

Submission on the first draft general recommendation no. 37 (2023) on racial discrimination in the enjoyment of the right to health

This submission is jointly presented to the Committee on the Elimination of Racial Discrimination (CERD) by Roojin Habibi, Faculty of Law, University of Ottawa; Matiangai Sirleaf, University of Maryland Francis King Carey School of Law and Department of Epidemiology and Public Health, University of Maryland School of Medicine; Judith Bueno de Mesquita, School of Law and Human Rights Centre, University of Essex; Gian Luca Burci, Geneva Graduate Institute; Stéphanie Dagron, Faculties of Law and Medicine, Université de Genève; Mark Eccleston-Turner, Department of Global Health and Social Medicine, Faculty of Social Science & Public Policy, King's College London; Luciano Bottini Filho, Helena Kennedy Centre for International Justice, Sheffield Hallam University; Lisa Forman, Dalla Lana School of Public Health, University of Toronto; Sam Halabi, O'Neill Institute for National and Global Health Law, Georgetown University; Tsung-Ling Lee, Taipei Medical University; Benjamin Mason Meier, Department of Public Policy, University of North Carolina at Chapel Hill; Stefania Negri, School of Law, UNISA; Alexandra Phelan, Johns Hopkins Bloomberg School of Public Health and Johns Hopkins Center for Health Security; Sharifah Sekalala, School of Law, University of Warwick; Allyn L. Taylor, School of Law, University of Washington; Pedro A. Villarreal, Max Planck Institute for Comparative Public Law and International Law; Alicia Ely Yamin, Harvard Law School and Partners in Health. We have provided institutional names for identification purposes solely.

The authors commend the Committee's leadership and efforts in developing a general recommendation on the right to health, building on significant normative advancements on securing equality in the enjoyment of the right to health. We cannot avert our gaze from the truth that the nefarious impacts of the pandemic were disproportionately experienced by groups protected by the International Convention on the Elimination of Racial Discrimination (ICERD). The draft general recommendation places emphasis with good reason on the historical injustices that give rise to current structural inequalities in the enjoyment of the right to health, particularly among protected groups. However, the social, economic, and public health shockwaves caused by COVID-19 require more careful assessment and engagement by this general recommendation. Such an assessment is ever more necessary as the world is on the brink of adopting new international legal instruments that will shape how the international community responds to the next global health emergency.

The authors also commend the Committee for recognizing the social construction of race and how it operates in society. The authors caution the Committee from adopting any recommendation or using any language that will reify a biological understanding of race, instead of emphasizing the social effects of racial discrimination and racism in health risks and public health outcomes.

We thus call on the Committee to undertake the following in their review of the draft general recommendation:

1. Further clarify the normative contours of the right to health in relation to racial discrimination and public health emergency prevention, preparedness, and response

The Committee should consider integrating more explicitly the lessons imparted by the COVID-19 pandemic and unpack how those lessons apply to groups protected by the Convention. Such reflections must address not only public health emergency responses, but also upstream efforts to prevent and prepare

for health emergencies, and eventually recover from such events. The Committee should consolidate these lessons learned as either a standalone section within the general recommendation or integrated where relevant throughout the recommendation. In this consideration of public health emergencies, the newly adopted *Principles and Guidelines on Human Rights and Public Health Emergencies* (the ‘Principles’) adopted by the Global Health Law Consortium and the International Commission of Jurists are a helpful resource that emphasize that:¹

- a. **Public health measures should be rights-based and evidence-informed:** The right to life and the right to health require States to protect the population against the incidence and prevalence of communicable diseases.² Public health measures may be effective tools for fulfilling that obligation. Depending on the nature of the disease, such measures may include contact tracing, case tracking, mandatory use of personal protective equipment, quarantines, isolations, closure of schools, businesses and other establishments, prohibitions of gatherings in public places, stay-at-home orders and curfews, cordons sanitaires, travel restrictions to and from specific places, among others. Any such public health measure that is adopted for disease prevention must be implemented in a non-discriminatory manner, enforced equitably and narrowly tailored in time, scope and place to respond to the public health need.

These measures must always be rights-based and evidence-informed, and refrain from any form of bias, discrimination, and disparate impact. As set out in the *Principles*, this means that States must ensure that a public health measure is (a) based on a risk assessment grounded in scientific principles and scientific, epidemiological and other available evidence; (b) compliant with applicable human rights obligations; (c) accompanied by special, targeted measures to mitigate any potential human rights harm(s) of such measures (including interim measures to enable access to justice in times of lockdown) and to ensure equitable access and benefit from such measures; (d) informed by public participation and deliberation mechanisms; and (e) subject to continuous review and lifted as soon as such review no longer supports having these measures in place.³ Where measures meeting the above criteria still result in limitations of human rights, such measures must be temporary, for a legitimate and specific public health purpose, and have strict regard for the principles of legality, necessity, proportionality, and non-discrimination.⁴

The framework set out in the Principles can be especially useful in formulating the Committee’s recommendation on specific aspects of the right to health in the context of public health emergencies. In Section II, Part C (on the “right to control one’s body”), for instance, paragraph 18 notes that “racial bias, stigmatization and structural inequalities expose individuals and groups within the purview of the Convention to various forms of coercion...” This paragraph, and elsewhere in this general recommendation, should also recognize that discrimination in the right

¹ The *Principles and Guidelines on Human Rights and Public Health Emergencies* reflect international, expert consensus on the most pressing human rights and rule of law issues relevant to public health emergency prevention, preparedness, response, and recovery. Global Health L. Consortium & Int’l Comm’n of Jurists, *Principles & Guidelines on Human Rights & Public Health Emergencies* (2023), <https://www.ohchr.org/sites/default/files/documents/new-york/events/hr75-future-generations/PGs-on-Human-Rights-and-Public-Health-Emergencies-26-June-2023.pdf>. [hereinafter Principles].

² U.N. Human Rights Comm., *General Comment No. 36, Article 6 (Right to Life)*, ¶ 26, U.N. Doc. CCPR/C/GC/6 (Sept. 3, 2019); U.N. Comm. on Econ., Soc. & Cultural Rights (CESCR), *General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12 of the Covenant)*, ¶ 16, U.N. Doc. E/C.12/2000/4 (Aug. 11, 2000) [hereinafter General Comment No. 14].

³ See Principles, *supra* note 2, at art. 15.

⁴ See *id.*, at art. 16.

to control one's health and body may arbitrarily and unjustly deny opportunities and access to rights for groups protected under the Convention. In the COVID-19 response, such denial was witnessed during the emergence of the Omicron variant first identified by South Africa, where countries, under the pretext of protecting their populations from COVID-19, imposed xenophobic and discriminatory travel bans against travellers from southern Africa, even where the variant had not been detected in the travellers' country of origin.⁵ Beyond the Omicron wave, a range of public health measures were implemented at the borders based on racial bias, stigma and discrimination, instead of on the basis of rights and science. Paragraph 17 in part alludes to discriminatory travel bans in addressing mandatory HIV/AIDS testing, but the COVID-19 pandemic, as well as other past outbreaks (e.g., Ebola), reveal a far more entrenched problem, well beyond HIV.⁶

- b. ***Participation and consultation processes should be institutionalized before emergencies arise:*** In addressing obligations under ICERD, Section III also rightly emphasizes at Paragraph 29 the importance of “participation and consultation of groups within the purview of the Convention in health decision-making,” noting that such actions enhance the “legitimacy and transparency of decisions” and build trust between health institutions and communities. Yet in times of public health emergencies, governments often sidestep the consultative process of health decision-making, justifying that such processes are untenable under conditions of high urgency and uncertainty.⁷ In line with the *Principles*, we call on the Committee to explicitly indicate that States must *pre-emptively* institutionalize public consultation and deliberation processes for groups protected under this Convention, so that when health emergencies arise, channels of dialogue and civil society participation are already delineated and ready to be leveraged.⁸ To build greater resilience against future pandemics, it is imperative that health policies, laws and regulations are responsive and adaptive to people's lived realities, and enable the full realization of the rights and freedoms of all individuals.⁹
- c. ***The Committee should engage fully with global health law reforms on public health emergencies:*** The scale, intensity and endurance of the COVID-19 health threat have created a window of opportunity for multilateral global health law reforms, including amendments to the World Health Organization's (WHO's) International Health Regulations (IHR) and negotiations for a new pandemic accord, as well as a forthcoming United Nations High-Level Meeting (HLM) on Pandemic Prevention, Preparedness and Response (PPR), which is widely expected to drive political momentum towards the two WHO reforms. Whether such law-making reforms will lead to improved prevention, preparedness and response depends, *inter alia*, on the degree to which states are willing to negotiate in good faith to ensure equity, inclusivity, and solidarity.¹⁰

⁵ Press Release, World Health Organization, WHO Advice for International Traffic in Relation to the SARS-CoV-2 Omicron Variant (B.1.1.529) (Nov. 30, 2021), <https://www.who.int/news-room/articles-detail/who-advice-for-international-traffic-in-relation-to-the-sars-cov-2-omicron-variant#cms>; Carly Jackson et al., *Between Rules and Resistance: Moving Public Health Emergency Responses Beyond Fear, Racism and Greed*, 7 *BMJ Global Health* 8 (2023), doi:10.1136/bmjgh-2022-009945.

⁶ Matiangai Sirleaf, *Ebola Does Not Fall from the Sky: Structural Violence & International Responsibility*, 51 *VAND. J. TRANSNAT'L L.* 477 (2018).

⁷ Ole F. Norheim et al., *Difficult Trade-offs in Response to COVID-19: The Case for Open and Inclusive Decision Making*, 27 *NATURE MED.* 10 (2021).

⁸ See *Principles*, *supra* note 2, at art. 13.2.

⁹ World Health Org., *VOICE, AGENCY, EMPOWERMENTS – HANDBOOK ON SOCIAL PARTICIPATION FOR UNIVERSAL HEALTH COVERAGE* (2021).

¹⁰ SHARIFAH SEKALALA, *SOFT LAW AND GLOBAL HEALTH PROBLEMS: LESSONS FROM RESPONSES TO HIV/AIDS, MALARIA AND TUBERCULOSIS* (2017).

In Section IV, on recommendations, the Committee calls for an alignment of the pandemic accord drafts with ICERD. We strongly recommend that the Committee go further, explicitly calling on States to ensure that any ongoing reforms of global health law at international and regional levels (including negotiations to amend the IHR) align with ICERD and with broader normative contours of the right to health in international law. For example, articles 2(1) and 22–23 of the International Covenant on Economic, Social and Cultural Rights (ICESCR) stipulate that it is the obligation of all state parties, especially those with economic and technical capacity, to take steps towards the full realization of rights in the Covenant both individually and through international assistance and cooperation, including through the adoption of treaties and recommendations, as well as the provision of technical assistance.¹¹ Further, the Committee responsible for interpreting the ICESCR has emphasized in its commentary that “State parties should recognize the essential role of international cooperation and comply with their commitment to take joint and separate action to achieve the full realization of the right to health.”¹²

We moreover urge the Committee to use the term “health goods, facilities, services, and technologies,” instead of the narrower “health care technologies” (para. 3), in line with CESCR General Comment 14 and to connote all manner of goods, facilities, and services that may be needed to prevent, prepare for, respond to, and recover from, a public health emergency, as well as the technologies and the knowledge, relating directly to the production or improvement of such goods, services and facilities.¹³ Examples of the foregoing include vaccines, therapeutics, diagnostic tests, personal protective equipment and other medical devices, including both the final and intermediate products used to produce and/or administer them.

2. The general recommendation should take care to avoid language that reifies race as a biological instead of a social construct.

- a. **Racializing diseases, stereotyping, and attributing health differences to race should not occur in the recommendations.** Historically, race was constructed as immutable and biologically-based, rather than recognized as the imposition of a legal and social regime of racial hierarchy.¹⁴ This racial hierarchy was shaped in part by scientific racism. Scientific racism was used to justify, propose, and project scientific findings and theories, which facilitated and reinforced the enactment of racist social policies. In Section 2 at paragraph 12(d), the Committee notes that it is not uncommon that groups within the purview of the Convention are excluded from medical research and studies on treatments and medicine. While it is laudable to encourage participation in clinical research, race should not be used as a stand in for ancestry, environmental factors, socioeconomic status, or other factors for clinical research.

Much effort has been made toward acknowledging that common observable phenotypical markers “exist on a continuum, not as discrete [racial] categories.”¹⁵ The scientific community has made

¹¹ International Covenant on Economic, Social and Cultural Rights, arts. 2(1), 22–23, Dec. 16, 1966, 993 U.N.T.S. 3.

¹² See General Comment, *supra* note 3, at ¶ 38.

¹³ General Conference of the U.N. Educational, Scientific & Cultural Org. (UNESCO), *Recommendation on Science and Scientific Researchers*, annex II, ¶ 1(b), U.N. Doc. 39 C/RESOLUTIONS (Nov. 13, 2017).

¹⁴ Matiangai Sirleaf, *Racial Valuation of Diseases*, 67 UCLA L. REV. 1820, 1824 (2021).

¹⁵ Matthew Clair & Jeffrey S. Denis, *Sociology of Racism*, in 19 INTERNATIONAL ENCYCLOPEDIA OF THE SOCIAL & BEHAVIORAL SCIENCES 857 (James D. Wright ed., 2d ed. 2015).

strides in recognizing that the use and significance of these markers varies across time, place, and even within the same individual. Advances in science brought on by the completion of the Human Genome Project, amongst others, has led to the increasing consensus that race does not exist as a biological category and that genetic variation is far greater within racialized groups. As such, the Committee's discussion that medication and other goods and services are not tested taking into consideration racial and ethnic groups situation is problematic because it relies on a biological understanding of race.¹⁶

Language rooted in and informed by scientific racism needs to be avoided and has no place in the recommendations. For instance, the Committee's reference in Section 2 at paragraph 12(d) to how the lack of knowledge by physicians and other health practitioners on how symptoms manifest on Black bodies is concerning. This phrasing should be removed from the recommendation because it dehumanizes Black people and others them as having a different physiological constitution. The United Nations released a series of statements on race in the 1950s and 60s that recognized the unity of humankind, biologically and otherwise, and sought to discredit much of the scientific racism project.¹⁷

- b. **The Committee should exercise caution when discussing disparate impact on racial and ethnic groups.** When the Committee refers to the disparate impact of climate change in Section 2 at paragraph 14, it notes that racial and ethnic minorities are disproportionately affected, due to geographical location, socio-economic situation, cultural norms, and intrinsic psychological factors. It is not clear what intrinsic psychological factors the Committee is referencing here. The use of essentializing language that others racial and ethnic groups as having a unique or distinct psychological makeup should be avoided. The project of scientific racism was instrumental in constructing and reifying norms reflecting stereotypes about the mental fitness or infirmity of people of color. As such, when the Committee refers to the disproportionate impact on racial and ethnic groups it must emphasize and make clear the influence of systemic racism and other social determinants of health, as reflected in current analyses of the impact of "environmental racism," as opposed to innate or supposedly natural differences among racial groups including their mental health.

The elimination of racialized language and the recognition of socially constructed racial categories in the recommendation does not negate the lived experience of race and racism.¹⁸ We commend the Committee's recommendations for special measures to target past and current racial discrimination to secure advancement and equality in the enjoyment of the right to health.

We applaud the Committee for its efforts thus far with the draft general recommendation. We welcome the opportunity to discuss these issues further and look forward to continuing engagement. All communications on this submission should be directed to rhabibi@uottawa.ca.

¹⁶ Matiangai Sirleaf, *Disposable Lives: COVID-19, Vaccines, and the Uprising*, 121 COL. L. REV. F. 71, 80 (2021).

¹⁷ See, e.g., UNESCO, *Statement on Race*, in FOUR STATEMENTS ON THE RACE QUESTION 30, 33–34 (1969); see also Declaration on Race and Racial Prejudice, U.N.E.S.C.O. Res. 3/1.1/2, Rec. of the Gen. Conf., 20th Sess., art. 1 (Nov. 27, 1978) (noting that "[a]ll human beings belong to a single species and are descended from a common stock").

¹⁸ For further discussion, see Luciano Bottini Filho, *Covid-19 Through Brazilian Courts: The Deserving and the Undeserving Vulnerable*, 22 GERMAN L. REV. 1098 (2021) (noting how commonly, isolated indigenous groups and physically segregated communities of a certain ethnic identity require special public health responses).