

Treatment Action Group

Written contribution by Treatment Action Group to the day of general discussion on Article 15 of the ICESCR: *on the right to enjoy the benefits of scientific progress and its applications*

1. Treatment Action Group (TAG) thanks the Committee on Economic, Social and Cultural Rights (CESCR) for its work to prepare a General Comment to provide guidance to States parties on the normative content of ICESCR Article 15, the right to enjoy the benefits of scientific progress and its applications (hereafter, the right to science). For the communities of people affected by the epidemics of HIV, tuberculosis (TB), and hepatitis C virus (HCV) that we represent, this is a timely and vitally important discussion.
2. TAG is an independent, activist, and community-based research and policy think tank fighting to end the HIV, TB, and HCV epidemics. We are science-based treatment activists working to expand and accelerate research and effective community engagement with research and policy institutions, and we work to ensure that all people with TB, HIV, and HCV receive lifesaving treatment, care, and information.
3. For several years, the right to science has provided the central frame for our advocacy and community engagement work. We have seen both the transformative impact scientific advances can have on the course of an epidemic when states support science through e.g., research and development (R&D) and take concerted steps to disseminate its benefits. We have also witnessed the grave harm that results from state inattention to the development and diffusion of science. And we have worked hard to raise awareness of the right among communities and scientists confronting HIV, TB, and HCV.
4. Based on these experiences, we believe that greater state attention to the right to science will be necessary to end these three epidemics, in line with the targets of Sustainable Development Goal 3, as well as advance other important health and development objectives of the 2030 Agenda. The guidance and clarity this Committee can provide to States parties on the normative content of the right will therefore be invaluable.
5. Among the many topics of discussion before the CESCR as it finalizes the general comment, we wish to call the Committee's attention to three issues. First, the relevance of the right to science in the context of health. Second, the dimensions of access under the right and what this means for corresponding state obligations to conserve, develop, and diffuse science. And third, the importance of recognizing participation as one of the foundational values of the right.

The right to science in the context of health

6. In a 2012 report, Farida Shaheed, former Special Rapporteur in the field of cultural rights, noted the strong interdependence of the right to science and other human rights, including the right to health.¹ Our work with communities and scientists on the frontlines of the TB, HIV, and HCV epidemics clearly demonstrates how science policy is human rights policy in the context of health.

7. In particular, we call the CESCR's attention to the following four human rights dimensions of science in relation to health:
- a. First, 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.
 - b. Second, state inattention to the development and diffusion of science can contribute to violations of human rights. Today, TB kills more people than any other infectious disease, and the World Health Organization has described “the present and future threat that TB poses to human health [as] mainly a consequence of the enormous neglect the TB research field has experienced over the past several decades.”² Only two 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.³ The result is an anemic innovation system unable to keep pace with the spread of drug-resistant TB, leaving patients and health systems to rely on outdated and inadequate technologies to prevent, diagnose, and treat TB.
 - c. Third, advances in science 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—when paired with supportive legal environments. For instance, the advent of direct-acting antivirals has made HCV curable for most people in 12 weeks, potentially lessening the stigma of an HCV diagnosis. In places where HCV transmission is criminalized, however, or where treatment is rationed in ways that deprive certain groups (e.g., drug users) of access, diagnosis may reify stigma and other harms even in the presence of transformative therapeutic potential.
 - d. Fourth, scientific knowledge can strengthen legal petitions for redress of disease-related harms. For example, knowledge of TB transmission dynamics, such as understanding that TB is rapidly rendered noninfectious after starting effective therapy, could ensure that deprivations of freedom of movement often 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.

The dimensions of access under the right to science

8. The four human rights dimensions of science in the context of health enumerated above are all, at some level, questions of access—to knowledge, to information, and to the tangible products of scientific advancement such as new medicines and vaccines. Recognizing this, we urge the CESCR in its general comment to position access as a cornerstone of the right.
9. In keeping with the normative interpretation of other rights in the ICESCR, access under Article 15 should be understood as encompassing multiple dimensions. For example, in General Comment 14, the CESCR framed access under the right to health in terms of four overlapping components: non-discrimination, physical accessibility, economic accessibility (affordability), and access to information. Article 15.2 establishes the obligation of states to take steps “necessary for the conservation, the development, and the diffusion of science and culture.” By speaking of conservation, development, and diffusion together, the Covenant puts forward a concept of access that connects state support for scientific innovation (development) with the obligation of states to ensure all people enjoy the

benefits of science and its applications without discrimination (diffusion), and that the benefits gained through scientific progress are lasting (conservation).

10. Thus, in order to ensure nondiscrimination in access under the right to science, states must distinguish between, on the one hand, the mere availability of scientific benefits that may not be within reach by all, and, on the other hand, the equitable dissemination of such benefits to everyone in need, both present and future generations.
11. In addition, we believe that access is important for both those who contribute to science—including scientists themselves as well as research participants—and for the intended beneficiaries of scientific progress.
12. Importantly, beneficiaries must not be assumed to be consumers in the market sense of purchasers or payers. Here, experience earned through efforts to secure the right to health offers a valuable lesson. In terms of achieving universal health coverage, it has become clear that framing the right to health primarily in terms of consumer rights, as some states have done, has created a barrier to advancing the health related goals of the 2030 Agenda.⁴
13. For beneficiaries, access under the right to science must not only refer to general knowledge, but to the tangible outputs of science. In this sense, we strongly echo the Special Rapporteur's 2012 report, which stated that one aspect of the right to science is "the right to have access to scientific applications and technologies." The Special Rapporteur continued: "One core principle is that innovations essential for a life with dignity should be accessible to everyone, in particular marginalized populations." We encourage the CESCR to devote space in the general comment to defining "innovations essential for a life with dignity," at least in terms of its broad categories. Medical technologies would clearly qualify, especially since access to essential medicines is already seen as a core obligation under Article 12, the right to health.
14. Scientists themselves must be able to access to the means, methods, and materials required for scientific exploration and discovery. Again, in Shaheed's words: "The 'benefits' of science encompass not only scientific results and outcomes but also the scientific process, its methodologies, and tools." Here, we draw the Committee's attention to the work of the American Association for the Advancement of Science, which has proposed a "continuum of access" spanning the general public on one side and scientists on the other. Tools for sustaining and creating access as identified by AAAS include funding, education, training, and communication and information technology.⁵
15. Access is also essential for the non-scientists who make scientific progress possible through, for example, enrolling into clinical trials. The marginalization of certain groups from clinical trials means that the benefits of medical research accrue to some segments of the population but not others. In the TB research field, the prevalent exclusion of children, pregnant women, people with HIV, and persons who use drugs from studies means that the very groups most at risk of the disease are often unable to benefit from new scientific applications because there is not enough evidence to recommend their use in such populations.⁶ The systemic exclusion of certain groups from participation in research—whether intentional or not—reinforces historic forms of marginalization and severely constrains the equity proposition of science.

16. On a larger scale, communities that are unable to access the benefits of science may be less likely to support science through e.g. the provision of public funding or participation in research. In our experience, communities that hold little reasonable expectation of ever benefitting from publicly funded research express less trust in the scientific process and more skepticism about the importance of science for human dignity and development. Equitable dissemination of science and its benefits is therefore necessary for continued public participation in science, a point contained in the 2012 report of the Special Rapporteur: “The diffusion of science is a precondition for public participation in decision-making and essential for fostering further research, development, and applications.”
17. Access under the right to science not only requires attention to diffusion, but also to development. States must invest sufficient financial resources in science and direct these investments in ways that meet the needs of marginalized communities (i.e. “purposive development”).⁷ Because the needs of the poor or marginalized are often left unaddressed by market-driven approaches to innovation in the absence of state action, the purposive development of science is necessary to ensure nondiscrimination in access under the right.
18. States have many tools at their disposal to support the purposive development of science. We draw the Committee’s attention to the recommendations contained in the final report of the UN Secretary-General’s High-Level Panel on Access to Medicines.⁸ The report calls on governments to increase their current levels of investment in health innovation through e.g., the use of innovative financing strategies. In addition, the report encourages governments to take steps to negotiate a binding R&D convention that delinks the cost of R&D from end prices and sales volumes (a concept known as delinkage). Delinkage is a way for governments to incentivize research without relying on high prices or the temporary monopolies afforded by patents to recoup R&D costs.
19. Currently, R&D for TB and other diseases primarily occurs within a system built around a “maximalist approach to intellectual property protection,” principally defined by the Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS).⁹ By setting required minimum levels of protection without specifying upper limits, TRIPS and related trade laws have allowed an ever-upward expansion of intellectual property (IP) protection that has produced a growing misalignment between the interests of inventors—often large, multinational corporations—and health. Using international human rights law to set ceilings on such protections would engender an approach to innovation that does not, from the outset, prioritize protection over access.
20. To this end, we strongly reaffirm the CESCR’s conclusion in General Comment 17 that the “right of everyone to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he or she is the author” [Art 15.1(c)] must not be equated with IP protections as currently defined through global trade agreements. However, many states continue to frame IP rights as human rights in contradiction to the CESCR’s position. We encourage the CESCR to reemphasize the distinction between IP protections and human rights in this new general comment.
21. In short, the right to science should be understood as a vehicle for promoting needs-driven development as an alternative to market-driven approaches. It is essential that purposive investments in science be accompanied by norms and safeguards that create the conditions

required for equitable access. This will require approaches to R&D that take into account human need and not merely market interest.

The importance of participation to the right to science

22. The dimensions of the right to science, its intersection with other human rights, and its application to health include the importance of participation in science and science-based policymaking, and the importance of science for participatory human rights-based policymaking.
23. Participation should unfold across multiple levels. Governments should involve public stakeholders in setting national plans of action to address unmet research needs. These plans should have clear timetables, goals, and milestones, enabling the public to track state progress. In this sense, participation is essential for accountability under the right.
24. As noted above, participation should extend to the inclusion and representation of communities in the scientific process and agenda. Of foremost importance, communities affected by a particular condition or disease should be empowered to participate in research as more than just clinical trial participants. One effective strategy in HIV and TB research has been the involvement of community advisory boards (CABs) in setting the research agenda, overseeing the conduct of trials, and advocating for research results to be made accessible through the translation of evidence into policy and practice. There are multiple guidelines on community engagement—often called “good participatory practice”—that states can consult when establishing CABs or other participatory mechanisms.¹⁰
25. Participation is also essential for honoring the related ethical value of reciprocity. Ethicists have defined reciprocity as returning goods in proportion to those received, and making reparations for harms that have been done. The individuals and communities that participate in research assume real risk in exchange for benefits that are by definition unknown and potential. In doing so, they create the conditions under which science advances—and therefore deserve to receive good in return by enjoying the benefits of science and its applications. This reciprocity should extend beyond any direct participants in science to include the countless others whom research participants stand in for.
26. In the context of health, some ethicists have taken the concept of reciprocity a step further to argue that reciprocity provides “means by which the state can accept responsibility for the conditions that have led to infection and disease.”¹¹ To the extent underlying social and economic conditions give rise to poverty, disease, or social precarity, reciprocity may compel states to invest in science and connect people to its benefits in order to address such conditions and any resulting harms. Action by states should proceed in ways that center affected individuals, not as mere informants, but as actual decision-makers in the conservation, development, and diffusion of science for the public good.
27. We thank the CESCR for the opportunity to raise these issues to its attention and offer our further assistance in developing and disseminating the general comment.

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- ¹ 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.
- ² World Health Organization. Global investments in TB research: past, present, and future. Geneva: World Health Organization; 2017.
- ³ Treatment Action Group. The ascent begins: report on TB research funding trends, 2005–2016. New York: Treatment Action Group; 2017.
- ⁴ Treatment Action Group. Submission to the Office of the United Nations high Commissioner for Human Rights to Report on Sustainable Development Goals and Health. 16 October 2017. <http://www.treatmentactiongroup.org/content/submission-office-united-nations-high-commissioner-human-rights-report-sustainable>
- ⁵ AAAS Science and Human Rights Coalition. Defining the right to enjoy the benefits of scientific progress and its application: American scientists’ perspectives. Washington, D.C.: AAAS; 2013.
- ⁶ Frick M, Henry I, Lessem E. Falling short of the rights to health and scientific progress: inadequate TB drug research and access. *Health Hum Rights*. 2016;18(1):9–24.
- ⁷ Chapman A. Towards an understanding of the right to enjoy the benefits of scientific progress and its applications. *Journal of Human Rights*. 2009;8:1–36.
- ⁸ Final Report of the UN Secretary-General’s High-Level Panel on Access to Medicines. Final report. 2016. <http://www.unsgaccessmeds.org/final-report/>.
- ⁹ Shaver L. The right to science and culture. *Wisconsin Law Review*;2010(1):121–184.
- ¹⁰ See, for example, Critical Path to TB Drug Regimens Stakeholder and Community Engagement Work Group. Good participatory practice guidelines for TB drug trials. Washington, D.C.: CPTR; 2012.
- ¹¹ Silva D, Dawson A, Upshur R. Reciprocity and ethical tuberculosis treatment and control. *J Bioeth Inq*. 2016;13:75–86.