

THE RIGHT TO SCIENCE FINALLY COMES INTO SIGHT

What the General Comment on the Right to Science Means for Health Advocacy

By Mike Frick

Cameroonian artist Barthélémy Toguo's 10-meter-long watercolor *Purification* takes up an entire gallery wall in London's Tate Modern museum.¹ Text from the Universal Declaration of Human Rights (UDHR) expressing basic human rights runs along the top and bottom of the paper, handwritten in pencil. In between these lines of cursive text, a procession of human heads, torsos, necks, and arms painted in blurred red and gray tumbles, reaches, and stretches horizontally across the paper. The motions resemble the movements a person would make to shield one's face from the sun, turn away from a threat, or brace for a fall.

The size of Toguo's watercolor makes it impossible for a viewer to simultaneously take in the entirety of the painting and clearly read the thirty articles of the UDHR. Appreciating the whole of the UDHR as reproduced by Toguo requires standing at a distance that renders individual rights illegible. To locate specific human rights, one must move closer to the piece, examining one section at a time. This forced compromise in perspective is similar to how human rights are interrelated, interdependent, and indivisible—all rights are equal in importance, and none can be fully enjoyed without the others. Even so, acting on human rights often requires that one focus attention on the meaning of a single right, without considering the whole.

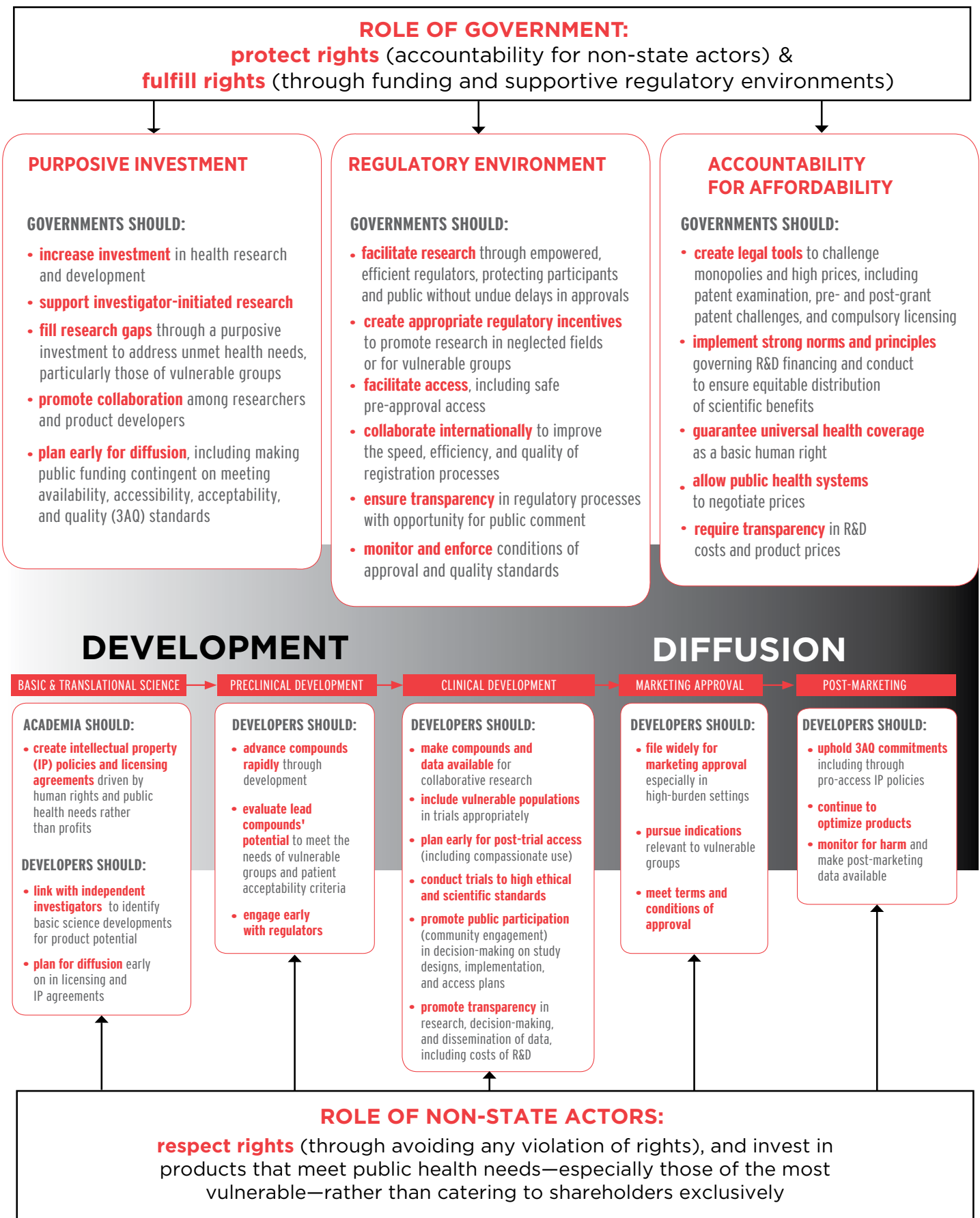
Article 27 of the UDHR—including the right of everyone “to share in scientific advancement and its benefits”—appears in the middle of Toguo's painting. Paradoxically, this positioning does not place the “right to science” in the center of the frame, but rather relegates it to a disappearing middle ground easily overlooked by the viewer. This placement—in plain sight, yet somehow just out of view—mirrors reality. The scope and nature of state obligations under the right to science, expressed in general terms by UDHR Article 27, are further elaborated on in Article 15 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). At fewer than 150 words, however, the ICESCR treaty text leaves much

unsaid. For their part, legal scholars, human rights activists, and governments have rarely acted on this right. As a result, human rights scholars have referred to the right to science as “the forgotten human right,” one so rarely invoked that it has occupied “the vanishing end of economic, social, and cultural rights.”^{2,3}

Finally, the right to science is becoming more visible. In April 2020, the Committee on Economic, Social and Cultural Rights (CESCR) released a general comment on Article 15 of the ICESCR. General Comment No. 25 offers the first authoritative legal interpretation of the right by the committee charged with guiding and monitoring how states implement economic, social, and cultural rights.⁴ The General Comment focuses on the parts of Article 15 that address the “right of everyone to enjoy the benefits of scientific progress and its applications” (Art. 15.1.b). This aspect of the right raises a long list of big questions: Who produces science? What do “scientific benefits” entail, and is there a difference between scientific knowledge and applications? Who can access these benefits? How should governments best promote science when non-state actors carry out so much research?

These questions are longstanding concerns for activists working to end HIV, tuberculosis (TB), and hepatitis C virus (HCV), and they are made freshly urgent as societies across the globe try to assemble the public health and scientific resources needed to confront the COVID-19 pandemic. In this sense, the General Comment arrives both long overdue and exactly on time.

General Comment No. 25 addresses the above questions and many more in 89 paragraphs written in straightforward prose. The potential impact of the General Comment in this moment extends far beyond the page: the document gives activists a framework for holding governments accountable for recognizing scientific progress and the enjoyment of its benefits as a fundamental human right.



General comments on other rights (e.g., General Comment No. 14 on the right to health) have helped galvanize advocacy by clarifying the individual entitlements and government obligations created by a right. A strong general comment might rally civil society to ensure that all people can enjoy the benefits and applications of scientific progress without discrimination. One can imagine right to science principles informing campaigns to increase government funding for research, achieve equitable access to essential medicines, or fight the privatization of knowledge by reclaiming science as a public good. A weak general comment would leave everyone from activists to governments confused and directionless.

With so much at stake, TAG carefully reviewed an earlier draft of the General Comment and submitted feedback to CESCR during an open comment period.⁵ This feedback adds to the significant body of work that TAG has produced to define and apply the right to science in the context of health.⁶ Overall, TAG felt that CESCR did a fantastic job. However, in some areas, particularly with respect to defining the actual steps governments must take to fulfill the right to science, TAG challenged CESCR to be more specific. It is gratifying to see that the final text reflects much of the feedback offered by TAG. The final General Comment stands out as one of the rare United Nations documents that becomes more concentrated in expression and focus between draft and publication rather than watered down with compromise between opposing constituencies (e.g., reconciling the divergent views of civil society and Big Pharma, or developed and developing country governments).

The following sections call attention to aspects of the General Comment particularly relevant to activists working on science and health. Throughout the following discussion, citations in parentheses refer to the paragraph of the General Comment where relevant text appears.

Participation

- CESCR has clearly identified participation as an animating value of the right to science. Crucially, participation must include more than the activities of scientists themselves: “The right...cannot be interpreted as establishing a rigid distinction between the scientist who produces science and the general population entitled only to enjoy benefits derived from research conducted by scientists” (¶19). Instead, every person has a right “to take part in scientific progress and in

decisions concerning its direction” (¶10). This language echoes the call for self-determination in medical care and research in the 1983 Denver Principles, as well as the “nothing about us, without us” mantra that underpins community engagement in research.⁷ Such a broad, inclusive view of participation supports the efforts of community advisory boards to shape health research agendas by elevating the perspectives of affected communities to the forefront of scientific decision-making.

- Participation is so central to the right to science that CESCR used the General Comment to greatly expand the scope of the right—starting by recasting its very name. The final text of General Comment No. 25 adds the phrase “to participate” to the longform name of the right: “Thus, it is the right to *participate* and to enjoy the benefits from scientific progress and its applications (Hereinafter: RPEBSPA)” (¶11, emphasis added). The long, unpronounceable acronym belies the significance of the shift in language here. In essence, CESCR decided to elevate participation from the background (one element of the right among many) to the foreground (something inherent to the idea of the right itself). CESCR justified this move through a careful textual analysis of UDHR Article 27, its evolution into Article 15 of the ICESCR, and the historical record of the debates that informed both processes. This is exactly the kind of conceptual advance one hopes to see a General Comment make, and advocates should celebrate CESCR for taking this bold step.

Access to scientific benefits

- Of central importance to TAG, CESCR has unequivocally stated that the “benefits” of science include both intangible knowledge and information as well as “the material results of the applications of scientific research, such as vaccination...” (¶18). This establishes a strong justification for claiming the tangible outputs of science (e.g., new health technologies) as benefits that should be accessible to all, and in doing so, strengthens the access to medicines movement. Although the General Comment does not use this language, former special rapporteur in the field of cultural rights Farida Shaheed has argued that a core principle of the right is that “innovations essential for a life with dignity should be accessible to everyone, in particular marginalized

populations.”⁸ Special attention to marginalized groups appears throughout the General Comment, suggesting that non-discrimination in access is at the heart of the right to science.

- One of the most practical parts of the General Comment stems from the decision by CESCR to define the right to science in terms of “five interrelated and essential elements”: availability, accessibility, acceptability, quality, and the protection of freedom of scientific research (¶16–20). The first four are known as the 3AQ, a framework that also appears in General Comment No. 14 on the right to health, where it has become one of the more powerful and enduring tools in the right to health movement. TAG was happy to see the 3AQ concept applied to the right to science and paired with protections for scientific freedom. Between draft and publication, CESCR significantly strengthened its analysis of what “availability” entails, specifying: “Research findings and research data funded by States should be accessible to the public.” This added point supports the position of TAG and other advocacy groups that public funding of science should result in public goods. Furthermore, CESCR established an explicit link between science and health, writing that states must make available and accessible “the best available applications of scientific progress necessary to enjoy the highest attainable standard of health.”

State obligations

- ICESCR Article Art 15.2 names three steps that states must take to fully realize the right to science: *develop*, *diffuse*, and *conserve*. The draft general comment was oddly silent on the specifics of these three actions. Because defining these terms is key to identifying state obligations under the right, TAG opened its feedback by proposing definitions. TAG framed development as a state responsibility to fund research and support a “purposive development” of science and technology to meet the needs of marginalized groups who are often overlooked by market-based incentives for research. TAG emphasized that diffusion is an “essential precondition” of participation in science since without access to scientific knowledge and applications, the public cannot engage with science in an informed, meaningful way. Finally, TAG argued that conservation means ensuring that the benefits of science are lasting, that is,

Major Milestones in the Development of the Right to Science

**May
1948**

Article XIII of the American Declaration of the Rights and Duties of Man contains the earliest expression of what will become the right to science.

**Dec
1966**

Article 27 of the Universal Declaration of Human Rights enshrines the right “to share in scientific advancement and its benefits.”

**Dec
1948**

Article 15 of the International Covenant on Economic, Social and Cultural Rights elaborates on the scope and nature of state obligations under the right to science.

**May
2012**

United Nations Educational, Scientific and Cultural Organization convenes series of expert meetings “to further elucidate the normative content of the right to enjoy the benefits of scientific progress,” culminating in the Venice Statement.

**July
2009**

Special Rapporteur in the field of cultural rights Farida Shaheed delivers the first report on the right to science to the United Nations Human Rights Council.

**April
2020**

Committee on Economic, Social and Cultural Rights (CESCR) releases draft general comment on Article 15; TAG comments.

**Jan
2020**

Publication of General Comment No. 25 on the right to science by CESCR.

available for present and future generations. The final General Comment contains a much stronger discussion of development, diffusion, and conservation along lines that largely reflect the definitions TAG suggested. Most importantly, the General Comment frames each as requiring action: “States must take positive steps for the advancement of science (development) and for the protection and dissemination of scientific knowledge and its applications (conservation and diffusion).” In other words, governments cannot sit back and merely observe that the right to science is not violated by others, they must actually do something themselves to fulfill entitlements under the right.

- The General Comment devotes an entire section to discussing special protections for Indigenous Peoples and their traditional knowledge (¶¶39–40). The text rightly points out that Indigenous Peoples’ free, prior, and informed consent to participate in research (or not) must be protected, and reaffirms “the rights of Indigenous Peoples [to] their land, their identity, and the protection of the moral and material interests resulting from their knowledge of which they are authors, individually or collectively.” This affirmation is powerful; however, the General Comment overlooks other important ethical and legal safeguards. TAG had urged CESCR to include references to relevant international law (e.g., the Bonn Guidelines and the Nagoya Protocol to the Convention on Biological Diversity), but these do not appear in the final draft. These treaties and protocols require states to ensure that any research involving traditional knowledge held by Indigenous Peoples proceeds with informed consent, under mutually agreed terms, and in the context of access and benefit-sharing agreements between traditional knowledge holders and those who use such knowledge, whether for academic study or commercialization.^{9,10}

Human rights and intellectual property

- The role of intellectual property (IP) in scientific research is one of the thorniest issues that any comprehensive discussion of Article 15 must confront. The same part of Article 15 that establishes the right of everyone to enjoy the benefits of scientific progress (15.1.b) also recognizes the rights of authors “to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production” (15.1.c). CESCR smartly addressed this apparent tension by referring to its earlier General Comment No. 17, which stated in no uncertain terms that moral and material interests in human rights law are not the same as IP protections as currently defined by international trade law.¹¹ A section of the General Comment on “private scientific research” (¶¶58–62) discusses three negative effects of IP: 1) it distorts scientific funding; 2) it blocks sharing of scientific results and methods; and 3) it prevents people from accessing scientific benefits that may be necessary to enjoy other rights (e.g., health rights). Although the language on IP softened a bit

after the public consultation, the heart of this analysis remains strong. Most importantly, CESCR recognized that IP protections such as patents are not the only way to encourage innovation. In ¶¶62, CESCR highlights alternative approaches that delink investments in research and development from the final product prices and volumes of sales (a concept called “delinkage”). In a later section on the right to health (¶¶67–71), CESCR calls on State parties to use flexibilities in patent law (e.g., compulsory licensing) to promote access to essential medicines and endorses the use of generic drugs over brand-name medicines. It appears that CESCR sought to position the right to science as a practical tool, one that can “become a significant mediator between a human right (the right to health) and a property right (IP)” (¶¶69).

Ultimately, the General Comment must become more than an object of study. It must provide a rallying point for activists and members of civil society seeking a more responsive research agenda, a more equitable distribution of scientific benefits, and a more secure commitment by states so that present and future generations will enjoy the benefits of scientific advancement free from discrimination. TAG stands ready to help communities that are working to end the epidemics of HIV, TB, and HCV apply the framework and principles set forth by General Comment No. 25 to advocacy so that they can claim scientific progress as a fundamental entitlement common to all peoples. Our hope at TAG is that the General Comment moves the right to science from the vanishing end of human rights to the center of state attention and civil society action.

Endnotes

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5. To read the draft general comment, see: Uprimny R, Mancisidor M. Draft general comment: Science and economic, social and cultural rights Art. 15: 15.1.b, 15.2, 15.3 and 15.4. Geneva: Committee on Economic Social and Cultural Rights; 2 Jan 2020. https://www.ohchr.org/EN/HRBodies/CESCR/Pages/DraftGeneralComment_Science.aspx.
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