

## 10. Communicable Diseases, Health Security, and Human Rights: From AIDS to Ebola

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This chapter examines the influence of human rights in the quest to control communicable diseases. Communicable diseases are emerging and spreading faster than ever before, with devastating consequences for the most vulnerable in a rapidly globalizing world. Human rights have come to frame infectious disease control, beginning in the early response to AIDS and expanding from the stigmatization of marginalized populations to include the provision of essential medicines. Human rights claims have correspondingly expanded, arising out of norms of non-discrimination, consent, and privacy and now including the right to health. As individual rights compete with state authority, WHO's International Health Regulations (2005) aim to guide states in a rights-based response to communicable disease. However, as seen in recent Ebola outbreaks, human rights have lost priority to health security as the dominant frame for health policy, and this securitization of disease control may undermine the gains of human rights, risking the future of global health.

Keywords: communicable diseases; stigma; HIV/AIDS; World Health Organization; International Health Regulations (IHR); health security; Ebola; anti-microbial resistance (AMR)

Communicable (or infectious) diseases spread across populations through close physical contact with animals or people, such as through fecal or oral transmission, through sexual intercourse, and through the air or contaminated surfaces. These diseases—including HIV, cholera, Severe Acute Respiratory Syndrome (SARS), swine flu, tuberculosis (TB), and yellow fever—remain one of the biggest challenges to global health. Although many

communicable diseases threaten the entire world—through globalized air travel, increasingly porous borders, and mass movements of people and goods—low-income countries in the Global South still bear the disproportionate burden of these diseases. Even as new diseases are rapidly emerging, longstanding “neglected diseases” such as lymphatic filariasis, hookworm diseases, trachoma, trypanosomiasis (sleeping sickness), and dengue continue to harm the poorest and most vulnerable in the Global South. Government attempts to contain these diseases can either infringe or realize human rights, and as a consequence, human rights must be considered in framing infectious disease prevention, detection, and response.

There are three main approaches to addressing communicable diseases: a public health approach, a human rights approach, and increasingly, a securitized approach. Traditionally, the public health model focused on controlling those suffering from communicable diseases in order to protect the larger population. Grounded in scientific evidence and epidemiologic understanding, this approach sought to contain diseases at the expense of individual rights, often allowing for compulsory screening, isolation, and treatment. However, the early HIV/AIDS response raised serious questions about the public health efficacy of this approach: those whose rights were violated experienced stigma and discrimination, leaving them marginalized and thus more vulnerable to HIV. Where coercive attempts to protect public health drove people underground, it became evident that health and human rights were inextricably linked. Yet, despite the development of a rights-based approach to infectious disease control, protecting individual rights to promote public health, there has been a resurgence of a securitized approach to infectious disease. With many countries fearing that highly infectious diseases in a globalizing world can threaten the very existence of the state, the securitization of public health poses a threat to the continuing realization of human rights.

This chapter examines the role of human rights in responding to communicable diseases. Part I looks back on the ways in which human rights activists used the exceptionalism of AIDS to fundamentally question how public health authorities respond to communicable diseases, raising human rights claims to prevent discrimination and mainstreaming rights-based governance for HIV prevention. Looking beyond this rights-based approach to HIV prevention, Part II examines how human rights address questions about access to essential medicines, consider other diseases such as TB, and shape global infectious disease governance. Although human rights have enormous potential to shape global health governance, a return to a “health security” framing has curtailed the use of human rights in responding to communicable diseases, and Part III examines how this securitization of infectious disease has undercut human rights in responding to rising disease threats such as Zika, Ebola, and anti-microbial resistance (AMR). This chapter concludes that a human rights approach that espouses dignity of the individual—in support of those from marginalized groups, in increased financing for treatments, and through underlying determinants of health—will be critical in responding to present and future responses to infectious disease.

#### <1> I. AIDS Exceptionalism and the Emergence of a Rights-Based Approach to HIV

The discipline of health and human rights developed out of the impact of the HIV/AIDS pandemic, which remains one of the most devastating global health crises of all time. Where HIV is transmitted in bodily fluids—through sexual intercourse, contaminated needles, blood transfusions, and from infected mothers to children (either in utero or through breastmilk)—the nature of the disease has put several key populations at particular risk: women, infants, sex workers, prisoners, migrants, people who inject drugs, men who have sex with men, and transgender people. These groups are often already poor, marginalized,

and at risk of discrimination; contracting HIV exacerbates these harms. Although huge strides have been made in responding to HIV, the AIDS pandemic remains exceptional due to the scale of morbidity and mortality, mode of disease transmission, effects on economic growth, elusiveness of a clinical cure, and social impact left in its wake. Where states responded to this unprecedented threat using public health approaches that violated individual rights, this public health response catalyzed the operationalization of human rights in global health – leading to advocacy that questioned discrimination against marginalized groups, campaigns for access to medicines to realize the right to health, and global health governance financing mechanisms for poorer countries to strengthen health systems.

#### <2> A. Human Rights Violations in the AIDS Response

The disproportionate impact of AIDS on marginalized groups led to an increase in discrimination through social stigmatization, in which many early AIDS sufferers, often sexual minorities, were accused of being “sinners” and blamed for their suffering. In the early days of the AIDS response, as introduced in chapter 4, many countries criminalized same sex relationships and sex work, introduced offenses for people who spread HIV, and ostracized vulnerable populations (Gruskin, Mills, and Tarantola 2007). At the time, the management of disease outbreaks relied on exercising authority over those people who were sick in order to contain the outbreak, and public health tools such as surveillance, quarantine, and isolation were often employed to protect the general population – without regard for the rights of individuals (Stemple 2008).

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*Case Study: Quarantine and Isolation as a Human Rights Violation*

Quarantine and isolation, screening and surveillance, testing, and compulsory treatment have traditionally been a mainstay of state public health responses to the spread of disease. In the past, quarantines have been used to protect populations from a variety of diseases, including smallpox, leprosy, syphilis, yellow fever, diphtheria, and TB. Historically, these disease control responses were framed as a matter of security, justifying unconstrained government action to protect public health. Since World War II and the birth of human rights under international law, this framing has been balanced against human rights imperatives, including privacy, self-determination, and freedom from physical coercion. In the early days of the AIDS pandemic, however, there were calls by policymakers to quarantine people with HIV in order to stem the spread of the disease. These calls were implemented through discriminatory public health policy – ranging from refusing HIV-positive people entry into countries, as then seen in the United States and Japan, to quarantining all HIV-positive people in order to move them to government health facilities where they would live separate from the rest of the population. Yet, isolating those with HIV was seen as a breach of human rights. As HIV is not contagious by touching or kissing, is not airborne, and cannot be spread by living in close proximity, such quarantine policies were epidemiologically unnecessary, overly restrictive, and violative of human rights. These quarantines most often targeted people from ethnic minorities, lower classes, and marginalized groups, perpetuating inequalities and stigma, and undercutting public health efforts. Poorly executed quarantine policies for HIV/AIDS did not curb the spread of disease and merely led to stigmatization of vulnerable populations and fear within at-risk groups, which prevented them from engaging with health education, early testing, and treatment.

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Advocates of vulnerable populations challenged these government responses, as described in chapter 6, and a health and human rights movement was born. Using the methods of the US civil rights movement—which had fought against discrimination on the grounds of race, religion, gender, and other categories—AIDS activists sought to provide both practical support and advocacy for those in need (Stoddard and Rieman 1990). Armed with scientific studies that clearly dispelled the fear that HIV could be spread through touching or kissing, advocates pushed for recognition that discrimination in employment and housing or through compulsory testing and compulsory quarantine would be contrary to civil liberties (Gostin, Curran, and Clark 1987). This advocacy led to an increasing awareness that state coercion was not the way forward in responding to the AIDS pandemic, providing an opening to look to human rights in the World Health Organization (WHO).

## <2> B. WHO Embraces Human Rights in the AIDS Response

In the absence of a treatment or cure for HIV, Jonathan Mann, Director of the WHO's Global Programme on AIDS (GPA), argued that a response to HIV/AIDS would need to combine public health, ethics, and human rights. He argued that the AIDS epidemic consisted of three “distinct yet intertwined” epidemics: infection, illness, and the “social, cultural, economic and political reaction to AIDS” (Mann 1988, 131). This led to recognition within WHO that health and human rights were “inextricably linked” in the AIDS response (Meier, Brugh, and Halima 2012). In 1987, when Mann briefed the UN General Assembly on the AIDS pandemic, the first time the UN General Assembly had ever focused on a disease, he called for the abolition of repressive public health policies, such as mandatory HIV testing and quarantine (Gostin and Lazzarini 1997). The GPA's attention to human

rights had a crucial normative influence on WHO's response to the AIDS pandemic, and in May 1988, the World Health Assembly officially adopted a policy of non-discrimination.

This focus on human rights became embedded in the AIDS response with the 1994 creation of UNAIDS, with this new UN program recognizing that human rights are integral to responding to the AIDS pandemic.<sup>1</sup> Drawing from past advocacy in this rights-based response, the 1994 Paris Declaration on Greater Involvement of People Living with HIV/AIDS sought to form a multi-sectoral response that included individuals who lived with HIV/AIDS as well as civil society organizations (Nygren-Krug 2018). UNAIDS thereafter collaborated with states and the UN High Commissioner for Human Rights to develop the 1998 International Guidelines on HIV/AIDS and Human Rights, which focused on the relationship between vulnerability and human rights. These collaborations enabled UNAIDS to address its initiatives toward key populations whose human rights had been violated, including gay men, sex workers, transgender people, and people who inject drugs – based on the recognition that HIV/AIDS disproportionately affected already marginalized, stigmatized, and even criminalized groups across populations (UNAIDS 2015).

In articulating these health-related human rights in 2000, the UN Committee on Economic, Social and Cultural Rights (CESCR) issued General Comment 14, as first introduced in chapter 3, which attempted to interpret for states what the right to health means in communicable disease practice. The CESCR focused on how education could help in preventing diseases (specifically including AIDS), emphasized the avoidance of

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<sup>1</sup> UNAIDS was established as a coordinating program in order to bring together the work of several UN organizations working on AIDS. From its inception, human rights-based approaches were integral to its mandate, and it has consistently engaged with human rights issues through its unique governance structure, which includes civil society representation and participation (Nygren-Krug 2018). Despite this rights-enabling structure and efforts to evaluate state efforts to realize rights in the AIDS response, UNAIDS has come to face pushback from some countries in its quest to institutionalize human rights, with these countries continuing to criminalize key populations threatened by HIV.

discrimination in disease control efforts, and urged states to address underlying determinants of health in order to enable the realization of the right to health (CESCR 2000). However, the CESCR recognized that fulfilling these underlying determinants for health—including preventive measures, curative care, and other health-related rights such as food, housing, and education—would require progressive realization over time and that some states would need international assistance to achieve this in practice.

### <2> C. Human Rights and Global Inequity: Financing Access to Essential Medicines

The framing of rights-based responses to the AIDS epidemic soon moved beyond the narrow focus on discriminated groups and raised more sweeping questions of global inequity. The AIDS pandemic had already exposed huge inequities in global health systems, as what had begun as a disease that rapidly spread among vulnerable populations quickly became a generalizable pandemic across low-income countries. Far more people contracted HIV in poor countries than in rich ones, with the majority of those people living with HIV/AIDS coming from the world's poorest region: sub-Saharan Africa. With growing international claims for a right of access to treatment, new global institutions arose to provide international assistance to finance access to these essential medicines as a human rights imperative.

The development of anti-retroviral medicines (ARVs) was thus a watershed moment in the fight against HIV/AIDS. ARVs discourage the progress of retroviruses such as HIV within the body, substantially improving the health outcomes of people living with AIDS and reducing mother-to-child transmission (also known as “vertical transmission”). Due to their efficacy, ARVs became so routinely prescribed in the Global North that vertical transmission of HIV was almost eliminated (Read 2006). However, global inequity in access to ARVs

persisted due to the high cost of patented medicines.<sup>2</sup> In the early days of HIV treatment, ARVs could cost as much as US \$10,000 – \$15,000 per person per year, which effectively excluded people from low-income countries from accessing life-saving medicines. These exorbitant costs created a bifurcated pandemic, as access to treatment became a geographic lottery, with the chance of life determined by the place of birth (Knight 2008).

Global inequity in access to medicines inspired rights-based activism from civil society groups in the Global South, galvanizing a transnational campaign around global inequity and giving birth to global governance to finance ARV access. As detailed in chapter 6, civil society organizations were heavily involved in framing access to ARVs as a human rights issue, shifting the narrative of AIDS treatment from intellectual property rights to health-related human rights (Odell and Sell 2006). Rights-based challenges from the Global South rallied public opinion through media campaigns that highlighted the underlying injustice of high prices and unequal access – challenging the global patent regime, spotlighting the actions of pharmaceutical companies, and drawing attention to the role of international financing in denying ARV access to millions. Advocating for access to essential medicines as a right, this campaign sought corresponding obligations on governments and the international community to ensure that individuals in low-income countries could access treatment (Sekalala 2014). This advocacy gave rise to a 2001 UN General Assembly Special Session on HIV/AIDS, through which states declared their commitment to “addressing factors affecting the provision of HIV-related drugs, including anti-retroviral drugs, inter alia, affordability and pricing,” with a view to progressively

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<sup>2</sup> Compounding the role of pharmaceutical patents in driving up the cost of medicines, the 1995 Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) expanded intellectual property protections for pharmaceuticals to the exclusion of public health considerations, raising costs and limiting access.

realizing access to ARVs (UN General Assembly 2001, para. 55).<sup>3</sup> Based upon this international recognition of a right to access essential ARVs, supported by a commitment to ARV access in the Millennium Development Goals, states in 2002 developed the Global Fund to Fight AIDS, TB and Malaria (Global Fund) as a basis to facilitate international financing for universal access to treatment. This reframing of the debate around access to treatment illustrated the tremendous potential of the right to health, expanding the boundaries of human rights through the emergence of new norms for communicable disease.

## <1> II. From Access to Medicines to Global Communicable Disease Governance

With human rights framing access to essential ARVs as a human rights obligation, these rights-based claims have provided a framework for establishing a human right to access essential medicines, extending beyond HIV financing to address a far larger set of communicable disease threats, and developing rights-based infectious disease governance under the International Health Regulations (IHR).

### <2> A. Establishing a Human Rights Consensus on Access to Essential Medicines

Human rights have framed claims to respond to infectious diseases through access to essential medicines. Because people with HIV/AIDS will die without ARVs, access to these medicines can be realized under either the right to life (under the International Covenant on Civil Political and Cultural Rights (ICCPR)) or the right to health (under the International Covenant on Economic, Social and Cultural Rights (ICESCR)). Through civil society litigation in domestic courts and evolving obligations under international law, pressure has been put on both states and pharmaceutical companies to recognize a human right to essential

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<sup>3</sup> In these international financing debates, civil society organizations continued to emphasize the role of human rights in relaxing intellectual property rules on access to essential medicines (Matthews 2004).

medicines, assuring the mobilization of international resources for universal access through global financing institutions.

Civil society activists have pursued human rights litigation across jurisdictions, with courts recognizing a human rights basis for access to ARVs. These court cases, as reviewed in chapter 8, have provided avenues to press governments to realize rights. In court cases at the national and regional levels—in countries ranging from Brazil to Venezuela to South Africa—courts have decided that the failure to provide ARVs to people suffering from HIV/AIDS is a violation of the right to health. This strategic litigation has inspired other organizations to bring similar cases in domestic courts throughout the world, especially in low- and middle-income countries, thereby entrenching access to essential medicines as central to the realization of human rights. Yet courts have taken different approaches in recognizing this human rights obligation and its implication for infectious disease policy. In Brazil, courts have decided that the state should pay for essential medicines immediately, while in South Africa, courts have been more cautious and argued that the state needs to take reasonable measures within their available resources to progressively realize the right to health (Sekalala 2017).

Beyond national litigation efforts, human rights claims have also evolved through international declarations to facilitate greater access to essential medicines in the Global South. These UN resolutions, including broad provisions for access to essential medicines as part of a realization of the right to health, have addressed access to essential medicines by calling on states to pursue policies promoting the availability and affordability of safe pharmaceutical products to treat pandemics such as HIV/AIDS, developing national health strategies to treat all affected individuals (UN General Assembly 2003). Within the UN human rights system, the UN Commission on Human Rights has recognized that access to medication in the context of pandemics is a fundamental element of achieving the full

realization of the right to health, calling on all states to promote the availability and accessibility of pharmaceuticals. Supporting the affordability of these essential medicines, the CESCR has subsequently provided guidance to resolve conflicts between intellectual property rights and human rights, clarifying the fundamental importance of the right to health over intellectual property concerns (Stemple 2008).<sup>4</sup>

Implementing these human rights norms for access to medicines has required global institutions to bring states together to finance treatments for the millions who cannot afford essential medicines. With these financing mechanisms evolving over the past two decades, UNAIDS partnered with WHO and the Global Fund in the “Three by Five” campaign, which aimed to get three million people onto ARV treatment by 2005; the World Bank introduced the Multi-Country HIV/AIDS Program (MAP), which aimed to increase access to HIV/AIDS prevention, care, and treatment programs, with emphasis on vulnerable groups within African countries; and a new body called Unitaid introduced a Medicines Patent Pool, which invests in innovations to prevent, diagnose, and treat HIV/AIDS, TB, and malaria more quickly, affordably, and effectively. Providing funding for essential medicines, these global institutions are framing a human rights-based approach to infectious disease control, ensuring that programs funded by these institutions are not discriminatory, promote equality for vulnerable groups, encourage participation from those affected by the disease, and are accountable to all stakeholders (Jürgens et al. 2018).<sup>5</sup> These financing institutions have been

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<sup>4</sup> The former Special Rapporteur on the right to health, Anand Grover, similarly addressed the role of intellectual property on the price of essential medicines, recognizing that while states have the primary duty to ensure that their citizens can access essential medicines, the international community and private actors (such as pharmaceutical companies) also have a role in assisting low-income countries by integrating the right to health in foreign assistance (Grover et al. 2012).

<sup>5</sup> Supporting these financing institutions in mainstreaming human rights in AIDS financing, UNAIDS has pushed under its “three zeros” plan for zero new HIV infections, zero discrimination, and zero AIDS-related deaths, acknowledging that vulnerable people such as women, LGBT populations, and prisoners must be at the core of the AIDS response (Nygren-Krug 2018).

heavily involved in health system strengthening as a human rights imperative, recognizing that underlying determinants of health are integral to access essential medicines. As a result, financing is now going not only to treatment but to training doctors, improving supply chains for the transportation and storage of essential medicines, building health facilities, and feeding programs for people on ARVs (Sekalala 2017). Although these institutions have faced resistance from states in mainstreaming human rights in their policies, programs, and practices, there has been ongoing engagement with states about the value of embedding human rights in health financing (Sekalala and Haastrup 2018).

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#### *Case Study: The Global Fund Mainstreams Human Rights*

The Global Fund is a public-private partnership organization, which is charged with coordinating international health financing for three main diseases: AIDS, malaria, and TB. Although it was initially conceived as merely a financing instrument to disburse grants to countries, the Global Fund since 2002 has espoused human rights values such as non-discrimination in its foundational documents. In 2008, the Global Fund embedded this rights-based approach in its Gender Equality Strategy, and in 2009, it approved a Sexual Orientation and Gender Identities Strategy as part of its burgeoning approach to human rights mainstreaming. These strategies demand that countries applying for financing illustrate how Global Fund grants will address the human rights challenges of women and sexual minorities to facilitate improved responses to AIDS, malaria, and TB. In 2010, the Executive Director of the Global Fund acknowledged that there was a tension between the agency’s “country ownership” approach—which gave autonomy to countries in spending decisions—and the

need to ensure that human rights are not violated as part of the grant allocation process. In an explicit commitment to human rights, the Global Fund now aims to: integrate human rights considerations throughout the grant cycle; increase investments in programs that address human rights-related barriers to access; and ensure that the Global Fund does not support programs that infringe upon human rights. The Global Fund has introduced accountability mechanisms to ensure human rights implementation in its grant process, developing a complaints procedure for people who may have witnessed human rights violations linked with Global Fund programs, enabling the Office of the Inspector General to investigate complaints and report directly to the Global Fund Board, giving technical assistance to NGOs working on human rights in affected countries, and implementing key indicators that focus on the human rights of vulnerable groups that benefit from Global Fund support.

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## <2> B. Extending Human Rights Beyond HIV: The Struggle Against Tuberculosis

The exceptional human rights response to AIDS has not been as successful with other infectious diseases, with an ongoing struggle to facilitate a rights-based response to TB. A highly-contagious airborne microorganism, TB leads to over nine million infections every year; yet, human rights have only recently been employed in the TB response. As in the early years of the AIDS response, many countries continue to isolate and quarantine those suffering from TB, who tend to be vulnerable—including prisoners, migrants, children, and the poorest people who live in slums or use drugs—and face stigma, discrimination, and marginalization (Citro et al. 2016). TB is still subject to coercive legal regimes throughout the world, leading to forced imprisonment of suspected TB sufferers and criminalization of those who are accused of spreading the disease (Maleche and Were 2016). TB patients have also been

denied their right to health where, until recently, WHO recommended that states use older medicines, less expensive but less efficient, which made it harder for TB sufferers to complete treatment courses.

However, there has been an increasing recognition that, as with AIDS, a human rights-based approach is necessary to respond to the TB pandemic, acknowledging that coercion of suspected sufferers only reinforces prejudice and discrimination and pushes people underground, where they are beyond the reach of health professionals and public health policy. While the airborne nature of TB may at times make it acceptable to employ the use of quarantine authorities in disease prevention, with chapter 2 discussing these acceptable forms of rights derogation under international law, a human rights-based approach demands that governments avoid compulsory isolation unless there is no other alternative. Rather than unnecessarily confining individuals, TB treatment should aim to take place in communities, where there can be high rates of successful treatment while respecting human rights (Yassin et al. 2013).

Facilitating accountability for human rights realization in the TB response, advocates have pursued judicial challenges, arguing that government efforts violate human rights to testing and treatment, rights to immigration and asylum, right to be free from torture, right to employment, and right to be free from discrimination, especially against certain socio-economic groups in detention facilities. However, the courts in these cases have been less progressive than in HIV/AIDS litigation, focusing their judgments on civil and political rights and avoiding jurisprudence to guarantee access to essential TB medicines pursuant to the progressive realization of the right to health (Sidhu et al. 2017).<sup>6</sup> With one of the highest rates of TB in the world, attempts have been made to hold the Indian government accountable

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<sup>6</sup> The absence of right to health claims has particular harm to incarcerated populations, who suffer disproportionately from TB but are often denied good quality and scientifically proven health goods and services in prison settings (Citro et al. 2016).

for access to TB medicines – arguing, as depicted in figure 2, that the Delhi government failed to provide available, accessible, acceptable, and quality TB goods, facilities, services, and information, in violation of constitutional and international law. Yet, while the judgment of the Indian Supreme Court called for better access to TB medicines, it shied away from deciding the case on human rights grounds.

Figure 2. Patients Protesting a Shortage of TB Medicines in Government Clinics, New Delhi  
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By contrast, civil and political rights challenges to the involuntary confinement of TB patients have proven more successful, with the High Court of Kenya rejecting imprisonment for those who do not adhere to their TB medications – even if confinement may be a justifiable limitation on rights to freedom of movement in order to limit transmission in the context of a public health emergency (Maleche and Were 2016).

Extending these rights-based efforts globally, WHO created the Stop TB Partnership to lead the global health response – bringing together over 1,300 partners in more than 100 countries to push TB higher on the global agenda and thereby increase rates of diagnosis, treatment, and care for all TB patients. The Stop TB Partnership’s Global Plan to End TB 2016–2020 calls for a human rights-based and gender-based approach to responding to TB, looking to international, regional, and domestic law standards of human rights and gender equity. This approach pushes for communities and people affected by TB to become equal partners in driving health policy so as to claim their rights, ensuring that human rights implications of TB policy, legislation, and programming are addressed by ensuring that human rights are central to the design, implementation, monitoring, and evaluating of TB related policies and programs. Through the Stop TB partnership, WHO has updated its

guidelines to enable access to better treatment options for multi-drug resistant tuberculosis (MDR-TB), assuring TB sufferers the right to the benefits of scientific progress (Frick, Henry, and Lessem 2016). The Global Fund has correspondingly included human rights considerations in its TB financing, and countries applying for Global Fund support must now, as with HIV/AIDS financing, address human rights and gender barriers to TB control, including national policies regarding involuntary detention, failure to adhere to TB treatment, and barriers to TB services in prisons (Jürgens et al. 2018).

## <2> C. Developing a Rights-Based Approach to Infectious Disease Governance

While international legal responses to communicable diseases have sought for centuries to interrupt the spread of infection, with measures such as quarantine and isolation long exempted from any legal scrutiny, this approach has been superseded since World War II by one that recognizes the fundamental interests of individual rights. The normative ideal of a rights-based approach to infectious disease governance requires national and international agencies to engage carefully with the human rights protections enumerated in the ICCPR and the right to health in the ICESCR. This ideal is reflected in the current IHR which form the cornerstone of the contemporary global legal regime for the control of communicable diseases, but it has proven more difficult to achieve in practice.<sup>7</sup>

From the birth of WHO, the IHR were rarely used, and indeed their focus was narrowed in 1969 to three named conditions: cholera, plague, and yellow fever. The regulations operated through a classically Westphalian framework, with states acting under

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<sup>7</sup> The IHR regime dates back to the International Sanitary Conventions of the nineteenth century, which balanced the competing interests of European empires in free trade on the one hand and protection against the spread of disease on the other (Aginam 2003). Restrictions on commerce and the movement of people were permitted only to the extent necessary to protect the state and its people. The WHO took over responsibility for this legal regime upon its 1948 inauguration.

sovereign authorities – as the only actors able to notify WHO of (suspected) diseases outbreaks, with the power to restrict individuals at national frontiers (e.g., ports and airports), and under the responsibility to protect their people (from external threats). This sovereignty was largely respected, with no direct provision for the rights of individuals in infectious disease control (Aginam 2003). Yet, with the rise of HIV, resurgence of TB, and emergence of new infectious diseases—driven by a greater frequency of travel and shipping—globalization raised new threats of communicable disease transmission. At the same time, structural adjustment programs imposed in the 1980s meant that national disease detection systems were weakened in those states where these diseases were most likely to (re-)emerge (Harrington 2018). This recognition of failing infectious disease control capacity in the Global South, along with long-held suspicions that states were not consistently reporting notifiable disease outbreaks to WHO, led to calls for a revision of the IHR.

The revised IHR, adopted in 2005, marked a shift away from the older fixation on sovereignty, borders, and a narrow list of diseases – moving toward a more flexible, Post-Westphalian regime that takes an “all hazards” approach to disease outbreaks (Fidler and Gostin 2011). Recognizing the reluctance of national governments to acknowledge the spread of disease within their borders, non-state actors are permitted to notify WHO of disease outbreaks, with WHO creating online systems for aggregating outbreak information – the Global Outbreak Alert and Response Network (Fidler 2003). The revised IHR seek to develop a national capacity for infectious disease surveillance and build WHO authority in global health governance, allowing the WHO Director-General to declare a Public Health Emergency of International Concern (PHEIC) based upon the advice of an Emergency Committee and to make recommendations on necessary public health measures in an emergency context.

The 2005 revision saw, for the first time, the inclusion of human rights under the IHR, shifting emphasis away from state power and toward consideration of the interests of individuals. IHR implementation is to be guided by the UN Charter, meaning that all of the regulations must be “implemented with full respect for the dignity, human rights, and fundamental freedoms of persons,” including where a PHEIC has been declared (IHR 2005, 10). Applied to specific state authorities, IHR 2005 contain explicit and detailed provisions on the rights of travelers, for example, regarding the confidentiality of personal medical data and the need for consent to medical examinations in all but the most extreme cases. Taken together, this new human rights foundation requires that the scope and nature of human rights limitations imposed during disease outbreaks must be defensible in practice and justifiable in scientific terms (Murphy 2013). It is true that the human rights components of IHR 2005 have weak normative force: there are no individual protections for non-state actors who report outbreaks to WHO (Davies 2017), no international obligations to assist states in building infectious disease surveillance capacity, and no enforcement mechanisms to compel states to follow the Director-General’s recommendations even where a PHEIC has been declared (Fidler and Gostin 2011). Overall, however, they represent an important broadening of the global infectious disease control regime and a first attempt to engage human rights in international disease control regulations.

### <1> III. Securitizing Infectious Disease Control

Like invasions, insurgencies, and terrorist attacks, communicable diseases have long been understood as threatening the existence of states themselves. Traditionally defined in terms of national interests, infectious disease control is now understood to raise questions of “global health security,” requiring action to reduce the vulnerability of people around the world to new, acute, or rapidly spreading risks to health, particularly those that threaten to

cross borders (WHO 2007). This representation of disease as a security threat is evident in the UN Security Council Resolutions, declaring that HIV/AIDS and then Ebola were threats to international peace and stability (UNSC 2000, 2014). The “securitization” of infectious diseases outbreaks, as existential threat to populations and state institutions, leads to demands for extensive restriction of fundamental rights (McInnes and Rushton 2012). As this “securitization” of infectious disease control is increasingly seen as a threat to human rights, policymakers are seeking to balance infectious disease control and human rights protections, employing this balance in addressing the cataclysmic threat of anti-microbial resistance.

#### <2> A. The Threat to Human Rights

Framing communicable diseases as a security threat can be positive in so far as it draws attention to public health in the Global South and galvanizes much needed resources for building national public health capacity. However, a number of negative consequences for human rights and global justice are likely to offset these gains. State efforts to promote global health security have been seen to threaten rights by: sharing personal information concerning health status and contact tracing to establish routes of infection (privacy); enacting compulsory testing and vaccination as well as quarantine and isolation (liberty); and refusing permission to leave a state’s territory, to enter it, or travel within it (freedom of movement) where one is a citizen of that state (Zidar 2015). Beyond these civil and political rights infringements, control measures can also limit the enjoyment of economic and social rights. For example, hospitals were shut down in areas of Guinea affected by the 2014 Ebola outbreak, effectively blocking access to health care for local communities (Frau 2016). It is recognized that such measures pursue the legitimate aim of securing the right to health, which includes protection against epidemic diseases, but such actions may threaten rights in a vain effort to establish security.

The threat to human rights is increased by two key features of security-led responses to disease outbreaks: speed and state-centrism. Interventions to stop the spread of disease are subject to the “tyranny of the urgent”: these are rapid responses, often delivered by military means, as depicted in figure 2, and without much scope for deliberation and reflection by parliaments, policy makers, or the judiciary (Annas 2016). Similarly, urgent development and deployment of “medical countermeasures” (i.e., new drugs and vaccines) may take precedence over important ethical and human rights constraints protecting individual autonomy and privacy, as well as health (Roemer-Mahler and Elbe 2016). Speed of transmission also means that more rapidly spreading diseases, like SARS and Ebola, are prioritized over endemic conditions, like malaria, diarrhea, and cholera, which impose a much greater burden on population health but are less likely to travel. Thus, overall progress toward realizing the right to health is impeded.

Figure 2. US Soldiers Preparing to Deploy to West Africa during the 2014 Ebola Outbreak  
[INSERT FIGURE 2 HERE]

The framing of disease outbreaks as a threat to states themselves is long-established and remains the default position in many cases. Responses tend to prioritize the interests of state institutions such as the army or of the economically powerful such as the export sector. Attempts by the UN Development Programme to widen the concept of “security” to include “human security” have largely failed to change this emphasis (McInnes and Lee 2012). The effects of state-centrism are reinforced by real world political inequalities and historical trajectories. It favors nations of the Global North who possess the power and resources to shape infrastructure and policy in countries of the Global South in order to protect themselves against rapidly spreading, rather than endemic diseases (Calain 2007). This reproduces

patterns of domination and exploitation that marked European colonialism in the nineteenth and twentieth centuries.

## <2> B. Responding to Securitization to Realize Human Rights

Human rights provide a separate frame capable of addressing the negative effects of securitization. Civil and political rights operate to “discipline” infectious disease control measures. While international law does permit restrictions on human rights to protect global health security,<sup>8</sup> these restrictions are not without limitation, requiring that measures are transparent, non-discriminatory, proportionate to the legitimate public health aim pursued, and no more restrictive than required by the public health circumstances (Zidar 2015). Bringing together these civil and political rights with economic and social rights, including the right to health, will be central to assuring underlying determinants of health, supporting gender equality, and facilitating international assistance.

In accordance with the inextricable linkages between health and human rights, the spread of Ebola in West Africa made clear that structural problems, including inaccessible and insufficient health care, poor sanitation, and economic disadvantage, are key factors in the spread of infectious diseases. Where these determinants of health reflect violations of human rights, the control of infectious disease requires more than targeted and limited measures like quarantine and isolation or the development of treatments and cures – highlighting the extent to which both negative and positive rights are interrelated in preventing disease and promoting health (Eba 2014). The right to health has incorporated this expansive approach to interconnected rights, extending beyond individual entitlements to

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<sup>8</sup> As addressed in chapter 2, the 1985 Siracusa Principles seek to permit restrictions on civil and political rights in two forms: 1) derogations, which involve the full suspension of certain rights, which may be permitted in case of “exceptional or imminent danger threatening the life of the nation”; and 2) limitations, which are permitted in less serious emergencies, where certain rights are limited to protect other rights (UNESCO 1985).

include underlying systems for the protection and promotion of health (Hunt and Leader 2010).

Further, where inequality violates human rights and drives disease transmission, women remain disproportionately affected by infectious disease as a result of their greater vulnerability to violence of all kinds, their traditional role as caretakers in the home and in the health system, and the endemic discrimination that blocks their access to adequate treatment and prevention systems. In spite of this, women and girls have often been “conspicuously invisible” in emergency responses and in longer term planning for disease outbreaks (Harman 2016). The spread of Ebola in West Africa posed specific, increased risks to women due to their widespread role in attending to the sick and preparing bodies for burial, yet little attempt was made to record or address these gender differences. Few scholarly papers concerned themselves with the scientific and policy implications of the outbreak as it affected women. The human rights-based approach, which calls on states and the international community to address the underlying determinants of health, can help to address this deficit in policy and science. It draws attention to structural discrimination, mandating suitable mechanisms to redress it, such as gender-specific indicators for data collection, targeted benchmarking to redress inequality of access, and a participatory approach which would actively engage women in shaping policy responses (Davies and Bennett 2016).

Finally, states bear international obligations to provide assistance to each other in support of global health security. IHR 2005 requires states and WHO to collaborate in developing capacities to detect and respond to outbreaks by sharing technical know-how and supplying needed financial resources. This provision was a response to concerns in the Global South that the revised IHR imposed obligations without addressing the limited ability of many states to meet them. IHR 2005 is thus underpinned by international human rights law, as well as global public health concerns and diplomatic necessity, with states owing a

duty of solidarity to each other in realizing the right to health. Admittedly, these obligations are currently weak, as there is no mechanism for enforcement, they focus on capacity to detect outbreaks rather than wider health system failings, and specific duties are not elaborated. Where the IHR have proven ineffective in galvanizing international efforts to build national capacity, states have sought to meet this imperative for international assistance in infectious disease control through the Global Health Security Agenda (Meier, Evans, and Phelan forthcoming).

[START TEXT BOX]

*Case Study: The Global Health Security Agenda*

In 2014, frustration with the slow implementation of the revised IHR led the United States and other high-income states, along with WHO and other international organizations, to launch the Global Health Security Agenda (GHSA), which securitizes public health as a basis to catalyze national efforts to prevent, detect, and respond to infectious diseases. Now bringing together more than 60 high-income and low-income states, the GHSA has established a clear commitment to support states in the Global South to build their IHR capacity to create “a world safe and secure from infectious disease threats.” The GHSA addresses three pillars of infectious disease control (prevention, detection, and response) through “action packages” – building capacity in areas such as biosecurity, real time surveillance, and medical countermeasures. Notwithstanding these advances, more progress could have been made. Many of the action packages reference human rights issues—including surveillance and privacy rights, medical countermeasures and bodily integrity, freedom of movement rights, and interventions that may raise procedural rights issues—yet,

the GHSA includes no safeguards such that these activities are conducted in ways that respect, protect, and fulfill human rights. The GHSA has set out targets, measurements, and specific action items for states to realize infectious disease control, but unlike the IHR, there is no requirement to comply with international human rights standards. This increased funding and policy attention is welcome, but the GHSA still represents a lost opportunity for human rights regarding accountability and enforceability.

[END TEXT BOX]

## <2> C. Human Rights and the Emerging Threat of Anti-Microbial Resistance

Undercutting the promise of human rights, AMR is recognized as one of the most serious threats to global health security, affecting tens of millions each year. AMR is caused by massive overuse and misuse of medicines,<sup>9</sup> leading to the emergence of bacteria (as well as fungi, parasites, and viruses) that are no longer susceptible to first-line therapies (Prestinaci, Pezzotti, and Pantosti 2015). Requiring patients to move to second- and third-line therapies, to the extent that they are available, such treatments are more likely to still be “on-patent” and thus much more expensive. Where they are not available, as in the case of Extensively Drug Resistant-Tuberculosis (XDR-TB), the burden of morbidity and mortality increases exponentially, with resistant infections spreading quickly among immunocompromised patients.

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<sup>9</sup> The origins of this overuse and misuse are widespread. In medicine, antibiotics are over-promoted by manufacturers seeking to maximize returns and over-prescribed by doctors uncertain about correct diagnoses. Patients in many countries of the Global South are able to purchase antibiotics without a prescription, self-medicating without advice or constraint. Farmers have used antimicrobials indiscriminately in industrial agriculture for growth-promotion in livestock and crop protection.

Effective anti-microbial medicines are a valuable but scarce resource in treating infectious diseases. However, the costs of stewardship measures to protect them, such as limiting use or furthering drug innovation, are felt immediately while the benefits are uncertain and lie in the future (Hollis and Maybarduk 2015). Policymakers have increasingly recognized the need for collective action at all levels of governance. The UN General Assembly convened a High-Level Meeting on the issue in 2016, and WHO partnered with the UN Food and Agriculture Organization (FAO) and the World Organization for Animal Health (OIE) to develop a Global Action Plan on AMR. Policymakers now accept that AMR requires an integrated, One Health approach that crosses sectoral boundaries between human, animal, and environmental health. Bringing these multisectoral actors together will require a normative foundation for global health policy.

Although human rights have been largely absent from these global health policy initiatives, they play a vital role in framing rights-based policies and shaping their implementation. Doing so requires moving beyond the focus on rights as exclusively focused on individuals (Meier 2006). The right to health is not simply concerned with access to medical care, also obliges states to take steps to secure the underlying determinants of health and establish mechanisms for ensuring public health. These determinants of health can only be delivered as “public goods” in the context of combatting AMR – addressing entire societies and increasingly the global population as a whole. Freedom from AMR is ultimately a collective right that complements and helps to realize the individual’s right to health.

Infectious diseases have been framed as a question of security for centuries. Securitization defines state-interests narrowly and demands an urgent, often drastic response which leaves little time or leeway for considering the interests of individuals or vulnerable groups. From the mid-twentieth century, human rights have offered a radically different,

normative frame for dealing with disease outbreaks. The exercise of state power is limited by a requirement to identify, consider, and balance the interests of individuals and communities within and beyond the national territory. This involves rights-based procedural factors—deliberation, transparency, accountability—as much as substantive rights such as privacy, autonomy, health, and life. Normative principles are not sufficient on their own. Each of these areas—women’s rights, international aid for capacity building, and global health security—show a need for further development and especially enforcement of human rights within disease prevention and control regimes. Each also showed continued relevance of the insight that respect for human rights, underpinned by a strong conception of global justice, is an essential component of effective responses to disease outbreaks (Baxi 2010).

## <1> Conclusion

In addressing these communicable disease threats, human rights have evolved to play a central role in infectious disease control policy. Human rights challenged the stigma, discrimination, and marginalization of vulnerable groups in the early years of the AIDS response and highlighted access to medicines as part of the realization of the right to health. Drawing from the successes of using human rights in the AIDS response, human rights advocates have also pushed for the promotion of human rights of people with TB, arguing that it is likely to foster more sustainable interventions, encourage testing, improve prevention, and lead to better treatment outcomes, thereby reducing drug resistance and improving public health. Increasingly, human rights have been mainstreamed across global health institutions, leading to greater health financing for infectious disease and health system strengthening for disease prevention.

This human rights integration into broader health governance is reflected in the revised IHR, which provides a global model for preventing outbreaks of infectious diseases

and responding to those outbreaks once they have occurred. Assuring the success of this international policy, the IHR commits to interpreting all the regulations in light of human rights considerations, which can enable respect for privacy, liberty, and freedom of movement – while preventing disease.

However, the future of rights-based policy is threatened by the return to a securitization lens in infectious disease control, reducing the impact of human rights in global health governance. Due to climate change, increased civil wars, rapid urbanization, and a greater regular and irregular movement of people and goods across the world, an increase in the rise of infectious diseases such as Lassa fever, avian flu, Ebola, and Zika is a certainty. Coupled with this, the global community is experiencing a resurgence of childhood diseases such as measles and chicken pox, even in high-income countries. It is natural for these diseases to provoke fear among citizens and governments, but it is important to note that many of these diseases arise out of a reluctance by states to engage with the human rights of marginalized groups, invest more in health systems, provide greater education, and supply more investment in the research and development of neglected diseases.

There is a need to revitalize human rights in infectious disease control, recognizing, as first proposed in the early years of the AIDS response, that public health protection is inextricably linked to human rights promotion. Even the most threatening infectious diseases can be fought by increasing dignity for individuals and marginalized groups, increasing access to essential treatment, strengthening health systems, and focusing on underlying determinants of health. Addressing health security through a rights-based approach will also be critical to providing a path forward for addressing the looming threat of AMR, where the lack of effective antibiotics will have a disproportionate effect on poorer and marginalized communities in the Global South, undercutting global efforts to contain infectious diseases.

## <1> Questions for Consideration

1. Why did states seek to restrict the rights of HIV-positive populations? How did human rights claims seek to end these discriminatory public health policies?
2. How did human rights frame the establishment of vast global governance structures to address the HIV/AIDS pandemic and finance HIV treatment?
3. Which human rights support access to essential medicines? How have advocates sought to implement a right to essential medicines in the context of the HIV/AIDS pandemic?
4. How does TB present different human rights challenges than the HIV/AIDS response? Have states met these challenges in assuring prevention and treatment of TB? Why has it proven more difficult to realize a right of access to essential medicines in the TB response?
5. In what ways did states seek to protect human rights in the 2005 revision of the IHR? Were they successful?
6. How can the “security” frame and the human rights frame be reconciled in infectious disease control? Should human rights and health security be seen as “inextricably linked”?
7. How were women “conspicuously invisible” to policy makers during the Ebola crisis in West Africa (2014-2016)? What were the consequences of this, and how can human rights address the problem?
8. What international obligations do high-income states bear to provide international assistance and support to low-income states to build capacity for infectious disease control? How can this international assistance be assessed?
9. How can human rights support states in coming together to address the growing threat of AMR?

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