



Treatment Action Group

**Treatment Action Group Submission to the Office of the High Commissioner for Human Rights
Input to HRC resolution 47/17**

9 February 2022

1. Treatment Action Group (TAG) is pleased to submit this input to Human Rights Council resolution 47/17 to the Office of the High Commissioner for Human Rights (OHCHR). TAG is an independent, activist, and community-based research and policy think tank committed to racial, gender, and LGBTQ+ equity; social justice; and liberation, fighting to end HIV, tuberculosis (TB), and hepatitis C virus (HCV). We catalyze open collective action by affected communities, scientists, and policymakers to ensure that all people living with or impacted by HIV, TB, or HCV—especially communities of color and other socially and economically marginalized communities experiencing inequities—receive life-saving prevention, diagnosis, treatment, care, and information.
2. The HIV Project at TAG works to maximize equitable, affordable access to the tools, services, policies, and approaches to care that we know can end HIV. With a focus on ethical and community-engaged dissemination of preventative, therapeutic, and curative biomedical innovations, TAG strives to ensure access—unencumbered by social or economic barriers—to effective interventions among populations within the United States and globally that are most heavily or disproportionately impacted by HIV.
3. The 2021 Political Declaration on HIV and AIDS sets important objectives based in human rights, in particular the right to the highest attainable standard of health; the right to life; the right to non-discrimination; and the right to participation.
4. Unfortunately, the Political Declaration does not reference an important human right that is central to the health goals, including those on HIV/AIDS, in the 2030 Agenda for Sustainable Development: the right to enjoy the benefits of scientific progress and its applications (right to science). As a cultural right, scientific progress is itself a key societal enabler of the HIV/AIDS response and a constitutive element of other societal enablers recognized in the Political Declaration. **We ask that OHCHR explicitly introduce the right to science as a fundamental human right and critical enabler of the HIV/AIDS response in its report to the HRC at its 50th session.**
5. Constituted in the International Covenant on Economic, Social and Cultural Rights (ICESCR) Art. 15 (1) (b), (2), (3) and (4),¹ and analyzed in the 2020 General Comment 25 (GC25) by the Committee on Economic, Social and Cultural Rights (CESCR),² the right to science establishes state obligations to develop, diffuse, and conserve scientific progress and its benefits. It defines values of participation, access, non-discrimination, and international cooperation in science as integral to responding to health challenges.³ The relevant sections on the right to science in the ICESCR read as follows:
 - a. Art. 15.1. “The States Parties to the present Covenant recognize the right of everyone: (b) To enjoy the benefits of scientific progress and its applications;”
 - b. Art. 15.2 “The steps to be taken by the States Parties to the present Covenant to achieve the full realization of this right shall include those necessary for the conservation, the development and the diffusion of science [...]”;
 - c. Art 15.3 “The States Parties to the present Covenant undertake to respect the freedom indispensable for scientific research [...]”; and

¹International Covenant on Economic, Social and Cultural Rights. Article 15. <https://www.ohchr.org/en/professionalinterest/pages/cescr.aspx>

²E/C.12/GC/25

³ Treatment Action Group. Letter to OHCHR re. COVID-19 and the right of everyone to participate in and enjoy the benefits of scientific progress and its applications. https://www.treatmentactiongroup.org/wp-content/uploads/2020/07/letter_to_OHCHR_COVID-19_and_right_to_science.pdf

- d. Art. 15.4 “The States Parties to the present Covenant recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific [...] fields.”
6. Under the right to science, States as duty bearers are obligated to ensure that everyone can share in the benefits of scientific advancement. States are also obligated to take steps to support scientific advances (i.e., develop), share tangible and intangible benefits of science including e.g., knowledge, therapeutics, diagnostics, etc. (i.e., diffuse), and provide a framework to sustain scientific knowledge and advances for future generations (i.e., conserve). Simultaneously, States must work to protect scientific freedom and support international cooperation.
7. TAG has witnessed how scientific advances can transform the course of an epidemic when States support science through e.g., investing in research and development (R&D) and disseminate its benefits. Grave harm results from States’ inattention to the development and diffusion of science.
8. The strong interdependence of the right to science, the right to health, and other human rights was expressed in GC25 where CESCR articulated the obligation of States to “Ensure access to those applications of scientific progress that are critical to the enjoyment of the right to health and other economic, social and cultural rights.”⁴ TAG’s work with communities and scientists on the frontlines of the HIV epidemic, as well as the intersecting epidemics of TB and HCV, clearly demonstrates how science policy is human rights policy in the context of health. The human rights dimensions of science policy manifest in the HIV/AIDS response in several ways, appearing in bold and explored below.

Science policy as human rights policy manifests in the **right to participation** in all domains of the HIV/AIDS response, particularly in research and in processes to determine effective, equitable, and culturally congruent dissemination of health technologies and strategies stemming from research.

9. As GC25 explains, the right to science “encompasses not only a right to receive the benefits of the applications of scientific progress but also a right to participate in scientific progress.” In CESCR’s authoritative interpretation, the right to science makes no rigid distinction between scientists and the general public. This validates the rich tradition of community engagement in global HIV/AIDS research and policy formulation and reaffirms ethical pillars of the HIV/AIDS response such as the Denver Principles and the Greater Involvement of People with AIDS (GIPA).
10. Through the GIPA principles, people affected by HIV/AIDS and its major co-infections TB and HCV have participated in shaping the scientific research agenda through mechanisms such as community advisory boards. The meaningful participation of people living with HIV in research must be both safeguarded where it already exists and strengthened where it is still lacking.
11. In a positive example, the U.S. National Institutes of Health-funded Community Partners program used the right to science to create a tool called the Representative Studies Rubric, designed to assess and encourage the participation of underrepresented groups in HIV clinical trials sponsored by the NIH, noting that the right to science framework necessitates a conscious, active approach to equal representation of all communities affected by HIV/AIDS in research.⁵
12. Recent examples of where communities affected by HIV have been excluded from the HIV/AIDS research agenda include inadequate engagement of heavily impacted populations during the earliest stages of research prior to regulatory approvals of oral PrEP; and exclusion of people assigned female at birth from initial trials of emtricitabine-tenofovir for PrEP. Other examples are suboptimal

⁴ E/C.12/GC/25. See also: Shaheed F. Report of the Special Rapporteur in the field of cultural rights, the right to enjoy the benefits of scientific progress and its applications. A/HRC/20/26. 14 May 2012.

⁵ See, Office of HIV/AIDS Network Coordination: <https://www.hanc.info/content/dam/hanc/resources/RSR-HANC-Website.pdf>

engagement of racial/ethnic minority populations and transgender populations in HIV cure-focused research⁶ as well as in U.S.-based vaccine clinical trials, including pediatric trials; although there has been progress toward higher representation of female adults⁷ and successful inclusion of sexual and gender minorities in some prevention trials (e.g., HPTN 085/HVTN 704).⁸

Science policy as human rights policy manifests in a **right of access** to the tangible and intangible results of scientific research on HIV/AIDS.

13. GC25 states that the right to science is underpinned by accessibility, acceptability, affordability, and quality (AAAQ) values. GC25 defines access as encompassing 1) intangible goods such knowledge and information, but also 2) the material results of scientific progress such as medicines and vaccines, as well as 3) the means, methods, and materials of scientific discovery.
14. As early as the 2006 Consolidated Version of the International Guidelines of HIV/AIDS and Human Rights, UNAIDS took note of the right to science, stating “In recognition of the human right to share in scientific advancement and its benefits, States should adopt laws and policies, at the domestic and international levels, ensuring that the outcomes of research and development are of national and global benefit, with particular attention to the needs of people in developing countries and people who are poor or otherwise marginalized.”⁹ More recently, UNAIDS’s leadership in the People’s Vaccine Alliance is an example of UNAIDS already supporting a right to science framework.
15. UNDP-sponsored reports of the Global Commission on HIV and the Law (2015 and 2018), and the report by the UNSG High-Level Panel on Access to Medicines invoke the right to science as a platform for States to address “the incoherencies between international human rights, trade, intellectual property rights and public health objectives.”¹⁰ The opening paragraph of the UNSG’s Report mentions the right to science alongside the right to health as necessary to achieve the vision of SDG3 on Health.
16. Of particular importance in today’s scientific landscape, TAG’s HIV Project is committed to advocating for maximal access to long-acting technologies for HIV treatment and prevention, which are critical for achieving goals of national and international strategic plans to reduce and ultimately altogether end new diagnoses of HIV.

Science policy as human rights policy further manifests in **the obligation of States to develop, disseminate, and conserve science** on HIV/AIDS and its major co-infections including TB and HCV.

17. The ways in which science is financed, conducted, owned, and disseminated can either advance or undermine the realization of other human rights. In HIV, tremendous scientific progress, coupled with generic competition and strong pro-access norms, has improved treatment regimens to the point of simple, safe, and effective single-pill regimens now taken by over 22 million people globally.

⁶ Flores, L. E., Frontera, W. R., Andrasik, M. P., del Rio, C., Mondríguez-González, A., Price, S. A., Krantz, E. M., Pergam, S. A., & Silver, J. K. (2021). Assessment of the inclusion of racial/ethnic minority, female, and older individuals in vaccine clinical trials. *JAMA Network Open*, 4(2), e2037640-e2037640. <https://doi.org/10.1001/jamanetworkopen.2020.37640>

⁷ Curno, M. J., Rossi, S., Hodges-Mameletzis, I., Johnston, R., Price, M. A., & Heidari, S. (2016). A systematic review of the inclusion (or exclusion) of women in HIV research: From clinical studies of antiretrovirals and vaccines to cure strategies. *Journal of Acquired Immune Deficiency Syndromes*, 71(2), 181-188. <https://doi.org/10.1097/qai.0000000000000842>

⁸ See: https://www.hptn.org/research/studies/704_085

⁹ OHCHR/UNAIDS. International Guidelines on HIV/AIDS and Human Rights. See e.g. para. 42 and 125. <https://www.ohchr.org/documents/publications/hivaidsguidelinesen.pdf>

¹⁰ See report of the UNSG High-Level Panel on Access to Medicines: <http://www.unsgaccessmeds.org/final-report/>

18. State inattention to the development and diffusion of science contributes to human rights violations. TB kills more people than any other infectious disease second to COVID-19 and is the leading cause of death among people living with HIV. Only three new drugs to treat TB have been developed in the last 40 years; and funding for TB R&D has never exceeded one-third of the estimated level required.¹¹ The result is an anemic innovation system that has left patients and health systems reliant on outdated and inadequate technologies to prevent, diagnose, and treat TB.

Science policy as human rights policy further manifests in the **right to nondiscrimination** at the heart of the HIV/AIDS response.

19. Scientific advances paired with a science-based legislative and policy environment can shift cultural perceptions of disease. At the community level, improved understandings of disease dynamics or new technological capabilities may aid efforts to combat stigma and discrimination. Scientific knowledge can also strengthen legal petitions for redress of disease-related harms.
20. For example, definitive determinations from scientific inquiries that HIV is non-transmissible by people living with HIV who have sustained viral suppression, nor transmissible to people who use either oral or injectable preexposure prophylaxis, provide the basis for repeal of laws that criminalize potential sexual exposure or transmission of HIV. Repealing laws criminalizing behavior, e.g., same-sex behavior and drug use, would contribute towards reducing fear of these communities to participate freely and voluntarily in certain types of HIV-related research, while at the same time reducing risk of acquiring HIV for communities that experience criminalization of behavior.¹²
21. TAG also asks OHCHR to address the negative impact the ongoing COVID-19 pandemic has had on HIV/AIDS. Many of the right to science concepts that have contributed to the success of the AIDS response have been lacking in responses to COVID-19, in particular participation and AAAQ. A right to science framework would allow policy makers to make connections across HIV/AIDS, COVID-19, other co-morbidities, and social determinants of health and thus yield synergistic benefits for all people.
22. The right to science is of urgent relevance to global AIDS response. The obligations and entitlements the right evokes must be part of future planning and implementation of the Political Declaration goals. Still, science alone cannot end AIDS. The right to science framework, with its close interconnection with other human rights, provides an additional framework and set of tools to support a rights-based response to HIV/AIDS by States, UN bodies, and civil society. Without a right to science framework, we will not succeed in realizing the right to health and making an AIDS-free world a reality.

¹¹ See Treatment Action Group and Stop TB Partnership reports on TB research funding: <https://www.treatmentactiongroup.org/resources/tbrd-report/>

¹² See for example: Millet et al. Common roots: a contextual review of HIV epidemics in black men who have sex with men across the African diaspora. 2012. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(12\)60722-3/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(12)60722-3/fulltext)