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Expanding the Debate: Citizen Participation for the Implementation of the Right to Health in Brazil

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Abstract

Brazil has established a well-known constitutional right to health. Legal scholars have focused largely on one aspect of this right: the role of the courts in enforcing health care access. Less attention has been paid to another aspect: citizens' right to participate in health planning. Participation is a constituent component of Brazil's right to health that is intended to guarantee accountability and fair resource distribution for improved population health. In this paper, drawing on constitutional analysis and interviews carried out for my doctoral research, I discuss Brazil's national-level participatory body, the National Health Council, and its potential for fostering accountability and balancing individual and societal interests in health policy. Effective participation, I contend, is a way to strengthen Brazil's health system to the benefit of the entire population, rather than only those who have access to the courts. This paper seeks to underline the constitutional requirement of participation as a core element of the realization of the right to health in Brazil and to invite other legal scholars to critically engage with the way in which Brazil's right to health is implemented.

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Introduction

The right to health in Latin America has been characterized by significant involvement of the courts. This, in turn, has raised a number of normative and empirical questions about the function of courts and the way in which the "judicialization" of the right to health affects health equality. Brazil's Constitution establishes a right to health with both substantive and procedural components. Drawing on my doctoral research, this paper underlines a core yet often overlooked component of Brazil's right to health: citizen participation in health planning as part of the right to health. (In this paper, the term "citizen participation" refers to citizen participation in the National Health Council, including in planning and monitoring programs and in resource allocation.) Although the constitutional right to participation is integral to Brazil's right to health framework, the attention of lawyers, courts, and legal scholars has been focused mainly on one aspect of the constitutional framework: the high volume of litigation and its impacts.[1] This focus on litigation, particularly on litigation for health care access, is important but incomplete.

The framers of Brazil's Constitution included citizen participation in health planning as a way to strengthen the accountability of political decisions and to ensure that resource allocations work to the benefit of the entire population.[2] The constitutional participation requirement was implemented through the creation of health councils at various levels of government. My research focused on the National Health Council (NHC), Brazil's national-level participatory body. The NHC has a promising role in balancing individual and wider population needs in health and health care. However, there are significant challenges for the effectiveness of the NHC, including statutory provisions that curtail the council's ability to perform its role, which I discuss below.

This paper unfolds in four parts. I first provide an overview of the development of the debate on Brazil's right to health. I then outline why participation matters and offer an overview of empirical studies that examine the effectiveness and challenges of participation in Brazil's health system. Next, I outline some findings of my research and explain how participation is operationalized at the NHC and why it is a promising way to foster responsiveness to the needs of the entire population. In conclusion, I tie my research findings to the ongoing dialogue in the literature and suggest that participation could be fostered through the courts.

Background

The right to health is enshrined in the 1988 Constitution of Brazil.[3] The Constitution, drafted when the country was returning to democracy after two decades of military dictatorship, was designed to overcome oppression and inequality and to lead the country to democracy and inclusion.[4] As a response to the authoritarian regime, the Constitution established popular sovereignty as one of the foundational values of the country (articles 1 and 14) and provided for citizen participation in areas such as social security (article 194), health (article 198(III)), social welfare (article 203), and education (article 206). The Constitution, moreover, established equality as the hallmark of the country and made clear that Brazil's new constitutional framework was intended to protect social, individual, and political rights and to foster social change (preamble and article 3).

The creation of an extensive catalogue of rights (articles 5 and 6) reinforced this transformative constitutional goal. In the case of health, the Constitution explicitly establishes "health as a duty of the state" and specifies how government officials are required to fulfill obligations concerning the right to health (articles 196–200). State obligations, as I discuss later, entail the creation of a public health system that includes participation in health planning.

The debate in Brazil

The development of the debate on the right to health in Brazil reflects evolving perspectives on the enforceability of that right. In the 1990s, questions such as whether the right to health entails an individually claimable right against the state and what forms state actions should take arrived before Brazilian courts.[5] Patients' advocacy groups, such as Duchenne muscular dystrophy and HIV/AIDS organizations, were pioneers in litigating cases associating Brazil's constitutional right to health with access to treatment.[6] By 2000, it became clear that the courts viewed the right to health as entailing an individually claimable right to public health care and as not being subject to resource constraints.[7]

The constitutionalization of the right to health, therefore, moved from moral, social, and political arguments to rights enforceable by the courts. Clearly, those pioneering lawsuits helped accelerate positive policy and therapy changes for certain patients' groups.[8] But, as Octavio Ferraz rightly suggests, the courts' view of Brazil's emerging right to health entailed "a favorable litigation environment" resulting in "an explosion of litigation … characterized by a prevalence of individualized claims demanding curative medical treatment (most often drugs) and by an extremely high success rate for the litigant …, irrespective of costs."[9]

The impacts of health litigation on Brazil's health system have generated prolific and polarized debate.[10] Those who approve of the litigation argue that it promotes health equality because it helps poor and older individuals get treatment that is already covered by governmental formularies but is inadequately supplied.[11] In their view, litigation advances the right to health and improves health care access. By contrast, some government officials and legal scholars argue that such lawsuits have the potential to worsen inequality in the system because they may siphon off funds from important primary health care or promotion measures that benefit the poorest and instead redirect resources toward expensive individual treatments benefiting those—often from economically advantaged groups—who have access to courts.[12]

While the overall impact of health litigation on equality of access remains to be determined, the evidence indicates that insufficient access to acute care is unlikely to be resolved by litigation. According to the evidence, inadequate access to acute care, specialists, and diagnostic support (which collectively form the bulk of health litigation claims) remains a problem in the Brazilian health system.[13] Further, resorting to litigation for access may not produce a more satisfied public either. For instance, despite the increased volume of litigation, according to a 2017 survey, health remains the major concern of Brazilians, who repeatedly complain about persistent problems: gaps in coverage, delays in care, and underfinancing of the health system.[14] These challenges in the public system are expected to intensify, for an increasing number of Brazilians are no longer purchasing private health insurance and are beginning to rely on the public system.[15] Simply put, access to litigation is not the only answer, and Brazil's right to participation offers the potential for improving equality of access and protecting the right to health for all Brazilians.

The value of participation

Brazil's constitutional mandate for citizen participation as a key component of its right to health is consistent with the emphasis given to participation internationally. For example, the 1978 International Conference on Primary Health Care, resulting in the Alma-Ata Declaration, linked health and participation in a clear and practical way.[16] The declaration affirms that "gross inequality in health status is … unacceptable" and states that to achieve equality, "[t]he people have the right and duty to participate … in the planning and implementation of their health care."[17] Since then, the instrumental value of participation in tackling the social roots of illness and fostering equality and accountability continues to influence health strategies and debates worldwide.[18]

Furthermore, United Nation treaty bodies have consistently reinforced the centrality of participation in health systems for improved health equity.[19] General Comment 14, issued by the Committee on Economic, Social and Cultural Rights in 2000, underscores participation as a means to address the social roots of disease, identifying necessary actions to be taken by states to include citizens in decision-making processes.[20] The World Health Organization has similarly reinforced participation as a crosscutting theme linked to good governance that fosters the responsiveness and accountability of health systems.[21]

Scholars have also suggested that participation is an important mechanism for addressing power imbalances in society. Orielle Solar and Alec Irwin, for instance, posit that participation can "shift the locus of decision-making about health to the people whose health status is at issue," allowing people "increased control over the major factors that influence their health" and permitting "communities [to gain] broader capacity to make decisions about how they wish to live."[22]

In the context of Brazil, the report resulting from the 8th National Health Conference in 1986 (often called the "blueprint" for the right to health) made explicit the instrumental value of participation in addressing persistent and ubiquitous inequity in the distribution of social and political power.[23] Section 1.4 of the report, for instance, affirmed that although legal recognition of health as a right and a state obligation is crucial due to the law's distinctive role in shaping and governing institutions and society, legal recognition alone is not enough to implement on-the-ground change.[24] Participation was articulated in section 1.12 as a strategy to include the needs of historically excluded groups into policy decisions and to hold state actors to account for meeting the transformative goals of the right to health.[25] Sections 1.5, 2.3.a, and 2.24–2.26 proposed a framework for participation consisting of institutional bodies (that is, health councils) for citizen participation in the formulation, implementation, and monitoring of health policies and resource allocation.[26] This is the vision of participation as part of the right to health incorporated into the constitutional and legal framework of Brazil's right to health, as I will discuss below.

Other legal commentators agree that the goal of including citizens in policy is to promote social change and social justice, which are part of the political project of the Constitution.[27] For example, Sueli Dallari has explored the idea of *democracia sanitária*, meaning civil society participation in public health decisions.[28] She describes citizen participation in light of public health, suggesting that participation is instrumental for allowing a comprehensive and context-sensitive assessment of individuals and societal needs, and for ensuring freedoms and equality.[29]

Participation as a legal obligation

The right to participation is a legal obligation under both Brazilian law and international treaties to which the state is party. From an international perspective, Gunilla Backman and colleagues have argued that human rights treaties establish state obligations to ensure public participation in health planning.[30] Paul Hunt and Backman explain that states are required to implement "institutional arrangements for active and informed participation of all relevant stakeholders, including disadvantaged communities."[31] Other scholars have explored the contours of state obligations to support participation, arguing that in addition to including marginalized populations, states must ensure "accessible, fair, transparent and continuous [participation] processes."[32] The Brazilian government has ratified the main international and regional treaties establishing obligations to health and human rights—including the obligation to enable and ensure participation in health policy—which it is therefore compelled to respect and fulfill.[33]

The Brazilian Constitution establishes "health as a duty of the state" and specifies how state actors must meet their right to health obligations. Articles 196 and 198 read as follows:

> *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 …, 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 directives: …*
> *III - Community participation.*

The right to health, therefore, is not simply a right to personalized medical services or goods. Significantly, the state is under a constitutional obligation to create a comprehensive and participatory health system that includes health promotion, health protection, and access to health care services. Of course, public policies and programs within the health system need to address the countless and diverse needs of individuals in order to prevent constitutional rights from becoming empty promises. But state actors must also carefully balance individual and societal needs as they seek to meet their constitutional obligations by addressing health, health care gaps, and the needs of 208 million Brazilians against a backdrop of ubiquitous inequalities.

The Constitution establishes participation as a fundamental requirement of the health system in order to foster accountability with regard to the diversity of health and health care needs.[34]

Federal legislation establishing Brazil's Unified Health System also mandates mechanisms for participation in the health system (Federal Law No. 8080/1990, article 7) and establishes health councils as institutional bodies for citizen participation in the system (Federal Law No. 8142/1990). Article 1 of Federal Law No. 8142/1990 reads:

> *Each level of the Unified Health System … will have … the following collegiate bodies … II - health council.*
>
> *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 funding matters, and council's decisions are subject to the relevant health authority for approval.*

Government officials are therefore required to establish health councils at the federal, state, and municipal levels, and each of these levels is tasked with determining its council's composition, election, and operational rules. At the national level, Executive Order No. 5839/2006 sets out specific provisions for the NHC. The NHC must consist of 48 members, including users' representatives (50%), health professionals (25%), and public and private providers (25%). Furthermore, this order specifies that the NHC must have an executive secretariat, hold monthly plenary meetings, and organize technical committees and working groups. Additionally, the order reaffirms the NHC's mandate: to develop health strategies and to monitor resource allocation at the national level of the health system. The NHC's decisions are subject to the approval of the minister of health.

Methods

The data presented in this paper are derived from my doctoral research, which includes an analysis of Brazil's constitutional and legislative framework, naturalistic observations of NHC meetings, and semi-structured interviews with various NHC members during the 2012–2015 term. The project received ethical approvals in Canada and Brazil, and the research design included protective measures to ensure participants' consent, voluntariness, privacy, confidentiality, and anonymity. All 48 NHC members were invited to participate, and of these, 26 respondents (54.17%) indicated their willingness to participate in the study; all 26 were interviewed. These respondents were representative of the NHC's entire population in that they represented all four groups (civil society organizations, health system workers, public providers, and private providers) that form the membership of the NHC. The sample was also representative in terms of gender, education, and age.

Interviews were conducted in Portuguese, audio recorded with participants' permission, and transcribed into computer files. The questions used in all 26 interviews explored three main themes: experience with participation, interpretation of the law, and implementation of the law. I systematically coded the interview transcripts 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 and adapted to the object of my study.[35] The inductive approach includes relying on the actual data to develop the structure of analysis based on the thematic content approach. This approach involved analyzing the transcripts, organizing the data into themes, and extracting examples of those themes from excerpts of the text.

Findings and discussion

This section explores three major questions addressed in my research: whether the composition of the NHC facilitated citizen participation, whether the NHC was successful in considering group needs and systemic concerns, and whether the law hinders the NHC's ability to carry out its mandate. My research results suggest that the NHC is a particularly important mechanism for participation because it facilitates the inclusion of marginalized communities and the consideration of system-wide concerns. My findings also identify potential initiatives that could strengthen the NHC's impact.

Representation

As noted above, Brazil's right to participation implies broad citizen inclusion in health governance, particularly by members of marginalized communities. Congress has implemented these constitutional requirements by providing for participation in health councils by representatives of organized civil society ("users"). This strategy raises an important question of law: whether the use of selective representation conflicts with the constitutional goal of broad inclusion in health planning.

The Constitution is silent concerning how participation should take place, which, in the context of Brazil's legal system, means that Congress has some degree of discretion regarding organizational rules for participation in health planning, including membership rules. Few would dispute the necessity of a membership limitation in a country with about 208 million people.[36] Furthermore, my doctoral research confirms that representative participation is also consistent with the intention of the framers.

My qualitative research, including interviews and naturalistic observations of NHC meetings, confirms that representative membership rules have not precluded citizens or groups without membership from participating in NHC meetings or from exerting direct pressure on council members. For example, one users' representative noted that he forwards the NHC's deliberative agenda to a network of over 700 community groups and explained that "we exchange ideas throughout the meetings by email and WhatsApp. I reply to all. I am under constant pressure." One users' representative suggested, however, that "more has to be done to include other voices in the NHC," and two other users' representatives provided suggestions for fostering inclusion, such as by "open[ing] virtual debates during the meetings" and "more clearly defining steps for citizens to hold [NHC] members to account."

My analysis of constitutional intent demonstrated that participation was expected to facilitate the inclusion of diverse groups, particularly those historically excluded from political arenas. My data confirm that the NHC has in fact included members of groups traditionally excluded from political arenas, such as the disabled, the elderly, Afro-Brazilians, LGBT persons, and people living with HIV/AIDS and hanseniasis. This is also consistent with previous studies concluding that the NHC has integrated historically marginalized groups into health planning.[37]

Systemic concerns

A further, and significant, empirical question raised by the literature is whether NHC representatives actually represent the interests of all citizens.[38] As Leonardo Avritzer summarizes, although the NHC's representatives are expected to represent the population as a whole, there is always the risk that personal or organizational interests will prevail over the public's interests.[39] My research indicated that respondents are well aware of this issue and continuously try to manage potential conflicts of interest appropriately. Respondents asserted that the NHC is a space for dialogue; one health workers' representative added that "here we are always learning about each other's pains." Although participation is associated with interest groups' representation, one users' representative explained, "We represent [interest group omitted] in the NHC. But we had to learn about other areas, pathologies, disabilities, challenges faced by health professionals to participate well." A users' representative commented, "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 [interest group omitted] specifically."

My analysis of the research data indicates that the NHC facilitates the flow of context-sensitive information that helps policy actors structure complementary efforts. Respondents from all groups cited the need to address health care needs by collaborating and forging a variety of alliances to support both specific initiatives and the improved operation of the system as a whole.

The results also echo Dallari's notion of *democracia sanitária*, or the process of broadening the basis on which health policy decisions are made. Several interviewees provided rich descriptions of ways in which they had sought to balance individual and collective expressions of health-related needs, with one health workers' respondent stating, "I think that there must be a clear, sensitive, and strongly balanced consideration between the twofold aspects of the right to health, and the collective interest should always prevail." A users' representative gave a detailed analysis of the steps he used to "transform" one individual's health care needs into a strategy to change the service as a whole:

> *One person needed a specific medication that the [Unified Health System] 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. 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 [the NHC's] pharmaceutical committee readdressed the demand to a more general dimension.*

The NHC was seen, in the words of one government's representative, as "a better place [than the courts] to understand constitutional principles such as comprehensiveness and integration of health-related services, which is key to balancing both dimensions of the right to health."

Strengthening participation: Legal authority

My research also suggests that some aspects of the NHC's legislation should be amended to improve the effectiveness of participation in the implementation of health policies. Consistent with the work of other scholars, my study identified legal barriers to the NHC's ability to carry out its mandate.[40] This is because the legal framework subjects the deliberative decisions of the NHC to the health minister's approval (Federal Law No. 8142/1990, article 1(II)(2); and Executive Order No. 5839/2006, article 1).

Most of the users' and some of the health workers' representatives interviewed believed that the ratification rule undercuts the autonomy of the NHC and hinders its ability to carry out its statutory function. In the views of some government representatives, however, government officials take the NHC's recommendations seriously. For example, one government representative stated, "If we look at the Ministry's financing report, we can see in every single report many explanations addressing [the NHC's] concerns." But one users' representative criticized the way in which the government addresses the NHC's concerns. In his view, government officials more often than not fail to make changes according to the NHC's recommendations, explaining that "the council approves budget statements with the same provisos every single year. The government repeats the same mistakes every single year." My study indicates the need to strengthen the NHC's authority, ideally through legal reform, to change the ratification rule and create an adequate enforcement framework to ensure that government officials take the NHC recommendations into account in a timely way.

Conclusion

Brazil's Constitution requires citizen participation in health planning. In 2014, Brazil's sanitary law journal published a special issue on participation, which called for evidence-based research on participation in the implementation of the right to health.[41] My research project responds to this call by offering new data on the workings of citizen participation in the NHC and by reinforcing the importance of continued research in this area.

My study indicates that the NHC has implemented the constitutional requirement of participation by including historically excluded groups. As a result, the NHC's decisions offer a context-sensitive balance between individual and societal health and health care needs. But this was a small-scale study focusing on the experiences of 26 NHC members during the 2013–2015 term. Further research is needed to examine whether and how NHC members as a whole continue to carry out the task of balancing the diversity of health-related needs over time. In addition, future research projects can explore the extent to which the NHC's recommendations are integrated into health policies and lead to improved access and overall population health. Similar studies can also be carried out in health councils at various levels of government.

My research raises an additional important concern: what is the role of courts in relation to participation? Dallari suggests that participation should be a procedural requirement in public policymaking and that courts should therefore serve as "evaluation sites" to assess whether and how policymaking processes integrate participation.[42] In 2013, Daniel Wang provided an insightful framework through which courts could assess the legitimacy of policy decisions.[43] Wang developed the concept of "procedural legitimacy" based on Norman Daniel and Charles Sabin's notion of "accountability for reasonableness." Procedural legitimacy is based on four conditions: relevance, publicity, appeals, and enforcement, all of which are expected to facilitate accountability in priority-setting decisions.[44] Brazilian courts, Wang suggests, could examine whether policy decisions meet those four conditions.[45] Building on Wang's and Dallari's work, and considering the importance of participation from a constitutional perspective, I posit that the government must genuinely engage with NHC decisions in order for the process to be legitimate, and that courts should act as evaluation sites of procedural legitimacy of health policies. Courts could examine, for instance, whether government officials provide the NHC reasonable (evidence-based), relevant (socially acceptable), and timely explanations for how resources are allocated.

Now more than ever, as challenges to democracy and health equality grow in Brazil and elsewhere, debates about how resources should be allocated and rationed are of utmost importance for the realization of the right to health. My research establishes the constitutional importance of participation in Brazil and reinforces calls to continue investigating this important area. With additional research and evidence-based interventions, participatory mechanisms such as the NHC may play an even more significant role in ensuring accountable resource allocations within health systems that both improve access and support population health. A renewed focus on citizen participation is needed to advance the realization of the right to health in Brazil. Brazil's approach to participation may also be of interest to other Latin American countries struggling with health inequalities.

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