued the lack of representation from disadvantaged groups in local health councils, but no mention of specific marginalized groups.	Barriers related to the social-cultural context were described to result in challenges with representation of marginalized groups in the health councils. Particularly, citizens of low education and of low socio-economic income.	Representation in local health councils in Brazil should consider: a) inclusion of a diverse and non-bias range of civil society segments; b) commitment from local public organizations; and c) effective and consistent communication between public managers and civil society sectors for collective action.
Cornwall & Shankland (2008)	Brazil	Case study	Municipal Health councils	Local health system development	A north-eastern municipality of Brazil characterized by high levels of deprivation and inequality, and comprised of various	Barriers were described to relate to power imbalances between different groups involved. The participatory councils	Features for CP were described to include: a) employing vigorous methods of challenging power; and b) partnerships

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
					civil society organizations.	were influenced by power among members on the council, the political culture, and politics.	that enhance accountability of the health system to communities.
Crowley et al. (2003)	United Kingdom (Newcastle)	Case study	Evaluation of the Community Action on Health Project to promote community participation in decision-making for local health services. The main data sources was from stakeholder perspectives and experiences employed by semi-structured interviews, postal questionnaires, and field notes. The Primary Care Trust Group hired a community developer to established networks and linkages in the community.	Local health service decision making	Ethnic minority groups and people with disabilities	The paper reported solely on the positive benefits of community development principles to involve a wide range of people in discussions about local health services. The study demonstrated how a community development approach was used to enable the Primary Care Group to engage in dialogue with of minority groups.	A community development approach was used in the public participation initiative. The evaluation reported positive changes in service delivery. The program aimed to address issues of representation and inclusion of marginal groups by establishing relationships with community activists.
Downey et al. (2009)	United States	Exploratory study of two public engagement	A combination of methods including: photovoice; participatory action research; and community forums.	Health promotion	Rural community in the Appalachian county	No specific barriers were reported	Features of CP were described to include: a) community/local citizens should take

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
		exercises: photovoice and community forums	The use of visual images to discuss local problems and potential solutions. Participants connected their personal stories and experiences with the pictures.				the initial step on identifying the problems within their community; b) framing or identifying the solutions collaboratively; and c) the community deliberates on the solutions.
Draper et al. (2010)	Not applicable	Literature review and retrospective analysis.	Three case studies were presented of community-based child survival programs in low-income countries with a focus on those that addressed micronutrient deficiencies to provide a worked example of the evaluation framework and its utility in the evaluation of community participation.	Program and health service development for micronutrient deficiency among impoverished children	Low-income communities facing inequalities in health	Barriers described were related to the social-cultural and political context	Process indicators for CP were suggested: a) leadership in the community; b) planning and management (e.g., forging partnerships between professionals and the community; c) monitoring and evaluation; and d) external funding support for programs.
El Ansari (2005)	South Africa	Case study	Collaborative research (community participation is viewed as a component in the process of collaboration between health providers, researchers and the	Public health planning	Five disadvantaged communities in South Africa	Challenges with partnerships were reported to include power imbalances between professionals and the disadvantaged	Components of effective partnerships include: a) understanding the community context; b) the problem and

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
			community)			group engaged.	solutions are reciprocally defined; c) enhancing relationships through participation (e.g., joining resources, networking and building skills); d) involving a multidisciplinary team and; e) clear and continuous communication between partners.
El Ansari (2010)	South Africa	Questionnaire	Partnerships in five different South African provinces	Health services planning	Reference was made to minority groups and the marginalized status of the communities	Challenges with community participation were related to interactions between managerial and operational factors within complex policy, organizational, physical, and social settings.	Partnerships were described to require: a) leadership and management skills; b) fair representation of community participants; c) coordination and collaboration; d) accountability and feedback; and e) good communication mechanisms to ensure proper leadership skills.

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El Ansari & Phillips (2001)	South Africa	Qualitative study	Collaboration and partnerships in primary health care planning among different sectors, diverse stakeholders, health organizations, and the community	Primary care delivery	Underserved communities with low-income status	Barriers to participation were reported on power imbalances between stakeholders engaged	Features of CP were described to include: a) community ownership; b) Commitment from all the actors involved in the initiative; c) adequate communication; d) attention to power; e) transparent goals and vision of participation; f) representation from diverse stakeholders and interests; and g) attempts to utilize the resources and skills of the community involved.
Etowa et al. (2007)	Canada	Case study	Participatory action research (PAR) - Enables co-learning and serves as a door to empowerment.	Health services planning	Women in a disadvantaged rural community	The limitations of participatory action research (PAR) with marginalized groups include power dynamics within the research process, which impedes the foregrounding of	Features of PAR include: a) equal and collaborative involvement of the community of research interest; b) the problem, issue, or desire for change is identified by the

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						participants' experience and their full involvement	community; and c) reflection on the action and its outcomes and a constant evaluation of its process is important.
Hartstock et al. (2006)	United States	Descriptive paper	Community Voices Dental Program that involved community-led collaborative efforts. Development of a task force including local dentists, state dental personnel, local school administrators, health department providers, and patients.	Dental care/public health services delivery	Children in rural communities that are comprised of multi-ethnic groups and have high rates of poverty	Barriers were described to relate to the social-cultural context and included, health illiteracy among ethnic minority families posed challenges to involve them in discussions about dental health.	Features of the CP process were described to include: a) the development of communication and collaboration strategies and referral mechanisms; b) enhanced leadership among collaborators in the task force; and c) creation of local partnerships and alliances among the dental health professional, school systems, pubic health departments and the community.
Jurkowski et al. (2002)	Canada and United States	Survey	Review of Collaborative partnerships among various organizations. A survey	Access to health services for disabled persons	People with disabilities	Changes in the political landscape were described to	A process of empowerment was described to be key to

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			administered to fourteen individuals noted as leaders within the Canadian Disability movement (or facilitating social change) was conducted.			influence the exclusion of disabled individuals from planning and decision-making opportunities for their health.	ensuring meaningful participation. The components of an empowerment process include: a) collaborative partnerships with clients and client groups; b) a focus and emphasis on client's strengths, capabilities, and resources; and c) the selective channeling of energies to disempowered groups.
Kano et al. (2009)	Mexico	Ethnographic research	Observations of the Local Collaboratives (LC)—a regionally based community organization.	Mental health program and service delivery	People with disabilities	Existing social and economic inequalities in the group (e.g., low income, poor education and social class differences) were described to prevent the involvement of disabled people in decision-making about their health.	The following challenges need to be considered in the participation process: a) recognition of diverse needs of the community; b) the nature of the community; and c) inequalities in power in the community magnified by ethnic,

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						The role and power of the LC can also affect the LC's relationship with the population.	economic and education differences.
Kashefi & Mort (2004)	United Kingdom (Southwest Burnley)	Case study and the development and evaluation of a public involvement exercise	Grounded citizens jury (12-14 participants) Participants were purposely selected as opposed to using random selection. The jury process acted effectively as a grass-roots health needs assessment and amongst other outcomes, resulted in the setting up of a community health centre run by a board consisting of members of the community (including two jurors) together with local agencies. The agenda for the jury was broad.	Primary health care delivery	A community suffering from health inequalities. Issues faced in the community include poverty, low pay, poor housing, ill health, poor access to health and social services, among other issues.	Reported only on the benefits of using the grounded citizen jury method for engaging marginalized populations.	Four elements of a citizens jury that were suggested include: a) deliberation on the issue(s); b) integration in the community context (the jury sessions must be embedded within the community; c) sustainability (needs to be developed in the community); and d) accountability of decision-makers involved.
Kegler et al. (2009) & Kegler et al. (2008)	United States	Case study	Evaluation of the California Health Cities and Communities Program – involved community participation and intersectoral collaboration	Program delivery addressing the social determinants of health	A community with varying socio-demographic characteristics.	Barriers to participation were related to the social and cultural context and included: a) lack of time and resources of community	A key value of the participation initiatives was to ensure broad based representation across socio-demographic groups. However,

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			The specific evaluation aims were to assess how the CHCC a) engaged residents; b) achieved broad representation; and c) facilitated civic engagement			residents to participate; b) distrust stemming from a history of discrimination and racism; and c) limited funding for community improvement initiatives were also noted.	there was no mention of how to sample or recruit participants. Features of the CP processes should include: a) creating a welcoming environment; b) establishing partnerships with trusted community organizations; and c) using varying types of community participation strategies
Kilpatrick (2009)	Australia	Case study	Community participation through partnerships	Rural health services planning and delivery	Rural Australian community	The political context (e.g., changes in government agenda and policies) was explained to hinder support for community participation at the local level. Genuine community partnerships require governments to	The importance of understanding "rural place" as a prerequisite for effective health development was emphasized. This understanding would: a) facilitate alignment between health programs and community

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						provide resources while relinquishing control to the community members engaged.	expectations, customs, values and norms; b) assist in identifying and incorporating relevant community assets, including social capital, skills and local organizational contexts; and c) provides information about health needs and priorities.
Lee et al. (2009)	Australia	Longitudinal and cross-sectional data	Consumer Reference Group (CRG) in a primary health care setting to assist with understanding and reducing the barriers to alcohol and other drug services for a heterogeneous, disadvantaged group that includes individuals from different cultural, language and educational backgrounds.	Primary health care delivery	Disadvantaged women of diverse cultural and linguistic backgrounds.	Not specified	Key features of CP were described to include: a) agreeing upon the purpose of the group and how it would operate within the structure of the organisation; b) language required by participants for the group to contribute; and c) ensuring an appropriate, workable demographic mix in terms of age, language, and

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							migration experiences.
Maalim (2006)	Kenya	A qualitative, descriptive research design using participatory rapid appraisal techniques.	Participatory rapid rural appraisal (PRA) techniques to health needs and plan nursing services for a disenfranchised, nomadic Somali community of north-eastern Kenya.	Rural health care services planning	Disenfranchised, nomadic Somali community of north-eastern Kenya	Barriers to participation were related to the social and cultural context and included: a) low literacy rate of the participants, especially among women; and b) strong Islamic religious beliefs and cultural practices present in the community. Women are only permitted to communicate with men that are related to them and often not permitted to give their views in the presence of males.	Innovative participatory rapid rural research techniques were used with the community such as, mapping and Venn diagrams. PRA can provide a better understanding of a community's health service needs. PRA underscored the community's perception of the available health care services including nursing and midwifery services.
Martin (2008)	United States	Qualitative study (interviews, participant observation and	Service-user involvement in cancer-genetics services	Cancer-genetics services	Socially disadvantaged communities	A formal procedural mechanism for recruitment might influence representation and involvement of	This study explores the issue of representation of marginalized communities in participation

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		documentary analysis)				marginalized populations.	initiatives. Experiential representation based on shared experiences, where needs are actively and subjectively assessed, were suggested to enhance representation. Representation should emphasize the practical knowledge and personal experiences that disadvantaged citizens can offer.
Milewa et al. (2002)	United Kingdom	Qualitative study (semi-structured interviews)	The creation of Primary Care Groups--organizations based on local groups of general practitioners--has been accompanied by a requirement that they involve users and the public.	Primary health care planning	Over 26% of these initiatives were oriented towards minority ethnic communities. About 16% of the activities were focused on older people with similar proportions aimed at deprived populations and people with	Barriers were described in relation to how managers and clinicians in Primary Care Groups and Trusts choose to prioritize the views of local service users and residents in relation to professional	The paper raises important questions about how public participation is conceptualized and viewed by professionals and government, which ultimately shapes the types of participation strategies that are

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					mental health problems. Just over 7% were aimed at those with physical impairments.	judgment, operational and planning constraints and limited resources.	implemented. The changing political discourse has over time characterized ideas of public and patient involvement in decision making within the NHS.
Moulton et al. (2007)	United States	Description of a community participation exercise	Use of informal meeting with communities. One way to examine health care issues in a community is to meet with residents of the community in an informal setting. The outcome of this approach led to new networks and collaborative opportunities and increased community capacity.	Health services planning	Rural populations	Barriers to participation involved challenges with logistics and setting up the initiative—Many small rural communities do not have the required facilities.	Planning steps of the CP process were described to include: a) a format for the meetings tailored to show respect to the culture. Each meeting began with a prayer, and a Native American faculty led the presentation and facilitated the conversation; b) a community member to serve as the official host for the meeting in their area; and c) Each attendee received information packets
Nathan et al.	Australia	Questionnaire	The study reports on the	Health service	Semi-rural area with a	Several barriers were	The positive changes

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(2006)	(Sydney)	of health service providers	attitudes of staff on key health service committees towards community participation before and after the appointment of community representatives to the Community Representatives Program (CRP). The intention of the CRP was to provide community members with the opportunity to have positive and effective input into service delivery, to provide input about issues and needs in the community, and to be active participants in the work of the committees of the health service.	planning and decision making	population of 42,740 (mixed demographics, varying in age, ethnicity and culture).	reported in relation to the organizational context: a) organizational structure; b) health service provider attitudes towards community participation; and c) staff beliefs about the role and influence of community members on committees.	found in staff attitudes to the role and value of community members on committees and in the area health service as a whole may have resulted in part from the structures and processes introduced at the health service. However, the positive changes between the two survey periods are likely to also be a result of the direct experience of staff working alongside community representatives.
Nimegeer et al. (2011)	Scotland	Action research project	A planning 'game' was developed that uses a number of types and levels of cards and allows community members, as part of a process of engagement, to express their priorities and designs in a form that is directly usable by health	Rural health service delivery	Rural/remote areas, primarily aimed at "fragile" communities identified as having small populations, are dependent upon a small group of health care and related workers, and are	Communication between health providers and the community lapsed after the project and the community expressed resentment at this breakdown of communication	Community member groups opted for the same type of health professional to provide local services, but this was a different (nurse practitioner) role from the one that was

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			service managers. The game was the Remote Service Futures Game to create a potential future community health service delivery plan The game was trialed in four communities, each with a population of under 500 people. The game involved two community member groups and one service provider group.		relatively distant from service centres.		anticipated. While all groups agreed regarding community needs, the community groups preferred a single, locally based, multi-skilled generalist worker and the service provider group opted for delivery on an outreach basis to the community by an external multidisciplinary team.
Payne (2001)	United States	Case study	Community-based coalition strategy. There are three basic components of the initiative: (1) The establishment of 27 geographic community health network areas,;(2) mandated participation by all MDPH-funded health service providers; and (3) the undertaking of collaborative activity upon health	Community-based public health program planning	No specific marginalized group mentioned	Barriers to participation that influenced the community participation process and outcomes involved funding constraints and issues of legitimacy among community participants	Features of a CP process include: a) articulating problems and designing solutions in collaboration with the community; b) fostering trust with participants; c) attention to social, cultural and linguistic differences of participants; and d)

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			improvement projects by the members of the network areas.				engaging persons who are experiencing health problems in articulating their problems and designing solutions promotes three beneficial consequences.
Quantz et al. (2006)	Canada (Region 4 Aboriginal Community Health Council, Calgary)	Case study	Aboriginal community participation strategies including: membership in the council, open- regular meetings, consultations, links and partnerships, education and awareness, traditional meeting process.	Input to Aboriginal communities' health service delivery and health policy development	Stakeholders (Aboriginal Health Council members, and the Calgary Regional Health Authority); Aboriginal groups within Calgary's Aboriginal communities. Canada's Aboriginal peoples do not reflect a homogenous population. Rather, they are a diverse group of communities composed of many nations and backgrounds.	One of the Council's identified challenges with reaching out to and involving the wider public in the Council's activities. To accomplish this task, the Council may need to employ appropriate techniques to facilitate the participation of those who do not have experience. These techniques need to reflect the daily lives, comfort level and experience of the target community.	Key features pertaining to the process of CP were described to include: appropriate technique to facilitate participation for those who do not have experience; and representativeness of Aboriginals in the council (e.g. membership in the council and inclusion of all Aboriginal groups). Outcome of the process described to include: identifying community needs,

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							community awareness, time of individual, and benefits to Aboriginal community.
Ramella & de la Cruz (2000)	Peru	Case study	A community-based adolescent sexual health promotion initiative	Public health/health Promotion program development	Highly deprived communities in Peru	Barriers to participation were related to the social and cultural and organizational context and included: a) issues of power and social and cultural changes within the community; and b) the long-term sustainability of projects shaped by community change.	The authors argue for the benefits of investing in participatory processes with the full agency of participants.
Rapport et al. (2008)	United Kingdom (Pembrokes-hire, West Wales)	Qualitative study (focus groups; evaluation of the Healthy Living Approach to community development in the UK)	A combination of participation methods include: Action research methodology; focus groups to address rural isolation, economic decline, social exclusion and poor health.	Primary health care delivery	Three marginal communities in Wales – two scoring highly on the deprivation scores, the third in an isolated rural location.	Barriers were described from the participants perspectives to result from: a) power imbalances which were described to be inevitable; b) limited involvement; and c) concerns with the	The Healthy Living Approach to community development in Pembrokeshire was initiated and evaluated as part of the Welsh Assembly Government's Sustainable Health

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						sustainability of the initiative and their long-term involvement.	Action Research Programme (SHARP) as an innovative response to a context of funding and service delivery. The findings suggest there is the potential for this Healthy Living Approach to enable communities to engage with locally defined health and wellbeing issues. However, the benefits of involvement are not sufficient to achieve real and sustainable change
Rath et al. (2010)	India (Jharkhand and Orissa)	Document analysis (review of intervention documents), qualitative structured discussions with group	A participatory learning and action cycle with 244 women's groups was implemented in 18 intervention clusters covering an estimated population of 114 141	Primary health care delivery (specifically, maternal health)	Marginalized women's groups	The factors that influenced the intervention's impact included: a) acceptability or willingness to participate; b) a participatory approach to the	Participatory interventions with community groups should be tailored to local contexts. Participatory interventions were suggested to involve: a) a detailed

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		members and non-group members, and meeting observations				development of knowledge, skills and 'critical consciousness'; and c) the active recruitment of newly pregnant women into groups.	understanding of the way in which context affects the acceptability and delivery of the intervention; b) planned but flexible replication of key content and implementation features; b) strong support for participatory methods from implementing agencies.
Stern & Green (2008)	United Kingdom and South Africa	Ethnography	Community meetings and multi-sectoral partnerships	The authors examine the role of representation in the Healthy Cities Initiative. The studied focused primarily on meetings, as a key site at which the structural imbalances of partnerships such as Healthy Cities programs are	No specific marginalized group was mentioned.	Barriers to participation involved tensions between public sector authorities and communities in two Healthy Cities Programs. Community partners are invited in on the terms set by the statutory sector, who continue to control both the form and	The authors described that certain controls need to be in place in establishing partnerships through community meetings. These include: a) control over representation (i.e., equality of individual contributions; b) organisational control over the content and outcomes of meetings

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				played out.		content of meetings.	through management of the agenda, and selective attendance; and c) controlling the agenda
Taylor et al. (2005)	Australia	Case study	The purpose of this paper was to establish how community participants understand their community and community participation in developing health services.	Primary health care delivery	Three rural communities were studied	In each rural community participants understood their community as a 'community of place' and their participation in health services organisation was about collective contributions to a task that was seen as a benefit to the community.	Key features of CP in a rural community were described to include: a) understanding the motives, values and different perspectives of the community; and b) understanding community narratives that may support, or work against, community participation in health service development is important.
Thurston et al. (2005)	Canada	Case study/theoretical development	Partnership between Calgary Health Region and Salvation Army (SA), several strategies (e.g. Women's Health Express Advisory Council, SA Health Council)	Delivery of women's health services.	Disadvantaged women	No specific barriers were mentioned.	A theoretical framework was proposed for public participation in a health region, which includes: a) the public participation initiative (e.g., technique used,

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							the public involved, profile and credibility of an initiative); b) the policy-making process within the health region; c) social context; d) policy community; and e) health of the population as the ultimate outcome of public participation. The development of a formal partnership was found both to open up political space for prioritizing women's health and to allow women's organizations to challenge the status quo in health service delivery.
Thurston et al. (2004)	Canada	Case study	Information is drawn from a case study of a Community advisory committee with diverse membership. Among the 14 members, two were	Public health/health promotion Planning	Sexually assaulted women	Accessing women who are non-verbal is challenging due to the many barriers to participation that they	A participatory evaluation of the the Community advisory committee illustrates the difficulties

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			specifically sought from non-verbal women who experienced sexual assault.			face, such as the inability to use the telephone or open mail, and their reliance on others to agree to assist or support their attendance at events. In recognition of these barriers, staff at the agency spoke personally to clients they thought might be interested in participating.	encountered when a community agency initiated a health promotion project to address the needs of women who are non-verbal and at risk of sexual assault.
Zapata (2009)	United States	Case study	A scenario planning method was used to support the Valley Futures Project (VFP) in Modesto, CA	Health (care) planning	Ethno-cultural community (mostly from Lao)	Barriers were related to power imbalances were reported among organizers and the marginalized population engaged	Features of CP were described to include: a) recruiting community leaders; b) ensuring diversity of representation; c) emphasis on story-telling to mitigate power imbalances and allow people to participate on a more equal playing field; and d) emphasis on dialogue as opposed

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							to deliberation on solving a concrete policy problem.
Published non-empirical papers							
Chessie (2009)	Canada	Secondary data from a 2001 survey of health system governors from Regional Health Authorities (RHA's)	Review of the composition and representation in community governance boards. The study explored the diversity in both demography and opinions between two types of citizen governors, those from outside the system (lay citizen governors) and those within the system (system-experienced citizen governors).	Health system planning (in the context of health care regionalization)	No specific marginalized group mentioned Authors explored whether the claims for "diversity" of representation on community boards, actually sought out representation from marginalized citizens.	Barriers were reported to relate to the over-representation by highly educated Canadians in the governance boards. Also, in the presence of experienced citizen governors, lay citizen governors were more likely to align their views and opinion with the experienced governors.	Features of CP were described to include: a) representation on community boards should not strive to represent the general population but those groups who are disproportionately affected by ill health and health system reform; b) community boards should be diverse across groups in the community and across opinions; and c) the community governance boards should establish a strong and trusting relationship with the community.
Murthy & Klugman (2004)	Asia (multiple countries)	Document analysis of 18 World Bank	An examination of the concept and practice of community participation in	Sexual and reproductive health (SRH)	Mention of marginalized groups in general and	No specific barriers were mentioned	The study emphasizes a clear definition of community and

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		project information documents and staff/project appraisal documents.)	World Bank-supported health sector reforms in Asia.	services delivery	marginalized women in particular.		investment in capacity-building; addressing issues of representation; and being clear about the rational for community participation in health.
Published conceptual papers							
Cornwall (2008)	Brazil	Conceptual (descriptive analysis of a case)	Various partnerships reviewed in the context of Brazil's universal, publicly-funded, rights-based health system	Health system reform	Reference was made to disadvantaged populations generally	Barriers were described to relate to issues of transparency from partnerships, in which there is a considerable power imbalances between government and community members.	Core features to enhance partnerships were described to include: a) agreement on a shared vision; b) transparency of information and resources; c) agreed roles and responsibilities; d) all interests are represented; and e) agreed mechanisms for conflict resolution.
De Vos et al. (2009)	Philippines	Conceptual development	Variety of community participation approaches examined in the Philippines	Health (care) planning	Individuals with a low socio-economic status	Barriers were described to include: social class	Features of CP were described to include: a) empower the

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						differences in the marginalized population, local and external power relations, and the role of state priorities that shape the sustainability of the community participation initiatives influenced the community participation process.	community to have control of the health issues that affect them; b) create opportunities to support participation of all groups in the community; c) objectives of participation should be transparent; and d) attention should be paid to issues of power and power relations between experts and the community.
Halabi (2009)	Indonesia	Conceptual development	Participation in the context of health care decentralization. Creating mechanisms for participation such as, forums, public meetings, and focus groups.	Health care delivery	Reference was made to marginalized populations generally	Several barriers were reported in the paper from their review and critique of right-based arguments towards participation, which include: a) the political context driven by financial pressures and demands of international lenders,	Features of CP were described to include: a) sensitivity of local capacity, that is to issues where locals have sufficient information and individual stake in improving health outcomes; and b) dialogue between practitioners,

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						which change the governments' agenda and policies; and b) accountability of decision-makers and political leaders to the public's views and concerns.	policymakers, and participants with the aim of educating and providing information, not only about health, but also about their rights to quality care.
Koelen (2008)	Not applicable	Conceptual development	Coordinated action (also referred to in the literature as intersectoral collaboration). (Coordinated action was defined in the paper to include getting involved with working in a new area or setting, with new people and with different backgrounds, knowledge domains, interests and perspectives)	Health promotion	No specific marginal population mentioned. The paper advocates for the use of coordinated action to address complex public health issues and health inequalities affecting marginalized populations in the broad sense.	The factors described to influence coordinated action were related to the representation of relevant societal sectors and members of the public; identifying roles and responsibilities among diverse stakeholders; and organizational structures.	Six factors were identified which are important in achieving and sustaining coordinated action: a) representation of relevant societal sectors including clients; b) discussing aims and objectives; c) discussing roles and responsibilities; d) communication infrastructure; e) visibility; and f) management.
Larson et al. (2009)	Not applicable	Conceptual/ theoretical development	Devised a framework for community-based participatory action/multi-stakeholder partnerships that	Health promotion/ health inequalities	No specific marginalized group mentioned	Not specific barriers were mentioned	Features of CP are related to the planning, implementation and

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			is founded on the social-ecology model to understand health inequalities and disparities.				evaluation phase. Planning involves: a) setting goals and objectives; b) assessment of assets and needs in the community; and c) capacity-building and community organization. Implementation involves: a) process evaluation; b) community action; and c) community mobilization. Evaluation involves: a) sustained action and outcomes; b) dissemination; c) data analysis; and d) interpretation. Also, community participation strategies should be culturally sensitive, and should involve multiple stakeholders with different skills

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							and expertise.
Mahmud (2004)	Bangladesh	Conceptual/ document analysis	The author explores prevailing notions about citizen participation as perceived by ordinary people and to determine people's perceptions about the boundaries of their participation space, which create barriers to citizen agency.	Health system (participation initiated under the Health Sector Reform Program)	Rural part of Bangladesh with high poverty rate.	Barriers that affect the outcome of a community participation strategy were described to include: a) experiences with poverty in the community which influence their self-confidence and capacity to participate; b) local and external power inequalities; c) low self-esteem; and d) social and economic exclusion of marginalized individuals from the public sphere.	Features for CP were described to include: a) acquiring social and human resources necessary for participation and engagement, like self-esteem, self-confidence, visibility and recognition; b) acquiring physical and institutional resources like space for participation and deliberation and requisite information, appropriate rules for deliberation and conflict resolution on a more equal basis, capabilities and skills for deliberation and participation; and c) establishing mechanisms for building trust, assessing change and learning deliberation

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							and engagement to be effective in reducing inequality and increasing access.
Grey literature (e.g., government or health services and policy organization reports)							
Dukeshire & Thurlow (2002)	Australia	Not applicable	Involvement of rural communities in planning and decision-making opportunities	Health policy development	Rural communities	Seven barriers to participation were described to include: (1) lack of understanding of the policy process (2) lack of community resources (3) reliance on volunteers (4) lack of access to information (5) absence of rural representation and certain community groups in the decision-making process. (6) relationship between government and rural communities (7) time and policy timeline restrictions	This report suggests ways to address the barriers and challenges in working with rural marginalized communities. Recent efforts to reduce the barriers and challenges to policy development at both the community and government levels has likely increased governments understanding of rural community needs as well as increased rural communities understanding of how they can work effectively with government and public policy makers.

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
Vancouver Costal Health (2009)	Vancouver, Canada	Not applicable	The report describes a framework to understand community engagement (CE) activities initiated by Vancouver Costal Health (VCH).	Health services and policy planning and development	No specific marginalized group mentioned	No specific barriers were mentioned	Community engagement was described to be beneficial in a number of ways (pg. 14): i) "Two-way interaction process between Vancouver Coastal Health and its communities"; ii) Enable communities to participate and have a role in the planning and decision-making of health care policies; and iii) Community engagement includes a wide variety of activities (consultations, community development, community capacity building) that are suitable for various

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
							subgroups (i.e. marginalized groups) and needs
Rugkasa & Boydell (2007)	Northern Ireland	Review of the literature and multiple case studies	Collaborative partnerships	Population health/public health program and service delivery	No specific marginalized population mentioned	Barriers to participation were described to relate to structural factors that produced health inequalities. Partnerships as a solution to address health issues of marginalized populations were also described to not be able to address all root causes of inequality	In-depth case studies of four partnerships were carried out with: Armagh and Dungannon Health Action Zone (ADHAZ); North and West Belfast Health Action Zone (NWBHAZ); Northern Neighbourhoods Health Action Zone (NNHAZ); and Western Investing for Health Partnership (WIHP). Based on these case studies, the IPH has developed a conceptual model linking the collaborative efforts of partnerships to benefits which impact upon the determinants of health and a set of

Citation	Jurisdiction	Study Design	Community Participation (CP) Method and Initiative Examined	The local health system issue being addressed	Marginalized populations/ groups involved	Structural Barriers to participation	Key messages about community participation (CP) approaches and how to enable participation with marginalized populations
							indicators for use in assessing progress.

Appendix 4: Overview of community participation methods that have been tailored to enable the participation of marginalized populations

Community Participation Method	Description of the method	Objective(s) of the method	Key features of the method to enable the participation of marginalized population
Scenario planning	The method focuses on "future oriented plans" that involve identifying long-term solutions to health and health service problems in a population (i.e., creating a "vision"). Participants are asked, through informal dialogue meetings, what health services and/or health outcomes they might look for in their community over a specified time frame (e.g., 10-15 years) by adopting (or not) a particular solution.	(1) To support different cultural groups to gather together to learn, communicate and deliberate on issues without the pressure to decide on a specific policy option or recommendation to be implemented; and (2) To reduce power imbalances between organizers and marginalized individuals	(1) To ensure broad community representation within the process by hand-selection and strategic recruitment of participants; (2) To foster reciprocity with the incorporation of storytelling and emphatic listening; (3) To eliminate power imbalances between participants and organizers by focusing on the broader planning for health service, rather than agree on a specified policy decision with the use of dialogue instead of deliberation.
Remote service future game	The method involves an interactive and educational game where participants identify health priorities that practitioners will consider for the design of health services. Individuals are divided into working groups, where each group discusses 5-10 of their most important health care needs, and devise plans for the delivery of health services. The groups then come together to debate the potential merits and disadvantages of each plan and attempt to reach a consensus.	To bring marginalized populations together to collectively create a potential future community health service delivery plan	(1) To identify community priorities; (2) To compare and contrast the priorities and choices of one or more stakeholder groups; (3) To create workable health care plans for the future; (4) To use the game as a learning tool for people who wish to know more about health and related services and how they are designed currently; and (6) To use the game as a training tool for staff to help them consider different viewpoints when planning
Photovoice	Participants are asked to represent their population/community or point of view by taking photographs, discussing them together, developing narratives to go with their photos, and conducting outreach or other action.	To use of visual images to discuss local problems and potential solutions. Participants connect their personal stories and experiences with the pictures.	a) The community identifies the problems within their community; and b) collaboratively framing or identifying the solutions

Chapter 3:

Enabling the Participation of Marginalized Populations through Community Development: A Case Study Analysis of Community Participation in Ontario, Canada

Abstract

Community participation has been identified as a key facilitator of community health among marginalized populations in international health statements. These international health statements, however, do not stipulate the ways and means to engage marginalized populations in community participation strategies. Despite strong commitments by health organizations to engage marginalized populations in the planning of and decision making about local health services, the concept of community participation remains poorly articulated and there is ambiguity about the features of participation initiatives (e.g., methods and techniques) that are appropriate for these populations. To improve our understanding of community participation with marginalized populations we examined efforts to engage marginalized populations in Ontario Community Health Centres (CHCs), which are primary health care organizations serving 74 high-risk communities throughout the province of Ontario.

We carried out a comparative analysis of four in-depth qualitative case studies of community participation initiatives in Ontario CHCs with three objectives: (1) to describe how participation with marginalized populations differs from engagement with other types of publics; (2) to identify the specific features of participation initiatives with

marginalized populations (e.g., the approaches and methods); and (3) to identify the challenges of engaging marginalized populations. Our data collection methods included 28 key informant interviews, a qualitative document analysis of publicly available and internal documents from each CHC, and site visits with each CHC prior to carrying out the interviews to learn more about its day-to-day operations.

Our findings demonstrate that enabling the participation of marginalized populations requires CHCs to attend to the barriers experienced by marginalized populations that constrain their participation. A community development approach to participation was described to address the barriers related to marginalization and the associated social and cultural characteristics of the marginalized population. Limitations of the community development principles were demonstrated by cultural values and beliefs that shape the motivation and willingness of a marginalized population to participate and resist efforts to enable their participation in health service planning and decision making. The community development approach has not been systematically evaluated by CHCs to assess whether the methods employed in their participation initiatives have been effective in eliminating barriers to participation that marginalized individual's experience. This absence of evaluation efforts by CHCs may contribute to difficulties in knowing which methods are suitable for particular marginalized populations because of changing cultural values and beliefs, gender roles, and social relationships of these populations.

Introduction

In the 1970s and 1980s, major Canadian social trends driven by public demands for greater responsiveness of health professionals and policy makers to communities (Zakus & Lysack, 1998) and interest in the role of community-level factors in shaping ‘‘healthy communities’’ (Veenstra & Lomas, 1999) influenced calls for community participation in health services planning and decision making. Community participation was identified as one of the key components of primary health care in the Alma Ata Declaration of 1978 (WHO, 1978). Almost a decade later, the Ottawa Charter for Health Promotion of 1986 included language that advocated for the strengthening of community action as a vehicle for community capacity and empowerment (WHO, 1986). These international statements also emphasized the right and duty of people to participate individually and collectively in the planning and implementation of their health care as a defining principle of community participation (WHO, 1986).

In these international statements, particular attention is given to the health of marginalized populations, who are at a greater risk of poor health. For the purposes of this paper, marginalized people are defined as individuals who are excluded from their society on the basis of characteristics such as race, class, or gender, socio-economic status, ethno-cultural identity, age, or other stigmatized identities (Jenson, 2000; Lyman & Cowley, 2007) by mechanisms of oppression, patriarchy, or stigmatization (Hall, 1999; Lyman & Cowley, 2007; Vasas, 2005). The participation of marginalized populations has been suggested as a strategy for reorienting health services that are accountable, efficient, contextualized, and targeted to the needs of marginalized individuals in underrepresented

and underserved areas (Boneham & Sixsmith, 2006; Carlisle, 2010; Church et al., 2006; Kashefi & Mort, 2004; Kilpatrick, 2009; Moulton, Miller, Offutt, & Gibbens, 2007). Local health service organizations, which are health service organization mandated to provide health services to a specific population in a geographical area—and the voluntary sector more generally—have advocated working with marginalized populations to identify specific health service problems and implement local approaches to resolve them (Downs & Larson, 2007; Minkler, Vasquez, Warner, Steussey, & Facente, 2006), with the goal to improve the physical health and mental well-being of marginalized individuals.

These international statements, however, do not stipulate the ways and means to engage marginalized populations in community participation initiatives (e.g., the methods for recruitment and engagement, and the necessary resources and support needed by local health service organizations to facilitate community participation with these populations) (Morgan, 2001). There is a growing consensus among scholars that further development of community participation theory requires several elements: i) improved clarity of concepts used to discuss participation among academics and practitioners; ii) further delineation of the factors believed to have an impact on participation; and iii) the development of rigorous methods for assessing the effectiveness of different participation modalities that can be applied in a variety of settings and with varying publics (Boyce, 2001; Burton, Goodlad, & Croft, 2006; Draper, Hewitt, & Rifkin, 2010). Despite strong commitments by local health service organizations to engage marginalized populations in the planning of and decision making about local health services, the concept of community participation remains poorly articulated and there is ambiguity about the

features of participation initiatives (e.g., methods and techniques) that are appropriate to these populations. This has resulted in scant practical guidance for health service organizations that want to meaningfully engage marginalized populations.

To address these knowledge gaps, we carried out a series of case studies with three overarching objectives: (1) to describe how participation with marginalized populations differs from engagement with other types of publics; (2) to identify the specific features of participation initiatives with marginalized populations (e.g., the approaches and methods); and (3) to identify the challenges of engaging marginalized populations. The case studies examined efforts to engage marginalized populations in health services and program planning within Ontario Community Health Centres (CHCs), which are primary health care organizations serving 74 high-risk communities throughout the Province of Ontario.

Conceptualizing Community, Participation and Marginalization

There are two significant knowledge gaps in the community participation literature. First, there is limited empirical evidence about the characteristics of participation initiatives, which appears to be influenced by conceptual ambiguity about the terms "community" and "participation." The community participation literature uses the term "community participation" vaguely without acknowledging that communities are comprised of diverse groups, who may each have different health needs, values, and perspectives on health (Cooke & Kothari, 2001, p. 5-6). Considerable challenges in defining community have been noted in the literature. Currently, the term community has two general meanings. The first—and relatively recent usage—refers to social ideals of

solidarity, sharing, and consensus. The second meaning of community refers to actual groupings of people (Amit & Rapport, 2002). Marginalization—what community participation efforts seek to address—has also been superficially conceptualized. Marginalization is a multi-layered concept, and individuals can be marginalized at certain stages of the life cycle and for different reasons. For instance, the marginalized status of adults may increase as they become elders. Marginalization can also be experienced by those who are born into particular minority groups (e.g., Roma people or Indigenous populations) (Lyman & Cowley, 2007).

A second critical knowledge gap is that existing frameworks and typologies of community participation that have been influential in guiding community participation practice with marginalized populations have failed to acknowledge that the decisions of marginalized populations to participate are influenced by their social and cultural context (e.g., social norms, beliefs and values) and vary according to their culture, ethnicity, gender and age among other categories (Arnstein, 1969; Rifkin, Muller & Bichmann, 1988). Moreover, in portraying community participation as occurring sequentially, within discrete and unambiguous phases, current frameworks and typologies ignore that community participation is shaped by the social and cultural context of these populations (Cornwall, 2008).

More recently, public engagement scholars have argued that community participation is contextual and situational, suggesting that the process of participation cannot be reduced to discrete categories or phases (Abelson, 2001; Butterfoss, 2006; Draper et al., 2010; Dressendorfer et al., 2005; Laverack & Labonte, 2000). Abelson and

colleagues note that the elaboration beyond general depictions of context in community, cultural, organizational and political terms have been rare. Also, the diversity within marginalized groups suggests that a "one-size-fits-all" approach is not appropriate. More than one approach can be used in a defined community, and the approach or method(s) will vary depending on the social-cultural characteristics of the population(s) involved, organizational resources available, and the health issue being addressed through the community participation initiative.

The portrayal of community participation with marginalized populations as a complex process fraught with various challenges (Draper et al., 2010), however, may discourage practitioners within local health service organizations from engaging these populations. These knowledge gaps suggest that, in order to support practitioners and decision-makers in local health service organizations who want to meaningfully engage marginalized populations, there is a need to critically examine and evaluate existing community participation efforts with these groups (Butterfoss, 2006; Dressendorfer et al., 2005; Laverack & Labonte, 2000). In doing so, the benefits of participation that have been promulgated in international primary care and health promotion policy statements can also be assessed (Cooke & Kothari, 2001).

Methods

We carried out comparative case studies of community participation initiatives in four Ontario CHCs to improve our understanding of community participation with marginalized populations. In particular, we explored in an in depth manner, the factors that influence the participation of marginalized populations, as well as the approaches,

strategies and methods for engaging them, to inform the criteria against which community participation initiatives might be evaluated in the future. The use of multiple case studies allows for an in-depth exploration of how one type of local health service organization—the community health centre—engages marginalized populations in the planning of and decision making about health services. In contrast to single case studies, the evidence from multiple case studies is considered more robust (Ayres, Kavanaugh, Knafl, 2003; Yin, 2009, p. 46).

Selection of cases

The selection of cases involved a two-stage approach, both of which used a maximum variation sampling strategy (Maxwell, 2005, p. 89; Patton, 2002). A *first level of sampling* involved the selection of CHCs to study the phenomenon of interest (community participation initiatives with marginalized populations in Ontario CHCs) in varied settings. The 74 CHCs in Ontario are established in urban, rural, and northern communities, providing services to populations with a higher risk of developing health problems such as low-income individuals, newcomers and immigrants, seniors, youth, homeless people, and Aboriginal populations (Ontario Community Health Centres, 2008). The CHCs selected for inclusion (Table 1) were chosen based on our interest in representing important variations in the following characteristics: geographical representation (i.e., selecting CHCs in urban and rural areas), and community representation (i.e., selecting CHCs that serve different types of marginalized populations, such as immigrants, newcomers, seniors, people with mental health and addiction problems). In order to select CHC case-study sites, we used information obtained from

Ontario CHC websites (e.g., demographic profile of the populations served, priority populations of each CHC, community participation mandates, values or principles for engaging marginalized populations).

A *second level of sampling* involved the selection of one community participation initiative from each CHC site, which provided opportunities to bring marginalized populations together in the planning of and decision-making about health services and/or programs. Selection of the initiatives was informed by a review of internal CHC documents and in consultation with a key contact person from each CHC site. These initiatives were also selected in order to maximize the differences according to the marginalized populations(s) engaged and the various techniques and methods that were used.

Description of the cases (Table 2)

The first case describes participation with Low-German Speaking Mennonites (LGSM) in a rural town, to identify culturally appropriate primary health care services that address the low-birth weights of infants in this population (The Gesundheit Fur Kinder Prenatal and Well Child Program, Woolwich CHC). The second case describes the participation of newcomer immigrants and refugees in an inner-city area in capacity-building initiatives that address mental stress from migration (Expressive Arts Program, Access Alliance Multicultural Health Centre). The third case describes the participation of socially isolated immigrant and francophone seniors in an inner-city area in capacity-building initiatives and in the planning of and decision-making about health services (Senior's Wrap Around Program, London InterCommunity Health Centre). Lastly, the

fourth case describes the participation of immigrant and refugee women in an inner-city area who experience physical and verbal partner abuse through partnership strategies that bring these women together to build social networks, raise awareness of the issue of abuse, and mobilize resources for implementing the appropriate health and social support services for them (Neighbours, Friends, and Family Campaign initiative, Hamilton Urban Core CHC).

Data Collection

Data were collected from three sources to promote an in-depth understanding of our phenomenon of interest, and to ensure analytical rigor (Creswell, 2007; Yin, 2009). Key informant interviews and document analysis (e.g., organizational documents and reports and surveys of community assessments) were used as principal sources of evidence, while direct observations were used in a complementary manner through field visits to the CHCs. A contact person was identified at each CHC site who assisted with the identification and recruitment of study participants.

Key Informant Interviews

A total of 32 invitations were sent to potential key informants—staff working in the four case study CHC sites—deliberately selected to obtain different perspectives on the subject of participation with marginalized populations in local health service planning (i.e., those who have experience working in the community, and manage, organize, or facilitate the participation initiatives). In this sampling strategy, *"the inquirer selects individuals and sites for the study because they can purposefully inform an understanding of the research problem and central phenomenon in the study."* (Creswell, 2007, p. 125)

Twenty-eight in-person interviews were conducted between November 2011 and February 2012. Interviews were conducted in English and audio recorded. Interview transcripts and audio files were stored on a password-protected computer. The interview guide included questions about how CHC staff members define community participation with marginalized populations, the community participation initiative with marginalized populations (e.g., the approach and methods employed by the CHC), the barriers to engaging marginalized populations in the community participation initiatives, and the strategies that were employed to enable their participation (see interview guide in Appendix 2).

Document Analysis

A descriptive qualitative document analysis (Bowen, 2009) of publicly available and internal documents from each CHC was carried out to gather relevant information on the organizational structures of each CHC site, and to corroborate information from key informant interviews on the community participation initiatives. The two categories of documents reviewed included: (1) documents providing information about the organizational structures of each CHC site (e.g., delivering and funding of health services and programs, priority populations served, community needs assessment reports, values and mission statements, and service accountability statements); and (2) documents providing information about the community participation initiatives that were selected. Documents pertaining to the organizational structure of CHCs were initially identified through CHC websites. The principal investigator (SM) then consulted with key contacts from each CHC to identify relevant internal documents.

Direct Observations

One to two site visits with each CHC were conducted prior to carrying out the interviews to learn more about the CHCs day-to-day operations. Observation notes were produced during these visits.

Ethical Considerations

This study was approved by the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board (HHS/FHS REB) of McMaster University. At the beginning of each key informant interview, participants were informed of the study's purpose, the expected contributions of participants, and the expected outcomes of the study. Participants were then asked to read and sign a consent form that outlined their role in the study and granted permission to the researchers to use their responses without individual identification in publications. Individuals had the option to stop their participation at any time during the interview. They were assured that their identity would not be released at any stage.

Data Management and Analysis

The analysis of key informant interviews was carried out with the qualitative data analysis software, QSR NVivo 10, to facilitate data management and to enhance the systematic organization and examination of the data. Each interview was transcribed verbatim and electronically coded through line-by-line analysis by the primary investigator (Corbin & Strauss, 2008). Key informant interview transcripts were analyzed in NVivo for similarities, differences, and relationships. The principal investigator and a

second member of the research team read through a subset of the transcripts to generate a set of preliminary themes. Constant comparative analysis was conducted using an iterative process to identify major themes and concepts that are both descriptive themes (coding text directly from transcripts) and interpretive themes (grouping similar descriptive codes together to identify themes) (Creswell, 2007; Corbin & Strauss, 2008). This process involved moving backwards and forwards between transcripts, memos, notes, and the documents, and comparing themes across the interview transcripts (Creswell, 2007; Corbin & Strauss, 2008).

Documents describing the community participation initiatives were analyzed using open-coding to search for general themes about participation approaches and methods with marginalized populations. The process involved reading through the documents and recording any patterns in these texts in the form of memos or notes in the margins of the documents (Bowen, 2009; Patton, 2002). Following each site visit, the principal investigator developed a one-page summary of key characteristics of each site (e.g., health services and programs provided, priority populations or clientele served, composition of staff and providers, etc.). Written debriefings were also conducted for the full research team to review.

A cross-case analysis compared the data collected from the four cases to achieve two purposes. The first purpose was to explore how CHC staff conceptualize community participation with marginalized populations, and the second was to describe and compare four community participation initiatives with respect to their approaches and methods for involving different marginalized populations.

Findings

Our findings are organized around the following three themes which emerged from our analysis: 1) the multiple layers of barriers that influence the participation of marginalized populations; 2) the approaches taken by CHCs to remove these barriers; and 3) the specific strategies and methods employed in the participation initiatives to enable the participation of the different marginalized populations.

Marginalization as a generic barrier to participation

When asked to define community participation with marginalized populations, key informants described it, first and foremost, in relation to the barriers posed by marginalization itself (Table 3). Regardless of how the marginality arises, informants described these populations as sharing similar experiences with social and economic exclusion. The result of this is described below:

> *[They] have relatively little control over their lives and the resources available to them; they may become stigmatized and are often at the receiving end of negative public attitudes.* (Key informant, Hamilton Urban Core CHC)

Marginalization was further described as limiting the opportunities for skill building which, in turn, has a negative influence on self-esteem and confidence and poses further barriers to participation, as depicted below:

> *A big challenge with engaging marginalized communities is that they are socially isolated, they're depressed, they don't care, they're disheartened, they're disappointed, and they don't believe change is possible. They simply do not have the luxury to participate because of their life circumstances, or the belief to envision how [their] life would look for them in 4, 5, 6, or 10 years [from now] because their realities are much bigger.* (Key informant, London InterCommunity Health Centre)

The challenges these barriers pose to recruiting and retaining the involvement of marginalized populations in community participation initiatives were also described.

> *You can have a focus group for instance, and people, I'm referring to general citizens, might show up. But, marginalized people will not just show up. You need to make sure they come.* (Key informant, London InterCommunity Health Centre)

Another key informant talked about "a loss of trust" as a challenge to recruiting marginalized populations. Distrust and skepticism towards community participation initiatives, in general, were shaped by their past experience with being excluded from political or community decision making.

> *We have to take the time to build their trust in us…[and] let them know we mean well…[then] they will open up to us…we need to ask what [participation] means to them, keeping in mind that these are people who have a history of exclusion from politics and community… and they want to know if it's beneficial and worth their time…sometimes we get asked by the community what they will get out of [participating*]… (Key Informant, Access Alliance Multicultural Health Centre)

The experience with marginalization, therefore, influences the participation of marginalized populations, and poses challenges for CHCs to engage with them. The social and economic circumstances of marginalized individuals can cause them to lose their confidence to express their views or believe that they will be heard.

Barriers related to the social and cultural characteristics of marginalized populations

As key informants discussed the details related to the four community participation initiatives, the specific barriers experienced by marginalized populations were described in a more nuanced way, as an additional layer, related to social and cultural characteristics and personal experiences with marginalization (Table 3).

There were similarities and differences in the barriers described in relation to the social and cultural characteristics of each marginalized population. Illiteracy and English language proficiency barriers were described for newcomers, immigrants, francophone seniors, and the Low-German Speaking Mennonites (LGSM). These communication barriers influenced their self-esteem and contributed to feelings of embarrassment in community participation opportunities. As a result, language barriers were identified as influencing the motivation of these populations to participate. As described by one key informant, the LGSM population "felt shy to expose their illiteracy [and] have had [negative] experiences with [schooling]…" (Key informant, Woolwich CHC).

In addition to generalized communication barriers, gender norms were noted as influencing LGSM women's participation in the Prenatal and Well Child initiative. Informants believed that gender norms of the Mennonite population delineated women to their role as caregivers of their family, which shaped their ability to participate in social and economic activities outside their home. Informants from Hamilton Urban Core described similar influences from gender norms for immigrant and refugee women in the Neighbours, Friends and Family Campaign initiative contributing to self-perceived limitations in their ability to participate in community participation initiatives.

Financial hardship resulting from unemployment was identified as a barrier to participation for newcomer immigrants. One informant explains that newcomers "are living in poverty with little or no income. Because of this, they cannot afford nutritional foods…" (Key informant, Access Alliance Multicultural Health Centre) The effects of unemployment have a significant impact on the physical health and mental well-being of

newcomers. The same informant, further expanding on the difficulties faced by newcomers, says that:

> *If you have to choose between groceries and rent or hydro this [causes] stress for newcomers. They find themselves in these situations regularly so it is no wonder that they are so sick all the time and have poor mental health.* (Key informant, Access Alliance Multicultural Health Centre)

The unemployment of newcomers negatively impacts their self-esteem and their belief that their economic conditions will improve. One informant describes this experience as such:

> *Unemployment is huge for our clients [...] The number of internationally educated immigrants who cannot find work in their field, it's just, that is probably the largest factor that has an impact on people's level of stress, mental health, their self-esteem, who they are, how they feel about having come here, what they think their future holds, their quality of life compared to the quality of life they had back home.* (Key informant, Access Alliance Multicultural Health Centre)

As expected, the mental stress caused by their economic circumstances shapes their motivation to attend community participation initiatives.

Social isolation, resulting from their limited functional capacity related to physical impairment or old age, is a predominant barrier for immigrant and francophone seniors. Informants suggested that the growing numbers of immigrant seniors who are living alone in private homes contributes to their social isolation in the form of limited social connections. One key informant described how they connect socially isolated seniors to health services and programs offered by their CHC:

> *We've gone directly to the seniors, we have a van and we go to where they live. We gather information about what they think, what would they would like to see, ways to improve their access to health services, to the health system, to social services and things like that.* (Key Informant, London InterCommunity Health Centre)

Social isolation among immigrant and francophone seniors in this area has resulted in low social capital and limited autonomy. In addition to social isolation, informants explained that memory loss, as a normal experience with old age, pose further challenges with the capacity of seniors to participate in the Senior's Wrap Around Program.

Addressing the barriers from marginalization through community development

As key informants continued to reflect on the concept of community participation with marginalized populations, their emphasis shifted from describing the barriers arising from marginalization to efforts aimed at addressing them. Fundamental to these efforts is a set of community development principles, which focus on "the relationships formed and the interaction with the community, and building the capacity of marginalized people…" (Key Informant, Hamilton Urban Core CHC) Building the capacities, skills, and knowledge of marginalized populations "increases their confidence to take ownership in planning and decision making for their health care." (Key Informant, London InterCommunity Health Centre) One informant talked about sharing experiences and gaining knowledge as a key element of community development principles: "it's about sharing stories and experiences, and challenging each other on some deeper reflections[…]assessing and expanding our knowledge and [that of] the population engaged." (Key Informant, London InterCommunity Health Centre) These guiding principles were referred to repeatedly throughout the interviews and were also found in the CHC documents where community development was described as "the process of supporting individuals in identifying their health issues, planning and acting upon their strategies for social action, social change, through activities aimed at building their

capacity and skills, and gaining increased self-reliance and decision making power as a result of their activities" (Association of Ontario Health Centres, 2011).

The process of building self-esteem and confidence was described as incremental, often beginning with activities that build relationships and "success around small issues" before moving on to tackle more "deeply rooted" issues.

> *[…] a community's readiness to participate in planning or decision-making processes is influenced by capacity-building and community organizing initiatives that foster relationships and trust with the CHC and foster social capital, self-esteem and confidence.[…][It's about]…[building] success around small issues that enhances their skills and capacity through capacity-building activities such as expressive arts group, exercise classes, or informal social meetings, before they can feel comfortable enough to move on to tackling the more deeply rooted problems of access to services, their social condition, etc. […].* (Key informant, Access Alliance Multicultural Health Centre)

In some situations, members of marginalized populations were able to identify and vocalize the skills and knowledge that would increase their confidence to participate. For example, immigrant and refugee women in the Hamilton Urban Core CHC identified concerns about the management of diabetes:

> *For the Somali women, one of the highest priority issues [for them] was diabetes and so we engaged our primary health care staff to provide outreach services which included a series of education sessions to answer the group's questions about managing diabetes […] The Roma population identified different issues, which [were] access to employment, and a secured income to manage their diets.* (Key informant, Hamilton Urban Core CHC)

Community development principles were also discussed in relation to the capacity-building among CHC staff and providers. The capacity of CHC staff and providers to effectively engage improves as they gain more knowledge of the barriers to participation and the specific social and cultural characteristics of the marginalized population whose participation they are facilitating. This was illustrated in two urban

CHC cases where anti-oppression training is provided for staff members, which "looks at the ways people can experience oppression and marginalization" (Key informant, Hamilton Urban Core CHC). Through this training, staff and providers are to gain a better understanding of how marginalization is experienced for some populations through the creation of hypothetical scenarios where they are asked to imagine themselves as a person in a marginalized category. The goal of the process is to gain better understanding of power dynamics:

> *The main thing to know is that society operates in hierarchies of difference where some people are valued and privileged and others are marginalized. When working with marginalized communities we need to know how to make them feel like valued citizens.* (Key Informant, Hamilton Urban Core CHC)

CHC staff and providers, therefore, described the importance of this training in learning how to be receptive to the social and economic conditions of the marginalized populations. They also talked about the need to "work with" members of the marginalized population to plan and deliver health services to make them feel that their participation is valued and respected. Key informants, however, did not describe any measures taken to assess the outcomes of this training program with respect to improved staff and provider capacity to engage marginalized populations.

Strategies for addressing the social and cultural barriers related to marginalization

As with the responses proposed for addressing marginalization as a generic barrier to participation, key informants also claimed to draw upon community development principles to develop strategies to overcome the more specific social and cultural barriers related to marginalization (Table 4). In table 4, we describe the processes involved in

employing these strategies and their desired outcomes for enabling participation with different marginalized populations. A common strategy used to address these barriers included the training of *peer-leaders or peer-mentors*—terms that were used interchangeably across the initiatives. Peer-leaders/mentors were employed in the Senior's Wrap Around Program (London InterCommunity Health Centre), the Neighbours, Friends and Family Campaign initiative (Hamilton Urban Core CHC), and the Prenatal and Well Child Program (Woolwich CHC). The roles of these facilitators were similar across the initiatives. Peer-leaders/mentors are normally members of the marginalized population and, therefore, provide valuable information to CHCs about the population's demographics, their culture, health problems, and their barriers to participation. They are believed to help to foster CHC relationships with members of the marginalized population. In addition, most peer-leaders/mentors assist CHC staff to deliver capacity-building programs to marginalized populations such as, English language training workshops, and have also been involved in facilitating community meetings with the populations. We describe the involvement of peer-leaders/mentors in each initiative in more detail below.

In the London InterCommunity Health Centre's Senior's Wrap Around Program, seniors who live alone and have limited social networks are matched-up with a peer-mentor, referred to in this initiative as "wrap around facilitators," to receive assistance with accessing health services. Wrap around facilitators are also intended to help facilitate capacity-building with these seniors, and in this process "build trust and rapport with them." (Key informant, London InterCommunity Health Centre) The CHC benefits from

the knowledge of the facilitators that has helped to "bridge connections and relationships with the seniors." (Key Informant, London InterCommunity Health Centre) In the design of these programs, it is expected that the wrap around facilitator also improve his or her own capacities and leadership skills from volunteering as a facilitator.

For the Hamilton Urban Core CHC's Neighbours, Friends and Family Campaign initiative, Roma women were employed as peer-leaders to strengthen their capacity and develop skills to enable their involvement in the planning for and decision making about their health. The training of these women involved "familiarizing them with the concept of social support and what a social support system entails…[and they were] taught appropriate self-help skills, communication skills, [and] how to listen and facilitate group discussion" (Key informant, Hamilton Urban Core CHC). Furthermore, the peer-leaders helped to

> *…bridge immigrant and refugee women in the community [with] the health center and other systems in the community… [and] foster leadership [which in turn can] play a tremendous role in providing support for staff to actually be able to do their work in a positive way[…]* (Key informant, Hamilton Urban Core CHC).

Similar to the peer-leaders in the Neighbours, Friends and Family Campaign initiative, the Prenatal and Well-Child Program trained LGSM women as peer-nutrition workers. The LGSM women provided CHC staff and providers with valuable knowledge about health behaviors and practices of the LGSM population. In their role, the women gained leadership skills and improved self-confidence to take ownership in the planning and decision making for their health care and were able to share their knowledge about prenatal and child health with their family.

Multiple stakeholder *partnerships* were another strategy used to address the social and cultural barriers of marginalized populations. These CHC partnerships involved a process of sharing resources and knowledge with other experienced organizations, community groups, and health professionals, along with the local knowledge and experience of marginalized populations. Partnerships were described to involve "service providers from other agencies to help [CHCs] understand their client's needs and build CHC capacity to engage, by sharing knowledge and resources, and [promote] the collaborative planning of community development programs" (Key Informant, London InterCommunity CHC). Some informants described that the escalating complexity of societal problems and health concerns for marginalized populations cannot be addressed by one health service organization alone, and these partnerships were valued for their knowledge, skills and resources that they contributed to tackling some of these issues.

From approaches to methods

In contrast to the emphasis placed on describing the barriers to participation and the strategies used to address them, key informants provided much less detail about the specific methods used to engage marginalized populations. Focus groups were described as the principal method used in three initiatives: 1) for the planning and decision-making about health services for immigrant and francophone seniors (Senior's Wrap Around Program, London InterCommunity Health Centre); 2) to discuss immigrant and refugee experiences with physical and verbal partner abuse and relevant health and social services (Neighbours, Friends and Family Campaign initiative, Hamilton Urban Core CHC); and 3) to discuss newcomers' mental health

and stress from migration and the appropriate health and social services (Expressive Arts Program, Access Alliance Multicultural Health Centre). Respondents reported that the informal and unstructured dialogue used in focus groups allowed marginalized populations to draw on their own capacities and knowledge to define the health issue(s) and "talk about what barriers they've experienced with their health and the health care system" (Key informant, Access Alliance Multicultural Health Centre). Culturally relevant knowledge was also gained through focus groups with immigrant and refugee women, who defined physical abuse according to their experience with it:

> *For immigrant and refugee women to come together and talk about women's abuse and contribute to decision making on the solutions that are required, we want to know what they think about women's abuse. How it is addressed in their home country? What are some of the challenges and barriers to seeking help and accessing health services? What they think are the solutions to address abuse? What are the conversations that the community, the CHC, and other agencies [those working with immigrant and refugee populations] should be having? What are the things that the community, agencies or the CHC are unaware of?* (Key informant, Hamilton Urban Core CHC)

Informants identified two specific features that were used to elicit discussion within the focus groups for the Senior's Wrap Around Program and the Neighbours, Friends and Family Campaign initiative. These included café style tables and storytelling conversations, which created a comfortable environment for immigrant refugee women to share difficult and painful stories with abuse and for seniors to improve their health literacy and build social relationships with other people.

Issue-oriented committees were used alongside focus groups in two community participation initiatives, the Senior's Wrap Around program and the Neighbours, Friends and Family Campaign initiative. These committees were facilitated by the marginalized

population and involved collaborations with other health and community-based service organizations to develop a common understanding of the issue at hand, the factors contributing to it, and possible solutions to address it. An example of this process in the Senior's Wrap Around Program was the formation of the Council of London Seniors that brought seniors together on an ongoing basis to share their experiences of social isolation, resources and knowledge with CHC service providers and experienced staff from other service organizations in the community. The Neighbours, Friends and Family Campaign initiative also involved a committee that was driven by the leadership of immigrant and refugee women. These women were instrumental in establishing partnerships with several local community agencies such as the Sexual Assault Centre of Hamilton, Immigrant Women's Centre, Good Shepherd Women's Services, and various community leaders representing immigrant and refugee communities in Hamilton, to share their experience and develop a common understanding of the problem of partner abuse and the appropriate health and support services for immigrant and refugee women.

In discussing their rationale for selecting the methods used in the community participation initiatives, informants described a trial by practice approach to "see what works" rather than decisions informed by prior assessment of methods. Key informants explained that changes in cultural values and beliefs, gender roles, and social relationships within marginalized populations made it difficult to know early on which method to use. This practice was illustrated in the Neighbours, Friends and Family Campaign initiative's engagement of immigrant and refugee women:

> *[…] We continue going through the community development cycle, or process. Sometimes, instead of assessing upfront the cycle [of community development], we*

> *just do it, and observe who comes to participate […]It's okay to kind of play around [with different methods of participation]. The difference, though, is that at that point we're already embedded into the community in a number of ways […] When you've been there, like we have, for a number of years, you begin doing it a little differently. But, we just kind of play around and see what works, what doesn't and what fits […]* (Key informant, Hamilton Urban Core CHC)

Choosing a method for participation, therefore, is not always straightforward. Key informants described that the methods they used to engage marginalized populations were shaped by their experience, by trying out different methods with different marginalized populations. CHC staff and provider uncertainty about the appropriate participation methods to use to engage marginalized populations may explain their limited focus on evaluating their community participation initiatives and, hence, their focus on reaching "desired outcomes" instead of actual or proximate outcomes from the initiatives. The limited focus on evaluation is likely also explained by their emphasis on broader strategies for addressing the barriers to participation for marginalized populations, rather than the specific methods for engaging them.

Challenges to the community development approach

In general, our key informants viewed the community development approach and related strategies for addressing the barriers to participation for marginalized populations very favourably. Some barriers, however, do not seem amenable to being addressed by the community development approach. For the LGSM population, for example, their cultural values and beliefs appear to have shaped their values towards participation. More specifically, their particular constructions of illness and prevention (i.e., beliefs of illness or disease causation and the remedies or practices for health protection), which are shaped by their cultural and religious beliefs were felt to influence their decision to participate in

the planning and decision making for health services. One key informant describes how the cultural values of LGSM's shaped preventative health practices among this population:

> *The idea of preventative health practices among our Mennonite clients is not part of their notion of health[…] self-management of their own health is not a practice that is of value to them. So for example, thinking about the low German speaking Mennonite population, the concept of eating healthy when you are pregnant because it will make sure that your baby is healthy is not something they value or practice…*(Key informant, Woolwich CHC)

The LGSM's lack of involvement in community participation initiatives is also believed to be influenced by their values towards education, which are portrayed as a "hesitation [among the LGSM] to become too worldly […] It is common for children of the [LGSM] to only complete up to grade eight schooling" (Key informant, Woolwich CHC). Another key informant explains that the low education among the Mennonite population relates to their world views and belief system: "their whole value system does have an impact on whether or not it is important to them to be educated or to self-educate. It determines how they value education. It determines how they value, even self-management of their own health" (Key informant, Woolwich CHC). Additionally, in the LGSM population, gender norms have prevented LGSM women from participating in formal education and other types of knowledge seeking opportunities. This gender hierarchy was described as inhibiting the participation of LGSM women in both capacity-building activities and in the planning and decision-making of programs and services.

Discussion

Our findings highlight several key messages regarding community participation with marginalized populations. First, our results demonstrate that engaging marginalized populations involves addressing several layers of barriers related to marginalization and the associated social and cultural characteristics of marginalized populations. CHCs and health service organizations seeking to involve marginalized populations in the planning of and decision making about health services need to acknowledge and attend to these barriers at an early stage in the design of community participation initiatives. For instance, anti-oppression training for staff and providers in the Neighbours, Friends and Family Campaign initiative helped them to better understand the experiences of marginalization for immigrant and refugee women, and to establish a meaningful relationship with this population that values their views and opinions. Other scholars have argued for the benefits of training staff and providers to enhance their capacity in facilitating participatory initiatives with local populations (Pickin, Popay, Staley, Bruce, Jones, Gowman, 2002; Zapata, 2009).

Second, our findings offer a more nuanced view of how community development principles might be used to address the barriers to participation for marginalized populations and the circumstances under which they may be more or less suitable. For example, for several of the community participation initiatives examined, community development principles shaped the strategies that were used to address the barriers to participation for marginalized populations such as, capacity-building, employing peer-mentors or leaders, and establishing partnerships with the marginalized population and

organizations across the health sector. While these strategies enabled the participation of most marginalized populations involved in the community participation initiatives examined, a notable exception was the LGSM population, whose cultural values and beliefs—that shape their cultural construction and understanding of health and illness, values towards education, and gender norms for women—appear to be at odds with community development principles.

Our findings challenge one of the principles of community development, which suggests that if the capacity and skills of marginalized populations are improved, then the barriers to community participation in health services planning and decision-making are more likely to be effectively addressed. Implicit in these principles is that there is an underlying willingness to participate but that there is a specific capacity or skill that impedes participation. Our findings suggest that willingness to participate may be motivated by cultural values and beliefs towards health promotion, disease causation and treatment, gender roles and views towards education, which may resist efforts to enable certain populations to contribute to health services planning and decision-making. These findings are consistent with current research examining the motivations of those who take part in participation initiatives (Barnes, Harrison & Murray, 2012; Barnes, Newman, Knops & Sullivan, 2003; Gould, 2007). Among the factors that have been identified in the literature to influence the decision of individuals to participate (or not) include: a commitment to a specific ethnic or cultural group (Barnes et al., 2003); commitments to a set of values (Harwood, 2005); personal experiences of marginalization, disadvantage or

oppression (Campbell & McLean, 2002); and the design of a participatory initiative (Barnes et al., 2012).

Third, our findings revealed similarities in the methods used to engage marginalized populations across our four cases, which were, in turn, shaped by the principles of community development. The two dominant methods of participation were focus groups and issue-based committees. Marginalized populations relied on their own experiences and capacities to identify health issues and the actions to resolve them. The unstructured and informal dialogue that is used in focus groups supported that sharing of personal stories among group members. Special efforts were made in two engagement processes (Senior's Wrap Around program and the Neighbours, Friends and Family Campaign initiative) to create a safe and comfortable environment for them to talk about difficult and sensitive health issues and strengthen capacities and relationships. For example, café meeting tables were used to help women in the Neighbours, Friends and Family Campaign initiative feel comfortable with sharing their personal stories about physical and verbal abuse in this informal setting. Several scholars including Young (1996), Dryzek (2000), and Williams, Labonte & O'Brien (2003) have promoted the benefits of storytelling as an appropriate form of communication within a public participation process involving marginalized populations. Through storytelling, people may discover new self-perceptions and strengths, express their frustrations, and build trust and connection with other people (Young, 1996; Labonte & O'Brien, 2003)

Our findings highlight a fourth key message related to the absence of evaluation efforts employed by CHCs to assess the effectiveness of the participation approaches,

strategies and methods they are using. This dearth of activity appears to be related to the 'trial by practice' approach described by key informants for engaging marginalized populations. Staff and providers focused their attention on the broader strategies for addressing the barriers to participation for marginalized populations, rather than focusing on the specific methods used to engage them informed by rigorous evaluation. Key informants talked in particular about the challenges of knowing which methods were suitable for particular marginalized populations because of the changes in cultural values and beliefs, gender roles and social relationships of these populations. Another challenge with evaluating community participation initiatives might relate to the different meanings ascribed to community development principles by different marginalized populations. For instance, applying community development principles to strategies for engaging newcomers means addressing language and unemployment barriers, and engaging seniors means addressing the barriers related to their social isolation. However, despite the social and cultural differences among marginalized populations, a similar method (e.g., focus groups) was used to engage them. This suggests that there may be common features in the methods and engagement process that are applicable to the design of community participation initiatives for a wide range of marginalized populations.

Our findings suggest a number of opportunities for future research initiatives. First, further research is needed to isolate the key influences that the community development approach to participation has had in enabling the participation of marginalized populations and on changes to health service delivery or policy for these populations. Second, in light of our findings on the barriers to participation for marginalized

populations, there is a need for further contextualized analysis of the motivations and willingness of marginalized populations to participate. Our findings demonstrate that creating opportunities to involve marginalized populations does not necessarily mean they will decide to participate. Distinctions, therefore, need to be made about how and on what basis different marginalized people engage. Third, there is the need for evaluation of the strategies and participation methods used by CHCs to delineate which strategies and methods are appropriate for different marginalized populations and in different contexts.

Our findings have deepened our understanding of community participation with marginalized populations by documenting the barriers to participation for marginalized populations, the strategies that support and enable their participation, and by identifying the core features of generic participation methods that are used to engage different marginalized populations. This enriched understanding has the potential to strengthen the capacity of CHCs and other health service organizations to evaluate community participation initiatives with these populations.

Despite the significant insights yielded from this study, our findings should be considered within the limitation of the study's methodology, which relied on the views of CHC staff and providers as an indirect source of information about how community development principles were used to address the barriers to participation for different marginalized populations, and how these principles enabled their participation. Further investigation is needed into how the community development approach to participation is perceived by those whom it is intended to engage.

Conclusion

CHCs seek to address the barriers to marginalized populations' participation by emphasizing a community development approach to participation, which aims to strengthen the community's capacity for ownership in the planning and decision-making for health services and programs. This approach has not been systematically evaluated to assess whether the methods employed in their participation initiatives have been effective in eliminating barriers to participation that marginalized individual's experience. The similarities revealed through our findings in the approaches and methods used provide a unique opportunity to evaluate participation initiatives with marginalized populations.

The emphasis placed on community development principles to enable the participation of marginalized populations assumes an underlying willingness to participate among all marginalized populations. The impediments to participation that relate to cultural values and beliefs suggest that there may be different levels of willingness to participate among different marginalized populations. Given these findings, the claims made for community development, as the one-size-fits-all approach to enabling community participation with marginalized populations, should be re-considered in the context of a population's values towards participating in the planning for and decision making about their health care. The challenge for community development is to be able to both enable marginalized populations to have a voice and influence, and help provide whatever support is needed – capacity-building, self-esteem, building relationships–while also acknowledging the different underlying values that marginalized populations hold towards participation in health service planning and decision making.

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Appendix 1: Tables

Table 1: CHC Demographic Profiles

Groups	Woolwich CHC	Access Alliance Multicultural Health Centre	London InterCommunity Health Centre	Hamilton Urban Core CHC
Geographic representation	Rural area (Southwestern Ontario)	Inner city (Southern Ontario)	Inner city (Southwestern Ontario)	Inner city (Southwestern Ontario)
Community representation (marginalized populations served by the CHC)	Mennonite farming population There are two townships in the region: Woolwich township and Wellesley township. Woolwich is predominately older Mennonite seniors. Wellesley has a younger Mennonite population. There are three types of Mennonite groups that reside in both townships: Old order Mennonites, Dave Martin Mennonites (reformed group), and Low-German Speaking Mennonites (LGSM).	Immigrants and refugees; and lesbian, gay, bi-sexual, transvestites and queer (LGBTQ) people of all ages.	Newcomers and immigrants; homeless individuals; individuals with mental health and addiction problems, First Nations population; and francophone population. Within these populations there is a higher proportion of seniors.	Immigrants and refugees (mainly Roma Refugees from Czech Republic); homeless and street youth; and individuals with mental health and addiction problems.

Table 2: Community participation initiatives within CHC cases

	The Gesundheit Fur Kinder Prenatal and Well Child Program at Woolwich CHC	Expressive Arts for Newcomers and Immigrants at Access Alliance Multicultural Health Centre	The Senior's Wrap Around Program for Immigrant and francophone Seniors at London InterCommunity Health Centre	Neighbours, friends, and family Campaign (NFF) at Hamilton Urban Core CHC
Marginalized population	Low-German Speaking Mennonites (LGSM) from Woolwich Township	Newcomer Immigrants and refugees	Immigrant and francophone seniors	Immigrant and refugee women
Background/ Program description	**Problem identification:** low birth-weight infants in LGSM community **Contributors to the problem:** low education and health literacy levels, language barriers, social isolation and transportation barriers to health services. **Impetus of program:** community partner concerns about health and well-being of infants in LGSM population. **Program goals:** to deliver culturally appropriate primary care services to serve the LGSM community (sponsored by Public Health Agency of Canada (PHAC) and Woolwich Community Health Centre.	**Problem identification:** high mental stress and anxiety among newcomer immigrants and refugees associated with settlement in a new environment. **Contributors to the problem:** immigration **Impetus of program:** newcomers expressed barriers to accessing health services and programs and the challenges with navigating a new health system **Program goals:** overcome limitations of linguistic, cultural and social boundaries through expressive arts (e.g., visual art, movement, sculpture, sound and poetry); empower individuals in a creative environment that is inclusive of participants' life experiences, through a program underscored by an anti-oppressive framework; and build a social support system based on shared experiences.	**Problem identification**: the program supports immigrant and francophone individuals, aged 55 and older, who are living in private homes but have few community or social supports **that** leave them isolated and at higher risk of hospitalization or long-term care placement. **Contributors to the problem:** social isolation of older adults **Impetus of program:** The London InterCommunity Health joined various agencies, organizations and service providers to organize the Age Friendly Task Force in support of World Health Organization Global Network of Age Friendly Cities. **Program goals:** The Senior's Wrap Around Program was implemented to assist immigrant seniors aged 55 and older, to receive care in the home as long as possible by facilitating the creation of a support team around them.	**Problem identification:** women's abuse was identified as a health concern among newcomer and immigrant refugee patients at Hamilton Urban Core. **Contributors to the problem:** for women, health is often linked to a host of other social and economic pressures including gender-related oppression and abuse. **Program goals:** NFF Campaign is an ongoing campaign to raise awareness of the warning signs of woman abuse identify and understand the cause of woman abuse, and the strategies for addressing the problem.
Purpose of the community participation initiative	To engage LGSM community members in discussions about the problem and potential solutions.	To encourage newcomers to express feelings about their migration experiences through the use of art, which promotes stress-reduction, relaxation, empowerment, and mental health and well-being. Also, to facilitate social interaction through art.	There are three objectives of this initiative: (1) To improve access to health services and programs for immigrant seniors through social networks and support among seniors and other community members in the community; (2) to encourage older adults to participate in decision-making for their health by involving them in the design of programs and services that will benefit them; and (3) improve older adults access to and experience with the health care system.	To engage community members, leaders and representatives from diverse communities and agencies serving women and their families in Hamilton in a collaborative effort to raise awareness about abuse among immigrant and refugee women, and respond to the needs of these women by involving them in the planning of services and resources such as a women's shelter, and a referral system to health and social services.

Table 3: Barriers related to marginalization and the social and cultural characteristics of marginalized populations in the CHC cases

	Low-German Speaking Mennonites (LGSM) from Woolwich Township	Newcomer Immigrants and refugees from Access Alliance Multicultural Health Centre	Immigrant and francophone Seniors at London InterCommunity Health Centre	Immigrant and Refugee women at Hamilton Urban Core CHC
Examples of barriers related to marginalization	– A lack of public transportation in the region, and resistance of LGSM to use any forms of technology including automobiles – Disperse living in remote and rural environments	– Lack of time resulting from working two or more jobs to afford basic necessities – Stress from adapting to a new environment from migration – Loss of trust in social and economic systems to support their needs	– Loss of trust in social and economic systems to support their needs – Exclusion from the social and economic system	– Exclusion from social and economic systems – Lack of available health and social services targeted to their needs
Barriers related to social and cultural characteristics of each marginalized population	– Cultural perceptions of health and illness – Values towards education – Gender norms that prevent women's mobility and interactions outside the home – Low literacy rate and lack of proficiency in English language	– Financial hardship from unemployment – Lack of proficiency in English language	– Social isolation – Lack of proficiency in English language for francophone seniors – Memory loss among the elderly	– Lack of proficiency in English language – Cultural and gender norms that prevent women's mobility and interactions outside the home

Table 4: Strategies for addressing the barriers through community development principles

	The Prenatal and Well Child Program at Woolwich CHC		Expressive Arts for Newcomers and Immigrants at Access Alliance Multicultural Health Centre		The Wrap Around Program for Immigrant and francophone Seniors at London InterCommunity Health Centre		Neighbours, /friends, and Family Campaign (NFF) at Hamilton Urban Core CHC	
Strategies for addressing the social and cultural barriers to participat-ion	**a) Employing and mentoring peer leaders**	**Process** a) Community volunteers are trained as peer-nutrition leaders who were responsible for facilitating outreach to the LGSM population b) They provide cultural and language interpretation at community dialogues and meetings c) Promote the shared knowledge on best practices for parental care and child/infant health and well-being with LGSM families **Desired Outcome** a) To bridge and connect Woolwich CHC and the LGSM population b) To increase capacity for and learning about health impacts; and c) Strengthen social support networks among Mennonite populations to: i) achieve mutual agreement on issues and collectively identify appropriate services and supports; ii) to reduce social isolation within this group; iii) to involve women from LGSM families outside their traditional roles as peer nutrition workers in a position of decision making and responsibility	**a) Partnerships with community groups and agencies who are assisting newcomer immigrant and refugees**	**Process** Multi-stakeholder partnerships were established with seven community-based organizations to provide support in the form of space to hold meetings, and share knowledge and resources **Desired Outcome** a) To foster relationships and trust with newcomers and immigrants, increase social capital, self-esteem and confidence b) Promote organizational capacity-building c) To share knowledge and experiences d) To provide financial support to facilitate engagement initiatives	**a) Training of Wrap Around facilitators, who are peer-leaders**	**Process** Seniors are matched-up with a Wrap Around facilitator to assist them in navigating the health system. The facilitator is someone with local knowledge who is able to bridge the connection between immigrant seniors and the CHC **Desired Outcome** a) To promote the skills, knowledge and leadership capacity of facilitators by volunteering in their community; b) To increase the skills and strengthened social relationships among seniors in their community; and c) To increase senior's knowledge about the health system and how to navigate services, with the help of their wrap around facilitator, and in turn ownership over decision-making for their health and improved self-autonomy	**a) Employing and mentoring cultural facilitators**	**Process** a) To facilitate outreach; b) To implement and facilitate educational forums, community meetings, special events and community specific activities **Desired Outcome** a) To bring immigrant and refugee women together in open dialogue to share stories and experiences; b) To build social relationships and networks among the group
	b) Partnerships with external groups	**Process** Partnerships are established with external community-based agencies such as the Mennonite Central Committee's St. Jacob's Family Support Centre, who assisted with capacity-building efforts and outreach with the LGSM population **Desired Outcome** a) To mobilize knowledge and share resources; and b) To ensure long-term sustainability of the program		**Process** Not applicable **Desired Outcome** Not applicable	**b) Multi-stakeholder partnerships**	**Process** Multi-stakeholder partnerships are established with community-based organizations for planning community development and health programs for immigrant seniors **Desired Outcome** a) To provide financial support to initiate the program b) To share knowledge among partners	**b) Partnership and collaboration with local community agencies**	**Process** Multi-stakeholder partnerships are established with community-based service organizations and immigrant and refugee women **Desired Outcome** To establish relationships with immigrant and refugee population

Appendix 2: Key Informant Interview Guide

1. How would you define community participation?

2. What do you think are important factors influencing the health of the marginalized community you serve? (Probe: has there been engagement of the community on addressing the particular health challenges the community face?)

3. What are the goals and objectives of your CHC surrounding community participation in local health system planning?

4. What are the values and guiding principles towards a community participation adhered to by your CHC?

5. Describe some examples of community participation initiatives by your CHC on local health system decision making. What were the outcomes or benefits of the initiative (to your CHC and the community)? What was the extent of their involvement? (e.g., planning or decision-making for health services?)

6. Describe _____ community participation initiative at your CHC. What were the goals or purpose of this initiative?

7. Which marginalized group(s) were engaged in this participation initiative? Do you follow selection criteria for who should be involved? Is your selection broad and diverse, with the aim to include varying marginalized groups?

8. What are the approaches or methods that your CHC has used to involve the community in this community participation initiative, particularly marginalized groups, in CHC decision-making on health services? (e.g. consultation, focus groups, collaborative decision-making, partnerships, deliberation). In your opinion, what approach or method of engagement is more effective to ensuring meaningful participation that involve equal contribution of different stakeholders involved and sustainable outcomes?

9. When was community participation sought in the decision-making process? (e.g. at the beginning or end of the decision-making process?) Describe.

10. Describe how community values have been incorporated into your CHC planning and development of health care services and/or programs.

11. What are some of the challenges or barriers that your CHC has faced in facilitating the community participation initiative you described with marginalized populations?

12. In your opinion, does the community you serve want to be involved in local health care decision making? If not, why do you think this might this be the case?

Chapter 4:

The value of frameworks as knowledge translation mechanisms to guide community participation practice in Ontario CHCs

Abstract

The community participation literature has produced numerous frameworks to guide practice and evaluation. Frameworks are one type of resource that can be useful for transferring and sharing knowledge about community participation processes among health service providers and staff within and across health service organizations. These frameworks are useful starting points for differentiating the approaches for involving people in the planning and decision-making for health services but have been critiqued for being too generic and ignoring that community participation is highly contextual and situational. Regional and local health service organizations across Canada and internationally have begun to respond to address this limitation by developing more context-specific community participation frameworks; however, such frameworks do not exist for Ontario Community Health Centres (CHCs)—local primary health care organizations with a mandate to engage marginalized groups in the planning and decision-making for health services and programs. We conducted a series of focus groups with staff members from four Ontario CHCs to (1) to examine the factors that would influence their use of a generic framework for community participation with marginalized populations; and (2) to improve the "context-specificity" of this framework, to enhance its relevance to CHCs. The role of

frameworks as mechanisms for knowledge translation about community participation practice with marginalized populations in CHCs was also explored. Focus groups discussions revealed that tacit knowledge, in the form of professional and personal experience and community contextualized knowledge, had a greater influence on guiding participation activities in Ontario CHCs than frameworks informed by research evidence. Reluctance to use community participation frameworks was also shaped by a heavy reliance on the community development approach and its emphasis on organizations' facilitative role in community participation processes and the ownership of marginalized populations in the planning and decision-making for their health care. Despite their views regarding the limited utility of community participation frameworks, focus group participants described several useful applications for such a framework within their organizations including the potential for elements of a generic framework to inform the design a community participation toolkit or guidebook for engaging marginalized populations that could be tailored to each CHC context.

Background and Rationale

Community Health Centres (CHCs) in Ontario are local primary health care organizations that provide highly valued programs and services to marginalized populations. For CHCs, community participation is argued to be at the very core of every program, service, or initiative (Hole, 2010). CHCs are mandated to engage marginalized groups in the planning and decision-making for health services and programs. Most CHCs, however, do not have a framework in place to guide the implementation and evaluation of their community participation initiatives.

The literature on community participation in health service planning and decision making has produced numerous frameworks to guide practice and evaluation. These frameworks are useful starting points for differentiating the approaches and extent of people's involvement in the planning for and decision-making about their health care. Two well-known frameworks frequently cited in the community participation literature include those of Sherry Arnstein (1969) and Susan Rifkin (1986) (see Appendix 1 for illustrations of both frameworks). Despite being several decades old, Arnstein's (1969) ladder of participation still draws considerable attention in the public participation literature. The ladder depicts citizen participation along a continuum. Each level represents a different degree of control that citizens should have in a planning or decision-making process, which dictates the approach that is used. Essentially, the higher the rung on the "ladder," the more that full citizen engagement (i.e., through citizen control) is achieved. Rifkin's typology of community participation has gained popularity in the health promotion and disease prevention fields. Rifkin (1986) characterizes three

approaches that health planners use to define community participation based on different assumptions about the effective ways that decision making can improve a population's health.

Scholars have critiqued both frameworks for being generic and ignoring that community participation is highly contextual and situational (Abelson, 2001; Campbell & McLean, 2002; Cornwall, 2008; Draper, Hewitt & Rifkin, 2010; Kenny et al., 2013; Tritter & McCallum, 2006). Furthermore, the application of these frameworks in different contexts and with different users has demonstrated that the search for a "gold standard" framework for community participation that can be replicated across different contexts is neither realistic nor appropriate (Draper et al., 2010; Rifkin, Muller & Bichmann, 1988; Tritter & McCallum 2006). The limitations in adapting these frameworks to different contexts and populations, pose challenges to practitioners in determining how these initiatives should be designed and the core features that make up a community participation process.

A plethora of community participation frameworks have been developed by health service organizations across Canada and internationally (e.g., regional health authorities and public health units, across Canada, and Local Health Districts in Australia, among others) that contextualize community participation to their specific goals for engagement. In this study, we examine the prospects for CHCs to adopt a community participation framework to guide the implementation of community participation initiatives within their CHC. A draft generic community participation framework was shared with staff members in focus groups from four Ontario CHCs (Appendix 2). Participants were asked

to examine the elements of the draft framework for community participation with marginalized populations to understand the factors that would influence their adopting such a framework. The draft framework was informed by preliminary findings from a systematic review of the community participation literature with a focus on marginalized populations and a multiple case study analysis of CHC community participation initiatives.

The Use of Community Participation Frameworks within Local Health Service Organizations

The *Ottawa Charter for Health Promotion Declaration* in 1986 formally recognized that the design and delivery of health services should incorporate input from populations who are users of the health system (WHO, 1986). Concepts such as empowerment and community development were used in many regional health reform changes to advocate for community-centred health care approaches in the design and delivery of health services (Frankish, Kwan, Ratner, Higgins, & Larsen, 2002). Local health service organizations now play important roles throughout the world, in delivering health services and programs to local populations with their involvement in the planning and decision-making of their health care (Minkler, 1997; Wilson, Lavis, Travers & Rouke, 2010). Moreover, scholarly research has also been influenced by this political commitment towards greater community participation, with a substantial body of literature on the study of community development processes and community participation in health service planning (Minkler, 1997; O'Neill, Lemieux, Groleau, Fortin, & Lamarche, 1997).

To guide health service organizations, health system managers, and community health planners in the design and implementation of their participation strategies, efforts have been made to conceptualize effective engagement based on evidence about participation practice through the development of frameworks of community participation (Arnstein, 1969; Charles & DeMaio, 1993; Rifkin, 1986; Rifkin, 2003; Thurston et al., 2005; Wiebe, MacKean & Thurston, 1998). There is significant variation across these frameworks: some are mere starting points for health service organizations or practitioners (which include a set of basic definitions and principles of community participation, and different levels or types of participation), while others include extensive resources that involve contextual analyses (Abelson, 2001; Draper et al., 2010; Thurston et al., 2005; Levac, 2012).

Regional and local health service organizations across Canada and internationally have developed their own community participation frameworks that are appropriate to their local context, organizational goals and values towards participation, and the population(s) they serve. Some Canadian examples of community participation frameworks developed within the organizational structure of local health service organizations include: the Alberta Health Services Community Engagement Framework, the Vancouver Coastal Health Community Engagement Framework (Vancouver Coastal Health, 2009), the Ontario Local Health Integration Network (LHIN) Community Engagement Frameworks (Ontario Ministry of Health and Long-term Care, 2011), and Waterloo Public Health iEngage initiative (Region of Waterloo Public Health, 2006). The

absence of empirical evaluations of these frameworks, however, has been noted in the research literature (Collaborative Health Innovation Network, 2012).

Frameworks are one type of resource that can be useful for transferring and sharing research evidence about community participation processes among service providers and staff within and across health service organizations. Knowledge translation (KT) is an interactive process of knowledge exchange and application between health researchers and users (Canadian Institutes of Health Research, 2010; Lavis, Ross, McLeod, & Gildiner, 2003). Within service organizations, research evidence is usually translated into the development of professional practice guidelines, toolkits, or evaluation frameworks, for service providers or health system managers (Kothari & Armstrong, 2011).

The limited support, to date, for community participation frameworks as a mechanism for translating knowledge about community participation practices within Ontario CHCs is of particular research interest in this study. An environmental scan of community engagement in governance and strategic planning of Ontario CHCs demonstrated that there is variability in the existence of such frameworks (Hole, 2010). A notable exception was found in one community where the boards of six CHCs have endorsed a particular strategy for community engagement that was first developed by South-East Ottawa CHC as *No Community Left Behind* (NCLB), and which has since been adopted by the City of Ottawa as the cornerstone of its Community Development Framework. The framework brings together residents, service providers, agencies, researchers, and funders to build the capacity of five vulnerable neighbourhoods by

following an engagement process that starts with community mobilization and neighbourhood capacity-building, and extends to the participation of neighbourhood residents in the planning and decision-making for health services (Hole, 2010).

An examination of the factors that influence CHCs use of community participation research to guide their participation initiatives can help to explain the likelihood of their adopting a community participation framework as a mechanism for transferring and sharing research evidence about community participation practice. Evaluation studies of community participation strategies argue that the conceptual ambiguity of the concept of community participation, as well as lack of agreement on the core features of participation processes, pose challenges to using research evidence since there is no consensus on the knowledge to be transferred (Burton, 2004; Cornwall, 2008; Draper et al., 2010; Lasker & Weiss, 2003).

The rationales for and pathways through which research evidence informs the professional practice of staff in health service organizations have been clearly articulated in the knowledge translation literature (Wilson et al., 2010). Organizational studies, in particular, highlight the role of organizational structures, organizational culture, preference for local and tacit knowledge to influence the adoption of research evidence, and the value of local health organizations towards community participation research (Dobrow, Goel, & Upshur, 2004; Dobrow, Goel & Lemieux-Charles & Black, 2006; Lavis, Oxman, Moynihan, & Paulsen, 2008; Kothari et al., 2012; Wilson et al., 2010). Dobrow et al. (2006) examined the role of context in influencing the use or adoption of research evidence, and make the argument for "context-based evidence-based decision

making." (p. 215) The authors argue, "to better understand how evidence-based decisions are, and should be made, further understanding of how context affects the introduction, interpretation and application of evidence is needed" (p. 215). Therefore, the context of an organization influences the adoption and use of research evidence relating to varying skills and expertise of staff and practitioners. Within local or community-based health organizations, then, emphasis is placed on the value of community strengths and the process of working in collaboration with stakeholders in order to achieve an outcome (Kothari & Armstrong, 2011; Wilson et al., 2010). This approach to working in collaboration has implications for traditional understandings of how knowledge translation is related to research dissemination (Kothari & Armstrong, 2011).

One specific type of knowledge - tacit knowledge - has been cited in the research literature as having an influence on the adoption of research by an organization. The term tacit knowledge has been used to describe knowledge that is acquired from practice and experience and has been used interchangeably with related concepts such as procedural knowledge, implicit knowledge, unarticulated knowledge, and practical or experiential knowledge (Abrosini, 2001). McAdam et al. (2007) define tacit knowledge as: "knowledge-in-practice developed from direct experience and action; highly pragmatic and situation specific; subconsciously understood and applied; difficult to articulate; usually shared through interactive conversation and shared experience" (p.46). Such knowledge gained through years of experience in a local context may be promoted in response to limited organizational or staff capacity to assess and apply research (Kothari et al., 2012). Moreover, the emphasis on tacit knowledge within local or community-

based health organizations demonstrates the value of local knowledge. Community-based organizations regularly engage in their own research—needs assessments, capacity/asset mapping, focus groups, and surveys—with target populations to capture this local knowledge (Kothari & Armstrong, 2011). Some CHCs have begun to conduct their own community-based research with the establishment of hired researcher positions within their centres. While "the information from local research efforts is highly valued for its contextual relevance, and is perhaps more likely to be put into action through health programs" (Kothari & Armstrong, 2011, p. 3), further investigation is still needed into the reasons why organizations prefer local knowledge over scholarly research or scientific evidence. We aim to fill this knowledge gap by gaining a better understanding of the use of frameworks as a mechanism for transferring and sharing knowledge about community participation practice applied to marginalized populations to inform community participation initiatives within CHCs in Ontario.

Research Objectives

The objective of this study was to examine the role of frameworks as one mechanism for transferring knowledge about community participation practice with marginalized populations in CHCs. Specifically, the study sought: (1) to examine the factors that would influence the use of a generic framework for community participation with marginalized populations by CHCs; and (2) to improve the "context-specificity" of this framework, to enhance relevance to CHC staff involved in the planning and design of community participation initiatives.

Methods and Data

Study design

Four focus groups were held in four Ontario CHCs as part of a larger comparative case study of community participation initiatives with marginalized populations (Table 1). These focus groups explored the adoption of a community participation framework to aid CHC staff in their implementation of participation initiatives with marginalized populations. The focus groups were convened between June and August 2012. Each group met once with each session lasting approximately 1.5 hours. Focus groups varied in size from five to twelve participants, for a total of 28 participants across four sites. A generic framework including the proposed core elements of a generic community participation approach was developed from a preliminary synthesis of literature, and was presented to participants at each focus group session. The design of the focus group allowed participants to collaboratively discuss and share their views about, and suggest revisions to, the generic framework that was presented to them. Ethics approval of the study was obtained from the McMaster University Health Sciences Research Ethics Board.

Table 1: CHC Demographic Profiles

Groups	Woolwich CHC	Access Alliance Multicultural Health Centre	London InterCommunity Health Centre	Hamilton Urban Core CHC
Geographic representation	Rural area (Southwestern Ontario)	Inner city (Southern Ontario)	Inner city (Southwestern Ontario)	Inner city (Southwestern Ontario)
Community representation (marginalized populations served by the CHC)	Mennonite farming population There are three types of Mennonite groups that reside	Immigrants and refugees; and lesbian, gay, bi-sexual, transvestites and queer (LGBTQ)	Newcomers and immigrants; homeless individuals; individuals with mental health and	Immigrants and refugees (mainly Roma Refugees from Czech Republic);

	in Woolwich township and Wellesley township: Old order Mennonites, Dave Martin Mennonites (reformed group), and Low-German Speaking Mennonites (LGSM).	people of all ages.	addiction problems, First Nations population; and francophone population. Within these populations there is a higher proportion of seniors.	homeless and street youth; and individuals with mental health and addiction problems.

Focus group participant selection and recruitment

The selection and recruitment of focus group participants was guided by our interest in gaining diverse perspectives about and experiences with community participation with marginalized groups. A key contact person was identified at each CHC site to assist with participant selection and recruitment. Prospective participants were selected from a range of positions held within the CHC (see Table 2 below). Invitation letters and consent forms were sent to prospective participants. The number of participants interviewed varied across the focus groups, relating to the number of staff at the CHC who were eligible to be included. The types of positions held by focus group participants at their CHC included:

(i) health promotion workers/peer outreach workers;

(ii) health care providers (e.g., physicians and nurses);

(iii) community planners/managers;

(iv) executive directors of the CHC; and,

(v) members of community board of directors.

Table 2: Focus group participant characteristics

Participants	Woolwich CHC	Access Alliance Multicultural Health Centre	London InterCommunity Health Centre	Hamilton Urban Core CHC
Health promotion workers/peer outreach workers	2	2	6	1
Health care providers	0	2	2	0
Community planners/managers	2	1	4	3
Executive Directors	1	0	0	1
Members of community board of directors	1	0	0	0
Total	**6**	**5**	**12**	**5**

Focus group participant discussion guide

A common set of focus group questions was used to explore staff views about community participation frameworks and the likelihood of adopting such frameworks in the CHC context. The following questions were included:

(1) Do you think this framework reflects the main components and key design features that are essential to involving marginalized communities?

(2) Could this framework be used to guide community participation initiatives within your CHC? What would the barriers be to adopting it? And what are the facilitators to assist with the use of the framework among CHC staff?

(3) What would you change in this framework? Do you think something is missing that explains the design or approach to participation with marginalized communities?

(4) What is the intention of your CHC to use this framework to guide future community participation strategies in local health system planning at your CHC?

Data collection and analysis

The focus groups were facilitated by the lead member of the research team (SM). All focus groups were audio recorded and transcribed verbatim, and extensive notes were also taken to supplement the recorded material. Formatted transcripts were imported into the qualitative software program QSR NVivo (version 10) for analysis. The primary investigator (SM) and one of the co-investigators (JA) read through a subset of the transcripts to generate a set of preliminary themes. We began with a constant comparative analysis that involved an iterative process of moving backwards and forwards between transcripts and memos, coding and analyzing passages (Addison, 1999; Charmaz, 2001; Strauss & Corbin, 1998; Leech & Onwuegbuzie, 2007; Leech & Onwuegbuzie, 2011).

During initial research team discussions about the transcript data, we identified an emerging theme across each of the focus groups that challenged our original research objective (to examine the prospects for CHCs to adopt a community participation framework derived from evidence about participation practice applied to marginalized populations). Instead, we found that CHC staff members did not strongly support the use of a framework to guide their community participation initiatives with marginalized populations. Focus group participants spoke about the limitations of using existing

community participation frameworks derived from evidence about participatory practice to guide their community participatory initiatives within CHCs. This unexpected theme was investigated more fully using a qualitative descriptive analytical approach, which is dynamic and reflexive. Sullivan-Bolyai, Bova, and Harper (2005) explain that the goal of qualitative description is "not thick description (ethnography), theory development (grounded theory) or interpretative meaning of an experience (phenomenology) but a rich description of the experience depicted in easily understood language" (p. 128). The researcher works hard to stay close to the "surface of the data and events" (Sandelowski, 2000, p. 336), where the experience is described from the viewpoint of the participants (Sullivan-Bolyai et al., 2005, p. 128).

Findings

Our findings are organized around five themes that explain the likelihood of CHCs to adopt a community participation framework in guiding how they engage marginalized populations. Our first theme described the contextual nature of engaging marginalized populations which involves a flexible and iterative process of participation. Our second theme described the preference among CHC staff and providers for drawing on tacit knowledge, in the form of their personal and professional experience and knowledge, to guide community participation initiatives with different marginalized populations. Our third theme described the likelihood of CHCs to use a community participation framework relating to the community development approach and its emphasis on their organizations' facilitative role in community participation processes. Our fourth theme described the limitations of generic community participation

frameworks for engaging marginalized populations. Finally, our fifth theme described the value of using frameworks within CHCs despite their opposition towards generic community participation frameworks.

"It all depends": Participants' description of the contextual nature of community participation processes with marginalized populations

When focus group participants were asked to review the generic community participation framework, they disagreed with the portrayal of community participation as a linear process with discrete phases that showed a progression from planning to implementation. Instead, they described the community participation process as context-specific and "depend[ing] on the population engaged and the issue at hand" (Participant, Woolwich CHC). They portrayed community participation initiatives as requiring a flexible process to allow planners or facilitators to "jump in at any point […] enter from different areas at different times, and go back to an earlier phase when an unexpected change happens […]" (Participant, London InterCommunity CHC). When asked about the phases of a community participation process, which include planning, implementation and assessment of outcomes, participants viewed these as "intertwined…[and] requires [staff] to go back to the planning stage after implementing an initiative [to] make changes and reconsider how to engage the population" (Participant, Hamilton Urban Core CHC).

Focus group participants identified barriers that would change the course of a community participation initiative which relate to the social and cultural characteristics of marginalized populations, or events within the political environment that influence the funding of CHC programs or health interventions. One participant explained that it is the

responsibility of CHC staff who facilitate community participation initiatives to become aware of the social and cultural characteristics of the population that is engaged:

> *I think the onus is upon the organization and the people within the organization to do their homework because you might think the people in the disadvantaged community…as a whole but [they are several groups] within the community. So you have to be really cautious and conscious about you know how the community is structured, how the community functions, how the community evolves over time, and all those things […] before you can actually approach the community.* (Participant, Hamilton Urban Core CHC)

Participants, therefore, argued that initiating engagement strategies without the knowledge of a population's characteristics could impede its success.

Participants further portrayed community participation with marginalized populations as a complex process involving multiple components and steps. They reflected on the difficulty of organizing the contextual, multi-faceted and situational process of community participation that they experienced with marginalized populations into a single framework, which led them to question the value of using a generic framework as a resource for CHC staff and providers. One participant used the analogy of a broccoli or cauliflower to express the multi-faceted process of community participation with this type of population:

> *Think about how broccoli and cauliflower are structured. You can see one whole thing in front of you, but it's got distinct parts […] That's what I think about when I think about, in real life, when you are engaging a community. That's what it's like. It's more like broccoli or cauliflower, because you can see the big thing that you're driving to, but there's all these other little things that are part of it too.* (Participant, Woolwich CHC)

The intricate components that reflect the elements of community participation processes that seek to involve marginalized populations demonstrate the difficulties of illustrating this engagement process in a framework.

The role of experiential knowledge

When focus group participants were asked whether they would use a community participation framework to guide their community participation initiatives, they indicated their preference for drawing on past experience (whether professional or personal), knowledgeable staff members, and interactions with members of relevant populations rather than rely solely on frameworks to guide their work. Participants reflected that knowing how to facilitate and manage community participation initiatives is best learned through experience with testing different methods or approaches that were learned from existing research evidence about community participation practice or personal experience with engaging marginalized populations to see what works best. One participant in the same focus group elaborated on their use of experiential knowledge in the following way:

> *...I think we're probably drawing on a whole host of our own education, our own knowledge of different kinds of models for community participation, community-based research, planning, evaluation, whatever, a variety of lived experience. So if we were to sit down and think about okay, we need to plan our next community capacity assessment or something like the contamination of ground water happened again or something like that, I don't know if we'd actually as our first step say let's find a framework.* (Participant, Woolwich CHC)

Focus group members all considered their CHC staff as experienced community participation practitioners who have been working in their community for a long time. The heavy reliance placed on specific members of the organization for this expertise was also emphasized:

> *If I think about our CHC and more than two decades of organizational history and wisdom […] I guess I take a very pragmatic view when I think about how we have approached in the past and how we would approach in the future a variety of community engagement activities. I think we probably draw on the experience of our staff, collectively and individually, and certainly not all of our staff, in fact the*

> *minority our staff are actually doing community engagement, and that's how it should be*. (Participant, Woolwich CHC)

Given the complexity of community participation, participants explained that their expertise in designing community participation processes for marginalization populations was developed over time in an experiential and contextual manner. Participants described experiential knowledge as knowledge gained by several years of working closely with engaging a specific population in the planning and decision making for their health care. The length of time that CHC staff spent engaging with a marginalized population was described as an important feature of community participation practice with marginalized populations. This also shaped the degree to which they felt it was necessary to rely on resources such as a community participation framework to guide their community participation practice. One participant explains:

> *[…] we've really stuck with it because those are our priority populations. And we really have built that trust and we really want to hear what they have to say. So for instance, with our prenatal nutrition clinic, it's taken many years to develop methods to get their feedback and input on the service. […] But now, after running the clinic for more than 15 years, the women are much more comfortable with giving feedback […] so it's really knowing that history and knowing what works with different groups, and really going at it from different angles to get everyone's voice and having a balanced perspective*. (Participant, Woolwich CHC)

Another participant articulated the importance of relying on the experiential knowledge of both self and others:

> *I think if you've been doing it for 20 plus years you're more likely to be looking at a number of frameworks and thinking okay, we've got this community issue, I need to think about this a little bit differently[…] but I also might be thinking hey, who can I talk to? What have we done in the past? You know, thinking about how other community organizations might have dealt with this issue before?* (Participant, Access Alliance Multicultural Health Centre)

As this reflection suggests, for many CHCs, the decision to use any type of resource, such as frameworks, toolkits, or guidebooks, is influenced by how much experiential knowledge they have from working with the population. Therefore, a strong preference was articulated among CHC staff and providers to rely on past experience, knowledgeable staff members, and in-depth knowledge of the community to inform community participation activities, as compared to a focus only on relevant research evidence.

The community development approach to participation

The likelihood of a CHC using a community participation framework also appeared to relate to a framework's relevance to their organization's particular approach to participation. Participants described that community participation frameworks that are not based on the principles of the community development approach were considered inappropriate for CHCs. Some participants noted, however, that some frameworks misuse key elements of community development theory. For instance, "empowerment" is often associated with a community development approach, but it is used inappropriately to describe community participation with marginalized populations:

> *The notion of empowerment implies that somebody's ability to or the outcome of them feeling so called empowered means that somebody else has to give them something in order to feel that way* (Participant, Hamilton Urban Core CHC).

One principle of the *community development approach* that was emphasized is the principle of ownership and decision making power of marginalized populations in health service planning and decision making. Based on this principle, the CHC's role in a community participation initiative is to facilitate and support the involvement of

marginalized populations, rather than dictate how marginalized populations can participate. Essentially, this requires building the capacities, skills, and knowledge of marginalized populations in order to better enable their active participation.

For a community initiative to be successful over the long term, participants indicated that the issue(s) to be addressed must be identified by the community as a priority that compels action. One participant describes the process of enabling the participation of marginalized populations as, "celebrating the sort of capacities of the community, and looking at assets and capacities first before assessing community needs in some ways. It's about both but it would even just visually help; one comes before the other" (Participant, London InterCommunity Health Centre). Another participant adds that "you have to get to know people and build a relationship with them…before you identify those strengths and capacities;" and that, furthermore, supporting marginalized population's ownership for their health care is about "getting information from them on how they interpret their health problems, as opposed to CHCs providing information and identifying the problems for them to share their views on" (Participant, London InterCommunity Health Centre). CHC staff and providers who are facilitating participation are expected to critically "hear what the needs of the community are, as opposed to telling the community what their needs are because their articulation of their needs may be completely different to what we think [...]" (Participant, Access Alliance Multicultural Health Centre).

Furthermore, in line with community development principles of ownership and decision making power of marginalized populations, participants viewed marginalized

populations as the drivers of community participation, "deciding how they want to be engaged…identifying their own health concerns…" (Participant, London InterCommunity Health Centre) and working collaboratively with CHCs to design and implement community participation initiatives. This focus on the marginalized population driving their own participation might reflect the reluctance of CHCs to rely on frameworks or other resources to assist them in guiding community participation initiatives.

Critiques of generic community participation frameworks

Participants felt that the framework they were asked to review was too generic and ignored the highly contextual nature of community participation. Any framework that would be applicable to their needs would have to be adapted to the local context of CHCs, which was described to be a difficult task given the complexity and multifaceted nature of community participation with marginalized populations. Generic frameworks were described as "one dimensional, suggesting that somebody [referring to practitioners] needs to assess and also identify the problem" (Participant, Hamilton Urban Core CHC). Participants across focus groups shared similar concerns about generic frameworks, and they talked about how methods of participation vary by marginalized populations (in order to relate to differences in their social and cultural characteristics). Many focus group members noted that the diversity of marginalized populations poses a challenge to using one generic community participation framework for all CHCs in the province. As one participant expressed:

> *[…]trying to get diverse groups and even individuals from the same group to work together is difficult, even though they all have the same problem, for instance*

> *they're all trauma survivors, they're all living in dire poverty, they're all marginalized, etc. […]* (Participant, London InterCommunity Health Centre)

Some participants went on to describe the limitations of generic frameworks for not specifying the tools for enabling the participation of diverse marginalized populations. For one CHC, participants in the focus group talked about the training of CHC staff and providers on the principles of anti-racism and anti-oppression as a core component in their community participation process, which would need to be included in a framework for their CHC. One participant addressed the limitations of the generic framework, arguing:

> *The steps here don't include that there has to be some awareness and education on behalf of people who want to engage marginalized populations. So where's the preparation around the providers or the organization…so for us anti-racism and discrimination or commitment to [those principles] would figure into the framework.* (Participant, Hamilton Urban Core CHC)

In contrast to using a generic framework to guide their community participation activities, there was a general view shared across the focus groups regarding the value of a framework tailored to their specific CHC context as opposed to a single framework that can be applied to all CHCs.

Participants also explained that generic frameworks usually use language or specific words that are not appropriate to some marginalized populations. These ill-fitting frameworks were critiqued, in particular, for ignoring the differences between engaging with marginalized populations and engaging with communities or populations in general. For CHCs, any effective framework requires flexibility and specificity:

> *… it seems a lot of frameworks or models suggest there is a problem and we got to fix it, we got to figure out what the problem is and then we got to assess the needs of the population… So I find that language is not one that is indeed trying to say you know we're partners in this and we're bringing different things to the table to improve your health*. (Participant, Hamilton Urban Core CHC)

As this quote expresses, the language that is used to describe community participation with marginalized populations is argued to influence the way CHC staff engage marginalized populations, and in turn, how marginalized populations perceive their role in participatory initiatives with CHCs.

Finding the value in community participation frameworks

Despite their general opposition to generic community participation frameworks, focus group participants considered how such a generic framework could be of use within their organization. A suggestion raised in all four focus groups included the use of frameworks to orient new staff or providers to the principles of community participation:

> *[…] if we were a new CHC, or if our own internal capacity was less, [if one health promoter] retired and we bring on a brand new health promoter who doesn't have that lived experience and that knowledge from the literature and etcetera, etcetera, then I can certainly see it being helpful*. (Participant, Woolwich CHC)

Another participant described how a framework could be used to inform new staff and volunteers about a typical community participation process:

> *[…] and I think that is a real asset to have, something that you can distribute and show and kind of walk through these are the various steps, these are things that need to be thought through, that's really helpful. Because some people are very naïve about how much goes into planning community engagement*. (Participant, Woolwich CHC)

Focus group participants also thought frameworks could be useful for CHCs and their partner organizations when establishing a common understanding of community participation principles and developing a process for engaging

marginalized populations. One participant stated that "for partners who may not have been involved in community participation before, being able to have something that lays out the components and also communicates the complexity of engaging marginalized populations" (Participant, Access Alliance Multicultural Health Centre). In particular, a common language among CHCs and their partners is "useful for creating a culture of inclusivity and a culture of understanding that it's essential to practice community participation in this way" (Participant, Woolwich CHC).

Another suggested use of a framework is to demonstrate that CHCs are being transparent about their community participation process, which can be valuable for requesting funding or support from funders and local decision-makers. One focus group participant explained:

> *So I think there's great value in a framework because it helps to legitimize what we do and why we do it the way we do it, how much effort and time it takes but how the outcomes are so meaningful. It is the basis of our work.* (Participant, Woolwich CHC)

Furthermore, some participants explained that for a framework to be useful to CHCs it would have to identify "the vision, the values, the principles that are reflected in the CHC model of care, and the core competencies for establishing partnerships for engagement, and outreach with the populations [...]" (Participant, Hamilton Urban Core CHC).

Discussion

Numerous community participation frameworks have been developed to address the knowledge gaps from limited empirical evidence about the core features of participation initiatives, and the conceptual ambiguity about the concept of community participation itself. These frameworks have been critiqued, however, for failing to

acknowledge that participation is heavily contextualized and situational (Abelson, 2001; Draper, 2010; Tritter & McCallum, 2006). Moreover, numerous studies have demonstrated the particular complexities and multifaceted nature of engaging diverse and marginalized populations (Campbell & McLean, 2002; Kenny, 2013; Rosato et al., 2008, Maalim, 2006; Maloff, 2000).

Our findings support these critiques but also reveal a clearly stated preference among community participation practitioners for relying on experiential knowledge of community participation with marginalized populations. Participants described the limitations of community participation frameworks derived from evidence about community participation practice for not specifying how to enable the participation of marginalized populations. Instead, experiential knowledge was felt to play an equal if not more important role in making sense of, and implementing, research evidence about community participation practice. The knowledge acquired from practice and experience is commonly referred to in the literature as tacit knowledge. First described by Polyani (1966), knowledge acquired through practice and experience rather than through language was portrayed as difficult to articulate (p. 4-5). More recently, scholars have rejected this definition and have argued that tacit knowledge can be articulated through social interaction (Nonaka, 1994; McAdams et al., 2007). This notion that tacit knowledge can be articulated and shared reflects participants' description of relying on their personal experience and the experiential knowledge of CHC staff for guidance in implementing community participation initiatives.

Although we did not set out to explicitly investigate the use of tacit knowledge to guide community participation practice in CHCs, participants repeatedly emphasized the role played by their professional and community-based knowledge over the use of explicit (research or scientific literature based) knowledge. In doing so, our findings reveal that tacit knowledge, in the form of professional and personal experience and community contextualized knowledge, exerted a greater influence on guiding participation activities in Ontario CHCs than frameworks informed by research evidence. Focus group participants expressed a reliance on their own situations and experiences to make sense of participation with marginalized populations. Additionally, the findings of this study demonstrate that tacit knowledge is drawn upon to inform the approach, methods and tools for engaging marginalized populations. A number of scholars have asserted that the knowledge of local people and communities is highly relevant to community participation processes (Eversole & Routh, 2005; Gaventa, 1993; Sillitoe, 2002; Warren, Slikkerveer & Brokensha, 1995). Eversole (2010) contends that "there is a broad agreement in the literature that the knowledge and insights of "local people" and "local communities" potentially complement, correct and/or provide alternative perspectives to the mainstream "scientific" or "professional" expert knowledge that typically informs [participation] practice." (p. 33)

Based on our analysis, there could be two explanations to explain the preferences of CHC staff for using tacit knowledge over research evidence alone to inform their community participation practices. First, there is limited research evidence that evaluates community participation efforts with marginalized populations and that can provide

CHCs with valuable knowledge on the outcome(s) for particular methods of participation with different marginalized populations. Second, there is a stated preference for relying on the knowledge of staff or practitioners who carry out community participation initiatives, as they are experts in their fields. Our findings on tacit knowledge support previous research on the use of evidence in the community-based health sector. Kothari et al. (2011) found that public health practitioners in Ontario Public Health Units used explicit and tacit forms of knowledge in several ways. For instance, both forms of knowledge were used to decide such issues as: what direction public health practitioners would take in program planning, who should be involved on the planning team, and working out program details, such as funding.

Another possible explanation for CHCs' hesitation to use community participation frameworks relates to their heavy reliance on the community development approach. As discussed, the role of CHCs is to facilitate and enable the participation of marginalized populations to have greater ownership in the planning and decision making for their health care. Specifically, marginalized populations are supported to identify their own health concerns and solutions for addressing them, in collaboration with CHCs. Given the facilitative role of CHCs in community participation, this might influence the perspectives of staff or providers on the need for guidance.

Despite their opposition to adopting a generic community participation framework, focus group participants described several useful applications for such a framework within their organizations. For example, a framework could be beneficial for orienting new staff at the CHC to the principles and practices of community participation, or to

establish a common understanding of community participation practice with partners. Used in a collaborative way with community partners, a framework was also seen as a way to promote the legitimacy of CHCs in facilitating community participation with the populations they serve.

While CHC staff and providers did not place a high value on community participation frameworks to guide their participation initiatives, they emphasized the important role of the community development approach in facilitating engagement with marginalized populations. The core principles of the community development approach—e.g., strengthening capacities and skills of marginalized people, fostering control and ownership of marginalized people in decision making, promoting collaborative relationships—describes the steps taken by CHCs to enable the participation of marginalized populations. Focus group participants, however, did not refer to the community development approach to participation as a framework that guides their community participation practice with marginalized populations. Their limited support for the use of frameworks, despite the important role of the community development approach to community participation within their CHC, warrants consideration about how frameworks are conceptualized by CHC staff and providers. CHCs' opposition to community participation frameworks might relate to their understanding of the meaning and purpose of frameworks for translating research evidence about community participation practice.

In light of the limited support for community participation frameworks to guide participation initiatives within CHCs, we propose that different outputs of the framework

which was presented to them could be used, instead, to design a community participation toolkit or guidebook for engaging marginalized populations for each CHC (acknowledging the differences with their local context). There are many community participation toolkits that have been successfully used in health organizations outside of CHCs. These toolkits have been targeted to a specific geographical region and health sector (Coyne & Cox, 2004) or more broadly to guide any health organization or agency in the local health system (Ardal, Buter, & Edwards, 2006; Health Canada, 2000), or for a specific population (Community Futures, 2008; Ortiz & Broad, 2005). There are also some well-known international examples from Australia and the U.K. (e.g., Queensland Community Engagement Model, 2008; Scottish Health Council, 2010). The toolkit or guidebook would assist CHCs with their implementation of community participation initiatives. To ensure its relevance to CHCs, the toolkit or guidebook would be adapted to the local context of the CHC and reflect the marginalized population(s) that they engage. Effectively, a community participation toolkit for CHCs could incorporate guidelines for: a) assessing and understanding the barriers to participation for marginalized population(s); b) identifying the strategies for addressing the barriers to participation for different marginalized populations; c) identifying a repertoire of participation methods that have been tried with marginalized populations (and the strengths and limitations of each method); and d) listing resources (references to current research and knowledge translation tools used by other health service organizations) for CHC staff and providers. The toolkit could also be designed with the tacit knowledge of CHC staff and providers from their experiences with engaging different marginalized populations, and include

scenarios that demonstrate how specific barriers to participation were overcome. Moreover, to truly ensure the toolkit is relevant and accountable to the population(s) intended to be engaged, the toolkit could be developed in collaboration with marginalized populations.

Our findings stimulate further discussion on the role of tacit knowledge in the community participation field. Further exploratory work is needed to identify the effectiveness of tacit knowledge to guide community participation practice in CHCs. Evaluations of community participation initiatives of CHCs—shaped by the experience of staff and providers and their interactions with members of relevant populations—could explain how tacit knowledge is used and the extent to which it facilitates community participation processes with marginalized populations. Further research is also needed to explore how CHCs can be supported to use research evidence (in combination with their own research activities such as, needs assessments, focus groups, surveys) in their community participation practice, and to evaluate different knowledge translation mechanisms (whether toolkits, guidebooks, or practice guidelines) that combine research evidence and tacit knowledge on community participation practice.

Our study has two main strengths. First, our findings provide a more nuanced understanding of the limitations of community participation frameworks for informing the community participation efforts within Ontario CHCs. Second, participants provided relevant insights about the key components that are missing from generic community participation frameworks, that could enhance their applicability to the CHC context. Our findings also demonstrate that a generic community participation framework that could be

used by all CHCs is likely inappropriate, given the varying contexts and diverse populations that CHCs serve.

Despite the significant insights from this study, our findings should be considered in light of several limitations. Since the study did not set out to examine the use of tacit knowledge explicitly, the findings might underrepresent the level of tacit knowledge used in CHCs for the planning and implementation of community participation initiatives. Kothari et al. (2011) stated that a participant observation method would reveal a skill-based asset of tacit knowledge not described by respondents. We concur that direct observation of CHCs staff or providers who are involved in community participation with marginalized populations would provide valuable insight on how tacit knowledge is actually used in practice.

Conclusion

Community participation lies at the core of most CHC activities in Ontario; it is an implicit goal of most of their programs, services and initiatives. The communities that are served by CHCs have the right to be active and equal participants with staff in the planning and decision-making of health services. For CHCs, community participation serves not only practical and strategic ends, it is also a principled undertaking that is part of the organizational culture. Although CHCs live and breathe community participation in so many ways, they do not have a framework in place that guides their community participation activities with marginalized populations. There are strong statements of principle and commitment towards community participation that are not supported by

procedural and evaluation frameworks for assessing the impacts from their participation initiatives.

Our findings suggest that tacit knowledge is an essential feature of community participation practice and requires further exploration regarding its role in the community participation field. Finding an appropriate place for tacit knowledge alongside the traditional elements of knowledge translation which emphasizes acquiring, assessing and applying research evidence seems like a promising way forward to promote the value of community participation frameworks as knowledge translation mechanisms.

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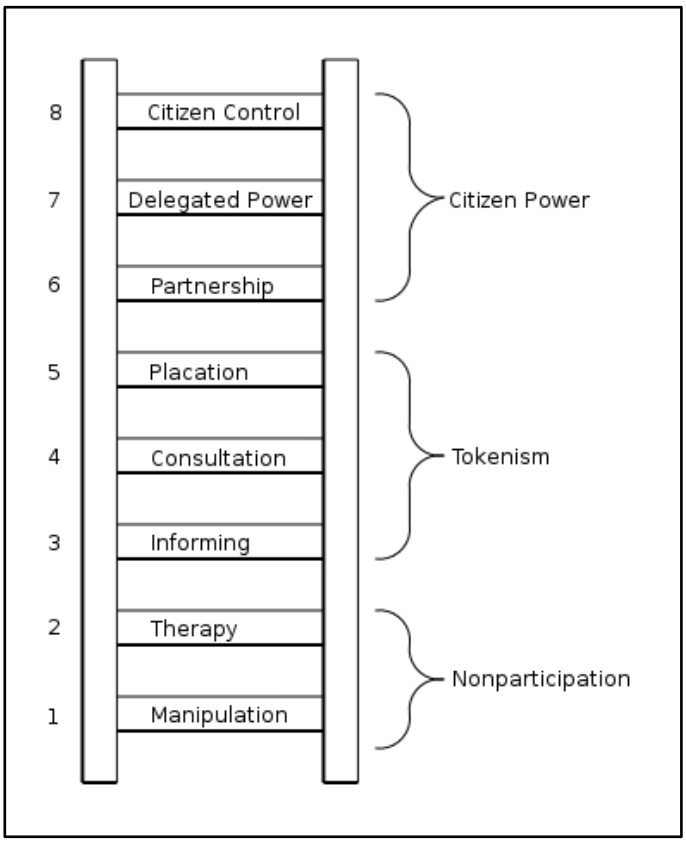
Appendix 1: Frameworks and Typologies of Community Participation

Figure 1: Sherry Arnstein's Ladder of Participation (1969)



Box 1: Susan Rifkin's Typology of Community Participation (1986)

Rifkin, (1986) reviewed 200 case studies for WHO and UNICEF, and this is what emerged from her analysis:

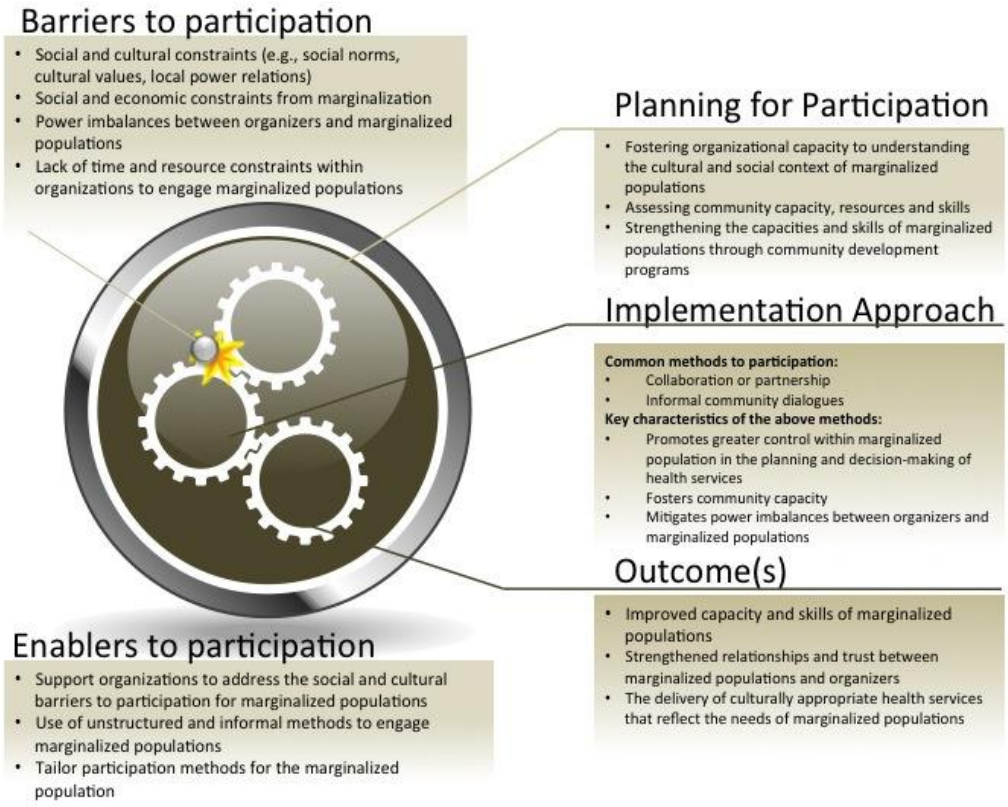
Health planners used three approaches to define community participation based on three similarly differing definitions of health:

- *the medical approach* - which defines health as absence of disease. Community participation is then defined as activities undertaken by community people following the directions of medical professionals in order to reduce individual illness and improve the general environment; for example using health services or cleaning the environment. It is based on the notion that health improves as a result of biomedical science and technology.
- *the health services approach* – which defines health in the WHO sense of the word: 'physical, social and mental well being of the individual'. It defines community participation as the mobilization of community people to take an active part in the delivery of health services; for example using community health workers (CHW), recruited from and by the community, trained and supervised by health professionals and 'accountable' to the community to deliver health care
- *the community development approach* – which defines health as a human condition which is a result of social, economic, and political development. It defines community participation as community members being actively involved in decisions about how to improve that condition; essentially, that health will improve with eradication of poverty brought about by a change in the existing system of power and control relations.

The first two came to be known as the 'top-down' and the last and third one as the 'bottom-up' approaches. In the former two approaches, the health professionals have the predominance in decision making; in the latter, stress is placed on the importance of community people learning to decide what is best for them and the process of how to achieve the change they desire. In short in the latter approach, the solution is secondary to the process that leads to the change that ensues in community members' attitudes and behavior.

Appendix 2

A Draft Generic Community Participation Framework Presented to Focus Groups



Chapter 5:

Conclusion

The principal goal of this doctoral thesis is to advance knowledge about community participation with marginalized populations in the planning and decision making for health services. This thesis presents the findings of three original scientific contributions that address the following knowledge gaps: (1) the limited evidence underpinning the community development principles for enabling the participation of marginalized populations; (2) the lack of empirical evidence about the features of a community participation process (e.g., the approach, methods, and strategies) involving marginalized populations; (3) the narrow understanding of the barriers to participation that shape the personal motivations, willingness and values of marginalized populations to participate; and (4) the limitations of existing community participation frameworks derived from evidence about community participation practice for guiding health system managers and community participation practitioners in their implementation of community participation initiatives for marginalized populations.

Each of the three studies (Chapters 2, 3, and 4) used a different set of research objectives and methods to address these knowledge gaps. In Chapter 2, a critical interpretive synthesis of the community participation literature was used to: (1) examine how the community development principles are used in community participation initiatives with marginalized populations; and (2) examine the factors that shape their influence. The purpose of the study featured in Chapter 3 was to move towards the identification of core features of participation with marginalized populations through an

in-depth analysis of community participation initiatives in four Ontario Community Health Centres (CHCs). Lastly, in Chapter 4 the value of community participation frameworks as knowledge translation mechanisms about community participation practice within Ontario CHCs was explored with a particular focus on: (1) examining the factors that would influence the use of a generic framework for community participation with marginalized populations by CHCs; and (2) improving the "context-specificity" of this framework, to enhance its relevance to CHC staff involved in the planning and design of community participation initiatives.

In this concluding chapter, I discuss the key contributions of this thesis to advancing our knowledge of community participation with marginalized populations, organized as follows: (1) knowledge contributions; (2) theoretical contributions; and (3) methodological contributions. I also address the strengths and limitations of my findings and conclude with some proposals for future research to expand on these contributions.

Knowledge Contributions

Taken together, there are three main knowledge contributions that arise from this thesis: (1) an improved understanding of the role of the community development approach in designing participation methods for engaging marginalized populations; (2) the lack of rigorous evaluation of community participation initiatives designed with the goal of including marginalized populations; and (3) the value of frameworks as one type of resource for guiding community participation practice within health service organizations.

The role of the community development approach in designing participation methods for engaging marginalized populations

The findings from two of the three studies in this thesis (Chapters 2 and 3) describe the role of the community development approach and its underlying principles in guiding community participation processes with marginalized populations for health services planning and decision making. In Chapter 2, the evidence underpinning arguments for the influence of community development principles in enabling the participation of marginalized populations was carefully examined. Synthesis findings identified that community participation strategies guided by community development principles, which are largely based on assumptions about *how* and *why* marginalized populations take part in community participation initiatives, have tended to underemphasize key structural factors—such as local power relations, social norms, experiences with marginalization, and power inequalities between organizers and marginalized individuals—that influence their decision to participate (or not). Structure, in this case, is understood as organized systems of rules (that is, the sanctioning of modes of conduct) that shape the values, beliefs, attitudes, and relationships of a population (Parsons, 1937; Giddens, 1984) and is central to understanding the barriers and enablers to participation.

For instance, one key assumption that underpins the principles of community development is that marginalized populations share similar knowledge of, and views and beliefs about health and illness. However, incorporating local knowledge requires an understanding of how it is uniquely socially constructed within different marginalized groups in a population. A second assumption is that the community development

principles claim that strengthening the capacities and skills of marginalized populations will enable their ownership and control of decisions to improve their health. However, the decision of marginalized populations to participate in capacity or skill-building activities to enhance their participation is often constrained by social norms, social relationships, and experiences with marginalization. Social and economic circumstances posed by marginalization, for instance, are influential in shaping personal motivations and willingness to participate (Archer, 2003; Boneham & Sixsmith, 2006; Mdee, 2008). Another assumption embedded in the principles of community development is the emphasis on establishing partnerships as an effective approach for addressing the health issues of marginalized populations. This principle, however, requires the consideration of power imbalances between organizers and marginalized people, who possess diverging perspectives on addressing health service issues.

The results from the four case studies of community participation initiatives in Ontario CHCs (Chapter 3) build on the synthesis findings and further our understanding of the role of community development principles in enabling the participation of marginalized populations. More specifically, the case studies suggest how these principles were used to shape the strategies developed to address the barriers to participation experienced from marginalization, which included capacity-building, employing peer-mentors or leaders, and the role of organizations to establish partnerships with marginalized populations and other stakeholders across the health sector.

However, the case studies also demonstrated that the influence of community development principles applied to community participation initiatives with marginalized

populations is limited by their values and personal motivations towards participating in the planning of and decision-making about health services. For instance, willingness to participate was observed to be motivated by cultural values and beliefs towards health promotion, disease causation and treatment, gender roles and gendered views towards education, which may resist efforts to enable certain populations to contribute to health services planning and decision making. This was especially visible in one case study where willingness to participate in the planning of primary care services for Low-German Speaking Mennonites appeared to be significantly affected by their cultural values and beliefs towards health and illness.

Despite the limited influence of community development principles in overcoming the structural barriers that constrain the participation of marginalized populations, the findings presented in Chapters 2 and 3 suggest that these principles can play a role in overcoming the structural barriers to participation when applied more effectively to the design of methods to participation with marginalized populations. For instance, the findings from the synthesis (Chapter 2) and case studies (Chapter 3) suggest that informal engagement processes can play important roles in allowing marginalized populations to share personal stories or experiences, learn from, and work together to define health service issues. The community development principles, which guide the capacity-building of marginalized individuals, enabled them to contribute their own skills, capacity and knowledge in the planning of health services. Two specific features were used in the informal engagement processes described in both the community participation literature and case studies to elicit discussion among marginalized individuals

participating. These included café style tables and storytelling conversations, which created a safe environment for marginalized individuals to feel comfortable to share their personal experiences with health, raise important questions about the delivery and design of health services, express different opinions, and voice new ideas about how health services can be improved.

The synthesis findings identified three participation methods, which are informed by the community development principles for building and strengthening capacities and skills of marginalized populations to participate, and fostering relationships between marginalized individuals and organizers. These methods, which also promote the use of informal and unstructured engagement processes in the discussion of issues and the development of solutions to address them, include: i) scenario planning (Zapata, 2009); ii) remote service future game (Nimegeer, Farmer, West & Currie, 2011; Zapata, 2009); and iii) photovoice (Downey, Ireson & Scutchfield, 2009).

The participation methods described in both the community participation literature and the case studies also suggest that the community development principles can be more effectively applied to enable the participation of marginalized populations by supporting health service organizations to recognize and attend to the structural constraints on participation. A common strategy identified in both the synthesis and case study was the use of a facilitator (with different labels such as peer-mentors, peer-leaders, or cultural facilitators). The facilitator is an individual who resides in, or is a member of, the marginalized population and is knowledgeable about the population's demographics, health issues, and experiences with marginalization, and has close ties to the groups in the

population. The use of a facilitator was viewed as a key element to build the capacity of health service organizations to understand the social-cultural characteristics that affect the participation of marginalized populations and support the staff and practitioners from these organizations in their implementation of community participation initiatives with these populations. The use of a facilitator was also viewed as a key element for enabling the participation of marginalized populations by aiding in establishing relationships between organizers and members of the marginalized population.

In sum, the synthesis and case studies of CHC community participation initiatives have moved us closer to being able to identify the core design features of participation methods for marginalized populations. These core features are shaped by the community development principles of strengthening capacities and skills of marginalized individuals and organizers, and building relationships between them, and include: (1) unstructured and informal dialogues that allow marginalized individuals to draw on their own capacity, knowledge, and experiences to discuss health issues and identify potential solutions; (2) facilitation of group discussions that create a safe environment for marginalized individuals to talk about difficult and sensitive health issues; and (3) strategies for building the appropriate capacity for health service organizations to foster key relationships with marginalized populations and gain important insight about the social-cultural factors that constrain the participation of these populations.

Limited evaluation of community participation initiatives with marginalized populations

While the methods identified in the community participation literature are promising examples, they have not been subjected to rigorous evaluation or used with a

range of marginalized populations to allow for comparison. In Chapter 3, CHC staff and providers described that the absence of evaluation efforts employed by CHCs to assess the effectiveness of the participation approaches they used was contributed by the challenges of knowing which methods were suitable for particular marginalized populations because of the changes in cultural values and beliefs, gender roles and social relationships of these populations. The possibility of changes that occur in the social and cultural life of marginalized populations, therefore, shapes the participation methods used to engage them at different points in time. As a result, key informants in the case study analysis described using a "trial by practice" approach for engaging marginalized populations. The key informants described how the community development principles are operationalized differently for different marginalized populations, in that different capacities and skills need to be developed with different marginalized populations, and some principles might be more suited to enabling the participation of some populations and not others. For instance, engaging newcomers means addressing language and unemployment barriers, and engaging seniors means addressing the barriers related to their social isolation. A notable exception was with the Low-German Speaking Mennonites, whose cultural construction of health and illness, values towards education, and gender norms appear to be at odds with the community development principles. The absence of evaluation efforts poses challenges to practitioners and staff in determining how these initiatives should be designed with different marginalized populations, and whether the core features that make up a community participation process can be applied with all marginalized populations or only a few.

Despite the challenges with evaluating community participation initiatives with marginalized populations, the results from Chapter 3 identified similarities in the methods used to engage marginalized populations across the four cases, which suggests that there may be common features in the methods and engagement process that are applicable to the design of community participation initiatives for a wide range of marginalized populations. The similarities revealed through these case studies in the approaches and methods used provide a unique opportunity to evaluate participation initiatives with marginalized populations.

The core design features of a community participation initiative with marginalized populations that were identified from the community participation literature and the case study analysis of community participation initiatives can be evaluated to determine their influence in enabling the participation of marginalized populations. For instance, by evaluating informal and unstructured participation methods that were promoted for engaging marginalized populations we can assess whether such methods were effective in strengthening and promoting the capacity and skills of marginalized populations. Evaluating informal participation methods can also help identify some of the similarities and differences in how different marginalized populations participate, and guide CHCs in knowing which methods are more suitable for some marginalized populations compared to others. An evaluation that compares the use of one method with a marginalized population at two points in time can assess the influence that changes in a culture's values and beliefs might have on how the population participates. Furthermore, evaluations of community participation initiatives can provide important insights into the experiences of

participation for marginalized populations. Given the emphasis placed on the community development principles for enabling the participation of marginalized populations, the principles can shape the development of indicators or domains for evaluating participation methods and would include: a) enabling the participation of marginalized populations; b) strengthening capacities and skills of marginalized populations; c) ownership and control by the marginalized populations; d) building relationships and trust; and e) organizational capacity.

The research presented in this thesis suggests that evaluations of community participation initiatives with marginalized populations are needed to: (1) better understand which methods are effective and with which marginalized populations; (2) learn from past experiences and determine whether community participation practices with marginalized populations have met their goals; (3) improve the evidentiary base for effective community participation with marginalized populations to support new and existing health service organizations in the implementation of their community participation initiatives; and 4) promote community participation practices with marginalized populations across health service organizations outside of CHCs, by providing practical guidance to health system managers and community participation practitioners who have an interest in engaging with marginalized populations.

The value of frameworks for guiding community participation practice within health service organizations

The core features in the design of community participation methods with marginalized populations that were identified in Chapter 2 and 3 were used to develop a draft community participation framework with a focus on marginalized populations. This

framework was shared with staff members in focus groups from four Ontario CHCs, to examine the factors that influence the likelihood of CHCs adopting a community participation framework to guide their community participation practice. The findings from the focus group study (Chapter 4) elaborated on explanations for the limited role played by research evidence in guiding community participation practice within Ontario CHCs. Numerous community participation frameworks that are informed by research evidence have been developed to guide community participation practice; however, these frameworks are largely generic ones that have not been developed specifically for marginalized populations and, as a result, have been critiqued for being too broad and ignoring the highly contextual and situational nature of community participation (Abelson, 2001; Campbell, 2002; Cornwall, 2008; Draper, 2010; Kenny et al., 2013; Tritter & McCallum, 2006). CHC staff and providers described the difficulties of organizing the contextual, multi-faceted and situational processes of community participation with marginalized populations into a single framework, which leads them to question the value of frameworks for guiding their work. Rather, they stated a strong preference for using tacit knowledge, in the form of professional and personal experience with community participation, over the use of research evidence for guiding their community participation planning efforts. The preference for tacit knowledge instead of relying solely on research evidence was explained in part by the paucity of evaluation evidence but also by their reliance on the knowledge of experienced staff and practitioners within their organizations. Scholars have described that the preference for tacit knowledge in health service organizations may be promoted in response to limited organization or staff

capacity to assess and apply research (Kothari & Armstrong, 2011; Wilson, Lavis, Travers, & Rouke, 2010). Therefore, the preference by CHC staff and providers for using tacit knowledge instead of community participation frameworks informed by research evidence to guide their community participation practice has implications for traditional elements of knowledge translation, which emphasizes acquiring, assessing and applying research evidence about community participation (Kothari & Armstrong, 2011).

Theoretical Contributions

The findings from this thesis contribute to an improved theoretical understanding of community participation in the health field by drawing on social theory to explore the pathways through which the participation of marginalized populations is enabled. The findings from chapters 2 and 3 illustrate how social theory is useful in explaining how key structural factors can shape the motivations, rationality, and values of marginalized people towards participating, and which contribute important insights into understanding *how* and *why* marginalized people participate in the planning and decision- making for health services. For example, the concepts of structure and agency, stalwarts of social theory, provide important theoretical lenses to facilitate a more sophisticated understanding of the barriers that constrain the involvement of marginalized populations. Previous sociological analyses of community participation initiatives involving disadvantaged groups (poor women, street youth, and disabled persons) in health promotion projects have also used social theory to explain how social–cultural, organizational, and political factors influence the participation of these groups (Boyce, 2001; Contandriopoulos, 2004; Mdee, 2008). Therefore, by understanding the structural

factors that constrain the agency of marginalized individuals to participate, we can gain a better understanding of how to apply the community development principles to address the structural constraints on their participation for the design of effective community participation initiatives with these populations.

A main strength of synthesizing different forms of research evidence from a range of disciplines allowed us to consider conceptual analyses of structural factors and individual agency as well as examples of their interactions in participation initiatives involving marginalized populations (Boeije, van Wesel, & Alisic, 2011). Structural factors such as social norms, cultural practices and values, and power inequalities between marginalized populations and organizers of community participation initiatives, can be seen to have a significant influence over which marginalized individuals are able to exert their agency in community participation initiatives. By including these conceptual works, we were able to offer a more comprehensive understanding of why marginalized populations participate (or not) and how community development principles might more effectively enable their participation.

Methodological Contributions

An integrated research design was used to link the methods of the synthesis, case study analysis and qualitative focus groups to explore the research questions in each of the three studies. By carefully linking each component, and drawing on the results of each to inform the other, this research design has allowed for a more comprehensive and enriched understanding of community participation with marginalized populations.

Each of the studies carried out for this thesis used new and innovative methods for examining the participation of marginalized populations. Critical interpretive synthesis is a relatively new review methodology that combines traditional systematic review methodology with interpretive inquiry for the synthesis of diverse literatures and the conceptual translation of a range of evidentiary sources (Dixon-Woods et al., 2006). The growing popularity of this method has been demonstrated in the health systems and health policy field, particularly for topics that are interdisciplinary and draw on a range of evidentiary sources (Boyko, Lavis, Abelson, Dobbins, & Carter, 2012; Dixon-Woods et al., 2006; Entwistle, Firnigl, Ryan, M., Francis, & Kinghorn, 2011; Flemming, 2010). While the case study method described in Chapter 3 is not novel, the comparative analysis of the participation methods and approaches used by a group of health service organizations (Ontario CHCs) with a common mission to engage marginalized populations in health services planning and decision making provided a uniquely rich research setting for this type of research. Finally, the focus groups conducted in Chapter 4 were used to explore the value of community participation frameworks as knowledge translation mechanisms to inform community participation initiatives within Ontario CHCs. Although others have examined the use and adoption of research evidence in the community-based health sector to guide the planning and development of health services (Kothari & Armstrong, 2011; Wilson et al., 2010), the examination of community participation frameworks as knowledge translation mechanisms in a particular community-based setting (Ontario CHCs) and through focus groups with community participation practitioners represents a novel application of previous work in this area.

Strengths and Limitations of the Thesis

Taken together, the studies that comprise this thesis have several strengths. First, while the community participation literature is vast and multidisciplinary, the participation of marginalized populations in health services planning and decision making has been given much less attention in the scholarly literature. Even fewer attempts have been made to examine, in depth, and integrate its conceptual underpinnings, and empirical contributions with real-world practice, which is a major strength of this thesis. The focused attention given to the examination of the community development approach, its core principles and how they can more effectively guide the design of community participation initiatives for marginalized populations is another strength of this thesis as well as the insights provided by drawing on key sociological theory—particularly the perspective of structuralism—to study the complex phenomenon of community participation with marginalized populations. The research has built on the work of others (Boyce, 2001; Mdee, 2008) by delineating important structural factors that affect the involvement of marginalized populations and the community participation process. Finally, Ontario CHCs provided a particularly rich setting to study community participation initiatives with marginalized populations, which is a core principle of their organizational culture, and given their mandate to provide essential primary health care through programs and services to marginalized populations.

There are also several study limitations that should be considered. In Chapter 2, the combination of different forms of research evidence may have resulted in pragmatic and methodological differences in understanding community participation. A focus on

English language papers and a one-decade time period is another limitation of the synthesis study, where potentially relevant non-English language and older papers were excluded. Also, most empirical papers reviewed were single-case studies with a focus on a particular marginalized population, which impeded the comparison of approaches and methods across different marginalized populations. In Chapter 3, I relied on the views of CHC staff and providers in key informant interviews as an indirect source of information about how community development principles were used to address the barriers to participation for different marginalized populations. As a result, my findings do not contribute insights into how the community development approach is perceived by marginalized populations and their experiences with their involvement in community participation initiatives. Lastly, as described in Chapter 4, the study did not set out to examine the use of tacit knowledge explicitly, and, as a result, the findings may have under-represented the level of tacit knowledge used in CHCs for the planning and implementation of community participation initiatives.

Further Research

This thesis lays the groundwork for further research and practice regarding community participation with marginalized populations in the planning of and decision-making about health services. There are a few specific areas for next steps that emerged directly from the three studies presented in the previous chapters. First, the challenges that have been raised in this thesis about the evaluation of community participation initiatives with marginalized populations require further exploration. These assessments might study the social structures that shape the social norms and practices of different

marginalized populations. They might also look at the key influences of the community development approach to participation in enabling the participation of marginalized populations. Evaluations of community participation initiatives could also explain how tacit knowledge is used and the extent to which it facilitates community participation processes with marginalized populations. Rigorous study must also consider the policy and health system context within which community participation initiatives are implemented.

Second, staff and providers in the CHCs emphasized the need to adapt and tailor community participation initiatives to the marginalized populations they are trying to engage, but described the difficulty of knowing which methods were most suitable for particular marginalized populations. These challenges can arise from the changes in the cultural values, beliefs and practices of marginalized populations, and how the community development principles are operationalized differently with different marginalized populations, or ambiguity in the community participation literature on the methods and approaches to engaging marginalized populations. Therefore, there is a pressing need to evaluate the strategies and participation methods used in order to determine the appropriate strategies and methods for different marginalized populations and in different contexts.

Third, further research is also needed to identify the appropriate mechanisms for transferring and sharing existing research evidence on community participation with CHCs—and other health services organizations more broadly—that complements the use of tacit knowledge for planning and implementing community participation initiatives. In

Chapter 4, I propose the development of a toolkit or guidebook of the methods and approaches, as well as the barriers, to participation with diverse marginalized populations in different contexts as an alternative resource to guide health system managers and community participation practitioners with their community participation efforts. While this toolkit for community participation with marginalized populations is one mechanism for transferring research evidence about community participation to CHCs and other health service organizations, further exploratory work is still needed to assess different knowledge translation mechanisms (whether toolkits, guidebooks, or practice guidelines) that combine research evidence and tacit knowledge about community participation with marginalized populations.

Fourth, further research is required about how the community development approach to participation is perceived by those who it is intended to engage. Much debate in analysis of community participation initiatives is the question of "who takes part?" Such questions also require consideration of *why* people are motivated to take part in participatory health initiatives. In Chapter 3, I relied on the views of CHC staff and providers in key informant interviews as an indirect source of information about community participation practices, which limits our understanding of the experiences with participation for marginalized populations. Our findings challenge the principles of community development, which suggest that if the capacity and skills of marginalized populations are improved they are more likely to participate. Rather, the motivations and willingness of individuals to participate are shaped by cultural values and beliefs towards health and illness, cultural gender norms, and social relationships. Participation may also

be prompted by specific experiences with marginalization that generate an "oppositional consciousness" (Loyal & Barnes, 2001; Mansbridge & Morris, 2001). Barnes, Newman, Knops and Sullivan (2006) have emphasized the role that participation processes have to play in generating different consciousness and understanding (and not as simply existing as spaces through which previously determined identities can be represented).

Summary

In summary, this thesis makes several scientific contributions to the field of participation with marginalized populations in health services planning and decision-making. My research provides insight into the community development approach to participation and its influence in enabling the participation of marginalized populations by addressing the different barriers to their participation in planning and decision-making about local health services. The findings from this thesis also describe the key features of the methods and strategies that are used to engage marginalized populations. The outcomes of this research provide the groundwork for other studies that aim to assess community participation strategies focusing on marginalized populations.

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