

# Health and Human Rights Journal

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## SPECIAL SECTIONS

Neglected Tropical Diseases and Human Rights  
Judicial Enforcement of Health Rights: Focus on Latin America

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## FOREWORD

# Embodying Law and Embedding Public Health with the Voices of Those Affected: Ending NTDs by 2030

ALICE CRUZ

In the mid-nineteenth century, when public health was establishing itself as a scientific field, the great physician-scientist Rudolph Virchow wrote, “Medicine is a social science, and politics is nothing more than medicine on a larger scale.”<sup>1</sup> With this statement, Virchow highlighted the interplay between human health and society.

A century and a half later, the looping effect—that is, the fundamental relationship between society and health, between culture and biology—remains inadequately addressed.<sup>2</sup> The difficulty lies in what Bruno Latour refers to as the modern cut of the Gordian Knot tying the different elements that make up the world; this cut drove the separation of science and knowledge from politics and power.<sup>3</sup> Hence, science became responsible for representing nature, and law for representing citizens. Accordingly, medicine and law grew apart as the modern state’s organizational structure became progressively bureaucratized and its intervention increasingly sectoral. Yet there have been significant attempts to combine medicine and legal theory. These include the notion that non-discriminatory access to health is fundamental to the right to the highest attainable standard of health, the social determinants of health, and civic participation in public health strategies.

I welcome this special section on neglected tropical diseases (NTDs) and human rights. It comes at a critical moment, soon after the Sustainable Development Goals (SDGs) were agreed on by 193 United Nations member states in 2015. I would like to highlight SDG 3.3, which calls for ending NTDs by 2030. But I also wish to draw attention to SDG 17, which calls for strengthening global multi-stakeholder partnerships for sustainable development. Goal 17 reminds us of the interrelatedness among many of the SDGs and the fact that multisectoral coordination and action will be required to reach every one of them. Thus, goal 3.3 is closely linked to the SDGs on eliminating poverty and hunger, realizing health and well-being, and achieving quality education, gender equality, clean water and sanitation, decent work and economic growth, and sustainable cities and communities.

This special section is also timely because it coincides with United Nations Resolution 35/9, issued in 2017, which calls for the elimination of leprosy-related discrimination. As Special Rapporteur for the elimination of discrimination against persons affected by leprosy and their family members, I accepted this challenge on November 1, 2017.

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The establishment of this mandate acknowledges the fact that diseases are not reducible to isolated biomedical categories. Indeed, some diseases are so strongly framed by socioeconomic and cultural factors that enforcement of the right to health, however critical it may be, is inadequate to restore and ensure full citizenship to affected persons. Some diseases, particularly those that affect populations subjected to structural violence, are complex biosocial phenomena that require a rights-based approach. Such an approach recognizes that all human rights are inalienable, indivisible, interdependent, and of equal hierarchy, and that they must be fulfilled on a non-discriminatory basis in agreement with the provisions of the Universal Declaration of Human Rights and other human rights instruments.<sup>4</sup>

As many persons affected by leprosy have noted, curing infection is not the same as healing. For the majority of affected women and men, healing is dependent not only on access to medical treatment and bacteriological cure but also on the quality of care, rehabilitation, and social inclusion and participation. For persons affected by leprosy, the Gordian Knot between biology, society, culture, and history is vividly tied, and so are their civil, political, social, economic, and cultural rights.

As Special Rapporteur, I welcome all NTDs into this position's mandate. Despite the structural invisibility of leprosy—which nourishes its social representation as a disease of the past—leprosy is probably one of the most well-known NTDs due to its history. Many of the factors that systematically result in negative outcomes for persons affected by leprosy are also active for other NTDs. Leprosy exemplifies the historically thick barriers to health that also exist for other NTDs, such as widespread stigma and institutionalized and multilayered discrimination. However, stigma and discriminatory laws, jurisprudence, and public policies (in the case of leprosy, there are still discriminatory laws in more than 20 countries, covering the topics of segregation, immigration, marriage, voting rights, public transportation, employment, and housing) are not the only reasons for the exclusion of persons affected by leprosy.<sup>5</sup> These persons also face dis-

crimination in the administration of public goods and services—and even when their rights are recognized, they are not effectively implemented. Access to rights, including the right to health, depends on extra-institutional factors, such as education, inclusion in the formal work market, gender equity, and racial non-discrimination. Given the generalized lack of material equality and prevalent conditions of vulnerability faced by persons affected by leprosy and other NTDs, the gap between the laws on the books and the laws in action is massive, with a correspondingly large impact on these persons' health and well-being.

Taking further the example of leprosy to address NTDs from a human rights perspective, I would like to draw attention to the insufficiency of a medicalized and pharmaceuticalized approach to leprosy.<sup>6</sup> While the groundbreaking role of multi-drug therapy cannot be dismissed—there has been an impressive decrease in the number of cases since multidrug therapy's introduction three decades ago (from over 5 million cases in the mid-1980s to fewer than 200,000 cases at the end of 2016), as well as improvements in the lives of persons affected by leprosy and in the public's image of the disease—there is still (1) considerable incidence and ongoing transmission, (2) a high proportion of late diagnoses, (3) under-notification of the disease by physicians and governments, (4) the emergence of new challenges, such as the increase in foreign-born cases in countries that no longer have expertise in diagnosing and treating leprosy, resulting in increased transmission, and (5) persistent stigma and discrimination.<sup>7</sup>

Of the 214,783 new cases reported to the World Health Organization in 2016, 12,437 occurred in persons with grade 2 disabilities—that is, visible impairments.<sup>8</sup> Such impairments are preventable. When they occur, they indicate a delay in access to diagnosis and high-quality treatment. Moreover, of the 12,437 new cases reported in 2016 with grade 2 disabilities, 281 were among children, a shamefully high figure, and the overall detection among children was nearly 9% of the 214,783 new cases. Additionally, the overall underreporting of women affected by leprosy reflects their vulnerability and

lack of access to health services in many settings, especially in poorer communities.<sup>9</sup> The epidemiology of leprosy is linked to the continuous violation of the human rights of vulnerable groups worldwide and within countries.

In recent decades, it has become increasingly obvious that reducing the incidence of leprosy will require more than just a medical approach. Yet the belief that the availability of medical treatment and dissemination of medical knowledge about leprosy will eliminate stigma and discrimination remains strong, despite the historically, socially, politically, economically, and culturally entrenched discrimination against persons affected by leprosy. In fact, stigma and discrimination hinder people from being diagnosed and treated, as well as from fully enjoying their civil, political, economic, social, and cultural rights.

For these reasons, in 2010 the United Nations approved Resolution 65/215 on the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members and the accompanying Principles and Guidelines for the Elimination of Discrimination against Persons Affected by Leprosy and Their Family Members.

Research on the intersection of health and human rights with regard to persons affected by leprosy and other NTDs is nevertheless lacking and urgently needed. I commend these principles and guidelines as a roadmap for research and action in the field of NTDs.

The commitment to leaving no one behind seems to draw inspiration from Virchow's statement, and it highlights the need to retie the Gordian Knot between science and politics, between health and human rights. This means reuniting the ethics upon which human rights are built with the soteriological concern of the practice of medicine, which places compassion at the center of public health efforts.<sup>10</sup> But this also means *embodying* law—that is, making law relevant to the individual body, where, as Eleanor Roosevelt noted decades ago, all human rights should begin.<sup>11</sup> Further, it means increasingly embedding public health with the human voices of those whose rights have been violated. We must listen to the human voice and respect the knowl-

edge of persons affected and of civil society if we wish to achieve positive outcomes in public health. Taking Virchow seriously means restoring an experiential body to the law and an experiential voice to public health. Both movements are critical for the fulfillment of the 2030 agenda and, particularly, for ending NTDs.

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## EDITORIAL

# “Equipping Practitioners”: Linking Neglected Tropical Diseases and Human Rights

JOSEPH J. AMON AND DAVID G. ADDISS

In 2007, Paul Hunt, the United Nations Special Rapporteur on the right to health, and colleagues published a report entitled *Neglected Diseases: A Human Rights Analysis*. In introducing the report, the authors wrote:

*The human rights implications of neglected diseases, and the contribution that human rights can make to addressing neglected diseases, have not been given the attention they deserve. This report aims to equip practitioners with an understanding of human rights, how human rights abuses cause and result from neglected diseases, and how a human rights approach can contribute to the fight against neglected diseases.<sup>1</sup>*

More than a decade later, the human rights implications of neglected tropical diseases (NTDs) are still only infrequently addressed, and there remains a need to “equip practitioners”—in both the NTD and the human rights fields—and to ensure that rights-based principles and approaches are examined and integrated into NTD programs. Seeking to expand this attention, the call for articles for this special issue of *Health and Human Rights Journal* asked NTD scholars and practitioners to share examples of how rights interact with NTDs and how current NTD programs respect, protect, and promote human rights.

The four articles in this issue respond to this call from different vantage points. Nina Sun and Joseph J. Amon present an overview that looks at how human rights intersect with NTD control and elimination efforts and focus on how rights-based interventions and advocacy can accelerate progress toward global goals. Jibril Abdulmalik and colleagues examine mental health status among persons with lymphatic filariasis (LF) in Plateau State, Nigeria, and how stigma, discrimination, and social exclusion toward people with LF result in significant and often unaddressed morbidity. Hunter Keys and colleagues describe how in the Dominican Republic, an LF program has managed to overcome discriminatory government policies to reach at-risk individuals, protecting their health, building greater trust in government health activities, and reducing the effects of social exclusion. Finally, Arianne Shahvisi, Enguday Meskele, and Gail Davey look at the human rights violations that cause, and are caused by, podoconiosis in Ethiopia, focusing on access to prevention (shoes), education, and affordable and accessible health care. Together, these articles describe some positive steps to integrate human rights into the response to NTDs. But they also highlight how

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despite more than a billion treatments provided and hundreds of millions of people no longer at risk of infection, tens of millions of people are still left behind, and how NTD programs neglect opportunities to advance broader health and human rights concerns among the world's poorest populations.

### “What gets counted gets done” versus “not everything that counts can be counted”

In their overview of human rights and NTD issues, Sun and Amon recount how, before international advocacy helped establish the goal of Guinea worm eradication, Nigeria reported about 5,000 cases of the disease to the World Health Organization (WHO) annually. After the goal was set, nationwide village-by-village searches found over 650,000 cases, some in communities previously unknown to government officials. Quantification of the disease burden provided a basis for accountability and for international donor funding toward eradication. From an estimated 3.5 million cases in 21 countries in Africa and Asia in 1986 at the start of eradication efforts, so far in 2018 only three cases have been reported worldwide. The expression “what gets counted gets done” can be understood in this context as not dissimilar from the first steps of human rights advocacy strategies, which include building coalitions, raising awareness, identifying government obligations, and securing commitments.<sup>2</sup>

However, public health programs generally, and NTD programs specifically, often follow an approach that seems closer to the philosophy of “what is easiest to count is counted.” As seen in the article by Abdulmalik and colleagues, mass drug administration programs often fail to address the large burden of mental health morbidity associated with NTDs. In their study, nearly all the respondents with LF revealed personal experiences of stigma and discrimination, frequently in the form of being shunned. They also reported that social interactions—including the ability to find marital partners, the quality of marital relationships, and participation in community social events—were negatively affected. And this experience is not lim-

ited to Nigeria: A recent paper estimated that the global burden of mental illness associated with LF was more than five million disability-adjusted life years (DALYs)—nearly twice as high as the DALYs directly attributed to the disease itself.<sup>3</sup>

Although mass drug administration programs may succeed at breaking LF transmission, can we declare victory when some 40 million people will continue to suffer lymphedema? What does it say about what we value in global health that funding for NTD morbidity management is a small fraction of what is allocated for mass drug administration programs? After transmission interruption goals are met, donor funding will undoubtedly become even more scarce. Even more striking is that this underfunding is happening even though WHO's LF elimination criteria stipulate that programs must assess LF disease burden and include morbidity management within health systems. As NTD (and polio) programs claim success in reaching their goals of interrupting transmission, it seems likely that the communities they served will once again fall off the radar of government health services.

Shahvisi, Meskele, and Davey highlight another disease often overlooked by traditional NTD programs despite occurring alongside other NTDs. Podoconiosis is a debilitating disease marked by chronic swelling of the foot and lower leg, and it is caused by long-term exposure to irritant red volcanic clay soil in highland regions of Africa, Central America, and India. It is so neglected that it is not even officially recognized by WHO as a neglected tropical disease.

In their case study from Ethiopia, the authors describe rights-based programs for podoconiosis and outline government obligations to address the disease. They highlight how civil society advocacy helped spur podoconiosis's integration into the National Master Plan for NTDs, with improved staff training and lymphedema management services at government clinics. In theory, this should promote sustainability. Yet funding remains insufficient and reliant on external donations. The authors also point out that government health care facilities do not serve all endemic rural populations and less

than 5% of Ethiopia's gross domestic product is spent on health care.

In contrast to the focus on diseases left out, Keys and colleagues examine people left out, by law if not always by practice. The authors describe how LF elimination efforts in the Dominican Republic have had to navigate between constitutional protections that guarantee that *toda persona*—every person—has the right to “integral health” and a law passed in 2013 that strips individuals of Haitian descent of their citizenship and rights, including access to health care.

The authors describe how extending LF treatment to individuals of Haitian descent required building trust and evolving from a centralized, vertical program to one grounded in the local health care system that mobilizes local primary care staff, neighborhood associations, and community volunteers. Post-elimination, can this trust, and the provision of care, be sustained? Or will the contribution of individuals of Haitian descent toward ridding the country of LF be rewarded with a return to discrimination and exclusion? Absent political reform, the status of individuals of Haitian descent in the Dominican Republic is unlikely to stabilize through disease-specific initiatives. While LF elimination may be sustained, inclusion and recognition by the public health sector may not.

### Finding a way to count what counts

In all four articles, there is a broadening of the lens to explore how NTD elimination efforts can intersect with universal health coverage goals and the promotion of the right to health, non-discrimination, and human dignity. While NTD donors and practitioners have often defined the goal of transmission interruption as the most important priority, the authors and programs highlighted in this issue show how incorporating a rights perspective can not only strengthen health outcomes (beyond breaking transmission) but also accelerate the achievement of NTD elimination goals.

Collectively, the articles can be read as a call for more attention to (and creativity in defining) indi-

cators that measure the capacity and sustainability of governments to fulfill the right to health in terms of NTD morbidity and mental health, as well as structural determinants of vulnerability to NTDs. Our challenge is to find new ways to count what we dismiss too easily as uncountable. To a large extent, social justice and health equity have served (only) as a rallying cry for advocacy for NTD programs. Rights are recognized implicitly, as NTD programs are intended to be “pro-poor.” But if we pursue NTD elimination because we recognize the extent to which these diseases both cause and result from injustice and inequity, then we must be sure that our efforts and means of achieving elimination address this underlying concern and advance equality and promote human dignity. Measuring reductions in stigma and discrimination and improvements in mental health and gender equity should be an essential part of NTD program evaluation.

In addition to the topics addressed by the four papers included in this special issue, NTDs engage with and pose many other challenges to human rights. For example, in Brazil, persons with Chagas disease face discrimination in securing employment and remaining employed.<sup>4</sup> As Alice Cruz states in her foreword to this special section, laws and policies that discriminate against persons affected by leprosy remain on the books in many countries, and affected persons and their families continue to experience stigmatization. Ongoing transmission of Zika virus, although not (yet) recognized by WHO as an NTD, highlights challenges to reproductive rights, as well as failures to collect or report data on Zika.<sup>5</sup> Massive dam-building schemes in areas endemic for schistosomiasis can both infringe on the human rights of persons living in these areas and increase communities' risk of contracting the disease.<sup>6</sup>

On a broader scale, a human rights approach can be valuable in addressing complex issues of intellectual property and the development of low-cost generic drugs for NTDs.<sup>7</sup> Recent examples of rogue companies purchasing the rights to license NTD drugs in the United States and then jacking up the price to astronomical levels highlight the fact that

access to safe and effective NTD drugs is not simply an issue for developing countries.<sup>8</sup> In addition, the inextricable link between NTDs and human rights violations makes it difficult, yet essential, to address them in refugee settings and areas of conflict.<sup>9</sup>

## Human rights and the future of NTD control and elimination

The 2012 London Declaration on Neglected Tropical Diseases mobilized substantial resources and attracted international attention to 10 NTDs in an effort to achieve the 2020 WHO targets for their control or elimination. Our laser-like focus on these targets, which are related largely to transmission, has yielded impressive results. Donated NTD drugs from pharmaceutical companies were used in mass drug administration programs to treat more than one billion persons in 2016. Since 2012, 20 countries have stopped mass drug administration for LF, either having received WHO validation or having passed their transmission assessment surveys.<sup>10</sup> Five countries have been recognized by WHO as having eliminated trachoma as a public health problem, including, most recently, Nepal and Malawi.<sup>11</sup>

However, although transmission has been significantly reduced, and in some cases nearly eliminated, for many NTDs the public health problem remains. Our focus on transmission has also had the negative effect of constricting our notion of what an NTD program is. NTD programs have been conceived of as vertical, military-like assaults on implicated pathogens, rather than as providing care for affected persons. Thus, chronic NTD morbidity, together with its accompanying stigma and mental health problems, has been viewed as falling largely outside the purview of NTD programs—as have the underlying causes of NTDs, such as poverty, inequity, and inadequate sanitation. Consequently, despite the NTD mantra of “integration” with broader health initiatives, NTD programs have remained relatively isolated within ministries of health. An important early justification for NTD programs was that they would extend and strengthen health systems. Yet our restricted notion of what NTD programs are

has limited their potential to relieve suffering and strengthen health systems.

Calls to expand the scope and vision of NTD programs—whether to address chronic morbidity, mental health, or health systems strengthening—have mostly been met with shrugs of resignation from donors, governments, and nongovernmental partners alike. At a recent international meeting on NTDs, the representative of a prominent donor, replying to a comment on the challenge of reaching geographically isolated (but affected) communities, said matter-of-factly that NTD programs had to consider indicators measuring the cost per person reached, which might lead to focusing on achieving elimination targets through high treatment coverage of populations living close to health facilities. Such an attitude is opposed to the spirit and the fundamental intent of the Sustainable Development Goals (SDGs). Given the radical and far-reaching vision of the SDGs, it is time to reflect on whether our current “donate to eliminate” approach to NTDs, which appeals primarily to the goals of eliminating specific diseases and advancing economic development, can carry us much further.

We suggest two major complementary shifts in approach that can both broaden and deepen NTD programs and equip them for realizing the SDGs. First, as we have outlined above and as the articles in this special issue detail, a human rights approach is needed to build on the successes of the NTD effort to date and expand progress to new areas. Second, in keeping with intent of the SDGs to “leave no one behind,” NTD programs must commit to caregiving for affected *persons* in addition to engaging the battle against infectious organisms.

Addressing the challenge of NTDs at the global level necessarily requires massive systems, partnerships, and bureaucracies. In the process, we tend to lose sight of the importance of providing care to affected individuals, and the human dimension of our efforts withers.<sup>12</sup> In recognition of this tendency, the WHO Global Learning Laboratory recently named compassion as a key component of high-quality universal health coverage and has issued a co-development call to better understand how to harness the essential human aspects required for quality health

care. For global health and NTD control programs to realize their full potential, they must simultaneously embrace and be informed by both human rights and human dignity.

In his 1935 book on typhus, entitled *Rats, Lice and History*, Hans Zinsser wrote that “however secure and well-regulated civilized life may become, bacteria, protozoa, viruses, infected fleas, lice, ticks, mosquitoes, and bedbugs will always lurk in the shadows ready to pounce when neglect, poverty, famine, or war lets down the defenses. And even in normal times they prey on the weak, the very young and the very old, living along with us, in mysterious obscurity waiting their opportunities.”<sup>3</sup> But those opportunities—at least for LF, trachoma, Guinea worm, and onchocerciasis—are waning because of the heroic work of NTD campaigns to map NTD prevalence and deliver effective drugs on a massive scale. These successes represent major victories for public health. But as the articles in this issue highlight, the chronic manifestations and public health burden of many NTDs remain—and with them, stigma, exclusion, and lack of access to care still lurk and lie waiting.

The SDGs, with their renewed emphasis on universal health coverage, underscore the need to turn our attention and shift our global health priorities from vertical programs targeting specific pathogens to programs aimed at strengthening systems of care. In support of this new perspective, the human rights approach is well positioned to inform, guide, and catalyze efforts to realize national and global goals for NTD control and elimination. To date, human rights principles and approaches have emphasized, to varying degrees, participation and transparency, in terms of community engagement and public accounting of NTD prevalence and progress toward elimination and control. But non-discrimination and accountability (including for greater country financial investment) have been less emphasized. Sun and Amon note three specific areas where rights-based approaches to NTDs can be expanded: addressing inequity and populations at risk of being left behind; combatting stigma and discrimination and ensuring attention to mental health needs among people living with NTDs; and

promoting patients’ rights and non-discrimination in health care settings. These three areas represent concrete starting points for NTD practitioners seeking to integrate rights into their work.

As Paul Hunt noted more than a decade ago, if fully deployed, human rights can help NTD programs—and the governments that run them—deliver on their fundamental promise of health equity and more effectively advance their unfinished “pro-poor” agenda. Building on Hunt’s call to action, the four articles in this issue begin to explore the opportunities and need for an enhanced collaboration between NTD programs and human rights principles and approaches. What is to be gained is not just the elimination of specific pathogens but more equitable communities and healthier populations.

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# Addressing Inequity: Neglected Tropical Diseases and Human Rights

NINA SUN AND JOSEPH J. AMON

## Abstract

Twenty neglected tropical diseases (NTDs) are currently recognized by the World Health Organization. They affect over one billion people globally and are responsible for significant morbidity, mortality, poverty, and social stigmatization. In May 2013, the World Health Assembly adopted a resolution calling on member states to intensify efforts to address NTDs, with the goal of reaching previously established targets for the elimination or eradication of 11 NTDs. The resolution also called for the integration of NTD efforts into primary health services. NTDs were subsequently included in Sustainable Development Goal (SDG) 3, which calls for an end to the “epidemics of AIDS, tuberculosis, malaria and NTDs” by 2030. While both the World Health Assembly resolution and SDG 3 provide a strong framework for action, neither explicitly references the human right to the highest attainable standard of health or describes a rights-based approach to NTDs’ elimination. This article identifies key human rights relevant to NTD control and elimination efforts and describes rights-based interventions that address (1) inequity in access to preventive chemotherapy and morbidity management; (2) stigma and discrimination; and (3) patients’ rights and non-discrimination in health care settings. In addition, the article describes how human rights mechanisms at the global, regional, and national levels can help accelerate the response to NTDs and promote accountability for access to universal health care.

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## Introduction

The World Health Organization (WHO) recognizes 20 “neglected tropical diseases” (NTDs).<sup>1</sup> These diseases share key common features, including disproportionately affecting poor communities and individuals with little social or political capital (see Box 1).<sup>2</sup>

While all 20 NTDs are preventable—and to varying degrees, treatable—they nonetheless affect over one billion people worldwide living in 149 countries and territories.<sup>3</sup> At least 100 countries are endemic for two or more diseases, and 30 countries are endemic for six or more.<sup>4</sup> NTDs also predominately affect those who are most disadvantaged—individuals living in low-income countries are most burdened with NTDs, and within those countries, the burden of NTDs is higher among poorer households. The people in these communities often live in inadequate housing, lack access to clean water and sanitation, and have little protection from insects and other disease vectors.<sup>5</sup>

NTDs are both a cause and a consequence of poverty, causing physical and intellectual impairments, preventing children from attending school,

and reducing economic productivity.<sup>6</sup> They can also be severely stigmatizing: for example, lymphatic filariasis causes swelling (lymphedema) in 40 million people and, as with the deformations resulting from Buruli ulcer and yaws, can be socially exclusionary, often affecting individuals’ ability to work, to marry, and to care for and live with their families.<sup>8</sup> Fear of the disfiguring effects of leprosy and a centuries-long ignorance of the disease have resulted in individuals being shunned or exiled by their communities.<sup>9</sup>

Recognition of the underinvestment in the response to NTDs, relative to their significant health, economic, and social impacts, has led to increased global attention and commitment to their control and elimination. In May 2013, the World Health Assembly adopted a resolution calling on WHO member states to intensify efforts to address NTDs, with the goal of reaching previously established targets for the elimination or eradication of 11 NTDs. The resolution also called for the integration of NTD efforts into primary health services and universal access to preventive chemotherapy and treatment. NTDs were subsequently included in Sustainable Development Goal (SDG) 3, adopted in September

Box 1. WHO-recognized NTDs and common features<sup>7</sup>

WHO Recognized NTDs	Common features of these diseases
<ul style="list-style-type: none"> <li>• Buruli ulcer</li> <li>• Chagas disease</li> <li>• Dengue and chikungunya</li> <li>• Dracunculiasis (guinea-worm disease)</li> <li>• Echinococcosis</li> <li>• Foodborne trematodiasis</li> <li>• Human African trypanosomiasis</li> <li>• Leishmaniasis</li> <li>• Leprosy (Hansen’s disease)</li> <li>• Lymphatic filariasis</li> <li>• Mycetoma</li> <li>• Onchocerciasis (river blindness)</li> <li>• Rabies</li> <li>• Schistosomiasis</li> <li>• Soil-transmitted helminthiasis</li> <li>• Taeniasis/cysticercosis</li> <li>• Trachoma and yaws</li> <li>• Chromoblastomycosis and other deep mycoses</li> <li>• Scabies (and other ectoparasites)</li> <li>• Snakebite envenoming</li> </ul>	<ul style="list-style-type: none"> <li>• Being a proxy for poverty and disadvantage</li> <li>• Affecting populations with low visibility and little political voice</li> <li>• Having a relatively stable endemic foci</li> <li>• Often overlapping geographically</li> <li>• Causing stigma and discrimination, especially for girls and women</li> <li>• Having an important impact on morbidity and mortality</li> <li>• Being relatively neglected by research</li> <li>• Can be controlled, prevented, and possibly eliminated using simple, effective, and feasible solutions</li> </ul>



2015, which calls for an end to the “epidemics of AIDS, tuberculosis, malaria and NTDs” by 2030.

Beyond setting disease-specific targets, the SDGs more generally seek to end health inequities and increase access to health care. Target 3.8, for example, calls on countries to “achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all.” Goal 1, ending poverty in all its forms everywhere, highlights the importance of social protection systems for the most impoverished and marginalized. Reducing inequalities (goal 10) and ensuring access to clean water and sanitation (goal 6) are also prioritized. Action across all of these goals will facilitate the control and elimination of NTDs.

Identifying and addressing health inequities requires strong links to human rights. The WHO Constitution recognizes this, identifying the enjoyment of the highest attainable standard of health as a fundamental right of every human being.<sup>10</sup> However, health practitioners and policymakers often have little understanding of how to translate support for a right to health into rights-based interventions, and examinations of the links between human rights and NTDs have been limited to date.

Public health practitioners working for NTD control and elimination can benefit from understanding how to integrate human rights principles into their programs and how engagement with human rights mechanisms, such as special rapporteurs and expert committees related to international human rights treaties, can complement the medical and clinical aspects of their interventions. Therefore, this paper seeks to (1) briefly describe the relationship between NTDs and human rights and human rights-based approaches to NTDs; and (2) examine how NTD advocacy, emphasizing the human rights consequences of NTDs, before human rights mechanisms and beyond, can support elimination efforts.

## Human rights and NTDs

While the impact of NTDs on human rights may be interconnected with various rights (for example, the

right to life with dignity, the right to enjoy the benefits of scientific progress, etc.), at its core, this relationship can best be understood through an examination of the rights to health and non-discrimination.

### *Right to health*

The right to enjoy the highest attainable standard of physical and mental health (commonly referred to as the right to health) is enshrined in several international human rights treaties, as well as regional agreements and national constitutions and laws.<sup>11</sup> While there are several sources of this right, the main global treaties that enshrine this right are the International Covenant on Economic, Social and Cultural Rights (ICESCR),<sup>12</sup> the Convention on the Elimination of All Forms of Discrimination against Women,<sup>13</sup> the International Convention on Protection of the Rights of All Migrant Workers and Members of Their Families,<sup>14</sup> the International Convention on the Elimination of Racial Discrimination,<sup>15</sup> and the Convention on the Rights of the Child.<sup>16</sup>

In addition to these treaties, the meaning of the right to health has been further defined by the Committee on Economic, Social and Cultural Rights, which monitors the implementation of state obligations under the ICESCR.<sup>17</sup> The committee outlines four important aspects of assessing the right to health: availability, accessibility (including non-discrimination and affordability), acceptability, and quality (also known as the AAAQ framework). It is important to note that the right to health does not guarantee the right to be healthy; instead, this right stands for an individual’s claim to the “enjoyment of a variety of goods, facilities, services and conditions necessary for its realization.”<sup>18</sup>

Identifying a relationship between NTDs and human rights does not automatically lead to action: given that states have different levels of resources, international law does not mandate the kind of health services to be provided, instead demanding their “progressive realization.”<sup>19</sup> However, states are recognized as having to fulfill certain minimum “core” obligations irrespective of resources, which includes ensuring access to health facilities and resources on a nondiscriminatory basis, especially for vulnerable and marginalized groups; the equi-

table distribution of all health facilities, goods, and services; and the adoption and implementation of a national public health strategy and plan of action, on the basis of epidemiological evidence, addressing the health concerns of the whole population. In addition, states should provide essential drugs, as defined by WHO.<sup>20</sup>

### *Non-discrimination*

The right to equality and non-discrimination is essential to the international human rights framework generally and, as described above, to the fulfillment of the right to health.<sup>21</sup> The Human Rights Committee and the Committee on Economic, Social and Cultural Rights define discrimination as any distinction, exclusion, restriction, preference, or other differential treatment that is based on prohibited grounds and which has the intention or effect of nullifying or impairing the recognition, enjoyment, or exercise of all fundamental rights and freedoms.<sup>22</sup> Prohibited grounds of discrimination include “race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status.”<sup>23</sup> Non-discrimination and other rights of indigenous populations have also been specifically recognized both by the creation of specialist bodies on indigenous peoples in UN and regional human rights bodies, and

through specific reference to indigenous peoples in human rights treaties, such as the Convention on the Rights of the Child. Relevant to NTDs, discrimination based on disability and health status are also generally prohibited.

The right to non-discrimination does not mean identical treatment for everyone in every situation. In some cases, differential treatment may not amount to discrimination if the criteria for different treatment are objective and reasonable and aim to advance progress toward a right or freedom.<sup>25</sup>

### Human rights-based programming

#### *Applying human rights principles to NTDs*

Public health programs based on human rights have been shown to improve service delivery and enhance equality, equity, inclusiveness, and accountability.<sup>26</sup> These programs, which traditionally include civil society engagement, high-level political leadership, and attention to equitable access to care, can also strengthen health systems and support successful NTD programs (see Box 2).<sup>27</sup>

WHO has described a rights-based approach to NTDs, emphasizing the human rights principles of participation, non-discrimination, and accountability.<sup>28</sup> Participation—and specifically the engagement of individuals and communities di-

#### Box 2. Strengthening health systems and the importance of the rights-based approach

A rights-based approach to NTDs should support strong and effective health systems, be responsive to national and local priorities, and be accessible to all.<sup>24</sup> In many countries, NTD control and elimination programs operate as stand-alone or vertical structures with poor integration into ministries of health. As NTD elimination goals are met, and as donor funding recedes, greater integration of NTDs into health systems is critical, both to ensure attention to post-elimination areas of endemic foci and for NTDs targeted for control that will require ongoing attention.

Rights-based NTD programs should ensure that NTD capacity building or health system strengthening efforts promote the integration of human rights principles into all of the WHO health system “building blocks,” which include the following: health services (medical and public health); health workforce; health information systems; medical products, vaccines, and technologies; health financing; and leadership, governance, and stewardship. Specific components of these—such as planning, resource allocation, monitoring and evaluation, and human resource management—represent concrete areas where participation, non-discrimination, and equity are implemented and where the performance of the government and its legitimacy are tested.

rectly affected by NTDs—has been long recognized as critical to effective NTD programs.<sup>29</sup> Two examples, highlighted by Paul Hunt, the United Nations (UN) Special Rapporteur on the right to health from 2002 to 2008, include the engagement of patients' associations for the control of leishmaniasis in Peru and community-directed treatment for onchocerciasis.<sup>30</sup> In the former case, individuals afflicted with leishmaniasis formed associations to advocate for and to promote and distribute treatment; these associations eventually evolved into a state-funded, regional control program. In the latter case, community-directed treatment for onchocerciasis supplanted more top-down approaches, empowering communities and providing greater flexibility for the distribution of preventive chemotherapy to interrupt onchocerciasis transmission. Community-chosen drug distributors in the program often subsequently became involved in other health activities, including immunization, water and sanitation-related activities, and development projects.

Similarly, a core component of the NTD response has been to increase transparency and accountability by mapping the distribution of disease, improving reporting of disease burden, and advocating for explicit objectives and goals to which governments can be held to account. A dramatic example is the change in the reported incidence of Guinea worm (dracunculiasis) before and after the initiation of eradication campaigns. For example, Nigeria and Ghana each officially reported about 3,000–5,000 cases of the disease to WHO annually in the 1980s. When the two countries conducted nationwide village-by-village searches for the disease in 1989, they enumerated over 650,000 and almost 180,000 cases, respectively. The surveillance effort also identified communities previously unknown to government officials.<sup>31</sup>

More rigorous measures of accountability—including formal assessments of whether governments, donors, and private actors are respecting, protecting, and fulfilling their obligations under human rights law—have been rare. Hunt addressed issues related to NTDs on country visits and in several reports to the Commission on Human Rights.<sup>32</sup> In his reports,

he highlighted the obligations for governments, international organizations, and the private sector (including pharmaceutical companies) to prevent, control, and eliminate NTDs. He also noted the importance of community participation and was a strong advocate for addressing NTDs through a human rights framework.<sup>33</sup>

As global efforts to control or eliminate NTDs continue, three specific areas for rights-based approaches can be highlighted: inequity and populations at risk of being “left behind”; combatting stigma and discrimination and ensuring attention to mental health needs among people living with NTDs; and promoting patients' rights and non-discrimination in health care settings.

### *Analyzing and addressing inequity*

In 2017, WHO released a working paper entitled *Towards Universal Coverage for Preventive Chemotherapy for NTDs: Guidance for Assessing “Who Is Being Left Behind and Why.”*<sup>34</sup> The paper seeks to provide guidance to NTD program managers and partners on how to better monitor “differences in access to and impact of preventive chemotherapy” according to demographic and geographic characteristics that could reveal inequity, “identify barriers driving inequities and facilitators for coverage,” and “catalyze integration of a focus on ‘who is being left behind and why’ into on-going country level monitoring and evaluation of PC [preventive chemotherapy] to trigger remedial action as appropriate.”

In order to achieve more effective PC coverage, the working paper suggests that program managers and partners look at both quantitative and qualitative data, using the right to health's AAAQ framework, to explore barriers and facilitating factors for effective PC coverage. Regarding availability, the paper explores various dimensions, including the availability of suitable drugs (for example, dosages and formulations available for children), the availability of resources to allow medicines to reach all districts and communities (for example, transport for medicines), and resources to support community drug distributors in effectively reaching all communities (for example, transport for personnel). With regard to accessibil-

ity, it looks at geographic (for example, distances required to receive treatment), financial (for example, direct and indirect costs), and organizational and informational accessibility (for example, attention to opening times for treatment provision; information delivered in appropriate formats about the medicines). In terms of acceptability, the guidance looks at various dimensions, including the selection process for health service providers (for example, whether they come from inside or outside the communities), gender norms and relations, and the age-appropriateness of services. Finally, with regard to quality, it calls for program managers and partners to ensure that medicines are safe and of high quality.<sup>35</sup> The paper's emphasis on the AAAQ framework as applied to PC coverage seeks to analyze the perceptions of different groups, communities, and health service providers and to address health inequity and gender inequality.

The need to address inequities has been highlighted in studies that have found differential rates of disease burden within NTD-endemic countries according to socioeconomic status, with the lowest socioeconomic groups disproportionately affected by NTDs.<sup>36</sup> For example, in Bihar, India, more than 80% of households in communities with high attack rates of visceral leishmaniasis belong to the two lowest quintiles (the poorest 40%) of the wealth distribution.<sup>37</sup> Indigenous communities like individuals in low socioeconomic groups unsurprisingly also face disproportionate burden of disease and often catastrophic consequence of NTD infection, including long-term indebtedness,

even when diagnosis and medicines are provided free of charge (see Box 3).<sup>38</sup>

Global progress on NTDs also reflects inequities: A recent analysis by Wilma A. Stolk et al. estimated the change in NTD-related burden of disease using disability-adjusted life-years (DALYs) between 1990 and 2010. In upper-income countries, DALYs attributed to NTDs decreased by 56%, compared to 16% in lower middle-income countries and 7% in low-income countries.<sup>40</sup> In addition, Cameron Seider et al. analyzed data from the 2013 demographic and health survey in Nigeria and found that access to child deworming increased linearly with level of maternal education (9.4% for children whose mothers had no formal education, compared to 42.5% for children whose mothers had more than secondary education) and wealth quintile (7.9% for the lowest wealth quintile, compared to 39.1% for the highest). It was also higher in urban (28.4%) than in rural (15.2%) areas.<sup>41</sup>

In addition to looking at socioeconomic and geographic disparities, greater attention should be paid to access to prevention and treatment for specific populations—including women (see Box 4), migrant or mobile populations, and ethnic minorities. Each of these populations may be at increased risk of NTD infection or may be less able to access prevention and treatment. While the focus of NTD elimination programs is on achieving universal coverage, more effort is needed on understanding who is left out and why, as well as on increasing funding and support to communities struggling to reach elimination targets and on ensuring continued

### Box 3. Indigenous populations and inequalities in Oceania

In the Oceania region, an area encompassing Australia, New Zealand, Melanesia, and the Polynesian and Micronesian islands, NTDs disproportionately affect impoverished and indigenous communities, reflecting transnational and national inequities. For example, in Papua New Guinea, where the population is nearly entirely of indigenous descent, over one-third of residents live below the World Bank's poverty line. In addition, high rates of hookworm infection, yaws, and trachoma are found in many parts of the country. In other countries, such as Australia, health inequalities are concentrated in aboriginal communities, who are burdened with disproportionately high rates of soil-transmitted helminth infections, including strongyloidiasis and hookworm, as well as trachoma and scabies.<sup>39</sup>

post-elimination interventions for individuals and communities, given that NTD goals for elimination as a public health problem explicitly allow for elimination to be certified despite low levels of disease transmission. The risk is that this will concentrate the remaining disease burden in the most vulnerable while simultaneously ending funding and outreach. Assuming that those not yet reached can be integrated into ongoing primary care efforts overlooks the reason why they have not been reached to date.

*Looking beyond mass drug administration to address stigma, social isolation, and mental health*

Stigma and discrimination, exclusion from full participation in society, and an inability to access care or seek educational opportunities or employment can result in poor mental health, including depression and suicide. While access to general health care is often limited in communities with high rates of NTD burden, access to mental health care can be even less available.

Drawing on studies of the prevalence of depression among lymphatic filariasis patients in India, Togo, Haiti, and Sri Lanka (which ranged from 8% in Sri Lanka to 97% in India), a recent paper estimated that the global burden of mental illness associated with lymphatic filariasis was more than five million DALYs—nearly twice as high as the DALYs directly attributed to the disease itself.<sup>42</sup> A similar range of depression prevalence was found among individuals with leprosy (from 12.5% to 76%), and infection with

cutaneous leishmaniasis has been found to be a significant predictor of poor mental health and higher rates of depression and anxiety.<sup>46</sup>

Interventions to address NTD-related stigma and social isolation are not new. Programs working with individuals with leprosy have long sought to reduce stigma by educating communities and alleviating irrational fears. A project funded by the UNICEF/UNDP/World Bank/WHO Special Programme for Research and Training in Tropical Diseases from 1998 to 2001 developed support groups in Haiti for individuals with lymphatic filariasis. These support groups integrated social support with treatment and financial assistance in order to help affected persons obtain appropriate footwear. An evaluation of the project found increased self-esteem, social relations, and quality of life among participants.<sup>47</sup>

Human rights-based approaches should recognize the comprehensive health and social needs of affected individuals and seek to expand both social support and access to effective treatment for mental health concerns.<sup>48</sup> The development of elimination criteria for lymphatic filariasis, developed by WHO, explicitly acknowledges the mental health burdens associated with the disease as part of the reason for the requirement for states to report on morbidity indicators in addition to evidence of the interruption of transmission.<sup>49</sup> Rights-based NTD programs should also recognize the potential need for mental health support for caregivers, who may suffer stigma from being associated with someone affected by NTDs

Box 4. Women and girls

Women and girls face differential—and in some cases, disproportionate—impacts from infection with NTDs due to biological and socio-cultural reasons.<sup>43</sup> For example, because of their traditional roles collecting water and acting as caregivers, women may be at higher risk of trachoma infection and more likely than men to develop trichiasis.<sup>44</sup> In addition, women with helminth infections who become pregnant are at increased risk of anemia, and women with schistosomiasis may experience ulcerative genital lesions.<sup>45</sup> Women may also be more likely to experience negative social and economic consequences, such as loss of income and educational opportunities, as a result of caring for others suffering with NTDs. Rights-based approaches, in order to promote equity, must recognize gender-related causes of vulnerability to NTDs and must design programs that address these factors.

or suffer other mental health concerns as a result of providing care to affected individuals.

### *Promote patients' rights and non-discrimination in health care settings*

Stigma and discrimination arise not only in community settings but also in health settings and among health care providers, which can result in the denial of care, poor-quality treatment, and abuse. Health care providers may be inadequately trained to care for certain NTDs or may feel overwhelmed by the care required. Alternatively, they may stigmatize or discriminate against individuals with NTDs because of perceptions of who is most at risk of disease or how it is acquired.

A qualitative study that looked at knowledge and health-seeking behaviors related to schistosomiasis in Kenya found that stigma and discrimination among health providers affected individuals' willingness to seek care. The article quotes a female participant in a focus group discussion as saying, "The fear that maybe if they go to the hospital the doctor how will he see me or how will he take me. So because of stigma they may not go."<sup>50</sup>

Another study, which examined knowledge of and attitudes toward podoconiosis among health professionals in public and private health institutions in Ethiopia, found that nearly all (98%) health professionals held at least one significant misconception about the cause of podoconiosis. Around half (54%) incorrectly considered podoconiosis to be an infectious disease and were afraid of acquiring podoconiosis while providing care. All care providers surveyed held one or more stigmatizing attitudes toward people with podoconiosis.<sup>51</sup>

Few quantitative studies have directly addressed the consequences of stigmatizing attitudes or discrimination in health settings for individuals with NTDs. However, studies on stigma and discrimination related to health-seeking behavior among people living with HIV found that people living with HIV who perceive high levels of HIV-related stigma are 2.4 times more likely to delay enrollment in care until they are very ill.<sup>52</sup> More research on attitudes toward NTDs among health care providers is needed, and where stigma

and discrimination in health settings are identified as a barrier to care, interventions to educate health providers and empower individuals living with NTDs on their right to care are needed.

### Human rights mechanisms and NTDs

In addition to implementing rights-based programs, addressing NTDs through human rights bodies provides a means to promote political will among, and accountability of, government leaders. Advocacy before specific human rights mechanisms may also lead to a greater global commitment to the NTD response while also ensuring that rights-based principles are strengthened.

#### *UN human rights mechanisms*

At the global level, the UN Human Rights Council is tasked with protecting, promoting, and strengthening human rights. It is an intergovernmental mechanism comprising 47 countries that are elected by the UN General Assembly.<sup>53</sup> As a subsidiary body of the General Assembly, the Human Rights Council has the ability to make recommendations directly to the General Assembly for further development and discussion.<sup>54</sup> It also has two human rights mechanisms linked to it: (1) the Special Procedures and (2) the Universal Periodic Review. The Special Procedures are independent experts with country or thematic mandates to report and advise on human rights. Hunt's aforementioned work related to NTDs and human rights under the mandate of the Special Rapporteur on the right to health falls under this mechanism. The Universal Periodic Review is a state-driven process that reviews the human rights record of all UN member states.

To date, attention to NTDs within the Human Rights Council and its mechanisms has focused mainly on leprosy. In 2009, the Council held a consultation on the elimination of discrimination against persons affected by leprosy and their family members. As a result, the following year the General Assembly issued a resolution on this topic.<sup>55</sup> Since then, the Council has issued several resolutions and reports highlighting the problem of leprosy-related discrimination and ways to address it. In 2015, for

example, the Council commissioned a study on the elimination of discrimination against persons affected by leprosy, which was presented to the Council in June 2017 and included a set of recommendations.<sup>56</sup> Also in June 2017, the Council established a mandate of the Special Procedures devoted to the elimination of discrimination against persons affected by leprosy and their family members.<sup>57</sup>

Another important human rights mechanism within the UN consists of treaty monitoring bodies, which are charged with monitoring and reviewing countries' progress on their obligations under the core international human rights treaties. These bodies consist of independent experts who are elected for four-year terms. They issue general comments on treaty provisions, review states' compliance with the treaties, hear individual complaints, and conduct country inquiries. When treaty bodies consider a state party's compliance, they examine the state's practices and issue concluding observations, which are recommendations on how the state can better fulfill its treaty obligations.<sup>58</sup>

These treaty bodies have issued many concluding observations on health-related rights. For example, the Human Rights Committee, which monitors states' compliance with the International Covenant on Civil and Political Rights, has made several recommendations regarding access to sexual and reproductive health services, including safe abortion.<sup>59</sup> In addition, the Committee on the Rights of the Child has made health-related recommendations on child development, such as by highlighting the importance of ensuring access to health care for impoverished communities in Nepal and increasing access to clean water and sanitation services in Pakistan.<sup>60</sup> NTD advocacy could encourage these treaty bodies to raise awareness of and hold countries accountable to their commitments to the control and elimination of NTDs (see Box 5).

### *Courts*

Courts, both regional and national, also provide an avenue for human rights and NTD accountability. Cases may be brought to court to seek redress

#### Box 5. NTD advocacy before human rights mechanisms and beyond

There are multiple ways in which the NTD response can interact with human rights mechanisms, including the following:

- Inviting the Special Rapporteur on the right to health to draft a report focused on NTDs and human rights, building on Hunt's previous work, or to do a country visit focused on NTDs
- Requesting Special Procedures with a country mandate to focus parts of their reports on the impact of NTDs on the most marginalized and states' responses to this issue
- Submitting shadow reports to UN treaty bodies for countries where it may be strategic to highlight the impact of NTDs or the country's response to these diseases
- Encouraging countries involved in the Universal Periodic Review process to engage in dialogue with member states under review about their national-level NTD response

In addition to interacting with the global human rights mechanisms, it may be strategic to raise awareness of the relationship between NTDs and human rights among a broader audience such as health care professionals, donor agencies, and the general public. These stakeholders could consider campaigns to highlight the human rights impact of NTDs in highly endemic communities and how NTDs disproportionately affect the poorest and most marginalized. Such campaigns may coincide with commemorative days, such as Zero Discrimination Day (March 1), International Women's Day (March 8), and Human Rights Day (December 10), or coincide with attention to health and human rights issues at the World Health Assembly or meetings of regional bodies such as the African Union Summit.

for individual rights violations. They may also be brought to defend an issue of broad public interest (this is known as strategic litigation). In such cases, petitioners may challenge the validity of a law or the way that it is applied. The outcome of the case can have a broad impact on society, beyond the lives of the litigants.<sup>61</sup> Courts can be transformative in supporting the realization of human rights, and specifically the right to health. Indeed, several courts have already issued groundbreaking precedents on health issues, such as reproductive rights and HIV.<sup>62</sup>

Nonetheless, few cases related to NTDs have been brought to the courts. In one case, the Inter-American Court of Human Rights found that Paraguay had violated an indigenous community's rights to life and non-discrimination when it forced the community to live on uninhabitable land where community members were exposed to Chagas disease (among other hardships).<sup>63</sup> The court ordered the government of Paraguay to improve medical facilities; to implement water, sanitation, and hygiene programs (specifically parasitic disease control programs) in the community; and to report back on its efforts. It also directed the government to provide nearly US\$1 million for a "community development fund" and for compensation for families of individuals who had died from the poor living conditions. In Argentina, the Supreme Court of Justice came to a similar conclusion—and issued protection orders—in a case in which the Human Rights Ombudsman alleged that the national and provincial governments had failed to ensure an indigenous community's fundamental rights, including the rights to life and health.<sup>64</sup>

### *National human rights institutes*

National human rights institutes (NHRIs) are another mechanism that can strengthen accountability related to NTD elimination. NHRIs are independent public agencies with a constitutional or legislative mandate to protect and promote human rights. They monitor and review a country's human rights record and can make recommendations to governments, hear individual complaints, and provide public information on human rights.<sup>65</sup>

NHRIs come in various forms: they can be commissions or ombudspersons, for instance, and they can have integrated mandates (for example, addressing human rights along with corruption and other matters).<sup>66</sup> Currently, there are 117 accredited NHRIs globally.<sup>67</sup> Several have already worked in some capacity on the right to health—for example, the Canadian Human Rights Commission has adopted a policy that explicitly states that the prohibition against disability-based discrimination includes discrimination based on HIV status.<sup>68</sup> Moreover, the National Human Rights Commission of India has issued recommendations on maternal anemia, HIV, and access to health care.<sup>69</sup>

Given that NHRIs can review a country's general human rights record, they are well placed to monitor general health and NTD concerns, such as in the context of progress toward achievement of the SDGs, particularly concerning NTD elimination (goal 3), gender inequality (goal 5), and clean water and sanitation (goal 6).

### Looking forward

A frequent concern about engaging in health and human rights advocacy is the opportunity cost and uncertainty about the potential impact from such efforts. Engaging human rights mechanisms is not always easy or timely, and the consequences of a UN treaty body resolution, an NHRI review, or even a court case may not always be clear. However, the benefits from increased engagement on NTDs within human rights mechanisms can be significant—and within the context of global NTD elimination efforts, the costs of advocacy are small.

The benefit of human rights advocacy on health issues can be clearly seen for other, previously neglected (and stigmatized) diseases, such as HIV, and increasingly for issues such as drug dependency and palliative care.<sup>70</sup> Similarly, human rights advocacy on NTDs can bring attention to the devastating effects of NTDs and the ongoing resource gap for disease prevention and treatment. Greater political commitment to NTDs, as well as more visibility in the general population, can result in prioritization in addressing NTDs at the



national level and increased resource mobilization for the development of vaccines and treatments and for disease control programs. It will also encourage uptake of existing research, as well as more funding to build on the current evidence base. From a programmatic perspective, rights-based advocacy and engagement with human rights mechanisms could support more comprehensive structural responses that can lead to sustainable NTD control and elimination results. Increasing NTD-related work within human rights mechanisms can also address the social determinants of these diseases, contributing to a stronger overall system that benefits other issues, such as access to clean water and sanitation, extreme poverty, and inequality. Working with human rights mechanisms is thus a holistic way to address NTDs, calling for integration and accountability beyond mainstreaming NTD indicators.

Given the multisectoral nature of the goals and work under the SDGs, partnerships will be more important than ever. Innovative partnerships, such as *Uniting to Combat NTDs*, which has produced critical information on NTDs and NTD-related advocacy, will be essential for moving forward the response.<sup>71</sup> Establishing and strengthening links between NTD advocacy groups and social justice organizations can leverage and expand these partnerships. Increased linkages also promote cross-sector accountability within the partners, between sectors, and across human rights mechanisms.

Of course, human rights advocacy on NTDs is not a panacea. While recommendations from human rights mechanisms are useful, more work needs to be done to guarantee stronger follow-up

and accountability by governments. It may also be worthwhile to consider linking the recommendations to indicators that countries already have to monitor, such as the SDG monitoring and evaluation framework.<sup>72</sup> This can be mutually beneficial to both the human rights system and the SDGs, as it addresses accountability issues at the country level.

## Conclusion

Countries' recognition of their obligation to fulfill the right to the highest attainable standard of health and to ensure that NTD programs incorporate human rights principles such as participation, non-discrimination, equity, and accountability may seem like a jargon-filled or complicated way of describing effective public health programs. However, public health interventions often privilege expediency over participation and equity and fail to guarantee non-discrimination. Accountability for government health systems, and for donor-funded efforts, is often lacking.

In the past 100 years, three out of every six disease eradication programs have failed. A common factor among those programs that failed was inadequate attention to social and political contexts.<sup>73</sup> Scaling up the linkages between NTDs and human rights, and securing greater investments in rights-based approaches within the NTDs response, can help ensure that local social and political actors support the global prioritization of NTD elimination and that NTD elimination programs are effective. A variety of institutions exist to advance human rights and can be used for NTD-related advocacy at the sub-national, national, and global

### Box 6. Summary of potential impact of rights-based NTD programs and engagement with human rights mechanisms

- Rights-based programs that emphasize community participation, attention to equity, and the elimination of stigma and discrimination can promote higher coverage for NTD prevention and morbidity management interventions.
- Rights-based advocacy and engagement with human rights mechanisms can encourage greater political commitment and support more comprehensive structural responses that can lead to sustainable NTD control and elimination results. Broader attention to issues such as equitable access to care and non-discrimination in health settings will have benefits across public health interventions and campaigns more generally.

levels. Increased engagement with human rights mechanisms can enhance accountability, promote non-discrimination, and support the participation of the most affected and marginalized in the development, implementation, and monitoring of NTD-related policies and programs. Such approaches are also consistent with and supportive of the cross-sectoral approach promoted by the SDGs.

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# Emotional Difficulties and Experiences of Stigma among Persons with Lymphatic Filariasis in Plateau State, Nigeria

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## Abstract

Lymphatic filariasis (LF) is a chronic and often disfiguring condition that predominantly affects the rural poor and leads to social exclusion, stigma, and discrimination. Little is currently known about the emotional difficulties and stigma experiences among persons living with LF in Nigeria. Our study evaluated the emotional difficulties and stigma experienced by persons with LF in Plateau State, Nigeria. We utilized a combination of qualitative data instruments comprising focus group discussions, McGill's Illness Narrative Interviews, and key informant interviews. We transcribed and analyzed the data using a combination of inductive and deductive coding approaches. Sixty-nine respondents were interviewed: 37 females and 32 males. The prevalent community perception of LF was the belief that it was a spiritual problem. Emotional reactions included feelings of sadness, hopelessness, anger, frustration, worry, and suicidal ideation. These experiences, including those of stigma, discrimination, and social exclusion, culminated in difficulties with occupational functioning, marital life, and community participation. Our findings highlight the value of a rights-based approach that emphasizes state and non-state actors' need to provide access to the highest attainable standard of health, including mental health, and to protect persons with LF from stigma, discrimination, and social exclusion.

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## Introduction

Lymphatic filariasis (LF) is a chronic and disfiguring condition that can lead to significant disability.<sup>1</sup> Global estimates project that infection with the filarial parasite, which causes LF, is present in at least 120 million persons, with about 40 million people exhibiting clinical symptoms and signs.<sup>2</sup> Thus, the condition is now recognized as a public health priority, along with other neglected tropical diseases (NTDs).<sup>3</sup>

This recognition has led to concerted efforts to eliminate the threat of LF and other NTDs, such as the launch of the Global Programme to Eliminate LF by 2020.<sup>4</sup> A combined approach using several initiatives—including the use of mass drug administration campaigns as preventive chemotherapy in endemic areas, the provision of effective treatment for infected persons, and sustainable water, sanitation, and hygiene programs—has been deployed globally with successful results. The prevalence of LF in Nigeria ranges from 14% to 32%, depending on the region.<sup>5</sup> Over 106 million people in the country have been found to be at risk of LF, making Nigeria the country with the largest at-risk population in Africa.<sup>6</sup> Nonetheless, significant progress is being made with respect to mass drug administration across endemic regions and treatment for affected persons. Indeed, two North Central states of Nigeria that were previously endemic for LF (Plateau and Nassarawa) recently met criteria to stop statewide mass drug administration for LF—the very first states in Nigeria to achieve this feat.<sup>7</sup> Despite this progress in prevention efforts, individuals already affected must live with the long-term consequences of the disease.

Increasingly, NTDs, including LF, have been recognized as being associated with a reduced quality of life as a result of social exclusion, stigma, and discrimination.<sup>8</sup> Stigma is the result of a real or perceived difference that causes affected individuals or groups to be identified as inferior. It pertains to “any attribute, trait or disorder that marks an individual as being unacceptably different from the accepted norm, and that elicits some form of community sanction.”<sup>9</sup> Such traits or attributes include physical deformity, disease condition, gender,

sexual orientation, and ethnicity, among others. Discrimination—also described as enacted stigma—is a closely associated concept that describes unfair and unjust treatment. Thus, stigma is best seen as a composite of three issues: (1) ignorance of a condition or people; (2) prejudice manifesting as fear, anxiety, and avoidance; and (3) discrimination resulting in systematic disadvantages in various domains of life, including work life, home and personal life, community participation, and access to health care.<sup>10</sup>

Several studies have explored stigma and its associated socioeconomic consequences among affected persons living with LF and other NTDs, but there is a paucity of studies seeking to understand the stigma, associated experiences of exclusion and discrimination, and emotional reactions and consequences among persons living with LF in Nigeria, despite the country having the largest disease burden in Africa.<sup>11</sup> Recent estimates conservatively estimate that 50% of clinical patients with LF have co-morbid depression.<sup>12</sup> Others have also postulated that stigma and discrimination lead to co-morbid mental health problems and to a reduction in health-related quality of life.<sup>13</sup> The wider burden of LF is therefore likely to be considerably higher if these co-morbidities are taken into account.

Furthermore, the spirit of the Sustainable Development Goals (SDGs) is to “leave no one behind,” thus emphasizing the importance of equity as a consideration in international development. LF and other NTDs are known to disproportionately affect the most disadvantaged: the rural poor with reduced access to health care services and clean potable water.<sup>14</sup> Such marginalized groups tend to have little power, and therefore a human rights-based approach should be an important consideration in efforts to combat LF and other NTDs. Nigeria has ratified most international treaties and conventions that provide a framework for respecting these rights, such as the International Covenant on Economic, Social and Cultural Rights, the Convention on the Rights of Persons with Disabilities, and the African Charter on Human and Peoples’ Rights. Unfortunately, implementation has been very weak, making the realization of these rights a



challenge for marginalized communities, including those with NTDs.

Thus, although previous studies from Nigeria have described the epidemiological and clinical characteristics of LF, the experiences of stigma, discrimination, and associated mental health challenges remain unclear for individuals living with this disease in Nigeria. A better understanding of such experiences is an important first step upon which to premise advocacy for a rights-based approach to address the identified problems. Our study sought to fill this gap. Specifically, it explored three aspects: (1) sociocultural perceptions and beliefs around LF, as experienced by persons affected by LF; (2) stigma experiences associated with LF, as well as the disease's impact on daily functioning, including work, family and community life, and enjoyment of human rights; and (3) the emotional and mental health consequences of the disease, as well as the coping strategies used by persons living with LF.

## Study methodology

### *Study setting*

Our study was conducted in Plateau State, across the five sites of Jos, Nyes, Amper, Dadur, and Gwam Lar, which are a combination of urban and rural communities that are endemic for LF. The communities are agrarian, with high levels of poverty and limited access to health services and social amenities, including potable water. The Carter Centre, in partnership with the state government of Plateau, has organized them into catchment groups for the provision of treatment. Thus, they provided a readily available convenience sample for our study. We utilized this pre-existing organization into catchment areas to identify designated treatment clinics that are in close proximity to each community, where patients can receive wound management, antibiotics and anti-fungal creams (for infections), and analgesia (for pain relief).

### *Sampling and recruitment procedures*

We used a combination of purposive and snowball sampling methods to recruit participants. We approached all individuals who presented at the

designated clinics in each of the five communities on the specified medication collection days (following a month's notice sent to them) and explained the study to them. All consenting patients were recruited and were also asked to nominate other individuals who might have useful information. We then approached these nominated individuals to encourage their participation as well. Efforts were made to ensure representativeness across gender and location (urban/rural). The inclusion criteria included a diagnosis of LF, the presence of lymphedema (with or without hydrocele), and an age of 18 years and above. Those who could neither understand nor speak English or the local Hausa languages were excluded. While most communities in north central Nigeria understand Hausa, they retain their specific ethnic identities and language, and a few may not understand the Hausa language.

### *Data collection methods*

We employed three qualitative methods, with different strengths, to ensure comprehensive and in-depth coverage of the study objectives. In total, we conducted eight focus group discussions, six key informant interviews, and seven McGill Illness Narrative Interviews (MINIs).<sup>15</sup> In addition to using a facilitator and note-taker at each session, we recorded the sessions using audio recording equipment. The key informant interviews provided in-depth but broad descriptions of the situation of persons living with LF, while the MINIs provided personalized insight into the lived experiences of those affected by LF. The focus group discussions aimed to achieve consensus from the respective groups about the experiences of affected persons.

### *Focus group discussions*

We conducted eight focus group discussions, each of which included six to eight participants who were affected by LF according to the criteria above. Special care was taken to ensure relative homogeneity within each group (urban/rural and gender) in order to promote free conversation and enhance the chances of attaining consensus around issues of discussion. Each session began by introducing the topic and then initiated a discussion using a topic

guide that was synthesized from previous research. The focus groups explored five broad themes: commonly held views about LF within the community; experiences of being treated differently (e.g., stigma and discrimination) on account of LF; emotional reactions to stigma and discrimination; experiences of support and encouragement; and what participants would like to see change for the better.

### *Key informant interviews*

We conducted key informant interviews with six respondents across the five sites. These interviews were focused on gaining a deep understanding of the research issues from individuals with extensive experience and knowledge of the subject. One of the respondents did not have LF but had more than two decades of field experience and first-hand involvement caring for persons with LF in one of the clinics. The other five respondents had lived with LF for at least five years and were identified by their peers as very well informed. Indeed, three of these five were serving unofficially as volunteers to provide peer support to other affected persons. For this method, it was not critical to achieve a representative sample; rather, the purpose was to select persons who were identified as clearly knowledgeable and experienced with regard to LF in these communities.

### *McGill Illness Narrative Interviews*

Persons identified either from the focus group discussions or via the snowball approach as having experienced significant stigma, life events, or psychological consequences as a result of their status as persons affected by LF were approached for the MINIs.<sup>16</sup> The MINI is a qualitative interview schedule for investigating meanings and experiences related to a specific illness—in this case, LF. The interviewee is asked to talk about the health problem in terms of a timeline of events that explores causes, symptoms and signs, effects, and what the person did or is doing about the problem, including seeking care in the formal biomedical system or with non-biomedical healers. MINIs have been found to be culturally valid and have been previously utilized to explore

experiences of perinatal depression in Nigeria.<sup>17</sup>

### *Data coding and analysis*

We transcribed and translated into English the audiotapes of the interviews, paying special attention to removing mentions of people's names and descriptions of specific individuals who may be identifiable from such descriptions. This task was performed by Samuel Dakwak, a clinical psychologist and a native Hausa speaker, and reviewed by Jibril Abdulmalik for accuracy. Back translation of randomly selected portions was performed by Abdulmalik to ensure that the meanings were retained.

The final transcript data was analyzed based on the qualitative content analysis method, using a sequential combination of deductive and inductive coding.<sup>18</sup> Two experienced qualitative researchers (Jibril Abdulmalik and Motunrayo Ayobola) independently performed this. Both researchers subsequently harmonized their themes and reconciled areas of disagreement.

Specifically, the qualitative data coding and analysis entailed the following steps:

1. A set of codes based on a previous review of the literature was prepared for use in interrogating the data (deductive coding).
2. An initial read-through of all the transcripts was performed to gain a feel for the responses and important themes that were immediately striking (inductive coding). Aspects or concepts that were unclear necessitated listening to the audio tapes again to gain appropriate insight into the intended meanings of the participants.
3. A thematic codebook was prepared as the final coding template for data analysis.
4. The transcripts were uploaded into the Atlas.ti software, and the transcripts were read and assigned thematic codes and memos within the software.
5. The software was utilized to pull, aggregate, and display salient quotations and segments for individual codes and themes.

### *Ethical considerations*

We obtained ethical clearance from the Ethics and Research Committee of the University of Jos Teaching Hospital. Privacy and confidentiality were ensured for all participants in the interview settings, and these issues were discussed prior to conducting the interviews. Written informed consent was also obtained from the participants. Those of us who conducted the interviews are experienced mental health clinicians (a psychiatrist and a clinical psychologist, each with several years of clinical experience), and where we identified respondents who required psychological interventions, qualified professionals on our team provided the respondents with brief psychosocial support and then referred them for ongoing care at the University of Jos Teaching Hospital. Furthermore, all participants were screened for depression as part of an associated study evaluating the prevalence and correlates of depression, and which included the provision of treatment for identified persons.<sup>19</sup> Any

participants who screened positive for depression in that study were referred for follow-up care.

### Results

#### *Sociodemographic profile of respondents*

Out of a total of 93 patients seen at the five sites, 69 respondents (74.2%) provided consent and were interviewed. Four respondents who provided consent were excluded due to language difficulties, while the others did not satisfy the inclusion criteria and were therefore excluded. The participants with language difficulties were unlikely to have different experiences of the illness, as they were living within their own communities and could speak their local dialects. While the qualitative methods employed do not demand large sample sizes, the high proportion of participants recruited for the study promoted the achievement of saturation for this sampled group, and the subsequent analysis of results confirmed this.<sup>20</sup> There were slightly more

Box 1. Community perceptions and beliefs around lymphatic filariasis, as reported by respondents

<p><b>Spiritual illness</b> “People began to tell me that the sickness was caused by others through charm, and it was because I stepped on a charm that was intended to harm someone else—if not, it would have killed me.” —MINI 2 (female)</p> <p><b>No treatment</b> “They usually pity the people that have this condition, because it cannot be cured.” —Focus group discussion 6 (male)</p> <p><b>Strange and scar</b> “Some of them get scared, and will not want to get close to us.” —Focus group discussion 1 (female)</p> <p><b>Dirty and undesirable:</b> “They see the sickness as very dirty, and they run away from us because of it, especially when it discharges fluid.” —Focus group discussion 6 (male)</p> <p>“Although I am handsome and good looking, people look at me as incapacitated and not clean because of this condition.” —Key informant interview 3 (male)</p> <p><b>Infectious</b> “From what I know people call it ‘ciwon sauro’ which means ‘mosquito sickness’ because they say that it is caused or spread by a mosquito.” —Focus group discussion 7 (female)</p> <p>“When my own sickness usually comes, my husband doesn’t want to come close to me; not even to help kindle the fire to warm me. He becomes afraid and says he doesn’t want to get infected also. He stays away from me.” —Focus group discussion 4 (female)</p>
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female participants (37) than male ones (32). The age of the participants ranged from 20 to 80 years, with a mean age of 53.8 years (SD=15.93). The results are presented below following the outline of our research themes.

### *Community perceptions of LF*

According to respondents, the most common belief about the cause of LF in their communities is that it is a spiritually inflicted illness that affects individuals who have stepped on a charm that was placed on the ground by their enemies. Thus, it is viewed with some apprehension, and community members wish to be far removed from affected individuals in

order to reduce the chances of the charms somehow affecting them as well.

Other commonly expressed perceptions include views that LF is a strange, scary, and poorly understood illness; that affected persons are dirty and foul smelling; that it is an infectious condition caused by mosquitoes; and that it is an incurable disease (see Box 1).

### *Experiences of stigma and discrimination*

Nearly all respondents revealed personal experiences of stigma and discrimination that included being shunned, receiving embarrassing stares and insults, and being viewed as inferior on account of the dis-

#### Box 2. Experiences of stigma and discrimination

##### **Insults and stares**

“They become afraid of us, and others even insult us because of the legs.”

—Focus group discussion 1 (female)

“Sometime when children see me, and adults too they stay away ... they just keep turning to look at my leg. This happens all the time, especially the people that don't know me. Sometimes others might even say ‘look at her leg, the way it is so big.’”

—Focus group discussion 1 (female)

“They call it ‘shi di magal’ or ‘shi fuk’ ... which means ‘big leg.’ They call us people with big leg.”

—Focus group discussion 5 (female)

##### **Discrimination**

“Some of them spit out saliva when they see us [in disgust or revulsion].”

—Focus group discussion 3 (male)

“I have had several difficulties with relationships. Sometime in 2006, I had a relationship with a lady and we were making plans to get married. Until one day she told me that her aunty saw my leg in their house and called her to talk to her about this kind of condition and what it entails to manage my condition and the risks if she decided to marry me. With such negative information, the lady gradually broke off the relationship.”

—Key informant interview 3 (male)

“People look down on those with this kind of sickness, such that they are uncomfortable with our presence in social gatherings. Such treatment [also] happens at work places and even in the homes.”

—Key informant interview 4 (female)

“Sometimes people don't want to offer us employment when they look at the nature of our leg.”

—Focus group discussion 7 (female)

“Yes, it happened to me. My wife left me, saying to me that I do not have the strength to provide adequately for her just because of this sickness.”

—Focus group discussion 3 (male)

##### **Non-discrimination**

A few respondents did not have negative relationship or marital experiences.

“Some of us here are widows ... but when our husbands were alive, we did not have any problems.”

—Focus group discussion 1 (female)

“I am married with children and I had this sickness before my marriage; it didn't bother my wife.”

—Key informant interview 1 (male)

ability. Social interactions—including the ability to find a marital partner, the quality of marital relationships, and participation in social events—were all negatively affected by the presence of LF for the majority of the respondents. These experiences, however, were directly linked to the severity of the illness, as individuals with minimal leg swellings could escape negative attention, unlike those with severe and disfiguring leg swellings (see Box 2).

### *Impact of LF on work, family life, and interpersonal relationships*

The presence of LF restricts affected individuals' ability to obtain employment or perform optimally at work or in school. This is especially true during periods when the person suffers acute attacks characterized by debilitating pain and fever, which may last for weeks. Thus, the individual may be forced to miss long spells of school or work. Furthermore, those who are self-employed, such as craftspeople and traders, also notice that people stop buying from them once they see their swollen legs. However, a few

respondents did not report a negative social impact, especially with respect to family life, as they enjoyed good support from their spouses, family members, and members of the community (see Box 3).

### *Personal coping strategies and family and community support*

Three broad categories of coping mechanisms emerged from the data: personal strategies, family support, and community support.

1. **Personal strategies:** Participants responded to their circumstances in a number of practical ways, including social withdrawal, in order to avoid awkward encounters and to avoid the need to wear long clothes that cover their feet, thus preventing stares. In addition, respondents reported a number of cultural rationalizations, such as resignation to fate and seeking solace in their faith in God. A few described turning to alcohol and drugs. Finally, some described their need to beg on the streets as a result of their lack

#### Box 3. Impact of LF on work, family life, and interpersonal relationships

“There was a time I went for a teaching job interview but was unsuccessful. I was later informed that I was not offered employment because of my condition, as they were concerned about my ability to stand and teach students.”

—Focus group discussion 6 (male)

“As a tailor, when my customers' attention and eyes are on my leg, I quickly pull down my trouser to cover it, and I don't feel comfortable to do my work.”

—Focus group discussion 8 (male)

“When I gained admission into a tertiary institution, I could not return to school on time after the semester holidays because my leg became swollen to the extent that I lost some of my nails [pointing to her toes]. After about five months, I managed to go and write the exams.”

—Focus group discussion 2 (female)

“They become poor because they usually produce little on their farms. When they fall sick, it affects their work in the farm and the harvest becomes very low, which in the end pushes the individual into more poverty.”

—Key informant interview 6 (male)

“About two years ago, I had fever and severe pains such that I stayed at home for about two months without going to work. I could not go anywhere within that period, other than to eat and use the restroom. Then my employer began to consider laying me off because I was unable to come to work for about two months in a row, but it took the grace of God for them to retain me and to pay me my salaries for those months. So, this condition really affects my work; when the sickness comes, I become incapacitated, to the point that I wouldn't be able to lift even a bucket of water by myself. But whenever the fever leaves me, I become strong enough to do work.”

—Key informant interview 3 (male)

“When the condition is not severe, then a person can get married without much difficulty. But when the sickness is very severe, it can be a deformity and no girl will want to marry you.”

—Focus group discussion 6 (male)

of other economic opportunities.

*“I have to dress and cover the leg well—if not, people will not want to be close to me.”*

—Focus group discussion 3 (male)

*“It [LF] is the will of God. He can afflict anyone with sickness. So, I look up to God for help.”*

—Focus group discussion 5 (female)

2. **Family:** Support and encouragement from family members was also an important way for some respondents to cope.

*“It was my family members that have been washing and dressing my wounds each morning during that period. In fact, our children were very happy for me and were even singing out of joy, when I eventually began walking with the aid of a walking stick after eight months of being bed-ridden. They were very happy for me.”*

—Focus group discussion 1 (female)

*“I know my family supported me all the way and they encouraged me when I was going to the hospital, and they have been there for me in my condition. My family has been very supportive.”*

—Key informant interview 4 (female)

3. **Community:** Some respondents described being helped by their communities through support, encouragement, and financial aid. Religious bodies, especially women’s church groups, provided regular visits, prayers, emotional support, and financial contributions to individuals with LF.

*“The women fellowship of my church and other people gave me money as a form of assistance because of this condition. And I used the money to go to the hospital.”*

—Key informant interview 5 (female)

*“The people of my own village supported and encouraged me ... It is only people that are not from*

Box 4. Emotional consequences of stigma and discrimination on persons with LF

**Emotional reactions**

*“When people tell me to stay away because of this sickness, it makes me angry.”*

—Focus group discussion 2 (female)

*“Sometimes it makes us to be ashamed, and angry.”*

—Focus group discussion 6 (male)

*“People insult me when they see me and I feel bad about it ... and I used to cry. Sometimes, I used to cry for up to three days.”*

—Focus group discussion 2 (female)

*“How can I be happy when I am unable to do my work?”*

—Focus group discussion 3 (male)

*“I feel very bad because of the experiences of discrimination I had. At such times, I weep a lot.”*

—Focus group discussion 6 (male)

*“Sometimes when I look at the leg, I become angry and always want to cry. It makes me to become discouraged because of the fact that the leg will remain big for the rest of my life. I usually become sad and frustrated.”*

—Focus group discussion 7 (female)

**Suicidal ideation**

*“I feel demoralized and very sad. There was a time that I was in severe pain and I prayed to God to just take my life so that I will be relieved of the pain. But when I am stigmatized, I also feel very bad and demoted.”*

—Key informant interview 3 (male)

*“When the sickness begins, it used to get swollen and secrete fluid. On account of the pains, I used to say that it is better to die so I can rest.”*

—Focus group discussion 2 (female)

*“I get worried and feel so sad because I wish to be able to work like others, and be able to feed myself but I cannot. I get so worried that I prayed to God to just take my life because I have no use in this life: I have a disease that I can’t walk and so people avoid me, and when I do business people don’t patronize me [participant started sobbing and required a break, as well as supportive therapy].”*

—MINI 3 (female)

*our community that did not [support me].”*

—Focus group discussion 1 (female)

Respondents reported receiving free medications and general health counseling from the Carter Centre but were unaware of any governmental support at the local, state, or federal level for persons with LF.

The majority of respondents indicated that they had initially sought treatment from traditional healers—to no avail and often at considerable expense—before eventually arriving at the designated clinics where the Carter Centre provided free treatment services. The counseling services at these clinics were aimed at providing information about medications and general health care issues; there was no systematic or coordinated manner of identifying or providing interventions for emotional and other mental health difficulties experienced by individuals with LF.

### *Changes desired by persons with LF*

The most pronounced wish of respondents was the discovery of a definitive solution for the physical disfigurement of their limbs so their lives could return to normal. Another recommendation was public awareness campaigns to increase the level of community understanding of LF and to reduce stigma and discrimination. Free and regularly available medications were also mentioned, as medications are sometimes either unavailable or available only for a fee. The respondents specifically requested opportunities to earn a livelihood and care for themselves independently. Given that they could no longer farm successfully, several respondents wanted the opportunity to receive government benefits such as supported employment, small loans to start a business, and other forms of welfare support. Such benefits are currently not available in Nigeria, apart from through charitable donations, which are not regular

## Discussion

### *Perceptions of LF within communities*

The perceptions of LF reported by respondents

reflected a mix of accurate information (such as knowledge that LF is an infection that may be transmitted by mosquitoes) and inaccurate information (such as the belief that it is a spiritual illness caused by “enemies”). This is in line with earlier reports from developing countries.<sup>21</sup> The pervasive nature of misconceptions about the causative mechanism for LF may have a negative impact on the effectiveness of prevention and eradication efforts. However, it is salient to note the overlap between the perception of LF as a form of spiritual affliction that can spread to others and the biomedical fact that it is an infectious condition that can be transmitted among people living in close proximity. This link may be exploited in public awareness campaigns.

### *Stigma experiences and impact on functioning*

A central theme from our study’s results is respondents’ overwhelmingly negative experiences of stigma and discrimination. Similar findings have also been reported for other NTDs, such as leprosy, which also has physical and cutaneous signs that are strongly associated with stigma and poor mental health outcomes.<sup>22</sup>

The social exclusion experienced by respondents resulted in high levels of disability, as many of them could not complete their education, secure employment, hold down jobs, engage in farming, or engage in business. These findings agree with earlier reports about the psychosocial consequences for persons with LF from low- and middle-income countries.<sup>23</sup> Indeed, another study illustrated how stigma and disability from LF not only resulted in social isolation and avoidance behavior (linked to self-stigma) but also led to reduced career aspirations and a downward spiral into poverty.<sup>24</sup>

Another salient finding was the association between increased levels of stigma and the severity of the disease—those with minimal swellings managed to get by with as near normal lives as possible, while those with more severe disability were unable to hide their condition and had more negative experiences in their social interactions. A recent study reported a similar observation about this association.<sup>25</sup> Enacted stigma is more pronounced with greater severity of the disease and obvious

physical deformities. This, in turn, can exacerbate the felt stigma of affected individuals.<sup>26</sup>

However, it is pertinent to note that some respondents had positive stories of spousal, family, and community support, which greatly enhanced their ability to cope. This positive finding in the face of widespread stigma has also been reported by previous studies.<sup>27</sup> Other coping strategies were both negative and positive. Examples of negative coping strategies were social withdrawal and isolation, street begging, and resorting to alcohol and drugs. The positive coping styles of resignation to fate, drawing comfort from religious beliefs, and use of loose clothing that covers the legs and feet demonstrate adaptation to the challenging realities faced in everyday life. These coping strategies hold promise for future research efforts aimed at developing simple psychological interventions to counter stigma. Such efforts are much more effective if they take cultural beliefs into account. Furthermore, a multimodal approach that looks at individual factors as well as community and other contextual factors is more likely to be effective.<sup>28</sup>

### *Emotional consequences*

The most common emotional reactions were suggestive of anxiety and depressive illness. A subset of this project with the same study population utilized standardized assessment instruments and found a 20% prevalence of depression in this population, which is high compared with the lifetime prevalence of 3.2% in the country's general population.<sup>29</sup> The presence of depressive symptoms in this study was also associated with expressions of suicidal ideation (but there were no reported suicidal attempts in this study). These findings are supported by the high prevalence of depression reported among individuals with LF from other studies, estimated at 70% in Togo and 97% in India.<sup>30</sup>

A recent review highlighted the extent of co-morbid mental illnesses among persons with NTDs such as LF. This is supported by a report which clearly illustrates how the experiences of stigma and discrimination, as well as other attendant social disadvantages among persons with NTDs (including LF), predispose them to mental health

problems.<sup>31</sup> Furthermore, while the initial burden of disability-adjusted life years (DALYs) attributed to LF (taking account of physical disabilities only) in the Global Burden of Disease Study of 2010 was estimated at 2.78 million DALYs, a more recent calculation of the attributable burden due to depressive illness alone among persons with LF puts the figure at about 5.09 million DALYs.<sup>32</sup> This doubling of the attributable burden of disease has important consequences for public health planning and resource prioritization. It is also worthy to note that the significant caregiver burden and impact on families as illustrated by our study results are often not captured in attributable disease burden calculations. The emotional toll and its resultant burden on these individuals and their communities deserve attention and urgent intervention—especially since the physical disfigurement, once established, is usually lifelong.

### *Using a human rights-based approach*

The association between LF (and other NTDs) and poverty and social disadvantage—such as difficulties with access to health, education, and employment—has been reported elsewhere.<sup>33</sup> Our findings support these observations: respondents reported difficulties in accessing their rights to health, education, and work, as well as meaningfully participating in their communities.<sup>34</sup> Their relative lack of power means that there are few opportunities for them to engage in democratic processes to advocate for their rights.

While the government of Nigeria has ratified several pertinent international conventions, such as the International Covenant on Economic, Social and Cultural Rights and the Convention on the Rights of Persons with Disabilities, these instruments lack legislative muscle since they have not been domesticated by the National Assembly. Indeed, section 12(1) of the Nigerian Constitution states that “[n]o treaty between the Federation and other countries shall have the force of law except to the extent to which any such treaty has been enacted into law by the National Assembly.”<sup>35</sup> People affected by NTDs are poorly represented in the national disability federation (the Joint National Association



of Persons With Disabilities), which has a mandate to engage in reporting under the Convention on the Rights of Persons with Disabilities.

A holistic approach to addressing the individual and structural discrimination faced by affected persons and their communities entails domesticating relevant legal instruments in order to guarantee and protect these persons' rights as enshrined in international and regional law.

The SDGs also provide opportunities for promoting the rights of persons with LF in Nigeria and reducing their experiences of stigma, discrimination, and social exclusion. As stated earlier, one overarching principle of the SDGs is a commitment to "leave no one behind", which might be achieved through the application of Universal Health Coverage, without financial hardships.<sup>36</sup> Considering that LF and other NTDs are most prevalent in poor populations, the success or failure of the universal health coverage paradigm within the SDGs can be measured against the extent of its effectiveness in reaching persons with NTDs.<sup>37</sup> In specific terms, SDGs 1, 2, 3, 4, 6, 10, and 16 lend themselves to the cause of promoting the human rights of persons with LF and other NTDs in Nigeria and elsewhere.<sup>38</sup>

SDG 1 aims to end poverty in all its forms, which stands to have an impact on the vulnerable population of persons (and their families) living with LF and other NTDs. Indeed, it has been proposed that LF is simultaneously an outcome and a driver of poverty.<sup>39</sup> SDG 2 aspires to "end hunger, achieve food security and improve nutrition and promote sustainable agriculture"; this is directly relevant to the Nigerian communities where LF is endemic, such as our study population. Participants were mainly farmers, and even those who had other vocations still maintained family farms on a subsistence basis. Episodes of painful infections of their limbs frequently interfered with their farming activities, resulting in reduced agricultural production and worsening food security while pushing them into poverty.

SDG 3 aims to achieve health for all, including persons with NTDs. SDG 4 aspires to achieve inclusive and equitable quality education and promote lifelong learning opportunities for all. This is

particularly relevant for our study's participants, who described how their experience with LF had disrupted their educational pursuits, particularly during episodes of acute and painful infections. SDG 6 focuses on ensuring the availability and sustainable management of water and sanitation for all, which is pertinent for all persons with NTDs.

Lastly, SDGs 10 and 16 have clear human rights implications for persons with LF and other NTDs and should be utilized to advocate for their rights. Goal 10 calls for addressing inequalities; here, the majority of affected persons are the rural poor, whose needs are often not prioritized. Reducing inequalities should translate into an improvement in their status in society and an overall reduction in their experience of stigma. Goal 16 calls on governments to "promote peaceful and inclusive societies for sustainable development, provide access to justice for all and build effective, accountable and inclusive institutions at all levels." Ensuring the inclusion of persons with LF and other NTDs in Nigeria will necessarily cut across several areas, including health care, social services, economic empowerment, and community participation. Health sector inclusiveness will entail not only the provision of physical therapies and interventions but also support for their mental health needs.

In order to achieve this health sector inclusiveness, the Nigerian government needs to provide training for health workers that allows them to identify and provide interventions for mental health problems among persons with LF and other NTDs. This could be via improvements in the integration of mental health into primary health care services (mental health is the ninth pillar of primary care in Nigeria). The World Health Organization's Mental Health Gap Action Programme Intervention Guide, which has been contextualized and piloted in Nigeria, provides a useful manual for this implementation.<sup>40</sup> In addition, the World Health Organization's QualityRights program, focused on realizing meaningful access to rights in mental health services, has also been piloted in Nigeria.<sup>41</sup> These and other resources can support the development of self-help groups that can advocate for their rights. Such groups may play a role in expanding

community education and outreach programs to improve individuals' knowledge and reduce stigma and discrimination. In addition, these groups also play a role in advocacy for the protection and promotion of their rights by the government.

Lastly, it is clear that current efforts to tackle LF and other NTDs—which are focused predominantly on mass drug administration for the prevention of disease transmission—neglect important associated rights (including the right to physical and mental health care, the right to live and participate fully in community life, and the right to education) of people affected by NTDs. The SDGs provide opportunities to advance the cause of persons living with LF and other NTDs through their commitment to Universal Health Coverage, which ensures that all populations, including those living with NTDs, have access to health care.

## Conclusion

Given the pervasive stigma and discrimination experienced by persons affected by LF, and the associated emotional consequences, interventions that address stigma and the psychosocial consequences of this condition must be considered an essential component of LF-related services. Such interventions can be supported through the enactment of a legislative framework that promotes and protects the human rights of affected citizens. The training of health workers, the provision of accessible services via primary care, and public education campaigns are additional steps that can be taken by the government and civil society organizations alike.

The screening, identification, and treatment of mental health needs, as well as social and economic inclusion, should gain prominence as rights-based considerations during policy discussions on contemporary challenges for LF in particular and NTDs in general.

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# Building Trust through Lymphatic Filariasis Elimination: A Platform to Address Social Exclusion and Human Rights in the Dominican Republic

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## Abstract

Hispaniola, the Caribbean island that includes the countries of Haiti and the Dominican Republic (DR), accounts for 90% of lymphatic filariasis (LF) in the Americas. Both countries have committed to LF elimination by 2020. In the DR, LF occurs mainly in *bateyes*, or company towns that historically hosted migrant laborers from Haiti. A legacy of anti-Haitian discrimination as well as the 2013 *Sentencia*, which stripped generations of Haitian-descended Dominicans of their citizenship, ensure that this population remains legally, economically, and socially marginalized. Despite this context, the country's LF elimination program (PELF) has worked in *bateyes* to eliminate LF through health education and annual drug treatment to interrupt parasite transmission. Based on interviews with *batey* residents and observations of PELF activities from February–April 2016, this study describes local understandings of social exclusion alongside the PELF community-based approach. The *Sentencia* reinforced a common perception shared by *batey* residents: that their lives were unimportant, even unrecognized, in Dominican society. At the same time, the government-run PELF has generated trust in government health activities and partially counteracts some of the effects of social exclusion. These findings suggest that neglected tropical disease (NTD) programs can not only improve the health of marginalized populations, but also create a platform for improving human rights.

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## Introduction

In the Western hemisphere, the story of lymphatic filariasis (LF)—or rather, the story of people who live with LF—begins with an ignoble chapter in human history.<sup>1</sup> Along with untold millions of enslaved Africans, the Atlantic slave trade brought the disease from Africa to the Caribbean island of Hispaniola.<sup>2</sup> The first site of European conquest in the so-called New World witnessed the decimation of an indigenous population and a plantation system so ruthless that it was cheaper to import new slaves and let the sick or injured die.<sup>3</sup> Haiti arose out of this colonial furnace as the first free black republic in the world. The Haitian Revolution (1791–1804) was so radical that, at the time, “not even the most extreme political left in France or England had a conceptual frame of reference” for what happened there: that African slaves would overthrow their masters, defeat a colonial army, and yearn for the same Enlightenment rights as white Europeans.<sup>4</sup> On Hispaniola, then, the long and conjoined relationship between human rights and this neglected tropical disease (NTD) goes deep.

LF is a mosquito-borne, parasitic disease with social and economic costs estimated at 2.8 million disability-adjusted life years (DALYs) globally.<sup>5</sup> LF is endemic in 72 countries, with 856 million people at risk for infection and 40 million currently suffering from the disfiguring and disabling complications of lymphedema or hydrocele.<sup>6</sup> The World Health Organization (WHO) targets elimination of LF as a public health problem through annual mass drug administration (MDA) to interrupt parasite transmission and provision of morbidity management and disability prevention (MMDP) services to alleviate suffering for those already affected.

At present, Hispaniola accounts for 90% of LF in the Americas.<sup>7</sup> Haiti, the poorest country in the hemisphere, bears a higher disease burden than the DR.<sup>8</sup> Haiti’s poverty has largely driven labor migration to the DR. Over time, Haitian migrants have gradually replaced ethnic Dominicans and other immigrant groups on Dominican sugar plantations, living in adjacent company settlement villages called *bateyes*. In 2016, Haitian-born migrants were estimated to comprise 23.2% of the nationwide

*batey* population.<sup>9</sup> LF is rare outside of *bateyes*, meaning that they have been the predominant foci of LF transmission, likely due to the regular influx of Haitian migrants that may inadvertently import infection from Haiti, combined with impoverished environmental and sanitary conditions that favor breeding of the *Culex* mosquito vector.<sup>10</sup>

The DR is distinct among Caribbean nations because it was there that large-scale sugar plantations expanded *after* the abolition of slavery.<sup>11</sup> Through the early 20<sup>th</sup> century, Haitian migrants were crucial to the growth of sugar production yet also were cast as a threat to Dominican society. The dictator Rafael Trujillo (1930–1961) manipulated colonial-era sentiments of race both to exploit the migrant workforce and to consolidate power over a bicultural and largely harmonious world made by Dominican and Haitian peasants.<sup>12</sup> It is unclear to what extent *anti-haitianismo* (anti-Haitianism) exists as popular ideology in the DR today. More likely, it continues to be a useful tool for the Dominican elites to justify their economic power.<sup>13</sup> Indeed, the ideology has generally served those wielding greatest power throughout the history of the DR: early colonial rulers; the intelligentsia of the newly formed republic; North American corporate enterprises and the American military; and certain contemporary Dominican political parties and policymakers.<sup>14</sup>

In addition to migrants from Haiti, *bateyes* are also home to Dominican-born persons of Haitian descent, who comprised an estimated 25.5% of the total *batey* population in 2016.<sup>15</sup> Like migrants, they too contend with a history of discrimination in the country. The 2013 Constitutional *Sentencia*, or “the Sentence,” which stripped citizenship from an estimated 200,000 people of mostly Haitian descent, further reinforced their marginalized status.<sup>16</sup> This decision reinterpreted the principle of birthright citizenship—in effect since 1929—by arguing that children born to those in an irregular migratory situation were “foreigners in transit” and not entitled to Dominican citizenship. Revoking citizenship has left them unable to perform basic civil functions such as registering children at birth, getting health insurance, enrolling in school and

university, participating in the formal economy, presenting legal claims in courts, or traveling within the country without risk of expulsion.<sup>17</sup>

These downstream effects point to how the 2013 *Sentencia* violates fundamental human rights already enshrined in Dominican law. For example, the Dominican Constitution contains articles on the rights to health (Art. 61) and equality (Art. 39) while the Criminal Code penalizes discrimination based on origin or race, among other distinctions (Art. 336).<sup>18</sup> Furthermore, the country has ratified multiple international frameworks pertaining to discrimination, including the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD). Just five months before the *Sentencia* verdict, an ICERD country report for the DR expressed concern over legislative and judicial hurdles that block access to identity documents for dark-skinned people and the Haitian irregular migrant population.<sup>19</sup>

The far-reaching consequences of statelessness on human rights should be quoted in full. The 2015 report released by the Inter-American Commission on Human Rights (IACHR) states that loss of nationality has increased vulnerability to other rights violations, including:

*the right to personal integrity, the right to the protection of their honor, dignity, and private life, the right to protection of the family and family life, the rights of the child, the right to education, the right to health, the right to work, the right to private property, the right to due process of law, the right to judicial protection, political rights, the right to movement and residence, as well as the right not to be arbitrarily deprived of their liberty, the right not to be expelled from the territory of which they are nationals or the right to enter in said territory, the prohibition of collective expulsions, among others.*<sup>20</sup>

In short, social exclusion in the DR creates exceptions to what the country would otherwise claim as universal rights.

There is, however, some alignment between policy and practice from the standpoint of the right to health. The Dominican Constitution declares that *toda persona*—every person—has the right to “integral health” and calls for the state to “procure

means for the prevention and treatment of all sicknesses, ensuring access to quality medication and giving medical and hospital assistance for free to those who need it.”<sup>21</sup> The Dominican Ministry of Health has operationalized this lofty goal in part by establishing government-funded primary care centers in or near *bateyes*. Each is staffed by a doctor, nurse, supervisor, and several community health promoters.<sup>22</sup>

In 1998, the Dominican Ministry of Health established the *Programa de Eliminación de la Filariasis Linfática* (PELF). Baseline mapping revealed LF infections among the *bateyes* in the southwest and east of the country, along with a small focus in an impoverished neighborhood of Santo Domingo (*La Ciénaga*). Due to funding limitations, PELF began interventions only in the most endemic region (southwest) in 2002, but gradually scaled up to each of the three foci. The main intervention is annual house-to-house MDA of albendazole (donated by GlaxoSmithKline) and diethylcarbamazine (donated by Eisai since 2013) in target communities.

Initially, PELF was a vertical program in which strategy, evaluation, and interventions were centrally directed. However, the program rapidly recognized the importance of community engagement to achieve sufficient MDA coverage—at least 65% of the total population in endemic areas.<sup>23</sup> Beginning in 2003, interventions were folded into the local health care system.<sup>24</sup> By mobilizing local primary care staff, neighborhood associations, and community volunteers, MDA campaigns have avoided a separate operational structure, helped to generate trust and job satisfaction, and improved MDA coverage.<sup>25</sup> Average population coverage has been 80.7% across all MDA campaigns. To date, LF antigen prevalence in the southwest and *La Ciénaga* has been reduced to less than 2%—the level at which MDA is no longer needed.<sup>26</sup> In the east, stop-MDA transmission assessment surveys are planned in 2018.

These accomplishments are especially noteworthy because the chronology of PELF and its MDA activities correspond to a period over which the Dominican political and judicial system took a more aggressive stance towards the migrant and

Haitian-descended population.<sup>27</sup> For example, in 2004, the Dominican legislature passed the Immigration Act, which adopted stricter nationality criteria; in 2007, administrative procedures were introduced to suspend or retain birth certificates to those born to parents without Dominican residency; in 2011, a regulation added more requirements, many of which were nearly impossible to fulfill, to acquire legal status; and in 2013, the Constitutional Court issued the *Sentencia*.<sup>28</sup> These legislative and judicial steps, coupled with the impoverished living conditions found in *bateyes*, have helped to create “a tragic cycle in which a future of poverty is almost inescapable.”<sup>29</sup>

How, then, to account for the successful public health campaign to eliminate LF in *bateyes* amid a context of social and legal exclusion? This paper responds to this question from two angles: by exploring social exclusion in *bateyes*; and by describing the community-directed approach of the PELF program. Here, *social exclusion* focuses on subjective experience, or how people perceive certain relations, events, or circumstances that signal their rejection or not mattering in a local world. The analysis of PELF gives attention to community engagement processes between PELF and the *bateyes*. Examining social exclusion alongside the approach taken by PELF reveals contrasting perspectives in how people see themselves in relation to institutions and each other, and informs human rights discussions in which the capability to live a dignified life is the primary benchmark.

## Methods and analysis

Data for this study are based on interviews and observations collected in February–April 2016, when PELF and The Carter Center, a health and human rights non-governmental organization (NGO) based in Atlanta, USA, undertook a survey of malaria and LF prevalence in extant *bateyes* nationwide (southwest, east, and north regions of the country).<sup>30</sup> Additional data come from a follow-up interview completed in March 2018.

During the 2016 survey, the lead author inter-

viewed 27 *batey* residents across three geographic regions to collect personal narratives of general life, hardships, and support systems in *bateyes*. These individuals were enrolled during surveying activities based on their personal and/or professional background and insight into daily life and local history of their *batey*. Interview participants were Haitian- or Dominican-born, ranged in age from early 20s to early 70s, and spoke in either Spanish or Kreyòl. Three were heads of their *juntas de vecinos* (neighborhood associations); two were community health volunteers in the *bateyes* where they were born. One woman was a school teacher in a *batey*. One man was the co-founder of a small advocacy group supporting the rights of Haitian migrants in the region. The rest were agricultural laborers, market vendors, or unemployed. Interview participants were selected through established networks with PELF colleagues, snowball referral from other informants, or relationships from previous fieldwork.<sup>31</sup> An interview guide was initially developed around core themes such as migration, livelihoods, coping and support, health and disease, care-seeking, and the 2013 *Sentencia*. Perceptions and reported experiences with PELF were not explicitly solicited; rather, interviews with *batey* residents sought to capture their personal narratives and to provide space to articulate daily life and social exclusion from their points of view. The structure of interviews was adapted over time in response to findings.

The lead author also accompanied PELF colleagues during the 2016 survey to observe their day-to-day responsibilities, which included making initial contact with *juntas de vecinos*, supervising survey teams, and ensuring adequate follow-up treatment for survey participants who tested positive for malaria or LF. Over three months, the lead author accompanied PELF colleagues in both formal and informal settings, including community meetings in *bateyes*, regional public health offices, and “street-level” interactions with *batey* residents.

Based on established rapport developed during these accompanying activities, a follow-up interview was done in March 2018 with two in-



dividuals at PELF. Since 2002, both individuals have worked as *facilitadores* (facilitators) for MDA campaigns, tasked with fostering links between the elimination program and the *bateyes*. The purpose of this interview was to seek feedback on emerging themes from the 2016 interviews and gain additional insight into community engagement for LF elimination.

After providing oral informed consent, interview participants spoke with the lead author for approximately 1–1.5 hours, typically at their residence or work place. Interviews with *batey* residents were audio-recorded and then transcribed verbatim in the original language into Word documents. Field notes and observations were also typed as Word documents. All documents were then uploaded into MAXQDA software for qualitative analysis. To protect confidentiality of participants, all names appearing are pseudonyms. Ethical approvals for both the survey and in-depth interviews were provided by ethical review committees in the DR (CONABIOS), the University of Amsterdam, and Emory University.

An initial reading of all documents was done to develop and apply a coding scheme. *A priori* codes ranged from economy and labor; documentation; health care; feelings of unimportance; support/coping; and community engagement/mobilization. *In vivo* codes sought to link recurrent explanations, incidents, and other phenomena as emphasized by participants, often in their own wording or idioms. Examples of these codes include *afectado* (or “affected” by the *Sentencia*); *chache lavi/buscar la vida*, or “to look for life” in reference to migration or finding work; *pa gen vale/no vale nada*, or worthless; *moun politik/gobierno* to refer to public authorities, the government, and local politicians; and *tèt ansanm* (“heads together”) to refer to social support among the Kreyòl-speaking population.

Following code assignment, text segments were retrieved based on shared codes and re-categorized under two contrasting themes: 1) *batey* residents share feelings of unimportance, especially since the 2013 *Sentencia*; 2) despite their social exclusion, PELF has been successful in reducing LF through mutual

respect and interpersonal relationships.

## Findings

### “Dead but alive”: Social exclusion in DR *bateyes*

The *Sentencia* re-classified Victor Fernandez, a man in his late 60s who served on the local neighborhood association, as a foreigner in the land of his birth. His parents had come from Haiti in the 1940s and were issued identity cards by an *ingenio* (sugar company) in cahoots with the government. Although he possessed a state-issued birth certificate and *cédula* (state-issued identity card), Victor was no longer considered a Dominican citizen due to supposed problems with his parents’ documents—which had been issued by Dominican authorities in the first place.

Sitting in a plastic chair on his patio, Victor grew animated, and asked rhetorically:

*The first Spanish who were born here, what blood did they have? They didn’t grow out of the earth like a plant. They came from somewhere else. We all did. We have the same rights, we are Dominican, but the laws say we aren’t.*

He attributed the *Sentencia* to, “people *a nivel de arriba* [at the top] [...] a few powerful economic sectors” that sow division, which then trickles into daily life. For example, Victor had once been stopped on a bus and asked for his passport. In his telling, this was prompted by his darker skin, as lighter-skinned individuals were not asked to show theirs. “I only show my passport when I travel outside my country,” he responded firmly.

“Erasing history,” notes Paul Farmer, “is perhaps the most common explanatory sleight-of-hand relied upon by architects of structural violence.”<sup>32</sup> Victor’s account forcefully pushes back against this erasure. He recalls that social exclusion on Hispaniola goes back a long way, from Spanish *conquistadores*, to the growth of Dominican sugar plantations that ensnared Haitian cane cutters like his parents, to the present day, in which his own life has been upended. This long reach of history figures into Victor’s interpretation of himself in

relation to others, including both people “at the top” and street-level agents, those tasked with the “dirty work” of selecting “good” citizens from the “bad.”<sup>33</sup> While he says that “we all” have come “from somewhere else” and “have the same rights,” Victor recognizes his own positionality in an unequal social order.

Other *batey* residents shared Victor’s diminished sense of personhood, that their lives were unimportant in the eyes of official institutions or authorities, whether sugar companies, the national government, or simply *gente de arriba*—“people at the top.” For example, another interview participant, a Haitian man in his 30s working as a market vendor, was told by an issuing office that his permit would last five years, only to discover that it was valid for only one. This bitter experience, along with not having enough time to comply with recent changes in documentation requirements, left him feeling that the Dominican government, “doesn’t consider us people.”

Being ignored or manipulated by public authorities has long been a part of life in *bateyes*. Antonio Guzman, a Dominican-born man who had risen to a supervisory role in the local sugar company in the north region before it closed over a decade ago, attributed a deep psychological wound to a lack of government concern:

*What do you do when there’s no work? You humiliate yourself, you grovel, beg, and plead. This is what the government has done to us in the last 10 years. They’ve eliminated all sources of work by closing the ingenios. Agriculture has been completely abandoned. That’s why we’re in the state that we’re in.*

Juan Carlos, an older man who had migrated from Haiti at age 12 and later became an advocate for migrants, shared an anecdote illustrating how *bateyes* could be manipulated for political ends. During the election campaign leading up to Joaquín Balaguer’s second administration (1986–1996)—one that breathed new life into Trujillo’s (1931–1960) *anti-haitianismo* (anti-Haitianism)—the government saw an opening to round up votes among the undocumented *batey* residents:

*At the time, everyone was given a cédula to go vote for Balaguer. Later, we were told that the cédula was fake, that it was only given to us to vote in their favor. We didn’t know anything, but we voted, [because] that was their plan.*

The 2013 *Sentencia* reinforced this pattern: taking away documents from Dominican-born persons of Haitian descent leaves them, as Juan Carlos said, *muerto con vida*—“dead but alive.” In his words, “These kids without documents, they can’t advance in life, they can’t go to school and find a good job.” His perspective was shared by two female community health volunteers, each in different regions of the country. One said, “If the child can’t study, they have to work hard, in the fields cutting wood to make charcoal,” while the other remarked, “If you don’t have documents, how can you care for your family?” Others linked unauthorized status to restricted mobility, expressly using the verb *to walk*. One woman said that documents were essential for those in *bateyes*, “so that they can walk,” while others would say that without documents, “you cannot walk far” due to risk of apprehension.

For those seeking to recover documents in the fallout of the *Sentencia*, interactions with local bureaucrats also generated sentiments of unimportance. One woman, a Dominican-born school teacher affected by the *Sentencia*, described the scene at the local registry office: “All they say are little words” (*palabritas*). “Without an important person (*alguien grande*)—they won’t make a case of me” (*no me van a hacer caso*), or in other words, they ignore me. Positioning herself in relation to “a big person,” one who can move the levers of clientelism, implied that she saw herself as powerless. Similar phrasing has been found among the Kreyòl-speaking population: Haitian migrants have referred to themselves as *ti malere*, or “little miserable ones,” toiling at the behest of *gwo nèg*, or “big men,” connoting smallness and disempowerment.<sup>34</sup>

This sense of powerlessness derived not only from recent government decisions such as the *Sentencia* or bureaucratic obstacles, but also from government *inaction*—from lack of concern for material hardships in *bateyes* or lack of follow-through by those promising to improve life and livelihoods.

Like Antonio Guzman, who remarked on the humiliation felt by those left unemployed in the *batey* after closure of the local *ingenio*, Esther Beauvil, a Haitian-born woman living in the southwest region, also communicated the perceived slight from government inattention.

In 1998, she and her family lost their home in the southwest region to Hurricane Georges. Living in a small *batey*, they moved further inland to another *batey*. Years earlier, Esther had migrated from Haiti and married a Dominican-born man. In the time since they relocated, she worked as a cleaning lady in the homes of wealthier people in the capital, because in the *batey*, *bagay yo di*—“things are hard.” (Figure 1)

At the time of the interview, the country was in the throes of an election. It was not uncommon to see pickup trucks carrying giant speakers blasting announcements to vote for some candidate. Sitting in the shade of a small, scraggly tree, Esther looked around her in disgust. She said people here eat only what grows from their *conucos*, or subsistence gardens. There was no water source, no decent roads, and no schools. She said:

*It's like the government doesn't even know there are people here. Only when there are elections will you see cars roll in with people to talk to us, and after, you'll never see them again. We'll vote for them, but they don't deserve it, because they don't remember us. The government doesn't sit down with us (Leta pa chitè avek nou).*

In sum, for *batey* residents, the relations and circumstances that signaled their rejection ranged from the empty promises of politicians, lack of improved livelihoods, or gestures and “little words” at local bureaucratic offices. The social cues of exclusion extended onto the street. Some participants cited instances of being called names, based on some physical trait such as hair texture or skin tone, for presumably being Haitian. Drawing on the Kreyòl idiom *pa gen vale*, or worthless, an older man, who had come to the DR decades before, said simply, “When they say you have no worth, it means you are not a person.” At stake was both a sense of self-worth and a sense of belonging to the broader social body: of being a full-fledged *moun* (Kreyòl, person) or *reconocido* (Spanish, recognized) in Dominican society. In short, these accounts reflect the “desire

FIGURE 1. Scene from *batey*, Dominican Republic, 2016. Photo by Hunter Keys.



to be recognized as socially ratified persons.”<sup>35</sup>

*“Public, because it’s for everyone”: The approach of PELF*

In March 2016, Yulisa Cáceres, a *facilitadora* (facilitator) and laboratory analyst for PELF, arrived late at night in a *batey* and knocked on the wooden door of a small, cinderblock structure. Earlier, this little home had been selected in the malaria and LF survey. Gertrude, a young Haitian woman who was living there with her husband and two children, had tested positive for LF antigen. Because antigen can persist after infection has cleared, night-time testing is required to test for the presence of LF parasites, which circulate in the blood stream primarily at night.

A light came on and a shirtless man unlocked the door and opened it a crack. He peered at the strangers on his doorstep, sheathed machete in hand. *Somos de salud pública*—“we are from public health,” said Yulisa. A few expressions in Kreyòl seemed to defuse any tension, and the man opened the door to welcome the PELF team inside.

Yulisa is in her 50s and has worked for PELF since 2002. She also assists a local non-profit that advocates for the rights of those left stateless after the *Sentencia*. In her words, the court decision “was an abuse.” She does not claim any Haitian descent, and explains, “I may not have the same culture [as those in the *bateyes*]. I cannot judge how people live.” Quite familiar with the poverty of *bateyes*, she went on. “I’m only there to give assistance or advice about health. If I see that you do not even have a table or chair, I won’t ask for a table and chair to do my job when I visit your home.”

Simple steps like these were, for Yulisa, *por la confianza*—to maintain trust. It would also seem as simple a matter as basic politeness. Still, others working for PELF remarked on the importance of maintaining trust with community members. One *promotora* (health promoter) described how some in her *batey* were cautious to approach another promoter in the area because she was known to gossip about her patients. To do the job right, she explained, “You have to know how to keep their trust.”

Yulisa completed several steps before going to Gertrude’s home. At PELF’s central headquarters, she reviewed the positive sample that had been collected weeks earlier. She then contacted the local health promoter in the area, and explained to the promoter that she would need to give advanced notice to Gertrude that another team would arrive for more testing.

Inside Gertrude’s home, a bare light bulb dangled overhead, casting a faint glow. *Ou met chitè, chitè*—“please, sit,” said her husband, offering their only piece of furniture aside from their bed: a little stool that barely rose more than a foot off the ground. True to her word, Yulisa declined the stool, preferring that Gertrude sit there for the blood draw. On the mattress were two infants sleeping quietly under a mosquito net, their soft breathing almost synchronized. The inside air was hot and stuffy. The high-pitched buzz of mosquitoes greeted the visitors, prompting Gertrude’s husband to take shelter under the mosquito net. With more frequency, Gertrude kept slapping at her legs, exclaiming with a little laugh, *Anpil moustik!*—“so many mosquitoes!” Yulisa drew the blood carefully, placed a drop onto a glass slide for later analysis, and packed up their materials. They told Gertrude they would return to provide treatment if her sample was positive (which it was, so they did). The team exchanged farewells.

Aside from following up with patients for treatment, facilitators like Yulisa are tasked with fostering relationships with *bateyes* to carry out MDA campaigns. Typically, their main point of contact in *bateyes* is at *juntas de vecinos* (neighborhood associations). The relevance of the *juntas* to daily life cannot be understated; as one association president explained:

*The community must be empapada [literally, “soaked,” or here, infused] with the junta and the junta with the community. [...] What we look for is a way for the community to feel more united, that we all need each other.*

Similarly, a traditional way in which rural Haitians band together to share tasks is called *tèt ansanm* (Kreyòl for “heads together”). In the DR, Haitian

migrants have expressed disappointment at the inability to form these support groups due to the transitory nature of migration or perceived misunderstanding with Dominican neighbors.<sup>36</sup> Still, in some *bateyes*, it appeared that residents tried to form groups like *tèt ansanm*, no matter how informal. For example, interview participants described *recolectas*, or collection drives, to help pay for medical care or food for those in need. “We live by the strength of our hands,” said a shop owner in one *batey*.

Collaboration with these support groups is central to the work of PELF. MDA efficacy is highly dependent on MDA coverage.<sup>37</sup> Thus, PELF extends drug coverage to as many eligible individuals as possible (excluding those who are pregnant or under two years of age), regardless of legal status, ability to pay, or seek care at a formal health structure.<sup>38</sup> One health promoter in the southwest emphasized the importance of reaching all persons in her work, particularly newly arrived Haitian migrants, who are often in dire need: “Some among them are sick, and they have nobody here to help them, no family, absolutely nothing.” Speaking Haitian Kreyòl is not usually a problem, either, she explained, because, “Some came from [Haiti], so we learned to speak Kreyòl. We’re joined together,” [*estamos ligados*] “Dominican and Haitian.”

Broadening the reach of MDA campaigns requires significant labor and resources, of course. Consequently, PELF engages with the community throughout the entire process: from initiating contact at *juntas de vecinos*, to conducting educative talks in the *bateyes*, to recruiting and training local volunteer *medicadores*, or medication administrators who go house to house.

The first step in this process involves identifying leaders at the neighborhood association or elsewhere and asking their permission to enter their communities. Working with these leaders, the PELF team then organizes larger meetings to explain the purpose of the MDA campaign and answer any questions. Yulisa and Wilson, another facilitator who has worked within PELF since 2002, underscore the need to explain everything in advance, including details of exactly how many tablets would be administered per person, so that,

as Yulisa says, “there will not be any surprises.” She goes further: “What is most important is community participation. [...] The person must feel like they are their own protagonist for their health.”

However, both Yulisa and Wilson emphasize that PELF does not broach the *tema caliente* (“hot topic”) of the *Sentencia*. While it is not within PELF’s mandate to address complex political issues directly, it was not lost on the PELF team that their work confronts problems tied up in a broader context of social injustice. As one figure within PELF confided, the situation of *bateyes* revolved around profit: “Exploitation would be far less if Haitians had rights,” because, as he went on, with legal status, they could then access social services and health insurance funded by employers and the government.

When entering *bateyes*, Yulisa explained that they take caution to explain that LF is a health problem “that affects everyone,” not just Haitians or Haitian migrants. Thus, everyone has a stake in resolving it. One community health volunteer echoed her perspective: “Because it’s called ‘public health,’ ‘public’ means it’s for everyone.”

“We are not nationalists,” Yulisa says. “We always say it’s a problem for the whole island, not just [Haiti]. [...] After all, mosquitoes don’t have passports!” Wilson adds, though, that because of migration, “so long as there are cases in Haiti, there will be cases” in the DR.

## Discussion

While this study was not designed to capture perspectives of residents towards PELF, the findings point to widespread feelings of unimportance that contrast with the elimination program’s approach of non-discriminatory access to testing and treatment. The program’s success in achieving high MDA participation rates and reducing LF despite this context of social and legal exclusion suggests ways to narrow the gap between human rights obligations and the present reality of violations resulting from the *Sentencia*.

Fundamentally, these findings reflect opposing viewpoints over how people should be recognized

in Dominican society. From a judicial perspective, the 2013 *Sentencia* reclassified entire generations of Dominican-born, Haitian-descended people as non-citizens. In effect, the *Sentencia* relocated exclusionary practices to the bureaucratic office, where digital registry lists determine who may have access to documents, and consequently, to life chances.<sup>39</sup> This “modernizing” shift in tactics, of course, follows a historical trajectory. In the early 20<sup>th</sup> century, the illegal status of Haitian migrant cane cutters formed the basis for increased state control over their labor, leading to physical confinement on *bateyes* and periodic expulsions going well into the 1990s.<sup>40</sup> From a historical perspective, the *Sentencia* was but the latest strategy to enlarge the proletarian sub-class.<sup>41</sup>

For participants in this study, the *Sentencia* affected not only daily life but also their internalized sense of who they were as people, as *yon moun* (Kreyòl, a person) or *una persona reconocida* (Spanish, a recognized person). This assault on dignity was evident in the comment that it was as though, “the government doesn’t even know there are people here”; in the humiliation felt by those without jobs; in the description of those rendered stateless as “dead but alive”; and in the experience of a Dominican-born man singled out to show his passport on a bus. Social exclusion in the DR continues to shape how people see themselves in relation to the government and each other.

Counter-current to this dynamic, PELF, through its operational goal of mass drug administration, qualifies all residents in areas of LF transmission as deserving of attention, regardless of documentation or immigrant status. This approach helps to counteract a major consequence of being undocumented: exclusion from health insurance schemes offered by employers or the government.<sup>42</sup> Indeed, as previous field studies have found, persons without identity documents are forced to pay out of pocket or receive less specialized care, even in the public system.<sup>43</sup> In their work, Yulisa and others explained that the disease was not isolated to Haiti, nor one brought by Haitians, but one, “for the whole island” to resolve. This global perspective makes everyone responsible for LF. For the PELF

team, the causative agent of LF went beyond the parasite, whose edematous effects on the body were depicted on informational posters carried door to door. Rather, LF was cause and consequence of poverty, migration, and disenfranchisement—distal forces, they admitted, that lay beyond the scope of their work.

Operationally, PELF recognized the need to collaborate with *bateyes*. Mobilizing communities entailed acknowledging local authority held by neighborhood associations, support systems that seemed to carry more respect among *batey* residents than the municipal or national government, whose candidates for office were said to make fleeting appearances motivated only by votes. Gaining trust was essential for approaching a population harboring deep skepticism of outsiders, particularly government agencies. Finally, trust and respect could be conveyed in simple interactions between PELF and those they try to reach—such as an unassuming attitude inside a home without a chair. Small gestures indeed, they nonetheless reflect an approach that recasts *batey* residents as participants in their own health, a rebuttal of the, “state politics of abandonment” that diminish their place in society.<sup>44</sup>

By rejecting a discriminatory approach, PELF acknowledges the right of all *batey* residents to one specific aspect of the right to health—protection from, and treatment for, LF. This process presupposes that the lives of *batey* residents are worth reaching, regardless of whether political or legal circles have declared them illegitimate. Recognition of *batey* residents by PELF contrasts starkly with the *loss* of recognition accumulated over years of discrimination, structural violence, and the recent *Sentencia*. In a way, PELF has found itself in the space between the powerful and the weak, between a political and judicial system that considers *batey* residents as nothing more than cheap laborers, and the residents themselves, whose claims for recognition *as people* are at stake.

A picture of perceived social exclusion in *bateyes* is evident. Yet observations and interviews, as well as epidemiological evidence of reduced LF transmission, reveal features of PELF’s successful

community engagement that can help to overcome exclusionary experiences: knowledge of the cultural and historical context; legitimation of local political authority; representation of residents in key positions, such as health promoters and medication administrators; use of existing resources at primary care centers; opportunities for residents to voice concerns; and communication between PELF and target communities.<sup>45</sup> Respect has for its foundation, “the recognition [...] of certain powers and capabilities” among those to whom it is carried.<sup>46</sup> In a context where many feel deeply disrespected—if not altogether ignored—such an approach helps to bring human rights ideals somewhat closer to reality.

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# A Human Right to Shoes? Establishing Rights and Duties in the Prevention and Treatment of Podoconiosis

ARIANNE SHAHVISI, ENGUDAY MESKELE, AND GAIL DAVEY

## Abstract

Podoconiosis is a debilitating chronic swelling of the foot and lower leg caused by long-term exposure to irritant red volcanic clay soil in the highland regions of Africa, Central America, and India. In this paper, we consider the human rights violations that cause, and are caused by, podoconiosis in Ethiopia. Specifically, we discuss the way in which the right to an adequate basic standard of living is not met in endemic regions, where the following basic necessities are not readily available: appropriate footwear, health education, and affordable, accessible health care. Those living with podoconiosis experience disablement, stigma and discrimination, and mental distress, contributing to greater impoverishment and a reduced quality of life. We suggest that while identifying rights violations is key to characterizing the scale and nature of the problem, identifying duties is critical to eliminating podoconiosis. To this end, we describe the duties of the Ethiopian government, the international community, and those sourcing Ethiopian agricultural products in relation to promoting shoe-wearing, providing adequate health care, and improving health literacy.

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## Background

Podoconiosis is a disabling and heavily stigmatized condition characterized by lower leg swelling (lymphedema) that, untreated, progresses to elephantiasis. It arises in genetically susceptible people who spend most of their lives barefoot and are thus exposed to clay soils found in tropical highlands.<sup>1</sup> Although the pathogenesis is not fully understood, soil particles penetrate the skin, are taken up by macrophage cells, and cause a chronic inflammatory process in the lymphatic system.<sup>2</sup> Lymphatic valvular dysfunction results in steadily progressive bilateral lymphedema, usually limited to below the knees.<sup>3</sup>

Globally, podoconiosis affects an estimated four million people, who live mainly in tropical Africa, Central and South America, and Southeast Asia. Recent mapping estimates suggest that there are 1.5 million people living with podoconiosis in Ethiopia and considerable numbers of affected people in Cameroon, Uganda, Rwanda, Burundi, and the Democratic Republic of Congo.<sup>4</sup> Podoconiosis has been reported in the Central American highlands in Mexico and Guatemala, as well as in Ecuador, Brazil, Suriname, and French Guiana in South America, but ongoing investigations suggest that few affected populations remain.<sup>5</sup> In Asia, podoconiosis has been reported in India, Sri Lanka, and Indonesia.

Although rarely a direct cause of mortality, podoconiosis disables those affected and leads to significant stigma within the community and health care settings.<sup>6</sup> Social stigma against people with podoconiosis leads to these individuals being excluded from school; denied participation in local meetings, churches, and mosques; and being barred from marrying unaffected individuals. Studies have documented low quality of life, mental distress, and depression.<sup>7</sup> Episodes of acute dermatolymphangioadenitis (“acute attacks”) are among the most severe clinical consequences of lymphedema, often confining individuals to bed while suffering malaise, fever, chills, lymphangitis, adenitis, and eventually skin peeling. These attacks occur frequently (reports vary from 5 to 23 episodes per year) and contribute substantially

to the disability and social impact associated with podoconiosis.<sup>8</sup>

Leg swelling and its consequences greatly reduce productivity, with affected individuals being half as productive as those with the same occupation but free of podoconiosis.<sup>9</sup> In one area of Ethiopia with 1.7 million residents, the annual economic cost of podoconiosis was more than US\$16 million in 2005—a figure that, when extrapolated to the country as a whole, suggests a cost of more than US\$200 million per annum.<sup>10</sup>

Despite the high impact of podoconiosis on rural farming communities in endemic countries, treatment and control are hampered by a range of issues. The key challenge faced is a general lack of awareness of the disease and the fact that it is different from lymphatic filariasis, the other main cause of lymphedema in the tropics. This lack of awareness is evident among health professionals, academics, and Ministry of Health staff. Podoconiosis-focused interventions are still so new that the challenges relate chiefly to program initiation rather than implementation. Fatalism is rife among health professionals in affected communities.<sup>11</sup> Where treatment is offered by small nongovernmental organizations (NGOs), issues such as distance, worries about stigma, illness, and misconceptions about treatment pose barriers to individuals’ continuing attendance for treatment.<sup>12</sup> These factors have led to an extreme neglect of individuals and communities affected by this debilitating disease.

## Introduction

Political and economic determinants are key to understanding the prevalence and epidemiology of any neglected tropical disease (NTD). Indeed, the category of NTDs is united not by biomedical commonalities but, as its name suggests, by commonalities of geographical distribution and neglect. This neglect has several components. NTDs are seriously under-funded, despite generally being inexpensive to treat. They and their treatments are also under-researched, especially in the pharmaceutical sector, as the populations they affect do not present opportunities for a return on investments.<sup>13</sup>

Relatedly, and perhaps most importantly, NTDs are under-represented in discourses on disease, mainly because they exclusively affect poor populations and therefore pose little threat to those in Global North contexts, but also because they are overshadowed by the “big three” diseases of the Global South: HIV/AIDS, malaria, and tuberculosis.<sup>14</sup>

It is therefore unsurprising that NTDs have received little attention in global health discussions, including in discussions of health and human rights. NTDs reveal the impact of structural factors on access to care and vulnerability to infection.

In this paper, we set aside the violation of the right to health in and of itself and instead turn to its constituent human rights violations. Unmanaged podoconiosis may be a violation of a person’s right to health, but it is more instructive to see it as a *symptom* of the fact that other rights have been violated and an indicator that still more rights *will* be violated. As Jonathan Mann et al. note, “[T]he extent to which human rights are realized may represent a better and more comprehensive index of well-being than traditional health status indicators.”<sup>15</sup> A major benefit of employing a rights discourse is that it centers on the *determinants* of health, allowing us to speak of entitlements to particular necessities rather than a vague, elusive entitlement to good health. And, of course, improving those determinants invariably has beneficial effects that extend beyond good health.

There are two ways of characterizing the interaction of podoconiosis with the human rights of those affected. The first concerns the way in which human rights violations contribute to podoconiosis; the second concerns the way in which podoconiosis then contributes to further human rights violations. The second set of violations may be seen as derivative of the first, but given that any strategy must address treatment as well as elimination, both are important.

Arguing that particular human rights have been denied is only the first part of the solution. Rights rely on a scaffold of duties for their realization. While rights generally apply to individuals and social groups, duties generally relate to agglomerate stakeholders in the form of governments and inter-

national organizations. In the case of podoconiosis, it is important to establish to whom the duties to provide treatments and efforts toward elimination fall. There are two ways of asking this question. One asks who is *responsible* for the well-being of those affected by the disease; this is a normative question. Another asks who is able to easily provide the necessary resources; this is a pragmatic question.

In the interest of maintaining a clear focus, this paper will consider podoconiosis in Ethiopia alone. This ought not to result in a significant loss of generality, since many of the rights violations in Ethiopia are also applicable in other endemic regions.

This article is structured as follows: in the first section, we describe the determinants of podoconiosis, including inadequate shoe-wearing practices, low health literacy, and the remoteness and inadequacy of health facilities. The following section then describes the ways in which podoconiosis leads to a series of additional human rights violations, mainly in the form of restricted health and employment possibilities, as well as stigma and discrimination. The final section explores strategies for improved treatment and elimination and identifies duty-holders in the achievement of these aims.

## Determinants of podoconiosis as human rights violations

Those living with podoconiosis are unable to realize their right to those basic necessities that are essential for reaching a standard of living that is adequate for health and well-being. This is despite the fact that low-cost, effective methods of prevention and treatment have been widely noted. In principle, podoconiosis is not a difficult disease to manage or eliminate: it occurs only in select geographies, it is not communicable, it is easily managed if spotted early, it is acquired only through long-term exposure to irritant soils, and its prevention requires neither pharmaceuticals nor large-scale infrastructural changes. Yet in practice, a series of complex, interrelated determinants collaborate to produce prodigious barriers to effective treatment and eventual elimination. Further, because podoconiosis is

not transmissible and tends to result in morbidity rather than mortality, it has been treated as a low priority.<sup>16</sup> As such, podoconiosis has been described as the most neglected tropical disease.<sup>17</sup>

The determinants of podoconiosis violate various human rights instruments. For example, article 11 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), which Ethiopia has ratified, recognizes the “right of everyone to an adequate standard of living for himself and his family, including adequate food, clothing and housing.”<sup>18</sup> Here, we understand that “adequate ... clothing” must be taken to include footwear, where its absence results in an inadequate standard of living. This closely parallels article 25 of the Universal Declaration of Human Rights, which states that “[e]veryone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services.”<sup>19</sup>

In addition, article 7(b) of the ICESCR enshrines the right to “safe and healthy working conditions” as a key realizer of the right to work.<sup>20</sup> This is important in the case of podoconiosis, since the majority of those affected by the disease are farmers working barefoot on irritant soils.<sup>21</sup> The African Charter on Human and Peoples’ Rights, which Ethiopia has also ratified, likewise calls for the right to work under “satisfactory conditions” (article 15).<sup>22</sup>

Article 16 of the African Charter on Human and Peoples’ Rights asserts the right to “enjoy the best attainable state of physical and mental health,” for which the state should “take the necessary measures to protect the health of their people and to ensure that they receive medical attention when they are sick.”<sup>23</sup> Similarly, article 12 of the ICESCR recognizes each person’s right to “the highest attainable standard of physical and mental health,” which is to be achieved by attending to

1. [t]he improvement of all aspects of environmental and industrial hygiene;
2. [t]he prevention, treatment and control of epidemic, endemic, occupational and other diseases; [and]

3. [t]he creation of conditions which would assure to all medical service and medical attention in the event of sickness.<sup>24</sup>

According to the Committee on Economic, Social and Cultural Rights, in order to realize the right to health, states are required to ensure that health care is available, accessible (physically, economically, and informationally, as well as without discrimination), of an acceptable ethical standard and with due regard to local cultural needs, and of good quality.<sup>25</sup>

It is clear that in Ethiopia, violations of the aforementioned articles contribute to the development of the disease. As described below, such human rights violations stem from a lack of suitable footwear for work and leisure, as well as resources for maintenance of good foot hygiene (for example, soap, water, bandages, and socks); inadequate health literacy; and inaccessible medical care.

#### *Footwear and foot hygiene*

Podoconiosis has been eliminated in endemic regions of North Africa and Europe due to the widespread adoption of shoe-wearing, which is a powerful demonstration of the effectiveness of this single behavioral change. Like many “tropical” diseases, podoconiosis is tropical only in its current instantiation; it was once noted at latitudes as high as Scotland.<sup>26</sup> It is soil type, rather than climate, that is necessary for the development of the disease. That it is now endemic *only* in tropical regions is testament to the poverty of those regions. So while the cause of podoconiosis is geochemical, the reasons for its persistence are economic, cultural, and political.

In endemic regions of rural Northern Ethiopia, there is limited adherence to shoe-wearing. Foremost among the reasons for this is poverty, with families prioritizing nutrition and education for children above buying shoes. Those who can afford to buy shoes are often not able to replace them when they wear out. Since affordability is key, these shoes are likely to be of low-quality materials and workmanship, which tends to limit their durability, comfort, and suitability for manual work, as well as their degree of coverage, which is correlated with the protection they offer from irritant soils. This

leads to inconsistent shoe use, as shoes are made to last by being worn only intermittently or for special occasions.<sup>27</sup> Gender disparities have been reported in the quality of footwear, with fewer women wearing the more expensive leather shoes that offer better protection.<sup>28</sup>

Once swelling sets in due to podoconiosis, it becomes difficult to find shoes that accommodate the larger foot size and shape. Standard footwear is often inappropriate, and affected individuals often rely on bespoke shoes designed and distributed by a few NGOs. However, these shoes are easily identifiable, which can lead to stigma and an aversion to shoe-wearing.<sup>29</sup>

Indeed, stigma plays an important role, with almost one-third of those affected refraining from wearing shoes in order to avoid being singled out.<sup>30</sup> In some cases, any variety of shoes, along with bandages or visible emollient use, is taken as a marker of disease or disease susceptibility—as a result, avoiding shoe-wearing may be a way of averting possible discrimination.<sup>31</sup>

A number of other practical concerns are relevant. A single pair of shoes worn continually in a warm climate without socks causes an unpleasant smell, which also leads to irregular shoe use, as people attempt to recurrently air their feet. Socks are therefore important in ensuring more comprehensive and comfortable shoe wearing. Furthermore, within podoconiosis-prevalent communities, clean water and soap are not always easily accessible, making foot hygiene difficult to maintain.<sup>32</sup>

In addition to shoe-wearing, household floor coverings are an important mechanism for minimizing foot-soil contact and thereby guarding against the development of podoconiosis. The lack of mats and cemented floors is common in endemic regions, largely because the importance of floor coverings is not well known and because covering household floors presents another expense.<sup>33</sup>

### *Health literacy*

Misconceptions concerning the causes of podoconiosis and preventative behaviors are common within endemic communities.<sup>34</sup> Various symbolic explanatory models for the disease circulate within

such communities, including the idea of podoconiosis as a form of religious punishment or a result of “magic,” often believed to be caused by stepping on dead animals.<sup>35</sup> In addition to posing barriers to preventing onset of the disease, these beliefs can lead to affected individuals seeking treatments from symbolic healers, which not only is costly and ineffective but sometimes leads to individuals being advised against attending podoconiosis clinics.<sup>36</sup>

Non-symbolic misconceptions also abound. There is the mistaken yet widespread belief that podoconiosis is infectious, which, coupled with the above symbolic beliefs, leads to considerable stigma around the disease. Other misnomers include the idea that the disease is transmitted by insects, by blood, or by affected individuals.<sup>37</sup> One study showed that only 41.4% of a podoconiosis-endemic community knew that the disease could be treated.<sup>38</sup>

Health literacy in relation to podoconiosis within endemic communities is low, with the average disease knowledge among women only half that among men.<sup>39</sup> Given that women’s beliefs are typically more determinative of children’s beliefs and behaviors, the effects of low health literacy in women are particularly concerning.

### *Health care*

Misconceptions among health professionals regarding podoconiosis are high, with one study reporting that 98% of respondents were ill informed about the causes of podoconiosis.<sup>40</sup> More than half believed that it was transmitted by insects, and half believed it to be infectious. Stigma toward affected individuals was high, and 86% of health professionals surveyed did not feel competent to treat the disease.<sup>41</sup> Further, 70% of the same group of health professionals reported lacking the basic resources (such as emollients and bandages) to provide treatment. Clearly, health care is held back as a result of inadequacies in both training and resources.

Even where health care is available, rural areas face barriers related to accessibility, with affected individuals citing distance from clinics and the need to meet other commitments (such as caregiving and other labor) as major reasons for discontinuing attendance.<sup>42</sup> Some individuals must

travel long distances by foot to reach clinics, which is physically challenging, while others rely on public transport, which is financially challenging. Those who live particularly far from clinics are also often deterred by the cost of an overnight stay.<sup>43</sup>

## The effects of podoconiosis on human rights

Podoconiosis has a major impact on affected individuals' enjoyment of human rights. Human rights are interrelated and interdependent, meaning that the violation of one right generally entails the violation of others. Neglecting the health vulnerabilities of those in disease-endemic regions eventually hampers social and economic opportunities and leads to further vulnerability.

Research conducted in endemic communities reveals that podoconiosis confers social, psychological, and economic burdens on affected individuals.<sup>44</sup> These individuals also experience absenteeism and reduced working hours due to frequent disease-related acute attacks.<sup>45</sup> Podoconiosis therefore poses a considerable threat to education and employment opportunities. In this section, we discuss how the disease can lead to the violation of three human rights in particular: the right to education, the right to work, and freedom from discrimination.

### *The right to education*

Article 13 of the ICESCR requires that primary and secondary education be "available and accessible to all by every appropriate means."<sup>46</sup> Those living with podoconiosis are deprived of this right on various fronts. They often have limited access to education due to disease-related acute attacks and due to stigma and discrimination. Disease-related acute attacks have a serious impact on school enrollment and completion, in addition to affecting attendance and performance. According to a recent study, pupils with podoconiosis may lose a considerable number of school days, drop out, underperform, and lack concentration as result of disease-related illness.<sup>47</sup> Schools in endemic rural areas are often located in remote villages, requiring students to walk long dis-

tances on foot, which is especially difficult because of the disabling effects of podoconiosis.

Moreover, students with podoconiosis often experience isolation, discrimination, verbal abuse, and harassment by peers within educational settings, leading their school attendance to fall.<sup>48</sup> Coupled with financial constraints, physical inaccessibility, and disease-related discomfort, stigma and discrimination pose major barriers to enjoyment of the right to education.

Although individuals with podoconiosis may appear to have the same notional access to education as unaffected individuals, the conjunction of these factors produces serious inequity. A particularly concerning byproduct of the lower level of education experienced by affected individuals is the effect on their health literacy and the ability to effectively manage the condition.

### *The right to work*

The right to work is essential for realizing other human rights and is a core source of personal development, as well as a facilitator of economic and social inclusion. The ICESCR enshrines the right to work under articles 6, 7, and 8. Since podoconiosis is so often *caused* by labor in the form of barefoot agricultural work, it is particularly lamentable that the disease frequently threatens a person's ability to work, both through physical impairment and through the effect of discrimination. Those whose education is disrupted as a result of podoconiosis may also find themselves less able to work by virtue of lacking necessary skills. The right to work is therefore undermined via violations of the right to health care, the right to healthy working conditions, the right to education, and the right to adequate footwear.

Individuals with podoconiosis experience rights violations in relation to access to, or continuation of, employment, which may occur due to discrimination or disease-related complications. They are often denied job opportunities, unfairly dismissed, and mistreated in the workplace.<sup>49</sup> Mirroring their behavior in educational settings, some affected individuals avoid employment as a way of minimizing stigmatization.<sup>50</sup> In addition, many are

unable to work due to physical impairment related to both ongoing lymphedema and acute attacks.<sup>51</sup>

### *The right to protection from discrimination*

The right to protection from discrimination recognizes the effect of stigma and discrimination on the social and economic opportunities of individuals, and the resulting increase in vulnerability. Stigmatizing attitudes continue to delimit the social and economic well-being of individuals with podocooniosis. This stigma is largely a result of low health literacy within endemic populations, including among health workers. In this way, it may be traced to a violation of the right to accessible information with regard to health issues.

Studies have demonstrated that individuals with podocooniosis face stigma and discrimination in the public and private realms. Both felt stigma (perceived fear of actual stigma) and enacted stigma (including unfair dismissal or school dropout due to discrimination) have been documented.<sup>52</sup> Stigma toward affected individuals is often manifested through differential treatment at social events, isolation from the community, limited marriage prospects, reduced access to education, and limited job opportunities.<sup>53</sup>

### Duties regarding treatment and elimination

Articulating rights violations paves the way for the identification of duty-holders and recommendations in relation to those rights. This section describes some extant initiatives that have been successful in tackling podocooniosis, identifies duties that must be met in order to address human rights violations, and explores the rightful duty-holders.

### *Promising interventions*

In Ethiopia, NGOs currently play a key role in offsetting the aforementioned rights violations. The most prominent of these are International Orthodox Christian Charities, Action against Podocooniosis Association, the Ethiopian Catholic Secretariat Social and Development Commission, and Mossy Foot International.<sup>54</sup> These organizations offer

programs focused on lymphedema management, awareness raising, and shoe distribution. Through the provision of health care, health literacy campaigns, and footwear, they respond neatly to the key human rights violations we have identified. However, their resources are understandably limited and unpredictable, and their geographical coverage is incomplete.

One particularly promising initiative was developed by Mossy Foot International, in which people with podocooniosis who have been successfully instructed in the management of their own podocooniosis (via shoe-wearing and foot hygiene) are trained to act as “community podocooniosis agents” within their local communities, inducting others into effective management of the disease and leading awareness-raising sessions and clinics in public spaces.<sup>55</sup> This highly effective scheme has the benefit of being patient led, which promises greater cultural sensitivity and credibility. (Importantly, it also meets the ICESCR requirement that the right to health be met in a “culturally acceptable” manner.) Furthermore, by offering good-quality, tailored care in each community, the program prevents affected individuals from having to travel long distances to reach clinics. This program could arguably be made even more effective by engaging expert patients in bridging the divide between biomedical health care and traditional healing, which could have the dual effect of increasing adherence to clinic treatments and ensuring that traditional healers provide medically sound advice.<sup>56</sup>

Such a scheme can be successful at larger scales only if health professionals are themselves adequately educated and resourced to be able to diagnose and treat podocooniosis, as well as to promote positive health behaviors among high-risk patient groups. At present, podocooniosis-endemic regions are not only deprived of the necessary resources for prevention and management (shoes, water, soap, bandages, and emollients) but also critically deprived in an *epistemic* sense. These epistemic lacunae are common in both patients and health professionals, and they provide fertile ground for the misconceptions that undermine comprehensive shoe-wearing and that promote stigma. As we have

shown, this stigma is a substantial barrier to the right to education for affected children, which in turn limits the capacity for employment and health literacy of those living with the disease. This point cannot be overstated: barriers to childhood education impede the capacity to work and the capacity to curb the development of podoconiosis, both of which affect vulnerability to poverty and disease. While shoe-wearing will be the key to eliminating podoconiosis, one cannot expect the practice to become widespread and enduring if it is not founded on an improved understanding of the disease.

The key area that is ripe for intervention is increasing the accessibility of durable, comfortable, protective shoes. A recent study demonstrated that almost three-quarters of those surveyed in Northern Ethiopia were willing to pay for footwear.<sup>57</sup> For the quarter unwilling to pay for footwear, the most important factor was poverty. Kebede Deribe et al. suggest that subsidized shoe-distribution schemes may be effective in ensuring more comprehensive shoe-wearing.<sup>58</sup> In addition to working alongside public health efforts to promote increased health literacy and the importance of consistent shoe-wearing, these schemes must capitalize on recent shifts toward shoe-wearing as a sign of respectability and fashion, especially among younger people.<sup>59</sup> Given the increasing desire for shoes—and the fact that most people are willing to pay for them—there is clearly a need for affordable footwear, which must be treated as a public health priority rather than a mere market opportunity. One way of meeting this need within communities is to extend schemes so that individuals with podoconiosis are trained to produce suitable footwear for sale or distribution within their communities.<sup>60</sup> Another option is for governments to collaborate with shoe companies in order to fund subsidies.<sup>61</sup> Partnerships have been formed with justice-oriented companies such as TOMS, which currently provides a free pair of children's shoes for every pair purchased, or Oliberté, which manufactures its shoes within a fair trade certified factory in Ethiopia.

### *Identifying duties*

The following interlocking changes are necessary

for the realization of human rights that will facilitate the elimination of podoconiosis and minimize its effects on individuals living with the disease:

1. The right to health:
  - Rural communities should have access to affordable health care services within walking distance, either via the establishment of permanent local clinics or via the regular presence of mobile clinics.
  - All curricula for health professionals working in endemic areas should include training on the pathogenesis, identification, and treatment of podoconiosis, and the physical resources for treatment should be readily available.
  - Health professionals should be tasked with training expert patients and working with traditional healers in order to improve health literacy within endemic populations.
  - Federal and regional governments should create cross-sectoral opportunities to raise awareness about podoconiosis in the wider community, through, for example, the agricultural, education, and development sectors.
2. The right to adequate clothing, including footwear:
  - Comfortable, affordable, long-lasting, protective footwear should be readily available within endemic populations for people of all ages. Promoting shoe-wearing should be an important part of the training for health professionals recommended above.
3. The right to safe and healthy working conditions:
  - Podoconiosis should be seen as an occupational health priority within the farming sector. Adequate footwear should be provided to workers as a health and safety measure, and shoe-wearing should be enforced.

Besides addressing rights violations, these recommendations respond to the aims of the United Nations Sustainable Development Goals, which call for the



elimination of neglected tropical diseases, universal access to high-quality medical care, improvements in the financing and training of health professionals, and safe working environments for all.<sup>62</sup>

### *Identifying duty-holders*

At the outset of this paper, we drew a distinction between the normative question of who is *responsible* for the well-being of those affected by podoconiosis, and the pragmatic question of who is able to easily *facilitate* the necessary changes. While NGOs have thus far played an important role in podoconiosis management—particularly in developing innovative techniques for management—larger-scale, better-resourced efforts, based on more extensive data, will be needed in order to bring about elimination.

The primary duty for preventing human rights abuses and seeking elimination must lie with the government of Ethiopia, which has sovereignty over the nation's land, one-fifth of the soils of which can cause podoconiosis.<sup>63</sup> In this regard, it is critical to note that agriculture is the cornerstone of the Ethiopian economy, accounting for almost half of the gross domestic product and 80% of the workforce.<sup>64</sup> This productivity is accounted for partly by the tremendous fertility of the soil, which is due largely to its volcanic origins.<sup>65</sup> Coffee growing, which represents 41% of the country's export earnings and 15% of the population's livelihood, is particularly reliant on these fertile volcanic soils.<sup>66</sup> In other words, the principal cause of podoconiosis is also a principal contributor to the nation's economic viability. Many of those affected by podoconiosis are coffee farmers or live in coffee-producing regions.<sup>67</sup>

The political economy of soil in Ethiopia reveals an important moral link between the nation's economy, which is currently in a period of promising growth, and some of the country's most neglected populations. It seems problematic for the nation's economy to benefit so vastly from its agricultural sector, while those living within podoconiosis-endemic agricultural communities are unable to access a "standard of living adequate for ... health and well-being ..., including food, clothing, housing and medical care and neces-

sary social services."<sup>68</sup> Failing to provide adequate health care and access to footwear is tantamount to environmental classism, with the rural poor being tied—both culturally and economically—to the land that is harming them, without the means to prevent those easily avoidable harms.<sup>69</sup> In other words, the right to safe and healthy working conditions is being violated for specific sectors of the population, amounting to a stark violation of article 2(2) of the ICESCR, which repudiates discrimination based on "social origin, property, birth, or other status." This is also a pressing occupational health issue, which links back to the way in which podoconiosis affects the right to work.

Care models such as that currently used by Mossy Foot International are highly effective and could be scaled up in an attempt to eliminate podoconiosis, provided the requisite resources and data are made available. As the principal duty-holder, the government of Ethiopia must provide these missing links in order to prevent the violations of human rights that are enshrined in the instruments the state has ratified. Indeed, ratification entails an obligation to respect, protect, promote, and fulfil these rights, and while progressive realization is an acceptable interpretation of this obligation, it is not clear that any notable progression has been made in reducing reliance on NGOs in managing and reducing podoconiosis. While there is a cost to implementing the improvements described above in endemic areas, this must be weighed against the 45% of working days lost each year and the increased health care costs of non-adherence to inadequate care options.<sup>70</sup> Clearly, a rigorous, well-resourced, shoe-wearing campaign, coupled with podoconiosis-specific training for health care workers, will be more cost-effective than managing the needs of an otherwise growing number of affected individuals.

Of course, one cannot ignore the fact that Ethiopia's health care system is weak, with the capacity to provide care to only half of the population and with a disproportionate share of funding focused on curative health care for urban populations, to the detriment of public health measures for rural populations. Only 42% of those in rural areas have access to health care facilities within walking

distance. The right to health of rural populations is patently not met. Until recently, efforts to treat podoconiosis had been led solely by NGOs, which have recently partnered with the Ethiopian Ministry of Health and have advocated for the integration of podoconiosis into the National Master Plan for NTDs. This promises to introduce lymphedema management services into government clinics and improve staff training, but the scheme is under-resourced (and still reliant on external donations), and government health care facilities do not serve all endemic rural populations.<sup>71</sup> This is perhaps unsurprising, given that only 4.9% of Ethiopia's gross domestic product is spent on health care.<sup>72</sup>

The poverty of Ethiopia must be seen relative to the wealth of the Global North; specifically, the capacity to provide vital services to Ethiopian people is hamstrung by the requirement that the state prioritize servicing high-interest debt to external funders. Ethiopia has been implementing a structural adjustment program since 1992, resulting in a diminished public sector, under-resourced health care services, and a reliance on NGOs to make up the shortfall.<sup>73</sup> This is not to absolve the government of Ethiopia of its aforementioned human rights duties but to be realistic about its capacity to deliver on those duties in light of its unrelenting economic dues. Ethiopia is not necessarily able to set its own priorities within a global economy that is hostile to the health needs of its population. Yet as noted by the Committee on Economic, Social and Cultural Rights in its General Comment 14, “[I]nternational financial institutions, notably the World Bank and the International Monetary Fund, should pay greater attention to the protection of the right to health in their lending policies, credit agreements and structural adjustment programmes.”<sup>74</sup>

Reforms to debt repayment in light of this consideration—or, more radically, some form of debt relief—may be the most robust way to advance Ethiopia's capacity to improve its health provision and devote the necessary resources to rural settings to tackle podoconiosis.

In addition to debt, Ethiopia has a considerable problem of illicit financial flows.<sup>75</sup> Much of this is due to trade mispricing, in which the sale

and purchase of goods take place at prices that do not match those of the market, facilitating tax avoidance, largely by multinational enterprises whose subsidiaries are distributed globally.<sup>76</sup> Curbing illicit financial flows by increased global tax transparency and accountability will be key to ensuring that nations like Ethiopia can stem the tide of capital flight and thereby finance initiatives for the improved health care, education, and specific resources (such as footwear) that are necessary to eliminate podoconiosis and prevent further losses, both economic and social. Given the way in which the soil *mobilizes* export products even as it *immobilizes* those who work on it and with it, perhaps one narratively coherent suggestion for funding the necessary public health improvements could be through export taxes on agricultural products.

An additional set of potential duty-holders may be identified by considering the beneficiaries of Ethiopia's agricultural products. Since podoconiosis is so often an occupational health issue, those situated on the product supply chain must be responsible, at least in part, for the well-being of farmers. Three of the world's wealthiest nations—Japan, Germany, and Saudi Arabia—are the leading importers of Ethiopian coffee, while prominent multinational brands such as Illy and Starbucks are major suppliers.<sup>77</sup> Global North consumers and suppliers should be conscious of the working conditions of Ethiopian coffee farmers, many of whom are at high risk of developing podoconiosis or are living and working with the disease. There is considerable potential for ethical consumerism to assist in the elimination of podoconiosis by requiring shoe-wearing among farmers and, crucially, by providing appropriate footwear. Many consumers would resist buying products whose farming disables workers. In the Global North, coffee (particularly premium varieties, such as those that are regionally trademarked within Ethiopia) has relatively inelastic demand, so that high prices (as a result of, say, providing footwear to workers) can easily be passed on to the consumer.<sup>78</sup> Similar arguments may be made about corporate and consumer responsibility with regard to other Ethiopian agricultural exports.

In a globalized world, there are also global responsibilities for global health issues, and podoconiosis should not be taken as an exception simply because of its geographical specificity, lack of mortality, and lack of transmissibility. If the government of Ethiopia (and the governments of other endemic regions) is to be successful in eliminating podoconiosis, it will require the assistance of other bodies. As Gorik Ooms and Rachel Hammonds point out, growing wealth inequality between nations determines the ability of states in the Global South to invest in health-related goods.<sup>79</sup> Since the determinants of NTDs are so interlinked and tend to overlap geographically in their endemic regions, tackling podoconiosis should be part of a multi-NTD strategy of improved health care and improved literacy.<sup>80</sup> This must be viewed as a global responsibility; it is not something Ethiopia can—or should be left to—address on its own.

## Conclusion

Podoconiosis is a disease that persists as the result of failures to provide the basic necessities required for its elimination. It is caused by inadequacies in access to appropriate footwear, resources for foot hygiene, health literacy, and health care. These constitute violations of the right to a standard of living adequate for health and well-being. Moreover, once podoconiosis has developed within an individual, further rights violations occur in the form of stigma and discrimination, as well as adverse effects on education, employment, and social participation.

Paul Farmer and Louise Ivers describe the quandary raised by easily eliminable diseases as the “dilemma of global health in the 21st century: finally, we have the tools for prevention and diagnosis and care; what we lack is an equity plan linked to a delivery system.”<sup>81</sup> In the case under consideration, the solution could not be simpler: comprehensive shoe-wearing would eliminate podoconiosis within a generation. Yet of course, the “right to shoes” is in fact a complex bricolage of other rights, and poverty currently undermines their joint realization.

Increased efforts toward health literacy and shoe-wearing initiatives will be critical to ensuring

enjoyment of the right to an adequate standard of living and the eventual elimination of podoconiosis, while improved access to health services is vital to those already living with the disease. Implementing these improvements is the duty of governments of endemic regions toward their own citizens—but without broader structural changes to, for example, stem illicit financial flows and liberate funds for health care, countries of the Global South cannot be expected to finance the robust public health measures needed. Podoconiosis may pose no health threats to those on safer ground, but a disease of poverty is also a disease of wealth, and there is a global duty to prioritize elimination and thereby secure the rights of those in endemic regions.

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## EDITORIAL

# Health in the Courts of Latin America

OCTÁVIO LUIZ MOTTA FERRAZ

To address any complex issue in a large and diverse geographical region of the world is always a daunting and risky task. Latin America is no exception. Despite the semblance of uniformity that the use of the term “Latin American” often misleadingly imparts, the truth is that there is no such thing as a homogeneous bloc of countries occupying the territory running from the border between the United States and Mexico down to Uruguay, plus a few islands in the Caribbean Sea. Not even a single language is shared, let alone a broader “Latin American culture.”

We are dealing with a large region spanning 20 million square kilometers (13% of the earth’s land surface), including very poor countries such as Haiti, middle-income ones such as Peru, Colombia, and Brazil, and relatively wealthy ones such as Uruguay and Argentina. There are democracies at different levels of maturity and stability alongside authoritarian regimes, as well as a diverse range of political-economic systems, from socialist Cuba to economically liberal Chile.<sup>1</sup> Health systems also vary significantly in their structures (from national health services in Brazil to social security and public insurance schemes in Mexico and Colombia), coverage, and quality. As an influential historian has recently claimed, the idea of Latin America should have probably vanished by now. But he also acknowledges that “[t]he term is here to stay, and it is important.”<sup>2</sup>

The topic addressed in this special section—the judicial enforcement of health rights—inevitably reflects this remarkable diversity. Despite some interesting common trends, no “Latin American model” of health litigation emerges, unsurprisingly, from the growing but still limited studies of the past few decades (including those published in this issue). On the contrary, there is significant variety in terms of the magnitude of the phenomenon, its main characteristics, its potential causes, the impact it has on equity and health systems, and the emerging initiatives in reaction to the phenomenon.

## Why Latin America?

What seems to unite many in Latin America and beyond is the perception that health litigation is particularly acute and often problematic in the region. Concern with the rise of health litigation is of course not unique to Latin America, but some of the traditional worries about judges interfering in the realm

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of public policy seem more intense in that region. This is due largely to what some describe as an “explosion” of litigation experienced in some of the region’s countries (thousands of cases in Costa Rica, and hundreds of thousands in Colombia and Brazil) and a heightened disposition of judges to enforce the right to health through strong remedies in comparison to non-Latin American countries.<sup>3</sup>

Studying judicialization in Latin America therefore seems to provide an ideal opportunity for us to extract broader lessons about this growing phenomenon, which is affecting an increasing number of countries throughout the world.<sup>4</sup>

Yet the literature on the topic, both in Latin American languages and in English, though growing, is still rather limited and, additionally, beset by the lack of a clear analytical framework to guide us in identifying the salient issues in need of empirical research and in drawing more robust conclusions that may assist in potential reform if and where it is needed.

The inspiration for this special section was the desire to enhance the body of research dedicated to understanding the phenomenon of health litigation as it relates to both of these aspects—in other words, not only regarding the specific knowledge about what goes on in specific countries but also with regard to refining our analytical framework to assess the phenomenon wherever it occurs.

### The importance of context and empirical data

Right to health litigation has attracted the attention of scholars, policy makers, politicians, and the general public for two interrelated reasons. Both have to do with the involvement of the courts in the realm of public policy in general and health policy in particular. The first relates to what we might call the *democratic legitimacy* of that involvement and pits those who see it as always inappropriate—a frontal breach of the principle of separation of powers—against those for whom the very recognition of health as a legal right, especially when done through the constitution, automatically legitimizes the participation of courts.<sup>5</sup> The latter disagree

among themselves, however, about the exact manner in which courts ought to intervene, with proposals ranging from more deferential and procedural approaches to more assertive and substantive ones.<sup>6</sup> The second line of reasoning has to do with what actually happens when courts interfere—that is, the *impacts*, good or bad, of judicialization. Some have drawn attention to the potentially negative effects of judicial involvement, such as distortions of rational health policies and the worsening of health inequities.<sup>7</sup> Others have stressed the role that judicialization can play in enhancing state accountability and citizens’ participation, especially in the health systems of countries where democratic control is weaker.<sup>8</sup>

I believe that the effects of right to health litigation, as with any complex phenomenon, can be both positive and negative and are likely to vary significantly from country to country. The legitimacy of courts’ involvement in health policy is also strongly dependent, in my view, on highly contextual factors related to the operation of courts (including the impacts of judicialization) and, more broadly, the structure and operation of the political and health systems of particular countries. The legitimacy question therefore cannot be settled in isolation from these empirical and contextual factors as if it were a matter of pure normative theory—that is, of determining the correct meaning of the principle of separation of powers.<sup>9</sup>

Latin America illustrates this point nicely. It seems increasingly clear from emerging empirical data that the judicialization of health in different Latin American countries reveals quite different pictures concerning both legitimacy and impacts. Take, for instance, Costa Rica and Brazil. We know that in both countries claims for medicines make up a large proportion of right to health litigation, that these claims are overwhelmingly individual in nature, that courts are very receptive (in other words, the success rates are quite high), and that a significant proportion of these medicines are not incorporated into the public health system, often for not passing mainstream priority-setting criteria.<sup>10</sup> Yet it would be a mistake to jump to the conclusion that, in both places, judicialization is therefore mostly illegitimate and produces largely



negative impacts.

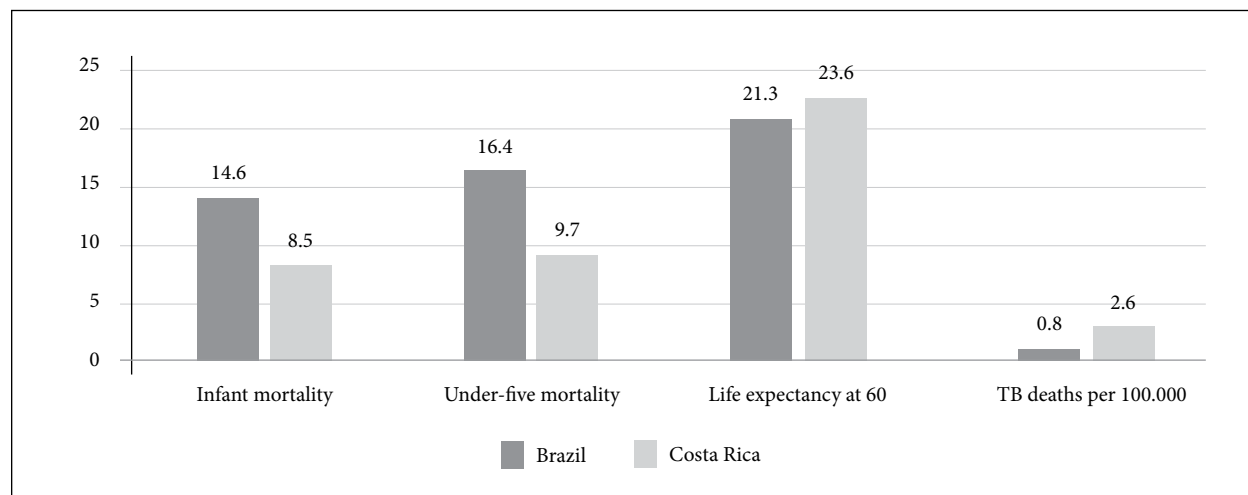
We need to know much more about each of these countries to build a comprehensive picture of judicialization—and once we have that, important differences are likely to emerge. Moreover, such differences may (I would even say are likely to) lead to different conclusions about the legitimacy and impacts of judicialization in these countries.

A few brief examples may help us here. Whereas in Costa Rica anyone can petition the Sala IV (the chamber of the Supreme Court that deals with right to health litigation) directly and without the need to be represented by a lawyer, in Brazil legal representation is compulsory: cases must start in local courts and can go all the way up to the Supreme Federal Tribunal, the fourth and last instance of the judicial system, in a lengthy and costly process. These differences in the judicial system are likely to result in easier access to courts in Costa Rica, which, in turn, will likely affect the socioeconomic profile of claimants, or those who benefit directly from successful litigation.

Other important differences related to the operation of the health system seem relevant. As empirical data show, Costa Rica displays a strong commitment, at least in comparative terms, to the funding of its health system. Government health expenditure is consistently around 7% of the gross domestic product (GDP), almost double the up-

per-middle-income country average. In per capita terms, this amounts to almost US\$1,000 (in terms of purchasing power parity), which is more than two-and-a-half times the upper-middle-income country average and one-and-a-half times the global average. As a result, out-of-pocket expenditure is low and private health insurance plays a very small role, about 1% of total health sector financing, which is much lower than the upper-middle-income country average of 7% and the global average of 15%.<sup>11</sup> In Brazil, despite the constitutional recognition of health as a fundamental right (in contrast to Costa Rica) and the largest state-funded national health service in the world in terms of beneficiaries (the Unified Health System), the funding commitment is much weaker. Government health expenditure barely reaches 4% of GDP, amounting to around US\$400 in per capita terms, significantly lower than Costa Rica.<sup>12</sup> Given such funding disparities, it is not surprising that Costa Rica's public health system is much more comprehensive than that of Brazil, despite the fact that both are upper-middle-income countries with similar levels of wealth (both around US\$14,000 GDP per capita). It is plausible to assume that the greater comprehensiveness of Costa Rica's health system is partly responsible for the better health of the Costa Rican population. Brazil is indeed well behind Costa Rica in many important health indicators, as illustrated in Figure 1.

FIGURE 1. Selected health indicators in Brazil and Costa Rica



Source: United Nations Development Programme, Human development report 2016: Human development for everyone (New York: United Nations Development Programme, 2016).

Differences in the operation of the health system, such as those just highlighted, are also relevant for a comprehensive and robust analysis and assessment of the legitimacy and impacts of right to health litigation in specific countries. As Olman Rodríguez Loaiza, Sigrid Morales, Ole Frithjof Norheim, and Bruce M. Wilson plausibly claim in their paper in this special issue, given Costa Rica's reasonably well-funded, comprehensive, and well-functioning health system, it seems difficult to conclude that the high volume of right to health litigation in that country is "a response to an ineffectual, inefficient health care system." But the same hypothesis cannot be discarded so easily in Brazil and other countries.

These are just two brief examples of how variables in the structure and operation of the judicial and health systems of different countries will likely affect the analysis and assessment of the legitimacy and impacts of the judicialization of health. Even within the same country, especially if it is large and diverse (Brazil immediately comes to mind), the judicialization of health is likely to display different characteristics across subnational regions.<sup>13</sup>

### Which data are relevant?

The still limited but growing number of in-depth studies of countries and regions within countries, especially those with reliable empirical data, are very important for those pursuing a better understanding of the judicialization of health. Some of the papers in this special issue add to this welcome trend. Loaiza et al.'s contribution analyzes all 98 successful medication cases filed in Costa Rica in 2016 in light of priority-setting criteria from the public health literature on the topic. According to these criteria—which combine severity of the health condition, effectiveness, and cost-effectiveness—medication (or any other health intervention) can be classified into four priority groups: high, medium, low, and experimental. They find that 62% of the successful cases fall into groups that the public health literature would consider of clearly low priority—that is, low-priority (53%) and experimental drugs (9%). Another interesting finding of their

study is that these medications share some common characteristics: "they are new on the market, have a very high cost compared to their benefits (often 3–5 times Costa Rica's GDP per capita), target severe conditions such as cancer or rare diseases, and are similarly disputed in countries with much higher levels of health care spending (such as the UK and Norway)."

Lucía Berro Pizarrossa, Katrina Pehudoff, and José Castela Forte's article on Uruguay is another important and welcome contribution along similar lines, and on a country that has featured much less in the literature than some of its counterparts. They look at a sample of 42 judicial claims (*amparos*) for medicines decided in Uruguay in 2015. As also found in studies in Brazil, Colombia, and Costa Rica, the success rate in these claims was high (74%), as was the percentage of claims for "off-formulary" drugs (drugs not incorporated into the medicines lists of the Uruguayan health system). Although they do not perform the same analysis of priority carried out by Loaiza et al., they do report that in at least eight claims (19% of their sample), drugs assessed and rejected by the Uruguayan health system as cost-ineffective (namely cetuximab, lenalidomide, and sorafenib) were nonetheless granted by the courts. These and another three drugs in the ten most claimed and granted in Uruguayan courts (abiraterone, ibrutinib, and TDM1–trastuzumab) are also in Loaiza et al.'s Costa Rican study. The first five are classified as low priority, and the last as medium priority.

The analytical framework of these two studies reveals a promising way forward in our quest to better understand judicialization's legitimacy and impacts. Knowing exactly what health benefits are claimed in court, whether they are part of the health package offered in the country, and how they rank in terms of priority-setting criteria is an essential precondition for a solid analysis of the phenomenon. It would be very welcome if future studies from other countries experiencing high levels of health litigation collected such data.

Both studies reach plausible conclusions about the potential negative effects of court orders that grant off-formulary and low-priority interventions.

Loaiza et al. highlight two: (1) it may become more difficult for the health system to negotiate price reductions, and (2) individuals suffering from similar conditions may receive unequal treatment if judicial orders end up benefiting only those who go to court. Pizzarossa et al. emphasize this second risk further: “successful plaintiffs inevitably receive and consume more health system resources than those who do not seek treatment through the courts.”

But it is also important to be aware of the limitations of this analytical framework. It provides merely a crucial starting point for discussion, not a final verdict of the legitimacy and impacts of judicialization. As Loaiza et al. appropriately warn, their suggested priority-setting criteria is not a “gold standard.” Although there is growing consensus in the literature about what should be taken into consideration when setting priority in health (such as the severity of the condition, effectiveness of treatment, and cost-effectiveness of treatment), “reasonable people may disagree on their relative weight and on the classification of new medications.”

This brings up what is perhaps the most difficult obstacle in the effort to find an appropriate framework to evaluate the legitimacy and impacts of judicialization. When disagreement about priority setting is rife, as it tends to be in most complex fields—and health is certainly one of them—how to determine the correctness of specific priority-setting decisions?<sup>14</sup> This is fundamentally what judges are being called on to do in all these cases in Costa Rica, Uruguay, and other countries where plaintiffs challenge the health system’s refusal to provide them with a certain health benefit. If we accept, as I think we must, that disagreement is bound to happen in many cases, then the question becomes whether and how courts should interfere with the decisions made by the public authorities in charge of running the health system on behalf of the population.

This is, of course, the perennial and intractable issue raised by courts’ increasing involvement in social policy that I mentioned earlier. All other contributions to this special issue grapple with it from different and interesting perspectives.

## What role for courts?

The difficulty—or impossibility in the view of many—is thus to define the exact content of the right to health in terms of the specific health benefits individuals are entitled to under conditions of resource limitation and disagreement about priority-setting criteria. Should the courts get involved? If so, how?

Christopher Newdick and Keith Syrett have both been grappling with these questions for a long time and have already made seminal contributions to the debate.<sup>15</sup> In their papers in this issue, they explore innovative frameworks and approaches to their longstanding concerns about judicialization.

Newdick’s paper starts with a bleak warning. If we thought that setting priorities in health was an intractable task, it is going to become even harder in the future. This is due to pressures on both sides of the equation: fewer resources due to diminishing revenue-raising capacity of states under the grips of austerity and increasing health needs due to higher longevity and chronic illnesses among populations. In such a context, he argues, judges will be called on even more often to resolve the intensifying distributive tensions that are likely to arise. His aim is not to present a solution but rather to offer what he calls a “resource allocation rights matrix” to assist in the debate. The matrix combines two core dichotomies (individual versus community rights and substantive versus procedural remedies) to produce four possible conceptions of the right to health and corresponding remedies: community rights and procedural remedies; individual rights and procedural remedies; community rights and substantive remedies; and individual rights and substantive remedies. Given the inescapability of opportunity costs generated by the need to set priorities, he argues that the logic of community rights and procedural remedies, which draws strongly on Norman Daniels and James Sabin’s accountability for reasonableness framework, is the most compelling, while the individual rights and substantive remedies logic, prevalent in some Latin American countries, is the least. But he clarifies that the former should not always prevail over the others. Special circumstances may call for the oth-

er approaches, such as exceptional clinical reasons (individual/procedural), serious cases of hardship for entire groups (community/substantive), and limited trust between resource allocators and the judiciary (substantive/individual). He helpfully illustrates each of these approaches with concrete examples from different jurisdictions across the world and finishes by arguing, persuasively in my view, that his matrix helps illuminate the costs and benefits of judicial policy and urging judges to be more transparent about which approach they adopt and why. This seems to chime with both Loaiza et al.'s and Pizzarossa et al.'s papers, which question the lack of coherent justification in decisions in Costa Rica and Uruguay. Moreover, both adopt what Newdick would call the individual rights and substantive remedy approach, the most problematic one in his view.

Syrett's article calls for the "[d]evelopment and clarification of the normative basis of the right to health in a manner which would enable courts to respond sensitively and appropriately to conditions of scarcity." This would entail, in his view, finding a "middle ground" between the two prevalent extremes: one that rejects the very possibility or usefulness of a rights-based approach to health and thus "seems to attach insufficient weight to the right [to health] as a claim *in law*," and another that sees that right as an absolute claim and thus "accords insufficient weight to the opportunity costs of giving effect to the right." Such a task, he admits, is "manifestly a highly demanding [one]," yet cannot be avoided in a climate of ever-growing contestation and litigation about access to scarce health resources, not only in Latin America but across the globe. In his exploratory endeavor, he looks into the prospects for proportionality, a "relational" conception of rights, and a "deliberative democracy" role for courts as potential "pathways through which this challenge might be addressed." All face important challenges, as he admits, but could, with further development, provide a sound basis for progress.

Out of the three pathways proposed by Syrett, proportionality seems to me the most problematic. Some have persuasively criticized its usefulness

in yielding specific answers even to the classical bilateral conflicts involved in civil liberties (for example, liberty versus security, and freedom of expression versus privacy).<sup>16</sup> In polycentric distributive conflicts such as those involved in social and economic rights, the likelihood of indeterminate results seems significantly higher. Proportionality thus seems incapable of either replacing or adding to the priority-setting criteria and the disagreement around them, discussed above. The relational reading of the right to health seems very plausible to me and in line with cherished public health ideas of equity and community or public interest. Yet, as Syrett properly alerts, "many will doubt whether this approach is consonant with ideas of rights at all." The deliberative democracy pathway, rather than an alternative to the other two, seems more like a compromise that may be able to incorporate what Syrett calls a "culture of justification" embedded in the other two, "permitting proper judicial consideration of the interconnectedness of individual rights to health care and obligations to the community in circumstances of scarcity." Yet, as Syrett admits, it would need much further development and testing than he is able to provide in his contribution.

Aquiles Ignacio Arrieta-Gómez's contribution on Colombia provides interesting insights from someone who has witnessed, from the inside, the workings of one of the most innovative and respected constitutional courts. He provides a detailed account of the landmark Decision T-760 of 2008, a structural ruling on the right to health in which the court ordered the state to remedy the inequality that existed between the more comprehensive contributory system and the subsidized system, which had lower benefits coverage. He also describes setbacks that followed T-760 but concludes, on a positive note, that the decision had at least three positive effects: "it helped establish the constitutional roots of the right to health and its justiciability (a living reform of the Constitution); it guaranteed better access to necessary health services; and it ensured that public health policies are rights oriented, including through the promotion of reasonable limits and public participation in decision making."

## Judicialization beyond courts

The two contributions focused on Brazil, by Danielle da Costa Leite Borges and Regiane Garcia, invite us to lift our gaze from courts in order to see some important developments happening elsewhere, often neglected in the literature on judicialization.

Borges's piece discusses improvements in what she calls "health governance," which health litigation has indirectly helped promote. She focusses on two fronts: (1) the creation of the National Commission for the Incorporation of Technologies in the Public Health System in 2012 and (2) several local and national initiatives aimed at reducing the need for litigation through different types of cooperation between the executive and judiciary. As she persuasively argues, "the creation of [the national commission] brought substantial improvements to the institutionalization of [health technology assessment], especially as compared to the old decision-making process." The system has become "more transparent, participatory, and accountable," which, in her view, "can contribute to the advancement of fairness in the health system ... by making drugs available to the population at large and not only to individual claimants." In terms of judicial-administrative cooperation, she highlights two recent initiatives: the creation of "advisory health committees" composed of permanent civil servants of the state health authority in the fields of medicine, nursing, pharmacy, nutrition, and management to provide technical advice to judges in right to health claims, and the establishment of mediation and conciliation centers, where health claims are mediated by a social worker who connects health authorities and claimants to assess the merits of the claim and try to reach a solution out of court. Both were initially adopted in the state of Rio de Janeiro but are now being extended to other states in the country. As Borges argues, although these developments are still too recent and not much data are available on them, they hold the potential to improve the fairness and efficiency of the Brazilian public health system and to contribute to the "dejudicialization" of health—that is, to decrease the large number of cases that end up in Brazilian courts.

It is interesting to note, here, that Loaiza et al.'s contribution also discusses a similar new process that has been adopted in Costa Rica. The authors are actually able to empirically test whether involving outside medical expertise has improved the Sala IV's health rights jurisprudence by comparing successful health rights litigation claims for medications before and after the rollout of this process. Their conclusion is that it has not, but the blame seems to lie more on the type of the expertise used (the Cochrane review, which does not include cost-effectiveness analysis) than in the judges, who tend "to follow the vast majority of these recommendations." A similar study on Brazil when data becomes available would be very welcome.

Garcia's piece focuses on an aspect of the right to health that seems even less discussed in the literature on judicialization: the participation of citizens in health policy decisions. After arguing that participation is a legal right both in Brazilian and international law, she goes on to describe the results of her doctoral empirical research project on the functioning of the Brazilian National Health Council (NHC), the participatory body created to comply with the requirement of "community participation" established in article 198 of the Constitution. Through naturalistic observations of NHC meetings and semi-structured interviews with various NHC members during 2012–2015, she attempted to shed light on three main questions: "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." Her tentative conclusion, necessarily limited by the scope of her research ("a small-scale study focusing on the experiences of 26 NHC members"), is 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."

Whether these concerns are then translated into concrete health policies and lead to improved access and better population health is something that Garcia was not able to establish but seems

important to determine through future research. Given the strong, and perhaps growing, body of opinion (see Newdick, Syrett, and Pizzarossa et al. in this issue) that courts should at least review the reasonableness of allocative decisions and that one of the crucial criteria is “participation,” we ought to know much more than we currently do about the working and effectiveness of institutional mechanisms for participation such as the Brazilian NHC studied by Garcia.

Sofia Charvel, Fernanda Cobo, Silvana Larrea, and Juliana Baglietto’s contribution also looks beyond the courts. They conduct a useful mapping of the legal instruments on priority setting in Brazil, Costa Rica, Chile, and Mexico with a view to determine the extent to which each reflects the elements of transparency, relevance, review and revision, and oversight and supervision, which they take from Daniels and Sabin’s accountability for reasonableness framework and Sarah Clark and Albert Weale’s social values framework. Their conclusion is that while all four countries fulfill these elements to some degree, there is significant variability in how they do so and improvements are needed in several areas. Perhaps the most homogenous findings are on the element of transparency. As the authors state, “it is difficult to find the information online and ... the information is not updated as required by law.” Moreover, the fragmentation of priority-setting systems—in other words, the lack of a single priority-setting mechanism—“makes even more complex the task of understanding how priority setting is performed.” In all other elements, variations and gaps are found in different countries, leading the authors to invite “countries to improve their legal frameworks.” This mapping and analysis of the legal framework is certainly interesting and valuable, yet one should avoid conclusions about the actual fairness of priority-setting institutional mechanisms based only on what the law states. As those familiar with social-legal scholarship could argue, “law on the books” can and often does diverge from “law in action.” Analysis of how priority setting actually takes place in each country is therefore important to allow us to know how effective these legal frameworks really are.

## International accountability

Most Latin American countries have recognized the right to health not only in their domestic law (often in the constitution) but also through international treaties, such as the International Covenant on Economic, Social and Cultural Rights and the Protocol of San Salvador of the Organization of American States. Moreover, out of the current 23 countries that have ratified the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights—an important new complaint mechanism—no fewer than 7 are from Latin America (Argentina, Uruguay, Bolivia, Ecuador, Costa Rica, El Salvador, and Honduras), and another 4 have signed but not yet ratified the treaty (Chile, Paraguay, Venezuela, and Guatemala).

Judicialization studies tend to focus on national courts, for several understandable reasons. The explosion of litigation in some countries takes place in these courts; many countries have included the right to health in their national constitutions, and domestic courts tend to focus on constitutional norms rather than international law; and the debate on the legal status and force of international human rights law, especially in the field of social and economic rights, still rages. Nonetheless, domestic courts in some countries are paying increasing attention to international human rights law, and it may thus become more relevant to look into the role of international human rights law when studying judicialization. This may be particularly so in those countries that have ratified the Optional Protocol to the International Covenant on Economic, Social and Cultural Rights and have thereby agreed to be subject to recommendations following the adjudication of individual or group complaints.

Pizzarossa et al.’s study of Uruguay, one of the first countries to ratify the Optional Protocol, uses the interpretation of the United Nations Committee on Economic, Social and Cultural Rights regarding minimum core obligations and non-discrimination as their framework to evaluate judicialization in that country. They seem to find the Uruguayan courts wanting in both areas when it comes to granting off-formulary low-priority drugs to claimants.

Another contribution to this issue that focuses on international law is that of Laura Pautassi. She studies the reports submitted by seven countries (Bolivia, Colombia, Ecuador, El Salvador, Mexico, Paraguay, and Uruguay) to the working group responsible for examining state parties' compliance with the Protocol of San Salvador, as well as the observations and recommendations made by the working group's experts. Her focus is on what she calls the "cross-cutting" category of access to justice, which she claims is a "key component of the right to health." It is interesting that in a region known for its high volume of litigation, one of her main findings is that there is "a lack of recognition regarding the need to 'enable' access to justice." This seems to reinforce the point about the significant diversity of the phenomenon across Latin America.

### Health improvement in Latin America: The role of rights and litigation

Most Latin American countries have made progress in the past three decades in terms of the well-being of their populations—some have made considerable progress, others not as much. In terms of the Human Development Index (HDI), the only country still in the "low human development" group is Haiti (0.493 in 2015), but even that represents an almost 20% improvement over its 1990s situation (0.408). All other countries are well above 0.55, the threshold for "medium human development"; many are in the "high human development" group (that is, above 0.7); and some score as high as 0.827 (Argentina) and 0.847 (Chile), placing them in the "very high human development" bracket. When we focus on the health components of the HDI, we also see significant progress. In life expectancy, for instance, no Latin American country is below 60 anymore, with Haiti (54.6 in 1990 and 63.1 today) and Bolivia (55.1 in 1990 and 68.7 today) having improved their situations. In addition, life expectancy in Chile (82), Costa Rica (79.6), and Cuba (79.6) is above that of the United States (79.2) and similar to that of the United Kingdom (80.8). Most other Latin American countries cluster around 75 and 76, with the regional average at 75.2. Infant mortality

has also fallen significantly: Haiti has decreased from a staggering 101 per 1,000 live births in 1990 to 52.2 today; Bolivia from 85.6 to 30.6; and Guatemala from 59.8 to 24.3. All other Latin American countries have rates under 20 (indeed, Uruguay, Costa Rica, and Cuba have rates under 10).

It is of course true that these are country averages that disguise inequalities—sometimes significant ones—among the population. Yet the scale of some of the progress is such that it could not have happened without improving the lives of those at the bottom of the socioeconomic pyramid as well.

That progress has occurred everywhere, that it varies among countries, and that there is still a lot to be done in all of them is clear. What is much more complex to establish is whether the right to health has had any role and, if so, of what precise nature, in such progress. Here, we must distinguish between three different ways in which the right to health may feature in such an impact analysis: as a moral claim, as a legal right, and as a justiciable guarantee. As a moral claim, the right to health imposes moral duties on society to ensure that the right is respected. This is how the right to health has been invoked, for instance, at least since the 1940s, most notably in the 1946 Constitution of the World Health Organization and, later, in the 1978 Declaration of Alma-Ata. When transformed into a legal right ("legalization"), as most countries have increasingly done since the 1970s through either the ratification of international treaties or the adoption of domestic legal instruments (often the national constitution), that moral claim becomes part of the law—it acquires a legal status that, depending on the context in which it operates, may add some clarity and strength to the moral idea. As a justiciable guarantee, it is supposed to acquire a further layer of potential protection through the possibility of being invoked in courts ("judicialization").

It seems clear that the right to health as a moral idea has played a significant role in the improvement of the health conditions of the population in Latin America described above. As Rifat Atun et al. show, the pioneering health system reforms in Latin America—aiming "to expand access to health services, improve health outcome, and increase

financial risk protection”—were strongly inspired by the idea of health as a human or a citizen’s right, and such reforms have played a direct role in the improvement of the health outcomes of the population. To quote the authors:

*Along with economic development and rising incomes, improvements in health systems and universal health coverage have contributed to improved health outcomes for women (reduced maternal mortality ratio) and children (reduced under-5 and infant mortality rates ... ) and for communicable diseases such as malaria, neglected tropical diseases, and tuberculosis, which predominantly affect the poor.<sup>17</sup>*

Whether the legalization and judicialization of the right to health can strengthen or accelerate the progress is less clear. Some of the most comprehensive and high-quality health systems in the world are in countries where the right to health has not been expressly legalized via domestic legislation (for example, the United Kingdom), suggesting that, at least in those countries, legalization may not be an important determinant of respect for the right to health. In many Latin American countries, however, there is a widespread belief that legalization, particularly through the constitution (“constitutionalization”), provides further protection to the moral idea of health as a human right and further guarantees against recalcitrant governments. The same is often thought of judicialization. If the government is unwilling to comply with its duties correlated to the right to health, citizens can go to the judiciary to force implementation. If that option is not available (that is, if the right to health is non-justiciable), an important source of motivation for the state to comply with its duties is thought to be lost.

The problem is that the real world of health policy practice and, in particular, priority setting (that is, the allocation of limited resources among virtually unlimited and growing health needs) is much more complicated than the neat theoretical universe of rights and duties. As briefly discussed above, such complexity affects significantly our ability to reach a consensus on the correctness of specific priority-settings decisions or, to put it in

legal terms, our ability to determine with precision the content of the right to health. This in turn makes the assessment of the legitimacy and impacts of the phenomenon of judicialization more difficult.

However, this complexity should not demotivate us from continuing the effort of collecting and analyzing more data and refining our analytical framework to help us better understand this fascinating phenomenon. The contributions of this special issue take us further in that direction.

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# Revisiting Health Rights Litigation and Access to Medications in Costa Rica: Preliminary Evidence from the Cochrane Collaboration Reform

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## Abstract

In response to the incremental creation of an expansive constitutional right to health in Costa Rica, the country's rights-friendly constitutional chamber of the Supreme Court (known as the Sala IV) unleashed a flood of litigation for medications, treatments, and other health care issues. This development was met by widespread criticism from within the health sector, which complained that the court's jurisprudence routinely elevated the right to health above financial considerations, thus posing a threat to the financial well-being of the state-run health care system.<sup>1</sup> Further, a 2014 study by Ole Frithjof Norheim and Bruce Wilson examining successful health rights litigation revealed that more than 70% of favorable rulings were for low-priority medications, suggesting a lack of fairness in access to medications in Costa Rica.<sup>2</sup> To address some of these criticisms, the Sala IV initiated a partnership in 2014 with the Cochrane Collaboration to incorporate medical expert evaluations into its decision-making process for claims seeking access to medications. This article examines the court's reformed decision-making process to determine whether the increased reliance on medical expertise has changed health rights jurisprudence. We reviewed all medication claims from 2016 and classified the successful cases into four groups using standard priority-setting criteria. We then compared these results with rulings issued in 2008, prior to the court's reform (and the year analyzed in Norheim and Wilson's study). Our analysis reveals that under the court's new rules, the probability of winning a medication lawsuit has increased significantly; moreover, the percentage of rulings granting experimental medications has declined while the percentage granting high-priority medications has increased. Based on these results, in comparison to the court's pre-reform jurisprudence, we can tentatively conclude that the new process has led to some minor gains in fairness.

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## Introduction

Starting in the mid-1990s, many Latin American countries witnessed an increased use of litigation to claim access to medical procedures and medications.<sup>3</sup> This judicialization of health care made courts “key actors of health policy” and generated an apparent conflict between two ethical imperatives: fair, efficient health spending priorities and individuals’ health rights.<sup>4</sup> The rapid increase in litigation for health rights was met by criticism from some national health system leaders who claimed that court decisions distorted their budgets, undermined the ability of national health systems to rationally allocate scarce resources, impaired the overall performance of health systems, and undermined these systems’ solvency.<sup>5</sup> Magistrates often pushed back, stating that court intervention is justified when “administrative inefficiencies or prioritization processes of health services fail to protect an individual’s right” and rejecting the idea that “access to care should be determined by the price mechanism.”<sup>6</sup>

While the judicialization of health care became a reality in many countries around the world, one court in particular came under intense criticism for its health rights jurisprudence: the Constitutional Chamber of the Supreme Court of Costa Rica (Sala Constitucional or Sala Cuarta, commonly written as Sala IV).<sup>7</sup> Costa Rica’s state-owned and -funded health care system, administered by the Costa Rican Social Security Fund (Caja Costarricense de Seguro Social, commonly referred to as the Caja), loudly and frequently complained that Sala IV health rights decisions harmed its capacity to manage the health system’s resources in a fair and efficient manner and that the magistrates lacked the medical training and knowledge necessary to issue rational, medically informed health-related rulings.<sup>8</sup> Two of this paper’s authors made an earlier contribution to this ongoing debate on ballooning health rights litigation.<sup>9</sup> Using standard priority-setting criteria, we examined the technical aspects of the court’s decisions in order to evaluate whether these decisions led to more fairness in access to medications. We found that in 2008, over 70% of the court’s decisions favoring litigants’

claims were for medications classified as “low priority,” while less than 3% of the decisions were for medications classified as “high priority” (these criteria are explained further below).

While that article did not address the financial impact of medication claims or non-medication health rights claims (which include requests for access to clinics or to treatments such as surgeries), or the suitability of health rights litigation, it concluded that in the case of Costa Rica, litigation does not necessarily lead to more fairness in access to medication. We noted that Sala IV magistrates, while strongly defending their constitutional right to decide health rights cases, were cognizant of the criticism leveled at the court’s lack of medical expertise and its deference to the opinions of claimants’ treating doctors. As a result, the court, with the support of the World Bank Institute, sought to expand its access to medical expertise through a technical cooperation agreement with the Cochrane Collaboration. The goal was to add a new layer of independent medical expert assessment that could inform and improve the fairness of Sala IV decisions on medication cases.<sup>10</sup> It is the development of this new process currently used by the court in the deliberation of health rights litigation that is of interest here. We analyze whether the new process involving outside medical expertise has improved the court’s health rights jurisprudence using priority-setting criteria. Little is known about the potential impact of medical expert assessment on jurisprudence and priority setting for new medications in any country. This article examines this new process in Costa Rica and compares successful health rights litigation claims for medications before (2008) and after (2016) the reform.

The article proceeds as follows. We first contextualize and describe the Costa Rican health care system, how it became judicialized from the mid-1990s onward, and how the Sala IV created an explicit constitutional right to health and gave little consideration to the economic impact of its decisions. We then detail the Sala IV’s process for deciding medication cases that developed over two decades prior to the initiation of the court’s reformed decision-making process, which includes

an additional layer of expert medical opinion. Next, we examine the impact of the new process through a priority-setting evaluation of all 108 medication cases decided by the Sala IV in 2016 (the only full year under the rules of the new process), which allows us to better understand who benefits and how much they benefit compared to other patients.<sup>11</sup> We then compare these priority-setting results with those of the pre-reform process outlined in Norheim and Wilson's 2014 study. Lastly, we present our conclusions concerning the impact of the Cochrane Collaboration and the new layer of expert opinion on the Sala IV's medication-related jurisprudence and suggest areas of future research to further investigate the impact of the judicialization of health care in Costa Rica and beyond.

## Costa Rica

Costa Rica is a small, upper-middle-income, largely urban Central American country, with a population of approximately 4.9 million.<sup>12</sup> The country has long stood out as one of the most democratic countries in the Americas for its universal adult franchise and free and fair elections held every four years without interruption or challenge since 1953.<sup>13</sup> The country enjoys an expansive public welfare system that includes education, insurance, pensions, and a well-funded public health system that received 6.8% of the gross domestic product (GDP) in 2014, which is among the top 30 highest state expenditures on public health in the world and almost double the Latin American average.<sup>14</sup> The country also has some of the highest social indicator values in Latin America, including a very high life expectancy (79.6 years), a Human Development Index score of 0.776 (66th highest in the world), and a low poverty rate (20.5%).<sup>15</sup> A region-wide United Nations report notes that Costa Rica is one of only two countries in the Americas with "optimal access" to basic medications and enjoys almost universal health care coverage.<sup>16</sup>

## Courts and health rights

The judicialization of health in Costa Rica was

therefore not a response to an ineffectual, inefficient health care system. Rather, it took place in the context of a well-functioning, effective, universal health care system that facilitated the attainment of impressive health statistics. Litigation claiming a right to health care began to emerge slowly in the mid-1990s and then expanded very rapidly in the late 1990s, and was sparked by two consecutive events: First, a judicial reform in 1989 created a constitutional chamber of the Supreme Court (the Sala IV), which opened a very accessible legal arena allowing anyone to approach the court to seek protection of his or her rights. Second, the inability or unwillingness of the public health system to respond to the HIV/AIDS epidemic in the 1990s pushed people living with HIV and AIDS to use the newly created court to seek medical help; this was a response to the public health care system's routinely voiced argument that antiretroviral medications were not a cure, were too expensive, and should not be provided.<sup>17</sup>

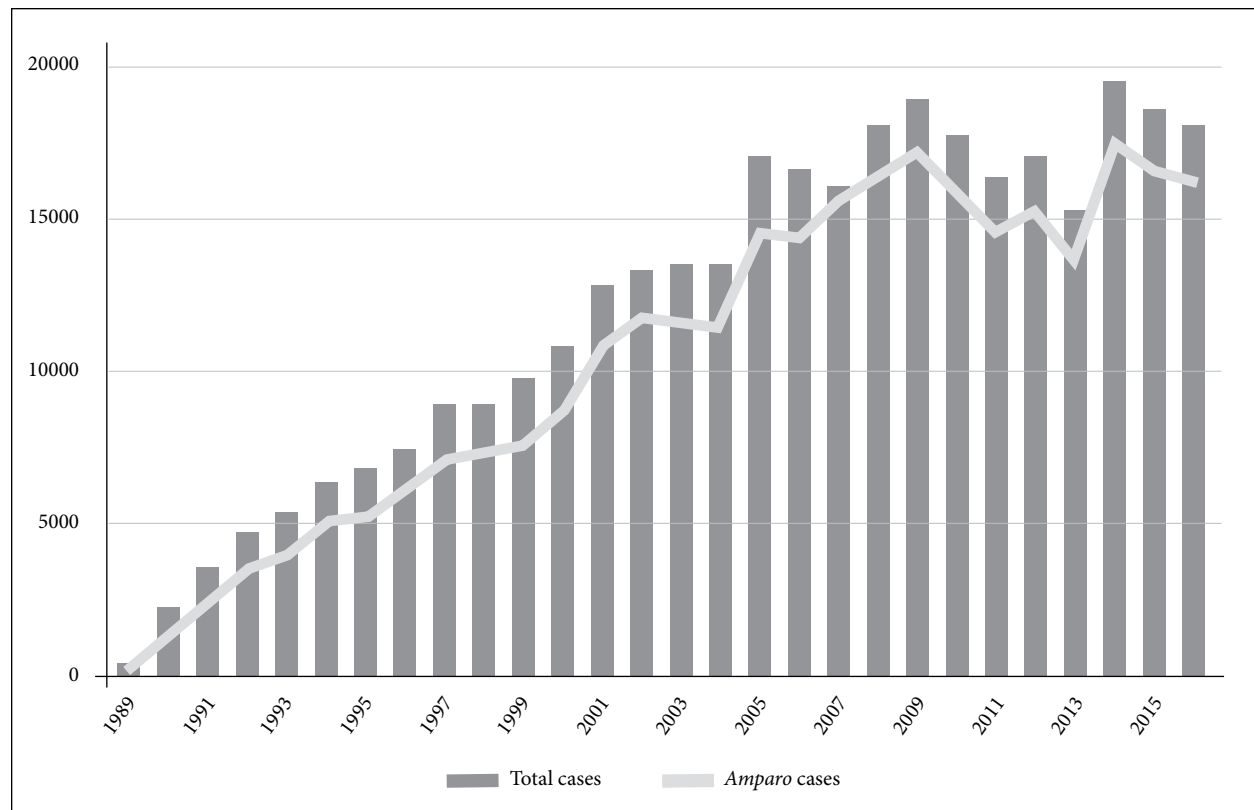
The creation of the Sala IV and its profound impact on the country's polity has been covered extensively elsewhere.<sup>18</sup> In short, it was a watershed event that transformed the country's superior court from a dormant institution that exercised little oversight of the other branches of government and had little interest in hearing cases on individuals' constitutional rights into one of the most powerful and assertive courts in the Americas.<sup>19</sup> Once it was rolled out in late 1989, the Sala IV immediately discarded the Supreme Court's strict legal formality and accepted *amparo* cases (writs of protection) from anyone in the country regardless of that person's age, sex, income, nationality, or ethnic origin. Filing a case before the Sala IV requires no lawyers, no fees, and very few hurdles. The court renders decisions quickly, and its decisions are binding on all people and institutions, with the exception of the court itself. The speed with which the court became a logical and recognizable venue to challenge perceived injustices is illustrated in Figure 1: the Sala IV's caseload increased from fewer than 2,300 cases in 1990 (its first full year of operation) to almost 20,000 in 2014, before settling at approximately 18,000 cases per year thereafter. Individuals

using the simple, low-cost writ of *amparo* account for more than 80% of all cases before the Sala IV.<sup>20</sup>

In the court’s early years, health rights cases were not part of its rapidly expanding docket. This was in part because the health system functioned well and, perhaps more importantly, because the Constitution lacked an explicitly encoded right to health. Yet, over the years, the court gradually and deliberately created an expansive right to health by building on explicit articles in the Constitution, including the protection of human life (article 21) and the right to social security protection (article 73), as well as international instruments to which Costa Rica was a signatory.<sup>21</sup> Under Costa Rican law, international instruments have an “almost supra constitutional value,” which allows the Sala IV to amplify and add to the existing explicit rights contained in the Constitution.<sup>22</sup> By the mid-1990s, court jurisprudence effectively created an expansive, justiciable “fundamental right” to health, but

with explicit financial limitations that the court considered in its rulings. By way of an example, in 1992 the Sala IV rejected an *amparo* claim filed by the president of the Association for the Struggle against AIDS, Jacobo Schifter, on behalf of people living with HIV/AIDS, demanding that the public health care system provide free access to azidothymidine. The court’s unanimous decision accepted the Caja’s argument that azidothymidine was not a cure for HIV/AIDS and that “the cost of purchasing the drug implies a very large sacrifice for [the Caja], which does not have a budget committed to such ends.”<sup>23</sup> The court noted the ethical dilemma of requiring the purchase of azidothymidine, pointing out that other people in similarly delicate or terminal situations had no access to budget allocations for their medications. It argued that this “aspect cannot be left unnoticed, as there are certain diseases for which there are still no budgets committed to them and, from that perspective, to demand that

FIGURE 1. Sala IV’s total and amparo caseload, 1998–2016



Source: Sala Constitucional, Sentencias relevantes (2018). Available at <https://www.poder-judicial.go.cr/salaconstitucional/>

the Caja disregard certain other programs to assist those suffering from AIDS, no matter how hard it seems, is not reasonable.”<sup>24</sup>

In 1997, however, the court changed tracks, issuing a decision ordering antiretroviral medications to be provided to people living with HIV/AIDS.<sup>25</sup> As a result, the previously slow stream of health rights cases quickly became a flood and ushered in the full judicialization of health care in Costa Rica. According to Carlos Zamora, an actuarial scientist at the Caja, the 1997 HIV/AIDS decision was central to the development of the Sala IV’s right to health jurisprudence; the legal arguments “served as a model that has shaped the field of health rights.”<sup>26</sup> In its decision, the court articulated its most expansive understanding of the right to health: “What good are the rest of the rights and guarantees ... if a person cannot count on the right to life and health assured?”<sup>27</sup> In the years following this decision, the court increasingly and consistently dismissed the Caja’s arguments that some medications were prohibitively expensive and should not be provided. Finally, in 2007, it issued a decision categorically stating that the Caja could not use “eminently economic reasons” to decline to fill a patient’s prescription when the prescribed medicine falls outside the Caja’s official list of medications (LOM).<sup>28</sup> The rapid growth in successful health rights litigation sparked a growing chorus of complaints concerning the financial burden on the Caja, which was forced to pay for medications that its own medical experts had already evaluated and declined to include in the LOM.<sup>29</sup>

Studies of the financial impact of the court’s decisions repeatedly invalidate the Caja’s allegation that costs incurred from compliance with these decisions are bankrupting the health system or causing an unwanted re-equilibration of expenditures. Indeed, a 2009 study sponsored by the Caja itself revealed that the total cost of providing all successfully litigated medications amounted to less than 1% of the institution’s medication budget.<sup>30</sup> Similar studies undertaken by other researchers, not affiliated with the Caja, corroborate the Caja’s initial results.

### *The new process for constitutional health rights adjudication for medications*

The 2014 article closes by noting that the Sala IV recognized its lack of medical technical expertise and initiated a collaborative program with an international agency, the Cochrane Collaboration, with the support of the World Bank Institute.<sup>31</sup> The Cochrane Collaboration, named for Scottish doctor Archie Cochrane, is a UK-based not-for-profit international collaboration of 37,000 medical experts from over 130 countries. The experts collaborate to “produce credible, accessible health information that is free from commercial sponsorship and other conflicts of interest.”<sup>32</sup> This partnership allowed the court access to evidence-based medicine databases in the Cochrane library that could be used in cases where the lawsuit involved a claim for a specific medication. As part of the agreement, in mid-2014, two groups of law clerks from the Sala IV—including two of the authors of this article (Morales and Rodriguez)—and forensic doctors attended a two-week workshop on how to use the Cochrane Library and other medical databases to assess medications that were the subject of litigation. It is noteworthy that Cochrane reviews typically summarize only the quality of evidence for a proven treatment effect of a new medication. A comprehensive health technology assessment (HTA) is necessary for a full assessment of evidence on cost-effectiveness and other organizational and ethical aspects of introducing the new technology in question. To overcome some of these limitations, the training was designed to teach law clerks to read and understand the latest available scientific evidence, how to interpret medical data and statistics, and how to analyze the benefits and weaknesses of specific medications for patients.

In the second half of 2015, the Sala IV implemented its new procedure for medication cases, which effectively diminished the court’s previous reliance on the testimony of patients’ treating physicians rather than evidence from the Caja.<sup>33</sup> The process replaced a “dogmatic approach of a medical case by a treating physician” with one more reliant on evidence-based medicine.<sup>34</sup> This system has proven a novel way to substantiate health rights

cases before rendering a final ruling and to publicly address the criticisms leveled against the Sala IV's health rights jurisprudence for being technically and scientifically uniformed. This new approach to medication cases is not the result of an amendment to Costa Rica's legal framework; rather, it is a court-led initiative to improve the court's performance using evidentiary rules that allow it to find new facts or information, at no cost to claimants, to deliver fair and balanced decisions.

The new process begins when a treating doctor prescribes a medication for a patient that is not part of the official LOM drawn up by the Caja's pharmacopoeia committee. In order to litigate for this medication, both the patient and the physician must be part of the Caja health care system; moreover, a claim may be filed with the Sala IV only after all appeals processes in the Caja have been exhausted. Under the court's pre-reform process, Sala IV magistrates tended to accept the evidence presented by the treating doctor as *santa palabra* (indisputable) and decide in favor of the patient under the belief that the treating doctor knows the patient's particular medical situation best. The new process follows the same path as the old one to the extent that cases are filed with the Sala IV and the court then requests relevant supporting evidentiary and argumentative documents from the Caja and the patient's treating doctor before deciding the case. In its post-reform process, however, the court might reject the case for technical reasons, refer it to the *medicatura forense* (forensic clinic), or issue a decision without requesting an external report for further evaluation. As Table 1 shows, in 2016, the first full year of the reformed process, approximately 72% of all medication cases included a request for a forensic doctor's

report, while 28% of cases did not.

If the court requests a report from one of the ten forensic units around the country, a Caja medical forensic doctor will provide a written evaluation. The assigned doctor must study the patient's medical records, perform a full physical examination of the patient, and evaluate the appropriateness of the claimed medication using international medical databases. Once this is complete, the doctor must send a written report to the Sala IV with his or her expert opinion concerning the competing claims of the treating doctor and the Caja with regard to the appropriateness of the medication for the patient in question. The court uses this report in its decision-making process. As Table 1 shows, the court overwhelmingly accepts the conclusions of forensic doctors: in 2016, Sala IV magistrates accepted all forensic doctors' reports, with the exception of one case in which the court overruled an unsupportive report.

## Data

Although the court's new process for deciding medication cases started with training workshops in mid-2014, implementation lagged until the second half of the following year. Thus, we elected to focus on all cases litigated in 2016, the only year thus far in which the court has operated under the new Cochrane Collaboration rules and for which complete data are available. We examined all 128 cases presented to the Sala IV that year claiming a specific medication and extracted information for the 98 cases for which the court issued a favorable ruling. We then used the same framework for priority classification that Norheim and Wilson

TABLE 1. Forensic doctors' reports and Sala IV decisions, 2016

	Decisions granting requested medication		Decisions denying requested medication	
	Number of cases	%	Number of cases	%
Supportive report	66	51.6	--	--
Unsupportive report	1	0.8	25	19.5
No report requested	31	24.2	5	3.9
Total cases	98	76.6	30	23.4

Source: Rodríguez and Morales 2018 dataset (on file with the authors)



used in their 2014 study. This framework is based on fairness and efficiency criteria from the public health and priority-setting literature.<sup>35</sup>

- Priority group I = High-priority interventions
- Priority group II = Medium-priority interventions
- Priority group III = Low-priority interventions
- Priority group IV = Experimental interventions

According to this framework, an intervention for a given condition is assigned high priority if the condition is severe (in terms of lost life years or the loss of quality of life in the absence of the drug in question); if the intervention is highly effective (in terms of improved health in terms of life years or quality of life); and if the intervention is reasonably cost-effective. The measure of effectiveness used in most HTA reports and cost-effectiveness studies is the quality-adjusted life year (QALY). To preserve comparability with Norheim and Wilson's 2014 study, we used the same thresholds for cost-effectiveness (incremental cost per QALY gained):

- cost-effective: < GDP per capita
- intermediate: > GDP per capita < 3 x GDP per capita
- not cost-effective: > 3 x GDP per capita

More recently, this classification has been criticized, and an alternative suggestion is to classify interventions as cost-effective if the incremental cost per QALY gained is below 0.5 GDP per capita.<sup>36</sup>

In addition, the framework's definition of "experimental interventions" refers to interventions judged as experimental according to independent experts (such as the Cochrane Collaboration) or trusted health technology assessment agencies (such as the National Institute of Health Care Excellence in the UK). Table 2 provides a breakdown of our classification of the 2016 cases.

Before we consider the results of the Sala IV's new process for deciding medication cases, a brief comment on the 23% unfavorable rulings (shown in Table 3) is in order, as it helps highlight the significance of forensic reports for the court's decision making. Of the 30 unfavorable rulings, 26 received unresponsive forensic reports; final court decisions accepted the findings of 25 of those cases. The unresponsive reports detail that evidence-based

medicine shows limited benefits to the patients of the medications claimed, that the required Caja medication protocol has not yet been completed, or that the patient's medical examination reveals possible harm from the claimed medication. For the remaining five unsuccessful cases, no report was requested. Those five cases were rejected for a variety of technicalities, such as the patient filing the case without the support of his or her treating doctor, the patient's death, and the patient's failure to attend the required medical examination at the forensic clinic.

## Results

Of the 98 successful medication cases (in other words, those with favorable rulings) filed in 2016, 15% fell into priority group I, 17% fell into group II, 53% fell into group III, 9% fell into group IV, and 5% were unclassifiable (see Table 4). This means that 62% of successful cases could be classified as being of clearly low priority (groups III and IV) by common standards. Medications that were assigned low priority share some common characteristics: they are new on the market, have a very high cost compared to their benefits (often 3–5 times Costa Rica's per capita GDP), target severe conditions such as cancer or rare diseases, and are similarly disputed in countries with much higher levels of health care spending (such as the UK and Norway).

## Discussion

Table 4 presents the priority classifications of successful medication claims from 2008 and 2016—that is, cases filed both before and after the rollout of the Sala IV's new system relying on independent expert advice. We found that a lower proportion of experimental cases were successful in 2016 (9%) compared to 2008 (22%). The proportion of high-priority cases increased from 3% in 2008 to 15% in 2016, while the proportion of medium-priority cases went down. Low-priority cases remained relatively stable between the two periods.

Although many other factors may explain this change, the reduction in successful cases

TABLE 2. Priority classification of cases, 2016\*

Medicine		Number of cases	Priority classification				
Generic name	Trade name		I	II	III	IV	N/A**
Abiraterone	Zytiga	8			8		
Bosentan	Tracleer	7			7		
Pertuzumab	Perjeta	7				7	
Riociguat	Adempas	6			6		
Sorafenib	Nexavar	4			4		
Sunitinib	Sutent	4		4			
Vemurafenib	Zelboraf	4			4		
Axitinib	Inlyta	4			4		
Levetiracetam	Keppra	3			3		
Natalizumab	Tysabri	3	3				
Bevacizumab	Avastin	3			3		
Clexane	Lovenox (low-molecular Heparin)	3	3				
Brilinta	Ticagrelor	2	2				
Krizotinib	Xalkori	2			2		
Tiotropium bromide	Spiriva	2		2			
TDM1 – Trastuzumab	Kadcyla	2		2			
Pemetrexed	Alimta	2	2				
Enzalutamide	Enzalutamide	2			2		
Sofosbuvir	Sovaldi	2		2			
Everolimus	Afinitor	2					2
Adalimumab	Humira	1		1			
Pyridostigmine	Mestinon	1	1				
Methylphenidate	Ritalin	1	1				
Topiramato	Topomax	1		1			
Cetuximab	Erbitux	1			1		
Fulvestrand	Faslodex	1				1	
Gabapentin	Neurontin	1		1			
Gosereline	Zoladex	1		1			
Ibrutinib	Imbruvica	1				1	
Iloprost	Ventavis	1			1		
Leflunomida	Arava	1	1				
Mesalazin	Pentasa	1	1				
Mycophenolate mofetil	Mycophenolate mofetil	1					1
Omalizumab	Xolair	1			1		
Omeprazol	Losec	1		1			
Oxcarbamazepine - Trileptal / Lamotrigina (lamictal)	Trilpetal	1					1
Pramipexol	Sifrol/Mirapex	1		1			
Riluzole	Rilutek and Teglutik	1			1		
Romioplostin	Nplate	1	1				

TABLE 2. *Continued*

Medicine		Number of cases	Priority classification				
Generic name	Trade name		I	II	III	IV	N/A**
Ruxolitinib	Jakavi	1			1		
Tadalafil	Cialis / Adcirca	1			1		
Lenalidomide	Revlimid	1			1		
Temozolomida	Temodar	1			1		
Tenoxicam	Mobiflex	1					1
Vandetanib	Caprelsa	1			1		
Ombitasvir, paritaprevir, and ritonavir	Viekira	1		1			
Total		98	15	17	52	9	5

\* References available on request from the authors

\*\* N/A no evidence found

for experimental drugs could be a result of more thorough, independent expert assessment. From a health systems and health policy perspective, this change might indicate a positive development. Yet we find that the proportion of low-priority medications is high (more than 50%) and relatively stable. These are medications that are typically new on the market, are not reimbursed in the public system, and have very high prices and low cost-effectiveness. This finding is unsurprising, since Cochrane reviews do not include considerations on cost-effectiveness and the court still maintains its belief that its decisions do not impose undue financial costs on the Caja's medications budget. A comprehensive HTA is needed for an assessment of evidence on cost-effectiveness. One possible interpretation of the results concerning successful cases is that the court is better informed than before about whether a new medication is proven to be effective, but not better informed about its cost-effectiveness. Another interpretation might be that the court has this information but chooses not to take it into account. The low-priority medications are well known in the HTA and priority-setting literature from Europe, such as in the UK and Norway. Several of them have not been prioritized in these countries, or at least not before undergoing substantial price reductions. Information about their cost-effectiveness in a European context is relatively easy to find from HTA databases.

We note two possibly negative implications from our findings. First, favorable court decisions for very costly new medications may undermine the opportunity for the Caja to engage in price negotiations with pharmaceutical companies. European countries have been successful in obtaining substantial price reductions through the strict and systematic use of comprehensive HTAs and through a clear system for priority setting. This favor patients in the long run, as lower prices benefit the health system and, as a consequence, its users. Second, we found fewer successful cases than one would expect based on the incidence of certain diseases that require particular medications. One possible interpretation is that many other patients in similar situations may not have received the treatment in question. Historically, though, the Caja has sometimes updated its LOM in response to increasing numbers of successful *amparos* seeking specific medications. For example, after the successful 1997 antiretroviral case and the following avalanche of cases, the Caja included antiretroviral medications in the LOM, thus extending coverage to people who did not go to court. It is also possible that patients who would have been denied access to non-LOM medications via litigation might have received them from the Caja through an administrative procedure instead. Indeed, the Caja can and does provide non-LOM medications to patients on a case-by-case basis. The cases that end up at the

TABLE 3. Unsuccessful medication claims filed with the Sala IV, 2016

Decision	Medication being claimed	Forensic report conclusion	Basis of the court's decision
2016000345	Switch from conventional to Determir and Aspart insulin	Insufficient medical information to support claim	Merits
2016000834	Abiraterona	Patient must be treated with other medications before using Abiraterona	Merits
2016000880	Abiraterona	Patient must be treated with other medications before using Abiraterona	Merits
2016001589	Rituximab	No report; claimant incorrect about denial of treatment; Caja already provided medication	Technical
2016002248	Tacrolimus generic medication instead of Prograf	No report; Caja treating doctor did not support the patient's claim	Technical
2016002591	Sunitinib	Patient did not present at the forensic medical evaluation	Technical
2016001898	Pregabalina	Treating doctor failed to show that the medication was appropriate at the time of the request	Technical
2016002179	Bevacizumab	No report; Caja treating doctor did not support the patient's claim	Technical
2016005626	Pertuzumab	Unsupportive report	Merits
2016005288	Sorafenib	Report requested; patient died	Technical
2016005313	Xofigo (Radio 223)	Patient will not benefit from drug	Merits
2016005473	Tramadol	Medical handling of the patient is correct and must start lowering medication doses	Merits
2016006212	Febuxostat instead of Alopurinol (LOM)	Patient must follow an allergen immunotherapy (desensitization) to alopurinol	Merits
2016005397	ARAVA	No report; Caja treating doctor did not support the patient's claim	Technical
2016008468	Fingolimod	There are several approaches to the patient's illness; the requested drug is not first in line	Merits
2016008252	After 9 months of Plavix 75 Clopidogrel, Caja doctor switched to Children's aspirin	No report; Caja treating doctor did not support the patient's claim	Technical
2016008722	Fingolimod	Patient must complete therapeutic treatment based on interferons; if unsuccessful, then Fingolimod	Merits
2016008724	Sorafenib	Insufficient information to conclude patient will benefit from drug	Merits
2016009295	Plavix (Clopidogrel)	Insufficient information to conclude patient will benefit from drug	Merits
2016009933	Fingolimod	Patient has not concluded treatment with Interferon Beta 1B (Betaferon)	Merits
2016010130	Infliximab	Greater probability of harm than benefit to patient	Merits
2016011368	Fulvestrant	No benefit to changing current treatment (Anastrozole)	Merits
2016011724	Topiramato	No benefit to changing current treatment (Gabapentina)	Merits
2016013835	AxitiniborInlyta	Unsupportive report; patient withdrew legal claim	Technical
2016012425	Bevacizumab	Medication has not been prescribed with other non-LOM drugs; it works in conjunction with other medications	Merits
2016011785	Teriparatida	Incomplete administrative process	Technical
2016013842	Nab-Pacitaxel in combination with gemcitabine	Evidence-based medicine does not support any benefits combining Gemcitabine (patient's treatment) with Nab-Pacitaxel	Merits
2016015736	Sorafenib	Patient did not present at the forensic medical evaluation	Technical
2016016217	Clopidogrel Sandoz	Incomplete administrative process	Technical
2016019046	Combining Iloprost (new) with Sildenafil and Bosetan (current treatment)	No evidence to support benefits from the combination of such medications	Merits

Source: Rodríguez and Morales 2018 dataset (on file with the authors)

Sala IV tend to be the more difficult ones, such as those in which a local Caja committee might side with the treating doctor but the central Caja committee might reject that recommendation and deny the medication. Thus, it is difficult to know what the exact budget impact of the low number of successful cases for each type of medication might be or to assess whether that impact is negative from a health system, legal, and ethical perspective: it is not entirely clear if persons with the same condition are necessarily being treated equally. Another way to look at the issue is that if a patient wins access to a specific medication for his or her condition, then a similarly situated patient denied that medication by the Caja will be able to subsequently litigate for the same medication.

Finally, this study suggests that the court may need to go beyond the Cochrane Collaboration and undertake comprehensive HTAs to evaluate whether a particular drug should be prioritized. Such evaluations are easily available from many countries, and the same drugs are assessed everywhere. This challenge is not national but international. A regional collaboration for rapid HTAs, horizon scanning, and translation of HTAs from other countries and a review of their recommendations could improve the situation further. Involving the Cochrane Collaboration and forensic doctors is a positive first step, but more can be done.

### *Strengths and limitations*

Although this article is, to the best of our knowledge, the first to evaluate Sala IV decisions from

a priority-setting perspective both before and after the court's reform expanding the use of evidence-based medicine, our findings should be interpreted with caution. Due to lack of detailed information, we classified the cases according to typical outcomes for the average patient in need of the relevant medication. Particular individual circumstances that could, on medical grounds, favor or disfavor the person in question were not taken into account.

We would also like to note that the court is not obligated to request expert medical advice on each case or to follow the recommendations contained in those reports. However, the court tends to follow the vast majority of these recommendations when requested; and when such reports are not requested, it generally follows the recommendation of the patient's treating doctor (as was the case before the Cochrane Collaboration reforms). But our study concerns the question only of fairness and not of costs, and it is limited to claims for medications not included in the Caja's official list of medications. While medications are an important and potentially expensive subcategory of health rights cases, they are not the universe of those cases. Litigation for surgeries, other treatments, and waiting lists is growing rapidly and taking up more of the court's docket, but for these cases the court does not request third-party expert reports to inform its decisions.

Our method is based on available evidence, and we use explicit criteria grounded in theories of fair priority setting in health. Our assessment, interpretation, and classification of the evidence into

TABLE 4. Favorable Sala IV decisions, pre- and post-reform

Year	Priority classification					Litigation success rate
	I	II	III	IV	N/A	
2008	3%	27%	49%	22%	—	57.9%
2016	15%	17%	53%	9%	5%	76.6%

Note: 2008 data consisted of a random sample, whereas 2016 data included all cases with a favorable ruling

priority groups involves discretion. There is some agreement on priority criteria, but reasonable people may disagree on their relative weight and on the classification of new medications. Every system of priority classification is bound to be controversial. Therefore, we do not regard our classification as the “gold standard,” and we invite further independent scrutiny; nonetheless, we believe our conclusions to be relatively reasonable. Finally, we would like to note that priority classification is based on data from other countries. Issues related to variability and comparability of cost, process, and use of health personnel may limit the transferability of results from HTAs in one country to another. However, some of the new medications appear to have such low cost-effectiveness that it is unlikely that national studies would change the conclusion.

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# How the Uruguayan Judiciary Shapes Access to High-Priced Medicines: A Critique through the Right to Health Lens

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## Abstract

Uruguay has witnessed an ever-increasing number of domestic court claims for high-priced medicines despite its comprehensive universal coverage of pharmaceuticals. In response to the current national debate and development of domestic legislation concerning high-priced medicines, we review whether Uruguayan courts adequately interpret the state's core obligations to provide essential medicines and ensure non-discriminatory access in line with the right to health in the International Covenant on Economic, Social and Cultural Rights. Using a sample of 42 *amparo* claims for the reimbursement of medicines in 2015, we found that the circuits of appeal fail to offer predictable legal argumentation, including for nearly identical cases. Moreover, the judiciary does not provide an interpretation of state obligations that is consistently aligned with the right to health in the International Covenant on Economic, Social and Cultural Rights. These findings illustrate that medicines litigation in Uruguay offers relief for some individual claims but may exacerbate systemic inequalities by failing to address the structural problems behind high medicines prices. We recommend that the judiciary adopt a consistent standard for assessing state action to realize the right to health within its available resources. Moreover, the legislature should address the need for medicines price control and offer a harmonized interpretation of the right to health. These transformations can increase the transparency and predictability of Uruguay's health and legal systems for patients and communities.

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## Introduction

Uruguay has witnessed an ever-increasing number of domestic court claims for high-priced medicines since the dawn of its comprehensive universal health coverage scheme based on the right to health.<sup>1</sup> These cases trigger debates in the courtroom, the media, Parliament, and elsewhere about the scope of the state's responsibility to provide medicines in an equal and non-discriminatory manner. Uruguay is a party to the International Covenant on Economic, Social and Cultural Rights (ICESCR), which requires that the domestic interpretation and implementation of these rights be consistent with international guidelines. In this case study of Uruguay, we critically examine domestic case law to assess whether and how the judiciary interprets the government's core obligations under the right to health. The results of our study may assist in current efforts to develop legislation concerning access to expensive medicines in Uruguay. It may also contribute evidence and analysis to the dearth of scholarly debate in the Uruguayan context of health rights litigation.

### *Uruguay*

Uruguay became a democratic republic in 1984 following a period of civil-military rule. With a small but stable population of 3.44 million people, Uruguayans have a longer average life expectancy and lower rate of under-five child mortality than the Latin American and Caribbean regional averages.<sup>2</sup> Uruguay has been a high-income country since 2012, with a gross national income of US\$15,230 per capita per year in 2016 (compared to the regional average of US\$8,252 per capita). Uruguay's Human Development Index score increased from 0.692 in 1990 to 0.795 in 2015 (out of 1.0), reflecting improvements to health and life expectancy, access to education and knowledge, and the overall standard of living.<sup>3</sup>

### *Access to medicines through national health insurance*

In 1970, Uruguay ratified the ICESCR and, in doing so, committed to realizing the right to the highest attainable standard of health. In 2007, Uruguay's

National Health Insurance Scheme was introduced as part of a major health system reform grounded in the legal protection of the right to health and access to comprehensive health services.<sup>4</sup> The reform consolidated various insurance financing instruments into the single National Health Fund (Fondo Nacional de Salud), financed by individual and employer contributions, as well as government funds.

The National Medicines Formulary (FTM by its Spanish initials) defines the pharmaceutical benefits package that must be universally available in the health system. It is updated by the Ministry of Public Health based on input from an expert advisory committee that considers the World Health Organization's Model List of Essential Medicines.<sup>5</sup> The FTM was updated in May 2011, August 2012, January and November 2013, and February 2015.<sup>6</sup>

Domestic legislation enshrines the right to access licensed, quality-assured medicines that are included in the FTM.<sup>7</sup> In practice, access to FTM medicines is granted through two insurance schemes. The first is the National Health Fund, which insures employees, the self-employed, and their families, who have access to the FTM package via a co-payment. The second is the Health Services Administration, which covers the financially vulnerable, who have free-of-charge access to the FTM package.<sup>8</sup> Annex I of the FTM includes the standard pharmaceutical package, while Annex III includes high-cost medicines and other expensive services. Annex III medicines are financed by the National Resource Fund (Fondo Nacional de Recursos), which receives funding from a variety of sources, including the National Health Fund and the Ministry of Economy and Finance.<sup>9</sup> Although 91% of prescribed medicines in Uruguay are generics, spending on high-priced medicines through the National Resource Fund increased from US\$2.74 million in 2006 (0.01% of the gross domestic product) to US\$19.61 million in 2015 (0.06% of the gross domestic product).<sup>10</sup>

### *Judicialization of health rights*

The judicialization of health is supported by the Uruguayan Constitution, which requires the state to provide the means for prevention and treatment

to “indigents” and those lacking sufficient financial resources.<sup>11</sup> The right to health and other fundamental rights—such as the rights to life and to equality and non-discrimination—are justiciable before domestic courts.<sup>12</sup>

Three features of the Uruguayan judicial system contribute to the complexity of health and medicines litigation.

First, the writ of *amparo* is the judicial mechanism that claimants use in cases where a fundamental constitutional right is at immediate and significant risk. The urgency of the matter warrants an expedited hearing and decision within one week of filing, where the court must render a decision during the hearing (immediately after hearing the respondent’s arguments) or within 24 hours. This expedited proceeding—despite being a key tool to redress alleged human rights violations—restricts the thorough analysis that this topic merits.

Second, the Ministry of Public Health generally appeals decisions against it. Therefore, we assume that most medicines ordered by a court of first instance are ultimately decided by a higher court of appeal.

Third, Uruguay’s civil legal system has seven circuits of appeal and is without binding precedents. Therefore, the result of an appeal will depend on the position adopted by each circuit in each individual case—different from, for example, Argentina’s collective *amparo*. Each circuit is not bound by previous judgments—not even its own. Moreover, the courts have stated that all cases will be analyzed independently given that, even though they may share certain characteristics, they are not identical.<sup>13</sup>

Fourth, the inconsistency of the decisions of the appellate courts cannot be addressed by a higher court, as the Uruguayan system does not allow for another instance of judicial review for *amparo* cases. As a result, there is no legal mechanism to require or enforce a harmonized interpretation across courts.

### *Litigation for expensive medicines*

Beginning in 2008, medicines litigation in Uruguay increased steadily, peaking in 2015 (see Figure 1). Such litigation often relates to high-priced med-

icines included in Annex III of the FTM.<sup>14</sup> The Ministry of Public Health reports that court-ordered expenditure on medicines, which increased 65% between 2010 and 2016, is likely to increase inequities in access to not only high-priced drugs but also basic health services across the population.<sup>15</sup> Moreover, the Ministry of Health spent US\$5.3 million providing court-ordered, high-cost medicines in 2017.<sup>16</sup> This unforeseen expenditure was in addition to the 9.2% of gross domestic product that Uruguay already spends on health.<sup>17</sup> This evolution triggered several curious developments in domestic law and policy for pharmaceuticals.

First, the 2015–2019 national budget initially stated that the Uruguayan government would not be “responsible” for medicines and treatments excluded from the FTM.<sup>18</sup> Following much debate, this article was later modified to read that the government would be responsible only for providing medicines of “proven effectiveness.” In this way, the national budget appealed to scientific criteria on “effectiveness” as a measure to discern which medicines the state must provide, rather than leaving the matter to a case-by-case analysis.

Second, Ministerial Order 86/2015 of February 2015 reiterated that an explicit list of pharmaceuticals—including cetuximab, lenalidomide, and sorafenib—were considered cost-ineffective for specific cancers and consequently would not be included in the FTM for these indications.<sup>19</sup> Curiously, decisions granting some of these medicines to plaintiffs continued throughout 2015 and 2016.<sup>20</sup>

Third, the Ministry of Public Health created a new administrative procedure as an alternative to the courts for patients seeking access to off-formulary medicines.<sup>21</sup> This procedure was introduced to stem the number *amparo* claims; however, it has been criticized as laborious and requiring substantial documentation.<sup>22</sup>

Despite these measures, *amparo* claims for medicines continued. In 2016, court-ordered medicines consumed 25% of the Ministry of Public Health’s operating expenses.<sup>23</sup> Currently, legislation is being developed to improve access to expensive medicines; however, there is a critical lack of analysis of these *amparo* claims to inform lawmakers.

Specifically, there has been little exploration of whether the courts adequately interpret the state's core obligations to provide essential medicines and ensure non-discriminatory access in line with the right to health in the ICESCR.

## Methods

Using the United Nations Committee on Economic, Social and Cultural Rights' authoritative interpretation of the right to health in General Comment 14 as its normative framework (described below), our study reviews domestic case law concerning access to medicines. It critically examines how Uruguayan courts determine the scope and boundaries of the state's action in light of two core obligations under the right to health in the ICESCR.

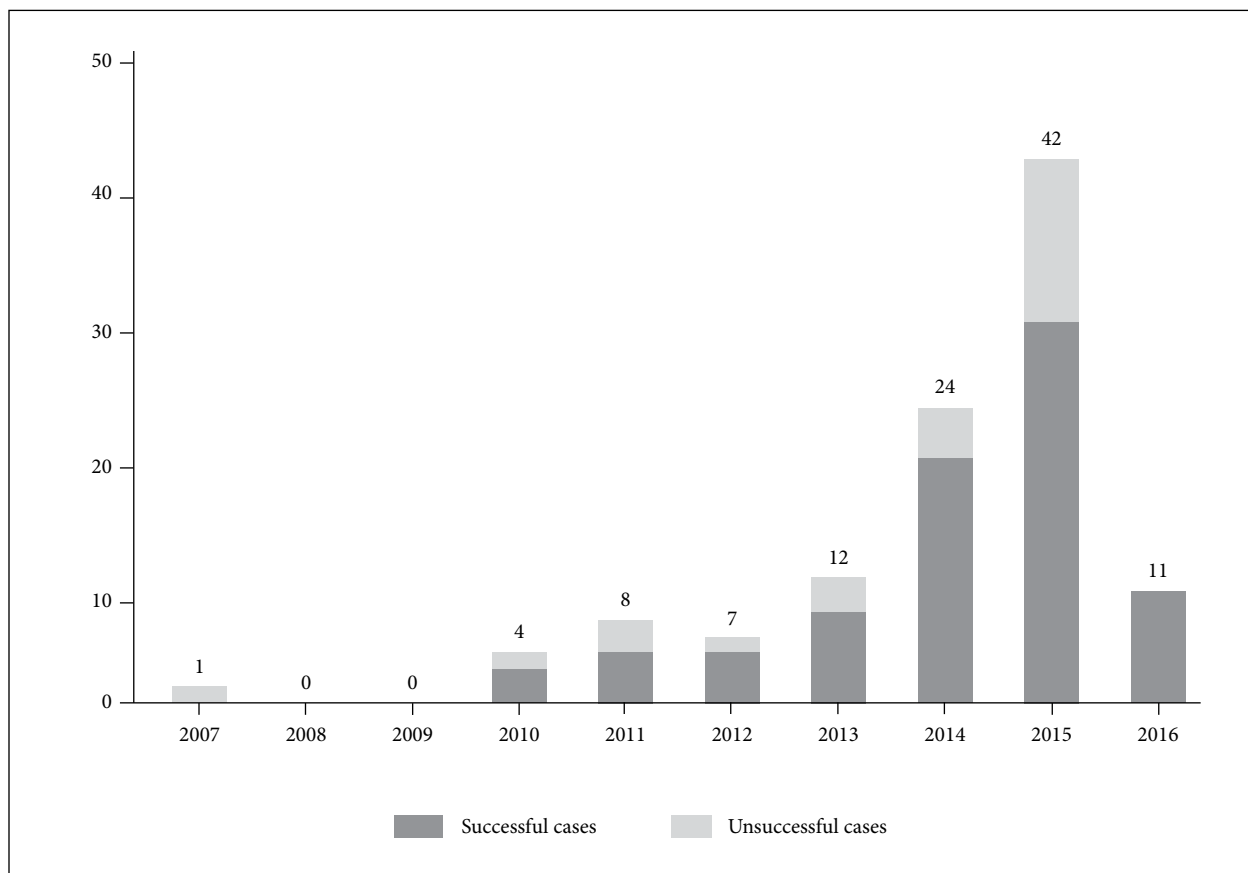
We selected *amparo* cases decided in 2015—

the year with the most medicines-related decisions since the 2006 health reform. This method offers a snapshot of judicial reasoning at the peak of pharmaceutical claims and in the period coinciding and immediately following a series of legislative changes that were designed to curb *amparo* cases for medicines.

Cases were retrieved from the online repository of the Uruguayan national judiciary using the keywords “acceso” and “medicamento.” Only cases claiming access to a pharmaceutical intervention through a writ of *amparo* were included.

We extracted key features of each case into a database for further analysis. These features include the medication and indication requested, the factual and legal basis of the plaintiff's claim, the legal reasoning of the court, and the decision.

FIGURE 1. Evolution of *amparo* claims for medicines in Uruguay, 2007–2016



Source: Base de Jurisprudencia Nacional Pública, <http://bjn.poderjudicial.gub.uy/BJNPUBLICA/busquedaSimple.seam>

### *Analytical framework*

Our analytical framework is founded on states' core obligations to realize the right to health, identified in General Comment 14, which was issued in 2000 by the Committee on Economic, Social and Cultural Rights. States' non-derogable core obligations to realize the right to health form the basic minimum floor of the right on which all other aspects should be built.<sup>24</sup> Core obligations include the duty to provide essential medicines, as defined by the World Health Organization (WHO), and the duty to ensure access to health facilities, goods, and services on a non-discriminatory basis.<sup>25</sup>

First, we examine whether Uruguayan courts have addressed the duty to provide essential medicines in a manner consistent with General Comment 14. Essential medicines are defined by WHO as effective, safe, and comparatively cost-effective to treat the priority health conditions of a population.<sup>26</sup> Every two years, WHO updates its Model List of Essential Medicines, which serves as a guide for domestic governments in their development of local and national lists of essential medicines that respond to local contingencies, such as available public resources and disease burden. In recent years, highly effective and expensive medicines for HIV, hepatitis C infections, and some cancers were added to the WHO model list despite their high price. This move proved that high cost as such does not preclude essentiality; instead, it confirmed the message from WHO's definition that essential medicines, once selected, must become affordable for all who require them.<sup>27</sup> In the Uruguayan context, the entire FTM (Annexes I and III) is compiled with a comparable objective and according to similar criteria as an essential medicines list. Therefore, the FTM can be considered the national list of essential medicines in the Uruguayan context.

Second, we investigate whether the courts address the core obligation to ensure the right of access to health facilities, goods, and services on a non-discriminatory basis in line with guidance in General Comment 14. According to this general comment, the state has a duty "to prevent any discrimination on internationally prohibited grounds

in the provision of health care and health services, especially with respect to the core obligations of the right to health."<sup>28</sup> It warns against "inappropriate health resource allocation" that may lead to discrete discrimination. It offers the example of favoring "expensive curative health services which are often accessible only to a small, privileged fraction of the population, rather than primary and preventive health care benefiting a far larger part of the population."<sup>29</sup> Moreover, it notes that the state has a "special obligation" to provide health insurance and care to those with insufficient means.<sup>30</sup> This duty is closely related to the universal entitlement to "a system of health protection which provides equality of opportunity" such that people can enjoy their health rights.<sup>31</sup>

### Results

Of the 52 claims decided in 2015 that were available in the judicial repository, 10 were excluded (3 claimed medical devices as opposed to pharmaceuticals, and 7 were not *amparo* cases), leaving 42 claims that were included in this study (see Table 1). Each of these claims sought one pharmaceutical. Of the 42 claims, 31 (74%) were decided in favor of the plaintiff (hereafter "successful claims").

Thirty-four claims (81%) accounted for 10 medicines (see Table 2). Requests were most frequently for licensed medicines not included in the FTM (hereafter "off-formulary"). Eight claims (19%) successfully acquired the off-formulary medicines cetuximab, lenalidomide, and sorafenib for cost-ineffective indications that were explicitly excluded from the FTM by Ministerial Order 86/2015.<sup>32</sup> The courts denied two claims for unlicensed medicines and accepted the only request for an on-formulary medicine.

### *Duty to provide essential medicines*

In cases requesting off-formulary medicines, the courts produced vague and sometimes contradictory evaluations of alleged violations of the fundamental right to health. For example, one court granted reimbursement of off-formulary medicines despite "bureaucratic reasons" for not adding the medicines to the list (for example, passage of the

TABLE 1. Characteristics of 42 *amparo* claims decided by Uruguayan circuits of appeal in 2015

	Categories	Number of successful claims (n=31) (% of successful claims)	Number of unsuccessful claims (n=11) (% of unsuccessful claims)
Essentiality	<ul style="list-style-type: none"> <li>In WHO's 2017 Model List of Essential Medicines</li> <li>In the National Medicines Formulary (FTM) for any indication</li> </ul>	2 (6%) 5 (16%)	1 (9%) 2 (18%)
Indications	<ul style="list-style-type: none"> <li>Oncological diseases</li> <li>Unspecified indication(s)</li> <li>Idiopathic pulmonary fibrosis (degenerative lung disease)</li> <li>Nephrotic syndrome</li> <li>Lupus</li> <li>Inflammatory bowel disease</li> <li>Multiple sclerosis</li> </ul>	20 (65%) 6 (19%) 2 (6%) 1 (3%) 0 1 (3%) 1 (3%)	9 (82%) 0 1 (9%) 0 1 (9%) 0 0
Human rights recognized in the court decisions	<ul style="list-style-type: none"> <li>Right to life</li> <li>Right to an adequate standard of living and health</li> <li>Right to the highest attainable standard of physical and mental health</li> <li>Right to freedom from discrimination</li> <li>Right to equality before the law</li> <li>No explicit rights</li> </ul>	30 (97%) 1 (3%) 28 (90%) 29 (94%) 17 (55%) 0	3 (27%) 0 3 (27%) 3 (27%) 0 6 (55%)
International law recognized in the court decisions	<ul style="list-style-type: none"> <li>International Covenant on Economic, Social and Cultural Rights</li> <li>American Convention on Human Rights</li> <li>Universal Declaration of Human Rights</li> <li>Additional Protocol to the American Convention on Human Rights</li> <li>None</li> </ul>	18 (55%) 18 (55%) 12 (36%) 12 (36%) 10 (30%)	2 (18%) 2 (18%) 0 1 (9%) 9 (82%)

TABLE 2. The 10 most frequently claimed medicines in 2015

Medicine	Number of claims (% of total)	Indications	Number of successful claims	Number of unsuccessful claims
Abiraterone acetate	4 (10%)	<ul style="list-style-type: none"> <li>Prostate cancer</li> </ul>	4	0
Cetuximab	8 (20%)	<ul style="list-style-type: none"> <li>Colon/colorectal cancer**</li> <li>Unspecified</li> <li>Endometrial cancer</li> </ul>	4 2 1	1 0 0
Lenalidomide	3 (7%)	<ul style="list-style-type: none"> <li>Multiple myeloma</li> </ul>	3	0
Regorafenib	4 (10%)	<ul style="list-style-type: none"> <li>Colon/colorectal cancer**</li> </ul>	3	1
Pirfenidone	3 (7%)	<ul style="list-style-type: none"> <li>Pulmonary fibrosis</li> </ul>	2	1
Sorafenib	3 (7%)	<ul style="list-style-type: none"> <li>Hepatocellular cancer</li> <li>Renal cancer</li> </ul>	2 0	0 1
Paclitaxel	2 (5%)	<ul style="list-style-type: none"> <li>Pancreatic cancer**</li> </ul>	2	0
Rituximab	2 (5%)	<ul style="list-style-type: none"> <li>Nephrotic syndrome</li> <li>Lupus</li> </ul>	1 0	0 1
TDM-1 (trastuzumab-emitansine)	3 (7%)	<ul style="list-style-type: none"> <li>Unspecified</li> <li>Metastatic breast cancer</li> </ul>	2 0	0 1
Ibrutinib	2 (5%)	<ul style="list-style-type: none"> <li>Chronic lymphoid leukemia</li> <li>Unspecified</li> </ul>	1 1	0 0

\*\* Includes both metastatic (advanced) and non-metastatic disease because the court decisions did not systematically differentiate between the two stages of the same pathology.

annual submission deadline to the advisory committee or insufficient time to complete the technical appraisal of a medicine for inclusion). However, in three other cases, the courts reasoned that an ongoing assessment or insufficient time to evaluate cost-effectiveness justified not reimbursing the medicine at that time. The latter three decisions are consistent with the core obligation to provide *essential* medicines, which presupposes that sufficient information and time has been given to adequately assess the essentiality of each medicine—an imperative step for inclusion in the FTM.

Similar inconsistencies are evident in decisions not to reimburse a high-priced medicine in light of limited public funds, which the courts interpreted as a breach of fundamental rights in six cases. However, in four other cases, the courts reasoned that not reimbursing expensive medicines due to limited resources or their lack of cost-effectiveness was consistent with fundamental rights. The former decisions are consistent with the concept of non-derogable core obligations in General Comment 14. The four latter cases reflect a softer approach to core obligations, which is addressed further in the Discussion section below.

Two similar claims for cetuximab demonstrate this inconsistent reasoning. Cetuximab's reported price for colon cancer is US\$190,483 per patient per year.<sup>33</sup> Excluded from the FTM due to its cost-ineffectiveness, cetuximab was claimed twice in our 2015 sample for the treatment of metastatic colon cancer. In the first case, decided on October 10, 2015, Circuit 7 determined that there was no scientific justification for excluding cetuximab for this indication. In reaching this conclusion, the court reasoned that a lack of cost-effectiveness did not justify denying reimbursement to a patient who could not otherwise afford it.<sup>34</sup> However, in the second case, decided on November 3, 2015, Circuit 5 decided that it must respect the decision to omit cetuximab for this indication from the FTM on economic grounds. In this court's appreciation, this decision was consistent with the patient's fundamental rights and previous court rulings.<sup>35</sup>

### *Duty to ensure non-discriminatory access to health care*

Uruguayan courts conceptualize equality and non-discrimination in two different ways, leading to two significantly different results.

On one hand, successful cases have generally found a breach of the principle of equality and non-discrimination on two grounds. First, some courts consider that the positive market authorization decision and negative reimbursement decision (in other words, exclusion from the FTM) regarding certain high-priced medicines breaches the right to equality and non-discrimination. This is because authorization without reimbursement allows access for those who can afford the medicines but not for those without the financial means and who are limited to the FTM selection. The reasoning is based on the idea that “every patient has the right to access medicines of quality, and the constitutional protection of this right does not distinguish whether these medicines are or are not included in the FTM.”<sup>36</sup> In the words of Circuit 7 “The effective protection of the right to life or health cannot depend ... on one's financial ability or privileged situation that enables them to access the medical treatment.”<sup>37</sup> According to this line of decisions, “economic accessibility” shall be guaranteed by the state through the provision of all medicines, irrespective of their cost or their inclusion in the FTM.<sup>38</sup> The courts' notion of providing for those who cannot provide for themselves appears to align with the right to health's concept of equality of opportunity. However, the state is not obliged to provide immediate access to health services of any cost to those dependent on state health care. Moreover, General Comment 14 cautions states against discrimination that can result from providing expensive curative care to the few at the expense of preventative and primary care for the many.

Second, courts have generally been receptive to the argument that since both the Health Services Administration (health insurance for the financially vulnerable) and the Ministry of Public Health may have provided a particular medicine to other patients who have requested it previously,

not granting a plaintiff's request would breach the principle of equality enshrined in article 8 of the Uruguayan Constitution. This is because other patients with similar conditions have been granted access to the medicine in question (either by judicial or administrative action). The courts consider that the Ministry of Public Health decides these issues in an arbitrary and discriminatory manner that breaches the right to equality. They conclude that the use of public resources cannot discriminate between citizens and that the Ministry of Public Health does not have a valid reason to justify the difference in treatment.

On the other hand, the courts have also used the argument of equality in their decisions not to grant a plaintiff's request. These decisions sustain that the government has limited resources to attend to the health care needs of the whole population and that the provision of certain high-priced medicines can clash with the needs of the rest of the population. For example, Circuit 6 has argued that "the primary obligation of the Ministry of Public Health is to attend to the general welfare applying the principle of equality, not just for one patient but for everybody".<sup>39</sup> Along the same lines, Circuit 5 has viewed plaintiffs' requests as a demand for special treatment "at a high cost and over the needs of the rest of the population".<sup>40</sup> This reasoning is somewhat consistent with the concept of "inappropriate health resource allocation" in General Comment 14. Circuit 5 has pointed out that "even when the condition of the patient is grave—unfortunately—this is not the only person that needs to be assisted ... That is the key issue here".<sup>41</sup> This argument points to the fact that increased judicialization distorts health planning and priority setting, forcing decisions that reflect on the individual cases being judged and not on society's collective needs. The courts emphasize the fact that decisions regarding health policies—which require the consideration of multiple factors—should be made by the executive branch. Judicial intervention to grant access to high-priced medicines—without a grave cause to justify it—can endanger the general well-being of the population by distorting the national health

budget. According to this approach, "[j]udges need to be guided by the law and what is just, not only for the plaintiff but for others and society as a whole".<sup>42</sup> It has been argued that deciding otherwise will turn the courts into a "judicial pharmacy".<sup>43</sup>

## Discussion

The majority of the claims in our sample concerned one of ten off-formulary medicines frequently requested to treat cancer. The courts provided inconsistent and unreliable legal reasoning in their decisions for the protection of the right to health. Our study shows that the courts' reasoning neither implicitly nor explicitly engages with the concept of core obligations to provide essential medicines in a non-discriminatory manner. Although some decisions are consistent with the Committee on Economic, Social and Cultural Rights' interpretation of core obligations, we cannot determine whether these were conscious or coincidental judicial rulings.

These findings illustrate that Uruguayan case law from 2015 fails to provide any legal certainty regarding the boundaries of the state's core obligation to provide essential medicines in a non-discriminatory manner. Due to a lack of consistency, these decisions may further exacerbate, rather than remedy, inequalities among patients with comparable health needs and within the publicly funded pharmaceutical reimbursement system as a whole.<sup>44</sup>

### *A softer approach to core obligations in international human rights law*

A more flexible approach to minimum core obligations seems to be condoned in the 2013 Optional Protocol to the ICESCR (hereafter ICESCR-OP), inspired by the 2000 *Grootboom* and 2001 *Treatment Action Campaign* decisions of the South African Constitutional Court.<sup>45</sup> ICESCR-OP is the first instrument to enable the international enforcement of the rights laid out in the ICESCR. It adopts a standard of reasonableness suggesting that social rights realization is contingent on an assessment of



whether the state has taken sufficiently appropriate measures to realize the right within its maximum resource limits. As Bruce Porter explains:

*Reasonableness is a contextual inquiry into the content of Covenant rights in particular circumstances, attending equally to both the voice and experiences of claimants, and to the realities, restraints, and difficult choices faced by governments. What is reasonable will depend as much on the nature of the interest at stake and the unique circumstances of the particular claimant or group, as on budgetary constraints, competing needs and policy rationale presented by the state.<sup>46</sup>*

By ratifying the ICESCR-OP in 2013, Uruguay expressly agreed to be held accountable before an international committee to the instrument's standards and principles, such as the nascent concept of reasonableness.

*The standard of reasonableness: A measure of state action for the Uruguayan judiciary?*

Our results show that despite considering the contextual needs and restraints of the plaintiff and the state in each decision, the Uruguayan judiciary has not applied a common measure to judge state action. One of the present authors (Katrina Perehudoff) and Lisa Forman propose that the standard of reasonableness, found in South African jurisprudence and the ICESCR-OP, may serve as a lens through which we can interpret core obligations. In other words, the standard of reasonableness can help give substance to the state's duty to use all available resources to satisfy its core obligations toward essential medicines.<sup>47</sup> In particular, Perehudoff and Forman suggest that satisfying core obligations in the context of available resources can be delineated into four duties: (1) ensure sufficient government spending on pharmaceuticals, (2) ensure efficient spending on pharmaceuticals, (3) generate efficiencies by seeking international cooperation and assistance, and (4) observe non-discrimination in pharmaceutical policy.<sup>48</sup> Uruguayan lawmakers could be expected to align the domestic interpretation and enforcement of social rights with the international standards to which the Uruguayan

state has agreed to be accountable.

In the case of Uruguay, we assert that the judiciary could seek inspiration from the standard of reasonableness to assess claims for high-priced medicines. An examination of core obligations consistent with the standard of reasonableness would assess whether the state had taken all "reasonable" measures to provide the medicine before determining whether the state violated rights.

Let us take a look at the three claims for lenalidomide identified in our study in order to illustrate an alternate line of judicial assessment inspired by the standard of reasonableness. The Ministry of Public Health determined in 2013 that lenalidomide is cost-ineffective for the second-line treatment of multiple myeloma and, consequently, did not include the medicine in the FTM. However, the health technology assessment notes that a 70% price reduction would render lenalidomide sufficiently cost-effective for FTM inclusion.<sup>49</sup> In 2015, we found that three patients who claimed lenalidomide were granted court-ordered reimbursement for multiple myeloma despite it being off-formulary for this indication. In each of these cases, the courts determined that failing to reimburse a high-priced medicine that is proven effective for a life-threatening condition on the grounds of limited state resources violates the rights to life, health, and non-discrimination.<sup>50</sup>

Uruguayan scholars note that in response to high-priced medicines, price regulation and international cooperation for joint purchasing and price transparency is being pursued in Uruguay.<sup>51</sup> Therefore, the courts could have considered whether similar measures were pursued in relation to lenalidomide prior to deciding in the plaintiffs' favor. Recalling the four duties proposed by Perehudoff and Forman, this line of reasoning could have examined whether the state took measures to maximize its public pharmaceutical budget (duty 1) and spend efficiently (duty 2), such as through the use of price controls and TRIPS flexibilities when all other measures fail to yield affordable medicines.<sup>52</sup> Sufficient and efficient spending can mitigate the need for discriminatory trade-offs and

care rationing (duty 4).<sup>53</sup> Finally, the court could have questioned whether the state took steps to jointly procure medicines with larger neighboring countries (duty 3) in order to leverage economies of scale. By examining the “reasonableness” of state efforts to fulfill Uruguay’s core obligations, the judiciary could have secured more equitable access to lenalidomide for the plaintiffs while also triggering important policy changes that would grant access to the other invisible patients with multiple myeloma who did not file a writ of *amparo*, while still respecting the separation of powers.

### *Does litigation stimulate rather than remedy health inequality?*

This “wave” of litigation since Uruguay’s health reform is likely to have affected equity in the country’s tax-funded universal health system in several ways. First, not all consumers with unmet health needs are equally able to access a court. This concern is corroborated by government representatives who claim that health rights litigation may result in preferential access for people of higher socioeconomic status.<sup>54</sup> Second, successful plaintiffs inevitably receive and consume more health system resources than those who do not seek treatment through the courts.<sup>55</sup> Third, these challenges are compounded by inconsistent judicial outcomes in highly similar cases.

Uruguayan case law in our sample provided little information about the plaintiffs’ socioeconomic status. Therefore, we are unable to assess whether litigation is exacerbating inequalities by providing preferential reimbursement of medicines to the better-off, as has been reported elsewhere in the region.<sup>56</sup> However, the question of inequality warrants further research in Uruguay considering the above factors at play.

Access to the courts for people who cannot afford a lawyer is stimulated through several initiatives of the law clinics of the Universidad de la República (a public university). However, securing representation by these clinics is limited by their case load and by patients’ ability to travel to the capital city in order to access the clinics’ services. While the clinics’ work may palliate inequalities in access

to the courts, unless all health consumers have the same political and economic resources, certain groups are more likely to be able to litigate—and therefore access high-priced drugs—more effectively than others. Considering that socioeconomic status is not only one of the most prominent social determinants of health but also an important indicator of one’s ability to access the courts, we must agree with Octavio Ferraz that “the ability to access the judiciary is not a fair criterion for the allocation of health resources.”<sup>57</sup>

### *Domestic policy recommendations*

Two key policy recommendations arise from these findings. First, the Uruguayan state should consider legislative measures to control the prices of expensive medicines that would otherwise be eligible for inclusion in the FTM if it were not for their prohibitive price. In this line, a bill is currently being debated in Parliament to provide tax cuts to private companies that donate to the National Resource Fund, which finances expensive medicines.<sup>58</sup> At the time of writing, it is unclear whether the bill will be adopted. In July 2017, the Committee on Economic, Social and Cultural Rights urged the country to accelerate the passing of this bill in order to guarantee access to all medicines needed to enjoy the right to health.<sup>59</sup> While the bill is an attempt to expand the available budget for and access to expensive medicines, it does not address the underlying reasons for high prices and the use of all available means of reducing prices as recommended by the *Lancet’s* Commission on Essential Medicines Policies.<sup>60</sup> This fragmented approach gives in to the lobbying power of pharmaceutical companies that will benefit from tax cuts for donating money to the National Resource Fund while having their high-priced medicines be included in the FTM. In principle, donations are not recommended as a means for improving access to high-priced products, as they allow pharmaceutical companies to maintain the underlying high prices.

We recommend that if the political climate allows for a legislative solution, Uruguay should pursue a more holistic law that regulates and supports all possible price control measures and

promotes international cooperation to evaluate and purchase medicines. Moreover, a more transparent and participatory process to establish the criteria for inclusion in the FTM would also foster open public debate and a deeper public understanding of the issues at play.<sup>61</sup> Technical decisions about whether to include new medicines in the FTM should be objective, consistent, and evidence based. Failing to take measures such as these to make essential medicines affordable to all is inconsistent with the right to health.<sup>62</sup>

Second, alternative approaches to the writ of *amparo* are needed. Uruguay should also allow for another instance of judicial review that harmonizes the inconsistent decisions on appeal. Such an alternative approach should ensure that all courts of appeal interpret the law in a uniform manner, which would help reduce disparate judicial outcomes in highly similar cases. Alternative approaches may be found in neighboring countries that also face numerous judicial claims for medicines.

### *Study limitations*

The limitations of our study relate to the accessibility and completeness of data in court decisions. First, our search of the official online repository produced only 52 decisions from 2015, while Uruguayan scholars report retrieving 80 such decisions for the same year.<sup>63</sup> We consulted one of these scholars, and although both of our research teams reported inconsistencies in the repository's search function, neither team could identify a solution. We could not access a list of the 80 medicines decisions, and time restraints precluded a manual search of the repository. Therefore, we proceeded with this convenience sample of 52 decisions. Although we cannot claim that our sample is representative of all medicines claims from 2015, it does represent the decisions that are most readily accessible to the Uruguayan judiciary, which uses the same online repository to access case law. We hypothesize that judges and their teams are most likely to consult case law that is the easiest to access, especially considering that the courts of appeal hear and decide *amparo* claims for medicines within one week of filing. Moreover, selection bias favoring claims for

high-cost, off-formulary medicines in our sample is unlikely because the Ministry of Public Health tends to appeal all decisions against it. This means that if a court of first instance ordered the ministry to reimburse an on-formulary medicine, then the government would appeal the decision, which would then be heard by a court of appeal and therefore appear in our sample.

Second, several court decisions contained little to no information about the pathologies that the medicine in question was requested to treat (see the five cases with an "unspecified" indication in Table 2). As a result, our finding that courts rule inconsistently on the same indication may be more frequent than we documented.

Third, the fact that General Comment 14 is not binding on states could call into question its legitimacy as an analytical framework. Nevertheless, this general comment is an authoritative interpretation of the right to health in the ICESCR. It instructs state parties on their goals and actions required to attain the right to health for all; it also reflects the monitoring criteria applied by the Committee on Economic, Social and Cultural Rights. General Comment 14 is also instructive for domestic law and policymaking, being explicitly and implicitly referenced in national medicines policies, domestic health legislation, and medicines case law from various jurisdictions.<sup>64</sup> From these examples, we can conclude that General Comment 14 is the most authoritative human rights guide for domestic health law and policymaking despite the fact that it does not reflect all aspects of a public health or health systems approach.

### Conclusion

Our findings show that Uruguayan case law concerning high-priced medicines fails to offer predictable legal argumentation among the country's seven circuits of appeal. Nor does this body of case law provide an interpretation of state obligations that is consistently aligned with the right to health in the ICESCR. While medicines litigation in Uruguay offers relief for some individual claims, the courts' inconsistent legal reasoning has the potential to ex-

acerbate systemic inequalities by failing to address the structural problems behind high medicines prices. In response, future court rulings should embrace a consistent standard for examining state action to realize the right to health within its available resources. Furthermore, future legislative responses should address the need for medicines price control and offer a harmonized interpretation of these rights and obligations. These steps will increase the transparency and predictability of Uruguay's health and legal systems for patients.

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# Can Judges Ration with Compassion? A Priority-Setting Rights Matrix

CHRISTOPHER NEWDICK

## Abstract

How should courts supervise health service resource allocation? Although practice varies widely, four broad approaches can be represented on a matrix comparing, on two axes, (a) individual-community rights and (b) substantive-procedural remedies. Examples from each compartment of the matrix are discussed and, although the community-procedural approach is recommended as a general rule, a range of other responses within the matrix may also be desirable.

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## Introduction

All over the world, public welfare services are struggling as “structural adjustment” reduces the resources available to public authorities.<sup>1</sup> In the past, governments could raise domestic taxes to respond to welfare demand. Now, their revenue-raising capacity is diminishing, especially from the wealthiest and most mobile sources.<sup>2</sup> Instead, governments are turning to international credit to support public services.<sup>3</sup> Today, private investors’ rights to bond repayments compete for priority over public rights to social welfare.<sup>4</sup> As demand for care accelerates, both from older patients living longer with chronic illness and younger ones suffering from our “obesogenic” environment, the *tax-state* is also becoming the *debt-state*.<sup>5</sup> While the subject of this article is health care, its *context* is of mounting pressure on health care systems precisely as demand for care is expanding faster than ever. While we may endorse the World Health Organization’s strong advice for governments to increase public investment in health and health care, the future for public services is more probably of greater austerity.<sup>6</sup> And as competition for limited resources intensifies, judges are more likely to be called upon to resolve the tension. How should they do so? What logic separates the choices before them, and what are the implications for patients and systems as a whole of the judicial policies adopted? In particular, is the “judicialization” of health care a help or a hindrance, friend or foe?<sup>7</sup> We discuss (a) framework issues common to claims made upon public welfare systems everywhere, and (b) a resource allocation rights matrix to assist clarity in the debate.

## Framework issues

Before turning to the rights matrix, what are the “framework” issues common to claims arising within public welfare systems generally? Assuming the decision-maker is an authority with duties to serve the public, the following three factors are surely axiomatic.

### *Opportunity costs engage rights*

Because demand for care generally exceeds the

public resources available, investment in one part of the system may require *disinvestment* from another. Judgments about resource allocation are not based on objective equations or immutable logic, but on a balance of ethical, legal, therapeutic, social, and economic values about which reasonable people differ. The term “commissioning” captures the responsibility to promote the interests not just of individuals (the usual priority of bioethics), but of whole communities of people over the longer term. It expresses concern for social citizenship in which we all share common interests with a community of others.<sup>8</sup>

For health care commissioners, this involves decisions about the opportunity costs involved in promoting social and economic rights. For example, how should we allocate resources between neonatal care, pediatric care, orthopedic care, oncology, and cardiology care? Should patients wait for hospital care for 18 days, 18 weeks, or 18 months? Should we focus less on individual patients after illness has struck, or promote community health before people become ill? These are crucial questions in bioethics (although they have been “almost totally ignored”), but they also engage rights.<sup>9</sup> We require responses that recognize social and economic rights as enforceable positive *rights* yet devise remedies that respect the “public” dimension of the claim in terms of opportunity costs.

### *Positive rights are justiciable*

Judges must surely retain supervisory authority over competing claims of this nature. The challenge is to find the proper balance between judicial usurpation of executive authority on the one hand and a complete abdication of judicial responsibility on the other.<sup>10</sup> This suggests that, although positive rights remain within judicial supervision, appropriate *remedies* must differ from those available for civil and political rights claims. Whereas civil and political rights are enforceable impartially and generally *by us all*, social and economic rights engage issues of distributive justice *between* people who may have competing interests, where the needs of the most underprivileged are often prominent. This distinction suggests that whereas civil and



political rights are amenable to *substantive* judicial enforcement, social and economic rights give rise to different concerns. For the latter, *procedural* remedies are more often appropriate to accommodate the politics inherent in promoting social welfare policy.<sup>11</sup> In the Constitutional Court of South Africa, Justice Albie Sachs explained the difference in a case concerning the allocation of scarce lifesaving kidney dialysis. An individual rights approach was insufficient to solve the problem. When others also have legitimate interests in the same resource, the court must reflect our human *interdependence* by accommodating the competing rights and interests of other people. This is not to undermine or dilute the notion of rights, rather:

*When rights by their very nature are shared and interdependent, striking appropriate balances between equally valid entitlements or expectations of a multitude of claimants should not be seen as imposing limitations on those rights..., but as defining the circumstances in which rights may most fairly and effectively be enjoyed.*<sup>12</sup>

Take the European Convention on Human Rights (ECHR). In respect of civil and political rights, the same principles of freedom of speech apply throughout Europe, east and west, irrespective of the differences in gross domestic product (GDP). Thus, despite the differences in national wealth, German and Romanian citizens should enjoy the same rights of freedom of expression, assembly, and religion. However, this is not true of social and economic rights. Inevitably, access to public health, housing, education, and social welfare differs significantly throughout Europe. This is not to say that social and economic rights do not exist in countries with a smaller GDP, or that their courts cannot enforce them. Rather, their legitimacy must be recognized within these constraints, without ignoring the rights of other people. The High Court of Israel refers to them as “budget-dependent rights” in which “the scope and extent of realization of the right to health and medical treatment is subject to the economic capability of the state and the resources at its disposal.”<sup>13</sup> Unless we acknowledge this difference, an *individualist* approach to

social and economic rights will damage precisely the communities and public institutions most in need of protection.<sup>14</sup> The concern is not that social and economic rights are non-justiciable; it is how best to avoid the collision with “negative rights” so as to respond properly to everyone’s needs, rather than the needs of articulate litigants in particular.

#### *Access rights are equality rights*

The state treads a delicate line between protecting liberty on the one hand and promoting equality on the other. If the starting point is “individualistic” and premised on the belief that the state is a necessary evil needed only to protect civil and political rights (as with Thomas Hobbes and John Locke), then the conclusion will differ radically from those who believe we are born into communities with social rights, mutual interests, and shared obligations of citizenship (as with Aristotle and Jean-Jacques Rousseau). Take an example that has troubled a number of health care systems. Concern is expressed that the public interest in a fair public health service is undermined if wealthier patients can jump the queue for services by accessing faster or better treatment through private care. Resources otherwise available to the public may be diverted into private practice, and the integrity of public sector care may be diluted. Waiting times in the public system may lengthen, the numbers of doctors and nurses in the wards may shorten, public support for the service may decline, and the ethical commitment to equality may be compromised. Confidence in the system may be undermined so that the service loses credibility.

Both the province of Quebec and the state of Israel responded to this problem in broadly similar ways. In Quebec, regulations made the market for private health insurance unlawful so as to protect the integrity of the public health care system. In Israel, since 1996, patients had been permitted to make extra payments to public hospitals to purchase the right to see the doctor of their choice. As in Quebec, this created a conflict between a right to buy care in a free market on the one hand and the principle that patients should be treated equally according to their need, by the staff best qualified

to do so, on the other. So the attorney general of Israel declared the practice illegal in 2002.<sup>15</sup> Both of these social policy responses were challenged. The difference in judicial reaction is illuminating. In *Chaoulli v Attorney Generals of Quebec and Canada*, the Canadian Supreme Court held that individual rights effectively “trump” public policy concerns, at least until there was cogent evidence that substantial harm would be done otherwise.<sup>16</sup> It struck down the Quebec regulation for infringing the private rights of individuals to enter the market for health insurance by obliging people to wait longer for treatment in the public system. By contrast, in *Kiryati v. Attorney General*, the Supreme Court of Israel was troubled by a scheme which permitted public health services to be supplemented by private payments.<sup>17</sup> Public hospitals should treat patients equally, according to their need rather than their ability to pay. Yet permitting wealthier patients to divert doctors from other, more needy patients undermined this ideal. Thus, the court upheld the attorney general’s decision as a legitimate measure promoting the fundamental principles of the public health care system in Israel.<sup>18</sup>

Tushnet says of the Canadian decision that it is based on “an unstated assumption that the default remedy is always reversion to the institutions of the private market economy.”<sup>19</sup> Hutchinson criticizes the decision in similar fashion:

*Chaoulli... is energised by a political ideology which encompasses, amongst other things, that*

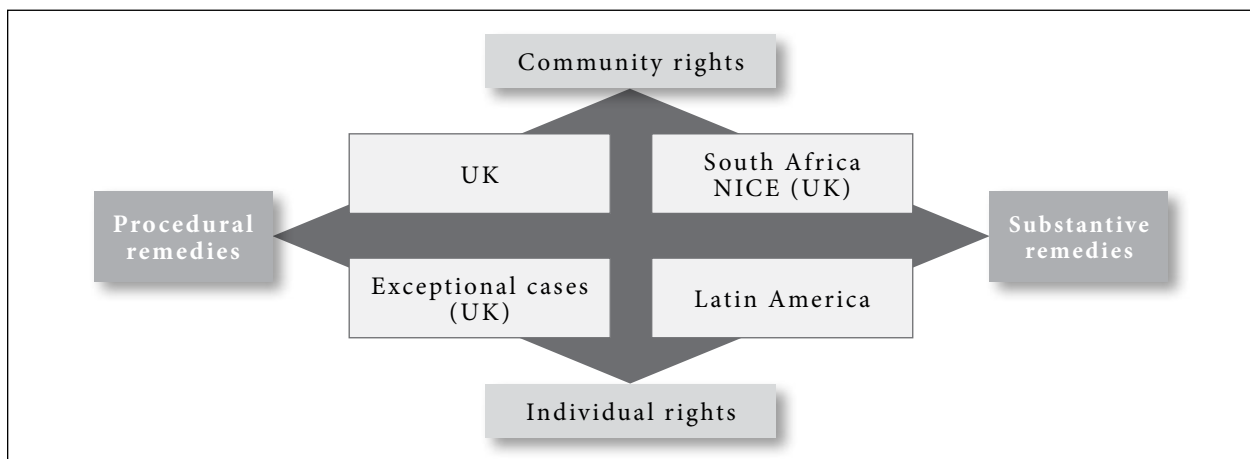
*individual entitlements are more important than social responsibilities, that negative liberty is to be promoted at the expense of positive liberty, that people’s capacity to exercise their rights is a matter of choice rather than circumstance and that legislatures... are the breeding grounds of capricious and arbitrary decision-making... This political vision... is highly individualistic and anti-state...<sup>20</sup>*

Courts more comfortable protecting individual liberty will be challenged by policies that constrain economic rights in order to promote equality and social citizenship. Nevertheless, it is surely axiomatic that public health systems should promote everyone’s interests equally, and we need to be candid that these matters of distributive ethics often involve political compromises.<sup>21</sup> The commitment to equality should have regard for the needs of particular patients today, but also to the sustainability of the system for those who need treatment in the future. It is to the balance between political priorities and legal rights that we now turn.

### A priority-setting rights matrix

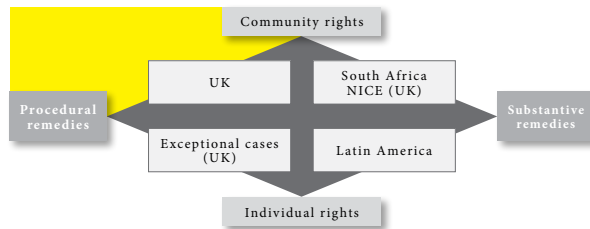
With these framework issues in mind, how should fair and equitable systems of health care resource allocation be designed? Ways of answering this question can be visualized on a rights matrix created from two axes contrasting: (a) on the vertical axis, the distinction between individual and community rights and (b) on the horizontal axis, the

FIGURE 1. Priority-setting rights matrix



distinction between procedural and substantive remedies. This produces four conceptions of rights inherent in claims to public welfare (see Figure 1). In its report on universal health coverage, WHO invites us to create “a vision for the future... because the paths countries choose towards universal coverage will necessarily differ.”<sup>22</sup> The matrix responds to that invitation by identifying the logic of the fundamental choices that confront us, the crucial differences between them, and the broad range of merits, or otherwise, of each. Some systems favor one compartment of the matrix rather than another, but many (including the UK system) comfortably occupy more than one compartment, depending on the circumstances of the individual case. The matrix is created as follows and we examine each compartment in turn.

### Community-procedural rights and remedies



Rights in the community-procedural segment of the matrix are concerned to scrutinize the “reasonableness” of decision-making and, if successful, to refer the decision back to public authorities to be reconsidered in the light of the court’s guidance. This describes the *accountability for reasonableness* (“A4R”) approach to priority setting.<sup>23</sup> The “right” is a guarantee of a fair and reasonable *procedure*. It is not a right to treatment itself. As the South African Constitutional Court has said, “Courts are ill-suited to adjudicate upon issues where court orders could have multiple social and economic consequences for the community” and impact adversely upon others whose interests are not known to the court.<sup>24</sup> Recognizing the opportunity costs inherent in public health promotion, the objective is to ensure that fair procedures have identified relevant matters and weighed and balanced them properly.

Procedural *rights* must be more than mere promises of good intentions. For example, Thames Valley National Health Service (NHS) commissioners have had a procedure in place for almost 20 years to balance these claims within a non-statutory “priorities committee,” by means of policy recommendations to local health care commissioners. The committee is subject to standing procedures on membership, regularity of meetings, cross-section of expertise, quoracy, voting rights, submission of evidence, and so on. The committee of 30 people includes NHS clinicians and managers as well as a lay chair, legal advisor, and ethical advisor, and reviews treatments that local stakeholders submit for consideration.<sup>25</sup> The committee is guided by a clinical effectiveness team, which produces a meta-analysis of the clinical research available in respect of treatments under consideration. This health technology appraisal is paid for by contributions from the Thames Valley commissioners, although the priorities committee’s work is unpaid.

As a means of generating fair, consistent, and transparent decisions, the committee is guided by the Thames Valley Ethical Framework of eight principles: (1) equity, (2) health care need and the capacity to benefit, (3) evidence of clinical effectiveness, (4) evidence of cost effectiveness, (5) the costs of the treatment and opportunity costs, (6) community needs, (7) national policy directives and guidance, and (8) exceptional cases.<sup>26</sup> The committee has created a suite of policy guidance to assist local health authorities which, in the majority of cases, CCGs adopt without modification. The guidance supplements National Institute for Health and Care Excellence (NICE) technology appraisals and covers a range of treatments from assisted conception to gender reassignment, percutaneous pulmonary valve implantation, lung metastases, bone-anchored hearing aids, and aesthetic/cosmetic surgery.<sup>27</sup> In each case, local clinicians are invited to submit evidence to the committee in writing and in person. This generates productive dialogue between decision-makers at the patient and community levels and broad cooperation between clinicians and resource allocators. Applying the ethical framework, the committee may recom-

mend that commissioners purchase treatment for the community or decide that the treatment is low priority because, for example, it is too expensive, the clinical evidence is poor, or better treatments are already available. A low-priority treatment is not normally funded unless individual patients will derive significant clinical benefit (see below). The current Thames Valley Priorities Committee commenced work in 2013 and has developed around 70 policy recommendations. Its predecessor, the South Central Priorities Committee, developed more than 100. Policy recommendations are constantly reviewed and updated. Because NHS commissioners must follow NICE's guidance (as discussed below), the priorities committee does not consider topics previously appraised there. The Thames Valley system is less sophisticated (and less expensive) than a NICE technology appraisal, but it is based on the same logic and purpose.<sup>28</sup> Systems like this confer community-procedural *rights and remedies* to the extent that their recommendations and processes command respect and recognition in judicial review.

Judicial review in the UK often favors this community-procedural approach. It acknowledges the constraints on the judiciary in terms of accountability and technical capacity, yet subjects the decision-making process to proper scrutiny in respect of the factors considered and the transparency of the process. In England, the NHS Constitution has codified the "hard-look" judicial review principles developed by the courts so they are binding throughout the NHS. Today, the NHS Constitution describes patients' procedural rights to transparent and accountable decision making.<sup>29</sup> This is a good example of "destabilisation rights" in which judicial intervention provokes a reconsideration of long-standing policies which have never been subject to critical re-evaluation.<sup>30</sup> As Tushnet says, recognizing strong social rights but enforcing them only through weak (that is, non-substantive) remedies may be attractive for developing "human capital" in social welfare rights and a constructive relationship with public authorities.<sup>31</sup> This defers to reasonable *systems* for decision making. The High Court of Israel took the same view in a challenge

to a decision-making tool applied to assist decisions about expensive cancer treatment where the clinical evidence was incomplete. Conceding the breadth of reasonable views surrounding these questions, it said:

*It is not up to us to recommend the adoption of one system of prioritization over another, as long as the current criteria comply with the provisions of the National Health Insurance Law, and are based on relevant and reasonable considerations.*<sup>32</sup>

Importantly, however, procedural review is complicated at the extremes. At one extreme, "hard look" scrutiny could be so intense as to browbeat decision-makers into conceding every claim. If every case is referred back to be reconsidered, then public authorities may be so intimidated by the courts that they concede every challenge. Clearly, this would be a sham; it would be in effect a *substantive-rights* response. The proper balance in UK law has been shaped by the case of *R v North West Lancashire Health Authority, ex parte A, D & G*, in which applicants for sex reassignment surgery succeeded in judicial review because the public authority failed to demonstrate that its refusal to fund the treatment had considered all the relevant circumstances fairly.<sup>33</sup> For example, it had demanded clinical evidence of effectiveness from randomized controlled trials when none were likely to be available for such a small cohort of patients, and it had failed to take into account the patients' own particular needs. Instead, it introduced a blanket ban on sex reassignment surgery. The court overturned the ban because a rational decision-making framework should have considered such questions.<sup>34</sup> Crucially, recognizing the nature of the treatment, it did not order that treatment be funded. Rather, it insisted upon fair and transparent systems for decision making.

At the other extreme, some jurisdictions prefer procedural review so weak as to render decision making unchallengeable. For example, the Supreme Court of Ireland has refused to go beyond a *declaratory* remedy. In *TD v Minister for Education*, education and health authorities had given specific undertakings to the High Court that particular children's health and education services

would be provided. However, the undertakings were not performed for many years and the matter was returned to the court for a mandatory remedy.<sup>35</sup> The trial court found that the timetable for implementation had been subject to “culpable slippage” through “manifest inefficiency,” which led to “the quite scandalous situation which has now obtained for years.”<sup>36</sup> The court ordered that the minister “lives up to his word and carries it into effect... within the time scale specified...” It stated that it was not making or influencing policy; rather it was requiring the public authorities to adhere to policy of its own making. However, the Supreme Court of Ireland emphatically rejected this response and set aside the mandatory order. Chief Justice Keane said “the granting of an order of this nature is inconsistent with the distribution of powers between the legislative, executive and judicial arms of Government mandated by the Constitution.” Even though the order simply enforced the executive’s own policy, it was unacceptable for precluding its right to vary and flex the policy without judicial approval. Justice Murray said the consequence of a mandatory declaration “would be to undermine the answerability of the Executive” with the danger that a minister “would be bound to respond that his hands were tied by an Order of the High Court...” Democratic judicial review, he said

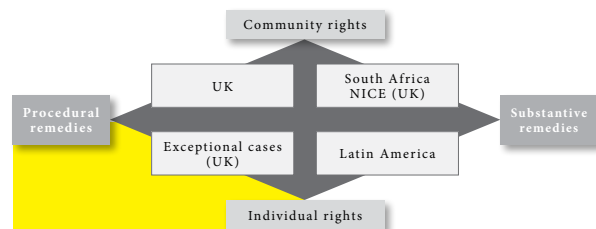
*does not... give the Courts jurisdiction to exercise rather than review Executive or legislative functions. Judicial review permits the Courts to place limits on the exercise of Executive or legislative power not to exercise it themselves. It deals with the limits of policy, not its substance.*<sup>37</sup>

But this declaratory-only response may be so ineffective as to rob the right of any meaning.<sup>38</sup> Although it exposes the authority to public opprobrium and may lead to better administrative standards in the long run, it does nothing for the litigants in question and may appear to render pointless the considerable time and expense of litigation. Clearly, then, application of the community/procedural response must be alive to these dangers at the extremes.

Also, many courts hesitate as the political and financial dimensions of the complaint expand. We

have noted how health care systems are struggling from austerity driven by the politics of neoliberalism. In an English case, for example, a public authority challenged the sufficiency of its annual financial allocation from the central government treasury. The House of Lords rejected its claim. The challenge was to the exercise of political judgment. Deferring to the authority of Parliament, the Law Lords said that it was constitutionally inappropriate to quash financial planning guidance by the secretary of state, implicitly approved by Parliament: “these are matters of political judgment for him and for the House of Commons. They are not matters for judges.”<sup>39</sup> Even with this *procedural* review, therefore, courts struggle to adjudicate between the “polycentric” claims of competing government departments.<sup>40</sup>

## Individual-procedural rights and remedies



A comprehensive resource allocation system must also be capable of reassuring *individual* patients as to its competence and, essentially, its compassion and humanity. A necessary consequence is that a general policy not to fund a treatment must be supplemented by a procedure for reviewing individual patients who possess plausible evidence that their circumstances merit an exceptional response. This is an *individual-procedural* right in the sense that it cannot guarantee access to treatment irrespective of cost. Yet it can reassure individuals that their individual circumstances have been considered properly in a way that is not possible when decisions are made at the community level. The argument is not that the patient has an exceptional *illness*. Rather, it is that the patient’s circumstances are such that they will derive significant *benefit* from a treatment not normally visible under the assessment made within the community-procedural approach.

Individual-procedural rights applications

should be *exceptional*. Exceptional cases have opportunity costs of their own: inescapably, “exceptionality” procedures require considerable commitment from doctors and managers with other demands on their time. For this reason, the patient and doctor present evidence that *this* patient is likely to derive significant clinical benefit from *this* treatment. For example, principle 8 of the Thames Valley Ethical Framework promises that:

*There will be no blanket bans on treatments since there may be cases in which a patient has special circumstances which present an exceptional need for treatment. Individual cases are considered by each respective CCG [Clinical Commissioning Group]. Each case will be considered on its own merits in light of the clinical evidence. CCGs have procedures in place to consider such exceptional cases through their Individual Funding Request Process [IFR].*

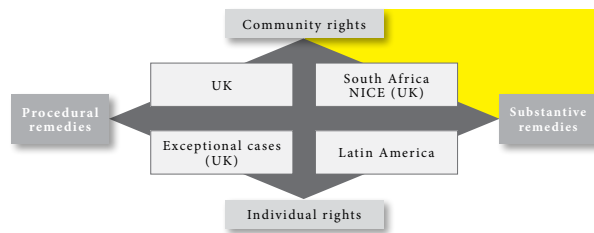
This is supported by a system in which exceptional funding applications are submitted as Individual Funding Requests, together with supporting clinical evidence, to an IFR panel. This system was challenged in *AC v. West Berkshire Primary Care Trust*.<sup>41</sup> The applicant was a male-to-female transgender patient who had received the treatment recommended locally. The patient had received hormone therapy intended to develop breast tissue, but remained dissatisfied with her body shape. Accordingly, she applied for prosthetic breast enlargement. However, the IFR panel rejected the application because this treatment is not available to women generally and it would be unfair and inconsistent to offer it to this patient as an exceptional case. Was it fair to compare this patient’s rights with those of the general community of women with similar concerns or, as she argued, should her position be compared to the much smaller number of transgender women undergoing male-to-female transition? There is merit on both sides, but the court found for the health authority and endorsed the reasonableness of its refusal to fund this treatment in fairness to the larger community of “natal” women (as the court described this group).

By contrast, in *Otley v Barking and Dagenham*

*PCT*,<sup>42</sup> the applicant was a lung cancer patient who had not responded well to the normal treatments. She had paid for experimental treatment with Avastin, more with a view to extending her survival by a matter of months than in expectation of a cure. Otley argued that she should have access to Avastin paid for by the NHS on evidence that her biochemical markers following treatment indicated that it might extend her life and that she was young compared to other lung cancer patients. The court said that her response was sufficiently exceptional and the experimental treatment was preferable. Similarly, in *SB v. NHS England*,<sup>43</sup> the patient was a boy suffering from phenylketonuria (PKU) and autism. Untreated PKU damages intellectual development, and for most children it is effectively managed through a low-protein diet. However, the patient’s autism made a consistent dietary regime impossible and he argued that this made him an exceptional case (of about 0.03 percent of the population). The court agreed that NHS England was duty-bound to consider whether the patient should have exceptional access to sapropterin dihydrochloride (*Kuvan*), and referred the case back for reconsideration. Although this remedy is strictly procedural, its *substantive* implications for the defendants are obvious.<sup>44</sup>

These cases illuminate also how UK courts generally accept that exceptionality should rest on *clinical* evidence, rather than personal or social circumstances. For example, in *R (on app Longstaff) v Newcastle NHS PCT*, the patient suffered from hemophilia and had an understandable distrust of human blood products following his brother’s death from contaminated blood. However, with the improvement in techniques for removing blood viruses, his request to be treated with more expensive, genetically modified blood products was rejected because it was not clinically necessary.<sup>45</sup> Similar “exceptionality” discussions have occurred in cases of terminally-ill mothers who have requested treatment to extend their lives so that they might spend as much time as possible resettling their young children.<sup>46</sup> These troubling cases obviously cause considerable concern.

## Community-substantive rights and remedies



NICE provides an example of community-substantive rights. The institute was introduced as a *political* expedient to encourage greater consistency among health authority commissioners in England who were otherwise free to differ from one another. This created disquiet because it could give rise to different policies governing access to treatment between health authorities. Consistency has improved after regulations were introduced requiring commissioners to purchase all the treatments NICE recommends in its technology appraisal guidance (TAG).<sup>47</sup> NICE has published over 300 TAGs, and patients may seek judicial review to enforce entitlement to the listed medicines.<sup>48</sup> This political initiative is having increasing community impact as NICE expands its work. NICE also publishes non-mandatory recommendations and these too may have a *substantive* impact on community rights. In *Rose v. Thanet CCG*, NICE published non-binding recommendations concerning the freezing of human reproductive material for patients undergoing chemotherapy.<sup>49</sup> The defendant health authority failed to adopt the guidance because it disagreed with it, although it could not present persuasive reasons why. The court held this to be irrational. NICE is an internationally recognized authority; if a health authority intends to depart from its non-mandatory guidelines, it is entitled to do so if it can advance cogent reasons for its decision. The case was referred back to be reconsidered. Here too, although a *procedural* response, the community-substantive implications for the defendants are obvious because evidence of the quality the court demanded was unlikely to be available.

Judges may also create community-substantive remedies on their own initiative. For example,

in *Minister of Health v Treatment Action Campaign*, the Constitutional Court of South Africa ordered the state to remove restrictions on patients' access to the drug nevirapine, a treatment to reduce the risk of mother-to-child transmission of HIV, but left to government discretion how best to make it available.<sup>50</sup> So too, in a case involving large numbers of homeless people claiming constitutional rights to housing and shelter, the court ordered, without prescribing specific standards, that the defendants:

*within four months of the date of this order to deliver a report or reports under oath, stating what steps it has taken to comply with its constitutional and statutory obligations as declared in this order, what future steps it will take in that regard, and when such future steps will be taken.*<sup>51</sup>

Recognizing the political challenge raised by opportunity costs, this returns the matter to legislative policy-makers for a solution.

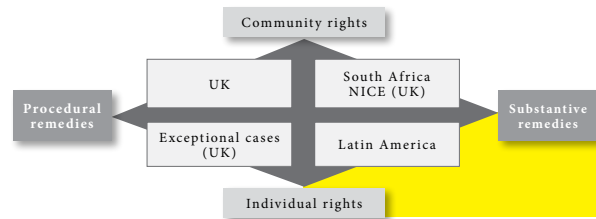
Similarly, the German Constitutional Court in the *Asylum Seekers' Benefits* case of 2012 considered the levels of welfare available to support asylum seekers. Welfare levels had not increased since 1993, and the court noted that inflation had eroded the real terms value of those benefits by 30%, rendering the level of subsistence incompatible with a "dignified minimum existence."<sup>52</sup> Although the court imposed a constitutional duty upon government to recalculate the benefits, it expressly left the ways and means of doing so to the discretion of parliament. The judges recognized the substantive rights of an entire class represented by these litigants and insisted on a response equally available to the entire group. In this way, it encouraged policies which grappled properly with the public dimension of the challenge. So too in the UK in the asylum seeker case of *Limbuela*. Government passed regulations which made it impossible for those who delayed their application for asylum to work or to obtain social welfare. The case involved an applicant for asylum who applied outside the time limits, without access to food, or shelter and who often slept rough, outside at night in the cold and wet. The House of Lords found that the action of the state amounted

to degrading treatment in breach of Article 3 of the European Convention on Human Rights. It decided that substantive social welfare had to be provided to everyone in these circumstances pending the resolution of their application for asylum.<sup>53</sup>

Perhaps the most ambitious attempt to introduce *community-substantive* rights has been from the Colombian Constitutional Court in a case that sought to set up new structures around the health care system, emphasizing the role of equality, accountability and participation.<sup>54</sup> Public Interest Litigation (PIL) in India promotes a similar community-substantive approach.<sup>55</sup> Judicial commissioners may be appointed to collect evidence and make recommendations to the court, but this too, while successful in some areas, is confronted by challenges.<sup>56</sup> For example, in PIL to reduce female infanticide and feticide the Supreme Court of India observed that “neither the State Governments nor the Central Government has taken appropriate actions for its implementation” (despite robust statutory regulations banning the practice).<sup>57</sup> Public authorities were ordered to implement the regulations, monitor their implementation, make quarterly returns of progress, take appropriate action, conduct public awareness campaigns, and introduce and enforce a code of conduct for public authorities. The public authorities were required to return to the court within three months to report on their progress. Similar action has been taken in respect of enforcing rights to education, health, and freedom from sexual harassment. Entering into collaboration to enforce existing regulations of significant public interest, based on reason and transparency, provides a good example of the power of PIL to encourage change.<sup>58</sup> On the other hand, the substantive-community response of PIL has not improved the systemic under-investment in health care by successive Indian governments.<sup>59</sup>

### Individual-substantive rights and remedies

Latin American jurisdictions are often cited as the paradigm example of individual-substantive rights. Within this logic, public rights are enforceable as if



they are private contractual rights arising within a contract for private health insurance. Community interests are not foremost. In Brazil, for example, it is reported that 97% of the rapidly increasing claims for access to health care are made by individual litigants requesting particular treatment.<sup>60</sup> In one case, the Supreme Federal Tribunal determined that drug eculizumab (Soliris), should be funded for an orphan disease at an annual cost per patient of more than US\$400,000.<sup>61</sup> But Latin America is not alone. The European Court of Justice has developed similar, individualized rights to publicly funded health care from the principles governing the free movement of services in the European Union. In a series of decisions, the court has promoted the idea that, as a general rule, patients are entitled to obtain treatment away from their own member state when (i) the treatment is included within the basket of services available and regarded as “*normal* in the professional circles concerned” and (ii) it cannot be obtained at home “without *undue delay*.”<sup>62</sup> As it said in *R (Watts) v. Bedfordshire PCT*, although resourcing restraints are relevant in the extreme event of a “risk of seriously undermining the financial balance of a social security system,” a refusal to authorize treatment in the EU was not justified by waiting lists based on clinical priorities without carrying out, in the individual case in question, an objective medical assessment of the patient’s medical condition.<sup>63</sup> The court continued,

*where the delay arising from such waiting lists appears to exceed in the individual case concerned an acceptable period having regard to an objective medical assessment of all the circumstances of the situation and the clinical needs of the person concerned, the competent institution may not refuse the authorisation sought on the grounds of the existence of those waiting lists, [or] an alleged*



*distortion of the normal order of priorities linked to the relative urgency of the cases to be treated.*<sup>64</sup>

Here too, by disregarding those not represented before the court, the court blinds itself to the opportunity costs upon the community of patients generally.<sup>65</sup>

The challenge of “individual-substantive” remedies is most sensitive in applications for expensive, “last chance, life-saving,” pharmaceuticals where evidence of efficacy is disputed. Measured on the quality-adjusted life year (QALY) scale, drugs of this nature may do no harm and may even assist a small proportion of patients for a limited time, yet absorb disproportionate resources otherwise available for other patients. Some might defend this as protecting an “existential minimum” commensurate with human dignity. Such an approach may be extended to patients with potentially fatal conditions by permitting substantive rights of access to treatments even when there is incomplete clinical evidence it will be effective. In *Nikolaus*,<sup>66</sup> the patient suffered Duchenne muscular dystrophy, a progressive and fatal disease for which there is no cure. The German Constitutional Court found that the constitution guaranteed those suffering a life-threatening disease for which there was no generally accepted treatment, access to medically approved treatment, even if a positive influence on the disease was unlikely. However, a single-minded “rule of rescue” which ignores finite public budgets exposes the community to considerable risk.<sup>67</sup> Unrestricted individual-substantive responses are poor examples of Sabel and Simon’s “destabilisation rights,” which encourage a more secure and constructive platform upon which to exercise public duties.<sup>68</sup> The danger is obvious. Lack of restraint over individual-substantive rights, far from encouraging constructive “destabilisation,” could be destructive of the rights of the many.

The European Court of Human Rights (ECtHR) has taken the opposite view in respect of patients seeking life-saving treatment outside their own health system. In *N. v. United Kingdom*, the ECtHR reconsidered its “individual-substantive” rights approach previously adopted in *D. v. United*

*Kingdom*.<sup>69</sup> The case concerned an HIV-positive visitor to the UK who was offered full access to NHS treatment while staying in the country. When her visitor visa expired, immigration authorities sought to remove her, knowing she would be unlikely to receive further treatment in her home state. Retreating from their decision in the case of *D.*, the court declined to insist on a substantive remedy. Instead, it referred to the “search for a fair balance between the demands of the general interest of the community and the requirements of the protection of the individual’s fundamental rights...” It continued,

*social and economic differences between countries, entail that the level of treatment available in the Contracting State and the country of origin may vary considerably... [However] Article 3 does not place an obligation on the Contracting State to alleviate such disparities through the provision of free and unlimited health care to all aliens without a right to stay within its jurisdiction. A finding to the contrary would place too great a burden on the Contracting States.*<sup>70</sup>

This denial of individual-substantive rights is difficult, but it acknowledges the macro-implications to states of unrestricted rights of access. Unattractive as it is from a patient-centered perspective, it clearly locates its analysis within a community-based approach to rights.

## Conclusion

Is judicialization a friend or a foe? The rights matrix illuminates the range of approaches available to courts, their costs and benefits. If we accept the framework issues discussed above, that is, that opportunity costs engage everyone’s rights and a central objective of public welfare rights is to mitigate health inequality, then the logic of the community-procedural approach (“A4R”) is the most compelling starting point to preserve legislative political will and promote community rights. Equally, a number of factors may modify this ideal. Community-procedural approaches are most likely to succeed in an environment of trust and dialogue

between health managers and judges, supported by satisfactory priority-setting systems. But this approach cannot always dominate all others. First, even within the community-procedural dimension, *individual* circumstances sometimes merit consideration for exceptional clinical reasons. Second, especially in serious cases of hardship, a substantive approach to *community* interests may be justified when entire groups of patients have been left behind. Indeed, as NICE demonstrates, community-substantive rights are also recognized as a response to the “politics” of resource allocation.<sup>71</sup> Lastly, in jurisdictions of limited trust between resource allocators and the judiciary, or where patients’ rights are thought to be inadequate, judges may feel justified to take a more robust, individual-substantive approach both for the benefit of individual applicants and, indeed, to attempt to destabilize the system to kick start improvement. However, as the funds available for public welfare continue to erode relative to demand, there is a serious threat to community interests if the individual-substantive approach becomes the predominant response.

Perhaps it would help if judges were more transparent about which approach they were engaging and why. The matrix illuminates the costs and benefits of judicial policy, and transparency would assist and clarify debate. That said, we should not overestimate the capacity of national courts to respond to these challenges alone for two reasons. First, while the primary concern of this discussion has been priority setting in health care, do not forget health *status* more generally, and the social determinants of health in particular. Yet this engages the polycentric needs of other departments of state with complimentary responsibility for the environment, employment, food, housing, and education,<sup>72</sup> about which, as we have noted, courts find adjudication very difficult. Second, as the “debt-state’s” obligations to private creditors expands and private investment underpins public welfare finances, the forum for dispute resolution will tend to move away from national judges into the less secure (and vastly more expensive) hands of international arbitrators.<sup>73</sup> The matrix is helpful, but for the future, as concern about health and

health care escalates, national courts and, indeed, national politics, may have a smaller role to play.

## Acknowledgments

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# Evolving the Right to Health: Rethinking the Normative Response to Problems of Judicialization

KEITH SYRETT

## Abstract

Judicial readings of the right to health—and related rights—frequently possess something of an “all or nothing” quality, exhibiting either straightforward deference to allocative choices or conceptualizing the right as absolute, with consequent disruption to health systems, as witnessed in Latin America. This article seeks to identify pathways through which a normatively intermediate approach might be developed that would accord weight to rights claims without overlooking the scarcity of health resources. It is argued that such development is most likely both to accompany and support a role for courts as institutions functioning within a society that is characterized by a deliberative conception of democracy.

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## Introduction: Why worry about judicialization?

As the debate on the recognition and enforcement of socio-economic rights, both within international law and as components of domestic constitutional frameworks, has shifted ground from the question of their justiciability to that of their scope and content, the likelihood of such rights becoming the subject of judicial determination has increased. In the case of the right to health (or cognate formulations, such as the right to have access to health care services), “judicialization” is a widely recognized occurrence with particular resonance for certain regions, such as Latin America, as is clearly attested by the contributions to this journal special section.

While frequently problematized, judicialization is a more nuanced phenomenon than accounts often suggest. In addition to serving a practical purpose as a mechanism for securing access to medicines and services which may have been denied or restricted by health care providers in violation of principles of equity or considerations of clinical or cost-effectiveness, adjudication in the courtroom may also fulfill a deeper democratic function. First, it can act as a forum for accountability, offering an opportunity for government to explain, and the public to understand, the steps taken (or not taken) in respect of realization of the right to health, thereby contributing to its progressive realization. In short, “it is a process that helps to identify what works, so it can be repeated, and what does not, so it can be revised.”<sup>1</sup> Even more broadly (and as noted hereafter), it can operate as a catalyst for public debate upon the need for limit-setting choices; upon the criteria upon which such choices might be based; and upon the particular choice itself. In this manner, courts can assist in “unblocking” political or managerial processes which might otherwise be unresponsive to legitimate demands for access to health care resources.<sup>2</sup> Hence, while the precise nature and impact of judicial intervention will, of course, vary according to the politico-legal context, it is certainly plausible, as noted by Brinks and Gauri, that “courts’ decisions do not so much stop or hijack the policy debate as inject the language of

rights into it and add another forum for debate.”<sup>3</sup>

Nonetheless, it remains the case that judicial decisions can also have a significant disruptive impact upon the pattern of services and treatments that are made available within health systems. Two examples from Latin America are illustrative of this possibility. Research into legal actions to obtain access to medicines in São Paulo, Brazil, found that a tendency to comply mechanically with judicial rulings meant that

*there is no assessment of whether it is the best treatment in terms of the cost/benefit ratio, whether the patient truly needs the medication requested, whether it can be replaced by another treatment provided by the [public national] pharmaceutical programs, or even whether provision of this medication breaks a fundamental law or principle of the health care system.*<sup>4</sup>

Similarly, an analysis of cases brought in the Constitutional Chamber of the Supreme Court in Costa Rica showed that around 70% resulted in access being granted to low-priority or experimental medicines that “can be described as providing “marginal” health benefits for very severe conditions at a high cost for the health care system.”<sup>5</sup>

On the basis of such studies, one might plausibly evaluate right to health litigation as an activity that falls well short of a rationalist ideal of policy-making, which centers upon the pursuit of optimal solutions—understood to be those which can objectively be demonstrated to maximize benefits and minimize costs—developed on the basis of comprehensive information about alternative courses of action.<sup>6</sup> Unfavorable comparisons are drawn with health technology assessment (HTA) as an evidence-based approach to problems of the allocation of scarce resources for health, founded upon instrumentally rationalist values of certainty, objectivity, method, and calculability.<sup>7</sup> Thus, the Pan-American Sanitary Conference has criticized regular use of the courts in Latin America for its propensity “to ensure access to health technologies, often without having verified their effectiveness, [but which] can distort the process of incorporating new technologies,” in contradistinction to HTA as

a transparent and rational means of safeguarding a right to health anchored in principles of equity, equality, and solidarity.<sup>8</sup>

The gradual evolution of HTA institutions across Latin America may, in due course, result in a reconfiguration of the socio-political environment in which decisions on allocation of scarce health care resources are made, as well as the criteria which underpin them. Even so, the constitutionalization of health rights across the region, coupled with the singular importance of such choices to individuals and their families, will render a continued role for courts inevitable; “the language of rights, the mechanism of courts, the intervention of lawyers, and the cumbersome tools of the law have become a permanent and prominent part of the policy-making landscape.”<sup>9</sup> It is therefore important to maintain a reflective attitude towards health rights adjudication as an activity of ongoing political, social, and economic significance.

Reflecting upon further avenues for future research and development in light of an analysis of health rights litigation (with a primary, but not exclusive, focus on Latin America), Yamin has argued that

*clarifying the normative foundations and conceptions of health will be critical in order for courts to provide a framework for facilitating appropriate decision-making processes relating to constantly evolving claims of what we owe each other in regard to health and health care.*<sup>10</sup>

This article seeks to undertake some initial steps in this direction, through critical consideration of possible normative bases through which the right to health might be further developed. The intention is not to offer a complete investigation of the matter, but rather to initiate a discussion of some mechanisms by way of which the right to health might stand alongside, and perhaps even facilitate, the types of “informed, well-thought choices involving trade-offs of societal values” that are increasingly imperative given the significant and growing problems of health system sustainability that prevail not only in Latin America, but worldwide.<sup>11</sup> As will be seen, several difficult issues remain unsettled,

providing fruitful scope for further analysis of, and debate upon, this highly complex topic.

### Reading the right to health against scarcity

Much important recent work in this context has focused upon the *impact* of health rights litigation, but the normative foundation of the right to health, described in 2011 as having generated “remarkably little literature,” has also received increasing attention.<sup>12</sup> Nonetheless, the tension between the existence of a presumptively conclusory right of access and the finite nature of resources for health care remains acute: indeed, one highly eminent scholar in the field has described the need to set priorities for allocation as a “blind spot” of the health and human rights movement.<sup>13</sup> Some authors have responded to this tension by expressing scepticism as to whether a right to health is feasible at all.<sup>14</sup> Others have noted that the fact of scarcity renders rights-based approaches of limited utility in addressing problems of health inequity *in practice*.<sup>15</sup> However, given the inevitability that rights to health will continue to be the subject of adjudication, this stance does not seem especially helpful: even if there are sound philosophical arguments for not according health (or access to health care) status as rights, the fact remains that they are presently so recognized, and are likely to remain so.

At the other end of the scale is a reading of the right to health that treats it as absolute, one which

*expresses demanding moral claims in a sort of ‘line item’ way, presenting each individual’s case peremptorily, as though it brooked no denial, no balancing, no compromise.*<sup>16</sup>

From this perspective, the fact of scarcity is irrelevant; the right must be upheld irrespective of the impact upon resources and the broader common good. As Rumbold observes, few would adhere to this absolutist reading of the nature of rights (whether generally, or in the health context in particular).<sup>17</sup> Nevertheless, rights carry very significant weight, both as legal claims and as modes of political discourse, as captured in Dworkin’s

influential metaphor of rights as “trumps over some background justification that states a goal for the community as a whole.”<sup>18</sup> Institutional factors further reinforce this approach: adjudication in the courtroom tends to focus judicial—and public—attention upon the individual claimant, especially in systems (such as that of Brazil) where health rights claims are almost always made on an individual basis rather than as collective or class actions, and the court’s ruling applies only to the parties directly involved in the litigation.<sup>19</sup>

Although rights to health contained within domestic constitutional or international human rights instruments at base embody legal and discursive claims of a substantive character, it is possible for courts to afford some degree of protection to claimants through *procedural* means, such as obliging decision-makers to publish their decisions and the criteria upon which they are based, or facilitating participation in processes of decision-making. In these instances, it may be argued that the effect of adjudication is to enforce the conditions of the “accountability for reasonableness” model of procedural justice.<sup>20</sup> In this manner, adjudication can contribute to facilitating “social learning” as to the need for limit-setting in health care and the criteria which might underpin decisions in this context. This is valuable as a means of securing legitimacy for difficult choices, even in the absence of an agreed ethical basis for achieving justice in the distribution of scarce resources. This dimension of judicialization has been explored at length in the literature and will not be developed further here.<sup>21</sup>

When judges engage with the right to health from a substantive perspective, they might be said (with a degree of simplification) to take any of three positions on the scale outlined above. First, the mere fact of scarcity may straightforwardly defeat the rights claim outright, calling into question the feasibility of giving effect to the right in any circumstances. At the other end of the scale, the rights claim acts as a “trump”, with the consequence that such resources are allocated as are necessary to give effect to the claimant’s right, irrespective of the possible impact upon others who are not appearing before the court. Both of these judicial

stances might be regarded as problematic. The first seems to attach insufficient weight to the right as a claim *in law* and appears incompatible with the trend towards the justiciability of socio-economic rights. The second accords insufficient weight to the opportunity costs of giving effect to the right, and thus carries particular potential for disruption to the rational distribution of scarce resources within a health system.

### A middle ground? Proportionality and the right to health

However, between these two extremes exists a potential position in which judges may scrutinize the decision-maker’s rationale for failing to give effect to the right, with a view to ensuring that the justifications offered accord with broadly shared community values as to what is appropriate within the particular society in question. In such circumstances, the court seeks to establish that the decision-maker’s explanations correspond with “public reason”, which may be understood as reasonable judgments about what justice and good policy requires under the circumstances: that is, reasons which are publicly appropriate in a liberal democracy.<sup>22</sup> If so, the court determines that the putative infringement of the right is justified, and thus not unlawful.

Adoption of an approach along these lines requires that judges continue to afford protection to the individual’s right, which retains significant weight. This is so in two ways: first, once the claimant has demonstrated that a right is engaged, the burden of explanation falls upon the decision-maker to show that there are justifiable reasons for restricting the right. If such explanations are not forthcoming or do not convince the court, the decision will be deemed unlawful, at least until adequate justification *is* provided. Secondly, the right is to be realized to the greatest extent possible given countervailing considerations; put differently, the interference with the right should be no greater than is necessary to achieve the legitimate countervailing objective(s). But, while weighty, the right is not absolute and, in appropriate circumstances,



will yield to legitimate policy goals. This therefore creates space for judges to recognize and give effect to considerations of scarcity, given that equitable distribution of scarce resources is, at least ostensibly, a policy goal that free and equal citizens of a liberal democratic society can reasonably accept.

Kumm notes that this necessitates a “re-characterization” of the nature of rights, and of adjudication upon them.<sup>23</sup> The focus is not solely on the interpretation and application of legal principles, but also (and primarily) on the assessment of justifications, with the right operating not as a demarcation of the boundaries of governmental actions and decisions (in effect operating as a “fire-wall” to insulate legal claims from political activity which might negate or defeat them), but instead as a trigger for an inquiry into the justifiability of these boundaries. This approach thus connects to “the emergence of a transnational culture of justification” in which the authority of government to act rests not on the exercise of power, but rather upon the provision of cogent and persuasive rationales for its decisions and actions.<sup>24</sup> More broadly still, it links to accounts of legitimacy in conceptions of deliberative democracy which emphasize the giving, weighing, acceptance, and rejection of reasons to encourage reflection upon, and possible transformation of, preferences in a non-coercive manner. This is notable, given that deliberative approaches have been viewed as especially germane to addressing problems of legitimacy arising from the need to make difficult choices on the allocation of scarce health care resources.<sup>25</sup>

Various tools exist through which judges can give effect to an approach of this type. These include balancing, which is especially prominent in US constitutional jurisprudence, and reasonableness, which carries a variety of meanings permitting courts to adopt stances towards governmental decisions and actions ranging from extreme deference to intense scrutiny.<sup>26</sup> However, the most widely used mechanism is proportionality, which entails a multi-stage analytical process. Once a putative infringement of a right has been established, the government (or other duty-bearer) must show (1) that the actions, decisions, or policy which impact-

ed upon the right were in pursuit of a legitimate aim; (2) that the actions, decisions, or policy were a suitable means of achieving the aim; (3) that there is no less intrusive but equally effective means of achieving the aim; and (4) that the actions, decisions, or policy represent a net gain when the infringement of the right is measured against the level of realization of the aim (the balancing stage, or proportionality in the strict sense).<sup>27</sup> In this manner, proportionality review can function to construct the content of socio-economic rights (including those to health) in such a way that these express “a proper balance between conflicting considerations and reflect appropriate means-end rationality.”<sup>28</sup> It appears, therefore, to represent an obvious tool by means of which the excesses of judicialization in the health context can be restrained: indeed, it has been said to have “a disciplining and rationalizing effect on judicial decision-making.”<sup>29</sup> Its use would therefore better enable this activity to approximate rationalist modes of allocative decision-making, such as HTA.

As Gardbaum observes, the connection between proportionality, reasonableness, and balancing is close: proportionality amounts to a particular form of reasonableness (reasonableness as proportionality), and incorporates a particular form of balancing, that is “whether the value, benefits, or gains of attaining the purpose are weightier than the value, costs, or injuries incurred in achieving it.”<sup>30</sup> Each of the three tests can be fitted within a “particular conception of liberal democracy in which all government actions interfering with individual rights and/or autonomy must be justified in terms of public reason,” in which

*the task of courts is to ensure not that the government has reached the one correct resolution of a contested rights issue but that the required justification for its actions falls within the parameters of the reasonable.*<sup>31</sup>

Hence, if, as suggested below, commitment to a particular conception of democracy is a prerequisite to adoption of a middle way between scarcity and the right to health, any one of these tests might be a suitable candidate for courts to adopt.

However, the value of adopting proportionality as a standard for review, apart from its familiarity to judges and decision-makers, would seem to lie in the fact that it functions by “setting a series of ground rules for the lawmaker,” which the lawmaker may satisfy

*by demonstrably showing that he carefully set the aim of measures that infringe on social rights; that he then considered the availability of other measures less impairing to the right; and that he went through this process elaborately and openly, so that his choice is reviewable by the courts,*

although political choices continue to reside with legislature and government.<sup>32</sup> It therefore imposes a greater degree of structure and transparency upon decision-making than do the looser tests of balancing or reasonableness, and thus, while functioning as a substantive form of review (insofar as its application is triggered by alleged violation of a substantive right), it has significant procedural benefits, serving as a means of ensuring that the conditions of the “accountability for reasonableness” model are realized.<sup>33</sup>

Proportionality has secured status as “a dominant technique of rights adjudication in the world.”<sup>34</sup> It is regarded as a central component of a “global model of constitutional rights.”<sup>35</sup> Yet its meaning and applicability remain the subject of significant scholarly disputation.<sup>36</sup> Within the context examined here, the primary matter of contention is its appropriateness as a standard for adjudication upon socio-economic rights. For example, Contiades and Fotiadou, Gardbaum, and Young all note judicial resistance to its use in cases of this type.<sup>37</sup> A central difficulty resides in its utility in situations of scarcity. This is well captured by Möller, who argues that the test is redundant in socio-economic cases

*because in almost all circumstances the realization of those rights requires scarce resources; therefore any limitation will always further the legitimate goal of saving resources and will always be suitable and necessary to the achievement of that goal.*<sup>38</sup>

However, this view has been challenged. Gardbaum argues that husbandry of scarce resources has not

been specified in constitutional documents or international rights instruments as a public policy objective which *can* legitimately be set against a right, and moreover that it is not always the case that limitation of a right *will* necessarily save resources. For example, permitting access to certain public health interventions (such as the provision of nevirapine for prevention of mother-to-child transmission of HIV/AIDS) may serve to reduce health expenditure in the longer term.<sup>39</sup> Furthermore, Contiades and Fotiadou emphasize that the “defensive aspect” of proportionality—protecting rights against limitations imposed by government, as outlined in Möller’s account—is not the basis of its applicability in cases involving socio-economic rights. Instead, it functions in more “creative” fashion, acknowledging the existence of competing legitimate interests and competition for resources, but ensuring that consideration of these by a decision-maker is undertaken “in a highly disciplined manner.”<sup>40</sup>

Disagreements of this sort are far from uncommon in the literature on proportionality. They demonstrate that the concept remains deeply contested.<sup>41</sup> This author would argue, therefore, that any agenda for future research on the right to health and the role of courts should incorporate close analysis of the applicability and utility of proportionality. This will allow for a more far-reaching assessment of whether it can plausibly function as a standard which facilitates a middle way between rights and scarcity in the manner suggested here.<sup>42</sup>

## Towards a relational reading of health rights

Deployment of the proportionality test as the standard of review in instances where health-related rights are undergoing adjudication is not the only plausible step towards reorienting these in a manner which would avoid both supine judicial deference to political and managerial choices in health care on the one hand, and a conclusory—perhaps peremptory—implementation of the right on the other. Rethinking the nature and meaning of the right to health itself represents a further avenue which might be pursued. Interestingly, there is

judicial support for an endeavor of this type in the following, written extra-judicially by South African Constitutional Court judge Albie Sachs:

*The progressive realization of socio-economic rights within available resources... indicates that a system of apportionment is fundamental to their very being. I am not sure as to the full implications of this distinction, both in terms of conceptualizing the nature of the right and in respect of determining appropriate remedies for a breach. Yet I am convinced that the exercise of a right that by its nature is shared, often competitively, with other holders of the right, must have different legal characteristics from the exercise of a classical individual civil right that is autonomous and complete in itself.<sup>43</sup>*

Sachs had himself given a pointer to the possible form that such a reconceptualization might take in the case of *Soobramoney v. Minister of Health (KwaZulu Natal)*, where he made the following observations:

*In all the open and democratic societies based upon dignity, freedom and equality with which I am familiar, the rationing of access to life-prolonging resources is regarded as integral to, rather than incompatible with, a human rights approach to health care... Health care rights by their very nature have to be considered not only in a traditional legal context structured around the ideas of human autonomy but in a new analytical framework based on the notion of human interdependence. A healthy life depends upon social interdependence: the quality of air, water, and sanitation which the state maintains for the public good; the quality of one's caring relationships, which are highly correlated to health; as well as the quality of health care and support furnished officially by medical institutions and provided informally by family, friends, and the community... Traditional rights analyses accordingly have to be adapted so as to take account of the special problems created by the need to provide a broad framework of constitutional principles governing the right of access to scarce resources and to adjudicate between competing rights bearers. When rights by their very nature are shared and interdependent, striking appropriate balances between the equally valid entitlements or expectations of a multitude of claimants should not be seen as imposing limits on those rights, but as*

*defining the circumstances in which the rights may most fairly and effectively be enjoyed.<sup>44</sup>*

Here, Sachs rejects the traditional “defensive” account of proportionality centered upon the judicial mitigation of limitations imposed by government. More broadly, and perhaps unknowingly, the judge appears to be articulating an approach to rights that is grounded in notions of relational autonomy, which have proved especially influential in the health care field in the context of care ethics and, more broadly, feminist bioethics.<sup>45</sup> This is:

*The label that has been given to an alternative conception of what it means to be a free, self-governing agent who is also socially constituted and who possibly defines her basic value commitments in terms of interpersonal relations and mutual dependencies. Relational views of the autonomous person, then, valuably underscore the social embeddedness of selves while not forsaking the basic value commitments of (for the most part, liberal) justice.<sup>46</sup>*

At least superficially, this conception, grounded in a view of the human condition and political life as fundamentally interdependent, seems to meet Sachs’ call for a “new analytical framework” that can incorporate allocative decision-making alongside, rather than in opposition to, health-related rights. As Tauber argues,

*rationing... assumes its moral force from a dual allegiance to notions of communal responsibilities of individuals (relational autonomy) and a social philosophy advocating equitable sharing of communal health care resources (distributive justice).<sup>47</sup>*

However, an important question is whether this approach is consonant with ideas of rights at all. For example, Tauber considers that a relational approach to autonomy “radically recasts widespread beliefs about individuality and rights. It shifts the burden of moral action on meeting obligations to others, as opposed to asserting self-defined liberties.”<sup>48</sup> Others working within the care ethics approach have been openly critical of rights for their (perceived) tendency to “insulate” existing structures of power

domination.<sup>49</sup> A further concern for relational theorists (and others) is the oppositional character of rights, which are seen in conflictual terms requiring determination of the weightier, “winning” claim and thus emphasizing the separation, rather than interconnectedness, of individuals from each other and from the collective.<sup>50</sup>

Can rights, then, be incorporated into a relational approach? One scholar who has taken on the challenge of addressing this question is Jennifer Nedelsky, who notes that “the practical issue is not *whether* but *how* the language of rights will be used” and who argues for a shift in understanding of the concept and how it is applied.<sup>51</sup>

Nedelsky argues that

*what rights do and have always done is construct relationships – of power, of responsibility, of trust and obligation... in defining and enforcing rights, the law routinely structures and sometimes self-consciously takes account of relationship;*

and she proposes that this structuring function should form the central focus of the idea of rights, their enforcement and interpretation.<sup>52</sup> From this perspective, she challenges the individualistic orientation of rights inherent in liberal political thought, rooted in “the image of protective boundaries as essential to the integrity and autonomy of the self [which] is deep and pervasive in Western culture.”<sup>53</sup> Rather, her goal is that

*the focus of analysis will shift from an abstraction of individual entitlement to an inquiry into the ways the right will shape relations and those relations, in turn, will promote (or undermine) the [collective societal] values at stake.<sup>54</sup>*

While Nedelsky accepts that this will not resolve all disagreements, given that the meaning both of rights and of the underlying community values they capture (such as equality, freedom, and adequate material resources) is contested and evolves over time, her argument is that those disagreements are better couched within a debate “in terms of why people think some patterns of human relationships are better than others... and what sorts of legal rights will foster those relationships.”<sup>55</sup> That debate

*might* end up according priority to individual over collective claims, but it would at least do so on the basis of justification of those claims, rather than “tacit assumption.”<sup>56</sup> This therefore returns us to the “culture of justification” and ideas of deliberative democracy which were sketched above and which will be explored further in the next section of this article.

Feasibility is perhaps the greatest obstacle to adoption of a relational approach along the lines Nedelsky suggests. Although she claims that there is scope to use existing legal systems, institutions, processes, and norms to give effect to the framework she advocates, Nedelsky acknowledges that it would amount to a “transformation,” a “gestalt-like change in how people see the world, in daily habits of thought as well as political theory and jurisprudence.”<sup>57</sup> In particular, it represents a counter-hegemonic challenge to the “dominance of the liberal consensus” on human rights, which is rooted in deeply held individualistic, perhaps atomistic, visions of autonomy.<sup>58</sup> Shifting the paradigm in such a way is clearly no straightforward matter. This is especially the case as the greater attention drawn by the relational reading to the contested nature of the societal values that underpin rights, and the different means by which these may best be given effect, tends to dilute the simplicity and absoluteness of a rights claim. Since it is these latter qualities that have made the right to health a valuable focus for campaigns for access, such as to treatment for HIV/AIDS, there would seem to be a lack of strong political incentive for claimants of health rights to endorse the relational approach.<sup>59</sup>

## Normative evolution and deliberative democracy

It might be concluded from the above discussion that, while normative evolution of the right to health in a manner that can accommodate the scarcity of resources is certainly possible, there remain awkward impediments to such development. At least for the present, the existence of these impediments means that work of a theoretical character on the normative basis of the right to health is un-

likely, *on its own*, to effect a transformation to the “all or nothing” quality of health rights litigation in practice. This is simply because, when confronted by such difficulties, it will be tempting for busy judges merely to reaffirm commitment to either of the activist or restrained positions identified above, rather than to seek to clear their own pathways through tricky normative territory in which, as practitioners rather than theoreticians, they are likely to be somewhat uncomfortable.

However, if the type of normative clarification and rethinking outlined here were to be accompanied by cultivation of a particular attitude to the role of courts within a democratic society, this would significantly enhance the prospects for development of a framework permitting proper judicial consideration of the interconnectedness of individual rights to health care and obligations to the community in circumstances of scarcity. The nature of that role has been alluded to above: a conceptualization of the courts as institutions contributing to and functioning within a deliberative democracy, rather than bodies whose determination of questions of rights is definitive and binding.

On this reading, the courtroom provides an arena in which argumentation, reasoning, and explanation for policies and decisions can be publicly advanced and scrutinized. The rationales put forward for judicial decisions seek to

*appeal to the political values [judges] think belong to the most reasonable understanding of the public conception and its political values of justice and public reason... that all citizens as reasonable and rational might reasonably be expected to endorse,*

and such decisions play an “educative” role, enabling wider “political discussion to take a principled form so as to address the constitutional question in line with the political values of justice and public reason.”<sup>60</sup>

Crucially, also, courts are viewed “as being not in a contestatory relationship with government but in a constitutional conversation with them,” with rights functioning not as absolutes or trumps but as standards of justification.<sup>61</sup> Hence, the determination of the meaning and applicability of rights is not

the sole province of the judiciary, since the legislative and executive branches also have an important part to play in deciding how to balance individual rights against competing rights and interests.<sup>62</sup>

The normative developments explored in this article clearly accord with a deliberative reading of democracy. As discussed above, proportionality is a judicial tool centered upon the provision of justification “in terms of public reasons, reasons of the kind that every citizen might reasonably accept, even if actually they don’t.”<sup>63</sup> Similarly, the relational approach proposed by Nedelsky connects closely to a deliberative conception. She notes that relationality requires “ways of continually asking whether our institutions of democratic decision-making are generating outcomes consistent with [basic] values.”<sup>64</sup> This connotes a “dialogue of democratic accountability” which is not premised upon the notion that certain values (rights) are trumps, but wherein those rights and the limits upon them are “open ended and shifting, requiring judgment and debate.”<sup>65</sup> For Nedelsky, therefore, accountability has a “back-and-forth” quality in which not only the institutions of government participate, but which also engenders wider public debate upon the societal values at stake, the kinds of relationships that would foster those values, and whether differing versions of rights would structure relations differently.<sup>66</sup>

Yet, while, as suggested above, there is *potential* for courts to act as mechanisms through which effect can be given to institutional—and by extension, public—deliberation of the type Nedelsky envisages, it might be objected that their engagement in such an undertaking is problematic, in that it is insufficiently democratic, since judges are usually unelected. Moreover, the act of adjudication (especially, perhaps, the act of interpreting the meaning of constitutional provisions) necessitates specialist legal training and expertise, which can render it relatively inaccessible to the wider public. These general concerns may be exacerbated by the particular socio-political environments in which courts function. For example, in an analysis of Latin America, Hammergren points to a tendency towards insulation from external debate, a lack of

transparency and accountability, and a failure to appreciate the broader societal impacts of judgments, none of which are properly consonant with a deliberative approach.<sup>67</sup>

It is notable, however, that other scholars have expressed much greater confidence in the deliberative capacity of courts, both in Latin America and elsewhere.<sup>68</sup> Here again, therefore, there exists much scope for further theoretical analysis and empirical investigation.

## Conclusion

Gargarella has observed that, while articulation of a justifiable role for courts in health rights cases that “defies the ambiguous and unattractive notions of judicial restraint and judicial activism” is certainly possible, it nonetheless represents a “challenge” to conventional views on judicial review, the separation of powers and democracy.<sup>69</sup> The analysis presented in this article serves strongly to reinforce this assessment. Development and clarification of the normative basis of the right to health in a manner which would enable courts to respond sensitively and appropriately to conditions of scarcity is manifestly a highly demanding task. However, grasping this nettle will continue to be necessary, given that further health rights litigation—both in Latin America and across the globe—is inevitable and that problems of allocation within health systems will continue to manifest themselves as a consequence. The modest intention of the present author has been to trace certain pathways through which this challenge might be addressed. It is hoped that this will provoke others to further engage with and evolve this important work.

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# Realizing the Fundamental Right to Health through Litigation: The Colombian Case

AQUILES IGNACIO ARRIETA-GÓMEZ

## Abstract

Colombia has made significant progress in the recognition and protection of the right to health. Using litigation—a structural element of the democratic Colombian design—many people have had to fight in order to enjoy effective access to health care. Such litigation has proven a pacific and democratic way to protect a constitutional principle: health as a fundamental and justiciable right. In 2008, in the wake of thousands of individual rulings on the right to health, Colombia's Constitutional Court issued a structural decision, T-760 of 2008, ordering government entities to identify flaws that made the country's health system outdated and inequitable and to take correctional measures. In the years following this decision, Congress and the executive branch have increasingly included a rights-oriented perspective in public policies. The Colombian case reveals judicial intervention as a legitimate way to extend pressure on the government to act according to constitutional boundaries. Although there is still a long road ahead, public institutions responsible for health care are now on a constitutionally acceptable track.

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After many political and judicial debates in light of the 1991 Constitution, Colombia passed a statutory law in 2015 (Law 1751) recognizing the constitutional right to health.<sup>1</sup> This law was the result of a long battle between those who consider health a fundamental right that is enforceable by the courts and those who claim that health is a social right that should instead be addressed through public policies set by the legislative and executive branches. This battle has taken place in one of the oldest uninterrupted constitutional jurisdictions.<sup>2</sup> This law was also the result of thousands of judicial decisions on the right to health issued over the span of more than two decades, especially Decision T-760 of 2008 in which the Colombian Constitutional Court ordered a restructuring of the health system. The purpose of this paper is to outline this constitutional process of change in Colombia and explore the role of judges in promoting the effective enjoyment of the right to health, mainly through structural orders.

First, it is worth highlighting the research to date on the impacts of judicial remedies. The literature on the justiciability of social rights has focused mainly on the implementation and impacts of structural judgments.<sup>3</sup> Debate over these impacts is relevant because in social rights cases, it is important to determine not just whether a right is being violated but also what to do to address the violation. It is a complex task to recognize both a good judicial order and a suitable process of enforcement. Some scholars have commented that judicial opinions, besides having a direct impact through the adopted remedies, can also have indirect and even symbolic impacts.<sup>4</sup>

There has been much academic debate about the impact of Decision T-760 of 2008, but we do not yet have adequate tools to settle this dispute. For example, César Rodríguez-Garavito has argued that along with Mark Tushnet's two criteria—the strength or weakness of judicial measures in terms of the scope of the orders and the degree of obligation—the type of compliance with the measures chosen by the court must also be taken into account.<sup>5</sup> It could also be argued that the number

of interests involved in and affected by a judicial decision, whether directly or indirectly, is a critical measure of a decision's impact. For instance, the protection of the rights of persons in a situation of displacement involves a particular part of society, the people close to them (family, friends, and so forth), and the authorities and organizations that deal with displacement. In contrast, the protection of the fundamental right to access health services affects all people in a given country, as well as all health providers and other stakeholders in the sector. In the first case (displacement), it is easier to enforce a court's orders, while in the second (health services), it is much more complex. The number of actors involved in the case and their relative power affects compliance with the court's judgment.

In this sense, the degree of resistance to the fulfillment of judicial orders varies between a scenario in which broad public and private interests (both national and international) are at stake and one in which the work and autonomy of smaller sectors of the local bureaucracy are at issue. This difference in contexts affects the measures that a court must order and the intensity with which it must demand compliance. It also affects the degree of the counter-majoritarian objection and the level of self-restraint that is expected of the judge. This last criterion of analysis is crucial to determining the real impact and advantages of structural rulings such as T-760 of 2008 in Colombia. As will be shown, the Uribe administration (2002–2010) tried to overrule the structural orders of that ruling, declaring a state of economic and social emergency and using exceptional executive powers to change the legal framework. Later, under the Santos administration (2010–2018), the minister of health and social protection, Alejandro Gaviria, has had to deal with the pharmaceutical industry to comply with orders to ensure access to medicines that people require.

The first part of this paper presents the history and context of the right to health in Colombia and the structural remedies adopted by the Constitutional Court in response to thousands of individual judicial orders. The second part presents

some achievements and setbacks after the structural judicial intervention (T-760 de 2008). The final section draws some conclusions.

### The foundations of the right to health in Colombia and individual lawsuits as a tool for access

*After more than 200 years, it is clear that the separation of public powers is not enough warranty against abuses. Nor is the detailed enumeration of the faculties of those who hold authority. What is missing is to attribute power to the citizens and create mechanisms for them to exercise it directly, peacefully ... : transfer power to the regular citizen so that when he or she has been treated arbitrarily, that person has an alternative to aggression, incendiary protest or submissive and alienating resignation ... That a single mother may ask the judge to order a school to promptly admit her son and cease discrimination against him. That medical care could not be denied to a poor person whose life is in danger, and a judge could order a hospital to provide immediate assistance to him ... In short, let arbitrariness cease.*

President César Gaviria, National Constituent Assembly, February 5, 1991

As mentioned above, the acceptance of health as a fundamental right in a 2015 statutory law enacted by Congress was the end of a long road of legal battles. The principal tool for realizing health as a fundamental constitutional right in Colombia has been individual litigation in the form of the *tutela* (writ of protection). Since the 1992 creation of the Constitutional Court, *tutelas* have been used by thousands of people to make claims regarding specific medical needs and to secure access to relevant health services. Through the *tutela*, individuals (or their relatives, friends, or lawyers) judicially claim their right to health in connection with their rights to life and dignity. Although the justiciability of the right to health was under debate by scholars and political leaders in the early 1990s, this kind of litigation was expected and common. Citizen litigation had become a structural part of the Colombian democratic design: to judicially claim a

constitutional right is as political and democratic an action as going to the polls or forming a political party.<sup>6</sup> Citizens were making use of their new constitutional powers.

At the end of 1993, through Law 100, Congress created the foundations of an “integral social security system” based on the principles of efficiency, universality, solidarity, integrality, unity, and participation (art. 2). Law 100, among other things, created a new health system for the country; this system was a mixed one, governed by the state, that included the participation of both public and private health care providers. The system was divided into two regimes: a contributory regime that provided full coverage to those who made financial contributions directly to the system, and a subsidized regime that provided partial coverage to those who did not contribute directly because of their low income. The contributory regime had access to all of the services included in the country’s benefits plan, while the subsidized had access to only some of them. This differentiation was temporary in order to allow the system to become financially viable (art. 162 of Law 100). For the contributory regime, the Constitutional Court held that health care providers were constitutionally obliged to guarantee access to required medical services and had the right to collect the cost of the services that were not covered by the benefits plan (then known as the Plan Obligatorio de Salud and today entitled the Plan de Beneficios en Salud). The order in these cases was “to take measures” within 48 hours to authorize the required medical service. For the subsidized regime, it held that health care providers were constitutionally obliged to inform, guide, and accompany patients in securing the required medical service through the public network and local authorities.<sup>7</sup> In 2000, the government extended the court’s protection, requiring institutions of the subsidized regime to deliver directly to patients any necessary medicines that fell outside the benefits plan (as in the contributory regime) and to collect reimbursement from the state (through local authorities) if necessary.<sup>8</sup> In 2001, the Constitutional Court decided to grant the same

protection to children regardless of which regime they were enrolled in.<sup>9</sup>

The first years of the 21st century were bittersweet. On one hand, the court finally unified the rules for cases concerning health services not covered. People and institutions had certainty regarding what the outcome of their claim would be and which *tutela* judicial order would be enforced.<sup>10</sup> But at the same time, different actors from the health system (some insurers, some providers, and even some patients) started to take advantage of the executive and administrative regulations and its loopholes.<sup>11</sup> The regulation allowed insurers, through their scientific technical committees, to approve and provide required medicines that fell outside the benefits plan, but they were not allowed to do the same with other medical services. According to the regulation, surgeries, laboratory tests, and other medical services could not be approved, despite the clear constitutional obligation. In other words, the system promoted litigation as a way to access required services. In fact, the *tutela* was seen in those days as a “prerequisite” to accessing the health system. For the “good” insurers, this situation was evidence of the system’s dysfunction. For the “bad” ones, it was a business opportunity. All this was clearly reported by the national ombudsman, who showed that, in most cases, the denied health services were included in the benefits plan (56.4% in general; 89% in the case of surgeries).<sup>12</sup> In other words, health *tutela* claims—a way to access not-included services—had become a way to access even the included ones.

By the turn of the century, after substantial jurisprudence from the Constitutional Court regarding the right to health, both as connected to the right to life and subsequently as an autonomously enforceable right, the court was receiving an increasing number of health-related *tutelas*. In fact, the right to health went from being an exceptional case of justiciability in 1992 to being the most claimed right by *tutela*.<sup>13</sup> Different analyses identified various causes, including regulatory problems (vacuums, contradictions, and perverse incentives); poor supervision; and a lack of control and the absence of political will to structurally address the

situation. For example, the benefits plan became obsolete (it had not been reviewed since its inception) and had a lot of gray areas (namely, doubts about which benefits should be included). It was becoming clear that the routine use of individual claims via *tutela* were leading to structural problems (including an obsolete *vade mecum*, regulatory gaps, inefficient and inadequate management of resources, and a lack of vigilance). The Constitutional Court understood the magnitude of this problem, which required structural solutions rather than specific orders for individual claims.

Thus, judicial rulings on the right to health began to seek structural solutions in addition to individual protections for the specific cases at hand, which would correct violations and, as a result, extend the right to health to more people. One such opinion was T-344 of 2002, which created a rule for resolving conflicts between treating physicians and health insurers with regard to health services being requested.<sup>14</sup> It was a judicial position that referred to constitutional rights in general, regardless of whether they are social, economic, or cultural, or whether they are procedural or freedom rights. In addition, the court’s jurisprudence established that every fundamental right, despite its nature, has facets that imply the decisive action of the state through the use of critical public resources. This position of the court was set in a case on the protection of a disabled person seeking mobility access to public spaces. This ruling, T-595 of 2002, established that when the protection and effective guarantee of a fundamental right depends on public policies, the minimum constitutional conditions of such a policy can be judicially claimed.<sup>15</sup> Eventually, Colombian constitutional case law evolved to protect the right to health in many instances, finally recognizing health as a fundamental right justiciable by itself.<sup>16</sup>

Subsequent legislative advances paved the way for the court’s structural judicial decisions. At the beginning of the 21st century, national, regional, and international debates were taking place on social rights.<sup>17</sup> Colombia’s Congress remained silent for many years, but its implicit support for the Constitutional Court was evident through its

rejection of bills that tried to overrule constitutional jurisprudence or that tried to limit the *tutela*. In 2005, however, Congress began to engage and passed a law to improve the care of people suffering from “ruinous or catastrophic” diseases, especially HIV/AIDS (Law 972 of 2005). Two years later, it passed a law amending the health system’s regulatory framework, which had been established in 1993, and expressly supporting the jurisprudence of the Constitutional Court and the use of the *tutela* to enforce the right to health (Law 1122 of 2007). However, despite the harmonious view shared by the judiciary and Congress, the right to health continued to be violated in a number of scenarios. By 2008, evidence of problems in the health care system was overwhelming. Indeed, by that point, the Ombudsman’s Office had, for three years running, been asking the Constitutional Court to declare the health system to be in an “unconstitutional state of affairs.” Those years (2005–2008) were a turning point, representing the period when the largest number of *tutelas* were filed and when the proportion of health claims as a percentage of all *tutelas* reached its peak. In addition to complaints and ambiguities, the benefits plan remained unequal and had not been updated for ten years.

#### *Decision T-760 of 2008*

The Constitutional Court addressed these issues in Decision T-760 of 2008. This ruling resolved 22 different claims that captured some of the most critical problems of the health system. With this decision, the court reiterated its previous opinions and issued a set of structural orders to fix the basic problems of the health system, in addition to taking measures to protect the right to health in the specific cases analyzed. Most of the orders were general ones that were created not by the court but by experts and public agencies that participated in the judicial process.

In T-760, which was considered by some authors a landmark judgment, the court concluded that the existence of flaws in the regulation of the health system represented a violation of the state’s constitutional obligations to respect, protect, and guarantee the right to health.<sup>18</sup>

First, the court identified various general problems in the contributory regime. To begin with, there was a high level of uncertainty regarding the health services that were included in and excluded from the current benefits plan. The plan had become obsolete. Furthermore, the majority of judicial decisions protecting access to health services for citizens were aimed at guaranteeing access to services expressly included. Lastly, there was no administrative procedure that allowed patients to access health services (as opposed to medications) not included in the plan, such as surgeries and other medical interventions, to effectively enjoy their right to health.

Second, the court recognized a structure tending toward inequity within the health system. It considered it unacceptable that the government had not designed a program to effectively overcome inequalities between the subsidized and contributory regimes, as part of its constitutional duty to move progressively toward the expansion of insured services (the fundamental right to health is guaranteed to everyone on an equal basis).

Third, the court considered the sustainability of the health system. Among the 22 cases, the court selected two *tutelas* filed by health care providers against the Ministry of Health and regulatory agencies alleging inadequate and delayed flows of financial resources into the system. These two cases were unusual. Normally, *tutelas* are used by patients who sue health care providers or insurers, but in these cases, the insurers sued the regulators, using the power of the *tutela* as a guarantor of the right to health of their clients. The problem identified by the court was the excessive red tape required in order for health care providers to receive reimbursements.

Fourth, the court identified a lack of available information when it came to citizens’ choice of health care providers. The need to remedy information asymmetry in the health care market was obvious. Patients needed adequate information to choose a provider that would be best for them. In this regard, the court ordered health care providers to make relevant information available to users before they joined the providers’ schemes.

Finally, the court made a structural ruling to assure that the objective of universalizing the coverage of Colombia's health system was achieved. It ordered the Ministry of Social Protection to adopt the necessary measures to achieve the goal of sustainable universal health coverage by 2010.

Although some of the orders were specific, most called for changes at the structural and policy levels. The court further emphasized that all the measures should be undertaken in a transparent and participatory manner and should be based on best evidence. In fact, T-760 recognized the duty of judges to support and respect the decision of when to limit the scope of the right to health, provided that such a decision was made on reasonable, public, transparent, and scientific grounds, including the possibility of an appeal based on better arguments.

But in those cases in which it is legitimate to impose limits and deny requested services, does it mean that the person denied treatment should feel that the system has turned its back on him or her? The court emphasized the need for procedures and processes that treated people with dignity, even when denying them care. This means that the system must acknowledge the seriousness of the situation faced by a particular patient and must assume a duty to inform, guide, and accompany that person through his or her health journey, in addition to providing services and compensatory guarantees. In other words, in a social state under the rule of law, it is possible to say "no"—but it should be a compassionate "no," not one that eviscerates the dignity of the other.

In response to T-760, the executive branch tried to reduce the scope of protection of the right to health recognized by the court. For example, it declared a state of emergency and enacted a set of executive decrees to "fix" the health system in its own restricted way, leaving aside the rights-based approach of constitutional jurisprudence and the political debate in Congress. These decrees were met with vigorous protest by unions, churches, health professionals, and others. The Constitutional Court later declared the decrees unconstitutional, forcing the administration to go to Congress to find

democratic solutions to the structural problems of the country's health system.<sup>19</sup>

## Progress and setbacks

The impact of constitutional jurisprudence on the protection of the right to health in Colombia is becoming evident. Thousands of people now live with dignity because a *tutela* has granted them access to a medication or medical service; indeed, many of these people would have died without such a judicial intervention.<sup>20</sup> Without individual rulings, it would not have been possible to achieve the current levels of protection and fulfillment of the right to health. But there were also a lot of critics of these case-by-case interventions in health policy, arguing that they lacked a broader perspective.<sup>21</sup> Thus, the structural remedies turn of the Colombian constitutional jurisprudence has embraced a new way to deal with the progressive realization of a fundamental right. T-760 enabled an analysis of health system controversies as part of a broader political system. It moved beyond the facts of individual cases to promote solutions that would overcome larger issues, such as the opportunity costs that regulatory policies allowed for several years without effective controls (for example, not providing timely health services to people with high-cost diseases, such as HIV/AIDS, to prevent them from getting worse). The court sought to go beyond protecting access to necessary medicines (which had made up the majority of *tutela* rulings at that time) to ensure the effective enjoyment of a higher standard of health for all Colombians.

Nonetheless, the situation remains far from perfect. The health system still has many problems. In a ranking based on an index of health outcomes conducted by the Colombian Association of Clinics and Hospitals, Colombia ranked 48th out of 99 countries, with a score of 80.6 out of 100.<sup>22</sup> Political debate on the right to health continues. There are even radical critical voices that have been arguing for a long time that the actual problem of Colombia's health care system is the liberal market-based model.<sup>23</sup>

But despite these problems and debates, Colombia faces a new legal scenario: the 2015 statutory health law—which defines the constitutional right to health as fundamental, autonomous, irrevocable, individual, and collective—has become the new common ground to settle disputes.<sup>24</sup> Health insurers and providers, as well as the three branches of power, have accepted these new rules. Decision T-760 of 2008 and the Statutory Health Act (Law 1751 of 2015) have become what Bruce Ackerman would call, respectively, a judicial “super-precedent” and a landmark statute that alter constitutional law without formally touching it.<sup>25</sup> This is an example of a “living constitution.”

There are two main observations to make. First, the health orders given by the Constitutional Court have favorably affected public policy. Second, the court’s T-760 ruling, on its own, could not have achieved these results—government and civil society support were also necessary.

Specifically, T-760 had at least three positive impacts: it helped establish the constitutional roots of the right to health and its justiciability (a living reform of the Constitution); it guaranteed better access to necessary health services; and it ensured that public health policies are rights oriented, including through the promotion of reasonable limits and public participation in decision making.

The following discussion explores some of the progress achieved in the health system in the wake of T-760.

### *Access to services*

Various government actions have been taken to remove barriers to access to health services. To improve access to medicines, one of the principal actions was a change in the pricing policy implemented from 2003 until 2013.<sup>26</sup> Changes in policy began to be discussed after the sentence, but it took a few years to implement them. Before 2013, medicines were priced using value-based pricing. This resulted in numerous high-cost medicines being paid for by the national budget. By 2013, two new types of regulations were adopted to price medicines. The first is a “supervised market freedom”

regime, which covers all medicines that are marketed in Colombia and included in a registry. The second regulation is a “direct control regime,” by which the National Commission for the Pricing of Medicines and Medical Devices establishes a maximum sales price for essential medicines, using the international reference pricing method.<sup>27</sup> According to the Ministry of Health, international reference pricing resulted in savings of approximately US\$1.5 billion between January 2014 and September 2017.<sup>28</sup> Controlling the high costs of medicines (some of the highest prices in Latin America) removes one of the greatest barriers to access. The policy changes and their impacts have been debated in both academic journals and national newspapers.<sup>29</sup> Oscar Andia, a member of the Colombian Medical Federation and director of the Colombian Observatory of Medicines, has described the deregulation policies of 10 years ago as “good for business but not for patients,” and has argued that the current pricing policy improves the sustainability of the system and removes barriers to access.<sup>30</sup> Another newspaper editorial strongly supported the government policy, describing it as necessary and reasonable.<sup>31</sup>

The number of *tutelas* addressing access to health care decreased after decision T-760 of 2008. Although health claims continue to represent a significant proportion of all *tutela* claims, they decreased from 37.56% of all claims in 2006 to 23.74% in 2014. There is evidence of new growth (26.57% in 2016 and 32.54% in 2017), prompting the court to declare that the administrative measures taken to avoid the use of *tutela* are not enough.<sup>32</sup> But there are signs that it is a “new wave” of health litigation related to new issues; the nature of the claims has changed.<sup>33</sup> Except for the case of specific health insurers with significant problems (such as Medimás), fewer claims regarding entitlement to services are being raised, and more are being made to overcome other barriers, such as transportation challenges, long waiting times to see specialists, and access to complementary services such as home care.<sup>34</sup> There is also evidence of significant differences in health protection levels among regions.<sup>35</sup> But there are still a large number of individual claims that have not

been studied. As the Ministry of Health informed the court, the *tutela* is not used in 97% of the services provided by the system.<sup>36</sup>

### *Rights-oriented policies*

Throughout the 1990s and early 2000s, the right to health was not “equal” to other rights. Other considerations were prioritized (such as investor confidence), even in cases where there were severe impacts on people’s health. Some government decisions during those years (such as the pricing policy) that were unreasonable even from an economic perspective posed significant barriers to access, especially for patients of the subsidized regime who suffered from costly illnesses, such as cancer. This scenario can be attributed to a power imbalance between patients and providers, with patients on the losing end. In the public debate, cost overruns due to inefficiency, corruption, and loopholes allowing providers to benefit financially from the health system were overshadowed by the costs of health services needed by patients as ordered by *tutelas*, despite the fact that the former were clearly higher.<sup>37</sup>

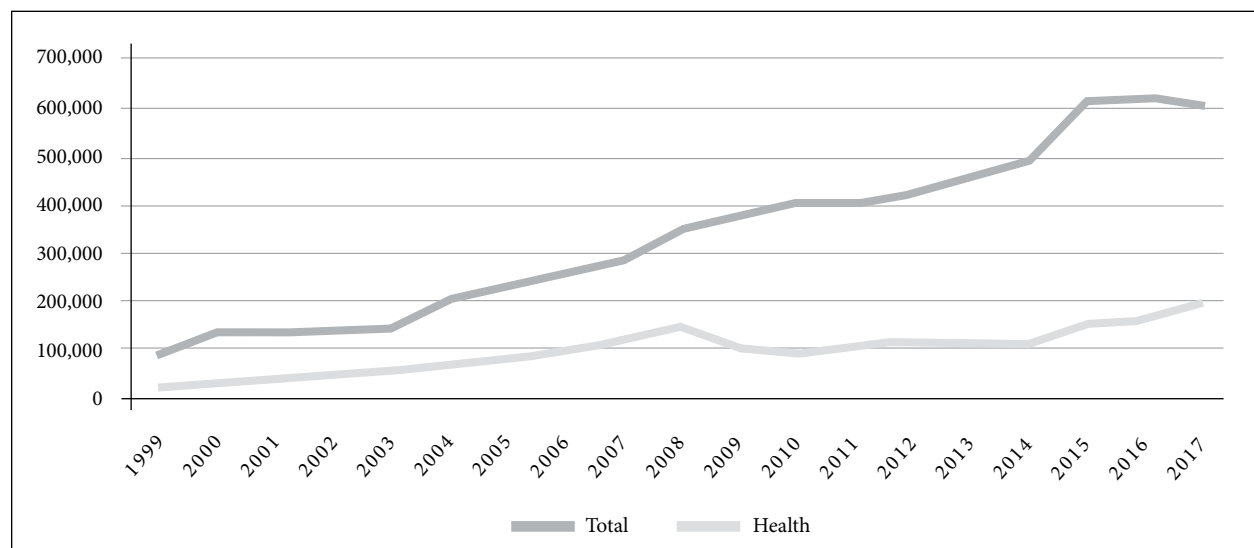
The result is that there was greater concern over the negative effects of jurisprudence on health than over fixing the structural problems of the system, which, among other perverse effects, were

propelling the health litigation.

State bodies appear to be addressing the significant problems of corruption and inefficiency in the health sector rather than trying to limit individual protection of the right to health by, for instance, pushing legislative amendments to stop this kind of claim. Currently, there is a bill from the Office of the Comptroller General and the Office of the Inspector General seeking to criminalize behavior that stands in the way of access to health care. In addition to saving lives, as some scholars have observed, this is also a victory for defending the critical role of the Constitution in shaping policies.<sup>38</sup> It has become clear that public policy is integral to the protection of fundamental rights (including the right to health). Further, the Constitution must be the basis of public policy in order to ensure that it is designed to be reasonable and accountable.

In addition to the battle for price controls on medicines, President Santos’s minister of health, for example, entered into important debates around the control of sugary drinks, which are considered a major contributor to obesity and weight-related diseases. Although Congress has not yet allowed a sugar tax, this battle is clear evidence of new winds.<sup>39</sup> The government is keeping the right to health central in new policies, even when it runs

FIGURE 1. Evolution of tutelas in Colombia



Source: Defensoría del Pueblo, *La tutela y el derecho a la salud y a la seguridad social 2014* (Bogotá: Defensoría del Pueblo, 2015); Rapporteurship of the Colombian Constitutional Court, data for 2015–2017, on file with the author.



against the interests of powerful industries. Policies that began by addressing the right to access necessary health services have now moved toward ensuring better health through disease prevention and reducing the probability of needing health care. The difficulties that have been encountered in the attempt to tax sugary drinks have demonstrated that “taking rights seriously” is not easy. The health minister, in keeping with Lawrence Lessig, argues that a healthy democracy is necessary before a fundamental problem of society, such as a weak health system, can be fixed.<sup>40</sup> Finally, good financial management is crucial because the financial sustainability of the health system remains at risk.

### *Reasonable and deliberated limits*

Colombian constitutional jurisprudence has always acknowledged the existence of reasonable limits to the right to health, which must be established through a participatory, transparent, and scientific process. This process is now happening (Resolutions 5267 of 2017 and 687 of 2018). Within the legal framework, the Ministry of Health is undertaking a public and open process to decide what services to exclude from the benefits plan. Determining limits in this way enables the health system to say “no” to requests for including certain health care services, but in a fair manner that respects human dignity. The Constitutional Court has tried to improve the deliberative process.<sup>41</sup> The process of enforcing complex and structural orders, by itself, could deepen democracy. Despite the challenges in enforcing the structural orders of T-760, the court has opened spaces for deliberation and public reflection. It has allowed, for example, the public scrutiny of cost overruns in the design of the current system and close inspection of the scarcity of resources as a justification for restrictions.<sup>42</sup>

### *Evidence of progress recognized*

The social rights advances made in Colombia have been recognized by scholars and institutions beyond the field of health. For example, the Organisation for Economic Co-operation and Development acknowledges the challenges that the system still faces (improving quality, efficiency, and sustain-

ability) but also recognizes the achievements.<sup>43</sup>

Since 2008, there have been important advances in the accuracy and periodic updating of the benefits plan. A participatory process to update the plan was undertaken every two years from 2009 to 2017.<sup>44</sup> Another concern was the lack of internal procedures allowing health care providers to directly authorize the provision of services (as distinct from medicines) not included in the benefits plan. As an initial measure, the Ministry of Health and Social Protection issued Resolution 3099 of August 19, 2008, expanding the competencies of health care providers’ technical scientific committees to authorize medical services not included in the benefits plan. Later, the 2015 statutory health law removed additional restrictions.

Furthermore, inequities between the contributory and subsidized regimes were removed in 2009, when the same benefits were guaranteed to children regardless of which regime they belonged to.<sup>45</sup> Then, in 2012, the benefits plans were unified through a decision (Agreement 032) of the Regulatory Body in Health. The court has declared a high level of compliance with the judicial order to unify the benefits plan of both regimes.<sup>46</sup> Advances have also been made regarding the availability of complete, clear, and timely information for users at the moment of selecting a health care provider. In 2009, the Ministry of Health and Social Protection issued Resolution 1817 to establish guidelines and operational processes for health care providers. This resolution outlines a patients’ bill of rights and a performance chart for health care providers. The Constitutional Court has also proposed that health care providers be ranked according to their level of performance to help people decide which provider to use.<sup>47</sup> But there is still a lot to do in this area; the court has declared a medium level of compliance with this order.<sup>48</sup>

Finally, advances have been made with regard to universal coverage. According to the Ministry of Health and Social Protection, in 2008, 83.26% of the population was affiliated with a health care provider. By 2016, this had reached 95.6%. This progress has also reduced inequities resulting from wealth inequalities. Ministry of Health data

reveal that in 2016, 92.6% of the population with a lower income and 91.1% of the population with the highest income were affiliated with the health system. This has occurred at the same time as the unification of benefit plans. Universal protection is being achieved under conditions of equality. Before T-760, the government intended to achieve universal health coverage but postpone the unification of the plans. However, the court prevented this, ordering it to do both at the same time. Currently, the inequity in accessing the system relates less to a person's financial position and more to barriers such as geographical accessibility and the lack of available services in conflict-affected areas.

Some critics have suggested that the Constitutional Court's order to offer the same benefit plan to those who contribute and those who do not contribute would encourage people not to contribute. But the court advised the government to take additional measures to avoid this perverse effect.<sup>49</sup> In practice, granting the same benefit plan to all people has not led to a decrease in affiliations to the contributory regime (see Figure 2).

As mentioned above, the situation is far from perfect. Some general indicators are mediocre, rather than good.<sup>50</sup> But if we compare today's sit-

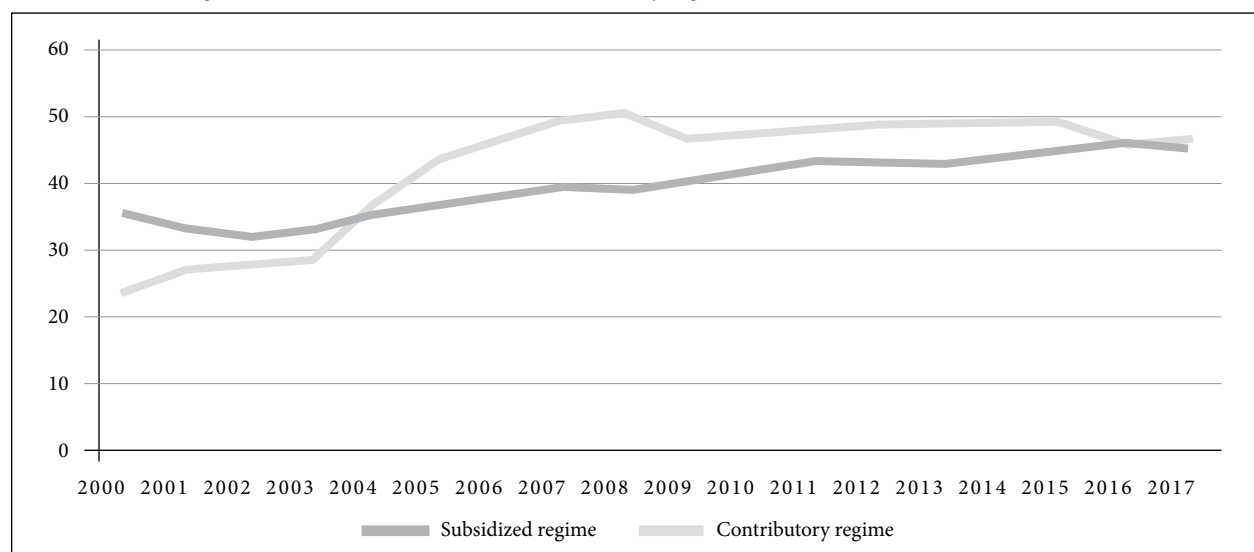
uation with that of 2008, the advances in health policies are evident.

## Conclusion

The Colombian experience shows how the power of the people to litigate can help secure the protection of their right to health. Judicial intervention can bring justice and equity to a health system when judges listen to both sides of the debate on aspects of the fundamental right to health. On the one hand, this right must be respected as a prerequisite for democracy. Judges must ensure that authorities recognize and enforce its effective enjoyment. On the other hand, the fulfillment of this right should be based on technically supported rational arguments, as well as on ethical grounds, principles, and values. This requires transparent decision-making processes open to public scrutiny and democratic participation. In these situations, judicial intervention does not become the "rule of the judges" but is instead a legitimate way to exert pressure on the government to act according to the rule of law, and within constitutional boundaries.

It is essential that public policies aimed at protecting a fundamental right ensure a reasonable

FIGURE 2. Percentage of users in the subsidized and contributory regimes



Source: Así Vamos en Salud. Available at <http://www.asivamosensalud.org/indicadores/aseguramiento/aseguramiento-georeferenciado>.

policy design, implementation, and evaluation. Colombia's courts and judges will still face many challenges in dealing with structural and complex orders. But today, through the *tutela*, there is finally democratic access to constitutionally controlled public policies.<sup>52</sup> It is settled that the right to health is a fundamental constitutional and justiciable right.

Constitutional litigation is one of several democratic tools. Structural and complex remedies to guarantee the effective enjoyment of a fundamental right function when supported by, and carried out in collaboration with, other branches of power. Courts by themselves cannot assure, for example, total coherence between national agencies

and local governments. The success of a structural remedy can be seen when the court is no longer needed.<sup>52</sup> When the policymaking process respects constitutional boundaries, judges should take a step aside—not when everything is perfect, but when policy makers take rights seriously and fully respect them.<sup>53</sup>

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TABLE 1. Ten years after T-760

2008	2018
<b>Accuracy and periodic update of the benefits plan</b>	
Unclear spectrum of services covered by the benefits plan; plan outdated since its creation (1994)	Four updates to the benefits plan since the T-760 ruling (2009, 2011, 2013, 2015, and 2017)
No internal procedure for authorizing services (other than medicines) not included in the benefits plan	An internal procedure for authorizing services not included in the benefits plan has been created
Increasingly high numbers of tutelas regarding health care (more than 40% of all tutelas)	The growing tendency of health care tutelas stopped for a while (23.74% in 2014); now there is a “new wave” with different triggers
<b>Progress related to the unification of the contributory and subsidized benefits plans</b>	
The benefits plans of the contributory and subsidized regimes were not equitable	The benefits plans are the same for both regimes (for children since 2009, for everybody since 2012)
<b>Advances related to the availability of complete, clear, and timely information at the moment of users' affiliation with health care providers</b>	
Substantial information asymmetry; little knowledge about benefits, rights, and the performance of the health care providers	Creation of a “patients' bill of rights” and a “performance chart for health care providers” (2009) Progress in the creation of a ranking of health care providers
<b>Advances related to universal health coverage throughout the national territory</b>	
In 2008, 83.26% of the Colombian population was affiliated with a health care provider	In 2016, 95.6% of the Colombian population was affiliated with a health care provider

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# Individual Health Care Litigation in Brazil through a Different Lens: Strengthening Health Technology Assessment and New Models of Health Care Governance

DANIELLE DA COSTA LEITE BORGES

## Abstract

This article investigates policy and bureaucracy changes provoked by individual litigation for health care rights in Brazil, especially the one regarding access to medicines, looking at the effects it produced in relation to health technology assessment (HTA) and health care governance. The article first contextualizes the social, legal, and political conditions for the development of individual litigation for health care rights in Brazil. Then it points out the changes brought about by this litigation model and discusses their potential to contribute to efficiency and fairness in the health care system by the improvement of the HTA decision-making process and health care governance.

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## Introduction

The legal enforcement of health care rights may take a multitude of forms, ranging from orders to provide a specific medicine or treatment to a particular individual or group, to broad structural decisions declaring a particular state of affairs unconstitutional or even ordering the structuring of health services in a certain geographical area.<sup>1</sup> David Landau, for example, identifies four remedial forms: a) individual enforcement; b) negative injunctions; c) weak-form enforcement; and d) structural enforcement.<sup>2</sup> According to the first one, courts grant rights to a single plaintiff, such as the provision of a medication or treatment. The negative injunction model is often used to strike down benefit cuts or other laws that diminish social benefits. With weak-enforcement, also called the dialogical model, courts point out political failures to uphold social rights but leave the remedy at the discretion of political branches. Finally, structural enforcement occurs when courts issue broad orders aimed at (re)structuring institutional or policy practices.

Courts in developing countries have relied mainly on two broad models of social rights enforcement: the individual model and the negative injunction model.<sup>3</sup> In Brazil, thus far, the most prevalent form of enforcement has been the individual model, especially when it comes to access to medicines claims, although in recent years the country has also experimented with the use of the structural model.<sup>4</sup> This way of litigating for health care rights, also found in other Latin American countries, consists of lawsuits brought mostly by individual plaintiffs represented by private or public attorneys (the latter in the case of plaintiffs with earnings below a certain threshold, which varies across the country) against public authorities—states, municipalities, or the federal government—claiming mostly the provision of a specific medication or treatment and encountering a very high success rate in the courts.<sup>5</sup> The effects of these decisions apply only *inter partes*, that is, between the parties of the case.

The threshold to win in the courts is very low, insofar as the individual litigant must simply prove that a health need (access to medication or

treatment), as described in a doctor's prescription, was not met. Therefore, in the Brazilian model of litigation, the doctor's prescription (from a state or private health facility) is very often the only relevant document necessary for a court to render a decision imposing on the state the obligation to provide a particular medication or treatment to a particular individual.<sup>6</sup>

Another reason explaining the prevalence of this model of litigation in Brazil is the fact that Brazilian courts are more open to individual claims than collective ones, creating a strong incentive for plaintiffs to bring forth individual action.<sup>7</sup> Collective claims have a much more far-reaching impact than individual ones because the effects of their decisions apply *erga omnes*. They are usually brought by the prosecutor's office (Ministério Público) through a legal procedure called *ação civil pública* and concern public authorities' failure to comply with legal obligations in guiding structural health policies. Brazil has also seen a slight increase in collective litigation through public class actions aimed at implementing health policies, however they are still low in numbers compared to individual claims.<sup>8</sup> Therefore, individual solutions tend to take precedence over structural orders.<sup>9</sup>

It is worth noting that, apart from the public (and universal) health care system in Brazil, there is also a parallel, private system of care. People using the private health care system are usually wealthier individuals who can afford private health insurance, or employees who have health insurance as part of their benefits package. However, lawsuits concerning the provision of medication can be brought against public authorities despite the fact that the individual is insured privately. Indeed, according to Brazilian law, private health insurers only have to provide medication in case of inpatient treatment. The only exception to this rule regards some anti-cancer drugs for outpatient cancer treatment.<sup>10</sup> Moreover, cases concerning the private provision of health care are mostly ruled according to private law—contract and consumer laws—whereas cases regarding the public provision of health care, such as the ones discussed in this article, are decided exclusively according to



constitutional law. Therefore, many health insured individuals resort to the public health system to access medicines that they would not be allowed to through private health insurance. Still, there is also a high number of individual claims brought against private health insurers in Brazil. These claims regard contract coverage, contract breach, health treatments, and only a residual part refers to medicines.<sup>11</sup>

The frequent use of individual litigation to enforce the right to health has been the subject of intense debate in the literature. Some have criticized it for rendering the public health system less fair and rational, since the often sole criterion used by courts to grant claims (individualized medical prescriptions) disregards the need to set priorities according to sound public health reasons. Moreover, given important difficulties of access to justice in Brazil, it can often favor those who are financially equipped to hire private lawyers or access the limited provision of state attorneys.<sup>12</sup> Therefore, judicialization could widen the social gap in Brazil, diverting public resources from the most deprived individuals and from other important areas of health. However, others have contested these conclusions and have argued that “judicialization may serve as a grassroots instrument for the poor to hold the state accountable.”<sup>13</sup>

In this article, however, I do not focus on these debates. Here, I approach individual litigation for health care rights in Brazil from a different perspective, looking at the effects it produced in relation to health technology assessment (HTA) and health care governance. More than triggering bureaucratic changes, as I have maintained elsewhere, here I argue that individual litigation for health care rights in Brazil has pushed forward policy changes that ranges from strengthening health technology assessment processes to better health care governance through institutional dialogue between different state actors.<sup>14</sup> Accordingly, by looking specifically at the case of individual litigation related to access to medicines, I will show that, although focusing mostly on individual cases, this phenomenon has brought about structural changes that have the potential to produce positive effects

in terms of efficiency and fairness in the Brazilian public health system.

In order to develop this argument, I will first provide a historic overview of the social and political contexts in which individual litigation developed in Brazil since the promulgation of the Brazilian constitution in 1988. Following this, I will describe the institutional changes produced by the health care-related individual model of litigation in Brazil, especially when it comes to health technology assessment and health care governance, presenting data available in these areas in order to demonstrate how these changes, although not directly related to social justice, can potentially contribute to the achievement of more fairness and efficiency in the Brazilian health system.

### An historic overview of individual litigation for health care rights in Brazil

Health care-related individual litigation in Brazil developed in a favorable historical time frame by virtue of Brazil’s democratization process. It started in the mid-1990s, following Brazil’s constitutional milestone in 1988, which reinstated democracy and provided a set of constitutionalised rights, including the right to health, and coincided with the peak of the AIDS epidemic, which explains, therefore, the reason why most of the lawsuits then regarded HIV medication. Although the institutionalized health program for HIV in Brazil dates from 1986, it was only in 1996 that a federal law established the free distribution of medication throughout the country.<sup>15</sup> Apart from the legal framework, the mobilisation of civil society was another major driving force behind the then on-going process of constructing and implementing a policy of free access to HIV medication in Brazil.<sup>16</sup> Nevertheless, since not all antiretroviral drugs were encompassed by the Brazilian HIV therapeutic guidelines, patients started to claim in courts antiretroviral drugs that were not yet made available by the national program. For instance, in Rio de Janeiro, between 1991 and 1998, lawsuits concerning HIV medication corresponded to 90% of all lawsuits regarding access to medicines, whereas in the Supreme Court they

corresponded to one third of health care-related litigation.<sup>17</sup>

Brazilian courts have been receptive to individual litigation since at least the late 1990s, granting in most of the cases the medication claimed by HIV patients.<sup>18</sup> From 1997 on, with the advancement and structuring of the Brazilian Program for AIDS, antiretrovirals started to be regularly dispensed by state health authorities, contributing to the fall of individual litigation in this area.<sup>19</sup> During these years, the government revealed itself to be committed to fighting the AIDS epidemic globally.<sup>20</sup> For instance, Brazil twice used the threat of compulsory license as a strategy to pressure drug companies into price negotiations for HIV medication and, in 2007, effectively issued a compulsory license for the antiretroviral Efavirenz.<sup>21</sup>

The favorable judicial environment found by patients during the 1990s led more people suffering from other diseases to claim medication before courts.<sup>22</sup> Currently, individual litigation concerns medication for a variety of diseases, ranging from rare diseases, such as Gaucher's Disease and Duchenne muscular dystrophy, to chronic diseases, such as diabetes, cancer, hypertension, and hepatitis C.<sup>23</sup>

In addition to the favorable judicial environment (that is, the low threshold established by Brazilian courts), other problems also contributed to the increment of individual litigation for medicines.<sup>24</sup> This includes, for example: a) the underfunding of the health sector, whose budget between 2002 and 2008 corresponded to an average of 3.6% of the GDP; b) the difficulties of establishing a basis for organizing services at a much-decentralized health system (the country is divided into 26 states, one federal district and more than 5,570 municipalities which have administrative autonomy in terms of health policy implementation); and c) the fragmentation of pharmaceutical assistance policies.<sup>25</sup> Many of these managerial problems regarding pharmaceutical assistance are for instance described by health officers themselves in inspection reports issued by the Brazilian Federal Court of Auditors.<sup>26</sup>

Therefore, the number of individual claims in Brazilian courts has risen steadily since 2000.

According to data available at the National Council of Justice, in 2014 there were about 62,291 lawsuits regarding medicines and treatments against the Federal Union, and about 330,603 against states, municipalities, and the federal district.<sup>27</sup> However, after 2009, new strategies and institutional changes were put in place in an attempt to control the number of lawsuits and public expenditure. These changes in bureaucracy at different levels and in different governmental institutions were already discussed by some authors, such as Wang, Ribeiro and Hartmann, and Duarte.<sup>28</sup> Although some of these authors are quite sceptical about such changes, in my view they have the potential to affect positively the Brazilian public health system, as they have established a more transparent health technology assessment process in the country and new forms of inter-institutional dialogue and of health care governance. This, in turn, may not only contribute to reducing individual litigation, but also to advancing efficiency and fairness in the Brazilian health system, as I will discuss in the following sections.

### Bureaucratic changes after 2009: Strengthening HTA and new forms of health care governance

In March 2009, acknowledging, on the one hand, the several cases pending before the Brazilian Supreme Court (STF) regarding individual litigation for the supply of medication, and, on the other hand, the limited institutional capacity of judicial power to alone deal with technical issues arising from these cases, the then-president of the STF, Justice Gilmar Mendes, convened health authorities and experts in the health field at a public hearing in order to clarify technical, scientific, administrative, political, and economic issues surrounding health care provision. During the opening of the public hearing, Justice Mendes declared that he expected the event not only to feed the court with technical information, but also to promote a broader and pluralist debate for the improvement of health policies.<sup>29</sup>

The main outcome of the public hearing was the establishment of criteria to guide the Court

on future and pending decisions on health care cases. In effect, in March 2010, the STF ruled on nine cases, establishing non-binding guidelines for how courts should deal with medicines claims from then on. Santos and colleagues, who analysed the STF public hearing in light of the social systems theory from Niklas Luhmann, concluded that it proved to be strategic insofar “there was a mutual learning between the political and legal systems by structural coupling of such public hearing.”<sup>30</sup> Moreover, the legal system incorporated important arguments discussed during the public hearing, such as the one on the rejection of legal requests for unregistered drugs before the National Health Surveillance Agency (ANVISA).<sup>31</sup>

In terms of institutional effects, the public hearing can be seen as a first formal step towards a constitutional dialogue between the executive and the judiciary branches of the government, as it triggered a sequel of communications between different state actors with the shared intention of improving the practice of interpreting the constitution.<sup>32</sup> Moreover, it demonstrates the judiciary’s potential for enhancing democracy and participation in a practical example of dialogic justice.<sup>33</sup>

In this regard, after the public hearing, and also as a response to the number of health care-related lawsuits pending at Brazilian courts, other important changes have taken place at the judiciary level. These include the creation of a working group by the National Council of Justice (CNJ)—which by this time was also under the presidency of Justice Gilmar Mendes—to study, propose measures and guidelines aimed at preventing health care-related litigation, and help the country’s tribunals in dealing with these cases.<sup>34</sup> In fact, the work developed by this group evolved, and in March 2010 the CNJ published a recommendation, providing some criteria to assist magistrates and other legal professionals to ensure greater efficiency in the settlement of health care-related lawsuits.<sup>35</sup> Following this, in April 2010, the CNJ established a permanent forum on health issues aimed at monitoring and finding solutions to health care litigation.<sup>36</sup> This forum meets frequently, and, for instance, in December 2017, the current president of CNJ, Justice Cármen

Lúcia, convened a new public hearing where the actors involved in the problem of individual litigation discussed the current state of affairs, presented data, and shared best practices.<sup>37</sup>

While these initiatives developed at the highest level of the judicial branch, other changes at different levels of the legislative and executive branches of the government took place, affecting the health technology assessment process and health care governance as will be demonstrated.

### *The HTA process in Brazil*

According to the World Health Organization (WHO), HTA refers to the systematic evaluation of properties, effects, and/or impacts of health technology. It is carried out through a multidisciplinary process which evaluates the social, economic, organizational and ethical issues of a health intervention or technology aiming to inform policy decision making.<sup>38</sup> It works as an important policy tool in the management of health care delivery in conditions of resource constraint and contributes to fostering health equity especially in developing and emerging countries.<sup>39</sup> However, the institutionalization of HTA in these countries is still considered immature, focusing mostly on training and instruction of personnel to perform HTA whereas this process also involves political commitment, capacity for investment, maturity of the decision-making process and the structure of national health systems.<sup>40</sup>

In Brazil, discussion about HTA began in 1983.<sup>41</sup> Although since 2000 there have been institutional changes aiming at establishing some kind of HTA process in the country, it was only in 2006 that this process was formally instituted through law with the establishment of the Commission for the Incorporation of Technologies (CITEC), which worked under the supervision of the Health Attention Secretariat of the Ministry of Health (Secretaria de Atenção à Saúde). In 2008, the Secretariat of Science, Technology, and Strategic Inputs (SCTIE) took over the role of coordinating and supervising the process of incorporation of new technologies. Under the auspices of SCTIE, the process flow was redefined and improved, with the establishment of

deadlines and criteria for the submission of proposals and issuing of reports on the incorporation of technologies.<sup>42</sup>

But only in 2011, following the constitutional dialogue started at the Brazilian Supreme Court in the public hearing on judicialization discussed in the previous section, that a new federal law (Law n. 12.401/2012) was enacted, creating a new HTA body named CONITEC (National Committee for the Incorporation of Technologies in the Public Health System, or *Comissão Nacional de Incorporação de Tecnologias no Sistema Único de Saúde*) under the auspices of the Ministry of Health. CONITEC replaced CITEC and the main justification for its creation—according to the explanatory notes of the two draft bills that led to the adoption of law n. 12.401/2012—was the phenomenon of individual health care litigation.<sup>43</sup> In terms of its operational structure, CONITEC consists of two different boards: the executive secretariat and the plenary. The latter is responsible for issuing recommendations and consists of 13 members, with seven of them coming from different secretariats of the Ministry of Health and the other six from different institutions across the health system: the National Council of Municipal Health Secretaries (*Conselho Nacional de Secretarias Municipais de Saúde*, CONASEMS), the National Council of State Health Secretaries (*Conselho Nacional de Secretários de Saúde*—CONASS), the National Health Council (*Conselho Nacional de Saúde*—CNS), the National Regulatory Agency for Private Health Insurance and Plans (*Agência Nacional de Saúde Suplementar*—ANS), the National Health Surveillance Agency (*Agência Nacional de Vigilância Sanitária*—ANVISA), and the Federal Council of Medicine (*Conselho Federal de Medicina*—CFM). The Executive Secretariat is in charge of managing and coordinating the activities of CONITEC, including the issuing of the final recommendation reports. Regarding its mission, CONITEC's main competence is to provide technical advice to the Ministry of Health in decisions regarding the incorporation, exclusion or alteration of health technologies within the Brazilian health system, as well as in the formulation or modification of clinical protocols and therapeutic

guidelines. According to Law 12.401/2012 and its accompanying decree (7.646/2011), this is to take effect through an administrative procedure that is open to public participation by means of public hearings and public consultation. Decisions made on these procedures are subject to administrative appeal from interested parties.

Recommendations take into account available scientific evidence regarding efficacy, effectiveness and safety of medicines, procedures and medical devices, as well as health economic evaluation and budget impact studies. In effect, CONITEC frequently cross-references HTA assessments made by other important international HTA agencies, such as the National Institute for Health and Clinical Excellence (NICE), the Canadian Agency for Drugs and Technologies in Health (CADTH), and the Australian Pharmaceutical Benefits Advisory Committee (PBAC).<sup>44</sup> In addition, due to CONITEC's membership in the International Network of Agencies for Health Technology Assessment (INAHTA), CONITEC's recommendations can benefit from shared information of the other 48 HTA agencies members of this network. In effect, another important attribution of CONITEC is to revise and update regularly the national list of essential medicines (RENAME).<sup>45</sup> Aiming at increased agility and efficiency, the process analysis of incorporation of technologies should take 180 days (extendable for another 90 days) and the full list of appraisals is regularly updated and made available at CONITEC's website.<sup>46</sup>

Therefore, the creation of CONITEC brought substantial improvements to the institutionalization of HTA, especially as compared to the old decision-making process. Previously, appraisals were not publicly disclosed, there was no clear timeline for a review and decision-making after a positive recommendation, there were no public hearings or public consultations, and the right of appeal was much more restricted.<sup>47</sup> The new process has also improved productivity in terms of the number of appraisals issued per year; it has in fact tripled the number of appraisals in a year when compared to the previous decision-making process.<sup>48</sup> Furthermore, there is also some evidence that

the quality of the decisions has been improved. For example, in a study on the relationship between the quality of evidences and CONITEC's recommendation reports on medicines between 2012 and 2015, Zimmerman and colleagues concluded that these recommendations present consistent trends on the use of quality of evidences as well as on the use of economic and implementation aspects. Moreover, their analysis also shows that CONITEC's recommendations use a multiple criteria analysis process, suggesting that they contribute to decisions in line with the Brazilian health system's needs.<sup>49</sup> A similar analysis carried out by Caetano and colleagues, which investigated the decision-making process, profile of demands and incorporation of new medicines in the Brazilian public health system (Sistema Único de Saúde – SUS) from January 2012 to June 2016, suggests incremental rationality and the presence of clinical and economic evidence based on CONITEC's decisions.<sup>50</sup>

Nevertheless, it is still difficult to assess other aspects regarding the impact of CONITEC over the Brazilian public health system, as there are still few studies on the substance of the decisions taken. Hence, further research is needed in this area in order to investigate other aspects, such as the scientific rigor, legitimacy, and independence of decisions.

With regard to health care-related litigation, CONITEC has established direct communication channels with the judiciary, which can send direct requests (via email) regarding information on a certain medication or health technology in order to subsidize judicial decisions. For instance, between 2014 and July 2017, CONITEC replied to around 1,500 requests emails sent by the judiciary.<sup>51</sup>

Moreover, there is some evidence that the new HTA process in Brazil, and thus the availability of technical decisions to the judiciary and administrative health authorities at the state level, have contributed to the decrease in health spending on health care individual litigation. In the state of São Paulo, for example, between 2013 and 2014 there was a decrease of around R\$5 million (approximately US\$1.5 million), reflecting a 1.5% reduction in health care spending with individual litigation at the state level. In relation to requests solved at the

administrative level, that is, requests for medicines which are presented to local health authorities and solved at this level without the need to file a lawsuit, there has been a decrease of about R\$150 million (approximately US\$ 46 million) or 40% between 2012 and 2014.<sup>52</sup> The number of requests decreased by 25% between 2014 and 2015 (Graph 1).<sup>53</sup>

Furthermore, at the federal level, although there has been a substantial increase in health spending with medicines in the last seven years, spending on lawsuits decreased by 20% between 2014 and 2015 (Graph 2).<sup>54</sup> Further investigation is still needed in order to explain this decrease, but a possible explanation could be related to the incorporation by CONITEC of some of the most requested drugs by individual litigants. For example, Trastuzumab for breast cancer, Palivizumabe for respiratory syncytial virus, Rituximab for rheumatoid arthritis, and drugs for treating hepatitis C (Sofosbuvir, Simeprevir, and Daclastavir) were all incorporated between 2012 and 2014.<sup>55</sup>

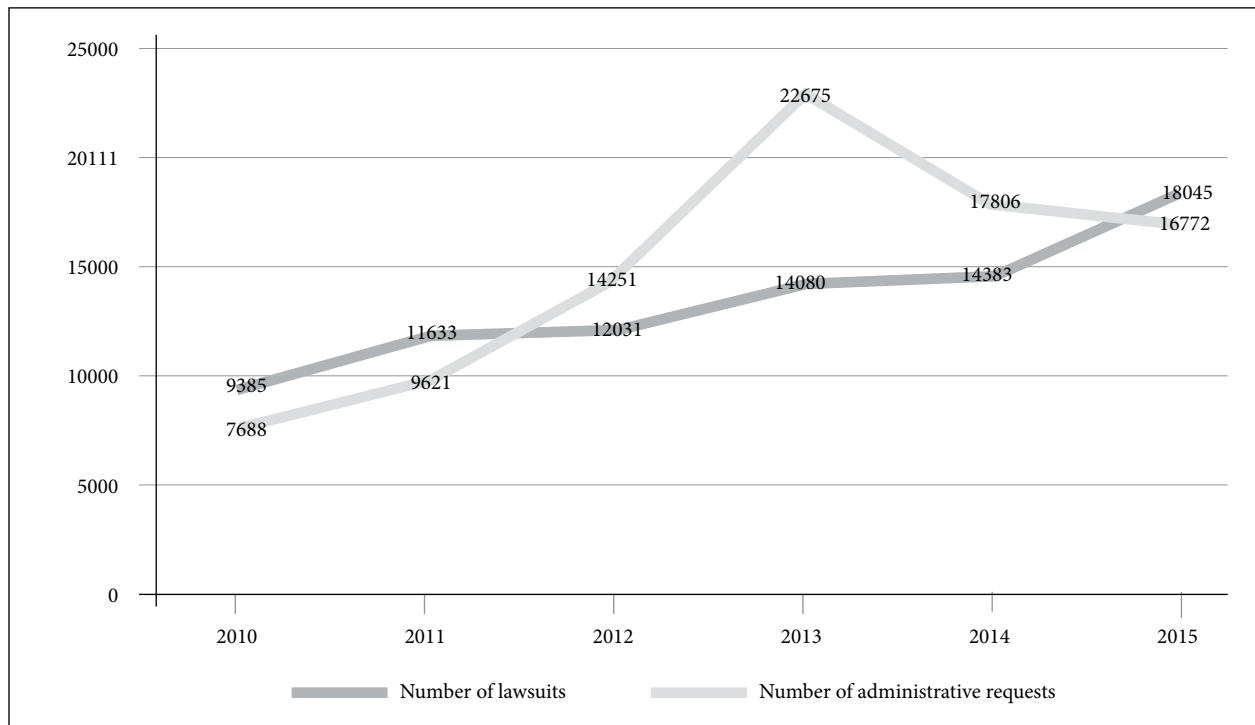
Individual litigation therefore influenced the establishment of a more transparent, participatory, and accountable decision-making process regarding HTA in Brazil with the creation of CONITEC. This, in turn, can contribute to the advancement of fairness in the health system, as health technology assessment is considered an important tool in this regard. It not only sets more transparent rules and procedures for allocating health resources but also promotes fairness by making drugs available to the population at large and not only to individual claimants.

#### *New strategies in health care governance: Collaborative governance and 'de-judicialization'*

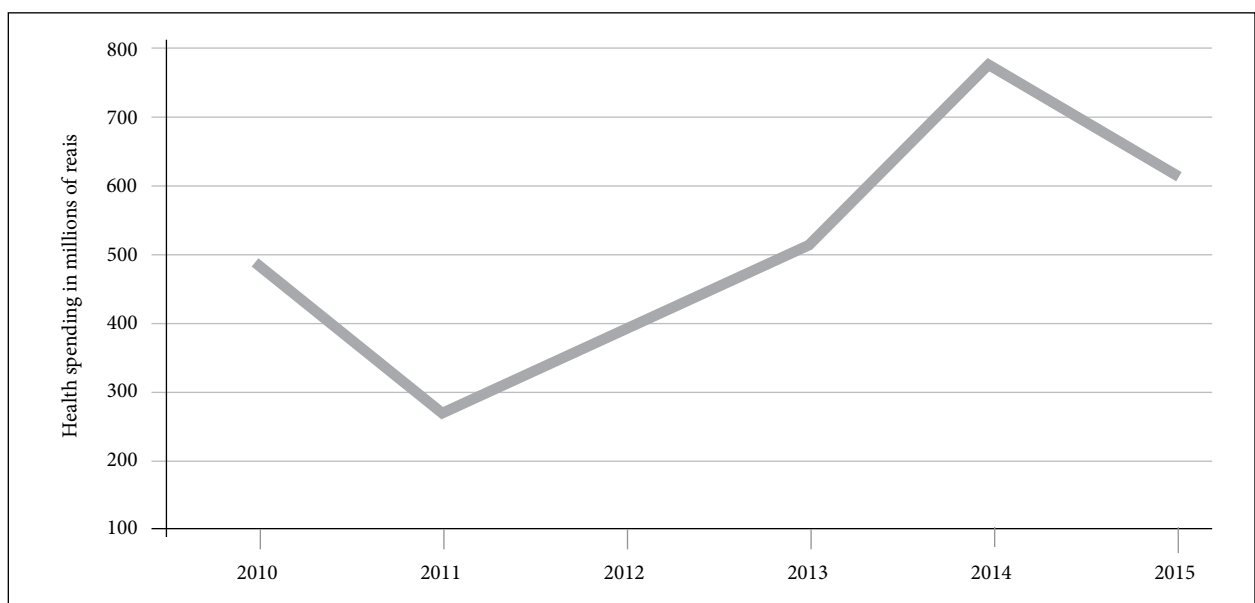
Health governance can be defined as “a wide range of steering and rule-making related functions carried out by governments/decisions makers as they seek to achieve national health policy objectives that are conducive to universal health coverage.”<sup>56</sup> It is thus an important mechanism in establishing health policies aimed at increasing efficiency and fairness in health systems.

The phenomenon of individual litigation has challenged not only health authorities, but all actors involved in it, to finding new strategies to deal

GRAPH 1. Number of administrative requests v. number of judicial claims for medicines in the State of São Paulo between 2010-2015. Source: Based on data collected by T.T. Toma, A.C. Soares, P.S.F. Siqueira, R. Domingues, “Strategies to deal with drug lawsuits in the state of São Paulo, Brazil”, *Cadernos Ibero-Americanos de Direito Sanitário* 6/1 (2017), pp. 35-54.



GRAPH 2. Federal health spending with lawsuits between 2010 and 2015. Source: Based on data collected by F. S. Vieira, “Garantia do direito à saúde, judicialização e o mito de que os recursos não são escassos: desafios atuais e futuros do Estado Brasileiro” (presentation at the IX CONSAD Congress, Brasília, Brasil, 8-10 July 16). Available at <http://consad.org.br/wp-content/uploads/2016/06/Painel-45-02.pdf>.



with and overcome this specific policy problem. The strategies adopted in Brazil to deal with individual litigation for health care affected, in my opinion, two elements of health governance: participation and capacity. According to Greer and colleagues, participation in health care governance means that affected parties have access to the decision-making process. One of the mechanisms to achieve participation is joint workforce, which works specifically in situations where the problem is the participation of different parts of government in a particular policy problem. The same authors refer to capacity, or policy capacity, as the ability to turn a political idea into a work proposal. Some of the mechanisms to improve it rely on intelligence on process (by, for example, understanding legal and budgetary issues that need to be changed) and specialist advice into policy formulation and recommendation.<sup>57</sup> As I will discuss in this section, the establishment of new institutional arrangements have improved participation and capacity advancing therefore health care governance in Brazil.

Since 2009, following the public hearing at the Brazilian Supreme Court, different actors involved in the phenomenon of health care individual litigation all over the country started to discuss policy improvements needed to overcome the problem. This involved, for example, state courts, local health authorities, state attorneys' offices (Procuradorias do Estado e Município), public defenders' offices (Defensoria Pública), public prosecutors' offices (Ministério Público) and technical health experts. In this regard, one of the first initiatives was the one of the Rio de Janeiro State Tribunal (TJRJ). In February 2009, this state court and the local health authority signed a cooperation agreement regarding the implementation of an advisory health committee (Núcleo de Assessoria Técnica—NAT) to provide technical advice to the state tribunal in cases concerning the supply of medication and other medical goods. The committee consists of permanent civil servants of the state health authority in the field of medicine, nursing, pharmacy, nutrition, and management and has a consultative status. Its main mission is to give advice on medi-

cation and other judicially claimed medical goods. Accordingly, NAT's advisors prepare appraisals considering objective and subjective aspects of lawsuits concerning the provision of medicines, such as: if the drug claimed is registered with the national surveillance agency (ANVISA), if it is part of the national list of essential medicines (RENAME) and if the drug requested is suitable for the treatment of the pathology in case, considering the claimant's age and the amount requested.

According to Normative Act 5/2012,<sup>58</sup> enacted by the Rio de Janeiro State Tribunal (TJRJ), all lawsuits concerning the provision of medicines or medical goods must be sent to NAT's advisors, who should prepare appraisals within 48 hours after receiving information on a certain lawsuit. Appraisals are prepared prior to any judicial decision. However, NAT's appraisals are not binding on judges, due to the principle of the independence of the judiciary.

Despite the non-binding status of NAT's technical appraisals, a qualitative study which investigated, among others, judges' opinions on the relevance of NAT's work, revealed that the idea of NAT is quite well accepted by magistrates, who feel more "safe" and "secure" to take decisions having these technical appraisals.<sup>59</sup> Nevertheless, due to the lack of other qualitative or quantitative studies on this topic, it is not possible to measure yet whether judges take into account these technical appraisals when deciding cases. Still, the establishment of NAT has brought advantages to the judgement of these lawsuits with regard to technical capacity, celerity and costs. Before the establishment of NAT, judges would either decide without a technical appraisal, relying only on the drug prescription presented, or would nominate a private technical advisor and commission an appraisal on the specific medicine claimed (*perito do juízo*). In this case, this is not only more costly, because private advisors charge for their appraisals, which are paid either by the parties or the judiciary (state), but it also takes much more time, insofar the procedure for technical appraisals established by the Brazilian Civil Procedural Code is much longer than the 48 hours

within which NAT should present its appraisals (see Articles 464 to 480 of Law n. 13.105/2015).<sup>60</sup>

The 2010 CNJ Recommendation n. 31, among other recommendations, called state and federal tribunals to provide technical aid to judges in order to assist their decisions on lawsuits regarding the provision of medicines and/or medical goods by the establishment of consultative bodies such as NAT. Accordingly, consultative bodies similar to NAT have been implemented across the country and, as of March 2017, 17 other states had established such bodies: Rio Grande do Sul, Espírito Santo, Mato Grosso, Mato Grosso do Sul, Pernambuco, Piauí, Acre, Bahia, Goiás, Paraíba, Paraná, Santa Catarina, Tocantins, Minas Gerais, Pará, Rio Grande do Norte, and São Paulo.<sup>61</sup>

Although as yet there are no scientific studies evaluating the impact of these bodies on the phenomenon of judicialization, some health authorities have reported that they had a positive impact, contributing to a decrease in the number of lawsuits and health spending concerning the provision of health care-related items requested by individual litigants. For example, Rio Grande do Sul, one of the leading states in terms of number of health lawsuits in Brazil, reported that due to the work of the advisory health committee, between 2010 and 2017, there was a 35% decrease in the number of lawsuits, representing a 17% decrease in health spending.<sup>62</sup> Likewise, in the state of São Paulo between 2013 and 2014 a 1.5% decrease in health spending with individual litigation was observed (R\$5 million or approximately US\$1.5 million), as previously mentioned in this article.<sup>63</sup>

In 2013, NAT's initiative gained a broader scope with the creation of a mediation and conciliation centre (Câmara de Resolução de Litígios de Saúde—CRLS) in the state of Rio de Janeiro. Devoted exclusively to health-related issues, the CRLS came about due to a partnership between the state attorney's office (Procuradoria do Estado do Rio de Janeiro), the public defender's and prosecutor's offices in Rio de Janeiro, and local health authorities.

The CRLS works at a preventive or pre-judicial level, before the filing of a lawsuit, and aims at preventing litigation. Accordingly, when receiving

medication requests from individuals, the local health authority either dispenses the item or, if this is rejected for some reason, the individual is redirected to the CRLS, which will set a first meeting with its social workers. They proceed to a "screening" of the case to check documents, including the prescription, and will send this data to the public defender and CRLS technical staff (medicine, nursing, and pharmacy professionals, for example, from the local health authority). This technical analysis aims at checking, for example, whether the drug requested is listed on the official lists, and, if not, if there is any substitute to the requested item in the national and local lists. If the item is part of the official lists, the local health authority simply issues the necessary documents for the collection of the medicine. When the medicine is not part of the lists, the individual is referred to a new medical visit with his own doctor or with one from a public facility, so that the doctor can inform whether the substitute medicine available is suitable for this individual. With a positive answer in this regard, the local health authority proceeds with the grant of the substitute item. In the case of negative feedback from the doctor, the health authority will assess the medical justification and decide whether or not to grant it. However, at any time, the individual or the public defender can opt to file a lawsuit.

Therefore, the CRLS opened a mediation channel which can prevent the file of new lawsuits. Before its creation, there was no structured process allowing for mediation at the administrative level or before the file of a lawsuit relating to health care-related items. Any conciliation would only take place at the judicial level, according to civil procedural rules, and would not count on the technical information provided by CRLS. Flow charts 1 and 2 represent the process flows with and without the participation of the CRLS.

Due to the lack of scientific studies on the subject, it is currently not possible to assert whether the work of the CRLS has actually reduced the filing of new lawsuits. Indeed, the chamber's activities have been in place for only a couple of years. However, the state attorney's office in Rio de Janeiro claims that the establishment of CRLS has been avoiding



the filing of new lawsuits. According to its data, between September and December 2013, 70 days after its establishment, there was a 38% decrease in the filing of new lawsuits.<sup>64</sup> This decrease trend remained constant after one year, when a 37.1% decrease was observed.<sup>65</sup> In terms of expenditure, the state attorney's office and the local health authority estimate that between 2014 and 2015, it represented an R\$11 million (approximately U\$3.4 million) decrease in health spending with litigation for health care-related items. In absolute numbers, they calculate that after three years, the CRLS prevented filing of around 15,000 lawsuits.<sup>66</sup>

Similar models of mediation chambers have been adopted by other local authorities around Brazil, such as Distrito Federal and Bahia. The former established in February 2013 a conciliation chamber called *Câmara Permanente Distrital de Mediação em Saúde – Camedis*. Public authorities from these states have also released data that indicate positive results of these initiatives. Accordingly, in relation to Distrito Federal, it is estimated that around 85% of the requests submitted to *Camedis* were settled at the administrative level, resulting in a 20% decrease in the number of lawsuits filed between 2013 and 2015.<sup>67</sup> In relation to Bahia, local authorities and the CNJ have reported that the work of the mediation and conciliation centre for health issues settled around 80% of the cases received.<sup>68</sup>

Along the same lines, the state of São Paulo has in recent years adopted many initiatives at the administrative level aimed at avoiding new lawsuits. Local authorities have reported that due to these initiatives, the number of lawsuits has dropped for two consecutive years (2016 and 2017): 2% in the first year and 16% in the second, reflecting a decrease of approximately US\$63 million in health spending with medication requested in individual lawsuits.<sup>69</sup> During its presentation at the public hearing in December 2017, the state health authority in São Paulo (Secretaria de Estado da Saúde do Governo de São Paulo) confirmed this decrease trend, breaking down data on health spending with individual litigation by month between 2015 and 2017.<sup>70</sup> Although these data have not yet been scientifically probed, these numbers are in line with

the decrease observed in previous years (2012 to 2015) discussed by the works of Silva and Toma and colleagues, already mentioned in this article.

Furthermore, in June 2017, the CNJ in cooperation with the Ministry of Health launched an online consultation platform called e-NATJUS, which gathers technical information on all health technologies available in the Brazilian public health system.<sup>71</sup> This database, with technical notes, scientific analysis, and recommendations issued by advisory health committees in the country (NATs) and CONITEC, is easily accessible and aims at subsidizing judges in taking decisions on health care-related cases.<sup>72</sup>

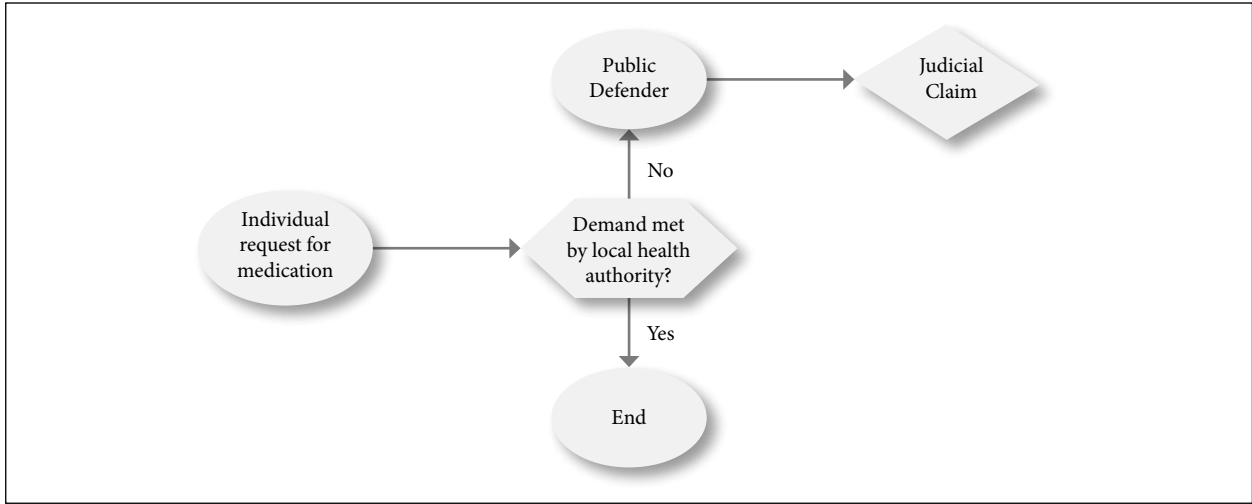
Therefore, the establishment of technical committees and conciliation chambers all over Brazil aiming at dealing with and overcoming the problem of individual litigation for health care can be understood as policy responses which improved participation and capacity, advancing new forms of health care governance. These initiatives are in effect considered intergovernmental networks characterized by shared values and quality interactions, whose application to the field of health has the advantage of contributing to efficiency in the health system due to increased communication between the actors involved, identification of shortcomings in health demands flow, and the gathering of data for policy discussion purposes.<sup>73</sup>

Although more scientific evidence is needed, there are signs, as demonstrated in this article, that the new forms of collaborative governance between state actors in Brazil have the potential to prevent health care-related litigation. Moreover, conciliation and mediation point toward a new movement of removing courts from health care decision-making and thus creating a path for “de-judicialization” of health policies.<sup>74</sup>

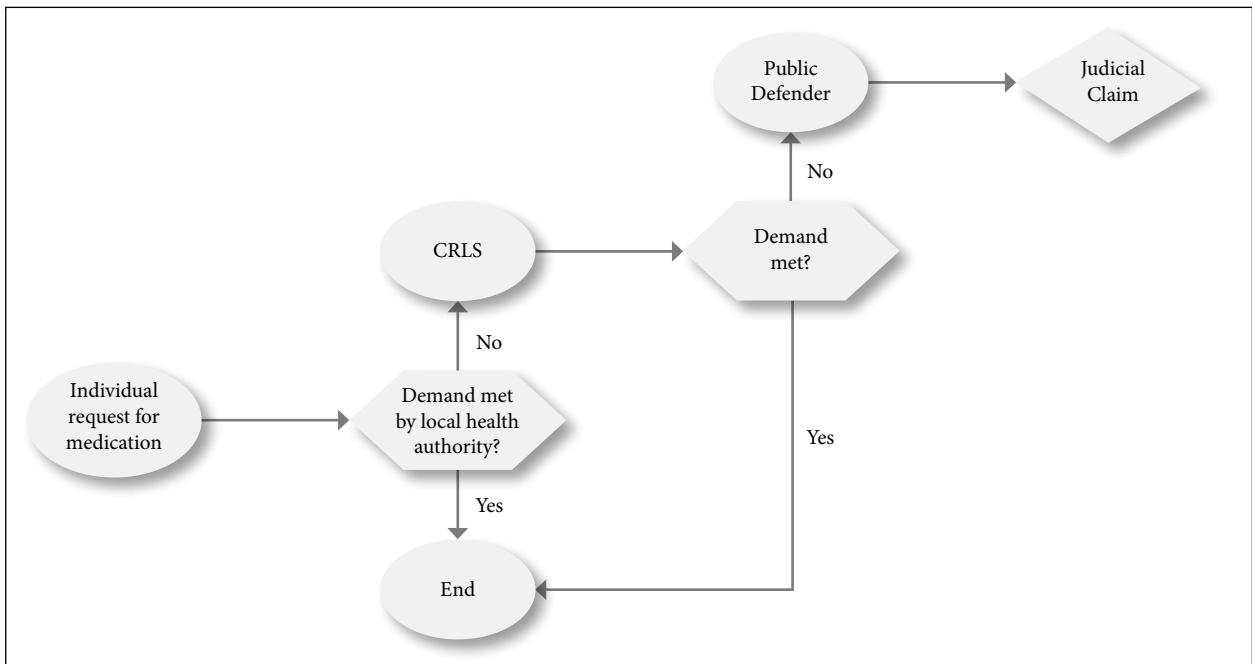
## Conclusion

The steady growth in the number of right to health claims in Brazil, which reportedly peaked in 2011 with more than 200,000 claims, led the judiciary to meet with institutions from other branches of the government.<sup>75</sup> This growth resulted in the Brazil-

FLOW CHART 1. Processing of health demands for the provision of medication at the administrative level without the participation of the conciliation chamber (CRLS). Source: Adapted from A. M. de Souza, *A atuação em rede de instituições governamentais na resolução de conflitos sobre demandas sanitárias no Rio de Janeiro*, Master Dissertation (Rio de Janeiro, RJ: Fundação Getulio Vargas – FGV, 2016), p. 50.



Flow Chart 2. Processing of health demands for the provision of medication at the administrative level with the participation of the conciliation chamber (CRLS) Source: Adapted from A. M. de Souza, *A atuação em rede de instituições governamentais na resolução de conflitos sobre demandas sanitárias no Rio de Janeiro*, Master Dissertation (Rio de Janeiro, RJ: Fundação Getulio Vargas – FGV, 2016), p. 50.



ian Supreme Court calling a landmark initiative, the Public Hearing on Health, in 2009. Since that public hearing, important changes have taken place at the judiciary level, such as the creation by CNJ of a working group focusing on health. These changes also developed at different levels of the executive branch of the government, affecting the HTA process and health care governance in the country. In this regard, the creation of CONITEC in 2012 is perhaps the highlight, establishing at least in principle a more transparent, participatory, and accountable HTA decision-making process in Brazil and having, therefore, the potential to contribute to the achievement of a more efficient and fair health system, not only through a more accountable allocation of health resources, but also through the availability of drugs to the population at large and not only to individual claimants.

The dialogical approach of the judiciary in this context opened the possibility of increased collaboration and partnerships between different state actors, such as state courts, state attorneys' offices, public defenders' offices, prosecutors' offices, NATs and the CRLS, with the aim of reducing or better responding to individual health care litigation. Altogether, these institutional changes resulted in new forms of health care governance which are likely to improve participation and policy capacity through inter-institutional dialogue and the use of health professionals' expertise.

Data available so far is very limited and is produced by the public institutions which run these initiatives; therefore it needs to be taken with caution. Yet states' reports of a decrease in the number of lawsuits and spending on litigation in the last years are not implausible. If these trends are confirmed and consolidated, the paradox speculated by Wang may well become reality: by creating unfairness and inefficiency, individual litigation will have forced the Brazilian health system to become fairer and more efficient.<sup>76</sup>

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*All Portuguese-language material has been translated from Portuguese into English by the author.*

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

REGIANE GARCIA

## 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.<sup>1</sup> 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.<sup>2</sup> 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.<sup>3</sup> 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.<sup>4</sup> 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.<sup>5</sup> 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.<sup>6</sup> 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.<sup>7</sup>

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.<sup>8</sup> 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."<sup>9</sup>

The impacts of health litigation on Brazil's health system have generated prolific and polarized debate.<sup>10</sup> 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.<sup>11</sup> 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.<sup>12</sup>

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.<sup>13</sup> 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.<sup>14</sup> 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.<sup>15</sup> 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.<sup>16</sup> 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."<sup>17</sup> 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.<sup>18</sup>

Furthermore, United Nation treaty bodies have consistently reinforced the centrality of participation in health systems for improved health equity.<sup>19</sup> 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.<sup>20</sup> 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.<sup>21</sup>

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.”<sup>22</sup>

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.<sup>23</sup> 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.<sup>24</sup> 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.<sup>25</sup> 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.<sup>26</sup> 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.<sup>27</sup> For example, Sueli Dallari has explored the idea of *democracia sanitária*, meaning civil society participation in public health decisions.<sup>28</sup> 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.<sup>29</sup>

### 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.<sup>30</sup> 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.”<sup>31</sup> 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.”<sup>32</sup> 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.<sup>33</sup>

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.<sup>34</sup>

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.<sup>35</sup> 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.<sup>36</sup> 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 mem-

bers. 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.<sup>37</sup>

### *Systemic concerns*

A further, and significant, empirical question raised by the literature is whether NHC representatives actually represent the interests of all citizens.<sup>38</sup> 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.<sup>39</sup> 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 partic-

ipate 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 two-fold 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 re-addressed 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.<sup>40</sup> 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.<sup>41</sup> 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.<sup>42</sup> In 2013, Daniel Wang provided an insightful framework through which courts could assess the legitimacy of policy decisions.<sup>43</sup> 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.<sup>44</sup> Brazilian courts, Wang suggests, could examine whether policy decisions meet those four conditions.<sup>45</sup> 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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# Challenges in Priority Setting from a Legal Perspective in Brazil, Costa Rica, Chile, and Mexico

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## Abstract

Priority setting is the process through which a country's health system establishes the drugs, interventions, and treatments it will provide to its population. Our study evaluated the priority-setting legal instruments of Brazil, Costa Rica, Chile, and Mexico to determine the extent to which each reflected the following elements: transparency, relevance, review and revision, and oversight and supervision, according to Norman Daniels's accountability for reasonableness framework and Sarah Clark and Albert Wale's social values framework. The elements were analyzed to determine whether priority setting, as established in each country's legal instruments, is fair and justifiable. While all four countries fulfilled these elements to some degree, there was important variability in how they did so. This paper aims to help these countries analyze their priority-setting legal frameworks to determine which elements need to be improved to make priority setting fair and justifiable.

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## Introduction

In the quest for universal health coverage, priority setting helps publicly financed national health systems allocate limited resources in a way that meets specific public health needs.<sup>1</sup> Priority setting should help ensure the financial sustainability of the health system, represent the population's health needs, fairly and transparently allocate resources, and create relevant and accountable procedures; additionally, priority setting can help ensure equitable access to standard health services and progressive coverage.<sup>2</sup> The result of priority setting can be seen in benefit packages and in positive/negative lists that outline covered health services.<sup>3</sup>

For priority setting, the study of law and its impact on health is relevant since legal norms establish minimum standards of accountability and tools that help us map out what a country has agreed to work on. For federal governments, norms and legislation can establish the criteria used for priority setting at the national and local levels; for central governments, priority setting establishes the criteria applicable to all territories.<sup>4</sup> Normative instruments are particularly important in the context of decentralized or fragmented health systems, as they set out the basic criteria that should be considered in priority setting. The existence of norms and legislation that spell out the criteria used for priority setting and that explain its process can contribute to the process's transparency, explicitness, and rationality.<sup>5</sup> Criteria should include not only "technical" judgments, such as clinical and cost-effectiveness, but also judgments regarding social values that can make priority setting ethical and reasonable.<sup>6</sup>

Sarah Clark and Albert Wale have said that decisions in priority setting must be justifiable and that they involve certain process and content values that can be assessed in any health system.<sup>7</sup> The content values that the authors identify are clinical effectiveness; cost-effectiveness; justice and equity; solidarity; and autonomy.<sup>8</sup> The process values they identify are transparency, accountability, and participation, which are commonly associated with Norman Daniels's accountability for reasonableness framework (A4R).<sup>9</sup> Daniels has argued that

since it is difficult in pluralistic societies to reach consensus on the principles of priority setting, it is better to study whether the process is fair through A4R.<sup>10</sup> To establish whether the priority-setting process is fair, A4R considers the following elements: transparency concerning the reasons why a certain health input (that is, a service, treatment, or intervention) is included; relevant reasons, as judged by appropriate stakeholders, about how to meet health needs fairly; and revisable decisions through an appeals procedure that allows relevant stakeholders to raise considerations in light of new evidence or arguments.<sup>11</sup> It is important to make explicit the values and principles inherent to priority setting since failing to do so can have a negative effect.<sup>12</sup> The absence of explicit priority setting has caused unfavorable outcomes in many low- and middle-income countries where multiple priorities coexist alongside a constrained budget, generating implicit rationing through unfair mechanisms that produce inequities.<sup>13</sup> The existence of explicit health benefit plans, of increased rights awareness among the public, and of legal instruments that outline the process and content of priority setting can improve accountability.<sup>14</sup> The study of Latin America is useful in this regard, given that many countries in the region have included explicit priority setting in their legal instruments.<sup>15</sup>

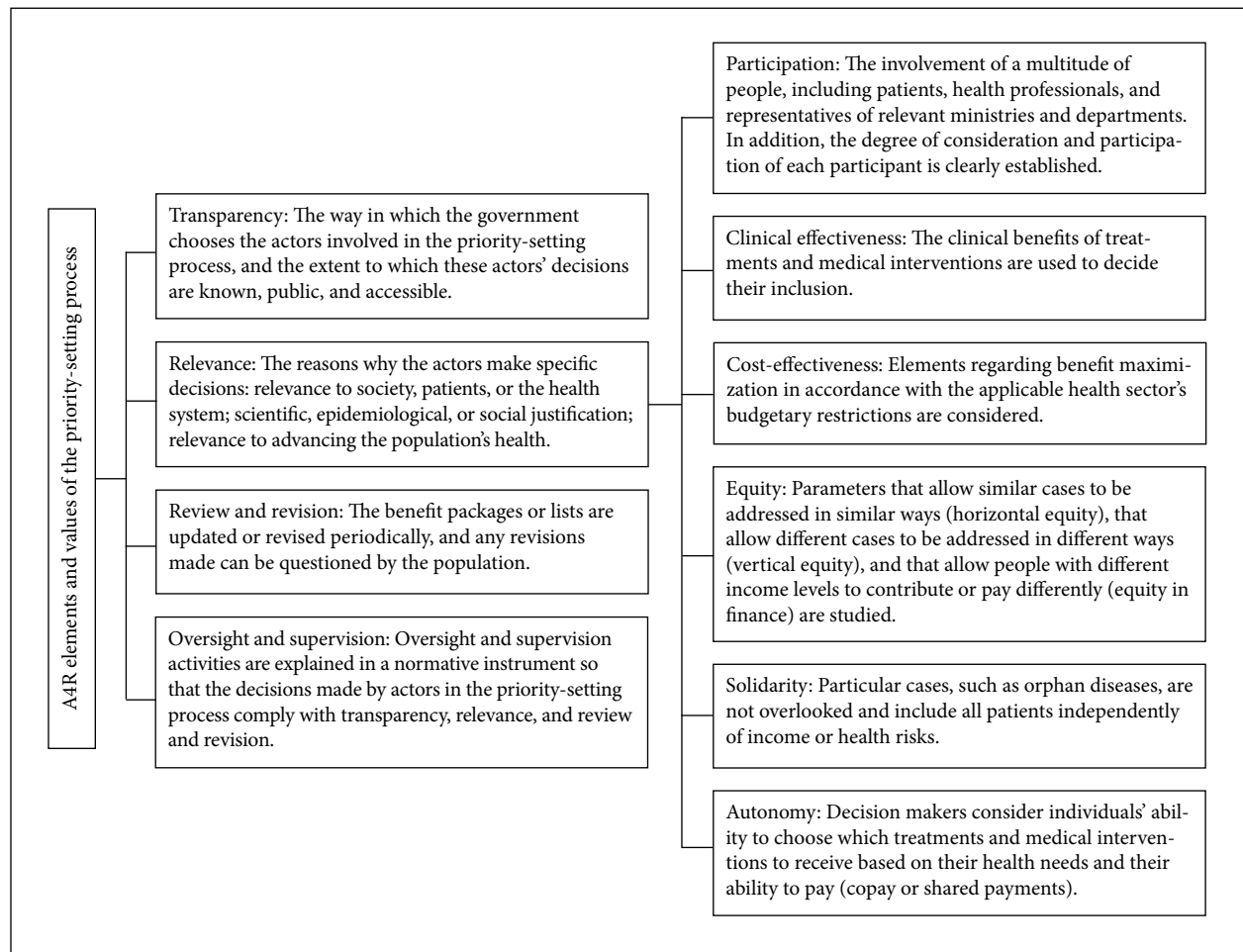
In this paper, we argue that priority setting in some Latin American countries tends to be fair and justifiable if the legal instruments that define its process provide for certain elements specified by the A4R framework and certain values outlined by Clark and Wale. Therefore, we redefined the four elements of A4R in a way that helped us identify whether the priority-setting process reflected some of its core ideas, as well as the extent to which the elements (transparency, relevance, review and revision, and oversight and supervision) are found in legal instruments. Additionally, we redefined six social values (participation, clinical effectiveness, cost-effectiveness, equity, solidarity, and autonomy) from Clark and Wale's framework to assess the priority-setting content in a way that allowed us to determine the extent to which they were incorporated into legal instruments. We included Clark and

Wale's values as part of A4R's relevance element in order to achieve clarity about the concepts involved in the reasons why actors make specific decisions in priority setting. The definitions can be found in Figure 1.<sup>16</sup>

We studied priority setting in Brazil, Costa Rica, Chile, and Mexico. We chose these countries in order to capture similarities (they all have a constitutional right to health, as well as public and private sectors of their national health systems) and differences that represent some variability among Latin American health systems. The proposed analysis fosters an understanding of the way in which

priority setting can contribute to the effective realization of the right to health.<sup>17</sup> It is important to note that this type of analysis has a limitation: legal analysis cannot account for what occurs beyond the law, since there is always a gap between what the law establishes and how it is executed. Nonetheless, it offers a possible starting point for an empirical analysis that can explain what happens in a country's specific context. This analysis does not provide a rationale for why certain requirements are included in the priority-setting norms but rather identifies the elements and values that are taken into account when deciding to include drugs, interventions, and

FIGURE 1. A4R elements and values



Sources: Based on definitions by S. Clark and A. Wale, "Social values in health priority setting: A conceptual framework," *Journal of Health Organization and Management* 26/3 (2012), pp. 293-316, N. Daniels and J. Sabin, "Limits to health care: Fair procedures, democratic deliberation, and the legitimacy problem for insurers," *Philosophy and Public Affairs* 26/4 (1997), pp. 303-350, J. Licht et al., "When does transparency generate legitimacy? Experimenting on a context-bound relationship," *Governance* 27/1 (2014), pp. 111-134, R. Hoedemaekers and W. Dekkers, "Justice and solidarity in priority setting in health care," *Health Care Analysis* 11/4 (2003), pp. 325-343, N. Daniels, "Accountability for reasonableness," *BMJ* 321/7272 (2000), p. 1300.

treatments in benefit packages or positive/negative lists that outline covered health services.

To assess how priority setting is regulated in a given Latin American country, it is necessary to understand the following: first, how the health system works and is organized; second, whether there are one or more types of benefit packages or lists of covered health services; and third, the different laws in which priority setting might be described. For this analysis, we consulted the available legal materials on government websites and in the literature regarding priority setting in each country. We then produced descriptive tables summarizing the main themes of the analyzed elements.

### Brazil

Brazil has a unified universal public health system, named the SUS after its acronym in Portuguese, and a private health system, named the Supplementary Health Care System. The SUS is divided into national, state, and county levels. Three main lists identify the health inputs and services provid-

ed by the SUS: the National Relation of Essential Medicines (RENAME), the National Relation of Actions and Services in Health (RENASES), and the Protocols and Guidelines for the Comprehensive Care of Rare Diseases.<sup>18</sup> The RENAME is based on the recommendations of the World Health Organization, and its purpose is to facilitate access to medicines among the entire Brazilian population.<sup>19</sup> The RENASES includes all of the health services offered by the SUS.<sup>20</sup> The Protocols and Guidelines for the Comprehensive Care of Rare Diseases were implemented in 2015.<sup>21</sup> The National Committee for Health Technology Incorporation (CONITEC) is in charge of updating the RENAME and RENASES and creating the Protocols and Guidelines for the Comprehensive Care of Rare Diseases.<sup>22</sup> Since CONITEC carries out the priority setting of these three lists in the same way, we decided to analyze them as a single process. We analyzed the process for including health inputs and services in the SUS, not the way resources are allocated between the SUS and the Supplementary Health Care System. Figure 2 describes the internal priority-setting process

FIGURE 2. CONITEC's priority-setting process

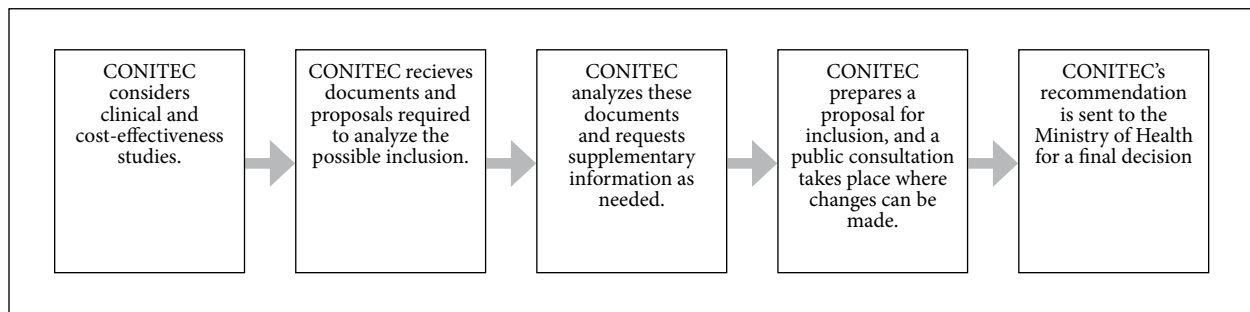


TABLE 1. Elements in Brazil's priority-setting legal instruments

Transparency	The priority-setting process and the way in which decision makers are chosen are described in Portaria No. 2009. <sup>24</sup> All decisions regarding priority setting must be made public. <sup>25</sup>
Relevance	The Ministry of Health and several health-related agencies are part of CONITEC. <sup>26</sup> Additionally, all decisions are subject to a public consultation in which regular citizens can participate. <sup>27</sup> Cost-effectiveness and clinical effectiveness studies are considered. <sup>28</sup> Equity is part of the universality mandate, which CONITEC must consider in its process. <sup>29</sup> Solidarity is present in the Protocols and Guidelines for the Comprehensive Care of Rare Diseases. <sup>30</sup> There is no mention of copayments or shared payments as criteria for priority setting or of the patient's ability to choose the treatment he or she wants.
Review and revision	The Protocols and Guidelines for the Comprehensive Care of Rare Diseases and RENAME can be modified whenever necessary. RENAME and RENASES are updated every two years. <sup>31</sup>
Oversight and supervision	The Health Surveillance Secretariat and the National Health Surveillance Agency are part of CONITEC, but there is no mention of their specific roles in oversight and supervision activities with regard to priority setting. <sup>32</sup>

carried out by CONITEC, although there is also an external process that involves several agencies of the Ministry of Health.<sup>23</sup> Table 1 provides a detailed definition of how the elements defined in Figure 1 were found in the consulted legal instruments.

### Costa Rica

Costa Rica's health system is divided into a private and a public sector, with the latter run by the Costa Rican Social Insurance Fund (CCSS).<sup>33</sup> The CCSS is responsible for managing the public fund for pensions, as well as health insurance for workers that offers sickness and maternity benefits.<sup>34</sup> The state is responsible for paying a supplementary contribution for the non-contributory population.<sup>35</sup>

The Central Committee of Pharmacotherapy (CCP), which is part of the CCSS, prepares and updates the Official Medicines List, Costa Rica's health benefit package.<sup>36</sup> The committee's composition and each of its members' and advisors' faculties

are described in its bylaws.<sup>37</sup> The Official Medicines List is part of the country's Institutional Policy of Essential Medicines and Generic Denomination, whose strategies must be framed according to the criteria of universality, equity, solidarity, compulsory, and unity.<sup>38</sup>

The Official Medicines List is the result of a priority-setting process carried out by the CCP.<sup>39</sup> The priority-setting process is established in the CCP's bylaws and in the regulations of the Official List of Medications.<sup>40</sup> Figure 3 describes the list's priority-setting process. Table 2 provides a detailed definition of how the elements defined in Figure 1 were found in the consulted legal instruments.

### Chile

Chile's health sector comprises a private sector, represented by health insurance institutions; the public sector, represented and administered by the National Health Fund; and the army's health ser-

FIGURE 3. The Official Medicines List's priority-setting process

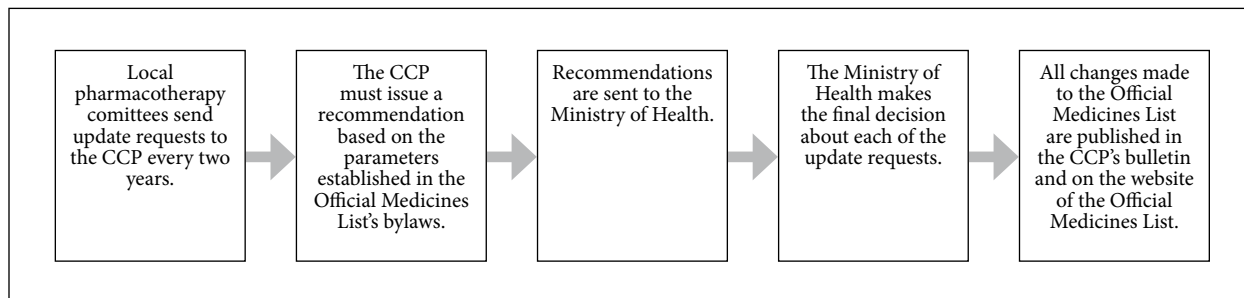


TABLE 2. Elements in Costa Rica's priority-setting legal instruments

Transparency	Transparency is one of the principles that regulate the CCP, as established in article 5 of the committee's regulations. <sup>41</sup> The priority-setting process and the way in which decision makers are chosen are described in the CCP's regulations and in the Official Medicines List; these legal instruments are made publicly available on the websites of the CCSS and the Attorney General's Office. Justifications for decisions must comply with the requirements established in article 11 of the Official Medicines List's regulations. <sup>42</sup> The Official Medicines List is revised and edited every two years. <sup>43</sup> The modifications are published in the CCP's bulletin, which can be found on the CCSS's website. <sup>44</sup>
Relevance	Only health professionals may participate in the priority-setting process; however, article 6 of the CCSS's health insurance bylaws establishes health councils for promoting citizen participation in health centers. <sup>45</sup> The decisions have scientific and epidemiological justifications since some of the criteria for decision making are clinical effectiveness, epidemiological data, and economic and pharmacological studies. <sup>46</sup> In addition, the national medication policy must be guided by the principles of universality, equity, and solidarity. <sup>47</sup>
Review and revision	The Official Medicines List is revised every two years. <sup>48</sup> Article 21 of the CCP's bylaws establish a process for decisions to be questioned by persons who have a legitimate interest in the issue; these requests must be filed no more than five days after the decision has been made. <sup>49</sup>
Oversight and supervision	There is no mention of how oversight and supervision activities should be conducted.

vices.<sup>50</sup> Services such as vaccines and the treatment of tuberculosis are free to the entire population. Since its health care reform of 2005, Chile has implemented different health benefits packages. The first of these is the National Drug Formulary, which contains drugs that must be covered and is essentially offered to the entire population. However, this formulary is no longer used in practice. Its last publication occurred in 2006, and in 2013 there was a slight change to only one phrase; for this reason, we did not analyze its priority-setting process. The second health benefits package is the Plan of Explicit Health Guarantees (GES, formerly known as the Plan of Universal Access to Explicit Guarantees), which must be offered to affiliates of the National Health Fund and health insurance institutions. Finally, the third package is the Ricarte Soto Plan, which creates the Financial Protection System for High-Cost Diagnostics and Treatments, includes a set of explicit guarantees for the diagnosis and treatment of diseases considered high cost, and includes diagnostic studies and treatments for oncological, immunological, and rare diseases.<sup>51</sup>

The GES was created by the Ministry of Health, the Ministry of Finance, and an advisory committee.<sup>52</sup> The guarantees included in the Ricarte Soto Plan are defined by different government ministries and by a citizen committee that is part of a special commission.<sup>53</sup> Figures 4 and 5 describe the priority-setting processes for the GES and the Ricarte Soto Plan, respectively. Table 3 provides a detailed definition of how the elements defined in Figure 1 were found in the consulted legal instruments.

## Mexico

In Mexico, the National Health System (NHS) is divided into a public and a private sector. The public sector comprises five providers. The providers are assigned to users depending on the type of work a person performs. Employees in the formal sector of economy are assigned to the Mexican Social Security Institute; government employees are assigned to the Institute for Social Security and Services for State Workers; employees of the public oil company Pemex are assigned to Pemex's health

TABLE 3. Elements in Chile's priority-setting legal instruments

Transparency	<b>GES:</b> The priority-setting process is established in Decree No. 121 and in Law 19966; the latter describes how members of the advisory committee are elected. <sup>54</sup> Justifications for decisions made in the priority-setting process must comply with the parameters established in Law 19966.
	<b>Ricarte Soto:</b> The priority-setting process is described in Law 20850, Decree No. 13, and Resolution No. 1457. <sup>55</sup> Decree No. 13 describes how persons involved in the process are chosen. <sup>56</sup> The elements considered for the priority-setting process are included in the above mentioned legal instruments. Law 20850 indicates that decisions must be made public on the Ministry of Health website. <sup>57</sup>
Relevance	<b>GES:</b> In the priority-setting process, public health professionals, scholars, representatives named by the president, and two ministries are involved. <sup>58</sup> All members of the advisory committee except for those representing the Ministries of Health and Finance have voice and vote. <sup>59</sup> Cost-effectiveness and clinical effectiveness analysis are part of the process. <sup>60</sup> Certain beneficiaries can freely choose which health service they want to receive, but they must make a shared payment with the government. <sup>61</sup> The GES establishes the same guarantees for everyone, except for cases in which different medical treatments are justified due to age, sex, gender, etc. <sup>62</sup>
	<b>Ricarte Soto:</b> The Ricarte Soto Plan was specially created to consider low-incidence and high-cost diseases. The various stages of the priority-setting process involve health professionals, patients, and the Ministries of Health and Finance. <sup>63</sup> Elements of cost- and clinical effectiveness are analyzed, as well as epidemiological data. <sup>64</sup> Elements regarding solidarity and equity are embraced via the statement that all explicit guarantees are universal and should be differentiated only by reasonable criteria. <sup>65</sup>
Review and revision	<b>GES:</b> The GES must be revised every three years; if not, it will be automatically extended for another three years. Only the president can change it in special situations. <sup>66</sup>
	<b>Ricarte Soto:</b> The Ricarte Soto Plan is revised every three years, but it can also be revised when a new technology requires it. In cases where the plan is not revised, it is automatically extended for another three years. The President can change it in special situations. <sup>67</sup>
Oversight and supervision	<b>GES:</b> Supervision activities are carried out by the advisory committee, which verifies that the assessment made by the Ministry of Health complies with the requirements established in Decree 121. <sup>68</sup>
	<b>Ricarte Soto:</b> Decree No. 13 establishes sanctions for any member who does not follow the rules of the priority-setting process. <sup>69</sup>

services; members of the marine and armed forces are assigned to the Armed Forces Social Security Institute; and those who work in the informal sector of the economy have the option of being covered by the Popular Insurance (Seguro Popular in Spanish). All public sector providers must abide by the National Drugs Catalogue, a list created by the General Health Council that names all the drugs that have been approved for use in the NHS. The drugs that are not part of the catalogue cannot be provided in the NHS. Based on this catalogue, each of the public providers must make its own institutional catalogue using its specific priority-setting process. It is important to note that not all of the drugs in the National Drugs Catalogue are part of these institutional catalogues. In Mexico, we can identify a national priority-setting process (National Drugs Catalogue) and six different internal priority-setting processes (the Protection Fund against Catastrophic Expenses, the Universal Catalogue of Health Services, the Mexican Social Security Institute, the Institute for Social Security and Services for State Workers, Pemex, and the Armed Forces Social Security Institute). The Seguro Popular has two different catalogues: one that

determines which drugs and interventions will be provided for its general population (the Universal Catalogue of Health Services), which is developed by the Seguro Popular, and one for determining coverage for catastrophic diseases (the Protection Fund against Catastrophic Expenses), which is developed by the General Health Council. It is important to note that before an orphan drug can be included in the National Drugs Catalogue, the disease that it addresses must be analyzed by a special commission that evaluates its inclusion or exclusion.<sup>70</sup> Figure 6 describes the priority-setting process for the National Drugs Catalogue. Table 4 provides a detailed definition of how the elements defined in Table 1 were found in the consulted legal instruments.

### Conclusions

Each country has incorporated the selected elements into their priority-setting legal frameworks in different ways. Most of the countries' legal frameworks include the elements analyzed here, but the extent to which each health system fulfills the definitions as described in Figure 1 varies.

FIGURE 4. The GES's priority-setting process

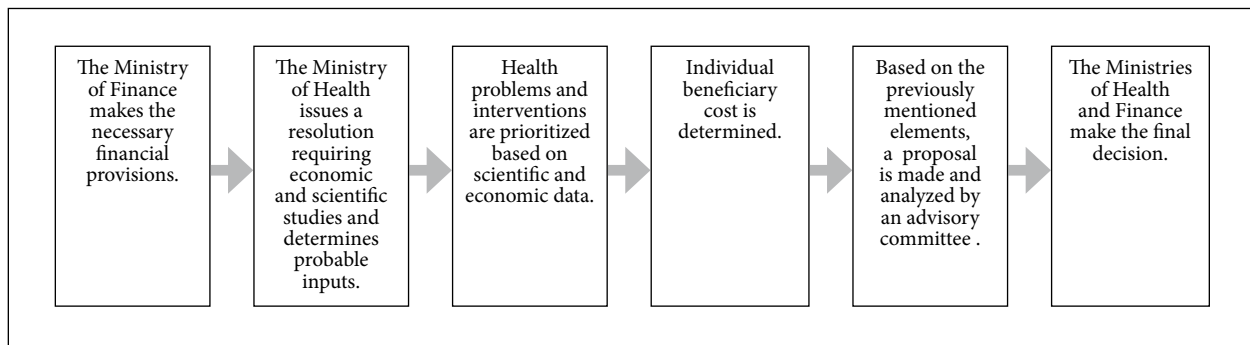
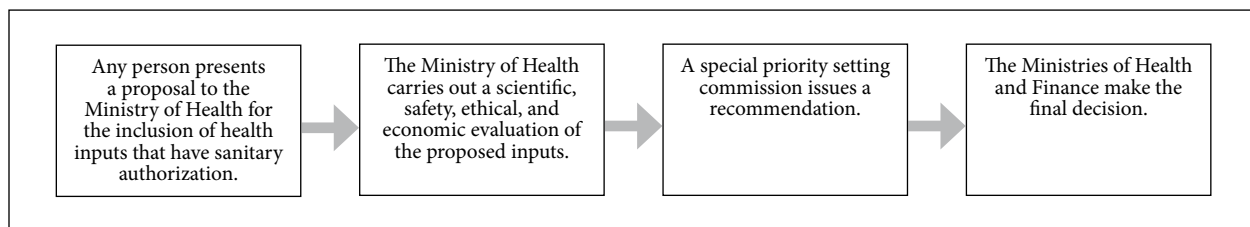


FIGURE 5. The Ricarte Soto Plan's priority-setting process



With regard to transparency, after studying each country's priority-setting process, we concluded that it is difficult to find the information online and that the information is not updated as required by law. The more fragmented and complicated the health system, the more onerous it is to find and understand the priority-setting process. Although we encountered barriers in finding information, we found that all of the countries' priority-setting processes are public and, to some degree, accessible since they are established in legal instruments that are published in official diaries. It is difficult to conclude whether the processes are fully accessible and truly known by the countries' respective populations since it is necessary to have a general knowledge of the health system and its norms to be able to search for, find, and understand these processes. Another important element of transparency is the justification for the inclusion of specific health inputs, which, in the countries analyzed here, is not easy to find.

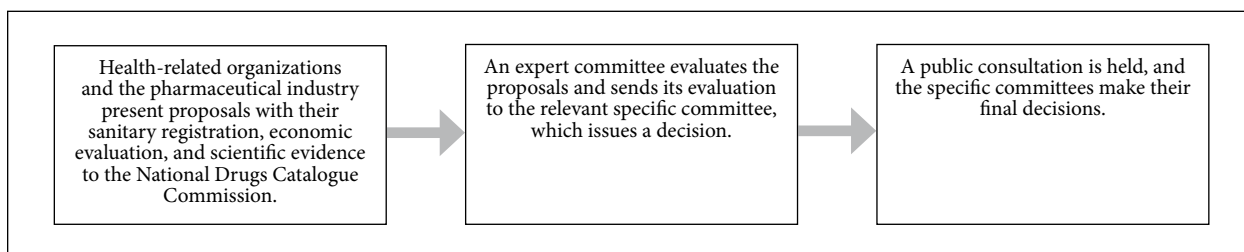
For the normative instruments in which priority setting is described, we determined that in Latin America, these instruments tend to be static or difficult to change—for example, they are often in the form of bylaws or executive decrees that must go through regulatory instances to modify their content. This is important because the priority-setting process could become outdated with respect to new technologies or methods to determine necessities.

Some countries have multiple priority-setting processes, even where the country has a unified health system. This is the case for Brazil, for example, which has one priority-setting process for the RENAME, another for the RENASES, and yet another for the Protocols and Guidelines for the Comprehensive Care of Rare Diseases. In Brazil, all levels of health care planning and delivery must be prioritized not only in terms of drugs, treatments, and interventions but also in terms of the national health policy. Moreover, countries with fragmented health systems, such as Mexico, can be even more

TABLE 4. Elements in Mexico's priority-setting legal instruments

Transparency	The priority-setting process and the way in which decision makers are chosen are established in the bylaws of the National Drugs Catalogue. <sup>71</sup> Justifications for specific decisions cannot be consulted, but it is possible to consult the guidelines that decision makers used to evaluate the evidence. <sup>72</sup>
Relevance	Health providers, health authorities, and a representative of the National System for Integral Family Development (which is part of the Ministry of Social Development) participate with voice and vote in the commission in charge of the National Drugs Catalogue. <sup>73</sup> Other health authorities and three representatives of the pharmaceutical industry participate only with voice; additionally, specific committees made up of members of the General Health Council, as well as an expert committee selected by the commission, analyze the proposals. <sup>74</sup> The public has 10 days to review and make comments on the projects. <sup>75</sup> Cost- and clinical effectiveness studies are considered in the priority-setting process. <sup>76</sup> Equity must be considered as part of the cost-effectiveness analysis. <sup>77</sup> Autonomy is not present in any of the legal instruments, but solidarity is considered to some extent: orphan diseases and drugs are analyzed with criteria that are difficult to comply with, such as the requirement that orphan drugs have an adequate financial impact study. <sup>78</sup>
Review and revision	The catalogue is updated three times a year. <sup>79</sup>
Oversight and supervision	Authorities responsible for the priority-setting process can be sanctioned under the public servants' liability law; other decision makers must abide by the General Health Council Code of Ethics. <sup>80</sup>

FIGURE 6. The National Drugs Catalogue's priority-setting process





complicated. Mexico has a national priority-setting process (for the National Drugs Catalogue), a process for each subsystem (the Mexican Social Security Institute, the Institute for Social Security and Services for State Workers, the Seguro Popular, Pemex, and the Armed Forces Social Security Institute), and even separate processes for subsystems (for example, the Seguro Popular has separate processes for the Protection Fund against Catastrophic Expenses and the Universal Catalogue of Health Services). This makes even more complex the task of understanding how priority setting is performed in a specific context and how it contributes to widening gaps in coverage between the various subsystems.

We found that all of the priority-setting processes analyzed here fulfill clinical and cost-effectiveness parameters. In the case of Mexico, the national priority-setting process for the National Drugs Catalogue involves a clear consideration of these elements, but this is not reflected in all of the subsystems; for example, the Institute for Social Security and Services for State Workers does not possess any of these elements, as its priority-setting process is not established in any legal instrument.<sup>81</sup>

Participation as a component of relevance is considered differently in each priority-setting process. In Brazil, there is a great emphasis on public participation, as the federal, state, and municipal levels are involved in health planning through national health conferences in which a more general priority setting than the one described here occurs to set national health policy.<sup>82</sup> Public participation is also a central part of CONITEC's priority-setting process. It is important to note that CONITEC comprises 13 members with a voice and vote, who are part of the Ministry of Health; there is no formal representation of other sectors. In Chile, the Ricarte Soto Plan has multiple stages in which different types of people participate; for example, patients are part of the Prioritized Recommendation Commission, but they are not part of the final decision, which involves only the Ministries of Health and Finance.<sup>83</sup> For the GES, however, it is not clear how public participation is achieved. Based on our study of Costa Rica's legal instruments, only

health professionals are directly involved in priority setting, and it is not clear how citizen participation is achieved through the health councils. In Mexico, the process for the National Drugs Catalogue involves a 10-day public consultation, but this is not the case for each of the subsystem's processes.

Equity, solidarity, and autonomy are considered differently in the countries analyzed here. Brazil's health system is based on social values such as universality and the integrality of health services. In Costa Rica, the national medication policy is guided by universality, equity, and solidarity. Additionally, solidarity is well defined since drugs that are not part of the Official Medicines List can be supplied to patients who do not respond to the list's drugs.<sup>84</sup> In Chile's GES, legal instruments do not mention equity, but the explicit guarantees must be available for everyone, and exceptions should be justified. The fact that the Ricarte Soto Plan exists provides evidence of certain guidelines for equity and solidarity. In Mexico, equity is part of the parameters for the National Drugs Catalogue; solidarity is not clear because of the difficulties in listing and including orphan diseases and drugs. In Brazil, Costa Rica, and Mexico, there is no mention of autonomy in the priority-setting mechanisms or the existence of copays or shared payments. Chile is the only country that has parameters for autonomy. In the GES, patients can choose their treatment by making a shared payment with the government. In the Ricarte Soto Plan, there is no mention of autonomy as part of the priority-setting process; it is present only when patients who have extreme necessities are treated in health establishments that are not part of the National Health Fund, and the patient, after being stabilized, chooses to be treated there. In Brazil, there is no clear consideration for autonomy in the priority-setting process.

The terms for the review and revision of the packages or lists are clearly stated in all the countries, but only Costa Rica has a process for the population to question a decision once it has been made. Oversight and supervision activities are weak in most countries. Brazil and Costa Rica do not mention them as part of their priority setting. Mexico has a slight mention of oversight and super-

vision activities in its normative instruments. Chile is the only country that has a more explicit mention in both of its priority-setting mechanisms.

From the legal instruments analyzed, we can conclude that the different priority-setting processes are partially fair and justifiable, as they somewhat fulfill the elements. There are windows of opportunity in all of the countries to improve their legal frameworks in a way that truly complies with the elements. Undertaking such improvements can increase governmental accountability vis-à-vis publicly financed health systems. In this way, the health sector can have a clear idea of what it is bound to in terms of priority setting, and the public can know the reasons why certain inputs are included. The closer that priority-setting mechanisms get to integrating all the elements, the more that possibilities open up to increase coverage in a fair and justifiable way.

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# Access to Justice in Health Matters: An Analysis Based on the Monitoring Mechanisms of the Inter-American System

LAURA PAUTASSI

## Abstract

This article analyzes how states are complying with their periodic reporting obligations under the Protocol of San Salvador (PSS) in one specific area: access to justice as a key component of the right to health. The sources of information for this analysis are seven reports submitted by the States parties, together with the observations and final recommendations made by the experts of the monitoring mechanism of the PSS. The reports are based on progress indicators, a group of indicators that the states must use to measure progress in compliance with its rights obligations. This system of indicators presents the cross-cutting category “access to justice,” which allows the identification of each branch of government’s involvement in the design of a health system and the guarantees of judicial protection of the right to health. The analysis focuses on the articulation of the empirical evidence presented by the States in the context of protection and fulfillment of the right to health, identifying progress made or limitations faced in the compliance with state responsibilities. The main findings reveal the weakness of the current mechanisms of access to justice in health and the reticence of the judiciary to take an active role towards accountability.

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## Introduction

Latin American states widely recognize the right to health. Most of these countries include a specific mention to the right to health in their constitutions and have ratified international agreements: the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural rights (ESCR), known as the Protocol of San Salvador (PSS).

ICESCR (1966) is a binding instrument for 18 Latin American states, while the PSS was opened for signature in 1988, came into effect in 1999, and has so far been ratified by 16 states. In both cases, the definition of the right to health is largely similar. While ICESCR states that the right to health is “the right of all persons to enjoy the highest possible level of physical and mental health” (Art. 1), the PSS defines it as “the enjoyment of the highest level of physical, mental and social well-being” (Art. 1). These instruments also require states to take similar measures, such as healthy working conditions and prevention, treatment, and medical assistance, with the purpose of guaranteeing the full effectiveness of this right. As a result of the work carried out by United Nations monitoring mechanisms such as the Committee of the ICESCR and the Office of the High Commissioner of the United Nations for Human Rights (OHCHR), the State parties reached a new consensus regarding the forms of verifying compliance with obligations related to the right to health. The necessary framework for the incorporation of human rights indicators was the result of the work of special rapporteurs, in particular the first special rapporteur for the right to health, Paul Hunt, who strongly emphasized the need to develop progress indicators to measure compliance with the right to health.<sup>1</sup> Subsequent documents from the United Nations supported his position.<sup>2</sup>

At the regional level, the Inter-American Human Rights System (IHRM) made a key contribution through the 2005 Resolution of the General Assembly of the Organization of American States

(OAS), which established that the monitoring mechanism of the PSS would be designed through human rights indicators, more precisely “progress indicators,” as described in the following section.<sup>3</sup> In 2007, another resolution of the general assembly established that the monitoring mechanism will be called the Working Group responsible for examining periodic reports of State parties to the Protocol of San Salvador (WGPSS) and be comprised of two independent experts, four governmental experts, and two members of the Inter-American Commission on Human Rights (IACHR).<sup>4</sup>

This milestone was the first step in an unprecedented process, which involved the design and implementation of a mechanism that combines obligations, accountability, and empirical evidence for eight rights: health, education, social security, work, trade union rights, adequate food, environment, and cultural rights. The system of progress indicators also takes into account guarantees for the protection of children and adolescents and elderly and disabled persons, while also incorporating a gender perspective and the recognition of indigenous populations and ethnic groups in a cross-cutting manner.

In order to analyze this innovative tool for measuring State parties’ compliance with the right to health, in section 3, I look at all seven countries that have to date been evaluated by the Working Group of the Protocol of San Salvador (WGPSS), the body in charge of monitoring the national reports. These countries are Bolivia, Colombia, Ecuador, El Salvador, México, Paraguay, and Uruguay.<sup>5</sup> For each country report, the analysis involves the states’ responses to the requested indicators regarding access to justice and the identification of the guarantees of justiciability in health matters. The sources of information are the reports submitted by the State parties and the observations and final recommendations made by Working Group experts.

Section 4 focuses on the shortcomings of information from the states, specifically regarding access to justice in health. Lastly, some key findings are presented on the conclusions.

## Support in the evidence: progress indicators

This section will describe the PSS system of progress indicators in terms of the cross-cutting category of access to justice within the right to health. As mentioned above, the PSS defines the right to health in a very similar way to ICESCR; therefore, the interpretive standards and the general observations made by the ICESCR Committee have been a relevant source for the elaboration of the PSS progress indicators.

The scope, content, and measures to be adopted by the State parties to the PSS in terms of the right to health require elements that allow the verification of coverage, universality, integrality, progressive realization, and non-regression, among other relevant information.<sup>6</sup> Progress indicators relate to social or development indicators regarding the sources of information, such as national statistics, census data, and surveys. However, their distinctive feature compared to development and other indicators lies in the fact that the unit of measurement is every economic, social, and cultural right (such as the right to health) defined in the PSS.

This analytical exercise requires the identification of different human rights dimensions, which

in turn are translated into categories and variables to be observed. This process presents many complexities, since the purpose is not only to quantify the extent of the policies adopted or laws passed, but also to qualify the state conduct in complying with its obligations. There is particular focus on quality, quantity, adequacy, availability, diversity, and universality.

Progress indicators defined by the PSS are divided into structural, process, and results indicators. *Structural indicators* reflect the ratification of international legal instruments and provide information on how the State party organizes its institutions and legal system to meet its international obligations. *Process indicators* seek to measure the quality and extent of the state's efforts to implement rights by tracking the scope, coverage, and content of strategies or policies designed to accomplish the goals necessary for the realization of a given right. *Result indicators* seek to measure the actual impact of government programs and interventions, offering a quantitatively verifiable and comparable measurement of the *performance* of the state in terms of the progressive realization of rights. In the case of the PSS follow-up mechanism, there has been advances in incorporating qualitative signs of

TABLE 1. Right to health and access to justice progress indicators

Structural indicators
<ol style="list-style-type: none"> <li>1. Existence of administrative recourse to submit complaints concerning violation of obligations connected with the right to health</li> <li>2. Competencies of ministries or oversight agencies in terms of receiving complaints from health system users</li> <li>3. Existence of constitutional remedies (actions for constitutional relief (amparo), protection, etc.)</li> <li>4. Existence of comprehensive, free legal services for protection of the right to health</li> <li>5. Existence of public mediation or conciliation offices for settling issues connected with health</li> <li>6. Application of procedural guarantees in judicial proceedings concerning health: (i) an independent and impartial tribunal; (ii) reasonableness of time; (iii) <i>égalité des armes</i>; (iv) <i>res judicata</i>; (v) right to appeal decisions to a higher authority</li> </ol>
Process Indicators
<ol style="list-style-type: none"> <li>1. Number of judicial decisions upholding guarantees with respect to health in general as well as in specific cases (sexual and reproductive health, HIV/AIDS, and others)</li> <li>2. Number and type of complaints received concerning the right to health investigated and resolved by the competent national human rights institutions</li> <li>3. Training policies for judges and lawyers on the right to health. Topics covered and scope</li> </ol>
Sings of Progress
<ol style="list-style-type: none"> <li>1. Characteristics and coverage of awareness-raising mechanisms on health-related rights</li> <li>2. Coverage of indigenous-language translation services</li> </ol>

Source: WGPSS, OAS, 2015<sup>7</sup>

progress into the three types of indicators described.

This methodology focuses on eight rights (health, social security, education, adequate food, healthy environment, benefits of culture, work, and trade union rights) and also on the state's obligations to respect, protect, and guarantee these rights. Other categories were developed in order to complete the system of indicators: institutional design adopted, financial context and budgetary commitment and state capacities. Finally, the conceptual framework is completed by the fundamental human rights principles: equality and nondiscrimination, social participation and accountability, access to information and to the justice system.

The General Assembly of the OAS requires compliance with the information required by the indicators.<sup>8</sup> All data thus produced by the State parties also advances the Sustainable Development Goals agenda.

The system designed by the Working Group of Protocol of San Salvador (WGPSS) requests 714 indicators in total. Specifically regarding the right to health, the WGPSS requests 85 indicators, as well as signs of qualitative progress (see Table 1).

The information that State parties submit under this recently created monitoring process provides a baseline for further measurement of progress. State parties must report every three years, which means that as of 2019 there will be a flow of relevant information that will allow a detailed analysis of the different elements involved in the compliance with the ICESCR.

On the other hand, as the WGPSS points out in its reports, the official information submitted by the states is the only element of analysis. Said reports do not necessarily cover the states' "degree of compliance" with their obligations to the right to health, rather only how those states are "reporting" to an international human rights mechanism, such as the one devised under the PSS. The WGPSS therefore bases its evaluation only on the information received officially by each state. While the WGPSS does take alternative civil society reports (shadow reports) into consideration as control elements for the mechanism, these shadow reports are not part of the State party's evaluation procedure.

## Access to justice for health matters according to the State parties' reports

This section analyzes the seven national reports submitted to the PSS monitoring mechanism, as well as the recommendations the WGPSS made regarding access to justice in health matters. The interest in analyzing the reports submitted by the State parties is that this is the only information that the states themselves show and provide, in light of a binding mechanism and in response to their international obligations regarding the right to health.

### *Bolivia*

Bolivia is a particular case, insofar as its definition as a plurinational and intercultural state, based on its constitution of 2009, establishes in Article 18 that

- I. Every person has the right to health.*
- II. The state guarantees the inclusion and access to health for all persons, without any exclusion or discrimination.*
- III. There shall be a single health system, which shall be universal, free, equitable, intra-cultural, intercultural, and participatory, with quality, kindness, and social control.*

Subsequent articles acknowledge that the health system should be universal and free, and should respect the Bolivian world view and the traditional practices of the nations and rural and/or native indigenous people. Articles 35 through 44 expressly and widely recognize the right to health and social security. The WGPSS pointed out that Bolivia presented a project related to the strengthening of access to justice and prevention of violence against women in indigenous populations and communities; and in rural, native and afro-descendant communities. The Working Group experts expressed:

*The state should advance in a prompt and timely manner the implementation of this project understanding that it represents the first step to increasing the guarantees to access to justice, in this case of women who are victims of violence, but it is the hope that they be incorporated in the various fields of guarantees of economic, social and cultural rights.<sup>9</sup>*



The lack of information submitted by the state of Bolivia with regard to indicators of access to justice in health is noteworthy. The report only mentions that, with regards to administrative matters, complaints must be filed with the Ministry of Health, the Ombuds office, or the medical school. Complaints must be submitted via a form that is available in person and on the Ministry of Health website. This is all the information that it offers in terms of access to justice in health.

The WGPSS has therefore indicated that in future, Bolivia should provide information regarding:

- number of judicial decisions that have granted guarantees in health generally and in specific cases (such as those dealing with sexual and reproductive health, treatment for people living with HIV/AIDS),
- number of complaints related to the right to health received, investigated, and resolved by the competent national human rights institutions, and
- policies for training judges and lawyers in right to health matters, topic coverage, and scope.

### *Colombia*

Colombia recognizes the right to health for children and adolescents (Articles 44 and 50 of the constitution) and the protection of and the assistance for elderly people (Article 46) where the state guarantees “the services of integral social security and food subsidies in the cases of indigence”. In 2009, Article 49 was amended to establish that “public health and environmental protection are public services under the responsibility of the State. All individuals are guaranteed access to the services that promote, protect and restore health.”

Colombia submitted more complete information than Bolivia regarding indicators related to access to justice. First, the state indicated that the National Health Superintendence (“Supersalud”) receives petitions related to the General Health Social Security System, and that there are other administrative bodies for filing complaints:

the Ministry of Health and Protection, Ombuds office, and national attorney general’s office; offices of the district and municipal attorneys of Bogota; and departmental, district, and municipal health departments. According to the report, the Ombudsman office registered the requests for counseling, attention, and intervention for violation of the right to health due to the deficiency in care provided by the territorial authorities and service providers. It states that health is the most frequent complaint received by this organism: Supersalud received a total of 239,584 petitions, complaints, and requests for information submitted in 2011.

With regard to conflict resolution, Supersalud has a delegate for the jurisdiction and conciliation procedures, who has been implementing conciliation as an alternative mechanism for conflict resolution between actors of the health service and acting as judge and mediator in these reconciliations. The state report adds that it offers conciliation workshops in different departments of the country as a strategy to offer this “tool as an alternative mechanism for conflicts as opposed to the judicial route and in a more expeditious manner allowing for the standardization of the flow of the resources of the General Health Social Security System.” The official information indicates that in 2010, 1,403 conciliation agreements were signed.

With regard to writ for protection of constitutional rights, Colombia states that “constitutional actions are becoming the best alternative that the Colombians have to assert their rights before the different entities when a fundamental right has been violated.” The report indicates that in 2011, 105,947 writs were filed invoking the right to health. However, background information was not provided, and neither was the scope or degree of the resolution of these actions.

In the Colombian case, it is particularly striking that the state affirms in its report that the “constitutional action (tutela) has constituted the best alternative for Colombians to claim their rights before the different entities when fundamental rights are violated.” The potential of using indicators to monitor rights can be seen here, as it allows the identification of this type of response,

and shows how the state itself recognizes the limits of its own health system.<sup>10</sup>

On the indicator requested by the WGPSS for procedural legal guarantees in matters of health, Colombia reports that the current judicial career system permits entrance based on merits to judges, court magistrates, and employees. In the high courts, magistrates are elected for a fixed period of eight years and cannot be reelected. There is also a training program at the Lara Bonilla Law School that specializes in labor and is mainly directed at labor magistrates and judges regarding international work standards, judicial practice in social security for health, and judicial practice in pensions.

It is interesting to note that Colombia is the only state that has submitted information about the length of time involved in administrative procedures related to health issues. They indicate that such procedures take twice as long as labor lawsuits.

However, the state indicates that “during 2012, in the writs for protection of constitutional rights that invoked the right to health, 27% of the judicial decisions in the lower court were decided in favor of the protection of the right.” They did not provide more information, including the source of this calculation or the motives for which the writs were granted. Nevertheless, these tendencies seem to indicate an excessive use of the writ for protection of constitutional rights for purposes of the realization of the right to health.

The WGPSS highlighted the overall high degree of response to the requested indicators, particularly the Comprehensive Information System for Social Protection (SISPRO) that “makes available to the public the results reached in terms of health statistics and indicators of the sector.” The WGPSS pointed out that Colombia has

*“proceedings that allow filing of complaints for noncompliance with the right to health, as well as public offices for mediation or conciliation. Likewise, it recognizes that the access to the justice system is free and that the Judiciary is independent and autonomous; in addition to the fact that there are in-depth courses for magistrates.”*

Therefore, the WGPSS has made specific mention

of the information submitted in matters of access to justice regarding health matters.

### *Ecuador*

Ecuador established in Article 32 of its 2008 Constitution that

*health is a right guaranteed by the State and whose fulfillment is linked to the exercise of other rights, among which the right to water, food, education, sports, work, social security, healthy environments and others that support the good way of living.*

Subsequent constitutional articles recognize that priority and specialized care in public and private sectors shall be given to: elderly persons; children; pregnant women; people with disabilities; people in prison; people with high-complexity illnesses; and/or people in situations of risk; and victims of domestic or sexual violence, child abuse, and natural or manmade disasters.<sup>11</sup>

Ecuador specifically reports that pursuant to Article 191 of the constitution, the responsible for filing complaints to guarantee the protection of the right to health is the office of the Attorney for the Defense of the People, a decentralized entity of the judicial function which offers free legal services and representation for those who cannot hire a lawyer. Likewise, the obligatory nature of guaranteeing access to justice is extended to universities.<sup>12</sup>

Ecuador states that it has 775 public defenders and 10 free legal advice offices in the country.<sup>13</sup> The Ombuds office reports that 2,079 consultations occurred between 2013 and 2015, most of which related to the right to health. Although there is a general description that the consultation related to the “right to health and good living,” the WGPSS pointed out that the State party made the effort to specify gender, education level, and ethnic background of each person who submitted an inquiry. Most inquiries were made by mixed-race individuals, followed by Afro-Ecuadorians. It remains uncertain whether many of the consultants may not have declared their indigenous origin.

The state declared that the judicial council registered 63 mediation centers on a national level, 14 of which are public centers and 49 private. In its

official report, the state informed that “no cases related with the right to health have been registered but they were able to be addressed as they dealt with admissible matters.” It is noteworthy to show how the state admits its own inaction in terms of guarantees or protection of rights. Finally, regarding the indicator for policies for training judges and lawyers in matters of the right to health, Ecuador points out that the Ministry of Public Health and the judicial council are working on an inter-institutional agreement to train judges and lawyers in matters of the right to health.

When responding to the structural indicator related to the application of procedural guarantees in judicial proceedings in matters of health, the state asserts that the constitution establishes from Articles 75 to 82 the rights to protection, among which are the independence and impartiality of tribunals, reasonable time period, equality of arms and avenues for appeals of decision to upper courts.<sup>14</sup> However, Ecuador responds that on a national level, as of April 2016 “they have not processed any information about the number of legal decisions that have granted health guarantees.”

The Ministry of Public Health implemented the model of comprehensive health care that prioritizes primary care, prevention, and promotion of health with citizen participation, including a National Department of Human Rights, Gender, and Inclusion at the Ministry of Public Health, which forms part of the national Vice-Ministry for the Promotion of Health, and whose purpose is to implement public policies for the protection of the right to health.

In turn, the state provided summaries of two cases before the Inter-American Court of Human Rights (IACHR) against the Ecuadorian state. Both cases are in the supervision stage of compliance with judgment and a provincial court in Pichincha regarding HIV and sexual and reproductive health. The first case, *Gonzales Lluy and others v. Ecuador*, referred to the state’s international responsibility for infringement of the right to dignity and personal integrity of the victim.<sup>15</sup> It concerns a child who in 1998 contracted HIV through a blood transfusion carried out when she was three years

old, and the multiple discriminations she endured as a result. The state reports that as of January 2014, the child had guaranteed access to health and medical services, including medical and psychological treatment and medications, as well as a scholarship for graduate and post-graduate studies and recognition of the state’s international responsibility.<sup>16</sup>

The other case reported is that of Laura Alban Cornejo, who in 1987 was admitted to Hospital Metropolitano in Quito with clinical evidence of bacterial meningitis. A resident prescribed an injection of 10 milligrams of morphine to treat the patient’s excruciating pain. Five days later, the patient died. On November 22, 2007, the IACHR ruled that the authorities did not provide the proper guarantees in response to the complaint filed by the victim’s parents, and did not initiate a timely investigation into her death. The state recognized the lack of a prompt, diligent investigation. Ten years after the judgment, Ecuador reported that “it has established rules and public policies aimed at preventing the facts that occurred in this case and guaranteeing expeditious and diligent legal proceedings.”

The reports analyzed by the WGPSS are based on the official information submitted by each State party. In the case of Ecuador, the state admitted that several cases were brought before the IACHR and that the right to health must be directly justiciable before the IACHR.

Ecuador reported that 26 cases related to the right to health were registered as having been received, investigated, and resolved.<sup>17</sup> Recognizing the presumed violation of rights, these complaints are directed to the Human Rights, Gender and Inclusion Directorate of the Ministry of Health, and an investigative process is carried out. The state indicates that “the investigations carried out in these cases also serve as an input for making improvements within the National Health System.” They also note that the Ministry of Public Health, through the directorate, is in the first phase of implementing the “Model of Management of Requirements and Citizen Complaints to improve the Health Service,” an online system that organizes and manages citizen requests, generates informa-

tion on the main problems for the development of favorable public policies, and is a tool for improving service quality.

### *El Salvador*

Article 65 of the constitution states:

*The health of the inhabitants of the Republic constitutes a public good. The State and people are obligated to see to its conservation and restoration. The State shall determine the national health policy and control and supervise its application.*<sup>18</sup>

Thereafter, the state commits to free assistance to all persons without resources and sets the foundation for the organization of health benefits. Throughout El Salvador's report and in accordance with the WGPSS evaluation, the state highlights the formulation of a five-year plan that seeks to progressively ensure universal health coverage. Furthermore, the report mentions the Intercultural Health Plan, initiated in 2011, in context of the Ministry of Health consultation of the national health policy for indigenous communities. It also notes advances in services for individuals who are elderly, mentally ill, or have a physical or mental disability. However, it notes with concern that the average coverage in the country only reaches 25% of the entire population and requires an increase in health resources.

Regarding access to justice, El Salvador indicates that between 2010 and 2015, the Ministry of Health processed 1,365 complaints. Most of these complaints were resolved, but the report does not indicate in whose favor.

Based on information from the Secretariat of the Constitutional Court of the Supreme Court, El Salvador indicated that from 2010-2014 there were 53 constitutional suits, judicial actions, and procedures for protection of rights. Thirty-one have a final judgement for habeas corpus and protection measures, mostly due to lack of medical treatment or assistance, provision of medications, or interruption of pregnancy due to imminent danger of death for the woman.

The state points out an "*amparo*" case specifically related to the right to life and to sexual

reproductive health that was dismissed on May 28, 2013<sup>19</sup> The judgment indicates that

*all the fundamental rights possess the same hierarchy despite the fact that article 1 paragraph 2 of the constitution establishes that women cannot allege the right to their own body or to the right to interruption of pregnancy. Decision compatible with the Constitutional and Democratic Rule of Law.*<sup>20</sup>

In clear opposition, the WGPSS has emphatically indicated that El Salvador must review its policy on sexual and reproductive health with the participation of civil society. In particular, it encourages El Salvador to review the legislation regarding the absolute criminalization of abortion, taking into consideration a comprehensive vision of human rights in line with recommendations of other international and regional protection organisms.

Finally, the report points out that the State party does not have a training policy for judges and lawyers in matters of right to health.

### *Mexico*

Mexico is a federal state that ensures on a constitutional level "access to health services through the expansion of coverage of the national system" with recognition of the principles of equality and nondiscrimination and the rights of the indigenous people. In its report submitted to the WGPSS, the state indicates that the administrative body competent for receiving health complaints is the National Medical Arbitration Commission (CONAMED) together with the National Commission of Human Rights and the State Commissions of Human Rights.

The state reports that the National Commission on Human Rights received 4,616 complaints regarding violations of the right to health in 2012, while in 2011 they registered 4,310 omissions without providing further information about the resolution.<sup>21</sup>

Although the constitution contemplates procedural guarantees in Articles 14 and 17, as well as in federal civil procedural code and *amparo* law, among other laws, the population has alarmingly limited access to the writ of protection of con-

stitutional rights. According to the state report, there are only four protection proceedings under review, regarding attention of persons with HIV (2014); disability (2014) and two cases regarding civil responsibility for medical negligence in private hospitals. The report adds that there are two actions of unconstitutionality (decriminalization of abortion in the Federal District and another regarding the law for protection of people with autism); a constitutional controversy (challenging the law on health and medical care services for family violence, sexual violence, and violence against women), and an administrative protection suit (regarding the right to health of a community in Mini Numa, Guerrero). Clearly, according to the report, the exercise of protection actions in health matters is highly insufficient. While this may be partially due to problems accessing the appropriate information, it is imperative to promote increased active surveillance to guarantee the access to justice in health and to underscore the state's responsibilities, in line with the recommendations of the WGPSS in its final observations.

### *Paraguay*

The constitution of Paraguay recognizes that "The State will protect and promote health as a fundamental right of the person and in the interest of the community."<sup>22</sup> Thereafter, the constitution establishes that the state shall promote a national health system under a commitment of integrality, including "social well-being" on the basis of strategies based on "health education and community participation."<sup>23</sup>

However, the State party's report does not present any indicators for access to justice in health. In general terms, the indicators presented regarding the right to health are very weak.<sup>24</sup> The state's report focuses the information provided on the National Service of Eradication of Malaria, including other programs referred to specific diseases. Given that this is a key organism in the health structure, the lack of answers referred to health indicators raises several concerns. No information was obtained from the report regarding guarantees of access to justice for health matters.

The WGPSS has described in its final recommendations the lack of information presented in relation to the right to health by Paraguay as an omission requiring the experts to resort to complementary sources. It also warns about the high rates of maternal mortality, adolescent pregnancy, and HIV/AIDS. Also, it strongly emphasizes the state's obligation to be accountable and to provide guarantees to access to information.

It is interesting to note that some information can be accessed through a search in the Ministry of Health Social Well-Being website, which has a portal for open data, in addition to a site for reporting corruption.<sup>25</sup> However, there is no information providing evidence of the ministry having taken action. The Ministry of Justice notes the existence of a human rights observatory publishing a series of protocols, including the protocol for the access to justice for people with psychosocial disabilities, for the elderly, and for the transgender population, among others.<sup>26</sup> Likewise, there is a portal of information and services where citizens can access information on the judicial branch.<sup>27</sup> It is equally interesting that the state has developed the SIMORE Monitoring and Recommendation System aimed at facilitating the search for international human rights recommendations, but only from the international system of protection and not the Inter-American system.

In other words, although there is no detailed information or evaluation indicators, this does not mean that there is a complete absence of information, but rather that the State party has failed to report it to the WGPSS. This is no minor detail, given the relevance of the binding mechanisms in international monitoring procedures.

### *Uruguay*

Article 44 of the constitution of Uruguay establishes the responsibilities of the state in health matters and provides that "All the inhabitants have the duty to take care of their health, as well as to get treatment in the case of sickness." In its report, the state notes its efforts to increase this limited conceptualization of the right to health by approving law 211/07 of the National Integrated Health System. This law seeks to

implement structural changes in the management model for the health system, and is based on the universality of access, coverage and increase in the investment and budgetary contributions.

In relation to guarantees to access to justice for right to health, Uruguay reported on the organization of the system but not on the results obtained. It indicated that there are administrative bodies to receive complaints under the responsibility of the Ministry of Health, in particular in the area of user support. It also indicated frequent use of the writ of protection for cases involving supply of expensive medications, but does not report how many writs are presented per year. In relation to the request regarding the number of judicial decisions, the state indicated that “Of the information processed by the judicial branch there is no information available regarding human rights matters.”

The WGPSS particularly stressed that the state should report the number, frequency, type of lawsuit, resolution, execution, and compliance with the judgment, among other indicators. Likewise, the WGPSS indicated that the state should break down the information provided using a gender and diversity perspective, and highlighted the need to make a more determined effort in order to obtain better performances in health. On the other hand, the monitoring mechanisms is a reminder, in line with the demands of the civil society organizations, of the need to direct a larger quantity of specific resources in matters of sexual and reproductive health towards the health sector in order to guarantee the implementation of the laws in force. Among other actions, this should provide for the training of health personnel and the information on reproductive rights for women and men.

It is worth noting that Uruguay, a state with significant development in its social security system and particularly the health system, which is expressed in the national report in other indicators, does not provide information on guarantees to access to justice. Although this is a common problem in the reports submitted by countries analyzed in this paper, it is important to point out the relevance of this information when planning and implementing public policies for access to justice.

## Shortcomings in information and protection mechanisms provided

Evidence from the reports submitted by the State parties before the WGPSS show an alarming lack of information regarding the realization of the right to health and the cross-cutting category of access to justice, when compared to other categories covered by the system of progress indicators. This lack of information has not enabled a systematic evaluation of the judicial systems at domestic level, a problem that is common to all State parties. In general, only judgments from the high courts of justice are available; however, little is known about the extent to which procedures for receiving complaints are effective, or remedies for damage compensation are available. Furthermore, little information is provided regarding the length and cost of judicial procedures, information which is central to analyze access to justice.

In spite of this information deficit, some conclusions can be drawn from this sample of almost half of the State parties (7) that are part of the PSS (16).

First, the information provided in the first round of evaluation shows the potential strength of this instrument. Also, it highlights the current deficits and shortcoming in the protection available for the right to health. The evident contrast between the wide constitutional recognition of the right to health and the inability to present indicators for access to justice unveils an important gap shared by all the transversal categories included in this system.

Even in the case of the countries that present more information, such as Colombia, the resistance of the judiciary to be evaluated or be held accountable is evident. In most cases, the State parties did not submit information regarding procedural guarantees, which is the sixth structural indicator mentioned in Table 1.

States failed to report regarding the respect and guarantees of: (i) an independent and impartial tribunal; (ii) reasonableness of times; (iii) equality of arms; (iv) *res judicata*; and (v) right to appeal decisions to a higher authority. Such a situation, connected to the weakness in administrative procedures to guarantee the right to health (whether in the ministries of health or other supervisory

institutions) shows the lack of guarantee to access to health as highlighted by the WGPSS in its final observations. Lack of information extended to the State parties' failure to report whether any training was available for magistrates and judges regarding the right to health, and to the indicator of process related to state capacities.

Access to health services requires compliance with minimum procedures of due process, and this is a requirement for progress in guarantees to access to the right. Therefore, each State party must be accountable to its citizens regarding the time required by judicial procedures, transparency and access to information, opportunities for involvement of beneficiaries of the health system, legal frameworks applicable, and objective and reasonable criteria for awarding services and benefits. Finally, state accountability should include information on the possibility to submit complaints related to abuses or arbitrary health service rejections, including the indicators that allow the monitoring system to evaluate the degree of compliance with state obligations.

In the specific field of access to justice in health, the lack of information on demands for accountability to the judiciary is all too evident. Failing to provide the necessary information constitutes a regression of the state's obligations regarding the exercise of the judiciary's functions. State authorities could argue that the problem lies not in the state actions but in the manner in which the PSS indicators were developed or in the current inaccessibility of data due to lacking sources of information. Accepting this argument, the future failure to develop the necessary sources of information to address the requirements of the PSS and other reporting mechanisms would expose the State parties' inaction to abide by its international obligations for the realization and protection of human rights.

Two additional remarks should be made. First, the WGPSS, like other committees and follow-up mechanism, does not compare countries nor does it establish a ranking among them. Each country is a unit of analysis itself. Second, through this exercise, the WGPSS is setting the baseline and in 2019 will be able to measure progressivity for all State parties.

Meanwhile, in terms of citizen and civil society participation, access and dissemination of information on PSS goals is a tool to promote government accountability. In this regard, the WGPSS insists that civil society organizations and specialized agencies submit reports in order to contribute information to the mechanism. Such information provided by civil society organizations is a powerful instrument to contrast the official data presented by states.

## Conclusion

The article described the mechanism for monitoring social rights in the Americas, focusing on the cross-cutting indicator of access to justice in relation to the right to health. Then, it analyzes the reports submitted by seven countries, evidencing the contrast between the indicators requested and the information submitted. The challenges, deficits, and potentialities of this mechanism were also identified.

The main findings of the experience analyzed refers to two substantive aspects. First, it addresses the centrality of monitoring access to justice in the broad sense that has been defined in the indicators, since it is normally not considered a "piece of information" generally informed by the public administration. Repeatedly, rights are included in governmental speeches and to a lesser extent are used to justify programs and policies, more often than not in an improper and narrative manner, without including its minimum standards. In particular, there is a lack of recognition regarding the need to "enable" access to justice. The mere fact that the State parties have not been able to provide information in a national compliance report—even though such information could often be available—is an indication of the deficiency in the state capacities and accountability and the lack of any record regarding the justiciability of ESCR. In other cases, the delay in the resolution of lawsuits from one forum to another also demands an explanation which as of today is not available.

The second aspect to be noted refers to the importance to reinforce and improve the forms of

measurement of compliance with rights. The possibility of including empirical evidence to measure progression as an essential standard for evaluating judicial action has the power to correct the “case by case” practices and move towards mechanisms that examine the health system in its entirety and promote its adjustment to constitutional and international standards. The preparation of the national report based on progress indicators questions not only the ministries of foreign affairs, but also forms an interjurisdictional instance (that is, a collaborative work among different ministries), as some states are beginning to develop. This procedure surpasses the “mere compliance report” and constitutes a fundamental step to treating the right to health in a comprehensive manner.

In other words, access to justice to enhance the right to health requires not only an evaluation of the rules of procedure that could favor or limit the models of judicial intervention, or even the availability of empirical evidence through new sources of information. Rather, access to justice could be served by a monitoring process based on indicators showing the need to implement a wide discussion agenda regarding the institutional designs that have an impact on the possibility of the courts and the judicial tribunals of complying with a relevant role in the control of governmental policies.<sup>28</sup> In this sense, the experience initiated by the PSS monitoring system, which is to be strengthened in the years to come, will contribute to a better understanding of the necessary system of protection of rights, based on empirical information. Therefore, the regular use of indicators as a mechanism of state control will enable the design of rights-based public policies.

The regional experience shows that many collective cases allowed structural problems of the health sector to be handled more adequately, and in some cases, enabled a better transfer between the judicial decision and the political system. Having information available and evaluating the state's actions is an indispensable condition to guaranteeing better health policies. Progress indicators are presented as connecting vessels between the organization of the health sector and access to justice in

a feedback that strengthens rather than obstructs channels of cooperation with the essential participation of the citizens and rights-holders.

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# A Comparison of Health Achievements in Rwanda and Burundi

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## Abstract

Strong primary health care systems are essential for implementing universal health coverage and fulfilling health rights entitlements, but disagreement exists over how best to create them. Comparing countries with similar histories, lifestyle practices, and geography but divergent health outcomes can yield insights into possible mechanisms for improvement. Rwanda and Burundi are two such countries. Both faced protracted periods of violence in the 1990s, leading to significant societal upheaval. In subsequent years, Rwanda's improvement in health has been far greater than Burundi's. To understand how this divergence occurred, we studied trends in life expectancy following the periods of instability in both countries, as well as the health policies implemented after these conflicts. We used the World Bank's World Development Indicators to assess trends in life expectancy in the two countries and then evaluated health policy reforms using Walt and Gilson's framework. Following both countries' implementation of health sector policies in 2005, we found a statistically significant increase in life expectancy in Rwanda after adjusting for GDP per capita (14.7 years, 95% CI: 11.4–18.0), relative to Burundi (4.6 years, 95% CI: 1.8–7.5). Strong public sector leadership, investments in health information systems, equity-driven policies, and the use of foreign aid to invest in local capacity helped Rwanda achieve greater health gains compared to Burundi.

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## Introduction

Countries in sub-Saharan Africa have faced significant challenges in improving population health.<sup>1</sup> To protect the right to the highest attainable standard of health for their citizens, several African states have become parties to the International Covenant on Economic, Social and Cultural Rights. This covenant commits state parties to take the steps necessary to promote child health, improve environmental and industrial hygiene, manage infectious disease outbreaks, and assure access to health services for all.<sup>2</sup> At the dawn of the twenty-first century, sub-Saharan Africa has made substantial progress in health, including a 52% reduction in under-five mortality from 1990 to 2015, a 49% reduction in maternal mortality from 1990 to 2013, and a 46% reduction in HIV infections from 2000 to 2013—partly through a renewed global commitment to poverty reduction and health promotion in response to the Millennium Development Goals.<sup>3</sup> However, much work remains to reduce the deprivations of the estimated 41% of people living on less than \$1.25 a day and of the 23% of undernourished people in sub-Saharan Africa.<sup>4</sup>

One country in the region that has seen remarkable improvements in health in recent years is Rwanda—a small, hilly, landlocked nation in East Africa. In 1994, it experienced ethnically driven genocide that claimed the lives of roughly one million of its citizens. Following this tragedy, Rwanda sought to build a stronger nation through reconciliation and poverty reduction.<sup>5</sup> Guided by principles of equity and led by a powerful central government that has implemented evidence-based policies, Rwanda has shown substantial achievements that belie its size and standing in the region. It is currently one of the only countries in the region to meet the health-related Millennium Development Goals and has recorded steep declines in under-five and maternal mortality over the past 15 years.<sup>6</sup>

Burundi, Rwanda's southern neighbor, despite similar geography, lifestyle practices, history, and resources, has struggled to keep pace. Burundi emerged from a decade-long civil war in the early 2000s that had ethnically driven causes, like Rwanda.<sup>7</sup> The parallels between the two countries have

been mirrored more recently. In the summer of 2015, both countries began the process of changing their constitutions to allow the president to run for a third term. Rwanda's legislature voted and approved the change, based on a popular petition and with very little opposition.<sup>8</sup> Burundi's Parliament rejected the proposed constitutional changes, and the country has experienced protracted civil unrest and concerns about renewed ethnic violence.<sup>9</sup>

The goal of this paper is to explain the differences in health achievements between Rwanda and Burundi following their respective periods of genocide and civil war. We begin by presenting time-series data from the World Bank highlighting the differing trends in life expectancy before and after the period of conflict. We then contrast the specific health policy reforms that were implemented in the two countries. Finally, we suggest hypotheses for the observed differences and discuss the generalizability of our findings to other sub-Saharan African contexts.

## Methods

### *Analytic overview*

To assess the association between health policy reform and health outcomes, we undertook two investigations. First, we compared trends in life expectancy from 1960 to 2015 in Rwanda and Burundi, controlling for macroeconomic variables using data from the World Bank's World Development Indicators in an interrupted time-series analysis (Statistical Appendix).<sup>10</sup> Second, we analyzed health policy reforms in Rwanda and Burundi from 2000 onward using Walt and Gilson's health policy analysis framework.<sup>11</sup>

### *Health and development indicators*

In 1990, the United Nations Development Programme released the Human Development Index (HDI), a composite index that could be standardized across countries to measure performance with respect to human development.<sup>12</sup> The HDI includes life expectancy, gross domestic product (GDP) per capita in constant purchasing power parity dollars, and education. For our analysis, we decided to

focus on health and macroeconomic indicators. We omitted the education variable due to a lack of data from 1960 to 2015. To assess changes in health over time, we decided to compare life expectancy in both countries as a core component of the HDI. Since we have data for GDP per capita over the full historical period, we chose to control for it in our regression model (see Statistical Appendix).

### *Statistical analysis*

We used controlled-interrupted time-series analysis to study trends in life expectancy following the implementation of health policy reforms adopted by both countries in 2005, specifically the First Health Sector Strategic Plan in Rwanda and the National Health Policy Plan in Burundi.<sup>13</sup> We chose the pre-conflict period to be 1960–1992 for both Rwanda and Burundi, corresponding to the start of the conflict in both countries. The post-implementation period was defined as 2005–2015 in both countries. Our outcome was national life expectancy for Rwanda and Burundi over the study period. We fitted segmented regression models using generalized least squares regression, with autoregressive and moving average terms to account for autocorrelation in the time series. Indicator variables for the pre- and post-implementation time

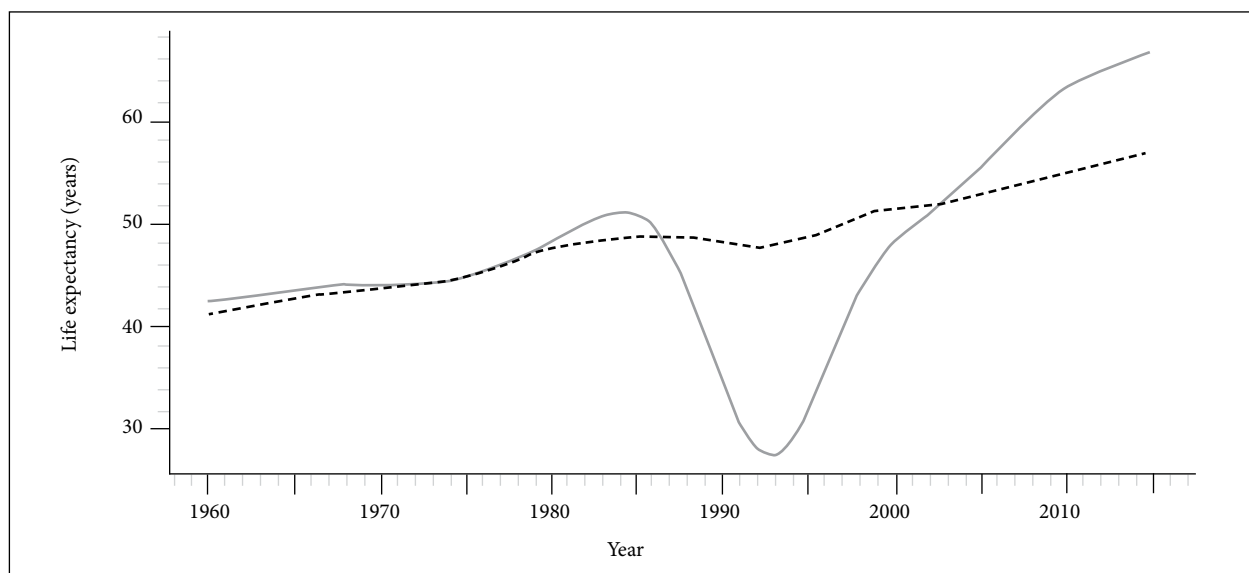
periods were used to compare relative trends in life expectancy between Rwanda and Burundi during these periods. GDP per capita was measured in constant 2010 US dollars. Full details regarding the statistical model are provided in the Statistical Appendix. We conducted our analysis using R v. 3.1.0.

### *Health policy analysis*

We compared Rwanda's and Burundi's health policy reforms using Walt and Gilson's framework for health policy analysis.<sup>14</sup> This approach defines the process of health policy reform through various components: context, actors, content, and process. We used these features to frame our analysis and determine how the different aspects of health policy reform were conducted in Rwanda and Burundi. We focused on institutional and individual actors in government and nonprofit sectors that were involved in setting and implementing health policy. We then discussed the similarities and differences in the health policies that were implemented in each country and concluded with a discussion of what could be learned from their respective experiences. We used the World Health Organization's health systems "building blocks" classifications to analyze health policy reforms.<sup>15</sup>

For the health policy analysis, we conducted a

FIGURE 1. Life expectancy at birth in Rwanda (solid) and Burundi (dotted), 1960–2015



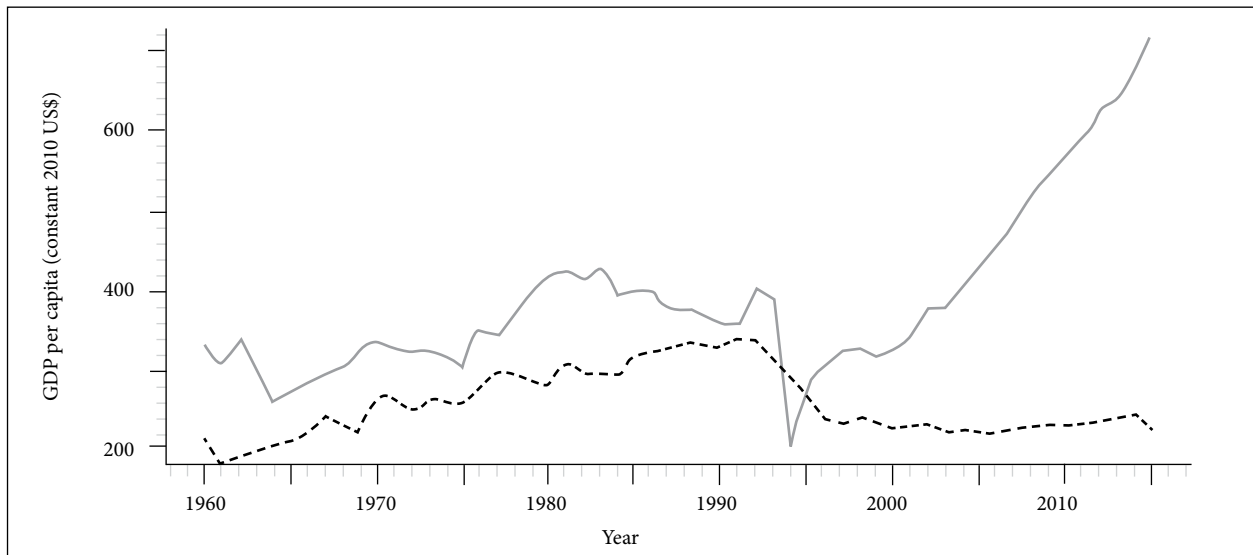
Source: World Bank's World Development Indicators

literature review on health policies implemented in Rwanda and Burundi after 2000, including a review of online research databases such as PubMed, and gray literature such as government press releases and local newspaper articles.

## Results

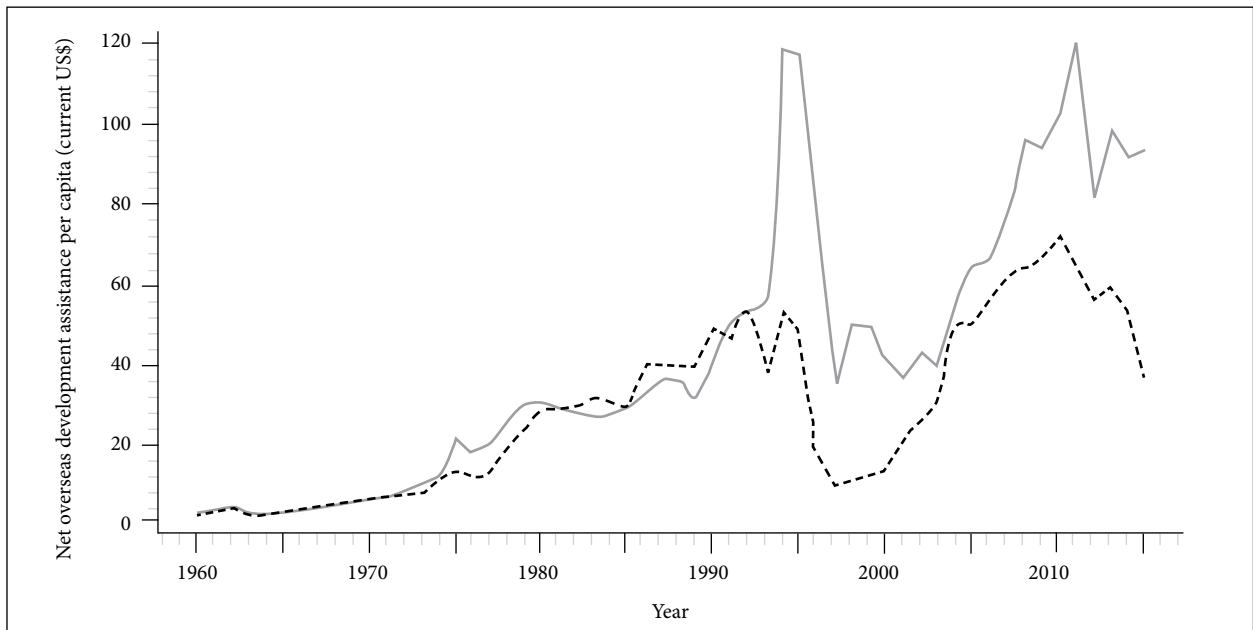
Figure 1 shows that life expectancy was similar in the two countries prior to 1984. The period from 1984 to 1994 showed a steep decline in life expectancy in Rwanda and a small decline in Burundi. The

FIGURE 2. GDP per capita (constant 2010 US\$) in Rwanda (solid) and Burundi (dotted), 1960–2015



Source: World Bank's World Development Indicators

FIGURE 3. Net overseas development assistance received per capita in Rwanda (solid) and Burundi (dotted), 1960–2015



Source: World Bank's World Development Indicators

steep decline preceding the genocide in 1994 was due to economic instability brought on by a drop in world coffee prices, at that time Rwanda's main export, and the onset of armed conflict between the Rwandan Patriotic Front and the national government in 1990.<sup>16</sup> The slight decline in Burundi during this period was due to its civil war (1993–2005). Starting in 2002, the curves diverged sharply, with life expectancy in Rwanda accelerating at a much faster rate than that of Burundi.

Figure 2 shows that trends in economic growth were weakly positive for both countries from 1960 to 1981. Rwanda experienced economic shocks due to falls in the prices of coffee and agricultural exports in 1985, which persisted through the 1990s.<sup>17</sup> In 1994, Rwanda experienced a steep decline in GDP per capita as a result of the genocide but rebounded from 2000 onward. Burundi also experienced a decline in GDP per capita during the civil war that coincided with the Rwandan genocide, from which it has not recovered.

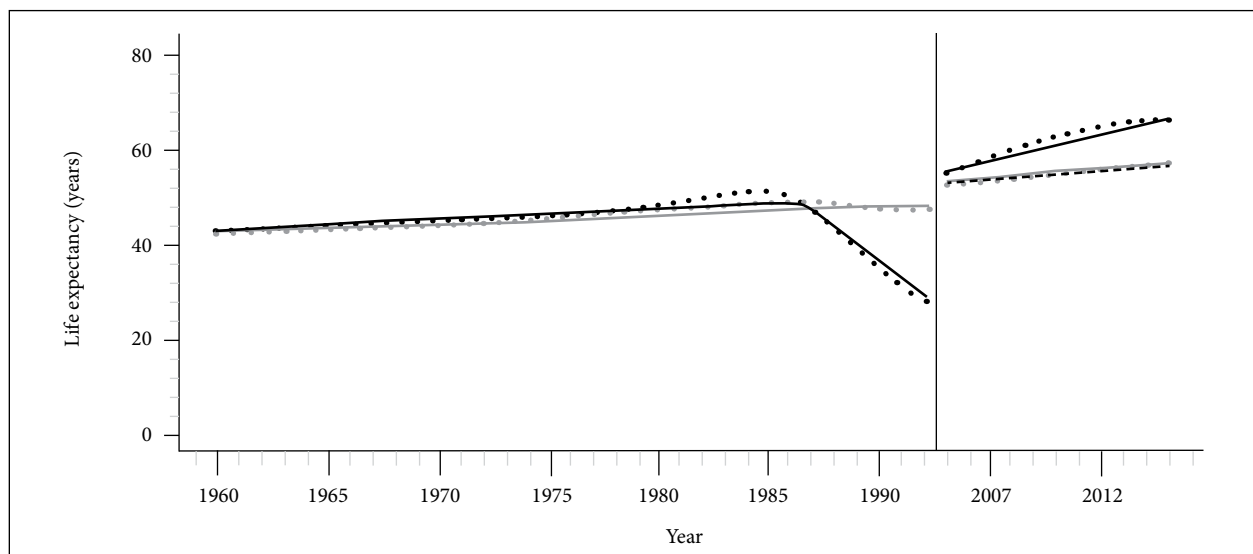
Overseas development assistance in Rwanda and Burundi accounts for a large proportion of overall government expenditure (between 30% and

40% in Rwanda and 60% in Burundi).<sup>18</sup> Foreign assistance in these two countries consists primarily of grants and loans from multilateral institutions. American and European donors are the major bilateral providers of such assistance. Reports in 2011 estimated that 25% (US\$322 million) of overseas aid in Rwanda is spent on health, compared to 17% (US\$102 million) in Burundi.<sup>19</sup>

Figure 3 shows similar levels of funding for both countries until 1992. Thereafter, overseas development assistance increased sharply for Rwanda but not for Burundi. Some authors argue that the rise in such assistance to Rwanda following the genocide could be attributed to guilt on the part of Western countries for their failure to intervene.<sup>20</sup> For the period from 2000 to 2010, Rwanda received increasing levels of overseas assistance. A decline in this assistance from 2010 to 2012 could be explained by the US government's restriction of funds to Rwanda following reports of the country's military intervention in the Congo.<sup>21</sup>

Figure 4 shows the level and trend in life expectancy in Rwanda compared to Burundi during the study period. During the postwar period, we found

FIGURE 4. Comparison of post-conflict observed and counterfactual life expectancy in Rwanda (black line) and Burundi (gray line), 1960–2015



Source: World Bank's World Development Indicators

NOTE: Vertical line indicates start of primary health systems strengthening (2005). Fitted (dotted) trend line shows predicted (counterfactual) trends and level shifts in life expectancy in Rwanda following the implementation of national health sector policy had it followed the observed trends in Burundi. Solid line plots fitted values.

a significant annual increase in Rwanda's life expectancy compared to Burundi's upon adjustment for GDP per capita ( $\beta=0.69$  years of life expectancy per annum, 95% CI: 0.19–3.56). This resulted in an estimated increase of 14.7 years (95% CI: 11.4–18.0) in life expectancy over the 11-year postwar period in Rwanda, compared to an estimated increase of 4.6 years (95% CI: 1.8–7.5) in Burundi over the same period.

### *Health policy analysis*

Our observations above demonstrate that trends in health indicators and economic development were quite similar in Rwanda and Burundi prior to the outbreak of conflict, driven by similar contexts and government approaches to improve in these areas. Both countries saw declines in economic and health gains during the periods of political instability, but following the end of the conflicts, Rwanda experienced a much larger increase in life expectancy than Burundi. Much has been written on Rwanda's progress in health and the observed successes of its health system with respect to maternal and child care and HIV control.<sup>22</sup> Far less has been written on Burundi, though analyses of some of its policies appear in the health and medical literature.<sup>23</sup> Below we compare the contexts, processes, and outcomes of health policy reform that occurred in Rwanda and Burundi after 2005.

### *Context*

At the time of independence (1962) in both countries, colonization by Germany and Belgium had resulted in inequalities of opportunity between the majority Hutu and the minority Tutsi, favoring Tutsi as the enforcers of colonial rule. The Tutsi were the political elite and tended to hold positions of power within society. During the colonial period, foreign powers codified these class groupings into ethnic groupings, going as far as providing identity cards that delineated a person's ethnicity. Following independence, the Hutu majority in Rwanda established a government that engaged in the oppression of minority Tutsi. In Burundi, Tutsi elite maintained their positions of power following independence, and used this power to intimidate and suppress Hutu opposition.<sup>24</sup>

The health systems in both countries were severely damaged following the genocide in Rwanda and the civil war in Burundi.<sup>25</sup> Infrastructure was destroyed, many health professionals lost their lives, and the war fueled the spread of HIV.<sup>26</sup> In such settings of endemic poverty and resource constraints, achieving adequate health coverage would prove to be a challenge following the wars in both countries.

### *Actors*

Health policy reforms in Rwanda and Burundi were guided by different actors and were directed in different ways. In Rwanda, decisions were made by the national government. Health policy was communicated to Ministry of Health officials at the central and district levels through a series of health sector strategic plans, emphasizing the key areas of focus.<sup>27</sup> Nongovernmental organizations (NGOs) and multilateral donors were then consulted for technical and financial support.<sup>28</sup> Rwanda discouraged the independent implementation of health programs by NGOs, mandating that the work be done in collaboration with the government. In this way, Rwanda successfully negotiated with foreign implementing partners to guide funding directly to its government rather than to NGO partners, as in other countries. These arrangements allowed Rwanda's government to maintain control over how projects were implemented and to steer policy.<sup>29</sup>

Burundi's health policy was guided by both the Ministry of Health and NGOs. The presidential office also unilaterally decreed policy, including an abolition of user fees for delivery services for pregnant women and care for children under five.<sup>30</sup> Due to foreign funding structures, the Burundian government had separate bodies for health and for HIV/AIDS, leading to political conflict between the two branches.<sup>31</sup> The significant influence of foreign NGOs in health policy and implementation in Burundi may have reduced local capacity to direct policy.<sup>32</sup> Furthermore, a lack of coordination among programs possibly led to reduced gains in health-system performance due to conflicting priorities of the various actors. In conclusion, while the Rwandan government acted in a stewardship role, set policy, and directed international part-



ners' implementation activities in its facilities, the Burundian government struggled to set effective policy due to a lack of coordination between international actors and two branches of government.

### *Process and content*

We categorized the major health policies adopted by each country using the World Health Organization's "building blocks" (Table 1) and analyzed the "process" and "content" components of Walt and Gilson's model.

Rwanda and Burundi adopted similar health policies to expand access to health care services. However, the manner in which these policies were

implemented varied between the two countries.

Though both countries invested in health information systems, Rwanda's political leadership in health drove its greater embrace of health information systems to monitor and study public health. Using a national health information system, Rwanda's health ministry was able to use data to inform its priority setting and strengthen research skills among health workers.<sup>65</sup> To this end, it also integrated disease-specific systems for HIV, malaria, and tuberculosis so that policy makers could easily monitor multiple health statistics using the same system. Burundi's health information system suffered from quality issues due to skills gaps.<sup>66</sup>

TABLE 1. Health policies implemented in Rwanda and Burundi during the postwar period

WHO building block	Rwanda	Burundi
Human resources	Human resources for health program to develop medical residency program (2013) <sup>33</sup> Nurse mentorship and supervision program (2012) <sup>34</sup> Community health worker training and implementation to improve access to care (2007) <sup>35</sup>	Launch of Burundi Health Workforce Observatory (2012) <sup>36</sup>
Health service delivery	Nationwide distribution of insecticide-treated bed nets to prevent malaria transmission (2005–2006) <sup>37</sup> Decentralization of health care decision making (2009) <sup>38</sup> Renovations of facilities through nonprofit and international partners (2009–2012) <sup>39</sup> Increased coverage of HIV and prevention of mother-to-child transmission services nationwide (2009–2012) <sup>40</sup>	Decentralization of health care decision making (2009) <sup>41</sup> Increased coverage of HIV and prevention of mother-to-child services nationwide (2015) <sup>42</sup> Ambulance referral network (2011) <sup>43</sup>
Health information systems	Implementation of nationwide health information system (2005) Trainings for data managers and data officers (2006) <sup>44</sup> Routine reporting and data quality assessments (2008–2012) <sup>45</sup> Emphasis on research training for health professionals (2012) <sup>46</sup> Rapid mobile messaging for community health workers to report vital events (2010) <sup>47</sup> Early infant diagnosis via mobile phone (2008) <sup>48</sup>	Implementation of health management information systems (2008) <sup>49</sup> Global Alliance for Vaccines and Immunization (GAVI) strengthens vaccine delivery and monitoring (2009) <sup>50</sup>
Health financing	Mutuelles de Santé community-based insurance (1999) <sup>51</sup> Performance-based financing incentives for health professionals (2005) <sup>52</sup>	Abolition of user fees for delivery services and under-five care (2006) <sup>53</sup> Performance-based financing incentives for health professionals (2010) <sup>54</sup> Flat-fee program to decrease poverty (2003) <sup>55</sup> Increased public funding for reproductive health (2010) <sup>56</sup>
Medicines, vaccines, and technology	Coordination of donors to improve access to essential medicines (2011) <sup>57</sup> Supply-chain improvement (2012) <sup>58</sup>	Supply-chain improvement (2014) <sup>59</sup>
Leadership and governance	National stewardship of health policy and coordination of international partners (2011) <sup>60</sup> Decentralized decision making at district level (targets set by district) (2009) <sup>61</sup> Development of strategic plan (2005, 2009, 2012)	Establishment of ministries of HIV/AIDS and health (2007) <sup>62</sup> Unilateral execution of health policy by the president (2006) <sup>63</sup> Development of strategic plan (2005, 2011) <sup>64</sup>

Rwanda also experienced quality issues when rolling out its national community health database, finding poor concordance between electronic and paper records.<sup>67</sup> However, Rwanda was able to address these challenges by incorporating routine data quality assessments into its national data capture systems. Evaluations of health service delivery interventions were thus possible using those same data.<sup>68</sup>

Human resource density has been shown to be a significant predictor of countries' ability to reduce under-five and maternal mortality and vaccine coverage.<sup>69</sup> During the postwar period, both Rwanda and Burundi struggled with a brain drain of medical personnel, which contributed to low health worker densities.<sup>70</sup> In response, Rwanda's human resource interventions prioritized the capacity building of local health workers through formal academic training programs for physicians and mentorship for nurses at local clinics to improve the quality of under-five care.<sup>71</sup> In Burundi, health worker productivity was adversely affected by other health policy reforms. For example, increased demand for services followed the abolition of user fees for maternal and child health services, which led to increased demands on the health workforce and in turn reduced the effectiveness of the user-fee intervention.<sup>72</sup> Qualitative studies of community members' perceptions of maternal services and neonatal care found that the poor quality of care in Burundi was related to health worker shortages and turnover.<sup>73</sup> Rwanda's approach to working with partners to build health workforce capacity led both to increased health worker density and improved quality of services, which contributed to greater efficiency in its health workforce compared to Burundi.

Both countries incorporated policies to increase access to care by removing financial barriers. In Rwanda, the government implemented a nationwide community-based health insurance scheme called *Mutuelles de Santé*, which enabled the poorest members of the population to access health care.<sup>74</sup> This program was later rebranded as "community-based health insurance." Evaluations of the policy showed that insurance-holders experienced very few episodes of catastrophic health expenditure.<sup>75</sup> Recent evaluations have also found

that children whose families have *Mutuelles* are significantly less likely to be stunted.<sup>76</sup> The same evaluation, conducted in 2010, estimated *Mutuelles* coverage to be 79% for children. Burundi attempted to address equity through the abolition of user fees for all under-five care and delivery-related expenses for all pregnant women.<sup>77</sup> This intervention led to increased utilization of services but also led to challenges for health providers in delivering the services because adequate financing mechanisms were not in place to recoup the costs.<sup>78</sup> Working with nonprofit partners, Burundi also implemented a policy to selectively target indigent members in a province covering roughly 330,000 people, through a card that would remove financial barriers to care. However, this intervention failed to remove the barrier for much of this population due to problems in correctly identifying its targeted beneficiaries.<sup>79</sup>

## Discussion

Our analysis shows that following periods of violence, Rwanda's and Burundi's life expectancies diverged. Though both countries attempted to implement health policy reforms aimed at addressing health inequities, Rwanda was far more successful in improving population health. The key factors responsible for Rwanda's relative success were stronger leadership, data-driven policy making, and greater political commitment to equitable health coverage.

Rwanda's governing bodies are characterized by the integration of services and information, and strong leadership. Rwanda's president has served for roughly 15 years. Effective health leadership was exercised in this period through an experienced public servant who served as executive secretary for Rwanda's National AIDS Commission, then as permanent secretary for health, and finally minister of health. Rwanda's stability in leadership over time allowed policies to be tested and scaled. Burundi, on the other hand, has had little stability in its executive office and has suffered from continued disruptions due to ongoing smaller conflicts with rebel groups.<sup>80</sup> Between 1993 and 2005, no fewer than seven people held the title of president, and

two of them were assassinated while in office. This instability of government in Burundi led to a lack of coordination of health policy, whereas Rwanda's relatively strong and stable institutions allowed it to make longer-term progress in health.

Another contributor to Rwanda's success was its investment in health information systems and direction of health research. This allowed Rwanda to monitor disease burden and design and evaluate policies to address it.<sup>81</sup> Rwanda also successfully developed the research skills of its health workforce. Rwanda's data-driven priorities for health research has made it attractive to foreign researchers and provided the country with the ability to develop lasting collaborations with them. On the other hand, Burundi has not succeeded in creating a government-led research infrastructure with strong national health information systems. The result has been that foreign groups have driven health research without creating local capacity.

Our analysis sought to estimate the effect of Rwanda's health policy reforms by contrasting the observed increase in life expectancy in Rwanda with predicted life expectancy estimated from our model, assuming that changes post-reform had the same level and trend that we witnessed in Burundi. Our estimate will be unbiased if there is no co-intervention that occurred in 2005 that differentially affected life expectancy in one country but not the other, and did not result from health policy reform. Time-varying factors that affect both Rwanda and Burundi are controlled for by design. Because rapid gains in life expectancy arise mainly from the prevention of deaths in children, co-occurring social, economic, and political factors are unlikely to lead to rapid decreases in under-five mortality in the absence of health interventions for children. We thus believe that changes in life expectancy are best attributed to health system reforms focused on primary care.<sup>82</sup>

A limitation of our health policy analysis is that while we attempted to review all primary health care policies implemented in both countries during the study period, we could access only those materials that were available as research articles or as technical reports. However, by examining a

wide range of policies in each country (using the health system building blocks approach), we have attempted to capture the mainstay of health policies explaining the divergence in life expectancy observed in Rwanda and Burundi.

Though Rwanda has made rapid gains due to strong leadership and evidence-based health policies, its government has come under criticism from the international community for its intolerance of opposition parties and limits to freedom of speech.<sup>83</sup> Despite these critiques, Rwanda has made remarkable progress in health and development following a period of acute instability, while Burundi's progress has been less successful. Renewed violence in Burundi following political conflict over presidential term limits could lead to difficulties in sustaining health gains. In response to the outbreaks of violence in Burundi, Rwanda has accepted inflows of Burundian refugees, who have decided that Rwanda offers them better health and economic opportunities.

This case study provides a few lessons to other low-income countries seeking to implement universal health coverage. First, countries should have national policies in place for primary care delivery, although this alone is not sufficient for achieving better health outcomes. In addition, national governments should be encouraged to take the lead in setting strategy and building strong teams capable of implementing them at the national and subnational levels. Partnering with international nonprofits and academic institutions can provide opportunities for skill transfer and collaboration. Finally, investments in information systems are essential for evaluating and refining policies. Adopting these approaches could help governments of other low-income countries attain the right to health for their people.

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### Statistical Appendix

This appendix outlines the statistical model and parameter estimates used to produce Figure 4 in the main paper. We tested for autocorrelation using Durban-Watson statistics and visual inspections of autocorrelation function graphs, partial autocorrelation function graphs, and normal QQ plots of residuals as described by Wagner et al.<sup>84</sup>

We fitted a generalized least square regression of the form below, with an autoregressive lag term of 2 (Equation 1):

### Equation 1

$$E[LEXP|C]=\beta_0+\beta_1 *RWADA+\beta_2 *TREND+\beta_3 *RWANDA *TREND+\beta_4 *POSTWAR+\beta_5 *POSTWAR *TREND+\beta_6 *RWPREGEN+\beta_7 *RWPREGEN *TREND+\beta_8 *RWANDA *POSTWAR+\beta_9 *RWANDA *POSTWAR *TREND+\beta_{10} *GDPPC$$

Where  $E[LEXP|C]$  is mean annual life expectancy conditional on covariates,  $RWANDA$  is a binary indicator variable coded as 1 for Rwanda and 0 for Burundi,  $TREND$  is an incremental time variable indicating number of years since 1959, and  $POSTWAR$  is a dummy variable indicating the postwar period compared to the pre-war period (starting in 2005). In inspecting the trends and levels of mean life expectancy in both countries, we found that Rwanda experienced unique, dramatic changes in life expectancy in the years immediately before and after the genocide. We decided to account for these changes in our linear regression model.  $RWPREGEN$  is a dummy variable indicating the pre-genocide period in Rwanda alone (defined as the period from 1987 to 1993), and  $GDPPC$  is the national estimate of GDP per capita for a given country in a given year and represented as constant

APPENDIX TABLE 1. Results from generalized least square ARMA (2)\* regression for trends in life expectancy in Rwanda and Burundi

Parameter		95% CI	p-value
Burundi prewar baseline ( $\beta_0$ )	41.35	(39.47, 43.24)	<.0001
Rwanda prewar ( $\beta_1$ )	0.30	(-2.38, 2.97)	0.8282
Burundi trend prewar ( $\beta_2$ )	0.21	(0.13, 0.30)	<.0001
Rwanda trend prewar ( $\beta_3$ )	0.051	(-0.082, 0.18)	0.4529
Burundi postwar level ( $\beta_4$ )	4.78	(4.53, 5.02)	<.0001
Burundi postwar annual trend ( $\beta_5$ )	0.15	(-0.12, 0.42)	0.2733
Pre-genocide level ( $\beta_6$ )	1.79	(1.49, 2.10)	<.0001
Pre-genocide annual trend ( $\beta_7$ )	-3.81	(-4.20, -3.42)	<.0001
Rwanda postwar level ( $\beta_8$ )	-0.90	(-3.26, 1.46)	0.4551
Rwanda postwar annual trend ( $\beta_9$ )	0.69	(0.31, 1.07)	0.0006
100 US\$ GDP Per capita ( $\beta_{10}$ )	0.071	(-0.095, 0.24)	0.4026

\*Autoregressive parameters: Phi1= 0.89, Theta1=1.00

2010 US dollars. To make the beta coefficient more interpretable, we divided *GDPPC* by 100 so that a one-unit increase could be interpreted as a US\$100 increase. Parameter estimates and 95% confidence intervals are provided in the table below.

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# Health, Human Rights, and the Transformation of Punishment: South African Litigation to Address HIV and Tuberculosis in Prisons

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## Abstract

South Africa experiences the world's highest HIV burden and one of the highest burdens for tuberculosis (TB). People in prison are particularly vulnerable to these diseases. Globally, and internally in South Africa, increased attention is being paid to HIV and TB treatment and prevention in prisons, with the public health community arguing for reforms that improve respect for the human rights of incarcerated people, for example, by calling for the reduction of overcrowding and unnecessary incarceration. Despite the retributive rhetoric that is popular among politicians and the public, the constitution mandates and recognizes the right of people in prison to humane and dignified conditions of detention. These values are diffused through law and policy, supported by an independent judiciary, and monitored by a small but vigilant prisons-focused human rights community. These factors enable the courts to make decisions that facilitate systemic improvements in prison conditions—counter to popular sentiment favoring punitive measures—and increase access to HIV and TB services in detention. This article examines a series of strategic litigation cases that illustrate this process of change to remedy disease-inducing and rights-violating conditions in South African prisons.

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## Introduction

This article examines the use of strategic litigation to develop and vindicate the health rights of incarcerated people in South Africa. As with many other countries in sub-Saharan Africa, HIV and tuberculosis (TB) in South African prisons cannot be de-linked from systemic failings—they are fueled by overcrowded and inhumane conditions and the excessive use of incarceration.<sup>1</sup> These diseases are often symptoms of “tough on crime” policies combined with slow and overburdened justice systems and outdated infrastructure.<sup>2</sup> The public health community identifies criminal justice reform and respect for human rights standards for incarcerated people as key to stemming the tide of HIV and TB behind bars.<sup>3</sup> While South Africa’s constitutional framework incorporates human rights protections for incarcerated people, including health services at state expense, these rights have largely remained paper bound. Over-incarceration results from the excessive use of pre-trial detention and the exponential growth in life sentences.<sup>4</sup> Serious human rights abuses including torture are reported yearly, and the penal system has often resisted delivering essential services to prevent and treat HIV and TB.<sup>5</sup>

Remediating disease-fueling conditions requires contending with the popular retributive narratives that influence the politics of punishment, and the content, resourcing, and implementation of the legal frameworks that regulate it.<sup>6</sup> This is an onerous prospect as incarcerated people are stigmatized and unsympathetic in the eyes of many in South Africa. This hostility is informed by high levels of crime as well as resource constraints, and makes it easier for the government to de-prioritize the needs of people in prison. It is therefore important to understand how public health prescriptions for penal reform to improve health outcomes can be actualized.

This article starts by situating South African prisons within a regional comparative framework examining incarceration trends and their relationship to HIV and TB. It then describes the drivers of overcrowding and inhumane conditions of deten-

tion in South African prisons, the domestic policies that contribute to these problems, as well as the laws and policies that govern prisons and afford incarcerated people their rights. It then examines the development of reforms to address HIV and TB in prisons, told through a series of strategic litigation cases that have defined the right to health and protected the human rights of incarcerated people in South Africa.

The South African experience illustrates the value of an incremental strategic litigation strategy that begins with tackling narrow issues, such as access to anti-retroviral therapy (ART), and progresses towards challenging systemic drivers of disease, such as overcrowding and unsanitary conditions. We examine how South Africa’s strong and independent judiciary has facilitated change through the courts—despite the absence of popular support for penal reform—and how sustained lobbying, coalition-building, and mass media advocacy by activists have increased the impact of litigation.

## HIV, TB, and health in prisons

In 2016, the *Lancet* dedicated an issue to HIV and related infections in prisons.<sup>7</sup> The series sought to unpack the “unique and complex nature of an HIV epidemic in an understudied and underserved population,” and “to bring widespread attention to incarcerated people as a key population in the HIV pandemic.”<sup>8</sup> The articles emphasize the ways in which human rights violations against incarcerated people contribute to disease burden. They underscore the need to reform criminal justice systems and re-think how we punish.<sup>9</sup>

In the *Lancet*’s article examining HIV and TB in sub-Saharan Africa, Telisinghe et al. pinpoint the excessive use of pre-trial detention and overcrowding as particular problems.<sup>10</sup> They recommend reforms that expand the provision of bail and reduce court delays to shorten pre-trial detention as interventions “that would probably reduce exposure to, and incidence of, disease.”<sup>11</sup> They further describe the limitation of arbitrary and extended pre-trial detention and the release of

people incarcerated for minor, non-violent offenses as “cost-effective” criminal justice measures to reduce the risk of acquiring HIV and TB, facilitate access to care, and ensure respect for international human rights laws.<sup>12</sup>

Various other authors argue that these kinds of reforms would eliminate what they describe to be hugely damaging practices. Experts underscore the urgency of reform, since HIV is a major predictor for TB, which is also the most common presenting illness for people living with HIV—indeed, TB is the major cause of HIV-related death.<sup>13</sup>

Overcrowding is severe in sub-Saharan African prisons—Telesinghe et al. show that 86% of countries for which data were available had prison occupancy rates over 100%.<sup>14</sup> Overcrowding and poor ventilation contribute to the risk of airborne TB infection.<sup>15</sup> Poor conditions can also heighten tension among inmates and fuel violence, including rape, which heightens the risk of blood-borne and sexually transmitted infections, including HIV.<sup>16</sup> These realities are a reflection of how many prisons in the region are operated against a background of severe infrastructural constraints, under-prioritization, and relative poverty.<sup>17</sup>

South Africa has the 12<sup>th</sup> highest incarcerated population in the world, with 158,111 people incarcerated as of April 2018.<sup>18</sup> It ranks 40<sup>th</sup> in the world for the rate of incarceration at 280 per 100,000 people, and remand detainees make up 25.8% of the population.<sup>19</sup> The vast majority of incarcerated people are male—females comprise 2.6% of the population.<sup>20</sup> The prison system experiences endemic overcrowding caused by and reflecting the popular punitiveness that contributes to increasingly severe sentences, an over-reliance on pre-trial detention, and dismal conditions of confinement.<sup>21</sup> The prison monitoring body, the Judicial Inspectorate for Correctional Services (JICS), has been reporting “deplorable” levels of systemic overcrowding in its annual reports for more than a decade, although this problem dates back two decades.<sup>22</sup> Overcrowding peaked in 2003 with a national average of 175% occupancy.<sup>23</sup> Currently it persists at 135%, and is most acute in remand facilities, some of which ex-

perience 300% occupancy.<sup>24</sup>

South Africa has the highest number of people living with HIV in the world—an estimated 7 million people.<sup>25</sup> Despite this, data on prevalence in prisons are limited.<sup>26</sup> The Department of Correctional Services (DCS) reported HIV prevalence among inmates to be 19.8% in 2006, 22.8% in 2009, and 15% in 2016.<sup>27</sup> Most recent data are based on voluntary testing and treatment access, which suggests that actual prevalence is likely higher.<sup>28</sup>

South Africa’s TB incidence was an estimated 454,000 in 2015.<sup>29</sup> It is one of six countries accounting for 60% of the global total TB incidence.<sup>30</sup> Multidrug-resistant (MDR) and extensively drug-resistant (XDR) TB cases are forecast to increase due to increased transmission of these strains.<sup>31</sup> TB is an acute concern in prisons and, according to the most recently available statistics, is the leading cause of natural death among inmates.<sup>32</sup> There are no representative data regarding TB prevalence in South African prisons.<sup>33</sup> A 2014 study from a large Johannesburg-area prison found a 3.5% prevalence of laboratory-confirmed undiagnosed TB, and 44.1% of those prisoners were also HIV-positive.<sup>34</sup>

Factors propelling the spread of HIV and TB in South African prisons include overcrowding, understaffing, poor ventilation, late case detection, debilitated prison infrastructure, limited access to health care, weak preventative interventions for HIV, sexual violence, inadequate funding, and disruption to treatment.<sup>35</sup> The public health community has called for short-term interventions such as training and mentoring DCS nurses in TB diagnosis and treatment, and increasing the number of facilities with decentralized HIV services to enable nurses to prescribe and dispense ART.<sup>36</sup> To reduce overcrowding, some have argued for the state to employ restorative justice for minor offenses; for the decriminalization of petty offenses; and for the release of offenders into community supervision.<sup>37</sup>

It is worth noting that DCS relies on funding from foreign donors for much of its HIV and TB services, which raises concerns about the sustainability of current interventions.<sup>38</sup>

## The legal framework for prisons in South Africa

Despite challenges plaguing South African prisons, the constitutional and legal framework protecting human rights in prisons is progressive. The South African Bill of Rights enshrines the rights to dignity, equality, and humane treatment of detainees, including access to justice, adequate accommodation, health care, exercise, food and water, and reading materials.<sup>39</sup> Incarcerated peoples' constitutional rights are supported by various statutes, policies, and regulations that provide minimum norms and standards for conditions in prisons and the treatment of people in prison.<sup>40</sup> These include the 2004 White Paper on Corrections, which emphasizes rehabilitation as a core function of the prison system, the 2014 White Paper on Remand Detention, and the National Strategic Plan on HIV, TB and STIs 2017-2022.<sup>41</sup> It also includes the Department of Health Guidelines for the Management of TB, HIV and STIs in Correctional Facilities, as well as the National Policy to Address Sexual Abuse of Inmates in Correctional Facilities.<sup>42</sup> These documents collectively guide HIV and TB detection, control, treatment, and prevention in prisons. The constitution further incorporates and makes justiciable international human rights laws that protect inmates' rights.<sup>43</sup> This includes the international covenants on civil and political rights and economic, social, and cultural rights, and the UN Convention Against Torture, Cruel, Inhuman and Degrading Treatment and Punishment.<sup>44</sup> The revised UN Standard Minimum Rules for the Treatment of Prisoners, the African Charter on Human and Peoples' Rights, the Kampala Declaration on Prison Conditions in Africa, and the Robben Island Guidelines form part of South Africa's soft law.<sup>45</sup>

The socio-political context in which the legal protections operate is hostile to the rights of incarcerated people, with a pervasive sentiment that "criminals' rights" enjoy primacy over victims' rights within the criminal justice system.<sup>46</sup> This is reinforced when government officials periodically assert that incarcerated people enjoy too many rights, that prison is like a "luxury hotel," or that prisons provide better medical facilities than the

public accesses.<sup>47</sup> The "common sense" of punishment in South Africa is reflected in this tension between rehabilitative policies that are sensitive to the rights of incarcerated people, and severe sentencing policies for certain crimes, accompanied by retributive rhetoric.

A series of legislative reforms have increased the onus placed on the accused in bail applications, making bail more difficult to secure and increasing the number of people in remand.<sup>48</sup> Mandatory minimum sentencing for serious crimes, initially temporarily enacted to placate the public over high rates of violent crime, became a feature of the penal system in 1997.<sup>49</sup> Mandatory sentencing increased the number of people receiving life sentences by over 2000% over the past 20 years.<sup>50</sup> Despite sentencing fewer people to terms of imprisonment, the prison population grew due to longer sentences served.<sup>51</sup> Meanwhile, the general public seems to support these trends. The National Victim of Crime Survey of 2016-2017 found that 41% of South Africans are satisfied that the length of sentences are sufficient to deter violent crime, and that 55% think DCS grants parole too easily.<sup>52</sup>

Current policies make life most difficult for those awaiting trial in detention. The punitive cascade created by mandatory sentencing means there is no room in correctional facilities to spare for those in remand.<sup>53</sup> With longer sentences at stake, individuals accused of serious offenses may be loath to plead guilty, contributing to systemic slow-downs, and their extended remand detention as they would be unlikely to be granted bail.<sup>54</sup> More than half of the remand population stays in custody for longer than three months, and nearly 20% stay in custody for longer than a year.<sup>55</sup> It is estimated that 15-20% of the remand population are granted but cannot afford to pay cash bail.<sup>56</sup>

Detention facilities are also severely outdated, as most were built prior to the democratic dispensation, when rights were limited, and were designed to cater to sentenced populations.<sup>57</sup> DCS acknowledges that its challenges are exacerbated by overcrowding, "with its consequent understaffing and difficulties in implementing any existing policy or new development."<sup>58</sup>

## Litigation and advocacy to transform South African prisons

With punitive rhetoric behind it, and within a context of resource constraints and high demand for government service delivery for the general population, there is little incentive for the government to counter its inertia in complying with human rights standards. Historically, there is often little consequence for unconstitutional conditions of detention that persist. The case law that elaborates the standards set in place through the constitutional and regulatory safeguards for the rights of incarcerated people remains under-developed.<sup>59</sup> The community of human rights advocates focused on prisons in South Africa is also relatively small and limited in its capacity.<sup>60</sup> In this difficult context, rights groups and previously incarcerated people have coordinated their actions, for example, through the national coalition, the Detention Justice Forum (DJF).<sup>61</sup> Through this coalition, activists have leveraged public impact litigation, engaged international and domestic human rights reporting mechanisms, and advocated in the media to influence policy change.<sup>62</sup>

While relatively limited, there is a growing body of jurisprudence concerning the health rights of incarcerated people, with a number of emblematic cases on health and HIV and TB in prisons that set important legal precedents. This jurisprudence is underpinned by the 1993 case *S v. Makwanyane*, which abolished the death penalty in the face of overwhelming oppositional public opinion.<sup>63</sup> In its judgment, the court declared that its role within the newly democratic state was to protect the rights of “outcasts and marginalised people”—including people in conflict with the law—who cannot adequately assert their rights through the democratic process, and that it would do so even where its judgments would not find favor with the public.<sup>64</sup>

Next, we examine a series of cases that illustrate a progressive trajectory in the jurisprudence for state accountability for rights to health and dignity in prison. The courts first established that the state has a higher duty of care to incarcerated people for health services, and determined and enforced the state’s obligation to deliver ART for

free in prison. Then, where adequate medical care could not be or was not delivered, the courts granted medical parole, incentivizing the improvement of health services. The courts then moved beyond ordering the delivery of specific medical treatment, and held the state responsible for its inadequate services and procedures to prevent the transmission of disease (TB). Finally, the courts countenanced a challenge to the overall disease-inducing and overcrowded detention conditions, which were roundly held unconstitutional.

In the 1997 case, *Van Biljon v. Minister of Correctional Services*, HIV-positive incarcerated people took DCS to court for denying them ART at state expense when they had reached a symptomatic stage of their disease and their CD4 count fell below 500/ml.<sup>65</sup> At the time, DCS policy was to provide incarcerated people with treatment equivalent to that provided at provincial hospitals, which in a context of severe budget constraints meant that only some patients qualified for free ART.<sup>66</sup> The state argued that it owed no higher duty in providing health services to incarcerated people than to citizens in general.<sup>67</sup> The court disagreed, holding that DCS bears a higher duty of care towards incarcerated people because it has incarcerated them, and ordered DCS to provide ART to those who had been prescribed treatment.<sup>68</sup> At first blush, *Van Biljon* was a major victory for incarcerated people, but it has been described as a “pyrrhic victory” given its limited impact.<sup>69</sup> Not all the incarcerated people who took part in the litigation received ART, and others received only some.<sup>70</sup> There was limited policy impact as external NGOs who would be able to provide follow-up advocacy were not involved.<sup>71</sup> Subsequently, DCS continued to refuse treatment to many HIV-positive incarcerated people, resulting in a large number of unnecessary deaths.<sup>72</sup>

After *Van Biljon*, the question of medical parole was raised in 2004 in two cases—*Stanfield v. Minister of Correctional Services*, and *Du Plooy v. Minister of Correctional Services*.<sup>73</sup> These cases had obvious implications for HIV-positive incarcerated people whose health was rapidly deteriorating without access to ART.<sup>74</sup> In *Stanfield*, the court ruled in favor of an incarcerated person with ter-

minal cancer who sought the review of a decision by the director of a prison to deny him medical parole.<sup>75</sup> The court held that because the medical facilities at the prison were inadequate to provide the incarcerated person with palliative care, the director's refusal to grant medical parole violated the right to conditions of detention consistent with human dignity.<sup>76</sup> The court required DCS to reconsider its restrictive practices relating to the release of terminally ill incarcerated people on medical parole.<sup>77</sup> Similarly, in *Du Plooy*, the court held that DCS's refusal to grant medical parole to an incarcerated person in need of palliative care that DCS could not provide was "in total conflict" with the person's rights to dignity, health care, and to not be punished in a cruel, inhuman, or degrading manner.<sup>78</sup> After these cases, the AIDS Law Project (now SECTION27) began lobbying for the medical parole of HIV-positive incarcerated people for whom ART remained unavailable.<sup>79</sup> Around the time of *Du Plooy*, it was estimated that 90% of deaths in prison were the result of HIV/AIDS.<sup>80</sup> But many incarcerated people still struggled to access ART, and the issue arose in the court again two years later.<sup>81</sup>

In 2006, with *EN and Others v. Government of RSA and Others*, a group of HIV-positive incarcerated people, together with the Treatment Action Campaign (TAC), sought a court order mandating the provision of ART to all people qualifying for treatment in Westville prison.<sup>82</sup> The court ruled in favor of the incarcerated people. Going beyond *Van Biljon*, the court ordered that all HIV-positive incarcerated people at the prison who qualified for treatment according to national policy be given ART—a group much larger than those who had already been prescribed treatment.<sup>83</sup> The judgment was sympathetic to the particular vulnerability of incarcerated people to HIV infection, and to the likelihood that many people in prison would in fact die from AIDS.<sup>84</sup> Initial non-compliance with the order was overcome by a supervisory interdict requiring DCS to report back to the court on its plan for providing treatment.<sup>85</sup> Nonetheless, it took three years and two more court orders to secure full roll-out of ART in Westville.<sup>86</sup>

The *EN and Others* ruling was handed down at

an auspicious time: in 2006, the same year in which the government finally reversed President Mbeki's AIDS-denialist policies.<sup>87</sup> While the supervisory interdict was critical, the lawsuit's success is also likely owed to the robust advocacy around the case conducted by the incarcerated people and NGOs.<sup>88</sup> People in prison undertook a hunger strike to demand access to treatment.<sup>89</sup> TAC activists also protested at the International AIDS Conference in Toronto, and conducted a sit-in at the South African Human Rights Commission, garnering media attention that publicly shamed the government.<sup>90</sup>

In 2012, in *Lee v. Minister of Correctional Services*, the Constitutional Court considered whether DCS could be held liable for damages due to its negligent omissions resulting in a remand detainee, Dudley Lee, contracting TB.<sup>91</sup> Mr. Lee had spent nearly five years in Pollsmoor remand detention before ultimately being acquitted.<sup>92</sup> He entered the facility in reasonably good health, but was diagnosed with active TB after his third year in custody.<sup>93</sup> The court held that DCS breached its constitutional obligations to provide adequate health care and conditions of detention that respected his human dignity.<sup>94</sup> It reasoned that TB was prevalent in the facility, that DCS was aware of the risk of TB infection, and that instead of implementing a comprehensive system to identify and manage TB cases, it had relied on a system of incarcerated people self-reporting their symptoms.<sup>95</sup> Pollsmoor remand was notoriously congested, and confined people to close contact for up to 23 hours a day in cells with poor ventilation—ideal conditions for TB transmission.<sup>96</sup> DCS had failed to provide Mr. Lee with adequate medical treatment to cure and prevent further spread of TB to others once he was diagnosed.<sup>97</sup> The court found that on the balance of probabilities, DCS's negligent omissions caused Mr. Lee's illness.<sup>98</sup> This case made DCS vulnerable to additional claims for monetary damages by other people who have contracted TB in prison, so long as the kind of accommodation and health services deemed inadequate under *Lee* persist.

The *Lee* case benefited from the support of human rights organizations that were admitted as *amici curiae*.<sup>99</sup> Their advocacy ensured widespread

media attention and coordinated direct action, like protests outside of Pollsmoor.<sup>100</sup> The risk of additional legal claims also spurred DCS to make policy reforms. DCS and the Department of Health adopted new guidelines on TB and HIV, and established a National Task Team on TB and HIV in Correctional Facilities to guide the implementation of this policy.<sup>101</sup> The government procured GeneXpert testing machines to expedite the identification of TB cases, and began screening people for TB upon admission. Within two years, nearly 10,000 incarcerated people at Pollsmoor had been tested, 701 of whom were diagnosed with TB, and 28 with MDR-TB.<sup>102</sup> However, DCS still did not address overcrowding, and reports of health care dysfunction, understaffing of health professionals, and treatment disruption in prisons continued to surface.<sup>103</sup>

Most recently, in 2016, *Sonke Gender Justice v. The Government of the Republic of South Africa* finally put the overcrowding of prisons on trial, once more focusing on Pollsmoor.<sup>104</sup> The NGOs Sonke Gender Justice and Lawyers for Human Rights challenged the severe overcrowding and inhumane conditions of confinement for remand detainees. When the litigation commenced, Pollsmoor's remand facility was operating at over 238% capacity, accommodating nearly 2,000 people more than approved under national regulations.<sup>105</sup> This meant that there were up to 70 detainees crammed into cells built for 30 people.<sup>106</sup> Individuals were doubled up on beds or forced to sleep on the floor, even underneath beds.<sup>107</sup> For 23 hours a day, detainees remained in their cells with no space to maneuver, and had only monthly access to exercise in the yard.<sup>108</sup>

The same conditions that were adjudicated under *Lee* persisted, but the narrative in the *Sonke Gender Justice* case captured the grim details. The complainant leveraged findings from a scathing report by an esteemed judge of the Constitutional Court, Justice Edwin Cameron, who had conducted an inspection of the facility in early 2015. Justice Cameron's report confirmed the testimonies of current and former remand detainees and found the conditions in Pollsmoor to be "daily hazardous and degrading" to its inhabitants.<sup>109</sup> The vivid report influenced public opinion and the presiding judge in

the case who cited its descriptions of how the facility was "thick with a palpable lack of ventilation," and that the conditions were "so filthy that detainees [had] boils, scabies, wounds and sores from lice-infested bedding that [had] never been washed."<sup>110</sup> Justice Cameron also reported frequent shortages in medicines for TB treatment, and difficulties for HIV-positive inmates in accessing ART.<sup>111</sup>

The court ruled against the government in *Sonke Gender Justice*, and declared the conditions of detention to be a violation of detainees' constitutional rights to health and conditions of detention consistent with human dignity.<sup>112</sup> The court ordered the government to reduce overcrowding to no more than 150% of its approved capacity within six months.<sup>113</sup> It also ordered DCS to develop a plan for rectifying detention conditions and to report to the court regularly on inspections of cell accommodation.<sup>114</sup>

While it is too close to the precipitating events to know the full impact *Sonke Gender Justice* will have, the government has taken some promising steps. By June 2017, DCS had reduced occupancy in Pollsmoor to 147%—the lowest level of overcrowding in the facility since 2002—although this space was created not by releasing remand detainees, but by shifting sentenced people to less crowded facilities.<sup>115</sup>

DCS leadership's rhetoric has also become less defensive—the National Commissioner for Correctional Services appealed to government security agencies to work together to reduce overcrowding.<sup>116</sup> The Minister of Justice and Correctional Services acknowledged that some "factors contributing to overcrowding [were] internal [to DCS] in nature," including management inefficiencies.<sup>117</sup> He noted that the criminal justice cluster intended to work with DCS to divert remand detainees from custody, develop alternatives to incarceration—including parole or community supervision for sentenced offenders—and redistribute incarcerated people across institutions.<sup>118</sup>

The court order did indeed spur some cooperation among criminal justice departments to address the upstream causes of overcrowding in remand detention.<sup>119</sup> The government's final plan to improve conditions in Pollsmoor remand indicated that they would be applying to the courts to review

bail conditions of detainees accused of non-violent offenses and those too poor to afford a small cash bail.<sup>120</sup> Further, the government adjusted the procedures for these bail review applications so they could be filed in bulk, which increases efficiency.<sup>121</sup>

The lack of cross-ventilation necessary to drastically reduce the risk of TB is impossible to address without an infrastructural intervention, but detainees are now able to exercise at least four times per week, as opposed to once or twice per month prior to the litigation. Detainees no longer share beds, and their blankets are washed regularly.<sup>122</sup> DCS also expedited the filling of staff vacancies for both custodial and health care staff, in order to improve safety and security of inmates, and increase access to medical services and more regular exercise.<sup>123</sup>

Like *Lee* and *EN and Others*, the *Sonke Gender Justice* case benefited from coordinated advocacy by NGOs and formerly incarcerated people. DJF members amplified the findings in Justice Cameron's report.<sup>124</sup> They identified people who had been detained in Pollsmoor Remand to provide testimony for the case and be featured in a short documentary about the lawsuit.<sup>125</sup> NGOs reported on the issues through the UN's Universal Periodic Review mechanism.<sup>126</sup> And local, national, and international media gave substantial attention to the case.<sup>127</sup>

## Conclusion

The impact of the cases discussed has varied in degree and reach, but collectively they provide content to constitutional rights to humane and dignified conditions of detention, access to adequate accommodation, and medical care in prison. *Van Biljon* clarified that the government has a heightened duty of care to incarcerated people with regard to their health care. *Stanfield*, *Du Plooy*, *EN and Others*, and *Lee* elaborated on what this heightened duty requires of DCS—granting medical parole for terminally ill people that prisons are unequipped to care for; providing ART to all qualified HIV-positive incarcerated people; and providing adequate TB prevention and treatment services. These cases

incentivized reform to DCS health policies. With *Sonke Gender Justice*, the conditions of confinement, and not just the delivery of specific health services, were adjudicated. The order to reduce overcrowding prompted the government to reflect on the wider criminal justice system, including systems of bail. The jurisprudence demonstrates that the government is vulnerable to constitutional challenge and to courts' supervision for failure to respect human rights in prisons.

Penal reform efforts in South Africa clearly benefit from a progressive legal framework that provides strong rights protections in prisons. This has enabled incarcerated people and human rights groups to challenge the rights abuses that drive HIV and TB in prison. South Africa's fiercely independent judiciary has proved willing to hold the executive branch accountable and make decisions counter to popular punitiveness.

While progress has been made, change requires more than litigation. However, the South African experience illustrates that it can be worthwhile to litigate on narrow legal issues, beginning with the low-hanging fruit, such as access to ART. As the rights were further articulated in case law, the courts demonstrated a willingness to countenance demands for larger systemic changes. Litigation was especially promising where it was part of a shared advocacy agenda among activists who employed complementary advocacy strategies. The South African experience gives reason for optimism that in other resource-constrained contexts, where the judiciary is receptive, incremental systemic changes may be achieved through litigation, lobbying, and mass media advocacy.

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# Political Priority for Abortion Law Reform in Malawi: Transnational and National Influences

JUDITH DAIRE, MAREN O. KLOSTER, AND KATERINI T. STORENG

## Abstract

In July 2015, Malawi's Special Law Commission on the Review of the Law on Abortion released a draft Termination of Pregnancy bill. If approved by Parliament, it will liberalize Malawi's strict abortion law, expanding the grounds for safe abortion and representing an important step toward safer abortion in Malawi. Drawing on prospective policy analysis (2013–2017), we identify factors that helped generate political will to address unsafe abortion. Notably, we show that transnational influences and domestic advocacy converged to make unsafe abortion a political issue in Malawi and to make abortion law reform a possibility. Since the 1980s, international actors have promoted global norms and provided financial and technical resources to advance ideas about women's reproductive health and rights and to support research on unsafe abortion. Meanwhile, domestic coalitions of actors and policy champions have mobilized new national evidence on the magnitude, costs, and public health impacts of unsafe abortion, framing action on unsafe abortion as part of a broader imperative to address Malawi's high level of maternal mortality. Although these efforts have generated substantial support for abortion law reform, an ongoing backlash from the international anti-choice movement has gained momentum by appealing to religious and nationalist values. Passage of the bill also antagonizes the United States' development work in Malawi due to US policies prohibiting the funding of safe abortion. This threatens existing political will and renders the outcome of the legal review uncertain.

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## Introduction

This paper describes how safe abortion became a political priority in Malawi, prompting efforts to reform Malawi's highly restrictive abortion law. The country's abortion law, dating from British colonial rule, allows induced abortion only to save a woman's life.<sup>1</sup> Nevertheless, induced abortions are common. A recent nationally representative survey estimated that there were approximately 141,044 induced abortions in Malawi in 2015.<sup>2</sup> Despite the legal restrictions, medical professionals in the private sector and traditional healers administer abortions, and many women self-induce, often with unsafe methods.<sup>3</sup> An estimated 51,693 abortions result in complications requiring post-abortion care. Unsafe abortion is among the top five direct causes of maternal deaths, contributing to nearly 18% of maternal mortality.<sup>4</sup> Though women or providers are rarely, if ever, prosecuted for inducing abortions, traditional religious values and societal norms underpin stigmatized and discriminatory attitudes toward those who have abortions.<sup>5</sup>

New evidence on the public health burden of unsafe abortion in Malawi became the basis of a review of abortion law and policy, which resulted in a draft Termination of Pregnancy (ToP) bill, released in July 2015. Currently, the ToP bill awaits debate in Parliament, and if approved, it will expand the grounds for legal abortion to include threats to the woman's physical or mental health; pregnancy resulting from rape, incest, or defilement; and severe fetal malformation.<sup>6</sup> Although advocates from national civil society organizations may have hoped for an even more liberal law, this bill represents a significant step forward for Malawi. Its adoption, however, is surrounded by uncertainty due to an opposition based on religious and cultural values, as well as a lack of popular public support for change.

Based on a prospective policy analysis of Malawi's changing reproductive health policy context since the 1980s, this paper discusses the developments leading to the drafting of the ToP bill and the growth of political will for safe abortion, as well as the factors surrounding current uncertainties in adopting the proposed law. Drawing on Jeremy Shiffman's framework for analyzing the generation

of political priority for different health issues, we emphasize the role of transnational influences, domestic advocacy, and the national political environment.<sup>7</sup> Here, political priority is "the degree to which international and national political leaders actively give attention to an issue, and back up that attention with the provision of financial, technical, and human resources that are commensurate with the severity of the issue."<sup>8</sup> We show that all of the influences outlined by Shiffman as important in generating political priority were present in Malawi. These include international agencies' efforts to implement global norms in national contexts; forums and major conferences drawing attention to the issue; international agencies' offers of financial and technical resources to address issues of concern; national actors coalescing as a political force to push the government to act; the presence of respected and capable national champions of the cause; and the availability and strategic deployment of evidence to demonstrate the severity of the problem. Moving beyond the analysis of these factors, we also document the emergent threats to the ToP bill, demonstrating that political and popular support for controversial policy issues such as abortion are very fragile and continually negotiated.

## Methodology

The study was conducted between 2013 and 2017 as part of an evaluation of a program to prevent deaths from unwanted pregnancy, funded by the UK Department for International Development. Adopting both retrospective and prospective policy analysis approaches, our aim was to understand the evolving sociopolitical context of reproductive health policy change in Malawi, with a focus on family planning and abortion. We analyzed changing popular and political discourses and sought to describe the history of laws and policies relating to reproductive health, as well as the landscape for policy change, disconnects between policy and practice, and the impact of critical policy events that unfolded during the study period.

We used a combination of qualitative methods. We analyzed a range of policy-related documents,

including peer-reviewed journal articles on unsafe abortion in Malawi, laws relating to human rights and access to reproductive health services, relevant Ministry of Health (MoH) policies, strategic planning documents, program and project documents, evaluation reports, technical documents, and studies. To monitor major events and debates related to reproductive health, we tracked local media for relevant coverage.

In addition, we conducted in-depth interviews with 56 national-level stakeholders identified through document review and snowballing methods, in some cases interviewing them more than once. They included national policy makers, MoH officials, parliamentarians, journalists, and representatives of national lawyers' groups, national health professional associations, civil society and nongovernmental organizations, and religious organizations. Lastly, we interviewed representatives of international nongovernmental organizations and bilateral, multilateral, and private donors funding reproductive health. Interviews were conducted in private and recorded when permitted. We anonymized personal statements since interviews covered highly sensitive issues. We exported our notes, interview transcripts, and electronic literature to Nvivo, which we used to store and analyze data thematically.

We obtained ethical approval for the study from the London School of Hygiene and Tropical Medicine, the College of Medicine in Malawi, and the National Commission for Science and Technology, Malawi.

### Political priority for safe abortion in Malawi

Hastings Banda, Malawi's first president after independence in 1964, initially resisted family planning, rejecting the notion that population growth was a problem and banning family planning entirely in the 1960s on grounds that it was foreign.<sup>9</sup> In line with global trends in medical care for women and children in developing countries like Malawi, however, maternal health soon became a key health policy priority in the country, with pregnancy care

as the focus until the mid-1980s.<sup>10</sup> With the introduction of democracy in the early 1990s, family planning became a political priority in response to rapid population growth. Following the Safe Motherhood Initiative in 1987, the International Conference on Population and Development (ICPD) in 1994, and the Fourth World Conference on Women in 1995, Malawi broadened its reproductive health remit in the early 2000s. The adoption of the Millennium Development Goals in 2000 led to increased national attention to reproductive health, especially maternal mortality, and the government expanded services, such as family planning and post-abortion care.<sup>11</sup>

Despite adopting these broader policy concepts, abortion care in Malawi remained limited to the treatment of complications of unsafe abortion (in other words, post-abortion care).<sup>12</sup> Post-abortion care had been recommended in the ICPD Programme of Action as a way to address the serious public health problem of unsafe abortion without changing the law. Such care, along with post-abortion family planning, is currently provided for free in Malawi's public health facilities, but mostly in urban areas. More than 80% of the Malawian population lives in rural areas and is characterized as poor.<sup>13</sup>

Political priority for safe abortion emerged alongside discourses related to family planning as a strategy for controlling population growth and unsafe abortion as a significant contributor to maternal mortality. From the 1980s onward, there were signs of an emerging policy window and enabling environment for addressing safe abortion in Malawi. The pace was slow from the beginning, but events ultimately culminated in the draft bill in 2015. Transnational influences and domestic advocacy work were key factors in this process.

### *Transnational influence focused on family planning*

Malawi is a low-income country that relies heavily on external funding for public services. As much as 40% of the country's total budget and 70% of its reproductive health funding come from external donors.<sup>14</sup> In addition to supporting government sectors, global health donors are increasingly fund-

ing international advocates, organizations, and intergovernmental bodies. These agencies have long encouraged political attention to unsafe abortion through the promotion of global norms related to human rights and women's access to reproductive health services.

As early as 1977, the United Nations Population Fund, World Bank, and World Health Organization supported a national survey to draw political attention to Malawi's rapid population growth, which led to the development and implementation of a child spacing policy. Adopted in 1982, the child spacing policy was a precursor to the national population policy.<sup>15</sup> Efforts to develop a population policy started in the late 1980s, when the International Labour Organization and United Nations Population Fund supported the establishment of a national population steering committee, which drafted a population policy in 1993. These agencies' technical and financial support also helped generate data on population growth and allowed MoH officials to attend international conferences on population health (including the International Safe Motherhood Conference in Nairobi in 1987, the ICPD in 1994, and the Fourth World Conference on Women in Beijing in 1995), study tours to African countries that had national population policies (such as Kenya), and national meetings on these issues.<sup>16</sup> Adopted in 1994, the national population policy served as an entry point for broadening awareness of the concepts of family planning, reproductive health, and women's rights.

### *Transnational influence focused on unsafe abortion*

Following multiparty elections in 1994, international reproductive health organizations began working in the country. They included Population Services International (1994), Care (1998), Ipas (1999), EngenderHealth, and Jhpiego (1999), in addition to the Family Planning Association of Malawi (registered as a national nongovernmental organization in 1999 and an affiliate of the International Planned Parenthood Federation from 2004 forward). These organizations began to influence the government to liberalize the service delivery

environment, including by creating family planning and post-abortion care programs. In 1999, Ipas, a US-based reproductive health and rights organization, provided medical supplies and equipment for manual vacuum aspiration at Queen Elizabeth Hospital in Blantyre.<sup>17</sup> In 2000, Jhpiego and EngenderHealth provided financial and technical resources for piloting and, in 2002, for the scale-up of post-abortion care services, training, the development of standard operating procedures, and participation in policy efforts to incorporate post-abortion care as a component of reproductive health.<sup>18</sup>

Ipas became a particularly important actor in the developments leading up to the draft ToP bill. The organization established an office in Malawi in 2008 in response to an invitation from the then minister of health, Marjorie Ngaunje.<sup>19</sup> From 2008, Ipas Malawi worked alongside the MoH's Reproductive Health Unit to train health professionals in post-abortion care and provide medical supplies and equipment. Along with the Special Programme of Research Development and Research Training in Human Reproduction, based at the World Health Organization, Ipas International provided the MoH with technical and financial support to conduct studies on abortion in 2009. These studies became crucial for building an evidence base on abortion in the country. They included a strategic assessment consisting of a human rights-based review of Malawi's laws and policies and of international agreements relating to sexual and reproductive health, as well as the production of new data on the epidemiology of unsafe abortion and its costs to the health system.<sup>20</sup> Ipas also supported the MoH in disseminating the findings from these studies to a wide range of stakeholders through nationwide workshops.

Meanwhile, Malawi was under growing international pressure to address unsafe abortion to meet its commitments to international and regional agreements, including the Convention on the Elimination of All Forms of Discrimination against Women, the Maputo Plan of Action, and the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa (Maputo Protocol).<sup>21</sup> For instance, the United Nations Committee on the Elimination of Discrimination



against Women noted its concern regarding Malawi's high maternal mortality rate, particularly from unsafe abortions, in 2010, a call that was reiterated in 2015, when it urged Malawi to implement laws and policies to expand and secure access to safe and legal abortion.<sup>22</sup>

### *National influences*

While international involvement brought policy ideas, research, new practices, and resources that highlighted the issue of unsafe abortion, the domestic political environment was also important in institutionalizing the case for abortion law reform.<sup>23</sup>

**Policy community cohesion.** When the MoH disseminated preliminary findings from the strategic assessment on abortion in 2010, participants at the dissemination workshop, including MoH officials and civil society representatives, developed a set of recommendations, including a recommendation to “review and reform restrictive abortion laws.”<sup>24</sup> In an effort to take the recommendations forward, Ipas and Women and Law Southern Africa-Malawi, a regional women's rights organization, spearheaded the creation of a coalition of actors called the Coalition for Prevention of Unsafe Abortion (COPUA) in 2010. From an initial network of 12 organizations at its inception, this network grew to include more than 60 by 2016. The coalition brings together legal, human rights, and health care professionals; reproductive health organizations; and influential individuals in the community.

In need of skills, resources, and funding, COPUA received a boost when Ipas Malawi became COPUA's secretariat and national coordinator in 2012.<sup>25</sup> With a new major donor grant focused on policy and advocacy work, Ipas led the development of COPUA's governance structure, funded (or mobilized funding for) activities, provided technical support for advocacy training workshops, provided information on best practices for advocacy strategies, and offered technical and financial support for COPUA's public campaigns and advocacy activities.<sup>26</sup>

In 2012, Ipas Malawi's policy associate (and currently country director), previously a lawyer with the Malawi Human Rights Commission, was

appointed head of COPUA. With his connections, he built on his predecessor's work to strengthen and expand COPUA's membership and scope of advocacy work. Ipas also mobilized donor funding for COPUA to work with the MoH's Reproductive Health Unit to strengthen the public health evidence on the burden of unsafe abortion and legal evidence upon which the government could rely to reform the country's abortion law.<sup>27</sup>

With this support, COPUA began an advocacy and lobbying campaign for abortion law reform. It organized formal and informal meetings to sensitize key stakeholders—including members of parliament (MP), chiefs, and religious leaders—on the magnitude of unsafe abortion in Malawi, its implications for women's health, and how it could be addressed through law reform. During these meetings, COPUA secured communiqués from participants supporting policy change on abortion and calling on the government to act. Advocacy work targeting the public took the form of training workshops, debates, social media discussions, radio shows, newspaper articles, TV appearances, concerts, and public rallies.<sup>28</sup>

In 2013, Ipas Malawi lobbied the Malawi Law Commission to appoint a Special Law Commission on the Review of the Law on Abortion (hereafter Special Law Commission), with commissioners from the Ministries of Health and Justice, religious councils, traditional communities, the Malawi Law Society, and the Malawi College of Medicine who would become involved in developing the ToP bill.<sup>29</sup> Throughout the review process, Ipas International funded members of the Special Law Commission to travel to Zambia, Ethiopia, and Mauritius to learn about those countries' experiences with liberalizing their abortion laws.<sup>30</sup> In addition, Ipas Malawi provided information on best practices on abortion and sample laws.<sup>31</sup> Through COPUA, Ipas Malawi also provided training on reproductive rights, human rights, and abortion for lawyers and judges (some of whom participated in drafting the ToP bill), as well for journalists (who published newspaper articles about unsafe abortion) and local organizations and youth organizations (who helped lobby for law reform).<sup>32</sup>

**Political entrepreneurship.** Ipas Malawi's country director became a very vocal policy champion who was frequently profiled in the media. Drawing on his extensive network and fundraising ability, he led COPUA's policy advocacy work in order to generate support on abortion law reform. As the political environment became more open to the idea of abortion law review, he recognized the need for other champions who could advocate policy change and, to this end, mobilized traditional authorities and representatives of medical and legal associations. These new champions provided their expertise and had a powerful impact on the public, such as through media appearances.

Obstetrician-gynecologists also played a leading role in generating and disseminating evidence on unsafe abortion, speaking openly in support of abortion law reform.<sup>33</sup> One such practitioner was Dr. Chisale Mhango, an academic researcher and practicing professional in both the public and private sector.<sup>34</sup> As a former director of the MoH Reproductive Health Unit who had participated in the development of the Maputo Plan of Action in 2006, together with the then minister of health, Marjorie Ngaunje, he sparked activity inside the MoH Reproductive Health Unit to follow up on the country's international and regional commitments. He was also one of the key figures who requested that the Malawi Law Commission review the country's abortion law in 2008. An emerging group of obstetrician-gynecologists was also involved as co-investigators for the 2009 MoH-commissioned abortion studies and had been guest speakers at COPUA's workshops and advocacy activities, where they shared personal stories of treating women with complications from unsafe abortion.<sup>35</sup> Drawing on their authority as doctors possessing first-hand knowledge of unsafe abortion, they persistently argued that the government must address unsafe abortion as part of its effort to reduce maternal mortality. Some of them became members of COPUA, while others were on the Special Law Commission, or both.

Lawyers in the Malawi Human Rights Commission also publicly called for a review of the country's abortion law and became involved in

COPUA's advocacy activities and in the bill's drafting.<sup>36</sup> Moreover, certain religious leaders supported the bill, including Prophet Amos Tchuma of the Faith of God Ministries, who was quoted in a 2015 news article expressing shock that "some women use bicycle spokes, cassava sticks and poisonous substances to induce abortions just because we have a restrictive law."<sup>37</sup> In 2016, after a sensitization meeting organized by COPUA, the Malawi Council of Churches expressed optimism that the faith community in Malawi would endorse the safe abortion bill in spite of the opposition that was being expressed.<sup>38</sup> The same year, the Obstetrician and Gynaecologist Association of Malawi was formed, and has since been a vocal actor in support of abortion law reform.

**Credible indicators and policy alternatives.** Even though there existed some epidemiological evidence of the severity of unsafe abortion in Malawi in the early 2000s, these numbers were not national and did not manage to create momentum for law review.<sup>39</sup> By contrast, new studies conducted in 2009 and published between 2011 and 2015 were population based and became very important in mobilizing support for abortion law reform, not least because they established a strong link between unsafe abortion and maternal mortality in Malawi.<sup>40</sup> The studies estimated that despite the strict law, an estimated 70,000 induced abortions occurred in Malawi in 2009, with unsafe abortions accounting for as much as 18% of the country's immensely high maternal mortality ratio of 846 per 100,000 live births.<sup>41</sup>

The growing evidence of the consequences of unsafe abortion opened spaces for new policy discourses on the issue, especially in light of Millennium Development Goal 5 on reducing maternal mortality. This evidence became crucial in the safe abortion campaign's reframing of unsafe abortion as a public health emergency rather than simply an issue of morality or rights. They used this framing strategically to raise awareness among the general population and key policy actors and to generate popular support for the abortion law review. With this repositioning of unsafe abortion, some actors

started to put forward arguments that post-abortion care alone was not sufficient to address unsafe abortion.<sup>42</sup> This, too, opened the door for proposals to reform the abortion law. The review by the Special Law Commission and the draft bill followed directly from these calls and strongly referred to this new evidence base.<sup>43</sup>

**National political environment.** COPUA and its allies worked concertedly to generate political momentum for safe abortion, such as by lobbying MPs and other state institutions. At the 2014 Pan African Parliament Conference, the deputy chair of the Women's Caucus and deputy secretary-general of the ruling party in Malawi declared that Malawi was committed to reforming its abortion law and that they supported legal reform for abortion.<sup>44</sup> The same year, Malawi's government expressed its commitment to review its restrictive abortion law in its reports to three human rights bodies: the African Commission on Human and Peoples' Rights, the Universal Periodic Review at the United Nations Human Rights Council, and the United Nations Human Rights Committee.<sup>45</sup> This willingness to be held accountable for its commitments regarding maternal and reproductive health marked a departure from its position in a 2010 report to the Universal Periodic Review, in which the government rejected calls from both local and international organizations to reform its abortion law.<sup>46</sup>

Nevertheless, political support at the domestic level proved to be vulnerable. COPUA's targeted lobbying helped secure support to pass the ToP bill among a majority of MPs prior to the 2014 general election. But after only 53 of 193 MPs were reelected in the 2014 general election, COPUA had to start afresh to lobby new MPs.<sup>47</sup> Even though all political parties officially supported the Special Law Commission's recommendations in a communiqué published in the media in August 2015, COPUA has, until now, been unable to secure support from the majority of MPs.<sup>48</sup> It has, however, managed to generate popular support among medical professional, lawyers, journalists, and civil society organizations. These actors form a large part of COPUA's membership and continue to work col-

laboratively to increase support among the general public, religious leaders, and MPs. COPUA's recent advocacy work has focused on MPs and religious leaders, which has led to a wavering support for abortion law reform among some leaders within the Malawi Council of Churches and among traditional leaders.<sup>49</sup>

### Uncertainties surrounding the ToP bill's adoption

Although targeted lobbying generated both political priority for and popular awareness of safe abortion in Malawi, ambivalence toward legal reform is present throughout society, even among the commissioners involved in drafting the bill. There is also religiously based opposition in the country, mainly from the Catholic and Evangelical congregations, as well as some Muslim leaders. As religious leaders expressed in an article in one of Malawi's main national newspapers, "After a critical reflection on these matters, we came to a conclusion that it was in fact the abortion bill that needed aborting."<sup>50</sup>

Passage of the bill requires support from MPs and key politicians, who at the constituency level must consider the views of traditional and religious leaders. Thus, support for legal reform remains fragile, and there is now more open resistance to law reform than was evident prior to the ToP bill's publication. The Catholic Church is one of the biggest civil society organizations in Malawi and has actively opposed modern contraceptives and abortion for a long time. This opposition has intensified with introduction of the bill, and the Catholic hierarchy—as well as the Muslim Association of Malawi and the Evangelical Association of Malawi—has published articles opposing change and campaigning against it.<sup>51</sup>

This national religious opposition has been compounded by an international anti-choice movement that claims that the bill represents international sexual and reproductive health and rights organizations' efforts to "deconstruct" African culture and pan-African values as part of Western "cultural imperialism."<sup>52</sup> These groups build on Ban-

da's discourse of family planning as un-Malawian and argue that both family planning and abortion services are the result of donors taking advantage of the country's developmental vulnerability.<sup>53</sup>

In recent years, international anti-choice organizations have supported national anti-abortion activists in hosting meetings to counter the pro-choice influence and have used religious radio stations to reach out to the public.<sup>54</sup> They have also organized workshops and trainings for religious leaders, traditional leaders, and MPs, and have encouraged them to publicly oppose the bill.<sup>55</sup> Their activities reached a high point in December 2016, when the Catholic Church, in collaboration with the Evangelical Association of Malawi, organized demonstrations in Malawi's main urban centers, where protestors opposed both the ToP bill and homosexuality.

In response to this increased opposition following the launch of the ToP bill, COPUA intensified its advocacy activities before MPs, religious leaders, and traditional leaders. For example, between 2016 and 2017, it conducted countrywide meetings with MPs and traditional leaders. In addition, through the Malawi Council of Churches, it organized meetings with church leaders to teach them about the content of the ToP bill and explain that it is not about abortion on demand. Based on this, they encouraged them to support the law review and the passage of the bill.<sup>56</sup>

Even though the bill seeks to liberalize Malawi's current abortion law, some of those who support legal reform argue that it falls short of what they had hoped and worked for. In September 2016, the bill was criticized as inadequate by COPUA's chairperson, who argued that it has failed to provide enough grounds on which women and girls can seek safe abortion services. This will force women and girls to continue to use unsafe abortion methods, the very thing the bill is fighting against.<sup>57</sup>

External factors also represent a major challenge for the enactment of the bill. Both national and international civil society groups have lobbied for a long time for the bill to be presented to Parliament during the autumn of 2017. However, according to a representative of a national nongovernmental

organization, the bill might not be presented to Parliament this year due to US President Trump's decision to reinstate and extend the Mexico City policy. This policy bans US funding for foreign nongovernmental organizations advocating for or providing abortion services.<sup>58</sup> With the United States Agency for International Development being one of Malawi's biggest bilateral donors toward health services and general budget support, the government might not be willing to risk antagonizing it.

## Conclusion

In this paper, we have described how transnational influences and domestic advocacy work were both influential in generating political priority for ensuring safe abortion in Malawi. Political priority for unsafe abortion emerged as an evolving international response to reproductive health and rights, driven first by data on rapid population growth and then by the linkage between maternal mortality and unsafe abortion. Following the introduction of multiparty democracy, which allowed more actors to be involved in policymaking and service provision, international and national actors provided technical and financial support for the generation of evidence on the impact and cost of unsafe abortion and politically supported the need to reform Malawi's strict abortion law. This stands in contrast to the anti-choice movement, which increased its activities in Malawi after the ToP bill was introduced in 2015 and based its opposition primarily on a rejection of abortion law reform as a form of "cultural imperialism."<sup>59</sup>

As the ToP bill awaits parliamentary debate, it is uncertain if or when it will be passed into law in light of political threats from the international anti-choice movement, which has strengthened opposition activities in the country among religious leaders, MPs, and traditional leaders. The government also needs to play its cards carefully given that passage of the law may threaten its development relationship with the United States Agency for International Development. Our observations on the uncertainties surrounding the bill's future highlight that in addition to the emphasis

on the facilitators of political priority in Shiffman's framework, attention to the factors that threaten or inhibit such progress is necessary. In this regard, it is important to consider how political priority can be maintained past the agenda-setting and policy-adoption stage to ensure that policy translates into practice.

For example, although many African countries, such as Mozambique, have expanded the legal grounds for abortion in recent years, their abortion policy environments remain restrictive due to entrenched discriminatory cultural and religious values and norms for reproductive health.<sup>60</sup> In Malawi, the increasing force of the anti-choice movement highlights that even if the bill is passed, changing the law alone will not guarantee a conducive environment for safe abortion. Experiences from other countries, such as Zambia, show that access to safe abortion services is sometimes poor despite liberal reproductive health laws and policies.<sup>61</sup> Addressing the myriad factors hindering access to safe abortion care therefore requires a multipronged strategy. Continued policy-implementation and value-clarification activities are useful for addressing barriers to access that stem from misinformation, the stigmatization of women and providers, and negative attitudes and obstructionist behaviors.<sup>62</sup> Continued advocacy is also necessary to obtain political commitment in the form of technical support and financial resources that ensure the rollout of required infrastructure, processes, and systems for the provision of safe abortion for all who need it. Given Malawi's reliance on external funding and expertise, policy changes and the implementation of safe abortion services will depend on continued external support for policy advocacy and the implementation of associated changes in practice. In addition, considering Malawi's significant health systems challenges, even if the ToP bill is enacted, access to safe abortion will require a significant strengthening of the health care system (especially at the primary health care level), the development of standards of comprehensive abortion care, and the availability of resources for health care services.

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# Access to Medicines in Times of Conflict: Overlapping Compliance and Accountability Frameworks for Syria

BRIANNE MCGONIGLE LEYH AND MARIE ELSKE GISPEN

## Abstract

Syria is currently experiencing the world's largest humanitarian crisis since World War II, and access to medicines for emergency care, pain control, and palliative care remains shockingly restricted in the country. Addressing the dire need for improved access to medicines in Syria from an international law compliance and accountability perspective, this article highlights four complementary legal frameworks: international human rights law, international drug control law, international humanitarian law, and international criminal law. It arrives at two central conclusions. First, all four bodies of law hold clear potential in terms of regulatory—hence compliance—and accountability mechanisms for improving access to medicines in times of conflict, but they are too weak on their own account. Second, the potential for on-the-ground change lies in the mutual reinforcement of these four legal frameworks. This reinforcement, however, remains rhetorical and far from practical. Finally, within this complex picture of complementary international legal frameworks, the article proposes concrete recommendations for a more integrated and mutually reinforcing interpretation and implementation of these areas of law to foster better access to medicines in Syria and elsewhere.

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## Introduction

Syria is currently experiencing the world's largest humanitarian crisis since World War II.<sup>1</sup> Over the last seven years, the world has witnessed the intentional and continuous targeting of the civilian population through bombings and the denial of basic necessities, including food, water, and medicine.<sup>2</sup> According to figures from the European Commission, there are currently an estimated 13.5 million people in need of humanitarian assistance inside Syria, including 4.9 million in difficult-to-reach or besieged areas and 6.1 million internally displaced.<sup>3</sup> The widespread disregard for human rights and humanitarian law has led to an “overwhelming” situation in which the long-term consequences in the area of health care are grave: a shortage of qualified medical personnel and medicines, the destruction and targeting of health infrastructure, and the intentional blocking of humanitarian assistance.<sup>4</sup>

Former Special Rapporteur on the right to health Anand Grover noted in a 2013 report that “conflict affects health not only through direct violence, but also through the breakdown of social structures and health systems, and the lack of availability of underlying determinants of health.”<sup>5</sup> Specifically, access to medicine can be affected since both state and non-state armed groups deploy numerous physical barriers for victims (such as travel bans and check points) and for health care providers (such as prohibited access to localities) during times of conflict.

This article addresses how four complementary international legal frameworks could be mutually reinforced to improve (though not necessarily remedy) the situation in Syria concerning access to medicines. After first addressing the dire situation in Syria, the article examines the frameworks of international human rights law, international drug control law, international humanitarian law, and international criminal law. These legal frameworks each have their own areas of focus and attention. While some are primarily focused on state *compliance* with norms and best practices, others are more concerned with ensuring *accountability*. And all are relevant to the topic of access to medicine in times of conflict. Although these areas of law are

complementary, the situation in Syria shows more than ever before the clear limits of the law in realizing access to medicines in practice and ensuring state compliance and individual accountability for, in particular, state actors failing to do so. The legal frameworks are therefore separately, and even in conjunction, inadequate to resolve the situation on the ground. Yet there is much that can be done, including formulating a joint general comment, supporting ad hoc humanitarian assistance by promoting the use of simplified procedures, and ensuring greater emphasis on violations of economic, social, and cultural rights violations—in particular right to health violations—within legal frameworks that offer some, albeit minimal, forms of individual criminal accountability.

## The situation in Syria

The conflict in Syria began in 2011, after government forces could not quell peaceful protests of the arrest and subsequent torture of a group of teenage boys who, inspired by the Arab Spring, had spray-painted antigovernment slogans on the wall of their school. By 2015, the United Nations (UN) Secretary-General reported that “there is a complete and utter absence of protection of civilians in the Syrian Arab Republic.”<sup>6</sup> From the beginning of the conflict, government forces in particular have used extreme and illegal tactics against civilian populations, including barrel bombs, chemical weapons, and the deliberate deprivation of food, water, and health care.<sup>7</sup>

According to a 2015 report on health care in Syria, “civilians as well as healthcare personnel, medical facilities, and ambulances are deliberately and routinely targeted as part of the military strategy of the Syrian Government.”<sup>8</sup> Until at least August 2015, no food or other type of humanitarian relief item reached any besieged area through official routes.<sup>9</sup> Even today, humanitarian relief within Syria has been sporadic and repeatedly thwarted by both the government and non-state armed groups.<sup>10</sup> A 2017 report of the Independent International Commission of Inquiry on the Syrian Arab Republic states that

*[r]epeated bombardments of hospitals and clinics in areas controlled by armed groups destroy vital infrastructure and kill medical personnel. The number of remaining doctors, nurses, and first responders is now so grossly inadequate to meet the needs of the population that many injured civilians die due to lack of access to adequate medical care. In besieged areas, the lack of access to medical supplies, including anaesthetics, surgical equipment, and medication, makes it impossible for hospitals and clinics to provide even the bare minimum care to patients.<sup>11</sup>*

Access to medical supplies and equipment has remained extremely restricted in some areas as a result of insecurity and access constraints imposed by parties to the conflict. In particular, Aleppo, Dar'a, Hama, Idlib, and, most recently, Ghouta have been badly affected.<sup>12</sup> The inquiry commission notes in relation to Aleppo that “even prior to the siege, civilians in eastern Aleppo city lacked sufficient food, medication, and fuel.”<sup>13</sup> While the situation for civilians in Syria is dire and unprecedented since World War II, the problem of access to medicine encountered in the Syrian conflict is all too familiar.<sup>14</sup> As with other conflict situations, the main obstacles include physical barriers, political barriers, and direct violence against medical personnel, all of which can severely affect access to health care facilities, goods, and services.<sup>15</sup>

Prior to the conflict, Syria's health care system was comparable with the health care systems of other middle-income countries.<sup>16</sup> Much of the health care system consisted of a government-run public scheme that provided mostly primary care services, with the private sector providing some of the advanced care services. The deteriorating security situation since 2012, leading to the emigration of qualified manpower and experts, has resulted in a shortage of medicine and access to medicine throughout Syria. In many parts of the country, the conflict has turned otherwise manageable chronic diseases into unnecessary terminal conditions because of the unavailability of curative treatment and medicines.<sup>17</sup> At the same time, urgently needed pain control medicines and palliative care also depend on a sufficient health care system and infrastructure. The express targeting of civil-

ians through the deprivation of food, water, and medicines has had a devastating impact. Civilian casualties have long accounted for the largest group of deaths within the conflict. The Secretary-General's 2015 report notes that the “total disregard for human life and dignity remains a defining feature of the Syrian conflict and continues on a daily basis with total impunity.”<sup>18</sup> And despite agreements to establish de-escalation zones—and, more recently, a 30-day ceasefire, which would help ensure access to medicines—the guarantees have not been met.<sup>19</sup>

### International legal framework in times of conflict

During times of conflict, there are essentially four bodies of international law that govern access to (essential) medicines. The first is international human rights law, which focuses on state responsibility. The second is international drug control law, which regulates the availability of controlled medicines, including morphine for trauma care, palliative care, and pain control, which is particularly needed during armed conflict. The third is international humanitarian law, focusing mainly on state responsibility in times of war but also, to an extent, on the responsibility of non-state armed groups. The fourth is domestic and international criminal law, which focuses on individual criminal responsibility.

All four legal frameworks are complementary and mutually reinforcing. International humanitarian law is often considered *lex specialis*, meaning that as a specialized area of law it would override more general law, such as international human rights law. Nevertheless, human rights law continues to apply in conflict situations. Moreover, international drug control law regulates the conditions on the basis of which governments can secure access to controlled medicines, also in times of conflict.

#### *International human rights law*

International human rights law (IHRL) is the body of law designed to promote and protect human dignity and the rights of individuals, largely vis-à-vis

state authorities. IHRL includes treaty-based and charter-based institutions that underpin the importance of access to medicines in times of conflict. Access to medicines falls within the framework of various individual human rights, including, in some cases, the rights to life and to freedom from torture. However, within IHRL's treaty-based system, the right to the highest attainable standard of health—often referred to as the right to health—provides for the most explicit framework on access to medicines.

Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) is the most elaborate provision on health within IHRL.<sup>20</sup> On the basis of this article, states have obligations to prevent, treat, and control diseases and to create “conditions which would assure to all medical service and medical attention in the event of sickness.”<sup>21</sup> The provision of access to medicines fits squarely into these obligations. Article 2 of the covenant notes that obligations incumbent on states are obligations of both conduct and result, the latter of which are subject to progressive realization.<sup>22</sup> The Committee on Economic, Social and Cultural Rights—which monitors compliance with the ICESCR—interprets the concept of progressive realization as requiring states to allocate their maximum available resources and to set specific targets and benchmarks to move as expeditiously as possible toward full realization of rights.<sup>23</sup> At the same time, the committee acknowledges that some aspects of the right to health are considered so vital to protect the dignity and well-being of individuals that prolonging their realization would undermine the *raison d'être* of the right to health itself.<sup>24</sup> So-called minimum core obligations and obligations of comparable priority therefore fall outside the scope of progressive realization and are subject to priority realization.<sup>25</sup>

There are a range of arguments to make that ensuring access to medicines in times of conflict is part of a set of minimum core obligations of the right to health.<sup>26</sup> This article singles out three grounds supporting the notion that ensuring access to medicines is part of a minimum core obligation subject to priority realization. First, according to the Com-

mittee on Economic, Social and Cultural Rights, the core obligation to ensure access to health facilities, goods, and services includes ensuring access to medicines.<sup>27</sup> Second, while access to medicines generally must be secured as a matter of priority under the right to health, those medicines that appear on the World Health Organization's Model List of Essential Medicines should be available in all health systems.<sup>28</sup> Morphine, as an important emergency and pain control medicine in times of conflict, appears on this list. The Committee on Economic, Social and Cultural Rights explicitly refers to essential medicines' availability as a core obligation.<sup>29</sup> Third, as part of their obligation of comparable priority to prevent, treat, and control diseases, states must create “a system of urgent medical care in cases of accidents ... [to provide] humanitarian assistance in emergency situations.”<sup>30</sup>

According to the Committee on Economic, Social and Cultural Rights, all health facilities, goods, and services, including medicines, should be available, accessible, acceptable, and of good quality. These criteria are often jointly referred to as the AAAQ standard of health care. In relation to access to medicines, this means that medicines should be available in sufficient quantities; physically available in health facilities within reasonable geographic distance to patients; affordable; culturally appropriate; and of sufficient evidence-based quality.<sup>31</sup> The committee explains that “the precise application of [these criteria] will depend on the conditions prevailing in a particular State party.”<sup>32</sup>

Since it is largely recognized that IHRL, including the ICESCR, applies in times of conflict, and that ensuring access to medicines is part of the core of the right to health, the question is whether states may adopt retrogressive measures due to scarce resources or derogate from their obligations during temporary and exceptional circumstances, such as armed conflict.<sup>33</sup> Article 2 of the ICESCR requires governments to progressively realize all rights in the covenant, including access to medicines as part of the right to health. As indicated in the Maastricht Guidelines on Violations of Economic, Social and Cultural Rights, governments are not allowed to adopt retrogressive measures aimed at deliberately

reducing the level of rights protections or changing public expenditures such that it would deprive people of at least minimum subsistence rights.<sup>34</sup> Retrogressive measures are allowed, however, when the progressive realization of a right is obstructed due to a permissible limitation (in light of the ICESCR), *force majeure*, or lack of resources.<sup>35</sup> That said, given the deterioration of health systems during conflict, it may be particularly difficult for states to ensure access to medicines as a matter of priority. The Committee on Economic, Social and Cultural Rights seems to accept armed conflict as a factor that influences the availability of resources, which may result in retrogressive measures.<sup>36</sup> However, while article 2 of the ICESCR generally allows for the adoption of retrogressive measures, it is unlikely that the committee would accept such measures “solely based on the existence of an armed conflict and the connected necessity to divert resources towards war efforts.”<sup>37</sup> Indeed, the committee holds that any retrogressive measure that conflicts with the core obligations of the right to health results in a breach of the ICESCR.<sup>38</sup>

In terms of limitations, legally most human rights may be limited; only a small selection of rights, such as freedom from torture, may not be limited or derogated from. Article 4 of the ICESCR includes the covenant’s general limitation clause, which states that any limitation of a right included in the covenant should be “compatible with the nature of these rights.”<sup>39</sup> Given that minimum core obligations are meant to “prevent the nullification” of the rights included in the covenant, one could argue that such rights and obligations can never be limited on the basis of article 4.<sup>40</sup> Indeed, article 4 also reinforces the importance of minimum core obligations as minimum standards of protection that must be guaranteed at all times.

However, in the absence of a specific mention of conflict in articles 2 and 4, it remains somewhat ambiguous what role conflict or war has on the required minimum level of realization of the right to health.<sup>41</sup> This is particularly acute in light of the AAAQ standard of health care that is set as a condition to the realization of the right to health. Despite this uncertainty, the Committee on Economic,

Social and Cultural Rights generally emphasizes that those states that struggle or fail to effectively discharge their right to health obligations should seek financial and technical assistance from other countries and international bodies to work toward the full realization of the right to health, including in relation to medicine provision.<sup>42</sup> Finally, unlike other human rights treaties, the ICESCR does not include a derogation clause. In the absence of such a clause, it is difficult to assess whether any degree of derogation would be allowed. Nevertheless, the committee explicitly recognizes the non-derogable nature of minimum core rights, which—as demonstrated above—includes access to medicines.<sup>43</sup> Only in extreme cases where “every effort has been made to use all the resources [at the disposal of the state] in an effort to satisfy, as a matter of priority, minimum core obligations” could the state in question not be considered at fault.<sup>44</sup>

As for Syria, the government has ratified the ICESCR, as well as most other human rights treaties.<sup>45</sup> The country was due for its fifth reporting cycle under the ICESCR in 2006. However, it has not submitted any reports since 1999.<sup>46</sup> It does sporadically participate in the country reporting requirements of other treaty bodies, even during the conflict.<sup>47</sup> Both the Committee against Torture and the Committee on the Elimination of Discrimination against Women have urged the Syrian government to improve access to medical care and services. The Committee against Torture has called on the Syrian government to

*ensure that all acts in violation of the [Convention against Torture] are brought to a halt; and cease widespread, gross and continued human rights violations of all persons under its jurisdiction, especially systematic denial, in some areas, of the basic requirements of human life, such as food, water and medical care.*<sup>48</sup>

Similarly, the Committee on the Elimination of Discrimination against Women has urged Syria to “ensure that accountability mechanisms are in place in all displacement settings; and provide victims with immediate access to medical services.”<sup>49</sup>

Yet, none of the other UN treaty bodies have

specifically expressed outrage or called for compliance or accountability on the topic of access to medicines or humanitarian assistance. Some observers argue that this silence is because Syria did not submit a country report—but regardless, such silence is particularly troubling coming from the Committee on Economic, Social and Cultural Rights since this committee monitors the implementation of the right to health. Even though treaty bodies' general comments include sections on humanitarian assistance, the complexity of rights realization, particularly in the area of health, deserves more focused and dedicated attention within human rights law and international law in general.

Within IHRL's charter-based system, the UN Security Council, General Assembly, and Human Rights Council play the predominant roles in overseeing state compliance with human rights norms and obligations. In 2006, the Human Rights Council adopted the Universal Period Review procedure, which is a process in which a troika of countries assesses the level of human rights protection in a given country. The process involves state reporting, questions, and input from the Office of the United Nations High Commissioner for Human Rights and civil society organizations. Within this Universal Periodic Review system, states have called on Syria to comply with its international legal obligations. For instance, Switzerland urged Syria to allow for unimpeded access to medical care, specifically ambulances and medical teams.<sup>50</sup>

The Human Rights Council also has the ability to hold special sessions on situations of immediate importance that lead to widespread human rights violations. It has done so five times to discuss the situation in Syria.<sup>51</sup> In four of these sessions and in three resulting resolutions, the council raised serious concerns about hindering access to medical treatment, blocking the safe passage of medical supplies, and attacks on health facilities and personnel. While reference to medical supplies is important, explicit reference to access to essential medicines would better reinforce the fact that access to medicines is considered a core aspect of the right to health.

Other UN charter-based bodies have also produced important reports on health issues in Syria—and some, including the Independent International Commission of Inquiry on the Syrian Arab Republic, have addressed the issues in a more comprehensive manner.<sup>52</sup> For example, the commission has urged the Syrian government to

*end attacks against humanitarian workers, including medical personnel and first responders, and safeguard the sanctity of hospitals and medical transport ... [and] ... allow rapid, safe, sustained, unhindered and unconditional access to humanitarian aid, particularly to besieged and hard-to-reach areas.*<sup>53</sup>

Additional IHRL actors, including the UN Special Rapporteur on the right to health, have also spoken out. In August 2016, Dainius Pūras urged all parties to the Syrian conflict to allow unimpeded access to humanitarian relief and to protect the rights of those in besieged and difficult-to-reach areas.<sup>54</sup> Such statements are welcome, but concrete declarations of state obligations from a treaty monitoring body would carry more weight because of the legal obligations attached to the UN treaty body system. Overall, the compliance and accountability mechanisms within IHRL, however, are not very powerful in turning around the health and human rights violations in a multiplayer seven-year conflict.

### *International drug control law*

International drug control law (IDCL) is the field of law that regulates the production, import, export, trade, distribution, and use of harmful substances such as psychotropic and narcotic drugs. Some of the medicines on the World Health Organization's Model List of Essential Medicines, such as morphine, are controlled medicines.<sup>55</sup> Controlled medicines are medicines whose active pharmaceutical ingredient falls within the scope of IDCL, because of its serious abuse potential.

The 1961 Single Convention on Narcotic Drugs regulates the use of morphine for both trauma care and pain control and palliative care.<sup>56</sup> Article 4 of the convention sets out a strict prohibition clause: all production, import, export, trade, distribution,

and use of controlled substances is forbidden except if they are—simply put—produced and used to serve medical and scientific purposes. Medicines for both emergency care and pain control in conflict settings fall within this limitation clause. Articles 17, 19, 20, and 30 set up an advanced licensing and monitoring system that states must adhere to in order to ensure access to medicines under IDCL. On the basis of these articles, states have to manage a separate administration (art. 17), submit annual overviews reflecting the country's estimated need of controlled substances for medical and scientific purposes in the following year (art. 19), submit quarterly statistical returns to account for the use of the same substances (art. 20), and adopt specific trade and distribution requirements. The International Narcotics Control Board is responsible for monitoring implementation of these articles and issuing trade licenses on the basis of the estimates submitted.

Adequate compliance with the licensing and monitoring system implies that states have smooth and well-functioning bureaucracies and health systems and that they have due insight in their country-specific epidemiology.<sup>57</sup> The available guidelines also demonstrate that a high level of capacity is a *conditio sine qua non* for effective compliance.<sup>58</sup> Countries with large remote areas or seriously constrained health systems—in terms of staff and finances—are put in a structurally disadvantaged position to implement and comply with these procedures.<sup>59</sup> This results in countries either refraining from submitting estimates or including insufficient consumption figures in their estimates, which means that consumption will be inadequate.<sup>60</sup>

While there is no provision in the SCND that discharges states of their drug control obligations in times of conflict, the International Narcotics Control Board manages simplified procedures in emergency situations. And in 1996, the World Health Organization adopted model guidelines for the international provision of controlled medicines for emergency care. Both the International Narcotics Control Board and the World Health Organization acknowledge that this issue is often

complex, especially if domestic control authorities, who have to report to the International Narcotics Control Board, are malfunctioning due to, among other things, conflict.<sup>61</sup> The simplified procedures reflect a practical solution to support access to controlled medicines for humanitarian assistance whereby suppliers can bypass control authorities in the receiving countries if unavailable, which partly reduces the administration involved. These simplified procedures are in place “when an emergency occurs which results in a disruption of the function of such authorities to issue import authorizations.”<sup>62</sup> In other words, only if the Syrian control authorities are no longer capable of fulfilling their control mandate will the simplified procedures apply. If, on first sight—despite a conflict situation—the responsible institution remains capable of fulfilling its obligations, the standard rules seem to apply, which carries the same structural complexities as mentioned before. The result may be that governments formally comply with the IDCL system because they submit the necessary paperwork but the consumption prognosis included in the estimate may be insufficient to the extent that it is inadequate to treat the country's absolute need of controlled medicines. This substantive gap seems apparent in the case of Syria.

Syria submits estimates to the International Narcotics Control Board, including a quantification of morphine, to give effect to its obligations under IDCL.<sup>63</sup> Yet, according to a 2014 study, Syria's morphine consumption figures remain far below par, reflecting only a 5.16% adequacy of consumption.<sup>64</sup> It is unclear whether organizations in Syria are supported by the Syrian government to make use of the simplified procedures because of its current conflict status.

Even though the International Narcotics Control Board flags the importance of access to emergency care in times of conflict and refers to the simplified procedures that it has adopted, it can do more. It calls upon governments to make use of these procedures, and its 2014 report even devotes a special section to the topic.<sup>65</sup> However, when assessing the particular concerns in Syria in this same report, the board stresses only that the conflict in Syria is dangerous in terms of illicit drug

trafficking. It does not stress the importance of the simplified procedures in this context, despite the inadequate medical use of morphine in the country.<sup>66</sup> One may wonder whether the Syrian government is indeed effectively capable of fulfilling its reporting and administrative tasks under IDCL. Hence, the role of the International Narcotics Control Board in fostering access to medicines for emergency care should not just focus on either the simplified procedures in absence of a functioning competent authority or the application of the regular rules, but rather embrace an integrated approach and address the aggravated structural complexities that governments face when estimating need in conflict situations. In doing so, the board should take notice of the human rights standards on access to medicines and take an integrated approach in monitoring progress. Instead, the currently fragmented discussion reflects a priority on law enforcement and control procedures within IDCL over access-to-medicine approaches. The IDCL system is frequently criticized for a one-sided and ineffective focus on harsh law enforcement. As was also concluded in a special edition of this journal on human rights and drug control, human rights are currently not adequately used to guide drug control efforts.<sup>67</sup> The critical health situation in Syria reflects the devastating effect that this one-sided approach has on adequate standards of health care provision, including access to medicines.

### *International humanitarian law*

International humanitarian law (IHL) is the law that regulates the conduct of armed conflict.<sup>68</sup> It seeks to limit the effects of war by protecting persons who are not participating in hostilities and by regulating and restricting the means and methods of warfare.<sup>69</sup> Unlike IHRL, IHL does not protect individuals based solely on the notion of “inherent dignity.” Rather, it protects different “statuses,” including civilian, medical personnel, combatants, and persons *hors de combat*, within a pragmatic legal framework that balances the principle of humanity with the principle of military necessity.<sup>70</sup>

The two primary sources of IHL are treaty law and custom.<sup>71</sup> With regard to treaty law, IHL

consists of the four Geneva Conventions and Additional Protocols I and II. IHL is generally divided between laws that apply to international armed conflicts and laws that apply to non-international armed conflicts, and it binds states and non-state armed groups.

With regard to international conflicts, the provisions of humanitarian assistance—including, for example, access to medicine and the protection of medical personnel—can be found in Geneva Convention IV and Additional Protocol I.<sup>72</sup> During non-international conflicts, the provisions of humanitarian assistance can likewise be found in common article 3 of the Geneva Conventions and Additional Protocol II (which Syria has not ratified).<sup>73</sup> The laws impose an obligation on the parties, whether the state or non-state armed group, to ensure access to necessary medical supplies for the civilian population. Generally, and certainly in the case of Syria, this would include medicines such as pain control medication. While Additional Protocols I and II require the consent of the parties concerned for relief actions, including medicine provision, to take place, such consent must not be refused on arbitrary grounds, and the parties may operate control over the relief provided.<sup>74</sup>

The most authoritative source on customary IHL is the study carried out by the International Committee of the Red Cross on the topic.<sup>75</sup> The committee recognizes that access to humanitarian relief for civilians in need, including medical supplies, is a recognized rule of customary IHL in international and non-international conflicts.<sup>76</sup> With regard to state practice, the obligation to allow and facilitate access to humanitarian relief for civilians in need, including access to medicines, is supported by official statements and actions by states and the UN.<sup>77</sup>

Therefore, regardless of the legal characterization of the conflict, IHL provides a legal framework obliging states and armed groups, under both customary and treaty law, to ensure humanitarian assistance and access to medicines.<sup>78</sup> It usually falls to the authority exercising control over persons or territory to ensure that IHL norms and standards related to humanitarian relief are adhered to.<sup>79</sup>



And, as with IHRL, when states or non-state armed groups fail in these obligations, the international community responds politically and otherwise.

In terms of the current practical potential of IHL to address the access-to-medicine problem in Syria, the UN Security Council has passed a number of resolutions guaranteeing access to humanitarian assistance, including medical and surgical supplies, and hence medicines.<sup>80</sup> The World Health Organization, UNICEF, International Committee of the Red Cross, and others are actively trying to deliver medical aid and provide access to medicines. However, for years, the Syrian government, coupled with the bombings carried out by Russia, continues to hinder the process. The UN Security Council has been made largely ineffective because of Russia's veto power. For a long time, this veto power blocked any attempt to implement no-fly zones, which could have significantly lessened civilian deaths and provided greater access to medicines. In terms of keeping pressure on Syria to comply with its IHL obligations, one response has been to better document the crimes and look toward a possible future prosecution, either domestically or internationally, for violations of war crimes or crimes against humanity.

### *International criminal law and documentation of crimes*

International criminal law is the body of law prohibiting certain categories of conduct commonly viewed as serious atrocities and holding perpetrators of such conduct criminally accountable for their acts. The core categories of crimes falling under the jurisdiction of international criminal courts include war crimes, crimes against humanity, and genocide.<sup>81</sup> While the International Criminal Court (ICC) was established to investigate and prosecute these crimes, it has only complementary jurisdiction, meaning that states are primarily responsible for prosecuting such crimes.

The ICC's governing provisions provide a solid framework for the criminalization of war crimes related to access to medicines, and many national jurisdictions have adopted similar provisions. There are a number of provisions of the Rome Statute of

the ICC that could apply to violations of access to medicines. The first is article 8(2)(a)(iii), which criminalizes the willful causing of great suffering or serious injury to body or health. The second is article 8(2)(b) and (e), which deals with intentionally directing attacks against civilians, civilian objects, hospitals, medical units, and medical staff. Likewise, with regard to crimes against humanity, the crimes of extermination and persecution could be used to prosecute individuals for intentionally depriving individuals of medicine or humanitarian assistance.<sup>82</sup>

There are therefore, in theory, a number of avenues for perusing individual accountability for violations of access to medicines, either under the Rome Statute of the ICC or in domestic criminal systems that may have jurisdiction over the crimes. However, there are also serious limitations. Bringing an individual before the ICC is not an easy process. The ICC prosecutor can begin an investigation only when the court has jurisdiction, including temporal, subject-matter, and territorial or personal jurisdiction. In fact, the ICC has jurisdiction only over alleged crimes committed on the territory of state parties, or by nationals of state parties, and Syria is not a state party to the Rome Statute of the ICC.<sup>83</sup> Alternatively, the court may also obtain jurisdiction over a situation by a referral from the UN Security Council (which has been blocked by Russia), or by a declaration to the court by a non-state party (which Syria is unlikely to do).<sup>84</sup> Moreover, even when jurisdiction exists, the challenges associated with an international prosecution are great. As a result, only a limited number of cases have been pursued to date, covering a small number of jurisdictions around the world. While pursuing domestic prosecutions for war crimes or crimes against humanity are an option, such prosecutions would require a state to have criminalized these acts under national legislation, to have jurisdiction over the alleged perpetrator, and to have the political will to prosecute the cases.

Yet, pressure is growing for some form of individual accountability for serious human rights and humanitarian law violations. Prosecutions would draw much-needed attention to violations of the

right to health—particularly access to medicines—and would provide some form of justice to victims. In response to the inability of the UN Security Council to take action, in late 2016, the General Assembly passed a resolution establishing the International, Impartial and Independent Mechanism to Assist in the Investigation and Prosecution of Those Responsible for the Most Serious Crimes in Syria.<sup>85</sup> This mechanism is mandated to collect, consolidate, investigate, and analyze information about crimes in Syria and to build a case file for prosecution.<sup>86</sup> The idea is to then *share* this information with national, regional, or international courts or tribunals that could exercise jurisdiction. It is the first such mechanism of its kind and, if successful, may pave the way for others like it. It will be important for the new head of the mechanism, Catherine Marchi-Uhel, to focus on collecting information related to violations of access to medicines.

### Complementary frameworks: Looking ahead

Within this complex picture of complementary legal frameworks, there are a number of things being done for the situation in Syria. Yet, none have been able to ensure compliance or provide accountability for violations of access to medicines. While this may simply reflect the inherent limitations of law generally, after reflecting on the complementarity of the legal frameworks discussed, looking ahead leads to a dual conclusion.

First, all four bodies of law discussed hold clear potential in terms of regulatory and accountability mechanisms for improving access to medicines in times of conflict, but they are too weak on their own account. The field of IHRL is strong in standard setting and identifying corresponding fundamental rights and obligations but lacks a powerful set of legal accountability measures. It needs to strengthen its existing institutions and make specific and unified points on access to medicines in times of conflict in its treaty monitoring system. The IDCL framework should be used to simplify and foster access to medicines in emergency situations on the

ground. International actors such as the International Narcotics Control Board should continue to actively promote the use of these simplified procedures.<sup>87</sup> And, at the same time, the board should take an integrated approach and focus on the structural challenges governments face, particularly in conflict situations. These challenges often hamper their ability to comply with the general rules in IDCL. Finally, there is a strong emphasis on violations of the right to access medicines and medical/relief supplies within the IHL framework, but it too lacks direct accountability structures. Instead, accountability processes fall within domestic criminal processes or the ICL framework, and as shown above, the limitations are clear. The failures of these legal frameworks in terms of compliance and accountability highlight the limits of law operating in highly volatile political environments. And while a legal framework, or a combination of legal frameworks, is clearly not going to solve the crisis in Syria, there are important steps that can be taken to strengthen these frameworks to better ensure compliance and accountability.

Second, the potential for on-the-ground change lies in the mutual reinforcement of the legal frameworks discussed. However, this reinforcement remains rhetorical and far from practical. There is too little synergy or “spillover effect” between these bodies of law, and international institutions should actively reach out to one another to strengthen the applicable law on access to medicine provision in times of conflict. They should also work toward a holistic interpretation and practical application of these four bodies of law in order to support better access to medicines in times of conflict and hold those accountable who are responsible for unlawfully obstructing this access. The newly established International, Impartial and Independent Mechanism to Assist in the Investigation and Prosecution of Those Responsible for the Most Serious Crimes in Syria offers some hope in this regard—but only if greater attention is paid to this topic when building individual case files. Moreover, both IHRL and IDCL should also mutually reinforce each other by, for example, the Committee on Economic, Social

and Cultural Rights and International Narcotics Control Board issuing a joint general comment on the issue. Within IHRL, humanitarian assistance is a crosscutting element of general comments; however, the case of Syria demonstrates that the complexity of health service delivery in times of conflict needs to be addressed at a more holistic level. Although specifically aimed at state accountability, these bodies of law should meanwhile pave the way for humanitarian organizations to deliver on-the-ground care, which requires, for instance, that the International Narcotics Control Board better and actively promote the use of the simplified procedures.

Overall, attention to access to medicines must remain a priority within all compliance and accountability processes and legal frameworks. The international community must act to strengthen these legal frameworks in response to the failures experienced thus far. The promotion of greater linkages between the health sector and legal and political environments, as well as greater collaboration between the various fields and legal frameworks are crucial starting points. The civilians in Syria who have been denied access to medicines deserve better protection.

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# Missing: Where Are the Migrants in Pandemic Influenza Preparedness Plans?

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## Background

Influenza pandemics are perennial global health security threats, with novel and seasonal influenza affecting a large proportion of the world's population, causing enormous economic and social destruction. Novel viruses such as influenza A(H7N9) continue to emerge, posing zoonotic and potential pandemic threats.<sup>1</sup> Many countries have developed pandemic influenza preparedness plans (PIPPs) aimed at guiding actions and investments to respond to such outbreak events.<sup>2</sup>

Migrant and mobile population groups—such as migrant workers, cross-border frontier workers, refugees, asylum seekers, and other non-citizen categories residing within national boundaries—may be disproportionately affected in the event of health emergencies, with irregular/undocumented migrants experiencing even greater vulnerabilities. Because of a combination of political, sociocultural, economic, and legal barriers, many migrants have limited access to and awareness of health and welfare services, as well

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as their legal rights.<sup>3</sup> The conditions in which migrants travel, live, and work often carry exceptional risks to their physical and mental well-being. Even if certain migrant groups have access to health services, they tend to avoid them due to fear of deportation, xenophobic and discriminatory attitudes within society, and other linguistic, cultural, and economic barriers.<sup>4</sup> Evidence indicates that social stigmatization and anxieties generated by restrictive immigration policies hinder undocumented immigrants' access to health rights and minimizes immigrants' sense of entitlement to such rights.<sup>5</sup>

### Migrant inclusivity in PIPPs

PIPPs that are migrant inclusive and mobility competent enable greater public health protection for all. The majority of human cases of influenza A (H5N1) infection have been associated with direct or indirect contact with infected live or dead poultry. Worldwide, migrant workers are overrepresented in sectors such as poultry farming and related industries.<sup>6</sup> If they are not reached by disease prevention services or surveillance systems, and if they are reluctant to seek public health services, they may constitute a high-risk population for pandemic influenza. Migrant workers also represent a possible "bridge population" for viral spread—defined as a population transmitting infection from a high-prevalence group to individuals who would otherwise be at low risk of infection—when they travel to their place of origin.<sup>7</sup> It is thus imperative to understand the linkages between formal and informal migration routes with networks of migrant labor in animal husbandry and related industries for instance in order, to develop evidence-based policies that anticipate and prevent the emergence of novel zoonosis.<sup>8</sup>

In 2017, an estimated 258 million people—including 26 million refugees and asylum seekers—lived in a country other than their country of birth, representing an increase of 49% since 2000.<sup>9</sup> The Asia-Pacific region housed the majority of these international migrants (80 million) and remains the leading region of destination for in-

ternational migrants, with 106 million inflows in 2017.<sup>10</sup> This region, which houses 17 of the world's 31 mega cities, also has some of the world's largest and most diverse migration corridors from the Global South to the Global North, as well as across countries of the Global South.

We sought to explore the extent to which migrant and mobile population groups have been included in national PIPPs for selected countries within the Asia-Pacific region. We obtained PIPPs from official government sources (namely, ministries of health) that were available at the time of review (between January and June 2016). Twenty-one countries were randomly selected based on the World Bank's classification of low- to middle-income countries. A framework analysis of each PIPP was undertaken by two of this paper's authors, who independently reviewed each plan to identify the extent to which it described migration and mobility dynamics. A data-abstraction instrument was designed based on key search terms.

We found only three countries (Thailand, Papua New Guinea, and the Maldives) that identified at least one migrant group within their respective national plans (see Annex 1). Furthermore, we found that most countries (18 of 21) specified health control measures along their borders, such as point-of-entry screening strategies for inbound travelers.

Papua New Guinea's plan identifies the potential for "stigma and discrimination" against West Papuan refugees carrying avian influenza, as well as the possible psychosocial and economic impact of public health measures on such individuals. The PIPP outlines coordination measures among community health and welfare service providers to support displaced populations and refugees. Meanwhile, Thailand undertook a comprehensive assessment of its previous PIPP and found that the plan was "incongruent" with the current health situation of migrant workers, internally displaced persons, and individuals within mobility corridors in cross-border areas.<sup>11</sup> Thus, its new PIPP has been formulated as part of a broader national strategy for emerging infectious diseases that goes beyond viral flu to integrate a "one health" approach. The new



plan makes specific reference to and designs strategies for rural and urban migrants and temporary migrant workers crossing international boundaries. It recognizes that such groups are at higher risk due to their limited access to health information, which leaves them with insufficient knowledge on how to prevent infectious diseases. Finally, the Maldives identifies “non-citizen expatriate workers” as a priority group within its PIPP and provides strategies for addressing shocks within the health system stemming from migration.

## Conclusions

To comply with international human rights law, states should provide essential health services, especially disease prevention services, to migrants as well as their own nationals. However, many have explicitly stated before international human rights bodies and in domestic legal frameworks that they cannot, or do not wish to, provide migrant groups with the same level of protection that they offer their own citizens.<sup>12</sup>

Despite the particular barriers they face, vulnerable groups within PIPPs are often presented as a homogeneous subpopulation.<sup>13</sup> A World Health Organization review of PIPPs in 2011 showed that only 13 of 119 countries (11%) had strategies to address the communication needs of minority groups (defined as ethnic minorities, refugees, immigrants, and indigenous peoples).<sup>14</sup> The invisibility of some migrant and mobile population groups is not surprising given that cultural identities are often ignored in the focus on these groups’ political, legal, and economic status.<sup>15</sup> The World Health Organization’s *Asia-Pacific Strategy for Emerging Diseases and Public Health Emergencies* (2017) emphasizes a focus on “gender, equity and human rights” in the development of national public health capacities, though it falls short of providing specific recommendations regarding vulnerable groups and on migrant inclusion.<sup>16</sup> States’ obligations under the right to health extend to all inhabitants and are not limited to citizens and lawful residents. The strategic framework makes specific calls for “individual

citizens” to identify and report unusual or unexpected events but falls short of outlining aspects for non-citizens such as irregular migrant workers at poultry farms, who may be at increased risk.<sup>17</sup> As previously highlighted in this Journal, the scope of protection and effectiveness of global health frameworks in guaranteeing health protection for non-nationals remains unclear and elusive.<sup>18</sup>

Asylum seekers, itinerant migrant workers, and other undocumented migrants are often exposed to high-risk working and living environments, yet they remain marginalized within national health systems. As reflected in the International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families, adopted by the United Nations General Assembly in 1990, their protections are limited to “life-saving” and “emergency” medical services.<sup>19</sup> Some states, such as those within Europe are making efforts to ensure more equal access to migrants and offer a greater range of health services—from primary to reproductive health care—irrespective of legal status. However, wide disparities in entitlements across irregular migrant groups remain.<sup>20</sup>

Work is a principal driver of human mobility. The majority (65%) of international migrants are workers who actively participate in the labor force of destination countries.<sup>21</sup> Ensuring the right to health for migrants also requires states to ensure occupational health and a safe working environment. International Labour Organization Conventions 155 and 161, the United Nations Guiding Principles on Business and Human Rights, the United Nations Resolution on the Protection of Migrants, and the Sustainable Development Goal 8 on “decent work and economic growth” all called upon governments to protect rights of migrant workers.<sup>22</sup>

During major disease outbreaks and health emergencies, such as the West African Ebola epidemic in 2014, migrants may also be unfairly discriminated against, be perceived as vectors of disease, and have their travel restricted.<sup>23</sup> In times of health emergencies where resources and vaccines are in demand, provision to vulnerable groups may also be contested. Politicization and factors such as

“othering”<sup>24</sup> may prompt non-evidence-informed decision making. Human rights concerns need to support the prioritization of vulnerable and stigmatized groups for vaccination during a pandemic.<sup>25</sup>

Migration governance rests upon the fulcrum of national sovereignty, whereas pandemics and other novel diseases transcend local, national, and regional boundaries. Migration is framed by general international law, where the human rights of all people, including migrants, are an integral part of public international law.<sup>26</sup> The legally binding nature of the right to health and its principle of non-discrimination remain key underpinnings to advocating for non-nationals’ access to health care.<sup>27</sup> The Committee on Economic, Social and Cultural Rights is clear that migrants of all stripes, “regardless of legal status and documentation,” shall be ensured their rights in full.<sup>28</sup> In essence, global health security should be expanded to include global health solidarity.<sup>29</sup> In reiterating the call of the Sustainable Development Goals to “leave no one behind” and to address global health security in a meaningful way, we contend that irrespective of a person’s migrant status, his or her access to health services and social protection must be included within pandemic preparedness and response efforts.

## ANNEX

TABLE 1. Analysis of PIPPs from 21 low- to middle-income countries in the Asia-Pacific region

Country and publication date of PIPP	WHO region*	Migrant and mobile population groups defined within PIPP?	Border control measures? **	Cross-border animal health measures? ***
Bangladesh (2009)	SEAR	No	Yes	No
Bhutan (2011)	SEAR	No	Yes	No
Cambodia (2006)	WPR	No	Yes	Yes
China (2006)	WPR	No	No	No
Cook Islands (2007)	WPR	No	Yes	No
Fiji (2006)	WPR	No	Yes	No
India (2009)	SEAR	No	Yes	No
Indonesia (2006)	SEAR	No	Yes	No
Laos (2006)	WPR	No	Yes	No
Maldives (2009)	SEAR	Yes	Yes	No
Mongolia (2007)	WPR	No	No	Yes
Myanmar (2006)	SEAR	No	Yes	No
Nauru (2005)	WPR	No	Yes	No
Palau (2005)	WPR	No	Yes	No
Papua New Guinea (2006)	WPR	Yes	Yes	Yes
Philippines (2005)	WPR	No	No	Yes
Sri Lanka (2012)	SEAR	No	Yes	No
Thailand (2013)	SEAR	Yes	Yes	Yes
Timor Leste (2006)	SEAR	No	Yes	No
Tonga (2006)	WPR	No	Yes	No
Vietnam (2011)	WPR	No	Yes	Yes

\* SEAR (South East Asian Region); WPR (Western Pacific Region)

\*\* For example, point-of-entry screening and health information for travelers at airports, seaports, and land crossings

\*\*\* Strategies to prevent avian influenza transmission via migratory bird populations and the importation of poultry

TABLE 2. Example of key words searched

Domain	Key words searched
Migrants and mobile population groups:	
Migrant workers	(*migrant* OR transient* OR *migrat* OR overseas OR “cross-border” OR non-citizen* OR non-national* OR “domestic maid”) AND (worker OR workforce OR laborer OR labourer OR gardener OR farmworker OR “farm-worker*” OR industr* OR poultry OR agriculture OR “high skilled” OR “low-skilled” OR driver) OR (“internat* *migrant worker*” OR “foreign home care worker*” OR “foreign domestic worker*” OR “foreign domestic helper*” OR “transnational domestic worker*” OR “foreign domestic employee*” OR “overseas domestic worker*” OR “domestic migrant worker*” OR “International Labour migrants” OR “internat* illegal *migrant*” OR “Temporary migrant worker” OR “migrant health worker*” OR “frontier migrant worker” OR “Expatriate workers” OR “Inbound *migrant* worker*” OR “irregular *migrant” OR “irregular migration” OR “irregular *migrant*” OR “labour migration” OR “labor migration”) OR non-national migrant worker OR non-citizen migrant worker OR “intra-regional migrant” OR consular OR military OR diplomat* OR “international health elective*” OR “internal migration” “international *migrant*” OR “international *migration”)
International students	“international student*” OR “foreign student”
Refugees, asylum seekers	refugee* OR “asylum seek*” OR “displaced person*” “forced migrants” OR “ displaced people” OR “stateless person” OR “exile” OR “uprooted person” OR “asylum process” OR “Asylum - seek”
Trafficking victims, victims of human smuggling	traffick* OR smuggl* human OR woman OR child* OR sex OR prostitute* OR girl* OR *migrant* “forced labour” OR “forced labor” OR “forced prostitution” OR “sexual slavery”
Patient mobility across borders	mobility OR movement OR transfer OR smuggl*) AND (patient* OR ill OR sick) AND (border* ) OR (“patient* *migrat”)
Cross-border measures	International points of entry OR Points of entry OR Ports OR Airport OR Seaport OR Land crossings OR Ground crossings OR Cross-border OR Entry/Exit point OR International boundaries OR International crossings OR Foreign borders OR Border control OR Immigration control.
Cross-border animal health measures	Birds OR poultry OR wild birds OR wild duck OR Chicken OR Chicken farms OR poultry farms OR poultry markets OR migratory birds

**Methodology:** We sought to examine the extent to which migrants and mobile populations are included in pandemic preparedness plans (PIPPs) for selected countries within the Asia-Pacific region. A total of 48 countries from this region (according to the World Health Organization’s classification) were listed, and 21 countries were randomly selected using a random number table. Two authors reviewed each PIPP using a data-reduction instrument. The documents were analyzed for content and meaning, as well as through key-word searches from a list of terms describing migrants and mobile population groups and cross-border measures (Table 2). An open-source web-based software application entitled *Voyant tool* (<https://voyant-tools.org>) was used to undertake the document analysis per search strings listed in Table 2.

TABLE 3. Example of a country-level summary

Country	Title of PIPP	Migrant and mobile populations cited	Border control measures
Papua New Guinea	National Contingency Plan for Preparedness and Response for Influenza Pandemic (2006)	The objective of the plan is to “prevent the spread of avian influenza virus from its native host (wild birds) into and amongst domestic poultry or other non-native species, including humans.” The plan makes specific reference to refugee and displaced populations (for instance, West Papuan refugees and the psychosocial and economic impact of public health measures on these groups). It calls for close collaboration with health and other welfare service providers, and the provision of support to internally displaced populations and refugees.	Relevant actions stipulated in PIPP addressing human mobility: Section 1.6 includes a review of public health legislation to ensure the legal mandate for emergency powers, social distancing, border controls, quarantine, and adherence with International Health Regulations (2005) for public health events of international concern. Enhanced measures at ports of entry are also stipulated for all inbound flows. The plan also calls for monitoring the import of bird products (such as dried meat and feathers) that could potentially spread the bird flu.

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# Case Study: Degree of Integration of Disability Rights Into Allied Health Professional Education

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AND STEPHANIE D. SHORT

## Abstract

Persons with disabilities are vulnerable to rights violations when accessing health care, including allied health care. However, the commitment of allied health professional education to disability rights has not been researched. This study is the first to investigate the extent to which disability rights principles are integrated into allied health competencies and education. Specifically, this paper explores the extent to which disability rights principles are integrated into the competencies and education of the six allied health professions taught by the University of Sydney's Faculty of Health Sciences. The study brings to light facilitators and barriers to professional curriculum renewal, and recommendations for future health professional education. This case study reveals that three allied health professions—exercise physiology, physiotherapy, and radiography—incorporate a rights-based approach to a lesser degree than the other three—speech pathology, occupational therapy, and rehabilitation counseling. We refer to this as an “allied health continuum.” The paper concludes that there is considerable scope for the allied health professions to strengthen human rights-based education and care provision through ethical codes of conduct, competencies, curriculum renewal, accreditation, and registration requirements, with the aim of reducing rights violations experienced by persons with disabilities when accessing allied health care.

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## Introduction

*Academic institutions can... ensure that professional training courses include adequate information about disability, based on human rights principles.*<sup>1</sup>

World report on disability 2011

The UN Convention on the Rights of Persons with Disabilities (the Convention) promotes and protects the “equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities.”<sup>2</sup> This imposes obligations on states to develop rights-based approaches in the planning and provision of health care for persons with disabilities.<sup>3</sup> As Australia ratified the Convention in 2008, the Australian government is legally obliged to ensure that all Australian persons with disabilities enjoy their human rights within the context of health care.<sup>4</sup>

This study was conducted as a first step toward holding universities to account in implementing their obligations under the Convention in the context of allied health professional education. The case study was conducted in the University of Sydney’s Faculty of Health Sciences, which provides education across six allied health professional disciplines: exercise physiology, occupational therapy, physiotherapy, radiography, rehabilitation counseling, and speech pathology.<sup>5</sup> The University of Sydney has demonstrated a commitment to the rights of persons with disabilities in the education of allied health care professionals, as the Faculty of Health Sciences 2011–2015 Strategic Plan is underpinned by the “values embedded in the moral and legal framework of the United Nations Convention on the Rights of Persons with Disabilities (2006).”<sup>6</sup>

Despite such commitments, persons with disabilities have reportedly faced rights violations when attempting to access health care.<sup>7</sup> As a consequence, the World Health Organization (WHO) and the World Bank recommended in *World report on disability 2011* that universities “ensure that professional training courses include adequate information about disability, based on human rights principles.”<sup>8</sup> This recommendation was the springboard for this study. As a starting point, we reviewed grey and academic literature, exploring the nature and extent to which human rights are incorporated

within allied health professional competencies and education in Australia and internationally.

### *Health professional competencies*

Competencies published by the peak governing bodies of the six allied health professions under investigation recognize the importance of human rights in their practice. However, some professions—most notably, occupational therapy and rehabilitation counseling—exhibit a greater interest in human rights and the rights-based approach to persons with disabilities than others. The World Federation of Occupational Therapists position statement on human rights asserts that all humans have the right to participate in occupations that enable them to fulfill their potential and experience satisfaction.<sup>9</sup> Occupational therapists have also demonstrated an interest in the right of all persons to participate in meaningful occupations that contribute positively to their well-being, which has been applied to persons with disabilities.<sup>10</sup> Additionally, the Australian Society of Rehabilitation Counsellors and the Rehabilitation Counselling Association of Australasia recognize that rehabilitation counselors ought to respect the rights of persons with disabilities by facilitating independence and providing accessible and non-discriminatory services.<sup>11</sup>

The professions of speech pathology and physiotherapy also recognize the importance of human rights, but it is less clear how far this extends to persons with disabilities.<sup>12</sup> The extent to which radiography and exercise physiology adopt a focus on the rights of persons with disabilities is not evident.<sup>13</sup>

To our knowledge, no previous research has compared the degree to which allied health professional competency documents exhibit a rights-based approach to disability and rehabilitation.

### *Health professional education*

Several studies conducted in the United Kingdom and United States are relevant to this study.<sup>14</sup> Vincent and colleagues surveyed 156 medical students from 26 medical schools in the UK.<sup>15</sup> While 57% of these students thought that human rights issues



were important, only 20% indicated that human rights were included in their education. Chamberlain surveyed 51 individuals responsible for teaching ethics and law to nursing students in the UK.<sup>16</sup> The majority of respondents taught only 10 of the 16 surveyed human rights issues.

In the United States, Sonis and colleagues surveyed 113 coordinators of compulsory bioethics units of study in medical schools.<sup>17</sup> Using a similar survey to Chamberlain, Sonis and colleagues found that medical schools only included approximately seven of the 16 human rights issues.<sup>18</sup> Additionally, Brenner reviewed the curricula of 28 graduate schools of public health and 15 masters of public health programs in the US, as well as 34 international schools of public health, for the inclusion of human rights units.<sup>19</sup> Within these schools, Brenner and colleagues identified only eight units that focused on human rights. More recently, Cotter and colleagues surveyed the deans from 108 medical and public health schools in the US.<sup>20</sup> Only 37% of the surveyed schools had offered some level of human rights education during the past academic year, and time constraints (82%), lack of qualified instructors (41%), and lack of funding (34%) were perceived as barriers to teaching about human rights.

Furthermore, Shakespeare and Kleine's 2013 analytical overview of interventions that have been conducted to improve health professional education on disability unearthed "some evidence that medical and health science training might actually distance practitioners from a holistic or human rights approach to disability, because it may lead to a reductionist, problem-centered approach."<sup>21</sup> Interestingly, the exclusion criteria employed in this useful study excluded clinical studies and papers solely concerned with improving teaching in rehabilitation sciences. It is relevant to note, too, that while this overview cited some papers relevant to allied health professional education about disability, many people, including those who would not be classed as people with disabilities, need rehabilitation (for example, after sports injury). It would be interesting to know what proportion of allied health professionals' clients are disabled people with long-term impairment, as that would make the exclusion

of the rights-based approach very relevant.

Findings from the literature indicate that human rights principles are not always incorporated into medical, nursing, and public health curricula. More importantly, the incorporation of education about the rights of persons with disabilities within allied health curricula remains under-researched.

### *The current study*

This study intended to rectify this omission in the literature, by exploring the degree to which the competencies and education of the six allied health professions taught by the University of Sydney's Faculty of Health Sciences respect the rights of persons with disabilities.

The study aimed to:

1. investigate the nature and extent to which allied health professional competencies exhibit a rights-based approach towards working with people with disabilities;
2. investigate the nature and extent to which allied health professional education respects the rights of persons with disabilities; and,
3. explicate the facilitators, barriers, and recommendations for the progressive incorporation of human rights principles within health professional education more generally.

## Method

### *Data collection*

Allied health professional competency documents and education documents were collected and interviews conducted with coordinators of units that focused on disability rights. The use of three data sources was used to reduce bias through methodological triangulation. Field notes detailing potential impacts on the reliability of the data were recorded before and after data collection.<sup>22</sup>

### *Allied health professional competency documents*

The Allied Health Professions Australia's (AHPA)

website was reviewed to identify the Australian peak governing bodies for the six allied health professions:

- Exercise and Sports Science Australia;
- Occupational Therapy Australia;
- Speech Pathology Australia; and
- The Australian Physiotherapy Association.

As AHPA does not represent rehabilitation counseling and radiography, their Australian peak governing bodies were identified through a Google search:

- The Australian Institute of Radiography; and
- The Rehabilitation Counselling Association of Australasia.

The websites were searched systematically for documents outlining the professions' codes of ethics. Where no code of ethics was available, codes of conduct were collected.

#### *Allied health professional education documents*

Summaries of all units taught by the six allied health disciplines were obtained from the university's website.

For those units whose summary referred to disability, unit outlines describing the learning

aims were obtained through telephone and/or email contact with the unit coordinators and/or program directors.

#### *Coordinator interviews of units focusing on disability rights*

Individuals who coordinated a unit that focused on disability rights were invited via email to participate in 30-minute semi-structured telephone interviews. Units were considered to have focused on disability rights if their outline included the keywords "disability and human rights" or "disability" and at least two keywords from the Convention's eight general principles (Table 1).<sup>23</sup>

In cases where unit coordinators were no longer at the university, outlines from 2015 were used. If the 2015 units were identified as focusing on disability rights and were taught during the first semester of 2015, coordinators were similarly invited to participate. Interviews were conducted using an interview guide, from a previous pilot study.<sup>24</sup> The interview guide included closed-ended and open-ended questions, and was divided into five sections:

1. enrollment details;
2. formal curriculum;
3. informal curriculum;

TABLE 1. Keywords (and corresponding search terms) derived from the Convention's human rights principles

Human rights principles	Keywords	Search terms
1. Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons	1. Respect 2. Dignity 3. Autonomy 4. Choice 5. Independence	1. Respect 2. Dignity 3. Autonom* 4. Choice 5. Independen*
2. Non-discrimination	6. Non-discrimination	6. Non-discrim* or discrim*
3. Full and effective participation and inclusion in society	7. Participation 8. Inclusion	7. Participa* 8. Inclusi*
4. Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity	(1. Respect)	(1. Respect)
5. Equality of opportunity	9. Equality	9. Equal* or equit*
6. Accessibility	10. Accessibility	10. Access*
7. Equality between men and women	(9. Equality)	(9. Equal* or equit*)
8. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities	(1. Respect)	(1. Respect)

4. supports and barriers; and
5. comments and suggestions.

Questions were designed to explore the nature and extent to which education focused on disability rights, and the supports, barriers, and recommendations for future incorporation of human rights within health professional education. The interviewer recorded responses in writing on the interview guide, and they were then typed into an electronic interview guide post-interview. Typed interview transcripts were emailed to participants for member checking.<sup>25</sup>

### *Data analysis*

A mixed-methods design using quantitative and qualitative analytical approaches was used, as there are few studies reviewing human rights within health professional competencies and education and therefore no obvious agreement on the best approaches to use.<sup>26</sup> The approaches that were used included a quantitative keyword search and qualitative content analysis.<sup>27</sup> The use of two approaches reduced bias through methodological triangulation.<sup>28</sup>

### *Quantitative data analysis*

A quantitative keyword search of the competency and education documents was used to investigate the extent to which the six professions focus on disability rights.

Keywords included 'disability' and 'human rights' (human right\* and/or right\*), as well as ten keywords from the Convention's eight general principles (Table 1).<sup>29</sup> The number of keywords referred to by each document was calculated. Keywords were only included in the final count if they referred to the expectations of health professionals when working with their clients and/or to the content taught within units of study.

### *Qualitative data analysis*

Competency documents, education documents, and member-checked interview transcripts were analyzed using a qualitative content analysis to investigate the *nature* of the competencies and education provided.

Competency documents, education documents, and interview transcripts were read multiple times to gain a sense of the whole. Content that referred specifically to the expectations of health professionals when working with their clients and/or to the content taught within units was included in the analyses. Using an inductive approach, selected content was then divided into meaning units, condensed, and abstracted and labeled with a code. After content from each document was coded, all codes were reviewed before proceeding to the next document. Codes that referred to human rights were sorted into sub-categories and categories, which were then arranged into an overarching human rights theme. Keywords from the Convention's eight general principles were used as a theoretical framework.<sup>30</sup> An audit trail detailing decisions made during data analysis was recorded, and education documents and interview transcripts were de-identified to protect participants' confidentiality.<sup>31</sup>

The University of Sydney's Human Research Ethics Committee provided ethical approval for this study (Project No. 2015/460).

## Results

### *Allied health professional competencies*

The following competency documents were collected for analysis.

1. Occupational Therapy Australia's code of ethics.<sup>32</sup>
2. Rehabilitation Counselling Association of Australasia's code of professional ethics for rehabilitation counselors.<sup>33</sup>
3. Speech Pathology Australia's code of ethics.<sup>34</sup>
4. Australian Physiotherapy Association's code of conduct.<sup>35</sup>
5. Australian Institute of Radiography's code of ethics.<sup>36</sup>
6. Exercise and Sports Science Australia's code of professional conduct and ethical practice.<sup>37</sup>

Table 2 shows the quantitative keyword results. Independence, participation, and inclusion were the least referenced keywords. Rehabilitation

counseling and speech pathology were the only disciplines to refer specifically to persons with disabilities. Rehabilitation counseling included the most keywords from the Convention's eight general principles (eight out of ten), closely followed by occupational therapy, speech pathology, and physiotherapy, which all included seven out of ten keywords.<sup>38</sup>

Total refers to the number of keywords included in the competency documents, within (vertical) and between (horizontal) documents. The white rows indicate the ten keywords from the Convention's eight general principles.

### *Qualitative analysis of documents*

The keyword 'respect' is recognized in the competency documents of all the allied health professions with the exception of exercise physiology. The documents that do refer to respect assert that health professionals are committed to practice in a manner that respects client's rights (for example, dignity and autonomy), as well as client's personal (for example, their health needs) and contextual factors (for example, their culture). The code of ethics from Speech Pathology Australia states, "we respect the rights and dignity of our clients and we respect the context in which they live."

Dignity is acknowledged within all competency documents, as all health professionals are

expected to promote the dignity of their clients by adhering to procedures and legislation that protect privacy and confidentiality. The code of conduct from the Australian Physiotherapy Association states, "members shall protect the confidentiality and privacy of client health information."

Most of the professions' documents assert that health professionals should respect and promote their clients right to autonomy; the exceptions are radiography and exercise physiology. Occupational therapy's competency document states that autonomy implies patients are: "active participants in any decision regarding their involvement in services," and the rehabilitation counseling competency documents asserts that rehabilitation counselors will advocate for their clients during situations where autonomy is reduced (for example, during involuntary admission to hospital).

Choice is recognized in all competency documents, as all the health professionals are expected to ensure clients are able to make informed choices (for example, informed on the likely benefits, risks, and costs of services). Health professionals are also expected to uphold their client's rights to withdraw from treatment, seek a second opinion, and determine who will be provided with their personal information.

Independence was only acknowledged by rehabilitation counseling, where rehabilitation

TABLE 2. Quantitative keyword search of the Allied Health Professional competency documents<sup>39</sup>

Keywords	Allied health profession						Total
	Occupational therapy	Rehabilitation counseling	Speech pathology	Physiotherapy	Radiography	Exercise physiology	
Disability		X	X				2
Human rights	X	X	X	X	X	X	6
Respect	X	X	X	X	X		5
Dignity	X	X	X	X	X	X	6
Autonomy	X	X	X	X			4
Choice	X	X	X	X	X	X	6
Independence		X					1
Non-discrimination	X	X	X	X	X	X	6
Participation	X	X					2
Inclusion							0
Equality			X	X	X	X	4
Accessibility	X	X	X	X	X	X	6
Total	8	10	9	8	7	6	48

counselors are expected to support their clients: “efforts at self-advocacy both on an individual and an organizational level.”

While all documents assert that allied health professionals shall provide non-discriminatory services, rehabilitation counseling and speech pathology are the only professions to refer specifically to persons with disabilities. The Australian Institute of Radiography’s code of ethics states that radiographers shall: “ensure the provision of non-discriminatory services to all people regardless of age, colour, gender, sexual orientation, religious affiliation, political allegiances, type of illness, ethnicity, race, and mental or physical status.”

Participation is recognized by occupational therapy and rehabilitation counseling, where both professions ought to ensure clients are: “afforded the opportunity for full participation in their own treatment team.”

Inclusion is not recognized in any competency document.

The right to equality is recognized in most competency documents; the exceptions are occupational therapy and rehabilitation counseling. The competency documents that do refer to equality assert that health professionals are obliged to ensure equitable availability of health care services and resources.

All of the allied health professions expect professionals to ensure that clients are able to access their personal information and services, including physical and attitudinal access. The code of professional conduct and ethical practice for Exercise and Sports Science Australia states: “An exercise and sports science professional must... uphold the Client’s right to gain access to the necessary level of health care.”

*Disability in allied health professional education*

Of the 349 units taught by the Faculty of Health Sciences in 2014, only 24 (7%) of the unit summaries included the keyword ‘disability’ (Table 3).

Total refers to the number of unit summaries that referred to the keywords, within (vertical) and between disciplines (horizontal). The white rows indicate the keywords from the Convention’s eight general principles.<sup>40</sup> UG = undergraduate. PG = postgraduate.

Unit outlines for the 24 unit summaries that referred to disability were obtained and analyzed using a quantitative keyword search. Of these 24 units, 14 were identified to focus on disability rights (Table 5); including units from occupational therapy, rehabilitation counseling, and speech pathology.

Across all unit outlines, human rights, par-

TABLE 3. Quantitative keyword search of units taught by the Sydney Faculty of Health Sciences

Keywords	Allied health profession													Total n=349
	Occupational therapy		Rehabilitation counseling	Speech pathology		Physiotherapy		Radiography		Exercise physiology		Faculty electives		
	UG n=33	PG n=27	PG n=19	UG n=52	PG n=18	UG n=33	PG n=30	UG n=8	PG n=23	UG n=36	PG n=16	UG n=32	PG n=22	
Disability	2	2	10	2			1			2	1	4		24
Human rights			1	1								1		3
Respect						1	1							2
Dignity														0
Autonomy														0
Choice	2	1												3
Independence			1											1
Non-discrimination			1							1				2
Participation	10	3	1			2	2			1	1	3	1	24
Inclusion	1											1		2
Equality			1										1	2
Accessibility														0
Total	15	6	15	3	0	3	4	0	0	4	2	9	2	63

ticipation, inclusion, and accessibility were the most frequently referenced keywords; followed by choice, independence, non-discrimination, and equality. Respect, dignity, and autonomy were the least referenced keywords.

Total refers to the number of keywords referred to in the unit outlines, within (vertical) and between units (horizontal). The white rows indicate the keywords from the Convention’s eight general principles.<sup>41</sup> UG = undergraduate. PG = postgraduate.\* = units whose coordinators participated in interviews.

*Qualitative interviews*

A qualitative content analysis was conducted to analyze the content of units whose coordinators participated in interviews, which included interview transcripts and corresponding unit outlines.

Coordinators of seven of the 14 units that referred to disability rights participated in interviews (50% response rate). As some units were taught across disciplines and levels (that is, undergraduate and postgraduate), four interviews were completed. All interviewees (“subjects”) referred to all ten keywords from the Convention’s eight general principles, outlined below.<sup>42</sup>

Subject 1 challenged students to respect the rights of persons with intellectual disabilities to

take risks (that is, dignity of risk), to express their autonomy (for example, the right to explore their sexuality) and to respect children with intellectual disabilities. Subject 1 also presented active support as a therapeutic approach used to increase client’s choice and independence. Subject 2 challenged students to consider how they might respect the dignity and autonomy of persons with disabilities to make independent choices, with a particular focus on access to services; where respect was considered to be “interwoven through the entire subject (unit).” Subject 3 focused on respecting the dignity and autonomy of persons with disabilities, through its focus on the Independent Living Movement’s message that persons with disabilities have a right to make independent choices regarding education, employment and housing, with assistance when required. Subject 4 challenged students to consider how they might respect the dignity and autonomy of persons with disabilities to make independent and informed choices, with a particular focus on employment. This subject also urged health professionals to respect their client’s personal factors (for example, diversity) and contextual factors (for example, culture).

Subject 1 recognized the right for non-discrimination in the education and criminal justice systems,

TABLE 4. Quantitative keyword search of unit outlines that focused on disability rights.

Keywords	Allied health profession														Total n = 14	
	Occupational therapy		Rehabilitation counseling								Speech pathology		Faculty electives			
	UG	PG	PG								UG		UG			
	UG OT1*	PG OT1*	PG RC1*	PG RC2*	PG RC3	PG RC4	PG RC5*	PG RC6	PG RC7	PG RC8	UG SP1	UG SP2*	UG FE1	UG FE2*		
Disability	X	X	X	X	X	X	X	X	X	X	X	X	X	X	X	14
Human rights	X	X	X					X				X	X	X	7	
Respect								X							1	
Dignity															0	
Autonomy															0	
Choice	X	X			X		X	X							5	
Independence	X	X		X				X							4	
Non-discrimination								X	X	X					3	
Participation			X		X		X	X	X		X	X	X	X	9	
Inclusion	X	X	X				X	X			X	X	X	X	9	
Equality			X			X		X		X		X		X	6	
Accessibility	X	X		X		X	X	X			X		X		8	
<b>Total</b>	<b>6</b>	<b>6</b>	<b>5</b>	<b>3</b>	<b>3</b>	<b>3</b>	<b>5</b>	<b>10</b>	<b>3</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>5</b>	<b>5</b>	<b>66</b>	

and active support was presented as a therapeutic approach that supports people “to participate fully (with support) in domestic and community life.” Additionally, personal and contextual factors that affect participation in domestic, community, vocational, and leisure activities were explored. This subject also focused on the inclusion and participation of children within education, and the inclusion and participation of adults in transition to adulthood, employment, retirement, and end of life supports. Subjects 2, 3, and 4 focused on the rights of persons with disabilities to access non-discriminatory communities, services and employment that encourage participation and inclusion.

Subjects 1 and 4 focused on equality of opportunity within the workplace. Subject 4 specifically taught students about workplace assessments and interventions that aim to increase employment equality and accessibility, in addition to the gendered and cultural aspects of employment participation. Subject 1 also explored physical and attitudinal factors that affect access to services, including a specific focus on issues of service accessibility for persons with intellectual disabilities living in rural areas. Subject 2 included a service learning component, which focused on providing accessible services that enhance the community participation of persons with disabilities, adding to the recognition of persons with disabilities as “equal members in their communities.” Additionally, subject 2 explored the rights of persons with disabilities for equal access to health resources and considered gendered aspects of access in terms of health seeking behaviors. Subject 3 provided information regarding the inequalities persons with disabilities face, including inequalities that occur between men and women. Additionally, subject 3 required students to complete a physical and attitudinal accessibility inventory of a community space (for example, a restaurant, university, or workplace), which assisted students to develop skills in advocating for the accessibility rights of persons with disabilities.

Subjects 1, 2, and 3 referred to legislation relevant to the rights of persons with disabilities, including the Convention.

Subjects 1 and 3 taught students how to recognize human rights violations, which “are sometimes subtle and not always obvious.”

Subjects 1, 3, and 4 challenged students to consider how a rights-based approach might be incorporated into practice. For example, Subject 1 involved a project where students worked therapeutically with an individual with an intellectual disability.

#### *Facilitators, barriers, and recommendations*

Unit coordinators identified a variety of factors that support the incorporation of disability rights within curricula:

- heads of disciplines;
- colleagues;
- students of the units themselves;
- the faculty’s external advisory committee;
- admissions policies to recruit educationally disadvantaged students;
- methods of teaching and learning that emphasize a rights-based approach (for example, client-centeredness); and
- awareness that “there is a move to audit disability teaching within the faculty.”

Supportive factors were particularly evident for rehabilitation counseling, as it was described as having “a major focus on this topic; more so than more clinically-focused Disciplines.”

Unit coordinators also identified a variety of barriers to incorporating disability rights into curricula:

- competition for time;
- lack of focus on encouraging and supporting persons with disabilities to complete the courses;
- “lack of awareness for the importance of human rights and a “medical model” focus is instead used”; and,
- “Systematic barriers to people talking, interacting and sharing across Faculties.”

Three of the four coordinators were not aware of other units that incorporated disability rights. However, the occupational therapy coordinator stated that they do embed human rights principles within their teaching in other occupational therapy units. The coordinator who was aware of other units that incorporated disability rights was aware of units within their own profession, rehabilitation counseling.

Unit coordinators made the following comments regarding the future incorporation of human rights principles into health professional education.

- “Attitudes around rights, choice, control, participation and inclusion for all people should be at the heart of all teaching,” not just for persons with disabilities;
- The medical model, while it has its purpose, does not always ascribe to a rights-based approach;
- The faculty should develop specific units of study on human rights that all students from all disciplines ought to complete; “They are trying to do this with Indigenous studies—they should do the same with rights”; and,
- “There is no one size fits all approach” when educating health professional students about the rights of persons with disabilities.

## Discussion

### *Allied health professional competencies*

We can first conclude that the commitment to human rights is recognized within the Australian competency documents relevant to the allied health professions under investigation, with some slight variation between professions.

This analysis of Australian competency documents was followed up with empirical investigations conducted in a case study within the Faculty of Health Sciences at the University of Sydney in Australia. These results cannot be generalized beyond Australia or this particular faculty. The quantitative analysis found that rehabilitation counseling and speech pathology competency

documents included the highest number of keywords, and were also the only professions to refer specifically to persons with disabilities. These two professions were closely followed by occupational therapy and physiotherapy, and next by radiography and exercise physiology. These varying levels of commitment have implications for practice and education. Given the multidisciplinary nature of health care, it is important that all health professionals share a similar commitment to human rights if health care is to be truly rights-focused.<sup>43</sup> The variations between professions suggest that this might not be the case. As governing bodies influence what is included within health professional education curricula, it is possible that varying levels of commitment will similarly influence the extent to which allied health professional education focuses on human rights principles.<sup>44</sup>

Findings from the qualitative analysis suggest that all the allied professions under investigation are committed to practice that respects and upholds their clients’ rights to dignity (that is, privacy and confidentiality), informed choice, non-discrimination, and accessibility. However, most professions overlooked the rights to independence, participation, and inclusion. Therefore, allied health professionals may not be explicitly aware of their obligations to promote and protect these human rights. This has significant implications for practice, as it may mean persons with disabilities are particularly vulnerable to violations of the rights to express their independence (for example, in terms of self-care) and for participation and inclusion (for example, in decisions regarding their treatment). When reviewing these findings, radiography and exercise physiology again demonstrated the weakest commitment to practice that upholds human rights principles.

### *An allied health professional continuum*

While acknowledging the limitations of the study, we have identified the emergence of a continuum within the allied health professions under review, which reflects the extent to which they integrate disability rights principles. We suggest this con-



tinuum should be subject to further verification or falsification. We also recognize that: the codes of ethic and conduct are not the only documents that outline health professional practice; curricula documents do not include all content that is presented within units of study; and that disability can be referred to with different terms (for example, the *Convention on the rights of persons with disabilities* defines persons with disabilities as persons with long-term impairments).

Quantitative results revealed that of the 349 units taught across all allied health professional disciplines in 2014, only 24 were identified as focusing on disability. No units from postgraduate speech pathology, undergraduate physiotherapy, or radiography referred to disability, let alone to disability rights. Of the 24 units that did refer to disability, 14 focused specifically on disability rights. These 14 units were taught within the rehabilitation counseling, occupational therapy, and speech pathology disciplines.

These findings may suggest that the education provided in physiotherapy, radiography, and exercise physiology may not be equipping students to promote and protect the rights of persons with disabilities. This possible educational neglect provides insight into why persons with disabilities might experience rights violations when attempting to access health care.<sup>45</sup> These findings are comparable to conclusions drawn from previous research, which suggested that human rights are not always successfully incorporated into medical, nursing, and public health curricula.<sup>46</sup>

While the quantitative analysis appeared to suggest that respect, dignity, autonomy, and non-discrimination were largely overlooked, qualitative results suggested that all interviewed subjects referred to all ten keywords from the Convention's eight general principles.<sup>47</sup> These findings reflect the fact that content taught within units is not always listed in curricula documents, and suggests that the interviews allowed the researchers to gain a greater understanding of the content that was taught by the allied health disciplines. Unit coordinators indicated that human rights were integrated as a theme

within all interviewed units and were presented as relevant to a range of settings (for example health care, education, and employment). This integrated approach was evident during the interviews, as most coordinators had difficulty talking about one human right without referring to another. These findings have positive implications for practice, as they suggest that when the university's allied health education does include a focus on disability rights, this focus is broad, integrated, and applicable to a range of practice areas. The interviews support conclusions drawn from research conducted by Chamberlain in nursing education, which noted that there is room for improvement in the incorporation of human rights principles into health professional education.<sup>48</sup>

#### *Facilitators, barriers, and recommendations*

Unit coordinators identified a range of factors that support the teaching of human rights, particularly within rehabilitation counseling. This study also unearthed a range of barriers. The most interesting barrier was the existence of systematic barriers to people interacting and sharing across faculties, with medicine, nursing, pharmacy, and so on. As allied health professionals are expected to work collaboratively as part of multidisciplinary teams, allied health disciplines within universities should work collaboratively in their efforts to educate future health professionals.<sup>49</sup> In support of this claim, one unit coordinator recommended that the faculty develop specific units on human rights and health that students from all health profession courses should undertake.

The study also suggests that a more biomedical model of disability, while it has its value, does not always incorporate a rights-based approach. Given that physiotherapy, exercise physiology, and radiography are arguably the most biomedically oriented professions of the six allied health professions, it is possible that this orientation creates a barrier to incorporating a rights-based approach within their competencies and education. Following this interpretation, we propose a continuum regarding the extent to which the six allied health professions

respect the rights of persons with disabilities in this case study (Figure 1).

### *Implications for future research*

Given that human rights principles are recognized to varying degrees within the competency documents of the six allied health professions under investigation, it is recommended that peak governing bodies review their competency documents to ensure that they are in fact meeting their obligations under the Convention. It is additionally recommended that universities strive to develop curricula that reflect their commitment to the rights of persons with disabilities, which is multidisciplinary in nature. Future research should investigate the effectiveness of such education, measured using pre/post assessment. Future research could also compare allied health professional education with competencies in medicine and nursing, and public health, as these professionals also play significant roles in multidisciplinary health care teams and in the care of persons with disabilities.<sup>50</sup>

### *Limitations*

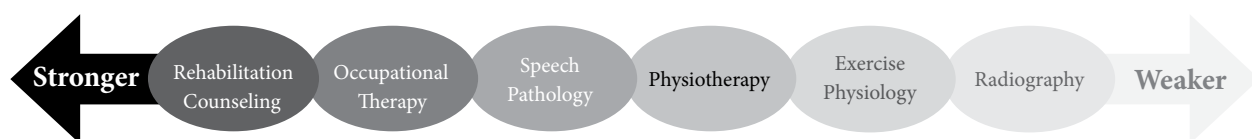
Findings from this case study should be understood within the context of several limitations. Codes of ethics and conduct are not the only documents that outline health professional practice expectations (for example, graduate competencies), and other organizations also provide guidelines for health professional practice within Australia (for example, the Australian Health Practitioner Regulation Agency). Additionally, curricula documents do not include all content that is presented within units, and disability can be referred to with different terms (for example, impairment, condi-

tion, disease, illness, or using diagnostic labels). Furthermore, interviews were only completed with coordinators of 50% of the units identified as focusing on disability rights, and results from interviews suggested that human rights principles were taught in additional units not identified in the keyword search. Therefore, this case study may have underestimated the commitment of the allied health profession educators to respect the rights of persons with disabilities.

### **Conclusion**

This is the first study undertaken to investigate the commitment of allied health professions to human rights-based education. Results from this empirical case study indicate that allied health professional competencies recognize the relevance of human rights principles to health professional practice, to varying degrees. It identifies an allied health continuum in the Faculty of Health Sciences at the University of Sydney, with rehabilitation counseling and occupational therapy providing evidence of a stronger commitment to human rights principles than speech pathology, physiotherapy, exercise physiology, and radiography. This study suggests that allied health professional education may not be equipping students adequately to promote and protect the rights of their clients with disabilities. Allied health professional governing bodies and universities have a legal obligation under the Convention to ensure that health professional practice and education respect the rights of persons with disabilities. The authors hope this study will enable progress toward that goal, with the aim of reducing human rights violations experienced by persons with disabilities when accessing allied health care.

FIGURE 1. An allied health continuum (degree of integration of disability rights into health professional course curricula in this case study)



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# Inequitable Physical Illness and Premature Mortality for People with Severe Mental Illness in Australia: A Social Analysis

MELANIE EDMUNDS

## Abstract

Australians with severe mental illness experience inequitably high rates of physical illness and shortened life expectancy compared to the general population. A social analysis of this phenomenon incorporating a precis of historical and contemporary public health approaches reveals persistent discrimination and entrenched social disadvantage influencing access to appropriate physical health care. People with severe mental illness in Australia are among the most vulnerable and marginalized populations in society, with fragmented and inadequate health and social services materially influencing their physical health status and longevity. Enhanced multi-sectoral collaboration, integrated physical and mental health care models, empowerment strategies, and privileging of a lay perspective within program design are critical to challenging this enduring infringement on the human right to health.

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## Introduction

The experience of inequitable physical illness and premature mortality for people with severe mental illness is a recognized phenomenon globally.<sup>1</sup> In Australia, people with severe mental illness experience significantly higher rates of physical illness and shortened life expectancy compared to the general population, with the majority of deaths the result of preventable physical conditions.<sup>2</sup> Co-morbid physical illness is estimated to occur in up to 50% of people with severe mental illness with substantial compound negative effects on quality of life.<sup>3</sup> An historical analysis in public health can generate critical thinking on social forces shaping health experiences and inequities over time. The following examination of both historical and contemporary public health approaches in Australia considers complex social factors shaping the experience of physical illness and premature mortality for people with severe mental illness, defining an enduring infringement on human rights for this population. For the purpose of this analysis, severe mental illness signifies the diagnostic group of psychotic disorders. Psychotic disorders are severe and less common forms of mental illness characterized by distortions to thinking, perception of reality, and emotional response, with schizophrenia the most common psychotic illness.<sup>4</sup>

### *Severe mental illness in Australia*

The prevalence of severe mental illness in Australia is estimated at 3.1 people per 1000 population.<sup>5</sup> Despite relative infrequency in comparison to common conditions such as anxiety and substance use disorders, people with severe mental illness are leading users of specialized mental health services.<sup>6</sup> People with severe mental illness in Australia report high rates of stigma, discrimination, and victimization and experience persistent and significant inequities across a range of health and social indicators.<sup>7</sup>

### *Physical morbidity*

Australians with severe mental illness experience physical illness at rates well above the general population, with subsequent amplification of the

burden of ill health already borne.<sup>8</sup> Diagnosis with chronic physical conditions occur at a younger age with a much higher rate of mortality five years from diagnosis compared to the general population.<sup>9</sup> Globally, after suicide and epilepsy, diabetes is the third leading cause of death for people with schizophrenia, together with a 10-fold risk of mortality from respiratory disease.<sup>10</sup> Infectious diseases such as HIV and hepatitis C virus are also over-represented in this population.<sup>11</sup>

Additionally, people with severe mental illness in Australia frequently present with lifestyle risk factors. This includes almost 50% incidence of obesity, generally very low physical activity levels, dietary and vitamin deficiencies, and high rates of substance misuse.<sup>12</sup> It is estimated that up to half the cigarettes consumed in the US, UK, and Australia are smoked by people with a mental illness.<sup>13</sup> Metabolic syndrome as a significant risk factor for cardiovascular disease is also particularly prevalent in people with severe mental illness, with nearly 50% presenting with this combination of medical symptoms.<sup>14</sup>

### *Mortality*

People with severe mental illness have significantly shortened life expectancy of between 10 and 25 years less than the general population.<sup>15</sup> Importantly, in contrast to increasing longevity for the general population, over the last 30 years there has been a consistent downward trend in life expectancy for those with severe mental illness.<sup>16</sup> In Australia, suicide presents the greatest relative risk for mortality for this population; however, up to three quarters of deaths are the result of preventable physical illness.<sup>17</sup>

### *Health equity and human rights in Australia*

To mitigate the risk of perpetuating discrimination through individualized and behavior-based research on health inequities in sub-populations, it is important to position studies within a context of human rights and the social determinants of health. An acknowledgment of Australia's human rights obligations is therefore of particular relevance to an analysis of inequitable physical morbidity and premature mortality for people with severe mental illness.

In 1975, Australia ratified the International Covenant on Economic, Social and Cultural Rights (ICESCR).<sup>18</sup> Article 12(1) of the Covenant clearly states, “the right of everyone to the enjoyment of the highest attainable standard of physical and mental health”.<sup>19</sup> To support the realization of this right, the Covenant mandated steps be taken to ensure prevention, treatment, and control of disease together with the creation of conditions enabling all peoples’ access to medical care in the event of illness.<sup>20</sup> Further relevant to this analysis is the clear description of equal entitlement of all people to benefit from scientific progress, which in this scenario includes advancements in the management of concomitant mental and physical illness.<sup>21</sup> Although a process of progressive realization of rights was originally provided for within the Covenant, the intention was for expeditious progression.<sup>22</sup>

More recently, in 2008, Australia ratified the United Nations Convention on the Rights of Persons with Disabilities (CRPD), together with the Optional Protocol in 2009.<sup>23</sup> These instruments provide further clarification of specific obligations to ensure the equal rights of people with disabilities.<sup>24</sup> Within the Covenant, the rights and fundamental freedoms of people with disabilities, inclusive of those with severe mental illness, are protected on an equal basis with all others.<sup>25</sup> These human rights considerations provide an important framework for interpreting social and political influences on physical health inequities for people with severe mental illness in Australia. Moreover, as Australia has committed to these legal instruments, not only is there a moral and professional obligation within the health and social sectors to address inequities in physical health status for people with severe mental illness, but also a legal requirement given the existence of complaint mechanisms within the Optional Protocol.<sup>26</sup>

## Historical public health perspective

### *Colonialism and the lunatic asylum*

In Australia, from early European colonization in the late 1700s through to the 1960s, care of people with severe mental illness was practiced

predominantly in institutional settings.<sup>27</sup> This was congruent with international trends of segregation of people with mental illness from general populations.<sup>28</sup> In early colonial times, people with mental illness were typically housed in prisons.<sup>29</sup> Although this was motivated by a desire to protect the community from the potential dangers of a person’s insanity, there was recognition of the potential benefits of safe custody insofar as protection from abuse and exploitation by relatives and the wider community.<sup>30</sup> Furthermore, prior to formal lunacy legislation in colonial Australia, there was evidence of regulated committal processes, stipulations for humane treatment, and segregation from the general prison population.<sup>31</sup>

This rudimentary public health consideration of the well-being of mentally ill persons was further developed with the implementation of formal lunacy legislation in the Australian colonies between 1843 and 1871, setting standards for humane treatment regulations and administrative safeguards for accommodation in private asylums.<sup>32</sup> Commonly known in Australia as lunatic asylums, these institutions were responsible for the care of people with psychotic illness.<sup>33</sup> The advent of these dedicated institutions triggered a shift from magisterial and religious oversight to medical professionals as custodians of asylums.<sup>34</sup> Management of people with psychotic disorders during this period was accordingly based on the medical model, utilizing concepts of organic psychiatry including early pharmaceuticals, electrotherapy, physical treatments, and mechanical restraint.<sup>35</sup>

Although there were later revealed incidences of ill-treatment, these asylums were initially established with good intentions.<sup>36</sup> Asylums, as separate entities from prisons, removed the indignity experienced by people with mental illness resulting from forced association with criminal inmates.<sup>37</sup> There were also examples in early colonial Australia of asylums incorporating cottage-style living rather than warehousing in large buildings, options for boarding-out for select patients, and ‘asylum farms’, established to reflect beliefs in the therapeutic benefits of interacting with nature and meaningful occupation.<sup>38</sup> Yet these examples were

isolated and did not prevail as mainstream practice due to economic constraints.<sup>39</sup>

The public health approach during this time appears dominated by a functionalist perspective on power, with asylums essentially designed to minimize impact on social order by people with psychosis, and the role of psychiatry to alleviate deviance in the 'mad'.<sup>40</sup> Public discourse on the care of mentally ill persons in the early 20th century focused on psychiatric management, with concern for humane treatment limited.<sup>41</sup> Institutionalized care significantly influenced stigmatization and discrimination of mentally unwell people, with subsequent violations to human rights and formation of inequitable power structures in psychiatry.<sup>42</sup> This systematic disempowerment contributed to the social exclusion and subsequent marginalization of people with severe mental illness both preceding and following the process of deinstitutionalization from the mid-20th century.<sup>43</sup>

### *Deinstitutionalization*

Deinstitutionalization in psychiatry describes the process of the transfer of responsibility for care of people with severe mental illness from custodial psychiatric institutions to community-based settings.<sup>44</sup> Deinstitutionalization is believed to have originated from theories of normalization and changing social standards of citizenship and human rights, and commenced from the 1950s in industrialized countries.<sup>45</sup> In the Australian context, criticisms of deinstitutionalization are centered on insufficient planning for systematic implementation and evaluation, and inadequate resourcing of community services.<sup>46</sup> Furthermore, the process of deinstitutionalization has been mirrored by a shift from core psychiatric services to increasing emphasis on population health promotion and prevention of mental illness.<sup>47</sup> Tension in the form of resource competition between functions of clinical psychiatry and public health approaches is described as another important factor contributing to the recognized failings of deinstitutionalization, namely under-resourcing of community mental health services, community health services more broadly, and vocational and housing services.<sup>48</sup>

Despite these limitations, deinstitutionalization in Australia activated significant reforms to the provision of both mental and physical health care for people with severe mental illness.<sup>49</sup> The advent of community mental health services and their evolution over time conveyed notable improvements to philosophies underpinning care provision for people with severe mental illness. These include illness prevention, early intervention, crisis management, recovery-oriented treatments, continuity of care, and person-centered care planning.<sup>50</sup> Evaluation of community-based mental health services in Australia has revealed improvements in quality of life and reduction in stigmatization for people with severe mental illness in comparison to institutionalized care.<sup>51</sup> Concomitantly, deinstitutionalization marked the advent of expanded rights and recognition of full citizenship for people with severe mental illness within Australian society, with progressive legislation aligning with international human rights advancements following.<sup>52</sup>

### Contemporary public health perspective

The process of deinstitutionalization and pharmaceutical innovation, in the form of antipsychotic medications, were pivotal to changes in the care of people with severe mental illness in contemporary Australia.<sup>53</sup> Attempts to understand causal factors producing inequity in physical health status for people with severe mental illness were likely to have been significantly influenced by these two phenomena. Although individualized biological and behavioral explanations persist, there is increasing awareness of social and cultural determinants of health in the experience of physical illness for this population.

#### *Individual factors: Influence of primary diagnosis and antipsychotic medications*

Psychotic disorders are associated with cognitive impairment and positive and negative symptoms which present as primary barriers to prevention and management of physical co-morbidities for people with severe mental illness.<sup>54</sup> Negative symptoms of psychosis are described as diminished



ability and motivation for healthy lifestyles and reduced self-care capacity, with subsequent increased risk of physical illness.<sup>55</sup> Furthermore, cognitive disruption reduces the likelihood of recognition of physical health problems, with suspicion, paranoia, and communication difficulties inhibiting health service access.<sup>56</sup>

Although antipsychotic medications are considered essential for reducing the impact of symptoms of psychosis for improved health, quality of life, and life expectancy, there are well-replicated correlations of, and several suggested mechanisms for, medication-induced weight gain for both typical and atypical antipsychotic medications.<sup>57</sup> These mechanisms include increased appetite and sedation, and altered endocrine function for increased incidence of cardiovascular risk factors.<sup>58</sup> There is a significant body of research investigating causal relationships between behavioral and lifestyle choices and side effects of atypical antipsychotic medications on the physical health of people with psychotic disorders.<sup>59</sup> Since deinstitutionalization, the public health approach to addressing inequity in physical health status for people with severe mental illness has subsequently had an individualized focus.<sup>60</sup>

However, availability of healthy lifestyle and self-management support programs appropriate for people with severe mental illness remains limited in Australia.<sup>61</sup> This is a significant deficit, requiring a committed response not only to achieve recognized integrated best practice care but also to meet Australia's agreed human rights obligations.<sup>62</sup> Stipulations exist within the CRPD for delivery of the same range, quality, and standard of health care for people living with disabilities as is available to all persons, together with additional programs specifically designed for people with disabilities to prevent, where possible, further illness or decline.<sup>63</sup> It appears remiss to endorse prescription of medications, the side-effects of which materially contribute to the occurrence of further life-limiting illness, and fail to provide effective treatment options to counteract the risks.

Globally, there is growing momentum supporting initiatives to improve the physical health

of people with severe mental illness, with particular emphasis on early intervention for youth.<sup>64</sup> In Australia, an example of innovative practice is the "Keeping the Body in Mind" program offered by South Eastern Sydney Local Health District in New South Wales.<sup>65</sup> This multidisciplinary, community-based program is accessible to people with severe mental illness prescribed with antipsychotic medications, with particular emphasis on youth for early intervention prior to onset of chronic illness. The program is individualized through client-centered goal-setting and supports healthy lifestyle and self-management practices, offers tailored education for chronic illness prevention, and access to exercise resources. Although similar programs are offered in some other jurisdictions, this model is not yet broadly available in Australia.

#### *Cultural and environmental factors: Health system structure and function*

Inequality in the experience of physical illness for people with severe mental illness cannot be explained by physical health factors alone.<sup>66</sup> There is increasing empirical evidence identifying systemic obstacles in health services preventing people with severe mental illness from receiving equitable care for physical illness.<sup>67</sup> Physical illness in people with severe mental illness is often undiagnosed and untreated, with high rates of physical co-morbidity and premature mortality believed to be largely preventable through early recognition and appropriate treatment.<sup>68</sup> Investigation of medical management of people with severe mental illness presenting with physical illness reveals reduced rates of medical treatment and hospitalization for physical conditions in comparison with the general population.<sup>69</sup> This is in direct contravention to the rights of people with severe mental illness to access an appropriate standard of health care available to all others.<sup>70</sup>

Enduring separation of mental and physical health services with subsequent role ambiguity and communication inadequacies is an obstacle to the integrated care systems necessary for improved physical health of people with severe mental illness.<sup>71</sup> Furthermore, 'diagnostic overshadowing',

the instance of psychiatric diagnosis detracting from recognition of physical illness, prevents people with severe mental illness from receiving appropriate physical health care.<sup>72</sup> Similarly, an acceptance of poor health of people with severe mental illness among practitioners and incompetence in the management of co-morbid mental and physical illness further contribute to inequitable health in this population.<sup>73</sup> These are further examples of infringements on the rights of people with severe mental illness to receive health care services specifically designed to prevent their experience of additional illness and disability.<sup>74</sup>

Finally, equity of access to, and quality of, available health care services are important social determinants of health.<sup>75</sup> Historic segregation and marginalization of people with severe mental illness impedes health care access today, with suggestion the consistently inequitable distribution of funding resources for mental health is the result of persistent discrimination.<sup>76</sup> Improved collaboration between health and social services is required to reduce physical morbidity and premature mortality for people with severe mental illness.<sup>77</sup> Regrettably, beyond this specific scenario, integrated policy and service delivery has been the focus of considerable debate in Australia and represents a continuing and complex challenge for the health and social domains.<sup>78</sup> Yet the health care sector is well positioned to take a leading role in advocating for the transfer of investments to mental health services, driving multi-sectoral collaboration, and supporting integrated physical and mental health programs to realize the human rights entitlements of people with severe mental illness in Australia.<sup>79</sup>

### *The social experience of health inequity*

The proportion of the Australian population experiencing psychosis is among the most marginalized and vulnerable groups in our society.<sup>80</sup> Socioeconomic disadvantage experienced by this population is extensively documented and clearly entrenched with pervasive social exclusion and stigmatization, lower levels of educational attainment, and high levels of unemployment, poverty, and homelessness.<sup>81</sup> Contemporary research sug-

gests socioeconomic factors which influence the health of the general population act as a microcosm for people with severe mental illness, producing a greater detrimental impact on their health status.<sup>82</sup> These are patent examples of human rights failings at a societal level for people with severe mental illness in Australia and are indicative of inadequate steps to fulfill the right to health for this population.

Additionally, within the academic sphere, empirical literature on the social determinants of physical morbidity and mortality for people with severe mental illness appears weighted with quantitative epidemiological research methodologies, with few prominent examples of studies accentuating lay experiences and knowledge. Research presents an opportunity for lay perspectives to influence future action on social contexts shaping this health inequity; a fundamental element for an empowerment approach to equity. Critical sociological examinations of the mechanisms producing this health inequity are likewise wanting, an oversight given the potential for such an approach to improve effectiveness of health equity policy interventions.<sup>83</sup>

Improving social and economic participation of people with mental illness is a priority action area for the current Roadmap for National Mental Health Reform 2012 – 2022.<sup>84</sup> This plan emphasizes social inclusion strategies, improving multi-sectoral collaboration, and addressing homelessness.<sup>85</sup> However, these same issues have persisted through three decades of human rights enquiries, advocacy campaigns, and mental health strategies.<sup>86</sup> Furthermore, across the disability sector more broadly, there has been acknowledgment of inadequacy and inequity in provision and coordination of services, with recognized impact on the human rights experience for people with disabilities.<sup>87</sup> To move toward addressing these complex issues, the National Disability Insurance Scheme (NDIS) is a new initiative designed to improve equity, accessibility, and choice for provision of disability services, with incremental implementation currently progressing throughout Australia.<sup>88</sup> People with severe mental illness are eligible to access the NDIS and it will be valuable to monitor the impact of this program on their health and human rights experience into the future.

## Conclusion

A contemporary public health perspective incorporates a range of health determinants, providing greater recognition of multiple mechanisms of inequity in the experience of physical illness and premature mortality for people with severe mental illness. However, this understanding has not yet translated to better health and well-being for this population. It could be argued there has been improvement in social participation and quality of life for people with severe mental illness in comparison to an earlier era of institutionalization, and there are notable examples of programs and initiatives nationally to address the physical health needs of this population in Australia. Yet greater recognition of the entitlements and expectations of people with severe mental illness is needed, together with a committed response to confronting physical health inequity and persistent marginalization to advance the human rights agenda for this population in Australia.

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# Cultural Rights and First Nations Health Care in Canada

STEPHEN WILMOT

## Abstract

In this paper, I apply Kymlicka's theory of cultural rights to the health care of Canada's First Nations, within the framework of human rights and the rights of indigenous peoples, as formulated by the United Nations. I extend Kymlicka's concept of cultural rights into a specific right to culturally appropriate health care, and I consider how this right can be categorized. I also explore how far the Canadian state recognizes a right to health care in general and to culturally appropriate health care in particular; and whether it has instituted a statutory or constitutional right in these areas. Finally, I consider the same questions with regard to First Nations health care in British Columbia. My conclusions are that the right to culturally appropriate health care is not recognized nationally, or in British Columbia, and that the potential exists to establish such a right politically.

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## Indigenous cultural rights

This paper focuses on the health care rights of indigenous peoples, and in particular on the bases for a right to culturally appropriate health care for indigenous peoples in Canada. It identifies conceptual scaffolding to support this particular subset of the broader human right to culture, and explores its application in Canada. To that end, it draws on arguments for the right to culture as a human right, and for the right to health care as a statutory or constitutional right.

The UN Universal Declaration of Human Rights states that everyone has the right to participate freely in the cultural life of the community.<sup>1</sup>

The International Covenant on Economic, Social and Cultural Rights (ICESCR) identifies a right to take part in cultural life and notes the obligation of governments to promote this.<sup>2</sup> This is elaborated in General Comment 14 and 21, where indigenous peoples right to culturally appropriate health care and to their specific cultural heritage, respectively, are identified.<sup>3</sup> Also in the UN Declaration of the Rights of Indigenous Peoples (DRIPS), 15 of the 45 articles assert the right to retention, protection, and continued practice of indigenous cultures.<sup>4</sup> Canada is a party to all these documents.

International agreements and treaties can be regarded as bases of human rights, but there is a case for looking behind these and seeking underpinning moral and political arguments to support them, as suggested by Nickel.<sup>5</sup> My agenda is to identify a robust moral argument that can provide support additional to the human rights agenda established by the above instruments, using a different starting point that falls within my competence. Therefore, I aim to identify first principles that are politically sustainable in the Canadian context, to support these rights, and to achieve this, I propose to draw on Will Kymlicka's theory of indigenous cultural rights.<sup>6</sup> Kymlicka is a Canadian political philosopher who over 30 years has developed theoretical analyses of both multiculturalism and the politics of indigenous-colonial relationships. His work is especially relevant to my inquiry in two ways. First, his starting point in terms of political theory is liberalism, with its basic premise in the

value of individual liberty. Liberalism is influential in Canada, and has often been hostile to the idea of collective rights and collective obligations relevant to indigenous rights. Nonetheless, Kymlicka justifies such rights and obligations from first (liberal) principles, providing a parsimonious argument for their existence. He argues that in order for the individual to exercise the autonomy at the heart of liberalism, they need to have an internalized system of values giving meaning to their interests, enabling them to evaluate their available choices. In his view, a "societal culture," with constituent ideas and assumptions encompassing the whole of the daily life of a society, is necessary to facilitate this. Otherwise, individuals cannot be properly autonomous or rational.

Institutions that purport to support individual autonomy (which in liberal democracies would include many state institutions, from law and order to education), should therefore, by virtue of that function, support a societal culture for every individual, and not contribute to the destruction of cultures. Kymlicka argues that it is sometimes justifiable for governments to make specific provision to help minority cultures to survive. Though this may apparently depart from the liberal principle of equality, he argues that the important equality to be pursued is equality of concern (that everyone is equally important), not equality of treatment. If we view everyone as equally important, and their cultural needs are not all the same, it is justified not to treat everyone the same.

His second point of particular relevance is that he views culture as dynamic and interactive with the wider world; he sees cultural communities as capable of choosing to change their cultural values and practices in major ways without losing cultural identity. This dynamic view of culture fits with some other contemporary perspectives in this field, accommodating as it does the cultural significance of colonialism.<sup>7</sup>

Culture is, in Kymlicka's view, a group right; that is, a right that can only be held by a group, not by an individual alone, as a culture must be a group rather than an individual good. Kymlicka sees this right as universal, but threatened in the case of



indigenous minorities who are under pressure to assimilate into dominant settler societies. Involuntary loss of their own culture would be disabling for the exercise of agency by individuals of these communities. The right to culture also has ramifications into the wider political status of indigenous peoples. Kymlicka argues that self-determination is a necessary concomitant to this right, as it is necessary for indigenous peoples to have political freedom to ensure their continued existence as cultural communities.<sup>8</sup>

### Canada's First Nations

In 2016, Canada had a total indigenous population of 1,673,785 (4.9% of the total population), including Inuit, Metis, and First Nations.<sup>9</sup> My paper focuses on First Nations (population 977,230 in 2016). This population, divided into 634 identifiable First Nation communities, has a distinct legal status, reflecting a colonizing agenda first of Britain, then of Canada; this status is embodied in legislation (the "Indian Act"), and in treaties with some individual nations.<sup>10</sup>

First Nations provide an example of an indigenous people whose right to a culture has been compromised, in that they have suffered punishment at various times for living according to their cultures, and the Canadian authorities have attempted to coerce them into cultural assimilation. Canada offers a high level of welfare provision to its citizens, including education and health care, and these provisions have the potential to inflict cultural damage.<sup>11</sup> Notably, residential schools have had a particularly negative effect on many First Nations people over more than a century.<sup>12</sup> However, my concern is health care, where decisions impact on many aspects of living and, according to Kymlicka's principle, should be made within the culture of those affected by the decisions. Where alien cultural values are imposed by the health care system, the cultural rights of indigenous service-users are compromised, and where this harm is imposed consistently, the ability of those affected to live within their culture, and indeed the viability of their culture, are compromised. On this basis, I

am arguing that it is a reasonable extension of the right to culture as argued by Kymlicka, to derive from it a right to cultural appropriateness in those interventions that are an essential part of living. Health care is one of these. My argument seems to be consistent with General Comment 14 (ICSECR) and Article 24 of DRIPS, as they assert a right to cultural appropriateness (paragraph 27 of General Comment 14) and to traditional medicines and social and health services (DRIPS).<sup>13</sup>

Canada's First Nations have cultural perspectives on health and health care that are distinct from Western health perspectives including, among other differences, a framing of health as environmental and communal rather than individual, and a greater emphasis on spirituality in health and health care compared with Western health traditions.<sup>14</sup> So culturally appropriate health care for First Nations is likely to be somewhat different from mainstream health care in Canada. Its content is ultimately for First Nations to decide, but a minimum expectation (in the context of rights I shall argue below) could include, first, personal health care employing the full resources of Western medicine but adapted to the priorities of First Nations; second, investment in public and environmental health reflecting First Nation priorities; and third, support for traditional medicine, accepting that traditional norms concerning the healer's role may require an "arm's length" approach by a publicly funded health care system.<sup>15</sup> There is extensive evidence that health care provided by the Canadian state to First Nations has been experienced as culturally inappropriate.<sup>16</sup> There is also evidence that it is ineffective and inadequate. First Nations have significantly worse health outcomes than other Canadians and though other health determinants probably contribute to this (inferior housing, education, and environmental conditions, as well as poverty and social exclusion), the state's health care provision has failed to counterbalance these problems.<sup>17</sup>

### Categories of rights

I am arguing for a right to culturally appropriate health care for First Nations on the basis of

Kymlicka's argument for cultural rights. But before I consider whether there is any evidence that such a right is recognized or implemented in Canada, I need to clarify the kind of rights involved in this enquiry. Influential definitions of rights, such as those offered by Raz and Dworkin, identify a right as an interest of a person or persons, which is so important to the interest holder(s) that it places a duty on others to accommodate that interest.<sup>18</sup> The claim on the other's duty can be defined as a right, and it overrules competing claims of utility or interest. Rights have been categorized in several ways, but I shall distinguish them on two axes. First, a distinction can be made between human rights and statutory or constitutional rights. Human rights can be judged to exist on the basis of a moral judgment, irrespective of whether that right is recognized by relevant persons or organizations. Indeed, where it is not so recognized, the existence of the human right, declared in a source such as Article 8 of DRIPS, can justify arguing that an equivalent statutory or constitutional right should be created in that state—a principle that can be traced back to Locke.<sup>19</sup> I would argue that Kymlicka's cultural right is a human right, derived from ethico-political argument and not dependent on recognition or provision by any existing persons, organizations, or states. My question is, does Canada translate Kymlicka's human right into an equivalent statutory or constitutional right?

The second distinction is between positive rights and negative rights. A negative right is a right to be left alone, not to be molested. It implies a duty on the part of others to refrain from interfering. A positive right is a right to be provided with something, and usually such a right implies a duty on the part of a specific other to make that provision.

Initially, a positive right to a culture does not seem to make sense. Culture is generated by communities, not normally claimed from a specific other as of right. It seems more appropriate to see the right to culture as a negative right not to have one's culture destroyed or eroded. However, given the close involvement of modern states with the lives of their citizens, including indigenous peoples, and given the centuries of encroachment by

those states upon the lives of indigenous peoples, it is not enough to leave them alone. The right to a culture needs more than benign neglect if it is to be respected in the modern context.

So what is the implication of the right asserted by Kymlicka on the provision of health care in Canada? Does it entail that First Nations have a positive right to culturally appropriate health care provided as a duty by the state, or does it simply entail that nobody should impose culturally inappropriate health care on First Nations; a negative right? If cultural right is negative, it may provide the basis for a right of First Nations to run their own health care, but it does not provide any right to resourcing for this. Canada could respect that negative right by leaving it to First Nations to provide their own private health insurance. But if it is a positive right then this places the Canadian state under a duty to resource culturally appropriate health care.

The key to the negative-positive right distinction is the principle that is the basis of Kymlicka's theory: equality of concern entails different needs justifying different treatment. Kymlicka's argument for the right of indigenous people to have their cultures respected by the state is a liberal argument—that every individual should be equally important to the state, and their interests equally valued; not that every individual should receive identical treatment from the state, as equal importance might involve different treatment. Equality of concern entails that the state, where it provides health care for its citizens, provides equally appropriate health care for all its citizens.<sup>20</sup> So for indigenous peoples, group-based cultural appropriateness is required. And in accordance with the equality principle, the cultural right in the Canadian context looks like a positive right involving a claim on the government to provide culturally appropriate health care. The only exception to this is where cultural appropriateness precludes direct government provision, as in some areas of traditional medicine, requiring a more background level of government support.

I should add here that providing something to which the recipient *has* a right does not in itself constitute providing it *as a right*. The Canadian

state may provide culturally appropriate health care to First Nations as a matter of policy but still not recognize or be bound by the relevant human right, and may not institute any statutory or constitutional right to that same care.

### Existing rights

We return now to my earlier question; is there any evidence that a statutory or constitutional right to culturally appropriate health care is recognized and implemented in Canada? To identify this, we need to look at legislation and official communications expressing the government's commitments and obligations.

Canada has externally recognized the aforementioned right through ratifying the ICESCR, which obliges governments to facilitate culturally appropriate health care. But internally, with regard to implementation, the picture is rather different. Canada's publicly-funded health care system is defined and regulated by the 1984 Canada Health Act, a federal law that allocates functions to the federal government (mostly supervisory and financial) and the provincial governments (managing and delivering). On examination, there seems to be no evidence of a right to culturally appropriate health care in the Act. Nor does the Indian Act contain anything that identifies such a right.<sup>21</sup> Some government documents have actually denied the existence of a legal responsibility on the federal government to provide health care to First Nations at all, at least in terms of treaty obligations. This seems to have been last explicitly stated at government level by the Minister of National Health and Welfare in 1974, but it has never been explicitly reversed.<sup>22</sup> The confusion around this area is described elsewhere, but suffice it to say here that there does not seem to be a firm basis for ascribing a right to culturally appropriate health care to First Nations on the basis of any internal statutory or constitutional obligation acknowledged at the federal level.<sup>23</sup> This disparity with Canada's ICESCR commitment has been noted by several parties, including Amnesty International, which in 2017 presented evidence to the UN Committee on Economic, Social and

Cultural Rights that was strongly critical of Canada's failure to adhere to its obligations under the Convention, with regard to (among other things) indigenous health care.<sup>24</sup> That said, the situation may be changing. Canada voted against DRIPS at the time of its adoption (together with Aotearoa New Zealand, Australia, and the US) and it has been argued that this represents a defensive reaction by colonial states to a questioning of their legitimacy and a potential threat to their economic interests.<sup>25</sup> But federal policy has shifted recently toward implementation of DRIPS, a development that may open the door for recognition of the right to culturally appropriate health care. However, that is as yet unclear.

Looking at other sources of government information, it is written in several places on the Health Canada website that the government intends to provide more appropriate care for First Nations.<sup>26</sup> However, despite several mentions of Canada's accession to the ICESCR on the federal government website, there seems to be nothing in Health Canada's online information that constitutes or implies the acknowledgement of a right to culturally appropriate care, or a duty to provide it. A more explicit commitment to provide culturally appropriate health care to cultural minorities is expressed by the British Columbia government, which stated in 2017, with reference to British Columbian health care regulators that "23 health regulatory bodies declared their commitment to making the health system more culturally safe for First Nations and Aboriginal People". However, that undertaking likewise includes no mention of a right to such care.<sup>27</sup>

It is worth asking at this point whether the Canadian state recognizes and implements a right to health care for citizens and residents in general. If it did, and combined this with recognition and implementation of Kymlicka's equality of concern principle in some form, we might take this as implying a right to culturally appropriate health care. And recognition of this general right seems to be indicated by the fact that Canada is a signatory to the Universal Declaration of Human Rights, which includes the right to health—a right that the ICE-

SCR interprets as requiring significant government obligation.<sup>28</sup> However, internally, in terms of implementation of such a right into statute, there is no consensus as to whether a statutory right to health care exists for Canadians. It is true that for many years health care has been widely regarded as a right of Canadian citizenship, a view echoed in the Romanow Report, but this has not translated clearly into a statutory right; Bhatia argues that since the 1990s, governments have recoiled from the idea of a social right to health care.<sup>29</sup> The Canada Health Act is ambiguous on the question of rights, stating that each province's health care insurance plan "must entitle" all insured persons in the province to health services provided on uniform terms.<sup>30</sup> The use of the term "entitle" is the nearest the Act comes to acknowledging rights, and in its 2002 report, the Standing Senate Committee on Social Affairs, Science, and Technology argued that the existence of a statutory right cannot be read into this or into any other statute or constitutional provision.<sup>31</sup> Court-recognized legal rights relating to health care have generally been limited to negative rights to particular courses of action, such as purchasing private health care.<sup>32</sup>

What about the above-mentioned principle of equal concern? This accords with Canada's liberal tradition and is echoed in the Charter of Rights and Freedoms, which states that citizens hold their rights equally, and ordains equality under the law.<sup>33</sup> However, equality in relation to state welfare provision (including health care) seems to have been interpreted in a limited way by the courts. For instance, although section 15 of the charter has been interpreted as being anti-discriminatory in preventing the exclusion of particular disadvantaged groups from state provision, the courts have not as yet interpreted it as warranting redistributive resourcing of the kind that would be needed for culturally appropriate health care for First Nations.<sup>34</sup> And although the Canada Health Act refers to "uniform terms" in relation to the principle of universality, this uniformity is ambiguous, perhaps requiring only the same kind of health care to be available to everyone, not necessarily the same

quality of health care (which would require cultural appropriateness).<sup>35</sup>

Finally, in this section, I shall look for rights derivable from duties. There is a tradition in moral philosophy that certain kinds of rights and duties correlate. Duties are often inferred from rights, but it has been argued by a number of writers that in some cases, rights can be inferred from duties.<sup>36</sup> The idea of welfare rights as a subcategory of positive rights rests upon this argument, in that a state that accepts a formal duty to specific others to make a specific provision to them (typically through legislation) is effectively conferring a right on those recipients. A statutory or constitutional duty on the part of the Canadian state to its citizens to provide them with health care could be taken as creating this kind of right, on the part of those citizens, to that health care provision. But again, that duty, though referred to at the political and administrative level, does not appear to have been instituted in statute, or in the constitution, despite the duties that are identified in the ICESCR.<sup>37</sup>

So, my conclusion is that though the Canadian state has externally recognized a human right to culturally appropriate health care, it has not clearly instituted such a right at a statutory or constitutional level.

### British Columbia's Tripartite Initiative

The second part of my inquiry concerns the degree to which a specific development in First Nations health care might change the situation with regard to cultural rights in Canada. Historically, First Nations health care has been provided by the federal government, but there has been movement since the 1980s toward giving First Nations more control over their own health care. Under the health transfer policy, various health services in different parts of Canada have been given to First Nation organizations.<sup>38</sup> This has been a piecemeal and uneven process, but substantial progress has been made in some areas. I propose to consider one of these initiatives, and ask whether it constitutes implementation of the right to culturally appropriate

health care.

2005 saw the inception of the Tripartite Initiative, a collaboration by the federal government, the British Columbia government, and British Columbia's First Nations, intended to develop a comprehensive First Nations health care system. This consists of a network of First Nation-based organizations, including the First Nations Health Authority (hereinafter the FNHA) as First Nations health care provider and, in some cases, funder.<sup>39</sup> In 2013, as part of this initiative, the FNHA began to take over specific health care provisions from the federal agency which had hitherto been the main provider, a process that is ongoing.<sup>40</sup> The FNHA has varying degrees of accountability to First Nation representative bodies and to the provincial and federal governments, the latter two being the paymasters of the system. It was created in part to provide culturally appropriate health care, so I want to consider specifically whether its creation realizes First Nation cultural rights.

The founding document of the Tripartite Initiative is the Tripartite Framework Agreement, and a number of documents including further agreements, annual reports, updates and plans have followed.<sup>41</sup> These give an evidently authoritative account of the intentions, commitments, and principles that the participants are working toward, so any positive statutory or constitutional right to culturally appropriate health care is likely referenced here. And there is in fact no mention of such a right by any of the parties, jointly or separately. Other rights are mentioned in several places, including patients rights, First Nations rights to self-determination, and DRIPS. The possibility of a charter of rights for First Nations health is mentioned. But the right to health care, and the right to culturally appropriate health care, are absent.

As already discussed, rights might also be identified in the existence and acknowledgement of duties. The federal government has not acknowledged any formal duty to provide health care to First Nations, arguing that its provision over the decades has been motivated by humanitarian considerations. However, the FNHA's takeover of these

provisions is an opportunity for it to accept that previously denied duty. But how might a duty ascribable to the FNHA create a corresponding right for its First Nations service users? For a FNHA duty to entail a First Nations right, the FNHA would need to owe its duty to First Nation users themselves, directly or through some other body. It is not enough for First Nations to be beneficiaries of a duty owed to someone else. The duty must be to them. The relationship needs to be such that the FNHA's purpose, as an organization, is to act in accordance with First Nation choices, and this requires that the FNHA exists and acts for the benefit of First Nation users. Insofar as that requirement is met, First Nations could be said to have a positive right to the FNHA's provision.

The FNHA has no representative structure of its own through which such a relationship with its First Nation service users could be structured. The body that aims to represent British Columbia First Nations in the Tripartite Initiative is the First Nations Health Council, one of the partners in the tripartite agreement. This body was instrumental in the negotiations with the federal and provincial governments in 2008–11, before the creation of the FNHA. It has a partly political, partly representative role and includes representatives of First Nation communities across British Columbia, with a remit that centers on representation and negotiation. It is the obvious candidate to enable British Columbia First Nations to hold the FNHA accountable for its provision. Given appropriate powers, it could act on the behalf of the First Nations it represents, to oversee the FNHA and hold it accountable on their behalf.

The documentation produced by the bodies involved in the Tripartite Initiative does not discuss in any detail questions of duty or responsibility in the relationships between the participating bodies. But they do discuss accountability, so it is worth noting the relationship between the concepts of duty and accountability. Duty is generally understood to involve an obligation to act in a certain way, either generally or toward certain others to whom the duty is owed. Where that action involves some kind of provision, those to whom the duty

is owed may or may not also be recipients of the provision. Where the duty is owed to the recipient, this could be seen as conferring a right on that recipient, as discussed above. Accountability, the requirement to account for one's actions (usually to another specified party), is logically distinct from duty, but in many situations the two relationships reinforce one another.

The FNHA's relationships of accountability connect it to the First Nations Health Council (FNHC) and also to the provincial and federal governments. But a close study of the documents defining these relationships makes it clear that explicit acknowledgement of a conventional chain of accountability and obligation have been avoided, and instead an alternative model has been used to define the relationships between these bodies. The concept of "reciprocal accountability" is presented in the documents as an important principle defining their organizational relationships, through which bodies can hold one another accountable for specific activities, in a negotiated way.<sup>42</sup> The emphasis here is clearly on what we may call "transactional" relationships, created between parties on the basis of agreements; as against what might be termed "structural" relationships, which fix organizations in a one-way chain of accountability ending formally (in the case of democratic government) with the electorate. The transactional emphasis clearly has advantages, but it creates difficulty in finding clear lines of accountability, a difficulty identified by Dwyer et al in their overview of health care contracting for indigenous peoples.<sup>43</sup> The relationships are not specified precisely enough to connect the FNHA, the FNHC, and the user population in a way that permits ascription of duty.

If the FNHA is anyone's agent within the tripartite system, it is probably that of the federal and provincial governments. They finance the FNHA.<sup>44</sup> It is spending money for which the governments are accountable to their electorates, so in real terms, the FNHA is answerable to these governments for that expenditure. Again, the language of reciprocal accountability softens this, but in the absence of other clear indices of accountability, it

generally tends to revert to the paymasters. It begins to look as if the rights that are being implemented by the creation of the FNHA are those of the federal and provincial governments, not First Nations.

## Rights at the political level

A further possibility remains. As mentioned previously, rights exist at several levels, and statutory and constitutional rights are not the only ones that are relevant. Clearly, in many cases human rights are not enforceable in the same way as rights codified in the statutes or constitutions of individual states, but nonetheless have some legal and/or political force. Those codified by the UN have force insofar as the UN has leverage through its own agencies and through international law.<sup>45</sup> And there are other kinds of leverage that can commit governments to respect rights that are not codified in statute or constitution. Agreements between governments and other bodies can do this, and the degree of commitment to the rights involved will depend on how binding those agreements are.

Moving to the political level allows us to look again at the relationships between the FNHA and the other bodies in the Tripartite Framework Agreement. If we leave aside their documented definitions of accountability and focus on the general relations of governance, we see collaboration of governments and non-governmental bodies, operating as partners, and committed to an enterprise that could span several decades. As a framework for this particular kind of enterprise, I propose to introduce an additional concept, that of multi-level governance. Multi-level governance was developed in the 2000s as a model of governance less bound by traditional political and administrative structures, focusing on negotiated collaboration by bodies at different levels in the formal structure.<sup>46</sup> It has been applied to governance involving indigenous peoples in several countries, not least because it circumvents political dominance of indigenous bodies by settler states.<sup>47</sup> Inequality of power is de-emphasized in favor of cooperation and negotiation. What I termed above "transactional" accountability, based prag-

matically on negotiation, better characterizes this situation than the “structural” accountability (my term again) of traditional government structures.

One of the virtues of multi-level governance is that it allows flexibility and mutuality in dealings between agencies at different levels. The lack of formal, exclusive lines of accountability opens the way for political relationships of de facto accountability and duty, which are mutually reinforcing, and allow a shared perception of duties that are not legally codified but command political acceptance. On past performance, federal and provincial governments preferred to avoid codification of health care rights for First Nations, but they may be persuaded to tacitly accept a de facto duty, which the FNHA owes to First Nation service-users. But by what arrangement might such a duty be established at the political level, in such a way that it establishes a right on the part of First Nations to culturally appropriate care? As stated above, there is no mechanism for First Nations people to directly hold the FNHA accountable, even less to bind it to a duty to them. There is no representative mechanism, in particular, in the running of the FNHA. However, the FNHC, a partly representative body, has a relationship with the FNHA that already includes elements of accountability in the “reciprocal accountability” format. Those could be firmed up and extended, at a negotiated political level, to create a stronger relationship of obligation. This relationship could allow the FNHC to hold the FNHA not only accountable to itself, but duty-bound to the population which it represents. The ability of the federal and provincial governments to tolerate this development would need to be stretched short of breaking point, and that would require very fine political judgment on the part of the FNHC and the FNHA, particularly in establishing the delicate phrasing that would establish the FNHA duty in practice, but not explicitly enough to evoke resistance from the governments. If this proves politically feasible in practice, and the FNHA and the First Nation population can accept their respective ends of the chain of accountability passing through the FNHC, then we have the structural components necessary for the establishment

of a political right to culturally appropriate health care on the part of British Columbia’s First Nations.

## Conclusion

The Tripartite Framework Agreement on First Nations health care provision in British Columbia was created partly in response to a perceived need for culturally appropriate health care. I have argued that a right to such health care was not built into the agreement. This is partly because Canada’s health care system does not clearly provide for health care as a right in general, and partly because the tripartite system (probably as a consequence of the general Canadian situation) does not offer culturally appropriate health care as a right, in particular. So Kymlicka’s argument for indigenous cultural rights has not been realized in this case; nor has my argued human right to culturally appropriate health care. However, I have suggested that by mobilizing the flexibility of multi-level governance, and aligning rights and duties, the right to culturally appropriate health care can be realized at a political level. It is clear that the establishment of that right in rules, practice, and discourse, against the established habits of Canada’s political class, will take time, and it will involve the application of political arts over that time. But if First Nations leaders in British Columbia are willing and able to pursue this, a major precedent could be set for Canada in the advancement of indigenous rights.

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## PERSPECTIVE

# Adolescent Rights and the “First 1,000 days” Global Nutrition Movement: A View from Guatemala

DAVID FLOOD, ANITA CHARY, ALEJANDRA COLOM, AND PETER ROHLOFF

The field of global nutrition has coalesced around the “first 1,000 days” concept, which prioritizes pregnancy and the first two years of life as a critical window to improve child health and development. In this Perspective, we explore the child-centric orientation of 1,000 days programs, with particular emphasis on its implications for young mothers. Using Guatemala as a case study, we argue that 1,000 days interventions may view adolescent mothers as a means to improve child health, rather than as children themselves who have a right to nurturing protection. We conclude by offering a framework that connects the first 1,000 days to the complementary global movement to advance adolescent rights and reduce child marriage.

### The first 1,000 days

The “first 1,000 days” is a conceptualization of child nutrition that has evolved into international policy consensus. The science underpinning the 1,000 days was propelled forward by the 2008 *Lancet* series on maternal and child undernutrition, which showed that the period from fetal conception to a child’s second birthday is a “golden interval” to improve nutrition and development.<sup>1</sup>

The *Lancet* series provoked a vigorous response from international institutions, development organizations, and the private sector to scale up global nutrition interventions during the 1,000 days window. These efforts included the 2010 launch of the Scaling Up Nutrition (SUN) coalition.<sup>2</sup> SUN emphasizes four main elements: securing support at the country level, implementing evidence-based and cost-effective interventions, integrating nutrition with other social programs, and increasing global nutrition aid. More than 50 countries have joined SUN since its inception.

By definition, SUN focuses on the well-being of fetuses and young children, but pregnant women and mothers are incorporated into the 1,000 days rubric through “nutrition-sensitive” and “nutrition-specific” interventions.<sup>3</sup> Examples of nutrition-sensitive maternal interventions include parenting support; conditional

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cash transfers; family planning; and water, sanitation, and hygiene (WASH) programs. Examples of nutrition-specific maternal interventions include nutrition in pregnancy; micronutrient supplementation; breastfeeding promotion; and complementary feeding education.

Since the early 20<sup>th</sup> century, global health policy has oscillated between twin philosophies of the delivery of narrow, top-down technical programs and more integrated models that emphasize equity and community participation.<sup>4</sup> Global child health has followed a similar trajectory, including the role of UNICEF's disease control efforts after the Second World War, the rise of the primary health care movement as expressed at Alma-Ata, and the swing back towards the child-centric interventions of selective primary care such as GOBI (growth monitoring, oral rehydration, breastfeeding, and immunizations).<sup>5</sup> The child-oriented focus of SUN should be viewed through a history that—with certain exceptions such as the United Nations Decade for Women from 1976-1985, which overlapped with Alma-Ata—has tended to view women primarily through a reproductive, technically oriented lens.<sup>6</sup> In Guatemala and elsewhere, SUN is thus the most recent development in a history of infant and young child nutrition that has tended to pay limited attention to the rights of girls and women.

### The first 1,000 days movement in Guatemala

Given its very high rate of child stunting and its history as a research setting for many foundational studies on early life nutrition, Guatemala was a compelling setting in which to scale up 1,000 days-aligned programs. In December 2010, the Central American nation of 16 million people became one of the first countries to join SUN formally.

In 2012, the SUN framework was officially integrated into Guatemala's nutrition policy with the release of then-President Otto Perez Molina's "Zero Hunger Plan."<sup>7</sup> A complementary private-sector organization emphasizing the economic repercussions of child malnutrition, the Alliance for

Malnutrition, was also formed. Founding members of the Alliance for Nutrition included the foundations of prominent Guatemala businesses (including the best-known beer brand and fast-food chain), the social responsibility arms of major industry trade associations (including sugar, coffee, and non-traditional export sectors), and the country's powerful business association.<sup>8</sup> While the global SUN movement has attempted to address conflict of interest concerns, there has been limited critical analysis in Guatemala of the private sector's role in shaping government nutrition policy.<sup>9</sup> An example of such influence is that the former head of the Presidential Commission for the Reduction of Chronic Malnutrition has close family and business ties to the sugar industry.<sup>10</sup>

Guatemala's current president, Jimmy Morales, renewed essential elements of the Zero Hunger Plan for 2016–2020. An independent evaluation of the SUN movement in 2015 singled out Guatemala as a country that had made significant political progress in addressing malnutrition due to SUN's influence.<sup>11</sup> Overall, stunting rates have improved in recent years but remain among the highest in the world.<sup>12</sup>

The authors of this Perspective have experience in rural areas of Guatemala implementing nutrition programs, carrying out anthropologic studies of child malnutrition, and working to foster women's rights. We previously have critiqued 1,000 days programs in Guatemala for envisioning women primarily as instruments to deliver nutrients and services to their infants.<sup>13</sup> This mother-centric view of women manifests in several ways.

First, the 1,000 days interventions highlighted in Guatemala—breastfeeding promotion, complementary feeding education, micronutrients in pregnancy, growth monitoring, WASH, and others—engage women solely in their reproductive and child-rearing roles. Founding documents of the Zero Hunger Plan paid limited attention to gender-based topics like sex education, reproductive rights, general women's health, adolescent pregnancy, or child marriage. The most recent national Strategic Plan for Food Security and Nutrition (PE-

SAN) describes maternal age as a risk factor for chronic malnutrition and calls for increased reproductive health services; however, there is no integration between PESAN and the National Plan to Prevent Adolescent Pregnancies (PLANEA).<sup>14</sup>

Second, the implementation of the Zero Hunger Plan has been complicated by political scandals, fiscal deficits, and discrepancies between actual and planned nutrition spending.<sup>15</sup> Services and products pledged under the 1,000 days rubric and related social programs, such as conditional cash transfer mechanisms, are not always available on the ground.<sup>16</sup> In practice, rural Guatemalan mothers who wish to receive highly desirable resources such as complementary foods and cash transfers are typically required to fulfill laborious prerequisites such as attendance at prenatal visits, participation in growth monitoring campaigns, and completion of child vaccinations.

Third, the high-level support of the 1,000 days agenda influences the priorities of the public health system, which already suffers from chronic underfunding and allegations of abuse toward rural and indigenous people. As an example, in some areas, women or girls who present to health care facilities are only attended if they are pregnant.<sup>17</sup>

Finally, in our experience, maternal education, the core of many 1,000 days interventions, can be insensitive and impractical. Mothers are often scolded and blamed if their child's growth is suboptimal. Nutrition workers may demand that mothers breastfeed more, preferentially invest scarce family resources to nourish younger children over older children, and buy more expensive food. Such educational messages belie the realities of rural mothers: that breastfeeding is physically and emotionally exhausting, that they often lack power to make family food purchasing decisions, and that meeting dietary minimums is not possible in many situations.<sup>18</sup>

In summary, in rural Guatemala, 1,000 days programs make onerous demands on the lives and bodies of very poor and vulnerable mothers for the benefit of their children. Complicating matters, these mothers themselves are often children.

## Adolescent health, marriage, and pregnancy

The mother-centric view of 1,000 days nutrition programs in Guatemala fails adolescent girls by overlooking the commonplace nature of adolescent pregnancies, by asking that adolescent mothers subsume their rights and privileges as children for their infants, by perpetuating the notion that motherhood is voluntary, and by minimizing the immense consequences of adolescent mothering on the mother herself.

Adolescent marriage and pregnancy are common in Guatemala. A 2015 national survey reported that 19.8% of girls aged 17 years had given birth or were pregnant.<sup>19</sup> In the first six months of 2017, there were nearly 17,000 births to girls under 18 years of age; approximately 1,100 births were to girls aged 14 or younger.<sup>20</sup> Recent Guatemalan law prohibits marriage before age 18 without exceptions, but de facto unions are likely to continue for some time.

The underlying causes of adolescent unions and pregnancies in Guatemala are multifactorial and include limited access to sexual education, poverty, and entrenched cultural practices.<sup>21</sup> Sexual violence against girls and women plays a central role in Guatemalan history, continues to be highly prevalent, and is a well-defined pathway to adolescent pregnancy.<sup>22</sup>

In Guatemala and other low- and middle-income countries (LMICs), adolescent marriage and pregnancies are associated with negative effects for both child and mother. Short-term health outcomes include higher rates of preterm birth, maternal mortality, and neonatal mortality.<sup>23</sup> In the long term, children born to adolescent mothers are more likely to be stunted, leading to shorter stature, worse educational attainment, and risk of adult-onset chronic diseases.<sup>24</sup>

The impact of adolescent unions and pregnancies on long-term outcomes for girls are less established, but evidence points to worse physical and mental health, higher risk of violence, and increased school dropout.<sup>25</sup> Adolescent girls stop growing when they become pregnant, so an ado-

lescent pregnancy confers stunting risk on two children: mother and infant.<sup>26</sup> According to the Global Burden of Disease Study, maternal disorders are one of the most frequent causes of death in teenage girls.<sup>27</sup>

## A global movement for adolescents

Historically, adolescents have been a neglected population within global health. However, there has been a recent groundswell of support for adolescent health, as epitomized by the inclusion of adolescents within the UN Secretary General's "Every Woman, Every Child" global strategy and the publication of the Lancet commission on adolescent health and wellbeing in 2016.<sup>28</sup> Adolescent health has emerged as a global health priority due to increased understanding of the role of adolescence within the multi-generational life course, new evidence pointing to the benefits of adolescent health investments, and the success of civil advocacy groups such as Girls Not Brides and the Population Council.

A rights-based discourse has been central to the rise of the global adolescent agenda.<sup>29</sup> As *Lancet* editorialists write, "Wouldn't interventions that protect the basic human rights of adolescents be justifiable even if the benefit-to-cost ratios were less favourable?"<sup>30</sup> At the international level, a UN General Comment in 2016 on the Convention on the Rights of the Child was a powerful articulation of adolescent rights.<sup>31</sup> This Comment affirmed that adolescents, especially adolescent girls, are a vulnerable population requiring special protection; at the same time, they are persons with evolving capacities who have a right to influence decisions affecting their lives. At the country level, however, legal frameworks often fail to live up to the principles of the CRC.<sup>32</sup>

## Toward an adolescent rights-oriented "first 1,000 days"

Since 2015, when we first wrote about the subordination of adolescent mothers within 1,000 days nutrition programs in Guatemala, we have witnessed the ascent of adolescent health—including

adolescent sexual and reproductive rights—as a priority issue on the global stage.

This is a breakthrough. Even in settings where health and development resources are scarce, like in Guatemala, adolescent rights and child nutrition priorities are not necessarily in competition with each other. Scientific and human rights frameworks alike make evident the synergistic and complementary nature of child nutrition and adolescent efforts.

In our own work designing health programs and advocating for adolescent rights in Guatemala, we continue to ask ourselves what an adolescent rights-oriented "first 1,000 days" might look like in practice.

We support public and civil society actions to reduce child marriage and child unions. Such actions include enforcing existing child marriage laws, improving sexual education, and expanding access to quality reproductive health services for adolescents. For example, one of the authors directs *Abriendo Oportunidades* ("Opening Opportunities"), a group-based mentoring program for indigenous adolescent girls fostering community safety, knowledge of rights, and education. Program mentors, who come from the same communities as the girls they serve, work to help girls to exercise their rights and to challenge cultural norms that remain mother-centric.<sup>33</sup>

We believe that national planning bodies for the prevention of child nutrition and adolescent pregnancy should coordinate strategies. We also urge policymakers to take a comprehensive vision of adolescent nutrition that includes not only undernutrition in pregnant or prospective mothers, but also prevention of obesity. In Guatemala, the "double burden of malnutrition," consisting of the co-existence of both child stunting and female obesity is common and leads to a disproportionate burden of disease and disability for women.<sup>34</sup>

We call for innovative programs to help adolescent girls who are pregnant or have children. This is a vulnerable population that merits special consideration in their dual roles as children and mothers. While programs targeting adolescent mothers and their children are not commonly described in LMICs, one intervention that has at-

tracted our attention are home-based care models for young mothers. Such programs, including the Nurse Family Partnership and Minding the Baby, have proven effective in the US.<sup>35</sup> Indeed, one group is adapting such a program to poor and urban districts in São Paulo, Brazil.<sup>36</sup>

More broadly, we encourage further reflection on the implications of first 1,000 days policies on the lives of mothers, older children, and men. Aside from the work of a few scholars, there have been limited critical appraisals of this movement and its scientific underpinnings.<sup>37</sup> The fields of anthropology, ethics, and human rights have much to offer in fostering a more comprehensive and inclusive first 1000 days.

### Postscript

As we finished drafting this Perspective, another political scandal racked Guatemala. Just two years after then-President Otto Perez Molina was arrested on corruption charges, an investigation into current President Jimmy Morales was opened for campaign finance abuses. The allegations led the Minister of Health, Lucrecia Hernández Mack, and her top deputies, to resign in protest. Massive street protests broke out after Congress voted to preserve Morales's immunity and to abrogate penalties for campaign finance crimes. In this explosive political climate, it is difficult to imagine the enactment of a robust national plan to foster adolescent rights. Yet the faces of so many young people in the crowds of peaceful protestors gives us hope of a future Guatemala that is fairer and more just. We remain optimistic that a health system premised on the rights of both young children and adolescent girls can be part of that future.

### Competing interests

In the course of their professional responsibilities, the authors occasionally solicit funding to implement health programs for children and adolescents in Guatemala. Peter Rohloff has received support from Grand Challenges Canada, the National Institutes of Health, and the Charles Hood Foundation.

Alejandra Colom is employed by the Population Council and the Universidad del Valle de Guatemala. David Flood, Anita Chary, and Peter Rohloff carry out child health programming and research with Wuqu' Kawoq in Guatemala. We declare that we have no other competing interests.

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