

**Advancing citizen participation in health governance and the right to health in
brazil: the role of the national health council**

by

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Abstract

Brazil has established a constitutional right to health for its citizens. The attention of commentators and the legal community has been focused on the role of the courts in defining the state's obligation to provide access to certain forms of healthcare services. This dissertation focuses on a rather neglected aspect of Brazil's right to health: citizen participation in health governance.

In this dissertation I argue that Brazil's right to health includes a state duty to establish a health system that incorporates citizen participation. The objectives of this dissertation are to analyze the constitutional requirements for citizen's participation and to examine whether the National Health Council ("NHC"), the participation body at the national level of health governance -- meets these constitutional requirements.

In pursuing these objectives, I analyzed Brazil's constitutional and legislative framework for citizen participation, conducted qualitative interviews with a selection of Council's members, and carried out naturalistic observations of Council's meetings. The dissertation uncovers questions and concerns about the National Health Council's compliance with constitutional requirements. The analysis identifies two key issues: Council members lack clarity with respect to the scope of the Council's legal role, and the Council has not been given full legal authority to carry out its constitutional mandate.

The legal analysis provides an understanding of the body of law governing participation in the NHC and its relation to the right to health requirements. The qualitative research yields important information about the practice of participation in the NHC, including the perspectives, understandings and critiques of NHC members. Together, the legal and qualitative research produce a deeper understanding of the constitutional mandate for citizen participation, as well as specific recommendations designed to ensure that participation in the National Council achieves the benefits sought through Brazil's ambitious constitutional mandate. In addition, Brazil's constitutional experience with

participation in health may provide useful guidance to other countries considering evidence-based policies to foster responsive and accountable health governance through citizen participation.

Lay Summary

This dissertation is about citizen participation in health governance in Brazil. I argue the Constitution creates a state duty to implement a health system that incorporates citizen participation in health planning. The objectives of this dissertation were to determine the constitutional requirements for participation and to evaluate whether the National Health Council -- the participation body at the national level of governance -- has fully met those requirements. I analyzed the constitutional and legislative framework for participation, interviewed a selection of Council's members, and conducted naturalistic observations of Council meetings. My research shows that the Council has not been as effective as it should be, partly because members lack clarity with respect to the scope of the Council's role, and partly because the statutory provisions that create the Council curtail its legal authority to carry out its legal mandate. I conclude the dissertation by providing recommendations to overcome these issues.

Preface

This dissertation is an original intellectual product of the author, Regiane Alves Garcia.

The research for this dissertation was conducted in Brazil's National Health Council in Brasília, Brazil. The design and methods of this research were submitted and approved by the Behavioural Research Ethics Board (BREB) of the University of British Columbia (Canada), and by the *Comitê de Ética em Pesquisa* (CEP) [Research Ethics Committee] of the University of Brasília (Brazil). The BREB's Ethics Certificates are: H13-02662 and H15-03121, and the CEP's Ethics Certificate is: 34492514.0.0000.5540.

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An early stage framework developed for my dissertation is reflected in another publication: Regiane Garcia, "A Governance Approach to Agricultural Genomics Intellectual Property–Regulatory Complex" in Emily Marden, R Nelson Godfrey & Rachael Manion, eds, *The Intellectual Property–Regulatory Complex: Overcoming Barriers to Innovation in Agricultural Genomics* (UBC Press, 2016).

An earlier version of parts of Chapter 4 formed the basis for my ideas in Regiane Garcia, "Nós Precisamos Falar Sobre Métodos de Interpretação Constitucional e o Papel do Direito Democrático à Saúde Para a Construção Social do SUS que Queremos" ["We Need to Talk About Constitutional Interpretation Canons and the Role of the Democratic

Right to Health in Building the Health System We Want”] (Nov 2017) Ensaios & Diálogos em Saúde Coletiva 5 art. 4.

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List of Abbreviations

ABRASCO	Associação Brasileira de Saúde Coletiva [Brazilian Association of Collective Health]
AIDS	Acquired Immune Deficiency Syndrome
AVRs	Antiretrovirals
BRA	Brazil
CA	Canada
CE	Ceará
CEBES	Centro Brasileiro de Estudos de Saúde [Brazilian Centre for Health Studies]
EU	European Union
FIOCRUZ	Fundação Oswaldo Cruz [Oswaldo Cruz Foundation]
GC14	General Comment No 14
HC	Health Council
HCS	Health Councils
HIV	Human Immunodeficiency Virus
HR	Human Rights
ICCPR	International Covenant on Civil and Political Rights
ICESCR	International Covenant on Economic, Social and Cultural Rights
IBGE	Instituto Brasileiro de Geografia e Estatística [Brazilian Institute of Geography and Statistics]
IPEA	Instituto de Pesquisa Econômica Aplicada [Institute for Applied Economic Research]
J	Justice [of the Brazilian Supreme Court]
MG	Minas Gerais
Min	Ministro [a Justice of the Brazilian Supreme Court]
NGO	Non-governmental Organization
NGOs	Non-governmental Organizations
NHC	National Health Council [of Brazil]
OECD	Organisation for Economic Co-operation and Development
SP	São Paulo
STF	Supremo Tribunal Federal [Supreme Court of Brazil]
RJ	Rio de Janeiro
RS	Rio Grande do Sul
UDHR	Universal Declaration of Human Rights
UN	United Nations
USP	Universidade de São Paulo [The University of São Paulo]
WHO	World Health Organization

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1 Introduction

Brazil has established a well-known constitutional right to health.¹ The attention of commentators and the legal community has been focused on one aspect of this constitutional right: individuals' access to certain forms of healthcare services and prescription drugs through the courts. In this dissertation, I will argue that Brazil's right to health includes a less-well known but important component: an explicit duty of the state to establish a health system that incorporates citizen participation in health governance. This constitutional right to citizen participation in health governance has been neglected.

Brazil's constitutional arrangement is unique and remarkable in inserting a form of democratic health governance into the constitutional right to health. There is relative consensus in Brazil's social and health fields concerning the importance of an adequate health system in ensuring healthy populations, as well as the essential role of citizen participation in policy making for more responsive health systems.²

This dissertation focuses on Brazil's right to citizen participation in health governance. The objectives are to examine the constitutional requirements for participation and whether and how the National Health Council (NHC) - the participation body at the

¹ The relevant provisions are Arts. 6, 196 and 198 of the Constitution of the Federative Republic of Brazil 1988 [Constitution]. The text of these provisions is analyzed later in this dissertation. For reference, Art. 6 reads: [H]ealth is a social right. Art. 196 reads: Health is a right of everyone and a duty of the state that shall be guaranteed by means of social and economic policies [based on] universal and equal access to actions and services for [health] promotion, protection, and recovery. Art. 198 reads: Health actions and services shall integrate a (...) single system organized according to: ... III – community participation. [Unless otherwise stated, all translations from Portuguese into English have been made by the present author].

² The claim is that ordinary citizens understand the health problems of their communities and how the problems might be addressed. See e.g. Rômulo Maciel Filho & José LC de Araújo Jr, "Discussing Community Participation in Health: An Approach from the Brazilian Experience" (2002) 2:2 Revista Brasileira de Saúde Materno Infantil 91. See also, Andrea Cornwall, Vera SP Coelho & Alex Shankland, "Taking a Seat on Brazil's Health Councils," (6 January 2010) Open Democracy, online: <<https://www.opendemocracy.net/andrea-cornwall-vera-schattan-p-coelho-alex-shankland/taking-seat-on-brazils-health-councils>>. Last retrieved: 4 February 2018.

national level of health governance, and the object of this study - meets these constitutional requirements.³ In pursuing the aims of this dissertation, I analyze Brazil's constitutional and legislative framework for participation, and present a qualitative analysis of interviews of a sample selection of National Health Council's members and naturalistic observations of two Council meetings. The dissertation will reveal questions and concerns about the National Health Council's compliance with constitutional requirements. The analysis identifies two key issues: the National Health Council members' confusion about the scope of the Council's legal role; and the fact that the Council has not been given full legal authority to carry out its legal mandate.

My legal analysis provides a new understanding of the body of enacted legislation governing participation in the NHC and its relation to the right to health requirements. My qualitative research yields new and important information about the practice of participation in the NHC, including the perspectives, interpretations and critiques of NHC members. Together, the legal and qualitative research produces a deeper understanding of the constitutional mandate for citizen participation, and generates recommendations designed to ensure that participation in the National Council achieves the benefits sought through the country's ambitious constitutional mandate. Furthermore, Brazil's constitutional experience with participation in health could provide useful guidance to other countries considering evidence-based policies designed to foster responsive and accountable health governance through citizen participation.

³ The NHC is a permanent and deliberative body part of the Health Ministry's structure in which citizens participate in health governance at the federal level of the health system. 48 members representing four groups form the NHC: civil society organizations; workers of the public health system; governments (federal, state and municipal); and private healthcare providers. The distribution of membership is as follows: 50% of the seats for organized civil society, 25% of seats for health workers, and 25% for government officials and private healthcare providers. To be clear, members of the NHC are not individual in these four eligible groups, but rather individual members from these four groups. In other words, in the NHC, public's involvement in health governance is through representation of citizens in governing institutions. See *infra* Chapter 5, Section 5.4.2 for the text and analysis of the statutory provisions governing membership in the NHC.

This research topic arose from my ongoing passionate interest and involvement in health and human rights activism and litigation in Brazil. In the 1990s, successful ground-breaking HIV-AIDS litigation demanding free treatment based on the newly created right to health played a key role in the ‘Brazilian AIDS Miracle’: the creation of a strong public AIDS program that included civil society in decision making and led to a remarkable drop in AIDS-related deaths since the 1990s.⁴ In my first months of law school in 1992, I was highly involved with health reform activists who were using strategic litigation to raise awareness about social issues related to the AIDS epidemic.

This was an exciting time in which Brazil’s constitutionalization of the right to health moved from moral, social and political arguments to rights enforceable by the courts. In a milestone decision involving HIV-AIDS, a court noted that in weighing the right to health against the state’s assertion of financial or other secondary interests, that “ethical and legal reasons impose on the judge one single and possible option: unswerving respect for health and life.”⁵ But, as a number of Brazilian constitutional commentators such as Octávio Ferraz have suggested, this new role for the courts created “a favorable litigation environment for individual claimants seeking satisfaction of all sorts of individual health needs [through litigation], including diabetes, Parkinson disease, Alzheimer’s hepatitis C, and multiple sclerosis.”⁶

As a result, debates on the right to health in Brazil over the past few decades have been dominated by litigation concerns, largely related to standards of judicial review and minimum core obligations.⁷ The problem with this focus on litigation, in my view, is that

⁴ See e.g. Amy Nunn et al, "The Impacts of AIDS Movements on the Policy Responses to HIV/AIDS in Brazil and South Africa: A Comparative Analysis" (2012) 7:10 Global Public Health 1031.

⁵ *Município de Porto Alegre v Diná Rosa Vieira*, RE 271.286 No AgR- RS. [Unless otherwise indicated, the names of the cases have been adjusted to conform to the Canadian format of citing cases. The adaptation is somewhat incomplete as the data provided in the Brazilian cases are different from Canada’s. But the cases’ citations contain all the information needed to locate the cases. See the bibliography for the original citations].

⁶ Octávio LM Ferraz, "The Right to Health in the Courts of Brazil: Worsening Health Inequities?" (2009) 11:2 Health and Human Rights 33 at 35-6.

⁷ See generally Colleen M Flood & Aeyal Gross, "Litigating the Right to Health: What Can We Learn from a Comparative Law and Health Care Systems Approach" (2014) 16:2 Health and Human Rights 62. See

it assumes, or at least does not challenge, the mainstream belief that the right to health is simply a tool for securing access to particular forms of public healthcare services. In my view, this narrow perspective neglects the true breadth of Brazilians' right to health, which lies in empowering communities to define the scope and content of the right to health. As a result of community involvement, the health system would become better aligned with local needs, knowledge and priorities, and therefore more responsive and effective.

In the remainder of this chapter, I establish the context and significance of this study by 1) summarizing current background and context within which this study is conducted; 2) stating the goals and questions; 3) explaining the methods used in this study; 4) highlighting the findings; and 5) outlining the structure of the remaining chapters of this dissertation.

1.1 International Context for Brazil's Rights to Health

It is hard to overstate the importance of good health for human functioning and flourishing. In fact, the importance of establishing "the highest attainable standard of health as a fundamental right of every human being" is protected in constitutions and laws of 191 countries in the world.⁸ Undoubtedly, this protection recognizes the key role that physical and emotional well-being plays in human freedom and flourishing – including the ability to engage economically, culturally, socially, and politically.⁹ Even though protecting health is traditionally most closely associated with access to healthcare, health is increasingly understood as a matter of social well-being, social and power relationships; therefore, health cannot be understood in the abstract and outside of social

infra Chapter 2, Section 2.2 for an overview and discussion of the literature regarding this litigation problem in the context of Brazil.

⁸ For a review of the world's constitutional and legal protection of the right to health, see e.g. Jody Heymann et al, "Constitutional Rights to Health, Public Health and Medical Care: The Status of Health Protections in 191 Countries" (2013) 8:6 Global Public Health 639.

⁹ In this study, I follow Amartya Sen's perspective on the value of health of individual human beings for human capability further elaborated by Jennifer Ruger that capability fosters on human flourishing. See generally Jennifer P Ruger, "Toward a Theory of a Right to Health: Capability and Incompletely Theorized Agreements" (2006) 18:2 Yale Journal of Law & the Humanities 273.

contexts.¹⁰ In other words, for the purpose of this study, health is understood as essential in order to enjoy and lead a good life. Moreover, health is dependent upon a myriad of biomedical as well as socio-economic factors, including a fair distribution of and access to medical care, education, housing and nutrition.¹¹ Health is also related to social inclusion.¹²

Distribution of and access to healthcare and to social factors for health promotion, prevention and recovery are provided within national health systems, which vary

¹⁰ I take a social approach to health as opposed to biomedical approach. The social approach to health in the context of this dissertation understands health beyond the dichotomy of health/disease traditionally held by the biomedical view. The approach broadly includes biomedical factors, as well as well-being, and necessarily connects these factors with societal influences on health and disease. In this view, social structures that influence patterns of health and disease across society need to be made clear and visible. For an overview of the social approach to health in Brazil, see e.g. Nísia T Lima, "Public Health and Social Ideas in *Modern Brazil*" (2007) 97:7 *American Journal of Public Health* 1168. Internationally, see e.g. Nancy Krieger, "Theories for Social Epidemiology in the 21st Century: An Ecosocial Perspective" (2001) 30:4 *International Journal of Epidemiology* 668. For a discussion of how a social approach to health relates to law, see e.g. Scott Burris, Ichiro Kawachi & Austin Sarat, "Integrating Law and Social Epidemiology" (2002) 30:4 *The Journal of Law, Medicine & Ethics* 510.

¹¹ These examples of underlying social conditions (also known as "social determinants of health"; I use both nomenclatures in this dissertation) are based on the health promotion conditions developed at The First International Conference on Health Promotion, *The Ottawa Charter for Health Promotion* (Ottawa: 21 November 1986) [*Ottawa Charter*]. At its core, the *Ottawa Charter* states that health is a process for enabling people to develop health through their own means and having access to opportunities to lead a good life: "fundamental conditions and resources needed for good health are: peace, shelter, education, food, income, a stable ecosystem, sustainable resources, and social justice and equity." The enshrinement of Brazil's right to health in the 1988 Constitution was a strong commitment by the framers to the ideals of the *Ottawa Charter*, as well as to the views articulated in The International Conference on Primary Health Care: *Declaration of Alma* (Alma-Ata, USSR: 6-12 September 1987) [*Alma-Ata*]. As I will discuss in Chapter 4, Section 4.5, Brazil's Sanitary Movement formed by health reform activists, the framers of the right to health, embraced the vision of health promotion in the late 1970s and 1980s, during the political opposition against the military dictatorship (1964-1985). The social and political struggles culminated in the 1988 Constitution and the enshrinement of health as citizens' right and a state obligation to provide universal and equal access to health services and promotion measures for the whole population of Brazil. For an overview of the *Ottawa Charter* at the 25th anniversary, see e.g. Louise Potvin & Catherine M Jones, "Twenty-Five Years after the Ottawa Charter: The Critical Role of Health Promotion for Public Health" (2011) *Canadian Journal of Public Health* 244. For an overview of the ideological foundation of Brazil's health promotion, see e.g. Luciana Kind & João L Ferreira-Neto, "Discourses and Polarities Concerning Health Promotion in the Brazilian Health System"(2013) 55:4 *Salud Pública de México* 427.

¹² See e.g. George L Engel, "The Need for a New Medical Model: A Challenge for Biomedicine" (1989) 4:1 *Holistic Medicine* 37. See also Chloe E Bird & Patricia P Rieker, "Gender Matters: An Integrated Model for Understanding Men's and Women's Health" (1999) 48:6 *Social Science & Medicine* 745. In the context of Brazil, see e.g. Daniela Ikawa & Laura Mattar, "Racial Discrimination in Access to Health: The Brazilian Experience"(2008) 57 *Kansas Law Review* 949.

significantly around the world.¹³ The unifying exemplar, against which the various health systems tend to be evaluated, is a normative vision of a health system structure that provides equal and universal access to unrestricted, timely, and appropriate high-quality care so that health inequalities are reduced and individuals and populations experience optimal health outcomes.¹⁴ These objectives, of course, are often in tension – particularly given resource constraints – so that the attempted balancing of the set as a whole sees some ambitions deprioritized or sacrificed altogether. In the end, every country falls short on at least one of these goals, and virtually all countries are experiencing health challenges. Although health challenges vary in shape, form and effect, health inequalities under limited resources are common challenges across and within most jurisdictions.¹⁵

Against this background, international bodies such as the World Health Organization (‘WHO’) have highlighted the importance of health governance to reconcile the tensions inherent in the provisioning of care and promotion measures in non-ideal circumstances. In particular, the WHO’s *Building Blocks* highlights the key role of a strategic governance framework that: “combines effective oversight, coalition building, attention

¹³ See e.g. World Health Organization, *Everybody's Business--Strengthening Health Systems to Improve Health Outcomes: WHO's Framework for Action* (Geneva: World Health Organization, 2007), online: <http://apps.who.int/iris/bitstream/10665/43918/1/9789241596077_eng.pdf>. Last retrieved: 4 February 2018. [WHO’s *Building Blocks*]. [The World Health Organization (WHO) enumerates core organizational elements, called ‘six building blocks’, for adequate health system structures in order to foster health equality, responsiveness, efficiency and financial risk protection, and ultimately, promote, restore or maintain health: leadership/governance; financing; health services; workforce; information systems; and goods]. For an overview of other health system classifications and approaches, see e.g. George Shakarishvili, “Building on Health Systems Framework for Developing a Common Approach to Health Systems Strengthening” Discussion Paper for the World Bank, Global Fund to Fight AIDS, Tuberculosis and Malaria, and GAVI Alliance, Technical Workshop on Health Systems Strengthening, Washington, DC, United States, June 25-27, 2009, online: <<http://siteresources.worldbank.org/INTHSD/Resources/376278-1114111154043/1011834-1246449110524/HealthSystemFrameworksFINAL.pdf>>. Last retrieved: 4 February 2018.

¹⁴ See e.g. World Health Organization, *Monitoring the Building Blocks of Health Systems: A Handbook of Indicators and Their Measurement Strategies* (Geneva: World Health Organization, 2010), online: <http://www.who.int/healthinfo/systems/WHO_MBHSS_2010_full_web.pdf>. Last retrieved: 4 February 2018. [WHO’s *Monitoring the Building Blocks*].

¹⁵ For data on health inequalities in developing countries, see e.g. the reports published by the World Health Organization, Global Health Observatory, online: <<http://www.who.int/gho/publications/en/>>. Last retrieved: 4 February 2018. For data on health inequalities in developed countries, see e.g. the reports by the Organization for Economic Co-operation and Development (OECD), online: <<http://www.oecd.org/health/inequalities-in-health.htm>>. Last retrieved: February 2018.

to system-design, and accountability”, and provides “the roles and responsibilities of state and social actors and their relationships with each other in pursuit of national health goals.”¹⁶

Within new and evolving health governance models, the WHO’s *Building Blocks* recommended community participation in the organization of health systems (‘participatory health governance’) as a key component for improved health governance.¹⁷ Community participation was described as an organizational feature of health systems intended to include systematically excluded voices and needs into health policy decisions.¹⁸ Inclusion was expected to allow a more balanced priority allocation of resources and foster more responsive, transparent, therefore, accountable health systems to the needs of all citizens.¹⁹ The WHO’s publications following the 2007 Report, including the WHO’s 2008 Report, *Closing the Gap*, continued to reinforce the centrality of health governance as a cross-cutting theme closely linked to accountability as well as the importance of including citizens’ voices in policy decisions regarding health systems as an integral element of working to improve health outcomes.²⁰

In the 2000s, the scholarly debate in vogue within health and human rights circles was about ways to implement effective strategies for community participation within health

¹⁶ WHO’s *Building Blocks*, *supra* note 14 at 86.

¹⁷ See e.g. World Health Organization, Regional Office for Europe, Division of Health Systems and Public Health, *Towards People Centered Health Systems – An Innovative Approach for Better Health Outcomes*, Report 2013, online: <http://www.euro.who.int/_data/assets/pdf_file/0006/186756/Towards-people-centred-health-systems-an-innovative-approach-for-better-health-outcomes.pdf>. Last retrieved: 4 February 2018. See also G Shabbir Cheema, “Devolution with Accountability: Learning from Good Practices” in G Shabbir Cheema & Dennis A Rondinelli, eds, *Decentralizing Governance: Emerging Concepts and Practices* (Washington: Brookings Institution Press, 2007) 170.

¹⁸ See e.g. Ronald Labonté, “Health Systems Governance for Health Equity: Critical Reflections” (2010) 12 *Revista de Salud Pública* 62.

¹⁹ *Ibid.*

²⁰ World Health Organization, Commission on Social Determinants of Health, *Closing the Gap in a Generation: Health Equity Through Action on the Social Determinants of Health* (Geneva: Commission on Social Determinants of Health, 2008) [WHO’s *Closing the Gap*]. For a discussion on the cost of health inequalities, see generally Harvard Gazette, ‘Inequalities’, online: <<http://news.harvard.edu/gazette/story/topic/inequality/>>. Last retrieved: 4 February 2018.

systems.²¹ In 2008, a group of 14 scholars, including some who helped to establish the health and human rights field, published a cross country study called “Health Systems and the Right to Health: An Assessment of 194 Countries.”²² The study identifies right-to-health features of health systems, and proposes 72 indicators to examine those features. Backman et al. compellingly argued that community participation in the development of national health plans is one of the required organizational features of health systems (Indicator 23).²³ Participation therefore, is an obligation under human-rights law rather than simply being a “best practice” suggested by progressive researchers, activists or policy-makers.²⁴

Brazil has ratified nearly all - certainly the major - international and regional treaties on health and human rights that lay down obligations which the Brazilian government is compelled to respect and fulfill.²⁵ In fact, according to Brazil’s Constitution, international and regional treaties become valid and binding obligations upon the Brazilian government, equal in rank to ordinary laws – upon Congress’ approval and Presidential ratification, to be precise.²⁶ However, as a practical matter the focus in Brazil has been on

²¹ See e.g. Asha George et al, “Community Participation in Health Systems Research: A Systematic Review Assessing the State of Research, the Nature of Interventions Involved and the Features of Engagement with Communities” (2015) 10:10 PLoS One 1.

²² Gunilla Backman et al, "Health Systems and the Right to Health: An Assessment of 194 Countries" (2008) 372:9655 The Lancet 2047.

²³ *Ibid* at 2051, 2057.

²⁴ *Ibid*. For a similar argument, see e.g. Benjamin M Meier, Caitlin Pardue & Leslie London, "Implementing Community Participation through Legislative Reform: A Study of the Policy Framework for Community Participation in the Western Cape Province of South Africa" (2012) 12:1 BMC International Health and Human Rights 15 at 3.

²⁵ For example, Brazil has ratified The International Convention on the Elimination of All Forms of Racial Discrimination; The International Covenant on Civil and Political Rights; and The International Covenant on Economic, Social and Cultural Rights. For a full list of treaties and ratification status, see e.g. United Nations’ Status of Ratification Interactive Dashboard, online: <<http://indicators.ohchr.org/>>. Last retrieved: 4 February 2018.

²⁶ With respect to internationalization of international treaties in Brazil, the Supreme Court of Brazil has recognized an internationalization process referred to in Brazil as “moderate dualism”. For a discussion on this matter, see e.g. Antonio M Maués, "Supra-Legality of International Human Rights Treaties and Constitutional Interpretation" (2013) 10:18 SUR International Journal on Human Rights 204. [The relevant constitutional provisions about international treaties are: Art. 1, section LXXVIII, paragraphs 2-3, and read: Art. 1: The rules defining fundamental rights and guarantees apply immediately”; Paragraph 2: The rights and guarantees established in this Constitution do not exclude others derived from the regime and principles adopted by it, or from international treaties to which the Federative Republic of Brazil is a

Brazil's own Constitution, which is well known world-wide for establishing the right to health and to community participation as a constitutional right and governmental obligation (Arts. 196 and 198). Furthermore, there is robust jurisprudence of the Brazilian Supreme Court recognizing state obligations to the right to health.²⁷

1.2 Brazil's Rights to Health and to Community Participation

Brazil's 1988 Constitution was developed through a Constitutional Congress, initiated as Brazil emerged from a military dictatorship (1964-1985).²⁸ The Constitution is designed as a legal and political instrument to overcome oppression and inequality, leading the country to democracy and social inclusion.²⁹ Art. 196 guarantees:³⁰

196. Health is a right of everyone and a duty of the state that shall be guaranteed by means of social and economic policies [based on] universal and equal access to actions and services for [health] promotion, protection, and recovery.

Furthermore, Art. 198 of the Constitution stipulates community participation as one of the core elements for the organization of the health system. Art. 198 establishes:³¹

party"; Paragraph 3: International treaties and conventions on human rights approved by both houses of the National Congress, in two different voting sessions, by three-fifths votes of their respective members, shall be equivalent to Constitutional Amendments].

²⁷ For an overview of the jurisprudence, see generally Ferraz, *supra* note 6. I do not use judicial case analysis in this study. The Brazilian legal system is based on the civil-law tradition, and therefore, the main source of law is codified laws. I should note that Brazil does not recognize judicial decisions interpreting constitutional provisions or other legal instruments as sources of constitutional law. I further elaborate on judicial cases in the context of Brazil in *infra* Chapter 3 (see note 136 and accompanying text).

²⁸ For an English version of the Constitution, see e.g. Câmara dos Deputados [House of Representatives], *Constitution of the Federative of the Republic of Brazil* 3rd ed (Biblioteca Digital da Câmara dos Deputados [House of Representative's Digital Library], Centro de Documentação e Informação [Documentation and Information Center], 2010), online: < <http://english.tse.jus.br/arquivos/federal-constitution>>. Last retrieved: 4 February 2018. [As noted (*supra* note 1), unless otherwise stated, all translations from Portuguese into English have been made by the present author, including translations of constitutional and statutory provisions].

²⁹ For an overview of political context leading to the Brazilian constituent process, see e.g. Maria H Versiani, "A Republic During the Constituent Assembly (1985-1988)" (2010) 30:60 *Revista Brasileira de História* 33. For an overview of the drafting of the right to health and to participation, see e.g. Maciel Filho & Araújo, *supra* note 2

³⁰ Constitution, Art. 196.

³¹ Constitution, Art. 198, I-III.

198. Health actions and services shall integrate a (...) single system organized according to:

I – decentralization;

II – comprehensive service; and

III – community participation.

Significantly, the points of Arts. 196 and 198, III are that Brazil's Constitution enshrines the right to health as a right of the whole population and establishes the duty of the state to implement a participatory health system for health promotion, prevention and recovery.

In response to the right to health obligations, Congress passed legislation creating the Unified Health System (*Sistema Único de Saúde - SUS*).³² Additionally, Congress also created health councils for community participation at the three levels of health governance (federal, state and municipal).³³ There are literally thousands of participatory, legally empowered health councils: 5,600-plus at the municipal level, 27 at the state level.³⁴ And, at the apex of the health council system is the National Health Council (or “NHC”), which is the object of this study. According to the legislation, health councils, including the National Health Council, are defined as permanent and deliberative bodies where civil society representatives participate in the elaboration of health strategies and monitor policy implementation.³⁵ In this study, I focus on the NHC as the key mechanism

³² Congress passed *Federal Law No 8080/1990* creating of Brazil's health system. [The titles of Brazil's legislation have been adjusted to conform to the Canadian format of citing legislation. The adaptation is somewhat incomplete as the titles provided in the Brazilian legislation are different from Canada's. See the bibliography for the original citations].

³³ Congress passed *Federal Law No 8142/1990* creating health councils, including the National Health Council.

³⁴ For a database of health councils, see e.g. the National Database of Health Councils published by the Brazilian National Health Council, online: <http://conselho.saude.gov.br/web_cadastro/index.html>. Last retrieved: 4 February 2018.

³⁵ Art. 1 of *Federal Law 8142/1990* reads: The Unified Health System, created by Law 8080/1990, has at each level of government, without prejudice to the functions of the legislature, the following collegial instances: II – Health Council. Paragraph 2: [The] Health Council, [is a] permanent and deliberative [and] collegiate body formed by government, service providers, health workers, and users' representatives, [in order to] act in the elaboration of health-related strategies and in the monitoring of policy implementation at the corresponding level of government, including in relation to financial matters, which decisions are subject to the respective health authority in Council for approval.

at the national level for giving implementing the constitutional requirements towards community participation in the right to health in Brazil.

1.3 Brazil's Health System

The constitutional underpinnings of the Brazilian Unified Health System (*Sistema Único de Saúde* – SUS) include the obligation of the state to create a universal health system and guarantee equal access to services and measures to promote, protect and restore health (Art. 196). Congress passed two statutes establishing the basic organizational and operational structure of the system: *Federal Law No. 8080/1990* establishes the direction, management and responsibilities, and *Federal Law No. 8142/1990* establishes community participation in the health system and intergovernmental transfers. This section provides a concise summary of the general structure of the system.³⁶

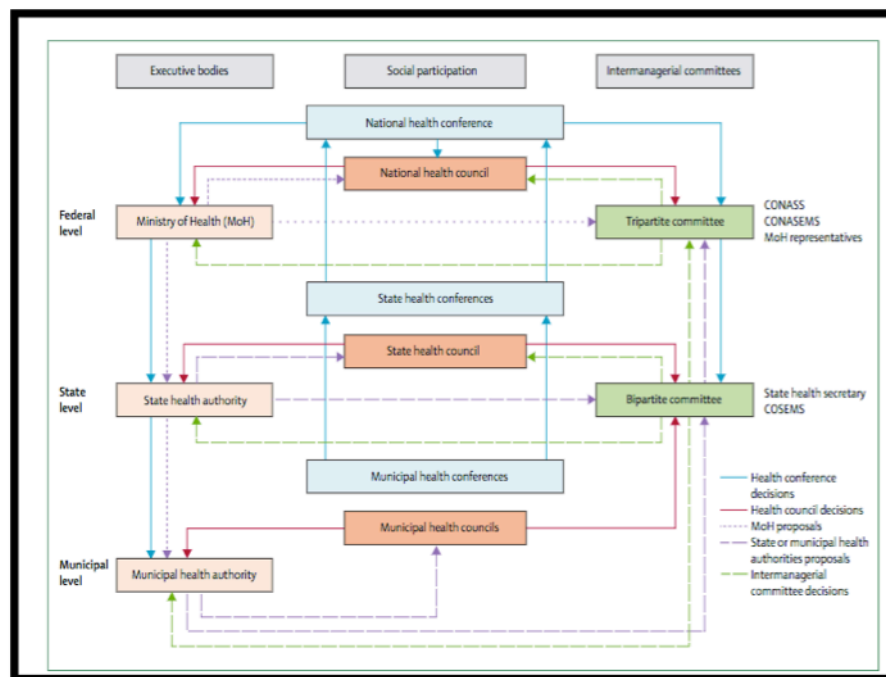
The statutory framework creates the Brazilian health system formed by a public-private mix of service providers roughly divided into two distinct but interrelated sectors: a public sector (SUS), and a private subsector (known as Supplementary Health System). The public sector is funded by taxes and social contributions by the three levels of government, and services are provided through a regionalized and hierarchically organized network of public clinics, hospitals, laboratories, as well as through contracts with private providers. The private sector, which is formed by group medicine, medical cooperatives and individual insurance plans, is a subsystem intended to complement the public system.³⁷ This private subsystem is financed by the public sector and private

³⁶ The Brazilian current health system consists of a variety of public and private organizations constituted in different historical and political contexts that influence both the *modus operandi* and outcomes of the system up to this day. Challenges regarding the interplay between the public and private sectors are beyond the scope of this study. For a helpful discussion of this public-private interface, see e.g. Jarinilson Paim et al, "The Brazilian Health System: History, Advances and Challenges" (2011) 377:9779 *The Lancet* 1778. [In fact, as Paim et al note, during the National Constituent Assembly (1987–88) the health reform activists pushing for state's obligation to create a universal health system faced strong opposition from a powerful and mobilized private health sector. In the 1990s, when the public system was been created, private health organizations were reorganizing in order to address new healthcare demands, and in order to do so, private companies received financial support from the government].

³⁷ While all Brazilians can use services in both the public and private sectors, depending on ease of access and/or their ability to pay, the public subsector covers approximately 75% of Brazilians while the private sector covers about 25% of the population. See e.g. Victor B Montekio, Guadalupe Medina, and Rosana Aquino, "Sistema de Salud de Brasil" ["Brazil's Health System"] (2011) 53:2 *Salud Pública Méx* 120.

sources, such as employment insurance and out-of-pocket spending, and interfaces with the public sector by providing services contracted-out by the public system such as specialist diagnostic and therapeutic support. By law, the private sector is subject to public regulation.³⁸

The governance structure of the public sector is decentralized with management structures and participatory bodies at each level of government, namely: the Health Ministry and National Health Council at the national level; Health Secretariats and state health councils at state level; and Health Secretariats and municipal health councils at municipal level.³⁹ The following graphic illustrates the governance/management/accountability structure of the public health system:⁴⁰



³⁸ *Ibid.* [The authors note that there is a dearth of regulation of the public sector, further challenging the provision of secondary and tertiary care in Brazil, largely because the public system is highly dependent on private sector providers for secondary and tertiary care, and these procedures involve high-cost interventions that are paid for by the public system at market value].

³⁹ The Health Ministry and other health agencies issue regulations and operational procedures to carry out the decentralized management, including in terms of responsibilities and funding mechanisms. Since 2006, less hierarchical agreements (i.e., “the Pact for Health”) and alliance-building mechanisms (e.g., inter-governmental committees, including health councils) have been replacing regulations, whereby health managers at each level of government sign commitments to health goals and responsibilities.

⁴⁰ Source: Paim et al, *supra* note 36 at 1785

The role and responsibilities of the public sector include services and measures to promote, protect and restore health that combine preventive and restorative services, including epidemiological surveillance; disease prevention; sanitation, food and drug safety; workplace health and safety; health education, as well as regulation of the private subsystem (*Law No 8080/1990*, Art. 5).

The organization and delivery of health services and promotion measures is organized and coordinated according to levels of complexity: primary care (or “basic attention” as is known in Brazil), secondary care and tertiary care. Primary care is the first contact point of continuing care to the health system and is responsible for coordinating more complex levels of care (e.g., specialist and hospital care). Primary care also implements intersectoral actions for health promotion and disease prevention. Secondary care includes acute care and medium-to-complex procedures, such as diagnostic and therapeutic support, as well as emergency departments. Tertiary care is specialized care for advanced medical investigations and interventions and involves high-cost and complex procedures such as cancer treatment, palliative care, cardiac surgery, neurosurgery, as well as other advanced clinic and surgical interventions.

Translating the rhetoric of health system transformation into reality is not always easy, particularly in one of the largest countries of the world and the largest country in South America, with a population of over 208 million inhabitants.⁴¹ Brazil is politically organized into a three-tier federal system composed of the federal government, 26 states, a federal district, and over 5,565 municipalities that are organized into five regions (north, north-east, central-west, south-east and south) with extensive regional differences,

⁴¹ Instituto Brasileiro de Geografia e Estatística – IBGE [Brazilian Institute of Geography and Statistics], “População do Brasil” [“Brazilian Population”], online: <<http://www.ibge.gov.br/apps/populacao/projecao/>>. Last retrieved: 4 February 2018.

including in terms of health needs.⁴² For example, while the north region suffers from structural problems such as the lack of sanitation, clean water and increased rates of mosquito-borne diseases such as malaria and Zika, the urbanized southeast faces higher incidence of respiratory diseases, and of disability and morbidity due to motorcycle accidents.⁴³

There is general agreement among health researchers that the creation of the *Sistema Único de Saúde* ('SUS') by Congress, bringing health coverage to millions of unemployed and poor Brazilians, revamped Brazil's primary healthcare services.⁴⁴ Studies evaluating the SUS have pointed to a significant increase in access to health care among rural populations, minorities, individuals with disabilities, and Indigenous Peoples.⁴⁵ One study refers to the fact that 3.1% of the Brazilian population was covered by Family Health Teams (i.e., teams of primary healthcare providers) in 1998, as opposed to 54.2% of the Brazilian population in 2012.⁴⁶ Another study reports progress with regard to health determinants between the years of 1991 and 2010: "poverty and illiteracy rates decreased significantly, while access to water, electricity, and sanitation have increased, with the major changes occurring in less developed municipalities."⁴⁷ The SUS is also credited with propelling important reductions in infant mortality (from 69/1000 to 19/1000) and fertility (from rates of 4.35 to 1.86), as well as significant increases in life

⁴² *Ibid.*

⁴³ Mariana Lajolo, "Trânsito Mata no Brasil 47 Mil por Ano e Deixa 400 Mil com Alguma Sequela" ["Traffic Kills 40 Thousand and Leaves 400 Thousands with Injuries," (31 May 2017) *Folha de São Paulo*, online: <<http://www1.folha.uol.com.br/seminariosfolha/2017/05/1888812-transito-no-brasil-mata-47-mil-por-ano-e-deixa-400-mil-com-alguma-sequela.shtml>>. Last retrieved: 4 February 2018. [Titles are originally in Portuguese and are translated by author, unless otherwise indicated].

⁴⁴ See e.g. Paim et al, *supra* note 36.

⁴⁵ Telma MG Menicucci, "O Sistema Unico de Saúde, 20 Anos: Balanço e Perspectivas" ["The Unified Health System, 20 Years – Overview and Perspectives"] (2009) 25:7 *Cadernos de Saúde Pública* 620. [Titles of academic articles are translated from Portuguese into English by the present author, unless otherwise indicated].

⁴⁶ Ana LA Viana, Hudson P da Silva & Ilcheong Yi, "Universalizing Health Care in Brazil: Opportunities and Challenges" in Ilcheong Yi, ed, *Towards Universal Health Care in Emerging Economies* (Palgrave Macmillan UK, 2017) at 182-3.

⁴⁷ Mauricio L Barreto et al, "Monitoring and Evaluating Progress Towards Universal Health Coverage in Brazil" (2014) 11:9 *PLoS Med* 1 at 1.

expectancy (from 62.6 to 72.8 years).⁴⁸ Nevertheless, the SUS still suffers from limited service capacity, gaps in coverage and delays in care, particularly with regard to secondary and tertiary care settings.⁴⁹ Here, rates of hospital admission for cardiovascular surgery, hemodialysis, and kidney transplants increased from 2008 to 2011, but significant discrepancies between more and less developed municipalities were unchanged.⁵⁰

In addition, social inequalities are systemic, widespread and “extreme” across and within Brazil’s states, regions and populations as Oxfam 2016 Report’s *An Economy for the 1%* underlines.⁵¹ Brazilian social scientist Marcelo Medeiros points out “inequality in Brazil fluctuates over time, but has been high since at least 1928, as a result of an impressive concentration of income among the rich.”⁵² Not to mention, there are the endless political corruption scandals and abusive judicial interventions, which threaten Brazil’s young democracy, social rights and the rule of the law.⁵³ Yet, high levels of inequality and

⁴⁸ See e.g. Gisele O'Dwyer et al, "The Current Scenario of Emergency Care Policies in Brazil" (2013) 13:1 BMC Health Services Research 70.

⁴⁹ See e.g. Viana, da Silva & Yi, *supra* note 46. [The authors point out that in 2012, an indicator measuring access to and effectiveness of the public system in Brazil (*Índice de Desempenho do SUS - IDSUS*) revealed a score of 5.47 (out of 10), which great variations among macro regions, states, and municipalities, online: <<http://idsus.saude.gov.br/index.html>>. Last retrieved: 4 February 2018].

⁵⁰ Accord Barreto et al, *supra* note 47.

⁵¹ Oxfam International, “An Economy For the 1% - How Privilege and Power in the Economy Drive Extreme Inequality and How This Can Be Stopped” (2016) Oxfam Briefing Paper No 210, online:< https://www.oxfam.org/sites/www.oxfam.org/files/file_attachments/bp210-economy-one-percent-tax-havens-180116-en_0.pdf >. Last retrieved: 4 February 2018.

⁵² Marcelo Medeiros, “Income Inequality in Brazil: New Evidence from Combined Tax and Survey Data” in ISSC, IDS and UNESCO, World Social Science Report, *Challenging Inequalities: Pathways to a Just World* (UNESCO Publishing, Paris, 2016), online: <<http://unesdoc.unesco.org/images/0024/002458/245825e.pdf>> at 107. Last retrieved: 4 February 2018.

⁵³ The last two years have been one of the most dramatic times in Brazil’s history since the country transitioned from military dictatorship to constitutional democracy in the mid-1980s. Brazil has been facing major political chaos, including the deeply controversial impeachment of Brazilian elected President Dilma Rousseff together with a plethora of corruption scandals across the three branches of government, cutting into the very fabric of Brazilian society. In the current climate of political chaos and debates, it remains vitally important to reinforce the importance of understanding and carrying out the requirements of Brazil’s Constitution. In a sense, the conflicts in healthcare mirror those found elsewhere in society: What does the Constitution require? What is the role of the courts in enforcing constitutional rights? How can the people, acting individually or through grass roots or other organizations, shape Brazil’s future? This dissertation’s focus on the role of public participation in shaping the right to health is thus both timely and important. For commentaries on Brazil’s political issues, see e.g. Jonathan Watts, “Dilma Rousseff Impeachment: What

political mistrust emphasize the importance of effective inclusion and participation in health policy, making it more pressing than ever to hold the state to account for its obligations relating to the rights to health and community participation.

In this context of unequal access to medical services and widespread distrust in the government and political institutions, the judiciary has become a panacea for the problems and pitfalls of the health system in Brazil. Thousands of individuals have turned to Brazilian courts to get the treatment they need, leading to ‘an explosion of healthcare litigation’, called the ‘judicialization of health’ in Brazil.⁵⁴ To illustrate the magnitude of this litigation problem, the Health Ministry faced one lawsuit in 2002, yet a staggering 1,311 in 2012; and health expenditures to comply with judicial orders increased from R\$2,441,041 (CAD\$1,269,341) in 2005, to R\$ 287,844,968 (CAD\$146,878,652) in 2012, with a roughly 500% increase between 2010 and 2014.⁵⁵ This data become even more problematic in light of the fact that 78% of health expenditure at the national level correlates with only 632 cases (patients), and “the most significant increase in spending

You Need to Know: The Guardian Briefing” (31 August 2016), The Guardian, online: <<https://www.theguardian.com/news/2016/aug/31/dilma-rousseff-impeachment-brazil-what-you-need-to-know>>. Last retrieved: 4 February 2018. See also, Jonathan Watts, “Operation Car Wash: Is This the Biggest Corruption Scandal in History?” (1 June 2017), The Guardian, online: <<https://www.theguardian.com/world/2017/jun/01/brazil-operation-car-wash-is-this-the-biggest-corruption-scandal-in-history>>. Last retrieved: 4 February 2018.

⁵⁴ João Biehl et al, “Judicialisation of the Right to Health in Brazil” (2009) 373:9682 The Lancet 2182.

⁵⁵ I should note that these conversions are based on the rate of today’s currency and are intended as a guide only. The federal expenses in Brazilian currency are reported in Advocacia Geral da União [Office General Attorney], “Intervenção Judicial na Saúde Pública: Panorama no Ambito da Justiça Federal e Apontamentos na Seara da Justiça Estadual” [“Judicial Intervention in Public Health – An Overview at the Federal Level and Some Considerations about the Provincial Level”] (2011) Assistência Jurídica do Ministério da Saúde [Legal Department of the Health Ministry] Working Paper, online: <<http://portal.arquivos.saude.gov.br/images/pdf/2014/maio/29/Panorama-da-judicializa-o-2012-modificado-em-junho-de-2013.pdf>>. Last retrieved: 4 February 2018. [The Health Ministry points out that 10,486 lawsuits were filed against the federal government in 2009; 11,203 in 2010; 12,811 in 2011; and 13,051 in 2012]. In related terms, Brazil’s rate of health litigation is higher than in other developing countries which constitutions embody free health care for at least some population subgroups (such as India, Indonesia, Nigeria, and South Africa). Accord Florian H Hoffman & Fernando RMN Bentes, “Accountability for Social and Economic Rights in Brazil” in Varun Gauri & Daniel M Brinks, *Courting Social Justice: Judicial Enforcement of Social and Economic Rights in the Developing World* (Cambridge University Press, 2008) 100. [Hoffman and Bentes report that 7,400 lawsuits were filed in state appellate courts in four states and at the federal level in Brazil between 1994 and 2004, while in India in the same period, with six times the Brazilian population, only 152 claims were filed in all high courts in all states and in the Supreme Court].

was observed with exceptional circumstance distribution drugs, 252% between 2003 and 2007.”⁵⁶ The federal government alone spent R\$122.6 million (CAD\$69.95 million) in 2010 and R\$ 1.2 billion (CAD\$436.3 million) in 2016, with the majority of these expenditures going to ten medications for exceptional circumstances (such as nephropathic cystinosis treated with Procsysbi and an enzyme replacement therapy with the trade name Naglazyme).⁵⁷ Significantly, this is the character of these lawsuits: pervasiveness of individual claims demanding healthcare services and prescription drugs, which can be enjoyed individually, and a high success rate for the individual claimant.⁵⁸

Despite this reliance - or overreliance - on the courts, there has been no judicial decision defining the right to community participation in the health system and policy making or analyzing the role of the National Health Council within the constitutional mandate for community participation.⁵⁹ In the context of healthcare litigation where health policy and service delivery have been discussed extensively, “community participation” in health policy making has been overlooked. In other words, constitutional requirements for community participation in decision-making processes as part of the right to health

⁵⁶ See e.g. Fabiola S Vieira, "Gasto do Ministério da Saúde com Medicamentos: Tendência dos Programas de 2002 a 2007" ["Health Ministry's Expenditure on Medication: Program Trends from 2002 to 2007"] (2009) 43:4 Revista Saúde Pública 677.

⁵⁷ For the most part, the data is from the federal government, but it is well known that states and municipalities have a huge bill as well. For instance, there were 23,000 new law lawsuits in the state of São Paulo in 2016, as pointed out in Brazilian newspapers (which became a popular venue for this debate). See e.g. Marcelle de Souza, “Gasto com 10 Remédios Mais Pedidos para a Justiça para o SUS é de Quase 1 Bi” [“Health Expenses with the 10 Most Requested Medications is Almost 1 Billion”], (06 April 2017), Uol notícias, online: <<https://noticias.uol.com.br/saude/ultimas-noticias/redacao/2017/04/06/gasto-com-10-remedios-mais-pedidos-na-justica-para-o-sus-chega-a-r-1-bi.htm>>. Last retrieved: 4 February 2018. Another example, Folha de São Paulo, “Entenda a Judicialização da Saúde e Debate do STF Sobre Acesso a Remédios” [“The Judicialization of Health and the Debate About Access to Medication Through the Supreme Court”] (20 September 2016), Folha de São Paulo, online: <<http://www1.folha.uol.com.br/cotidiano/2016/09/1817519-entenda-a-judicializacao-da-saude-e-debate-do-stf-sobre-acesso-a-remedios.shtml>>. Last retrieved: 4 February 2018.

⁵⁸ See e.g. Ferraz, *supra* note 6 at 35.

⁵⁹ *Governadora do Estado do Rio de Janeiro v Conselho Nacional de Saúde*, ADI No 2999-RJ. [In 2003, the former governor of the Rio de Janeiro, Rosa Garotinho, filed a constitutional challenge against the deliberative power of the National Health Council to establish criteria for federal health expenditure. The challenge was intended to have the NHC's Resolution 322/2003 to be declared null and void by the Supreme Court. But in 2008, the case before the Higher Court was closed given procedural issues without decision on its merits. In other words, the Court has not considered issues of authority and responsibility of the NHC].

remain neglected by the courts. It is thus not surprising that there has been little exploration of how legally structured community participation (in the NHC, for instance) should or does function as part of the right to health.

That is not to say that Brazilians do not have a right to take the state to court or that Brazil's right to health does not entail individual remedies: Brazil's right to health is enforceable through the courts and entails remedies in cases of violation.⁶⁰ In my view however, the issue is that healthcare litigation should be *one possible avenue* for citizens to hold the state to account when the government provides inadequate services – but not *the ordinary mechanism* to (re) distribute resources and guarantee the right to health for the whole population.⁶¹ In fact, as Brazilian social science scholar Soraya Cortes suggests, the Constitution creates a framework for community participation in policy making as a way to strengthen formal structures and rules to ensure a more democratic and responsive distribution and priority allocation of health resources to the benefit of the whole population.⁶² The claim, Cortes states, is that individuals and communities can ensure acceptable, appropriate, and effective responses to tackle entrenched health inequalities in society.⁶³ In my view, attention to the legal structures of participatory policy making is a way to strengthen the health system outside of the courts to the benefit of the whole population, rather than improved access through the courts primarily to the benefit of only those individuals who have access to courts.

⁶⁰ For a discussion about individual healthcare litigation as a form of remedy in the context of Brazil, see generally Ingo W Sarlet, "A Titularidade Simultaneamente Individual e Transindividual dos Direitos Sociais Analisada à Luz do Exemplo do Direito à Promoção da Saúde" ["The Individual and Collective Expression of Social Rights – the Example of the Right to Health Protection and Promotion"] in Felipe D Asensi & Roseni Pinheiro, eds, *Direito Sanitário [Sanitary Law]* (Elsevier Editora: 2012) 99.

⁶¹ For a discussion and case study about health litigation as a way to advance underlying conditions for health promotion in the context of Brazil, see e.g. Ana P Barcellos, "Sanitation Rights, Public Law Litigation, and Inequality: A Case Study from Brazil" (2014) 16:2 Health and Human Rights 35.

⁶² Soraya V Cortes, "Conselhos e Conferências de Saúde: Papel Institucional e Mudança nas Relações entre Estado e Dociedade" ["Health Councils and Health Conferences: Institutional Role and Changes in the Relationship Between the State and Society"] in Sonia Fleury & Lenaura Lobato, eds, *Participação, Democracia e Saúde [Participation, Democracy and Health]* (Rio de Janeiro: Cebes, 2009) 102.

⁶³ *Ibid.*

1.4 An Overview of the Study

The aim of this study therefore, is to bring community participation in the National Health Council (NHC) to the fore of Brazil's right to health. In particular, the aims are to establish the scope of the constitutional requirements for participation as part of the right to health, and the National Health Council's legal roles in meeting the constitutional requirements. As a socio-legal study concerned with on-the-ground implementation of the right to health, the aims of this study are: : 1) to gain a systematic understanding of the existing body of law governing participation as part of the right to health, particularly how the legally empowered participatory body: the National Health Council, relates to the constitutional framework of participation in health; and 2) to generate new data and knowledge about the workings of the NHC in relation to the right to health framework through qualitative interviews with key informants and observational research. I pursued the aims of this study through the following main strategies:

- Applying constitutional interpretation and analysis of community participation and Brazil's right to health, to explore the constitutional requirements of participation within the right to health framework.
- Utilizing statutory interpretation and analysis of the legal roles of the National Health Council, to explore the NHC's structure (i.e., nature, composition and mandate) with regard to the right to health requirements, and to analyze whether the structure meets constitutional requirements.
- Interviewing a sample of the NHC's members in 2014, to (a) determine their understanding of the NHC's structure and purpose in relation to the constitutional framework; and (b) gather data on the experiences of Council members in carrying out their participatory roles, including their views about any legal barriers to the implementation of the participation requirement through the NHC.
- Observing council members in action in their natural space (two plenary meetings in 2014, where Council members meet to debate and deliberate health policies and internal issues), and documenting the manner in which the meetings were held, the content of the agenda, and the roles of members within the meetings. I also

read the meeting minutes and watched the videos of the meetings to better understand the context within which council members operate.

1.5 Findings and Limitations of this Study

The constitutional analysis reveals that Brazil's fundamental right to health as protected and envisaged by Arts. 6, 196, and 198 of the Constitution requires the implementation of a participatory health system. Therefore, the analysis confirms the argument that community participation is at the core of the right to health and that ensuring people's participation in the organization of the health system is in fact a constitutional obligation of the Brazilian government. The constitutional analysis, furthermore, reveals that any arrangement relating to the selection of community participants should involve grassroots community representation to guarantee and to monitor whether the health system functions at all levels of the system according to the right to health framework.

The statutory analysis reveals that the legislation establishing the SUS and the National Health Council is consistent with the mandatory nature of community participation in the health system. The legislation carries out the constitutional mandates relating to the selection of community participants and the function of institutional participatory mechanisms. The community participates in the elaboration of health strategies and in monitoring policy implementation through representatives of civil society organizations in health councils at the three levels of the system.

The qualitative data reveal a lack of consensus with regard to how the constitutional requirements actually shape the membership, operations and impact of the National Health Council. Participants were unclear about how the NHC's legal roles are related to the government's right to health obligations. Furthermore, there were some questions about the government's obligation to carry out or to be accountable for National Health Council's recommendations or decisions.

Overall, the legal and qualitative analysis was helpful in establishing the constitutional dimensions of the right to community participation and in developing internal and external recommendations for future reforms designed to realize the promise of that right in the National Health Council. The internal recommendations include clarification of the NHC's legal role and improvement of its operations in alignment with its constitutional responsibilities. The external recommendations seek to promote accountability through legal reforms and greater monitoring and engagement by civil society.

With regard to the limitations of this study, one of the problems is sample selection: this is a small-scale study focusing only on a sample of Council members and one mandate of the national level of health council. A further limitation of this study relates to my own potential biases in data collection and data analysis regarding how information was solicited and interpreted. As a practicing lawyer I interviewed clients to fit their problems into the proper legal framework. Being aware of my legal knowledge regarding the state's obligations to the right to health, such as the obligation to create a participatory health system, I exercised continuous self-awareness to avoid encouraging certain answers over others. For example, upon realizing that the question "Is participation in health governance an obligation of the right to health?" was encouraging certain responses, such as state's compliance or the lack thereof, I immediately made amends by encouraging respondents to speak of "how participation in health governance relates to the right to health." I discuss these limitations and strategies used to overcome the limitations in Chapter 3.⁶⁴

1.6 Overview of the Chapters

This study of the constitutional dimensions of Brazil's right to community participation raises several important questions that provide a frame for this dissertation: What are the constitutional requirements for participation as part of the right to health? How does the legally empowered participatory mechanism, the National Health Council, relate to the

⁶⁴ See *infra* Chapter 3, Section 3.3.5 for detailed discussion.

constitutional requirements of participation? What are the perceived legal barriers to the implementation of the law? These questions are analyzed in the following chapters of this dissertation.

In Chapter 2, I provide an overview of the international and Brazilian literature on health and human rights, as well as the literature on population and public health. This literature review is designed to clarify concepts that ground this study, including the notion of community participation, the rights to health and to healthcare, and the role of constitutional rights in this area. I then present the current Brazilian constitutional debate on the judicialization of healthcare and situate my study within the debate, concluding this section by underlining my contributions to the field.

Chapter 3 turns to the methodological choices and methods selected and applied in this study. The Chapter starts by stating the questions and objectives of the research and describes the design to meet the objectives. The Chapter then provides a general overview of my approach to the constitutional analysis and explains my use of Brazilian constitutional scholar Lênio Streck's approach to constitutional interpretation. The Chapter briefly summarizes other methodological aspects of my statutory analysis. The Chapter then turns to a discussion about the qualitative research and elaborates the choices of methods, data collection and analysis of the fieldwork, as well as limitations of this study.

Chapter 4 develops the argument that community participation is at the core of the right to health obligations in Brazil in order to realize the right to health for the whole population. The Chapter examines the definition and purpose of the constitutional provision of community participation in the right to health. It starts by providing an overview of the 1988 Federal Constitution of Brazil, followed by a section describing the constitutional arrangement of the right to health, outlining the right to participation within the constitutional structure. I then interpret and analyze the scope of Brazil's right to health and the role of community participation as part of the right to health arrangement intended to secure the right to health in Brazil.

Chapter 5 focuses on the legislative implementation of community participation and examines the structure of the National Health Council, as well as the connections between the NHC's structure and the constitutional requirements of participation in health. I analyze the relevant legislation, including federal statutes, a presidential decree, and an operational resolution issued by the NHC. This Chapter confirms that participation through the NHC is a state obligation toward the realization of the right to health for the whole population.

In Chapter 6, I present and analyze my original interview and observational data. I describe and discuss participant members of the NHC's perspectives with regard to the NHC's legal roles and the right to health. I also analyze the NHC's practices in relation to its constitutional role and identify barriers to the NHC's work. The analysis of the data confirms that participation is imperative for the realization of the right to health for the whole population and that the NHC is an important vehicle for ensuring participation. The qualitative data also support the development of specific strategies to enhance the effectiveness and impact of this important body.

Finally, Chapter 7 reviews the central argument of this study and makes concluding remarks that can be drawn from the research discussed in Chapters 3 to 6. The Chapter also reflects on the intricacies associated with implementing participation through legislation, including 'internal issues' (e.g., legal interpretation) and 'external issues' (e.g., accountability to stakeholders). The Chapter discusses the strengths and weaknesses of this study, including my own limitations as a Brazilian lawyer and right to health activist. I make final recommendations to improve participation through the NHC. I end this Chapter, and this dissertation, by setting out future avenues of research: development of accountability frameworks holding council members answerable to the population at large, and the creation of criteria to evaluate the actions of health councils as a component of the right to health.

2 Literature on the Right to Health and Participation in Brazil

2.1 Introduction

Over the last decade, scholars, activists and policymakers from around the world have focused on Brazil's right to health.⁶⁵ This increased attention is largely because Brazil has experienced a remarkably high volume of health litigation in recent years, and Brazilian courts have not shied away from ordering government officials to take positive actions to secure individual citizen's right to health. Unsurprisingly therefore, legal scholarship has focused largely on litigation-related questions, such as proper remedies and standards of judicial review, and empirical studies of the impact of litigation on health planning and access to care.⁶⁶

Although the constitutional right to participation is integral to the right to health framework in Brazil, and participation occurs at the three levels of Brazil's health system, the attention of lawyers, courts and legal scholars has been largely focused on one aspect of this constitutional framework: the role of the courts in defining the state's obligation to provide access to certain healthcare services. The constitutional framework of participation and the actual practice of participation in health planning have been largely neglected in Brazil's legal circles. As a result, little is known regarding the constitutional requirements set forth for participation as part of Brazil's right to health. In addition,

⁶⁵ In Brazil's publication, see e.g. Felipe RS Machado & Sulamis Dain, "Direito e Saúde: Contribuições para o Estudo da Judicialização" ["Law and Health – Contributions to Studies about Judicialization"] in Felipe D Asensi & Roseni Pinheiro, eds, *Direito Sanitário [Sanitary Law]* (São Paulo: Elsevier, 2012) 463. See also Biehl et al 2009, *supra* note 54. Internationally, see e.g. Octávio LM Ferraz, "Brazil: Health Inequalities, Rights, and Courts: The Social Impact of the Judicialization of Health" in Alicia E Yamin & Siri Gloppen, eds, *Litigating Health Rights: Can Courts Bring More Justice to Health?* (Harvard University Press, 2011). See also Everaldo Lamprea, "The Judicialization of Health Care: A Global South Perspective" (2017) Annual Review of Law and Social Science; Hoffman & Bentes, *supra* note 55.

⁶⁶ For a concise overview of the debate in the context of Brazil, see e.g. Octávio LM Ferraz, "Moving the Debate Forward in Right to Health Litigation" (2016) 18:2 Health and Human Rights 265. See also João Biehl, Mariana P Socal & Joseph J Amon, "On the Heterogeneity and Politics of the Judicialization of Health in Brazil" (2016) 18:2 Health and Human Rights 269.

there has been little exploration of whether and how the current modes of community participation in Brazil's health system meet the constitutional requirements.

In this Chapter, I provide an overview of the academic work on participation in health and the right to health, paying special attention to Brazilians' right to participation as part of the right to health. This chapter is organized as follows. Section 2.2 introduces the development of the literature focused on Brazil's right to health. Building on the health and human rights literature, section 2.3 discusses why participation in the health system matters. Section 2.4 provides an overview of contemporary scholarship in the fields of social and political science that examines participation in general, and participation from within Brazil's health system. In conclusion, section 2.5 turns to emerging debates, particularly in the Brazilian field of *Direito Sanitário* (studies on constitutional and administrative health law), and ends by situating this research within this field of knowledge.

2.2 The Development of Legal Debates Over Brazil's Right to Health

The legal academic literature on Brazil's right to health reflects evolving perspectives on the enforceability and implementation of the right. The rights to health and to participation in the health system were enshrined in the 1988 Federal Constitution of Brazil. The constitutional provisions relevant to this study were presented in the preceding Chapter, while here I will focus on the specific elements, reproduced for convenience.⁶⁷

196. Health is a right of everyone and a duty of the state.

Significantly, Art. 196 explicitly establish that health is a duty of the state. And, because of the novelty -- it was the first time in Brazil's history that health was accorded constitutional status -- lawyers and legal scholars in the early 1990s focused

⁶⁷ See *supra* note 1 for the text of Art. 196 of the Constitution.

predominantly on justifying the legal nature of the right to health.⁶⁸ The focus was largely on questions such as whether Brazil's right to health required government to take positive actions and what types of 'positive actions' government owed to the people. The aim of the legal community then was to ensure that Brazil's right to health entailed an individually claimable right against the state and what forms state actions.⁶⁹ Patients' advocacy groups, including Duchenne muscular dystrophy and HIV/AIDS organizations, were pioneers in litigation associating the constitutional right to health with access to treatment.⁷⁰ By 2000, it became clear that the courts viewed the right to health as entailing an individually claimable right to healthcare services and prescription medication, and as not being subject to resource constraints.⁷¹

It is irrefutable that the forerunner HIV-AIDS strategic litigation grounded on the right to health has generated positive policy changes for Brazilians living with HIV-AIDS.⁷² Yet, as a number of Brazilian constitutional commentators such as Octávio Ferraz have suggested, the HIV-AIDS strategic litigation set out a problematic model of health litigation. Brazil's model of health litigation has encouraged what Professor Ferraz calls "a favourable litigation environment ... characterized by individualized claims demanding curative medical treatment (most often drugs) and by an extremely high

⁶⁸ See e.g. Ana P Barcellos, "Neoconstitucionalismo, Direitos Fundamentais e Controle das Políticas Públicas" ["Neoconstitutionalism, Fundamental Rights and Control of Public Policies"] (2005) 240 *Revista de Direito Administrativo* 83.

⁶⁹ *Ibid.*

⁷⁰ For a literature review of empirical studies on the development of healthcare litigation in Brazil, see e.g. Daniel Wang, "Courts as Healthcare Policy-Makers: The Problem, the Responses to the Problem and Problem in the Responses" (2013) *Direito GV Research Paper Series—Legal Studies* No. 75, pp. 1–60. See also Lamprea, *supra* note 65; João Biehl, *Will to Live: AIDS Therapies and the Politics of Survival* (Princeton University Press, 2007).

⁷¹ See e.g. Ministério da Saúde [Ministry of Health], "O Remédio via Justiça: Um Estudo sobre o Acesso a Novos Medicamentos e Exames em HIV/AIDS no Brasil por Meio de Ações Judiciais" ["Judicial Remedy – A Study About Access to New HIV/AIDS Drugs and Tests in Brazil Through Litigation"] (Brasília: Ministry of Health, 2005). See also Jane Galvão, "Brazil and Access to HIV/AIDS Drugs: A Question of Human Rights and Public Health" (2005) 95:7 *American Journal of Public Health* 1110.

⁷² For an overview of the positive aspects of the HIV-AIDS litigation in Brazil, see e.g. Nunn et al, *supra* note 4. For a critical overview of the HIV-AIDS litigation in Brazil, see e.g. Machado & Dain, *supra* note 65.

success rate for the litigant.”⁷³ Brazil has experienced a remarkably high volume of health litigation in recent years, and as noted, Brazilian courts have not shied away from ordering government officials to take positive actions to secure individual citizen’s right to health. As a result, a number of constitutional commentators contend that people use litigation to seek satisfaction of all sorts of health needs, from adult diapers and baby formula to multiple sclerosis drugs and complex surgeries.⁷⁴

By the end of the 2000s, legal scholarship on Brazil’s right to health shifted its focus away from the enforceability of the right toward the impact of judicial enforcement in health planning and health equity.⁷⁵ The high volume of health litigation in Brazil (and in Latin America in general) has caught the attention of international scholars as well.⁷⁶ As one example of this scholarly attention, in 2017, the *Health and Human Rights Journal*, an international peer-reviewed journal on health and human rights, issued an open call for original research papers and perspectives for a thematic special issue on the impact of right to health judicialization in Latin America.⁷⁷

The impact of health litigation on Brazil’s health system has generated a prolific debate, drawing approval from some quarters and criticism from others.⁷⁸ Those who approve argue that health litigation promotes health equality in that it helps poor and older individuals to get the treatment they need, which is already covered by governmental

⁷³ Ferraz, *supra* note 6.

⁷⁴ See e.g. Virgílio A da Silva & Fernanda V Terrazas, "Claiming the Right to Health in Brazilian Courts: The Exclusion of the Already Excluded?" (2011) 36:4 Law & Social Inquiry 825. See also, Mariana M Prado, "The Debatable Role of Courts in Brazil’s Health Care System: Does Litigation Harm or Help?" (2013) 41:1 Journal of Law, Medicine & Ethics 124; Daniel WL Wang, "Right to Health Litigation in Brazil: The Problem and the Institutional Responses" (2015) 15:4 Human Rights Law Review 617.

⁷⁵ With respect to the impact of litigation in health planning and health equity, see e.g. Ferraz, *supra* note 65. See also Biehl, Socal & Amon, *supra* note 65. With respect to the interference of the judiciary on the executive branch power, see e.g. Mariana F Figueiredo, *Direito Fundamental à Saúde - Parâmetros para sua Eficácia e Efetividade* [Fundamental Right to Health – Parameters for Its Efficacy and Effectiveness] (Porto Alegre: Livraria do Advogado, 2007) at 222.

⁷⁶ See e.g. Flood & Gross, *supra* note 7. See also Hoffman & Bentes, *supra* note 55; Ferraz, *supra* note 65.

⁷⁷ Editors, Call for Submissions, Health and Human Rights Journal, online: <<https://www.hhrjournal.org/submissions/call-for-submissions-upcoming-issues/#jud>>. Last retrieved: 4 February 2018. [Special issue forthcoming 2018].

⁷⁸ See generally Ferraz, *supra* note 65.

formularies, yet inadequately supplied by the government.⁷⁹ Moreover, commentators assert that government officials in fact contribute to the high volume of litigation insofar as officials are generally indifferent or disorganized and ineffective in improving healthcare access.⁸⁰ By and large, commentators in favour of health litigation thus believe that courts can bring about change in healthcare access and secure the right to health in Brazil.

By contrast, government officials and a number of legal scholars from Brazil and elsewhere, argue that health litigation has a potential to foster inequality in the system because litigants (who already have more privileged health status than those who cannot afford litigation) get to skip the waiting lines for medical services.⁸¹ Further, litigation may even siphon off funds from important primary healthcare or promotion measures that benefit the poorest, redirecting resources towards expensive individual treatments benefiting those that have access to courts.⁸²

Debates on the right to health in Brazil over the past few decades, in a nutshell, have developed largely into considerations about the impact of litigation on equitable access to healthcare, largely related to standards of judicial review and judicial remedies. I should note, however, that more recently some Brazilian constitutional scholars have turned to the scope of the right to health. For example, constitutional scholar Ingo Wolfgang Sarlet

⁷⁹ João Biehl, Mariana P Socal & Joseph J Amon, "The Judicialization of Health and the Quest for State Accountability: Evidence from 1,262 Lawsuits for Access to Medicines in Southern Brazil" (2016) 18:1 Health and Human Rights 209.

⁸⁰ Daisy B de Mattos, "A Judicialização do Direito à Saúde no Brasil: Considerações sobre a Reserva do Possível e a Efetivação do Direito pelo Poder Judiciário" ["The Judicialization of the Right to Health in Brazil: Considerations about the 'Reserva do Possível' [Notion of Reasonableness] and the Implementation of the Right through the Judiciary"] in Matheus P Silva and Ruth MP Santos, eds, *O Papel do Direito na Solução das Demandas Contemporâneas* [The Role of the Law in Addressing Contemporary Demands] (Brasília: Vestnik, 2016) 267.

⁸¹ For an argument that health litigation in the context of Brazil has potential to increase health inequity, see e.g. Ferraz, *supra* note 6. See also Prado, *supra* note 74. In addition, a number of policy-makers and judges have echoed similar concern. For an overview of the policy argument, see e.g. Angélica Carlini, "A Saúde Pública e as Decisões dos Tribunais – Apontamentos para uma Reflexão Crítica" ["Public Health and Court Decisions – Notes for Critical Reflections"] in Fernando Asensi & Roseni Pinheiro, eds, *Direito Sanitário* (Sanitary Law) (São Paulo: Elsevier, 2012) 497.

⁸² Silva & Terrazas, *supra* note 74.

draws a distinction between individualized and collective expressions of the right to health, which he calls right to healthcare and to health promotion, respectively.⁸³ Individualized expression of the right to health has to do with healthcare treatment to the satisfaction of an individual's health needs, whereas collective expression of the right relates to the needs of the population as whole usually associated with prevention and promotion measures. Along the same lines, constitutional scholar Ana Paula Barcellos writes about what she terms 'a right to sanitation', explained as an entitlement to sanitation services, an example of health promotion measures.⁸⁴ Both Sarlet and Barcellos seem to imply that Brazil's right to health entails distinct state obligations: the provision of healthcare on individual basis, and the provision of sanitary and epidemiological services. While this distinction is problematic and deserves attention, this debate is beyond the scope of this study.⁸⁵ My aim here is simply to indicate the growing concern about exploring a broader conception of the right to health in Brazil. Although scholars such as Sarlet and Barcellos have shifted the focus from judicial review and remedies to the scope of the right to health more broadly, still the participation part of the right to health has not been brought to the fore as a core feature of the right to health in Brazil.

⁸³ Accord Sarlet, *supra* note 60. See also Ingo W Sarlet, *A Eficácia dos Direitos Fundamentais: uma Teoria Geral dos Direitos Fundamentais na Perspectiva Constitucional [The Enforceability of Fundamental Rights: A Theory of Fundamental Rights in the Perspective of the Constitution]* 12th ed (Imprensa: Porto Alegre, Livraria do Advogado, 2015).

⁸⁴ Accord Barcellos, *supra* note 61.

⁸⁵ Suffice it to say here that while I understand the rationale for this categorization, as Barcellos (*ibid*) suggests, public law litigation demanding access to water and sanitation services might advance public health services and policies to benefit communities, in my view, a division into individuals' entitlement to healthcare and communities' entitlement to health promotion is problematic. For instance, this classification seems to imply a return to the biomedical perspective of health and may propel a hierarchy of interests associated to the right to health. In reality, Brazil's right to health means a right to a health system that includes a comprehensive access to both healthcare as well as actions to promote health, including sanitation services and other public health measures.

2.3 Limits of Brazil's Right to Health Debate and the Importance of Participation

The problem with the current focus on litigation, in my view, is that it assumes, or at least does not challenge, the mainstream belief that the right to health is simply a tool for securing access to only a limited range of public healthcare services. This narrow perspective neglects the true breadth of Brazil's right to health which in fact intends to empower communities to define the scope and content of the right to health to make the health system more aligned with local needs, knowledge and priorities. The role of community participation is to make the health system more responsive and effective. To fulfill Brazil's right to health for all, the State is required to implement and maintain a public and comprehensive health system (*i.e.*, aimed at health promotion, prevention and recovery) that includes community participation in the organization of the whole system (Federal Constitution, Art. 198, III). Community participation in the organization of Brazil's health system is not only a political commitment or a constitutional obligation yet to be implemented, but rather a reality: the country has over 5,565 participation bodies and over 100,000 citizens actively engaged in the organization of Brazil's health system.

As will be discussed later in this Chapter, health and human rights scholars have devoted considerable attention to the normative justification for participation, and social science scholars have focused on the theoretical underpinnings of community participation, the procedural components of the participation process, and the evaluation of the impact of community participation in Brazil's health sector. Nonetheless, there is a significant gap in that the current right to health literature neglects important questions, such as whether or not participatory bodies fully meet the constitutional requirements of participation as part of the right to health, and the role of courts in ensuring participation in the health system.

There are therefore many reasons to support the expansion of scholarship on the constitutional right to participation. First and foremost, we need to expand the debate to

challenge the prevailing view of Brazil's right to health as being merely restricted to healthcare services and prescription medication. For example, interviews carried out by health anthropologists João Biehl and Adriana Petryna revealed that Brazilians perceive the right to health less in terms of health prevention and health promotion and more in terms of access to treatment and prescription medication.⁸⁶ Similarly, the right to participate in health planning and resource allocation has also been neglected by Brazilian citizens. In fact, this association between the right to health and access to individual healthcare is so deeply ingrained in the perception of Brazilians that as reported in mass media outlet, "[it] would be crazy and impossible for any government to change that."⁸⁷

But, there is more to the right to health than free access to healthcare and medication. In fact, it is hard to overstate the importance of political, social and economic contexts on health outcomes and human flourishing.⁸⁸ Health is increasingly understood as a matter of social well-being, social and power relationships; therefore, health cannot be understood in abstract terms and outside of social contexts.⁸⁹ Health as established by the Brazilian Constitution should be interpreted as essential in order to enjoy and lead a good life, and dependent upon a myriad of biomedical as well as socio-economic factors, including a fair distribution of and access to medical care, education, housing and nutrition. Health is also related to social inclusion.⁹⁰

⁸⁶ Accord John Biehl & Adriana Petryna, "Legal Remedies – Therapeutic Markets and the Judicialization of the Right to Health" in John Biehl and Adriana Petryna, eds, *When People Come First: Critical Studies in Global Health* (Princeton University Press, 2013) 325. For a quick reference, see e.g. John Biehl, "Right to Health Litigation", John Biehl (blog), online <<http://joaobiehl.net/global-health-research/right-to-health-litigation/>>. Last retrieved: 4 February 2018.

⁸⁷ Olga Khazan, "What the U.S. Can Learn From Brazil's Healthcare Mess - Here's What It Looks Like When a Sprawling, Diverse Nation Tries to Cover Everybody," *The Atlantic Magazine* (May 8, 2014), online November 8, 2017: <<http://www.theatlantic.com/health/archive/2014/05/the-struggle-for-universal-healthcare/361854/>>. Last retrieved: 4 February 2018. [The quote is attributed to Brazilian health policy scholar Alexandre Chiavegatto Filho].

⁸⁸ See e.g. Ruger, *supra* note 9.

⁸⁹ See e.g. Burris, Kawachi & Sarat, *supra* note 10.

⁹⁰ Cortes, *supra* note 62 at 102.

Further, participation in the organization of the health system is a core element of Brazil's right to health to achieve the full scope of the right; that is, citizens becoming part of political decisions to foster social change and health equality in the country.⁹¹

Contemporary debates need to change the negative stereotypes of the people of Brazil as simple beneficiaries of healthcare provided for by a paternal state whereby government or the judiciary knows what is appropriate to the people and decides what healthcare services are owed to them. As legal scholar Angélica Carlini writes, the goal of including citizens in policy is to promote social change and social justice, part of the political project of the Federal Constitution.⁹²

2.4 Scholarship on Participation in the Health System Generally and in Brazil

The relevance of participation for the achievement of the right to health has been systematically discussed and examined in theoretical and empirical research in the field of health and human rights. By way of background, the principle of participation was first articulated in 1978 at the first International Conference on Primary Health Care in Alma-Ata, Kazakhstan, an event of paramount importance for population health.⁹³ In 2000, the United Nations' Committee on Economic, Social and Cultural Rights issued General Comment 14, a core document interpreting the provisions related to the right to health.⁹⁴ Since the Alma-Ata Declaration, there is a considerably better understanding of the many theoretical and empirical aspects of participation as part of the right to health.⁹⁵ For example, the World Health Organization's (WHO) *Framework for Action* recommended participation in the organization of health systems ('participatory health governance') as a

⁹¹ *Ibid.*

⁹² Carlini, *supra* note 81.

⁹³ *Alma-Ata*, *supra* note 11.

⁹⁴ Committee on Economic, Social and Cultural Rights, *General Comment No. 14, The Right to the Highest Attainable Standard of Health* (Twenty-second session) U.N. Doc. E/C.12/2000/4 (2000), reprinted in *Compilation of General Comments and General Recommendations adopted by Human Rights Treaty Bodies*, U.N. Doc. HRI/GEN/1/Rev.6 [GC 14] paras. 11 and 54.

⁹⁵ See e.g. Alicia E Yamin, "Suffering and Powerlessness: the Significance of Promoting Participation in Rights-Based Approaches to Health" (2009) 11:1 *Health and Human Rights* 5.

key component for improved health governance.⁹⁶ Community participation was described as an organizing feature of health systems intended to include systematically excluded voices and needs into health policy decisions.⁹⁷ Inclusion was expected to allow a more balanced priority allocation of resources and foster more responsive, transparent, and therefore accountable health systems to the needs of all citizens.⁹⁸ The WHO's publications following the 2007 Report, including the WHO's 2008 Report, *Closing the Gap*, continued to reinforce the centrality of health governance as a cross-cutting theme closely linked to accountability as well as the importance of including citizens' voices in policy decisions regarding health systems as an integral element of working to improve health outcomes.⁹⁹

In the 2000s, the scholarly debate in health and human rights circles was about ways to implement effective strategies for community participation within health systems.¹⁰⁰ In 2008, health and human rights scholars Gunilla Backman and co-authors argued that community participation in health systems is a required feature of the organization of health systems and an obligation under human-rights law rather than simply being a “best practice” suggested by progressive researchers, activists or policy-makers.¹⁰¹ The aim of participation, as health and human rights scholars Orielle Solar and Alec Irwin write, is to “shift the locus of decision-making about health to the people whose health status is at issue” so people gain “increased control over the major factors that influence their health”

⁹⁶ WHO's *Building Blocks*, *supra* note 14.

⁹⁷ See e.g. Yamin, *supra* note 95.

⁹⁷ WHO's *Building Block*, *supra* note 14.

⁹⁷ See e.g. Labonté, *supra* note 18.

⁹⁸ *Ibid.*

⁹⁹ WHO's *Closing the Gap*, *supra* note 20. About evidence on the cost of health inequalities, see e.g. Harvard Gazette, “Inequality”, online: <<http://news.harvard.edu/gazette/story/topic/inequality/>>. Last retrieved: 4 February 2018.

¹⁰⁰ For a recent systematic review of the literature, see e.g. George et al, *supra* note 21.

¹⁰¹ Accord Backman et al, *supra* note 22.

and “communities [gain] broader capacity to make decisions about how they wish to live.”¹⁰²

Further, health and human rights scholars Paul Hunt and Gunilla Backman advance some of the state’s obligations toward participation by advocating for “the obligation to establish institutional arrangements for active and informed participation of all relevant stakeholders, including disadvantaged communities.”¹⁰³ In addition, according to health and human rights scholars Pol De Vos and colleagues, participation not only requires inclusion of marginalized populations, but also genuine and equal opportunities to influence policy making, including “accessible, fair, transparent and continuous [participation] processes.”¹⁰⁴

In the case of Brazil, as noted in the preceding Chapter (at page 8), the country has ratified the major international and regional treaties on related to the right to health, and the treaties become valid and bound state obligations.¹⁰⁵ Hence, the international dialogue about the centrality of public participation in the right to health provides additional justification for examining Brazil’s “constitutionalization” of community participation within its right to health framework.

Since the health reforms in the 1990s that created the Brazilian Unified Health System and health councils, there has been substantial academic work in the health and social

¹⁰² See e.g. Orielle Solar & Alec Irwin, “A Conceptual Framework for Action on the Social Determinants of Health” (2010) Social Determinants of Health Discussion Paper No 2 at 13, online: <http://www.who.int/sdhconference/resources/ConceptualframeworkforactiononSDH_eng.pdf>. Last retrieved: 4 February 2018. Citing Alicia E Yamin, “Defining Questions: Situating Issues of Power in the Formulation of a Right to Health under International Law” (1996) 18:2 Human Rights Quarterly 398.

¹⁰³ Paul Hunt & Gunilla Backman, “Health Systems and the Right to the Highest Attainable Standard of Health” (2008) 10:1 Health and Human Rights 81 at 83.

¹⁰⁴ Pol de Vos et al, “Health Through People’s Empowerment: A Rights-Based Approach to Participation” (2009) 11:1 Health and Human Rights 23.

¹⁰⁵ See *supra* notes 25 and 26 and accompanying text.

science fields.¹⁰⁶ In the case of participation in the health system, there is a general consensus that participation in the health sector is carried out through health councils, meaning institutional bodies whereby civil society interests are represented and representatives of civil society together with representatives of government and health workers participate in the decision-making process.¹⁰⁷ Some Brazilian health and social science scholars have been examining the relevance of citizen participation for improved responsiveness and accountability of the health system.¹⁰⁸ For example, political science scholar Vera Coelho has assessed the outcomes of citizen participation in health councils in the city of São Paulo and concluded that participation has in fact contributed to a more equitable and accountable distribution of public health services and funds.¹⁰⁹ The findings led Coelho to conclude that health councils closely connected with grassroots movements have contributed to greater integration between the councils and their respective health managers.¹¹⁰ As she explains, “[i]n a situation of heated disputes over resources between sub-municipalities.... those [managers] with the support and endorsement of civil society will be in a better position to negotiate their demands with the Municipal Secretariat of Health. The gains from this strategy are reflected in the increased ability to raise funds as shown by the three sub-municipalities which have more

¹⁰⁶ For an overview of the scholarly and empirical literature, see e.g. Adrian Lavallo & Cícero Araújo, “O Futuro da Representação: Nota Introdutória” [“The Future of Representation: Introductory Considerations”] (2006) 67 *Lua Nova: Revista de Cultura e Política* 9.

¹⁰⁷ See e.g. Maciel Filho & Araújo, *supra* note 2.

¹⁰⁸ For a historical overview of participation in Brazil’s health sector, see e.g. Soraya V Cortes, “Building up User Participation: Councils and Conferences in the Brazilian Health System” (2006) Translated by Cristina Perna. *Sociologias* 1. Online: <http://socialsciences.scielo.org/scielo.php?script=sci_arttext&pid=S1517-45222006000100005>. Last retrieved: 4 February 2018. See also Ana M. Costa & Natália Vieira, “Participação e Controle Social em Saúde” [“Participation and Social Control in Health”] in Fundação Oswaldo Cruz, *A Saúde no Brasil em 2030 - Prospecção Estratégica do Sistema de Saúde Brasileiro: Organização e Gestão do Sistema de Saúde* [Health in Brazil in 2030 – Forecasts of Population Health: Organization and Governance of the Health System] (Rio de Janeiro: Fiocruz/Ipea/Ministério da Saúde/Secretaria de Assuntos Estratégicos da Presidência da República, 2013) vol 3 at 27; Sonia Fleury, “Brazilian Sanitary Reform: Dilemmas Between the Instituting and the Institutionalized” (2009) 14:3 *Ciência & Saúde Coletiva* 746.

¹⁰⁹ Accord Vera SP Coelho, “What Did We Learn about Citizen Involvement in the Health Policy Process: Lessons from Brazil” (2010) 9:1 *Journal of Public Deliberation* Art. 9. [Coelho acknowledges however that this is a small-scale study and that further research is needed].

¹¹⁰ *Ibid.*

active councils.”¹¹¹ It is important to note, however, that a full understanding of this form of institutional participation in health councils, integrating participation and representation, is still at a developmental stage in Brazil.¹¹²

In some countries, the notion of participation in health can be vague and on-the-ground implementation may vary significantly according to political will and group interests.¹¹³ In Brazil, the term ‘participation’ is generally understood as the involvement of citizens or civil society organizations intended to influence or take part in political decisions, and also can involve various activities and processes to influence political decisions.¹¹⁴ There are many different terminologies used to describe the various activities and processes of participation, and some terms have been applied at times inconsistently and blurred.¹¹⁵ For example, terms such as “social participation”, “popular participation” and “community participation” appear to have been used in an overarching way to describe any form of collective action by which citizens or groups of citizens are involved in political matters. Terms such as “*controle social*” (“social control”, meaning civil society overseeing governmental action), “institutional participation”, “health council” have been used to describe any form of participation structured by legislation. In this study, I use the term ‘citizen participation’ as an umbrella term to mean the public’s involvement in health governance in Brazil. I use the term ‘community participation’ to refer to any form of collective action, and the term ‘institutional participation’ or ‘participation in health

¹¹¹ *Ibid* at 9.

¹¹² See e.g. the work by Brazilian political science scholar Leonardo Avritzer, who has been working on a theoretical model to understand the form of participation that occurs in Brazil’s health councils that integrates participation and representation into its design. See e.g. Leonardo Avritzer, “Democracy beyond aggregation: the participatory dimension of public deliberation” (2012) 8:2 *Journal of Public Deliberation*. See also Leonardo Avritzer, *Participatory Institutions in Democratic Brazil* (Washington, DC: Woodrow Wilson Center Press, 2009).

¹¹³ See George et al, *supra* note 21. For an overview of the concept and definition, see e.g. Susan Rifkin, “Paradigms Lost: Toward a New Understanding of Community Participation in Health Programs” (1996) 61 *Acta Tropica* 79. The classic piece on this matter is Sherry Arnstein, “A Ladder of Citizen Participation” (1969) 35:4 *Journal of the American Institute of Planners* 216.

¹¹⁴ See e.g. Maciel Filho & Araújo, *supra* note 2 at 91.

¹¹⁵ See e.g. Leonardo Rolim, Rachel Cruz & Karla Sampaio, “Participação Popular e o Controle Social como Diretriz do SUS: Uma Revisão Narrativa” [“Popular Participation and *Controle Social* as Principles of The SUS [Unified Health System]: A Narrative Review”] (2013) 37: 96 *Saúde Debate* 141.

council’ to refer to participation within the structure of the health system (i.e., health councils). In addition, I use the term ‘community participation’ when referring to the Constitution, because ‘community participation’ reflects the language used in the constitutional provision.

The Constitution explicitly establishes “community participation in the organization of the health system” as part of the right to health framework.¹¹⁶ Subsequent legislation creates health councils, institutional mechanisms by which communities are involved in the health system through representatives of organized civil society.¹¹⁷ But, the legal framework itself is not explicit with respect to how health councils are expected to meet the constitutional requirements to the right to health.¹¹⁸

The political science literature has contributed significantly to the understanding of the social and institutional conditions likely to further effective institutional participation, calling for particular attention to who participates, their motives for participation, and the conditions for effective participation.¹¹⁹ In general, studies are concerned with the strength of democratic policy making.¹²⁰ Empirical studies have generated substantial knowledge about issues such as a) the inclusion of marginalized groups and an assessment of their influence; b) the accessibility to participatory mechanisms; c) the power dynamics within the process; d) community representation within the participatory process and the accountability of representatives to the communities they represent; and

¹¹⁶ See *infra* Chapter 4 for discussion and analysis of the constitutional framework.

¹¹⁷ See *infra* Chapter 5 for discussion and analysis of the statutory framework.

¹¹⁸ *Ibid.*

¹¹⁹ See e.g. Vera SP Coelho, “Brazilian Health Councils: Including the Excluded?” in Andrea Cornwall & Vera SP Coelho, eds, *Spaces for Change? - The Politics of Citizen Participation in New Democratic Arenas* (Zed Books, 2007) 33. See also, Andrea Cornwall, “Democratizing the Governance of Health Systems: The Case of the Cabo of Santo Agostinho, Brazil” in Andrea Cornwall and Vera SP Coelho, eds, *Spaces for Change? - The Politics of Citizen Participation in New Democratic Arenas* (New York: Zed Books, 2007). For a general overview of evaluation criteria, see e.g. Andrea Cornwall, “Unpacking “Participation: Models, Meanings and Practices” (2008) 43:3 Community Development Journal 269.

¹²⁰ Costa & Vieira, *supra* note 108.

e) types of outcomes from participation.¹²¹ Health councils, therefore, have been largely examined from an institutional perspective with considerable attention devoted to the procedural components of the participation process. Departing from this procedural perspective, a small-scale study led by political science scholar Vera Coelho has examined the influence of participatory bodies in the distribution of public health resources.¹²² The preliminary findings of researcher Coelho's study indicate that citizen participation in municipal health councils has helped to advance a more equitable distribution of public health services.¹²³ This emerging literature underlines the relevance of citizen participation for improving health system performance and outcomes. Thinking through these contributions and limitations identified in the political science literature could usefully foster a better understanding of the role of citizen participation to advance the transformative role of Brazil's right to health.

¹²¹ In the context of Brazil, see e.g. Mauro Vieira & Maria CM Calvo, "Avaliação das Condições de Atuação de Conselhos Municipais de Saúde no Estado de Santa Catarina, Brasil" ["Evaluation of the Conditions and Actions of Municipal Health Councils in the State of Santa Catarina, Brazil"] (2011) 27:12 *Caderno Saúde Pública* 2315. See also, Vera SP Coelho et al, "Mobilization and Participation: A Win-Win Game?" in Vera SP Coelho & Bettina Lieres, eds, *Mobilizing for Democracy – Citizen Action and the Politics of Public Participation* (Zed books: London, 2010); Ligia HH Luchmann & Julian Borba, "Participação, Desigualdades e Novas Institucionalidades: Uma Análise a Partir de Instituições Participativas em Santa Catarina" ["Participation, Inequalities and New institutions: An Analysis of Participatory Institutions in Santa Catarina"] (2008) 44:1 *Ciências Sociais Unisinos* 58; Agada Wendhausen & Sandra Caponi, "O Diálogo e a Participação em um Conselho de Saúde em Santa Catarina, Brasil" ["Dialogue and Participation in one Health Council in Santa Catarina"] (2002) 18:6 *Caderno Saúde Pública* 1621; Ana C Teixeira & Lizandra Serafim, "O Impacto da Participação nas Políticas Públicas: O Caso da Saúde em São Paulo" ["The Impact of Participation in Health Policy: The Case of Health in São Paulo"] (Paper delivered at the 3rd Annual Conference and Workshop on International Social Movements, Participation and Democracy at the Federal University of Florianópolis, Brazil, August 2010) [unpublished]; Maria E Kleba & Agueda Wendausen, "Empoderamento: Processo de Fortalecimento dos Sujeitos nos Espaços de Participação Social e Democratização Política" ("Empowerment – The Process of Empowerment in Spaces of Social Participation and Democratization of Policy") (2009) 18:4 *Saúde e Sociedade* 733. In the context of participation in the North, see e.g. Julia Abelson et al, "Bringing 'the Public' into Health Assessment and Coverage Policy Decisions: From Principles to Practice" (2007) 82 *Health Policy* at 37.

¹²² See e.g. Coelho, *supra* note 119.

¹²³ *Ibid.*

2.5 The Legal Debate About Participation in the Brazilian Health

System and the Right to Health

Legal scholar Sueli Dallari has written extensively about the value and relevance of community participation in health policy making to various societal health-related needs and expectations.¹²⁴ In a 2012 book, *Direito Sanitário (Sanitary Law)*, health and legal scholars Roseni Pinheiro, Sueli Dallari, Felipe Machado, Sulami Dain, Angélica Carlini, and Francini Guizardi raised concerns about the scholarly gap between Brazil's rights to health and to participation in the health system.¹²⁵ In 2015, the *Revista de Direito Sanitário (Sanitary Law Journal)*, a key academic publication of health law in Brazil, published a special issue discussing the knowledge gap in Brazil's right to health and participation in public health decisions.¹²⁶ The editors issued a call for further studies in the constitutional field, arguing that there is a dearth of evidence-based studies on participation and the right to health. The journal used the term “*democracia sanitaria*” (“sanitary democracy”, or civil society participation in public health decisions), suggesting that citizen participation in health policies should be interpreted and articulated as a procedural requirement in health policy-making, according to Brazil's right to health framework.

The relationship between policy-making process and the right to health was also raised by health and human rights scholar Daniel Wang in his 2013 doctoral thesis: *Can Litigation Promote Fairness in Healthcare? The Judicial Review of Rationing Decisions in Brazil*

¹²⁴ Sueli G Dallari, "A Participação Popular e o Direito à Saúde no Sistema Nacional de Saúde Brasileiro" ["Popular Participation and the Right to Health in the Brazilian National Health System"] (2005) *Revista de Direito Sanitário* 6:1-3 at 9. See also Sueli G Dallari, "A Construção do Direito à Saúde no Brasil" ["Developing Sanitary Health Law in Brazil"] (2008) 9:3 *Revista de Direito Sanitário* 9.

¹²⁵ Fernando Asensi & Roseni Pinheiro, eds, *Direito Sanitário (Sanitary Law)* (Rio de Janeiro: Elsevier, 2012).

¹²⁶ Fernando M Aith & Sueli G Dallari, "Produção de Normas Jurídicas sobre Saúde no Ambito do Estado Democrático de Direito Brasileiro" ["Legal Norms Concerning Health in the Brazilian Democratic State"] (2014) 30:10 *Cadernos de Saúde Pública* 1.

And England.¹²⁷ Wang dealt with the question of whether courts interfering in rationing decisions promote or impair “procedural legitimacy”, a concept that Wang builds on the notion of “accountability for reasonableness” developed by Norman Daniels and Charles Sabin.¹²⁸ In his study, Wang developed practical rules for policy decisions to ensure “procedural legitimacy”, and these rules include (i) transparent; (ii) evidence-based decision making processes; (iii) revision and appeal mechanisms; (iv) and are subject to public regulation that requires transparent, evidence-based decision making processes and appeal mechanisms.¹²⁹ Brazilian courts, Wang suggests, could help identify whether or not health policy decisions comply with his model of procedural legitimacy. Despite promising decision-making procedures, Wang’s thesis makes no reference to community participation in policy-making, and leaving community participation up in the air is a problem, in my view. Talking about health policy-making in Brazil implies making reference to citizen entitlement and state obligation to secure community participation in decision-making, and yet Wang overlooks this requirement in his procedural legitimacy model. It is unclear, for example, whether and how citizen participation fits within Wang’s procedural legitimacy proposal.

Echoing aspects of Daniel Wang’s proposal, legal scholar Sueli Dallari suggests that courts could assess the legitimacy of the decision-making process.¹³⁰ Dallari, however, takes one step further and suggests that courts could serve as ‘evaluation sites’ to determine whether or not policy-making decisions actually include citizens in decision

¹²⁷ Daniel WL Wang, *Can Litigation Promote Fairness in Healthcare? The Judicial Review of Rationing Decisions in Brazil and England*, (PhD thesis, The London School of Economics and Political Science, 2013) [unpublished], online <http://etheses.lse.ac.uk/739/1/Wang_can_litigation-promote.pdf>. Last retrieved: 4 February 2018.

¹²⁸ See e.g. Norman Daniels & James Sabin, *Setting Limits Fairly: Learning to Share Resources for Health* (Oxford: Oxford University Press, 2008). See also, Norman Daniels, *Just Health: Meeting Health Need Fairly* (Cambridge: Cambridge University Press, 2009); Norman Daniels & James E Sabin, “Accountability for Reasonableness: An Update” (2008) *BMJ: British Medical Journal* 337; Norman Daniels, “Accountability for Reasonableness: Establishing a Fair Process for Priority Setting is Easier than Agreeing on Principles” (2000) 321:7272 *BMJ: British Medical Journal* 1300.

¹²⁹ Wang, *supra* note 127 at 13.

¹³⁰ Sueli G Dallari, “A Democracia Sanitária e o Direito à Saúde: Uma Estratégia para sua Efetivação” [“Sanitary Democracy and the Right to Health: A Strategy for its Achievement”] (Lecture delivered at the Brazilian National Council of Justice, São Paulo, May 2014), online: <<http://www.cnj.jus.br/images/CNJdsauDeDALLARI.pdf>>. Last retrieved: 4 February 2018.

making in the health system.¹³¹ Additionally, Ana Paula Barcellos suggests that courts could act as ‘experimentalist courts’ (or problem-solving courts) when structuring judicial remedies in health litigation cases.¹³² Barcellos explains that courts could employ experimentalist solutions in which parties collaborate in designing solutions and the role of courts is to negotiate and monitor parties’ performance and compliance with judicial orders.¹³³ Empirical studies in the social field provide helpful understanding and data of ideal conditions and structural designs for improved inclusiveness and participation, in Brazil’s participation fora in the health system. Proposals such as those by legal scholars Daniel Wang and Sueli Dallari would benefit from drawing on empirical studies from fields such as health and social science.

2.6 Conclusion

In conclusion, despite the significant development of Brazil’s right to health research over the last decade, the literature is still far from achieving a full understanding of the political and transformative role of the right to health. There is a significant gap in that the current right to health and social science literature, particularly with respect to the constitutional requirements set forth for participation as part of the right to health. Further, empirically, there is also a gap in the literature regarding whether and how health councils actually meet the constitutional requirements set forth by the right to health framework. This study joins the literature in the field of *Direito Sanitário*, and aims to develop a new understanding of the requirements related to participation in health councils as part of the right to health, and empirically, how members of the national level participation body interpret participation in the National Health Council, as part of Brazil’s right to health. Ultimately, this study intends to expand the debate on Brazil’s

¹³¹ *Ibid.*

¹³² Accord Barcellos, *supra* note 61 at 41. [This notion of “experimentalism” and “experimentalist courts” was originally developed by Charles Sabel and William Simon, and refer to courts acting as institutional vehicles in which multiple stakeholders and experts identify and implement solutions to structural problems on an ongoing basis. See generally Michael C Dorf & Charles F Sabel, “A Constitution of Democratic Experimentalism” (1998) 98:2 Columbia Law Review 267].

¹³³ *Ibid.*

right to health by providing a more holistic understanding of Brazil's right to health as a whole.

This study focuses on securing effective citizen participation in Brazil's health system with the hope that success will enhance the responsiveness and accountability of a health system that has well-known challenges, including unequal access and inadequate service delivery. However, while my study focuses on citizen participation in securing the right to health in Brazil, neither unequal access nor inadequate service delivery are challenges limited to Brazil.¹³⁴ Fostering "citizens' expectations about health and healthcare and ensuring that [their] voice and choice decisively influence[s] the way in which health services are designed and operate" are goals encouraged and pursued around the world.¹³⁵ This dissertation about Brazil's citizen participation in the health system might also provide an insightful case study of the intricate realities of translating codified participation into reality elsewhere.

¹³⁴ Backman et al, *supra* note 22 at 2047, 2057, 2070-1. [Indicator 23 – Participation reads: "Is there a legal requirement for participation [of] marginalised groups in the development of the national health plan?" Backman and co-authors found no available data for any country with regard to Indicator 23 during the period of data collection (August 2007 to August 2008), including with relation to Brazil, which is one of the countries assessed. With respect to Brazil, Backman et al point to the fact that Brazil has adopted legislation for citizen participation in the health sector, yet the legislation makes no provision for the inclusion of marginalized groups in the development of Brazil's National Health Plan. But in my view, as I will discuss later in this dissertation, the Brazilian constitutional and legal framework do require inclusion of previously marginalized social actors in health planning. The problem, in my view, is that the legal framework provides no legal mechanism to ensure that government officials take citizens' input truly into consideration when elaborating the Brazilian National Health Plan (see *infra* Chapter 4, Section 4.5.1, and *infra* Chapter 5, Sections 5.4.2 and 5.4.3)].

¹³⁵ World Health Organization Regional Office for Europe, Reforming Health Care, The Ljubljana Charter (Ljubljana, Slovenia: 18 June 1996), online: <http://www.euro.who.int/_data/assets/pdf_file/0010/113302/E55363.pdf>. Last retrieved: 4 February 2018.

3 Study Methodology

3.1 Introduction

In this chapter, I present the methodological framework and research strategies used to achieve the aims of this study. The discussion is organized as follows. Section 3.2 provides an overview of the law and society literature that is relied on in this study, discusses the overall study design, which involves both legal and qualitative research methodologies, and provides an overview of the legal analysis. Section 3.3 provides an overview of the qualitative research methodology, including the sources, collection and analysis of the data, as well as the limitations of this study and strategies to ameliorate the limitations.

3.2 Law and Society Methodology

3.2.1 Law and Society Tradition

This study follows the law and society tradition. In general terms, this tradition underlines the complexity and interrelationship of law-related issues in their social context. Law and society scholarship examines laws and legal phenomena by analyzing insights, theoretical perspectives and methods drawn from a broad range of disciplines, such as anthropology, sociology, political science, and critical studies.¹³⁶ Studies in this tradition vary considerably in terms of subject areas, disciplinary debates, and methodological approaches, but the typical characteristic of this scholarly practice is to draw on legal texts and legal analysis, as well as on empirical research and methods from the social sciences.¹³⁷ In 2013, legal scholars Scott Burris and colleagues published *Publish Health Law Research*, surveying empirical studies about public health-related laws and legal

¹³⁶ See e.g. Austin Sarat, ed, *The Blackwell Companion to Law and Society* (John Wiley & Sons, 2008).

¹³⁷ For a review of subject matters and methods, see e.g. Joachim J Savelsberg et al, "Law & Society Review at Fifty: A Debate on the Future of Publishing by the Law & Society Association" (2016) 50:4 Law & Society Review 1017. For a review of methods more specifically, see e.g. Mike McConville & Hon Chui Wing, *Research Methods for Law* (Edinburgh University, 2007).

practices in relation to population health, largely within the context of North America and United States.¹³⁸ In their chapter, Scott Burris et al note that qualitative studies on law and public health have traditionally focused on questions such as how legislation positively or negatively influences public health, and what types of public health interventions could promote the overall health of populations.¹³⁹ Burris and his colleagues, furthermore, point to new governance scholars who broadened the scope of public health law research. This new approach explores, for example, how laws operate through social life and how social actors interpret legal texts and procedures to organize and manage themselves.¹⁴⁰ As a way forward, Burris and his colleagues believe that ‘the study of techniques of regulation and governance has become an important part of broader empirical legal research and scholarship’.¹⁴¹ Consistent with this emerging law and society tradition, in order to pursue its aims, this study draws not only on legal texts and legal analysis, but also on empirical research and qualitative interviews and observation.

3.2.2 Overall Study Design

To recap, the objectives of this study are to analyze Brazil’s constitutional requirements for citizen participation in health governance, and to evaluate whether and how the National Health Council body, through which citizens participate at the national level of health governance, meets these constitutional requirements. My study is based on the law and society tradition, therefore, is concerned with on-the-ground implementation of the

¹³⁸ Alexander C Wagenaar & Scott Burris, eds, *Public Health Law and Research: Theory and Methods* (San Francisco: Jossey-Bass, 2013) [Wagenaar & Burris].

¹³⁹ Scott Burris et al, “A Framework for Public Health Law Research” in Wagenaar & Burris 3.

¹⁴⁰ *Ibid.* [Burris and co-authors cite Orly Lobel, “The Renew Deal: The Fall of Regulation and the Rise of Governance in Contemporary Legal Thought” (2004) 89 Minnesota Law Review 342; and Louise Trubek, “New Governance and Soft Law in Health Care Reform” (2006) 3 Indiana Law Review 139]. See also Scott Burris et al, “Making the Case for Laws that Improve Health: A Framework for Public Health Law Research” (2010) 82:2 The Milbank Quarterly 169.

¹⁴¹ Burris et al, *supra* note 139. See also Regiane Garcia, “A Governance Approach to the Agricultural Genomics Intellectual Property–Regulatory Complex” in Emily Marden, Nelson Godfrey & Rachael Manion, eds, *The Intellectual Property–Regulatory Complex: Overcoming Barriers to Innovation in Agricultural Genomics* (UBC Press, 2016) 195. [In this paper I have discussed the influence of governance studies in health-related studies elsewhere, including the relevance of participatory governance and ways in which hard law (enacted legislation) and soft law (guidelines for participation in policy-making) could complement each other].

law. In pursuing these objectives, my research design consists of two phases: legal and qualitative. The legal phase consists of constitutional and legal analysis and is intended to systematically analyze the body of law governing participation in the health system as part of the right to health. The qualitative phase consists of interviews with a sample of NHC members and naturalistic observation of two NHC plenary meetings to generate new data about the workings of the NHC in relation to the body of law governing participation as part of Brazil's right to health.

The assumptions underlying the design and analysis of this study can be described as involving two interrelated notions. I recognize that laws have a social construction component in that social actors interpret the language of law and procedures to organize their lives and relationships. But I also recognize that there are limitations to social actors' construction of legal meanings. In other words, social actors (members of the National Health Council in this case) have a set of grammatical structures and legal interpretation canons to ascribe legal meaning to constitutional and statutory provisions.¹⁴² To be clear, the conception of law that I use in this study is constrained to state-enacted laws, and include constitutional and statutory provisions, as well as procedures issued by government officials.¹⁴³

¹⁴² See e.g. Lênio L Streck, "Deconstructing the Models of Judges: Legal Hermeneutics and Beyond the Subject-Object Paradigm" (2010) 10:3 Nevada Law Journal 683.

¹⁴³ This conception of law follows the Brazilian civil-law legal tradition in which legislation is the primary source of law within the country. Judicial decisions are not considered a source of law, and no judicial decision is binding in Brazil. Having said that however, I should note that since 2004, the Brazilian Supreme Court is allowed to issue binding decisions (called *súmula vinculante*) in cases that a constitutional matter has been repeatedly decided in the same way by two-thirds of the Court. *Súmula vinculante*, in a nutshell, functions as a 'model' within which the limits of subsequent cases must be decided. A full discussion of *súmula vinculante* is beyond the scope of this study, and – most importantly – irrelevant as there is no *súmula vinculante* regarding community participation or the right to health. For a database of the 56 *súmulas vinculantes*, see e.g. Supremo Tribunal Federal [Supreme Court], "Súmulas Vinculantes – Versão Resumida" ["Súmulas Vinculantes – Summary"], online: <http://www.stf.jus.br/arquivo/cms/jurisprudenciaSumulaVinculante/anexo/Enunciados_Sumula_Vinculante_STF_Resumido.pdf>. Last retrieved: 4 February 2018. For an overview of *súmulas vinculantes*, see e.g. Anna S Brunno, "Bringing Uniformity to Brazilian Court Decisions: Looking at the American Precedent and at Italian Living Law," online: (2007) 11:4 *Electronic Journal of Comparative Law* <<https://www.ejcl.org/114/art114-3.pdf>>. Last retrieved: 4 February 2018. For a critical perspective of *súmulas vinculantes*, see e.g. Lênio L Streck, "O Efeito Vinculante e a Busca da Efetividade da Prestação Jurisdicional: Da Revisão Constitucional de 1993 à Reforma do Judiciário (EC 45/04)." ["The Binding Effect and the Search for Effectiveness of Judicial Enforceability – From the Constitutional Review

To get to a broad perspective on the meaning of legal provisions and social interpretations of those provisions, this study combines two interrelated parts: 1) constitutional and legal research to determine the constitutional requirements for citizen participation at the national level of health governance; and 2) empirical research to explore whether and how the National Health Council meets these constitutional requirements, as well as the complexities of translating the legal requirements into reality, as experienced by actors responsible for implementing the law.

3.2.3 Statutory Analysis

This study's legal analysis is found in Chapters 4 & 5. Each chapter includes a detailed discussion of methodology and the application of that methodology.

Without getting into a meticulous discussion about the framework of constitutional interpretation, suffice it to say in this Chapter that I follow Brazilian constitutional scholar Lênio Streck's critical hermeneutic approach to constitutional interpretation.¹⁴⁴ To be clear, Streck's approach is a process of critical construction of meaning, rather than methods of constitutional interpretation. According to Streck, the action of interpreting should involve reflection and acknowledgement of prior attitude, prior view and prior conception that taken together feed what we know about something.¹⁴⁵ In Streck's words, "in order to interpret, we need to comprehend, and in order to comprehend, we need to have a pre-comprehension, composed of a prior meaning."¹⁴⁶ Interpreting a legal text therefore in this approach requires one to understand the text before interpreting it, which means to convey what one thinks a text means. The next step is to interpret the text,

Established in 1993 to the Judiciary Reform 45/04"] in Walber de M Agra, ed, *Comentários à Reforma do Poder Judiciário [Comments to the Reform of the Judiciary]* (Rio de Janeiro: Forense, 2005) 119.

¹⁴⁴ Streck has written extensively about constitutional interpretation in the context of Brazil, and his work has been published in Brazil, and internationally. In Brazil, see generally Lênio L Streck, *Hermeneutica Jurídica em Crise – Uma Exploração Hermenêutica da Construção do Direito [Legal Hermeneutics in Crisis – A Hermeneutic Exploration of Legal Construction]* 8th ed (Porto Alegre: Livraria do Advogado, 2009). Internationally, see generally Streck, *supra* note 142.

¹⁴⁵ Streck, *supra* note 142 at 686.

¹⁴⁶ *Ibid.*

which means to draw conclusions from a concept, taking into account one's own prior views and conceptions.

Following Streck's critical approach to interpretation, I discuss how my presumptions in favor of certain meanings permeate the analysis and influence the conclusions in this study. In particular, I discuss: a) how legislative drafting techniques have influenced the selection of the text to be interpreted; b) how different types of meanings, such as first-impression, literal, technical and historical meanings, influence my understanding and relate to my interpretations; c) how similar usage of a given term throughout the constitutional document and the grammatical organization of the provision influence my understanding and interpretation of the scope of constitutional provisions.

On the surface, these points may seem obvious. After all, this interpretation process may come instinctively to legal scholars used to traditional analytical exercises of reading statutes and judicial cases, determining original meanings, and drawing conclusions. But these are important points in Brazil, where constitutional interpreters, including judges, rarely discuss interpretative choices, such as the rationale for employing one canon of interpretation or selecting a given scholarly work rather than another.¹⁴⁷ For example, J. Carmen Lúcia of Brazil's Supreme Court cited the constitutional scholarship by José Afonso da Silva to support her decision on the meaning of the term "guarantee".¹⁴⁸ Relying on Silva's scholarly work, J. Carmen Lúcia determined that the word "guarantee" entails state obligations to create the means by which the people can enjoy their rights; in the case, to enjoy the rights to dignity, and to come and go.¹⁴⁹ This decision is an example of the common practice in Brazil, where judges often simply cite

¹⁴⁷ In Brazil, judges use legal scholarship, such as law books and law journal articles (so-called "*doutrina*" in Brazil) in reported opinions in their decisions. Even though judges do not have to cite legal scholarship, in my experience judges do so regularly.

¹⁴⁸ Ação Direta de Inconstitucionalidade No 2649-DF, Relatora Min. Cármen Lúcia, julgamento em 08 de junho de 2008, Plenário, *DJE* de 17-10-2008. [*Associação Brasileira das Empresas de Transporte Rodoviário Interestadual, Intermunicipal e Internacional de Passageiros v Presidente da República & Congresso Nacional ADI 2649-DF*].

¹⁴⁹ This case is about whether or not a federal legislation entitling persons with disabilities to a free public transportation is constitutional.

legal scholarship (called “*doutrina*”) as a source of legal authority for a given proposition, but without justifying their choices or discussing contrary academic opinions, for instance.¹⁵⁰ Constitutional interpretation in Brazil, as Lênio Streck rightly suggests in his work, has become a picking and choosing practice.¹⁵¹ Streck’s interpretative approach, in my view, is a better way to interpret constitutional text. His approach brings transparency to interpretation choices and fosters intellectual honesty in determining the meaning of legal language.

Chapter 4 focuses on the constitutional analysis of the right to participation as part of the right to health, and seeks to determine what the constitutional framework of participation means and entails. Brazil has neither strict analytical methods nor firm procedures for carrying out legal interpretation. Chapter 4 will explore some of the debates about constitutional interpretation in Brazil and will set out an interpretative framework based on grammatical, systematic, historical and teleological canons of interpretation.¹⁵² With respect to the analytical methods, I use general canons of interpretation/ construction, as employed in Brazil, namely: grammatical (known as fixed or ordinary meaning),

¹⁵⁰ More examples can be found at the Supreme Court database whereby the Court highlights its core decisions with respect to constitutional provisions, online: <<http://www.stf.jus.br/portal/constituicao/constituicao.asp>>. Last retrieved: 4 February 2018.

¹⁵¹ Streck uses many examples of judicial interpretations in criminal cases, including in the so-called Car Wash Operation cases to illustrate this pick and choose approach. See e.g. Lênio L Streck, “A lavajatolatria, o Carnaval e o Habeas Corpus de Gilmar Mendes” [“*Lavajatolatria*, Carnival, and the Habeas Corpus of Gilmar Mendes”] (18 January 2018) Consultor Jurídico, Senso Incomum, online: <<https://www.conjur.com.br/2018-jan-18/senso-incomum-lavajatolatria-carnaval-habeas-corpus-gilmar>>. Last retrieved: 4 February 2018. See also Lênio L Streck, “De 458 a.C. a 2018 d.C.: Da Derrota da Vingança à Vitória da Moral” [“From 458 B.C. to 2018 A.D.: From the Defeat of Revenge to the Victory of Moral”] (25 January 2018) Consultor Jurídico, Senso Incomum, online: <<https://www.conjur.com.br/2018-jan-25/senso-incomum-458-ac-2018-dc-derrota-vinganca-vitoria-moral>>. Last retrieved: 4 February 2018. For an academic article providing an example of how judges pick and choose, see e.g. Lênio L Streck, “O Caso da ADPF 132: Defender o Texto da Constituição é uma Atitude Positivista (ou “Originalista”)?” [“The Case ADPF 132: Is Defending the Constitutional Text a Positivist (or Originalist) Attitude?”] (2014) 1:1 *Revista de Direito da Universidade de Brasília* 270. But see Luís R Barroso, “Unões Homoafetivas: Reconhecimento Jurídico das Uniões Estáveis Entre Parceiros do Mesmo Sexo” [“Same-Sex Unions: Legal Recognition of Common Law Unions Between Same-Sex Partners”] (2014) 1:1 *Revista de Direito da Universidade de Brasília* 211 [J Barroso, author of the article, is the author of the decision criticized by Streck (*ibid*)].

¹⁵² In addition, Brazil also has general principles of legal interpretation for cases in which enacted legislation is silent, which is not the case in this analysis. Therefore, I do not discuss these principles in this Chapter.

systematic, historical and teleological.¹⁵³ The grammatical canon helps to determine the text-to-be-interpreted by establishing the fixed meaning of written words according to today's usage and/or technical sense, as well as the meaning of phrases in relation to the grammar rules of the Portuguese language.¹⁵⁴ The systematic canon (also known in Brazil as the structural canon) serves to determine the meaning of written words in relation to the purpose of the entire legislation, and the legal system as a whole.¹⁵⁵ This canon relies on two aids: 1) consistent usage of words and phrases used throughout a statute or in similar statutes; that is, the notion that words have the same meaning; and 2) structural arrangements such as titles, preambles and headings of a statute.¹⁵⁶ I also rely on the historical canon to determine historical context, rationale, and the intended purpose for establishing participation as part of the right to health.¹⁵⁷ Finally, I rely on the teleological approach that holds that interpreters should strive to interpret constitutional provisions toward the realization of the foundational values of Brazil.¹⁵⁸ I use a teleological approach when discussing the transformative purpose of the right to health.

Chapter 5 shifts the focus from the constitutional to the legislative framework establishing the National Health Council. This chapter analyzes the law to determine the role of the NHC in relation to the constitutional arrangement. The analysis starts from an examination of two pieces of legislation enacted by Congress according to powers derived from the 1988 Constitution. This legislation establishes conditions that governments and health council must comply with in carrying out their mandate. The Chapter will also consider an executive order, known in Brazil as a presidential decree, that establishes binding directives issued by the federal government according to powers

¹⁵³ I follow the technical terms of canons of interpretation/construction of legal instruments as used in Brazil. See e.g. R Limongi França, *Hermenêutica Jurídica* [*Legal Hermeneutics*] 6th ed (São Paulo: Saraiva, 1997) at 8.

¹⁵⁴ *Ibid.*

¹⁵⁵ See e.g. Humberto Ávila, *Teoria dos Princípios* [*Theory of Principles*] 4th ed (São Paulo: Editora Malheiros, 2004).

¹⁵⁶ França, *supra* note 153.

¹⁵⁷ Tércio S Ferraz Jr, *Introdução ao Estudo do Direito: Técnica, Decisão, Dominação* [Introduction to the Study of Law – Technique, Decision and Domination] 6th ed (São Paulo: Atlas, 2008).

¹⁵⁸ *Ibid* at 266-7.

derived from the enacted legislation. The decree provides the mandate of the National Health Council. Finally, Chapter 5 will analyze NHC's internal bylaw, known as a Resolution, issued by the Plenary Board of the NHC according to powers delegated by enacted legislation and the presidential decree. This Resolution consists of a set of written rules that establish further responsibilities for the NHC. The Resolution does not have the force of law.

As far as approaches to legal interpretation, despite the similarities in interpretative canons used in the constitutional analysis, the approach to the legal interpretation of legislation is rooted in more formalistic methods (e.g., textual analysis of statutory provisions and ordinary meanings) than the approach to constitutional interpretation in the preceding Chapter.¹⁵⁹

3.3 Qualitative Research Methodology

3.3.1 Study Design

Study design, as qualitative researcher John Creswell explains, is typically structured within five approach traditions, namely: narrative research, phenomenology, grounded theory, ethnography and case study.¹⁶⁰ Each approach, Creswell adds, depends on the aim of the research in practice.¹⁶¹ This study follows the case study approach, which social scientist Robert Yin explains, allows the researcher to use a combination of data sources to draw in-depth insights about real-world phenomena.¹⁶²

In the field of empirical legal research in particular, legal scholar Lisa Webley notes, a case study is used “to investigate how actors consider, interpret and understand

¹⁵⁹ França, *supra* note 153 at 8.

¹⁶⁰ John W Creswell, *Qualitative Inquiry and Research Design: Choosing Among Five Approaches* (Los Angeles: Sage Publications, 2013).

¹⁶¹ *Ibid.*

¹⁶² Robert K Yin, ed, *Case Study Research Design and Methods* 5th ed (Sage Publications, 2014).

phenomena (*e.g.*, law, procedure, policy), and therefore allows the researcher to study perceptions of processes and how they influence behavior.”¹⁶³ Accordingly, I adopted a case study approach to answer the following questions: how do Council members interpret the role of the National Health Council in relation to the right to health requirements, and what are the challenges to the National Health Council’s compliance with constitutional requirements. I selected the NHC members for three main reasons. First, the NHC integrates civil society actors in the overall directions of the health system. Second, the NHC’s members have long lasting experience in health activism and health policy making in Brazil, including at lower level councils. This vast experience of NHC’s members could provide a wider and richer data, which ended up being the case as discussed in Chapter 6.¹⁶⁴ Third, I selected the NHC as the unit of analysis because it was found to exercise a great degree of influence over state and municipal level council, even though there is no structural hierarchy among health councils.¹⁶⁵

In order to ensure the feasibility of this study, two considerations are in order.¹⁶⁶ The case in this study is Council members’ perceptions and experiences with respect to both legal meanings and practical challenges for the National Health Council’s compliance with constitutional requirements during the 2013-2015 term.¹⁶⁷

¹⁶³ See *e.g.* Lisa Webley, “Stumbling Blocks in Empirical Legal Research: Case Study Research” (2016) Law and Methods, online: http://westminsterresearch.wmin.ac.uk/17879/1/Stumbling_Blocks_in_Empirical_Legal_Research_Case_Study_Research.pdf. Last retrieved: 4 February 2018. See also, Lisa Webley, “Qualitative Approaches to ELS” in Peter Cane & Mark V Tushnet, eds, *The Oxford Handbook of Legal Studies* (Oxford: Oxford University Press, 2005).

¹⁶⁴ See *infra* Chapter 6 for the data collected in this study.

¹⁶⁵ Instituto de Pesquisa Econômica Aplicada (IPEA) [Brazilian Institute of Applied Economic Research], “O Conselho Nacional de Saúde na Visão de seus Conselheiros” [“The National Health Council through the Eyes of its Members”] Research Report [Project: National Councils: Profile and Action of Councillors] (Brasília 2012), online: http://www.ipea.gov.br/portal/images/stories/PDFs/relatoriopesquisa/120307_relatorio_cns.pdf >. Last retrieved: 4 February 2018. [IPEA’s Research Report].

¹⁶⁶ See *e.g.* Pamela Baxter & Susan Jack, “Qualitative Case Study Methodology: Study Design and Implementation for Novice Researchers” (2008) 13:4 *The Qualitative Report* 544.

¹⁶⁷ Hence for the purposes of this dissertation I am less concerned with the rationale or the activity of decision-making that led respondents to their viewpoints. In other words, I am not concerned with finding out how respondents make sense of their experience or how and why respondents interpret the law in the way they do. I am not concerned with respondents’ views on lower levels of health councils or with respondents’ experiences during previous terms.

Further, I should note that this is a single intrinsic case study. According to social science researchers, cases studies can be classified as explanatory, exploratory, descriptive, intrinsic, instrumental or collective, as well as single or multiple.¹⁶⁸ An intrinsic case study, Baxter and Frank explain, is recommended when the intent is to better understand a case, and not because the case represents other cases or illustrates a particular or a general problem at hand.¹⁶⁹

Ethical approval was obtained, and all ethical guideline steps to ensure participants' privacy, confidentiality, anonymity, and dignity were taken. Participation was voluntary and participants signed an Informed Consent prior to the interview.¹⁷⁰ At the beginning of each interview, I explained the academic purpose of the study, the data collection method and time-commitment for participating; I also underlined that respondents could withdraw from participation including the interview at any time. Further, no participant was put in situation in which they might be physically or psychologically harmed as a result of their participation in this study. Moreover, I took all steps possible to ensure privacy, confidentiality and anonymity of participants. I should note however, that as some research participants have made some of their views public, total anonymity might not be possible. Among the steps taken, I removed any identifying characteristics in the text to ensure participants' confidentiality and anonymity, and assured participants that no information revealing their identities will be shared for any purpose.

3.3.2 Data Sources

The primary data sources are drawn from qualitative interviews and naturalistic observations. The interviews were conducted with a sample of NHC's members, all

¹⁶⁸ For a quick overview, see e.g. Baxter & Jack, *supra* note 166. [Baxter & Jack built their summary on the work by Robert Yin *supra* note 162, and on the work by Robert E Stake, *The Art of Case Study Research* (Thousand Oaks, CA: Sage, 1995)].

¹⁶⁹ *Ibid.*

¹⁷⁰ See *infra* Appendix A- Informed Consent.

members at the time of the interviews.¹⁷¹ The observation was conducted in two NHC plenary meetings in the year of 2014.

The sample consists of 26 National Health Council's members; the NHC consists of 48 members plus two sets of substitutive members, making 144 in total.¹⁷² I sent an invitation to participate in this study to all 48 permanent members for the term of 2013-2015. I did not send invitations to substitute members because they are not involved in the activities of the NHC on an ongoing basis, as permanent members are. The invitation to participate was sent to email accounts of Council's members; two messages were sent from the email account of the researcher, and two messages from the email account of the NHC's executive secretary. Ideally, I intended to interview all 48 NHC's members. But, as with all research involving human participants, interviews are dependent on participant interest and availability to participate. And in this case, 26 or 54.17% of the 48 NHC permanent members were interested and available to participate.

I believe that this number is a representative sample of the whole population of the NHC. As I explain in Chapter 5, the NHC is formed by four groups of representatives: organized civil society; government officials; health workers (of the public health system); and private healthcare providers.¹⁷³ The sample contains members from all four groups that form the membership of the National Health Council at the time of the interviews.¹⁷⁴ In addition, I found that the sample was adequate in relation to gender, education and age. For example, I interviewed 11 females and 15 males, which is

¹⁷¹ The research participants were appointed as representatives of their respective organizations within the National Health Council for the 2012-2015 term. A new election occurred for the 2015-2018 term on December 5th 2015, when new organizations were elected to the Council, thus appointing their representatives. Some participants remain in the council while others are no longer part.

¹⁷² In 2014 the NHC consisted of 48 members as well. Since Congress passed *Federal Law No 8142/1990*, the NHC always has the same number of members.

¹⁷³ See *infra* Chapter 5, Section 5.4 for membership of the NHC.

¹⁷⁴ Because of distinctive understandings and features of the groups and segments within the groups, in order to preserve privacy and confidentiality of participants, the section does not provide a thorough description of specific segments represented in the sample, for example, x number of research participants from users, and within the users group, x number of research participants from social movements and x numbers from patient organizations, x number of research participants from private providers, and x number from professional associations from workers.

consistent with the gender ratio on the Council.¹⁷⁵ As for education, 25 participants reported university education, which was also in tandem with the overall education level of the Council, but undeniably above the average of Brazilians as a whole.¹⁷⁶ The ages of the participants ranged from approximately 30 to 70-years-old. Regardless of age, all participants reported lifelong experience in political and health-related matters, including in healthcare service delivery and/or activism related to social determinants of health in a series of differentiated rights and dimensions of rights.¹⁷⁷

Furthermore, throughout the interview process I was confident that research participants supplied diverse and detailed accounts for the study questions. Virtually all respondents had a deep knowledge about the research topic, except one participant who, although familiar with the right to health framework, this participant was less familiar with the ins-and-outs of the NHC. And, as social scholar Glenn Bowen suggests, “an ‘appropriate’ sample is composed of participants who best represent or have knowledge of the research topic.”¹⁷⁸ Furthermore, naturalistic observation was conducted to supplement the interview data.

3.3.3 Data Collection

Two data collection techniques were used in this research study: semi-structured interviews and naturalistic observation. Qualitative interviewing is one of the most common methods of data collection in qualitative research and consists of researchers gathering in-depth accounts and descriptions of lived experience as reported by research

¹⁷⁵ IPEA’s Research Report, *supra* note 166.

¹⁷⁶ *Ibid.*

¹⁷⁷ This review does not provide specific details of demographic attributes or backgrounds to ensure participants’ privacy as many of their expertise could identify participants. Certain understandings can be associated with certain groups and individuals; thus, I have omitted these details to reduce the risk of breaching the privacy and confidentiality of research participants.

¹⁷⁸ Glenn A Bowen, “Naturalistic Inquiry and the Saturation Concept: A Research Note” (2008) 8:1 Qualitative Research at 140.

participant themselves.¹⁷⁹ In particular, the semi-structured face-to-face interview is one of the most common ways to collect accounts and descriptions of people's lived experiences.¹⁸⁰ Semi-structured interviews are advised as strategies to keep the interview focused on the desired line of action, and foster more reliable and similar qualitative data throughout all interviews.¹⁸¹ In this study, I conducted semi-structured face-to-face interviews in order to gain an in-depth understanding with respect to the role of the National Health Council as part of the right to health. I prepared a set of questions (the research protocol) to guide the interview and ensure consistency.¹⁸² The same topics were covered throughout the 26 interviews. The questions revolved around three main themes: personal experience/opinion ("experience"), interpretation of the legislation ("legal framework"), and implementation of the framework ("practice of the Council"). Participants' opinions on these themes are described and discussed in Chapter 6.¹⁸³

Prior to the interviews, I sent formal letters of invitation to each research participant alongside a copy of the consent form as well as the research protocol. Participants signed the consent forms before the beginning of the interviews. Interviews were conducted face-to-face or using Skype video when face-to-face was not possible. The author interviewed research participants for approximately 45 minutes to one hour in each interview. The interviews were conducted in Portuguese, audio recorded with the permission of the participants, and transcribed into computer files.

Naturalistic (also known as non-intrusive) observation is a type of qualitative research method in which the researchers simply observe and record the behaviour of participants

¹⁷⁹ See e.g. Ann Oakley, "Gender, Methodology and People's Ways of Knowing: Some Problems with Feminism and the Paradigm Debate in Social Science" (1998) 32:4 Sociology 707.

¹⁸⁰ Steinar Kvale, *InterViews: An Introduction to Qualitative Research Interviews* (Thousand Oaks, CA: Sage Publications, 1996).

¹⁸¹ For a discussion on the benefits of semi-structured interviews, see e.g. Andrea Fontana & James H Frey, "Interviewing: The Art of Science" in Norman K Denzin and Yvonna S Lincoln, eds, *Handbook of Qualitative Research* (Sage Publications, 1994) 361. See also Shazia Jamshed, "Qualitative Research Method-Interviewing and Observation" (2014) 5:4 Journal of Basic and Clinical Pharmacy 87.

¹⁸² See *infra* Appendix C for Research Protocol.

¹⁸³ See *infra* Chapter 6 for data discussion and analysis.

in natural settings. Observational data can serve as auxiliary research data for other qualitative methods.¹⁸⁴

I observed two National Health Council plenary meetings in 2014 to see research participants in action within their natural surroundings. Consent was requested through the organizational head of the National Health Council, through a letter of initial contact detailing the study and a consent form. Plenary meetings are meetings in which members deliberate on recommendations for the Health Ministry. In both meetings, I acted as an external observer with no interference in the meetings. Information was recorded through written notes, either during or right after the meetings. I took 'scratch notes' during the meetings, consisting essentially of general outlines and impressions of specific points.¹⁸⁵ No individual was identified by name, title or by any other personal identifying features in the notes. I did not audio record the meetings, but I gained access to a copy of the audio-video record and minutes of the meetings from the National Health Council.

3.3.4 Data Analysis

The content of all interview transcripts was coded systematically using the QSR NVivo 11.2.0 software (Doncaster, Australia). The inductively generated coding guide and grid were both inspired by previous content analysis of qualitative research,¹⁸⁶ adapted to the object of this study.¹⁸⁷

In this case, the inductive approach includes analyzing the data with little fixed structure, and largely relying on the actual data itself to develop the structure of analysis based on

¹⁸⁴ David E Gray, *Doing Research in the Real World* 2nd ed (Thousand Oaks, California: Sage Publications; 2009).

¹⁸⁵ H Russell Bernard, "Field Notes: How to Take Them, Code Them and Manage Them" in H Russell Bernard, *Research Methods in Anthropology: Qualitative and Quantitative Approaches* 4th ed (Rowman Altamira, 2011) at 389.

¹⁸⁶ Philip Burnard et al, "Analysing and Presenting Qualitative Data" (2008) 204:8 British Dental Journal 429.

¹⁸⁷ The inductively generated coding guide and grid adapted to the objective of this study were both inspired by Burnard et al (*ibid*), as well as from a previous methodology course Advanced Seminar in Qualitative Research/CCFI 565, Fall 2012, with Professor Lisa W. Loutzenheiser at the Faculty of Education, University of British Columbia.

the ‘thematic content approach’. This approach involves analyzing the transcripts, organizing the data into themes, and extracting examples of those themes from excerpts of the text.

To analyze the data, I proceeded with the general understanding that there would be an interactive process between my interpretation of the legal meaning of “participation” and the views of those directly involved as participants in the NHC. I began to analyze the data using ‘open coding’ to organize the data into broad thematic areas, guided by general questions such as, “What is this about? What is the topic being discussed?” My legal perspective undoubtedly guided the coding in the search of themes, such as ‘legal meanings’, ‘legal functions’ and ‘legal policy purpose’.

Once the data were organized in those broad thematic areas which offered a summary statement for the topics within the transcripts, the analysis evolved to a more analytical coding, refining the content of the ‘open codes’ based on deeper questions such as “What is this data really about? And how does it relate to the research question?” This step helped to organize the data into patterns, connections and contradictions across the data. For instance, the open code: ‘conceptual dimension’ was refined to a more specific code: ‘applied label’ describing how the research participant actually perceived the practical implementation of the legislation as opposed to an ideal view as to how it should be. Other ‘open codes’ were split into a few additional codes. For example, ‘participant’s experience’ was restructured into codes such as ‘applied label’, ‘actual practice’, and ‘policy objective’. The final layer of coding - final coding - organized the data into the author’s own reflection about the data, for instance, reality *versus* ideal, likes and dislikes about the performance of the Council, and tensions among the different segments of participants. An overarching story emerged from my interviews, retold by research participants whose backgrounds and segments within the National Health Council differed. Chapter 6 provides a full discussion on participants’ perceptions.

With regard to the theme ‘experience’, the intended goal was to encourage participants to share as much background information as possible. This means that the questions were

intended to learn more about participants' life trajectories, and encourage participants to think about and share their perspectives based on experiences as they actually occurred. At the same time, as social scholars Barbara DiCicco and Benjamin Crabtree suggest, these types of questions help to establish rapport based on trust and respect for the participant and the information shared.¹⁸⁸ Rapport, the authors suggest, is an essential element of in-depth interviews in order to establish a positive relationship between the researcher and research participants.¹⁸⁹ Two set of sub-themes fall under the experience theme: 1) participants' own background experience, and 2) background of the entity they represent within the National Council. Examples of the former include questions about professional background; relationship with the organization representing the National Council; and experience as a National Council member and other levels of council. Examples of the latter include participant knowledge about NHC mandate; trajectory to obtain a seat and years within the National Council; appointment of interviewee representative; and respondents' accountability process to their entity. To deal with respondents providing only their own personal views - instead of the organization they represent – I asked questions about mechanisms and processes by which respondents communicate with their organizations and communities.

The theme “law” was intended to delve into participants' conceptual understanding of the right to health in general, and their interpretation regarding the relationship among ‘community participation’, ‘health councils’ and the right to health more broadly. The theme also intended to examine the meaning of terms and the rules governing these concepts, such as the meaning of legal obligations of key players. At first, respondents were asked to share their understanding of the right to health and the related obligations of community participation as a component of the right to health. After the third interview, the question was modified to include the word ‘conceptions’, rather than the word ‘obligations’.

¹⁸⁸ Barbara DiCicco-Bloom & Benjamin F Crabtree, "The Qualitative Research Interview" (2006) 40:4 Medical Education 314.

Finally, responses under the theme ‘practice’ were intended to grasp participants’ views on the actual implementation of the legal framework through the practice of the National Health Council. Originally, I asked about how participants perceived the legal role of the NHC as part of *the obligations* of the right to health. Analyzing the transcripts and field notes I realized that participants made no reference to the word ‘obligation’ at all, or any other word with a sense of enforceable duty for that matter. In fact, at my first interview, the research participant said that one of the protocol questions was “too lawyer-like to [his] taste.”¹⁹⁰ This statement “too lawyer-like” led me to revisit my own thinking about the project, and how I approached respondents. In practical terms, I decided to change the original question to the following: ‘How does the participant perceive the legal role of the NHC as part of the right to health’. In addition, I exercised continuous self-awareness to reduce bias. This realization allowed me to step away from my understanding of the right to health as “state obligations” to tell the story of how participants understand the right to health and the National Health Council, and how participants think the right to health influences the actions of the Council.

I analyzed and organized my scratch notes of observations from the meetings using technical aspects of the meeting (e.g., agenda, organization of seats, members engagement with the agenda) and conceptual aspects (e.g., discussions about racism and gender discrimination in health access). I then organized my notes in order to connect content discussed in the meetings to the different groups of representatives interviewed in this study.

Overall, the data showed a richness of information across all respondents, for example, female and male, as well as new and experienced council members. Participants relatively new to the National Health Council provided rich information about the workings of the Council in relation to their understanding about the right to health and issues that were also at times blurred. Respondents reported having gained this knowledge through participation in lower level councils or in standing committees and

¹⁹⁰ Respondent #12.

working groups of the National Health Council. Participation in lower level councils or standing committees was considered a sort of “rite of passage” before joining the National Health Council.

3.3.5 Limitations and Ameliorative Strategies

I should note a few significant limitations of this study. First, this is a small-scale study focusing only on the experience of 26 Council members, representative of their Council entity/interest group. As noted, in order to reach beyond respondents’ own personal views, I asked questions about mechanisms and processes by which respondents communicate with their organizations and communities. But, because I have not examined mandates, bylaws, minutes of meetings of respondents’ entities, I cannot confirm whether or not respondents’ views in fact reflect the views of the organizations and their membership. To overcome the limitation of sample size, I observed plenary meetings, which involved the 26 respondents, as well as the remaining 22 council members who were not part of this study.¹⁹¹

A further limitation of this study relates to my own biases in data collection and data analysis. Although as practicing lawyer I interviewed clients in my work, the aims for these qualitative interviews were different from my regular work. Interviewing clients was intended to fit specific problems into the proper legal framework for a civil remedy, or to characterize a lack of culpability. In other words, the purpose of lawyer-client interviews was to fit clients into legal boxes. The aim of the qualitative research, however, was to find out the perception of research participants, ignoring my previous assumptions and categories. I exercised continuous self-awareness to reduce my bias. But I also believe that the fact that I am a lawyer has encouraged respondents to speak about legal intricacies of law and reflect more deeply on their own interpretation of legal instruments in a way that someone without a legal background and interest in legal analysis might not be sensitive to.

¹⁹¹ I should note that the NHC’s plenary meetings are open to the public and the minutes of the meetings are made available to the public through the NHC’s website. Thus, the data involving non-participants was collected in these public meetings and makes no specific reference to individuals, unless individuals identify themselves in the meeting’s public minutes.

An additional strategy to deal with my bias (e.g., government officials would be more likely to discuss technical matters than civil society representatives) was to watch the video of the meetings several times. Observing the meetings helped me to gain a better contextual understanding of participants' experiences and challenges, but I did not attempt to keep my scratch notes neutral or unbiased; I followed the "salience hierarchy" approach to note taking, which is a description of whatever observations struck researchers, the most interesting or the most telling.¹⁹² In fact, I identified things that struck me as the most noteworthy for the research, such as attendees X and Y repeatedly left the meeting; attendee X makes the same point repeatedly; chair finally asked for order; presentation X was confusing; and people didn't read the files about X in advance.

Watching the videos and reading the field notes and transcripts over and over again made me realize that my scratch notes provided me with a good starting point for understanding my own bias toward the practice of participation. For example, the video made me reflect on my first impression that plenary meetings were a mess, without practical solution, but watching the video showed me that in reality many viewpoints were brought to the fore and a deferral to further analysis provided an opportunity to handle all these views in a more hands-on and coherent way. Furthermore, the field notes and the video challenged my view that, for instance, private provider representatives could in fact think in terms of political issues, while civil society representatives could focus on technical issues.

Furthermore, I have used measures during the empirical research process and evaluative measures to ensure data credibility, and the trustworthiness of the empirical study such as reflexivity and dense descriptions. For example, I have included detailed accounts of my decisions throughout the research and analytical processes, the rationale for research protocol and layers of coding, as well as reflections on how my bias might have influenced the data collection and analysis and strategies to minimize the effects of bias

¹⁹² See e.g. Ragnhild Hellesø, Line Melby, & Solveig Hauge, "Implications of Observing and Writing Field Notes through Different Lenses" (2015) 8 *Journal of Multidisciplinary Healthcare* 189.

such changing the protocol questions to include more open-ended questions.

Furthermore, I included a number of representative quotations from the interview data to support the identified themes, as well as to provide the reader with the flavour of participants' rich experiences in this text.

3.4 Conclusion

The legal research helped to articulate the core legal relationship between participation as part of the right to health and participation in the National Health Council. The empirical research provided rich primary material on the ways in which individuals interpret the role of the NHC as a means to secure the right to health. The empirical research, moreover, offered a nuanced and informed view of individuals involved in participation bodies with respect to the role of legislation and the role of the right to health in relation to the NHC. This nuanced understanding may prove useful in advancing and sharpening contribution to law reform toward better regulations and operational guidelines in order to advance constitutional goals related to broad inclusion of citizens in health planning as part of the right to health. I will now turn and apply the methodological framework discussed in this Chapter to the subsequent analytical Chapters 4 and 5, and field work Chapter 6.

4 Participation and the Right to Health in Brazil – A Constitutional Analysis

4.1 Introduction

The objective of this chapter is to use constitutional interpretation and legal analysis to develop an understanding of the participation requirement within Brazil's constitutional right to health framework.¹⁹³ This Chapter is organized as follows. Section 4.2 provides an overview of the Constitution in order to provide context for the analysis, and briefly describes the analytical approach to constitutional interpretation used in this analysis. Section 4.3 describes the methodological choices regarding relevant provisions for the purpose of this chapter. Section 4.4 analyzes the right to health framework, and section 4.5 interprets and analyzes the provision for community participation in the right to health. In conclusion, section 4.6 discusses the findings in light of the objectives of this chapter.

4.2 The Transformative Constitution

The 1988 Federal Constitution of Brazil ('Constitution') is the seventh constitutional document in Brazil's history, in force since October 5th 1988.¹⁹⁴ The document was

¹⁹³ As noted in *supra* Chapter 2, Section 2.4 I use the term 'citizen participation' as an umbrella term to refer to public's involvement in health policy matters in Brazil. I also noted in that Section that the term 'community participation' is used in two contexts throughout this dissertation. 1) I use 'community participation' when I specifically refer to the constitutional provision establishing the right to participation, because this is the term used in the Constitution. Therefore, I use the term 'community participation' in this Chapter. 2) I also use the term 'community participation' when referring to any form of collective action other than citizen participation within the structure of the health system (i.e., health councils). See *infra* Chapter 6, Section 6.2 for a discussion of how respondents use the term.

¹⁹⁴ For an overview of Brazilian constitutions, see e.g. Keith S Rosenn, "Conflict Resolution and Constitutionalism: The Making of the Brazilian Constitution of 1988" in Laurel E Miller & Louis Aucoin, eds, *Framing the State in Times of Transition: Case Studies in Constitution Making* (US Institute of Peace Press, 2010). [In short, the history of the Constitution, through: the 1824 Constitution, after Brazilian self-proclaimed emancipation; the 1891 Constitution, abolition of Brazilian monarchy; the 1934 Constitution, post-political elite revolution culminating in the 1930 coup d'état; the 1937 Constitution, the beginning of Getúlio Vargas' dictatorship; the 1946 Constitution, the end of Getúlio Vargas dictatorship and establishment of individual rights; the 1967 Constitution, after the 1964 military coup d'état; and the 1988 — and current — Constitution, end of the military dictatorship and return to democracy and creation of rights].

adopted at a time of brisk transformation and high hopes in Brazil, the so-called ‘transition to democracy’, after two decades of callous military dictatorship.¹⁹⁵ Needless to say, prior to the 1988 Constitution, the military dictatorship regime increased the powers of the executive, rendered the legislative and judiciary useless, suppressed freedoms and individual rights without judicial review — in practice, this was institutionalized torture, and heightened social inequalities in the country.¹⁹⁶ The Constitution was a response and commitment to fight social wrongs from the past, and foster political and social change. The final document is the ultimate expression of popular sovereignty, a result of negotiations carried out over the course of nineteen months by 559 elected members (including senators and federal deputies) gathered in the 1986 Constituent Assembly.¹⁹⁷

In sharp contrast to the military dictatorship, the Constitution establishes democracy and equality as the hallmarks of the new political structure, and makes clear that the new government objectives are to ensure social, individual and political rights to guide and foster social change. Or, as Ulysses Guimarães, the chair of the Constituent Assembly stated: “the Nation wants to change. The Nation should change. The Nation will change. The Constitution intends to be the voice, the letter, and the public will toward social change.”¹⁹⁸ The Preamble reads:

¹⁹⁵ The Brazilian Army ruled Brazil from the 1964 coup d'état led by the Armed Forces until 1985 with the election of a civilian government. For an overview, see e.g. Carlos Fico, *O Golpe de 1964 [The Coup of 1964]* (Rio de Janeiro: Editora da FGV, 2014). For an overview of the Brazilian *coup* in English, see e.g. Scott Mainwaring, "The Transition to Democracy in Brazil" (1986) 28:1 *Journal of Interamerican Studies and World Affairs* 149. For a critical overview of the Brazilian Coup from a North American perspective, see e.g. James N Green, *We Cannot Remain Silent: Opposition to the Brazilian Military Dictatorship in the United States* (Durham: Duke University Press, 2010).

¹⁹⁶ See e.g. Gilberto Dimenstein, *Democracia em Pedacos: Direitos Humanos no Brasil [Democracy in Pieces: Human Rights in Brazil]* (São Paulo: Companhia das Letras, 1996). See also Adriano N Codato, "A Political History of the Brazilian Transition from Military Dictatorship to Democracy" translated by Miriam Adelman (2006) *Revista de Sociologia e Política* 2.

¹⁹⁷ I should note that the constituent process leading to the adoption of the 1988 Constitution was highly inclusive in terms of public involvement during the debates and in terms of popular bills proposed by citizens during the drafting process. For an overview of the constitution-making process, see e.g. Márcia T Souza, "O Processo Decisório na Constituição de 1988: Práticas Institucionais" ["Decision-making Process in the 1988 Constitution: Institutional Practices"] (2003) 58 *Lua Nova* 37.

¹⁹⁸ Ulysses Guimarães, (Inaugural speech delivered at the promulgation of the Brazilian Constitution, October 5th 1988), online: <<http://www2.camara.leg.br/camaranoticias/radio/materias/CAMARA-E->

We, the representatives of the Brazilian people, assembled in the National Constituent Assembly to institute a Democratic State for the purpose of ensuring the exercise of social and individual rights, liberty, security, well-being, development, equality and justice as supreme values of a fraternal, pluralist and unprejudiced society, based on social harmony and committed, in the internal and international spheres, to the peaceful solution of disputes, promulgate, under the protection of God, this Constitution of the Federative Republic of Brazil.¹⁹⁹

Thus, this transformative constitutional goal is made clear from the outset in the Preamble to the Constitution. By way of background, the Constitution is the highest law of the country, and overrides any legislation or policy that conflicts with constitutional provisions. Constitutional provisions are codified in a single document (called ‘The Constitution’) and are the supreme law in Brazil.²⁰⁰ When the Constitution was adopted in 1988, the instrument contained 245 Articles, further divided into a number of paragraphs, sections and subsections, all organized under nine titles and 70 transitory provisions.²⁰¹ Furthermore, the Constitution has elements of rigid constitutions in that it requires a special majority of Congress for constitutional amendments (Art. 60) and establishes that

[HISTORIA/339277-INTEGRA-DO-DISCURSO-PRESIDENTE-DA-ASSEMBLEIA-NACIONAL-CONSTITUINTE,-DR.-ULYSSES-GUIMARAES-\(10-23\).html](https://historia/339277-INTEGRA-DO-DISCURSO-PRESIDENTE-DA-ASSEMBLEIA-NACIONAL-CONSTITUINTE,-DR.-ULYSSES-GUIMARAES-(10-23).html)>. Last retrieved: 4 February 2018.

¹⁹⁹ Brazilian Constitution, Preamble. [As noted (*supra* note 1), all translations from Portuguese into English have been made by the present author].

²⁰⁰ While constitutional supremacy is not explicitly provided in the constitutional text, the supremacy of the Constitution is well understood and accepted in Brazil. For this point, see e.g. José A da Silva, *Curso de Direito Constitucional Positivo* [Constitutional Law] 39th ed (São Paulo: Malheiros, 2016). With respect to “one single document”, it is important to recall that Brazil does not recognize judicial decisions interpreting constitutional provisions or other legal instruments as sources of constitutional law, with exception of some forms of binding decisions (called *súmula vinculante*) (see *supra* note 143, and accompanying text).

²⁰¹ In this dissertation, I follow the standard nomenclature and number structure used in Brazil’s legislative drafting technique established by *Federal Law No 95/1998* [The citations of legislation have been adopted to conform to Canadian Legal Citation style. See the bibliography for the original citations]. The term ‘Article’ (‘Art.’), similar to the term ‘Section’ in Canada’s standard nomenclature, refers to the primary unity of Brazil’s enacted laws. ‘*Incisos*’ are similar to subsections, ‘*páragrafos*’ are similar to paragraphs, and ‘*alíneas*’ are similar to subparagraphs. Some Articles cover more than five pages, for example, Art. 5 that establishes individual rights has 78 subsections (called ‘*incisos*’), further divided into a number of paragraphs (called ‘*páragrafos*’) and subparagraphs (called ‘*alíneas*’). The nine titles are: Fundamental Principles, Fundamental Rights and Guarantees, Organization of the State, Organization of the Powers, Defense of the State and of Democratic Institutions, Taxing and Budgeting, Economic and Financial Order, Social Order, General Constitutional Dispositions, and Transitional Constitutional Measures.

some sections cannot be amended at all - i.e., the section establishing fundamental rights such as the right to health (Art. 60, paragraph 4).²⁰²

The Constitution, moreover, functions as a ‘directive constitution’— that is, the Constitution sets out obligations upon political actors and government officials are required to implementing certain policies.²⁰³ A ‘directive constitution’, constitutional scholar Gilberto Bercovici defines, is a “program for the future [that] links, positively or negatively, the legislator to the Constitution.”²⁰⁴ This function lies at the heart of the new constitutional order introduced by the Constitution and is intended to transform Brazilian society.²⁰⁵ This perspective of the Constitution as transformative plays a fundamental role in how I interpret the right to health.

4.2.1 Social Rights and Constitutional Jurisdiction – Constitutional Hallmarks

Rights are one of the most significant features of the Constitution. The Constitution sought to guarantee virtually all human rights, including civil, political, social, economic and cultural rights; the extensive catalogue of rights led to the nickname of ‘Citizen’s

²⁰² The Constitution can only be amended when more than two thirds of Congress’s votes for an amendment. But, even though the amendment process is complex, the 1988 Constitution has undergone a number of important reforms at the hands of the Congress and the Supreme Court of Brazil. According to political science scholars Rogério Arantes and Cláudio Couto, the reasons for so many amendments is because the 1988 Constitution is an extensive document that covers significant portions of political governance. See generally Cláudio G Couto & Rogério B Arantes, "Constituição, Governo e Democracia no Brasil" ["Constitution, Government and Democracy in Brazil"] (2006) 21:61 *Revista Brasileira de Ciências Sociais* 41. Nonetheless, fundamental rights remain unchanged, which suggests that rights are fairly entrenched in Brazil and taken seriously in the legal system. For an overview of fundamental rights and *cláusulas pétreas*, see e.g. Fábio M de Andrade, “As Cláusulas Pétreas como Instrumentos de Proteção do Direito Fundamental” [“Eternity Clauses as Instruments for the Protection of Fundamental Rights”] (2009) 46:181 *Revista de Informação Legislativa* 207.

²⁰³ This function is in addition to establishing the organization of government and the limits on governmental power.

²⁰⁴ Gilberto Bercovici, "Revolution Through Constitution: The Brazilian's Directive Constitution Debate" (2014) 1:1 *Revista de Investigações Constitucionais* 7.

²⁰⁵ Frederico A Riani, “Constituições Programáticas, Funções Estatais, Políticas Públicas e a (In)competência do Judiciário” [“Programmatic Constitutions, Separation of Powers, Public Policies and the Judiciary’s Constitutional (In)competence”] (2013) 66 *Sequência* (Florianópolis) 137. For this notion of transformative constitution and adjudication in the context of South Africa, see e.g. Sandra Liebenberg, *Socio-Economic Rights. Adjudication under a Transformative Constitution* (Claremont: Juta, 2010).

Constitution'.²⁰⁶ Civil liberties and individual rights are expressed in Art. 5 and its 78 subsections, and provide definitions to protect life and freedoms, *inter alia*, free elections, rotation in power, government accountability mechanisms, as well as freedoms of opinion, expression, association and social organization.²⁰⁷

But, the protection of socio-economic rights is one of the most significant constitutional features given Brazil's historical and systematic inequality. It was the first time that a constitutional document in Brazil enshrined social rights, as well as the state's obligations to those rights (i.e., create the means for the people of Brazil to have a dignified life). Art. 3 establishes the goals of "reducing poverty and inequality" as fundamental objectives of the country, and Art. 6 establishes priority areas for action such as education, health, social security and assistance.²⁰⁸ In the case of health in particular, the Constitution takes a step further, and explicitly establishes "health as a duty of the state" and spells out how government officials are required to fulfill obligations toward the right to health (Art. 196 to 200).²⁰⁹ State obligations toward the right to health, as I discuss in detail later in this chapter, entail the creation of a public health security system that includes participation in the organization of the system.

Constitutional jurisdiction is another hallmark of the Brazilian Constitution. The Constitution expanded financial independence and provided all levels of courts with judicial review powers to review political actions in Brazil.²¹⁰ In addition, the instrument

²⁰⁶ Nickname given by Ulysses Guimarães in the inaugural speech (*supra* note 198).

²⁰⁷ Art. 5, caput, reads: Art. 5 All persons are equal before the law, without any distinction whatsoever, and Brazilians and foreigners residing in the country being ensured of inviolability of the right to life, to liberty, to equality, to security and to property.

²⁰⁸ Art. 3 reads: The fundamental objectives of the Federative Republic of Brazil are: I – to build a free, just and solidary society; II – to guarantee national development; III – to eradicate poverty and substandard living conditions, and to reduce social and regional inequalities; IV – to promote the well-being of all, without prejudice as to origin, race, sex, color, age and any other form of discrimination. Art. 6 reads: Education, health, food, work, housing, transportation, leisure, security, social welfare, protection of motherhood and childhood, and assistance to the destitute, are social rights, as provided by this Constitution.

²⁰⁹ The text of the relevant provisions is reproduced later in this Chapter (see *infra* Section 4.3).

²¹⁰ The model of the Brazilian judicial review combines a diffuse model of review with an abstract model, and every judge is entitled to declare a statute unconstitutional in the case to be decided. See e.g. Maria

accords the Brazilian Supreme Court the role of “guardian of the Constitution” (Art. 102), and enlarges significantly the competence of the Court. In practice, the Court is granted powers not only to strike down and invalidate laws and policies inconsistent with the Constitution, but also to define constitutional obligations as rights and to order government officials to take positive steps to fulfill such obligations as discussed in Chapter 2.

Increased judicial power alongside financial independence gave real teeth to social rights in Brazil. For example, the right to health litigation in the early 1990s, as discussed in Chapter 2, yielded dramatic results in the government response to the HIV-AIDS pandemic.²¹¹ But, providing courts with powers to enforce social rights also means providing courts with authority to determine the constitutional meaning of rights and obligations.²¹² And, Brazilian courts have not stepped away from defining healthcare obligations and ordering government officials to provide healthcare on an individual basis.²¹³ Good or bad, the fact is that over a span of two decades the judiciary went from lethargy to one of the most powerful players in Brazil’s polity, particularly in the health sector. Against this backdrop, Brazil’s constitutional circles have been witnessing a growing and passionate debate about the role of courts in the implementation of rights,

ASC Oliveira, “Reforming the Brazilian Supreme Federal Court: A Comparative Approach” (2006) 5:1 Washington University Global Studies Law Review 99. For a critical overview of how the Brazilian Supreme Court proceeds to judicial review, see e.g. Virgílio A da Silva, “Deciding Without Deliberating” (2013) 11:3 International Journal of Constitutional Law 557 at 567-9.

²¹¹ See e.g. Eduardo J Gómez, “What the United States Can Learn from Brazil in Response to HIV/AIDS: International Reputation and Strategic Centralization in a Context of Health Policy Devolution” (2010) 25:6 Health Policy and Planning 529.

²¹² See e.g. Glaucio S Leite & Marcelo C Continentino, “Desafios da Jurisdição Constitucional Brasileira Contemporânea” [“Contemporary Challenges of the Brazilian Constitutional Jurisdiction”] in George S Leite et al, eds, *Ontem os Códigos, Hoje as Constituições – Homenagem a Paulo Bonavides* [Yesterday, the Codes. Today, the Constitutions – Studies in Honor of Paula Bonavides] (São Paulo: Malheiros, 2016) ch 12.

²¹³ See *supra* Chapter 2, Section 2.2 for an overview of the debate. See also *supra* notes 74 and 75 for some of the academic literature examining issues of health litigation in Brazil and how the courts interfere with health resource allocation in Brazil.

and in particular, debates about the proper way to interpret rights, often of a vague nature.²¹⁴ This chapter therefore must address issues of constitutional interpretation.

By way of background, constitutional provisions prior to the 1988 Constitution were considered political commitments, and not enforceable in courts. It goes without saying, of course, that the judiciary had virtually no say on constitutional affairs, and only limited say on legal matters during the military dictatorship. When courts decided legal disputes, interpretation was based on the letter of the law using the canons to understand the semantic (ordinary) meaning of a legal text.²¹⁵ The adoption of the 1988 Constitution challenged the traditional legal culture and interpretation in Brazil. At first, as discussed in Chapter 2, lawyers and legal scholars attempted to establish the binding and enforceable nature of social rights.²¹⁶ Once the enforceability of social rights was asserted, lawyers and legal scholars turned to debates about proper ways to interpret vague and ambiguous constitutional provisions and advance the transformative constitutional goals.²¹⁷ The remainder of this section outlines the interpretative approach and methodological choices I use in this study.

²¹⁴ This new way of interpreting constitutional provisions is referred to as ‘neoconstitutionalism approach’ or ‘contemporary constitutionalism’, as I discuss below. For a critical discussion on this approach to interpretation, see e.g. Clarissa Tassinari, *Jurisdição e Ativismo Judicial: Limites da Atuação do Judiciário* [*Jurisdiction and Activism Judicial: Limits of Judicial Power*] (Livraria do Advogado Editora, 2013). See also, Clarissa Tassinari, “Ativismo Judicial - Uma análise da Atuação do Judiciário nas Experiências Brasileira e Norte-Americana” [“Judicial Activism – A comparative analysis of the Brazilian and American experiences”] (Master’s Thesis, Universidade do Vale do Rio dos Sinos, Law, 2012). [unpublished], online: <http://www.repositorio.jesuita.org.br/bitstream/handle/UNISINOS/3522/ativismo_judicial.pdf?sequence=1&isAllowed=y>. Last retrieved: 4 February 2018.

²¹⁵ For e.g. Luís R Barroso, *Interpretação e Aplicação da Constituição: Fundamentos de uma Dogmática Constitucional Transformadora* [Interpretation and Application of the Constitution – Foundations for a Constitutional Doctrine of Transformation] (Saraiva, 2009) at 80 n 290. For a critical discussion, see e.g. Lênio L Streck, *Verdade e Consenso: Constituição, Hermenêutica e Teorias Discursivas – da Possibilidade à Necessidade de Respostas Corretas em Direito* [Truth and Consensus: Constitution, Hermeneutics and Deliberative Theories – From Possibility to the Necessity of Right Answers in Law] 5th ed (Saraiva, 2014).

²¹⁶ See *supra* Chapter 2, Section 2.2 for a discussion and some studies on this matter.

²¹⁷ The debates on constitutional interpretation are beyond the scope of this study, and in a nutshell, are about the methods of interpretation. For a general overview of the debate, see e.g. Daniel Sarmento, *O Neoconstitucionalismo no Brasil: Riscos e Possibilidades* [*Neoconstitutionalism in Brazil – Risks and Possibilities*] (Rio de Janeiro: Forense, 2009). For a philosophical discussion of the debate, see e.g. Écio Oto, *Constitucionalismo Global ou Pluriversalismo Internacional? O Neoconstitucionalismo na Perspectiva da Teoria e da Filosofia Políticas Contemporâneas* [*Global Constitutionalism or International ‘Pluriversalism’? Neoconstitutionalism from the Lenses of Contemporary Political Philosophy*] (Lumen Juris, 2014). See also Gustavo Just, *Interpretatando as Teorias da Interpretação* [*Interpreting Theories of*

4.2.2 Approach and Canons of Interpretation

In this study, I follow the critical hermeneutic approach to constitutional interpretation proposed by Brazilian constitutional scholar Lênio Streck.²¹⁸ His approach recognizes that constitutional interpretation is not neutral, but built upon assumptions and pre-judgments.²¹⁹ By contrast, his approach holds that the interpreter should be an active participant in the interpretation.²²⁰ As noted in an earlier chapter, Streck proposes that “in order to interpret, one needs to comprehend, and in order to comprehend, one needs to have a pre-comprehension, composed of a prior meaning.”²²¹ In practice, the action of comprehending is essentially an action that requires the interpreter’s reflection on ‘prior attitude, prior view and prior conception’, and interpreting has to do with drawing conclusions from a concept that one understands.²²² This approach, in summary, is not so much to provide methods through which one can determine the meaning of constitutional words, as it is giving a means for accomplishing a critical construction of constitutional meaning.²²³ Streck’s approach provides more transparency for interpretative choices than the usual practice of constitutional interpretation in Brazil today, where legal interpreters -- including judges -- largely pick and choose canons, as well as values that transcend the text of the Constitution, which in the end support and reflect their own preferences.²²⁴

As described in more detail in *supra* Section 3.2.3, although there is no accepted procedure in Brazil for constitutional interpretation, for this study I have employed the

Interpretation] (São Paulo: Saraiva, 2014). For a critical overview of today’s approach to constitutional interpretation, see generally Streck, *supra* note 144.

²¹⁸ Streck has written extensively on this matter for over 40 years, and his scholarship ranges from philosophical underpinnings of constitutional interpretation to criticism of current practice of interpretation by Brazil’s judges and lawyers. See generally Streck, *supra* note 142.

²¹⁹ This point might seem obvious and petty in established constitutional democracies, but it is not the case in Brazil where interpretation culture is still associated with the idea of interpreter’s neutrality, and the idea that legal text ‘holds’ meaning in it.

²²⁰ Lênio L Streck, *Jurisdição Constitucional e Decisão Jurídica* [Constitutional Jurisdiction and Judicial Decision] 4th ed (São Paulo: Revista dos Tribunais, 2014).

²²¹ Streck, *supra* note 142 at 686.

²²² *Ibid.*

²²³ See *supra* Chapter 3, Section 3.2.3 for more detailed discussion.

²²⁴ See *supra* note 151 for academic articles, supporting and contradicting, this “pick and choose” practice.

general canons of interpretation in legal research (grammatical, systematic, historical and teleological).

4.3 Selecting the Text to Be Interpreted

In this descriptive section, I identify the text to be examined, and consider the baseline position (my preconceived notions) from which I make choices throughout the analysis. Identifying the text to be interpreted, and how to approach the text presupposes choices that affect judgments and influence outcomes.²²⁵ For example, most of the right to health claims, and judicial decisions for that matter, focus on the text “health is a right of everyone and a duty of the government” expressed in Art. 196.²²⁶ The literal interpretation of this sentence alone is that the state is required to provide individual claimants with access to their health needs such as healthcare or prescription medication. The other aspects of the right to health are overlooked such as participation as part of the right to health. In this Chapter, I focus on the following constitutional provisions, and specifically on the words and sentences that appear in bold. (I do not however, necessarily analyze the provisions in the order below). The provisions read:²²⁷

Title II - Fundamental Rights and Guarantees
Chapter II - Social Rights

Art. 6. Education, **health**, work, leisure, social security, protection of motherhood and childhood and welfare are social rights, as provided by the Constitution.

Title VIII - Social Order
Chapter I – General Provision

Art. 193. The social order is based on the primacy of work and aimed at social wellbeing and justice.

²²⁵ For e.g. Ruth Sullivan, “The Plain Meaning Rule and Other Ways to Cheat at Statutory Interpretation,” Legal Drafting, online: < <http://aix1.uottawa.ca/~resulliv/legdr/pmr.html> >. Last retrieved: 4 February 2018. [The author provides examples in which choices of ‘relevant’ provisions and ‘relevant’ words of given provisions might disregard equally important provisions or words, as well as choices with respect to ‘proper’ order to carry out legal analysis might also favour certain preferences].

²²⁶ Most of decisions of Brazil’s Supreme Court cite this excerpt of the right to health.

²²⁷ The text of some of these provisions has been reproduced in previous sections of this dissertation. I reproduce the texts here for convenience. [Emphasis added].

Chapter II - Social Security
Section I - General Provisions

Art. 194. The social security system comprises of an integrated network of [social] actions initiated by the government and by society with the scope of ensuring the rights to health, social insurance and welfare.

Section II – Health

Art. 196. Health is a right of all and a duty of the State and shall be guaranteed by means of social and economic policies aimed at reducing the risk of illness and disabilities, and at the universal and equal access to actions and services for [health] promotion, protection and recovery.

Art. 198. Health actions and services integrate a regionalized and hierarchical network and constitute a single system, organized according to the following *diretrizes*:

- I - Decentralization, with a single management at each level of government;
- II - Comprehensive services, priority given to preventive measures, without prejudice to healthcare; and
- III - Community participation.

I should note that these choices are directly related to my prior knowledge and experience. To start with, Brazil's legislative drafting technique has a strong influence on how I understand the degrees of importance and specificities of legal texts.²²⁸ Two features of the legislative drafting technique greatly influenced my choices. First, my training on legislative drafting technique influenced my choices regarding relevant sections that deal with health matters. The legislative drafting technique established by law provides that subject matters in a legal text are grouped together and organized under basic units called 'Articles' (roughly translated to 'sections' in North-American tradition); and the core content ('head') of an Article is referred to as a 'caput'. Moreover, according to legislative drafting rules, Articles can be grouped (in ascending order) in sections, chapters and titles according to similar subject matters. In addition, Articles can be further divided (in descending order) into several unities as follows: as discussed (see

²²⁸ See *supra* note 201, and accompanying text for more detail regarding Brazil's legislative drafting technique.

supra note 194), ‘*incisos*’ (similar to paragraphs in Canada’s standard nomenclature) state the basic features of Articles and can be further divided into ‘paragraphs’ to explain or modify the content of Articles or *incisos*. In this way, I focus primarily on Articles that provide for the right to health and community participation only.

Second, and related to the first, my analytical process follows the importance of meanings according to the legal arrangement. Therefore, any unity in which an Article is further divided is dependent upon and applicable only according to the content of the respective caput.²²⁹ In this way, my understanding of a provision, including driving concerns, was selected and ascribed from the structure of the provisions. In practice, it means that I start by analyzing the general right to health, followed by the analysis of Art. 196 and 198, which establish state obligations to the right to health.

Additionally, my choices with regard to relevant words within relevant provisions (i.e., words in bold text) are drawn on my linguistic and grammatical competence. In principle, the entire text of Art. 198 would constitute relevant text for the purpose of interpreting ‘community participation’. But, in the analysis I take issue only with the following words: ‘community participation’, ‘organized according to’ and ‘*diretrizes*’.²³⁰ In the case of ‘community participation’ and ‘organized according to’, my linguistic knowledge enabled me to recognize that both terms are vague. As for the word ‘*diretrizes*’, my legal experience triggered the need for contextual assessment because as a rule it is an ambiguous term, in which at least two meanings with different consequences would be possible: it can entail an obligation or simply a guideline. In addition, my linguistic knowledge also influences my decision about disregarding in this analysis four Articles structured under the section on ‘Social Order’ and ‘Health’, namely: Arts. 195, 197, 199 and 200. This is because, in my view, even though the meanings of the words expressed in those provisions relate to the health system, these sections are not directly related to

²²⁹ For further details, see e.g. Gilmar Mendes, “Questões Fundamentais de Técnica Legislativa” [“Key Considerations Regarding Legislative Drafting Technique”] (1993) 1:2 *Cadernos de Direito Constitucional e Ciência Política* 6.

²³⁰ I use the word in Portuguese because the literal translation into English - ‘directive’ - does not capture the complexities of the word in Portuguese, as I will discuss later in this Chapter.

the purpose of a provision that deals with ‘community participation’ in the health system.²³¹

Finally, there is my theoretical view that the right to health is more than a right to receive free healthcare: the introductory sentence of Art. 196 indicates that the right is everyone’s right and the state’s duty. The full breadth of the right to health intends to promote participatory health governance by including citizens in health planning. This perspective of a constitutional transformative project that is also enforceable, as I will discuss below, plays a fundamental role in how I select the text and interpret the right to health.

4.4 Understanding the Right to Health as a Fundamental and a Social Right

Art. 6 establishes health as a fundamental and a social right; Art. 6 is structurally located under the heading ‘Fundamental Rights and Guarantees’, and under the subheading ‘Social Rights’.²³² What does it mean to enshrine health as a fundamental and a social right? What does health as a fundamental right entail? What does health as a social right entail?

As I mentioned in the preceding methodology section, and discussed in detail in Chapter 3, a core approach to determine the meaning of words expressed in constitutional provisions is how the words are used in Portuguese language.²³³ The well-known *Dicionário Brasileiro de Direito Constitucional* defines “fundamental right” as: “a set of human rights codified in the Constitution, including individual, social, economic, cultural

²³¹ In brief, Art. 195 is about social welfare; Art. 197 establishes health actions and services as of ‘public interest’, which roughly means that health services cannot be interrupted; Art. 199 allows private provision of healthcare services (a matter of great importance and debate that I do not deal with in this thesis, but propose as further research, see Chapter 7); and Art. 200 establishes duties upon governments, but not regarding to governance of the system or participation in health governance.

²³² For easy reference, Art. 6 of the Constitution establishes: Education, health, work, leisure, social security, protection of motherhood and childhood and welfare are social rights, as provided by the Constitution.

²³³ See e.g. Barroso, *supra* note 215.

and collective rights enforceable by courts.”²³⁴ In other words, fundamental rights in the context of Brazil are described as constitutional rights that are enforceable in courts.²³⁵

Judicial decisions have embodied this perspective. For example, Supreme Court Justice Celso Mello speaking for the Court states: “the right to health—a fundamental right of all individuals—represents an inextricable constitutional consequence of the right to life. (...) The interpretation of a programmatic norm cannot transform it into a useless constitutional promise (...).”²³⁶ Health as a fundamental right, in a nutshell, is understood as a constitutional right enforceable in court. But, what is interesting to note here is the reason why health is considered a fundamental right, that outweighs state economic interests: the right to health “represents an inextricable constitutional consequence of the right to life.”²³⁷

Justice Mello’s view, now prevalent in all levels of Brazilian courts, interprets the right to health as an interest to protect individual citizens’ right to life.²³⁸ It is one thing for the right to health to protect individual citizens’ lives. It is quite another to limit the scope of the right to state obligations to ensure that Brazilians are free from disease and are not at risk of death. But, as discussed in *supra* Chapter 2 and further articulated in this Chapter, it is well accepted in the relevant Brazilian literature that Brazil’s constitutional right to health has both collective and individual dimensions and is not simply about securing an individual’s right to certain health care services. Thus, this dissertation does not seek to

²³⁴ André R Tavares, “Direitos Fundamentais (Definição)” [“Fundamental Rights (Definition)”] in Dimitri Dimoulis et al, eds, *Dicionário Brasileiro de Direito Constitucional* [Brazilian Dictionary of Constitutional Law] 2nd ed (Saraiva, 2012) 143.

²³⁵ For an academic discussion of the concept and reach of fundamental rights in Brazil, see e.g. Figueiredo, *supra* note 75.

²³⁶ *Município de Porto Alegre v Diná Rosa Vieira*, *supra* note 5.

²³⁷ Ferraz, *supra* note 6 at 65 [Ferraz quotes Justice Celso Mello’s decision in *Município de Porto Alegre v Diná Rosa Vieira* (*supra* note 5)]. For a rhetorical analysis of the concept “fundamental right to health” in the Supreme Court, see e.g. Roberto Freitas Filho & Camila JD Brum, “A Retórica do Direito à Saúde no Supremo Tribunal Federal” [“Right to Health’s Rhetoric at the Supreme Court”] (2014) 25:1 *Universitas Just* 47.

²³⁸ See e.g. Ferraz, *supra* note 6.

establish a hierarchy between individual rights (i.e., held by individual people) and collective rights (i.e., held by a group).

In fact, Art. 6 of the Constitution, which I reproduce here for convenience, establishes health as a social right, which therefore protects social dimensions associated with ‘health’, equally important aspects of the right. Art. 6 reads:²³⁹

Art. 6. Education, *health*, work, leisure, social security, protection of motherhood and childhood and welfare *are social rights*, as provided by the Constitution.

While the constitutional text provides no definition for ‘social right’, the term is well understood and accepted in the health and human rights literature, and linked to the notions of social determinants of health and rights-based-approach to health.²⁴⁰ A social-determinants approach to health, in a nutshell, understands that individual and population health is shaped to a great degree by social conditions such as employment, housing and food security.²⁴¹ Healthcare is important for improved health, but so are the institutional structures by which public goods and resources are distributed.²⁴² A rights-based approach to health underlines the obligation of government to enabling and ensuring equal opportunities for everyone to be healthy and lead a good life.²⁴³

The term ‘social right’, as constitutional scholar Ingo Sarlet defines, is “a set of entitlements recognized by our Constitution and/or international law intended to redress

²³⁹ Emphasis added.

²⁴⁰ See e.g. Jairnilson S Paim & Naomar de Almeida Filho, “Collective Health: A ‘New Public Health’ or a Field Open to New Paradigms?” (1998) 32:4 *Revista de Saúde Pública* 299.

²⁴¹ See e.g. Lígia M Vieira-da-Silva & Patrice Pinell, “The Genesis of Collective Health in Brazil” (2014) 36:3 *Sociology of Health & Illness* 432. See also Howard Waitzkin et al, “Social Medicine Then and Now: Lessons from Latin America” (2001) 91:10 *American Journal of Public Health* 1592.

²⁴² For e.g. Naomar de Almeida Filho, “*O Que é Saúde? - Temas em Saúde*” [*What is Health? – Themes in Health*] (Rio de Janeiro: Fiocruz, 2013).

²⁴³ For the connections between social epidemiology and law, see e.g. Burris, Kawachi & Sarat, *supra* note 10. See also Scott Burris, “Law in a Social Determinants Strategy: A Public Health Law Research Perspective” (2011) 126:3 *Public Health Reports* 22.

inequalities through the provision of public services.”²⁴⁴ Sarlet’s definition, in combination with the literal reading of Art. 196 of the Constitution (which reads: “health is an entitlement of everyone and an obligation of the state”), makes clear that the right creates positive obligations upon state actors. Significantly however, Professor Sarlet’s definition suggests that ‘social rights’ not only requires positive actions from state actors, but also that those actions must be aimed at redressing inequalities in society.

In fact, the Constitution explicitly establishes the reduction of inequalities as one of its fundamental objectives.²⁴⁵ Significantly, Art. 3 of the Constitution establishes that: “the objectives of the Federative Republic of Brazil are: III. to reduce social and regional inequalities.” The Constitution, as discussed earlier in this Chapter, was built on the widespread agreement that the pre-constitutional order was unfair, and that the constitutional instrument would set the goals for change, and would comprise the mechanisms to foster social change in the country.²⁴⁶ In fact, prior to the Constitution there was a wide consensus that opportunities to be healthy were not equally available to everyone in Brazil as healthcare services were based on employment insurance or the ability to pay.²⁴⁷ The Constitution ordered the creation of a universal health system available to everyone, regardless of employment or the ability to pay.

Hence Brazil’s right to health does not only create the state’s obligation to ensure that Brazilians are free from disease and from the risk of death, as the prevalent judicial interpretation of the fundamental right to health seems to imply. And, though I admire the courts’ commitment to ensure that individual Brazilians have the healthcare they need,

²⁴⁴ Ingo W Sarlet, “Direitos Sociais” [“Social Rights”] in Dimitri Dimoulis et al, eds, *Dicionário Brasileiro de Direito Constitucional* [Brazilian Dictionary of Constitutional Law] 2nd ed (Saraiva, 2012) 150.

²⁴⁵ Art. 3 establishes: The objectives of the Federative Republic of Brazil are: III. to eradicate poverty and substandard living conditions and to reduce social and regional inequalities.

²⁴⁶ See Chapter 4, *supra* Section 4.2 for a discussion on this matter.

²⁴⁷ For a concise summary, see e.g. Ferraz, *supra* note 6 at 38. For a detailed overview, see e.g. Paulo EM Elias, “Estado e Saúde – Desafios do Brasil Contemporâneo” [“State and Health – Challenges of Contemporary Brazil”] (2004) 18:3 São Paulo em Perspectiva 41. See also, Paulo HA Rodrigues, “Desafios Políticos para a Consolidação do Sistema Único de Saúde: Uma Abordagem Histórica” [“Political Challenges for Brazil’s Unified Health System – Historical Considerations”] (2014) 21:1 História, Ciência, Saúde-Maguinhos 37.

this perspective disregards the full depth and breadth of Brazil’s social right to health aimed at redressing underlying inequalities in society. Brazil’s fundamental right to health intends to promote and protect health of the population as a whole, which therefore requires health planning and resource allocation that the courts often disregard when ordering the provision of healthcare on an individual basis. As constitutional scholar Marlon Weichert suggests, the Constitution creates state obligations in relation to “the Unified Health System [which] is the public policy established by the Constitution in order for the state to comply with its obligations to the right to health.”²⁴⁸

In practical terms, the right should serve as an accountability framework to hold state officials to account for the health system as a whole as provided by the Constitution. At a general level, the right to health in Brazil creates positive and enforceable obligations upon state actors to take action creating a health system that at the very least provides access on an equal basis for everyone who needs the services.²⁴⁹ In other words, central to Brazil’s fundamental and social right of health is an evaluation of an individual’s health needs in relation to the health needs of the population, because as constitutional scholar Octavio Ferraz properly contends, “it is simply impossible to provide everyone with the most advanced treatment for their health needs.”²⁵⁰ As pointed out in Chapter 2, the

²⁴⁸ Marlon A Weichert, “Direito à Saúde” [“Right to Health”] in Dimitri Dimoulis et al, eds, *Dicionário Brasileiro de Direito Constitucional* [Brazilian Dictionary of Constitutional Law] 2nd ed (Saraiva, 2012), *sub verbo* “direito à saúde”.

²⁴⁹ Brazilian constitutional Professor Ana Paula Barcellos makes similar point when she discusses the idea of litigation to advance fundamental rights related to water and sanitation in Brazil. Accord Barcellos, *supra* note 61. For an overview of this line of argument internally, see generally Krieger, *supra* note 9. In particular, a focus on equality of access as I propose here would target issues such as discrimination, including in terms of resource allocation and priority setting, and would not serve as a free pass for all sorts of healthcare services and prescription medication on an individual basis, particularly in cases of untested treatments or prescription drugs not approved by the Brazilian Health Surveillance Agency (*Agência Nacional de Vigilância Sanitária - Anvisa*). [In 2016, there was a controversy in Brazil with respect to the use of phosphoethanolamine (so called ‘cancer pill’), an untested chemical compound which several individuals had accessed through litigation. This controversy was widely reported in media outlets in Brazil and internationally. See e.g., Fábio de Castro, “Supremo Libera USP de Fornecer ‘Pílula do Câncer’ a Pacientes” [“The Supreme Court Releases USP [The University of São Paulo] from [the Obligation to] Provide ‘the Cancer Pill’ to Patients” (5 April 2016) Estado de São Paulo, online: <<http://saude.estadao.com.br/noticias/geral,stf-libera-usp-de-fornecer-pilula-do-cancer,10000025070>>. Last retrieved: 4 February 2018. See also Heidi Ledford, “Brazilian Courts Tussle Over Unproved Cancer Treatment” (24 November 2015) Nature Weekly Journal of Science, online: <<https://www.nature.com/news/brazilian-courts-tussle-over-unproven-cancer-treatment-1.18864>>].

²⁵⁰ Ferraz, *supra* note 6 at 34.

Brazilian model of right to health adjudication is a critical and intricate issue, but beyond the scope of this study.²⁵¹ My focus in this section, in particular, is to draw attention to Art. 6 of the Constitution that sets forth “health as a social right”, and to stress that understanding health as a social right creates an obligation on state actors to ensure access to a health system that provides everyone with equal opportunities to be healthy. I will now analyze the framework of the health system as provided by the Constitution, including in relation to participation in health governance.

4.5 The Right to Health Framework

The right to health is further specified in the Constitution under the heading ‘Social Order’, Chapter ‘Social Security’ and Section ‘Health’.²⁵² The ‘Social Order’ consists of eight provisions (Arts. 193 to 200), and the relevant provisions here are Arts. 193, 194, 196 and 198, III.²⁵³

The text of Arts. 193 and 194 of the Constitution provides:

Art. 193. The social order is based on the primacy of work and aimed at social well-being and justice.

Art. 194. Social welfare comprises an integrated whole of actions initiated by the Government and by society, with the purpose of ensuring the rights to health, social security and assistance

Significantly here is the term ‘social order’, which is well accepted as it is intended to promote well-being and social justice for all through the provision of public services and social protection policies.²⁵⁴ In the case of Brazil, Art. 194 specifically establishes three

²⁵¹ Chapter 2, *supra* Section 2.2 overviews this debate and refers to scholarship and empirical work on this issue.

²⁵² The Title ‘Social Order’ contains Arts. 193 to 232. For the text of the provisions that are not analyzed in this dissertation, see e.g. an English version of the Constitution *supra* note 28.

²⁵³ See *supra* Section 4.3 above for the selection of the relevant provisions analyzed in this dissertation.

²⁵⁴ See e.g. Armando Barrientos & David Hulme, “Social Protection for the Poor and Poorest in Developing Countries: Reflections on a Quiet Revolution: Commentary” (2009) 37:4 Oxford Development Studies 439. In general, debates revolve around conceptual approaches to analyzing the objectives and impacts of social

interrelated social security systems in order to ensure the right to health and social security to the people of Brazil: the health system, social security in the strict sense ('pension'), and the social assistance system (a sort of complementary policy to the pension system).

More specifically, in order to realize the right to health for all as part of Brazil's social security protection net, the Constitution establishes an entire structure for the health system. Of relevance to this study are Arts. 196 to 200, Arts. 196 and 198, III.²⁵⁵ The text of the relevant provisions was set up earlier in Section 4.3; I want to focus on the specific elements reproduced here:

Art. 196. Health is ... a duty of the State and shall be guaranteed by means of social and economic policies aimed at reducing the risk of illness and disabilities, and at the universal and equal access to actions and services for [health] promotion, protection and recovery.

Art. 198. Health actions and services integrate a regionalized and hierarchical network and constitute a single system, organized according to the following *diretrizes*: III - Community participation

Arts. 196 and 198 conceive and organize the health system toward health promotion, protection and recovery. Art. 196, in particular, requires government officials to implement a universal and comprehensive health system and to provide equal access to healthcare, as well as to promotion and protection measures.²⁵⁶ In other words, the right to health entails an entitlement to equal access to a comprehensive health system designed to prevent, manage and overcome circumstances that adversely affect people's health and social well-being.²⁵⁷

protection. See e.g. Evie Browne, "Theories of Change for Cash Transfers" (2013) Governance and Social Development Resource Center (GSDRC)'s Helpdesk Research Report, online: <<http://www.gsdrc.org/publications/theories-of-change-for-cash-transfers/>>. Last retrieved: 4 February 2018.

²⁵⁵ See *supra* Section 4.3 for the selection of the relevant provisions analyzed in this dissertation.

²⁵⁶ Weichert, *supra* note 248.

²⁵⁷ Combining the health, social pension and social assistance systems into one comprehensive public system for social protection was the result of decades of debates and demands from social movements. See

Simply put, the right to health is not simply a right to personalized healthcare. Of course, public policies and programs within the health system need to address the countless and diverse needs of individuals, to prevent constitutional rights from becoming empty promises. But, addressing the spectrum of health-related needs within the health system requires organizational strategy and planning, at the very least. It is important to recall that the structure of the Constitution clearly establishes Brazil's right to health as part of a transformative project to promote and protect social well-being and social justice across the country. The right to health is a fundamental and social right—enforceable in court and entailing positive obligations. Constitutional interpreters should pay attention to whether or not government officials operationalize the health system as fully required by the Constitution.

Let me offer an example for the sake of clarity (keeping in mind, however, that this thesis is not about judicial interpretation or standards of judicial review). If a person launches a lawsuit against the state to obtain free hypertension medication to prevent premature death or severe disability, a fundamental social right to health perspective would require a review of a number of matters: first, why a certain drug was not available, but also the process employed in making administrative decisions about covering the drug, as well as the extent to which the government has implemented prevention and health promotion measures to address hypertension. Or, to put this another way, Brazil's fundamental social right to health would function as an accountability framework to hold the state to account for delivering healthcare so that people can recover from illness but would also require government to address underlying social determinants so that people do not get sick in the first place. In sum, my point is that issues of healthcare delivery are, while important, only the tip of the iceberg, and therefore, a more comprehensive and transformative interpretation of the right to health is in order.

e.g. Modesto Dall'Agnol, Ana Costa & Lígia Bahia, "Health and Social Determinants in Brazil: A Study on the Influence of Public Participation on the Formulation of the Expanded Concept of Health and Liberating Practices" Report prepared for the World Health Organization's Commission on Social Determinants of Health. Online: <http://www.who.int/social_determinants/resources/isa_public_participation_bra.pdf>. Last retrieved: 4 February 2018.

4.5.1 Operationalization of the Health System and the Right to Health Framework

As noted, Art. 198 of the Constitution establishes core requirements concerning the health system: it describes a single, regionalized, hierarchical and comprehensive system containing healthcare services, as well as health promotion and prevention measures. Furthermore, Art. 198 establishes three core principles for the operation of the health system: I) decentralization, II) comprehensiveness, and III) community participation. This study focuses on community participation.

The text ‘community participation’ is located as a subsection (*inciso*) of Art. 198. As referred to above, the most basic agreement in Brazil’s legislative drafting technique is that an *inciso* is dependent upon the meaning of head of an Article or caput; and therefore, an *inciso* must be analyzed in relation to the caput. In the case of Art. 198, caput, the intent of the provision can be ascertained from the first sentence: to lay down the fundamental structure of the health system. In other words, it is not any type of health system, but a single comprehensive and regionalized network of healthcare services and promotion measures. The provision establishes additional aspects of the operation of the health system: decentralization, comprehensiveness and community participation. It is important to note that the caput uses the word *diretrizes* to establish the features for operation of the system, and this word *diretrizes* could go either way: an obligation upon the state or a recommended political choice.

At first sight, and inferred from my training in Brazilian law, the word *diretrizes* means guidelines for action or yardsticks to assess governmental performance, rather than an authoritative command to implement participation. If the framers intended to make clear that community participation was a state obligation, then the constitutional text would have included a modal verb, for example, ‘the health system *must* be organized according to the following directives: (...)’ If that were the case, the word *diretriz* would mean state obligation in my view. But, because no modal verb precedes the nominal verb in the provision, the word *diretrizes* requires closer consideration as to whether or not the term can be associated with some degree of state obligation, as I have posited.

To start, one could argue that the Constitution is a ‘directive constitution’, and thus, that government officials must do what the Constitution determines. Under this argument, government officials *must* incorporate community participation in the organization of the health system in order to fulfill the state’s obligation to the right to health. But, in the context of Brazil’s Constitution, constitutional provisions might mean political commitments that government officials should strive to achieve, too. For example, the Constitution orders government officials to reduce poverty and inequality (Art. 3), but how to do so involves political choices.

Moving on to the ordinary use of the word *diretrizes*:²⁵⁸ The *Dicionário Houaiss da Língua Portuguesa*, for example, registers six entries for the word *diretrizes*, which literally describes a geometric term (roughly translated as straight line), while entry 2 registers a figurative description: “sketch, outline of a plan or project”; entry 3 lists it as synonymous with *diretiva*, or “instruction or a set of instructions for carrying out a plan, an action, an enterprise, etc.”²⁵⁹ The *Michaelis Dicionário da Língua Portuguesa* has six entries for the word, and similarly defines the word *diretrizes* as: “general guidelines for a project”.²⁶⁰ Thus the text analysis suggests that today’s ordinary meaning of the word *diretrizes* indicates a direction or guideline that government officials should strive to promote when organizing the health system, rather than an authoritative instruction to do

²⁵⁸ Ordinary meaning ‘as used in contemporary Portuguese’ is a standard canon (using a grammatical method), used in Brazil’s civil-law legal tradition for constitutional interpretation. See Chapter 3, Section 3.2.3 for detailed explanation of how I employ this interpretative canon in this study. For a summary of the grammatical and other canons of interpretation in the context of Brazil, see e.g. Barroso 2009, *supra* note 215.

²⁵⁹ Online: *Dicionário Houaiss da Língua Portuguesa* [*Houaiss Dictionary of Portuguese*], *sub verbo* “diretrizes”, accessed on February 4, 2018: <<https://houaiss.uol.com.br/pub/apps/www/v3-3/html/index.php#2>>. [*Houaiss Dictionary*].

²⁶⁰ Online: *Michaelis Dicionário da Língua Portuguesa* [*Michaelis Dictionary of Portuguese*], *sub verbo* “diretrizes”, accessed on February 4, 2018: <http://michaelis.uol.com.br/moderno-portugues/busca/portugues-brasileiro/diretriz/>. [*Michaelis Dictionary*]. [Expanding beyond first-impression meaning, the dictionary shows three alternative meanings for *diretriz* including a sense of a geometric measurement (i.e. a line surrounded by other imaginary lines producing a flat geometric figure), and the idea expressed above].

so. And, the word today has the same nuance as it did when it first appeared in the Constitution.

To ensure a coherent approach to the Constitution as a whole, I now analyze the use of the word *diretrizes* throughout the constitutional instrument. The word *diretriz* appears in 30 provisions of the Constitution (both in the singular and plural forms – *diretriz* and *diretrizes*).²⁶¹ Overall, the meaning of the word *diretrizes* resonates with the sense of ‘guidelines’ or choice rather than mandate or legal duty. By way of illustration, Arts. 48, 51, 57 and 69 use the word *diretrizes* immediately after the word ‘budget’, and in turn is directly preceded by the word ‘law’ (in Portuguese, *Lei de Diretrizes Orçamentárias*).²⁶² All four provisions employ the word *diretrizes* to reflect guidance regarding objectives and priorities for fiscal budgets.²⁶³

What is important to note here is that in several occasions the word *diretriz* – and *diretrizes* – is followed by the word ‘guidelines’. Art. 21, for instance, establishes state authority to develop “*diretrizes* and guidelines for the national space” and Art. 165 establishes executive authority to create “*diretrizes*, guidelines, objectives and priorities for public budgets.”²⁶⁴ The word *diretrizes* might not necessarily mean ‘guidelines’; otherwise, the word ‘guidelines’ would not appear alongside the word *diretrizes*. In other words, it seems that the word *diretrizes* can have a different connotation from the ordinary sense ‘guidelines’. Even accepting the word *diretrizes* might have a different

²⁶¹ The search used CTRL-F to search and accounted for matches in the singular as well as in the plural forms.

²⁶² ‘*Diretrizes orçamentárias*’ in English means fiscal budget law. Examples of provisions using the words *diretrizes orçamentárias* are: Arts. 48 II; 51 IV; 57 paragraph 2; 68 paragraph 1 III.

²⁶³ *Lei de Diretrizes Orçamentárias* are officially described by Congress as statutes that establish guidelines for fiscal budgeting and contains targets and priorities for subsequent federal fiscal years, and the objective of these statutes is to guide, orient the government to develop annual public budgets, modify taxes rules, define fiscal policies and intergovernmental transfers, among other money allocations. Online: <<https://www12.senado.leg.br/orcamento/legislacao-orientadora>>. Last retrieved: 4 February 2018.

²⁶⁴ Art. 21 reads: it falls within the Federal government’s power to: XXI – establish principles and *diretrizes* for the national airspace system’. Art. 165 reads: The Executive Power shall create laws that establish: II – pluri-annual budget plans; III – budgetary *diretrizes*; §1o The law creating pluri-annual budget plans shall establish...*diretrizes*, objectives, targets for the federal public administration (...) §2o The law creating the budgetary *diretrizes* shall include targets and priorities for the federal public administration (...).

meaning, the consistent use analysis provides no clear guidance in any given way. In addition, one could argue that the framers simply made a mistake using two similar words in the same provision, for example.

Back to Art. 198, caput as a whole, I examine the grammatical structure expressed in the sentences. Art. 198, caput uses the two following verbs: ‘consists of’ (*constituem*) and ‘form’ (*formam*), expressed in the imperative mood. The caput reads: “the health system *consists of* a single comprehensive system” and “a regionalized and hierarchical network of health actions and public health services *form* the single system.” By following the Brazilian Portuguese parallel structure rule—verbs in the same sentence follow the same grammatical conjugation—the verb ‘organize’ should have been expressed in imperative mood, too: “[the health system] *is organized* according to the following *diretrizes*”. Just as the other two verbs in the caput express the idea that government *must* act in certain ways in relation to the form of the health system, the verb preceding the word *diretrizes* should also follow similar grammatical pattern. In other words, the grammatical structure of the provision should indicate the same imperative mood of the preceding verbs expressed in Art. 198.

Put simply, my argument is that in the same way that the government *must* organize the system in a regionalized network of healthcare and promotion measures, the government *must* also ensure community participation in the organization of the health system.²⁶⁵ The questions then are: what does community participation in the organization of the health system mean and entail? What does ‘organization’ of the health system mean? And, what do community and participation mean and entail?

²⁶⁵ In the case of the text of Art. 198, the provision establishes three *diretrizes* listed in the form of *incisos*: “I - decentralization; II - integrality [integration of services and actions]; III - community participation.” The text of *incisos* ‘I’ and ‘II’ ends with semi-colons, and the text of *inciso* ‘III’ ends with a period.

According to Brazilian Portuguese grammar rules, a semi-colon is used to separate items in a list, and very commonly used in legal instruments. The three features expressed have value on their own and should be accounted as such. The same inference that applies to ‘community participation’ applies to *incisos* ‘I’ and ‘II’ as well.

4.5.2 Interpreting ‘Organization’ of the Health System

The use of the word ‘organization’ in ordinary Portuguese suggests an action of organizing something. For example, the *Dicionário Houaiss da Língua Portuguesa*, provides two definitions for the word ‘organization’, with the first definition being the closest to the constitutional text: “an action, process or effect of organizing or arranging [something].”²⁶⁶ Another traditional Brazilian dictionary, the *Michaelis Dicionário*, carries out six definitions for the word ‘organization’, of which two are relevant here: entry 5: “arrangement of parts with respect to a whole”; and entry 6: “planning a project, definition of procedures and outcomes.”²⁶⁷ All in all, the ordinary use of the word ‘organization’ indicates the action of planning and defining procedures and desirable outcomes.

In addition, the words ‘organization’ and ‘health system’ have specialized meanings in the health science field that seem more appropriate for this analysis. The World Health Organization’s *Health Systems Strengthening Glossary* defines ‘health system’ as: “all activities whose primary purpose is to promote, restore and/or maintain health.”²⁶⁸

In the case of Brazil, federal legislation defines the Unified Health System as: “the set of health actions and services provided for by federal, state and municipal governments, other public entities and foundations maintained by public authorities.”²⁶⁹ The word ‘organization’, according to the WHO’s *Glossary*, encompasses an action of organizing

²⁶⁶ Online: *Houaiss Dictionary*, *sub verbo* “organização”, accessed on February 4, 2018: <https://houaiss.uol.com.br/pub/apps/www/v3-3/html/index.php#1>.

²⁶⁷ Online: *Michaelis Dictionary*, *sub verbo* “organização”, accessed on February 4, 2018: <http://michaelis.uol.com.br/busca?r=0&f=0&t=0&palavra=organiza%C3%A7%C3%A3o>

²⁶⁸ World Health Organization’s *Health Systems Strengthening Glossary* [WHO’s *Glossary*], *sub verbo* “health system”, accessed on February 4, 2018: http://www.who.int/healthsystems/hss_glossary/en/index5.html. Last retrieved: 4 February 2018. [The Glossary defines “organization” as: “(i) all the activities whose primary purpose is to promote, restore and/or maintain health, (ii) the people, institutions and resources, arranged together in accordance with established policies, to improve the health of the population they serve, while responding to people’s legitimate expectations and protecting them against the cost of ill-health through a variety of activities whose primary intent is to improve health”].

²⁶⁹ *Lei Orgânica da Saúde [Organic Health Law]*, Art. 4. Online: http://www.planalto.gov.br/ccivil_03/leis/L8080.htm. Last retrieved: 4 February 2018. [Translated by the author].

human, financial and facilities resources, as well as processes and procedures in order to carry out actions and implement services to protect and promote population health.²⁷⁰

In essence, ‘health system’ means health-related services and actions, and the word ‘organization’ describes the idea of structural and administrative activities put in place for the operation of the health system. In the case of Brazil’s Unified Health System, a federal statute establishes specifically how the ‘organization’, or administrative activities shall be arranged, that is: “health actions and services [provided for by the Unified Health System] will be organized in a decentralized fashion, as well as a hierarchical and increasing complexity.”²⁷¹ Community participation in the organization of the health system therefore, does not mean participation in service or finance planning, but rather on the full spectrum of activities to make sure that the system works properly, including to ensure that the system is organized in a decentralized and hierarchical level of complexity.

4.5.3 Interpreting ‘Community’ and ‘Participation’

At first glance, my impression of the word ‘community’ is a close group of people who are in the same geographic space, share similar interests, beliefs and goals. The *Dicionário Houaiss da Língua Portuguesa*, for example, registers 15 entries for the word ‘community’, and three could be a ‘description’ of the term under consideration.²⁷² Entry 4 provides: “a group of inhabitants of the same [region] or any social group which individuals live in a given area, under the same government and united by the same culture and history.” Entry 8 provides a sociological description: “people who live in a given place or region and are connected by a common life”. Entries 12, and 12.1 to 12.4 refer to: “a group of individuals who share common characteristics, beliefs, historical factors, social, economic or political interests or social policies.”

²⁷⁰ WHO’s *Glossary*, *supra* note 268.

²⁷¹ *Organic Health Law*, Art. 8.

²⁷² Online: *Houaiss Dictionary*, *sub verbo* “comunidade”, accessed on February 4, 2018: <https://houaiss.uol.com.br/pub/apps/www/v3-3/html/index.php#1>.

A different Brazilian dictionary, *Michaelis Dicionário da Língua Portuguesa*, registers ten alternative meanings for the word ‘community’.²⁷³ This includes a general description, Entry 3: “group of people who live in a same geographic location, under the same government and share the same historical and cultural traditions”, and sociological descriptions, such as Entry 5: “population who lives in a given location or region connected by common interests”, and Entry 7: “any group of individuals united by interests (cultural, economic, political, religious, etc.), which meets often or lives in the same location.” In this sociological sense, the definition of the word ‘community’ aligns with my own perception of the word: a group of individuals with a shared geographic, social or cultural features, identities or interests constitutes a community.

With respect to the word ‘participation’, my understanding has to do with processes and mechanisms by which communities are involved in health policy decisions. In an ordinary sense, the *Dicionário Houaiss*, as well as the *Michaelis Dicionário* define the word ‘participation’ along the lines of “the act or effect of participating.”²⁷⁴ Moreover, the *Dicionário Houaiss* contains five entries for the verb ‘participate’, which help to explain the meaning of the word ‘participation’.²⁷⁵ Entry 2, for example, defines ‘participate’ as: “the act of taking part in” and entry 4 states: “to take part in something in feelings or thoughts.” The *Michaelis Dicionário* registers five entries for the related verb ‘participate’, which the noun ‘participation’ is derived from. For example, Entry 3 describes participate as: “the action of taking part in [something].”²⁷⁶ On the basis of the ordinary use, the word ‘participation’ may be used as ‘taking action to become involved in something’ or ‘just becoming involved in something’. The former conveys the notion

²⁷³ Online: *Michaelis Dictionary*, sub verbo “comunidade”, accessed on February 4, 2018: <<http://michaelis.uol.com.br/busca?r=0&f=0&t=0&palavra=comunidade>>.

²⁷⁴ Online: *Houaiss Dictionary*, sub verbo “participação”, accessed February 4, 2018: <https://houaiss.uol.com.br/pub/apps/www/v3-3/html/index.php#1>. See also, online: *Michaelis Dictionary*, sub verbo “participação”, accessed February 4, 2018: <<http://michaelis.uol.com.br/busca?r=0&f=0&t=0&palavra=participa%C3%A7%C3%A3o>>.

²⁷⁵ Online: *Houaiss Dictionary*, sub verbo “participar”, accessed February 4, 2018: <https://houaiss.uol.com.br/pub/apps/www/v3-3/html/index.php#1>.

²⁷⁶ Online: *Michaelis Dictionary*, sub verbo “participate”, accessed on February 4, 2018: <<http://michaelis.uol.com.br/busca?r=0&f=0&t=0&palavra=participar>>.

of certain agency ‘getting involved’, and the latter, by contrast, delivers the idea of individuals ‘becoming involved’, perhaps due to circumstances or needs.

My initial perception of the meaning of ‘participation’ aligns with the notion of agency and active participation in the full spectrum of health governance. But, the ordinary use of the word ‘participation’ in Portuguese language does not eliminate ambiguity. In other words, the text of the Constitution is too open to provide clear guidance in any given direction, and any attribution of meaning based on the semantic canon would mean an imposition of my policy preference on the reading of the constitutional language.

Turning now to the consistent usage of ‘community participation’ throughout the Constitution, the words combined have been expressed only in Art. 198, III under analysis. But, the word ‘community’ alone can be found 12 times and the word ‘participation’ alone has been identified 35 times.²⁷⁷ All in all, the meaning of ‘community’ serves to confirm the ordinary use in the Portuguese language: a group of individuals who share similar features (material or immaterial).²⁷⁸ A search for the word ‘participation’ throughout the constitutional text retrieved 30 occurrences.²⁷⁹ The meaning of the word ‘participation’ throughout the Constitution also serves to confirm its ordinary use in the Portuguese language: the action of taking part in something.²⁸⁰ Together, the meaning of ‘community participation’ suggests a group of individuals united by

²⁷⁷ The search used CTRL-F to search and accounted for matches in the singular as well as in the plural forms.

²⁷⁸ For instance, Art. 210 paragraph 2 refers to language rights in education for the indigenous ‘community; Art.216 V paragraph 1 protects the rights of groups who share similar cultural heritage; and Art.226 paragraph 4 refers to family unity as a category of ‘community’.

²⁷⁹ The search used CTRL-F to search tool and accounted for ‘participation’ and verb ‘participate’.

²⁸⁰ For instance, Art. 8 VI establishes a right for unions to ‘participate’ in collective agreements; Art.10 refers to the right of employees ‘participate’ in public agencies; Art.7 XI creates the right for employees to ‘participate’ in the profits and management of their company; Art.95 II determines that judges are not allowed to ‘participate’ in [Bar Association] processes; and Art.230 articulates the ‘participation’ of older persons in society in general. The word ‘participation’ is also used to refer to a Public Fund known as “*Fundo de Participação*” [“Participation Fund”], less relevant for the present purpose. The use of a Participation Fund refers to a government fund wherein public taxes and revenues are levied and transferred amongst the three levels of government for public purposes. For instance, Art. 159 I ‘a’ and ‘b’ refer to the proportion from the ‘Participation’ Fund that the federal government shall transfer to state and municipal governments.

geographic locations, identities, features or interests, who take action in something. However this ordinary usage of the words: ‘community participation’ does not clarify the processes and mechanisms through which communities should be involved.

The historical canon sheds light on the framers’ intention with respect to the purpose of community participation in the health system. The enshrinement of participation and the right to health in the Constitution is a well-known victory of the so-called Sanitary Movement, a group of health reform activists that emerged in the mid-1970, fighting against the military dictatorship and for constitutional rights, including the right to universalized access to health services, as well as to promotion and prevention measures.²⁸¹ In 1986, the Sanitary Movement organized the 8th National Health Conference in Brazil (known as a pre-constituent assembly), and produced specific recommendations concerning health reforms, and the Final Report of the 8th Health Conference is taken to be the blueprint for the right to health.²⁸² Section 1.4 of the Report acknowledges that legal recognition of health as a right and a state obligation is essential because of the law’s ability to create and uphold institutions, but yet legal recognition alone is not enough to implement on-the-ground change. In addition, according to the Report, “popular control” over state actions is fundamental in order to monitor political action and hold state actors to account for the realization of the right to health toward social change. Sections 2.3 together with Sections 2.23 to 2.25 define more clearly this notion of popular control, which involves civil society representatives participating in health planning, policy development, governance, as well as in the implementation and

²⁸¹ For a study on the Sanitary Movement, see generally Sarah Escorel, *Reviravolta na Saúde: Origem e Articulação do Movimento Sanitário* [The Turnaround in Health: Origin and Articulation of the Sanitary Movement] (Rio de Janeiro: Fiocruz, 1999). For an overview of the Sanitary Movement in English, see e.g. Kurt Weyland, “Social Movements and the State: The Politics of Health Reform in Brazil” (1995) 23:10 World Development at 1699. For a general overview of the health reforms in Brazil and the role of the Sanitary Movement in these reforms, see e.g. Sonia Fleury, “Brazil’s Health-Care Reform: Social Movements and Civil Society” (2011) 377:9779 The Lancet 1724.

²⁸² For e.g. Paulo EM Elias & Amelia Cohn, “Health Reform in Brazil: Lessons to Consider” (2003) 93:1 American Journal of Public Health 44.

evaluation of health actions in all aspect of the health system, from formulation of policies and programs to monitoring health finance and program implementation.²⁸³

Interestingly, the Report does not use the constitutional language of “community participation”. The Report instead uses “popular control”, “population participation”, “civil society representatives”, “health councils” and “national health council”. The use of these terms may be understood in relation to Brazil’s practice of participation at the time.²⁸⁴ During the dictatorship, participation was suppressed, except in special cases intended to promote adherence to preventive programs.²⁸⁵

By way of background, the first federal statute establishing public participation in the health system (*Federal Law n. 378/1937*) created the National Health Council, an advisory body formed by civil society’s representatives appointed by the Health Minister with the purpose of advising the Health Minister on administrative matters (Art. 67).²⁸⁶ In 1954, another executive order (Presidential Decree 34.347/1954) stipulated 17 members for the Council and assigned operational secretariat functions to the health ministry. The Decree also expanded the NHC’s mandate to advise the Health Minister on programs related to health protection as well. In 1959, a third executive order (Presidential Decree 45.913/1959) changed the number of members to 24. In 1962, another executive order was issued (Presidential Decree 847/1962) that reaffirmed the advisory mandate of the national council and increased the number of members to 27. In 1970, the executive issued another order (Presidential Decree 67.300/1970) expanding the mandate of the

²⁸³ 8th Conferência Nacional de Saúde [8th National Health Conference]: *Relatório Final* [Final Report] (Brasília, Brazil: 17-21 March 1986), online: <http://conselho.saude.gov.br/biblioteca/relatorios/relatorio_8.pdf>. Last retrieved: 4 February 2018.

²⁸⁴ See *infra* Chapter 6, Section 6.2 for a discussion of the terms used by respondents in this study, which mirror the terminology used in the Report of the 8th National Health Conference.

²⁸⁵ For a critical overview of the political context before the 1988 Constitution, see e.g. Jaime A Oliveira & Sonia Fleury, (Im)previdência Social: 60 Anos de História da Previdência Social no Brasil [(The Lack of) Social Welfare: 60 Years of Social Welfare in Brazil] (Petrópolis: Vozes-Abrasco, 1986).

²⁸⁶ *Federal Law No 378/1937*, Chapter IV – Cooperation Bodies [to the Health Ministry], Art. 67 reads: in addition to the National Education Council, the National Health Council shall assist the Ministry of Health. III. The composition and attributions of the National Health Council shall be defined by statute. Online: <<http://www2.camara.leg.br/legin/fed/lei/1930-1939/lei-378-13-janeiro-1937-398059-publicacaooriginal-1-pl.html>>. Last retrieved: 4 February 2018.

NHC to advise the Minister on health promotion, protection and recovery. Finally, the last act enacted prior to the 1988 Constitution was issued - (Presidential Decree 93.333/1987) which changed the composition of the National Council to 13 members and appointed members who were knowledgeable civil society representatives with experience in health promotion, prevention and recovery.

This pre-constitutional practice of participation could explain the terms expressed in the 8th Conference Report. And, the term “community participation” in the constitutional text, as population health scholar Eleutério Rodriguez Neto posits, could be explained as “the only agreement possible at the time.”²⁸⁷ According to collective health scholar Eduardo Navarro Stroz, the term ‘community participation’ is associated with limited approaches to public participation in the context of Brazil.²⁸⁸ In fact, according to Strotz, “the constitutional text is very limited for using ‘community participation’ as one of the *diretrizes* of the Unified Health System. (...) *Federal Law n. 8142/1990* addresses this constitutional limitation.” The statute, which I discuss in detail in the next Chapter, creates health councils—a form of participation mechanisms in which organized civil society representatives take part in health governance.²⁸⁹

Regardless of critical historical conceptions, the constitutional reference to ‘community participation’ needs to be understood in light of the Constitution’s transformative project as a whole. Perhaps in isolation, the term ‘community participation’ might carry certain connotations not conducive to power sharing as collective health scholar Navarro Strotz indicates. But, through the lens of the health and human rights literature discussed in Chapter 2, participation as part of the right to health entails the state’s “obligation to establish institutional arrangements for active and informed participation of all relevant

²⁸⁷ Eleutério Rodriguez Neto, *Saúde – Promessas e Limites da Constituição* [Health – Promises and Limits of the Constitution] (Rio de Janeiro: Editora Fiocruz, 2003).

²⁸⁸ Online: *Dicionário da Educação Profissional em Saúde* [Professional Health Education Dictionary], *sub verb* “social participation,” accessed on February 4, 2018: <<http://www.sites.epsjv.fiocruz.br/dicionario/verbetes/parsoc.html>>.

²⁸⁹ See *infra* Chapter, 5 Section 5.4 for the text and analysis of the statutory provisions governing these participatory bodies.

stakeholders, including disadvantaged communities.”²⁹⁰ In addition, as proposed by health and human rights scholars Pol De Vos and colleagues, defining features for participation in a right to health framework include processes and conditions that enable and ensure that mechanisms and processes are accessible, transparent and continuous.²⁹¹

4.6 Conclusion

The objectives of this Chapter were to determine the meaning and scope of community participation as part of Brazil’s right to health, and the requirements for the realization of participation as part of the right to health.

I analyzed the right to health framework and the provision of community participation within the right to health framework. The analytical process included textual (the so-called grammatical canon in Brazil), structural, historical and teleological canons. These canons reinforced the importance of understanding that Brazil’s Constitution was intended to play a transformative role in establishing both the right to health and public participation as a key component of that right.

The Constitution is also a binding ‘directive document’; that is, the Constitution provides a specific course of legal action in order to pursue the transformative goals of the right to health. In other words, as Lênio Streck posits, the constitutional language provides a guide and some limits to the interpretive project.²⁹² The Constitution requires government officials to provide and ensure equal access to health services and action. Community participation as part of this transformative project was aimed at providing genuine opportunities for the people to be part in the organization of the health system. This specific course of action requires government officials to provide and ensure equal access to health services and promotion measures. Community participation as part of this

²⁹⁰ Hunt and Backman, *supra* note 103 at 81.

²⁹¹ Vos et al, *supra* note 104.

²⁹² See generally Streck, *supra* note 220.

transformative project was aimed at providing genuine opportunities for the people to take part in the organization of the health system, including with respect to health services and promotion measures. Although the text of the Constitution provides no specific steps for its implementation, my analysis concludes that participation as part of the right to health framework requires substantive opportunities to influence policy-making, and the mechanisms by which the people participate in the system must be accessible, fair, transparent and continuous.

5 Participation in the National Health Council

5.1 Introduction

Participation as part of Brazil's right to health framework was analyzed in the preceding Chapter. The analysis led me to conclude that participation in the organization of the health system is a requirement established by the right to health. The participation requirement, as envisioned by the "blueprint" for the right to health, was intended to foster the constitutional goals of democracy, inclusion in policy making, and health equality in the country. As part of the right to health framework, participation implies broad inclusion in public decision making, and genuine and equal opportunities to influence health policies and programs through mechanisms and processes that are accessible, transparent and continuous.

In this Chapter, I interpret and analyze the relevant statutes and executive orders governing the National Health Council in relation to the constitutional requirements of participation. In particular, I will examine whether the NHC's structure (i.e., nature, composition and mandate) meet the constitutional goals of broad and ongoing societal inclusion in the health system, such as through health planning and resource allocation policies or decisions.

By way of background, Congress passed legislation creating "health councils": bodies for citizen participation within the health system at the three levels of health governance, i.e., national, state and municipal. The focus of this study is on the National Health Council (NHC), at the national level of health governance. The discussion is organized as follows. Section 5.2 provides an overview of the characteristics of Brazil's civil law legal tradition in relation to legal interpretation and sets out my approach to statutory interpretation. Section 5.3 examines the legislation governing health councils within the health system, and section 5.4 turns to the legal framework governing participation in the NHC in particular. In conclusion, I summarize the law governing the NHC and discuss the findings in relation to Chapter 4's constitutional analysis.

5.2 Legal Interpretation Context

Brazil is home to a civil-law legal system rooted in the belief that the legal system forms a comprehensive, coherent and hierarchical system of rules and norms. Core principles and rules are codified documents (e.g., statutes, regulations, executive orders, etc.) that serve the primary source of law in Brazil. Codified law is the primary source of law in Brazil, and has priority over judicial decisions.²⁹³ In this analysis I focus on statutes and procedural rules issued by government officials; judicial decisions are beyond the scope of this study. By way of background, federal statutes establish the mandate and structural rules for health councils in general, including the NHC. Executive orders and NHC's Resolutions further specify the mandate and responsibilities for the NHC. I also follow the legal hierarchy continuum related to the National Health Council: enacted legislation passed by Congress, followed by executive orders issued by the federal government, and then procedures issued by the NHC.

As for legal interpretation, I focus on the text and structure of the legal instruments and rely on canons of statutory interpretation such as dictionary meaning, grammatical structure and statutory context.

With respect to interpretation canons, the systematic canon (also known in Brazil as the structural canon) is used to determine meaning in relation to the purpose of the entire legislation.²⁹⁴ This canon is based on the belief that no single statutory provision can be taken out of its context and interpreted by itself; rather, statutory provisions are part of a coherent set of rules, whereby different provisions within one single legal instrument

²⁹³ It is true that if someone goes to court and challenges a piece of codified law and the court declares it unconstitutional, the court decision prevails. But my point here is to underline the fact that enacted legislation in Brazil's civil law system is the primary source of law. See *supra* note 143 and accompanying text for an overview of this matter. Very briefly, judicial decisions serve as a loose guide for judges in determining subsequent similar cases. As mentioned in the previous Chapter, since 2004, Brazil has a *sui generis* form of precedent – called *Súmula Vinculante*, which is a compilation of similar decisions developed by the Brazilian Supreme Court that is authoritative and binding. No *Súmula Vinculante* has been issued on the right to health to date.

²⁹⁴ Ávila, *supra* note 155.

interact in different and complementary ways to foster desired policy goals.²⁹⁵ I rely on two external aids: 1) consistent usage of words and phrases; that is, the notion that words used throughout a statute or in similar statutes have the same meaning; and 2) structural arrangements such as titles, preambles and headings of a statute. I turn to the grammatical canon (also known as textual canon) to determine the legislative intent and establish limitations on interpretive ingenuity by setting out semantic boundaries within which words and phrases can be interpreted.²⁹⁶ The grammatical canon is based on the actual written words and phrases according to today's usage.²⁹⁷ In order to determine current meanings, I rely on my knowledge of the Portuguese language, as well as the use of general or specialized Brazilian dictionaries, not necessarily in that order.

5.3 *The Organic Health Law*

In September 1990, Congress enacted the first piece of health law (*Federal Law 8080/1990*, known as *the Organic Health Law*), creating Brazil's health system – the Unified Health System (or *Sistema Único de Saúde*—SUS, in Portuguese).

The purpose of this statute, as stated in the title is to: “provide for the strategies for health promotion, protection and recovery, organization and functioning of health services, among other things.”²⁹⁸ Though not directly dealing with the structure or mandate of health councils, this piece of legislation provides operational rules for the health system within which the National Health System must operate and strive to achieve. In addition, this statute also provides some responsibilities for health councils, and for the National Health Council in particular.

²⁹⁵ See e.g. Carlos Maximiliano, *Hermenêutica e Aplicação do Direito* [*Hermeneutics and Application of the Law*] 19th ed (Rio de Janeiro: Forense, 2002) at 104-5.

²⁹⁶ See e.g. Ávila, *supra* note 148.

²⁹⁷ See e.g. França, *supra* note 146 at 8.

²⁹⁸ *Federal Law No 8080/1990*, title. [The citation of Brazilian legislation has been adapted to conform to the Canadian English format of citing statutes. See the bibliography for the original citation]. All translations of Brazilian legislation and legal terms cited in this dissertation are translated by the author, unless otherwise stated.

This statute consists of 55 Articles providing for a range of matters such as the organization, management of the health system, government responsibilities, as well as the role of private healthcare providers in the SUS. A comprehensive analysis of the statute is beyond the scope of this chapter, rather I will only focus on the provisions that relate to participation and obligations to the right to health, namely: Arts. 2, 7, 12, 26, 33 and 37. The selection of Arts. 2 and 7 (reproduced in the next section) are straightforward: the Articles further define the scope of government officials' responsibilities to the right to health, including with respect to participation in the health system. The selection of Arts. 12, 26, 33 and 37 (also reproduced in the next section) are less straightforward, and some background information needed.

In 1990, Bill n. 3110/1990 was introduced to the legislature, and after passing through a number of readings, was enacted into *Federal Law No 8080/1990*, or the *Organic Health Law*.²⁹⁹ Originally, Bill 3110/1990 referred to the terms 'community participation' and the terms 'health councils' and 'National Health Council'. Bill n. 3110/1990 explicitly defined 'health council' as an institutional body for community participation in the SUS and established the basic structure and rules for health council operation. In Brazil's presidential system, bills require further approval by the head of government to become law, and governmental refusal is known as a veto.³⁰⁰ When Bill n. 3110/1990 was presented for executive approval, the then-President Fernando Collor de Mello exercised presidential veto power over the provisions creating and regulating health councils and returned the unsigned Bill for Congress' consideration and revision. By way of justification, former President Collor the Mello stated two technical objections: 1) previous legislation had already established rules for health councils, and 2) any change

²⁹⁹ *Projeto de Lei No 3110 de 1989* [Proposal for the creation of the public health system and community participation in the health system], online: <<http://www.camara.gov.br/proposicoesWeb/fichadetramitacao?idProposicao=209729>>. Last retrieved: 4 February 2018.

³⁰⁰ Brazilian Constitution. Art. 66, paragraph 1, reads: The house in which voting is concluded shall send the bill of law to the President of the Republic, who, if he concurs, shall sanction it. Paragraph 1. If the President of the Republic considers the bill of law, wholly or in part, unconstitutional or contrary to public interest, he shall veto it, wholly or in part, within fifteen work days, counted from the date of receipt and he shall, within forty-eight hours, inform the president of the senate of the reasons of his veto.

concerning the composition, structure or mandate of health councils fell within the powers reserved for government rather than Congress.³⁰¹

Eventually, Congress passed the *Federal Law No 8080/1990*, the *Organic Health Law*, without provisions establishing structural rules for health councils. Intriguingly, however, four Articles providing for health councils and the National Health Council survived presidential vetoes, namely: Arts. 12, 26, 33 and 37. The text of these provisions is reproduced later in this Chapter. In the legislative history examined for this dissertation, Congress has never explicitly explained the reasons why these provisions survived, but again, the reasons are not relevant for the purpose of this study. Of relevance, however, is that eventually Congress enacted a subsequent statute, *Federal Law No 8142/1990* (in which relevant provisions are analyzed in the next section), reinserting very similar language to the provisions once vetoed from Bill n. 3110/1990. In fact, in its opening Article, *Law No 8142/1990* specifically states that the statute is to be read in conjunction with the *Organic Health Law*, indicating that both pieces of legislation work in a continuum for the operation of health councils.³⁰² My focus here is simply to provide some background information in order to explain why I will analyze Arts. 12, 26, 33 and 37 of the *Organic Health Law*.

5.3.1 Participation as a State's Obligation

Art. 2 sets out the scope of the government's obligation to the Constitution's right to health. Art 2, paragraph 1, reads:³⁰³

Art. 2: Health is a fundamental human right, and the state must provide the means by which people can enjoy the right.

Paragraph 1. The duty of the State to ensure health consists in the elaboration and implementation of social and economic policies aimed at reducing the risk of illness and other hazards, and at ensuring opportunities for universal and equal

³⁰¹ Mensagem de Veto No 680 de 19 de setembro de 1990 [Presidential vetoes to the *Federal Law No 8080/1990*, ss 11 & 42, related to participation in the health system], online: <<http://www2.camara.leg.br/legin/fed/lei/1990/lei-8080-19-setembro-1990-365093-veto-27098-pl.html>>. Last retrieved: 4 February 2018.

³⁰² Art. 1 is discussed in detail in the next section.

³⁰³ *Federal Law No 8080/1990*, Art. 2, paragraph 1.

access to measures and health services for [health] promotion, protection and recovery.

Significantly, Art. 2 emphasizes the duty of the state to the right to health, and the means by which state officials are required to guarantee the right: implementing social and economic policies, as well as healthcare services for health promotion, protection and recovery, ensuring that everyone has equal access to health-related services and promotion measures. In the preceding Chapter, I concluded that government officials are required to implement a comprehensive and participatory health system, rather than a system that simply provides personalized medicine on individual basis.³⁰⁴ The Constitution establishes “health as a social right established in the form of this Constitution”, and Arts. 196 and 198 establish the form in which political actors and government officials are required to legislate about and give effect to the right to health.³⁰⁵ In Art. 2 of the *Organic Health Law*, Congress gives effect to the constitutional provisions establishing that the obligation of government officials toward the right to health is to implement a comprehensive health system, ensuring equal access to both health services and promotion measures.

The social determinants and collective nature of the right to health is also reinforced in Art. 3, and reads:³⁰⁶

Art. 3. Health is determined by factors and conditions, including food, housing, basic sanitation, environment, work, income, education, transport, leisure and access to essential services and goods; population health status express the socio-economic organization of the country.

Sole paragraph: Health is also associated with health measures intended to guarantee individuals and populations the conditions for physical, mental and social wellbeing.

Further, Art. 7, VIII is also relevant, and reads:³⁰⁷

³⁰⁴ See *supra* Chapter 4, Sections 4.4 and 4.5 for this analysis.

³⁰⁵ *Ibid.*

³⁰⁶ *Federal Law No 8080/1990*, Art. 3, sole paragraph.

³⁰⁷ *Federal Law No 8080/1990*, Art. 7, VIII.

Title. Principles and *Diretrizes*

Art. 7. Health actions and services within the Unified Health System, including [actions and services provided] by private actors, shall be implemented according to the *diretrizes* established by Art. 198 of the Constitution, and obey the following principles:

(...)

VIII – community participation.

Structural and textual analyses are required to further my argument. Starting from a structural analysis, Art. 7, VIII is arranged under the section ‘Principles and *Diretrizes*’ and lists 14 principles as the foundation for the operation of the health system (SUS); and community participation is one of the principles.³⁰⁸ In light of Brazil’s legislative drafting technique, the arrangement of Art. 7 implies that the meaning of ‘community participation’ (an *inciso* of the Article) is essentially associated with the meaning of the core text or *caput* of the Article.³⁰⁹ Put simply, the context for determining meaning and scope of community participation in the SUS is provided by a proper account of the meaning and scope of the *caput* of Art. 7. The question then is: what does Art. 7, *caput* actually mean and entail?

Turning to a textual analysis of Art. 7, its opening sentence reiterates the constitutional *diretrizes* for the operation of the health system: decentralization, comprehensiveness and community participation. It should come as no surprise that Art. 7 starts by restating constitutional Art. 198, III; after all, Congress only holds powers to implement—not modify, let alone revoke—constitutional norms. At first sight, Art. 7 appears to essentially reassert the constitutional Art. 198, that is, community participation is a *diretriz* for the health system. But, on closer look it becomes clear that Art. 7 is not just a repetition of constitutional Art. 198, III. The final sentence of Art. 7, *caput* incorporates a significant change: the text adds a word of obligation ‘obey’ to the text: “(...) obey the following principles (...): VIII. community participation.”

³⁰⁸ *Federal Law No 8080/1990*, Art. 7.

³⁰⁹ For e.g. Mendes, *supra* note 229.

The word ‘obey’ suggests that ‘community participation’ was special and of utmost importance, so much so that Congress established community participation as a state obligation.

Glimpses into what the meaning of the word ‘obey’ meant to Congress can be found in Brazilian dictionaries. The ordinary use of the word ‘obey’, according to the *Michaelis Moderno Dicionário da Língua Portuguesa*, conveys the notion that something is mandatory: “3. acting according to established rules; comply with, respect.”³¹⁰ Similarly, other Brazilian *Dicionário Aurélio da Língua Portuguesa* provides five definitions for the word ‘obey’ along the same lines of mandate, including: “2, acting according to something. “3, being under the authority of [someone or something], and “5, acting in response to an order.”³¹¹ As such, the word ‘obey’ was what set Art. 7 apart from the constitutional text. Thus, this word of obligation in the context of the *Organic Health Law* makes clear Congress’ intention with respect to the mandatory nature of community participation in the health system. If any doubt remained from the analysis in the preceding Chapter, Art. 7 of this statute reinforces that community participation in the organization of the SUS is in fact a state’s obligation to the full realization of the right to health system.³¹²

5.3.2 State’s Obligations to Participation in the National Health Council (NHC)

Arts. 12 and 13 of the *Organic Health Law* establish.³¹³

Art. 12: Inter-sectoral committees shall be created at the national level of government, [the committees are] formed by Ministries, relevant bodies, as well as civil society organizations, [and the committees shall be] subject to the National Health Council.

³¹⁰ Online: *Michaelis Dictionary*, *sub verbo* “obedecer”, accessed on February 4, 2018: <<http://michaelis.uol.com.br/busca?id=yV247>>.

³¹¹ Online: *Aurélio Dictionary*, *sub verbo* “obedecer”, accessed on February 4, 2018: <<https://dicionariodoaurelio.com/obedecer>>.

³¹² See *supra* Chapter 4, Section 4.5.1 for this discussion and analysis.

³¹³ *Federal Law No 8080/1990*, Arts. 12 and 13.

Sole paragraph: The aim of the inter-sectoral committees is to liaise [with other bodies on relevant] health-related policies and programs, which implementation [requires efforts] beyond the realm of the Unified Health System (SUS).

Art. 13. The scope of the liaisons is the following areas:

- I - food and nutrition;
- II - sanitation and environment;
- III - health surveillance and pharmaco-epidemiology;
- IV - human resources;
- V - science and technology; and
- VI – workers' health.

Significantly, these two provisions establish legal requirements for government to report to health councils, and to the National Health Council, in particular, on matters related to strategic partnership, health financing, and service delivery.³¹⁴

Art. 26, moreover, creates obligations for health authorities with respect to the National Health Council as follows.³¹⁵

Art. 26. The National Health Authority shall set up the criteria and amount for private provision of health services, [decisions about the criteria and amount shall be] subject to the National Health Council for approval.

Notably, this provision establishes requirements for the National Health Authority to report to the National Health Council on compensation frameworks for private healthcare delivery. Further, Art. 33 also creates obligations to government officials in relation to accountability to health councils. Art. 33 reads:³¹⁶

Art. 33. Financial resources for the Unified Health System (SUS) shall be deposited into a [bank] account at each level of government, and [any financial transaction] shall be subject to the supervision of the respective level of health council.

³¹⁴ Upon a structural analysis of the regulatory body of the legislation governing health councils, particularly *Federal Law No 8142/1990* that legally creates 'health councils', the requirements regarding health councils under the *Organic Health Law* will become more tangible.

³¹⁵ *Federal Law No 8080/1990*, Art. 26.

³¹⁶ *Federal Law No 8080/1990*, Art. 33.

This provision focuses on health finance accountability, and finally, Art. 37 sets out some requirements that for the National Health Council with respect to including citizens in health planning. Art. 37 reads:³¹⁷

Art. 37. The National Health Council shall establish guidelines for the development of health plans, based on epidemiological characteristics and on the organization of services at each level of health management.

Significantly, Art. 37 uses the language “health plans”, which are strategic plans developed every four years in which the government presents the status of the health services and promotion measures and policy goals intended to foster better services and outcomes.³¹⁸ Overall, Arts. 12, 13, 26 and 33 serve as a legal framework of public accountability for participation in health councils in matters related to health finance, private provision of healthcare, strategic partnership, and program development. Art. 37, in turn, serves as the initial legal framework to hold government officials to account for public participation in health planning.

Despite this detailed framework, three potential issues merit further consideration. First, the language expressed in Arts. 12, 26 and 33, for example, is too general to provide clear guidance regarding specific requirements for government to report on strategic partnerships, compensation frameworks or health finance. Second, there is no provision of oversight activities such as the requirement for government to provide a written summary of activities and accomplishments concerning partnerships. Third, although Art. 37 provides for the NHC to develop guidelines for the national health plan, there is no requirement for government officials to actually take the NHC’s guidelines into account when designing the national health plan. In this way, these provisions provide no real

³¹⁷ *Federal Law No 8080/1990*, Art. 37.

³¹⁸ The Brazilian National Health Plan is a document issued by the Health Ministry every four years that assesses unmet health needs, and establishes policy goals and steps, such as priority actions and resources, in order to meet the unmet needs. The current, *Plano Nacional de Saúde: PNS 2016-2019* was issued for the years 2016-2019. This study was conducted during the preceding *Plano Nacional de Saúde: PNS 2012-2016*

mechanism to ensure government compliance and to hold government to account for failure to do so. But, of course, these provisions need to be interpreted in combination with the second piece of health law, discussed in the next section.

5.4 The National Health Council's Regulatory Framework

Acting under its regulation-making powers, Congress passed a second binding piece of health law in 1990 (*Federal Law No 8142/1990*), creating health councils. I should note that the constitutional language “community participation” appears only in the title; operative sections use the language “health councils”. As stated in its ‘preamble’, the aim of the statute is: “to provide for community participation in the *gestão* of the health system, intergovernmental cash transfers, among other provisions.”³¹⁹ The health councils are thus the mechanism through which Congress has implemented the constitutional requirement for community participation in the operation of the health system. Because the word “*gestão*” [of the system] replaces the word “organization” [of the system] expressed in the Constitution (Art. 198), it becomes important to determine what ‘*gestão*’ actually means.³²⁰

As discussed in the preceding Chapter, the constitutional language “organization” relates to “the process of organizing something in order to achieve certain goals”, but the analysis provided no further specifics.³²¹ The word ‘*gestão*’ affords some guidance with respect to the scope of community participation in the ‘organization’ of the health system. Ordinarily, the current use of the word ‘*gestão*’ in Brazil according to the *Houaiss Dicionário da Língua Portuguesa* is: “1, [the] act or effect of managing; running a business.”³²² The dictionary *Michaelis Moderno Dicionário Inglês & Português* translates

³¹⁹ *Federal Law No 8142/1990*, Title. [I use the word “*gestão*” in Portuguese because the translation into English fails to capture its complex meaning].

³²⁰ See *supra* Chapter 4, Section 4.5.2 for the analysis of the term ‘organization’ used in the Constitution.

³²¹ *Ibid.*

³²² Online: *Houaiss Dictionary*, *sub verbo* “*gestão*”, accessed on February 4, 2018: <<https://houaiss.uol.com.br/pub/apps/www/v3-3/html/index.php#3>>

the word ‘*gestão*’ into English as: “1, management, administration, conduct.”³²³ The meaning of the word ‘management’ in English, according to the *Oxford Dictionary of English*, is: “1. the process of dealing with or controlling things or people”,³²⁴ and the meaning of the word ‘administration’ is: “1. the process or activity of running a business, organization, etc. (...) 3. the management of public affairs; government”.³²⁵ Both the ordinary use of the word ‘*gestão*’ in Portuguese and the ordinary use of its translation into English define the word in its “management, administrative, technical” sense.

The word ‘*gestão*’, however, has a specialized term applied to the collective health field, which the ordinary use fails to capture. In the well-known *Dicionário da Educação Profissional em Saúde*, collective health scholars Gastão Wagner and Rosana Campos explains that the term *gestão* in Brazil’s health sector reaches beyond the notion of managing people, organizations or institutions to refer to the process of governing.³²⁶ The specialized meaning of the word ‘*gestão*’, according to Wagner and Campos, carries out a political definition: “the power to govern – that is, [the term is] intertwined with the exercise of power.”³²⁷ Metaphorically, “management” suggests something like ‘rowing’, or conducting day-to-day business whereas the term “*gestão*” indicates ‘steering’, or the notion of directing the course of action related to the governance of Brazil’s health system.

In this ‘governance’ sense, the word ‘*gestão*’ would entail decision-making power while in its ‘management’ sense ‘*gestão*’ would entail technical support for decisions already

³²³ Online: *Michaelis Dictionary*, *sub verbo* “gestão”, accessed on February 4, 2018:
<<http://michaelis.uol.com.br/moderno-portugues/busca/portugues-brasileiro/gest%C3%A3o%20/>>

³²⁴ Online: *Oxford Dictionary*, *sub verbo* “management”, accessed on February 4, 2018:
<<https://en.oxforddictionaries.com/definition/management>>

³²⁵ Online: *Oxford Dictionary*, *sub verbo* “administration”, accessed on February 4, 2018:
<<https://en.oxforddictionaries.com/definition/administration>>.

³²⁶ Online: Gastão W Campos & Rosana T Campos, “Gestão em Saúde – Um Campo do Conhecimento Aplicado” [“*Gestão in Health – An Area of Applied Knowledge*”] in Isabel B Pereira & Júlio C Lima, eds, *Dicionário da Educação Profissional em Saúde* [*Dictionary of Professional Education in Health Science*] 2nd ed (Fundação Oswaldo Cruz, 2009), *sub verbo* “gestão em saúde”, accessed on February 4, 2018:
<<http://www.epsjv.fiocruz.br/dicionario/verbetes/gessau.html>>.

³²⁷ *Ibid.*

made by governments. The ordinary sense thus reduces considerably the reach of the specialized meaning. The issue comes down to considering whether ordinary or specialized meaning prevail. In this case, judging by the technical content of the statute and specific audience—health authorities—a reliance on the specialized meaning seems more adequate in my view. This notion is important because it indicates that in addition to being mandatory, community participation also implies that communities are involved in decision-making as well.

Federal Law No 8142/1990 contains seven Articles, the most relevant for the purpose of this chapter being those set forth with respect to the nature, structure and responsibility for health councils in general, including the National Health Council.³²⁸ Art. 1 reads as follows:

Art. 1. Each level of the Unified Health System dealt with in Federal Law n. 8080 of September 19, 1990 [Organic Health Law] will have (...) the following collegiate bodies, without prejudice to the functions of the legislative branch:

- I – health conference, and
- II - health council.

Health conferences and health councils are two participatory mechanisms and processes of deliberation and consensus formation between government and civil society. By way of background, health conferences consist of institutional mechanisms of representation, deliberation and participation intended to provide guidelines for the formulation of Brazil's four-year national health plan. Conferences occur every four years and take place at the three levels of government as following: the national conference is preceded by conferences at state level, which in turn are preceded by municipal conferences. Discussion, brainstorming, deliberation and decision-making processes are held in workgroups and plenaries in all conference rounds. The aggregate results of deliberations at the municipal level of conferences are the object of deliberation at the state level, and subsequently at the national level, which is attended by delegates from the previous

³²⁸ The other Articles refer to the financing of the health system, an issue beyond the scope of this study.

municipal and state rounds. Delegates attending at all levels of conferences consist of four groups (similar to the groups that seat at health councils): civil society (or “users” of the health system) (50% of delegates); health workers (25% of delegates); as well as public managers and health service providers (25% of delegates are split between these two groups). Delegates at the national level of health conference then discuss, brainstorm and deliberate over a final document (called “Report”), which contains guidelines for the design of the four-year national health plan.³²⁹

With respect to health councils, the object of this study, Art. 1, paragraph two establishes:

Paragraph 2: health council, permanent and deliberative [and] collegiate body formed by government, service providers, health workers, and users’ representatives, [to] act in the elaboration of health-related strategies and in the monitoring of policy implementation at the corresponding level of government, including in relation to health finance matters, and council’s decisions are subject to the respective health authority in Council for approval.³³⁰

In 2006, Presidential Decree No 5839/2006 issued during former President Lula administration set out specific provisions for the National Health Council. Art. 1 reads:

At. 1. The National Health Council (NHC) is a collegiate, permanent and deliberative body, part of the structure of the Health Ministry, formed by government, service providers, health workers, and users’ representatives, and decisions in the form of resolutions are ratified by the Health Minister in council.³³¹

³²⁹ See e.g., Brasil, Conselho Nacional de Secretários de Saúde, *As Conferências Nacionais de Saúde: Evolução e Perspectivas* [National Health Conferences: Development and Perspectives] (Brasília, Conselho Nacional de Secretários de Saúde – CONASS, 2009). See also, Francini L Guizardi *et al.*, “Participação da Comunidade em Espaços Públicos de Saúde: Uma Análise das Conferências Nacionais de Saúde” [“Community Participation in Public Spaces in Health: An Analysis of National Health Conferences”] (2004) 14 *Physis: Revista de Saúde Coletiva* 15.

³³⁰ *Federal Law No 8142/1990*, Art. 1, I, II, paragraph 2.

³³¹ Executive Order No 5839/2006, Art. 1.

Federal Law No 8142/1990, Art. 1 creates two mechanisms for participation in the health system: health conferences and health councils at all levels of government. The opening sentence of Art. 1 provides two important points. First, the health councils are established as part of the state structure of health governance dealt with in the *Organic Health Law*. In addition to the provisions set forth in this statute, health councils are subject to the *Organic Health Law*, too. In other words, both pieces of legislation work together when it comes to regulating participation through health councils in Brazil's Unified Health System. The second relevant point is that 'health councils' are part of the structure of state (that is why health councils are often referred to as 'institutional participation'). In practice, the NHC is subject to health authorities, which can be challenging for reasons discussed later in this Chapter.

5.4.1 Nature

This statute also establishes that a health council is a "permanent, deliberative, and collegiate body". The meanings of the word 'permanent', according to Brazil's *Michaelis Dicionário Brasileiro da Língua Portuguesa*, comprise: "1, relating to lasting." "2, definitive." "3, regular, constant.", and, "4, stable."³³² The use of the word 'permanent' reinforces Congress' intention to make sure that the NHC is not disbanded at the will of the executive branch.

The adjective "deliberative" brings to the fore the idea of a matter intended for consideration and discussion. The *Michaelis Dicionário Brasileiro da Língua Portuguesa* presents a political sense for 'deliberative': "1, involving deliberation; having deliberation." "2, "relating to or inherent to deliberation." and "3, related to rhetorical persuasion".³³³ In fact, the term 'deliberative' has been subject to a prolific scholarly debate fueled by the experiences with health councils throughout the country.³³⁴ Generally

³³² Online: *Michaelis Dictionary*, sub verbo "permanente", accessed on February 4, 2018: <http://michaelis.uol.com.br/busca?id=NyVE8>

³³³ Online: *Michaelis Dictionary*, sub verbo "deliberativo", accessed on February 4, 2018: <http://michaelis.uol.com.br/busca?r=0&f=0&t=0&palavra=deliberativo>.

³³⁴ It is not the scope of this study to overview the nuanced meanings of the word "deliberative" as it relates to health councils. See *supra* note 121 for some political science studies on this matter.

speaking, the political literature lends support to the conclusion that “deliberative” has to do with the notion of shared decision-making, in contrast to advisory committees intended to provide relevant (yet non-binding) recommendations to governmental officials.

Finally, the meaning of the word ‘collegiate’ suggests a formal body in which group members are considered equals.³³⁵ For example, the *Michaelis Moderno Dicionário da Língua Portuguesa* defines ‘collegiate’ in the political sense as: “1, a system of government in which executive power is delegated to a collective body formed by several members, under the direction of a chairperson; in which the members exercise power collectively and equally and have different functions”; and, “2, members of a body of equals.”³³⁶ In this way, the notion of “collegiate” would incorporate into the notion of “deliberative council”, or collective decision making by equals after consideration or discussion.

Virgílio Afonso da Silva, Brazilian constitutional scholar, had this to say about the matter:

Collegiate implies, *inter alia*: (i) an aptitude to work as part of a team; (ii) the absence of hierarchy among judges (in the sense that arguments have the same value); (iii) a willingness and openness to listen to each other’s arguments; (iv) engage in collaborative decision-making processes; (v) mutual respect; (vi) an aptitude to engage in consensus seeking deliberations.³³⁷

Professor da Silva suggests that the political meaning of ‘collegiate’ has a distinct but related political meaning to the word ‘deliberative’ – that is, the idea of shared-power among equals within health councils. The nature of the NHC serves as first grant of balance of power within council members. But the actions of government officials toward NHC’s decisions will determine to a significant degree the statutorily recognized

³³⁵ Unlike the English language, in which collegiate has also a meaning associated with college students, Brazilian Portuguese has only a specialized meaning for the word “*colegiado*”. The word relating to “college” is “*collegial*” in Portuguese.

³³⁶ Online: *Michaelis Dictionary*, *sub verbo* “colegiado”, accessed on February 4, 2018: <<http://michaelis.uol.com.br/busca?r=0&f=0&t=0&palavra=colegiado>>.

³³⁷ Silva, *supra* note 210 at 562-3.

authority exerted by these participation bodies. In fact, the institutional connection between the NHC and the Health Ministry established in Art. 1, caput (and required approval from the Health Ministry as I will discuss later) might shadow the deliberative decisions from the NHC. It is important to note here that this statutory arrangement might also shadow the democratic goal set forth by the transformative constitutional goals discussed in Chapter 4. As a response to the authoritarian regime, Art 1 of the Constitution creates a new political structure that integrates participatory governance; explicitly establishing that sovereignty rests in the people and can be exercised through representatives and in direct form (Art 1, sole paragraph). In fact, the Constitution provided for involvement of participatory councils in all major public policies such as social security (Art.194), health (Art. 198, III) – the object of this study, social welfare (Art. 203), and education (Art. 206). It is imperative therefore, that the deliberative nature of the National Health Council be understood within the broader constitutional project designed to further the ideal of democratic public policy-making in Brazil, allowing broad citizen inclusion in the formulation of public policies.³³⁸

The NHC is structurally connected to the Health Ministry, and deliberative decisions from the NHC (resolutions) are legally subject to the Health Minister in council. Put simply, the NHC lacks authority to act independently from the Health Ministry. Of course, the fact that not all decisions (only resolutions) are subject to the Health Minister might increase to some extent NHC's independence from the Health Ministry. The difficulty with this argument is that decisions by the plenary board are in principle more important than day-to-day decisions such as secretarial matters, which remain subject to governmental approval.

Thus, the creation of health councils as permanent bodies may provide some political leverage for the NHC to make decisions that conflict with government interest without being disbanded by unhappy government officials. Yet, the NHC's important status as a

³³⁸ For a discussion on participatory councils as mechanisms to deepen democracy in Brazil, see e.g. Leonardo Avritzer, "The Different Designs of Public Participation in Brazil: Deliberation, Power Sharing and Public Ratification" (2002) 6:2 Critical Policy Studies (113-127) at 117-8.

permanent, deliberative and collegiate body is not sufficient to overcome the NHC's subordination to governmental authority. This issue is particularly problematic when the government lacks political will to approve subject matters addressed in the NHC's resolutions.

This legislative analysis suggests a key question: Is there a legal basis to hold the government accountable for incorporating NHC's resolutions? My analysis suggests that such a claim would be difficult to sustain.

It is true that the regulatory framework makes provision for federal cash transfer only if state and municipal governments have active health councils. Art. 4, II, for instance, provides that in order to qualify for federal funding, state and municipal governments must meet six requirements, including: "II. the creation of a health council (...)". And if otherwise, Art. 4, sole paragraph provides that: "the funding [of the noncompliant government] shall be managed by the corresponding state or federal government".³³⁹ Art. 4, II combined with Art. 1, II might indicate that state and municipal levels of government are required to create health councils according to the terms of Law 8142/1990. Additionally, since government officials are required to review councils' resolutions, it follows that state compliance with the rules in this statutory scheme would unavoidably involve reviewing health council's decisions (Art. 4, II).

There exists a difficulty though: Law 8142/1990 establishes penalties regarding state and municipal governments and is silent with respect to the federal government. One might

³³⁹ This has not happened before because virtually all governments have created health councils. Today, health councils are present in 98% of Brazilian cities as reported in Avritzer 2009, *supra* note 112. Furthermore, Kohler & Martinez point out that the National Health Council has adopted the rule of parity, but only 81% of state health councils and 73% of municipal health councils have enforced the rule. Accord Jillian C Kohler & Martha G. Martinez, "Participatory Health Councils and Good Governance: Healthy Democracy in Brazil?" (2015) 14:1 International Journal for Equity in Health 21. But, of course, I am not saying that all health councils are equally effective. In fact, many empirical studies have shown that some councils are mere window dressing. For an overview of studies on health councils, see for e.g. Marcelo R Moreira & Sarah Escorel, "Conselhos Municipais de Saúde do Brasil: Um Debate Sobre a Democratização da Política de Saúde nos Vinte Anos do SUS" ["Municipal Health Councils in Brazil: One debate About the Democratization of Health Policy in Light of the 20th Anniversary of the SUS – [Unified Health System]"] (2009) 14:3 Ciência & Saúde Coletiva 795.

argue by legal analogy that, in the event of federal government failure to comply with *Federal Law No 8142/1990*'s provisions regarding health councils, similar financial penalties would apply to federal government. Yet this argument undeniably stretches textual interpretation.

Additionally, even accepting that legal penalties might apply to the federal government, the absence of a specific reference to penalties for the federal government poses a major roadblock in terms of legal enforcement. Moreover, technically speaking, *Federal Law No 8142/1990* provides no statutory time limit for governmental consideration of NHC's resolutions.

In conclusion, while perhaps structurally coherent in terms of the nature of the NHC, the provision subjecting NHC's decisions to governmental approval, especially without statutory time limit for governmental review, seems at odds with the legal deliberative nature of the NHC. This provision seems to conflict with the constitutional requirement to ensure community participation in the health system.

5.4.2 Representation

Participation in the NHC takes place through representation. *Federal Law No 8142/1990* establishes specific rules for representation. Four groups are eligible to sit on health councils, including the NHC, namely: users of the system, health system workers, government officials, and private service providers. The statute, furthermore, sets out parity in representation between users' representatives and the sum of the remaining representatives (Art. 1, paragraph 4). In other words, users' representatives have a similar presence (in number and equal voting right) alongside the remaining other representatives in the NHC.

In the case of the NHC, Resolution 407/2008 establishes 48 full-time members (called "*membro titular*") with voting rights, plus two sets of alternate members (called "*membro*

suplente” without voting rights, for a total of 144 members.³⁴⁰ Decree n. 5839/2006, Art 3 restates the number of full-time members and the proportion of seats among the groups, as well as the eligibility criteria of each group. Art. 3 reads:

Art. 3. The NHC consists of 48 members, being that:
I – fifty percent are representatives of users’ organizations and social movements;
II - fifty percent are representatives of health workers organizations and academia; representatives of government; service provider organizations; the National Council of Health Secretaries (CONASS); the National Council of Municipal Health Secretaries (CONASEMS); and private healthcare providers.³⁴¹

The statute makes provision for the allocation of seats among health workers, government and private healthcare providers. Art. 3, paragraph 1 reads:

Paragraph 1. The percentage established in Art. 3, II shall respect the following representation:
I – twenty-five per cent to representatives of health workers organizations, including the academic health field;
II – twenty-five per cent to representatives distributed in the following way:
a) six members representing the federal government;
b) one member representing CONASS;
c) one member representing CONASEMS;
d) two members representing of health service providers; and
e) two members representing private healthcare providers.³⁴²

In addition, Art. 4, sole paragraph contains specific requirements for eligibility to sit on the NHC:

Art. 4. Members representing users’ organizations and social movements, health workers organizations, the academic health field, health service providers and private healthcare providers are elected every three years considered from the first election, and each elected organization shall appoint their representatives to the NHC.

³⁴⁰ NHC/Resolution No 407/2008.

³⁴¹ *Federal Law No 8142/1990*, Art. 3.

³⁴² *Federal Law No 8142/1990*, paragraph 1 of Art. 3. [CONASS stands for National Health Council to the National Council of Health Secretaries, and CONASEMS stands for the National Council of Municipal Health Secretaries].

Sole paragraph. Only social organizations referred to in Art. 5, I to IV, and in existence for a period of at least two years, are eligible to run for election.³⁴³

The final rule about representation provides additional criteria regarding a social organization's eligibility to run for election:

Art. 5, I. Users' organizations that have presence and representation in two-thirds of federative units at least, and in three geographic regions of the country.³⁴⁴

The term of membership service is three years. Exceptions to this limit are made for permanent members, namely: government representatives. At the end of each term, representatives of users and health workers elect representatives for the subsequent term, and representatives of government and private providers appoint their representatives for the next term.³⁴⁵ In the first plenary meeting of each term, council members elect the Chair for the three-year term and appoint members for standing committees. Aside from these binding statutory rules, it is up to the NHC's Plenary Board at the end of each three-year term to set out the terms of election procedures from administrative matters, such as time frame and selection committee, to membership criteria, keeping in mind existing representation on the committee and relevant expertise (Art. 8).

Collectively, these provisions provide comprehensive rules about institutional citizen participation within the health system. Participation in the NHC occurs through organized civil society representation.

Representatives, in turn, assume the role of representing the interest of their organization members, as well as the interests of all Brazilian citizens (users of the health system by

³⁴³ *Federal Law No 8142/1990*, Art. 4, and sole paragraph.

³⁴⁴ *Federal Law No 8142/1990*, Art. 5.

³⁴⁵ Organized civil societies representing the group "users" and the group "health workers" can change from term to term, for example, a given social organization might be replaced by another social organization with a different mandate. But, government officials, namely, the National Health Council to the National Council of Health Secretaries (CONASS), and to the National Council of Municipal Health Secretaries (CONASEMS) will always be represented in the NHC.

virtue of Brazil's universal right to health).³⁴⁶ As noted in Chapter 2, political scientists and others have debated the notions of representation and representativeness in health councils.³⁴⁷ This literature is concerned with questions such as who is allowed/elected to sit in the NHC and whose interests representative members actually represent.³⁴⁸ The problem, as political science scholar Leonardo Avritzer indicates, is that representatives are expected to represent the whole population of Brazil, but there is always the risk that personal or organizational interests will prevail over the public's interests.³⁴⁹ This can be an issue in terms of meeting the constitutional goals of broad inclusion, for instance. Notwithstanding its importance, the debate on representation and representativeness falls beyond the scope of this chapter.³⁵⁰

The question for the purposes of this Chapter is whether Congress narrowing down participation in the National Health Council, to selective representation of 24 civil society organization representatives (50% of NHC's members) conflicts with the constitutional goal of broad inclusion in health planning. In my view, there is no conflict for the following reasons.³⁵¹

³⁴⁶ For e.g. Moreira & Escorel, *supra* note 340.

³⁴⁷ See *supra* note 121 for some political science scholars examining this matter.

³⁴⁸ For e.g. Águeda Wendhausen, *O Duplo Sentido do Controle Social: (Des)caminhos da Participação em Saúde* [The Dual Meaning of Social Control: (Backwards and Forward) Paths of Participation in Health] (Itajaí: Uni-Vali, 2002).

³⁴⁹ For e.g. Boaventura de Souza Santos & Leonardo Avritzer, "Para Ampliar o Cânone Democrático" ["Enlarging the Democratic Canon"] in Boaventura de Sousa Santos, ed, *Democratizar a Democracia – Os Caminhos da Democracia Participativa* [Democratizing the Democracy – The Paths of Participatory Democracy] (Rio de Janeiro: Civilização Brasileira, 2002) 39.

³⁵⁰ For an overview of the debate about representation and representativeness, see e.g. Lavallo & Araújo, *supra* note 106.

³⁵¹ I should note, however, that this Section is not intended to provide a comprehensive analysis of the constitutionality of the statute as a whole. There is a vast literature assessing the problems with the legislation. Commentators have identified problems with clauses related to private providers conflicting with the constitutional principle of equity, and the fact that the statute is silent with relation to the financing of the system, which also allows too much discretion to governments in relation to how much invest in the system. For a review of these arguments, see e.g. Nelson R dos Santos, "SUS, Política Pública de Estado: Seu Desenvolvimento Instituído e Instituinte e a Busca de Saídas" [Unified Health System, Public Policy of the State – Its Development and the Search for Solutions] (2013) 18:1 *Ciência & Saúde Coletiva* 273. For a quick overview, see e.g. José P Bispo Júnior, "Reforma Sanitária Brasileira: Contribuição para a Compreensão e Crítica" ["Brazilian Sanitary Reform – Some Thoughts and Critics"] (2009) 25: 8 *Caderno de Saúde Pública* 1866.

First, the content of the rule does not violate the Constitution. While the Constitution mandates community participation in the organization of the health system, the constitutional instrument is silent with respect to the form of participation within the health system. Constitutional silence, in the context of Brazil's legal system, means that Congress has some degree of discretion regarding the organizational rules for community participation in health planning, such as in relation to the rules of inclusion, as long as the rules are not discriminatory. Furthermore, nothing compels Congress to address all matters when legislating on any given matter. Additionally, and perhaps most importantly, participation through representation does not conflict with the broad terms of the Constitution because Congress established health councils as one of several mechanisms for Brazilian citizens to participate in health planning. For example, *Federal Law No 8142/1990* also establishes health conferences as another way in which citizens can participate in the shaping of Brazil's health system.

A further question is whether restricting membership to only a few civil society groups conflicts with the constitutional purpose of broad inclusion in health planning. At first sight, this exclusionary rule appears to function as a form of triage of whose health needs is highest. However, it is not feasible to include 208 million people in the NHC.³⁵² Since Alexis de Tocqueville's classic *Democracy in America*, political science scholars, and more recently, governance scholars, too, have pointed out that small groups of people are more conducive to meaningful and effective debate and deliberation in participatory spaces.³⁵³ In addition to the NHC, citizens can participate in health planning through state and municipal levels of health councils.

³⁵² See *supra* note 41 for an official projection of the population of Brazil by the Brazilian Institute of Geography and Statistics.

³⁵³ Alexis de Tocqueville, *Democracy in America* (Regnery Publishing, 2003) vol 10. See also Carrie Menkel-Meadow, "Scaling up Deliberative Democracy as Dispute Resolution in Healthcare Reform: A Work in Progress" (2011) 74:3 *Law and Contemporary Problems* 1; Alison Kadlec & Will Friedman, "Deliberative Democracy and the Problem of Power" (2007) 3:1 *Journal of Public Deliberation* art 8.

Membership restrictions, moreover, do not preclude individual citizens from attending the meetings of any level of health council. Citizens may also voice their concerns in NHC plenary meetings and exert pressure upon Council members through other forms of civic engagement. There are also various other forms of institutional participation created by other types of legislation, for example, health councils at the hospital level in which civil society organizations alongside individual patients take part in the organization of healthcare service delivery, including with voting rights.³⁵⁴ In addition, representative participation in the NHC seems to be consistent with the views of the framers of the Constitution, as discussed in the preceding Chapter, *supra* Section 4.5.3.

5.4.3 Responsibilities

Federal Law No 8142/1990, Art. 1 makes provision for general responsibilities for health councils to “act in the elaboration of health strategies and monitor policy implementation at the respective level of government, including in relation to health finance matters.”³⁵⁵

Ordinarily, the use of the verb “act” suggests discretion. For example, the *Michaelis Moderno Dicionário da Língua Portuguesa*, provides six definitions for the word “act”, the most suitable is: “1, carry out an action or activity; proceed.”³⁵⁶ Consistent use of the word in the *Organic Health Law*, for example, indicates delegation of power to handle certain subject matters.³⁵⁷ The word “act” appears in seven provisions, and the provisions were arranged under the headings “responsibilities and jurisdiction” and “concurrent jurisdiction”.³⁵⁸ Similar meaning of the word “act” is found in the 1988 Constitution. For instance, Art. 200, V uses the word “act” (in noun form, *atuação*) to refer to specific

³⁵⁴ For e.g. Coelho, *supra* note 119.

³⁵⁵ *Federal Law No 8142/1990*, Art. 1, II, paragraph 2.

³⁵⁶ Online: *Michaelis Dictionary*, *sub verbo* “atuar”, accessed on February 4, 2018: <<http://michaelis.uol.com.br/busca?r=0&f=0&t=0&palavra=atuar>>.

³⁵⁷ I should note that *Federal Law No 8142/1990* uses the word “act” only in the provision under analysis, therefore, my choice of examining *Federal Law No 8080/1990*. I should note that *Federal Law No 8080/1990* does not use the exact form “act”, but rather the noun form of the word “acts”.

³⁵⁸ For instance, headings include ‘Objectives and Competences’ (Arts. 6, X); ‘Concurrent Competences’ (Art. 15, XIII); ‘Competence of the National Health Authority’ (Art. 16 XIII); ‘Competence of Municipal Health Authorities’ (Art. 18 VI).

authority granted to the health system to participate in technological development.³⁵⁹ Likewise, Art. 149 uses the word “act” (also as a noun, *atuação*) to refer to exclusive power of the federal government to collect certain taxes.³⁶⁰ Finally, Art. 211, paragraph 2 uses the word (as well, the noun form, *atuação*) to refer to the competence of municipal governments to act upon matters related to fundamental education.³⁶¹

The Executive Order no 5839/2006, defined more clearly the responsibilities of the NHC include acting in the elaboration and monitoring of health policies. The relevant provisions for the purpose here is Art. 2, which reads:

Art. 2: The ‘competências’ of the National Health Council are:

- I - Act in the elaboration of health strategies and monitor policy implementation related to the national health plan at the federal level of government, including with regard to financing aspects;
- II - Establish directives for the National Health Plan based on epidemiological information and service delivery organization;
- III - Elaborate chronograms for federal cash transfer to states, federal district and municipalities;
- IV - Approve framework for reimbursement of health services and standards for healthcare service coverage;
- V - Propose criteria to define standards and parameters for healthcare service;
- VI – Monitor and control private provision of health services that are contracted out by the public system;

³⁵⁹ Brazilian Constitution, Art. 200 reads: It is incumbent upon the unified health system, in addition to other duties, as set forth by the law: i – to supervise and control proceedings, products and substances of interest to health and to participate in the production of drugs, equipment, immunobiological products, blood products and other inputs; ii – to carry out actions of sanitary and epidemiologic vigilance as well as those relating to the health of workers; iii – to organize the training of personnel in the area of health; iv – to participate in the definition of the policy and in the implementation of basic sanitation actions; v – to foster, within its scope of action, scientific and technological development; vi – to supervise and control foodstuffs, including their nutritional contents, as well as drinks and water for human consumption; vii – to participate in the supervision and control of the production, transportation, storage and use of psychoactive, toxic and radioactive substances and products; viii – to cooperate in the preservation of the environment, including that of the workplace.

³⁶⁰ Brazilian Constitution, Art. 149 reads: the union shall have the exclusive competence to institute social contributions regarding intervention in the economic order and the interest of categories of employees or employers

³⁶¹ Brazilian Constitution, Art. 211, paragraph 2 reads: the union shall have the exclusive competence to institute social contributions regarding intervention in the economic order and the interest of categories of employees or employers

VII - Monitor the process of technological development and incorporation of technology within the health sector taking into account ethical standards and socio-cultural development of the country; and
VIII – Liaise with the Education Ministry about the creation of new university-level courses in the health field intended to address social demands.³⁶²

Significantly here is the word ‘*competências*’ in the caput of Art. 2. This word provides guidance in relation to the mandate of the NHC.³⁶³ According to the *Dicionário Houaiss da Língua Portuguesa*, ‘*competências*’ has ten definitions, including a legal definition: “1, ability of public authority to carry out certain actions.” “1.1, legitimacy or authority granted to judges or courts to make legal decisions and judgments within a given territory.” “1.2, power held by an individual in relation to a given position or function, in order to carry out the position or function duties.” “2, *atribuições*, assignments.”³⁶⁴ Essentially, the word *competências* can be used with a sense of duty to deal with or being accountable for something, and in a sense of authority to act independently and make choices without authorization.

The word “*competências*”, furthermore, has been used in related legislation. For instance, Arts.16, 17 and 18 of the *Organic Health Law* use the word ‘*competete*’ (the verb form of the word *competências*) to distribute responsibilities amongst the three levels of government. The language employed in Arts. 16 to 18 makes clear that the word *competências* means responsibilities of each government level. For example, the Supreme Court held that all levels of government are co-responsible for guaranteeing the right to health in Brazil, regardless of statutory division of responsibilities among governments.³⁶⁵

³⁶² Executive Order no 5839/2006, Art. 2, I-VIII.

³⁶³ The term “*competências*” carries a specialized meaning in Portuguese that does not work well as an English translation, and this is why I use the Portuguese term in this section. The literal translation to English is ‘competency’ and ‘competent’, which means capability or specialized knowledge to carry out a course of action or in a more specialized sense along the lines of the absence disabilities or presence of specialized or personal qualification to act in certain ways.

³⁶⁴ Online: *Houaiss Dictionary*, *sub verbo* “*competências*”, accessed February 4, 2018: <<https://houaiss.uol.com.br/pub/apps/www/v3-2/html/index.php#1>>.

³⁶⁵ For e.g. Mariana Pretel, “O Direito Constitucional da Saúde e o Dever do Estado de Fornecer Medicamentos e Tratamentos” [“The Constitutional Right to Health and the State’s Obligation to Provide Medications and Treatments”], OAB Santo Anastácio, Conteúdo Jurídico, online 22 March 2010. Online:

Thus, unlike the more flexible meaning of the statutory language “act”, the word “*competete*” in the *Organic Health Law*, at least in the case of Arts. 16 to 18, has been interpreted as the government’s duty to implement health-related actions and health services. In other words, the word “*competências*” in the case of Arts. 16 to 18 cannot be read so as to indicate government discretion to take action. But, in the case of Executive Order No 5839/2006, “*competências*” might simply mean an intention to define more clearly the responsibilities of the NHC rather than create duties to act in certain way.

As for content, Art. 2 essentially reaffirms the basic responsibilities as expressed in *Federal Law n. 8142/1990* and *Organic Health Law*. With respect to the former, Art. 2 reaffirms NHC’s responsibilities to act in the elaboration of health strategies and to monitor implementation of health policies. In relation to the latter, Art. 2 restates the NHC’s responsibilities for developing guidelines for the national health plan; reviewing intergovernmental cash transfers; developing standards and compensation frameworks for healthcare coverage; as well as overseeing NHC’s engagement with other key stakeholders.

But, Art. 2, II further defines that the NHC is to “act in the elaboration of health strategies and to monitor policy implementation related to the national health plan at the federal level of government.” One way to interpret Art. 2 is as a restatement of Art. 37 of the *Organic Health Law* that prescribes NHC participation in the national health plan, but that gives no further guidance as to NHC involvement in other instances of policy elaboration. Another way to interpret the Article is as a limitation on the NHC’s responsibilities: NHC’s responsibility relates to the four-year national health plan only. The question then is whether this limited scope excludes the NHC from other instances of policy elaboration, such as operating procedures setting responsibilities and time-frames in order to meet the goals of the national health plan, that might be desirable for a fully participatory health system as required by the 1988 Constitution. In any case, the text of Art. 2 provides no guidance concerning steps to translate these responsibilities into

<http://www.conteudojuridico.com.br/index.php?colunas&colunista=151_&ver=578>. Last retrieved: 4 February 2018.

actions. Or, to put another way, it is not clear how elaboration and oversight responsibilities shall be carried out, which at the very least challenges oversight of whether or not the NHC meets its statutory responsibilities. More fundamentally, as discussed earlier in this Chapter, *Federal Law No 8142/1990*, Art. 1, subjects NHC's resolutions to the Health Minister. In practice, this legal arrangement means that the NHC has authority to act in the elaboration and monitoring, but that the final say belongs to government.

In 2012, Congress passed other piece of legislation (*Federal Law No 141/2012*) regulating intergovernmental transfers for the health system.³⁶⁶ The purpose of this Act is to establish responsibilities for the federal, states and municipality levels of government for health finance.³⁶⁷ In addition, this statute makes particular provisions for the National Health Council with respect to reviewing ('monitoring') health finance, the relevant Articles being Arts. 36, paragraph 4; 38; 41; and 46.³⁶⁸ Significantly, this statute establishes

³⁶⁶ *Federal Law No 141, 2012*. Online: <http://www.planalto.gov.br/ccivil_03/leis/LCP/Lcp141.htm>. Last retrieved: 4 February 2018.

³⁶⁷ Many Brazilian commentators rightly criticize the legislation for not defining an adequate cap for the federal government. Despite the importance of this problem, the issue is beyond the scope of this study. For a concise overview of issues related to health financing, see e.g. Alethele O Santos, Maria C Delduque & Sandra MC Alves, "The Three Branches of Government and Financing of the Brazilian Unified National Health System: 2015 in Review" (2016) 32:1 *Cadernos de Saúde Pública* 1. See also Sandra MC Alves and Alethele O Santos, "Public Health System in Brazil Nowadays: Challenges for its Operation and Funding" (2016) 5:3 *Cadernos Ibero-Americanos de Direito Sanitário* 65. In fact, there has been an endless struggle for adequate financing of the health system since initial debates about the creation of a universal health system (for example, at the 8th Health Conference), and more vigorously, from the actual creation of the Unified Health System by *Federal Law No 8080/1990*. On the one hand, supporters of a universal health system advocate for mandatory minimum health investment, and on the other hand, neoliberal forces interested in private healthcare delivery lobby the government against mandatory minimum health investment. Universal health system advocates argue that *Federal Law No 141/2012* (regulation of constitutional amendment 29 of 2000) did not guarantee new financial resources for universal health, especially from the federal government. For e.g. Áquilas Mendes, "Brazilian Public Health in the Context of a State Crisis or a Crisis of Capitalism?" (2015) 24:1 *Saúde Social* 66. See also, Armando de Negri Filho, "Brazil: A Long Journey Towards a Universal Healthcare System" in José M Zuniga, Stephen P Marks & Lawrence O Gostin, eds, *Advancing the Human Right to Health* (OUP Oxford, 2013).

³⁶⁸ *Federal Law No 141/2012*, Art. 36 reads: Each level of health governance will prepare detailed reports for the previous quarter, which will contain the following information: I - amount and source of the funds invested in the period; II - audits carried out or in progress in the period and its recommendations and determinations; III - supply and delivery of public services in their own region, hired and contracted, comparing this data with the health indicators of the population in its area of operation. § 4. The report will be prepared in accordance with standard model approved by the National Health Council, adopted simplified model for municipalities with less than R\$50,000 (fifty thousand); Art. 38 reads: The Legislature, directly or with the assistance of the Court of Auditors, internal audit department of the health

thorough procedures for government reporting to the NHC in every quarter, and criteria by which the NHC is required to review performance and budget reports and financial statements related to the health system. Furthermore, this statute establishes that contravention of this statute is made an offence under Art. 46, and both government officials and NHC's members can be charged with violations. In contrast to the language used in the preceding legal instruments, this statute uses obligation language such as "health councils are responsible for", "the report will be prepared" and "each level of health authority will provide". In other words, government officials and the NHC must meet these requirements and face legal consequences for failures to do so.

In May 2012, four months after Congress passed *Federal Law No 141/2012*, the Plenary Board of the National Health Council issued NHC/Resolution n. 453/2012 ("Resolution") defining more clearly the NHC's responsibilities and steps for carrying out its responsibilities, including with respect to reviewing health finance.³⁶⁹ This Resolution consists of a seven-page document, organized in six whereas-clauses providing background and context alongside five operative clauses providing for administrative matters (clauses 1 to 3), as well as operational and responsibility matters (clauses 4 and 5). For instance, 17 items expressed in Clause 5 further clarify how the NHC carries out

system and the health council at each level of government, without prejudice to the terms of this statute, oversees compliance with the rules of this statute, in particular with regards to: I - the preparation and execution of the Annual Health Plan; II - to meeting the targets for health established in the law of budget directives; III - the application of minimum amount required for public health services, according to the terms of this statute; IV - the transfers to the 'Health Funding'; V - the mandatory resources related to SUS; VI - the allocation of the proceeds from the disposition of assets purchased with funds linked to health; Art. 41 reads: Health councils are responsible for assessing each quarter the consolidated report of the result of budgetary and financial execution in the field of health and the health officer's report on the impact of the implementation of this statute, under the conditions health and quality of health services of the population and submit the report to the respective health authority in order to make the necessary corrections. Art. 44 reads: Each level of health authority will provide permanent education to qualify council members [in the sense of providing support for their decision making], priority given to representatives of users and health workers, to enhance members' role in the elaboration of health strategies and monitoring of policy implementation according to Law 8142/1990; Art. 46 reads: Failure to comply with the provisions under this statute is subject to the Penal Code, Law 1070/1950, Decree 201/1967, Law 8249/1992, among other relevant legislation.

³⁶⁹ Source: National Health Council. Online: <<http://www.conselho.saude.gov.br/resolucoes/2012/Reso453.pdf>>. Last retrieved: 4 February 2018. Official version at: <http://bvsms.saude.gov.br/bvs/saudelegis/cns/2012/res0453_10_05_2012.html>. Last retrieved: 4 February 2018.

the responsibilities under Law 141/2012, including specific activities and timelines for review of budget and performance reports, as well as health finance statements (XII through XVI). Clause 4, VI and XI, furthermore, provide ancillary steps to support responsibilities related to health finance, such as the establishment of Working Group and special committees.

Moreover, Resolution 453/2012 further develops the responsibilities with respect to the function ‘elaboration of health strategies’ expressed in Law 8142/1990. Clause 5, for instance, states that this responsibility includes the development of an action-plan to implement recommendations from health conferences (III). This clause furthermore further clarifies that the elaboration function has to do with the national health plan as well as with two other areas: guidelines to assess the quality of private health providers (V), and criteria to assess the quality of health programs (IX).³⁷⁰ In addition, Clause 5 also enumerates ancillary actions to foster collaboration with lower levels of health councils, governmental bodies, legislative, judiciary, as well as media outlets, and non-governmental organizations, including organizations that are not part of the NHC (VII, XX, XXV).

An important aspect of this Resolution is that it clarifies the scope of the NHC’s exclusive authority. For example, the NHC is responsible for its own executive secretariat (Clause 4, II), developing its internal budget (Clause 4, III), and operational rules (Clause V, VII, VIII).³⁷¹ The Resolution, moreover, establishes a 30-day time period for health authorities to review resolutions, and in the event of governmental failure to do so, it orients the NHC to seek judicial remedies (Clause 4, XII). In my view, a further

³⁷⁰ Noting here that one of the actions reasserts the functions of acting in the formulation and monitoring of health policies as determined by *Federal Law No 8142/1990* (IV).

³⁷¹ Clause 4 ‘V’, ‘VII’ and ‘VIII’ provide thorough instructions and objectives: “V – the plenary meetings shall be open to the public and be carried out in venues and times that allow broad participation of civil society”; “VII – the council shall create an executive board elected in a plenary meeting, respecting the proportion of members expressed in this resolution”; and “VIII – decisions of the council shall be adopted by minimum quorum of voting members (50% plus one), except in cases that the by-law requires otherwise. Clause 4 even specifies quorum as follows: a) simple majority means the number of present members plus one; b) absolute majority means the number of MHC’s members plus one; c) qualified majority means two thirds of the total number of NHC’s members.

significant step towards greater independence from the Health Ministry is to clarify the NHC's authority. This clarification is particularly important because one of the major legal roadblocks to genuine and effective participation is that NHC's resolutions are subject to the Health Minister's ratification.³⁷² This Resolution provides an important road map for action that will clarify state and social actors' responsibilities and roles. It is true that resolutions are hierarchically inferior to law or executive order, and are not binding upon government officials, meaning that in theory this Resolution has not resolved the authority issue. However, even such a legally "non-binding" instrument could be very difficult to disregard if the NHC develops and maintains broad credibility, authority and legitimacy on all these tasks. In other words, just as has been the case with several "non-binding" recommendations from other advisory committees, such as Brazil's *Conselho Nacional de Justiça* (the National Judicial Committee) or the 2005 *Referendo do Desarmamento* (referendum on the prohibition of the sales of firearms and ammunition), it would become politically very difficult for the Executive not to follow the NHC's recommendations.

5.5 Conclusion

Participation in the organization of the health system is a requirement part of the right to health, and as such, needs to be inclusive and offer equal opportunities for participants to influence public policies through mechanisms and processes that are accessible, transparent and continuous. Congress passed legislation creating health councils, which are permanent, deliberative and collegiate bodies for citizen participation within the health system and at the three levels of health governance (national, state and municipal).

In this Chapter, I analyzed core legislation governing participation in the National Health Council against the constitutional ~~goals~~ requirements of participation in a right to health

³⁷² See *supra* Section 5.4.1 for this discussion.

framework. In particular, I examined whether the nature, composition and mandate of the NHC meet the constitutional goals of broad and ongoing inclusion in the health system.

The analysis concluded that the statutory framework establishes a mandatory nature of citizen participation in the health system, and therefore, the legal connection between ‘community participation’ enshrined in the Constitution and ‘participation in the NHC’ established by statutes. Clear definitions are steps towards holding governmental officials to account for ensuring genuine participation in the NHC.

In addition, the legal instruments examined, in particular, NHC/Resolution 453/2012 also indicated well defined responsibilities and steps to carry out the responsibilities. These steps are also important towards more transparent and accountable representative participation to the citizenry, as is demonstrated by the case of the NHC. With respect to participation through representation, the analysis concluded that although participation in the NHC is constrained to representation and to a certain number of civil society organizations, lay citizens and civil society representatives with no seat on the NHC may still attend meetings, voice concerns, and exert pressure over NHC’s representatives.

Finally, the analysis concluded that, overall, the legal framework for participation in the NHC is consistent with the goals of being inclusive and offering equal opportunities for participants to influence public policies. However, the analysis also determined two features for improvement.

First, a major legal challenge concerns the rule that the NHC’s resolutions are subject to the Health Minister. This rule presents a challenge to the ability of the NHC to effectively influence public health decisions, which is core to the transformative goal of the right to health, and the democratic political project more broadly, as noted above. The legal analysis suggests the need for adequate accountability and enforcement mechanisms to hold state officials to account as to whether and how the NHC recommendations have been considered and integrated in health strategies in a timely and effectively way. In particular, it is critical to review the legal framework (i.e., Federal Law No 8142/1990,

Art. 1, II, paragraph 2) with respect to the role of the NHC's resolutions within overall health governance (see graphic page 12), and at the very least, to add a timeframe for governmental review, perhaps a 30-day timeframe as Resolution 453/2012 proposes.

Second, legal instruments analyzed provide detailed guidance with respect to the responsibilities about health finance. The legal framework is less clear with respect to responsibilities for participation in the elaboration of health strategies, for example, whether or not participation in health planning has to do with the national health plan only. The legal framework would also benefit from a revision defining more clearly the scope of the elaboration function.

6 Citizen Participation in the National Health Council– A Qualitative Study

6.1 Introduction

This Chapter relies directly on the data gathered from a sample of members of the National Health Council and intends to provide insight about the role of participation in Brazil's NHC in meeting the right to health.³⁷³ Semi-structured interviews were conducted with a sample of 26 Council members, who spoke about their experiences and interpretations of participation in health governance while acting as members of the National Health Council in Brazil. Respondents addressed matters concerning the legal structure of the NHC, as well as the perceived legal barriers to the implementation of the participation requirement through the NHC among other matters. The research also included naturalistic observation of two plenary meetings attended by the respondents.³⁷⁴ This observation provided insights on the context within which respondents operate.

The data set comprised written text and audible data: field notes and recorded interviews that were transcribed into written form for thematic analysis and content coding. In selecting excerpts from the data for inclusion in this Chapter, I will endeavor to provide context where participants shared common perspectives and to indicate where there were conflicting views or perspectives. As the research project included a wide range of participants, the data set will also allow me to highlight unique and important perspectives offered by participants from different backgrounds. Combined, the empirical

³⁷³ See *supra* Chapter 3 for detailed discussion on the methodology of this research.

³⁷⁴ The plenary meetings are the sessions in which all the NHC's members meet in order to discuss and deliberate, approving or rejecting NHC's own agenda's matters, including administrative matters, timetable of work, items to be referred to the NHC's internal committees, as well as "resolutions", which are the final NHC's recommendations to be sent to the Health Minister. The Plenary meets once a month every month, usually for two days, and I observed two meetings of the NHC for this study.

insights contribute to improved understanding about the practice of participation in the NHC toward the implementation of the right to health and help to inform future research.

I proceed to the discussion as follows. Section 6.2 begins by outlining respondents' view on citizen participation as part of the right to health. Section 6.3 examines the question of participation in the NHC, and draws upon respondents' interpretations of the legislation governing the NHC, particularly regarding respondents' views regarding the scope of the legal roles ascribed to the NHC. In section 6.4, respondents consider the connections between participation in the NHC and the right to health and offer their thoughts on how the NHC meets the right to health requirements. In closing, section 6.5 provides a summary of this Chapter, and introduces the final Chapter that will proceed to draw conclusions in relation to the study as a whole.

6.2 Participation and the Right to Health

Respondents were invited to weigh in on the constitutional framework of 'community participation' in relation to the right to health, and discussions followed from there. To the question, "What is your perception of community participation as part of the obligations to the right to health?", virtually all respondents went to great lengths to explain why in their view community participation was fundamental to guarantee the right to health in Brazil. Asked to elaborate on this notion of 'community participation being fundamental for the right to health', respondents often described their views in terms of citizen engagement in health policy matters, typically revolving around the idea of groups of people acting together towards common goals and social change. Or, as one respondent suggested, "community participation meant people taking action into their own hands."³⁷⁵ Explaining this idea further, another respondent stated:

³⁷⁵ Respondent #2 [I have assigned random number to refer to specific respondents' comments in order to provide clarity as to whether responses are from the same or from a different respondent. And, I use no specific reference but quotation marks when a given comment is used to describe the sentiment of several respondents].

Participation is extremely important. Without participation, without people's participation, we would have to wait for good ideas and the good will of the government and opinions of healthcare officials about what is needed and what is necessary for us.³⁷⁶

Virtually all respondents explained that when people take action into their own hands and pressure government officials in 'collective action' the right to health is realized.

Participation, therefore, was regarded as collective action for social change. There was a widespread feeling among social organization representatives who participated in this study that the people of Brazil couldn't trust government officials to take action on people's behalf. A number of them reported that without participation driven by social and health reform activists in the 1970s and 1980s, Brazil's right to health would likely not have been enshrined in the 1988 Constitution. Even government representatives who took part in this study also agreed with this perspective. One such respondent indicated that the legal and health reforms leading to the creation the Brazilian health system would not have occurred without such pressures. He posited:

If social movements had not demanded changes, we would not have had our SUS [health system]. If it were not for participation of the people through the sanitary movement, if we were to depend on our politicians, we would not have the SUS that we have today.³⁷⁷

I was intrigued by the fact that respondents did not refer to the National Health Council when describing their views on 'participation as part of the right to health'. This lack of reference to the NHC sparked a follow-up question, "How do you view participation in the National Health Council in relation to the right to health?" It was only when specifically asked about 'participation in the NHC' and the right to health that conceptual

³⁷⁶ Respondent #6

³⁷⁷ Respondent #1 [As noted in *supra* Chapter 4, Section 4.5.3, the so-called Sanitary Movement emerged in the 1970, and intensified in the 1980s in the fight against the military dictatorship in Brazil. The Movement was formed by social and health reform activists, such as academics, health students and health professionals, union and church leaders, and left-wing politicians, and advanced transformative ideas such as the integration of health promotion, prevention and treatment and health as basic right of citizenship in Brazil. The recommendations of the Sanitary Movement are regarded as the blueprint for Brazil's right to health].

and practical differences between ‘community participation’ (expressed in the Constitution) and ‘participation in the NHC’ (expressed in federal legislation) emerged. The following quote sums up respondents’ prompt responses to ‘community participation’ and ‘participation in the NHC’: “Ah, community participation is one thing. Participation in the NHC is something else”.³⁷⁸

As outlined in the literature review in Chapter 2, there is considerable variation in terms to refer to this notion of citizen input in public health matters in Brazil.³⁷⁹ In the two preceding legal chapters, two terms—‘community participation’ and ‘participation in the National Health Council’—were given particular attention because those are the terms used in the constitutional and statutory provisions governing citizen participation in health governance. In this qualitative research, however, respondents used six different terms to describe citizen participation in public health matters: ‘constitutional participation’, ‘social participation’, ‘popular participation’, ‘institutional participation’, ‘council participation’ and ‘*controle social*’ (‘social control’, meaning citizen oversight of political activities). At first, respondents appeared to use those terms interchangeably. But, quite often clarification statements were used for mutual understanding such as “I am now talking about social control in the Council”, and, “Ah, that participation—ah, participation of the Constitution.” Hence upon a closer look it became clear that terms differ from area to area and imply different plans for action. For example, respondents noted:

Well, what do I understand by social control? It seems different from what the Council [members] understands from social control. Actually, I am still learning what [social control] is from an institutional perspective, from a Council’s view. I am not sure yet.³⁸⁰

³⁷⁸ Respondent #3.

³⁷⁹ See *supra* Chapter 2, Section 2.4 for the different terms used in the literature. In this study, (see *supra* Sections 2.4 and 4.1), I use the term ‘community participation’ meaning any form of collective action, and the term ‘institutional participation’ or ‘participation in health council’ to refer to participation within the structure of the health system (i.e., health councils).

³⁸⁰ Respondent #17.

When social movements talk about social control, maybe they do not mean they are against social participation. But this is not clearly understood outside [social] movements.³⁸¹

Notwithstanding the majority of respondents explicitly expressed their unique views on the meanings of participation, it should be noted that one respondent suggested that conceptual labels do not matter: “people use different terms. I don’t really care. I don’t think different terms matter that much.”³⁸² And yet, his statement is further complemented by a qualification of the type of ‘participation’ he was referring to:

The type of participation I am talking about now, the type of participation I defend is social participation. I mean that participation that allows everyone in. But participation that allows one to vote, ah, only then is that participation through organized civil society.³⁸³

Therefore, despite asserting that “terms do not matter”, this full statement qualifying the type of participation suggests otherwise.

Overall, three main findings emerged from this original data. First, clearly defined terms matter because different accounts of participation affect who is involved and how one participates. Second, the terms ‘social control’, ‘institutional participation’ and ‘council participation’ are used interchangeably to refer to institutional participation through health councils, including participation in Brazil’s National Health Council. Third, the terms ‘community participation’, ‘constitutional participation’ and ‘popular participation’ are used interchangeably to refer to any form of participation, excepting “institutional participation” in health councils. These insights are crucial when it comes to thinking about the purpose of and assessment criteria to evaluate the different forms of participation.

³⁸¹ Respondent #10.

³⁸² Respondent #1.

³⁸³ *Ibid.*

Asked to elaborate on the purposes of both forms of participation, respondents explained that ‘community participation’ (also referred to as ‘constitutional participation’ or ‘popular participation’) and ‘institutional participation’ (or ‘participation in the NHC’) are two different forms of civil society engagement in health matters and imply different plans for action. Respondents had much to say about the way they understood and defined both forms of participation, from which emerges rich description of the way in which each concept relates to the right to health. This original data indicates a general perception that “community participation is broader in terms of actions than participation in the NHC.” According to one civil society respondent: “community participation does not require membership in civil society organizations.... ‘unorganized’ civil society members, everyone can participate.”³⁸⁴

‘Community participation’ was perceived as an entitlement by which one person can take rights into her own hands to demand, for instance, healthcare for herself, but also whereby groups of individuals can take rights into their own hands and demand public healthcare for themselves or others. ‘Everyone is welcome’ and ‘there is no string attached’ as to whom and how one could exercise the constitutional right to participation in Brazil, both individually and collectively. In one respondent’s words:

Community participation, the constitutional participation means social participation. This participation has to do with grassroots and political struggles of marginalized groups.³⁸⁵

In general, respondents’ accounts of ‘constitutional participation’ follow the lines of advocacy grounded in a human rights framework, whereby individuals form close partnerships with other individuals or civil society organized groups to take part in or initiate purposeful collective action in order to fight for a common goal: the achievement of rights.³⁸⁶ During the interview process, respondents gave examples of many forms in

³⁸⁴ Respondent #3.

³⁸⁵ Respondent #14.

³⁸⁶ See generally Vos et al, *supra* note 104. See also *supra* Chapter 2, Section 2.4 for an overview of the health and human rights literature on this matter.

which ‘everyone can participate to demand the right to health in the sense of constitutional participation.’ For example, one respondent explained how the people could participate in the sense of the Constitution:

A person goes to a clinic. She is mistreated and makes a complaint. This complaint can help her, but also might reach beyond her individual case. This complaint has also to do with the inadequacy of services for an entire population.³⁸⁷

Another civil society respondent explained that collective actions to pressure government officials to deliver unmet health-related needs regardless of whether such needs were included or not in the health system:

Participation means the peoples’ will to access certain benefits that have been denied to them. These benefits may exist or may not exist, and people want such benefits to exist.³⁸⁸

Overall, it became clear the value respondents place on ‘community participation’—broadly understood as societal engagement in public health matters—as allowing citizens greater opportunities to demand health services and advance both individual and collective health. It also became clear that ‘participation in the NHC’ was not directly associated with the right to health; in fact, respondents made no reference to participation in the NHC and the right to health without being asked to do so, as I will discuss later in this Chapter. Interestingly, no respondent spoke of community participation in relation to the right to health in terms of the state’s obligation, for example, an obligation to ensure participatory health governance, as concluded in the constitutional analysis carried out in Chapter 4.³⁸⁹ In terms of the state’s obligations, respondents identified the obligation to implement a comprehensive health system for health promotion, protection and recovery (the obligation also identified in Chapter 4).³⁹⁰ But, Chapter 4 also concluded that participatory health governance is constitutionally structured as an obligation of the state

³⁸⁷ Respondent #11.

³⁸⁸ Respondent #6.

³⁸⁹ See *supra* Chapter 4, Section 4.5.1 for detailed analysis.

³⁹⁰ *Ibid.*

to the right to health.³⁹¹ Respondents however, described community participation solely in terms of freedoms for citizens, individually or collectively, to take action and demand the realization of their right to health. Respondents made no reference to ‘community participation’ as a state’s obligation of the right to health.

My first reading of this finding was to observe that respondents’ general sense of disapproval regarding the notion of ‘participation as a requirement’. As one respondent noted, “there are many gray areas in participation, and participation does not fit in legal boxes of legal obligations.”³⁹² It is true that at no point did respondents use words such as ‘requirements’ and ‘obligations’ in relation to ‘participation and the right to health.’ But, respondents did indicate that government officials have some obligations toward participation, at least on a very general level such as obligations to respecting freedom of assembly, information sharing and civic education. For example, during one of the observed plenary meetings there was a discussion about allocation of federal resources for NHC’s members to participate in a strategic planning retreat. Council members, including some members who participated in this study, commented on the inadequacy of public funding for this sort of expense. And at no point in the meeting did respondents indicate that the government was not responsible for providing resources for NHC’s members to attend the retreat. In other words, this silence may suggest that for respondents governmental officials may have some obligations to participation in the NHC.

6.3 Obligations Related to Participation in the National Health Council

In sharp contrast to the previous section, respondents explained ‘participation in the NHC’ entirely in terms of the state’s obligations to carry out legal functions. And, the roles of the NHC were instead explained solely in relation to statutory rules—predominantly rules established by *Federal Law No 8142/1990*. Only one respondent

³⁹¹ *Ibid.*

³⁹² Respondent #12.

cited a different piece of legislation: “the NHC follows Law 141/2012 as well”.³⁹³ *Federal Law No 8142/1990* is so embedded in respondents’ interpretation of the body of law that their comments basically reiterated the very language of that statute, in particular, Art. 1, II, paragraph 1, which defines the nature, mandate and composition of health councils.³⁹⁴ In fact, one respondent asked if he could read the rules straight from that statute so he would make no mistake. In general, respondents featured the following excerpt of the legal text:

Health councils are permanent and deliberative bodies formed by 50% of users’ representatives and 50% of government, providers and [health system’s] workers to act in the elaboration and monitoring of health policies.³⁹⁵

Virtually all respondents reported that the aim of participation in the NHC is to act in the elaboration of health strategies and to monitor policy implementation and indicated general agreement on the question of what these roles entail. The following statement summarizes one of the most fundamental beliefs throughout the interview data: “the law is clear: the health council acts in the elaboration of health strategies and monitors health policies, including health finance matters.”³⁹⁶

While there is a great deal of agreement about the NHC’s roles being ‘the elaboration and monitoring’ of health policies, when asked to elaborate on the scope of each role, the data presented below suggested that the text of the law was not equally understood across respondents. The striking fact, however, was that respondents held a general perception that ‘the law was clear’ and ‘the legal roles were clear’, ‘everybody knows the roles of the NHC are to elaborate and monitor policy.’ Their different comments however suggested otherwise; that is, a significant disagreement regarding what ‘elaboration and monitoring’ actually involve. In particular, respondents’ comments offered puzzling

³⁹³ Respondent #4.

³⁹⁴ See *supra* Chapter 5, Section 5.4 or the text and analysis of the provision.

³⁹⁵ Respondent #7.

³⁹⁶ Respondent #16.

mismatches with respect to: 1) what subject matters could be included in the elaboration role; and 2) the actual authority of the NHC to carry out the monitoring role.

6.3.1 Interpretations of the Elaboration Role

Expressing consensus, there was a general agreement about ‘the elaboration of health strategies to include themes raised in health conferences.’ Asked about the connections between the NHC and health conference, respondents explained that the sequential convening of health conferences—starting at municipal, then state and ending at the national level of conferences—are aimed to gather Brazilian citizens every four years with the view of identifying health problems and proposing health strategies.³⁹⁷

Throughout the interview process, there was general agreement that the statutory role of the NHC (‘to act in the elaboration of health strategy’) had to do with converting the reports of the national round of health conferences into a strategic action plan with the view of informing Brazil’s National Strategic Health Plan.³⁹⁸ In fact, one respondent expressed a conviction that the NHC was subordinate to health conferences, and explained:

The NHC is the second highest level of policy-strategy-making in the country. We are here, the law says, at the second level of health governance, and the health conference is the first level of governance. Health conferences define health directives, the NHC articulates and defines policies according to the directives proposed by conferences and then the Health Ministry implements policies according to the directives provided by the Council and defined by the Conference.³⁹⁹

³⁹⁷ By way of background, health conferences are an additional form of institutional participation established by *Federal Law No 8142/1990*, Art, 1, I, paragraph 1. According to the statute, a series of health conference (starting at the municipal level, moving to the state level and ending at the national level of health governance) occurs every four years, with the purpose of debating health needs and proposing solutions.

³⁹⁸ As noted (*supra* note 319), the National Health Plan is Brazil’s core document listing health needs, priorities and goals for the next four years, as well as resources and steps to address the needs and meet and evaluate the goals.

³⁹⁹ Respondent #15.

Throughout the interview process it became clear that respondents' views about the elaboration role is that health conferences identify and define policy directions, and health councils design strategies to address the conference directions. One respondent, who strongly argued in favour of the scope of the 'elaboration role' being likened solely to health conferences posited: "we [the NHC] are not here to define policies in general. We are here to translate issues raised in health conferences into action plans. Period."⁴⁰⁰

While the majority of respondents spoke of the interplay between the roles of the NHC and national health conference, one respondent specifically used the language of 'obligations' to explain the elaboration role of the NHC. He stated:

Health conferences have deliberative power to approve [health-related] proposals, but the NHC has the obligation to elaborate [strategies from] conference reports and make sure that those reports are incorporated into health plans. This is the obligation of the Council [with respect to] elaboration according to Art. 2 [*Federal Law No 8142/1990*].⁴⁰¹

But, general consensus stopped at this general formulation: the NHC is responsible for converting health conference reports into recommendations for the Brazilian National Health Plan. A number of other respondents described the scope of the elaboration role in broader terms. According to this broader view, this role encompasses policy matters emerging from urgent demands that might arise, and other policy matters relevant to social organizations that constitute the NHC. Respondents who shared this broader stance promptly acknowledged that the simple fact that a wide range of policy matters (beyond conference reports) is allowable in the NHC's deliberative agenda does not mean that the NHC will in fact include broader policy matters into its agenda. As one respondent indicated, "it is easier said than done."⁴⁰² The respondent explained this lack of broad inclusion as due to the fact that the NHC's deliberative agenda was often swamped with permanent and time-sensitive matters, such as reviewing health finance statements,

⁴⁰⁰ *Ibid.*

⁴⁰¹ Respondent #7.

⁴⁰² Respondent #14.

projects of professional health-related courses, and ethical issues regarding health research, which according to her are legal obligations of the NHC. Thus, although in her view, urgent and context-sensitive matters are in principle allowed to enter the NHC's agenda as part of the elaboration role, she recognized that in practice, broad inclusion is not always the case.

In addition, other respondents indicated that procedural rules also stand in the way of meaningful consideration of social organization issues. In one respondent's experience, even when social organization issues manage to enter the busy deliberative agenda of the NHC, these issues usually go unnoticed because of the operational structure of plenary meetings. She explained:

There is little space to include local issues in the National Health Council. I tried to add [an event (omitted for privacy)] to the agenda, but [the event (omitted for privacy)] had little impact. Usually, these things are included as mere *informes* [report and information sharing]. *Informes* are the last matter [of the agenda], and usually the NHC has no quorum, no one to listen to [informes]. Then, what can we do? We can't do much.⁴⁰³

I should note, however, that respondents who do not also think that the elaboration role includes matters beyond health conference topics also reported procedural challenges. For example, one such respondent indicated concerns with the lack of organization during the meetings: "The meetings do not have a beginning, middle and a useful end."⁴⁰⁴ In his view, the structure of the meetings is messy because of this lack of organization. Or in his words, "If you put up a rooftop, [the Council] becomes a circus. If you build a fence around [the Council], this becomes a madhouse."⁴⁰⁵ One respondent, who favours a broader scope of the elaboration role also agreed that the meetings could be messy. He

⁴⁰³ Respondent #20.

⁴⁰⁴ Respondent #15.

⁴⁰⁵ *Ibid.*

suggested, “the Council is a Tower of Babel, it looks like people talk in tongues. People don’t seem to understand each other.”⁴⁰⁶

Throughout the interview process, many respondents expressed frustration with the way in which the elaboration role is carried out and the sentiment of failing the people they represent. One respondent explained: “the population does not receive the benefits from our participation in the NHC. The NHC is disconnected from grassroots communities.”⁴⁰⁷

But, the other perspective is that that not all grassroots matters belong to the agenda of the NHC. From this perspective, the NHC was required to focus on structural matters such as national health directives, goals and objectives such as health finance and health education. As one respondent explained:

It is different from the local level that looks at healthcare delivery. Here [at the NHC level], we discuss *Mais Médicos*, the law, national programs, the role of physicians, the role of the Ministry of Education, human resources, etc. With regard to *Mais Médicos*, we discuss education, hiring and residency, while at municipal level, *Mais Médicos* looks into whether physicians are attending more and better, whether doctors fulfill their workload, if communities see any difference in [population] health.⁴⁰⁸

In this respondent’s view, “not all council members understand exactly what matters belong to the NHC’s agenda.”⁴⁰⁹ Yet, the respondent who reported frustration with the lack of consideration of grassroots policy matters also expressed frustration over the fact that “many [NHC’s members] do not get the relevance of certain structural matters for

⁴⁰⁶ Respondent #6. [The expression “Tower of Babel” was used in reference to the mythological city in which God confused people’s speech, and people could not understand each other even though they were speaking the same language].

⁴⁰⁷ Respondent #20.

⁴⁰⁸ Respondent #14. [“Programa Mais Médicos” is a national program introduced in July 2013 as part of a series of measures to address unequal access to primary health care in the country. The Program consists of three components: improvement of healthcare network infrastructure; implementation of extension and education reforms of the medical courses and medical residence in the country; and an emergency physician provision program for areas deprived of doctors. For a comparative overview of this program, see e.g. Felipe P Oliveira et al, “Mais Médicos”: A Brazilian Program in an International Perspective” (2015) 19:54 Interface: Comunicação, Saúde, Educação (Botucatu) 623].

⁴⁰⁹ *Ibid.*

the population [she] represents in the NHC.”⁴¹⁰ By structural matters she meant embedded matters, such as racism and sexism, which directly affect health-related services, and ultimately, the health of certain population groups. By way of illustrating ‘deeply problematic themes’, other respondents listed topics such as pesticides, abortion, stem cells and racism.

While respondents seem to believe that procedural issues represent the core challenges for improved participation in the NHC, the finding that ‘not all grassroots policy matters belong to the Council’s agenda’ added a further piece of the puzzle: what type of grassroots policy matter actually belongs to the NHC’s agenda. This original finding hence suggests that more clearly defined roles are critical to improve the practice of the NHC. For example, 1) whether elaboration is only about translating health conference recommendations into a strategic action report for the National Health Plan or as material to be included as grassroots strategic issues; and 2) what constitutes timely and sensitive strategic grassroots issues to enter the NHC’s agenda. A lack of clarity among council members may reflect limitations in debate and discussion of the nature of the NHC’s role in relation to the right to health, resulting in differing perceptions.

6.3.2 Interpretations of the Monitoring Role

The monitoring role, known as ‘*controle social*’ (or ‘social control’), was consistently defined throughout the interviews as a mechanism by which the NHC holds government to account for the proper operation of the health system. Respondents explained that, with time, health finance and resource allocation became of paramount concern to this notion of *controle social*. Respondents believed that the monitoring role is a form of ‘policing approach’, partly due to the adoption of fiscal responsibility legislation, in particular *Federal Law No 141/2012*.⁴¹¹ As discussed in Chapter 5, the statute relates to caps and government cash transfers for the health system; it also creates a legal obligation for the NHC to review budget reports and health finance statements.⁴¹² Other respondents

⁴¹⁰ Respondent #20.

⁴¹¹ See *supra* notes 361 and 369 for the text of the relevant provisions.

⁴¹² *Ibid.*

believed that this notion of policing is rooted in the sanitary movement's proposal that the NHC oversees state action.⁴¹³ Regardless of the cause, virtually all respondents believe that the monitoring role is associated with the notion of *controle social* and related to policing (i.e., whether or not public resources were properly allocated and accounted for).

Notwithstanding the common understanding that enacted legislation required the NHC to review health finance statements and budget proposals, two respondents, one from civil society and the other from private providers, believed that the NHC lacks legal authority to review or audit health financing. For both of these respondents, the monitoring role is simply an informal means of providing expert and strategic yet non-binding advice to the Health Minister. For example, one respondent posited: "the NHC is entitled to say what is right and what is moral."⁴¹⁴ Another respondent stated:

The NHC can criticize and show problems to government actors. This idea that the NHC can exert control over state action is wrong. The NHC does not have police power to inspect government action. The law does not say that the NHC has the authority to audit state expenses.⁴¹⁵

In marked contrast, a number of other respondents—from all member groups, including government representatives—believed that the NHC has legal authority to examine government actions and health finance matters. For some respondents, the source of NHC's authority emerges from two different legal sources. According to these respondents, the NHC's legal authority derives from *Federal Law No 8142/1990*, and relates to the provision that establishes cash transfer penalties in case of government's failure to uphold NHC's resolutions regarding health financial statements. One government respondent posited:

⁴¹³ See *supra* Chapter 4, Section 4.5.3 for an overview of the Sanitary Movement in relation to the right to health and participation in the health system.

⁴¹⁴ Respondent #1.

⁴¹⁵ Respondent #16.

If the NHC does not approve the [financial] reports, the law says the [federal] government cannot transfer money to state and municipal governments. It would break the whole system.⁴¹⁶

Others maintained that the NHC's legal authority is derived from *Federal Law No 141/2012* and relates to the provision that establishes criminal liability upon council members in the case of disregarding fiscal responsibility legislation. One civil society respondent explained:

This legal responsibility was not clear before, but Law 141/2012 made it clear, council members have legal obligations now, and are criminally liable for negligent actions in relation to the finance reports.⁴¹⁷

Overall, respondents' views on the NHC's legal authority were further explored in naturalistic observation. During one of the observed plenary meetings, one council member, speaking on behalf of the NHC's Health System's Budget and Finance Committee, stated that the NHC is not for people to contribute speech only.⁴¹⁸ In his view, *Federal Law No 141/2012* directs the NHC to review the Health Ministry's finance statements.⁴¹⁹

In contrast, another council member also attending the meeting (not interviewed for this research project) reacted to the preceding statement, affirming that only the *Departamento Nacional de Auditoria do SUS – Denasus* (internal governmental controller) has the authority to audit resource allocation, including the authority to impose punishment by fine or any other penalty. Later in the same meeting, a different council member (not interviewed for this project) clarified that the *Denasus* could rely on the

⁴¹⁶ Respondent #9.

⁴¹⁷ Respondent #1.

⁴¹⁸ The NHC has a number of internal committees, including the Health System's Budget and Finance Committee (called *Comissão do Orçamento e Financiamento – COFIN*). Part of the mission of the Budget and Finance Committee is to assist the NHC to review the budget and finance statement of the health system. A full list of the NHC's committees as of January 21, 2018, as well as committee representatives and missions are included on the NHC's webpage, online: http://www.conselho.saude.gov.br/web_comissoes/index.html. Last retrieved: 4 February 2018.

⁴¹⁹ Presentation at the Council meeting, field notes at 37.

report of the NHC's Health Finance Committee, but neither the Health Finance Committee nor the NHC as a whole has the legal authority to audit resource allocations.

It seems that the NHC has some powers to review the budget of the health system. But this leads to additional questions, such as whether the NHC must therefore have additional authority, for example, the power to secure information from the federal government or to penalize government failure to address the NHC's resolutions. For a number of respondents, the NHC's authority is limited to making recommendations to government officials, who may ignore or reject these recommendations as they allocate resources in the system. This finding raises questions about whether the monitoring role is more 'pro forma' than part of an effective process that truly allows the NHC to exert influence over health resource allocation decisions and implementation.

In addition, throughout the interview process, a number of respondents (excluding government representatives) raised concerns regarding the reach of the NHC's monitoring role because of the rule that subjects NHC's decisions to governmental approval. One civil society respondent recalled that the NHC is part of the Health Ministry, and that in his view, the NHC is therefore dependent upon government officials. He noted: "our social control has little control. I often joke that we have power only to control ourselves."⁴²⁰ Such respondents perceived this ratification rule as weakening the effectiveness of the NHC and granting the Health Minister the power to selectively acknowledge the NHC's recommendations, without having an accountability to report on action or inaction. Another civil society respondent illustrated how recommendations not in line with government interests are ignored, and not even registered. He explained:

We have about 10 Resolutions. I mean, it is not one or two, I mean 10 [resolutions] waiting for publication from the health manager since 2012. You know, the manager—not us, we need to wait for the health manager, the Health Minister—to approve and publish [our resolutions]. We are in 2014, and up to now; none of

⁴²⁰ Respondent #6.

those 10 resolutions have been published only because it is not of interest of the manager.⁴²¹

In contrast, government representatives who participated in this study felt that government officials take the NHC's recommendations seriously. Indeed, participation in the NHC according to one respondent is "at the core of health governance in Brazil."⁴²² To illustrate, this respondent used the NHC's health finance reports as an example, and stated:

If we look at the Ministry's financing report, we can see many explanations addressing concerns [of the Council], for instance, often the [Health] Minister explains issues of money allocation that weren't put in a given specialty as the Council wanted because that money was [allocated within more] general budgets that incorporate the specialty. These [types of] comments happen in every single report.⁴²³

Another respondent, also from the government group, spoke of this accountability role as a state obligation to address any concern of the NHC. Yet, both government respondents have not elaborated on what they meant by "addressing" the NHS' concerns. For example, it is unclear whether in their view 'addressing' simply means clarifying issues or actually making changes according to NHC's recommendations. In fact, another respondent criticized the way in which the government addresses NHC's concerns. In his view, government officials more often than not fail to make changes according to the NHC's recommendations. He provided the following example:

The Council approves financing and budgets statements with the same provisos every single year. The government repeats the same mistakes every single year. The government does not fix [the budget allocation according to] the [Council's] provisos from the previous year.⁴²⁴

⁴²¹ Respondent #4.

⁴²² Respondent #5.

⁴²³ *Ibid.*

⁴²⁴ Respondent #4.

In his view, this recurring behaviour is problematic in two ways. On the one hand, government officials simply put off the NHC's health finance recommendations over and over again without truly addressing the reported problems. On the other hand, he considered council members too lenient toward government budgets because in reality governmental budgets should have been rejected altogether. He posited:

It is always the same old same old. Hmm, the thing would be OK once, twice, perhaps three times. But five, six times? No, it is not OK. It is too much.⁴²⁵

While the criticism about 'approving similar provisos time and time again' refers to health finance statements, this failure to take more severe actions could also speak to the fact that as discussed above, about 10 NHC's resolutions remained 'under governmental review', yet without any accountability. Two respondents believed that this leniency on the part of the NHC persists because a large number of council members favoured the then-political party in power, the Workers' Party. One respondent sarcastically stated: "anything that comes from this government passes."⁴²⁶ Yet, although in theory respondents could pursue legal action against government officials, and although NHC/Resolution 453/2012 orients legal action after 30 days (as discussed in the preceding Chapter), litigation is not seen as an effective means to hold government officials to account in relation to the NHC because of the length of legal actions.⁴²⁷ One civil society respondent noted, "the Council and the government change every few year years. Courts take time, and when the case is resolved, the government is gone. It is a waste of time."⁴²⁸

In addition, as noted in the legal analysis carried out in Chapter 5, it may be difficult for the Health Council to challenge the failure of the Minister to consider its recommendations because the legislation does not establish any particular time frame for

⁴²⁵ *Ibid.*

⁴²⁶ Respondent #15.

⁴²⁷ See *supra* Chapter 5, Section 5.4.3 for a discussion of this Resolution in general, and the clause providing a time frame for governmental response to NHC's resolutions in particular.

⁴²⁸ Respondent #12.

decision-making.⁴²⁹ For all of these reasons, consistent with the legal analysis, many respondents cautioned that the statutory arrangement governing the NHC undercuts the autonomy of the Council and hinders its ability to carry out its social control function.

6.4 The National Health Council and the Right to Health

The fact that the legal roles of the NHC are not explicitly described in association with the right to health does not mean that respondents think that participation in the NHC has nothing to do with the right to health. When asked about the NHC's role in relation to the right to health, virtually all respondents started by describing their views on the right to health. Health was commonly described in terms of physical and mental health and well-being for people to lead healthy and fulfilling lives. As two respondents suggested:

The right to health according to the law is connected with the goal of a life with dignity and quality of life. Therefore, in order to be healthy, one needs to have an adequate wage, adequate work, education, adequate food, leisure, access to culture—these are the [social] conditions of health. This is also connected with policies related to the democratic development of the country.⁴³⁰

The right to health is very broad. I do not see the right to health only as an access to medical care. I see the right to health as something much broader; for example, food sustainability and security is also part of the right to health.⁴³¹

In policy terms, respondents generally agreed that the right to health requires government officials to implement healthcare services, as well as health promotion and prevention actions by which people could access opportunities to improve their health and lives. As one respondent noted, “treatment is the tip of the iceberg. It is the last thing. It is critical to create social contexts in which people can have good health.”⁴³² There was consensus among respondents that the constitutional provisions create the right to health as interrelated with other rights, in order to ensure a good life, because “we may have

⁴²⁹ See *supra* Chapter 5 for detailed discussion of this argument.

⁴³⁰ Respondent #11.

⁴³¹ Respondent #6.

⁴³² Respondent #17.

excellent healthcare, but if people do not have jobs or food to eat, people won't be healthy.⁴³³ As one respondent observed:

We need to finance healthcare and implement policies to provide immediate healthcare for the sick. But, we need to finance access to work, education, leisure, culture and all other underlying conditions for good health, too.⁴³⁴

Asked about how the NHC's legal roles relate to the right to health, an overwhelming majority explained the relation between the NHC's roles and the right to health in terms of 'aptitudes' and 'feelings', rather than obligations to carry out specific course of action. For example, one respondent stated:

When I am in the NHC, I ask myself if this [service or action] is in favor or against the principles of the SUS [health system]? If I feel that I am acting in line with the principles of the SUS, I do not even question my decision. I simply do it.⁴³⁵

And, when asked to elaborate, the most common narrative throughout the interview process explained this feeling in terms of 'balancing individual and collective expressions of entitlements and state obligations', with one respondent in fact suggesting:

There must be a balance. It is obvious that in the event of an exceptional case, urgent situations must be dealt by the SUS [health system]. But overall, collective interests must prevail. I think it is critical to better define expectations for health-related actions that are possible to implement at this point in time.⁴³⁶

One respondent pointed out how the healthcare needs of one individual citizen can be 'transformed' in a broader need to change health policies and improve the system as a whole. He explained:

⁴³³ Respondent #6.

⁴³⁴ Respondent #17.

⁴³⁵ Respondent #3.

⁴³⁶ Respondent #9.

Some time ago, one person needed a specific medication that the SUS didn't cover. Then, a physician from [city omitted] asked me 'you are there at the NHC, why don't you ask the people there to ask the state to update the medication list more frequently?' If the list were updated more often, and included more efficient medications, procedures and equipment, it would help all of us in many diseases, including cancers, AIDS, *etc.* Then, we [the NHC] worked on a proposal in collaboration with the government to have a team revising these things more often. So this demand came to us as an individual demand to access a specific medication, but our [NHC's] pharmaceutical committee re-addressed the demand to a more general dimension.⁴³⁷

There was consensus among respondents that the NHC should work as a catalytic space in which individual and collective expressions of the right are discussed and negotiated on an ongoing basis for improvement of the health system as a whole. One respondent, for instance, reported that in the NHC, people could feel the pain of others:

What I notice is that people in the NHC feel the pain deeply in their own skin, not only physical pain. A person with celiac disease, for instance, fights with a profound awareness that she has to fight for her right to have adequate food labels, etc. I can feel their pain.⁴³⁸

Another respondent reported that she had learned about others' needs and fights, as well as about various healthcare services, and she felt that she could collaborate in different health-related demands to make sure that the health system worked in the best way possible. For example, she stated:

We are representing [specific area omitted], but we had to learn about other areas, a little about each pathology and disability, about the issues that health professionals face in the system. So, we want health professionals with career goals and plans, we feel bad for regions with physician shortage. We take part in fights that don't belong to [organization omitted] specifically.⁴³⁹

While the overwhelming majority acknowledged the motivation behind the NHC for 'negotiation of different expectations', some respondents—from all groups—reported

⁴³⁷ Respondent #7.

⁴³⁸ Respondent #18.

⁴³⁹ Respondent #13.

legal and procedural barriers that stood in the way of meeting such a goal, including the issues related to NHC's authority and organization of the meetings, as discussed above.

Furthermore, some respondents expressed concerns with what a respondent described as an "excessive right to health litigation".⁴⁴⁰ There was a consensus among respondents that 'an individual's right to health does not mean individual citizens suing the government to access medication'. One government respondent posited:

I can say that [litigation] is a dilemma that worries health managers and government officials. It disorganizes health planning completely. Why? Health managers allocate resources for a given area, but judicial decisions order the government to provide this or that. This judicial pressure smashes the planning, and we have to comply with the order or we go to jail. Judicial decisions putting a lien on official's assets has become trendy nowadays (...) Public prosecutors and judges look from the perspective of the individual and based simply on Art. 196, the judge says the individual has a right and the state has to give her right. The end.⁴⁴¹

The majority of respondents seem to share a common sentiment that judicial orders for individualized healthcare provision of treatment not being covered by the health system is not an individual expression of the right to health. As noted in the preceding Chapters, the basis of the courts to order healthcare services or goods that are not covered by the health system is grounded on individuals' risk of death if not received the requested healthcare service. But, as one civil society respondent explained:

Individuals that feel entitled to obtain a medication or a service that isn't covered by the health system go to the *Ministério Público* [Brazil's public prosecutor's office], and if the judge tells the system to do it, then the system has to do it. This isn't an obligation that is part of the health system. The government is only complying with a judicial order.⁴⁴²

It is almost as if health-related judicial orders are simply court orders, but not part of the health system. In contrast, the individual expression of the right to health part of the

⁴⁴⁰ Respondent #9.

⁴⁴¹ Respondent #8.

⁴⁴² Respondent #7.

health system as articulated by many respondents revolved around the notion of making sure the health system provides equal access to actions and services to specific needs in the health system. As respondents explained, individual expression of the right to health means health officials incorporating specific healthcare treatments to the health system and ensuring adequate and equal access to everyone who needs similar treatment. One respondent gave an example of how this interaction works:

A person with sickle cell anemia has an individual right to receive healthcare, but because [the treatment for sickle cell anemia] is a public policy that is part of the health system interlinked to other health programs, this [individual need or] right becomes a social [or collective expression of] right.⁴⁴³

That is why respondents believed that when courts order government officials to provide an uncovered treatment to individuals, it is simply an isolated judicial order, and not a health policy in which the individual and collective expression of health-related needs is duly taken into account. Respondents, furthermore, believed that judicial cases in the context of Brazil are problematic because there are not enough resources to provide everyone with all sorts of health-related needs.⁴⁴⁴ If priority were given to an individual claimant's needs without due consideration of the needs of the whole population, the feasibility of the health system would be compromised in respondents' view. One respondent suggested, "Better understanding of constitutional principles such as comprehensiveness and integration of health-related services is key to balancing both dimensions of the right to health."⁴⁴⁵

The discussion by respondents suggest that one of the significant contributions of the NHC to the right to health is its unique approach to exploring the implications of the collective, community-focused underpinnings of Brazil's right to health. The basic idea is that the right to health requires the state to implement a whole set of actions (i.e., a

⁴⁴³ Respondent #2.

⁴⁴⁴ See *supra* Chapter 2, Section 2.3 for this debate in the context of Brazil. See generally Ferraz, *supra* note 6.

⁴⁴⁵ Respondent #9.

system) that will protect and recover the health of everyone, and specific health-related needs are addressed within this whole system.⁴⁴⁶ The NHC provides a broader context within which to understand the implications and risks of the individual versus the collective perspective inherent in much of the right to health litigation. In general, respondents' narratives about the NHC in relation to the right to health revolved around commitments to the constitutional principles of the health system: universal and equal access to all available services.⁴⁴⁷ The following quotation reflects the common understanding among respondents as to whether an individual right or a collective right to a system should prevail:

I think that there must be a clear, sensitive, and strongly balanced consideration between the twofold aspects of the right to health, but that the collective interest should prevail.⁴⁴⁸

Consistent with the literature discussed in Chapter 2, some respondents have pointed to a need of balancing this notion of individual interest (access to individual healthcare) and collective interest (access to a health system in place); in particular, to deal with the issues of justiciability of the right to health.⁴⁴⁹ That is not to say that respondents are unaware of the high rates of disease and poor conditions of healthcare services within the country. But there was a consensus among respondents that in a country like Brazil that has such large unmet healthcare demand, something is wrong in terms of health financing across the full spectrum of care. As one government respondent observed, the lack of adequate promotion and prevention is to blame for poor healthcare for many Brazilians:

Poor health conditions will reflect first on the health of individuals; people get sick, epidemics spread contributing to poor health, and healthcare demands increase. In Brazil, this problem of healthcare demand means that health promotion and prevention are failing the people.⁴⁵⁰

⁴⁴⁶ See *supra* Chapter 4, Section 4.5 for this discussion and analysis of the right to health framework.

⁴⁴⁷ *Ibid.*

⁴⁴⁸ Respondent #9.

⁴⁴⁹ See *supra* Chapter 2, Section 2.3 for this debate.

⁴⁵⁰ Respondent #19.

Several respondents provided various examples of the challenge of establishing a balance between promoting health and treating disease in the health system, noting in particular the public's focus on treatment over prevention. For example, as one respondent noted:

We wanted to discuss the National Health Promotion Plan but people wanted to talk about healthcare only. (...). They did not want to discuss ways to stop smoking; they wanted to talk about the lack of doctors to treat their cough. They wanted to talk about the lack of access to services.⁴⁵¹

Additionally, a few respondents blamed this excessive concern with treatment on what they called culture of disease and private healthcare. For example, one civil society respondent expounded:

Health promotion and prevention work is critical to prevent people from getting sick. Prevention requires investment and interventions, but it also requires information and education. Because it is not enough to have money if we don't educate people that they need to take care of themselves, because if they don't, they will get sick. We need to build a culture of health in the people's minds, in the media, because this culture of healthcare, of private healthcare, is a problem.⁴⁵²

In short, respondents involved with the National Health Council recognized that there is no simple formula for determining the individual and collective dimensions of health or state compliance with the right to health. Respondents did not deny the individual dimension of the right to healthcare either. Indeed, respondents recognized that the government has a constitutional duty to provide the means to achieve the right to health for all. But, at the same time, respondents challenged the individual versus state conception of right to health developed through litigation in Brazil. Respondents commonly expressed the view that the state's obligations with regard to the right to health require state implementation of a full spectrum of health-related prevention, promotion and recovery policies and services. In addition, the NHC was perceived as a democratic and catalytic space for change in that the various health-related needs are

⁴⁵¹ Respondent #12.

⁴⁵² Respondent #11.

brought up, duly taken into account and balanced against one another.

6.4.1 The National Health Council's Outcomes

For one respondent from the users group, “the National Health Council is disconnected from a local basis.”⁴⁵³ As quoted above, other respondents, from users, health workers and private providers groups, believe that the meetings of the NHC are messy and ineffective.⁴⁵⁴

My first impressions in observing two plenary meetings of the NHC were consistent with the view that ‘the Council is a Tower of Babel’ and far from local needs. The Council was like the mythological city and council members/citizens appeared to speak past each other without any understanding despite the fact that they were all using the right to health as a framework to assess state actions. At the end of a five-hour meeting, whose objective was to vote on approving or rejecting a food guide from the Health Minister, the chairperson adjourned the vote until further notice, which made me think that the whole five-hour wide-ranging discussion was a waste of time.

However, analyzing the transcripts and field notes, I understood—indeed, appreciated—what the data was telling me: the meeting showed the Council as a space to raise the breadth and diversity of perspectives regarding all dimensions of the fundamental right to a health system. The points brought up in the meeting illustrated that the Council worked as a catalytic space for applying nuanced views to assess state action, in light of the right to health framework. For instance, one of the goals of a meeting I observed (the meeting of February 5, 2014) was for NHC members to provide input on the food manual elaborated by the Health Ministry. As is the case for any decision from the Council, it has to be decided by vote; thus, the core aim for the meeting was to agree and vote on considerations for the guide.

⁴⁵³ Respondent #20.

⁴⁵⁴ See e.g. *supra* notes 405 and 406 (Respondent #15). See also, *supra* note 407 (Respondent #6)

After two presentations on the food guide, the chairperson opened debate, and virtually all Council's members requested time to speak. While some members were concerned with political aspects related to the promotion and collective dimension of the right to health (e.g. for the relevance of including a pesticide-free food section in the food manual). Others were concerned with practical aspects related to individual and preventive dimensions of the right to health (e.g. for accessibility and effectiveness of the manual, and labels). Still others were concerned with the overall food policy of the Health Ministry—for instance, inter-sectorial actions amongst Ministries in order to promote access to affordable and nutritious foods, in relation to different groups and health-related needs; and to address health insecurity, in particular with regard of marginalized populations. All concerns aimed to assess the various dimensions in which the food guide, and the policy as a whole, complied with state obligations towards the social dimension of the right to health and access to food. At the end of the meeting, the discussion looked like a mess: one member talking about printing the guide in braille, others talking about rural and agricultural communities having experienced higher rates of abortion due to pesticides, and others yet talking about practical aspects of the guide consultation process. The desired objective—voting on the content of the manual—was deferred to a Committee of the Council for further analysis.

Even though some Council member participants in the study used the food manual discussion to illustrate the lack of understanding amongst members and the seeming waste of time in the meetings, the meeting clearly represented a broad assessment of state action, in this case, with regard to the adequacy and effectiveness of the guide manual to address issues related to the rights to health and food. Truly evaluating the outputs of the meeting requires, for instance, an assessment of the Committee that examined the food guide, as well as how the food guide incorporated the outputs of the Council, whether and how the guide has affected people on the ground, and how the Council has been fostering inter-sectoral policies related to food. In this way, instead of thinking about shortfalls of plenary meetings or the efficiency of the meeting, it is perhaps useful to consider plenary meetings as spaces whereby the various dimensions of the right to health are taken into account. And even though not all dimensions are appreciated in all meetings, or included

in a single resolution, the meetings, and the Council in general, serve as catalytic spaces to include the various dimensions of the right to health a system.

Despite these important contributions, the NHC's ability to truly participate in health planning is undercut by the absence of a clear government obligation to provide a timely and meaningful response to the Council's recommendations. The accountability and responsiveness of the health planning process would be improved if governmental officials were required both to respond to the Council's recommendations within a set time frame and to provide an explanation about whether and how the Council's recommendations have been incorporated into health planning. And, as I established in the constitutional analysis carried out in Chapter 4, Brazil's right to health includes within its broad scope a requirement to integrate social actors in an accountable and responsive health planning process.

6.5 Conclusion

The aim of this Chapter was to discuss the interpretations ~~and critiques~~ of a sample of NHC members regarding the legal structure of the NHC, as well as the perceived legal barriers to the implementation of the participation required by the Constitution and the framework of the NHC as a participatory entity. The questions guiding this chapter were aimed at gathering data about how respondents understand the legal structure of NHC (i.e. nature, composition and mandate) in relation to the constitutional requirements of Brazil's right to health, and the perceived legal barriers to the implementation of the law.

A core finding of this study is that respondents interpret participation in the NHC in terms of legal obligations to carry out the legal roles of the Council, particularly the legal roles established by *Federal Law No 8142/1990*. Clearly defined roles thus are particularly important considering the fact that respondents describe participation in the NHC precisely in terms of carrying out the statutory roles of the NHC. The data however, indicated that Council members who participated in this study did not understand the legal roles of the NHC in the same way. With much of today's legal and political

literature on health councils focused on compliance with procedural rules, this research underlines more fundamental sources of misperception: what the legal roles entail and how the legal roles relate to the right to health.

Another study finding is that respondents do not explicitly associate participation in the NHC with the state's constitutional obligations to the right to health. Respondents interpret the state's obligations in terms of creating an adequate health system based on comprehensiveness of services and equality of access. Respondents do not see participation in the NHC in terms of the state's obligation to ensure participatory health governance as determined by the constitutional analysis and expounded in Chapter 4.⁴⁵⁵ A better understanding of the interconnection between the NHC's legal roles and the state's obligations to enable and ensure participatory health governance, may promote more effective tools for the NHC to report on governmental action or inaction in relation to participatory health governance. More attention to legal arrangements could also aid some solutions to problems indicated in this study such as government setting aside NHC recommendations or Council members' frustration with respect to the scope of the legal roles.

Finally, the qualitative findings revealed that the National Health Council is perceived to act from a local and individual point of view, accompanied by some consideration of the dimension towards a collective dimension of the right to health, to the benefit of all. In particular, respondents' approaches to the individual and collective dimensions of the right to health provided a helpful framework for understanding how council members who participated in this study use the right to health as a framework to navigate the various dimensions of the right and to hold the state to account for the principles of universality and equality. An example is the case in which participants use the right to health to transform demands (that are framed as an individual's right to improve one's health, e.g., access to a medication) into a health policy strategy framed as a collective

⁴⁵⁵ See *supra* Chapter 4, Section 4.5.1 for the analysis and conclusion.

right to improve the workings of the system as a whole (e.g., dropping timeframes for reassessing medication coverage).

In the next and final Chapter I will discuss how the overall research answered the questions set forth in this study, consider the implications of this study and propose recommendations for future research.

7 Synthesis and Conclusion

7.1 Introduction

In Brazil, participation in the organization of the health system was accorded constitutional status as part of the right to health in the 1988 Federal Constitution. It is hard to overstate how significant this development was, in a country riddled by 20 years of military dictatorship, furthering Brazil's systemic and historical problems with health inequalities, and inequality in general for that matter. Citizen participation in the health system was thought to not only promote a more responsive and accountable health system, but also a vital part of Brazil's new constitutional democratic government.⁴⁵⁶ For other societies that through their own experiences have developed an interest in what operationalizing a 'right to health' entails, the Brazilian experience is of particular interest as a 'natural experiment'.

Thirty years forward, the country has created a remarkable network of participatory bodies at the three levels of health governance and across the five regions of the country, involving over 100,000 citizens in the governance of Brazil's health system. Brazil's participatory governance has caught the worldwide attention of researchers and policy makers.⁴⁵⁷ As discussed in *supra* Chapter 2, notwithstanding the significant scholarly and empirical interest in social and political science circles in Brazil and elsewhere, I was utterly intrigued by the slight attention that citizen participation in health planning and resource allocation has elicited in the (Brazilian) legal community.⁴⁵⁸

⁴⁵⁶ See *supra* Chapter 4, Section 4.2 for this argument, and Section 4.5.3 historical context of the Constitution.

⁴⁵⁷ See e.g. Sabine Kleinert and Richard Horton, "Brazil: Towards Sustainability and Equity in Health" (2011) 377:9779 *The Lancet* 1721. [This article is part of *The Lancet's* special issue entitled 'Series Brazil' in 2011 discussing Brazil's experience in public health. In the opening comments, Sabine Kleinert and Richard Horton refers to Brazil's experience as a source of inspiration and evidence: "strong emphasis on health as a political right, together with a high level of engagement by civil society in that quest, might also mean that other countries can look to Brazil for inspiration (and evidence) to solve their own health predicaments" (*ibid* at 1721-22)]. See also Archon Fung & Erik O Wright, "Deepening Democracy: Innovations in Empowered Participatory Governance" (2001) 29:1 *Politics and Society* 5.

⁴⁵⁸ See *supra* Chapter 2, Section 2.4 for an overview of the literature about citizen participation in the health system as part of the right to health.

In this investigation, I argued that citizen participation in the health system is a requirement of Brazil's right to health, and that the National Health Council is the key mechanism to meet the constitutional requirements at the national level of health governance. The objectives set forth in this study were to analyze the constitutional requirements for citizen participation and to gather qualitative data about the implementation of the participation requirement in the National Health Council. The specific questions guiding this study were: What is the content and scope of the participation requirement found within Brazil's constitutional right to health? How does the legally empowered participatory body, the National Health Council, relate to the constitutional requirements of participation? What do National Health Council members perceive to be the legal barriers to the implementation of the participation requirements?

In pursuing the aims of this study, I analyzed the constitutional and legislative basis for participation in the NHC, and presented the results of qualitative interviews of a selection of NHC's members and non-intrusive observation of two meetings of the NHC. My research method was selected to gather data about how NHC's members understand their participatory roles and to identify possible legal barriers to participation. Based on the analysis and evidence, I identified two key issues: National Health Council members generally lacked clarity about the scope of the Council's legal role and the Council has not been given full legal authority to carry out its legal mandate.

In this concluding Chapter, I offer a summary analysis of the previous Chapters and synthesize the research outcomes to offer a context-sensitive view of the constitutional and legislative basis for participation in the NHC. This Chapter, furthermore, discusses the implications of this research, the specific contributions to the legal literature and practical recommendations. I conclude this Chapter, and dissertation, by offering directions for future research.

7.2 A Synthesis of the Findings

7.2.1 Participation is a Requirement of Brazil's Right to Health

As discussed in Chapter 4, it is widely accepted in the Brazilian legal community that health is a fundamental right, that the right entails positive obligations against state actors, and that these obligations are enforceable in the courts.⁴⁵⁹ The courts, as discussed in Chapter 2, have not shied away from enforcing the right to health against government officials.⁴⁶⁰ In Chapter 2, I also noted that there has been one *positive* basic *right* persistently recognized by the Brazilian courts: the right of individual citizens to certain types of healthcare treatment and prescription medication.⁴⁶¹ As discussed in Chapters 2 and 4, while healthcare litigation might serve as a catalyst for change in healthcare access of those individuals who access the courts, healthcare litigation poses serious challenges to health planning and resource allocation in Brazil.

While I espouse this serious concern, I believe that the legal community has been so absorbed in issues of health litigation and healthcare delivery that the majority of legal scholars have overlooked other equally important elements of Brazil's fundamental right to health. Some legal scholars have turned to issues such as this interpretation and others have proposed broader interpretations to include the right to health promotion and prevention measures such as access to sanitation interventions.⁴⁶² As discussed in Chapter 2, this study contributes to other dimensions of Brazil's fundamental right to health: community participation in health planning.

Chapter 4 carried out a systematic constitutional analysis to determine the meaning and scope of citizen participation as part of the right to health as established by the 1988 Constitution of Brazil. The Constitution establishes 'participation' as a '*diretriz*' for the organization of the health system, and the health system as an obligation of the state

⁴⁵⁹ See *supra* Chapter 4, Section 4.4 for this discussion.

⁴⁶⁰ See *supra* Chapter 2, Section 2.2 for an overview of the role of the courts in healthcare litigation.

⁴⁶¹ *Ibid.*

⁴⁶² For this debate, see generally Ferraz, *supra* note 6.

toward the right to health. A core task of Chapter 4 therefore was to determine the nature of ‘community participation’ in the right to health framework. The guiding question focused on whether the state is required to include participation in the organization of the health system. As explained in Chapter 4, an answer to this question was sought by examining the understanding of the concepts designated by the terms ‘fundamental’ and ‘social right’ and the meaning of the word ‘*diretriz*’.⁴⁶³

Following this in Chapter 4, I also carried out a semantic and structural analysis of the concepts ‘fundamental’, ‘social right’, and the word ‘*diretriz*’, and concluded that the right to health entails more than the *right* to certain types of healthcare.⁴⁶⁴ The right to health also entails the right to a comprehensive health system, which includes healthcare treatment. But, to be clear, it is not a right to any type of health system, as political actors please. It is worth recalling that the Brazilian Constitution is a directive instrument, meaning that the Constitution provides not only principles, but also enforceable obligations given to political actors to be carried out while framing and implementing laws and policies. In the case of the state’s obligations to the health system, as discussed in Chapter 4, government officials are required to create and implement a decentralized, comprehensive and *participatory* health system based on universal and equal access to healthcare, as well as to health promotion and prevention measures. This study focused exclusively on the participatory dimension of the state’s obligation and concluded that participation is in fact a requirement of the right to health.

The analysis in Chapter 4 produces two important lessons.⁴⁶⁵ First and foremost, community participation is a state requirement, as part of Brazil’s fundamental social right to health. Second, and related, Congress and government officials are required to integrate some sort of participation in the organization of the health system as part of the obligation of the state toward the right to health.

⁴⁶³ See *supra* Chapter 4, Section 4.5 for detailed explanation of this point.

⁴⁶⁴ See *supra* Chapter 4, Section 4.5.1 for the analysis.

⁴⁶⁵ See *supra* Chapter 4, Section 4.5 for this conclusion.

Moving beyond analysis of law and legal interpretations, I sought to explore the question: How do the respondents understand the concept of participation? One of the findings to emerge from my qualitative analysis concerning the right to health, discussed in Chapter 6, is that respondents perceive Brazil's right to health far outside of narrower notions of healthcare and prescription medication.⁴⁶⁶ Consistent with the constitutional analysis therefore, respondents understood the right to health as the right for the people of Brazil to have an adequate and comprehensive health security system provided by the state. Common responses included, "the right to health is not a right to healthcare as people think" and "the right to health includes not going to court for medication."⁴⁶⁷ Respondents went to great lengths to explain the problems with today's prevalent judicial interpretation of the right to health in Brazil, and the need to weigh individual healthcare needs against the health-related needs of over 208 million Brazilians.⁴⁶⁸

Responses, moreover, included rich descriptions of ways in which participation in the NHC carried out a more balanced analysis between individual and collective expressions of health-related needs. In one respondent's view, "this [judicial] interpretation will break the system to say the right to health in Brazil means only the provision of individual healthcare."⁴⁶⁹ One avenue for future research is to systematically examine how council members, and the NHC as a whole, carries out this imperative task of balancing the diversity of health-related needs, involving how the plural needs are included and discussed in the NHC's agenda, and the NHC's recommendations on resource priority and allocation.⁴⁷⁰

Another important and interesting finding to emerge from my qualitative analysis is NHC

⁴⁶⁶ See *supra* Chapter 6, Section 6.4 for an overview of respondents' understanding of the right to health in Brazil.

⁴⁶⁷ See *supra* Chapter 6, Section 6.4 for respondents' views on the right to health.

⁴⁶⁸ *Ibid.*

⁴⁶⁹ Respondent #9.

⁴⁷⁰ As pointed out in Chapter 6, *supra* Section 6.4, one way is by transforming individual healthcare needs into better health services, such as the example of one individual's need to receive a given medication can drive change in the drug review process for the system as a whole.

Council member respondents' perceptions of participation and the right to health. From the data analysis, as discussed in Chapter 6, it could not be determined for certain that respondents perceive participation in the health system as a requirement of the right to health. In other words, for those seeking to operationalize this aspect of the right to health, further research is needed to explore, more deeply the extent to which it might be helpful for participants to have a more thorough understanding of their constitutional role.

The qualitative analysis in Chapter 6 determined, however, that respondents interpret participation as part of the right to health and specifically understand this as including freedoms to assemble and to speak out as a group or individually, as well as the ability to associate with social organizations or trade unions, and to take part in collective actions for social change.⁴⁷¹ As noted above, the constitutional analysis also concluded that participation as part of the right to health as expressed in the Constitution holds a loose meaning likened to wide citizen inclusion in the full spectrum of health system governance.⁴⁷² But, while the constitutional analysis concluded that the state is required to create a participatory health system—that is, to integrate citizen participation into health governance, respondents' comments did not go that far. In other words, at no point did respondents use words such as 'requirements', 'obligations' or 'duties' to refer to citizen participation and the right to health.

My first reading of this finding was to observe respondents' general sense of disapproval regarding the notion of 'participation as a requirement'. As one respondent noted, "there are many gray areas in participation, and participation does not fit in legal boxes of legal obligations."⁴⁷³ But as I immersed myself in the original data reading the transcripts and field notes over and over again and closely engaging in the coding, I realized that perhaps respondents' worldviews might have prevented them from describing participation as a requirement of the right to health. It is true that at no point did respondents use words such as 'requirements' and 'obligations' in relation to participation and the right to

⁴⁷¹ See *supra* Chapter 6, Section 6.2 for detailed report of respondents' views.

⁴⁷² See *supra* Chapter 4, Section 4.5.1 for this analysis.

⁴⁷³ Respondent #12.

health. And yet, when similar codes were gathered together into categories it seemed plausible to assume that respondents would agree with the proposition that government officials have some obligation toward participation, at least on a very general level such as obligations to respecting freedom of assembly, information sharing and civic education. Let me offer an illustration to support my argument. As reported in Chapter 6, during one of the observed plenary meetings, some respondents commented on the inadequacy of public funding for Council members to participate in a strategic planning retreat.⁴⁷⁴ And as noted, at no point in the meeting did respondents indicate that the government was not responsible for providing resources for NHC members to attend the retreat.

After extensive analysis, I came up with an explanatory framework to describe this research outcome. ‘Participation’ and ‘requirement’ are both loaded terms that elicit strongly positive or negative reactions informed by worldview frames and background experiences.⁴⁷⁵ Generally speaking, ‘participation’ for social and health activists in Brazil (in the case of participants in this study) refers to the notion of ‘freedom’, ‘liberty’ and ‘choice’ to demand action from political actors and government officials to implement adequate health-related actions and services.⁴⁷⁶ The term ‘requirement’ instead refers to legally binding duties and subject to judicial intervention.

Conversely, from the lens of a health and human rights researcher like myself, the notion of participation as a requirement of the right to health raises a notion of holding state actors to account for enabling and ensuring genuine participation in health planning.⁴⁷⁷ Participation as a requirement does not imply therefore that people are compelled to participate in health planning. Rather, this notion places responsibility upon political

⁴⁷⁴ See *supra* Chapter 6, Section 6.2 for this point.

⁴⁷⁵ See especially *supra* note 121 for an overview of the literature on this matter. See also *supra* Chapter 6, Section 6.2 for respondents’ perceptions on this matter.

⁴⁷⁶ See *supra* Chapter 4, Section 4.5.3 for a historical analysis of health activists who participate in the drafting of Brazil’s right to health, and participation as part of the right.

⁴⁷⁷ See *supra* Chapter 2, Section 2.4 for an overview of the health and human rights literature on participation.

actors to provide the means by which citizens have genuine opportunities to influence health planning. From this perspective, government officials can be held accountable for providing the means and enabling the conditions by which the people of Brazil— those who choose to participate—can exercise the freedom to participate in health planning. Hence participation as a state obligation would work as a catalyst for advancing active participation in health planning.

Put simply, my argument is that particular worldview frames might have prevented respondents from seeing participation as a requirement. Further research is needed to assess this claim. But, even though this study still leaves such an important concern unresolved, in no way do the qualitative findings refute the fact that participation is a core component of the right to health in Brazil or diminish the value of institutional participation for the betterment of the health system.

Further, while my empirical findings suggest that NHC participation in health planning and resource allocation can potentially foster systemic change, I have to point out that this study was not designed to “prove” that participation has actually led to effective on-the-ground change. As discussed in Chapter 3, this is a small-scale study that draws on the experience of 26 NHC members during the 2013-2015 term. Further research is critical to systematically explore the perspective of other NHC members, the degree to which the NHC’s recommendations are integrated into national health policies, and whether and how these recommendations in fact contribute to improved access and overall population health.

As a final word, I would suggest that more research is also needed to develop indicators to examine institutional participation in health councils and health conferences in a continuous-process-driven way rather than an outcome-based fashion. While my findings suggest that a specific NHC recommendation is important (e.g., provisos to financial statements), my findings also point out to the fact that the way state actors react to and act upon the NHC recommendations, as well as the impact of NHC recommendations to access and population health are equally important. Indicators need to integrate this

continuum of participation.

7.2.2 Constitutional Requirements for Participation in the Health System

Having determined that the right to health entails the state's obligation to implement a participatory health system, Chapter 4 turned to the meaning and scope of participation in the health system. In other words, Chapter 4 examined the meaning of the words 'organization', 'community' and 'participation' in order to determine the basic constitutional requirements of participation as part of the right to health.

'Community participation' as established by the Brazilian Constitution means broad inclusion. Although the constitutional language is too vague to provide a clear definition for 'community' and the processes and conditions by which community participates in the health system, nevertheless a semantic and theoretic consensus informed the analysis. The term 'community' is ordinarily and sociologically understood in broad terms to refer to social groups united by geographic spaces, identities or interests. The term 'participation' is understood through semantic and theoretic consensus as any form of action by which social groups intend to improve their health and wellbeing either on their own initiative or as encouraged by others. Hence, Chapter 4 concluded that both the ordinary and specialized meanings of the words 'community' and 'participation' are loosely used in the Constitution in order to allow wide involvement in the health system of everyone possibly affected by or interested in health policy decisions.⁴⁷⁸

A further important examination involved the meaning of the word 'organization', as it might be understood in the phrase 'community participation in the organization of the health system'. As discussed in Chapter 4, the word 'organization' is also used in the Constitution in a broad sense. 'Organization' means the full spectrum of health system interventions from planning and implementation to evaluation, and from promotion and prevention to treatment.⁴⁷⁹

⁴⁷⁸ See *supra* Chapter 4, Section 4.5.3 for detailed analysis.

⁴⁷⁹ See *supra* Chapter 4, Section 4.5.2 for detailed analysis.

The most fundamental requirements for participation as part of the right to health therefore includes broad citizen inclusion and the genuine opportunity to influence the entire spectrum of health system interventions on an ongoing basis.

The qualitative findings discussed in Chapter 6 are consistent with the conclusion arrived at the constitutional analysis in Chapter 4. A key theme to emerge from the original data is the belief that ‘community’ means civil society at large, and ‘participation’ means civil society inclusion in political matters. There is a consensus amongst respondents that ‘participation in the Constitution allows everyone in’ and that there are no strings attached to participate, for example, “people don’t need to be part of any social organization.”⁴⁸⁰ In general, ‘community participation’ is perceived as people taking rights into their own hands to demand change, a powerful force able to change people’s lived experience.

Consistent with the constitutional analysis, respondents also explained the scope of potential activities for community participation involvement in the ‘organization’ of the health system in very broad terms. As noted above, a common understanding across the data is that the right to health is related to entitlements to access a comprehensive health security system, including healthcare services, promotion and prevention measures. As respondents explained, “we may have excellent healthcare, but if people do not have jobs or food to eat, people won’t be healthy.”⁴⁸¹ “Treatment is the tip of the iceberg. It is critical to create social contexts in which people can have good health.”⁴⁸² Community participation can take place at any of these health system interventions to demand “certain benefits that have been denied to them, benefits may exist or may not exist and people want such benefits to exist.”⁴⁸³ Thus conceived, for respondents, ‘participation in the Constitution’ meant broad inclusion and broad range of activities, from individual

⁴⁸⁰ See *supra* Chapter 6, Section 6.2 for respondents’ views on this matter.

⁴⁸¹ Respondent #6.

⁴⁸² Respondent #17.

⁴⁸³ Respondent #6.

citizens demanding certain healthcare services to civil society organizations pressuring political decisions.

Based on the constitutional analysis and qualitative evidence, I concluded that the basic requirement for ‘community participation in the health system’ is freedom to take part in political action similar to a right of association. Particularly with respect to the health system, the fundamental requirement is broad inclusion in the full spectrum of health system interventions, ranging from planning and implementation to evaluation, and from promotion and prevention to treatment, on an ongoing basis.

One can speculate whether it would be acceptable for Congress to pass legislation creating consultation processes, rather than power-shared participation mechanisms such as the NHC represents. In principle, consultations would not be unconstitutional, as long as consultation happened along the entire spectrum of health system interventions and were integrated into policy development. Consultation would likely run against the opposition of the health reform activists behind the drafting of the right to health (who advocated for power-sharing and social change), as discussed in Chapter 4.⁴⁸⁴ Nonetheless, in light of the constitutional silence concerning specific requirements for participation processes, and therefore, some degree of political discretion, any form of broad inclusion could in theory be acceptable.

The point here is not to advocate for consultation as a means of giving effect to participation in the health system. The point is to make clear that the constitutional finding detailed in Chapter 4 neither starts nor ends with a claim that institutional participation, and participation in the NHC in particular (as I discuss later in this Chapter), is the only way to give effect to the constitutional requirement of participation. Indeed, the possibility of other forms of community participation (for e.g., consultation or mobilization) was recognized in Chapter 5.⁴⁸⁵ People may choose to not get involved in

⁴⁸⁴ See *supra* Chapter 4, Section 4.5.3 for the historical analysis of the framers’ intention.

⁴⁸⁵ See *supra* Chapter 5, Section 5.4.2 for this point.

state institutions, such as health councils, and rally against public cuts to healthcare and education or send letters to pressure politicians to pass more flexible abortion legislation, for instance. The state is responsible for respecting and protecting people's fundamental freedoms. But, there is also the fact that participatory governance is a requirement of the right to health.⁴⁸⁶ Community participation as part of the organization of the health system is also a requirement of the right to health and entails broad inclusion in all aspects of health system interventions.

7.2.3 Participation in the National Health Council

Having established the general requirements for participation in the health system in Chapter 4, the dissertation turned to the legal framework to examine the specific rules for participation in relation to the constitutional requirements in Chapter 5. The legal analysis in Chapter 5 concluded that participation in the NHC is the key mechanism created to give effect to the constitutional commitment to participation in the health system.⁴⁸⁷ The straightforward explanation is that in 1990 Congress passed two pieces of legislation purposely to create Brazil's Unified Health System (*Federal Law No 8080/1990*), and to establish health councils as the mechanisms by which civil society representatives are integrated in health governance (*Federal Law No 8142/1990*).

As discussed in Chapter 5, the closest that health laws get to the right to health framework is found in the *Organic Health Law* (Art. 7), which establishes that health actions and health services within the Unified Health System should obey the constitutional framework.⁴⁸⁸ Generally speaking, the legal analysis carried out in Chapter 5 concluded that the legislation reflects the constitutional goals of broad inclusion, and participation in the entire spectrum of health system interventions. This conclusion, nevertheless, in no way discounts critical considerations with respect to membership and the reach of the NHC.

⁴⁸⁶ See *supra* Chapter 4, Section 4.5.1 for this point.

⁴⁸⁷ See *supra* Chapter 5, Section 5.3.1 for this analysis.

⁴⁸⁸ See *supra* Chapter 5, Section 5.3 for this analysis.

7.2.3.1 Membership

Participation in the NHC is constrained to a selected number of civil society organizations. The NHC has 24 seats for civil society organizations, and Brazil, of course, has more than 24 civil society organizations that in theory would be eligible for a seat on the NHC. If one of the basic requirements for participation is broad inclusion, participation through a limited number of civil society organizations at first sight could raise issues for meeting the constitutional requirement.

The choice of participation through representation, as discussed in Chapter 5, does not in itself conflict with the constitutional requirement for broad inclusion.⁴⁸⁹ First, this rule, and the legislation for that matter, does not preclude citizens from influencing health planning through exerting pressure over those organizations with seats on the NHC. Second, for pragmatic reasons some sort of limitation to participation in institutional bodies is needed and desirable to ensure feasibility of participation in a country as populous as Brazil.

Of course, rules for representation are not flawless, for example, decision-making processes for inclusion and election processes are defined and carried out by the NHC itself without input of the population at large. Indeed, some respondents were very critical with respect to the election process, going so far as to suggest more inclusive feedback mechanisms to include more grassroots voices in the election process and NHC's agenda.

Respondents did not raise any concerns with the legal arrangement of participation in the NHC through representation. To be clear however, this lack of comment is not due to a lack of opportunity to reflect on who can participate through the NHC and who can participate in 'the participation in the Constitution.' In reality, respondents had many opportunities to reflect on the issue about 'participation through representation' when elaborating on the differences between 'participation as defined by the Constitution' and participation in the NHC. For instance, respondents provided rich information explaining

⁴⁸⁹ See *supra* Chapter 5, Section 5.4.2 for this conclusion.

that ‘participation as defined by the Constitution welcomes everyone’ but that ‘participation in the NHC comes with strings attached to social organizations.’⁴⁹⁰

After extensive analysis of the qualitative data, I found no evidence indicating that participation through representation conflicted with broad inclusion as established by the Constitution. A possible explanation is that respondents do not directly associate participation in the NHC with the right to health requirements. Thus respondents do not have to measure limited representation in the NHC against broad participation as enshrined in the Constitution. In this way, political actors were granted a high degree of discretion to design membership rules for participation in the NHC.

A related explanation might be that the respondents and/or the entities have connections with the health reform activists framing the legal structure of the health system and health councils. Many of the respondents, as noted in Chapter 4, were directly involved in both the creation of the right to health and health laws creating the health system and health councils. As discussed in Chapter 4, the draft for the constitutional provision of community participation in the health system was closely related to today’s arrangement of the NHC.⁴⁹¹ The report of the 8th National Health Conference of 1986, the so-called blueprint of the right to health, specifically referred to citizen representation in the health system.⁴⁹² I should note, however, the proposal made no reference to health councils’ decisions being subject to the approval of health authorities, which is part of today’s legislation, an issue I discuss later in this section.

7.2.3.2 Legal Roles

The legislation establishes two broad roles for the NHC: “To act in the elaboration of health strategy and to monitor the implementation of health policies.” The legal analysis carried out in Chapter 5 concluded that in replacing the constitutional language ‘organization’ for ‘governance’ (or ‘*gestão*’ in Portuguese), the legislation more clearly

⁴⁹⁰ In fact, respondents spoke extensively on this matter. See *supra* Chapter 6, Section 6.2 for this discussion.

⁴⁹¹ See *supra* Chapter 4, Section 4.5.3 for detailed discussion.

⁴⁹² *Ibid.*

defined the scope of participation in the entire spectrum of health system interventions, from the elaboration of health strategies to the monitoring of policy implementation, including in health finance. In theory, therefore, the reach of NHC's roles offers opportunities for citizen representatives to participate in all aspects of the health system. The extent to which the NHC in fact influences health planning and the social and political barriers to the effectiveness of the NHC are empirical questions pursued in Brazilian social and political circles, as discussed in Chapter 2.⁴⁹³

I should also note that in principle the nature and composition of the NHC also provides genuine opportunities for civil society representatives to influence health planning. As discussed in Chapter 5, membership in the NHC is based on the parity of civil society representatives in relation to the remaining representatives (government, private providers and health system workers), and power is exercised collectively and equally (one-person, one-vote rule). While the effectiveness of this rule is an empirical matter, the scholarly literature noted in Chapter 2 expresses a relative consensus that the parity and one-person, one-vote rules are conditions for more effective deliberation in the NHC.⁴⁹⁴

The legal analysis in Chapter 5 concluded, in a nutshell, that Congress created the NHC as the key mechanism to integrate community participation in the organization of Brazil's health system. In Chapter 5, I also concluded that health laws provide an important framework to legitimize the existence of community participation in the planning, service delivery, budgeting and monitoring of Brazil's health system. In addition, the nature and inclusion rules for the NHC are generally consistent with the constitutional requirements for broad inclusion in the entire spectrum of health system interventions on an ongoing basis.⁴⁹⁵

⁴⁹³ See *supra* Chapter 2, Section 2.4 (especially *supra* note 121) for some of these empirical studies.

⁴⁹⁴ See generally Lavallo & Araújo, *supra* note 106.

⁴⁹⁵ See *supra* Chapter 5, Section 5.4 for this analysis.

7.2.4 Issues and Concerns

The legal analysis in Chapter 5 identified two procedural issues that possibly inhibit the NHC from acting effectively in the entire spectrum of health governance: one issue relates to the mandate of the NHC, and the other issue relates to the actual ‘authority’ of the NHC to carry out its mandate.

With respect to the mandate, the legal analysis in Chapter 5 concluded that the provisions establishing the ‘elaboration role’ (to act in the elaboration of health policy), could be interpreted as a means to restrain participation to policy matters of concern only to the National Health Plan. The qualitative findings discussed in Chapter 6 indicated that in fact some respondents interpret the ‘elaboration role’ as the responsibility toward the National Health Plan only. One respondent posited: “we are not here [in the NHC] to define policies [operating procedures] in general.”⁴⁹⁶ As the respondent explained, the elaboration role requires the NHC to convert the reports of the national round of health conferences into a strategic-action plan to inform the Brazilian National Strategic Health Plan.⁴⁹⁷

While this form of participation is essential, because the four-year-National Health Plan sets the direction for health programs, restricting participation to matters relating to the National Health Plan would prevent citizen participation in other equally important decision-making processes, such as in the operational guidelines and procedures that implement the goals and measure the outcomes of the national health plan. As one example, while the national health plan sets forth as one of the strategic directions for Brazil’s health system the prevention of tuberculosis infection, the operating procedures will determine what drugs would be provided and purchased, as well as clinical protocols for tuberculosis, including who would be hospitalized and where, and what diagnostic tests would be offered, how, where, and so forth.

⁴⁹⁶ Respondent #15.

⁴⁹⁷ *Ibid.*

Indeed, a majority of respondents interpret the elaboration role beyond simply converting health conference reports into an action plan for the National Health Plan. From a broader perspective, the elaboration role extends to policy matters emerging from urgent demands, as well as policy matters raised by social organizations with seats on the NHC. Respondents sharing this broader perspective on the elaboration role, however, recognized the challenge to include any policy matter in the deliberative agenda of the NHC, ‘it is easier said than done.’⁴⁹⁸ Respondents’ prompt explanation for the challenges of including policy matters in the NHC’s agenda was primarily procedural: they noted that the NHC’s mandate was in itself overwhelming (e.g., permanent agenda and deadlines), and that there were specific operational structures (e.g., lack of time in plenary meetings, order of voting).

After a careful analysis of the qualitative evidence, I concluded in Chapter 6 that respondents possibly interpreted the scope of the elaboration role differently, and that different interpretations affect not only respondents’ actions but also their expectations and evaluations of the NHC’s as a whole.⁴⁹⁹ For example, respondents who interpret the elaboration role in relation to the National Health Plan reported the plenary meetings as a “waste of time”, because people want to discuss local problems that are irrelevant to the general directives of the National Health Plan.⁵⁰⁰ In contrast, one respondent who believed that the elaboration role includes grassroots policy matters reported frustration with plenary meetings because “people do not get the local problems. I don’t know what I am representing at the NHC.”⁵⁰¹

The most controversial finding perhaps is the fact that respondents themselves believe that the NHC’s roles are clear, and the majority of respondents assume that everybody else interprets the roles of the NHC in the same way. But, after an extensive analysis of the qualitative data in Chapter 6, I concluded that at the heart of respondents’

⁴⁹⁸ Respondent #14.

⁴⁹⁹ See *supra* Chapter 6, Section 6.3.1 for detailed discussion.

⁵⁰⁰ Respondent #15.

⁵⁰¹ Respondent #20.

disagreement lay two questions: 1) whether elaboration is only about translating health conference reports into action plans or if it included grassroots strategic issues, and 2) what constitutes timely and sensitive strategic grassroots issues to enter the NHC's agenda.⁵⁰² Further research is needed to investigate these questions, and the implications for the actions of the people participating in the NHC and the NHC's influence over health planning.

As noted above, a further issue arising out of the legal analysis carried out in Chapter 5 relates to the authority of the NHC to carry out its mandate.⁵⁰³ In particular, the issue relates to the legal rule subjecting the NHC's deliberative decisions to governmental review. The legal analysis in Chapter 5 concluded that in principle this rule curtails the authority of the NHC. Further, the analysis suggested that this rule is particularly problematic when government lacks the political will to approve subject matters addressed by the NHC's deliberative decisions.

This problem was further investigated and confirmed by the original data, as discussed in detail in Chapter 6.⁵⁰⁴ According to respondents, the ratification rule weakens the effectiveness of the NHC. One respondent suggested that the NHC in reality "has the power only to control itself."⁵⁰⁵ Another respondent stated that silence has essentially been the government's response to over 10 resolutions issued by the NHC from 2012 to 2014. "Resolutions that the government is not interested in remain in the piles on the desk of the Health Minister."⁵⁰⁶

The qualitative findings suggested that a piece of legislation passed in 2012 establishing governmental obligations to report to the NHC has been a strong motivational factor for

⁵⁰² See *supra* Chapter 6, Section 6.3.2 for detailed discussion.

⁵⁰³ See *supra* Chapter 5, Section 5.4.1 for this analysis.

⁵⁰⁴ See *supra* Chapter 6, Section 6.3.2 for this analysis.

⁵⁰⁵ Respondent #6.

⁵⁰⁶ Respondent #4. [But as noted above, this is a small-scale study based on the experience of 26 NHC members during the 2013-2015 term. Further research therefore, is important to systematically examine the subject matters of these resolutions, as well as whether and why the government opposes these resolutions.]

government officials to take the NHC's decisions more seriously. For example, one respondent explained, "if we look at the Ministry's finance report, we can see many explanations addressing concerns of the NHC."⁵⁰⁷ Other respondent more critically stated that the law is unclear regarding what 'addressing the concerns of the NHC' really means: if it means to only clarify issues, or if it means actually requiring government to make changes in accordance with the recommendations of the NHC.

The legal analysis in Chapter 5 concluded however, that not even this further piece of federal legislation passed in 2012 establishing governmental obligations to report to the NHC or the NHC/Resolution 453/2012 setting time frame for state review of NHC's resolutions have resolved the authority issue.⁵⁰⁸ The NHC issued a resolution in 2012 recommending legal action in the event of the Health Minister's disregard NHC's deliberative decisions after a period of 30 days.⁵⁰⁹ While respondents confirmed the option to take government officials to the courts, comments across the data indicated that respondents do not favour this approach. As one respondent indicated, "the government changes every four years, and legal disputes take longer than that."⁵¹⁰ But in my view, even if legal action was a favoured option, the NHC's decisions remain subject to the Health Minister in Council, the statutory text itself provides no time limit to governmental review.

7.3 Contributions to the Literature

This study contributes to the understanding about participatory health governance as a requirement of the right to health in Brazil. In particular, this study builds on Brazil's health law literature, so-called *Direito Sanitário* (*Sanitary Law*), and on the work by health law scholars such as Sueli Dallari. This body of health law has been largely conceptual in nature, contributing significantly to our understanding of the value and

⁵⁰⁷ Respondent #5.

⁵⁰⁸ See *supra* Chapter 5, Section 5.4.3 for detailed discussion.

⁵⁰⁹ *Ibid.*

⁵¹⁰ Respondent #12.

relevance of participation in health planning as part of Brazil's right to health.

This study, the first of its kind, offers a comprehensive and systematic analysis from the constitutional framework for participation in the health sector, to the legal implementation of the constitutional framework and actual practice of participation, through the lens of key informants. I employed traditional canons of legal interpretation informed by a critical approach to meaning construction to account for my policy preferences, and to increase the quality and trustworthiness of the analytical process and conclusions. The constitutional analysis concluded that participation in the organization of the health system is a requirement of the right to health; the analysis also determined the basic constitutional requirements for participation. The next stage of the legal analysis considered Brazil's legislation establishing institutional mechanisms for citizen participation in health planning. The analysis focused on the legislative underpinnings of one of these mechanisms: the National Health Council. The statutory analysis concluded that the NHC generally complied with the constitutional participation requirements but also identified important gaps in the legislation that created structural challenges for inclusion and effective participation in the organization of the health system.

Furthermore, this legal study was enriched in breadth and depth by empirical research. The field work provided a firsthand look at how a sample of NHC members perceive the role of the NHC in relation to the right to health, and their views on existing legal barriers to effective implementation of the legal roles of the Council. Drawing on social science research methods—interview and observation—the qualitative research reinforces the NHC's potential as an important component of Brazil's constitutional right to health and a catalytic space for continuously conveying context-sensitive needs and perspectives. This study also left me in no doubt that shedding light on the scope of legal roles might improve the ability of the NHC to play a positive role in health planning. On the negative side, this study confirmed that the authority of the NHC is an issue, stifling the potential of the NHC to carry out its role. That said, legal action might not be an effective tool to redress this authority issue.

Finally, having a better understanding of how participatory health governance contributes to the full realization of Brazil's right to health framework can provide transferable lessons. It is worth remembering that the expectation that participatory health governance can improve health equality is by no means unique to Brazil.⁵¹¹ Therefore, this study takes stock of Brazil's 'natural experiment' with the right to health and citizen participation providing guidance for Brazil's legal and population health literature (called collective health in Brazil). My research also provides lessons that may relate to the debate in other contexts seeking to put the full breadth of the right to health into practice.⁵¹²

7.4 Autobiographical Reflection

This research journey has been an invaluable learning experience. My study originally sought to underscore how the Brazilian government had a responsibility to implement citizen participation in health, and determine the criteria that would hold government officials to account on behalf of the citizenry. I started my legal career as a litigation lawyer, and legal procedure was my passion from the start. Similar to most of my fellow colleagues, I perceived litigation as a solution to address state failure to deliver public services, and the courts as pathways to remedy the state's wrongdoings.

At the beginning of my field work I quickly learned that 'doing fieldwork' meant being observed by other people as much as it meant to observe others. I felt at a crossroads of two worldview frames: 'enacted law' and 'participation as a right'. Enacted law meant constrained actions and participation from the view of interviewees, entailing freedom to express ideas without interference by rule or authority. Throughout my field work I felt

⁵¹¹ For example, in an informal conversation with Professor Jaime Breilh, a leading Ecuadorian scholar in social epidemiology, he indicated that a similar situation seems to have happened in Ecuador, in that federal statutes regulating Ecuador's constitutional principle of health have focused on the narrow dimension of biomedical cause/effect of disease at the expense of the social dimensions of health. In his view, this narrow statutory interpretation of a broad constitutional right to health seems to be spreading across Latin America.

⁵¹² I should note once again that this dissertation is based on democratic contexts, and any lesson may apply only to other democratic contexts. When this "regime" passes in Brazil, it is my belief—and hope—that my study will be of interest in revisiting and reinstituting socially progressive systems as Brazil's once was, and so these lessons will be highly relevant not only for Brazil but also for other countries.

that my ‘loyalty’ to the law was threatened by my deep belief in participation in health planning and ideals of political participation and civil society empowerment. It felt like ‘empowered civil society’ took on a life of its own, and the right to health framework became a supporting actor.

In attempting to distance myself from my legal training to properly analyze the qualitative data, I quickly realized how challenging a task this is. I learned that the research process is messy, and research outcomes do not fit neatly into categories. Eventually, what I once perceived as a ‘conflicted’ feeling between ‘law’ and ‘participation’ became a catalytic force of critical analysis, of my own observations, analytical processes, and conclusions.

By immersing myself deeper and deeper into the qualitative data, I understood that respondents perceive participation in the NHC as a critical component for an improved health system, while participation in the health system is associated with political freedom to pressure the government. Framing participation as a requirement of the right to health can provide a helpful framework to hold the state to account for enabling and ensuring institutional participation in health planning for the betterment of the health system. But I realized that worldview frames and perhaps disciplinary silos might be important challenges to applying the notion of participation as a requirement of the right to health, and as a means to hold the state to account for participation in the NHC.

7.5 Recommendations

This study has at least three recommendations for improved practice. First, I hope that this study has shed light on the need for more clarity about the scope and reading of the NHC’s legal roles, particularly in relation to the meaning and scope of ‘acting in the elaboration of health strategies’. This study demonstrates that different interpretations influence performance expectations of the NHC as a whole. Clarification of the roles may prove particularly useful to council members who often feel their representation is ‘toothless’, and that they lack the power to effectively influence the NHC’s recommendations, and health policy decisions more generally. Further, more clearly

defined roles can also enhance performance and the accountability of the NHC to the citizenry.

Second, this study echoes previous concerns such as those of health policy analysts Martha Martinez and Jillian Kohler about the need to strengthen the NHC's authority.⁵¹³ In an ideal world, the recommendation would be for legal reforms to change the rule subjecting NHC's decisions to governmental approval, and to create an enforcement framework to ensure that government officials take the NHC recommendations into account in a timely and meaningful way. But, I do not believe that progressive law reform will be possible in the current political climate in Brazil.

Finally, this study recommends a pedagogical focus on the education and training of lawyers and judges about the legal roles of the NHC in the health system. The aim is to stimulate the legal community to think of participation in the health system as part of the right to health and as an essential component of health planning and priority setting. This requires firm leadership, recruiting and preparing council members to act as coaches.

7.6 Further Research

While the main legal instruments governing participation in the NHC have been examined, this study does not examine all legal structures and players impacting the NHC's influence over health planning and resources. For instance, this study has not examined the legal framework and the practice of intergovernmental committees for coordinating and ensuring strategic alignment of health planning and the implementation of health action plans.⁵¹⁴ Further research examining the legal framework and the role of the NHC in these intergovernmental committees is needed.

⁵¹³ See e.g. *supra* note 340. See also Martha G Martinez and Jillian C Kohler, "Civil Society Participation in the Health System: The Case of Brazil's Health Councils" (2016) *Globalization and Health* 12:64 at 1.

⁵¹⁴ For e.g., *Comissão Intergestora Tripartite* is the Intergovernmental Committee Tripartite formed by national, state and municipal health authorities, and *Comissão Intergestora Bipartite*, which is the Intergovernmental Committee Bipartite formed by state and municipal health authorities.

This dissertation, furthermore, has not examined issues related to health system financing and to the private provision of healthcare services in Brazil. The way that “health system financing” and “the private provision of healthcare services” are structured can be complex and deeply problematic issues with the potential to affect health governance, as well as the allocation of resources and distribution of health services and promotion measures. Areas of further empirical research include, for instance, the NHC’s influence over health system financing, and over regulations and/or limitations of private healthcare provision.

In addition, this study assumes that NHC participation in health planning contributes to a more egalitarian health system. Two lines of research emerge from this assumption. An area for further research is to examine what types of deliberative decisions are produced by the NHC, followed by what influence such decisions have over policy planning and resource allocation, and on population health as a whole (e.g., whether and the extent to which reducing the time frame for drug coverage improved access to treatment). Related to the NHC’s outcomes (deliberative decisions), further research is also needed to examine the Health Minister’s approach to the NHC’s decisions, such as the rate of approvals and subject matters approved. Researchers could also develop a systematic analysis of issues identified by the NHC, the nature of governmental responses, the time-frame for approvals (e.g., provisos on the financial statements), and the reactions or responses from the NHC or other actors when government officials disregard deliberative decisions from the NHC.

There is also room for further research in relation to citizen participation in Brazil and the broader literature on the right to health. For example, future research could examine the relevance/importance of citizen participation in health governance as a means to change the roots of health inequality (the so-called “social determinants of health”). Social determinants are described as the “circumstances in which people are born, grow up, live,

work and age, and the systems put in place to deal with illness.”⁵¹⁵ The right to health literature has largely examined what conditions and structures can increase individuals and groups’ vulnerability to disease and injury. With Kristi Kenyon, I have argued elsewhere that citizen participation in health governance in Brazil could be framed as a ‘positive social determinant’, and therefore, with potential to empower people to tackle some of the roots of health inequality.⁵¹⁶ Based on Brazil’s experience, it would be interesting to develop indicators intended to assess the extent to which citizen participation in Brazil has in fact acted as a ‘positive social determinant’, reducing people’s vulnerability to disease and injury and contributed to health equality.

Another interesting area of research is to explore the tension between individualized healthcare litigation and systemic and collective citizen participation, in articulating what the health system does. In my view, the right to health has been determined individualistically and litigiously so the power of collective and systemic health system reform has been scattered, at the expense of giving treatments on an individual basis achieved through the courts. I also believe that more attention to legal structures of participatory policy making is a way to strengthen the health system outside of the courts, to the benefit of the whole population, rather than improved access through the courts, which is primarily to the benefit of only those individuals who have access to courts. A potentially interesting area for research is to explore whether the courts 'should' be deferring in some way decisions emerging out of citizen participation. Additional research could explore whether in fact citizen participation in health councils makes the health system a 'more responsive and accountable health system' compared to the results produced by the courts via litigation.

In addition, this study shows that participation is a requirement of the right to health and

⁵¹⁵ World Health Organization, “Social Determinants of Health, Key Concepts”, online: <http://www.who.int/social_determinants/thecommission/finalreport/key_concepts/en/>. Last retrieved: 5 February 2018.

⁵¹⁶ Kristy H Kenyon & Regiane A Garcia, “Exploring Human Rights-Based Activism as a Social Determinant of Health: Insights from Brazil and South Africa” (2016) 8:2 *Journal of Human Rights Practice* 198.

suggests that the courts could serve as pathways toward holding government officials to account for adequate participation. Future research is also needed to determine judicial review criteria for evaluating participation in priority settings, in the pursuit of the full realization of health rights. Furthermore, to the extent that respondents made no reference to participation as an obligation of the state, further research is required to make sense of what are the implications of this finding, if any. Is this qualitative finding related to council members' theoretical assumptions of participation as an individual's entitlement, rather than an obligation of the state? Or is this finding related to council members' negative perception that the courts interfere with the functioning of the health system?

Reframing participation in the NHC as an obligation of the state in order to ensure genuine participation in health planning and resource allocation may have the potential of strengthening the role of institutional participation in health governance in Brazil. And, this reframing may also have the potential to foster more dialogue amongst council members, government officials and the legal community, advancing citizen participation as part of the transformative project of Brazil's right to health toward social change.

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Appendix A: Informed Consent Sample Form

Termo de Consentimento Livre e Esclarecido

Você está sendo convidado a participar da pesquisa “Participação da Comunidade no Sistema Único de Saúde – Lei e Realidade”, de responsabilidade de Regiane Alves Garcia, aluna de doutorado da Universidade de British Columbia, Canadá. O objetivo desta pesquisa é estudar o processo de participação da comunidade na garantia do direito à saúde no Brasil. A pesquisa tem duas etapas: uma etapa examina textos legais e uma etapa examina o que acontece na realidade da participação. O foco da pesquisa é a Constituição Federal de 1988 e a prática dos conselheiros/as do Conselho Nacional de Saúde. Assim, gostaria de consultá-lo(a) sobre seu interesse e disponibilidade de cooperar com a pesquisa.

Você receberá todos os esclarecimentos necessários antes, durante e após a finalização da pesquisa, e lhe asseguro que o seu nome não será divulgado, sendo mantido o mais rigoroso sigilo mediante a omissão total de informações que permitam identificá-lo(a). Os dados provenientes de sua participação na pesquisa, tais como entrevistas e fitas de gravação, ficarão sob a guarda do pesquisador responsável pela pesquisa.

A coleta de dados será realizada por meio de entrevista com um roteiro de perguntas. É para estes procedimentos que você está sendo convidado a participar. Sua participação na pesquisa não implica em nenhum risco. Espera-se com esta pesquisa contribuir para um entendimento melhor do processo de participação na garantia do direito à saúde.

Sua participação é voluntária e livre de qualquer remuneração ou benefício. Você é livre para recusar-se a participar, retirar seu consentimento ou interromper sua participação a qualquer momento. A recusa em participar não irá acarretar qualquer penalidade ou perda de benefícios.

Se você tiver qualquer dúvida em relação à pesquisa, você pode me contatar através do telefone xxxx ou pelo e-mail xxxx

Os resultados do estudo serão devolvidos aos participantes por meio do envio de uma cópia da dissertação, bem como a versão eletrônica, ao Conselho Nacional de Saúde para que a mesma seja disponibilizada no website do Conselho. Além disso, a pesquisa será apresentada em sessão ordinária do CNS. Os resultados podem ser publicados posteriormente na comunidade científica nacional e internacional.

Este projeto foi revisado e aprovado pelo Comitê de Ética em Pesquisa da Universidade de British Columbia, Vancouver, Canadá (H13-02662 and H15-03121) e no *Comitê de Ética em Pesquisa* (CEP) da Universidade de Brasília, Brasil (34492514.0.0000.5540). As informações com relação à assinatura do TCLE ou os direitos do sujeito da pesquisa podem ser obtidos através dos contatos UBC: (1) 604-822-8598, ligação gratuita 1-877-822-8598 ou e-mail RSIL@ors.ubc.ca. Bem como através do e-mail da UBC: CEP/IH cep_ih@unb.br.

Este documento foi elaborado em duas vias, uma ficará com a pesquisadora responsável pela pesquisa e a outra com o senhor(a).

Diante desse entendimento eu concordo em participar do estudo com minha entrevista.

Data: ____ / ____ / ____

Assinaturas:

1. Participante da pesquisa:

2. Pesquisadora:

Translation of the Informed Consent

You are invited to participate in this research "Citizen participation in the Unified Health System - Law and Reality" of responsibility Regiane Alves Garcia, doctoral student at the University of British Columbia, Canada. The objective of this study is to examine how the process of participation contributes to the realization of the right to health in Brazil. The study has two stages: one stage examines relevant legal instruments and another step examines what happens in the practice of participation. This study focuses on the practice of National Health Council and the experiences of Council members. I would like to invite you to participate in with this study.

You will receive all the information needed before, during and after the completion of this study and I assure you that your name will not be disclosed. I take all the necessarily steps to maintain confidentiality, including omitting names and any other information that may identify you. Data from your participation, such as interviews and tapes, will be under the custody of the researcher responsible for the research.

Data collection will be carried out through interviews with a sample of questions to guide the interviews. In a nutshell, these are the procedures you are being invited to participate. Your participation in this research does not imply any risk. And, it is hoped that this research will contribute to a better understanding of the process of participation in contributing to the right to health.

Your participation is voluntary and free of any compensation or benefit. You are free to refuse to participate, withdraw your consent or discontinue participation at any time. The refusal to participate will not result in any penalty or loss of benefits.

If you have any question regarding this study, you can contact me via phone xxxx or by e-mail xxxx

The study results will be returned to participants by sending a copy of the dissertation, as well as the electronic version to the Nacional Health Council to be made available on the website of the Council. In addition, the research will be presented at an annual meeting of the Council, if possible. The results can be published later in the national and international scientific community.

This project has been reviewed and approved by the Research Ethics Committee of the University of British Columbia, Vancouver, Canada, (H13-02662 and H15-03121) and the Research Ethics Committee of the University of Brasília, Brazil (34492514.0.0000.5540). Information regarding the signing of the IC or research subjects' rights can be obtained through the UBC contacts: (1) 604-822-8598, toll free 1-877-822-8598 or email RSIL@ors.ubc.ca. As well as via e-mail at UBC: CEP / IH cep_ih@unb.br.

This document was prepared in duplicate, one will get the researcher responsible for this research and the other with you.

Given this understanding I agree to participate in the study with my interview.

Date: _____ / _____ / _____

Signatures:

1. Participating in the research:

2. Researcher:

Appendix B: Request for Observation Sample

CARTA SOLICITAÇÃO PARA OBSERVAR REUNIÕES PLENÁRIAS

Ao Conselho Nacional de Saúde,

A/C Sra. Maria do Socorro de Souza, Presidenta do Conselho Nacional de Saúde

Ref.: Solicitação para observar as reuniões plenárias de janeiro e fevereiro de 2014 para fins de pesquisa para projeto de doutorado

Prezada Senhora,

Sou brasileira, advogada formada pelo Mackenzie, mestre em Direito pela Universidade de Direito de Toronto, Canada, e residente no Canadá desde 2006. Hoje como doutorando do Programa de Pós-Graduação da Faculdade de Direito da Universidade de British Columbia (UBC) em Vancouver, Canadá, escrevo para solicitar sua autorização para observar as reuniões plenárias dos meses de janeiro e fevereiro de 2014.

Estou ciente que reuniões plenárias são públicas e abertas a todos cidadãos e que as minutas das reuniões são disponibilizadas via internet. Entretanto, como minha presença nas reuniões será como pesquisadora ao invés de cidadã, e como usarei as informações observadas nas reuniões na minha pesquisa, o Comitê de Ética da UBC exige uma resposta formal do CNS autorizando observação das reuniões.

A pesquisa versa sobre o princípio constitucional do direito à saúde e a participação da comunidade na organização das políticas de saúde. Bem como a aplicação dos princípios constitucionais no CNS.

A observação das reuniões plenárias contribuirá para a compreensão de como os conselheiros agem dentro dos conselhos e para o entendimento de como a lei é executada na prática. A “Observação” consistirá em:

- Assistir a duas reuniões plenárias, janeiro e fevereiro de 2014 respectivamente
- Observar, para fins acadêmicos, como as reuniões ocorrem e como os conselheiros exercem suas funções
- Tomar notas por escrito das minhas observações, notas que posteriormente serão usadas na minha tese e correlacionadas publicações.

Se por ventura algum comentário feito por conselheiros(as) ou membros do público presentes nas reuniões for relevante para o projeto, ao final da reunião, eu pedirei autorização (por escrito) ao próprio indivíduo para utilizar o comentário no projeto. Se autorizado, o comentário não será atribuído ao indivíduo, exceto se o mesmo expressamente autorizar a atribuição de seu nome ou de sua organização. Entretanto, o

risco de indireta atribuição de autoria será informado, uma vez que minutas das reuniões serão disponibilizadas ao público e cruzamento de referências podem ocorrer. Esse risco será expressamente informado no formulário de consentimento.

Agradeço a atenção, e fico a disposição para quaisquer esclarecimentos.

Atenciosamente,

Regiane Garcia B.C.L. LL.M., Doutoranda

E-mail:

Telefone:

TRANSLATION of REQUEST LETTER TO OBSERVE PLENARY MEETINGS

To the National Health Council,

Attn: Ms. Maria do Socorro Souza, President of the National Health Council

Ref .: Request to observe plenary sessions of January and February, 2014 for research purposes, doctoral project

Dear Madam,

I am a Brazilian trained lawyer by Mackenzie. I hold master's of Law, University of Law Toronto, Canada, living in Canada since 2006. Today, I am writing as a doctoral candidate of the School of Law at the University of British Columbia (UBC), Vancouver, Canada, to request your permission to observe the plenary meetings of the months of January and February, 2014.

I am aware of the fact that plenary meetings are public and open to all citizens and that the minutes of the meetings are available via internet. However, as my presence at the meetings will be as researcher rather than a citizen, and because I intend to use the information observed in the meetings in my research, the Ethics Committee of the UBC requires a formal response from the Council allowing observation of such meetings.

My research examines the constitutional principle of the right to health and community participation in the organization of health policies. And the application of constitutional requirements in the Council.

The observation of the plenary meetings will contribute to the understanding of how the Council members act within the Council and the understanding of how the law is actually implemented. The "observation" consist of:

- Attend two plenary meetings, in January and February, 2014,
- Observe, for academic purposes, how those meetings occur and how Council members perform their duties, and
- Write my observations (field notes) and the notes will later be used in my thesis and related publications.

In the event of any comment made by Council members or members of the public present at the meetings being relevant to this study, I will ask permission (in writing) to the individual himself to use the comment on this study. If authorized, the statement will not be assigned to the individual, unless it explicitly authorized. However, the risk of indirect attribution of authorship will be informed, as the minutes of plenary meetings are made available to the public and cross-references may occur. This risk will be expressly stated in the consent form.

I appreciate the attention, and I'm available for any clarification.

Sincerely,

Regiane Garcia BCL LL.M., Ph.D.

E-mail:

Phone:

Appendix C: Research Protocol

Guia Conversa

Sua experiência no CNS:

Sua experiência como conselheiro(a) no CNS. Por exemplo:

há quanto tempo está no CNS

como chegou no CNS

histórico como conselheiro(a)

sua entidade no CNS, sua relação com sua entidade (devolução para a entidade)

Atividades desenvolvidas pelo CNS: controle social? participação social? Exemplos, se possível.

Como aprendeu/adquiriu as competências e habilidades para executar as funções de conselheiro(a)? Recebeu algum treinamento especial? Se sim, de quem, quando e como foi o treinamento?

Quais são as novas habilidades e competências que aprendeu ao longo de sua experiência como conselheiro(a)?

Entidades, conselheiro(a), CNS e a Constituição de 1988:

Qual seu entendimento por ‘participação da comunidade’ na garantia do direito à saúde? Na sua visão, como participação se relaciona com o direito à saúde (ex., individual, coletiva, promoção, prevenção e curative dimensões)?

Na sua opinião, as práticas do CNS refletem o seu entendimento sobre participação como parte do direito à saúde?

Se sim, pode dar exemplos das principais atividades realizadas e objetivos alcançados, pelo CNS para a efetivação do direito à saúde?

Se não, quais são as barreiras para participação ser efetiva na prática?

Guide Conversation

Experience in National Health Council:

1. Your experience as a member of the National Council. For example:
 - how long have you been in the Council,
 - election process,
 - experience at other levels of council,
 - accountability process to entity you represent.
2. Activities carried out by the Council: ‘social control’, ‘social participation’; examples,
3. Skills and abilities learned to perform the functions at the Council. For e.g., any special training? If so, when and how was the training?,
4. New skills and competencies learned throughout your experience as Council member.

National Council and the right to health:

5. What is your understanding of 'community participation' in ensuring the right to health? In your view, how participation relates to the right to health (e.g., individual, collective, promotion, prevention and curative dimensions)?
6. In your opinion, the National Council’s practices reflect your understanding of participation as part of the right to health?
 - 6.1 If so, could you give me an example of the main activities carried out and goals achieved by the Council for the realization of the right to health?
 - 6.2 If not, what are the barriers participation in the Council to be effective?