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# Committee on the Elimination of Racial Discrimination

# First draft General recommendation No. 37 (2023) on Racial discrimination in the enjoyment of the right to health\*

# I. Introduction

1. This general recommendation aims to clarify the obligations undertaken under the International Convention on the Elimination of All Forms of Racial Discrimination (ICERD) regarding the right to health. It identifies common issues of concern and provides guidance on measures to address them, in line with the Convention. As part of the process of elaborating this General Recommendation, the Committee on the Elimination of Racial Discrimination (CERD) held a thematic discussion, organised at the 107<sup>th</sup> session. The CERD brought together States parties, other international organisations, and agencies, NHRIs, civil society organisations and health professionals' associations. Submissions by all relevant stakeholders, including by grassroots organisations, demonstrate the urgency of measures to eliminate all forms of racial discrimination in the enjoyment of the right to health and provide clarity on the Convention's potential. This general recommendation integrates this knowledge and focuses on the legal standards and principles set by the Convention.

2. This draft builds upon the evidence-based link between racial discrimination and the right to health. In 2008, the World Health Organisation's (WHO's) Commission on Social Determinants of Health included ethnicity in structural social determinants of health, along with gender, education, occupation, income, and place of residence.<sup>1</sup> Social determinants of health refer to the social conditions, in which people are born, grow, live, work, and age, that shape their health and disease exposures, vulnerabilities and outcomes.<sup>2</sup> Over several decades, numerous epidemiological studies have analysed how racism and racial discrimination affect health, beyond the effect on access to health care.<sup>3</sup>

<sup>\*</sup> Adopted by the Committee at its 109<sup>th</sup> session (11–28 April 2023).

<sup>&</sup>lt;sup>1</sup> Commission on Social Determinants of Health, "Closing the gap in a generation: health equity through action on the social determinants of health" 2008, p. 12.; WHO, A62/9 (2009); WHA Res 62.14 'Reducing Health Inequities through Action on the Social Determinants of Health' (21 May 2009); WHA Res 65.8 'The Outcome of the World Conference on Social Determinants of Health' (26 May 2012); WHA Res 72.2.

<sup>&</sup>lt;sup>2</sup> WHO, Putting Our Own House in Order: Examples of Health System Action on Socially Determined Health Inequalities. (2010), 11; O. Solar and A. Irwin, "A Conceptual Framework for Action on the Social Determinants of Health," Discussion Paper 2 (Geneva: World Health Organization, 2010, 34-35; EB152/2, paras. 6-9 and WHA Res. 74.16 (2021).

<sup>&</sup>lt;sup>3</sup> Vernellia R. Randall, Race, Health Care and the Law: Regulating Racial Discrimination in Health Care / United Nations Research Institute for Social Development (UNRISD) Conference on Racism and Public Policy (2001); Paradies Y, Ben J, Denson N, Elias A, Priest N, Pieterse A, Gupta A, Kelaher M, Gee G. Racism as a Determinant of Health: A Systematic Review and Meta-Analysis. PLoS One. 2015 Sep 23;10(9): e0138511. doi: 10.1371/journal.pone.0138511. PMID: 26398658; PMCID: PMC4580597; see also The Lancet Series on racism, xenophobia, discrimination, and health published online in December 2022.

3. The Committee has repeatedly stressed the ongoing effects of the historical and structural racial discrimination, such as high rates of poverty and social exclusion, faced by persons and groups within the purview of the Convention.<sup>4</sup> Historical and cultural contexts in each State, as well as social and economic systems, must be taken into consideration to recognise and combat patterns of hierarchies, classifications, unequal representation and distribution of power and resources. Racial discrimination in the enjoyment of the right to health follows similar trajectories for indigenous peoples, people of African descent, castes, national or ethnic minorities, and non-citizens. During their life, persons, and groups within the purview of the Convention are subjected to overlapping interpersonal, institutional, and structural racial discrimination in all components of the right to health. Cumulative exposure to racial discrimination during their life-cycle implies an inter-generational predetermined set of unequal opportunities and outcomes in health.

4. Racism, along with other key social determinants, such as economic and gender inequality undermine the enjoyment of the right to health globally, due to lack of willingness to address their root causes.<sup>5</sup> The Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health recalled that "[r]ooted in colonialism, slavery and other historical power imbalances, racism continues to manifest itself in poor and preventable health outcomes worldwide, such as glaring disparities in maternal mortality and morbidity, and higher risk levels of communicable and non-communicable diseases".<sup>6</sup> There is growing recognition within the Human Rights Council that "legacies of colonialism, such as economic exploitation, inequality within and among States, systemic racism, violations of indigenous peoples' rights, contemporary form of slavery and damage to cultural heritage",<sup>7</sup> have a negative impact on the effective enjoyment of all human rights.

5. The COVID-19 pandemic tragically exposed and further deepened structural inequalities affecting vulnerable groups protected under the Convention, based on entrenched structures and practices of discrimination and exclusion.<sup>8</sup> The responses to the pandemic exacerbated the specific vulnerability of women and girls, children, and persons with disabilities, leading to multiple or intersecting forms of discrimination.<sup>9</sup> The CERD stressed that the disproportionate impact of the pandemic on those groups protected by the Convention in terms of higher levels of morbidity and mortality was in significant part attributed to consequences of the historic racial injustices of slavery and colonialism that remain largely unaccounted for today and the contemporary racially discriminatory effects of structures of inequality and subordination resulting from failures to redress the effects of racism rooted in slavery, colonialism and apartheid and acknowledged that "failures to redress these injustices have impeded the ability of communities to enjoy fully the right to life, health and health care, and the capacity of States to address entrenched structural inequities which have been exposed and deepened by the pandemic and enduring practices of discrimination and exclusion." 10

# II. The Convention and the right to health

# A. The meaning and content of the right to health under Article 5(e)(iv)

6. Health is understood in the practice of the Committee as "the highest attainable standard of physical and mental health", echoing both Article 12 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), as interpreted by the

<sup>&</sup>lt;sup>4</sup> CERD/C/SLV/CO/18-19, para. 14; CERD/C/HUN/CO/18-25, para. 20.

<sup>&</sup>lt;sup>5</sup> WHO, EB152/2, paras. 6-9. WHA Res. 74.16 (2021).

<sup>&</sup>lt;sup>6</sup> A/77/197, para.7.

<sup>&</sup>lt;sup>7</sup> A/HRC/RES/48/7.

<sup>&</sup>lt;sup>8</sup> Statement on the coronavirus (COVID-19) pandemic and its implications under the International Convention on the Elimination of All Forms of Racial Discrimination (3/2020).

<sup>&</sup>lt;sup>9</sup> Ibid.

<sup>&</sup>lt;sup>10</sup> CERD Statement on the lack of equitable and non-discriminatory access to COVID-19 vaccines (2/2022).

Committee on Economic, Social and Cultural Rights (CESCR), as well as the definition in the Constitution and the practice of the World Health Organisation (WHO), according to which "[h]ealth is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity".<sup>11</sup> For indigenous peoples, this definition is increasingly interpreted by the Committee as encompassing their holistic understanding of health that takes into account physical, mental, spiritual, social, and ecological dimensions.<sup>12</sup> The Committee recognised explicitly a link between the desecration of sacred sites and the negative impact on the environment, health and traditional ways of life of indigenous communities due to the installation of waste disposal sites on their territories, as well as the negative health impact by extractive and manufacturing industries.<sup>13</sup>

7. Under the reporting procedure, the Committee interpreted Article 5 (e)(iv) as encompassing in its negative dimension freedom from racial discrimination and in its positive dimension entitlements to the right to equality before the law, including by the adoption of special measures, in a wide range of human rights issues related to the right to health. Article 5 (e)(iv) provides for an individual right to equal and unhindered access to a whole range of culturally appropriate and gender-sensitive health facilities, goods, services, and information, as well as the protection of the patient's right to privacy and confidentiality. Persons within the purview of the Convention have the right not to be subjected to arbitrary interference, such as non-consensual medical treatment and experimentation.

Article 5 (e)(iv) prohibits racial discrimination and guarantees equality in a set of areas 8. ("public health, medical care, social security and social services") related to the right to health, without clarifying how they interact and to what extent they should be taken into consideration separately, or as a group. The wording in Article 5 (e)(iv), read in conjunction with the chapeau of Article 5 ("notably"), allows a non-restrictive interpretation of its scope, in line with the interpretation of the right to health as an inclusive right. The object and purpose of the Convention to eliminate all forms and manifestations of racial discrimination supports a systemic interpretation, conducive to unmask and tackle accordingly racial discrimination in interconnected areas in the context of health. First, "public health" focuses on health of the population, with a view, on the one hand, to identify and prevent diseases among groups within the purview of the Convention, and on the other hand, to promote, and protect their health by improving underlying determinants. Second, racial discrimination in the enjoyment of the right to health cannot be eliminated unless concrete measures are taken with regard to health care facilities, goods, and services. Neither the standard of health, nor the availability, accessibility, acceptability, and quality of health systems on a nondiscriminatory basis can be assessed under the Convention outside this framework. Third, social security and social services are inextricably linked to societal efforts to improve determinants of health.<sup>14</sup> Recognising that individuals and groups within the purview of the Convention face deeply rooted structural inequalities in accessing acceptable and affordable healthcare due to racial discrimination in employment and other rights closely interrelated with the right to health, the Committee has always identified social services and social security as strategic areas in eliminating racial discrimination in health.<sup>15</sup> This approach promotes consistency with the 2030 Agenda: Leave No One Behind (LNOB), which places equality and non-discrimination at the heart of sustainable development.<sup>16</sup> In addition, the Committee takes into consideration the support expressed in the UN General Assembly and

<sup>&</sup>lt;sup>11</sup> WHO Constitution.

<sup>&</sup>lt;sup>12</sup> The Permanent Forum on Indigenous Issues notes that the right to health "materializes through the well-being of an individual as well as the social, emotional, spiritual and cultural well-being of the whole community" (see E/2013/43-E/C.19/2013/25, para. 4). See also A/HRC/33/57 (2018).

<sup>&</sup>lt;sup>13</sup> CERD/C/CHL/CO/22-23, para. 28; CERD/C/USA/CO/7-9, para 10.

<sup>&</sup>lt;sup>14</sup> CESCR, General Comment No. 19, The Right to Social Security, E/C.12/GC/19 (2008), para. 2.

<sup>&</sup>lt;sup>15</sup> General Recommendation No. 27 on discrimination against Roma (para.33); General recommendation No. 34 on racial discrimination against people of African descent (para. 55).

<sup>&</sup>lt;sup>16</sup> Leaving No One Behind: Equality and Non-Discrimination at the Heart of Sustainable Development. The United Nations System Shared Framework for Action. See also UNGA Res 70/1 'Transforming Our World: The 2030 Agenda for Sustainable Development' (25 September 2015) Goal 3.8.

the World Health Assembly resolutions and Political Declarations on Universal Health Coverage.<sup>17</sup>

# **B.** Racial discrimination in the enjoyment of the right to health under Article 5 (e)(iv)

#### 1. General principles, including intersectionality

9. Racial discrimination, as defined under Article 1 (1), affects the enjoyment of the right to health as separate health risk and as structural social determinant of health. As separate health risk, racial discrimination nullifies or impairs the enjoyment of the right to health. Distinctions, exclusions, and restrictions based on race, colour, descent, national or ethnic origin, often intersecting with other grounds of discrimination, such as gender, age, disability, migratory status, class, social status, or income, occur in the right to healthcare, health information, services, and goods, including medicine and benefits of scientific progress. Differentiation of treatment in the right to health will 'constitute discrimination if the criteria for such differentiation, judged in the light of the objectives and purposes of the Convention, are not applied pursuant to a legitimate aim, and are not proportional to the achievement of this aim.' <sup>18</sup> As structural social determinant, racial discrimination affects underlying determinants, such as access to safe and potable water and adequate sanitation, adequate supply of safe food, nutrition and housing, occupational and environmental conditions. Racial discrimination produces and exacerbates health inequities, leading to, or increasing, preventable diseases and deaths. Evidence-based knowledge of this correlation allows for better identifying, preventing, mitigating, and protecting against this effect. Racial discrimination as a structural social determinant introduces a separate standard of scrutiny in designing and providing public and global health. Intersectional discrimination, on grounds of race, colour, descent, national or ethnic origin operating and interacting at the same time with any other ground, such as gender, age, disability, migratory status, class, social status, or income, in such a way that they are inseparable, is a form of racial discrimination which must be eliminated. Health laws and policies fail to measure and take into account intersectionality and fail to mirror how gender, age, disability, migratory status, class, social status, or income, and other grounds of discrimination operate inseparably with race, colour, descent, or national or ethnic origin, resulting in lower availability of health for groups within the purview of the Convention, or even exclusion, and in strengthening racial barriers. As an example, violations of the right to health, including barriers to access to reproductive health, shorter life expectancy and higher rates of maternal and infant mortality have a cumulative effect on indigenous women, women of African descent or women belonging to ethnic minorities or castes, in particular adolescents and those socioeconomically disadvantaged, or those living in rural areas.<sup>19</sup> Treating these cases solely as gender-based discrimination or disability-based discrimination essentializes victims and only partly satisfies human rights obligations while failing to unmask and tackle accordingly racial discrimination.

10. Exclusion from the enjoyment of the right to health, as an act or omission of racial discrimination, occurs in several areas of its material scope. *A priori* exclusion from access to documents or identification required to exercise the right to health on an equal footing, in line with the Convention, constitutes direct discrimination.<sup>20</sup> Conflicts, disasters, and development-induced internal displacement, often result in forced movement, loss of documents and legal status, depriving individuals, and groups from the regime of protection against racial discrimination, including special measures (Article 2(2)).

<sup>&</sup>lt;sup>17</sup> UNGA. Political Declaration of the High-Level Meeting on Universal Health Coverage. UNGA Res 74/2, 18 October 2019.

<sup>&</sup>lt;sup>18</sup> CERD, General Recommendation No. 30, para. 4.

<sup>&</sup>lt;sup>19</sup> CERD/C/ISR/CO/17-19, paras. 32 and 38.

<sup>&</sup>lt;sup>20</sup> CERD/C/ZMB/CO/17-19, paras. 25-26; CERD/C/CHL/CO/22-23, para. 32; CERD/C/USA/CO/7-9, para. 15.

# 2. Racial discrimination in the right to public health, including healthcare facilities, services and goods

11. Effect of racism and racial discrimination on physical and mental health at the microlevel and the macro-level: racial discrimination, alone or intersecting with other grounds of discrimination, micro-aggressions, racist hate crimes and racist hate speech has been linked to a range of negative health outcomes, including increased stress, depression, anxiety, and physical health problems, such as hypertension and cardiovascular disease. The ongoing effects of slavery and colonialism, experienced today as an intergenerational trauma, has not been sufficiently measured and addressed in public health as a separate factor, or in conjunction with other individual factors, such as health behaviours, social and community integration and support. Based on the assumption that persons exposed to racial discrimination are more vulnerable due to innate reasons, or their living conditions, high rates of morbidity in the areas of mental health, non-communicable diseases, and reproductive health, including maternal and perinatal health, as well as rates in mortality have not received sufficient attention in public health as matters related alone to racial discrimination.<sup>21</sup>

12. Due to unequal distribution of material resources, lack of, or unequal, representation in medical research and development, decision-making and political processes, individuals, and groups within the purview of the Convention are subject to racial discrimination in all essential elements of the right to public health, including preventive, curative, and rehabilitative healthcare facilities, services and goods:

#### (a) Racial discrimination in availability of public health, including essential medicine:

Failure to provide public health on an equal footing includes:

(i) Failure to recognize causes of mortality and morbidity affecting disproportionately groups within the purview of the Convention as public health preventable risks, diseases and deaths.<sup>22</sup> Mental health issues for groups within the purview of the Convention are disproportionately neglected in public health, resulting in exponentially nullifying or impairing their treatment on an equal footing. Despite evidence-based racial tobacco and alcohol disparities, public health does not address them as such, leading to a vicious circle of morbidity and mortality reifying bias and stigmatisation among health professionals;<sup>23</sup>

(ii) Failure to eliminate racial discrimination in other determinants of health, such as safe and potable drinking water and adequate sanitation facilities,

(iii) Failure to provide reasonable, proportionate and steadily progressive availability of primary health care, hospitals, clinics and other health-related services, trained medical and professional personnel, and essential medicine. Distribution of public health and health-care facilities, goods and services, as well as programmes, are oftentimes disproportionately lacking in areas where individuals and groups protected under the Convention are spatially concentrated.<sup>24</sup> Public and private health systems, policies, and programmes fail to take into account high rates of maternal mortality among women belonging to groups within the purview of the Convention, or high rates of violence and their effect on physical and mental health of individuals, families and communities.

#### (b) Racial discrimination in physical, affordable, and information accessibility:

Structural racial discrimination nullifies or restricts disproportionately access of groups within the purview of the Convention to public health, healthcare facilities, services, and goods. Under the reporting procedure, the Committee has found that high number of persons belonging to groups within the purview of the Convention do not have access to stable and affordable health care. A number of causes, acts and omissions, lead to this outcome:

<sup>&</sup>lt;sup>21</sup> CERD/C/CZE/CO/12-13, para. 15 (c); CERD/C/USA/CO/7-9, para. 15.

<sup>&</sup>lt;sup>22</sup> CERD/C/CZE/CO/12-13, para. 15(c);

<sup>&</sup>lt;sup>23</sup> WHO's submission to the thematic discussion: Racial Discrimination and the Right to Health, p. 3.

<sup>&</sup>lt;sup>24</sup> CERD/C/SLV/CO/18-19, paras. 34-35; CERD/C/HUN/CO/18-25, para. 20;

(i) Lack, or limited scope, of legislation and policies recognising accessibility as a matter of equal treatment and prohibiting racial discrimination, alone or/and intersecting with other grounds of discrimination, such as gender, disability, age, migratory status, class, social status or income, and other status;

 (ii) Disproportionately unequal coverage due to discrepancies of distribution of resources within the State;<sup>25</sup>

(iii) Systemic failures and discrepancies in including persons belonging to groups exposed to racial discrimination, such as migrants and refugees, persons deprived of their liberty, or in applying without racial discrimination legislation related to occupational health and safety;

(iv) Interpersonal and institutional bias in applying legal requirements in access to healthcare;

(v) Privatisation and commercialisation without due regard to accessibility in practice by persons subject to racial discrimination, including undocumented pregnant women, thus increasing the risk of obstetric emergencies and complications during childbirth;<sup>26</sup>

(vi) Restrictive conditions under which law permits access to sexual and reproductive information, services, and medicine, including family planning, vii) harassment, violence and criminalization of services related to sexual and reproductive health, <sup>27</sup> especially abortions,<sup>28</sup>

(vii) Lack of information and digital divide.<sup>29</sup>

#### (c) Racial discrimination in acceptability and sensitivity:

The Committee has received numerous reports supporting the finding of limited availability of culturally sensitive and respectful health care.<sup>30</sup> Public health and health care is not designed and/or provided with the clear aim to include groups within the purview of the Convention and improve their health status based on gender and life-cycle requirements. The history of medicine, and its role in supporting theories of racial superiority and in justifying slavery and colonialism,<sup>31</sup> shaped and sustained hierarchies in the creation of health systems, stereotyping and perpetuating bias against traditional medicine and the role of culturally sensitive personnel and practices, including midwifery care. The lack of recognition or arbitrary prohibition of traditional healers, traditional medicines and pharmacopoeia specific to certain ethnic groups make members of these groups vulnerable to diseases whose response is found in their tribal cultures. This approach has curtailed disproportionately access and acceptability of health care of those protected under the Convention, in particular, those with low incomes and those living in rural areas.

#### (d) Racial discrimination in quality and adaptability, including "race corrections":

Racial discrimination affects also scientific and medically appropriate quality. Exclusion or disproportionate restrictions of groups within the purview of the Convention in access to skilled medical personnel, scientifically approved and unexpired drugs, and hospital equipment, are often the outcome of unequal distribution of resources and underestimation of racial discrimination as a matter of public health. Moreover, reports show that institutional bias continues to impair and restrict access to adequate health goods and services. Adopting a self-critical approach, health providers' associations and medical schools acknowledge the broad effect of the use of "race-based corrections", namely the use of "race", and not racism

<sup>&</sup>lt;sup>25</sup> CERD/C/BRA/CO/18-20

<sup>&</sup>lt;sup>26</sup> CERD/C/CZE/CO/12-13, para. 23.

<sup>&</sup>lt;sup>27</sup> CERD/C/HUN/CO/18-25, para. 20.

<sup>&</sup>lt;sup>28</sup> CERD/C/SLV/CO/18-19, paras. 26-27.

<sup>&</sup>lt;sup>29</sup> CERD/C/SLV/CO/18-19, paras. 34-35

<sup>&</sup>lt;sup>30</sup> (CERD/C/GTM/CO/16-17, para. 13 c); CERD/C/MNG/CO/23-24, para. 23 (e)

<sup>&</sup>lt;sup>31</sup> A/77/197, paras. 47-60.

or racial discrimination, to explain differences in disease prevalence and outcomes.<sup>32</sup> In that sense, health mirrors how "race", as a social construct, operates in society; instead of dissecting the effects of racial discrimination and racism in health risks and outcomes, "race" has been normalized and internalized in health practices, protocols and policies, in "the full spectrum of care, from what medicines and dosages are selected to which patients are granted access to specialists, organ transplants, clinical trials, and insurance coverage."<sup>33</sup> Disease stereotyping and bias in medical training approaches and materials are perpetuated by conflating race and ancestry and by using terms with racial connotations, or by teaching differences in disease among "white and black population" without historical or social context. Women and men, under the historical legacy of slavery, are considered physically stronger and durable. Women of African descent, indigenous and Roma women often wait longer during labour before they have access to medicine.<sup>34</sup> It is not uncommon that groups within the purview of the Convention are excluded from medical research and studies on treatments and medicine. Although pharmaceutical and other relevant corporations do not make available such data, physicians report that due to bias, structural barriers, and unwillingness to show flexibility and responsiveness to integrate participation by ethnic and racial groups, medication and other goods and services are not tested taking into consideration their situation. Lack of knowledge by physicians and other health practitioners on how symptoms manifest on black bodies was also reported to the Working Group of Experts on People of African Descent.35

13. Artificial intelligence and racial discrimination in the context of health: racial discrimination may permeate artificial intelligence through electronic health records and machine learning algorithms, while their use in health is increasing. As in other fields, details about their development remain largely unknown and lack of transparency does not allow any adjustment by health providers in practice.<sup>36</sup> However, studies demonstrate how clinical algorithms reproduce structural inequalities outcomes in hospitals by translating them into health indicators. As just one of the examples, studies show that the algorithm using health costs as a proxy for health needs, reproduces bias based on how money is spent on patients of African descent who have the same level of need, and the algorithm thus falsely concludes that they are healthier than other equally sick patients. Due to missing data, an AI algorithm that depends on genetic test results is more likely to mischaracterize the risk of breast cancer for patients protected under the Convention. Bias is also instilled through studies that do not challenge embedded racial ideologies and fail to assess the synergies between psychosocial, genetic, and environmental factors in explaining differences in health outcomes, such as hypertension.37

14. Spatial concentration of groups within the purview of the Convention in areas with high exposure to environmental health hazards fails to be reflected in public health policies and programmes, as human rights issues closely interrelated with racial discrimination.<sup>38</sup> This has multiple and cumulative effects on the enjoyment of the right to health: first, exposure to health hazards are underestimated and not mitigated by appropriate environmental, precautionary and mitigating, measures; second, in most cases, health policies and laws do not respond to these risks, by appropriate epidemiological studies, continuing monitoring of health outcomes and appropriate health services; third, communities lack access to appropriate information and are in no position to adopt any individual protective measures.

15. Climate change results in several negative heat-related health outcomes, along with increase in air-pollution, extreme weather events and natural disasters. Climate change also expands disease vectors, by destroying infrastructure and by reducing access to underlying

<sup>&</sup>lt;sup>32</sup> Field Correction | Harvard Medicine magazine 2021.

<sup>33</sup> Ibid.

<sup>&</sup>lt;sup>34</sup> CERD/C/CHL/CO/22-23, para. 12-13.

<sup>&</sup>lt;sup>35</sup> Working Group of Experts on People of African People, Submission to the Thematic discussion: Racial discrimination and the right to health, para. 11

<sup>&</sup>lt;sup>36</sup> Getting the Future Right. Artificial Intelligence and Fundamental Rights, European Union Agency for Fundamental Rights, 2020.

<sup>&</sup>lt;sup>37</sup> Schmidt, Insa M.; Waikar, Sushrut S., Separate and Unequal: Race-Based Algorithms and Implications for Nephrology, JASN <u>32(3)</u>:p <u>529-533</u>, March 2021. | DOI: 10.1681/ASN.2020081175

<sup>&</sup>lt;sup>38</sup> CERD/C/USA/CO/10-12, paras 45-46.

determinants of health, such as water and nutrition. It affects profoundly mental health, both directly and indirectly due to its impact on social networks and cultural traditions. Racial and ethnic minorities are disproportionately affected, due to geographical location, socio-economic situation, cultural norms and intrinsic psychological factors.<sup>39</sup>

16. Non-citizens, migrants, refugees, asylum seekers and stateless persons face health risks linked to poor living conditions, difficult work situations and a multitude of factors that are determinants of health. The legal status often shifts the attention disproportionately from public health to other concerns, without providing any alternative path of protection or mitigation of health risks and outcomes. Lack of integration of non-citizens into local health systems contributes to deteriorating their physical and mental well-being. In many contexts, non-citizens do not enjoy the right to occupational health and safety, as they are often involved in informal labour markets. The live-in requirement for foreign domestic workers as well as situations reported to the Committee of physical and mental abuse and confiscation of their passports by their employers expose migrants to systemic racial discrimination in the right to health.<sup>40</sup> Providing access to preventive and primary care beyond emergency care is proven to reduce health costs. In this sense, an EU study shows that extending access to primary health care to irregular migrants could generate a potential saving of 49% or more in terms of direct medical and non-medical expenditure.<sup>41</sup>

## C. Racial discrimination in the right to control one's health and body

17. Article 5 (e)(iv) requires States to respect, protect and fulfil the freedom from racial discrimination in the right to control one's health and body, including sexual and reproductive freedom, and the freedom from interference, such as the right to be free from torture, non-consensual medical treatment and experimentation.<sup>42</sup> Mandatory HIV/AIDS testing limited to non-citizens, or based on race, colour, descent, national or ethnic origin, for employment purposes, as well as for entry, stay and residence purposes, without objective and reasonable justification on public health grounds, is ineffective for public health purposes, discriminatory, and harmful to the enjoyment of fundamental rights.<sup>43</sup>

18. Racial bias, stigmatization and structural inequalities expose individuals and groups within the purview of the Convention to various forms of coercion, either by imposing treatments or by denying health services. Access to information is corollary to these rights, considering the barriers groups within the purview of the Convention face in accessing information. Building upon lack of trust in public institutions, often aggravated by health policies involving police and other law enforcement agencies, misinformation targets and affects disproportionately the quality of preventive, curative, and rehabilitative health of groups within the purview of the Convention. Infodemic operates as an excuse for justifying exclusion and reinforcing the stigma and bias against groups within the purview of the Convention. They are treated as "ignorant", potential "threats" for public health, and instead of being prioritised due to their increased exposure to racial discrimination and vulnerability, they are left behind. Lack of access to information reinforces inequalities and facilitates coercive practices with serious and even irreversible health consequences. Lack of access to information nullifies and impairs access to the right to informed consent.

19. Deprivation of liberty, due to over policing, racial profiling, and overrepresentation in the penitentiary system, leads to disproportionate restrictions in the right to control their health and bodies and be free from non-consensual medical treatment, including as a preventative measure to address the impact of imprisonment on mental health. Criminalization of traditional medicine and practices, without any consultation and

<sup>&</sup>lt;sup>39</sup> A/HRC/32/23 (2016).

<sup>&</sup>lt;sup>40</sup> CERD/C/CHN/CO/14-17, paras. 30-31.

 $<sup>^{41}\</sup> http://europe.ohchr.org/Documents/Publications/RightToHealthForMigrants\_EN.pdf$ 

<sup>&</sup>lt;sup>42</sup> CESCR General Comment 14 para. 8; A/HRC/35/21, Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health, 28.3.2017, paras. 30-34.

<sup>&</sup>lt;sup>43</sup> *L.G. v. Repulbic of Korea*, CERD/C/86/D/51/2012. The State party abolished the mandatory HIV/AIDS testing and the petitioner received compensation.

consideration of integration, exposes persons protected under the Convention to unreasonable dilemmas between their right to life and bodily autonomy and their right to security of person and protection by the State against violence or bodily harm, whether inflicted by government officials or by any individual group or institution (Article 5 (b)). In both cases, their right to health is compromised.

20. Racial discrimination in the right to sexual and reproductive health: a long-standing practice in the treaty bodies system on "the right to make free and responsible decisions and choices, free of violence, coercion and discrimination, regarding matters concerning one's body and sexual and reproductive health"<sup>44</sup> shows how structural racial discrimination, intersecting with other forms of discrimination, such as gender, gender identity, disability, migratory status, class, social status or income, reflecting hierarchies and patterns of unequal distribution of resources and power, is one of the main sources of violations of the right to sexual and reproductive health under the Convention.

#### (i) Forced sterilizations:

21. The Committee recognized that some forms of racial discrimination, such as coerced or forced sterilization, may be specifically directed towards women due to their gender.<sup>45</sup> Indigenous, women of African descent, Roma and women belonging to other ethnic groups and castes, including women suffering from mental health illness within these groups, have been disproportionately targeted in policies related to population control or control of infectious diseases, such as HIV/AIDS, including coercive sterilizations.<sup>46</sup> Within these groups, women with disabilities have been denied their legal capacity and as a consequence, their right to provide consent. Forced sterilizations violate the rights of women within the purview of the Convention to reproductive autonomy, access to information, personal integrity, privacy, and the right to be free from racial and gender-based violence and discrimination.<sup>47</sup>

#### (ii) Unsafe abortions and racial discrimination:

22. Persons within the purview of the Convention are at a higher risk of unwanted pregnancies and of lacking the means to overcome socioeconomic and other barriers to access to safe abortion. Laws, rulings and practices nullifying in law and in practice access of women and persons with reproductive rights protected under the Convention to safe and legal abortion have a disproportionate impact on the sexual and reproductive health and rights of groups and minorities within the purview of the Convention, in particular those with low incomes.<sup>48</sup> Safe, legal and effective access to abortion is part of the right to control one's health and body and the right to life of persons protected under the Convention.<sup>49</sup> Women protected under the Convention are often trapped between the failure to recognize and eliminate the effect of racial discrimination on sexual and reproductive health and the measures exposing them to further stigmatization, marginalization, and disadvantage. Failing to recognize the impact of racially motivated sexual violence, hindering access of groups within the purview of the Convention and programmes on involuntary

<sup>&</sup>lt;sup>44</sup> CESCR, General Comment No. 22, para. 5.

<sup>&</sup>lt;sup>45</sup> General Recommendation No. 25 on gender-related aspects of racial discrimination, paras. 2-3 (2000).

<sup>&</sup>lt;sup>46</sup> Eliminating forced, coercive and otherwise involuntary sterilization An interagency statement OHCHR, UN Women, UNAIDS, UNDP, UNFPA, UNICEF and WHO, 2014; CESCR, General Comment No. 22, paras. 5, 10, 30

<sup>&</sup>lt;sup>47</sup> InterAmerican Court Human Rights., *I.V. v. Bolivia*. Preliminary Objections, Merits, Reparations and Costs. Judgment of 30 November 2016. Series C No. 329; *A.P., Garçon and Nicot v. France*, nos. 79885/12 52471/13 52596/13, Judgment of 6 April 2017; African Commission for Human Rights, *General Comment No. 4 on the African Charter on Human and Peoples' Rights: The Right to Redress for Victims of Torture and Other Cruel, Inhuman or Degrading Punishment or Treatment (Article 5) (2017), para. 58; CESCR, General comment No. 22 (2016), para. 3; CRPD, General comment No. 3 on women and girls with disabilities (2016), para. 32; A/HRC/ 31/57, para. 45.* 

<sup>&</sup>lt;sup>48</sup> CERD/C/USA/CO/10-12, para. 35; CERD/C/BRA/CO/18-20, para. 16 (b).

<sup>&</sup>lt;sup>49</sup> Abortion care guideline, Annex A. Key international human rights standards on abortion, World Health Organisation 2022.

pregnancies, stigmatizing and criminalizing the role of midwives belonging to these groups and, finally, criminalizing and punishing the access to abortion depicts a chain of causation where racial discrimination operates both as a separate health risk and as structural social determinant.

# **III.** Obligations under ICERD

23. Racial discrimination in the enjoyment of the right to health is prohibited under the Convention and States parties are required to eliminate it in all its forms and to guarantee equality before the law. Obligations should be read in light of the objectives set in the Preamble and the Convention as a whole. Eliminating racial discrimination in all its forms and manifestations requires prompt action and has a clear purpose: promote understanding between people and build an international community free from all forms of racial segregation and racial discrimination.

## A. General and cross-cutting obligations

24. Article 5(e)(iv) requires States to eliminate racial discrimination and guarantee equality in their measures aiming to respect, protect and fulfil the right to health. The Convention sets a framework for identifying, preventing, and eliminating the risks and outcomes of racial discrimination in the enjoyment of the right to health, removing structural racial barriers, and providing individuals and groups within the purview of the Convention for opportunities to improve on an equal footing their well-being and enjoy the highest attainable standard of physical and mental health. Article 5(e)(iv) must be read in conjunction with Articles 2, 4, 6 and 7 of the Convention.

25. Article 5 refers to Article 2 as the provision setting the fundamental obligations on rights under the Convention. Article 2 is a comprehensive provision addressing all aspects of States parties' obligations to pursue a policy of eliminating discrimination,<sup>50</sup> indicating that a wide range of measures is necessary to eliminate racial discrimination "in all its forms" and "without delay". Article 2, in conjunction with Article 5 (e)(iv), entails negative and positive obligations to respect, protect and fulfil the right to health for all persons and groups within the purview of the Convention. The causation between health vulnerabilities and outcomes and racial discrimination as a structural social determinant and as separate health risk determine the standard in assessing measures adopted to comply with the Convention. The status of the prohibition of racial discrimination in international law, as one of the most egregious forms of discrimination, and the link between the right to health and the right to life leave States a very narrow margin of appreciation in differentiations of treatment in fulfilling their obligations to respect the right to health. States must refrain from interfering with the right of persons and groups protected under the Convention to control their health and body, and with their freedom from torture, and they should protect them against racially motivated acts in relation to their right to health, including disclosure of patient's health information without their consent. Article 5(e)(iv) should be read in conjunction with Article 4. States must refrain and protect against stigmatisation, incitement to racial hatred and acts of discrimination against persons and groups within the purview of the Convention on the ground of health status. Moreover, failure to act upon this knowledge of correlation by adopting and implementing preventative, protective, mitigating, and restorative measures related to racial discrimination with a view to improve underlying determinants and health outcomes constitutes a failure to comply with the obligation to prevent and protect the right to health. Finally, States must adopt appropriate legislative, administrative, budgetary, judicial, promotional, and other measures towards the full realization of the prohibition of racial discrimination and the guarantee of equality in the enjoyment of the right to health.

26. States parties must ensure that "the principle of self-governance of local and regional bodies does not hamper its human rights obligations to promote economic, social and cultural

<sup>&</sup>lt;sup>50</sup> Views of the CERD on the Implementation of the Convention on the Elimination of All Forms of Racial Discrimination and its Effectiveness, submitted under the rubric of 'complementary standards', E/CN.4/2004/WG.21/10/Add.1, 17 September 2004, p. 13.

rights of disadvantaged or discrimination groups, as per the Convention".<sup>51</sup> Central or federal governments must ensure, by coordinating or exercising any other power their constitutions allow, that Article 5 (e)(iv), is implemented at all levels of administration. Local and regional authorities must be involved in identifying risks and needs, in allocating resources and providing health services and goods, in particular in rural areas, taking into consideration environmental harms on health and land rights.

27. Representation in medical research and development, decision-making, healthcare facilities, services and goods: Representation of groups within the purview of the Convention in health is crucial for identifying health risks and outcomes related to racial discrimination, improving quality of health, building trust with communities subjected to racial discrimination and cultivating a culture of equality and non-discrimination. States must actively encourage representation of groups exposed to racial discrimination in the enjoyment of the right to health, taking into account their population composition, including intersectionality and life-cycle requirements.

28. States must adopt concrete measures to encourage multi-dimensional representation of groups protected under the Convention within their own remit, both as health-related actors (such as nurses, physicians, laboratorial technical staff, public health experts, regulators, monitoring bodies), and as actors at the receiving end of health (patients, family members, associations) within public or semi-public bodies. Specific indicators of representativity must comply with other international obligations on human rights, equality and non-discrimination, while taking into account the context and the scope of the situation. States should also promote in the supply chain policies and transactions with private entities, such as pharmaceutical and other corporations, insurance companies, and healthcare organizations, that representation of groups within the purview of the Convention is a measurable indicator of quality of health, including preventive, curative, and rehabilitative healthcare facilities, services and goods.

29. Participation, consultation, empowerment: Article 2(1)(e) provides for the obligation of State parties "to encourage, where appropriate, integrationist multiracial organizations and movements and other means of eliminating barriers between races, and to discourage anything which tends to strengthen racial division." This obligation echoes the statement in the Preamble that "... the existence of racial barriers is repugnant to the ideals of any human society". Integrationist multiracial organizations and movements should be understood as those supporting the principles of the Convention, grassroots and community organisations and civil society organisations, including health-related organisations. Anti-discrimination law and public health often operate in silos. Participation and consultation of groups within the purview of the Convention in health decision-making integrates their knowledge and improves the quality of the decisions. Legitimacy and transparency of decisions is increased, and trust is built between health institutions and communities. If communities within the purview of the Convention are involved in the decision-making, at community, local, regional, or national level, they exercise their right to be heard and their right to information.

30. States must guarantee that access to information and the right to participation is provided to persons protected under the Convention as individuals, taking into account language and other cultural barriers.

31. Special measures: States must recognise that groups within the purview of the Convention have different needs for health and social services and report to the Committee on this.<sup>52</sup> They must adopt special measures, in line with Article 2 (2) to secure advancement and equality in the enjoyment of the right to health.

## B. Monitoring racial inequalities in health

32. No policy can be effectively designed, implemented, and assessed, without continuous monitoring of racial discrimination in the enjoyment of rights under Article 5. States parties

<sup>&</sup>lt;sup>51</sup> CERD/C/SVK/CO/9-10, para. 16.

<sup>&</sup>lt;sup>52</sup> CERD/C/2007/1, Guidelines for the CERD-specific document to be submitted by States Parties under Article 9, paragraph 1, of the Convention.

must be in position to measure racial discrimination, identify quantitative and qualitative trends and adopt specific and concrete measures within a broader policy. Monitoring of racial discrimination at national level goes hand in hand with Articles 2(2), 8 and 9. Keeping under review policies based on indicators, assessing human rights impact of policies and observe progress in eliminating racial discrimination is an essential tool for reporting obligations under the Convention. Statistics related to the enjoyment of the right to health in compliance with the Convention should be available and should rely on comparable periods of time, relevant geographic scope, and population groups. In absence of comprehensive statistics, it is impossible to assess effectively if laws, health policies and programmes, apparently neutral, result in racial discrimination. One of the fundamental obligations under the Convention is to provide persons within the purview of the Convention the right to self-identify as such and be included in statistics and social surveys related to the right to health.<sup>53</sup>

33. The Durban Declaration and Programme of Action urges States to "collect, compile, analyse, disseminate and publish reliable statistical data at the national and local levels and undertake all other related measures which are necessary to assess regularly the situation of individuals and groups of individuals who are victims of racism, racial discrimination, xenophobia and related intolerance; (...) The information should take into account economic and social indicators, including, where appropriate, health and health status, infant and maternal mortality, life expectancy, literacy, education, employment, housing, land ownership, mental and physical health care, water, sanitation, energy and communications services, poverty and average disposable income, in order to elaborate social and economic development policies with a view to closing the existing gaps in social and economic conditions."<sup>54</sup>

34. As to the right to health, States are urged and non-governmental organizations and the private sector are encouraged "to provide effective mechanisms for monitoring and eliminating racism, racial discrimination, xenophobia and related intolerance in the health-care system, such as the development and enforcement of effective anti-discrimination laws" and "to establish, on the basis of statistical information, national programmes, including affirmative or positive measures, to promote the access of individuals and groups of individuals who are or may be victims of racial discrimination to basic health care, and to promote strong efforts to eliminate disparities, inter alia in the infant and maternal mortality rates, childhood immunizations, HIV/AIDS, heart diseases, cancer and contagious diseases."<sup>55</sup>

35. States parties often raise concerns of their conflicting obligation to respect and protect the right to privacy of individuals and groups within the purview of the Convention, while also avoiding the negative impact of markers, such as "race", reinforcing divisions, hierarchies, and false theories of racial superiority. The Committee recalls that understanding and identifying the effect of racial discrimination often puts authorities in the position to examine how potential victims of racial discrimination are seen, perceived, and classified by potentially discriminating laws, policies, or systems. Bias, stigmatization, and racial discrimination operate by ascribing to persons characteristics and identifies that need to be conceptualised in broad terms to be inclusive of all grounds and forms of racial discrimination under Article 1. States are advised and encouraged to develop appropriate methodologies for the collection of relevant information, in cooperation with specialised UN and regional agencies.<sup>56</sup>

36. Lack of statistics and comprehensive data on the situation of groups within the purview of the Convention should not pose an extraordinary burden on victims of racial discrimination in proving racial discrimination. In many areas related to health, data and facts lie wholly, or in large part, within the exclusive knowledge of national authorities or private actors involved in installations, services and goods. Persons and groups within the purview

<sup>&</sup>lt;sup>53</sup> CERD/C/ZMB/CO/17-19, paras. 25-26

<sup>&</sup>lt;sup>54</sup> Durban Declaration and Programme of Action, para.92.

<sup>&</sup>lt;sup>55</sup> Ibid, paras. 100-101.

<sup>&</sup>lt;sup>56</sup> E.g., EU High Level Group on Non-discrimination, Equality and Diversity, Guidance Note on the collection and use of equality data based on racial or ethnic origin (2021).

of the Convention must have the necessary information to document and request special meausres, as provided by Article 2(2).

# **IV. Recommendations**

37. States are required under the ICERD to respect, protect and fulfil the freedom from racial discrimination in the enjoyment of the right to health and to remedy any such violation. Equality in the right to health is achieved through measures combining resources, institutions and systems across all sectors related to the right to health. Good practices and strategies developed within the UN system and at national and regional level by States parties, independent authorities, and civil society, as well as lessons learnt during the pandemic COVID-19, provide a good basis for addressing recommendations to States parties and other stakeholders.

#### A. Legislative and policy related measures

Adoption of comprehensive legislation against racial discrimination in the right to 38. health in civil, administrative and criminal law. Such legislation must make explicit reference to all grounds of racial discrimination in Article 1 (1) and extend the prohibition of racial discrimination to all State authorities, public institutions, and private persons, natural and legal, in accordance with Article 2. The scope of the prohibition of racial discrimination should include both the right to a system of health protection and the right to control one's individual health and body, as well as the freedom from torture, non-consensual medical treatment, and experimentation, while any reference to Article 12 ICESCR, as interpreted by the CESCR, would enhance harmonisation across the UN treaty system. Explicit reference to intersectionality recognising the prohibition of racial discrimination, as defined in Article 1(1) of the Convention, intersecting with other grounds of discrimination, such as gender, age, disability and migratory status, class, social status or income, is strongly encouraged, as promoting consistency with international and regional human rights law obligations, and strengthening effectiveness of measures of implementation under the Convention. National legislation should provide the framework for fulfilling the obligation under Article 2(2) to adopt special and concrete measures to ensure the adequate development and protection of disadvantaged groups within the purview of the Convention with a view to facilitate the full and equal enjoyment of the right to health.

39. Operationalisation of the legislation against racial discrimination in the enjoyment of the right to health by:

(i) Adopting and implementing administrative measures, including in public procurement, and internal policies providing for concrete and specific measures to respect and ensure availability, physical, affordable and information accessibility, acceptability and quality of health as well as measures to prevent, respect and protect against coercive measures in breach of the prohibition of racial discrimination in the right to control ones' body and health and in breach of the freedom from torture, non-consensual medical treatment and experimentation. States should ensure that health and other related agencies develop detailed guidelines for integrating and applying in practice measures ensuring equality before the law and the prohibition of racial discrimination with precise standards in consultation with relevant groups;

(ii) Identifying racial inequalities and reviewing, amending, or rescinding legislation, policies and practices which maintain and perpetuate racial discrimination in the right to health. States should conduct studies to identify such laws and practices, in consultation with relevant communities, and amend or repeal them accordingly;

(iii) Provide for clear guidance to all health-related agencies and institutions, including any other authorities and institutions involved, such as law enforcement, ensuring that internal policies, including standard operating procedures and codes of conduct, are in line with human rights standards and principles related to equality and the prohibition of racial discrimination;

(iv) National strategies and plans of action, in consultation with relevant groups, institutions and authorities, may be an effective tool to identify gaps and provide for clear objectives and special measures, in accordance with Article 2(2), as well as coordination of all relevant authorities and effective budgeting.<sup>57</sup>

40. Community-centred approaches, gender-based and culturally sensitive practices should be adopted to ensure availability, accessibility, adaptability and quality of health care, based on the needs, traditions and cultural specificities of racial and ethnic minorities. States should provide and strengthen effective collaboration between modern and traditional medicine and support the implementation of a national policy on midwives.<sup>58</sup> States are strongly encouraged to coordinate effectively support services by promoting models of cooperation between the authorities, the communities and the civil society organizations including those representing groups experiencing intersecting forms of discrimination, Equality Bodies and National Human Rights Institutions and private health providers. States should explore as a mitigating special measure the possibility, in consultation with the communities of providing health-care support through mobile health clinics,<sup>59</sup> or specific health prevention programmes, comprehensive emergency health care and any care related to childbirth free of charge for all and, ensure that medical practitioners and staff at medical facilities do not report undocumented migrants.<sup>60</sup>

41. Regulate the use of artificial intelligence in all health-related sectors: States should ensure compliance of artificial intelligence in health with the prohibition of racial discrimination. Such systems should be deployed only if their use has as clear objective to advance the enjoyment of the right to health for all without racial or any other discrimination. Both the legitimate aim of their use and their interference with human rights should be assessed taking into account to what extent they contribute to eliminate racial discrimination. Demographic and socioeconomic data should reflect the population as a whole to avoid any a priori exclusion of persons protected under the Convention.

42. Before procuring or deploying such systems, States should adopt appropriate legislative, administrative and other measures to determine the purpose of their use and to regulate as accurately as possible the parameters and to provide guarantees that prevent and protect against racial discrimination in the right to health. States should adopt a human rights-based approach in artificial intelligence, where the elimination of racial discrimination is embodied at all stages and permeates all minimum standards, such as: i) human agency and oversight; ii) technical robustness and safety; iii) privacy and data governance; iv) transparency; v) diversity, non-discrimination and fairness; vi) societal and environmental well-being; vii) accountability. <sup>61</sup>

43. States should assess the human rights impact prior to deploying artificial intelligence in health and they should consider a pilot period under the supervision of an independent multidisciplinary oversight body inclusive of individuals that reflect the diverse composition of the population.

## **B.** Data and statistics

44. In cooperation with the WHO, other UN and regional organisations and agencies, States should monitor related racial inequalities and racial discrimination in health, alone and in conjunction with other social and underlying determinants.<sup>62</sup> They should collect and

<sup>57</sup> CERD/C/SLV/CO/18-19, para. 5

<sup>&</sup>lt;sup>58</sup> CERD/C/GTM/CO/16-17, para. 13 (c); CERD/C/GTM/CO/16-17, paras. 33-34; CERD/C/MUS/CO/20-23, paras. 26-27; CERD/C/ISR/CO/17-19, paras. 28-31.

<sup>&</sup>lt;sup>59</sup> General recommendation No. 30 (2004) on discrimination against non-citizens; CERD/C/MNG/CO/23-24, para. 23 (e).

<sup>&</sup>lt;sup>60</sup> CERD/C/CZE/CO/12-13 para. 24.

<sup>&</sup>lt;sup>61</sup> European Commission, High-Level Expert Group on Artificial Intelligence (AI HLEG), Assessment List for Trustworthy Artificial Intelligence (2020).

<sup>&</sup>lt;sup>62</sup> National health inequality monitoring: a step-by-step manual, WHO 2017. See also Health Equity Assessment Toolkit (HEAT and HEAT Plus), elearning and other tools developed by the WHO on monitoring health inequality.

monitor anonymized disaggregated quantitative and qualitative data, based on demographic and health indicators. Data should be disaggregated by any information about race, colour, descent, or national or ethnic origin and indigeneity, in conjunction with gender, age, disability, migratory and any other status.

45. Monitoring of racial discrimination in health should include indicators on differential exposure to health risks and differential vulnerability, in terms of health availability, accessibility, acceptability and quality of health. Monitoring should also cover areas where coercive measures may disproportionately apply and affect groups within the purview of the Convention, such as reproductive health-care providers, mental health institutions, prisons, refugee, and migrants' settlements, including at the borders, with a view to identify systemic exposure to health risks and vulnerabilities. States should assess, measure and report on racial inequalities. States should also monitor, assess, and make available demographic statistics disaggregated by underlying determinants of health, such as access to safe and potable water and adequate sanitation, adequate supply of safe food, nutrition and housing, healthy occupational and environmental conditions. Persons belonging to groups within the purview of the Convention should have access to this information to control their exposure to health risks and exercise other related rights of consultation and participation in health-related or environmental procedures.

46. Disaggregated health statistics should at least include data collected by hospitals, community and other health-care centres, doctors, and health insurers, in conjunction with survey data and establish linkages with administrative data systems to measure and assess availability and accessibility of health. Acceptability and quality should also be measured and assessed based on survey data with the communities. The anonymized statistics generated by such practices should be made available to the public and the communities within the purview of the Convention. Such data should be collected voluntarily, anonymously and on the basis of self-identification and in accordance with human rights standards and principles, such as data protection regulations and privacy guarantees, including guarantees on informed consent. Persons protected under the Convention should have access to information regarding collection of their data, their use, and outcomes.

47. In cooperation with regional and national authorities, States should adopt and implement specific strategies of respect and protection against racial discrimination in electronic health data access and sharing. Any regulation of electronic data sharing should always include explicitly rules preventing, protecting against and remedying racial discrimination.<sup>63</sup>

## C. Education, training, and access to information

48. In line with article 7 of the Convention, States should develop and offer human rights education and training with a focus on racial discrimination to a wide range of actors involved in health. Health professionals, social workers, and other key civil servants and third parties involved in health, including in humanitarian settlements, at local, regional, and national level should be provided with mandatory training. Groups within the purview of the Convention, including persons experiencing intersecting forms of discrimination should be engaged in the development and delivery of such training, where possible. Hospitals, primary healthcare centres and social services should ensure that training is complemented by institutional interventions regarding limiting discretion and increased oversight in areas vulnerable to stereotyping and biases.

49. Human rights education should be included as mandatory course in curricula of medical schools and other health related schools and departments. Medical schools are encouraged to review their curricula and identify bias and stereotyping in medical training approaches and materials. Health providers should be conscious about racial discrimination and prevent race-based simplifications.

<sup>&</sup>lt;sup>63</sup> European Commission proposal for regulation to set up the European Health Data Space, COM(2022) 197 final, 2022/0140 (COD).

50. Health professionals' associations are strongly encouraged to consider integrating in their membership policies human rights and anti-discrimination trainings.

51. States should conduct targeted awareness-raising campaigns with information about available health services and the requirements for compulsory health insurance coverage.<sup>64</sup> They should prevent false or misleading information from spreading in digital and physical environments.

# **D.** Private actors

52. States have the primary responsibility to identify, measure and protect against racial discrimination in the right to health in all areas of life. Racial discrimination should be explicitly recognised as health risk and structural determinant of health to prevent and mitigate in procurement and any other authorisation of business activities. States should adopt legislation and policies prohibiting, monitoring, investigating and punishing accordingly any racially motivated conduct with the purpose or effect to harm physical and mental integrity of persons protected under the Convention, and any interference with the right to equality and the freedom from racial discrimination in the right to health. Harm is understood as the outcome of racial discrimination on the right to health, in accordance with Article 1 (1).

53. States should adopt regulation ensuring that private business enterprises, private health-care facilities, insurance and pharmaceutical companies, manufacturers of health-related goods and equipment and other relevant organizations comply with the principle of equality and non-discrimination in the right to health, in line with the 2011 Guiding Principles on Business and Human Rights (Guiding Principles 1, 2, 3, 11 and 24). Development of mandatory human rights due diligence regimes may provide for a comprehensive framework where racial discrimination risk management should be integrated across business operations. Private actors should: i) identify and assess actual or potential adverse impacts on the right to health based on race, colour, descent, or national or ethnic origin with which they may be involved either through their own activities or as a result of their business relationships; ii) integrate the findings arising from these assessments across relevant internal functions and processes, and take appropriate action; iii) track the effectiveness of their response; and iv) account for how they address their human rights impacts.<sup>65</sup>

54. In the process of identifying, assessing, preventing, and mitigating adverse human rights impacts, companies should pay particular attention to the data-related factors which may have discriminatory purpose or effect. The selection of training data and the design of their models should be done in a way that prevents discriminatory outcomes in the right to health. Companies should also be open to independent third-party audits of their artificial intelligence systems.<sup>66</sup> Where the risk of discrimination or other human rights violations has been assessed to be too high or impossible to mitigate, including because of the nature of the planned or foreseeable use by a State, private actors should refrain from deploying such systems before they ensure that the discriminatory outcome is effectively mitigated. Exposure and vulnerability to health risks due to racial discrimination should be incorporated in this ex-ante and ex-post assessment, with the cooperation of a multidisciplinary team understanding how racism and racial discrimination may be experienced.

55. States should ensure that private actors, subject to their involvement, respond and account on the harm caused on the right to health. If the private actors caused the harm, they should cease their action causing the harm and remedy it. If the private actors contributed to the harm by another, they should cease their action contributing to the harm, seek to use or build leverage with the other party to prevent or mitigate the risk of future harm, and contribute to remedy of the harm, including through compensation. Finally, if the private actors are only linked to harm that that they did not cause or contribute to, they should try to

<sup>&</sup>lt;sup>64</sup> CERD/C/LTU/CO/9-10, para. 18.

<sup>&</sup>lt;sup>65</sup> UNGPs 17-21; OHCHR, The Corporate Responsibility to Respect: An Interpretative Guide, pp. 31-63.

<sup>&</sup>lt;sup>66</sup> Toronto <u>Declaration</u>: Protecting the right to equality and non-discrimination in machine learning systems.

use or build their leverage to prevent or mitigate the risk of future harm by the other party but is not expected to contribute to the remedy.

56. States should document and include information in their reports to the Committee, about cases of racial discrimination associated with private actors, as well as prevention measures, sanctions, and remedies.

# E. Accountability

57. In accordance with article 6, States must assure to everyone within their jurisdiction effective protection and remedies against any acts of racial discrimination which violate his or her right to health contrary to the Convention, as well as the right to seek just and adequate reparation or satisfaction for any damage suffered as a result of such discrimination.

58. States should establish effective and independent monitoring and accountability mechanisms, both internal in health-care installations and external, and envisage disciplinary measures in cases of misconduct. They should also carry out periodic audits, with the help of independent experts, to identify gaps in internal policies and practices. Transparency about the outcomes of these procedures is strongly recommended as it may strengthen accountability and strengthen individuals' and communities' trust.

59. States should sensitize judicial authorities regarding their obligations related to racial discrimination. They must establish independent non-judicial accountability and grievance mechanisms, with the competence to establish facts, identify those responsible for the act or the omission of racial discrimination and provide reparation for any harm on the right to health. Non-judicial remedies may be more appropriate in cases of structural discrimination and if the harm cannot be individually established, or in cases the act of racial discrimination is not an offence. Any such mechanism should comply with equality and non-discrimination guarantees under Article 5 (a) and ensure effective access to justice.

60. States should integrate in accountability and redress mechanisms integrationist multiracial organizations and movements and other means of eliminating barriers. They are strongly encouraged to adopt a victim-centred and community-driven approach by empowering persons and communities affected to participate actively and support actual and potential victims and survivors of racial discrimination in the right to health. Where appropriate, the structural and intergenerational nature of the harm should be recognised and redressed, by prioritising general measures or by complementing individual reparation.

61. States have the primary responsibility to ensure that any violation of the Convention that has resulted in harm entails a duty to make full reparation for the injury caused.<sup>67</sup> States should make full reparation for the violation of their obligations under the Convention and the rights of persons harmed. Reparation under the Convention should include general measures to ensure that laws, policies, and practices, are reviewed and amended to prevent repetition of the Convention. General measures should include positive measures, such as education and trainings, guarantees on participation and empowerment of the community affected, to comply with the obligation breached.

## F. International cooperation

62. International cooperation in health is a key element in respecting freedom from racial discrimination, preventing, protecting against violations and remedying them. Many States rely on international cooperation to comply with their obligations to respect, protect and fulfil the right to health. States should ensure compliance with their obligations under ICERD in their requests or provision of international assistance and cooperation in the WHO or any other organization, including international and regional financial and development institutions.

63. Guided by the principle of international solidarity through international assistance and cooperation, States should take all necessary national and multilateral measures, including

<sup>&</sup>lt;sup>67</sup> Pérez Guartambel v. Ecuador, <u>CERD/C/106/D/61/2017</u>, para. 6.

temporary waivers of intellectual property protections on healthcare technologies, to mitigate the disparate impact of global challenges, such as pandemics, climate change and disasters, and their socioeconomic consequences on groups and minorities protected under the Convention.

64. States should ensure effective and non-discriminatory access to preventive, curative, and rehabilitative health facilities, goods, and services technologies taking into account the situation and needs of groups which are marginalized and subjected to discrimination. To this end, international assistance should prevent and protect against restrictions affecting disproportionately groups within the purview of the Convention. Donor States should not promote, condone, or perpetuate policies and practices which establish, reinforce, and do not aim at removing barriers of groups exposed to racial discrimination in the enjoyment of the right to health.

65. In the negotiations and drafting of the WHO convention, agreement or other international instrument on pandemic prevention, preparedness and response ("WHO CA+"), <sup>68</sup> States are strongly encouraged to align Article 4, paragraph 12 "Guiding principles and rights" ("All individuals should have fair, equitable and timely access to pandemic-related products, health services and support, without fear of discrimination or distinction based on race, religion, political belief, economic or social condition") the right to equality and non-discrimination with Article 1 (1) ICERD by prohibiting racial discrimination based on race, colour, descent, or national or ethnic origin. States are also encouraged to include in Article 12 "Strengthening and sustaining a skilled and competent health and care workforce" the obligation to eliminate racial discrimination, taking into account that a vast majority of the workforce are women within the purview of the Convention.

<sup>&</sup>lt;sup>68</sup> Zero draft of the WHO CA+ for the consideration of the Intergovernmental Negotiating Body at its fourth meeting, A/INB/4/3 1 February 2023.