PUBLIC INVOLVEMENT USE IN HEALTH POLICY DECISION-MAKING

THE USE OF PUBLIC INVOLVEMENT IN CANADIAN HEALTH POLICY DECISION-MAKING

By

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Abstract

In this age of accountability, responsiveness, and transparency, governments are increasingly pressured to develop ways to demonstrate the value of public involvement in policy decision-making. Yet the extent to which policy decisions actually reflect citizens' views and input from public involvement processes remains relatively unknown. The main purpose of my dissertation is to examine the internal dynamics of how public involvement is used in the health policy decision-making process. It is guided by two research questions: i) How is public involvement used in the health policy decision-making process; and ii) What factors influence the use of public involvement in the health policy decision-making process? These questions are explored through three independent but complementary studies: i) through a concept analysis, to clarify the concept of public involvement use in health policy decision-making; ii) through a document analysis, to examine the values and assumptions that underpin current and proposed relationships between publics and government, how these have evolved over time, and the meaning of public involvement itself; and iii) through a literature review and key informant interviews, to identify the range of factors influencing the nature of how public involvement is used. The concept of public involvement use, as presented in this thesis, is a complex concept that may be understood, interpreted and operationalized through three interrelated questions: What is the meaning of use in relation to other similar concepts? What is public involvement used for? And, how do we know public involvement was used in health policy decision-making? The results of this dissertation also reveal numerous tensions that characterize the dynamics of how public involvement is used in policy decision-making. Taken together, the three studies provide insights into ways in which public administrators and policy decision-makers could respond to calls for greater accountability and transparency regarding the use of public involvement in policy decision-making.

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I can do all things through him who strengthens me (Philippians 4:13)

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Declaration of Academic Achievement

This thesis presents three original scientific contributions (chapters 2-4) as well as an introduction and conclusion (chapters 1 and 5). I am the lead investigator of the three studies and I conceived each chapter in collaboration with my supervisor (Dr. Julia Abelson), my current supervisory committee (Dr. Mita Giacomini and Dr. Damien Contandriopoulos), as well as past supervisory committee members (Dr. Cathy Charles and Dr. Alina Gildiner). Additionally, I conducted all data collection and analysis for each chapter. I drafted all chapters and have incorporated comments and suggested revisions from my supervisor and 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 will begin with a reflection on the conceptualization and goals of public involvement, and the context surrounding the main topic of interest—the use of public involvement in health policy decision-making. It will also briefly outline the research objectives and methods used for each of the qualitative studies.

Conceptualization and goals of public involvement

Public involvement researchers have provided varied answers to the question of “who constitutes the ‘public’”. Gauvin and colleagues (2010) argue that there is a multiplicity of “publics”, including individual citizens and their representatives (e.g., elected officials and organizations), individual patients and users, and their representatives (e.g. patient advocacy groups, health professionals, ethicists). For Boote and colleagues (2010), the “public” includes patients, service users, carers, program recipients, and organizations that represent people who use services. A systematic scoping review of public involvement in health care policy finds that definitions of the public included representatives of patient organizations, ordinary citizens, community/local residents, and the community (Conklin, Morris, & Nolte, 2012). These findings suggest that there is no single definition of “the public”, but instead, a “plethora of publics” (Gauvin et al., 2010, p.1524). In this dissertation, we adopt Lomas’ (1997) conception that the public can assume one or more of the roles—the taxpayer, collective community decision-maker or patient/consumer, when providing input to policy decision-making in health care. Definitions of “public involvement” also abound with associated terms variously expressed as “public participation”, “public consultation”, “public engagement” and more recently, “patient and public involvement” (Conklin et al., 2012). It is widely accepted that public involvement is a highly complex and contested concept with varied purposes, methods and the type of individuals involved (Contandriopoulos, 2004; Tritter, 2009). In general, conceptualizations of "public involvement" include one or more of the following elements (Church et al., 2002)—who is involved, in what types of decisions, at what level of input and with what goals. For instance, Florin and Dixon (2004) define public involvement as the "involvement of members of the public in strategic decisions about health services and policy at local or national level". This definition consists of the elements, "who is involved" and "in what types of decisions", but does not detail the level of involvement and the goals of involvement. Wait and Nolte (2006) consider the level of involvement in their definition of public involvement but did not include the other elements as noted above. In the field of health technology assessment (HTA), Gauvin and colleagues (2010) present a comprehensive framework of public involvement. Their "public involvement mosaic" (Gauvin et al., 2010, p.1524) consists of multiple elements, including the types of publics, the levels of involvement, and three domains and phases of involvement (policy, organizational and research). They further elaborate that public involvement is a socially constructed concept, influenced by a myriad of factors including the characteristics of the HTA project, the institutional context of the HTA agencies, the ideas held by members of the HTA agency and stakeholder interests. In this dissertation, Gauvin et al.'s (2008, p.21) definition of public involvement is used, which is described as the "passive and active procedures used by the government or an organization to interact with the public and its representatives". Gauvin et al.'s (2008) definition is chosen because it captures the elements of "who is involved, "the purpose of involvement" and "what level of involvement". The definition focuses on a narrower conception of public involvement and excludes bottom-up grassroots movements or actions initiated by groups to gain the government's attention (e.g. Greenpeace style). The decision to use Gauvin et al.'s (2008) definition is made to reflect the scope of the dissertation, which is to examine top-down involvement processes and how governments act on and respond to public involvement processes that they initiate to interact with the public and its representatives. The scope of dissertation is also limited to collective involvement (e.g. group processes) rather than individual involvement (e.g.

individual making decisions about his/her own health care, patient complaints) (Tritter, 2009).

Various goals for involving the public in policy decision-making have been identified in the literature— to improve the quality and legitimacy of decision-making, to enhance accountability for decision-making, and lastly to inform, educate, and build citizen capacity. Taken together, these goals reflect a democratic orientation to public involvement (Abelson & Eyles, 2004; Abelson et al., 2002; Beierle, 1999; Pateman, 1975) which emphasizes the right of citizens to participate in decision-making. Another model for expressing the goals of public involvement is through a consumerist orientation. Hirschman's (1970) theory suggests that dissatisfied consumers have two options when confronted with the deterioration of products or services. Consumers can exert control of their choice through "exit" and switch to another organization offering similar services. As an alternative to exiting the relationship, consumers can exert influence through voicing their concerns to advocate for change (Hirschman, 1970). In market research terms, a consumerist approach to public involvement translates into market testing and feedback for purposes of improving service or product quality (Beresford, 2002). This approach has been documented by a number of scholars in the United Kingdom as a dominant approach to involving the public under the UK New Labour government, where quasi-market National Health Services reforms, and the Patient's Charter were introduced in the 1990s (Clarke, Smith, & Vidler, 2006; Clarke, 2006; Forster & Gabe, 2008; Fotaki, 2011). Such changes marked a shift in health policy towards the right of the consumer to choice and voice (Alford, 2002; Callaghan & Wistow, 2006; Clarke et al., 2006; Clarke, 2006; Crinson, 1998; Forster & Gabe, 2008; Fotaki, 2011; Gilleard & Higgs, 1998; Mold, 2010; Newman & Vidler, 2006; Tritter, 2009; Tritter, 2011).

Conceptualization of health policy decision-making

An examination of the use of public involvement in health policy decision-making should also be accompanied by a clear understanding of what is meant by "health policy decision-making". "Policy" has been described as the "course of action or inaction chosen by public authorities to address a given problem or interrelated set of problems" (Pal, 2006, p.2). This conception of policy is based on a rational model of decision-making, where decision-makers are involved in a process of "choosing" from alternate solutions to a particular problem or set of problems. Other depictions of policy give greater emphasis to the role of political contests and power through a much less rational process of policy making (Walt, 2004; Stone 2012). For the purposes of this dissertation, health policy is broadly conceived as referring to the decisions, commitments and goal-oriented behaviours that are undertaken by different levels of government to address a range of health system problems. These actions are influenced by the complex interplay of institutions, interests and ideas (Atkinson & Coleman, 2005; Campbell, 2002; Hall & Taylor, 2006). The dissertation also recognizes that in general, policy making is a process that involves how "problems are conceptualized and brought to government for solution; governmental institutions formulate alternatives and select policy solutions; and those solutions get implemented, evaluated and revised" (Sabatier, 1999, p.3). This definition takes into account that governments and decision-makers could use public involvement processes in various phases of policy decision-making—setting the political agenda, exploring objectives for a policy issue, filtering of policy alternatives, policy implementation and evaluation. Having said that, it should be noted that policymaking does not necessarily follow the sequence and could sometimes cycle back and forth between phases, for example, between problem identification and formulation of alternatives.

The way in which public involvement is used in policy decision-making process could also vary depending on the type of policy. Policies may be specified by the objective and the type of issues they contend with (Frenk, 1994; Litva et al., 2002; Walt, 2004). Walt (2004) differentiates between two broad types of policies, depending on whether they address high politics issues or low politics issues. Macro (systemic) policies address high politics issues, for example, regulation and financing. Micro (sectoral) policy contends with low politics issues, such as clinically based decision-making such as introduction of breast screening. Frenk's (2004) categorization provides further differentiation and specifies four major levels of health policy: systemic, programmatic, organizational and instrumental. The systemic level pertains to broad system structure and functions (regulation and financing), such as private/public mix. The programmatic level contends with issues related to resource allocation, which includes priority setting and defining the scope and location of health services. The organizational level is concerned with issues related to service production, such as quality of care and maximization of productivity. Finally, the instrumental level (clinical interface) refers to issues related to system performance by way of human resource development and technological innovation. Along the same lines, Litva et al. (2002) propose three policy categorizations that could be appropriate when examining public involvement and policy decision-making. The levels of decision-making are: health system level decisions which address resource/service allocation issues such as placement of nurse-led practitioner clinics in rural areas; programme level decisions which address the funding allocation of services, such as choosing to fund a cancer centre or a complex continuing care hospital; individual level decisions which address the choice of treatment for the individual patient. This dissertation is most concerned with the use of public involvement in systemic, programmatic and operational levels of policy decision-making. Clinical or individual level decision-making is excluded. However, it should be noted that past research indicates that the public as collective decision-makers often feel ill-equipped to make systemic, programmatic and organizational policy decisions, where issues are highly contested and complex (Lomas, 1997; Church et al., 2002).

Public involvement in Canadian health policy decision-making

The public contributes to federal health policy decision making through various means such as public consultations to inform federal regulatory policies related to the safety of drugs and health products and the provision of input into the development of new strategic policy directions (e.g., the development of a mental health strategy for Canadians). However, given the structural arrangements that guide the funding, organization and delivery of health care in Canada, most of the systemic, organizational and operational policy decisions occur at the provincial and regional/local levels. As such, this dissertation focuses on the use of public involvement at the regional and local level, followed by provincial level, and less on federal and Pan-Canadian types of public involvement processes.

Throughout the 1990s, provincial and territorial governments in Canada underwent significant health system reforms (Abelson, Lomas, Eyles, Birch, & Veenstra, 1995; Church & Barker, 1998; Lomas, Woods, & Veenstra, 1997). Central to these reforms was the decentralization of decision-making through regionalization and the creation of regional, community or district authorities or councils (Church & Barker, 1998; Church et al., 2002; Frankish, Kwan, Ratner, Higgins, & Larsen, 2002; Lomas et al., 1997). Provincial governments believed that such changes would promote better coordination and integration of health services delivery, and bring about a more efficient and cost-effective way of managing health care systems (Church & Barker, 1998; Wismar, Blau, Ernst, & Figueras, 2007). In shifting decision-making responsibilities to the regional level, health authorities were also expected to be more responsive to the needs and preferences of local citizens, as well as allow for increased public participation in health care decision-making (Abelson et al., 1995; Church & Barker, 1998; Frankish et al., 2002). Fiscal constraints and challenges to contain costs also seemed to have fuelled the government's interest in public participation as a way of sharing ownership and shifting responsibility to citizens for difficult decisions such as rationing and allocation of health care resources (Chessie, 2009; Lomas et al., 1997; Lomas, 1997). During this period of structural change, several provinces (Alberta[1], Nova Scotia[2], Saskatchewan[3], Quebec[4] and

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[1] Alberta *Regulation 202/97*, which outlines basic roles and requirements for Community Health Councils.

[2] Saskatchewan, *The Regional Health Services Act, 2002,* which establishes Community Advisory Networks.

[3] Ontario, *Local Health System Integration Act*, *2006*, which establishes LHINs and outlines basic requirement to engage community in planning and setting priority.

[4] Quebec, *An Act Respecting Health Services and Social Services (2001 Revisions)*, which establishes the "People's Forum", and *An Act Respecting the Health and Welfare Commissioner, 2005*, which establishes the Consultation Forum. In 2004 the regional boards in Quebec were reorganized (Bill 25) and public involvement at the regional level was abandoned.

Ontario[5]) introduced changes to legislation and/or regulations to mandate public involvement in health policy decision-making**.** For instance, in 1997 the Alberta government established a regulation that outlines the basic roles and requirements for Community Health Councils in the *Regional Health Authorities Act* (1997). A year later, Nova Scotia formed Community Health Boards as mandated by the *Regional and Community Health Boards* Act (1998). In both provinces, these new entities were established to provide ongoing opportunities for input from community members on health care services and policy issues. The Nova Scotia legislation stipulated that health authorities must consider the advice generated by Community Health Boards.

Around the same time, governments across Canada were experimenting with different methods and structures for incorporating the public values and needs in health system planning, priority setting, resource allocation, and policy development (Abelson & Eyles, 2004; Chessie, 2009; Church et al., 2002). Mechanisms to involve citizens in regional policy decision-making were centred around public consultations and participation on locally appointed community health boards and councils. Little is known about whether these citizen participation mechanisms were effective in enhancing citizen participation, accountability and responsiveness (Aronson, 1993; Chessie, 2009; Church et al., 2002).

From structures and methods to outputs and outcomes: the need for a critical examination of the use of public involvement in health policy decision-making

Given the time, effort, and resources spent on public involvement activities, it seems sensible to ask how the findings gathered from public involvement processes are considered in decision-making. In this age of accountability, responsiveness, and transparency, governments are increasingly pressured to develop ways to demonstrate the value of public involvement in policy decision-making. Yet the extent to which policy decisions actually reflect citizens' views and input from public involvement processes

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[5] Nova Scotia, *Regional Health Boards Act, 1998,* which establishes Community Health Boards; and *Health Authorities Act, 2000,* which strengthens Community Health Boards.

remains relatively unknown (Alexander, McCarthy-Reckard, & Paterline, 2010; Anton, McKee, Harrison, & Farrar, 2007; Marin, 2010).

Previous research has highlighted the need for an improved understanding of the use of public involvement in policy decision-making. A systematic review of the impact of UK National Health Services patient and public involvement activities has found that very few studies provided a detailed account of the extent to which participants' recommendations were used to inform health systems decision-making (Mockford, Staniszewska, Griffiths, & Herron-Marx, 2012). Mitton and colleagues (2009a) also note a gap in the understanding of how best to incorporate public involvement alongside other forms of evidence in health policy decision-making. Thurston and colleagues (2005a) has developed a theoretical framework illustrating the influence of public involvement on the policy-making process. Their framework depicts the interaction of public involvement with the policy community, as well as the coupling of the policy and problem streams, to open a window for policy change. While providing a helpful starting point for understanding how public involvement may influence health policy, additional conceptualizing is needed to detail the pathways and processes through which public involvement is used in health policy decision-making. Scholars have highlighted this need for more extensive analysis of *how* public involvement is used in health care service planning and development (Mitton, Smith, Peacock, Evoy, & Abelson, 2009b; Mockford et al., 2012) and the role of specific shaping influences. Finally, efforts to operationalize or define the concept of "use", at the root of any attempt to better understand how public involvement is used, have been rare (Ananda, 2007; Askim & Hanssen, 2008; Coenen, 2009; Copus, 2003; Dalton, 2006; Ebdon & Franklin, 2004; Kane & Bishop, 2002; OECD, 2001; Tenbensel, 2002; Wiseman, Mooney, & Berry, 2003).

Research questions and objectives

The main purpose of my dissertation is to elucidate and understand the internal dynamics of how public involvement is used in the health policy decision-making process. It is guided by the following research questions: i) How is public involvement used in the health policy decision-making process; and ii) What factors influence the use of public involvement in the health policy decision-making process? The dissertation is organized around three main objectives carried out through three qualitative studies:

i) To examine and clarify the concept and process of public involvement use in health policy decision-making;

ii) To examine the values and assumptions that underpin current and proposed relationships between publics and government, how these have evolved over time, and the meaning of public involvement itself;

iii) To identify the range of factors that influence how public involvement is used in health policy decision-making, while acknowledging the nuances and complexity of the concept of 'use' as well as the considerable political and institutional constraints.

Overview of the dissertation

The first study aims to improve the conceptual clarity of public involvement use in health policy decision-making. A qualitative concept analysis methodology is used consisting of a theoretical phase, a fieldwork phase and a synthesis phase to guide data collection and analysis (Schwartz-Barcott & Kim, 1986; 2000). The first phase encompasses a comprehensive review of the literature on the use of public involvement. The search includes the grey literature and a total of 19 academic databases spanning a multitude of disciplines, including health sciences, geography, political science, public administration, and sociology. The second phase is comprised of semi-structured interviews with key informants who have theoretical and/or practical insights on public involvement and its use in policy decision-making. Key informants are identified through an extensive search of the public involvement literature and snowballing sampling techniques to capture a wide range of experts on public involvement, including: i) public involvement practitioners and administrators; ii) researchers and scholars on the impact of public involvement; iii) key figures in think-tanks and policy research agencies on public involvement. All key informants must have ten years of field or research experience in public involvement and fluent in English. Eligibility criteria for public involvement practitioners and administrators are that they: i) must have experience with conducting public involvement processes and producing results for use in policy decision-making. For researchers and scholars, they must have published on the topic of public involvement and its use in the policy process in the last five years. Thirdly, key figures in think-tanks and policy research agencies on public involvement must be primary contacts or authors of their agency's published documents on public involvement. Sampling concludes when data saturation has been obtained, where additional participants do not yield substantially new information to our overall understanding of the concept of public involvement use. Analysis is conducted separately for each of the data sources to identify the key attributes of the concept of public involvement use. A synthesis of the theoretical and empirical findings is also carried out to compare and contrast the findings of the two data sources. The synthesis is guided by questions such as: To what extent do the data from the in-depth literature review and interviews converge and diverge? How and why? How do the same types of findings confirm and disconfirm each other?

The second study examines the operative values and underlying assumptions regarding key concepts such as the public and the government, as well as the meaning of public involvement itself, to inform an analysis of how public involvement is likely to be used in health policy decision-making. A qualitative interpretive content analysis approach (Giacomini, Kenny, & DeJean, 2009; Krippendorff, 2004) is used to examine how the public, the government, and public involvement are conceptualized within key health policy documents on public involvement between 2000 and 2011. Strategic health policy documents are included in the analysis, which are defined as "policy recommendations, guidelines, action plans, strategic plans, or similar forward-looking directives" (Giacomini et al., 2009, p.59).

The third study aims to identify the range of factors that influence the nature of public involvement use while acknowledging the nuances and complexity of the concept of 'use' and the considerable political and institutional constraints. Data are drawn from the same source as for the first study, which includes a comprehensive review of the public involvement literature, in addition to semi-structured interviews. Through this qualitative analysis, the role of prevailing values, decision-maker involvement in public involvement processes, and organizational culture are highlighted as facilitating the use of public involvement in policy decision-making, while acknowledging the considerable political constraints.

Finally, the concluding chapter weaves the three studies into a coherent narrative by reflecting on the significance of the findings, as well as how the dissertation advances the field of public involvement and health policy.

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Chapter 2 - The blind men and the elephant: conceptualizing the use of public involvement in health policy decision-making

Abstract

The concept of public involvement use is not well-defined in the literature. Previous research studies have provided brief accounts of how public involvement may influence health policy, but have not detailed the internal dynamics and process through which it is actually used in the policy process. The study objective is to examine and clarify the concept and process of public involvement use in health policy decision-making.

We employed qualitative concept analysis to address the lack of clarity about the concept of public involvement use, consisting of a theoretical phase, fieldwork phase and synthesis phase to guide data collection and analysis. In the first phase, we conducted an extensive review of the literature on the use of public involvement. In the second phase, we conducted semi-structured interviews (n=26) with key informants who have theoretical and/or practical insights on public involvement and its use in policy decision-making. In the final phase, we synthesized theoretical and empirical findings to finalize the key attributes of the concept of public involvement use. Our findings are organized around three interrelated questions that animate how the concept of use is understood, interpreted, and operationalized: What is the meaning of use in relation to other similar concepts? What is public involvement used for? And, how do we know public involvement was used in health policy decision-making? In asking, “What is the meaning of use in relation to other similar concepts?” meanings are constructed for the concept by identifying differences and drawing connections between “use” and related terms. In asking “Use of public involvement to what end?” respondents specified different ways in which public involvement is used in health policy decision-making. Finally, in asking “How would one know if public involvement was used in health policy decision-making?” our findings weigh in the act of listening as a precursor to use, the ways in which use is

mediated, and responses to the input obtained from public involvement processes as signals of use. These findings are a first step toward improving conceptual clarity about what public involvement use means, how it is understood and interpreted by relevant actors in the public involvement and public policy fields, and how it might be operationalized. We expect our findings to be particularly useful for public involvement practitioners who are often confronted with questions from public involvement participants regarding how their recommendations are used in health policy decision-making.

Introduction

Public involvement is recognized as a core function of health system planning and policy decision-making in Canada (Abelson & Eyles, 2004; Chessie, 2009; Church et al., 2002). Decision-makers have involved citizens in policy decision-making through various means, such as citizens' assemblies, citizens' juries, dialogue circles, and town hall meetings. Stated goals of public involvement are to improve the quality and legitimacy of decision-making, to enhance accountability for decision-making, and lastly to inform, educate, and build citizen capacity (Abelson & Eyles, 2004; Abelson, Giacomini, Lehoux, & Gauvin, 2007). Recent attention has focused on the extent to which findings of public involvement processes are used in policy decision-making (Alexander et al., 2010; Anton et al., 2007; Marin, 2010).

The challenges of measuring the impact of public involvement, in particular, and its use in health policy decision-making, have been well documented in the literature. Mockford and colleagues (2012) note that while many studies report the impact of patient and public involvement, very few provide a detailed account of the ways in which participants' recommendations were used to inform service planning and development. A scoping review of public participation in health care priority-setting by Mitton and colleagues (2009a) suggests that there is great uncertainty about how best to incorporate the public's voice alongside other forms of evidence. In studies where the term "use" is directly referenced (Ananda, 2007; Askim & Hanssen, 2008; Coenen, 2009; Copus, 2003; Dalton, 2006; Ebdon & Franklin, 2004; Kane & Bishop, 2002; OECD, 2001; Tenbensel, 2002; Wiseman et al., 2003), authors often fail to clarify what they mean by the term. On the rare occasions where efforts have been made to clarify the term, emphasis has been given to what public involvement is used for (e.g., to set a local political agenda) rather than to define "use" per se (Askim & Hanssen, 2008).

To illuminate the processes that link public involvement to health policy decision-making, Thurston and colleagues (2005a) have developed a theoretical framework to illustrate the role of public participation in regionalized health governance and its links to the health of the population, which they posit as the ultimate outcome of public participation. In their framework, the influence of public involvement on policy-making is described in terms of its interactions with the policy community, as well as the coupling of policy and problem streams, to facilitate policy change. Although their theoretical framework provides a helpful starting point for understanding how public involvement may influence health policy, additional conceptual work is needed to detail the pathways and processes through which public involvement is actually used in health policy decision-making.

While theoretical frameworks for exploring and explaining the use of public involvement in health policy decision-making seem to be lacking, there is a vast literature on the use and translation of knowledge that may offer some promising insights. The development of models for understanding the utilization of research in the policy process has been a major emphasis of this literature (Contandriopoulos, Lemire, Denis, & Tremblay, 2010; Innvær, Vist, Trommald, & Oxman, 2002; Mitton, Adair, McKenzie, Patten, & Perry, 2007), with landmark theoretical and methodological contributions having been made over the past thirty years (Beyer & Trice, 1982; Knott & Wildavsky, 1980; Pelz, 1978; Rich, 1997; Sunesson & Nilsson, 1988; Weiss, 1979). More recently, Landry and colleagues (2001a; 2001b; 2003) and others (Contandriopoulos et al., 2010; Ginsburg, Lewis, Zackheim, & Casebeer, 2007; Lavis, Ross, & Hurley, 2002) have renewed and extended this work to produce a robust body of knowledge about the inner workings of research use and how it can be facilitated to inform policy.

As with the theoretical and methodological advances that have been made in the research utilization field, we see the need to improve the conceptual clarity of the use of public involvement in health policy decision-making. In this paper, we take the first step towards this goal using a qualitative concept analysis methodology (Schwartz-Barcott & Kim, 1986; 2000). Our objective is to inform both the public involvement scholarly and practice communities that are concerned, respectively, with assessing and improving the use of public involvement in Canadian health policy decision-making. We use the definition of public involvement articulated by Gauvin et al. (2008, p.21), which is the "passive and active procedures used by the government or an organization to interact with the public and its representatives". We use Sabatier's (1999) definition of policy decision-making which is described as a process through which "problems are conceptualized and brought to government for solution; governmental institutions formulate alternatives and select policy solutions; and those solutions get implemented, evaluated and revised" (Sabatier, 1999,p.3).

Methods

Our analysis was guided by Schwartz-Barcott and Kim's hybrid model (1986; 2000) of concept development. This model was chosen because it includes a clear process for integrating both theoretical perspectives from the literature and empirical data from real-world settings. The initial, theoretical phase involved an extensive review of the literature to identify key attributes of the concept of "use". This first phase was followed by a fieldwork phase to confirm and expand upon the concept's attributes with key informants. Analysis was conducted separately for each of the data sources to identify the key attributes of the concept of public involvement use. In the final phase, both sets of findings from the theoretical and fieldwork phase were compared and synthesized to finalize the concept's definition and key attributes. This paper seeks to triangulate three main types of evidence on public involvement use: i) theoretical discussions from the published literature; ii) citizens' perspectives on public involvement use drawn from the published literature; and iii) key informants with theoretical and/or practical insights on public involvement and its use in policy decision-making.

Theoretical phase—in-depth literature review

Literature was drawn from a broad range of disciplines (Schwartz-Barcott & Kim, 1986; 2000). The search was focused on the use of public involvement in health policy decision-making. A total of 19 databases[6] spanning a multitude of disciplines – including

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[6] AgeLine, Arts & Humanities Citation Index, Applied Social Sciences Index and Abstracts, BioOne Abstracts and Indexes, British Humanities Index, Communication & Mass Media Abstract and Communication & Mass Media Index, E-Journals@Scholars Portal, Materials Business File, ERIC, International Bibliography of the Social Sciences, PAIS International, PsycARTICLES, PsycINFO, Public

health sciences, geography, political science, public administration, and sociology – were searched. Grey literature was searched using the Canadian Electronic Library platform, which includes three primary collections (Canadian Publishers Collection, Canadian Public Policy Collection and Canadian Health Research Collection) as well as eight other collections[7]. The cross-disciplinary search was intended to capture a broad range of literature types. A manual search of the websites of selected Canadian organizations was also conducted. In addition, reference lists of in-depth literature reviews were reviewed to ensure that key works on this topic were not missed. The search terms were grouped into three categories: actors, action, and output[8] . Searches were limited to articles published in English between 1995 and 2011.

The search strategy[9] included three main terms – public involvement, policy decision-making, and use – as well as variants of each of the terms identified in

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Administration Abstracts, Science Citation Index Expanded, Social Sciences Citation Index, Social Services Abstracts, Sociological Abstracts, and Worldwide Political Science Abstracts.

[7] Bibliothèque numerique Canadienne francaise, Public Library Collections, BC Books Online, Orca Digital Collection, Ulysses Travel Guide Library, Oxford University Press, Irwin Law Collection, and Grey House Directories.

[8] Search strategy for Scholars Portal : DE=("public involvement" OR "public participation" OR "public engagement" OR "public input" OR "public representation" OR "citizen involvement" OR "citizen participation" OR "citizen engagement" OR "citizen input" OR "citizen representation" OR "community involvement" OR "community participation" OR "community engagement" OR "community input" OR "community representation") and DE=("decision making" OR "policy decisions" OR "policy development" OR "policy making" OR "agenda setting") and KW=(Use* OR utiliz* OR incorporat* OR integrat* OR consider* OR influenc* OR role*);
Search strategy for Medline: KW=("public involvement" OR "public participation" OR "public engagement" OR "public input" OR "public representation" OR "citizen involvement" OR "citizen participation" OR "citizen engagement" OR "citizen input" OR "citizen representation" OR "community involvement" OR "community participation" OR "community engagement" OR "community input" OR "community representation") and KW=("decision making" OR "policy decisions" OR "policy development" OR "policy making" OR "agenda setting" OR "priority setting") and KW=(Use* OR utiliz* OR incorporat* OR integrat* OR consider* OR influenc* OR role*) CINAHL search strategy is the same as Medline`s Search strategy for the Canadian Electronic Library: SUBJECT= "Citizen participation" OR "Public opinion" OR "political participation" OR "community power"

[9] Search strategy for Scholars Portal : DE=("public involvement" OR "public participation" OR "public engagement" OR "public input" OR "public representation" OR "citizen involvement" OR "citizen participation" OR "citizen engagement" OR "citizen input" OR "citizen representation" OR "community involvement" OR "community participation" OR "community engagement" OR "community input" OR "community representation") and DE=("decision making" OR "policy

consultation with a research librarian at our institution. We applied inclusion and exclusion criteria for screening studies. First, the article must be about public involvement (i.e. public communication, public consultation, and public participation). Second, the output must be related to public policy (i.e., system, service, program) decision-making. Studies about patient involvement and individual-level decision-making processes were excluded. The article must also include a description or discussion (whether implicit or explicit) of the concept of "use" and any of its variants (i.e., utilize, incorporate, integrate, consider, role, influence, etc.). The lead author reviewed the search results to identify articles relevant to the in-depth literature review based on title and abstract. After title and abstract review, 288 of the 1823 articles retrieved were eligible for full text appraisal. The resultant data set consisted of 84 documents.

Although the main focus of the in-depth literature review was to identify relevant sources on the use of public involvement, we carried out a parallel, targeted review of the major contributions and key research studies in well-developed fields of knowledge on evaluation utilization and research/knowledge utilization. The purpose of this review was to help us situate and compare our theoretical framework of public involvement use in relation to these large bodies of research.

Fieldwork phase—interviews

Participants were recruited through a combination of purposive and snowballing sampling strategies in an effort to identify experts with theoretical and/or practical

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decisions" OR "policy development" OR "policy making" OR "agenda setting") and KW=(Use* OR utiliz* OR incorporat* OR integrat* OR consider* OR influenc* OR role*);
Search strategy for Medline: KW=("public involvement" OR "public participation" OR "public engagement" OR "public input" OR "public representation" OR "citizen involvement" OR "citizen participation" OR "citizen engagement" OR "citizen input" OR "citizen representation" OR "community involvement" OR "community participation" OR "community engagement" OR "community input" OR "community representation") and KW=("decision making" OR "policy decisions" OR "policy development" OR "policy making" OR "agenda setting" OR "priority setting") and KW=(Use* OR utiliz* OR incorporat* OR integrat* OR consider* OR influenc* OR role*)
CINAHL search strategy is the same as Medline`s
Search strategy for the Canadian Electronic Library: SUBJECT= "Citizen participation" OR "Public opinion" OR "political participation" OR "community power"

insights on public involvement and its use in policy decision-making. Key informants are identified through an extensive search of the public involvement literature and snowballing sampling techniques to capture a wide range of experts on public involvement, including: i) public involvement practitioners and administrators; ii) researchers and scholars on the impact of public involvement; iii) key figures in think-tanks and policy research agencies on public involvement. Key informants were eligible to participate in the study if they had over ten years of experience in public policy and public involvement. Potential interviewees were contacted by email or telephone and invited to participate in an interview (see Appendix A). An interview guide (see Appendix C) was used to provide structure to the interview, and to ensure that the interview was focused on obtaining key informants' views and experiences with using public involvement in the policy process. We sampled until data saturation was obtained, where additional participants did not yield substantially new information.

We conducted semi-structured interviews with twenty-six informants, each lasting approximately an hour to an hour and a half. Of those, twelve interviewees were experts with practical insights on public involvement and its use in policy decision-making (labelled in the findings as a 'practice expert'), holding positions as community engagement practitioners (individuals who are actively involved in public involvement initiatives to support policy decision-making), or public involvement policy advisors and managers with regional health authorities, and provincial or national governments in Canada. Fourteen interviewees were experts with both theoretical and or practical insights on public involvement and its use in policy decision-making (labelled in the findings as a 'content and practice expert'), holding positions as researchers and directors/principles within university- and non-university-based research groups, leading consultancy agencies and think tanks on public involvement in Canada, the United Kingdom, and the United States.

This study was approved by and carried out according to the guidelines set by the Research Ethics Board of Hamilton Health Sciences and the Faculty of Health Sciences at

McMaster University. All study participants provided written informed consent before participating in the study (see Appendix B).

Data Analysis

Findings from the in-depth literature review and interviews were analyzed through an iterative process of identifying, describing, and comparing the similarities and differences between the findings. The goal of this comparison was to develop a refined set of attributes of the concept of public involvement use. Specifically, the analysis followed the interpretive process described by Crabtree and Miller (1999, p.127-143), which included describing, organizing, connecting, corroborating/ legitimizing, and representing the account. Reflective memos, documents, and interview transcripts were analyzed and coded using a coding template based on a preliminary review of the literature. The coding template was based on the attributes of a concept, which included constituents of a definition (i.e., what, when, why, where, how, influencing factors), antecedents (i.e., what is happening preceding the concept), consequences (i.e., what happens after or as a result of the concept), references (i.e., what are the actual situations in which the concept is applied?), surrogate terms (i.e., other terms used interchangeably with the concept), and related concepts (i.e., concepts that may be related but do not necessarily share the same set of attributes) (Schwartz-Barcott & Kim, 1986; 2000). The comparison and synthesis of the data sources was guided by questions such as: To what extent do the data from the in-depth literature review and interviews converge and diverge? How and why? How do the same types of findings confirm and disconfirm each other?

Codes were constantly compared and contrasted to identify patterns and determine how they were related to one another. Emerging ideas were also compared and contrasted to determine how they were related to one another. Throughout the interpretive process, memos were kept for each of the documents reviewed and interviews conducted, and a running log of methodology and theoretical memos was maintained. All interviews were tape-recorded and transcribed by the investigator and imported into the N-Vivo qualitative data management software. Documentary data was coded manually using the same software.

Findings

Our findings are organized around three interrelated questions that animate how the concept of use is understood, interpreted, and operationalized: What is the meaning of use in relation to other similar concepts, what is public involvement used for, and, how do we know public involvement was used in health policy decision-making? In asking, "What is the meaning of use in relation to other similar concepts?" meanings are constructed for the concept by identifying differences and drawing connections between "use" and related terms. In asking "What is public involvement used for?" respondents specified different ways in which public involvement is used in health policy decision-making. Finally, in asking "How would one know if public involvement was used in health policy decision-making?" our findings shed light on the act of listening as a precursor to use, the ways in which use is mediated, and responses to the input obtained from public involvement processes as signals of use.

How is use different from other alternative concepts?

A number of interviewees indicated that they did not like the term "use," noting that it oversimplifies the complex reality of policy decision-making. The idea of "use" as explained by one interviewee, leaves a false impression that policy decisions are solely based on or driven by public involvement:

> "No. I don't think it is the right term, probably because of what it implies, I think, particularly from the public's perspective – and this is where lots of public engagement is wrong – is that what the public says will essentially be the primary, if not the only, source of the decision, I think. I think it certainly has that element to it." (Content and practice expert J, public involvement consulting agency, United Kingdom)

Instead, interviewees preferred to speak of public involvement as being “factored in,” “considered,” “taken into account,” or “incorporated in the policy process”.

> “Incorporating, to me, is a bit more to say ‘We believe in what we're doing. There's a space for it to be part of the overall process.’ So incorporate means that it's part of the whole.” (Practice expert H - provincial health ministry, Canada)

Others preferred to use the term “influence”. The two terms “use” and “influence” were believed to be “very closely connected” (Practice expert B - district/regional health authority) or even “synonymous” (Content and practice expert F- United Kingdom). Keough and Blahna (2006, p.1375) describe “influence” as whether the “input was actually used and does it have real impact on final decisions, such that stakeholders are empowered through meaningful participation”. In this definition, influence consists of three elements: the action or process of “use,” the overall effects or impact of the input on the “final decision” (whether there was a change or not), and empowerment through meaningful participation. Keough and Blahna (2006, p.1375) further expand on the notion of empowerment by suggesting that “simply listening to stakeholder concerns and showing them how their input is used” is an indication of informal power sharing.

The power of public input to affect a policy decision is also described elsewhere in the literature. Koontz (1999, p.254) describes influence as the “degree to which citizen input caused a particular agency decision or action”. The interconnectedness between influence and use was further expanded on by a number of interviewees.

> “I think power is related to this question about influence. If you have the power to influence an agency decision, you have influence on the agency decision. To me, that’s tied into this idea of using. Are these agencies using public involvement to affect their choices? Are they just doing public involvement so they can say they did it, but then they are not using it to affect or influence their decisions?” (Content and practice expert D - United States)

In this portrayal, influence means the power to produce effects on the “agency decision,” where “using” narrows the attention to the actions that the agencies take to achieve a certain end (in this case, to affect their choices).

Public involvement for what purpose?

A second theme revealed by our findings is that discourse on public involvement use is often accompanied by discussions about the purpose of use. The literature commonly describes public involvement as being used for the purpose of contributing to policy decision-making in response to a knowledge gap (Askim & Hanssen, 2008; Julian, Reischl, Carrick, & Katrenich, 1997; Koontz, 1999). Similarly, the public involvement practice community provides accounts of how public involvement can be used to open and change policy and political debates, to enhance the understanding of a policy problem, to choose between policy alternatives, and to address challenges of policy implementation.

> “So, what we said to the community is, ‘We're going to hold four meetings, and we would like you to participate in each of these four meetings. The first meeting is going to be about ‘Do we have a problem?’ ‘Is there a problem that needs to be solved?’ The second meeting is going to be about if there is a problem, if we've identified that there's a problem that needs to be solved, we'd like some community input on how we could solve those problems. The third meeting is going to be about how [organization name] thinks that we could solve those problems’. We came back at the fourth meeting and said, ‘This is the only one that we think can work, so how can we mitigate any of the concerns that you have?’” (Practice expert E - district/regional health authority, Canada)

Although public involvement may be considered an important source of information, interviewees were quick to note that one should not overgeneralize and attribute public involvement as the primary or sole contributor to the decision. As described by an interviewee, public involvement is incorporated within a complex process of information gathering for decision-making that includes interacting with other types of evidence and influences.

> “It's one source of usually a lot of data. I would say it's definitely for us almost never the full story because there are so many things that are providing input.” (Practice expert D - district/regional health authority, Canada)

In addition to being a source of knowledge for policy decision-making, findings suggest that public involvement can be used for purposes of pre-empting potential problems and mitigating risks. As described by one practitioner, public involvement may be used to validate or test a certain policy direction.

> “So, sometimes it's projects that have already been in the works and some of the feedback from the community has just kind of been there to validate what's already being done. And so then, the board will also report on those types of things. So, they'll say, "This has been in the works for a little while, but we're really happy to get the feedback we did because it really showed us that we're on the right track with some of these bigger projects.” (Practice expert I- district/regional health authority, Canada)

Thirdly, the use of public involvement in health policy decision-making can be interpreted as an organization’s attempt to placate the public or to fulfill institutional requirements. In a participatory coastal and marine resource management process, participants viewed decision-makers’ receptiveness to input as a “symbolic gesture” (Dalton, 2006, p.363). Scholars have also described how organizations have used the public involvement process to sanction decisions that have already been made (Abel & Stephan, 2000, p.618; Collier & Scott, 2009; Graves, 2002). A number of interviewees also echoed this observation, suggesting that sometimes organizations “use it [public involvement] to tick a box to prove to somebody that we talked to people” (Content and practice expert A - public involvement agency, Canada). Another interviewee noted the potential danger of outcome-oriented processes designed to meet an institutional requirement

> “...Consultation has now become a requirement. And as soon as you make something a requirement, people look at it as the end. They look to the process as the end and not the means.” (Practice expert G - private company, Canada)

How would you know public involvement was used in health policy decision-making?

Our findings reveal three key dimensions of public involvement use: listening as a precursor to use, mediating use via a public involvement broker, and lastly, responding back to the public as a signal of use.

Listening as a precursor to use

The literature shows that the public thinks about listening in one of two ways. First, from the public's perspective, a "willingness to listen" is a pre-disposition—that it is a sign that policymakers intend to do something with the public's feedback. In other words, the willingness to listen indicates that policymakers are open to communication with the public and considering their input regardless of whether their views align with each other (Ebdon & Franklin, 2004; Graves, 2002; Halvorsen, 2006; Horne, 2010). Second, being "listened to" or "heard" is seen as a criterion for assessing the success of a public involvement process. This perception is clearly articulated by a member of the Citizen's Dialogue on the Ontario Budget Strategy, who noted that he/she will "judge based on how well we are listened to" (Nolte, MacKinnon, & Maxwell, 2004). A case study by Anton and colleagues (2007, p.481) also consider "being listened to" as a defining component of a "good outcome" for a public involvement process.

Interviews with key informants shed further light on what is considered sufficient evidence of listening.

> "If you can listen and work to understand that perspective, you don't respond defensively by explaining why things are done the way they are. You don't do that. You're not defensive. You're open. You're listening. You're "Hmm, okay. Tell me more." You're wanting to understand that better. That would be listening. To me, it would look like that." (Practice expert C - district/regional health authority, Canada)

In the quotation above, the interviewee noted that decision-makers who are truly listening would be receptive to what is being said, rather than reacting defensively and justifying their actions. The absence of listening suggests that there may be a pre-determined decision such that public involvement is merely a "symbolic gesture" (Dalton, 2006, p.363) or a “rubberstamp” (Abel & Stephan, 2000, p.618). In such situations, policymakers have already made up their minds and in response, defend their positions.

> "Oh, they weren't really listening," that means that there was a predisposition to the answer and the public feel like it's just a snow job, it's been spun.” (Content and practice expert M - public involvement agency, International)

> “And I know what it looks like when you're not [listening] and you're just trying to prepare your defense while someone is shooting down whatever [your viewpoints].” (Practice expert C - district/regional health authority, Canada)

Mediating use through a “public involvement broker”

In the field of health priority setting, Tenbensel (2002) approaches the problem of “use” by examining what happens to the public input after it is gathered. He asserts that “mediating bodies” or “mediating institutions,” such as the Oregon Health Services Commission or the National Health Committee in New Zealand, played a crucial role in interpreting the public voice in policy decision-making. Tenbensel (2002) notes that results from public involvement commissioned by governmental agencies require “active interpretation” by mediating bodies to be considered in health policy decision-making. Without some degree of mediation, policy-makers may have difficulty grasping “raw” public input, and therefore disregard its use in policy decision-making (Tenbensel, 2002).

Our findings from the interviews also confirm the role for “mediating bodies” in interpreting the findings of public involvement. Within some organizations, these mediating bodies may be one or two dedicated in-house staff or department/subgroup that specializes in community engagement or public involvement. For example, a staff member in one regional health organization noted that their Community Engagement department is responsible for engaging communities, gathering feedback, producing summary reports, and reporting back to the Senior Executive Team and Board of Directors. It plays the dual role of the trusted advisory body to the organization’s leadership and the champion for the community residents. Some community engagement practitioners regard themselves as the “middle person” (Practice expert I- district/regional health authority, Canada) or “the glue” in their organizations (Practice expert J- district/regional health authority, Canada).

> “One of the ways to provide value is to make sure there's glue. That things are followed up with, that there's movement between meetings. There's movement… Terrific, so I have now been attending this network with my specific set of skills to animate and to be the glue.” (Practice expert J- district/regional health authority, Canada)

As this interviewee noted, community engagement practitioners facilitate interactions so that decision makers and the public can better understand the goals and expectations of public involvement, as well as the contextual factors that surround the local community and health policy decision-making. In fact, many of them also have training in mediation, conflict resolution, and negotiation. They are often well-versed in both the language of policy/decision-makers and of the community/citizens. As a result, they are able to establish relationships and facilitate the exchange of ideas and feedback between the government and the public. At the provincial level, interviewees spoke of the importance of cross-departmental mediating bodies, such as Public Engagement Support Units or Stakeholder Support Units in Nova Scotia, Prince Edward Island, and Newfoundland. As an interviewee explained,

> “We [Public Engagement Support Unit] are a staff sitting within a central agency of government, within a central policy shop of government, and we're there to provide support and advice to departments, but not to actually go out and do the engagements ourselves. It's been a bit of give and take. In some cases, we're able to offer some advice and direct them to some tools. In other cases, I think those departments are going to be able to help their colleagues.” (Practice expert H - provincial health ministry, Canada)

Signaling use by responding back

The consensus across the literature and interviews is that organizations’ response on how the public’s input was used in health policy decision-making was an important indicator of use. Relaying information back to the public is seen as a form of documentation of use to demonstrate accountability and transparency (Anton et al., 2007; Bruni, Laupacis, Levinson, & Martin, 2007; Cook, 2002; Ebdon & Franklin, 2004; MacMillan, 2010; Phillips & Orsini, 2002; Sheedy, 2008). Participants in a province-wide consultation process on the proposed Alberta Health Act believed that "how input is used and acted upon, is more important than the method used to gather that input" (Horne, 2010, p.14). This means citizens should be able to "see how input was considered and reflected in the next phase of work," as well as "on what basis decisions have been made" (Horne, 2010, p.14).

What counts as a response? Our analysis shows that there is a spectrum of responses that demonstrate authenticity and transparency. As described by several interviewees, this spectrum can include an acknowledgement or expression of gratitude for participating at one end, to a detailed reporting of how and why the input was used or not used in health policy decision-making. A statement that public input has been taken into account or used in the decision might fall somewhere between the two extremes.

> "You do see more consistently now where there's a report or wherever the official communicator or documentation does acknowledge the input, that we did engage the public and we are grateful for their input. And then where they'll go more and say, "We have taken their input into account in coming to our decision." Sometimes that's all they say. And then, when you see it's more authentic or transparent, they'll say, "We've incorporated their input in the following ways," and "We have not incorporated it for the following reasons." That, for me, is how you know because you hear back from those responsible, whether that's at a public service level or at the political level, a clear indication of how it was used." (Content and practice expert G - public involvement agency, Canada)

Other interviewees agreed with this position. Several examples of how organizations report back to the public were provided. For example, some provincial organizations keep track of how ideas and suggestions from public involvement processes are used internally by the Board and program areas, as well as externally by relevant stakeholders. Others provide detailed reports of decision-makers' consideration and responses to public input, which are sometimes made publicly available on organization websites. At an independent federal regulatory tribunal, results from public involvement activities are recorded and published as part of the environmental study report. The impact or final decision is also recorded, along with a compendium of public feedback, and the rationale for acting or not acting on the public input is then made publicly available. These documents are all publicly available. Some interviewees suggested that these reports provide a glimpse into the trajectory of how public involvement has been used in health policy decision-making.

> "When you say, 'How would you recognize that it has been used?' you need to be able to see some kind of line, some kind of trajectory, even if that's a trajectory that says, 'You know what? We assessed it. We took that into consideration and, ultimately, we did not accept that and these are the reasons.'" (Content and practice expert G - public involvement agency, Canada)

Other interviewees suggested that the report-back response may be even be used as a proxy measure for public involvement use.

> "…Even if they didn't agree with the [public] feedback, they could articulate for you, in their own terms, why the government had taken the decision it had taken and that they were content with that, or even if they weren't happy with it….They provide feedback, so they genuinely care what the public thinks. They care enough to spend time telling the public, 'This is what we've done.' That would be quite a good proxy measure, if there is feedback or not." (Content and practice expert J - public involvement consulting agency, United Kingdom)

Interviewees also noted that the public involvement participants can be accepting of the fact that there may be no opportunity for their opinions to have an impact on the policy decisions, as long as there is adequate explanation and justification. "In some ways," an interviewee explained, "they [the public] just want to know what's going on" (Practice expert H - provincial health ministry).

Discussion

As we reflect on our findings we are reminded of the fable of the six curious blind men who visited an elephant to learn what it was like. Depending on which part of the elephant was touched, the men described the animal in very different ways. The poem by John Godfrey Saxe (1882) of “The Blind Men and the Elephant” concluded:

> So oft in theologic wars,
> The disputants, I ween,
> Rail on in utter ignorance
> Of what each other mean,
> And prate about an Elephant
> Not one of them has seen!

While the subjective experience of each blind man represents an element of truth, it does not represent the totality of what is. Their task – describing a whole elephant – and the method they used to carry out it – grasping only the nearest part – were inappropriate given their disability. Instead, they might have asked more helpful questions, such as: “How is an elephant different from other beasts?” “What are elephants for, what do they do?” or “How can you tell there is an elephant?” Similarly, in this paper, we set out to provide clarity to the concept of “use” of public involvement in health policy decision-making. Using Schwartz-Barcott and Kim’s (1986; 2000) concept analysis methodology, we reviewed the literature on public involvement use and conducted semi-structured interviews with key informants, including policy advisors, scholars, public involvement practitioners, and consultants. Conceptual clarity can be obtained through three interrelated questions: What is the meaning of use in relation to other similar concepts? What is public involvement used for? And, how would one know public involvement was used in health policy decision-making?

Our first question allows us to gain a better understanding of use by comparing it with related terms. Our analysis reveals slippage between “use” and other concepts such as “influence,” “incorporate,” and “consider”. As such, we draw on the literature’s and interviewees’ discourse of use in relation to other similar terms. While influence refers to the power of public involvement to produce effects on health policy decision-making, “use” narrows the attention to the actions that organizations take to achieve a certain end. Furthermore, interviewees preferred terms such as “incorporate” and “taken into consideration” over “use”. While interviewees interpreted public involvement use as a complicated process that interacts with other types of evidence and influences, they cautioned that the language or terminology of “use” does not necessarily impart such an interpretation for the general public. Instead, the term “use” portrays a false reality that public involvement dominates and functions as the main driving force in policy decision-making. As such, we suggest that the term “use” may be an imperfect fit for our phenomenon of interest. Our findings are consistent with those in the evaluation utilization literature. Kirkhart (2000, p.6) also criticizes the term “use” for being “awkward” and “inadequate”. Instead, he suggests a shift of terminology in the field to “evaluation influence”, which he describes as the “capacity or power of persons or things to produce effects on others by intangible or indirect means” (Kirkhart, 2000, p. 7).

Key to our understanding of “use” are discussions related to the question, “Use of public involvement input to what end?” In answering this question, we come to understand “use” as a process, as opposed to an outcome. In the knowledge utilization literature, Rich (1997) also articulates the importance of differentiating “use” as an outcome or a process—that it is a proximate outcome to the ultimate outcome (possibly change in a policy). As such, rather than examining public involvement as an end in itself, examining public involvement use as a process requires public involvement practitioners and evaluators to confront the question of, “toward what end should the process of use be oriented?” (Rich, 1997). Our findings suggest that public involvement can be used for a variety of purposes. Similar to previous research on instrumental use (Amara, Ouimet, & Landry, 2004; Beyer, 1997; Knorr, 1977; Rich, 1997; Weiss, 1979), public involvement can be used to solve a policy problem and to fill an information gap. As previous research has suggested, it is, however, often difficult to establish a linear trajectory of public involvement use in health policy decision-making (Amara et al., 2004; Weiss, 1979). Instead, public involvement interacts with other types of evidence and is one factor among many others that influence health policy decision-making. Our findings also suggest that public involvement can sometimes be used in policy decision-making as a way to pre-empt potential problems. Finally, public involvement may be used for disingenuous purposes—to placate the public or to fulfill institutional requirements. These findings are consistent with several similar types of use identified in the research and knowledge utilization literature—political and tactical (Greenberg & Mandell, 1991), strategic (Greenberg & Mandell, 1991; Trostle, Bronfman, & Langer, 1999), and symbolic (Amara et al., 2004).

The question "How would you know public involvement was used in policy decision-making?" deepens our understanding of key dimensions of public involvement use: listening as a precursor to use, mediating use via a public broker, as well as responding to the public as a signal of use. Findings suggest that the willingness of policymakers to listen is a good indication that they will respond and use public involvement in policy decision-making. As with Dobson's (2012) observations, we found that the presence of listening suggests that policymakers are likely to be open to the public's feedback. Rather than holding a defensive stance, the "listening bureaucrat" (Stivers, 1994) actively engages with and works to understand the public's perspective. Good listening has the capacity to improve the legitimacy of the policy decision, resolve deep disagreements, enhance empowerment, and to facilitate understanding between citizens and the government (Dobson, 2012).

Despite the best efforts to listen, however, policymakers often face difficulties in determining the relevance and meaning of the public's wishes. The use of public involvement therefore, requires active interpretation of the public's voice through mediating bodies (Tenbensel, 2002) or public involvement brokers. Our findings closely mirror research on "knowledge brokers" (Gold, 2009) in the knowledge translation and exchange literature. These entities or individuals act as a conduit of communication between the public and the institution and facilitate mutual interaction. The openness of listening coupled with active interpretation promotes a trusting relationship between the public and policymakers. Finally, the act of "responding" highlights the public's expectation to know how their input has been used in health policy decision-making. It is considered as the element that closes the loop between what the public has said, what the government has heard, and the interpretation of what was said. Bryer (2007) described six types of "bureaucratic responsiveness" and of those, purposive and entrepreneurial responsiveness can be helpful in further elaborating questions about how policymakers ought to respond to the public. Purposive responsiveness, on the one hand, describes how policymakers respond based on public goals or values (for example, equity, justice, citizenship goals). Entrepreneurial responsiveness, on the other, focuses on responses to individuals as customers or clients of government. For example, to what extent has the institution acted according to the expressed needs and demands of their customers? We suggest that institutions have been leaning more heavily towards entrepreneurial responsiveness as opposed to purposive responsiveness, which may not be adequate to address calls for increased accountability and legitimacy of policy decision-making.

Our study has a few limitations. First, key informants such as public involvement practitioners often spoke for members of the public, as the latter were not selected to participate in the interviews. To overcome these shortcomings, we obtained the views of scholars and the views of the public through the in-depth literature review. Although it was challenging to integrate the study's two data sources (in-depth literature review and interviews), we developed a guide to facilitate the analysis, asking questions such as "To what extent do the data from the in-depth literature review and interviews converge and diverge? How and why?" and "How do the same types of findings confirm and disconfirm each other?" Having offered many new insights into how the concept of public involvement use is understood, interpreted, and operationalized, there remain a number of questions which can be further explored in future research. While we address the question of "who" mediates use, our findings do not provide insights as to how this mediating process occurs. Given our findings on the lack of documentation of use, further research can explore effective strategies for detailing the use process.

Our findings are a first step toward improving conceptual clarity about what public involvement use means, how it is understood and interpreted by relevant actors in the public involvement and public policy fields, and how it might be operationalized. We expect our findings to be particularly useful for public involvement practitioners who are often confronted with questions from public involvement participants regarding how their recommendations are used in health policy decision-making. It is hoped that our study will address calls for improved transparency and accountability of decision-making, which is a contributor to increased public trust in the health care system.

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Chapter 3 - Rights and Responsibilities: A critical examination of public involvement in Canadian health policy decision-making

Abstract

In the early 1990s, interest in public participation reflected governments' desire to ensure the rights of the public to participate in decision-making and to strengthen public accountability for decisions about healthcare resource allocation. Despite the push for public involvement, governments have not delivered fully on their promises to enhance public accountability and responsiveness. Recognizing the challenges of pursuing public participation in the policy process, over the last decade, scholars have focused primarily on issues related to the design and evaluation of public participation processes. Less attention has been given to the influence of prevailing values and guiding principles that are currently shaping public involvement in the Canadian health policy context, as well as how it is used in health systems. The objective of this paper is to examine the values and assumptions that underpin current and proposed relationships between publics and government, how these have evolved over time, and the meaning of public involvement itself.

We used qualitative interpretive content analysis to examine the conceptual basis of public involvement policy documents in health systems decision-making. We reviewed only strategic health policy documents, which included policy recommendations, guidelines, action plans, strategic plans, or similar forward-looking directives. A total of 78 documents were included in the final analysis. Our findings yielded three thematic areas. First, there has been a shift in policy discourse from a focus on the collective towards framing patients or publics as individual consumers of health care. Accompanying this shift is an emphasis on consumer choice and involvement in health care decision-making. Secondly, the rhetoric of consumer choice and involvement is accompanied by policy narratives about consumer responsibilities. Thirdly, while governments set out their responsibility as a convener, enabler, facilitator, and partner to involve consumers, the policy discourse rarely explains how the consumer voice has been

used in health care decision-making. Our findings suggest that current public involvement efforts may be accompanied by motivations to devolve responsibilities to the individual. Policy discourse on public involvement also shows undertones of consumerist ideology. Within the Canadian health policy discourse, the tension between the rights of consumers of health care to be involved for purposes of promoting user interests versus the rights of citizens/taxpayers to be involved for purposes of assuring accountable, transparent and open decision-making is yet to be resolved.

Introduction

Canada has had a long history of experimentation with public involvement. In the 1990s, much of this experimentation was fuelled by large-scale health system reforms that involved the decentralization of health care decision-making. In shifting decision-making responsibilities to the regional level, health authorities were expected to be more responsive to the needs and preferences of local citizens, and in doing so, to provide greater opportunities for public participation in health care decision-making (Church & Barker, 1998; Church et al., 2002; Frankish et al., 2002; Lomas et al., 1997). Fiscal challenges also seem to have fuelled the government's interest in public participation as a way of sharing ownership and shifting responsibility to citizens for difficult decisions such as the allocation of scarce health care resources (Chessie, 2009; Lomas et al., 1997; Lomas, 1997). The widespread interest in public involvement in health policy decision-making also reflects shifts in political and societal norms. Despite the push for public involvement, governments have not fully delivered on their promises to enhance accountability and responsiveness (Aronson, 1993; Chessie, 2009; Church et al., 2002). Recognizing the challenges of pursuing public participation in the policy process, over the past decade, scholars have focused primarily on issues related to the design and evaluation of public participation processes. Consequently, less attention has been given to the influence of prevailing values and guiding principles that are currently shaping public involvement in the Canadian health policy context, as well as how it is used in health policy decision-making. To address this knowledge gap, we explore the values and assumptions that underpin current and proposed relationships between publics and government, how these have evolved over time, and the meaning of public involvement itself.

Two main paradigms have shaped public involvement discourse over the past two decades. Through the late 1990s and early 2000s, deliberative democratic theory and deliberative public involvement methods gained popularity as alternatives to traditional public consultations for engaging citizens in value-based discussions, resource allocation and priority setting processes (Abelson et al., 2003a; Abelson et al., 2003b; Abelson, 2009; Einsiedel & Ross, 2002; Lang, 2007). The stated goals of these public involvement initiatives include improving the quality and legitimacy of decision-making, enhancing accountability for decision-making, and lastly informing, educating and building citizen capacity (Abelson & Eyles, 2004; Abelson et al., 2002; Beierle, 1999; Pateman, 1975). This democratic orientation to public involvement emphasizes citizens' rights to participate in policy decision-making and to exert control over their own lives. The values of equity and empowerment are central guiding principles to this approach (Lupton, Peckham, & Taylor, 1998), as well as inclusion in the sense of ensuring that diverse interests are represented in the policy process.

Growing interest and experimentation with public involvement has also been shaped by a more consumerist orientation, which emphasizes the rights, preferences, and needs of consumers based on a market model where consumers exercise control of their choices through the exit and/or voice (Hirschman, 1970). In Hirschman's (1970) seminal theory, he suggests that dissatisfied consumers could voice their concerns as an alternative to exiting the relationship. This theory has links to the field of market research where consumers provide feedback through market testing for the purposes of improving service or product quality (Beresford, 2002).

An added dimension to Canadian health policy discourse related to public involvement was the federal government's establishment of the Commission on the Future of Health Care in Canada in 2001 to revisit the fundamental values guiding the Canadian medicare program. The deliberative dialogues and consultations that were held with over 16,000 Canadians through the commission process were purported to have influenced the Commission Report's recommendations and generated heightened interest in public engagement within governments across Canada (Maxwell, Rosell, & Forest, 2003). In the Commission's final report, a health covenant for Canadians was proposed, which drew links between public participation, on the one hand, and the responsibilities and entitlements of Canadians and their governments, on the other. As stated in the proposed health covenant, Canadians are entitled to "have appropriate input into, as well as to be informed of relevant policies and laws" (Commission on the Future of Health

Care in Canada. & Romanow, 2002, p.51), while governments have the “responsibility to establish appropriate mechanisms that allow the public and health care providers meaningful input into decisions on the future of our health care system” (Commission on the Future of Health Care in Canada. & Romanow, 2002, p.52). Furthermore, citizen involvement is to be guided by the need to enhance the legitimacy and sustainability of public policies, the aim to design policies reflective of Canadian values, as well as the willingness of policymakers to learn and listen (Commission on the Future of Health Care in Canada. & Romanow, 2002). From the citizens’ perspective, as noted at the national dialogues, “the government must listen to what they have said” and “make use of the information” (Maxwell, Jackson, Legowski, Rosell, & and Yankelovich, 2002, p.66).

A decade has passed since the Romanow Commission. What are the prevailing values and assumptions that are currently shaping the practice of public involvement in the Canadian health policy context and how are they likely to be used in policy decision-making? The objective of this paper is to reflect on these questions in examining current developments relevant to public involvement in Canadian health policy decision-making.

Methods

A qualitative interpretive content analysis of Canadian government policy documents about public involvement was used to address the study objectives (Giacomini et al., 2009; Krippendorff, 2004). This method is particularly well suited for comparing and finding patterns within large volumes of unstructured text (Krippendorff, 2004). It also allows the analyst to examine the assumptions and values that permeate public involvement policies in health policy decision-making.

Documents were identified through the Canadian Research Index, Canadian Health Research Collection, Canadian Public Policy Collection, and provincial government publication catalogues. These databases contain publications produced by Canadian governments (i.e., federal, provincial, territorial, and municipal), government agencies, research institutes, Canadian public policy institutes, advocacy groups, think-tanks, university research centres, and other public interest groups. The search strategy included three groups of terms: i) actors (citizen, public, community), ii) action (involvement, participation, engagement, input, representation), and iii) subject (health). A research librarian was consulted to verify each of the search strategies for the Canadian Public Policy Collection[10], Canadian Health Research Collection[11], and Canadian Research Index[12] . In addition to searching databases, the lead investigator hand-searched website domains of federal health agencies, provincial health ministries, regional health authorities, and provincial government publications catalogues. The ":site" Google functionality was used to perform searches within each website domain. Through this functionality, Google returned webpages containing text from the search strategy. The search strategy applied to the Google Site Search[13] included only all variants of the 'actor' and 'action' because we were already searching within website domains of health ministries, agencies, and authorities.

Searches were limited to English language documents authored by a government or government-appointed entity (i.e., ministry, regional health authority, agency, advisory committee, inquiry, commission) between 2000 and 2011. This time frame was selected to reflect the growing experimentation with public involvement processes in health system planning, priority setting, and policy development. Only strategic health policy documents which included "policy recommendations, guidelines, action plans, strategic plans, or similar forward-looking directives" were included in the sample (Giacomini et al., 2009, p.59). An additional inclusion criterion was that public/community involvement must be the main focus or a major section of the document. A total of 430

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[10] Search strategy for Canadian Public Policy Collection: SUBJECT= "Citizen participation" OR "Public opinion" OR "political participation" OR "community power" AND health;

[11] Search strategy for Canadian Health Research Collection: SUBJECT= "Citizen participation" OR "Public opinion" OR "political participation" OR "community power" AND health

[12] Search strategy for Canadian Research Index: "citizen engagement" OR "citizen participation" OR "citizen involvement" OR "citizen consultation" OR "public engagement" OR "public participation" OR "public involvement" OR "public consultation" OR "community involvement" OR "community participation" OR "community engagement" OR "community consultation" AND health

[13] Search strategy for hand-searching: searched within site domains "citizen engagement" OR "citizen participation" OR "citizen involvement" OR "citizen consultation" OR "public engagement" OR "public participation" OR "public involvement" OR "public consultation" OR "community involvement" OR "community participation" OR "community engagement" OR "community consultation"

documents were retrieved through database and hand searches. One reviewer independently reviewed the search results to identify documents relevant to the review based on title and abstract. After title and abstract review, 86 documents were eligible for full text appraisal. A total of 78 documents were included in the final analysis (Appendix D). All documents were imported into the N-Vivo qualitative data management software.

An inductive approach to analysis was used to examine the text. This type of analysis allows the researcher to stay close to the text and note key words as the basis for forming categories. The unit of analysis in this study was health policy documents on the topic of public involvement. Multiple documents authored by the same organization were analyzed individually and interpreted as a collective source. The manifest content (surface-level meaning, taken 'as is') of the text was first examined (Krippendorff, 2004). The documents were read several times to gain a better understanding and sense of the entire collection. The text was then sorted into seven content areas: Who is 'the public'? What is the role of the public in public involvement? What is the role of the government in public involvement? What is involvement? What are the goals of public involvement? How is the public involved? When is the public involved? The text was condensed into smaller textual units (Krippendorff, 2004) and textual units were assigned and labeled with a code. Similar codes were grouped together and segments of text were sorted into potential categories. Segments of related text from both the coded text and memos were then grouped together. Sorted segments were re-organized in this iterative process of coding and sorting. To understand and organize the large number of related text segments and memos, clustering strategies to visually conceptualize the categories were employed. These strategies helped to determine how the categories interact with and relate to each other.

Throughout the interpretive process, memos were kept for each of the reviewed documents, and a running log of methodology and theoretical memos was also maintained. Throughout the process of writing memos, initial codes were systematically explored and elaborated through an examination of the properties and conditions under which these categories occur. Emerging ideas were also compared and contrasted to determine how they relate to one another.

Findings

Our findings are structured around three thematic areas. First, we discuss the shift in policy discourse from a focus on the collective towards framing patients or publics as individual consumers of health care. Accompanying this shift is an emphasis on consumer choice and involvement in health care decision-making. Secondly, the rhetoric of consumer choice and involvement is discussed in the context of policy narratives about consumer responsibilities. Thirdly, we consider governments' self-assigned roles as convener, enabler, facilitator, and partner with respect to the involvement of consumers, in the absence of considerations about how the consumer voice has been used in health care decision-making.

The shift from the public (collective) to consumers (individuals)

Our document analysis reveals a notable shift over the past decade from a focus on the collective to the individual patient, consumer, and client. In the early 2000s, governments focused primarily on the public and their right to participate in decision-making based on democratic principles. For example in 2000, Health Canada's policy toolkit for public involvement in decision-making was introduced as a direct response to the "growing gap between Canadians' actual and desired level of influence in government decision-making which is leading them to demand a greater voice in public policy formulation" (Health Canada, 2000, p.8). Governments also emphasized the importance of collectivist values to achieve effective public participation. For example, the goals of the Romanow Commission dialogues were to better understand what Canadians "collectively value as important and believe to be the right path to take and why" (Maxwell et al., 2002, p.v). Effective public participation was also described in a Health Canada Population and Public Health Branch document as requiring "that all (citizen, community, and sponsor) demonstrate respect for each other and commitment to the process, and have the patience and discipline to work together towards shared perspectives and commonly desired outcomes" (Smith, 2003, p.34).

Towards the mid-2000s, there appears to be a shift in emphasis from addressing the preferences and needs of citizens to conceiving of the public as consumers and clients of the health care system. Policy documents invoke strong consumerist language consistent with market model approaches when discussing how the public should be involved in policy making. This consumerist language – in which patients are referred to as consumers of health care services – often, takes center stage in policy discourse. For example, in a 2009 Strategic Direction document, Alberta Health Services discuss the "need[s] to view all interactions through the eyes of the consumer and strive to improve their experience through the health care system" (Alberta Health Services, 2009, p.8). In the Ontario Local Health Integration Network (LHIN) context, there is widespread support for a 'consumer-focused' or 'consumer-centred' health care system, where consumers are said to have a central role in health system planning. Improved consumer satisfaction and experience has been cited as one of the targets and outcomes of improved primary care access and service (Central East Local Health Integration Network, 2006; Erie St. Clair Local Health Integration Network, 2006; North East Local Health Integration Network, 2006).

> "A consumer focused health care system must engage the end-user in the planning process as they are most knowledgeable about their needs, experience and satisfaction with health care services." (Central East Local Health Integration Network, 2006, p.2)

Our analysis further illustrates that within a consumer-focused health care model, public involvement is portrayed alongside the goal of empowering individuals to make informed choices—to live a healthy lifestyle, and to choose health care providers, services, programs, and treatment. Choice, however, has been portrayed in various policy documents as a double-edged sword. While the freedom of choice allows consumers to choose between options to maximize their health, they are also expected to take responsibility for their own health. As noted in a document from Alberta Health Services (2009, p.4), the organization "value[s] engagement, as shown by facilitating people to understand choices and take responsibility for their own health". Similarly, Vancouver Coastal Health's (2009, p.4) commitment to the public has been to support involvement strategies that will "promote informed choice, involvement, and support self-responsibility". These claims further suggest that public involvement is viewed as the means to help individuals make choices that involve taking responsibility for their own health.

In addition to discourse about individual consumer choice, there are narratives about the role of the public in making collective choices about complex issues to achieve societal goals (Lenihan, 2008b; Ministry of Health and Long-Term Care and Ontario's Local Health Integration Networks, 2011). The Province of New Brunswick declares,

> "We believe the public has a part to play in developing both public policy and community-wide goals that reflect the community's culture and values. This includes considering the options, making choices, developing plans and taking action to achieve societal goals." (Lenihan, 2008b, p.2)

In short, our analysis reveals that public involvement viewed through a health care consumer lens can be interpreted as the right to be involved, to have an active role in decision-making; however, this right to consumer choice also comes with responsibilities.

Responsibilities of the health care consumer

As discussed above, our analysis of health policy documents reveals that the right of the individual, consumer, and client to voice and choice is attached to certain responsibilities and expectations. We identify three types of responsibilities in the documents reviewed: individual/personal, social and political. *Individual* responsibilities include taking personal action for one's health, self-care, and management, as well as assuming an active role in making choices and decisions. In the current health policy discourse, these individual responsibilities are framed as necessary conditions for achieving policy goals or pre-defined objectives, such as a high-performing health system and better health outcomes. For example, as illustrated in an Ontario Health Quality Council policy document, access to a "high-performing health system that commits to continuous quality improvement" must "involve you in maintaining and improving your own health" (Ontario Health Quality Council, 2008, p.3). A document by the Fraser Health Authority in British Columbia similarly suggests that quality can be improved "through empowering individuals, families and local communities to take responsibility for self-care and management" (Fraser Health, 2009, p.8). There is also an expectation that individuals exercise responsibilities that are constructed as a constituent part of the consumer model of health care. In other words, the right to be involved is moderated by the responsibility to work towards the achievement of certain pre-defined objectives. As illustrated in the quotation below, these responsibilities are said to be requisites to involvement in policy decision-making.

> "Most important of all, the patient's role is going to have to change, too. People and their loved ones need to be empowered with the ability to self-manage their care. We each need to become a central member of our health team and accept the responsibility that goes along with a seat at the table." (South West LHIN, 2011, p.18)

In addition to individual responsibilities, government organizations also perceive the public as having collective responsibility for protecting and improving the public's welfare, and for supporting the sustainability of the health care system. As illustrated in the quotations below, governments have perceived the health care system's sustainability as dependent on the public's involvement and advocacy.

> "The sustainability of the health care system depends upon the support of the community it serves." (PEI Health Governance Advisory Council, 2009, p.25)

> "Our [citizens] responsibilities include making decisions and taking action to ensure the highest quality of personal and family health; advocating for and participating in action that leads to a sustainable and quality health

> system; and, as stewards of the health system, holding ourselves and others accountable for achieving optimal performance.” (Capital Health, 2011, p.6)

Conventionally, the rights and responsibilities of the citizenship have been focused on the current generation of citizens; but the notion of collective responsibility for health system sustainability includes taking into consideration of current and future health needs. South East LHIN (2006, p.2) defines it as “an integrated health system that delivers health services that people need, now, and in the future”, while Romanow (2002, p.1) defines it as “ensuring that sufficient resources are available over the long term to provide timely access to quality services that address Canadians’ evolving health needs”.

While patients, consumers, and clients have been encouraged to support health system sustainability through public involvement, our analysis further illustrates that governments are also approaching these processes as platforms to promote *political* responsibilities, such as the responsibility to “resolve complex issues” (Lenihan, 2008b, p.14) and to “achieve common goals” (Lenihan, 2008b, p.48).

> “We have seen that in a process like this, dialogue and deliberation are the keys to transferring ownership and responsibility. Our planning group realized that if we wanted that transfer to happen, we had to ensure that each participant would work through the decision-making steps one at a time…We need leaders who are ready, willing and able to challenge the public to assume ownership of, and responsibility for, solving issues.” (Lenihan, 2008b, p.44, 72)

Furthermore, the public is also expected to “find their own solutions to the issues” (Lenihan, 2008b, p.72) and to “take on some of the responsibility for implementing those solutions” (Lenihan, 2008b, p.72). Through public involvement processes, as illustrated below, governments are seeking commitment to common goals and to shared responsibility for difficult decisions.

> “Through this process [community engagement] and the results it achieves, we will learn and educate, promote ownership, shared accountability and a

> commitment to common goals, and restore confidence in our public health care system. For we believe engaged communities are stronger and healthier communities.” (Central East Local Health Integration Network, 2006, p.1)
>
> “The process [community engagement] is designed to create transparency, increase buy-in, promote responsibility for priority-setting and encourage involvement with subsequent change related activities. Ultimately, members of the community will share in the challenges of “building a true system” and take pride in the successful results achieved through engagement.” (Waterloo Wellington Local Health Integration Network, 2006, p.1)

Redefining the role of the government and its relationship with the public

While the public is routinely portrayed as consumers of health care, governments have been increasingly assigning themselves a participatory role. New Brunswick’s Provincial Advisor on Public Engagement describes the government’s role as follows: “The new model of public engagement proposes a new role for government as a convener, facilitator, participant and enabler, and partner” (Lenihan, 2008b). As *conveners and enablers,* the government’s main role is to “bring people together” (Champlain Local Health Integration Network, 2006, p.5; Health Canada, 2000, p.93; Ministry of Health and Long-Term Care and Ontario's Local Health Integration Networks, 2011, p.22; South West LHIN, 2011, p.49; Vancouver Coastal Health, 2009, p.9), and through this action, to enable these ‘people’ to achieve certain aims or arrive at a goal, decision, or plan. The purpose of convening and enabling is said to achieve “collective change” (Champlain Local Health Integration Network, 2006, p.5; Champlain Local Health Integration Network, 2011, p.6), “creat[e] movement in communities” (Champlain Local Health Integration Network, 2006, p.5), enable “collective innovation” (Mississauga Halton Local Health Integration Network, 2011, p.7), and permit “individuals to direct their lives and to live with and produce change in their environment” (Saskatchewan Health, 2004, p.17). Our analysis also suggests that governments prefer to take on the role as *facilitators* for involvement processes or dialogues (Central East Local Health Integration Network, 2006; Central Local Health Integration Network, 2006; Central West Local Health Integration Network, 2006; Champlain Local Health Integration Network, 2006;

Manitoba Health, 2003). The goal of engaging stakeholders and the public is to facilitate linkages and integration among various geographic areas, programs and service areas (Central Local Health Integration Network, 2006; Government of Newfoundland and Labrador, 2005; North East Local Health Integration Network, 2006; North Simcoe Muskoka Local Health Integration Network, 2011; North West Local Health Integration Network, 2011; Toronto Central Local Health Integration Network, 2006). In addition to adopting the role of a convener, enabler, and facilitator, governments have perceived themselves as *partners* in the sense of working together in partnerships with communities and stakeholders to accomplish policy goals (Central East Local Health Integration Network, 2006; Central Local Health Integration Network, 2006; Central West Local Health Integration Network, 2006; Champlain Local Health Integration Network, 2011; Erie St. Clair Local Health Integration Network, 2006; Fraser Health, 2009; Manitoba Health, 2003). Although governments have constructed these multiple roles for themselves – that is, as conveners, enablers, facilitators and partners – they have provided little guidance as to who would be held responsible and accountable for using public involvement in health policy decision-making and for reconciling the viewpoints of various individuals and groups.

As governments adopt the roles of the convener, enabler, facilitator, and partner, they also carve out new meanings of the relationship between themselves and the public.

> "It [the public consultation report] is an expression of the group's commitment to begin a dialogue that will become the foundation of a new relationship…this new relationship also makes them [the participants—including government departments] accountable to each other through their commitment to solve common issues and achieve common goals." (Lenihan, 2008a, p.48)

As seen in the quotation above, the new relationship described between governments and the public is characterized by notions of working together, and being "accountable to each other" (Lenihan, 2008a, p.48). These notions contrast with traditional views of "us versus them" that construct the government as accountable to the public. Instead, governments emphasize the importance of working together to address a common issue, such as "collectively bringing about positive change in our treasured public healthcare system" (Central East Local Health Integration Network, 2006, p.II), "working together in developing solutions" (Central East Local Health Integration Network, 2006, p.1), "working together in partnership to build a stronger health care system" (Alberta Health Services, 2010, p.18), and "working together for a common purpose" (Fraser Health, 2009, p.10). Governments have also referred to "shared accountability" (Central East Local Health Integration Network, 2006, p.1; Erie St. Clair Local Health Integration Network, 2006, p.8; Government of New Brunswick, 2008, p.11) as a product of engaging the public in health and health care.

> "Engaging people (patients, families, citizens, stakeholders) in health and health care is a pathway to shared accountability for health. To that end, engagement is about creating sustainable, trust-based relationships through dialogue and conversation that lead to shared accountability for health care." (Capital Health, 2011, p.5)

The reinvention of the relationship between the government and the public involves changes in governments' responsibilities. Some of these responsibilities have been *organizational*—involving the development of new skills, tools, processes, and culture change within the organization to work together with the public (Fraser Health, 2009), and harnessing local knowledge of needs and solutions (Central East Local Health Integration Network, 2006). Other responsibilities, however, have been *relational*—involving building and strengthening relationships and networks. Examples of relational responsibilities include efforts to establish effective and strong partnerships (Saskatchewan Health, 2004; Vancouver Island Health Authority, 2009; Yukon Health and Social Services Council, 2010), enhance collaboration and shared purpose (Central East Local Health Integration Network, 2006; Central Local Health Integration Network, 2006; Champlain Local Health Integration Network, 2011; Fraser Health, 2009; Manitoba Health, 2003), promote horizontal and vertical integration (Erie St. Clair Local Health

Integration Network, 2006), align groups behind a common goal (Lenihan, 2008b), and bring people together (Champlain Local Health Integration Network, 2006; Ministry of Health and Long-Term Care and Ontario's Local Health Integration Networks, 2011; South West LHIN, 2011; Vancouver Coastal Health, 2009). Finally, governments have perceived themselves as responsible for public involvement and community engagement. In various policy documents, governments refer to involving and/or engaging various groups of individuals, including: i) consumers, clients, and customers; ii) patients; iii) stakeholders; iv) community and residents; and v) citizens and members of the public. However, they provide few details on the process of selecting public involvement participants.

Policy documents also provide limited guidance on the means and methods by which individuals can *exercise their right to* voice, although a number of health organization claim that they intend to engage individuals across the full spectrum of participation levels (Capital Health, 2011; Central East Local Health Integration Network, 2006; Central Local Health Integration Network, 2006; Champlain Local Health Integration Network, 2006; Fraser Health, 2009; Health Canada, 2000; Interior Health Authority, 2011; North East Local Health Integration Network, 2006). The spectrum of public involvement approaches described range from passive one-way information sharing to strategies with higher level of public impact, such as engagement collaboratives that allow for partnering with the public and empowerment strategies that position the public as the final decision-making authority. Falling at various points in between the spectrum are consultation and involvement strategies focusing on the two-way communication process between the public and the government. It is unknown, however, whether governments utilize the full range of participation strategies in practice.

Discussion

In this paper, we set out to examine the prevailing values and assumptions that are currently shaping the practice of public involvement in the Canadian health policy context.

We also aim to reflect on how these values and assumptions are likely to influence whether and how public involvement is used in health policy decision-making. Our analysis identifies three emerging themes relevant to public involvement practice in Canada. First, there has been a shift in policy discourse from an emphasis on the "collective" and the public, to an emphasis on the individual patient as a consumer of health care. Accompanying this shift has been a focus on the rights of the health care consumer to involvement and choice. Secondly, the discourse on the rights of the health care consumer has emerged alongside the discourse on the responsibilities of the health care consumer. Thirdly, while governments have perceived themselves as fulfilling the roles of convener, enabler, facilitator, and partner, the policy discourse has rarely discussed who is responsible and accountable for reconciling the choices and voices of the consumers, patients, and the public, and how public involvement is used in health policy decision-making.

The shift in focus within policy discourse from the collective public to individual consumer of health care, as well as the focus on the rights of the consumer to choice and voice, is not unique to Canada. Several European countries, namely the United Kingdom, Sweden and Germany, have seen the development of health consumerism and its related categories (i.e. the patient-consumer, citizen-consumer, and user-consumer) (Alford, 2002; Callaghan & Wistow, 2006; Clarke et al., 2006; Clarke, 2006; Crinson, 1998; Forster & Gabe, 2008; Fotaki, 2011; Gilleard & Higgs, 1998; Mold, 2010; Newman & Vidler, 2006; Tritter, 2009; Tritter, 2011). Although our analysis documents this shift, we did not examine the factors that have contributed to the construction of the collective public as individual consumers of health care. Previous research documenting the rise of health consumerism in the United Kingdom points to the role of institutions and interests. Institutional factors include the introduction of a key United Kingdom policy document, Patient's Charter, introduced in 1991 under the then Conservative government, as well as the New Labour's reforms of the National Health Services (NHS), which marked a shift in health policy towards principles of increased patient choice and voice (Clarke et al., 2006; Clarke, 2006; Forster & Gabe, 2008; Fotaki, 2011). In addition to the influences of institutional factors, other scholars point to the role of patient groups and the construction of the patient-consumer in Britain (Mold, 2010). In Canada, the shift towards viewing the public as consumers of health care can perhaps be in part explained by the growing emphasis on principles of consumer rights and responsibilities as values in Canadian health reform documents (Giacomini, Hurley, Gold, Smith, & Abelson, 2004). Firstly, the shift reflects general trends towards consumerism and "notions of consumer sovereignty in healthcare decision-making" (Charles, Whelan, & Gafni, 1999, p.780). Secondly, the shift may be indicative of changes in models of care—from a paternalistic model to a patient-centered model based on principles of patient preferences, needs, and values (Davis, Schoenbaum, & Audet, 2005; Epstein, Fiscella, Lesser, & Stange, 2010).

Our analysis further illustrates that viewed through the health care consumer lens, public involvement or engagement processes can be interpreted as ways in which the consumer can exercise his/her right to an active role in decision-making (to voice his/her preferences, needs, and values), as well as his/her right to choice. This interpretation is an apparent departure from the rhetoric of the democratic public involvement prevalent in the 1980s and 1990s, which emphasized the right of citizens to participate in democratic decision-making and to enhance transparency, openness, and accountability concerning health policy decision-making. Instead, we are moving towards the adoption of patient involvement ideals and principles as the perceived means to achieving a high-performing health care system and improving quality of health services (Kreindler, 2009).

The path towards the "individualization of involvement" (Tritter, 2011) should be approached with caution. Patient empowerment can have negative consequences. As Greenhalgh and Wesseley have warned, "the down side of empowerment can be demanding and manipulative behaviour by individuals for whom 'health for me' takes precedence over any notions of equity, fairness or citizenship" (2004, p.207). In contrast to collective choices that are made based on social and normative goals, private choices generate private value that takes into consideration only the needs and preferences of the individual, while neglecting the needs and preferences of the greater good (Alford, 2002). As such, health system managers, policy makers, and health services providers should exercise prudence when faced with trade-offs between private values versus collective public goals such as equity, efficiency, security, and liberty (Stone, 2002, p.37). While patient involvement emphasizes the right to voice and choice, we should also reflect on whether individuals have equal capacity, based on their social and cultural capital, to make these choices (Clarke, 2006; Sinding, Miller, Hudak, Keller-Olaman, & Sussman, 2012). Furthermore, the critical issue of whether the patient is truly speaking on behalf of himself/herself should be addressed—are the "voices" represented in patient engagement processes the voices of the patient advocate, or the voices of the patient? What also remains unclear is whether health users prefer to think of themselves as consumers, customers, or clients of health care rather than patients. Interviews with health users in the United Kingdom and Canada, for example, suggest that they perceive themselves as patients rather than consumers and may prefer the label 'patient' to 'consumers' and 'customers' (Clarke & Newman, 2007; Deber, Kraetschmer, Urowitz, & Sharpe, 2005)

Alongside discourse about the rights of the patient-consumer are policy narratives about the responsibilities of the health care consumer—to self-care and management, to individual accountability, to problem solving, and to maintaining sustainability of the health care system. On the other hand, governments identify their responsibilities as mostly relational—to bring together stakeholder groups and communities, and to convene, facilitate, and enable processes that serve to empower the patient-consumer. However, these policy narratives fail to mention governments' responsibilities or accountabilities for making use of public involvement or listening to the voices of the health care consumers in health policy decision-making. If consumers have the right to choice and voice, to what extent should they also have the right to decide how their voices should be used in health policy decision-making? There also appears to be an underlying optimism in policy narratives that involvement processes will generate coherent input, as opposed to new conflicts or more uncertainty. The possibility that input generated from public involvements could be fragmented and divided should be noted, especially within a consumerist paradigm where individuals privately voice their opinions based on personal preferences and needs (Kreindler, 2009). If governments are to take on the role of the convener, facilitator, enabler, and partner, who takes on the difficult task of reconciling the viewpoints of various individuals and groups, and incorporating these viewpoints into health policy decision-making? Overlooking this question may compromise governments' ability to provide high-quality health services and be responsive to the individual needs of health care consumers. Our analysis exposes these notable gaps and unresolved issues in the current health policy discourse.

As new partnerships and relationships between the government and the public are forged, Fotaki (2011) reflects on the future roles of health and social services users in England and Sweden. With the benefits of collaboration, empowerment, and involvement associated with consumerism, the public can potentially assume the role of co-producer of public services (Fotaki, 2011). The public as co-producer of services is empowered to become actively involved in decision-making that is based on a "dialogic and learning partnership" (Dunston, Lee, Boud, Brodie, & Chiarella, 2009, p.46; Fotaki, 2011). Their right to voice is also accompanied by political influence. By contrast, in situations where there is a high degree of individualism but a low level of power, health services users instead become responsibilized agents with little to no control over choice and voice (Fotaki, 2011). Within the Canadian health policy discourse, the tension between consumers as co-producers of health services versus responsibilized agents is yet to be resolved. Overall, these tensions reflect precarious shifts in values and ideas about public involvement in health policy decision-making in Canada.

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Chapter 4 - Factors influencing the use of public involvement in health policy decision-making

Abstract

The democratizing promises of public involvement—to improve the quality and legitimacy of decision-making, to enhance accountability and to build citizen capacity, are often not fully realized. Past research has examined the role of individual and organizational influences in encouraging the use of public involvement in policy decision-making. This body of literature, however, does not take into consideration the complexity of public involvement use—what it means, how it is understood and interpreted, and how it might be operationalized. The objective of this study, therefore, aims to construct a more complex and nuanced understanding of the range of factors influencing the nature of public involvement use. We used a qualitative concept analysis approach, which involved an extensive review of the literature on the use of public involvement, and semi-structured interviews with key informants. While we recognize the role of values, decision-maker participation in public involvement processes, and organizational culture in influencing the nature of public involvement use, our findings suggest that it is also important to acknowledge the considerable political constraints and tensions. Public involvement operates in highly politicized contexts characterized by complex and contentious policy problems such as resource allocation and priority-setting decisions. Struggles between interests and actors within the policy process as well as countervailing pressures can thwart even the most committed efforts to use public involvement in policy decision-making.

Introduction

Canada has had a long history of experimentation with public involvement, motivated by different goals, situated in different levels of governments and political contexts (Abelson & Eyles, 2004; Chessie, 2009; Church et al., 2002). Governments have used a variety of mechanism to engage citizens in value-based discussions and priority-setting processes (Abelson et al., 2003a; Abelson et al., 2003b; Abelson, 2009; Einsiedel & Ross, 2002; Lang, 2007). Despite this long history and fertile area of activity, there is evidence to suggest that the democratizing promises of public involvement—to improve the quality and legitimacy of decision-making, to enhance accountability and to build citizen capacity—have not been fully realized (Aronson, 1993; Chessie, 2009; Church et al., 2002). More broadly, a recent systematic review of patient and public involvement processes in the United Kingdom finds that little is known about how or how often participants' recommendations are used to inform health systems decision-making (Mockford et al., 2012). Over the past several years researchers and public involvement practitioners alike have highlighted the need for more extensive analysis of how public involvement is used in health care service planning and development and the role of specific factors in support public involvement use (Mitton et al., 2009b; Mockford et al., 2012).

Researchers who study the role of individual and organizational influences on the impact of public involvement in policy decision-making have explored these relationships in an effort to attribute particular factors to the fostering of use. Among the many factors found to be important are policy instruments such as regulations and standards, perceptions about the value of public involvement processes, and the level of leadership and organizational commitment (Ananda, 2007; Appelstrand, 2002; Askim & Hanssen, 2008; Coenen, 2009; Ebdon & Franklin, 2004; Graves, 2002; Patten, Mitton, & Donaldson, 2006). This body of literature, however, does not take into consideration the complexity of public involvement use—what it means, how it is understood and interpreted, and how it might be operationalized. The objective of this study, therefore, aims to construct a more complex and nuanced understanding of the range of factors that influence public involvement use.

In this paper, we use the definition of public involvement articulated by Gauvin et al. (2008, p.21), which is the “passive and active procedures used by the government or an organization to interact with the public and its representatives.” Policymaking is defined as the process through which “problems are conceptualized and brought to government for solution; governmental institutions formulate alternatives and select policy solutions; and those solutions get implemented, evaluated and revised” (Sabatier, 1999,p.3).

Methods

To explore factors that influence the use of public involvement in policy decision-making, we conducted an in-depth literature review and a thematic analysis of semi-structured telephone interviews with key informants who offered both theoretical and practical insights on public involvement and its use in policy decision-making. Findings from the literature review and semi-structured interviews were triangulated to identify factors that influence the use of public involvement in health policy decision-making.

For the in-depth literature review, nineteen databases[14] representing a broad range of disciplines, including health sciences, geography, political science, public administration, and sociology were searched in November 2010. The grey literature was also searched through the Canadian Electronic Library platform, which houses three large Canadian research collections including Canadian Publishers Collection, Canadian Public Policy Collection, and Canadian Health Research Collection, as well as eight smaller

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[14] AgeLine, Arts & Humanities Citation Index, Applied Social Sciences Index and Abstracts, BioOne Abstracts and Indexes, British Humanities Index, Communication & Mass Media Abstract and Communication & Mass Media Index, E-Journals@Scholars Portal, Materials Business File, ERIC, International Bibliography of the Social Sciences, PAIS International, PsycARTICLES, PsycINFO, Public Administration Abstracts, Science Citation Index Expanded, Social Sciences Citation Index, Social Services Abstracts, Sociological Abstracts, Worldwide Political Science Abstracts.

research collections[15]. We also reviewed reference lists of empirical reviews to identify potential studies for inclusion. We restricted the search to only English language articles published between 2005 to 2011. The search strategy[16] included three main terms – public involvement, policy decision-making, and use – as well as variants of each of the terms identified in consultation with a research librarian at our institution. We applied inclusion and exclusion criteria for screening studies. First, the article must be about public involvement (i.e. public communication, public consultation, and public participation) in public policy (i.e. system, service, program) decision-making. Second, the article must have a description or discussion of factors influencing the use of public involvement in policy decision-making. Studies about patient involvement and individual-level decision-making processes were excluded. One reviewer reviewed the search results to identify articles relevant to the literature review based on title and abstract. A total of 1823 articles were identified for potential inclusion, of which 288 were eligible for full text review after applying inclusion and exclusion criteria. Eighty-four articles were included in the final set of data for analysis. One reviewer independently reviewed the search results.

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[15] Bibliothèque numerique Canadienne francaise, Public Library Collections, BC Books Online, Orca Digital Collection, Ulysses Travel Guide Library, Oxford University Press, Irwin Law Collection, Grey House Directories.

[16] Search strategy for Scholars Portal : DE=("public involvement" OR "public participation" OR "public engagement" OR "public input" OR "public representation" OR "citizen involvement" OR "citizen participation" OR "citizen engagement" OR "citizen input" OR "citizen representation" OR "community involvement" OR "community participation" OR "community engagement" OR "community input" OR "community representation") and DE=("decision making" OR "policy decisions" OR "policy development" OR "policy making" OR "agenda setting") and KW=(Use* OR utiliz* OR incorporat* OR integrat* OR consider* OR influenc* OR role*);
Search strategy for Medline: KW=("public involvement" OR "public participation" OR "public engagement" OR "public input" OR "public representation" OR "citizen involvement" OR "citizen participation" OR "citizen engagement" OR "citizen input" OR "citizen representation" OR "community involvement" OR "community participation" OR "community engagement" OR "community input" OR "community representation") and KW=("decision making" OR "policy decisions" OR "policy development" OR "policy making" OR "agenda setting" OR "priority setting") and KW=(Use* OR utiliz* OR incorporat* OR integrat* OR consider* OR influenc* OR role*)
CINAHL search strategy is the same as Medline`s
Search strategy for the Canadian Electronic Library: SUBJECT= "Citizen participation" OR "Public opinion" OR "political participation" OR "community power"

We also conducted semi-structured telephone interviews to obtain the perspectives of key informants with theoretical and/or practical expertise about factors influencing the use of public involvement in public policy decision-making. Key informants were recruited and selected using a combination of purposive and snowball sampling strategies. These informants were chosen mainly because they could provide both theoretical and practical insights on the topic of interest based on their experience with gathering, producing, or using public involvement in policy decision-making. We included only interviewees who had more than ten years of field or research experience in public involvement. Potential interviewees were contacted by email or telephone and invited to participate in an interview (Appendix A). We sampled until data saturation was obtained, where additional participants did not yield substantially new information.

We conducted interviews with twenty-six key informants, each lasting from one hour to an hour and a half. An interview guide (see Appendix C) was used to provide structure to the interview, and to ensure that the interview was focused on obtaining key informants' views and experiences with using public involvement in the policy process. Of the 26 interviewees, twelve were experts with practical insights on public involvement and its use in policy decision-making (labelled in the findings as a 'practice expert'). Fourteen interviewees were experts with both theoretical and or practical insights on public involvement and its use in policy decision-making (labelled in the findings as a 'content and practice expert'), holding positions as researchers and directors/principles within university- and non-university-based research groups, leading consultancy agencies and think tanks on public involvement in Canada, the United Kingdom, and the United States.

This study was approved by and carried out according to the guidelines set by the Research Ethics Board of Hamilton Health Sciences and Faculty of Health Sciences at McMaster University. All study participants provided written informed consent before participating in the study (Appendix B).

Data Analysis

We followed the interpretive process for qualitative data analysis as described by Crabtree and Miller (1999, p.127-143). This process involved describing, organizing, connecting, corroborating/legitimizing, and representing the account. We analyzed the literature and interviews while identifying, describing, and comparing similarities and differences between the findings. The goal of this comparison was to characterize and further refine the set of factors that influence how public involvement is used in policy decision-making. Based on a preliminary review of the literature, we developed a coding template to guide the analysis of reflective memos, literature, and interview transcripts. As we coded, we constantly compared and contrasted different codes to identify patterns and draw links between them. We kept a running log of methodological and theoretical memos, as well as memos for each of the articles reviewed and interviews conducted. The comparison and synthesis of the data sources was guided by questions such as: To what extent do the data from the in-depth literature review and interviews converge and diverge? How and why? How do the same types of findings confirm and disconfirm each other? To improve the rigour of data analysis, we searched for disconfirming data that contradicted expectations and assumptions. The search for disconfirming evidence allowed the investigators to further revise and strengthen working hypotheses.

All interviews were audiotaped and transcribed verbatim and imported into the N-Vivo qualitative data management software. Documentary data was coded by hand using the same software.

Findings

Our analysis reveals that the use of public involvement in health policy decision-making is influenced by three main factors—prevailing values and beliefs about its value, decision-maker participation in public involvement processes, and lastly, organizational influences including leadership and the organizational culture.

Prevailing values and beliefs about public involvement

Previous studies have shown that decision-makers' attitudes towards the public and public involvement are a key factor influencing how public involvement is used in policy decision-making (Halvorsen, 2006; Hanssen, 2010; Klijn & Koppenjan, 2002). Interviewees further explained that while some decision-makers look at public involvement processes as nuisances or risks that must be managed, others view them as a valuable source of information for making policy decisions. These attitudes shape subsequent behaviours. Decision-makers who do not value public involvement may reject findings from these processes based on fear of the public "threaten their political primacy" (Klijn & Koppenjan, 2002, p. 365). Public involvement processes are also likely become "ritualized exercises" (Halvorsen, 2006, p.156) if decision-makers viewed them as an added administrative burden. In contrast, decision-makers who recognize the 'use value' of public involvement would actively engage the public in policy issues, gauge the public's information needs, as well as make organizational adjustments to listen and respond to public involvement participants.

> "People feel they have to do it, rather than actually having thought carefully about its use value or how to incorporate it… Use value is simply how is our organization going to make it possible for the public to really get under the hood of whatever issue it is we're trying to resolve, and then be responsive to its output and what do they need from us in order to make an informed and valuable contribution? And how are we going to change as an organization so that we can genuinely engage in this conversation?"
> (Content and practice expert N - involvement agency, Canada)

Our analysis further shows that there is a prevailing belief among decision-makers that public involvement processes must meet robust design criteria to be considered as a credible source of information for policy decision-making. The representativeness of public involvement participants has been described in past research as an important criterion for assessing the credibility of the process (Cook, 2002; O'Doherty & Hawkins, 2010). Similarly, our interviewees, in particular a content and practice expert from the

United Kingdom, lamented that policy-makers often make assumptions about the legitimacy of a public involvement process based on the number of people involved:

> "If they have doubts about the process, they will worry about whether they should or should not take into account what comes out of it. If it's 12 people meeting for a couple of hours, then that may not have huge credibility with policy-makers as opposed to 1000 people meeting for two days" (Content and practice expert H - public involvement agency, United Kingdom)

Some interviewees suggested that uncertainty about the credibility and legitimacy of public involvement processes may be alleviated by ensuring their rigour through, for example, exacting recruitment and screening processes. Such was the case for a major consultation exercise on the future of civil nuclear power in the United Kingdom led by the Department of Trade and Industry. One of our key informants explained that decision-makers were confident in using the public's feedback because it was the product of a robust process that included strong procedural rules and strategies to ensure representativeness and inclusivity:

> "For the decision-makers, they felt like it was really a robust process. They were really getting a very good cross-section of people. The people were recruited especially so that they had a good demographic mix. It was very carefully structured so nobody dominated the conversation. All the things which you would have in terms of good practice and process are really important before the policy-makers will actually listen and will feel that they can legitimately take account of what's coming out of a public involvement process." (Content and practice expert H - public involvement agency, United Kingdom)

While the example above suggests a prevailing belief among decision-makers that public involvement processes must meet robust design criteria to be used in the policy process, other values run contrary to these views. In recounting the experience of the U.K.'s public consultation on genetically modified (GM) foods known as *GM Nation?*, one interviewee suggested that decision-makers were willing to use the results of a public involvement process despite a poorly designed process as those findings supported a favoured policy direction. The interviewee, who was heavily involved in the evaluation of

GM Nation?, postulated that the government used the results to support its policy of doing nothing about the technology. A case analysis published by the Open University (2012) suggested that the findings were used as a smokescreen to conceal actual plans and to legitimize pre-determined decisions.

Decision-maker participation in public involvement

Findings from the literature and interviews further illustrate that the active participation of decision-makers in public involvement processes provides opportunities for mutual learning and relationship-building. A Norwegian study suggests that decision-makers in frequent and regular contact with citizens found it less difficult to interpret citizen input and to use such information for agenda setting (Askim, 2008). Such findings were echoed by numerous interviewees, who noted that decision-makers often gave more thought and attention to the citizens' voices when they were also part of the public involvement process or events.

> "It's that level of buy-in with the important decision-makers. Oftentimes it's not about the process itself or the information that comes out. Unless the key people are there to hear it first hand and to get involved and to feel emotion and the feel of the room, then oftentimes it is a harder sell"
> (Practice expert K - provincial health ministry)

Another interviewee further explained, citing an example of consultations on pandemic flu planning, that decision-makers who frequently attended and were actively involved in consultations would gravitate towards using the consultation feedback in decision-making even though there were competing types of evidence and considerations, such as scientific, technical, legal, international, and ethical perspectives:

> "Their [decision-makers'] intent was to look at them [the different types of evidence] all in tandem and see how things emerged. But decision-makers who were part of that process told us that because so much attention was given to the citizen process in terms of its design and having a representative at each session and so on, they found themselves always thinking afterwards: What would the citizens say

> about this? What would the citizens think about this, given that they had heard them and been part of that process?” (Content and practice expert L - public involvement agency, International)

The literature further shows that decision-makers, through direct participation in public involvement processes, may find themselves brokering ideas between their peers and public involvement participants and becoming champions and advocates of public involvement (Damodaran & Olphert, 2006; Lenihan, 2008a). These findings were confirmed in the interviews. A practice expert recounted that the regular involvement of Board liaisons in citizen council meetings at her regional health authority led to increased mutual trust and learning—to the point where decision-makers became strong champions and advocates for the citizen council members. These champions acted as the “voice of those voices going forward” and advocated for public involvement participants.

> “And so, they [staff liaison and board liaison] build relationships amongst each other [public involvement participants and themselves]. So then, I think what's cool about that is then when we get to the Board, then, because some of those Board liaisons have been a part of that [the public involvement process], and they've built the relationships, that they really speak up and advocate for them.” (Practice expert I- district/regional health authority)

Harrison and Mort (1998) have drawn attention to the intentions behind advocating for public involvement work in their organizations, suggesting that issues of power imbalances might be at play. In case studies of public consultation processes involving the ‘general public’ and where the public played an advisory role, “participation entrepreneurs” acted as champions and “persuaders” for public involvement work within their organization (Harrison & Mort, 1998, p.64). These individuals were mostly professionals in public relations and/or communications departments. For user involvement processes occurring within a highly pluralistic policy arena, however, the motivations of champions for supporting involvement findings are thought to be much more strategic and political in nature. Harrison and Mort (1998) describe their actions as “[playing the] user card” in organizational micropolitics where the use of user group opinions functioned to "buttress one or other manager's or professional's or their institution's preferred course of action as against that of a colleague's or other institution's" (Harrison & Mort, 1998, p.66). Depending on their motivations, the champions might express positive views and build up the legitimacy of the public involvement process to achieve certain means (for example, to strengthen their argument against other stakeholders or decision-makers with opposing views).

Organizational influences

The literature suggests that political leadership supportive of public involvement is a key factor in creating an organizational culture and climate that is open to its use in policy decision-making (Appelstrand, 2002; Coenen, 2009; Graves, 2002; Hampton, 2009). The majority of interviewees echoed this theme, noting that the support of the Executive and other high level decision-makers often drives a culture supportive of public involvement use.

> "But in just speaking with other public engagement practitioners and community engagement practitioners across the country, anybody who's gotten real traction in the organization acknowledges that it happens when they've got a CEO [Chief Executive Officer] who is supportive of public involvement. And when that CEO changes, the community engagement or public engagement influence changes as well, because it's very much about the philosophy of that CEO. So I think that's such a foundational piece of whether or not public involvement happens at all, or to what degree, and then to what degree it will have influence on actual services and planning on the ground." (Practice expert A - district/regional health authority)

What is culture? Thurston and colleagues (2005) describe culture as the "practices, expressive symbols, values, and beliefs that shape what is appropriate behaviour in that organization," (p.244) and further note that a culture of secrecy or fears of reprisal within an organization run counter to the openness and exchange of ideas required for mutual learning to occur. A culture of openness to public involvement within an organization was described in the literature as having an important role in shaping the way decision-makers listen and respond to public involvement findings (OECD, 2001; Phillips & Orsini, 2002; Thurston et al., 2005a). These findings closely align with the experiences of key informants, who explained that a culture supportive of public involvement means that organizations can be upfront with citizens about how such processes are going to be used in policy decision-making, for example, to open up policy discussions and as a source of information representing collective wisdom and knowledge.

> "…when we did our first initiative the first thing we communicated to citizens was what we were going to do with the information we obtained….we were open and transparent by saying, 'what you tell us will be the cornerstone of where we start. But what you say will not be verbatim in any recommendation, but this is where we start.'" (Practice expert K - provincial health ministry)

A number of interviewees also gave examples of the approaches that could be used to help organizations be upfront about how they intend to incorporate public involvement findings in policy decision-making. The practices described ranged from formalized agreements such as a terms of reference or contract that would be established at the start of a public involvement process to informal dialogues with participants about the purpose of the public involvement process.

> "We also sometimes sign what we call a dual contract….The other contract is what the client will do with the recommendations. It doesn't oblige them to act on all of them because that wouldn't be appropriate. It does oblige them to acknowledge the whole process quite publicly, to respond in great detail to the recommendations that come forward and ultimately to act on the spirit of this thing, if not the letter. That's a public contract so it's something that anyone could review. We found that that's very helpful in reassuring the participants that this is more than window dressing." (Content and practice expert N - public involvement agency, Canada)

Interviewees also talked about their experiences with tracking tools and reporting processes to facilitate the process of responding back to the public regarding how they have used public involvement findings in policy decision-making. Some interviewees noted that these processes have been met with "good success" in terms of reporting back and closing the communication feedback loop with the public. Tracking tools and report back processes described ranged from simple three- to four-page bi-annual reports posted on the organization’s website on how the organization and other stakeholders have generally used recommendations to advisory councils for planning and decision-making processes (e.g. to develop a charter for a specific project). Some interviewees described detailed and systematic ways for documenting public involvement participants’ feedback, including explanations regarding the progress made on the recommendations. Others talked about sophisticated tracking tools, such as specialized software packages that send email reminders to respond to or follow-up on commitments previously made in response to a recommendation.

> “In the case of [the client], our panelists made more than 100 recommendations concerning cancer care and they [the client] prepared a spreadsheet with 100 lines which explains what's happened, why it has, why it hasn't. Our other client is [name of client]. One year later they're preparing a project management spreadsheet with green, yellow, red indicators about progress on the recommendations that the panel proposed.” (Content and practice expert N - public involvement agency, Canada)

While some key informants praised the value of report-back mechanisms, others were less enthused about their practicality in articulating the complexities of the policy decision-making process.

> “We know that decision-making is an incredibly messy process. It doesn't look anything like the policy cycle. We know that lobby groups, pressure groups, solid, quantitative, economic and environmental studies will have a huge impact on decision-makers, as will personal political prejudices and, indeed, political expediency.” (Content and practice expert J - public involvement consulting agency, United Kingdom)

The utility of report-back mechanisms in demonstrating how public involvement is used in policy decision-making has also not been fully supported in the literature, especially for complex, value-laden policy issues of concern to the public. Thurston and colleagues (Thurston et al., 2005a) suggest that the influence of a public participation initiative in local health policy is characterized by the interactions with the policy community, while taking into consideration the political space and processes of problem development (problem stream) and solution generation (policy stream). Past research has also examined how the transfer and influence of public involvement results in policy decision-making by examining the role of power processes (Simmons, 2008; van Tatenhove, Edelenbos, & Klok, 2010). For example, in a study evaluating the role of public participation in decisions concerning the disposal of the VX nerve agent (a potent US Army weapon), Simmons (2008, p.129) suggest the need to examine power processes (defined as "access to, and direct influence in the decision-making process") as a criteria for evaluating the extent to which the decision-making process was just—whether public participation was taken seriously, who listens to publics, is there frequent and substantial discourse among affected parties and how public participation affects the final policy. Similarly, van Tatenhove and colleagues (2010) examine the role of relational, dispositional and structural power in the negotiations and translation of results of interactive projects (e.g. citizen panels, collaborative policy dialogues) into formal decision-making processes in the Netherlands. Both studies bring to light the unequal power relations and struggles in policy decision-making processes—who is included and excluded in the decision-making processes, who is considered the public, what is the status of members of the public as decision-makers (Simmons, 2008, p.19)

Discussion

In this paper, we set out to identify and examine the range of factors influencing the nature of public involvement use. Findings from our in-depth literature review and key informant interviews suggest that decision-makers who expressed doubts about the credibility and representativeness of public involvement processes have reservations about whether they should use the public's feedback for decision-making. Some interviewees suggested that such doubts may be alleviated by ensuring representativeness through rigorous recruitment and screening processes. These strategies, however, are at odds with past research suggesting that decision-makers could challenge or be overly critical of the representativeness of public involvement processes in order to undermine the legitimacy of the process and its results (Contandriopoulos, 2004; Martin, 2008; Timotijevic, Barnett, & Raats, 2011). Through a posture of critique, decision-makers can guard against threats to existing power relationships between themselves and the public, as well as retain control over policy decision-making. Our interview findings are consistent with such views. While there is a prevailing belief among decision-makers that public involvement processes must meet robust design criteria to be considered a credible source of information in the policy decision-making process, results gathered from a poorly designed process (i.e. the UK *GM Nation?)* have been used to support a favoured policy direction or to legitimize pre-determined decisions. Harrison and Mort (1998, p.67) viewed these practices as “technologies of legitimation,” the use of which is merely tokenistic in nature. Our findings suggest that there is a palpable tension between a ‘genuine’ desire to be fair about using public involvement to improve the quality of health policy decision-making and a self-centred interest in using it to advance health system managers’ and decision-makers’ personal agendas.

Our analysis is consistent with previous research showing that decision-maker participation in public involvement processes could help to foster new alliances between public involvement participants and decision-makers. Occasionally, however, these new forms of relationships might spawn tensions and conflicts where decision-makers are torn between accountabilities to their own organization and their new allegiances to public involvement participants (Newman et al., 2004). As in our interview findings, some decision-makers might become internal champions who would advocate for the use of public involvement findings within their organizations. The effectiveness of these internal champions, however, is often restricted by the lack of organizational commitment to taking action on the results of the involvement processes (Harrison and Mort, 1998). The extent to which champions can truly advocate for public involvement participants might also be constrained by demands of vertical managerial accountability, as observed by Martin (2009). In the context of pluralistic policy arenas as noted in case studies of user involvement processes by Harrison and Mort (1998), champions tend to strategize and use public involvement for purposes of advancing their own agendas or supporting their own views. Pilgrim and Waldron (1998) echo such concerns, noting that findings from user involvement processes were often ignored without the support of professionals and health system managers.

The third factor influencing the nature of public involvement use relates to leadership and organizational culture. Our analysis suggests that the support of the leadership such as executives and other high level decision-makers is critical to maintaining a culture of public involvement use. These findings are consistent with evidence from the literature suggesting that an organizational culture is reinforced at the deepest level of underlying assumptions or values, which are often highly influenced by the leadership or dominant figures in an organization (Schein, 1990). These dominant figures "provide a visible and articulated model of how the group should be structured and how it should function" (Schein, 1990, p.115). Our analysis of the organizational culture also reveals that there were mixed opinions about the practicality of tracking tools and reporting processes in articulating the complexity of the process of public involvement in policy decision-making. A mechanistic response based on a judgement or perception of how public involvement predicated an action within the decision-making process is likely inadequate. In light of these findings, what additional details might governments provide to meet expectations for greater transparency and accountability? Theories of the policy process might be helpful in bringing to light the patterns of relationships among members of the policy community, as well as decisional structures and tensions inherent in policy decision-making.

While we recognize the role of values, decision-maker participation in public involvement processes, and organizational culture in influencing the nature of public involvement use, it is also important to acknowledge the considerable political constraints and tensions. As other scholars have pointed out (Abelson, Forest et al., 2003; Contandriopoulos, 2004), public involvement operates in highly politicized contexts characterized by complex, 'wicked' policy problems (Ackoff, 1974; Head & Alford, 2013; Innes & Booher, 2004). Struggles between interests and actors within the policy process as well as countervailing pressures can thwart even the most committed efforts to use public involvement in policy decision-making. Past research suggests that the dynamics of these tensions might be resolved by moving towards collaborative processes whereby the public is constructed as co-producers of governments based on a “dialogic and learning partnership” (Dunston et al., 2009; Fotaki, 2011, p.46; Whitaker, 1980).

In this study we addressed three factors – values, decision-maker involvement in public involvement processes, and organizational factors – that could influence the nature of public involvement use. Further research could explore the interaction between each of these factors in greater depth, as well as validate our findings through survey research with government advisors and decision-makers at health services organizations. We expect that our findings will be of particular interest to practice communities that are concerned with unpacking and assessing the multiplicity of factors influencing how public involvement use is understood, interpreted, and operationalized in health policy decision-making.

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Chapter 5 – Conclusion

My doctoral thesis set out to examine how public involvement is used in health policy decision-making. Given the time, effort, and resources spent on public involvement activities, it seems sensible to ask how policy decision-making takes into consideration the findings gathered from these public involvement processes. Previous research studies have provided brief accounts of how public involvement may influence health policy, but have not detailed the internal dynamics and process through which it is actually used in the policy process. Hence, this thesis is guided by the following research questions: i) How is public involvement used in the health decision-making process? and ii) What factors influence the use of public involvement in the health decision-making process? These research questions are addressed through three qualitative studies organized around three main objectives:

i) To examine and clarify the concept and process of public involvement use in health policy decision-making;

ii) To examine the values and assumptions that underpin current and proposed relationships between publics and government, how these values and assumptions have evolved over time, and the meaning of public involvement itself;

iii) To identify the range of factors that might enable the use of public involvement in policy decision-making while acknowledging the considerable political and institutional constraints to such use.

In this final chapter, I will summarize the key contributions of my dissertation research and reflect on their implications for policy decision-makers and public involvement field practitioners alike, as well as for future research.

“And then a miracle occurs…”

In the famous Sidney Harris cartoon, two scientists are at the blackboard reviewing a series of steps for solving a mathematical problem. Between the series of equations to the solution, the junior professor writes, “then a miracle occurs.” The senior professor, looking vexed, points at the gap and replies, “I think you should be more explicit here in step two”.

One can draw parallels between this cartoon and the problem of how public involvement is used in policy decision-making. Traditionally, research on this topic has followed an explanatory and reductionist approach. Those who have studied the use of public involvement in policy decision-making have tended to pose questions such as:

1. What is the degree to which state legislators consider citizen input when making day-to-day policy decisions (not at all, somewhat, to a great extent)? (Alexander et al., 2010)
2. What is the degree to which citizen input causes a particular agency decision or action? (Koontz, 1999)
3. What is the congruence between the funding priorities advocated by the participants of a public involvement process and the policy decision? (Julian et al., 1997)
4. Is stakeholder input actually used and does it have real impact on final decisions? (Keough & Blahna, 2006)

As with Rich’s (1997) critique of the traditions in the study of knowledge utilization, these questions are limited to a deterministic view of how public involvement is used. This approach hinges on attribution—in other words, attributing a particular outcome to the use of specific information (e.g. the use of specific pieces of recommendations gathered from public involvement processes). It also assumes an input/output or user-producer model in which *somehow* (a.k.a. “the miracle”) findings from public involvement processes ‘enter’ the decision-making process and predicate an action of ‘use’ within the policy decision-making process (Rich, 1997). This assumption, however, runs counter to the messy and complex conditions of health policy decision-making, which is heavily influenced by institutions, interests and ideas (Atkinson & Coleman, 1992; Béland, 2005; Campbell, 2002; Hall, 1993; Hall & Taylor, 1996; Sabatier, 1991).

Taken together, my dissertation constructs a more complex and nuanced understanding of how public involvement is used in policy decision-making by recognizing the need to examine: (1) the many faces of public involvement use; (2) the fuzzy and unstable boundaries of the concept; (3) the shifting patterns and tensions of the relationship between the public and decision-makers.

The many faces of public involvement use

A main strand of philosophical discussion about concepts and concept analysis among scholars is that concepts are the “building blocks of theory” (Chinn & Kramer, 1991, p.8; Walker & Avant, 2011; Watson, 1991). In other words, concepts represent an inherent ‘truth’ and are individual units that can be linked together to form a theoretical representation of reality. This essentialist position has been criticized for the lack of consideration of changes in time, across disciplines and context or relationship with other concepts (Paley, 1996; Rodgers, 1989; Morse, 1995, p.42).

Findings from all three studies suggest that public involvement “use” is not a monolithic concept, but rather, a dynamic and complex concept that consists of many faces. First, the use of public involvement in policy decision-making can be interpreted as the relationship or interactive process between the public and the government. The presence of listening, described as being attentive to what is being said, is indicative of whether policymakers are open to providing a response to findings from public involvement, or whether it is merely glossed over as a symbolic gesture or a rubberstamping exercise. Our findings further suggest that “mediating bodies” play an important role in facilitating the process of listening and interpreting the public’s voice.

These "mediating bodies" may be staff members within organizations who play the dual role of being the trusted advisor to the government and also the champion for community residents. Their ability to "speak" and "understand" both languages allows them to facilitate the exchange of feedback between the government and the public. This feedback, or response from the government is an important component that "closes the loop" for public involvement use. A second conception of public involvement use defines it in terms of the roles and responsibilities in the relationship between the public and the government. This notion of use prompts normative questions such as, "to what extent should consumers have the right to decide how their voices are used in policy decision-making process?", and "what should be the government's responsibility to provide an account of how input was acted upon and how decisions were made?" These questions bring to light the context—a democratic versus consumerist orientation—in which public involvement operates within. Thirdly, the notion of use of public involvement in policy decision-making can be viewed as a political process in itself. In this conception, the interconnectedness between influence, power and use is characterized. As noted by Keough and Blahna (2006, p.1375), "simply listening to stakeholder concerns and showing them how their input is used" is an indication of informal power sharing. In contrast to a rationalistic process, public involvement processes interact with other types of evidence and influences within a complex and dynamic policy environment. Within this model of decision-making, public involvement processes become part of the discourse and debates within and between networks in the policy community (Pal, 1997) and are intimately intertwined in the process of "negotiation, bargaining and adjustment to influence policy" (Walt, 1994, p.49).

Fuzzy vs. well-defined boundaries

The conceptual boundaries of terms such as "the public," "involvement", and "use" are fuzzy, contingent, and unstable. In chapter 2, significant slippage was found between "use" and other concepts such as "influence," "incorporate", and "consider". The interpretation of public involvement use depends on the context and the perspective from which it is viewed. Interviewees understood public involvement use as a complicated process that interacts with other types of evidence and influences and voiced concerns that this reality might be oversimplified from the public's perspective. For example, the public might have the impression that policy decisions are solely based on or driven by public involvement.

In chapter 3, the results of the document analysis demonstrate how prevailing values and assumptions are currently shaping the practice of public involvement and how it is used, revealing a shift over the past decade from a focus on the collective public to the individual patient, consumer, and client. Viewed through the health care consumer lens, public involvement or engagement processes can be interpreted as ways in which the consumer can exercise his/her right to an active role in decision-making (to voice his/her preferences, needs, and values), as well as the right to choice. Alternately, the democratic promises of public involvement emphasize the right of citizens to participate in democratic decision-making and to enhance transparency, openness, and accountability concerning health policy decision-making. These findings suggest that the concept of public involvement use is not static and therefore cannot possibly be captured with a single definition. Moreover, they suggest that the public involvement field would benefit from asking questions that recognize the fuzzy boundaries and dynamics of public involvement, such as: How do changes to the perception of public involvement influence its use in policy decision-making? In what ways do the concepts of public involvement "use" and "influence" intersect"?

Inherent tensions

The results of this dissertation also reveal numerous tensions that characterize the dynamics of how public involvement is used in policy decision-making. In Chapter 2, three dimensions of public involvement use are observed to animate the interactions between the public and decision-makers—the decision-makers' willingness to listen to the public's input, the mediation of their relationship through "public involvement brokers", and the response from decision-makers as a signal of use. In this chapter, the tension between a democratic and consumerist approach to public involvement is brought to the forefront in reflecting on how decision-makers and governments have responded to public involvement—based on purposive (decision-makers respond based on public goals or values) vs. entrepreneurial responsiveness (responses to individuals as customers or clients of government).

This theme is further explored in Chapter 3, where findings suggest that the role of the government and its relationship with the public is currently being redefined. While the public is routinely portrayed as consumers of health care (with a focus on their rights and responsibilities), governments are increasingly assigning themselves the role of convener and enabler, facilitator, and partner. The tension between health care consumers as responsibilized agents versus co-producers of health services is yet to be resolved within the Canadian health policy discourse (Fotaki, 2011). These tensions reflect precarious shifts in values and ideas about the government, the public and public involvement in health policy decision-making in Canada.

In Chapter 4, I highlighted the range of factors that influence the nature of how public involvement is used in policy decision-making and the political constraints to such use. For instance, while there is a prevailing belief among decision-makers that public involvement processes must meet robust design criteria to be used in the policy process, results gathered from a poorly designed process might still be used if it supports a favoured policy direction (i.e. strategic use) (Greenberg & Mandell, 1991; Trostle et al., 1999). There also appears to be a palpable tension between a 'genuine' desire to be fair about using public involvement to improve health policy and a self-centred interest in using it to advance decision-makers' personal agendas. While internal champions might genuinely want to advocate for public involvement in their organizations, their effectiveness tended to be restricted by the lack of organizational commitment to taking action on the results of the involvement processes (Harrison and Mort, 1998). Past research by Harrison and Mort (1998) also suggests that the motivations of champions for supporting involvement findings might be more strategic and political in nature—

especially for user involvement processes occurring within a highly pluralistic policy arena. Harrison and Mort described their actions as "[playing the] user card" in organizational micropolitics (Harrison & Mort, 1998, p.66).

As seen, struggles between interests and actors within the policy process as well as countervailing pressures can thwart even the most committed efforts to use public involvement in policy decision-making. An analysis that includes a discussion of these inherent tensions offers a unique lens to capture the complexities of public involvement use. Future studies in public involvement could benefit from examining the role of interests to further revise and strengthen working hypotheses.

Towards accountability and transparency: moving beyond a 'miracle occurs here' analysis

In this day and age of expectations for greater transparency and accountability, how might governments respond to calls to be 'more explicit' about the use of public involvement in policy decision-making? As shown above, the traditional reductionist and deterministic approach to the study of public involvement use is wholly inadequate for capturing the system of complex, dynamic effects and tensions that emerge as an organization interacts with the public. Taken together, the studies in Chapters 2, 3, and 4 provide insight into ways in which public administrators and policy decision-makers could respond to calls for greater accountability and transparency regarding the use of public involvement in policy decision-making. Together they suggest the need to: (i) close the communication feedback loop with the public; (ii) explain public involvement use through theories of the policy process; (iii*)* consider the prospect of the public as co-producers of health care services.

Closing the communication feedback loop with the public

The lack of a report-back or response from the government to the public on how public involvement has been used in policy decision-making was a key area of concern observed in the literature and interviews. Chapter 2 findings suggest that relaying information back to the public provides the basis for the documentation of use and for demonstrating accountability and transparency (Anton et al., 2007; Bruni et al., 2007; Cook, 2002; Ebdon & Franklin, 2004; MacMillan, 2010; Phillips & Orsini, 2002; Sheedy, 2008). The public wants to know how its input is used and acted upon, and the difference (if any) that has been made in decision-making or future policy work. Being able to see and understand how decisions are reached was found to be a key factor in gauging the fairness and transparency of the decision-making process. In Chapter 2, the idea of a spectrum of responses ranging from a brief acknowledgement or expression of participation to a detailed report of how public involvement is used in policy decision-making was put forward. Given its perceived importance, what constitutes an appropriate response and what forms should it take?

As noted in Chapter 2 and 3, the general approach to responding depends on how the ‘public’ is characterized—as citizens, customers, co-producers, or a mix thereof. Bryer (2007) describes six types of “bureaucratic responsiveness” and of those, purposive, entrepreneurial, and collaborative responsiveness might be helpful in further extricating questions of how decision-makers ought to respond to the public. Purposive responsiveness appeals to the public as citizens, reflecting the extent to which public involvement contributes to helping decision-makers achieve public goals (for example, equity, justice, citizenship goals). Whereas purposive responsiveness is based on goals of equity and need, entrepreneurial responsiveness views individuals as customers or clients of government (Bryer, 2007). Entrepreneurial responsiveness might be assessed through questions focusing on the quality of customer service, and the extent to which the government has responded according to the individual needs and demands of their customers. Questions might include: “Do decision-makers listen carefully to the public’s requests and complaints? Have they helped to the extent they can? Have they personalized their responses? Have they responded promptly and courteously?" (Thomas, 2012, p.199). The aforementioned approaches to responsiveness underscore the assumption that decisions are made based on the discretion of what is right or wrong (Bryer, 2007). The third type of responsiveness that Bryer (2007) describes is collaborative responsiveness where the public is characterized as partners, collaborators, or co-producers with governments. In the partnership view, the argument for greater accountability and transparency becomes moot since the public, stakeholders, and decision-makers are seen as working together to achieving the public good. However, the extent to which collaboration and partnership occurs in Canadian health policy decision-making remains elusive.

Explaining public involvement use through theories of the policy process

As discussed earlier, public involvement is often not situated within a rational model of decision-making nor is it the primary or sole contributor to the decision. Given the complexity of the policy process, a mechanistic response based on a judgement or perception of how public involvement predicated an action within the decision-making process is likely inadequate. This type of response will likely render a reply from an unsatisfied public of the kind, "I think you should be more explicit here in step two."

What additional details might governments provide to meet expectations for greater transparency and accountability? Thurston and colleagues' (2005b) framework outlining the role of public participation in regionalized health governance might shed some light. In their framework, the influence of public involvement on the policy-making process was described in terms of its interactions with the policy community, as well as the coupling of the policy and problem streams, to provide a window for policy change. Drawing from their research and the literature on theories of policy process, policy analysts or public involvement practitioners could use the following recommendations to frame their responses to the public. These recommendations bring to light the patterns of relationships among members of the policy community, as well as decisional structures and tensions inherent in policy decision-making:

1. Explore the role played by participation entrepreneurs and champions both inside and outside of government in constructing and utilizing agenda-setting opportunities (Kingdon, 2002).
2. Monitor the way in which public involvement contributes to changes in the national mood, and how changes in the national mood may affect agenda-setting processes (Kingdon, 2002).
3. Explore how public involvement contributes to the policy image—the beliefs and values related to a policy issue—and how changes to the policy image as a result of the interaction of public involvement and other influences could dissolve powerful stakeholder groups and lead to changes in policy outcomes (Baumgartner & Jones, 1991).
4. Explore how public involvement contributes to changes in public opinion, which can disrupt the status quo of stakeholders and policy actors who seek to influence policy (for example, focusing public attention, attract attention of key decision-makers, redistribution of resources) and thereby influencing policy change (Weible & Sabatier, 2006).
5. Characterize the patterns and tensions of social relations between interdependent actors and how public involvement contributes to the potential and type of policy change through the structure of the policy network (i.e. the distribution of power—concentrated or fragmented, and the type of interaction—conflict, negotiation, or cooperation) (Adam & Kriesi, 2007).

The next frontier—the public as co-producers of health care services?

Public involvement operates in highly politicized contexts characterized by complex, ‘wicked’ policy problems (Ackoff, 1974; Head & Alford, 2013; Innes &

Booher, 2004). Past research has shown that issues of accountability and transparency might be resolved by moving towards collaborative processes where the public act as co-producers of health care services and policies. Again, I draw on the Sidney Harris' cartoon as an analogy. If the junior scientist worked out the steps to the mathematical problem in collaboration with the senior professor, the point, "be more explicit here in step two", becomes moot since both of them arrived at the solution together and were 'co-producers' of the final solution.

According to Dunston and colleagues (2009), however, the public is often considered as being outside of the domain of health service production within the context of public involvement—where consumers and citizens are providing 'voice' and exercising 'choice' in relation to the consumption of health services or on health service priorities. In a co-production model, the public works alongside with health professionals and other stakeholders as co-participants, co-designers and co-producers of the process for producing health care services (Dunston et al., 2009). Co-production is therefore, "the provision of services through regular, long-term relationships between professionalized service providers (in any sector) and service users or other members of the community, where all parties make substantial resource contributions" (Bovaird, 2007, p.847). As co-producers, the public is considered as being inside the domain of health service production. The public as co-producers of services is empowered to become actively involved in decision-making that is based on co-learning and a "dialogic partnership" (Dunston et al., 2009; Fotaki, 2011, p.46; Whitaker, 1980). Their right to voice is also accompanied by political influence. However, researchers have been careful to note that co-production "is not a panacea" (Bovaird, 2007, p.856). The promises of co-production might be spoiled by problems such as conflicting values, unclear roles and responsibilities, and power imbalances. In situations where there is a high degree of individualism but a low level of power, health services users instead become responsibilized agents with little to no control over choice and voice (Fotaki, 2011). Future research could examine the prospect of decision-makers, service providers, stakeholders and citizens in working and learning together for the co-production of health care services in Canada.

Strengths and limitations

Together, the three studies in this dissertation provide unique insights into previously uncharted territory about the internal dynamics of how public involvement is used in policy decision-making. The concept of public involvement use, as presented in this thesis, is complex, constructed, and context dependent. It does not have confined boundaries but can be characterized by its inherent patterns, paradoxes, and tensions. This approach to analyzing the internal dynamics of public involvement use represents a unique opportunity to reveal the dynamics of changes and evolution, as well as its relationship within a network of related constructs.

Issues of trustworthiness and authenticity, including credibility, transferability, dependability, and confirmability are important to consider for any qualitative studies (Lincoln & Guba, 1986). The credibility of this thesis was addressed by ensuring that data was collected from a variety of sources, including the academic literature, grey literature, semi-structured interviews with experts who have theoretical and practical insights on public involvement, as well as Canadian government policy documents. A potential threat to the credibility of this thesis was that key informants often spoke for members of the public as the latter were not selected to participate in the interviews. Furthermore, there was a bias and overemphasis in the interview responses on rational processes and bureaucratic rules to explain factors influencing the nature of how public involvement is used in chapter 4. This bias might be explained by factors related to the sample of key informants and the type of policy issue. Since our sample relied more heavily on public involvement practitioners and did not include senior decision-makers (due to issues of access), findings might have reflected a more naïve set of perspectives on public involvement use. Alternately, public involvement practitioners might have felt that it was not socially acceptable to acknowledge the tensions of policy decision-making. To overcome these shortcomings, I obtained the views of scholars and the views of the public through the in-depth literature review. I also maintained self-reflective memos throughout the research process to document possible biases and preconceptions. To ensure the transferability of this study, which refers to the degree to which findings of a study can be applied to other areas, I provided a detailed description of the data collection and analysis process. The audit trail will enable other researchers to determine if the conclusions of this thesis can be transferred to their area of study. I have also addressed the issue of dependability by providing a clear explanation of the process of coding and categorizing, thus ensuring that other researchers can be confident about the quality of data collection, analysis, and theory generation. Finally, I overcame the challenge of integrating the range of data sources by developing a guide to facilitate analysis, asking questions such as: To what extent do the data from the in-depth literature review and interviews converge and diverge? How and why? How do the same types of findings confirm and disconfirm each other? This approach to analysis was key to establishing the thesis' confirmability.

Future research

Having offered many new insights into the internal dynamics of how public involvement is used in policy decision-making, there remain areas of research that can be further explored. First, while we addressed the question of "who" mediates use in Chapter 2, our findings did not provide insights as to how this mediating process occurs. Given our findings on the lack of documentation of use, further research can explore effective strategies for detailing the use process. Second, findings on the prevailing values and assumptions that are currently shaping the practice of public involvement in the Canadian health policy context could be further validated through in-depth interviews with health system managers, policy makers, and decision-makers. What remains unclear is whether health users think of themselves as consumers, customers, or clients of health care. Interviews with health users in the United Kingdom suggested that they perceive themselves as patients rather than consumers (Clarke & Newman, 2007). The Canadian public's perspective on the shift from the collective to the individual patient, consumer, and client is warranted. Similarly, emerging trends of co-production, collaboration, and partnership in the United Kingdom and elsewhere in Europe could be explored in the Canadian context to assess the public's willingness to assume the role of co-producers of health and social services (Dunston et al., 2009; Fotaki, 2011). Lastly, future research could also focus on extending and validating our findings on the factors identified in Chapter 4 through survey research with government advisors and decision-makers in health service organizations.

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APPENDICES

Appendix A

INVITATION LETTER TO PROSPECTIVE INTERVIEWEES

The Use of Public Involvement in Canadian Health Policy Decision-making

Date

Dear Dr./Mr./Ms. [Name of prospective interviewee],

I am writing to invite you to participate in an interview for a research study: *The Use of Public Involvement in Canadian Health Policy Decision-making*. The study is part of a doctoral thesis in the Health Policy program at McMaster University (Ontario, Canada). The members of the supervisory committee are researchers from McMaster University: Dr. Julia Abelson, Dr. Mita Giacomini, Dr. Damien Contandriopoulos. This study is funded by the Canadian Institutes of Health Research.

The purpose of this study is to explore and understand the concept of 'use' of public involvement in health policy decision-making. This study is part of a larger project to understand how public involvement is used in health policy decision-making, and the factors that influence its use. As part of this study, I will interview scholars, policy-makers, health system managers and representatives of non-governmental agencies and think tank groups across Canada. The expected outcome of this project is a conceptual framework that describes how public involvement is used in health system decision-making.

I expect the telephone interview to take approximately 1 hour. Your responses will be kept confidential. The interview will be tape recorded (with your permission), and identified by a confidential number. Data will not be reported in a way that could potentially identify individual study participants. Study reports may, however, include examples presented during the interview. I will contact your office following receipt of this letter to ask if you are willing to participate. I hope very much that you will. Obtaining the perspectives of individuals with your expertise is critical to the project's success.

If you have questions or wish to obtain additional information about this study, please do not hesitate to contact me.

Sincerely,

Kathy Li

Appendix B

INFORMATION/CONSENT FORM FOR INTERVIEW PARTICIPANTS

The Use of Public Involvement in Canadian Health Policy Decision-making

Local Principal Investigator: Dr. Julia Abelson, PhD, McMaster University, Centre for Health Economics and Policy Analysis (Supervisor)

Principal Investigator: Kathy Li, PhD in Health Policy (Candidate), McMaster University, Centre for Health Economics and Policy Analysis

Purpose of the Study

You are invited to participate in a research study on the use of public involvement in Canadian health policy decision-making. The purpose of this study is to explore and understand the concept of 'use' of public involvement in health policy decision-making. This study is part of a larger project to understand how public involvement is used in health policy decision-making, and the factors that influence its use. Obtaining the perspectives of individuals with your expertise is critical to the project's success.

As part of this study, we will be interviewing about 30-40 scholars, policy-makers, health system managers and representatives of non-governmental agencies and think tank groups across Canada. The expected outcome of this project is a conceptual framework that describes how public involvement is used in health policy decision-making.

The study is part of a doctoral thesis in the Health Policy program at McMaster University (Ontario, Canada). The members of the supervisory committee are researchers from McMaster University: Dr. Julia Abelson, Dr. Mita Giacomini, Dr. Damien Contandriopoulos. This study is funded by the Canadian Institutes of Health Research.

Procedures Involved in the Study

In signing this form, you agree to participate in a telephone interview as part of the research study. This interview will take approximately 1 hour.

Voluntarism

Your participation in this research study is voluntary. You are free to withdraw at any time from the study and without prejudice. If you decide to withdraw from the interview, any data you have provided to that point will be destroyed unless you indicate otherwise.

Confidentiality

Your interview will be recorded with your permission and transcribed for later analysis by the investigator. Your name and contact information will be collected but will be kept separate from your interview transcript, which will be labeled with an anonymous number/letter code. Your identity will be kept confidential by removing your name and position in the research reports so that readers cannot attribute any quote to you. We will not be seeking permission for unattributed quotes, but in instances where the unattributed quote deals with a sensitive matter, we will contact you and ask for your permission to quote this specific statement.

During the interview, if there is any private, confidential or sensitive information that you provide to the interviewer, we ask that you clarify whether this information may be quoted or cited in the research report. If the information is sensitive for any reason, it will be considered during the analysis but will not be cited in the research reports. All data collected will be kept for 10 years as recommended by the Hamilton Health Sciences/Faculty of Health Sciences Research Ethics Board. The data will be kept in a locked office in secure paper and electronic files that will be accessible only to the investigator.

The Costs and Benefits of Taking Part in the Study

There are no physical risks involved in participating in this study. The main cost to you is the time you take to participate in the interview. We will pay for all telephone charges associated with conducting the interview. There may also be some modest social and psychological costs associated with your participation in the study. You may feel that you are revealing information that could negatively affect you or your organization when we ask you to comment on your experiences about the use of public involvement in your organization's decision-making processes. We will minimize these costs by ensuring complete confidentiality of your responses, and by offering you're the flexibility to choose the time and location for the interview, and to provide you with assurances that you may withdraw from your interview/and or study without prejudice at any time if you feel uncomfortable with your participation.

There may or may not be any direct benefit to you if you agree to participate in this study. We believe that study participants may directly benefit from our research as they approach the topic of the 'use of public involvement in health system decision-making' in the future. We hope that the results will be of interest to you, and that they will be of great value to the investigator. We will send you a copy of all research reports prepared throughout the study.

Questions

Please contact Kathy Li, the Principal Investigator for this study, if you have questions or require more information about the study itself. You may also contact the Local Principal Investigator and PhD supervisor, Dr. Julia Abelson.

CONSENT FORM FOR INTERVIEW PARTICIPANTS

The Use of Public Involvement in Canadian Health Policy Decision-making

Participant
I have read the preceding information thoroughly. I have had an opportunity to ask questions and all of my questions have been answered to my satisfaction. I agree to participate in this study. I understand that I will receive a signed copy of this form.

Name	Signature	Date

Person obtaining consent
I have discussed this study in detail with the participant. I believe the participant understands what is involved in this study.

Name, Role in Study	Signature	Date

This study has been reviewed by the Hamilton Health Sciences/McMaster Faculty of Health Sciences Research Ethics Board (HHS/FHS REB). The REB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call The Office of the Chair, HHS/FHS REB at 905.521.2100 x 42013.

Appendix C

INTERVIEW GUIDE

Draft Interview Guide – Key Informant Interviews

The Use of Public Involvement in Canadian Health Policy Decision-making

Introduction

- Description of the study and ethical guidelines
- Confirmation of interview length (approximately 1 hour)
- Any questions from interviewee before we start the interview

Biographical questions about the interviewee

1. Could you please describe your position and work?

   Probes:
   - How long have you been in this position?
   - Please describe how your position related, if at all, to public involvement and health system decision-making (e.g. role in decision-making, experiences with public involvement)

Questions about 'the use of public involvement in health system decision-making'

3. How is 'use of public involvement' defined or talked about among decision makers (in your organization, in the LHIN, among the clients with whom you have worked?)

4. What other words/terms or phrases have you heard used in the health sector to describe 'use' of public involvement in decision-making? In other words, what other terms can you think of that are used interchangeably with 'use'? (surrogate terms)

   Probe:
   - *How would you distinguish between the concept of 'use' and the following terms—'considered', 'contributes', 'incorporate', 'integrate', 'incorporate'—in the context of public involvement in decision-making?*

5. Do you think that there is interest about the use of public involvement [results] in health system decision-making? (context)

   Probes:
   - *Why or why not is there interest in this issue?*

- *Who has been interested? Who has not been interested?*
- *Why have they been interested in this issue?*
- *Is this an issue that we should be interested in? Why or why not?*

6. Could you tell me about your definition or characteristics that best reflect 'use' of public involvement in health system decision-making? (attributes of the concept)

7. What are the types of 'use' of public involvement in decision-making? (reference)

   Probes:
   - *Can you provide an example for each of the types of 'use' you mentioned? Try to describe the process in detail?*
   - *Which type(s) of 'use' would you say is most frequently observed in your organization? In general?*

8. What other concepts can you think of that are closely related to the concept of 'use' (related terms)?

   Probes:
   - *What do you see as the relationship between 'use' of public involvement results in decision-making and 'accountability'?*
   - *What about between 'use' and 'transparency'?*
   - *What about between 'use' and 'public trust'?*

9. Is there any evidence of 'use' of public involvement in the decision-making process in your organization (measurement)?

   Probes:
   - *If so, to what extent would you say that public involvement are used in the decision-making process in your organization?*
   - *Do you think there were differences between how public involvement was intended vs. how it was actually used in the decision-making process?*

10. What do you see as some of the necessary conditions/circumstances required before public involvement results can be used in decision-making? (antecedent conditions)

    Probe:
    - *What stands in the way of using public involvement results in decision-making?*

11. What would be the consequences/outcomes of using public involvement in decision-making? What are the consequences of not using public involvement in decision-making? (consequences)
12. What factors should health care managers or decision-makers be aware of when 'using' public involvement in decision-making? (context)
    Probe:
    - *Policy goals*
    - *Power relations and control over the policy process*
    - *Institutional factors—functions and roles of the Cabinet, legislators, bureaucracy, government officials*
    - *Role of competing interests/stakeholders, and their voices*
    - *Role of culture, preferences and ideologies about the use of public involvement in decision-making (e.g. value of public involvement)*

13. How should public involvement be used in the decision-making process? (e.g. what role do you hope public involvement plays in the decision-making process) (context)

Conclusion
I have no other questions for you. Is there anything you would like to add before we complete the interview? Do you know of any individuals who could greatly contribute to the study? (e.g., scholars, policy-makers, representatives of think tank groups).

Thank you very much for your participation!

Appendix D

LIST OF DOCUMENTS ANALYZED IN CHAPTER 3

Province	Organization	Date	Title
AB	Alberta Health Services	2009	Health Advisory Council Charter
AB	Alberta Health Services	2009	Alberta Health Services Strategic Direction 2009-2012
AB	Government of Alberta	2010	Alberta Health Act
AB	Calgary Regional Health Authority	2001	Public Participation Framework
BC	Interior Health	2011	Community Engagement Framework
BC	Fraser Health	2009	Community Engagement Framework
BC	Fraser Health	2006	Fraser Health/Municipal Government Advisory Council Terms of Reference
BC	Vancouver Coastal Health	2009	Community Engagement Framework
BC	Vancouver Coastal Health	2010	Community Engagement Advisory Network Terms of Reference
BC	Vancouver Coastal Health	2010	Community Engagement 2009-2010
BC	Vancouver Coastal Health	2011	Community Engagement 2010-2011
BC	Vancouver Island Health Authority	2009	Five year strategic plan 2008-2013
MB	Manitoba Health	2003	Consumer participation in mental health services planning, implementation and evaluation
MB	North Eastman DHAC	2011	Board Policy GP.22 Board Linkages -District Health Advisory Council
MB	Parkland DHAC	2010	Health Advisory Council Terms of Reference
MB	Winnipeg DHAC	2005	Winnipeg CHAC Terms of Reference
MB	Manitoba Health	2009	Community Health Assessment Guidelines
MB	Manitoba Health	2002	Primary Health Care Policy Framework
NAT	Health Canada	2000	The Health Canada Policy Toolkit for Public Involvement in Decision Making
NAT	Health Canada	2000	Health Canada decision-making framework for identifying, assessing, and managing health risks
NAT	Health Canada	2000	HPFB Public Involvement Framework
NAT	Mental Health Commission of Canada	2009	Toward Recovery and Well-Being: A Framework for a Mental Health Strategy for Canada
NAT	Romanow Commission	2002	Building on Values: The Future of Health Care in Canada
NAT	Public Health Agency for Canada	2004	A Public Health Agency for Canada: Citizen Engagement
NB	New Brunswick	2009	It's more than talk: listen learn and act a new model for public engagement. The final report of the Public Engagement Initiative

Province	Organization	Date	Title
NB	New Brunswick Health Council	2010	2010-2011 Business Plan
NL	Newfoundland and Labrador- Multi-jurisdictional collaboration	2006	Guiding facilitation in the Canadian context: enhancing primary health care
NL	Government of Newfoundland and Labrador	2005	Working together for mental health: A provincial policy framework for mental health & additions services
NS	Nova Scotia Capital Health	2011	Engagement policy
NS	Nova Scotia Capital Health	2011	Engagement framework and toolkit
NS	NS Legislature	2009	Bill No. 52 Emergency Department Accountability Act
NWT	Health and Social Services	2002	NWT Primary Community Care Framework
NWT	Health and Social Services	2004	NWT Integrated Service Delivery Model
ON	Health Quality Council	2008	Strategic Plan
ON	Ministry of Health and Long-Term Care	2010	The Excellent Care for All Act
ON	Central East LHIN	2006	Framework for Community Engagement & Local Health Planning
ON	Central East LHIN	2011	Central East LHIN Community Engagement Workplan 2011-12
ON	Central LHIN	2011	Central LHIN 2011-2012 Community Engagement Plan
ON	Central LHIN	2006	Community Engagement Strategy/Framework
ON	Central West LHIN	2011	Central West LHIN Community Engagement Plan 2011-12
ON	Central West LHIN	2006	Community Engagement Strategy/Framework
ON	Champlain LHIN	2011	Champlain LHIN Community Engagement Strategy 2011-12
ON	Champlain LHIN	2006	Community Engagement Strategy/Framework
ON	Erie St Clair LHIN	2011	Erie St Clair LHIN Annual Community Engagement Annual Plan
ON	OHTAC	2010	OHTAC Decision Determinants Guidance Document
ON	Erie St Clair LHIN	2006	Community Engagement Strategy/Framework
ON	Hamilton Niagara Haldimand Brant LHIN	2011	Hamilton Niagara Haldimand Brant LHIN Community Engagement Plan
ON	Hamilton Niagara Haldimand Brant LHIN	2006	Community Engagement Strategy/Framework
ON	LHIN	2011	LHIN Community Engagement Guidelines and Toolkit
ON	Ministry of Health	2006	Health Planner's ToolKit- Community Engagement
ON	Mississauga Halton LHIN	2011	Mississauga Halton LHIN Community Engagement Plan 2011-12
ON	Mississauga Halton LHIN	2006	Community Engagement Strategy/Framework
ON	North East LHIN	2011	North East LHIN Annual Community Engagement Plan 2011-12

Province	Organization	Date	Title
ON	North East LHIN	2006	Community Engagement Strategy/Framework
ON	North East LHIN	2006	Engaging Aboriginal Peoples
ON	North Simcoe Muskoka LHIN	2006	Community Engagement Strategy/Framework
ON	North Simcoe Muskoka LHIN	2016	North Simcoe Muskoka LHIN Community Engagement Plan 2011-12
ON	North West LHIN	2011	North West LHIN Annual Community Engagement Plan 2011-12
ON	North West LHIN	2006	Community Engagement Strategy/Framework
ON	South East LHIN	2006	Community Engagement Framework
ON	South West LHIN	2012	South West LHIN Communications & Community Engagement Plan 2011-2013
ON	South West LHIN	2013	South West LHIN Communications & Community Engagement Plan 2010-11
ON	South West LHIN	2006	IHSP 2007-2010 Community Engagement Framework
ON	Toronto Central LHIN	2006	Community Engagement Strategy/Framework
ON	Toronto Central LHIN	2014	Toronto Central LHIN Community Engagement Plan 2011-12
ON	Waterloo Wellington LHIN	2006	Community Engagement Strategy/Framework
ON	Waterloo Wellington LHIN	2015	Waterloo Wellington LHIN Community Engagement Plan
ON	Government of Ontario	2006	LHIN Act, 2006
QC	Government of Quebec	2012	An Act Respecting Health Services and Social Services R.S.Q., chapter S-4.2
QC	Government of Quebec	2012	An Act Respecting the Health and Welfare Commissioner R.S.Q. chapter C-32.1.1
QC	The Health and Welfare Commission of Quebec	2008	Code of Ethics for the Consultation Forum of the Health and Welfare Commissioner
QC	The Health and Welfare Commission of Quebec	2009	2009 Appraisal Report on the Performance of Quebec's Health and Social Services System
PEI	Saskatchewan Ministry of Health	2009	Health Governance Advisory Council
SK	Saskatchewan Health Population Health Branch	2010	Saskatchewan's HIV Strategy 2010-2014
SK	Saskatchewan Ministry of Health	2002	A Population Health Promotion Framework for Saskatchewan Regional Health Authority
SK	Saskatchewan Health	2003	Guidelines for the Development of A Regional Health Authority Plan for Primary Health Care Services
SK	Saskatchewan Primary Health Services Branch	2004	Healthier places to live, work and play: A Population Health Promotion Strategy for Saskatchewan
SK	Department of Health and Social Services	2002	The Saskatchewan Action Plan for Primary Health Care
YU	Yukon Health and Social Services Council	2010	Yukon Health and Social Services Council Terms of Reference