Examining Civil Society Participation in the Health Sector: The Case of Brazil’s Health Councils

by

Martha Gabriela Martinez Malagon

A thesis submitted in conformity with the requirements for the degree of Masters of Science
Department of Pharmaceutical Sciences
University of Toronto

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Department of Pharmaceutical Sciences
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Abstract

This thesis focuses on Brazil’s Health Councils (Conselhos de Saude) to explore challenges in institutionalizing civil society participation. By conducting interviews with Health Council members at the municipal, state and national levels, this thesis examines how Health Councils operate and identifies some of the challenges evident in institutionalizing civil society participation. The thesis reports that Health Councils lack autonomy from the government to fulfill their mandate, membership guidelines limit the level of inclusion of civil society members, government representatives manipulate other members and provide limited support for Health Councils. In addition, it also reports that there is a lack of resources necessary to run Health Councils, there is an inadequate level of training of Health Council members, and there is a reported strong sense of individualism amongst members. These issues appear to have an impact on Health Councils’ ability to successfully fulfill their mandate.
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Chapter 1
Introduction

During Brazil’s transition from a military regime to a democratic one, a new constitution was introduced in 1988. During this time, Brazil’s healthcare system was concurrently reformed, resulting in the creation of the Sistema Único de Saúde (SUS) (Collins, Araujo, & Barbosa, 2000). SUS is rooted in principles of universal and equitable healthcare access, decentralization and civil society participation and provides health services and medicines to 202 million people (Pan American Health Organization, 2012). It is estimated to be the sole healthcare provider for at least 75% of the entire Brazilian population, making it the biggest public health care system in the world (de Vettori, 2014; Pan American Health Organization, 2012).

The decision-making processes in SUS are comprised of a network of state and non-state actors that operate at the municipal, state and federal levels, each of which play a different role in the provision of health services. The multiple state and non-state actors involved in decision-making, coupled with high degrees of decentralization, have created challenges for the implementation of national health plans, the provision of healthcare services, and the overall performance of SUS (Collins et al., 2000). The Brazilian federal government has focused on addressing these challenges by introducing institutions that aim to increase good governance in the public healthcare sector. Civil society participation is a principle of good governance that Brazil has focused on promoting, as it is said to improve “development outcomes, reduce poverty, and encourage peace by promoting social inclusion” (Bhargava, 2015, p. 3).

Today, civil society plays a role in Brazil’s public sector through the participation of various advisory groups formally recognized by the government. For example, specific to the healthcare sector are Health Councils (Conselhos de Saúde), which were created in 1990 (Barnes & Coelho, 2009). Brazil’s Health Councils are permanent advisory bodies that are part of SUS and that exist at the federal, state and municipal levels of government. Health Councils provide civil society with opportunities to participate in decision-making, in the monitoring of the public health budget and the performance of the healthcare system.

This thesis aims to explore how Health Councils operate and to identify the challenges to civil society’s participation within them. This thesis was carried out with the aim of providing a
greater understanding of the challenges involved in institutionalizing civil society participation within Health Councils.

1 Good Governance and Civil Society Participation

1.1 What is Governance?

In a report published in 2006, the United Nations Economic and Social Council acknowledged that there is a lack of consensus on what ‘governance’ means (United Nations, 2006). The term governance has been used for centuries and its definition has changed over time (Singleton & Rubin, 2014). Generally, governance is considered to be a synonym for ‘government’ and was used to describe how a nation was administered, governed and regulated (Weiss, 2000).

However, definitions for the term have recently moved away from a focus on state actors and towards considering and recognizing non-state actors and the role they play in the decision-making process (Weiss, 2000). As a result, the term ‘governance’ is often used to go beyond domestic politics and the traditional views of ‘government’ (Weiss, 2000).

International organizations, such as the United Nations Development Program (UNDP) and the World Bank define governance differently. For example, in 1997 governance was defined by the UNDP as “the exercise of political, economic and administrative authority in the management of a country’s affairs at all levels. It comprises the mechanisms, processes and institutions through which citizens and groups articulate their interests, exercise their legal rights, meet their obligations and mediate their differences” (United Nations, 2006). In comparison, in 1993, the World Bank defined governance as “the manner in which power is exercised in the management of a country’s political, economic and social resources for development” (World Bank, 1994, p. vii). These different definitions of governance are a result of its adaptation into different disciplines (van Doeveren, 2011). Rosenau (1999) argues that definitions for governance ultimately “refer to mechanisms for steering social systems towards their goals” (Rosenau, 1999, p. 296).

The term governance gained traction within the international community in the 20th Century, specifically after the collapse of the Soviet Union. The World Bank and the International Monetary Fund (IMF) (United Nations, 2006) both promoted governance in their policy and programming in client countries. In 1989, the World Bank published a report that attributed the
failures in development strategies used by financial institution to countries’ weak institutional arrangements (World Bank, 1989). As a result, the World Bank began to focus on addressing ‘bad governance’, which it characterized as the presence of a lack of human rights, high levels of corruption and a lack of accountable and democratic governments (van Doeveren, 2011; Weiss, 2000). With this change, the term governance eventually morphed into ‘good governance’, becoming a policy strategy and a pre-condition for providing foreign aid (van Doeveren, 2011; Weiss, 2000).

1.2 What is Good Governance?

Like governance, good governance is a term that also lacks a common working definition. Good governance can be considered to be a ‘meta-concept’ due to the inability to concretely define the characteristics it is based upon (van Doeveren, 2011). Nevertheless, good governance is often defined by describing a variety of principles, which also vary depending on organizational ideologies (van Doeveren, 2011). For example, the United Nations defines good governance as a form of governance that is “participatory, consensus oriented, accountable, transparent, responsive, effective and efficient, equitable and inclusive and follows the rule of law. It can help to minimize corruption, take the views of minorities into account and help to ensure that the voices of the most vulnerable in society are heard in decision-making. It is also responsive to the present and future needs of society” (Srivastava, 2009). In contrast, the World Bank’s view on good governance is centered on the promotion of economic growth through the effective management of the public sector. It identifies six dimensions: voice and accountability, political stability and the absence of violence, regulatory quality, government effectiveness, control of corruption and rule of law (World Bank, 2016). Critics of the World Bank’s conceptualization of good governance argue that it puts too much emphasis on public sector performance and downplays the important role non-state actors such as the private sector and donor agencies play in governance structures (Dodgson, Lee, & Drager, 2002). The UNDP’s definition of good governance focuses, on the other hand, on empowerment through the promotion of human rights and civil liberties (Weiss, 2000). It emphasizes the importance of democracy, freedom of association, participation and freedom of press (Dodgson et al., 2002). Weiss (2000) summarizes that the discourse on good governance is ultimately centered on improving governance structures and institutions in order to promote democracy, human rights and economic growth (Weiss, 2000).
In the healthcare sector, good governance is a focal point of discussion due to rising healthcare costs, the increase in funding and foreign aid to improve health outcomes, and the need to ensure return-on-investment (Siddiqi et al., 2009; WHO, 2010). Governance is one of the six building blocks of the health system and it “involves ensuring strategic policy frameworks exist and are combined with effective oversight, coalition-building, regulation, attention to system-design and accountability” (World Health Organization, 2007, p. vi). Good governance in the healthcare sector is considered to be important because of the sector’s complex governance structure. The healthcare sector is made up of a complex network of state and non-state actors (such as government, the private sector, not-for-profit providers, civil society) that play an active role in the provision of healthcare services (Avelino, Barberia, & Biderman, 2014; Siddiqi et al., 2009). The sector is also highly decentralized, which creates challenges for the effective standardization and monitoring of health service provision and for effectively governing all the actors involved in the healthcare system (European Commission, 2013; Siddiqi et al., 2009). Good governance is said to help manage these challenges by creating proper checks and balances for managerial and financial oversight, increasing accountability and promoting human rights. Hence, good governance in the healthcare sector is considered to be an approach that can likely help improve health outcomes (Siddiqi et al., 2009).

1.3 Civil Society Participation

Civil society participation in the design, implementation, and monitoring of policies and programs is considered to be a key feature of good governance (Srivastava, 2009). Connor (1999) defines civil society as consisting of “a range of local groups, specialized organizations and linkages between them to amplify the corrective voices of civil society as a partner in governance and the market” (Connor, 1999). It is considered to be a ‘third sector’ of society that is increasingly becoming a key player in state affairs.

Civil society participation in decision-making has been used since the ancient Greek times. Its contemporary use was shaped in the 18th Century by political theorists, such as Thomas Paine and George Hegel, who put forward the argument that civil society is a separate entity of the state but operates side-by-side to it (Ghaus-Pasha, 2005). In the healthcare sector, civil society participation in decision-making was formally endorsed globally at the Alma Ata Declaration in 1978. In this Declaration, access to health services was recognized as a human right and equity in
healthcare access through the encouragement of public participation was endorsed (WHO, 1978). It is a principle of good governance that is endorsed by international players such as the United Nations (UN), the European Union (EU) and the Organization for Economic Co-operation and Development (OECD). Today, civil society participation takes shape in a variety of forms that range from religious organizations, patient groups, mass movements and professional organizations to registered formal bodies (Ghaus-Pasha, 2005). Within the healthcare sector, civil society participation has been used in many countries like the United Kingdom, Canada, and Brazil (Abelson & Gauvin, 2006; Tritter, 2011). Brazil’s Health Councils, which are the focus of this thesis, illuminate how civil society participation has been involved in the health sector.

Civil society participation is thought to promote good governance in a variety of ways. It is perceived to empower civil society, especially marginalized civil society groups, by increasing access to information on decisions taken by governing bodies (Ghaus-Pasha, 2005; McGee & Gaventa, 2010; Mitton, Smith, Peacock, Evoy, & Abelson, 2009). Civil society participation is also said to facilitate the articulation of societal demands and concerns and the mobilization of marginalized groups into politics and decision-making (Abelson, Warren, & Forest, 2012; Blacksher, Diebel, Forest, Goold, & Abelson, 2012). This may then translate into policies that are well informed and reflective of societal needs, which can increase equitability in healthcare access (Abelson et al., 2012; Blacksher et al., 2012). This is particularly relevant to the healthcare sector, since it can help governments select what initiatives to prioritize and how to allocate funding based on public demand and preferences (Solomon & Abelson, 2012).

Depending on the level of engagement with civil society, their participation is said to increase the probability of change by taking part in the decision-making process and by operating as regulators and monitors of the performance of the public sector and its governing bodies (McGee & Gaventa, 2010).

Governments can use civil society participation to reduce public opposition to new or existing initiatives. Irwin (2006) argues that civil society participation increases transparency in the decision-making process, which can then decrease skepticism towards government decisions and can increase ownership of decisions taken among the public (Irwin, 2006). Lastly, civil society participation is also said to help increase social capital, which is defined by the OECD as
“networks together with shared norms, values and understandings that facilitate co-operation within or among groups” (Côté, Helliwell, & Field, 2001, p. 12).

All of these features of civil society participation support two other good governance principles, transparency and accountability, both of which are typically intertwined. Transparency is defined as “the principle of enabling the public to gain information about the operations and structures of a given entity” (Etzioni, 2010, p. 389). Transparency can reduce uncertainty in stakeholder behavior and information asymmetries between decision-makers and those affected by their decisions, which helps the public gain a better understanding of the reasons why decisions are taken (de Fine Licht, 2011). It also can help expose inefficiency and corrupt activity by providing access to information that facilitates the monitoring of the performance of the public sector (Cucciniello, Porumbescu, & Grimmelikhuijsen, 2016; European Commission, 2013; Hussmann, 2011; Kohler, 2011; OECD, 2015; Vian, 2008; Wiehen & Transparency International, 2006). Civil society participation promotes transparency by giving civil society access to important information. Thus, civil society participation can be considered a mechanism through which transparency can be increased in the public sector.

In addition to the above, accountability is defined as “the obligation of individuals or agencies to provide information about, and/or justification for, their actions to other actors, along with the imposition of sanctions for failure to comply and/or to engage in appropriate action” (Brinkerhoff, 2004, p. 372). Accountability involves the establishment of goals, the monitoring and evaluation of performance, the enforcement of rules and regulations, sanctions for under-performance or illegal behavior, and the institutional capacity to carry out all of these functions (Brinkerhoff, 2004). Civil society participation is considered to be a way to ensure accountability in the public sector, since it can be used to monitor performance and the allocation of resources (Brinkerhoff, 2004). In the healthcare sector, civil society participation can help hold actors involved in the provision of health services accountable for their actions and performance (Ghaus-Pasha, 2005). Thus, civil society participation promotes transparency and accountability by creating a process whereby information is more readily accessible and civil society can actively participate in the monitoring and evaluation of public sector policies, programmes and their impact (Ghaus-Pasha, 2005).
2 Institutionalizing Civil Society Participation

As previously outlined, civil society participation is a principle of good governance that can help increase transparency and accountability by providing access to important information on the decision-making process to citizens and by engaging them in the formulation and monitoring of policies and programmes. Good governance, and more specifically, civil society participation are supported globally. The former United Nations Secretary General Kofi Annan stated that “good governance is perhaps the single most important factor in eradicating poverty and promoting development” (Siddiqi et al., 2009). Good governance is considered to be a key determinant for economic growth, social advancement and development (Siddiqi et al., 2009). Most recently the newly established Sustainable Development Goals (SDGs)\(^1\), which define the future global development agenda, specifically discuss the need to “develop effective, accountable and transparent institutions at all levels,” along with “responsive, inclusive, participatory and representative decision-making at all levels” (Nino, 2016).

Despite the international support for good governance and civil society participation, there is little to no guidance on how to institutionalize them (Singleton & Rubin, 2014). This is a problem that involves a general discussion on institutional design. Institutions are defined as the formal and informal “constraints that human beings devise to shape human interaction” that define “both what individuals are prohibited from doing, and, sometimes, under what conditions some individuals are permitted to undertake certain activities” (North, 1990, p. 4). Institutions include “the political organizations, laws and rules that are central to every political system and they constrain how decision-makers behave” (John, 1998, p. 38). Since good governance involves establishing institutions that serve as the mechanisms through which good governance principles are achieved, institutional design plays a key role in the institutionalization of good governance and civil society participation. No concrete guidance exists on how to design institutions that promote civil society participation and good governance, which creates challenges for effective policymaking (Singleton & Rubin, 2014).

In addition, empirical evidence that directly links good governance and civil society participation to positive health outcomes is generally lacking (van Doeveren, 2011). For example, at the

\(^1\) A full list of the Sustainable Development Goals can be found at https://sustainabledevelopment.un.org/sdgs.
international level, the multi-stakeholder initiative, most recently led by the WHO and Health Action International, the Medicines Transparency Alliance (MeTA) has focused on increasing transparency and accountability in countries’ pharmaceutical sectors by creating workshops and roundtables where civil society can engage in dialogue with the government and the private sector. A recent WHO evaluation of the outcomes of such initiatives concluded that while these forums have helped build trust among all the stakeholders involved, their actual impact remains unclear (Vian & Kohler, 2016). This lack of empirical evidence linking civil society to positive outcomes, coupled with the push for increased civil society participation and good governance by governments and the international community, has been recognized as a global problem by the OECD, which stated in 2005,

... there is a striking imbalance between the amount of time, money and energy that governments in OECD countries invest in engaging citizens and civil society in public decision-making and the amount of attention they pay to evaluating the effectiveness and impact of such efforts.

(Organization for Economic Co-Operation and Development (OECD), 2005, p. 10)

A contributing factor to this problem is the lack of understanding of what civil society participation is, what it should be used for and how. Van Doeveren (2011) argues that good governance and its principles, in theory, produce positive results. However, operationally, “these principles apply to the process of decision-making, not its outcomes. Countries are considered to be well governed when the political policy process adheres to these principles, even if it produces perverse outcomes” (van Doeveren, 2011, p. 302). For example, the World Health Organization (WHO) identifies two types of mechanisms to measure good governance. The first, outcome-based indicators, measure the performance of institutions that promote good governance, assess their impact and their effectiveness (WHO, 2010). These type of indicators often use interviews with relevant stakeholders (WHO, 2010). Rules-based indicators, on the other hand, focus on whether countries have institutions that promote good governance, and the sheer existence of certain institutional arrangements is the measure of good governance within a country. Neither performance nor outcomes are components of these indicators (WHO, 2010). Thus, discussing the outcomes of civil society and good governance involves having a clear
understanding of what these terms mean and of the outcomes being pursued (McGee & Gaventa, 2010). These two factors are discussed below.

2.1 Defining Civil Society Participation

Multiple definitions of good governance and civil society participation exist, which creates challenges for their institutionalization and for measuring their outcomes (van Doeveren, 2011). Civil society participation is becoming increasingly popular but also remains widely misunderstood (Ghaus-Pasha, 2005). Ghaus-Pasha (2005) argues that “number, size, area of activity, sources of revenue and the policy framework within which [civil society] operate[s] – is not available in any systematic way” (Ghaus-Pasha, 2005, p. 2). Like good governance, there is no agreed upon definition of what is meant by civil society participation and what it requires. Existing forms of civil society participation use terms such as ‘citizens’, ‘users’, ‘consumers’, ‘individuals, and ‘the public’ interchangeably without a clear definition of exactly what is being referenced. Most forums aim to ensure an “accurate” representation of civil society to increase legitimacy in government decisions. However, the term “accurate” is conceptually difficult to materialize. For example, using a statistically representative sample of the population based on factors such as gender, ethnicity or social status may not translate into an accurate representation of public needs and opinions, while electoral mandates may result in the exclusion of marginalized groups (Martin, 2008).

There is also a lack of consensus on what ‘participation’ entails. Civil society participation can take several forms such as advisory councils, workshops, focus groups, surveys, and social movements. In addition, degrees of civil society participation can range from being consultative to collaborative in nature (Gregory, Hartz-Karp, & Watson, 2008). Bhargava (2015) outlines four ways in which civil society participation can take place. The first is by increasing access to information through right-to-information legislation, databases, and the publication of information such as procurement contracts, audits and organizational structures. The second is through consultation with civil society through focus groups and surveys to collect information on their opinions and concerns. The third, is through direct collaboration with them by engaging them in the decision-making process and formulation of policies and initiatives (Bhargava, 2015). The last is by allowing them to monitor the public sector through initiatives such as social audits and community scorecards. Each of these modes for civil society participation are used to
achieve different objectives, require different conditions from civil society and the government, and produce different outcomes.

How ‘civil society’ and ‘participation’ are defined has a direct impact on how civil society participation is institutionalized. For example, defining which segments of civil society are included in decision-making dictates whose needs and concerns will be heard, as well as which segments of civil society will benefit over others (Bertoldi, Helfer, Camargo, Tavares, & Kanavos, 2012). Similarly, different levels of engagement with civil society call for different goals, requirements, processes and obligations from all stakeholders involved. For example, including civil society in order to help monitor the healthcare sector, factors such as how much access to information they should be given, in what format, and what type of information so that they can effectively monitor it are to be considered. It is also important to determine what conditions are a prerequisite for civil society participation to succeed. Van Doeveren (2011) argues that the interaction between civil society participation and other good governance principles remains unclear (van Doeveren, 2011). That is to say, can civil society participation be successfully used in policymaking without transparency and accountability, or is the sole presence of civil society participation sufficient for yielding positive outcomes? (van Doeveren, 2011). These are all questions that remain unanswered.

2.2 Using Civil Society Participation

Solomon and Abelson (2012) argue that not all policy issues are an appropriate fit for the use of civil society participation (Solomon & Abelson, 2012). Two factors should be considered when aiming to include civil society in policymaking: whether the issue can be best resolved through civil society participation and at which stages in the policymaking process civil society should be included (Solomon & Abelson, 2012). They argue that problems that are highly controversial, that need a combination of expert and real world knowledge, have low levels of support and conflicting opinions from the public are best suited for the use of civil society participation. Civil society participation is appropriate in these situations because it can help governments understand citizens’ demands and preference and increase acceptance of decisions being made (Solomon & Abelson, 2012).

Similarly, considerations should also be made about when civil society should be included in the policymaking process. They can either be included at the very beginning of the process...
(upstream policymaking) or at later stages (downstream policymaking). Both of these options come with advantages and disadvantages. Those that support downstream policymaking argue that civil society’s input is most likely to have an impact when they are being given options that are feasible and highly likely to be implemented. However, it is argued that by doing this, civil society is given a list of predefined options that may not be fully reflective of their needs and demands (Solomon & Abelson, 2012). Upstream policymaking can help address this problem by including civil society in the beginning stages of policymaking. However, it can also leave civil society feeling discontent if their input isn’t implemented in the decision-making process the way they envisioned (Solomon & Abelson, 2012). Given all of these considerations, using civil society participation to solve issues in the public sector requires careful consideration of goals and expectations (Solomon & Abelson, 2012).

3 Debates on Effective Policymaking

The factors outlined above suggest that the institutionalization of civil society participation and good governance in general is still evolving. This process has multiple goals, one being about improving the policymaking process, which is defined as “the process by which governments translate their political vision into programmes and actions to deliver ‘outcomes’ – desired changes in the real world” (United Kingdom Cabinet Office, 1999, p. 15). Hallsworth et al. (2011) argue that, “the strength of policymaking is integral to the strength of government as a whole, and that of the country at large. When policies fail, the cost can be significant” (Hallsworth, Parker, & Rutter, 2011, p. 17). Ineffective policymaking can lead to poor public services, low economic and social growth and unnecessary increases in public expenditure (Hallsworth, Parker, & Rutter, 2011). Two debates about institutional policymaking exist within the existing literature. The first is centered on whether or not experimentation is needed, while the second relates to whether or not it is necessary to consider contextual factors for effective policymaking. These two debates are discussed in more detailed below.

3.1 Experimentation vs. Observation

The first ongoing debate among scholars and practitioners is about whether effective policymaking can be done through observation or whether experimentation is necessary. The first side of this debate argues that proper institutional design can be achieved through observation and prior knowledge. Hallsworth (2011) describes the policymaking process as
generally being a top-down process whereby “centrally-planned initiatives” are “implemented faithfully by other agents, under supervision from the centre” (Hallsworth, 2011, p. 15). He uses the United Kingdom’s policymaking model to explain how policymaking is seen as a linear, straightforward process in which policymakers are in complete control of policy outcomes (Hallsworth, 2011). The main underlying assumption is that theories and existing research can successfully guide policymakers to design policies that will produce planned outcomes. Institutions are therefore designed to focus on the content of policies rather than on how these are implemented (Hallsworth, 2011).

The other school of thought rebuts this by arguing that experimental research – the use of randomized experiments to identify and measure the causality between factors through the manipulation of variables – is necessary for effective policymaking (Banerjee & Duflo, 2009). This is based on the assumption that no matter how much we know about a phenomenon, there remains a high degree of uncertainty about the outcomes that policies will yield once they are implemented (Banerjee & Duflo, 2009). Hypotheses can be made about what will happen when a policy, legislation, or initiative is implemented based on its design. However, there will always be outcomes, intended and unintended, that cannot be accounted for. As a result, the policymaking process must involve experimentation in order to evaluate their outcomes to understand what is working (or not working) and address shortcomings (Banerjee & Duflo, 2009). Hallsworth (2011) supports experimentation by arguing that the traditional top-down approach to policymaking does not account for the close relationship between policy design and implementation, the unintended potential outcomes that can be produced in the implementation process and policymakers’ inability to control the production of these outcomes (Hallsworth, 2011). He argues that the separation between policymaking and implementation is an artificial one, since policy implementation is what ultimately defines a policy (Hallsworth, 2011).

### 3.2 Blueprint vs. Contextualization

Another school of thought that is involved in policymaking is one that ponders whether the policymaking process requires contextual considerations (Hallsworth, 2011). The other side of this debate, which was most predominant in the 1980s and 1990s and was part of the “Washington Consensus”, puts forward the view that a ‘blueprint’ can be developed and implemented across different contexts uniformly to yield the same outcomes (Kornai, Mátyás, &
Advocates for the ‘blueprint’ approach to policymaking, argue it is possible to design a model that can be used across multiple environments, since institutions ultimately dictate human behavior. The blueprint model for policymaking is undercut by much of the existing literature on good governance today. Instead, the focus has been placed on contextualizing good governance initiatives to increase the probability of producing positive outcomes.

Hallsworth (2011) supports contextualization, as he argues that policy implementation is subject to interpretation by those involved in the implementation process. Those in charge of implementing policies play a key role in how policies will be translated into practice, and consequently, the outcomes they will yield. Policymaking, therefore, does not only involve policymakers, but also other actors such as the private sector and civil society. These actors generate a level of unpredictability that also calls for the need for adaptability to context, rapid change and experimentation (Hallsworth, 2011). This view is supported by McGee and Gaventa (2010), as they highlight that the context in which policies are implemented determines the feasibility and appropriateness of the policy objective (McGee & Gaventa, 2010). For example, initiatives that aim to increase transparency in medicine prices through the creation of online databases may be successful in countries with high levels of financial resources but may not work in settings where there is a lack of technological infrastructure to set up and make use of such databases.

Lastly, Hallsworth also argues that the environment in which policies are implemented is important and should be considered in the policymaking process because this process does not take place in a vacuum. New policies are created in an environment where other policies already exist (Hallsworth, 2011). Interactions between new and existing institutions and policies therefore affect policy implementation. For example, the outcomes of an increase in civil society participation in decision-making may be affected by an environment where there is a lack of civil liberties, freedom of press, or accountability (McGee & Gaventa, 2010). Therefore, although there will be similarities between countries’ political structures, cultures and economies, the same laws and regulations may work differently depending on the setting in which they are implemented (Shirley, 2008).
In the case of civil society participation, studies on various initiatives that have increased civil society participation have demonstrated that contextual considerations are crucial for their success. McGee and Gaventa (2010) found that government responsiveness, levels of democratization (such as freedom of press, freedom of association), and political will in any given country will affect the success of such initiatives (McGee & Gaventa, 2010). For example, when initiatives that aim to increase civil society participation are implemented in an environment where there is limited government support, hostility and fear among civil society can arise, and can also lead to elite capture (Bhargava, 2015). Additional contextual factors exist at a civil society level, such as the opportunity costs of participation, the level of mobilization among civil society, the incentives civil society has to participate, and the level of knowledge and expertise needed from civil society to effectively participate (Bhargava, 2015).

4 Brazil’s Health Councils

As stated earlier, this thesis explores the good governance principle of civil society participation by focusing on civil society’s participation in Brazil’s Health Councils (Conselhos de Saude). Brazil’s Health Councils are advisory bodies that are part of Brazil’s healthcare sector and operate at the state, municipal and federal level. Health Councils’ mandate includes designing and approving annual health plans, approving and monitoring the allocation of health budgets and monitoring the private health sector. Their membership is based on a parity principle: half (50%) of its members must come from civil society groups and the other half is divided into government officials (25%) and healthcare representatives (25%). Civil society groups must be active in at least three geographical regions in Brazil to be eligible to participate. An independent committee elects these groups every three years. Once a civil society group has been elected to participate, they are in charge of appointing a representative to attend Health Council meetings. Members meet once a month to discuss healthcare issues, health plans and policies, and healthcare budget allocation within their regional mandate (Kohler & Martinez 2015).

Health Councils were created during Brazil’s transition out of a military regime in the late 1980s. The Sanitarista movement, which played a key role in reforming Brazil’s healthcare system, advocated for the creation of mechanisms through which civil society could participate in the formulation of policies, the management and monitoring of the public sector (Barnes & Coelho, 2009). The rationale behind the inclusion of civil society was based on wanting to guarantee the
involvement of civil society, who are the users of the healthcare system, in the policymaking process to ensure health policies and plans reflect needs (Barnes & Coelho, 2009).

Despite their predominance throughout Brazil and their ambitious mandate, government efforts to increase civil society participation in the health sector through Health Councils have not led to conclusive outputs. A variety of studies on Health Councils report that while they have allowed new actors to be involved in the public health sector, operationally, they face a multitude of challenges (Vera Schattan P. Coelho, 2004; Vera Schattan P. Coelho & Nobre, 2004; Vera Schattan P. Coelho, Pozzoni, & Cifuentes, 2005; Stralen et al., 2006). For example, a study conducted by Cornwall (2008) found that civil society representatives lack the necessary knowledge to effectively engage in discussions during meetings. She also reported a lack of trust between members that affects their willingness to work together in a collaborative way (Cornwall, 2008). Another study conducted on Health Councils by Barnes and Coelho (2009) reported that state actors, through government representatives, have a high level of undue influence on Health Councils that creates tensions between Health Council members (Barnes & Coelho, 2009). Other studies have also found that Health Councils’ membership guidelines are not inclusive enough, resulting in marginalized groups being excluded from participating (Vera S. P. Coelho & Verissimo, 2004; Vera Schattan P. Coelho, 2004; Vera Schattan P. Coelho et al., 2005). Another study by Van Stralen et al (2006) concluded that Health Councils do not have a significant effect on the overall health system (Stralen et al., 2006). These studies suggest that how Health Councils have been designed and operate has created challenges for achieving their mandate. More importantly, they also suggest that how Health Councils operate may be affecting how civil society participates within them.

5 Research Objectives

Mindful of the lack of consensus on why and clarity on how to best advance civil society participation, as well as previously conducted research on Brazil’s Health Councils, this thesis focuses on Brazil’s Health Councils (Conselhos de Saude) to explore what are the reported challenges in terms of institutionalizing civil society participation. This thesis uses the term “civil society” to refer to “ordinary citizens” who are independent of the government. It also uses the term “participation” to describe a process, by which civil society and government come
together to engage in active dialogue to take a decision in a collaborative manner (European Commission, 2013; Maloff, Bilan, & Thurston, 2000).

Civil society participation is said to promote good governance by increasing access to information on decision-making processes to civil society, providing them with the opportunity to voice their demands and concerns to decision-makers and by allowing them to participate in the monitoring of the public health sector to ensure accountability (Abelson et al., 2012; Blacksher et al., 2012). However, the lack of consensus on when and how civil society participation should be used, coupled with the absence of a detailed outline of how to effectively institutionalize civil society participation and good governance in general create challenges for effective institutional design. Moreover, the existing debates on whether policymaking should be an experimental process or not, and whether contextual factors should be a key consideration, highlight the need for more research on the institutionalization of civil society participation. Brazil’s Health Councils will make for a good case study given the large role civil society plays with them, their prevalence throughout the country, their ambitious mandate and the lack of empirical evidence on their impact. By using Health Councils as an example, this thesis may help inform future initiatives as well as reform existing ones, where needed. How this thesis will carry out this objective is discussed in the next chapter.
References


Chapter 2
Methods

This chapter provides a detailed explanation of the methods used for this thesis. The methods section in Chapter 3 conforms to the publishing guidelines of the journal *Globalization and Health*, and integrates the comments provided by reviewers during the peer-review process.

1 Rationale for the use of Qualitative Methods

As Chapter 1 outlined, civil society participation and good governance in general are widely used and endorsed by the international community despite the lack of consensus on what they mean and how to best operationalize them. In short, there is a lack of clarity on how to define them, how to implement them, and how to measure their outcomes. In addition, previously conducted research on Health Councils, which are the focus of this thesis, reports that they have a limited impact on Brazil’s healthcare sector (Vera Schattan P. Coelho, 2004; Vera Schattan P. Coelho & Nobre, 2004; Vera Schattan P. Coelho, Pozzoni, & Cifuentes, 2005; Stralen et al., 2006). This thesis hopes to fill this gap by exploring what are the reported challenges in terms of institutionalizing civil society participation in Brazil’s Health Councils (*Conselhos de Saúde*). Ideally, “lessons learned” from this experience may be informative to other models that include civil society participation in policy and decision-making.

Qualitative methods were used to help answer the research question. These methods can help answer questions that cannot be approached through the use of quantitative methods (Green & Thorogood, 2009). Quantitative studies, such as those that use pre-determined indicators, are useful for measuring outcomes but they lack the ability to tell us how these outcomes are being produced or why some policies for civil society participation work better than others (Fukuyama, 2013; Shirley, 2008, 2013; Siddiqi et al., 2009). For example, the World Bank’s Good Governance Index is a methodological approach that ranks countries’ level of good governance based on six pre-determined indicators (World Bank, 2016). While this approach allows for cross country comparisons, it has been criticized for its inability to provide insights into the quality of good governance manifested in each country (McGee & Gaventa, 2010). The use of such methods to answer policy questions thus fails to capture in detail the complexities of policy
implementation and does not help provide guidance on institutional reform that is detailed and specific (Shirley, 2008).

Using a qualitative approach helps address these issues by helping collect data that provides insights on why policies produce certain outcomes (McGee & Gaventa, 2010; Siddiqi et al., 2009). For example, conducting a study on the level of the rule of law within a country’s judicial system that solely focuses on measuring the time it takes for a case to clear and the procedures in place will not help better understand the quality of the justice being produced by such a legal system or why such outcomes are being produced (Fukuyama, 2013). Green and Thorogood (2009) argue that “at the policy level, qualitative studies have the potential to provide evidence for population needs, the development of appropriate policy, and evidence for how to implement policy” (Green & Thorogood, 2009, p. 32). For this reason, qualitative methods are used to study good governance in the provision of public services such as healthcare (McGee & Gaventa, 2010).

Interviews with stakeholders and experts on good governance are widely used to study good governance and its principles within the healthcare sector (McGee & Gaventa, 2010). The type of interviews ranges from structured to loosely structured interviews and are often conducted with ‘experts’ in the phenomenon under study such as academics, international organization representatives, policymakers, or intended beneficiaries of good governance initiatives like patients and citizens. Findings from these studies are often triangulated with other data sources through statistical analyses and legislative reviews (McGee & Gaventa, 2010). Multiple studies conducted by top experts in the field of good governance and international organizations have used this approach. For example, WHO published in 2009 a study on transparency in Jordan’s public pharmaceutical sector in which 61 key informant interviews were conducted (WHO, 2009). Studies have also been done on Health Councils that have used semi-structured interviews (Cornwall, 2008; de Oliveira & Pinheiro, 2010), focus groups (Sozzi de Moraes, Veiga, Vasconcellos, & Rangel dos Santos, 2009) and a combination of semi-structured interviews and document analyses (Mitre Cotta, de Melo Cazal, & Cardoso Martins, 2010). For this thesis, semi-structured interviews were conducted to explore the challenges concerning the institutionalization of civil society participation in Brazil’s Health Councils.
2 Researcher’s Epistemological Stance

In this thesis I take a positivistic approach to research in so far as I recognize knowledge to be neutral and value free (Bunniss & Kelly, 2010). This thesis is nomothetic rather than idiographic in nature, as it aims to provide an understanding of the process of institutionalizing civil society participation by examining Brazil’s Health Councils rather than to provide an in-depth understanding of Health Council members, their views and perceptions (Ponterotto, 2005). The thesis was designed to not focus on the subjective points of view that make up participants’ accounts in the data collection and analysis processes, but instead make visible the challenges related to institutional design within Health Councils (Broom & Willis, 2007; Green & Thorogood, 2009; Maxwell, 2011).

In the design of this thesis, I also strived to maintain neutrality between myself and the participants during the data collection and analysis processes (Fischer, 1998). I did not aim to analyze participants’ views and perceptions and how these shaped this thesis. Instead, I aimed to take a ‘snapshot’ of what is taking place within Health Councils from a neutral stand. This stance was taken in the hopes of generating knowledge that may be applicable to other settings (Clark, 1998).

3 Interview Data Analysis and Collection

3.1 Data Sampling

A total of 40 semi-structured interviews were conducted with Health Council Members at the municipal, state and national levels by the first author and a Research Assistant. In June and July of 2013, the first author and a Research Assistant interviewed eight municipal, seven state, and six national Health Council members. In May of 2014 a Research Assistant interviewed an additional nine municipal, nine state and one national Health Council members. The geographical location of the interviewees covered all five regions of Brazil (North, Northeast, Midwest, Southeast, South) for a total of 5 different municipal Health Councils, 8 different state Health Councils, and the national Health Council in Brasilia. Table 1 provides a breakdown of the study sample.
Table 1. Breakdown of Study Sample Groups

<table>
<thead>
<tr>
<th></th>
<th>Municipal Level (n=17)</th>
<th>State Level (n=16)</th>
<th>National Level (n=7)</th>
<th>TOTAL (n=40)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Civil Society Representatives</td>
<td>8</td>
<td>9</td>
<td>4</td>
<td>21</td>
</tr>
<tr>
<td>Health Sector Representatives</td>
<td>7</td>
<td>4</td>
<td>1</td>
<td>12</td>
</tr>
<tr>
<td>Government Representatives</td>
<td>2</td>
<td>3</td>
<td>2</td>
<td>7</td>
</tr>
</tbody>
</table>

Study participants were initially selected through purposeful sampling. This sampling method is used by researchers to identify participants that are knowledgeable about the subject matter and are available and willing to participate (Bernard 2005). The criteria for selecting study participants was solely based on whether they were at one point in time Health Council members in any of the three levels of government in Brazil. The researcher did not aim to identify differences or similarities between municipal, state and national Health Councils or between states. Initially, study participants were identified by accessing membership lists of Health Council at the national, state and municipal levels available online. All Health Council members on these lists found online were invited through an email invitation. When a phone number was available, non-respondents were contacted a second time via telephone to solicit a response. However, due to the low response rate we received through this recruitment process, the researchers resorted to snowball sampling. This helped reach a larger number of study participants.

3.2 Formulation of the Interview Guide

The study’s interview guide was informed by a scan of existing literature on Health Councils conducted in 2013 to gain a greater understanding of how Health Councils work as well as a paper on Health Councils published in 2015 by Kohler and Martinez (Kohler & Martinez, 2015). Because the study was exploratory in nature, the literature scanned only included journal articles in English and Portuguese and did not follow a rigid systematic searching or quality criteria.
However, it helped formulate the interview guide by helping to identify issues that previously conducted studies on Health Councils had found. More specifically, the thesis aimed to explore the dynamics and relationships among Health Council members, if there was participation from the outside public, what resources were at Health Councils’ disposal for their operations, how meetings are run, the level of training provided to Health Council members, and the relationship between Health Councils and the government. A copy of the interview guide can be found in Appendix 1. The interview guide was semi-structured in nature, as the researchers conducting the interviews were allowed to change the sequence of questions and could ask questions outside of the interview guide to probe study participants (DiCicco-Bloom & Crabtree, 2006). In addition, changes in the wording of questions were also allowed to clarify questions to participants.

3.3 Data Collection

The interviews were 40-50 minutes long and were conducted in Portuguese over the phone and Skype. The 2013 interviews were not tape-recorded because the topic and questions could be perceived by study participants as being sensitive and controversial, which would make study participants unwilling to participate if they were being tape recorded. Therefore, the Principal Researcher, with the help of a Brazilian Research Assistant, captured the content of the interviews by note-taking instead. The notes from these interviews were combined and written down in Portuguese straight after each interview was conducted in order to retain on paper as much of the interview data as possible. The Brazilian Research Assistant translated the interviews into English from Portuguese. After these first interviews were conducted, the researchers found that study participants were more comfortable with sharing their accounts than initially anticipated. For this reason, the interviews conducted in 2014 were tape recorded. They were then transcribed and translated from Portuguese to English by the Brazilian researcher. Filler words such as ‘umm’ and ‘ehh’ were discarded during the transcription of the interviews to improve readability. In order to address any losses in meaning due to translation, all of the interviewee quotes in this paper are provided in the original Portuguese in Appendix 2.

3.4 Data Analysis

The data were analyzed as follows:
1. **Initial Read Through of Data:** All interview data were read over once. At this stage, a list of recurring topics was created by inductively analyzing the data. Inductive approaches “are those that start from the data, and from those data, search for regularities and patterns that suggest general laws” (Green & Thorogood, 2009, p. 28). This was done in order for the researcher to familiarize herself with the data and the topics being discussed by the study participants.

2. **Data Coding:** Interview data was inductively coded using the software HyperResearch to facilitate the data management process. Codes were assigned based on the topic being discussed (e.g. budget issues, government support, corruption, etc.). Coded extracts were reviewed to ensure cohesiveness within each code.

3. **Generating Themes:** First, codes that did not directly relate to the research question were discarded. The leftover codes were then grouped together by relevance to one another to create themes.

4. **Finalizing Themes:** The data extracts for each theme and sub-theme were reviewed to create a detailed summary (with quotes) that captured the main messages in the extracts. Whenever possible, differences between civil society representatives, healthcare representatives and government representatives within each theme were identified and noted in the theme summaries. These summaries were then used to help present the themes in the results section.

### 3.5 Ethical Considerations

This study was reviewed and approved by the University of Toronto’s Research Ethics Board (Protocol Reference # 28320) as well as Brazil’s National Commission of Ethical Research (Comissão Nacional de Ética em Pesquisa – CONEP) (Approval # 686.734).

### 4 Review of Legislation

After the interview data was analyzed, the documents in Table 2 were reviewed to understand the operational structure and design of Health Councils, using the National Health Council as the reference point for Health Councils at the state and municipal levels. More specifically, these resolutions were chosen because they discuss in detail Health Councils’ mandate, Health Council
decisions, membership requirements for all of the three membership groups and the resources allocated for their operation. They regulate these specific aspects of the Health Councils at all three levels of government. The information provided by these documents was used to complement the interview data analysis and confirm the accuracy of participants’ accounts in relation to these documents.

Table 2. List of Documents Reviewed

<table>
<thead>
<tr>
<th>Document</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resolution No. 291, 6 May 1999</td>
<td>Outlines what each of the three types of Health Council decisions are (motions, recommendations, resolutions)</td>
</tr>
<tr>
<td>Resolution No. 407, 12 September 2008</td>
<td>Outlines the overall design of Health Councils</td>
</tr>
<tr>
<td>Decree No. 4839, 11 July 2006</td>
<td>Provides details of membership guidelines</td>
</tr>
<tr>
<td>Resolution No. 453, 10 May 2012</td>
<td>Provides details of the Health Council budget</td>
</tr>
</tbody>
</table>

To summarize, this study falls under a positivist stance. Interviews with Health Council members at the municipal, state and national levels were carried out to explore their experiences within Health Councils. Participant accounts were complemented by a review of the pieces of legislation that dictate the operational structure and design of Health Councils. Chapter Three will outline the findings of this study, while Chapter Four will provide an overview of the limitations of this study based on the methodology described above.
References


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Chapter 3
Civil Society Participation in the Health system: The Case of Brazil’s Health Councils

Preface

This paper was submitted to Globalization and Health on 2 June 2016 for peer review. It was then revised and resubmitted on 8 August 2016 and accepted for publication on 20 September 2016. As per the Department of Pharmaceutical Sciences’ thesis formatting guidelines for manuscript-based theses, this chapter provides a copy of the manuscript exactly as published in Globalization and Health but formatted to comply with the University of Toronto’s School of Graduate Studies standards. Given that the manuscript was accepted for publication before the thesis was finalized, more in-depth reflections on the study findings are discussed in Chapter 4.


Authors: Martha Gabriela Martinez, Jillian Clare Kohler

Declaration of Work: The conception and design of the study was carried out by GMG and JCK. The 2013 interviews were carried out by GMG and Joao Batista da Silva Junior. The 2014 interviews were carried out by Joao Batista da Silva Junior. The interviews were transcribed and translated by Joao Batista da Silva Junior. The interview data was coded by MGM and the themes were verified by JCK and Joao Batista da Silva Junior. The manuscript was written by MGM and JCK.

Abstract

Background: Brazil created Health Councils to bring together civil society groups, health professionals, and government officials in the discussion of health policies and health system resource allocation. However, several studies have concluded that Health Councils are not very
influential on healthcare policy. This study probes this issue further by providing a descriptive account of some of the challenges civil society face within Brazil’s Health Councils.

**Methods:** Forty semi-structured interviews with Health Council Members at the municipal, state and national levels were conducted in June and July of 2013 and May of 2014. The geographical location of the interviewees covered all five regions of Brazil (North, Northeast, Midwest, Southeast, South) for a total of 5 different municipal Health Councils, 8 different state Health Councils, and the national Health Council in Brasilia. Interview data was analyzed using a thematic approach.

**Results:** Health Councils are limited by a lack of legal authority, which limits their ability to hold the government accountable for its health service performance, and thus hinders their ability to fulfill their mandate. Equally important, their membership guidelines create a limited level of inclusivity that seems to benefit only well-organized civil society groups. There is a reported lack of support and recognition from the relevant government that negatively affects the degree to which Health Council deliberations are implemented. Other deficiencies include an insufficient amount of resources for Health Council operations, and a lack of training for Health Council members. Lastly, strong individual interests among Health Council members tend to influence how members participate in Health Council discussions.

**Conclusions:** Brazil’s Health Councils fall short in providing an effective forum through which civil society can actively participate in health policy and resource allocation decision-making processes. Restrictive membership guidelines, a lack of autonomy from the government, vulnerability to government manipulation, a lack of support and recognition from the government and insufficient training and operational budgets have made Health Council largely a forum for consultation. Our conclusions highlight, that among other issues, Health Councils
need to have the legal authority to act independently to promote government accountability, membership guidelines need to be revised in order include members of marginalized groups, and better training of civil society representatives is required to help them make more informed decisions.

**Key Words:** Participatory governance, Civil society participation, Civil society inclusion, Good governance, Institutional design, Conselhos de Saude, Health Councils

## 1 Background

Institutional reforms within the international development field have increasingly focused on establishing **civil society participation** in decision-making and policy formulation to promote social justice and increase good governance in the public sector (Martin, 2008). In our paper, we use the term “civil society” to refer to “ordinary citizens,” who are independent of the government. We also use the term “participation” to describe a process, by which civil society and government come together to engage in active dialogue to take a decision in a collaborative manner (European Commission, 2013; Maloff, Bilan, & Thurston, 2000).

The recent Sustainable Development Goals (SDGs) recognize that, “responsive, inclusive, participatory and representative decision-making at all levels” is a crucial component for development (Nino, 2016). Governments commonly create a forum or space in policy making, through which civil society can voice demands and concerns. Ideally, the inclusion of civil society raises the potential for decision-making to be well informed and reflective of societal needs (Abelson et al., 2012; Blacksher et al., 2012). This, in turn, can make civil society more supportive of government decisions and increases (either real or perceived) government support and legitimacy (Abelson et al., 2012; Blacksher et al., 2012). The inclusion of civil society in the decision-making process can also increase transparency by helping inform citizens about how decisions that affect their everyday lives are made (Abelson et al., 2012). Transparency is linked to accountability in that government transparency requires that citizens be fully informed about how and why decisions are made, including the decision-making procedures followed, criteria applied by policy-makers, and the information or evidence drawn upon to reach decisions (Scott, 2007). This information can then be used to hold relevant government officials accountable to
their actions to ensure satisfactory public sector services (J. Kohler, 2011; Mitton et al., 2009). This can also help monitor the performance of the health system and resource allocation in the public sector (Bochel et al., 2008; J. C. Kohler, Mackey, & Ovtcharenko, 2014; Srivastava, 2009).

Globally, there are many examples of forums for civil society participation in the health sector; many of these have been established in the past two decades. For example, the Province of Quebec’s Hospital Boards, that include civil society in the decision making process in Quebec’s hospitals, the United Kingdom’s Public Participation Forums that include civil society in the allocation of resources of the United Kingdom’s National Health Service, and Brazil’s Health Councils, the latter is the focus of this paper.

Civil society participation in the health sector assumed a central role in the restructuring of Brazil’s unified health system, *the Sistema Único de Saúde* (SUS), which took place during the country’s period of transition out a military regime during the 1980s. This focus on civil society participation grew out of the Sanitarista movement, which advanced the decentralization of Brazil’s health system and universal health coverage for the population. This same social movement promoted the establishment of Health Councils in 1990 to provide a forum for civil society participation in the implementation and monitoring of health policies for social accountability (*controle social* in Portuguese) at the municipal, state and federal levels (Vera Schattan P. Coelho, 2004; Couttolenc, Gragnolati, & Lindelow, 2013; Mahoney & Thelen, 2010). Today, these councils serve as advisory bodies with an ambitious mandate that includes monitoring the health system and the allocation of resources, bringing together civil society groups, health professionals and government officials.

The 48 members of any given Health Council are represented as follows: 50% are ‘users’ of the healthcare system (civil society groups), 25% are healthcare representatives and 25% are government representatives. Government representatives may be appointed by the following: the National Council of Secretaries of Health (CONASS), the Federal Government, the National Council of Municipal Health Secretaries (CONASEMS), healthcare service providers, and lastly, private sector representatives. Civil society and healthcare representatives, on the other hand, are appointed to Health Councils by their respective organizations/institution. The creation of the Health Councils is considered to be a milestone in the history of health policies in Brazil; Health
Councils have also received international praise for their capacity to advance participatory democracy (Santos, Vargas, & Lucas, 2011).

Still, there is not always clear evidence of what impact civil society has had on policy within forums like the Health Councils. Indeed, in reference to efforts by its own member states, the Organization for Economic Co-operation and Development (OECD), has noted that, “... there is a striking imbalance between the amount of time, money and energy that governments in OECD countries invest in engaging citizens and civil society in public decision-making and the amount of attention they pay to evaluating the effectiveness and impact of such efforts” (Organization for Economic Co-Operation and Development (OECD), 2005, p. 10). Studies of different models for civil society participation in the health policy process have illuminated some of limitations. For example, a study conducted on British Columbia’s Regional Health Boards found widespread feelings of discontent among civil society members about their role within the Boards, as the government failed to clearly articulate during their formalization why these Boards were being created or how civil society was to be included in decision-making (Frankish, Kwan, Ratner, Higgins, & Larsen, 2002).

In the case of Brazil, much of the existing literature on Health Councils focuses on their prevalence throughout the country, as well as the status that they hold, which gives them the potential to serve as a deterrence mechanism for corruption and also as a way to increase social accountability by the government in its health sector services (Joshi, 2013). Yet, there is evidence from some studies that certain aspects of the Health Councils, such as meeting guidelines and council membership procedures, have resulted in the unintended consequence of creating barriers to the influence of civil society in health policy formulation (Barnes & Coelho, 2009; Vera Schattan P. Coelho, 2004; Vera Schattan P. Coelho & Nobre, 2004; Vera Schattan P. Coelho et al., 2005; Cornwall, 2008; J. Kohler & Martinez, 2015; Schönleitner, 2005; Stralen et al., 2006).

To be sure, a challenge in any effort to include civil society in the policy process is first to determine who should be included. Often terms such as ‘citizens’, ‘users’, ‘civil society’, and ‘the public’ are used interchangeably across different models without a clear definition of who exactly they are referring to and thus whom these forums are aiming to include (Church et al., 2002). This is particularly important for the health sector given the mix of technical and non-
technical knowledge necessary for making decisions for health policy formulation (Mitton et al., 2009). On a similar note, words like ‘engagement’, ‘participation’ and ‘involvement’ are used often without an explicit explanation of the degree to which civil society will be engaged in decision-making or the roles and expectations of civil society participants (Blacksher et al., 2012; Church et al., 2002; Gregory et al., 2008). Governments rarely specify how and when civil society’s views and demands will be included in the policy and decision-making process (Solomon & Abelson, 2012). This lack of clarity suggests the need to understand better the strengths and weaknesses of how current participatory policy models are designed so that future efforts incorporate lessons (Charles & DeMaio, 1993; Mitton et al., 2009). To this end, we have explored one of these – Brazil’s Health Councils.

2 Methods

2.1 Semi-Structured Interviews

2.1.1 Data Collection

A total of 40 semi-structured interviews were conducted with Health Council Members at the municipal, state and national levels by the first author and a Research Assistant. In June and July of 2013, the first author and a Research Assistant interviewed eight municipal, seven state, and six national Health Council members. In May of 2014 a Research Assistant interviewed an additional nine municipal, nine state and one national Health Council members. The geographical location of the interviewees covered all five regions of Brazil (North, Northeast, Midwest, Southeast, South) for a total of 5 different municipal Health Councils, 8 different state Health Councils, and the national Health Council in Brasilia. Due to confidentiality concerns, the location of study participants cannot be disclosed. Table 1 provides a breakdown of the study sample.

<table>
<thead>
<tr>
<th>Civil Society Representatives</th>
<th>Municipal Level</th>
<th>State Level</th>
<th>National Level</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health Sector Representatives</td>
<td>8</td>
<td>9</td>
<td>4</td>
<td>21 Civil Society Representatives</td>
</tr>
</tbody>
</table>

| Health Sector Representatives | 7               | 4           | 1              | 12 Health Sector Representatives |
Study participants were identified by accessing membership lists of Health Council at the national, state and municipal levels available online. We began with the membership list of Brazil’s national Health Council, followed by searching for state Health Councils that had a membership list available online. We then identified the municipal Health Councils by using state Health Councils’ websites that had links to municipal health councils’ websites in them. We invited all Health Council members on the available lists through an email invitation, for a total of about 1,400 invitations. When a phone number was available, non-respondents were contacted a second time via telephone to solicit a response. Due to the low number of respondents reached in this manner, we also used snowball sampling. Written consent was received from each interviewee prior to the interview. Interview questions (Appendix 1) were formulated based on issues highlighted in existing literature on civil society participation in Brazil and focused on their views and perceptions of interviewees’ respective Health Councils. The interviews were conducted in Portuguese over the phone and Skype. The 2013 interviews were not tape-recorded but two note takers captured the content of the interviews. The 2014 interviews were tape recorded, transcribed and translated from Portuguese to English with the support of a Brazilian researcher. The first set of interviews was not tape-recorded because the study participants did not consent to being tape-recorded. In order to address any loss in meaning due to translation, all of the interviewee quotes in this paper are provided Portuguese in Appendix 2.

### 2.1.2 Data Management and Analysis

Data was coded using an inductive approach and themes were generated using a thematic approach. We first read through the interview content to generate a preliminary list of codes using inductive analysis. Then, we coded the interview data using inductive analysis with the software HyperResearch. We created a final list of codes by selecting the codes that were most relevant to the research question. These codes were then grouped together based on their relevance to one another to form themes. The data extracts for each theme were reviewed to create a detailed summary (with quotes) that captured the main messages from each set of

<table>
<thead>
<tr>
<th>Government Representatives</th>
<th>2</th>
<th>3</th>
<th>2</th>
<th>7 Government Representatives</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>TOTAL</strong></td>
<td>17 Municipal Health Council Members</td>
<td>16 State Heath Council Members</td>
<td>7 National Health Council Members</td>
<td>40 Health Council Members</td>
</tr>
</tbody>
</table>
extracts. At this stage differences between civil society representatives, healthcare representatives and government representatives within each theme were identified by the researcher and noted in the theme summaries. These summaries were then used to help present the themes in the results section. The analysis conducted did not focus on identifying underlying assumptions and ideas that gave form to interviewees’ views and perceptions in the data collected.

2.2 Legislative Review

Once interviews were analyzed and themes were identified, a scan of the decrees, resolutions and amendments that are relevant for Health Councils was conducted, using the National Health Council as the reference point for Health Councils at the state and municipal levels. This scan only focused on documents that related to the issues identified through the interviews. For example, if one of the identified themes was ‘issues with membership guidelines’, only legal documents pertaining to Health Councils’ membership rules were considered. This was done in order to corroborate the findings from the interviews conducted. Table 2 outlines the documents reviewed.

<table>
<thead>
<tr>
<th>Document</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Resolution No. 291, 6 May 1999</td>
<td>Outlines what each of the three types of Health Council decisions are (motions, recommendations, resolutions)</td>
</tr>
<tr>
<td>Resolution No. 407, 12 Sept 2008</td>
<td>Outlines the overall design of Health Councils</td>
</tr>
<tr>
<td>Decree No. 4839, 11 July 2006</td>
<td>Provides greater detail on membership guidelines</td>
</tr>
<tr>
<td>Resolution No. 453, 10 May 2012</td>
<td>Provides greater detail on the Health Council budget</td>
</tr>
</tbody>
</table>

2.3 Ethical Considerations

This study was reviewed and approved by the University of Toronto’s Research Ethics Board (Protocol Reference # 28320) as well as Brazil’s National Commission of Ethical Research (Comissão Nacional de Ética em Pesquisa – CONEP) (Approval # 686.734).
3 Results

The study findings are organized around the following themes: 1) Lack of autonomous authority; 2) Membership guidelines that limit inclusion; 3) Government pressure on Health Council members; 4) Lack of support and recognition from government; 5) Insufficient resources for Health Councils; and, 6) Health Council members’ strong individual interests.

3.1 Lack of Autonomous Authority

Brazil’s Health Councils were established to monitor both the public and private health sectors, to monitor and approve the country’s health budget and its allocations, and to assist in the implementation of the national health policy. Decisions taken in Health Council meetings are divided into motions, recommendations, and resolutions. Motions are used to express recognition, support, and criticism of a specific subject, and they are non-binding. Recommendations are, on the other hand, suggestions, warnings, or notices about specific issues but they are also non-binding. Health Councils also can put forward resolutions that can be implemented into law, if and only if, the Ministry of Health approves them. Therefore, Health Councils do not stand as autonomous bodies independent of the government and have no legal authority through which they can ensure that their resolutions are implemented.

Health Council members at the national, state and municipal levels reported that the decisions taken during meetings are not followed up well. A Health Council member at the state level reported,

“A resolution that had been passed in the Council about abolishing the privatization of the health system was shut down by the last two Health Secretariat of my state. One of them said he wasn’t going to ‘shoot himself in the foot’ by implementing it.”

(Civil Society Representative, State Health Council Member #2)

It seems that civil society’s participation in Health Councils is more consultative in nature, as the government holds the ultimate decision-making power because it has the legal authority to implement decisions. This dependency on the government to implement Health Council decisions also means that there is no guarantee that civil society’s input will be part of the final decision-making process, as this is solely dependent on the given government’s willingness to take their input into account. This has not only created a sense of frustration among Health
Council members, but it also puts into question how effectively Health Councils’ can fulfill their mandate, given that they cannot take action to hold governments accountable without, somewhat paradoxically, having that same support from the government.

3.2 Membership Guidelines Limit Inclusion

Health Councils’ membership guidelines were designed to include government officials, civil society representatives (referred to in Portuguese as usuarios, or users of the healthcare system), and healthcare representatives. Fifty percent of any Health Council must be composed of civil society representatives, which are defined as “representatives of organizations and social movements that have expertise and representation in at least one third of the units of the Federation and three geographical regions of the country for at least two years” (“Decreto No. 5.839, de 11 de Julho de 2006,” 2006). Twenty-five percent of membership seats must be filled by healthcare representatives, which are defined as “representatives of health professional organizations, including the scientific community” (“Decreto No. 5.839, de 11 de Julho de 2006,” 2006). The other 25 % is to be comprised of government representatives from the National Council of Secretaries of Health (CONASS), the federal government, the National Council of Municipal Health Secretaries (CONASEMS), healthcare service providers, and business entities that conduct business within in the health system (“Decreto No. 5.839, de 11 de Julho de 2006,” 2006). Civil society representatives are appointed by their respective organization and an independent committee must elect each organization every three years. No minimum technical qualification is required from civil society representatives to participate. However, membership guidelines are limiting in scope, as only organized groups that have a strong presence throughout Brazil and are formally recognized by the government can qualify to participate.

A reported lack of interest from civil society in participating in Health Councils has resulted in limits to the breadth of the membership. Interviewees at all three levels of government, underscored that the public is often unaware of the existence of Health Councils, and those who do have some knowledge about Health Councils, are often not interested in learning more about what they do or how to participate within them. A Health Council member representing civil society at the municipal level stated,
“Civil society participation is very fragile. Our society doesn’t have a culture of participation in the creation of public policies, and in the 21st Century they don’t realize the power that it has by being a taxpayer, a citizen with rights. Society in general is unaware of that the State exists to give back the high taxes that are levied and collected in the form of services like education and health. Brazilian society is taking too long to wake up.” (Civil Society Representative, Municipal Health Council Member #8)

This suggests that civil society needs to have a better understanding about Health Councils and how they can effectively participate in them. Coupled with restrictive membership guidelines, Health Councils do not necessarily represent the ‘users’ of the healthcare system well. Rather, membership tends to be limited to well-resourced and organized members of Brazil’s population. This leaves behind poor-resourced populations that use SUS’s services but lack the necessary time and money to be organized and qualify to participate. Health Councils’ breadth of population inclusion is therefore narrow in scope.

### 3.3 Government Pressure on Health Council Members

Health Councils members at all three levels reported feeling “pressured” by their respective government representatives; thus affecting their ability to work impartially and openly. Health Council members stated that government representatives often used bribery and intimidation tactics to sway member decisions and how they voted. At the national level, a Health Council member expressed that, “…in order to get things done you need to be good friends with the government.” (Government Representative, National Health Council Member #1) Another Health Council member at the state level reported that members are “constantly being manipulated by government representatives” (Healthcare Representative, State Health Council Member #1) through favor exchanges such as job offers or punishments through lay-offs and threats. Members are often threatened or pressured to take decisions that will not create a negative image for a given government. Not surprisingly, this has reportedly created a hostile environment during Health Council meetings.

A Health Council member representing civil society at the state level reported,

“There is a legal framework. We try to work impartially, defending the interests of the public [pause] but the government pressures us, especially when it comes to decisions
that have to do with the health budget. Health workers are the most vulnerable ones.”
(Civil Society Representative, State Health Council Member #11)

Another Health Council member representing the health sector at the state level stated,

“Civil society representatives are vulnerable to the government’s interests. Government representatives, as one might expect, support almost blindly the interests of the government. These interests are often contradictory of those of civil society. They will do anything under their power to avoid embarrassing situations for the government. Health representatives act pretty much the same way... they show a real disconnect from the real needs of society. It seems that there is no real commitment to meet societal needs.”
(Healthcare Representative, State Health Council Member #8)

Health Council members are thus often reluctant to engage in open discussion due to possible retaliation by the government. A Health Council member representing civil society at the municipal level reported,

“We do what we can. Sometimes, we personally go and talk to patients, doctors. Other times, we write to them to reach out. Laws are there to be followed but sometimes we do not report issues because of fear. Council members work for or may have relatives who work for the government and we are afraid to lose our jobs or our position in the council. It’s really a shame. If there were equal rights and laws were enforced, our Brazil would be a model to follow.”
(Civil Society Representative, Municipal Health Council Member #12)

Another Health Council member representing the healthcare sector at the municipal level reported that,

“The Health Council that I belonged to always works with the information available and decisions are taken according to the law. Sometimes, the government is uncomfortable with that, mainly when it comes to embezzlements. The government threatens some Health Council members, especially those working for the government. If a Health Council member works for a private company and goes against the government during Health Council meetings, the government will intimate them by asking for an inspection of their company. Health Council members feel threatened because according to the law,
the Health Council will be punished if it approves any process in which resources are suspected to be stolen or misuse. That is why some members prefer to leave the Health Council. Their participation is voluntary, they are not paid for that, and it takes time to participate, oversee how the budget has been used and investigate civil society’s accusations of irregularities in the health care system. I don’t blame them.” (Healthcare Sector Representative, Municipal Health Council Member #15)

These accounts suggest power imbalances among council members; it seems that government representatives have the greatest power over civil society and healthcare representatives, putting the latter groups in a vulnerable position. This can clearly have an influence on what is discussed during Health Council meetings and the type of decisions that are taken as a result of the discussions. Ultimately, power imbalances limit the Health Council’s ability to effectively monitor the healthcare sector, given that they have no authority over the same government they aim to monitor and hold accountable to the public.

3.4 Lack of Support and Respect from the Government

Healthcare and civil society representatives at all three levels of government also stated that there is a lack of support from their respective governments (e.g. national, state or municipal). Not surprisingly, governments will support health councils and implement their decision only if they are aligned with their own agenda. A Health Council member representing civil society at the municipal level stated,

“The government decides when to interfere with partisan politics. Sometimes they do more than they need to, but most of the time they just do what is required of them.” (Civil Society Representative, Municipal Health Council Member #12)

A Health Council member representing civil society at the national level stated,

“The government does not really support the councils, it tolerates them. There is tension between the two because of the differences in interests. It is more of an instrumental relationship. They don’t realize the power that Health Councils have. The government is more concerned with the opinion of government representatives than those of civil society or healthcare representatives, maybe because other interests are involved.” (Civil Society Representative, National Health Council Member #6)
Health Council members expressed that their respective government is generally not interested in having Health Councils work effectively in case they create a threat to their power. A Health Council member representing civil society at the municipal level stated,

“The government does not recognize the Council as an autonomous body and has no real interest in making sure it’s working properly. The State Health Council conducts trainings, meetings, but the most important thing is encouraging civil society to participate, but the government is afraid of making this happen because they don't want to lose the power they believe is theirs and not of the people who elected them.”

(Civil Society Representative, Municipal Health Council Member #8)

At the state and municipal levels, this lack of recognition and support from their government sometimes results in a government failing to address issues that are critical, within the jurisdiction of Health Councils, such as the approval of health budgets. A municipal Health Council member representing civil society stated,

“For the last 4 months, the government has failed to provide us with the budget reports that need to be approved by the Health Council. We are often not consulted on issues that correspond to us and things get approved without our consent even though it is needed under the law.”

(Civil Society Representative, Municipal Health Council Member #12)

As noted earlier, Health Councils will be effective only if their respective government decides to do so. The lack of power or legal authority Health Councils holds has meant that they have largely not been able to have a real impact on the policy process.

3.5 Insufficient Resources for Health Councils

3.5.1 Budget

Pursuant to Resolution 453/2012 taken by the National Health Council, the three levels of government must provide the necessary financial and administrative resources for their respective Health Councils to have administrative autonomy to function effectively. For example, the respective government of any given Health Council is required to provide a physical space so that Health Councils are able to hold meetings and financially support administrative staff and promotional materials. The Ministry of Health, in conjunction with the
Federal government, is charged with working with the state and municipal governments to ensure the funds are transferred and provided to the Health Councils. However, in practice, at the state and municipal levels, there are budget constraints have limited Health Council meetings and their ability to disseminate information relevant information to the public. A Health Council member representing civil society at the state level shared that,

“The government doesn’t support us a lot but our existence is guaranteed by the law. Once in a while the Internet is suspended because the government doesn’t pay it on time. When this happens we use our cellphones and make things work, even with these challenges.”11 (Civil Society Representative, State Health Council Member #2)

Another Health Council member representing civil society at the state level reported that,

“The government says they support the councils but it’s far from reality. We don’t have our own website to disseminate information to the public. The website we have we paid for out of our own pockets and it doesn’t support a lot of data.”12 (Civil Society Representative, State Health Council Member #5)

In addition, Health Council members also reported that the management of their budgets lack transparency and noted that there examples of budget mismanagement by government officials who are in charge of it. At the state and municipal levels, Health Council members reported that their budget allocation is rarely discussed during meetings. Also, at the municipal level, Health Council members reported that there is no planning process regarding how the budget is to be spent during the year, which results in the budget not being used or mismanaged.

3.5.2 Training

Under the National Policy of Permanent Education for Social Accountability in the Health System (Política Nacional de Educação Permanente para o Controle Social no Sistema Único de Saúde), training for Health Council members is mandated. This policy expresses that municipal, state and federal Secretaries of Health must provide funding to train Health Council members on the structure of the health sector, their mandate and any relevant laws and policies. However, it does not explicitly outline how training is to be provided, how long it should take place, nor does it provide a curriculum that explicitly states what needs to be taught to Health Council members. This ambiguity may explain why many Health Council members reported
feeling unprepared and unable to engage in discussions during meetings. This lack of training was further supported by healthcare representatives at all three levels of government who stated that civil society representatives are unable to engage in active discussions on the health sector due to their limited knowledge. For example, a healthcare representative at the state level reported,

“Some Health Council members are not prepared to engage in discussion. The training provided is definitely not enough for them.”13 (Healthcare Sector Representative, State Health Council Member #7)

The inadequate allocation and management of the operational budget of Health Councils, as well as poorly trained members, have contributed to weakness of Health Councils. Health Council members need to have a solid foundation of knowledge about how the health system and Brazil’s legal system works, as well as their rights as Health Council members and the government’s obligations to them.

3.6 Health Council Members’ Strong Individual Interests

Evidently, there are Health Council members who are pursuing their own interests over above those of the entity they represent. There was indeed wide agreement among interviewees that Health Council members often advance their own private interests. A Health Council member representing the government at the municipal level stated,

“Does the council work in an impartial way? For me, that is the main problem of Health Councils. Unfortunately, they were created to mobilize civil society into SUS, but it did not work. People are there to defend their own interests or the interests of the institutions they represent, with some exception. For example, I have been participating in different management positions of this Municipal Health Council over the years, and depending on who is in the management position, the agenda of the Secretariat changes ... There was a management period that was focused on mental health. My Goodness, we had to be careful to present anything related to mental health … In another time, the management was focused on dental health. Currently, this management focus is on workers’ health.”14 (Government Representative, Municipal Health Council Member #9)
There is also a reported apathy among some members. A Health Council member representing civil society at the state level reported that,

“Some civil society groups have ties to the Health Councils, but they don’t care about [Health Councils]. They send people to represent them who do not know why they are even there.”

(Civil Society Representative, State Health Council Member #5)

Another Health Council member representing civil society at the municipal level stated that,

“A big issue that I see is that most of the council members don’t like to read, work all day and sometimes this limits their ability to act. There is a lot of information on laws, resolutions, and regulations.”

(Civil Society Representative, Municipal Health Council Member #8)

While some of members interviewed reported having a genuine interest in improving the overall state of the health system, they also reported that many of their peers on the Council did not share this goal.

4 Discussion

The findings of this study illuminate some of the challenges present in Health Councils that limit their effective functioning and the capacity of civil society to have a meaningful input into the health policy process. One clear limitation is the absence of a legal framework that provides Health Councils with the authority to ensure accountability of their respective government and to enforce the rule of law. Government representatives, it seems, have greater incentives to dominate and even manipulate discussions and decisions in Health Councils, since their livelihood and power is directly tied to their outcomes (Church et al., 2002). Meanwhile, civil society’s participation seems to be largely limited to well-resourced groups so that the most marginalized populations are, in fact, not represented in the Health Councils. We found that in many Health Councils, government representatives often use manipulative tactics. When they are unable to “buy” support from other members, they have allegedly resorted to threats, particularly towards healthcare representatives. This patently fosters a climate, whereby many Health Council members will be reluctant to voice their real demands and concerns. Indeed a study conducted by Cornwall (2008), highlighted that given the hierarchical nature of the healthcare system and their reliance on the government for work contracts, healthcare representatives feared
being fired for voicing their concerns and opinions (Cornwall, 2008). As a result, government representatives have seem to share the greatest influence Health Council meetings, which puts into question how well participatory democracy works within them.

The apparent power asymmetry between civil society and government representatives present in Health Councils is further magnified by the reported lack of training that is provided to Health Council members. Due to the complexity of the healthcare sector and the policymaking process, civil society representatives need to possess a sufficient level of technical knowledge for informed discussion about health sector policy issues. We found training is insufficient, which has had a reported negative effect on civil society representatives’ ability to engage in active and meaningful discussions and make informed and evidence-based decisions. Within Health Councils, civil society is generally less equipped to participate in discussions, compared with healthcare and government representatives, who have greater technical knowledge (Vera Schattan P. Coelho et al., 2005).

Additionally, the membership guidelines of Health Councils are not conducive to broad membership of the population, as they are best suited for well-organized and active civil society groups. Marginalized groups of Brazilian society need to be represented as they are most likely to depend the most on the healthcare services provided by SUS due to their financial inability to turn to the private sector (WHO, 2008). Socioeconomic factors such as income and educational levels contribute to which members of the population represent civil society within Health Councils (Blacksher et al., 2012; Vera Schattan P. Coelho et al., 2005). The membership guidelines effectively create a restrictive level of civil society inclusion, whereby only those who are willing to participate and have the means to form an organized civil society group can qualify for membership. A prior study on the State Health Council of São Paulo also concluded that membership guidelines create “a pre-existing network of relationships among representatives of government and social movements” and exclude those that lack the means to form such ties (Vera Schattan P. Coelho, 2004, p. 36).

The low level of participatory culture that can be found in Brazil has had a reported effect on civil society’s level of participation and interest in Health Councils. And even when civil society participates, representatives may only use Health Councils to advance their own interests. Many
members use their membership as a stepping-stone for a government career or as a mean to gain prestige among peers (Cornwall, 2008).

Other studies conducted on Health Councils in Brazil have also highlighted their limitations. For example, one study reported that Health Council members felt that they have failed to have a meaningful effect on health policies (Vera Schattan P. Coelho et al., 2005). Another study concluded that while multiple issues in the healthcare system are raised within Health Council discussions, they have failed to influence any decisions taken by the government (Vera Schattan P. Coelho, 2004). And lastly, even though Health Councils permit the inclusion of new actors in health policy discussions, they have not had a significant effect on the restructuring of the SUS (Stralen et al., 2006).

If Brazil’s Health Councils are to become a meaningful forum for inclusive health policy discussion and outcomes, a number of changes are likely needed. First, Health Councils need greater authority and autonomy from the government. Second, membership guidelines need to incentivize participation amongst all members of the population and specifically make greater efforts to have provisions that will include marginalized groups. This will ideally yield greater levels of civil society participation and help ensure that marginalized group issues and concerns are factored into the decision-making process. Third, the Federal government must clearly outline how civil society’s input will be incorporated in the decision-making process in order to ensure policy that is reflective of societal needs, healthcare representatives’ expertise, and the governments’ knowledge of policy making. This will help promote more transparency in the decision-making process and manage expectations among Health Council members better. Lastly, clear training guidelines and sufficient curricula, along with the requisite resources, are needed to ensure sufficient training is provided to Health Council members, particularly those from civil society. Training will give civil society representatives the requisite knowledge to actively engage in discussions and health sector policy processes.

4.1 Limitations

The authors analyzed the interview data with the assumption that participants’ accounts are purely objective. This therefore led to the generation and analysis of data that does not take into account participants’ beliefs and values and how those shaped the study’s reported findings. Therefore, future studies can address this limitation by using different ontological assumptions to
help understand how these conditions and context may have had an effect on this study’s findings.

In addition, our decision to conduct interviews with Health Council members was based the study’s objective of creating a descriptive account of issues present in this specific forum for civil society participation in decision-making. However, despite the researchers’ best efforts, the response rate from government representatives was low, which created an overrepresentation of healthcare professionals and civil society representatives in our sample. This may explain the predominance of issues surrounding government support in our results. Future work on Health Councils could explore government representatives’ views and perceptions in more detail to have a more balanced recount of some of the issues present in Health Councils from the perceptions of all the parties involved. In addition, while our findings may be similar to studies conducted on other models of participatory governance, they are not representative of all forms of participatory governance models. Therefore, transferability of our research findings must be mindful of the context under which this research was conducted as well as the researchers’ assumptions that guided the data analysis process. Lastly, despite our best efforts, the authors acknowledge that the analysis of the interview data may have been affected during the translation process in a way that certain words or phrases may have been “lost in translation”. This was mitigated as much as possible by actively consulting with a Brazilian researcher fluent in both English and Portuguese on the appropriateness of word selection and meaning.

5 Conclusions

This study highlighted how Brazil’s Health Councils have not necessarily led to meaningful participation by civil society in the health policy process. They certainly provide a forum for stakeholders to come together to discuss issues in the health sector and they have the potential to make members of civil society feel empowered and better informed about the healthcare sector. However, we found that they do not necessarily provide a sufficient forum through which civil society can actively and meaningfully participate in the decision-making process. This puts into question how well participatory democracy is served by the Health Councils.

We found that civil society is limited in Health Councils throughout Brazil by restrictive membership guidelines, a lack of autonomy from the government, vulnerability to government manipulation, a lack of support and recognition from the government, and a lack of necessary
training and budget (Blacksher et al., 2012; Solomon & Abelson, 2012). As a result of these issues, Health Councils may not be an effective forum through which civil society can engage in discussion to promote policy that is reflective of societal needs. There is certainly no one size fits all model to achieve this. However, this study has shed light on the need for Health Councils to have more defined terms and goals and to have its mandate backed up by a strong and independent legislative framework to achieve it. This would help guide policy makers’ decisions on who should be included, how their views will be included in decision-making, and when civil society should be included. Health Councils would also benefit from having the legal authority to act independently in order to minimize vulnerabilities to government manipulation. Lastly, membership guidelines ideally should be revised to ensure greater inclusion that does not rely on the organizational capabilities of civil society groups and better training for civil society representatives to take more evidence-based decisions.

6 List of Abbreviations

CONASEMS  Conselho Nacional de Secretários Municipais de Saúde, Brazil’s National Council of Municipal Health Secretaries

CONASS  Conselho Nacional de Secretários de Saúde, Brazil’s National Council of Secretaries of Health

OECD  Organization for Economic Co-operation and Development

SDGs  Sustainable Development Goals

SUS  Sistema Unico de Saúde, Brazil’s Unified Health System

7 Declarations

7.1 Acknowledgements

We would like to thank Dr. Elise Paradise and Dr. Mariana Prado for their valuable feedback as well as Joao Batista da Silva Junior for translating and research assistance.
7.2 Funding
The Canadian Institute of Health Research (CIHR) provided funding for this study.

7.3 Availability of Data and Material
Due to the participant anonymity requirements outlined during the study’s ethics approval process by the University of Toronto’s Research Ethics Board and CONEP, only the quotes provided in this manuscript will be disclosed. All other data will be kept confidential.

7.4 Authors Contribution
MGM and JCK contributed to the conception and design of the research project, analysis and interpretation of all data. MGM conducted 21 of the 40 interviews with the help of a Research Assistant. The remaining 19 of the 40 interviews and the translation of all of the interviews were carried out by a Research Assistant. Both authors read and approved the final manuscript.

7.5 Authors’ Information
Jillian Clare Kohler is a Professor at the Leslie Dan Faculty of Pharmacy, the Munk School of Global Affairs, and Dalla Lana School of Public Health at the University of Toronto. She is also the Director of the WHO Collaborating Centre for Governance, Accountability and Transparency for the Pharmaceutical Sector at the University of Toronto. She holds a PhD in Political Science from New York University. Martha Gabriela Martinez is a Masters of Science student at the Leslie Dan Faculty of Pharmacy, University of Toronto. She holds a BA in Political Science from the University of Toronto.

7.6 Competing Interests
There are no potential competing interests to be declared.

7.7 Consent for Publication
Not applicable
7.8 Ethics Approval and Consent to Participate

This study was reviewed and approved by the University of Toronto’s Research Ethics Board as well as Brazil’s National Commission of Ethical Research (*Comissão Nacional de Ética em Pesquisa – CONEP*).

8 Open Access

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Chapter 4
Discussion and Conclusions

1 Summary of Findings

Civil society participation in policy and decision-making is becoming increasingly popular in the international development field (Ghaus-Pasha 2005; Nino 2016). Depending on the level of engagement with civil society, civil society participation is said to help empower citizens by increasing access to information, by providing an opportunity for citizens to voice their demands and needs directly to governing bodies, and by creating opportunities for citizens to influence policymaking (Ghaus-Pasha, 2005; McGee & Gaventa, 2010; Mitton, Smith, Peacock, Evoy, & Abelson, 2009). This can in turn help promote transparency, accountability and achieve policy outcomes, enhancing good governance overall. For governments, civil society participation can also be used to minimize public opposition by decreasing skepticism of government decision-making (Irwin, 2006).

Although there continues to be a lack of consensus on how to best include civil society in decision-making, civil society participation continues to be popular in policy efforts by many governments. In the case of Brazil, its Health Councils make for an interesting example of how civil society participation can be used in the public health sector. Through Health Councils, civil society is said to help formulate national health plans, approve health budgets, monitor the allocation of public resources, and evaluate the overall performance of the Health System (Ministério da Saúde, 2008). However, the experiences of some Health Council members captured by this thesis illuminate that challenges remain for achieving their goals. These challenges are: ensuring that marginalized segments of civil society are included, creating a space where civil society is comfortable with voicing their demands and concerns, and having the resources and training necessary for Health Councils to function effectively.

The first challenge within Health Councils is the level of inclusion permitted by membership guidelines. Membership guidelines set the parameters for whose opinions and demands will be heard and included in the decision-making process. In the case of Health Councils, their membership guidelines limit participation to organized civil society groups that have are highly organized and have the means to participate. This creates a large cost of participation, since not
all civil society groups have the necessary resources, time and infrastructure to fulfill these membership requirements, especially vulnerable and marginalize groups. Health Councils’ membership requirements create a system whereby civil society groups with more resource have a greater advantage over those that may not be as organized or lack such resources. Barnes and Coelho (2009) reinforce this finding, stating that, “in Brazil the efforts to assure legitimacy ended up opening space to weak forms of accountability that may reinforce the exclusion of the worse off” (Barnes & Coelho, 2009, p. 234). In addition, this thesis’s study participants also reported the public is often unaware of the existence of Health Councils, and those who do have some knowledge about Health Councils, are often not interested in learning more about what they do or how to participate within them. This also limits the breath of the membership within Health Councils creating a level of inclusion that is limited in scope.

The second challenge is the reported disconnect between the Health Councils’ mandate, which is to provide a space for civil society to safely and effectively articulate their demands directly to the government to have an impact on health policies and what is taking place in practice. While civil society, through Health Councils, can voice their concerns and demand change through motions, recommendations and solutions, they do not have the authority to implement change. They are dependent on the government to implement the decisions taken during Health Council meetings. It is also up to the government to provide Health Councils with the necessary information to monitor the healthcare sector. As a result, Health Councils have a limited ability to affect the healthcare sector since they can help bring to light underperformance, inefficiencies and irregularities but they cannot impose sanctions nor have a direct effect on health policies without the support from the government.

In addition, there are reported high levels of government manipulation and party politics within Health Councils. Although civil society representatives constitute half of all members within each of the Health Councils, there appears to be a hierarchy between civil society, healthcare and government representative in which government representatives appear to be on top. This made some study participants who are not representing the government feel vulnerable to their manipulation and fearful of any negative backlash from government representatives if they bring to light controversial topics during Health Council meetings. The dynamics between the three member groups creates a hostile environment for civil society and healthcare representatives, which makes them less willing to voice their concerns and engage in discussions about issues in
the healthcare sector. These findings align with previously conducted studies on Health Councils, which have concluded that this hierarchical relationship among Health Council members makes these forums vulnerable to manipulation from the government (Barnes & Coelho, 2009; Coelho & Nobre, 2004; Cornwall, 2008). For example, Cornwall (2008) reports that healthcare representatives are often fearful of being fired for reporting issues in the healthcare sector. They also reported feeling frustrated and disrespected by the way government representatives interact with them. Cornwall goes on to conclude that respect and trust between Health Council members is important to make Health Councils work (Cornwall, 2008). Another study conducted by Coelho (2004) concludes that Health Councils have failed to have an influence on health policy changes because those involved in Health Councils have failed to create a collaborative environment (Coelho, 2004). This hierarchical relationship affects Health Councils’ ability to ensure accountability in the health sector.

The third challenge is a reported lack of support and respect from Health Councils’ respective governments. Health Council members reported that the government is not interested in ensuring they are able to fulfill their mandate. At the state and municipal levels, it was reported that this lack of political will and support sometimes resulted in the government failing to report to Health Councils issues that are within their jurisdiction, such as the approval of public health budgets. Coelho (2004) reports similar findings, stating that Health Councils cannot succeed without the commitment and recognition of the government (Coelho, 2004).

This lack of recognition is also manifested through the lack of resources and training provided to Health Council members, which affects their ability to promote accountability in the health sector. Health Councils’ membership guidelines do not require any level of knowledge or experience in the healthcare sector. Instead, the government is responsible for providing training to civil society representatives. It was reported that when training is provided, there is a lack of uniformity in its duration, quality and frequency to civil society representatives. As a result, some representatives may lack the necessary knowledge to effectively engage in discussions during Health Council meetings. Cornwall (2008) reports similar findings, stating that government representatives often felt that certain topics could not be brought up during meetings because citizens were unlikely to understand them (Cornwall, 2008). Thus, this affects the type of discussions taking place within Health Councils. This issue is further highlighted by the reported lack of resources provided by the government for Health Councils to operate
effectively. Without proper training and resources, Health Councils are limited in their ability to monitor the health sector and promote accountability.

All of these findings suggest that while Brazil has put forward civil society participation through Health Councils, challenges remain for their effective use in the public health sector. Within Health Councils, there are limitations as to how civil society is able to participate, as well as how their input is included in policy and decision-making. One of the biggest questions brought forward by this research’s findings is whether Health Councils should have the legal capacity to call for policy changes in the public health sector and enforce the rule of law by imposing sanctions and calling for investigations independently of government approval. This question relates back to the lack of clarity on what civil society participation should be used for and how it should be designed. Future studies can further explore this issue.

Other questions that this thesis’ findings bring forward is how to address the reported lack of technical knowledge among civil society representatives and whether or not there is a need to include larger segments of civil society within Health Councils. The former question may be addressed by either requiring some level of technical knowledge from civil society representatives or by creating and implementing a strong training curriculum for them. This can help ensure that civil society representatives are well equipped to voice their opinions and understand discussions taking place. The latter question involves who within civil society is to be included through membership guidelines. Currently, Health Councils’ guidelines exclude the poorest members of society due to participation costs associated with participating. Future studies can explore this issue further by creating a detailed account of strengths and limitations of different modes of inclusion. Overall, this thesis’ findings highlight the importance of conducting further research on civil society participation in general and Health Councils specifically.

2 Reflections on Institutional Design

As previously discussed in Chapter 1, civil society participation in policymaking has been advocated by the international community (e.g. the World Health Organization, the World Bank and within the recent United Nations’ Sustainable Development Goals), without necessarily advocating how to best operationalize it. In the case of civil society participation, it remains unclear who is to be included and how, as well as how the success of civil society participation
should be evaluated. This thesis’ findings reflect to some extent that these questions remain even within Health Councils, which have been around since 1990.

The findings from this thesis also briefly discuss contextual considerations for the realization of civil society participation. Gaus-Pasha (2005) argues that contextual impediments for civil society participation exist, such as authoritarian political control and government distrust in civil society movements that can create a hostile environment for civil society participation, combined with low income and education levels among civil society as well as funding constraints that limit the scale of civil society participation (Ghaus-Pasha, 2005). These contextual considerations have been briefly explored in this thesis. While the debate on whether or not contextual considerations should be a focus in policymaking continues, how to effectively move from theoretical models of civil society participation to applicable frameworks also remains a challenge. More research on this will help provide greater insight on potential solutions for how to effectively and appropriately design civil society participation in a way that ensures these challenges are minimized.

3 Study Limitations and Possible Areas for Future Research

This study’s limitations relate to the level of rigor in the study design and how this affects the thesis findings. The following is a breakdown of this study’s limitations:

Sampling Strategy

This thesis’ limitations related to the sampling strategy include the unsystematic recruitment process, changes to the sampling strategy from purposeful to snowball sampling, and the overall size of the study sample. Because of the low response rate received during the recruitment process as well as changes in the sampling strategy from purposeful to snowball sampling, the thesis’ sample size is small and homogenous in relation to the size of the country and its population. Snowball sampling does not produce a representative sample of large populations, since this approach creates a sample of individuals that are more well-known than others within a given network. In addition, the small sample size and the lack of consideration for factors such as geographical location, socioeconomic status within that geographical location, and the level of government (municipal, state, national) created a sample group that is not representative of every
Health Council member. Because of this, the findings reported in this thesis are dominated by the perceptions of a very small and homogenous group, predominantly made up of civil society representatives at the municipal level. While we aimed to provide a greater understanding of Health Councils as a whole, the reported findings may not be reflective of all Health Councils in Brazil and may even be a product of outlier perspectives.

Future studies with more resources can address this limitation by having a larger sample group that is more representative of healthcare and government representatives, and by targeting all geographical regions of Brazil and all levels of government equally in order to generate findings that are more representative of Health Councils. Equally, future studies can instead focus solely on recruiting every Health Council member in one specific Health Council. Moreover, given the continued debate on the need to consider contextual factors during institutional design, future studies can also account for contextual differences between Health Councils in their sampling strategy such as government level (municipal, state and national) or geographical location (between states, across regions, etc.). This would help examine in detail whether and how factors such as public resources, geographical location, population density, average income and literacy levels affect Health Councils.

In addition, there is a possibility that the experiences reported by the study participants were based on how Health Councils operated prior to the enactment of some of the documents reviewed. Future studies can address this by taking into consideration participants’ membership timelines to ensure that the reported experiences are accurately reflective of the legislation that currently governs Health Councils. In addition, during the sampling process, the researcher did not keep records of the response rate received from participants. This uncertainty limits the researcher’s ability to provide exact information on how many Health Council members accepted to participate in the study in relation to those who did not, as well as a breakdown per sample group.

**Data Collection and Analysis**

The data collection process was guided by the study questionnaire, which was created after conducting an unsystematic literature scan on civil society participation and Health Councils. By not conducting a systematic literature review, relevant literature on the topic may have been omitted. Future studies can address this by conducting a systematic literature review to ensure all
existing literature relevant to the topic at hand is taken into consideration during the design of the study questionnaire.

In addition, because the interviews were semi-structured in nature, each interview conducted may have varied to some degree on what was being asked and how, thus affecting the degree of rigor in the data collection process. This may have affected the reported findings, given that not all interviews were conducted similarly. What is more, not all interviews were recorded. Therefore, some details may have been omitted during the transcription of the interview data. Lastly, the translation of interview would have benefited from undergoing an a verification process with a certified translator in order to ensure accuracy in the translation and that no important information was omitted.

Level of Neutrality between Researcher and Researched

Lastly, the researcher’s views, values and perceptions may have affected the design of the study as well as the data analysis and reporting processes. For example, the researchers’ previous knowledge on Brazil, civil society participation and Health Councils may have influenced how the data were analyzed to generate themes and what findings were ultimately reported. Similarly, the researcher’s views and perceptions may have affected the interview process, given the semi-structured nature of the study questionnaire. For example, the researcher’s use of probing was unsystematic and varied from interview to interview. Future studies can address this challenge to increase the level of neutrality and objectivity by conducting structured interviews with limited probing, as well as by using a systematic approach to code and analyze the study data.

4 Conclusions

This thesis focused on Brazil’s Health Councils (Conselhos de Saude) to explore challenges in institutionalizing civil society participation. Chapter 1 provided an overview of good governance and civil society participation, as well as how the lack of clarity on what good governance and civil society participation truly mean has affected efforts to establish civil society participation and good governance within countries. Chapter 2 provided a detailed summary of the methodological approach used for this thesis, which involved taking a positivist approach to design and carry out this thesis, conducting interviews with Health Council members across
Brazil, and analyzing key legislation that outlines how Health Councils operate. Chapter 3 reported the thesis findings in detail.

The existing literature on civil society participation (Abelson et al., 2012; Blacksher et al., 2012; Ghaus-Pasha, 2005; Irwin, 2006; McGee & Gaventa, 2010; Mitton, Smith, Peacock, Evoy, & Abelson, 2009) provides a positive narrative by focusing on its potential to improve the effectiveness of service delivery, serve the public interest, strengthen transparency and accountability, and increase government legitimacy. However, this thesis found that challenges remain when civil society members participate in Brazil’s Health Councils.

Health Councils lack the authority to implement change, its membership guidelines limit the level of inclusion of marginalized civil society groups, government representatives create a hostile environment that trumps collaboration among Health Council members, there is a lack of budget for Health Council operations and training for civil society representatives, and there are strong individual interests present among Health Council members. The findings from this thesis, although not universally generalizable, help illuminate the importance of institutional design, policy making and the many contextual factors that can affect civil society participation within Health Councils.

The thesis highlighting a number of challenges in seeking to go beyond descriptions of governance processes and practices and into specifying what the actual characteristics of good governance are and should look like when are institutionalized. While this debate continues, it is hoped that this research can help illuminate why design matters for civil society participation. Given the large variation on the type of healthcare models around the world, governance structures, as well as cultural, political and economic environments, research that examines this will be useful for better understanding institutional design in order to successfully achieve SDG 16 of developing “responsive, inclusive, participatory and representative decision-making at all levels” (Nino, 2016).
References


Appendices

Appendix 1 – Interview Guide for Health Council Members

Please introduce yourself and state which group you present on your Health Council?

How long have you been involved in the council? Why did you join?

Do all council members actively engage in discussions? Why or why not?

How would you describe the relationships between council members?

How does your Health Council communicate with the public? Is it effective? Why? Why not?

How do citizens participate with the Health Councils?

Is the budget used effectively? Who is in charge of it?

Is the way in which meetings are run effective? Why or why not?

What type of training council do members have? Is it enough?

Are Health Council decisions implemented by the government? Give examples.

Do Health Councils have any power to enforce any of their decisions?

Does the government support Health Councils? How? Or if no, why not?

What is the biggest strength/weakness of the councils?

What improvements would you make?

Is there anything else we haven’t discussed that you would like to add?
Appendix 2 – Quotes in Portuguese

1. “Uma resolução que foi aprovada no Conselho contra a privatização do sistema de saúde não foi assinada pelos dois Secretários de Saúde anteriores do meu estado. Um deles disse que não ‘ia dar um tiro no próprio pé’.”

2. “A participação da sociedade civil e muito frágil. Nossa sociedade não tem a cultura de participação na construção das políticas públicas e, ainda, em pleno século XXI não se deu conta do poder que possui por ser contribuinte, cidadão de direitos. A sociedade em geral desconhece a finalidade da existência do Estado em devolver-lhe sob a forma de serviços como educação e saúde, os altos impostos que são cobrados e recolhidos. A sociedade brasileira está demorando muito a despertar.”

3. “Existem leis. A gente tenta trabalhar com imparcialidade, defendendo os interesses do público [pausa], mas há pressões do governo, especialmente quando se trata de decisões sobre o orçamento da saúde. Os trabalhadores de saúde são definitivamente os mais vulneráveis.”

4. “Os usuários são vulneráveis aos interesses do governo. Os gestores, como esperado, apoiam o governo com cegos. Esses interesses não são idênticos aos da sociedade. Eles vão fazer qualquer coisa para evitar escândalos. Os trabalhadores de saúde atuar da mesma forma ... suas ações não refletem as necessidades da sociedade. Parece que não há nenhum compromisso real para atender as necessidades da nossa sociedade.”

5. “A gente fazem o que podem. Às vezes, falamos com pacientes, médicos. Outras vezes, escrever-lhes. Leis existem para ser seguidas, mas às vezes temos medo de reportar problemas. Os membros do Conselho trabalham para ou pode ter parentes que trabalham para o governo e nós estamos com medo de perder nossos empregos ou nossa posição no conselho. É realmente uma vergonha. Se houvesse direitos e leis foram aplicadas, nosso Brasil seria um modelo a seguir.”

6. “O conselho de saúde que presidia sempre trabalha com as informações e depois de analisadas e que poderá afetar um lado ou outro, mas afirmo que as decisões serão tomadas conforme a legalidade e isso aplicará certo desconforto ao gestor, principalmente nos desvio de recurso que a tomada de decisão reprovada pelo conselho, faz com que este procedimento gera perseguição a conselheiro que é funcionário público e também da iniciativa privada que tem
empresas e é perseguida por mandato de fiscalização para intimidar as ações aplicadas que a contrarie a sua gestão. Os conselheiros se sentem ameaçados, por que, a legislação joga a responsabilidade no conselho, o mesmo responde criminalmente aprovar qualquer procedimento que envolva recurso que haja suspeita de fraude ou desvio. A onde em que cada membro prefere sair do conselho por que é uma participação voluntária e não ganha nada com isso e toma tempo para dedicar às atividades das comissões nas fiscalizações dos recursos, ações e denúncias dos usuários do sistema de saúde. Não os culpo.”


8. “Na realidade, o governo não apoia os conselhos, eles os toleraram. Há uma tensão entre os dois devido às diferenças de interesses. É mais uma relação instrumental. Eles não percebem o poder que os conselhos de saúde têm. O governo se preocupa mais com a opinião de seus representantes do que os usuários ou profissionais de saúde, talvez porque outros interesses estão envolvidos.”

9. “O governo municipal não reconhece o Conselho como órgão autônomo, deliberativo, não tem interesse real em qualificá-lo. O Conselho Estadual realiza capacitações, reuniões, orienta, mas o cerne da questão seria incentivar a participação social e, isso, os administradores públicos não fazem com medo de perder o poder que acreditam ser deles e não do povo que pediu para representá-lo.”

10. “Por os últimos 4 meses, o governo não nos deu os relatórios orçamentais que devem ser aprovados pelo Conselho. Muitas vezes não nos dizem coisas que devemos aprovar e as coisas são aprovadas sem nosso consentimento, mesmo que é exigido antes de a lei.”

11. ”O governo não nos apoia muito, mas nossa existência é garantida por lei. No entanto, de vez em quando a internet fica suspensa por falta de pagamento do governo estadual aos fornecedores. Mas nós usamos nossos celulares e fazemos acontecer mesmo com dificuldades.”

12. “O governo diz que apoia os conselhos, mas está longe de ser realidade. Eles não têm o seu próprio website para divulgação de informações. O site que existe a assessoria de comunicação paga com dinheiro do próprio bolso. Ele não suporta muitos dados. Há falta de apoio do governo.”

14. “Funciona de forma imparcial? Para mim esse é o principal problema do CMS, infelizmente foi uma forma inventada para o SUS de mobilização da sociedade que não deu certo. As pessoas estão lá para defender interesses próprios, salvo exceção, interesses das instituições que representam. Exemplo disso, já passei por algumas gestões do CMS e dependendo de quem está lá o foco de cobrança para a Secretaria muda… Houve uma gestão que foi saúde mental, minha nossa, tínhamos o maior cuidado para apresentar qualquer coisa de saúde mental.. outra era Saúde Bucal. Nessa gestão o foco é saúde do trabalhador….”

15. “Algumas entidades têm cadeiras no conselho, mas não se importam. Mandam pessoas que não sabem o que estão fazendo lá.”

16. “Um grande problema que vejo é que a maioria dos conselheiros não gosta de ler, trabalha o dia inteiro e, às vezes, sofre restrições para poder atuar. Mas há muita informação nas leis, nas resoluções e portarias.”
Appendix 3 – Article as it appears on *Globalization and Health*

(Continued on the next page)
Civil society participation in the health system: the case of Brazil’s Health Councils

Martha Gabriela Martinez* and Jillian Clare Kohler

Abstract

Background: Brazil created Health Councils to bring together civil society groups, health professionals, and government officials in the discussion of health policies and health system resource allocation. However, several studies have concluded that Health Councils are not very influential on healthcare policy. This study probes this issue further by providing a descriptive account of some of the challenges civil society face within Brazil’s Health Councils.

Methods: Forty semi-structured interviews with Health Council Members at the municipal, state and national levels were conducted in June and July of 2013 and May of 2014. The geographical location of the interviewees covered all five regions of Brazil (North, Northeast, Midwest, Southeast, South) for a total of 5 different municipal Health Councils, 8 different state Health Councils, and the national Health Council in Brasilia. Interview data was analyzed using a thematic approach.

Results: Health Councils are limited by a lack of legal authority, which limits their ability to hold the government accountable for its health service performance, and thus hinders their ability to fulfill their mandate. Equally important, their membership guidelines create a limited level of inclusivity that seems to benefit only well-organized civil society groups. There is a reported lack of support and recognition from the relevant government that negatively affects the degree to which Health Council deliberations are implemented. Other deficiencies include an insufficient amount of resources for Health Council operations, and a lack of training for Health Council members. Lastly, strong individual interests among Health Council members tend to influence how members participate in Health Council discussions.

Conclusions: Brazil’s Health Councils fall short in providing an effective forum through which civil society can actively participate in health policy and resource allocation decision-making processes. Restrictive membership guidelines, a lack of autonomy from the government, vulnerability to government manipulation, a lack of support and recognition from the government and insufficient training and operational budgets have made Health Council largely a forum for consultation. Our conclusions highlight, that among other issues, Health Councils need to have the legal authority to act independently to promote government accountability, membership guidelines need to be revised in order include members of marginalized groups, and better training of civil society representatives is required to help them make more informed decisions.

Keywords: Participatory governance, Civil society participation, Civil society inclusion, Good governance, Institutional design, Conselhos de saude, Health Councils

* Correspondence: g.martinezmalagon@utoronto.ca
Leslie Dan Faculty of Pharmacy, University of Toronto, 144 College Street, Toronto, ON M4R 1V5, Canada

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Background

Institutional reforms within the international development field have increasingly focused on establishing civil society participation in decision-making and policy formulation to promote social justice and increase good governance in the public sector [1]. In our paper, we use the term “civil society” to refer to “ordinary citizens,” who are independent of the government. We also use the term “participation” to describe a process by which civil society and government come together to engage in active dialogue to take a decision in a collaborative manner [2, 3].

The recent Sustainable Development Goals (SDGs) recognize that, “responsive, inclusive, participatory and representative decision-making at all levels” is a crucial component for development [4]. Governments commonly create a forum or space in policy making, through which civil society can voice demands and concerns. Ideally, the inclusion of civil society raises the potential for decision-making to be well informed and reflective of societal needs [5, 6]. This, in turn, can make civil society more supportive of government decisions and increases (either real or perceived) government support and legitimacy [5, 6]. The inclusion of civil society in the decision-making process can also increase transparency by helping inform citizens about how decisions that affect their everyday lives are made [5]. Transparency is linked to accountability in that government transparency requires that citizens be fully informed about how and why decisions are made, including the decision-making procedures followed, criteria applied by policy-makers, and the information or evidence drawn upon to reach decisions [7]. This information can then be used to hold relevant government officials accountable to their actions to ensure satisfactory public sector services [8, 9]. This can also help monitor the performance of the health system and resource allocation in the public sector [10–12].

Globally, there are many examples of forums for civil society participation in the health sector; many of these have been established in the past two decades. For example, the Province of Quebec’s Hospital Boards, that include civil society in the decision making process in Quebec’s hospitals, the United Kingdom’s Public Participation Forums that include civil society in the allocation of resources of the United Kingdom’s National Health Service, and Brazil’s Health Councils, the latter is the focus of this paper.

Civil society participation in the health sector assumed a central role in the restructuring of Brazil’s unified health system, the Sistema Único de Saúde (SUS), which took place during the country’s period of transition out a military regime during the 1980s. This focus on civil society participation grew out of the Sanitarista movement, which advanced the decentralization of Brazil’s health system and universal health coverage for the population. This same social movement promoted the establishment of Health Councils in 1990 to provide a forum for civil society participation in the implementation and monitoring of health policies for social accountability (control social in Portuguese) at the municipal, state and federal levels [13–15]. Today, these councils serve as advisory bodies with an ambitious mandate that includes monitoring the health system and the allocation of resources, bringing together civil society groups, health professionals, and government officials.

The 48 members of any given Health Council are represented as follows: 50 % are ‘users’ of the healthcare system (civil society groups), 25 % are healthcare representatives and 25 % are government representatives. Government representatives may be appointed by the following: the National Council of Secretaries of Health (CONASS), the Federal Government, the National Council of Municipal Health Secretaries (CONASEMS), healthcare service providers, and lastly, private sector representatives. Civil society and healthcare representatives, on the other hand, are appointed to Health Councils by their respective organizations/institution. The creation of the Health Councils is considered to be a milestone in the history of health policies in Brazil; Health Councils have also received international praise for their capacity to advance participatory democracy [16].

Still, there is not always clear evidence of what impact civil society has had on policy within forums like the Health Councils. Indeed, in reference to efforts by its own member states, the Organization for Economic Cooperation and Development (OECD), has noted that, “...there is a striking imbalance between the amount of time, money and energy that governments in OECD countries invest in engaging citizens and civil society in public decision-making and the amount of attention they pay to evaluating the effectiveness and impact of such efforts” [17]. Studies of different models for civil society participation in the health policy process have illuminated some of their limitations. For example, a study conducted on British Columbia’s Regional Health Boards found widespread feelings of discontent among civil society members about their role within the Boards, as the government failed to clearly articulate during their formalization why these Boards were being created or how civil society was to be included in decision-making [18].

In the case of Brazil, much of the existing literature on Health Councils focuses on their prevalence throughout the country, as well as the status that they hold, which gives them the potential to serve as a deterrence mechanism for corruption and also as a way to increase social accountability by the government in the provision of health services [19]. Yet, there is evidence from some
studies that that certain aspects of the Health Councils, such as meeting guidelines and council membership procedures, have unintended created barriers for civil society engagement in health policy formulation [13, 20–26].

To be sure, a challenge in any effort to include civil society in the policy process is first to determine who should represent civil society. Often terms such as ‘citizens’, ‘users’, ‘civil society’, and ‘the public’ are used interchangeably across different models without a clear definition of who exactly they are referring to and thus whom these forums aim to include [27]. This is particularly important for the health sector given the mix of technical and non-technical knowledge necessary for making decisions for health policy formulation [9]. On a similar note, terms like ‘engagement’, ‘participation’ and ‘involvement’ are used often without an explicit explanation of the degree to which civil society will be engaged in decision-making or the roles and expectations of civil society participants [6, 27, 28]. Governments rarely specify how and when civil society’s views and demands will be included in the policy and decision-making process [29]. This lack of clarity suggests the need to understand better the strengths and weaknesses of how current participatory policy models are designed so that future efforts incorporate lessons [9, 30]. To this end, we have explored one of these models – Brazil’s Health Councils.

Methods
Semi-structured interviews
Data collection
A total of 40 semi-structured interviews were conducted with Health Council Members at the municipal, state and national levels by the first author and a Research Assistant. In June and July of 2013, the first author and a Research Assistant interviewed eight municipal, seven state, and six national Health Council members. In May of 2014 a Research Assistant interviewed an additional nine municipal, nine state and one national Health Council members. The geographical location of the interviewees covered all five regions of Brazil (North, Northeast, Midwest, Southeast, South) for a total of 5 different municipal Health Councils, 8 different state Health Councils, and the national Health Council in Brasilia. Due to confidentiality concerns, the location of study participants cannot be disclosed. Table 1 provides a breakdown of the study sample.

Study participants were identified by accessing membership lists of Health Council at the national, state and municipal levels which were available online. We began with the membership list of Brazil’s national Health Council, followed by searching for state Health Councils that had a membership list available online. We then identified the municipal Health Councils by using state Health Councils’ websites that had links to municipal health councils’ websites in them. We invited all Health Council members on the available lists through an email invitation, for a total of about 1,400 invitations. When a phone number was available, non-respondents were contacted a second time via telephone to solicit a response. Due to the low number of respondents reached in this manner, we also used snowball sampling. Written consent was received from each interviewee prior to the interview. Interview questions (Appendix 1) were formulated based on issues highlighted in existing literature on civil society participation in Brazil and focused on their views and perceptions of interviewees’ respective Health Councils. The interviews were conducted in Portuguese over the phone and Skype. The 2013 interviews were not tape-recorded but two note takers captured the content of the interviews. The 2014 interviews were tape-recorded, transcribed and translated from Portuguese to English with the support of a Brazilian researcher. The first set of interviews was not tape-recorded because the study participants did not consent to being tape-recorded. In order to address any loss in meaning due to translation, all of the interviewee quotes in this paper are provided Portuguese in Appendix 2.

Data management and analysis
Data was coded using an inductive approach and themes were generated using a thematic approach. We first read through the interview content to generate a preliminary list of codes using inductive analysis. Then, we coded the interview data using inductive analysis with the software HyperResearch. We created a final list of codes by selecting the codes that were most relevant to the research question. These codes were then grouped together based on their relevance to one another to form themes. The data extracts for each theme were reviewed to create a

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<th>Table 1 Breakdown of study sample</th>
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detailed summary (with quotes) that captured the main messages from each set of extracts. At this stage differences between civil society representatives, healthcare representatives and government representatives within each theme were identified by the researcher and noted in the theme summaries. These summaries were then used to help present the themes in the results section. The analysis conducted did not focus on identifying underlying assumptions and ideas that gave form to interviewees’ views and perceptions in the data collected.

**Legislative review**

Once interviews were analyzed and themes were identified, a scan of the decrees, resolutions and amendments that are relevant for Health Councils was conducted, using the National Health Council as the reference point for Health Councils at the state and municipal levels. This scan only focused on documents that related to the issues identified through the interviews. For example, if one of the identified themes was ‘issues with membership guidelines,’ only legal documents pertaining to Health Councils’ membership rules were considered. This was done in order to corroborate the findings from the interviews conducted. Table 2 outlines the documents reviewed.

**Ethical considerations**

This study was reviewed and approved by the University of Toronto’s Research Ethics Board (Protocol Reference # 28320) as well as Brazil’s National Commission of Ethical Research (Comissão Nacional de Ética em Pesquisa – CONEP) (Approval # 686.734).

**Results**

The study findings are organized around the following themes: 1) Lack of autonomous authority; 2) Membership guidelines that limit inclusion; 3) Government pressure on Health Council members; 4) Lack of support and recognition from government; 5) Insufficient resources for Health Councils; and, 6) Health Council members’ strong individual interests.

**Lack of autonomous authority**

Brazil’s Health Councils were established to monitor both the public and private health sectors, to monitor and approve the country’s health budget and its allocations, and to assist in the implementation of the national health policy. Decisions taken in Health Council meetings are divided into motions, recommendations, and resolutions. Motions are used to express recognition, support, and criticism of a specific subject, and they are non-binding. Recommendations are, on the other hand, suggestions, warnings, or notices about specific issues but they are also non-binding. Health Councils also can put forward resolutions that can be implemented into law, if and only if, the Ministry of Health approves them. Therefore, Health Councils do not stand as autonomous bodies independent of the government and have no legal authority through which they can ensure that their resolutions are implemented.

Health Council members at the national, state and municipal levels reported that the decisions taken during meetings are not followed up well. A Health Council member at the state level reported,

“A resolution that had been passed in the Council about abolishing the privatization of the health system was shut down by the last two Health Secretariat of my state. One of them said he wasn’t going to ‘shoot himself in the foot’ by implementing it.’” (Civil Society Representative, State Health Council Member #2)

It seems that civil society’s participation in Health Councils is more consultative in nature, as the government holds the ultimate decision-making power because it has the legal authority to implement decisions. This dependency on the government to implement Health Council decisions also means that there is no guarantee that civil society’s input will be part of the final decision-making process, as this is solely dependent on the given government’s willingness to take their input into account. This has not only created a sense of frustration among Health Council members, but it also puts into question how effectively Health Councils’ can fulfill their mandate, given that they cannot take action to hold governments accountable without, somewhat paradoxically, having that same support from the government.

**Membership guidelines limit inclusion**

Health Councils’ membership guidelines were designed to include government officials, civil society representatives (referred to in Portuguese as usuários, or users of the healthcare system), and healthcare representatives. Fifty percent of any Health Council must be composed of civil society representatives, which are defined as “representatives of organizations and social movements that have

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<tr>
<td>Outlines what each of the three types of Health Council decisions are (motions, recommendations, resolutions)</td>
<td>Resolution No. 291, 6 May 1999</td>
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<tr>
<td>Outlines the overall design of Health Councils</td>
<td>Resolution No. 407, 12 September 2008</td>
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<tr>
<td>Provides greater detail on membership guidelines</td>
<td>Decree No. 4839, 11 July 2006</td>
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<tr>
<td>Provides greater detail on the Health Council budget</td>
<td>Resolution No. 453, 10 May 2012</td>
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expertise and representation in at least one third of the units of the Federation and three geographical regions of the country for at least two years” [31]. Twenty-five percent of membership seats must be filled by healthcare representatives, which are defined as "representatives of health professional organizations, including the scientific community" [31]. The other 25% is to be comprised of government representatives from the National Council of Secretaries of Health (CONASS), the federal government, the National Council of Municipal Health Secretaries (CONASEM), healthcare service providers, and business entities that conduct business within in the health system [31]. Civil society representatives are appointed by their respective organization and an independent committee must elect each organization every three years. No minimum technical qualification is required from civil society representatives to participate. However, membership guidelines are limiting in scope, as only organized groups that have a strong presence throughout Brazil and are formally recognized by the government can qualify to participate.

A reported lack of interest from civil society in participating in Health Councils has resulted in limits to the breadth of the membership. Interviewees at all three levels of government, underscored that the public is often unaware of the existence of Health Councils, and those who do have some knowledge about Health Councils, are often not interested in learning more about what they do or how to participate within them. A Health Council member representing civil society at the municipal level stated,

"Civil society participation is very fragile. Our society doesn’t have a culture of participation in the creation of public policies, and in the 21st Century they don’t realize the power that it has by being a taxpayer, a citizen with rights. Society in general is unaware of that the State exists to give back the high taxes that are levied and collected in the form of services like education and health. Brazilian society is taking too long to wake up."[2] (Civil Society Representative, Municipal Health Council Member #8)

This suggests that civil society needs to have a better understanding about Health Councils and how they can effectively participate in them. Coupled with restrictive membership guidelines, Health Councils do not necessarily represent the 'users' of the healthcare system well. Rather, membership tends to be limited to well-resourced and organized members of Brazil’s population. This leaves behind poor-resourced populations that use SUS's services but lack the necessary time and money to be organized and qualify to participate. Health Councils’ breadth of population inclusion is therefore narrow in scope.

**Government pressure on health council members**

Health Councils members at all three levels reported feeling “pressured” by their respective government representatives; thus affecting their ability to work impartially and openly. Health Council members stated that government representatives often used bribery and intimidation tactics to sway member decisions and how they voted. At the national level, a Health Council member expressed that, “... in order to get things done you need to be good friends with the government.” (Government Representative, National Health Council Member #1)

Another Health Council member at the state level reported that members are “constantly being manipulated by government representatives” (Healthcare Representative, State Health Council Member #1) through favor exchanges such as job offers or punishments through lay-offs and threats. Members are often threatened or pressured to take decisions that will not create a negative image for a given government. Not surprisingly, this has reportedly created a hostile environment during Health Council meetings.

A Health Council member representing civil society at the state level reported,

“There is a legal framework. We try to work impartially, defending the interests of the public [pause] but the government pressures us, especially when it comes to decisions that have to do to with the health budget. Health workers are the most vulnerable ones."[3] (Civil Society Representative, State Health Council Member #11)

Another Health Council member representing the health sector at the state level stated,

“Civil society representatives are vulnerable to the government’s interests. Government representatives, as one might expect, support almost blindly the interests of the government. These interests are often contradictory of those of civil society. They will do anything under their power to avoid embarrassing situations for the government. Health representatives act pretty much the same way... they show a real disconnect from the real needs of society. It seems that there is no real commitment to meet societal needs.”[4] (Healthcare Representative, State Health Council Member #8)

Health Council members are thus often reluctant to engage in open discussion due to possible retaliation by the government. A Health Council member representing civil society at the municipal level reported,

“We do what we can. Sometimes, we personally go and talk to patients, doctors. Other times, we write to
them to reach out. Laws are there to be followed but sometimes we do not report issues because of fear. Council members work for or may have relatives who work for the government and we are afraid to lose our jobs or our position in the council. It’s really a shame. If there were equal rights and laws were enforced, our Brazil would be a model to follow." (Civil Society Representative, Municipal Health Council Member #12)

Another Health Council member representing the healthcare sector at the municipal level reported that,

“The Health Council that I belonged to always works with the information available and decisions are taken according to the law. Sometimes, the government is uncomfortable with that, mainly when it comes to embezzlements. The government threatens some Health Council members, especially those working for the government. If a Health Council member works for a private company and goes against the government during Health Council meetings, the government will intimidate them by asking for an inspection of their company. Health Council members feel threatened because according to the law, the Health Council will be punished if it approves any process in which resources are suspected to be stolen or misuse. That is why some members prefer to leave the Health Council. Their participation is voluntary, they are not paid for that, and it takes time to participate, oversee how the budget has been used and investigate civil society’s accusations of irregularities in the health care system. I don’t blame them.” (Healthcare Sector Representative, Municipal Health Council Member #15)

These accounts suggest power imbalances among council members; it seems that government representatives have the greatest power over civil society and healthcare representatives, putting the latter groups in a vulnerable position. This can clearly have an influence on what is discussed during Health Council meetings and the type of decisions that are taken as a result of the discussions. Ultimately, power imbalances limit the Health Council’s ability to effectively monitor the healthcare sector, given that they have no authority over the same government they aim to monitor and hold accountable to the public.

**Lack of support and respect from the government**

Healthcare and civil society representatives at all three levels of government also stated that there is a lack of support from their respective governments (e.g. national, state or municipal). Not surprisingly, governments will support health councils and implement their decision only if they are aligned with their own agenda. A Health Council member representing civil society at the municipal level stated,

“The government decides when to interfere with partisan politics. Sometimes they do more than they need to, but most of the time they just do what is required of them.” (Civil Society Representative, Municipal Health Council Member #12)

A Health Council member representing civil society at the national level stated,

“The government does not really support the councils, it tolerates them. There is tension between the two because of the differences in interests. It is more of an instrumental relationship. They don’t realize the power that Health Councils have. The government is more concerned with the opinion of government representatives than those of civil society or healthcare representatives, maybe because other interests are involved.” (Civil Society Representative, National Health Council Member #6)

Health Council members expressed that their respective government is generally not interested in having Health Councils work effectively in case they create a threat to their power. A Health Council member representing civil society at the municipal level stated,

“The government does not recognize the Council as an autonomous body and has no real interest in making sure it’s working properly. The State Health Council conducts trainings, meetings, but the most important thing is encouraging civil society to participate, but the government is afraid of making this happen because they don’t want to lose the power they believe is theirs and not of the people who elected them.” (Civil Society Representative, Municipal Health Council Member #8)

At the state and municipal levels, this lack of recognition and support from their government sometimes results in a government failing to address issues that are critical, within the jurisdiction of Health Councils, such as the approval of health budgets. A municipal Health Council member representing civil society stated,

“For the last 4 months, the government has failed to provide us with the budget reports that need to be approved by the Health Council. We are often not consulted on issues that correspond to us and things get approved without our consent even though it is needed under the law.” (Civil Society Representative, Municipal Health Council Member #12)
As noted earlier, Health Councils will be effective only if their respective government decides to do so. The lack of power or legal authority Health Councils holds has meant that they have largely not been able to have a real impact on the policy process.

**Insufficient resources for health councils**

**Budget**

Pursuant to Resolution 453/2012, taken by the National Health Council, the three levels of government must provide the necessary financial and administrative resources for their respective Health Councils to have administrative autonomy to function effectively. For example, the respective government of any given Health Council is required to provide a physical space so that Health Councils are able to hold meetings and financially support administrative staff and promotional materials. The Ministry of Health, in conjunction with the Federal government, is charged with working with the state and municipal governments to ensure the funds are transferred and provided to the Health Councils. However, in practice, at the state and municipal levels, there are budget constraints have limited Health Council meetings and their ability to disseminate information relevant to the public. A Health Council member representing civil society at the state level shared that,

“The government doesn’t support us a lot but our existence is guaranteed by the law. Once in a while the Internet is suspended because the government doesn’t pay it on time. When this happens we use our cellphones and make things work, even with these challenges.”

(Civil Society Representative, State Health Council Member #2)

Another Health Council member representing civil society at the state level reported that,

“The government says they support the councils but it’s far from reality. We don’t have our own website to disseminate information to the public. The website we have paid for out of our own pockets and it doesn’t support a lot of data.”

(Civil Society Representative, State Health Council Member #5)

In addition, Health Council members also reported that the management of their budgets lack transparency and noted that there examples of budget mismanagement by government officials who are in charge of it. At the state and municipal levels, Health Council members reported that their budget allocation is rarely discussed during meetings. Also, at the municipal level, Health Council members reported that there is no planning process regarding how the budget is to be spent during the year, which results in the budget not being used or mismanaged.

**Training**

Under the *National Policy of Permanent Education for Social Accountability in the Health System* (*Política Nacional de Educação Permanente para o Controle Social no Sistema Único de Saúde*), training for Health Council members is a mandated requirement. This policy expresses further that municipal, state and federal Secretaries of Health must provide funding to train Health Council members on the structure of the health sector, their mandate and any relevant laws and policies. However, it does not explicitly outline how training is to be provided, how long it should take place, nor does it provide a curriculum that explicitly states what needs to be taught to Health Council members. This ambiguity may explain why many Health Council members reported feeling unprepared and unable to engage in discussions during meetings. This lack of training was further supported by healthcare representatives at all three levels of government who stated that civil society representatives are unable to engage in active discussions on the health sector due to their limited knowledge. For example, a healthcare representative at the state level reported,

“Some Health Council members are not prepared to engage in discussion. The training provided is definitely not enough for them.”

(Healthcare Sector Representative, State Health Council Member #7)

The inadequate allocation and management of the operational budget of Health Councils, as well as poorly trained members, have contributed to weakness of Health Councils. Health Council members need to have a solid foundation of knowledge about how the health system and Brazil’s legal system works, as well as their rights as Health Council members and the government’s obligations to them.

**Health council members’ strong individual interests**

Evidently, there are Health Council members who are pursuing their own interests over and above those of the institution they represent. There was indeed wide agreement among interviewees that Health Council members often advance their own private interests. A Health Council member representing the government at the municipal level stated,

“Does the council work in an impartial way? For me, that is the main problem of Health Councils. Unfortunately, they were created to mobilize civil society into SUS, but it did not work. People are there
to defend their own interests or the interests of the institutions they represent, with some exception. For example, I have been participating in different management positions of this Municipal Health Council over the years, and depending on who is in the management position, the agenda of the Secretariat changes... There was a management period that was focused on mental health. My Goodness, we had to be careful to present anything related to mental health... In another time, the management was focused on dental health. Currently, this management focus is on workers' health.”

(Government Representative, Municipal Health Council Member #9)

There is also a reported apathy among some members. A Health Council member representing civil society at the state level reported that,

“Some civil society groups have ties to the Health Councils, but they don’t care about [Health Councils]. They send people to represent them who do not know why they are even there.”

(Civil Society Representative, State Health Council Member #5)

Another Health Council member representing civil society at the municipal level stated that,

“A big issue that I see is that most of the council members don’t like to read, work all day and sometimes this limits their ability to act. There is a lot of information on laws, resolutions, and regulations.”

(Civil Society Representative, Municipal Health Council Member #8)

While some of members interviewed reported having a genuine interest in improving the overall state of the health system, they also reported that many of their peers on the Council did not share this goal.

Discussion

The findings of this study illuminate some of the challenges present in Health Councils that limit their effective functioning and the capacity of civil society to have a meaningful input into the health policy process. One clear limitation is the absence of a legal framework that provides Health Councils with the authority to ensure accountability of their respective government and to enforce the rule of law. Government representatives, it seems, have greater incentives to dominate and even manipulate discussions and decisions in Health Councils, since their livelihood and power is directly tied to their outcomes [27]. Meanwhile, civil society’s participation seems to be largely limited to well-resourced groups so that the most marginalized populations are, in fact, not represented in the Health Councils. We found that in many Health Councils, government representatives often use manipulative tactics. When they are unable to "buy" support from other members, they have allegedly resorted to threats, particularly towards healthcare representatives. This patently fosters a climate, whereby many Health Council members will be reluctant to voice their real demands and concerns. Indeed a study conducted by Cornwall (2008), highlighted that given the hierarchical nature of the healthcare system and their reliance on the government for work contracts, healthcare representatives feared being fired for voicing their concerns and opinions [23]. As a result, government representatives have seem to share the greatest influence Health Council meetings, which puts into question how well participatory democracy works within them.

The apparent power asymmetry between civil society and government representatives present in Health Councils is further magnified by the reported lack of training that is provided to Health Council members. Due to the complexity of the healthcare sector and the policymaking process, civil society representatives need to possess a sufficient level of technical knowledge for informed discussion about health sector policy issues. We found training is insufficient, which has had a reported negative effect on civil society representatives’ ability to engage in active and meaningful discussions and make informed and evidence-based decisions. Within Health Councils, civil society is generally less equipped to participate in discussions, compared with healthcare and government representatives, who have greater technical knowledge [22].

Additionally, the membership guidelines of Health Councils are not conducive to broad membership of the population, as they are best suited for well-organized and active civil society groups. Marginalized groups of Brazilian society need to be represented as they are most likely to depend the most on the healthcare services provided by SUS due to their financial inability to turn to the private sector [32]. Socioeconomic factors such as income and educational levels contribute to which members of the population represent civil society within Health Councils [6, 22]. The membership guidelines effectively create a restrictive level of civil society inclusion, whereby only those who are willing to participate and have the means to form an organized civil society group can qualify for membership. A prior study on the State Health Council of São Paulo also concluded that membership guidelines create “a pre-existing network of relationships among representatives of government and social movements” and exclude those that lack the means to form such ties [13].

The low level of participatory culture that can be found in Brazil has had a reported effect on civil society’s
level of participation and interest in Health Councils. And even when civil society participates, representatives may only use Health Councils to advance their own interests. Many members use their membership as a stepping-stone for a government career or as a mean to gain prestige among peers [23].

Other studies conducted on Health Councils in Brazil have also highlighted their limitations. For example, one study reported that Health Council members felt that they have failed to have a meaningful effect on health policies [22]. Another study concluded that while multiple issues in the healthcare system are raised within Health Council discussions, they have failed to influence any decisions taken by the government [13]. And lastly, even though Health Councils permit the inclusion of new actors in health policy discussions, they have not had a significant effect on the restructuring of the SUS [26].

If Brazil’s Health Councils are to become a meaningful forum for inclusive health policy discussion and outcomes, a number of changes are likely needed. First, Health Councils need greater authority and autonomy from the government. Second, membership guidelines need to incentivize participation amongst all members of the population and specifically make greater efforts to have provisions that will include marginalized groups. This will ideally yield greater levels of civil society participation and help ensure that marginalized group issues and concerns are factored into the decision-making process. Third, the Federal government must clearly outline how civil society’s input will be incorporated in the decision-making process in order to ensure policy that is reflective of societal needs, healthcare representatives’ expertise, and the governments’ knowledge of policy making. This will help promote more transparency in the decision-making process and manage expectations among Health Council members better. Lastly, clear training guidelines and sufficient curricula, along with the requisite resources, are needed to ensure sufficient training is provided to Health Council members, particularly those from civil society. Training will give civil society representatives the requisite knowledge to actively engage in discussions and health sector policy processes.

In addition, our decision to conduct interviews with Health Council members was based on the study’s objective of creating a descriptive account of issues present in this specific forum for civil society participation in decision-making. However, despite the researchers’ best efforts, the response rate from government representatives was low, which created an overrepresentation of healthcare professionals and civil society representatives in our sample. This may explain the predominance of issues surrounding government support in our results. Future work on Health Councils could explore government representatives’ views and perceptions in more detail to have a more balanced recount of some of the issues present in Health Councils from the perceptions of all the parties involved. In addition, while our findings may be similar to studies conducted on other models of participatory governance, they are not representative of all forms of participatory governance models. Therefore, transferability of our research findings must be mindful of the context under which this research was conducted as well as the researchers’ assumptions that guided the data analysis process. Lastly, despite our best efforts, the authors acknowledge that the analysis of the interview data may have been affected during the translation process in a way that certain words or phrases may have been “lost in translation”. This was mitigated as much as possible by actively consulting with a Brazilian researcher fluent in both English and Portuguese on the appropriateness of word selection and meaning.

Conclusions
This study highlighted how Brazil’s Health Councils have not necessarily led to meaningful participation by civil society in the health policy process. They certainly provide a forum for stakeholders to come together to discuss issues in the health sector and they have the potential to make members of civil society feel empowered and better informed about the healthcare sector. However, we found that they do not necessarily provide a sufficient forum through which civil society can actively and meaningfully participate in the decision-making process. This puts into question how well participatory democracy is served by the Health Councils.

We found that civil society is limited in Health Councils throughout Brazil by restrictive membership guidelines, a lack of autonomy from the government, vulnerability to government manipulation, a lack of support and recognition from the government, and a lack of necessary training and budget [6, 29]. As a result of these issues, Health Councils may not be an effective forum through which civil society can engage in discussion to promote policy that is reflective of societal needs. There is certainly no one size fits all model to achieve this. However, this study has shed light on the need for Health Councils to have
more defined terms and goals and to have its mandate backed up by a strong and independent legislative framework to achieve it. This would help guide policy makers’ decisions on who should be included, how their views will be included in decision-making, and when civil society should be included. Health Councils would also benefit from having the legal authority to act independently in order to minimize vulnerabilities to government manipulation. Lastly, membership guidelines ideally should be revised to ensure greater inclusion that does not rely on the organizational capabilities of civil society groups and better training for civil society representatives to take more evidence-based decisions.

Appendix 1

Interview guide

Please introduce yourself and state which group you present on your Health Council?

How long have you been involved in the council? Why did you join?

Do all council members actively engage in discussions? Why or why not?

How would you describe the relationships between council members?

How does your Health Council communicate with the public? Is it effective? Why? Why not?

How do citizens participate with the Health Councils?

Is the budget used effectively? Who is in charge of it?

Is the way in which meetings are run effective? Why or why not?

What type of training council do members have? Is it enough?

Are Health Council decisions implemented by the government? Give examples.

Do Health Councils have any power to enforce any of their decisions?

Does the government support Health Councils? How? Or if no, why not?

What is the biggest strength/weakness of the councils?

What improvements would you make?

Appendix 2

Quotes from interviews in Portuguese

1ª Uma resolução que foi aprovada no Conselho contra a privatização do sistema de saúde não foi assinada pelos dois Secretários de Saúde anteriores do meu estado. Um deles disse que não ‘ia dar um tiro no próprio pé’.

2ª A participação da sociedade civil e muito frágil. Nossa sociedade não tem a cultura de participação na construção das políticas públicas e, ainda, em pleno século XXI não se deu conta do poder que possui por ser contribuinte, cidadão de direitos. A sociedade em geral desconhece a finalidade da existência do Estado em devolver-lhe sob a forma de serviços como educação e saúde, os altos impostos que são cobrados e recolhidos. A sociedade brasileira está demorando muito a despertar.”

3ª Existem leis. A gente tenta trabalhar com imparcialidade, defendendo os interesses do público [pausa], mas há pressões do governo, especialmente quando se trata de decisões sobre o orçamento da saúde. Os trabalhadores de saúde são definitivamente os mais vulneráveis.”

4ª Os usuários são vulneráveis aos interesses do governo. Os gestores, como esperado, apoiam o governo com cegos. Esses interesses não são idênticos aos da sociedade. Eles vão fazer qualquer coisa para evitar escândalos. Os trabalhadores de saúde atuar da mesma forma ... suas ações não refletem as necessidades da sociedade. Parece que não há nenhum compromisso real para atender as necessidades da nossa sociedade.”

5ª “A gente fazem o que podem. Às vezes, falamos com pacientes, médicos. Outras vezes, escrever-lhes. Leis existem para ser seguidas, mas às vezes temos medo de reportar problemas. Os membros do Conselho trabalham para ou pode ter parentes que trabalham para o governo e nós estamos com medo de perder nossos empregos ou nossa posição no conselho. É realmente uma vergonha. Se houvesse direitos e leis foram aplicadas, nosso Brasil seria um modelo a seguir.”

6ª “O conselho de saúde que presidia sempre trabalha com as informações e depois de analisadas e que poderá afetar um lado ou outro, mas afirmo que as decisões serão tomadas conforme a legalidade e isso aplicará certo desconforto ao gestor, principalmente nos desvios de recurso que a tomada de decisão reprovara pelo conselho, faz com que este procedimento gera perseguição a conselheiro que é funcionário público e também da iniciativa privada que tem empresas e é perseguida por mandato de fiscalização para intimidar as ações aplicadas que a contrarie a sua gestão. Os conselheiros se sentem ameaçados, por que, a legislação joga a responsabilidade no conselho, o mesmo responde criminalmente aprovar qualquer procedimento que envolva recurso que haja suspeita de fraude ou desvio. Aonde em que cada membro prefere sair do conselho por que é uma participação voluntária e não ganha nada com isso e toma tempo para dedicar às atividades das comissões nas fiscalizações dos recursos, ações e denúncias dos usuários do sistema de saúde. Não os culpo.”

7ª “Os gestores decidem quando fazer interferência na política partidária. Muitas vezes podem fazer mais, outros fazem o que são mandado.”

8ª “Na realidade, o governo não apoia os conselhos, eles os toleraram. Há uma tensão entre os dois devido às diferenças de interesses. É mais uma relação instrumental. Ele não percebem o poder que os conselhos de saúde têm. O governo se preocupa mais com a opinião de seus representantes do que os usuários ou profissionais de saúde, talvez porque outros interesses estão envolvidos.”
O governo municipal não reconhece o Conselho como órgão autônomo, deliberativo, não tem interesse real em qualificá-lo. O Conselho Estadual realiza capacitações, reuniões, orienta, mas o cerne da questão seria incentivar a participação social e, isso, os administradores públicos não fazem com medo de perder o poder que acreditam ser deles e não do povo que pediu para representá-lo."

"Por os últimos 4 meses, o governo não nos deu os relatórios orçamentais que devem ser aprovados pelo Conselho. Muitas vezes não nos dizem coisas que devemos aprovar e as coisas são aprovadas sem nosso consenso, mesmo que seja exigido antes de uma lei.”

"O governo não nos apoia muito, mas nossa existência é garantida por lei. No entanto, de vez em quando a internet fica suspensa por falta de pagamento do governo estadual aos fornecedores. Mas nós usamos nossos celulares e fazemos a mesma coisa com mais dificuldades."

"O governo diz que apoia os conselhos, mas está longe de ser realidade. Eles não têm o seu próprio website para divulgação de informações. O site deve ser a assessoria de comunicação paga com dinheiro do próprio bolso. Eles não são grandes da informação. O site que existe a assessoria de comunicação paga com dinheiro do próprio bolso. Eles não usam da internet safe para a Secretaria muda... Houve uma gestão que foi saúde mental, minha nossa, tínhamos o maior cuidado para apresentar qualquer coisa de saúde mental... outra era Saúde Bucal. Nessa gestão o foco é saúde do cuidado para apresentar qualquer coisa de saúde mental."

"Alguns entidades têm cadeiras no conselho, mas não se importam. Mandam pessoas que não sabem o que está fazendo lá."

"Algumas entidades têm cadeiras no conselho, mas não se importam. Mandam pessoas que não sabem o que estão fazendo lá."

"Um grande problema que vejo é que a maioria dos conselheiros não gosta de ler, trabalha o dia inteiro e, às vezes, sofre restrições para poder atuar. Mas há muita informação nas leis, nas resoluções e portarias."

Abbreviations
CONASEMS: Conselho Nacional de Secretários Municipais de Saúde, Brazil’s National Council of Municipal Health Secretaries; CONASS: Conselho Nacional de Secretários de Saúde, Brazil’s National Council of Secretaries of Health; OECD: Organization for Economic Co-operation and Development; SDGs: Sustainable Development Goals; SUS: Sistema Único de Saúde, Brazil’s Unified Health System

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Due to the participant anonymity requirements outlined during the study’s ethics approval process by the University of Toronto’s Research Ethics Board and CONEP, only the quotes provided in this manuscript will be disclosed. All other data will be kept confidential.

Authors’ contributions
MGM and JCK contributed to the conception and design of the research project, analysis and interpretation of all data. MGM conducted 21 of the 40 interviews with the help of a Research Assistant. The remaining 19 of the 40 interviews and the translation of all of the interviews were carried out by a Research Assistant. Both authors read and approved the final manuscript.

Authors’ information
Jillian Clare Kohler is a Professor at the Leslie Dan Faculty of Pharmacy, the Munk School of Global Affairs, and Dalla Lana School of Public Health at the University of Toronto. She holds a PhD in Political Science from New York University. Martha Gabriela Martinez is a Masters of Science student at the Leslie Dan Faculty of Pharmacy, University of Toronto. She holds a BA in Political Science from the University of Toronto.

Competing interests
The authors declare that they have no competing interests.

Consent for publication
Not applicable.

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This study was reviewed and approved by the University of Toronto’s Research Ethics Board as well as Brazil’s National Commission of Ethical Research (Comissão Nacional de Ética em Pesquisa – CONEP).

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