

Conceptualizing a Human Right to Prevention in Global HIV Policy

Benjamin Mason Meier & Yasmin Halima

Given current constraints on universal treatment campaigns, an imperative has reemerged to stem the tide of global HIV transmission. Yet despite this prevention imperative, the human rights framework remains normatively limited in addressing collective prevention policy through global health governance. This research analyzes the evolution of rights-based approaches to global HIV/AIDS policy, finding human rights to have shifted from collective public health to individual treatment access. Concluding that human rights frameworks must be developed to reflect the complementarity of individual treatment and collective prevention, this article conceptualizes collective human rights to public health in framing global health policy supportive of comprehensive HIV prevention.

Benjamin Mason Meier is Assistant Professor of Global Health Policy at the University of North Carolina at Chapel Hill, Faculty Fellow at UNC's Center for AIDS Research, and Scholar at Georgetown University's O'Neill Institute for National and Global Health Law. Yasmin Halima is Director of the Global Campaign for Microbicides and Adjunct Professor at American University's School of International Studies. The authors are grateful to Kristen Brugh for her research assistance and insightful comments on global HIV policy.

Despite the human rights-based mantra of “treatment for all,” circumstances may soon make this goal no more than empty words – one more regret upon the altar of failed commitments in global HIV policy. With a rising imperative for HIV prevention—supported by the promise of behavioral, structural, and biomedical approaches to lower the incidence of HIV—human rights have been neglected in framing prevention interventions. This article analyzes the limited success of individual human rights in supporting HIV prevention efforts and proposes a collective rights-based response for addressing prevention through global health policy.

BACKGROUND: THE PREVENTION IMPERATIVE

Since first reported in 1981, prevention long held primacy in global HIV policy. With no medical response available in the period before clinical advances in antiretroviral (ARV) therapy, early responses to the growing pandemic were confined to behavioral prevention in the belief that testing, education, and counseling—combined with the availability of condoms and clean needles—would drive self-interested behavioral change.ⁱ Although prevention messages could be meaningfully conveyed from the mid-1980s to early 1990s, prevention policy faded as the public wearied, combination ARVs emerged, and HIV was rebranded a chronic manageable disease.ⁱⁱ As a result, global HIV policy experienced an inexorable shift from prevention to treatment, driven by an imperative to respond to the dying individual regardless of the broader public health impact.ⁱⁱⁱ The 1987 approval of zidovudine (AZT) gave lifesaving hope for universal HIV treatment; however, this hope was immediately tempered by its prohibitive costs, a limitation extended through the 1996 innovation of combination therapy as the standard of care for people living with HIV. With the costs of treatment rendering therapy financially inaccessible for 90% of the HIV-positive world,^{iv} HIV infection remained a largely fatal diagnosis as infection rates climbed in developing countries, with Sub-Saharan Africa bearing the largest share of the global burden.^v

Yet as the costs of treatment fell and antiretroviral options expanded, institutions of global health governance have emerged to assure access to treatment and ensure the preservation of life – with states creating the Millennium Development Goals (MDGs) and various declarations on HIV treatment; the United Nations (UN) holding a General Assembly Special Session on HIV/AIDS and creating the Global Fund to Fight AIDS, Tuberculosis, and Malaria; the United States funding the President’s Emergency Plan for AIDS Relief (PEPFAR); and the Joint United Nations Programme on HIV/AIDS (UNAIDS) and World Health Organization (WHO) launching the 3 by 5 Initiative. Moved by the scale of the pandemic, the most powerful nations of the world came together in 2005 to endorse a foreign assistance commitment to attain universal access to HIV treatment by the year 2010 – a target subsequently endorsed by the UN General Assembly.^{vi} While the goal of universal access has enabled the mobilization of vast resources, unprecedented for any other disease, it is clear that the goal of universal access will not be reached, with the reversal of treatment gains a distinct possibility in the current economic climate.^{vii}

Despite advocacy to the contrary, it will not be possible to treat every HIV-positive person in

the world and commit to doing so for the rest of his or her life. Although 5.25 million people were receiving HIV treatment in low- and middle-income countries by the end of 2009 (compared with 4 million the previous year), only an estimated 36% of those in need currently have access, leaving an astonishing 9.35 million people who need treatment but are not receiving it.^{viii} In the face of unprecedented global efforts to assure treatment, HIV prevalence has continued to grow in the last fifteen years, with new HIV infections outpacing antiretroviral treatment initiation and straining treatment distribution programs; for every two people initiating treatment, an estimated five new HIV infections occur, 60% of which are among women.^{ix} Given that “medical and ethical considerations endow each patient currently on treatment with a life-long ‘entitlement’ to receive at least his or her current treatment regimen,” many now consider HIV treatment efforts “unsustainable.”^x With current standards for HIV treatment focusing on longer treatment regimens, assuring combination ARVs and regular monitoring to ensure the continued efficacy of treatment, this standard of care is often not available for those in resource-limited settings. As additional people begin first-line treatment—and are forced by resistance to progress to more expensive second- and third-line therapies—the growing costs of a lifetime of therapy, care, and support will put treatment out of reach for an increasing share of HIV-positive persons.^{xi} Given current budgetary commitments, donors may soon reach an untenable retrogression in human rights – where they will be forced to take away lifesaving treatment from those already on it. This inability to “treat our way out” of the HIV pandemic has forced a return to HIV prevention initiatives.

Given this imperative for a shift in global health governance for AIDS, a number of initiatives have been developed in the last decade to investigate the promise of HIV prevention – that is, to reduce individual HIV transmission and societal HIV incidence. Operating at both the individual and population levels, prevention engages with policy—as described below and delineated in table 1—through a combination of:

- Behavioral approaches, involving an “attempt to motivate behavioral change within individuals and social units by use of a range of educational, motivational, peer-group, skills-building approaches, and community normative approaches;”^{xii}
- Structural approaches, involving an “aim to change the social, economic, political, or environmental factors that determine HIV risk and vulnerability in specified contexts;”^{xiii} and
- Biomedical approaches, involving “technological” interventions that do not purely rely on behavior change to prevent HIV transmission.^{xiv}

Table 1: Types of Prevention Interventions

Behavioral Approaches

education
 stigma reduction
 access to services
 delay of onset of first intercourse
 decrease in number of partners
 increased use of condoms
 increased use of clean injection drug equipment

Structural Approaches

law and policy development
 gender equity
 decriminalizing determinants of infection

Biomedical Approaches

male condom
 female condom
 cervical barrier
 treating sexually transmitted infections (STIs)
 male circumcision
 antimicrobials
 pre-exposure prophylaxis (PrEP)
 test and treat
 vaccines

Under this revitalized prevention agenda, international organizations and national foreign assistance programs have incorporated prevention under global policies for “universal access,” drafting country-level prevention targets to complement those for treatment and

care.^{xv} At the forefront of clinical prevention initiatives, global policy attention has turned to the effectiveness of scaling-up individual HIV treatment as a form of public health prevention, using this “test and treat” model as a means to reduce the rate of HIV infectivity as path to limit the onward transmission of HIV.^{xvi} Compounded by the recent success of clinical trials for male circumcision and vaginal microbicides, policymakers have begun to examine the relative prioritization of treatment and prevention in global health policy.^{xvii} In this state where public health realities have forced such a shift in global HIV/AIDS policy, it becomes necessary to recalibrate human rights to reflect this growing imperative for HIV prevention, shifting human rights norms to consider public health frameworks for global HIV prevention policy.

FINDINGS: HUMAN RIGHTS TO TREATMENT OVER PREVENTION

Despite the evolution of a health and human rights movement in response to the HIV pandemic and the application of human rights in developing HIV/AIDS policy, human rights obligations are rarely applied to frame current global HIV prevention efforts. Where HIV prevention is discussed, such collective prevention interventions are not implemented under the aegis of human rights; where human rights fulfillment is considered, these rights are applied overwhelmingly to individual treatment. Based upon archival research within WHO, legal analysis of global health governance frameworks, and consultations with national health ministries, this part describes how rights-based global health policy developed normatively to create collective obligations for prevention but was enforced programmatically through an individual right to treatment.

Jonathan Mann and the Birth of the Health & Human Rights Movement

Reversing a history of neglect for human rights in global health governance, the advent of the HIV/AIDS pandemic would concretize these rights as scholars and advocates looked explicitly to human rights in framing global health policy. With governments responding reflexively to the emergent threat of AIDS through traditional public health policies—including compulsory testing, named reporting, travel restrictions, and coercive isolation or quarantine—human rights were seen as a reaction to intrusive public health infringements on individual liberty and a bond for stigma-induced cohesion among HIV-positive activists.^{xviii} In this period of burgeoning fear and advocacy, Jonathan Mann’s tenure at WHO would mark a turning point in the application of individual human rights to public health policy – viewing discrimination as counterproductive to public health goals, abandoning coercive tools of public health, and applying human rights to focus on the individual risk behaviors leading to HIV transmission.^{xix} Given Mann’s vocal leadership of WHO’s Global Programme on AIDS, WHO would seek to create a rights-based framework for national risk reduction programs.^{xx} In the absence of medical treatment or biomedical prevention, global AIDS governance would develop in opposition to both the historical biomedical framing of international health rights and the contemporaneous individual responsibility of neoliberal health policy.^{xxi} Leveraging behavioral science to develop HIV prevention campaigns, WHO’s first Global Strategy for the Prevention and Control of AIDS emphasized rights-based access to information, education, and services as a means to support personal responsibility among vulnerable individuals.^{xxii} Drawn explicitly from this human rights framework, specifically Western conceptions of individual freedom from government

intrusion, national policies would stress the need for programs to respect and protect human rights as a means to achieve the individual behavior change that was thought necessary to reduce HIV transmission.^{xxiii} Although such rights-based discourses would decline precipitously following Mann’s contentious 1990 exit from WHO,^{xxiv} Mann would continue to develop this health and human rights movement to frame the global HIV response.

Mann sought the continuing promise of human rights in addressing underlying societal determinants of health – looking beyond individual behavior and viewing rights realization as supportive of “a broader, societal approach to the complex problem of human wellbeing.”^{xxv} With recognition of these underlying determinants of HIV, Mann cautioned that the disease would inevitably descend the social gradient, calling for rights-based consideration of socioeconomic, racial, and gender disparities in abetting the spread of HIV.^{xxvi} Through social scientific examination of collective determinants of vulnerability to HIV infection—refuting the paradigm of complete individual control for health behaviors,^{xxvii} a basic premise of the individual rights framework—the health and human rights movement could move away from its early fixation on the conflicts between public health goals and human rights norms.^{xxviii} Out of this recognition of an “inextricable linkage” between public health and human rights, Mann proposed a tripartite framework to describe the effects of (1) human rights violations on health, (2) public health policies on human rights violations and (3) human rights protection on public health promotion.^{xxix} Given this focus on societal-level determinants of vulnerability, Mann argued that “since society is an essential part of the problem, a societal-level analysis and action will be required,”^{xxx} calling for a rights-based AIDS agenda that would frame policies for the distribution of costly medical treatments while maintaining a commitment to prevention efforts focused on education, access to health services, and a supportive societal environment.^{xxxi} Understanding such rights to be a tool for policy change, these discourses would take root in civil society—driven by transnational networks of gay rights organizations—and, despite Mann’s untimely death, would take hold of a nascent rights-based movement for global HIV policy.^{xxxii}

International Legal Standards and Public Health Prevention

Negotiating conflicting agendas in global HIV/AIDS policy—torn between individual medical treatment for the present and collective disease prevention for the future—global health governance would look to human rights to chart a path forward. Integrating human rights norms in HIV/AIDS agendas and strategies, these ideological tensions would manifest themselves in governmental, intergovernmental, and nongovernmental responses:

- Governmental – the 1994 International Conference on Population and Development (ICPD) gave programmatic direction to rights-based HIV policy, framing national policies to assure HIV-positive individuals of lives with dignity.^{xxxiii}
- Intergovernmental – the 1996 creation of UNAIDS, drawing on the 1994 Paris Declaration on Greater Involvement of People Living with HIV and AIDS, extended efforts to focus on the participation of affected communities in rights-based policy development and implementation.^{xxxiv}
- Nongovernmental – the 1996 launch of the International AIDS Vaccine Initiative (IAVI) encouraged rights-based scientific research through public-private partnerships for HIV prevention.^{xxxv}

With these budding rights-based initiatives for nondiscrimination, participation, and treatment, the UN High Commissioner for Human Rights would join this dialogue in 1996, advancing International Guidelines on HIV/AIDS and Human Rights to elaborate the human rights implicated by vulnerability to HIV and access to treatment.^{xxxvi}

Reflecting these rights-based developments in HIV policy, the UN Committee on Economic, Social and Cultural Rights (CESCR) in 2000 took up these evolving issues at the intersection of health and human rights in drafting its fourteenth General Comment on economic, social and cultural rights. As the legal body charged with drafting official interpretations of the International Covenant on Economic, Social and Cultural Rights (ICESCR), the CESCR interpreted the human right to “disease prevention, treatment and control”—codified in Article 12 of the ICESCR—to extend “not only to timely and appropriate health care but also to the underlying determinants of health.”^{xxxvii} Implementing this right through the tools of public health, General Comment 14 includes specific state obligations for “the establishment of prevention and education programmes for behaviour-related health concerns such as sexually transmitted diseases, in particular HIV/AIDS....”^{xxxviii} While acknowledging core obligations for the “provision of essential drugs,” the CESCR explicitly cautions in General Comment 14 that:

investments should not disproportionately favour 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.^{xxxix}

Looking past individual behavior and medical care, the CESCR sought to realize a “right to the enjoyment of a variety of facilities, goods, services and conditions,” with state obligations for underlying determinants of health assessed on the basis of their availability, accessibility, acceptability, and quality.^{xl} Proclaimed by the 2001 UN General Assembly Special Session on AIDS,^{xli} reified in the 2002 revision of the International Guidelines on HIV/AIDS and Human Rights,^{xlii} and elaborated following the 2002 appointment of the first UN Special Rapporteur on the right to health,^{xliii} this rights-based approach to health was seen as crucial to national policy and was employed as a means to frame and assess HIV prevention, treatment, care and support for all.

However, with these systemic recommendations for underlying determinants of health beyond the reach of many developing countries,^{xliv} HIV advocacy shifted from societal prevention policy to individual medical treatment through antiretroviral drugs.^{xlv} Even as experts warned that this access to treatment agenda came at the expense of public health prevention programs,^{xlvi} human rights litigation to advance treatment access would provide an impactful means to hold states accountable for their HIV policies.^{xlvii}

International Jurisprudence and an Individual Right to Treatment

The normative evolution of human rights would catalyze a burgeoning enforcement movement at the intersection of health and human rights, empowering NGOs to raise individual human rights claims in national courts.^{xlviii} With global health policies emphasizing the importance of the law, legal recourse, and public accountability, litigation

sought to rectify “policy gaps” and “implementation gaps” in national HIV/AIDS programs.^{xlix} However, with this litigation often driven by HIV-positive activists—pressing to deliver medications, as an immediate matter of life and death—this enforcement agenda focused predominantly on treatment to the exclusion of prevention, neglecting long-term systemic challenges to address short-term medical imperatives and consequently distorting the rights-based response to HIV.

Leading this jurisprudence, the South African Supreme Court heard an early rights-based challenge for access to medicines in the seminal 2002 case *Minister of Health v. Treatment Action Campaign*.¹ Brought pursuant to South Africa’s constitutional codification of the human rights to life and health—providing positive rights for the provision of health care, including reproductive services and access to HIV treatment and prevention—this legal challenge sought to overturn the national government’s unwillingness to expand the distribution of Nevirapine, a drug that researchers had found to be effective in reducing the transmission of HIV from mother to child. With this civil society-driven litigation led by the Treatment Action Campaign, a South African NGO focused on treatment for the HIV-positive, these advocates successfully held the South African government responsible for pharmaceutical access.^{li}

Despite the origins of this rights-based litigation in the prevention of mother-to-child transmission, these rights-based claims would shift toward claims for access to individual treatment at the expense of policies for prevention systems.^{lii} The Treatment Action Campaign’s successful claim for pharmaceutical prevention set a precedent for a wide range of HIV treatment claims—building in academia and expanding across NGOs^{liii}—which challenged the monopolistic practices of the international patent regime and sought distributive justice through human rights litigation. Recognizing the limits of developing states, this movement soon broadened to implicate international obligations on all manner of powerful states, organizations, and corporations with the ability to either support or impede access to ARVs in the developing world.^{liv} In the wake of this paradigm shift—reconceptualizing pharmaceutical knowledge as a global public good—the CESCR returned in 2006 to these issues in its seventeenth General Comment, applying the right to health to find that states “have a duty to prevent unreasonably high costs for access to essential medicines.”^{lv} When the UN Special Rapporteur on the right to health commented shortly thereafter, he found a “human right to medicines” to form an “indispensable part” of the right to health, holding that “states have to do all they reasonably can to make sure that existing medicines are available in sufficient quantities in their jurisdictions.”^{lvi}

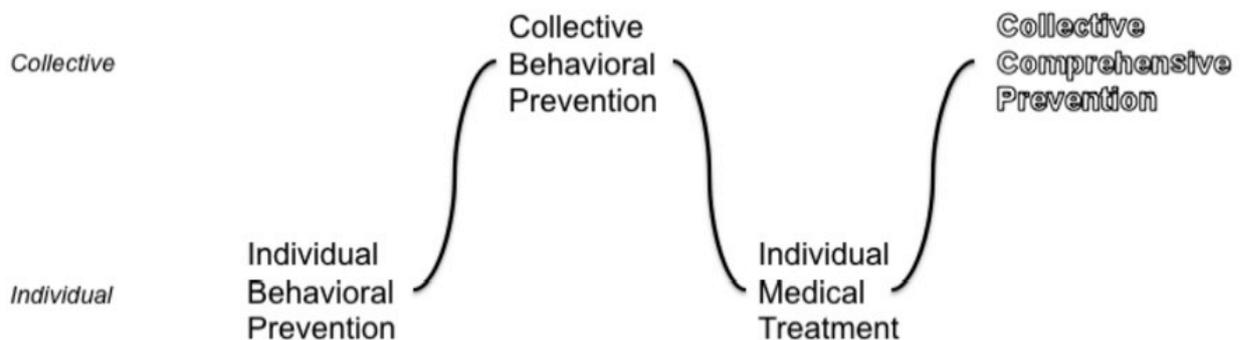
Although scholars and advocates in the health and human rights movement have talked passionately about a human right of access to essential medicines,^{lvii} this medicines debate has proved the limit of legal advocacy. Despite substantial evidence that medicines alone cannot reduce the global HIV burden, activists continue to demand that these therapies—beyond the reach of most in the developing world—should be universally available. Accused of operating without regard for national resource limitations and at the expense of universal public health measures, this activist litigation to realize the highest attainable standard of health for each individual has been criticized for resulting in programs that: promote selective medical care over primary health care, distort health policy in ways that take resources away from other diseases, undermine national health equity through privileging legal claims, and

entrench power rather than empowering the vulnerable.^{lviii} Notwithstanding the rights-based rhetoric that “universal access” includes prevention as well as treatment, access remains primarily equated with treatment, denying prevention policy the operational specificity and rights-based accountability necessary for programmatic implementation.^{lix} While AIDS is no longer considered exceptional, this focus on treatment—to the detriment of prevention—is a public health aberration that has distorted rights-based HIV policy.

DISCUSSION: A HUMAN RIGHTS BASIS FOR PREVENTION

Where the health and human rights movement has been incapable of moving beyond access to treatment, focusing strategically within the limits of international law, this analysis finds that these limitations stem from an inability of human rights to speak with the collective voice through which HIV prevention must be heard. Enforced as an individual right against a state duty-bearer, these inherently limited, atomized rights—a remnant of post-War Western thought—have proven incomplete in creating accountability for global HIV prevention policy in a globalized world, leaving deteriorating national health systems that lack the ability to address an expanding set of public health prevention claims. With human rights in HIV developing from individual behavioral prevention to individual medical treatment, it becomes necessary for this sinuous evolution—as depicted in figure 1—to encompass collective comprehensive prevention.

Figure 1: The Evolution of Human Rights: Wavering between Individual and Collective HIV Policy



Where scholars have contributed ethical arguments positing moral obligations to shift global priorities from treatment to prevention,^{lx} there is a need to ground these prevention frameworks in international law while maintaining the political commitments attendant to treatment. To bridge the growing disconnect between individual rights litigation and public health imperative, international law must incorporate collective rights to public health – rights of societies that can account for obligations to realize underlying determinants of HIV prevention through primary health care systems.

Collective rights operate in ways similar to individual rights; however, rather than seeking the empowerment of the individual, collective rights act at a societal level to assure cost-effective public benefits that cannot be fulfilled through the absolutist mechanisms of individual entitlements.^{lxi} Despite the inherent conceptual weaknesses attendant to such nascent rights frameworks, collective rights claims have shown themselves effective in

responding to a globalized world, shifting the balance of power in international relations and creating widely recognized, if not always realized, entitlements within the international community.^{lxii} In shifting the human rights debate in HIV from treatment to prevention, collective rights can prove a synergistic means to individual capability, health equity, and public health utility:

- At an individual level, collective rights can address health capability through prevention, empowering individuals vulnerable to infection—including the young, women, men who have sex with men, intravenous drug users, and commercial sex workers—to control their own functioning for health without relying on their partners to remove the threat of HIV.^{lxiii}
- Moving from individual agency to population-level agency, collective rights can assure equity, reducing unjust health disparities across groups by focusing not simply on the number of individuals on treatment but on the demographic distribution of prevention.^{lxiv}
- At a societal level, collective rights can ensure rights-based utility through the public's health, with prevention serving as a public good – protecting all of society by: blunting the chain of HIV infection; reducing burdens of mortality and morbidity through “herd immunity;” and improving productivity among the healthy population, treatment efficiency in caring for a smaller infected population, and reduction in drug resistance.^{lxv}

Where individual rights are incapable of securing the public good of disease prevention, incapable of addressing the rights of those who are not infected, the collective enjoyment of public health can be seen as a precondition to the individual human right to health, with public health prevention addressing collective determinants of health outside the control of the individual and supporting societal-level health benefits for the common good.

Thus, collective rights to public health can provide a legal framework for asserting HIV prevention as a legal duty of the state, with international obligations arising where the state is unable or unwilling to assert its authority to control the spread of HIV.^{lxvi} Implemented through the active support of developing states for collective rights and buttressed by the rhetorical force of health and human rights networks, such an approach could be codified in international law and incorporated into political advocacy for HIV prevention, framing institutional reforms, budgetary commitments, and accountability mechanisms in national policy and international organizations. Operating at both domestic and international levels, such collective rights would empower states to seek or provide international assistance and cooperation for HIV prevention in accordance with their respective abilities – meeting global public health goals through national primary health care systems and examining national-level epidemiologic data through human rights adjudicatory bodies. As with other rights-based movements, the interplay between rights-based legal developments and rights-based social justice movements would create a mutually reinforcing accountability in the progressive realization of collective rights for HIV prevention.^{lxvii}

Such a collective lens comports with the rights-based approach advocated by those who have proposed early treatment as a means to the public health benefits of prevention:

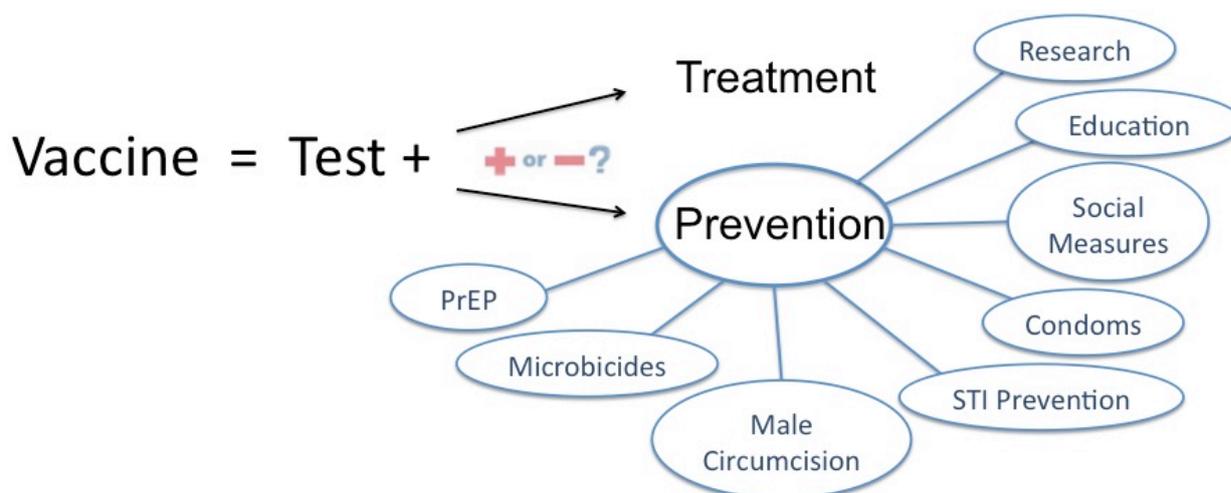
Expanded HIV testing and immediate treatment would offer opportunity for highest quality positive prevention, a holistic approach that protects the physical, sexual, and reproductive health of individuals with HIV, and maximally reduces onward transmission. Provided coercion is avoided and confidentiality and dignity maintained, individual health and societal safety should benefit through reduced HIV transmission, which would enhance human rights overall.^{lxviii}

While concerns have been voiced that such a “test and treat” model would pose the risk of individual human rights violations,^{lxix} particularly as routinized HIV testing has become the consensus recommendation of global health policymakers,^{lxx} the preponderance of debate has surrounded the prospect of collective human rights benefits from public health prevention, contemplating the programmatic feasibility of early treatment to lower HIV infectivity and thereby reduce the societal incidence of HIV.

Yet despite the collective advantages of this test and treat model, this model leaves out the rights of those who are not HIV-positive, denying them the capability to prevent infection and stem the tide of the HIV pandemic. If collective rights are to frame a public health gateway to access for all, global health governance must assure that everyone can come together to reduce the incidence of HIV toward zero – normalizing HIV testing, reducing stigma, and increasing health system utilization through both treatment (for those who are positive) and prevention (for those who are negative).

In operationalizing a collective right to prevention for the progressive reduction of HIV transmission, the most obvious approach would be to develop an AIDS vaccine and require its universal application to those who are HIV-negative. Implemented efficiently, a vaccine would promote equitable societal-level protection against disease—offering full or partial protection from HIV, regardless of group or status—while placing few additional demands on national primary health care systems.^{lxxi} Similar to the eradication of smallpox, such a universal vaccination campaign, supporting the public good of disease elimination, would be uniquely conducive to a collective rights-based approach to prevention. However, in a world without the immediate prospect of a vaccine,^{lxxii} the most realistic operationalization of collective rights would be—as diagrammed in Figure 2—the holistic combination of individual treatment and collective comprehensive prevention.

Figure 2: The Rights-Based Equivalency of Universal Vaccination and Universal Treatment and Prevention



Implemented in combination, such an approach would be the rights-based equivalent of vaccination – with each prevention intervention only partially effective but together serving as a more perfect societal barrier against a rise in HIV incidence. To assure the country-specific scale-up of HIV testing, treatment, and prevention—providing rights-based frameworks by which interventions are appropriate to the resources and epidemiology of the nation and are available, accessible, acceptable, and of effective quality—the implementation of collective rights through global prevention policy will become crucially important as research advances, technologies are distributed, and national health systems expand for HIV prevention.

CONCLUSION: PREVENTION FOR THE PUBLIC'S HEALTH

With human rights bearing a vital role in the development of global AIDS policy, collective rights can frame the obligations of global health governance, projecting a vision of greater justice by addressing the public's health through HIV prevention. Given the disproportionate funding targeted at HIV treatment—with AIDS activists successfully elevating universal treatment as a paramount goal in global health policy—human rights advocates must not fall prey to this absolutist activism, but rather should do what they always have done – represent the most vulnerable in order to give hope for life with dignity. While a collective rights-based approach will necessarily involve tradeoffs, bearing the immeasurable cost of individual lives lost for the societal benefit of public health prevention, such tradeoffs will be essential to assuring the conditions underlying HIV protection for all.

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