

Michelle Bachelet United Nations High Commissioner for Human Rights Palais Wilson 52 rue des Pâquis CH-1201 Geneva Switzerland

23 June 2020

Re: COVID-19 and the right of everyone to participate in and enjoy the benefits of scientific progress and its applications

Dear Madame High Commissioner,

Treatment Action Group (TAG) applauds the High Commissioner on your attention to the human rights dimensions of the COVID-19 pandemic. Following the President of the Human Rights Council's statement at the 43rd session of the Human Rights Council (A/HRC/43/L.42), TAG would like to bring to the High Commissioner's attention the aptness of the right of everyone to participate in and enjoy the benefits of scientific progress and its applications (right to science)¹ for formulating an effective human rights-based response to COVID-19.

TAG 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. As science-based treatment activists working to expand and accelerate vital research and effective community engagement with research and policy institutions, TAG expresses grave concern that states are again responding to an infectious disease epidemic with human rights infringements and lack of community participation in formulating a rights-based response to COVID-19.

The COVID-19 pandemic continues to confront societies across the globe with the incontrovertible connections between human rights, science, and health. In April 2020, CESCR published General Comment 25 (E/C.12/GC/25) on the right to science. General Comment 25 (GC 25) tasks all governments with incorporating into their public health and scientific responses to COVID-19 principles such as participation, non-discrimination, transparency, equity, and solidarity. Yet, the right to science is rarely invoked and remains largely unknown even among UN bodies. It is thus imperative that the Office of the High Commissioner for Human Rights, through your oral and written reports to the upcoming Human Rights Council sessions, and the Human Rights Council itself, explicitly acknowledge the human rights dimensions of science and reaffirm the right of everyone to participate in and enjoy the benefits of scientific progress and its applications.

¹ UDHR Art. 27; ICESCR Art. 15

TAG's continuous work on the right to science and infectious diseases demonstrates that the right to science is a powerful analytical companion to the right to health, one that can guide states in developing rights-based responses to public health emergencies that place equity at the center of innovation.

For an effective COVID-19 response, the right to science emphasizes the following elements which TAG wishes to raise to your attention:

1. **State obligations to science** fall into three broad categories of action: develop, diffuse, and conserve. This includes supporting innovation through funding and policy (develop); safeguarding existing knowledge to enable future scientific inquiry (conserve); and disseminating the benefits and applications of science to all without discrimination (diffuse). "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 its analysis of state obligations, GC 25 points to five interrelated and essential elements, i.e. availability, accessibility, acceptability, quality, and freedom of scientific research.

States are pledging unprecedented levels of funding for collaborative COVID-19 research endeavors. However, TAG is concerned that states are not equally committed to protecting public funding with rigorous pro-access safeguards to ensure that the resulting products of research will be available, accessible (affordable), and acceptable to all people without discrimination and be of high quality. We call on OHCHR to support states to enact policies on scientific innovation that simultaneously fulfill government obligations to develop new technologies against COVID-19 while also diffusing and conserving scientific benefits in ways that ensure the availability, accessibility, acceptability, and quality of resulting medicines, diagnostics, vaccines, and other health technologies.

2. **Participation** is the animating value of the right. GC 25 is clear that 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." Importantly, GC 25 does not endorse a rigid distinction between scientists and the general public. This stance validates the rich tradition of community engagement in global health research and policy formulation, for example through the formation of community advisory boards.

TAG joined over 200 other civil society organizations in expressing concern that COVID-19 research is progressing without the meaningful involvement and representation of affected communities. People have a right to participate in medical research as more than just clinical trial participants. We call on OHCHR to endorse the greater participation of communities affected by COVID-19, in particular marginalized and vulnerable populations, in all aspects of COVID-19 research and development.⁴

³ GC 25 paragraph 11

² GC 25 paragraph 14

⁴ AVAC. "Advocates call for ethical research for COVID-19 solutions." See: https://www.avac.org/blog/advocates-call-ethical-research-covid19

3. Access sits at the heart of the right to science. Access not only encompasses knowledge and information, but also the material results of scientific progress such as medicines and vaccines as well as the means, methods, and materials of scientific discovery. GC 25 identifies access as an important element connecting the right to science to the right to health: "State parties have a duty to make available and accessible to all persons, without discrimination, especially to the most vulnerable, all the best available applications of scientific progress necessary to enjoy the highest attainable standard of heath." 5

Since the WHO declared COVID-19 a pandemic, advocates have articulated global principles on access, participation, and transparency and have called for their integration into research and development strategies, including Open Science approaches, for all prospective COVID-19-related technologies. Over 500 civil society organizations have signed on to the COVID-19 Principles for Global Access, Innovation, and Cooperation. We call on OHCHR to endorse these principles, which are embodied by the right to science, to ensure that equitable access guides all COVID-19 research efforts.

4. **Non-discrimination** in the enjoyment of scientific progress and its benefits is fundamental, as it is with all human rights. States must take special steps to ensure that vulnerable and marginalized groups can participate in and access science and the fruits of its advancement. "Scientific progress and its applications should be, as far as possible, accessible and affordable to persons in specific need of certain goods or services. Public institutions in different sectors should be provided with a clear mandate to actively overcome exclusion from such progress and applications, especially in the health sectors and education."⁷

As is evident from experience with other infectious disease responses, e.g. continued unaffordability of hepatitis C treatment or slow uptake of more effective, less-toxic TB drugs, scientific innovation in public health has a tendency to exacerbate existing divides between developing countries and richer countries. Understanding the global harm that similarly discriminatory access to COVID-19 drugs will cause, over 300 creative activists in 29 countries started the grassroots 'free the vaccine' campaign to encourage universities to sign non-exclusive licensing agreements and ensure equitable access. UNAIDS and Oxfam coordinated a letter of over 140 world leaders and experts calling for a "People's Vaccine," free of patent barriers and provided free of charge to everyone, everywhere, with priority given to vulnerable groups. We call on OHCHR to endorse the UNAIDS call for a People's Vaccine and to provide guidance to states on how to realize the enjoyment of scientific benefits for all without discrimination.

5. **Intellectual property and international cooperation** interact with tensions around universal, equitable access to COVID-19 technologies. GC 25 explicitly references

⁵ GC 25 paragraph 70

⁶ Public Citizen. "COVID-19 Principles for global access, innovation, and cooperation." See: https://www.citizen.org/article/covid-19-principles-for-global-access-innovation-and-cooperation/
⁷ GC 25 paragraph 47

⁸ UNAIDS. "World leaders unite in call for a people's vaccine against COVID-19." See: https://www.unaids.org/en/resources/presscentre/pressreleaseandstatementarchive/2020/may/20200514_covid19-vaccine

pandemics because, as we are currently witnessing, "a local epidemic can become very quickly a pandemic with devastating consequences." States therefore should respond with transparency by "sharing the best scientific knowledge and its applications [...]." Intellectual property (IP) protections often act counter to non-discriminatory, transparent, and participatory approaches to R&D. States that do not work to balance IP protections with the public good risk falling short of several human rights obligations. GC 25 notes that the right to science can mediate tensions between IP protections and other human rights, e.g. the right to health, right to education, and right to food.

The principles manifested in several global initiatives, e.g., the WHO COVID-19 Technology Access Pool (C-TAP), first proposed by the Government of Costa Rica, represent efforts to ensure that IP does not become a barrier to the availability, accessibility, acceptability, quality, and freedom of scientific research against COVID-19. We call on OHCHR to work with states to develop approaches to intellectual property governance, including but not limited to the exercise of existing flexibilities, that promote access to the benefits and applications of scientific research through means that recognize the primacy of the human rights to health and science.

COVID-19 continues to raise a plethora of urgent challenges for states. GC 25 presents states with the opportunity to codify effective, collaborative, and innovative national and global policy responses that—through respecting human rights and existing international law—will engender the development, diffusion, and conservation of science needed to overcome the COVID-19 pandemic and avoid future epidemic threats. We encourage OHCHR to recognize the right to science in all of its communications and work with states to define and realize a rights-based response to COVID-19.

We invite the opportunity for further dialogue on the right to science and its important role in connecting global public health, science, and human rights in this unprecedented time.

Respectfully,

Mike Frick

Treatment Action Group

Gisa Dang

Treatment Action Group

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⁹ GC 25 paragraph 82.