



Treatment Action Group

Committee on Economic Social and Cultural Rights

Draft General Comment: Science and economic, social and cultural rights Art. 15: 15.1b, 15.2, 15.3 and 15.4 | 2 January 2020 draft

Feedback from Treatment Action Group

1. Treatment Action Group (TAG) congratulates the Committee on Economic, Social, and Cultural Rights (CESCR) on the publication of the General Comment (GC) draft. TAG is grateful for the opportunity to contribute to the very strong content and analysis of the right to science.
2. The draft GC analysis illustrates the many concrete ways that the right to science is interrelated, interdependent, and indivisible from other human rights. The right to science is a human right, which is clear not least because of its inclusion in the Universal Declaration of Human Rights (UDHR), and existing real-world application within the human rights framework.
3. TAG strongly supports the articulation of the 3AQ framework detailing the four interrelated and essential elements of the right. TAG encourages CESCR to expand the discussion of what constitutes availability under the right and the corresponding state obligations.
4. The current text of the GC does not define the “steps to be taken by states parties to achieve the full realization of the right,” namely the *conservation, development, and diffusion* of science and culture (Art 15.2). TAG strongly encourages CESCR to define these terms in the GC so that States may better understand their obligations and the range of possible actions. CESCR could adopt the definitions in the 2012 report of Special Rapporteur (SR) Farida Shaheed:¹
 - a. Conservation requires “the identification and safeguarding of scientific knowledge, products and tools, [...]” To this TAG would add that conservation demands ensuring that the benefits and applications of science are lasting i.e., available for the enjoyment of present and future generations.
 - b. Development demands “an explicit commitment to the development of science and technology for human benefit [...] which implies the adoption of programs to support and strengthen publicly funded research.” TAG encourages CESCR to strengthen the discussion of public funding for research within the GC as per suggested edits noted below related to the “purposive development” of science and technology.
 - c. Diffusion encompasses “the dissemination of scientific knowledge and applications both within the scientific community and in society at large...” The GC draft already contains a strong discussion of diffusion; TAG draws CESCR’s attention to the SR’s point that “The diffusion of science is a precondition for public participation in decision-making and essential for fostering further research, development, and applications.” This last aspect of diffusion would benefit from stronger emphasis.
5. Below, TAG presents concrete suggested amendments to the GC draft for CESCR’s consideration. New/revised text is presented in [blue underscore](#).

Para.no.	Comment	Suggested Amendment
¶19	The paragraph regarding interdependence with other rights should more explicitly link to General Comments 13 and 15 on the rights to education	“The development of science is also strongly linked with the enjoyment of the right to education, General Comment 13, and to the

¹ A/ HRC/20/26

	and water, respectively, to frame the right to science in similar ways as a public good.	right to water, General Comment 15, in which both rights protect public goods. Benefits from scientific progress are public goods.
¶121	The discussion of availability is not nearly comprehensive enough and should be expanded. As written, availability only references “the services ensuring access to scientific knowledge” and focuses on dissemination of knowledge without explicit mention that scientific knowledge includes the methodologies as well as tangible <i>benefits</i> or <i>applications</i> of science, i.e. products and tools, as defined in ¶17. The development and conservation elements of the right should be addressed here. For development, availability requires funding R&D, including that which is not purely market-driven (since solutions for many problems are unavailable because they are nonexistent or have not yet been developed—e.g., new medicines for resistant forms of TB or a preventive vaccine for HCV). For conservation, availability requires ensuring that the <i>benefits</i> of science are available to present and future generations.	“Availability refers to the services ensuring access to scientific knowledge and methodologies which everyone can enjoy and use, e.g. libraries, museums, universities, exhibitions, internet networks, etc.; as well as applications and tangible benefits resulting from science, e.g. effective, simpler diagnostics and treatment . State parties are expected to provide adequate support to scientific research, including, for example, research and development for under-resourced and neglected disease areas . State parties are also expected to provide funding to the long-term conservation and dissemination of scientific knowledge and benefits in order to ensure that such knowledge and benefits can effectively be relied upon by current and future generations .”
¶122	This paragraph refers to the physical, financial, and cultural accessibility of “assets and services.” The word assets appears for the first time here, and would be better replaced by the term “benefits” throughout the GC in order to use terminology that the GC has defined. The discussion of accessibility refers to “fair access.” TAG notes that “fairness” as a concept and term is not defined within the GC. Among civil society and within UN reports and political declarations, the term “equitable access” is more common than “fair access” (e.g., see political declarations of recent UN High-Level Meetings on Tuberculosis and Antimicrobial Resistance and the final report of the UN Secretary-General’s High-Level Panel on Access to Medicines). The discussion of the “financial accessibility” of benefits and services should further emphasize affordability. By comparison, GC 14 on the right to health includes the word “affordability” when introducing “economic accessibility (affordability).”	“Accessibility consists in these benefits and services being physically, financially, and culturally accessible without discrimination, both in urban and in rural areas, in the majority and in the minority languages, and for all groups and persons. Financial accessibility (affordability) requires that these benefits and services be affordable for all. ” Replace “fair access” with “ equitable access.” We encourage the same change for relevant text in ¶23. E.g., “States parties should take measures to ensure equitable access by everyone, not only to the process of producing science, but also to its applications and products.”
¶129	The current draft refers to protecting the “free, prior and informed consent” of Indigenous Peoples and ethnic minorities in research. Respecting free, prior and informed consent (FPIC), in accordance with community-determined protocols that outline the FPIC standards and procedures within	“When this research affects specific populations, such as Indigenous Peoples or ethnic minorities, their right to free, prior and informed consent must be protected in accordance to community-defined protocols ,

	customary, national, and international laws and policies, is one of two responsibilities states hold concerning research affecting Indigenous Peoples. The second is that any such research should occur under “mutually agreed terms.” The text should mention both of these principles, which are recognized in the Bonn Guidelines (2002) adopted by the Convention on Biological Diversity (CBD). ²	and states must ensure any such research proceeds under mutually agreed terms.”
¶133–35	An important part of ensuring non-discrimination under the right is action by States to support the “purposive development” (Chapman 2009) of science to meet the needs of vulnerable and marginalized groups, which may not draw industry investment without state intervention. Similarly, the 2012 report of SR Farida Shaheed discusses the obligation of non-discrimination by highlighting specific measures, including “facilitating targeted research by both public and private sector institutions.”	TAG encourages CESCR to add the notion of purposive or targeted development of science to section B. Non-discrimination. For instance, in ¶135 add the sentence: “States should facilitate targeted research and purposively develop science to meet the needs of vulnerable and marginalized groups, ensuring the full and equal participation of such groups in any research directed toward their needs.”
¶136	The lead paragraph on special protections lacks specific reference to exclusion of people of color to remediate and mitigate historical harms and exclusions in the scientific field.	“Temporary special measures are necessary to remediate past inequalities and patterns of exclusion of these groups, actively encourage women, persons of color , and persons of other underrepresented groups to consider careers in sciences, and to eliminate biases against these groups. Without prejudice to the duty of States to eliminate discrimination in relation to all groups, special attention should be paid to women, persons of color , persons with disabilities, and low-income persons.”
¶137–40	The section on special protections for women should include cis- and trans-gender people, with recognition of the specific exclusion and marginalization of women’s needs, throughout these paragraphs. ¶140 should reference the inclusion and needs of pregnant individuals.	Amend ¶140: “A gender-sensitive approach is not a luxury for scientific research but a crucial tool in order that scientific progress and new technologies adequately take into account the special characteristics and needs of all women and girls, including pregnant individuals. ”
¶144	The discussion of equality in this paragraph is another place where CESCR should link equitable access to the purposive development of science to meet the needs of vulnerable and marginalized groups left behind by market-driven innovation.	Add a fourth element to the three-pronged strategy outlined—e.g., “Fourth, since market-driven approaches to innovation can leave the needs of marginalized groups unaddressed, States should support a purposive development of science and technology to ensure that all persons can benefit from scientific progress.”
¶149-51	These paragraphs discuss the need for State Parties to fulfill the right by adopting measures through legislation, budgetary allocations, or participation in global schemes to ensure the financing and dissemination of science. This	To the end of ¶149 add: “The development of model legislation and guidance on such measures, particularly for States with nascent scientific infrastructure, would guide States on the steps to be taken to fulfill the right to

² Bonn Guidelines on Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilization. <https://www.cbd.int/decision/cop/?id=7198>

	<p>sections’ recommendations could be strengthened with specificity on such mechanisms to guide state action on how to legislate in support of the right to science, and consider the breadth of legislative strategies that could shift resources or strengthen a states’ dissemination of science. Model legislation and innovative models, for example can be used to guide science funding in accordance with seeing science as a public good and with respect to States’ other human rights obligations. Similarly, fulfilling the right to science will require creating space for public and community involvement in developing legislation, setting priorities, and allocating budgets.</p>	<p>science. The development of model legislation and guidance could articulate the norms, values, and principles inherent in approaching science as a human right placing both positive and negative obligations on states.”</p> <p>Amend ¶150: “This includes engaging communities and the broader public in approving policies and regulations which foster scientific research, allocating appropriate resources in the budgets and, in general, creating an enabling and participatory environment for the conservation, development and diffusion of science and technology, [...]”</p>
¶151	<p>The GC laudably states that all States should contribute towards the common task of developing science within their budgetary means, calling on poorer countries to spend at least 1% and advanced countries 3% of GDP on R&D. TAG recommends also considering calls to set aside a specific proportion of overall R&D spending to address urgent global challenges or the specific needs of marginalized groups, including through global cooperative frameworks that would pool funding across States. In health, generally, this is backed by the recommendation of the World Health Organization Consultative Expert Working Group on Research and Development report that: <i>“1) Developing countries with a potential research capacity should aim to commit 0.05–0.1% of GDP to government-funded health research of all kinds, 2) Developed countries should aim to commit 0.15–0.2% of GDP to government-funded health research of all kinds.”</i> In the TB response, specifically, this has resulted in the ‘fair share’ funding targets calling on all states to devote 0.1% of their overall spending on R&D to research on TB, recognizing that TB research efforts are a “shared responsibility” (see political declaration of the UN High-Level Meeting on TB).</p> <p>TAG cautions here that State fiscal contributions to science should not justify the unilateral implementation of policies, laws, and measures to limit the diffusion of the benefits of science to other States in the name of protecting IP, national interest, or domestic investments (through e.g., trade agreements).</p>	<p>To the end of ¶151 add: “Other targeted funding frameworks aimed at enhancing international cooperation on funding science-based solutions to address specific and urgent global challenges can also be considered. For example, States can consider devoting a certain percentage of overall R&D spending for health research or research directed toward a particular health concern of global importance, e.g., HIV, TB, or hepatitis C virus.”</p>
¶162–66	<p>TAG commends CESCR for the clear and nuanced discussion of IP and the privatization of research in these paragraphs. We encourage the Committee</p>	<p>To ¶166 add: “States should recognize IP as one of several ways that scientific research is privatized and should take measures to prevent</p>

	to think beyond IP barriers, which focuses the discussion on patents, to recognize that the right to science must embody values, norms, and principles that prevent other forms of monopoly, exclusivity, and anti-competitive practice that are detrimental to the conservation, development, and diffusion of science and technology in accordance with the duty to non-discrimination.	monopolies and anti-competitive practices that limit the sharing of scientific knowledge and access to the benefits of science, e.g. exclusive licensing, trade secrets, or other anti-competitive behavior. ”
¶168	Similar to ¶129, the GC draft would be strengthened by pairing the existing reference to FPIC with references to <i>mutually agreed terms</i> and <i>access and benefit sharing</i> . Currently, this paragraph only cites a set of disciplinary-specific guidelines from the American Anthropological Association. The argument would be strengthened by referencing international law on this subject, including the Bonn Guidelines and the Nagoya Protocol to the Convention on Biological Diversity. ^{3,4}	Amend ¶168: “Consultation in order to obtain free, prior and informed consent, in accordance with community-defined protocols , is necessary, whenever the State party or non-state actors make decisions or create policies related to science that have an impact on indigenous peoples.” To the end of the ¶168 add: “ Any research involving traditional knowledge held by Indigenous Peoples should proceed under mutually agreed terms and in the context of access and benefit sharing agreements between traditional knowledge holders and those that use such knowledge, whether for academic study or commercialization. ”
¶185	Beyond IP barriers, the right to science must embody principles, values, and norms that prevent other forms of monopoly, exclusivity, and anti-competitive practice that are detrimental to the development and diffusion of the benefits of scientific progress.	To the description of the normative framework introduced in ¶185, add: “...measures to harmonize intellectual property with the right of all persons to access science and its benefits; measures to prevent monopolies, exclusive licensing, and other anti-competitive behavior and practices that can privatize science ; and adequate protection against all forms of discrimination.”
¶189	The closing paragraph should reference the right’s grounding in the UDHR. TAG’s history of working at the intersection of AIDS research, policy, and community mobilization demonstrates the power of recognizing a human right to science. AIDS teaches us that science policy is human rights policy, and that policies that attack human rights threaten science. TAG’s work on HIV, TB, and HCV demonstrates that the values, entitlements, and obligations under the right to science discussed in the GC cohere into a single and conceptually distinct “right to science.”	Amend ¶189: “This set of rights, entitlements, liberties, duties or obligations related to science, analysed in this General Comment and originating in the UDHR , might be brought together in a single broad concept named the human right to science , [...]. This approach and name has already been adopted by the Special Rapporteur on Cultural Rights, by UNESCO, by some international conferences and summits, by civil society, and by some important scientific organizations and publications. The legitimacy and applicability of a human right to science has been established through the right’s utilization to address human rights challenges ranging from health, environment, food, and

³ Bonn Guidelines on Access to Genetic Resources and Fair and Equitable Sharing of the Benefits Arising out of their Utilization. <https://www.cbd.int/doc/publications/cbd-bonn-gdls-en.pdf>

⁴ Nagoya Protocol. <https://www.cbd.int/abs/>

		water rights; thus demonstrating how the right to science is interrelated and interdependent, and indivisible from these other human rights.
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