



Treatment Action Group

Treatment Action Group Response to Questionnaire on the Implementation of Cultural Rights and Sustained or Emerging Issues

October 24, 2018

A. Background

1. Treatment Action Group (TAG) is delighted to submit the below response on the occasion of the 10th Anniversary of the Cultural Rights Mandate.
2. TAG, established in January 1992, is an independent, activist and community-based research and policy think tank fighting for better treatment, prevention, a vaccine, and a cure for HIV, tuberculosis (TB), and hepatitis C virus (HCV). TAG works to ensure that all people with HIV, TB, or HCV receive lifesaving treatment, care, and information. We are science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions. TAG catalyzes open collective action by all affected communities, scientists, and policy makers to end HIV, TB, and HCV.
3. The practice of science; scientific knowledge and understanding by affected communities; exchanges about science between public and private institutions, scientists, affected community and policy makers; and advocacy for development of scientific advances and their diffusion have always been at the core of TAG's vision.
4. TAG has seen the transformative impact scientific advances can have on the course of an epidemic when states both support science --e.g., through research and development (R&D)-- and take concerted steps to disseminate its benefits. We have also witnessed the grave harm that results from states' inattention to the development and diffusion of science.
5. A central part of TAG's efforts is to increase stakeholders' awareness of the right to science and its application. The work of the mandate, in particular the earlier reports exploring the dimensions of access, have allowed TAG and partners to reframe existing issues from a right to science perspective, as well as deploy a human rights framework for underexplored issues of concern.
6. TAG seeks to illuminate the right's relationship with other human rights. These include but are not limited to: the right to health, the right to non-discrimination and equitable access, the right to participation and self-determination, the right to information, the right to privacy, the rights of migrants, the rights of indigenous people, freedom of assembly, and freedom of association.
7. Based on TAG's experiences, we believe it is imperative to increase states' attention to and normative understanding of the right to science.

B. Right to Scientific Progress

I. The right in legal and policy frameworks

8. The content of this submission makes clear that TAG has encountered many more shortcomings of state obligations than we have discovered positive examples of progressive applications of the right to science and its dimensions of access.
9. During research for TAG's submissions to the Universal Periodic Reviews (UPR) of the United Arab Emirates (UAE) in 2017¹, the United Mexican States (Mexico)² and People's Republic of China (China)³ in 2018 analyzing the states' compliance with right to science, TAG was heartened to see that the UAE and Mexico reference the right to science in their regional human rights frameworks, i.e., The Arab Charter on Human Rights Art. 42 and the American Convention on Human Rights Art. 26 together with the Charter of the Organization of American States Art. 34, 38, and 47, respectively.
10. Representation of the right to science in states' national legal and policy frameworks, however, remains weak or non-existent.
11. While CESCR has referenced the right to science, it had not previously been an aspect of each state's reporting under the UPR, nor had parallel civil society submissions referenced the right. As follows, concluding UPR recommendations to each state did not include emphasis on the right to science.
12. TAG has been actively engaged in the drafting process for the General Comment (GC) for Article 15 of the ICESCR; in October 2018 TAG submitted oral and written interventions to the day of general discussion (see Annex I). TAG strongly believes that the GC, with additional thematic reports by the Special Rapporteur, will play an important role in mainstreaming the understanding of the right to science among stakeholders. Additional normative guidance and the consideration of minimum core obligations will strengthen states' ability to begin reporting on the right to science.

II. Sustained and Emerging Issues

13. States' inattention to their obligations under the right to science can contribute to human rights violations. Similarly, the ways in which science is financed, conducted, owned, and disseminated play a large role in advancing human rights.

¹<http://www.treatmentactiongroup.org/content/tag-statement-human-rights-council-human-rights-concerns-uae>

² <https://www.ohchr.org/EN/HRBodies/UPR/Pages/UPRMXStakeholdersInfoS31.aspx>

³ <https://www.ohchr.org/EN/HRBodies/UPR/Pages/UPRCNStakeholdersInfoS31.aspx>

14. Though TB is the world's deadliest infectious disease, only two new drugs from new drug classes have been developed to treat TB in the last 40 years, and funding for TB R&D has never exceeded one-third of the estimated level required.⁴
15. Similarly, state inattention inhibits access to safer treatment regimens and more accurate diagnostic tools that already exist.
16. In the context of non-discrimination, scientific advances can shift cultural perceptions of disease. For instance, the breakthrough of direct-acting antivirals (DAAs) has made HCV curable for over 95% of people in 12 weeks. In places where HCV transmission is criminalized, however, or where treatment is rationed in ways that exclude certain groups' (e.g., people who use drugs) access, diagnosis may reify stigma and other harms despite the availability of a cure.
17. Scientific knowledge can strengthen legal routes to redress disease-related rights violations. For example, knowledge of TB transmission dynamics, such as understanding that the disease is rapidly rendered noninfectious after starting effective therapy, could ensure that limitations on the freedom of movement placed on people with TB are evidence-based, time-limited, proportional to the potential public health risks at hand, and not taken as justification for limiting other rights.
18. For UPR submissions on the UAE, Mexico, and China, TAG analyzed states' obligations under the right to science with regards to ending the TB epidemic. TAG's submissions paid particular attention to a) the right's dimensions of access; b) the right's relationship with other human rights; and c) global recommendations by United Nations (UN) agencies, incl. World Health Organization (WHO).
19. In each country, TAG has found state laws and practices that impede rather than incentivize broad access by persons from marginalized groups to information as well as the benefits and applications of scientific advancement. Infectious disease laws and policies often directly undermine right to science obligations, while other laws and policies violate human rights that are central to realizing the right to science.
20. In the UAE, unscientific screening methods are used to deport migrants that may have had or may currently have TB. First-time migrants found to have lung scars are deported, often without any access to their medical records nor complete communication on their actual state of health, without any scientific basis for deportation (lung scars are not an accurate sign of current/previous TB infection or disease).
21. The same migrants sometimes are subject to unscientific and medically unnecessary deprivation of liberty in the form of forced isolation prior to deportation.

⁴ Treatment Action Group. The ascent begins: report on TB research funding trends, 2005–2016. New York: Treatment Action Group; 2017.

22. In China, one example of inequities in access manifests most acutely in the context of drug-resistant (DR) TB. In 2016, only 50% of notified DR-TB cases started treatment. An even greater number of people with DR-TB were not notified, indicating they went undiagnosed or their diagnosis was never reported to China's National TB Program. Of the total estimated number of people in China who develop DR-TB each year, only 8% start treatment.⁵
23. Persistent anecdotal evidence suggests forced testing and treatment in Chinese detention settings alongside limited access to necessary medication.
24. In Mexico, TAG found that the state clearly fails its obligations to diffuse scientific benefits in an equitable manner. The shortcomings pertain not only to the material lack of health products, but also to the lack of policies on their use, the disarray of procurement systems, and the lack of investment in research to ensure the availability of better innovations required to end TB. This results in TB cases often going undiagnosed, and those that are diagnosed may have to significantly delay treatment due to unavailability of medicines. Many die before receiving treatment.
25. Often, international property (IP) regimes add to these grave challenges of affordable access, a critical element of diffusion.
26. The 2016 final report of the Secretary General's (SG) High-Level Panel on Access to Medicines (HLPAM) highlights the utility of states drawing on the right to science to "remedy the policy incoherence between the justifiable rights of inventors, international human rights law, trade rules, and public health in the context of health technologies." The prevailing research and development (R&D) system is market driven and defined by the maximalist approach to the intellectual property protection as established by the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS). As such, public health needs are neglected in favor of lucrative conditions. In response, the SG HLPAM report notes the importance of the right to science in "resolving the incoherence between market-driven approaches [to R&D] and public health needs."
27. State laws regularly fail to account for the fact that publicly funded research contributes to scientific results that end up being commercialized, i.e. the intellectual property resides with private owners or private sector actors. The public often must pay twice—first to develop the science, and again through public payor systems, to pay for the new technology, e.g., a drug or vaccine, at a price set by a private developer.
28. Over the past decade, a proliferation of free trade agreements and bilateral investment treaties have supplanted the multilateral TRIPS Agreement. These treaties include

⁵ WHO Global TB Report (2017). http://www.who.int/tb/publications/global_report/en/

far-reaching provisions that lengthen the duration of patent protection, prolong data exclusivity terms, and strengthen investment-dispute mechanisms. More stringent IP provisions and political pressure from negotiating governments, influenced by patent-owning corporations, prevent states from exercising their rights and flexibilities (e.g., compulsory licenses) under the TRIPS Agreement that enable technology transfer and generic production of medicines.

29. Analysis of IP applications filed and granted show a significant North-South divide, i.e., the majority of patents, including for health technologies and medicines, are registered in high-income countries. As a result, scientists and researchers in low and middle-income countries (LMICs) face lengthy wait periods and pay exorbitant fees to obtain data. Scientists in LMICs that participate in regional or global R&D networks may not see the fruits of their scientific labor made available in their own country due to restrictive licensing and unaffordability of the technology (i.e., medicine prices) under patent monopolies.
30. These factors have supported a trend to misuse the IP system to protect monopolies and weaken patentability criteria. Thus, states face additional hurdles to guarantee development and access to scientific advances.
31. To counter this development, several states - including Brazil, India, and South Africa - have included stronger patentability criteria in their regulations and have re-examined the validity of patents on some medicines, including DAAs.

III. Lessons Learned and Recommendations

32. TAG's own evolution exemplifies how scientific knowledge coupled with human rights expertise in the hands of community-based activists has been vital for achievements in the global HIV/AIDS, TB, and HCV movements. Therefore, TAG uses various platforms to mainstream knowledge of the right to science among community actors and other stakeholders.
33. One benefit of TAG's engagement in the UPR process is that it makes issue-based analyses of states' compliance with the right to science available as public record. This allows local activists to develop and access structured and human rights-based recommendations for their work.
34. Building on experience of mainstreaming the right to health, grassroots organizations and actors need to be aware that the right science in fact exists; how it complements their existing human rights advocacy; how it supports their claims and demands of their states, i.e. that their states have in fact obligations to develop and diffuse scientific advancements. TAG has developed the *Know Your Rights Guide*⁶ for TB,

⁶ <http://www.treatmentactiongroup.org/content/know-your-rights-tuberculosis-prevention-diagnosis-and-treatment-guide>

available in eight languages. Often, this is the first time readers encounter the right to science. Much more accessible information and learning opportunities are needed to support mainstreaming the right to science as a tool for community participation and advocacy.

35. States, UN Human Rights Mechanisms, Treaty Bodies and UN agencies similarly need to be educated on the right to science. While TAG's submission to the China UPR was mentioned in the summary of stakeholder information, it was listed under right to health, even though the submission referenced right to science throughout as its normative basis.

36. In order to mainstream the right to science, TAG recommends that the SR:

- a. Issue additional thematic reports on the right to science, in particular on:
 - i. the rights' relationship with other human rights and within specific contexts;
 - ii. the need to ensure all research, development, and implementation evaluations of experimental and existing biomedical prevention modalities meaningfully prioritizes highly affected, but often neglected, populations. These include youth, unstably housed individuals, transgender men and women, sex workers, people of color, undocumented migrants, refugees, and people with disabilities; and
 - iii. the dynamics of IP and R&D in the context of access to medicines. E.g. explore the benefits of a global binding R&D financing agreement that places responsibility on all states for catalyzing development of needed health technologies, including for non-communicable, rare, and neglected diseases.
- b. Explore initiatives to sensitize UN agencies, Treaty Bodies, Special Procedures etc. to the right to science, e.g. through joining forces with other SR to issue thematic reports, guidelines, and fact sheets.
- c. Explore instances in which interagency coordination and coherence is needed to realize the right to science. Issue analyses and guidance for mitigation.
- d. Provide normative guidance to CESCR and the UPR procedures that aid development of guidelines for state reporting on the right to science.
- e. Emphasize in public declarations that science and medicines are considered public goods and that national laws should prioritize public health interests above stringent intellectual property protections.
- f. Examine the limits of IP as an incentive to innovation and promote alternative incentives to innovation, e.g., the "3Ps" model (push, pull, pool financing, data,

trials, research collaboration). The 3Ps model considers alternative financing and licensing mechanisms for innovation, e.g., government or collective ownership of a scientific innovation which could be subject to non-exclusive licensing, or financing R&D with prize funds.

- g. Review the relevance and applicability of the open software development model, focused on academic freedom as providing the freedom to research, which guarantees the researcher/developer a return on investment, attribution, and adequate remuneration.
- h. Promote the formation of partnerships that follow open source and collaborative research networks, e.g., McGill University Neuroscience Institute and India's Open Source Drug Discovery.
- i. Express support for the global access licensing framework, developed by University Allied for Essential Medicines, that strives for every university-developed technology with potential for further development into a drug, vaccine, or medical diagnostic to be licensed with a concrete and transparent strategy to make affordable versions available in resource-limited countries.