
Advance edited versionDistr.: General
21 February 2024

Original: English

Human Rights Council**Fifty-fifth session**

26 February–5 April 2024

Agenda item 3

**Promotion and protection of all human rights, civil,
political, economic, social and cultural rights,
including the right to development****Right to participate in science****Report of the Special Rapporteur in the field of cultural rights,
Alexandra Xanthaki****Summary*

In her report to the Human Rights Council, the Special Rapporteur in the field of cultural rights, Alexandra Xanthaki, emphasizes the importance of an inclusive approach to the right to science. She recalls the evolution of the meaning of science, which now encompasses all scientific approaches. The Special Rapporteur stresses that the right to participate in science through varied modalities must be guaranteed for all and she advocates for multiple and wide-ranging science-policy interfaces and special measures to remove obstacles to the exercise of that right. Scientific freedom must be guaranteed and a human rights approach to science must be implemented at all levels by all actors.

* The present report was submitted after the deadline so as to include the most recent information.

Contents

	<i>Page</i>
I. Introduction	3
II. International law context and recent developments	3
III. Right to participate in science as an element of the right to participate in cultural life.....	6
IV. Defining participation in science.....	9
V. Limits of the right to access to and participation in science.....	15
VI. Obstacles and challenges to participation in science.....	16
VII. Conclusions and recommendations	20

Advance edited version

I. Introduction

1. Much hope is being invested today in science-based solutions to prevent loss of life, facilitate our lives and expand our horizons. As the United Nations High Commissioner for Human Rights has stated, science and technology carry extraordinary potential for human rights.¹ Science has had a transformative effect on efforts to address complex and interconnected environmental, social and economic challenges for people and the planet, including poverty, access to health and education, natural resource depletion, biodiversity loss, land degradation, climate change, natural and human-made disasters and spiralling conflicts and related humanitarian crises.²

2. Science cannot produce long-lasting positive results, however, unless conducted within a human rights framework that ensures that it benefits all of humanity. Science is powerful. Hence, it is necessary to continuously review and improve the understanding of what science is, its biases and blind spots, who sits at the table to decide on its direction, which scientific evidence must inform decision-making, who benefits and who suffers from scientific advancements and how to mitigate risks. Answers to all such questions require a human rights approach to science.

3. The present report is aimed at clarifying what a human rights approach to science means in the twenty-first century. It is based on the principles of the universality and indivisibility of rights, non-discrimination, equality, participation and respect for cultural diversity, including scientific diversity. It includes the encouragement of the democratization of science and its production, use and advancement and support for the improved protection of scientists and those engaged in scientific endeavours and of science as a common good, ensuring participation and access for all and safeguarding science from manipulation, disinformation and misinformation.

4. In the report, the Special Rapporteur places the right to participate at the centre of the right to science and explores its meaning and contours, identifies obstacles and makes specific recommendations. Both dimensions of science – participation in science and access to science, including, for example, the enjoyment of benefits – are crucial and interlinked, in that participation in science is not guaranteed unless access is guaranteed and vice versa.

5. In preparation for the report, the Special Rapporteur held two consultations, one in New York, organized by PEN America, which she warmly thanks, and one in Geneva, organized by the Office of the United Nations High Commissioner for Human Rights (OHCHR).³ She also benefited from her participation in the dialogue on the right to science, held in Geneva in 2022.⁴ To collect views and experiences, a questionnaire was distributed widely, with 36 responses received.⁵

II. International law context and recent developments

A. International human rights law context

6. The Special Rapporteurs on cultural rights have addressed various dimensions of the right to access to and participation in science, on the basis, in particular, of article 27 of the Universal Declaration of Human Rights and article 15 of the International Covenant on

¹ See <https://www.ohchr.org/en/statements-and-speeches/2023/11/high-commissioner-addresses-2023-social-forum>.

² United Nations Educational, Scientific and Cultural Organization (UNESCO), Recommendation on Open Science, preamble.

³ The lists of participants are available at <https://www.ohchr.org/en/calls-for-input/2023/call-input-right-access-and-take-part-scientific-progress>.

⁴ See Swiss Commission for UNESCO, “The right to science: understanding trends in and enhancing the effectiveness of human rights mechanisms and partnership approaches” (Bern, Switzerland, 2022).

⁵ The contributions are available at <https://www.ohchr.org/en/calls-for-input/2023/call-input-right-access-and-take-part-scientific-progress>.

Economic, Social and Cultural Rights. A first report on the right to enjoy the benefits of scientific progress and its applications contained the conclusion that the normative content of that right included (a) access to the benefits of science and its applications, including scientific knowledge, by everyone, without discrimination; (b) opportunities for all to contribute to the scientific enterprise and freedom indispensable for scientific research; (c) participation of individuals and communities in decision-making and the related right to information; and (d) an enabling environment fostering the conservation, development and diffusion of science and technology.⁶ That report was followed by two reports, one on the impact of copyright policy⁷ and the other on the impact of patent policy⁸ on the realization of cultural rights. Those reports and their recommendations are still relevant today.

7. Since science and technology are crucial for the implementation of the Sustainable Development Goals, the report of the Special Rapporteur on development and cultural rights: the principles is also relevant. In that report, she recalled that people and peoples must be the primary beneficiaries of sustainable development processes and that such development should be culturally sensitive, self-determined and community led. She underlined the close ties between development and cultural rights as set out in international human rights law, declarations and resolutions.⁹

8. Within the United Nations Educational, Scientific and Cultural Organization (UNESCO), several important recommendations have been adopted, notably the Recommendation on Science and Scientific Researchers, in 2017, and the Recommendation on Open Science and the Recommendation on the Ethics of Artificial Intelligence, both adopted in 2021. One important outcome of the Recommendation on Science and Scientific Researchers was a definition of the terms “science” (para. 1) and “the sciences” (para. 2), and a clear recognition that research and development are not carried in isolation, but should be aimed at the well-being of people in the present and the future and the fulfilment of the goals of the United Nations, while giving sufficient attention to the advancement of science and scientific knowledge per se. Such understanding that science should promote human rights and global justice is the basis of the present report.

9. In 2020, the Committee on Economic, Social and Cultural Rights confirmed that science was a part of culture and that the right protected by article 15 (1) (b) of the International Covenant on Economic, Social and Cultural Rights was a right to participate in and to enjoy the benefits of scientific progress, in terms of both knowledge and application.¹⁰

10. The Special Rapporteur also stresses the importance, under international human rights law, of the principle of participation for all based, in particular, on article 25 of the International Covenant on Civil and Political Rights but also on article 15 of the International Covenant on Economic, Social and Cultural Rights regarding participation in cultural life. The cultural element of participation is often forgotten, however, and should be strengthened. Participation is meaningless if it is not embedded in one’s own context and does not integrate people and peoples with their identities, values, aspirations and resources. That is what community-led development means. Furthermore, people involved in scientific endeavours contribute crucially to vivid civic spaces. The cultural element of participation should therefore be fully considered when implementing the guidelines for States on the effective implementation of the right to participate in public affairs, endorsed by the Human Rights Council in its resolution 39/11.

11. Of particular relevance is the additional protection granted in international law to marginalized and vulnerable groups that face structural discrimination, including women and girls, persons with disabilities or living in poverty, members of minority communities and Indigenous Peoples. On the basis of their right to self-determination, Indigenous Peoples have the right to participate fully, if they so choose, in the cultural and public life of the wider society and to maintain, protect and develop all manifestations of their cultures, including

⁶ A/HRC/20/26, para. 25.

⁷ A/HRC/28/57.

⁸ A/70/279 and A/70/279/Corr.1.

⁹ A/77/290, paras. 11–15 and 98.

¹⁰ Committee on Economic, Social and Cultural Rights, general comment No. 25 (2020), paras. 8 and 11.

their sciences, technologies and traditional knowledge. They must be guaranteed free, prior and informed consent in any projects and decision-making that affect them.¹¹

B. Urgent need for a coherent approach

12. Outside of the international human rights law framework, many treaties also have scientific components, some of them setting out guarantees regarding information, participation, education and awareness-raising and the sharing of benefits and responsibilities. Such treaties include the Convention on Biological Diversity, the United Nations Framework Convention on Climate Change and subsequent agreements on climate change, the Convention on Access to Information, Public Participation in Decision-Making and Access to Justice in Environmental Matters, the Regional Agreement on Access to Information, Public Participation and Justice in Environmental Matters in Latin America and the Caribbean and a myriad of conventions and protocols relating to toxics.¹²

13. Consistency is needed in the application of the instruments using a right-to-science approach. As mentioned in several responses to the questionnaire of the Special Rapporteur, working in parallel ways on cross-cutting issues leads to policy incoherence at both the international and national levels.¹³ Only by fostering systemic integration and cross-fertilization among the different domains of international law can effective solutions be found to address the complex current challenges.¹⁴ A human rights-based approach helps to ensure that policies, including those designed to respond to such challenges as climate change and migration are not regressive in terms of human rights and can effectively improve the lives of all people.¹⁵

14. Specifically on climate change, the General Assembly and the Human Rights Council have stressed that climate change action needs to happen in accordance with States' human rights obligations and commitments. The principles of participation and information, transparency, accountability, (intergenerational) equity and non-discrimination need to guide global efforts to mitigate and adapt to climate change¹⁶ and, more broadly, the triple planetary crisis and development challenges. Sectors of the population that are more affected by climate change, especially Indigenous Peoples, must see their scientific knowledge reflected in the solutions.¹⁷

C. Current situation and recent developments

15. Science liberates people, minds and communities and offers solutions to major challenges that the humanity faces. It enables people to understand the world, dogma to be pushed aside for progress, authority to be questioned, people to communicate, communities to prosper, individuals to attain knowledge and cultures to evolve.

16. Too little attention has been given, however, to the human rights dimensions of science. Participation is not ensured, science-related institutions are underfunded, civic space continues to shrink and knowledge emanating from epistemic communities is not valued. The situation undermines people's opportunities to enjoy their science-related rights. It leads to a huge waste of knowledge, constitutes an attack on the dignity of people, harms the design of decisions and their applications, reduces the quality of debates, undermines social progress,

¹¹ United Nations Declaration on the Rights of Indigenous Peoples, arts. 5, 11, 19 and 31.

¹² Special Rapporteur on the implications for human rights of the environmentally sound management and disposal of hazardous substances and wastes, "International standards", available at <https://www.ohchr.org/en/special-procedures/sr-toxics-and-human-rights/international-standards>.

¹³ See contribution from Henry McGhie, *Curating Tomorrow*, in reference to the United Kingdom of Great Britain and Northern Ireland.

¹⁴ See contributions from Monika Plozza and One Ocean Hub.

¹⁵ A/HRC/54/47, para. 6.

¹⁶ *Ibid.*, para. 5. See also www.ohchr.org/en/climate-change/human-rights-council-resolutions-human-rights-and-climate-change.

¹⁷ See Kunming-Montreal Global Biodiversity Framework, sect. C, paras. 7 (a) and (l); sect. G, goal C; sect. H, targets 13, 21 and 22; and sect. K, para 22 (a).

dramatically heightens inequality and results in the neglect of the shared responsibilities to current and future generations.¹⁸ Without much debate or people's participation, science is currently presented in an uncritical and undisputed way as the main solution to current challenges, missing the paradox that those challenges partially result from scientific products, including the genetic modification of crops, climate change, artificial intelligence and big data.

17. The coronavirus disease (COVID 19) crisis confirmed the need to reflect on science as a human right. Proving once again the importance of science, it also highlighted the clear inequalities in access to science outcomes within and among countries, the inadequacy and failure of intellectual property regimes to ensure the right to health globally and the impact of discrimination and poverty on realizing the right to access to and participation in science. In 2012, participants to a seminar organized upon the request of the Human Rights Council drew similar conclusions.¹⁹ The Special Rapporteur also notes that the recommendations made under the mandate on ensuring the compatibility of intellectual property regimes with human rights and providing for a robust and flexible system of exceptions and limitations to honour their human rights obligations have not been implemented.²⁰ She also recalls that the Committee on the Elimination of Racial Discrimination expressed concern in 2023 regarding the decision of Germany, Switzerland, the United Kingdom of Great Britain and Northern Ireland and the United States of America to withhold intellectual property rights for emerging coronavirus vaccines and medical technologies.²¹

18. The pandemic and more recently the achievements on artificial intelligence have triggered important discussions around the respective role and influence, in the making of science-related decisions, of scientific expertise, private commercial interests, and public participation. They confirmed the crucial need for trustful science-institutions and science-policy interfaces and the urgency of combating disinformation and misinformation in the area of science while respecting and protecting human rights, in particular the rights to freedom of expression and information. As science-based solutions are geared to tackle the many crises ahead, it is crucial to guarantee the autonomy and integrity of scientists while ensuring human rights guarantees on science issues.

III. Right to participate in science as an element of the right to participate in cultural life

A. Science is a part of culture

19. Science is an element of culture. In paragraph 10 of its general comment No. 25 (2020), the Committee on Economic, Social and Cultural Rights clarified that culture was an inclusive concept encompassing all manifestations of human existence and that cultural life was therefore larger than science, as it included other aspects of human existence; it was, however, reasonable to include scientific activity in cultural life. Individuals and groups draw from all cultural resources, including scientific resources, to develop themselves, arranging such resources in a way that is very particular to them, including to express their visions, to influence their living conditions or to overcome an ordeal, such as an illness or a disaster. It is through such resources that people can aspire to a better future by identifying the elements they consider essential for a life with dignity.²²

¹⁸ See contributions from *Curating Tomorrow* and Patrice Meyer-Bisch, *Observatoire de la diversité et des droits culturels* (in French).

¹⁹ [A/HRC/26/19](#), para. 43.

²⁰ [A/70/279](#), paras. 95–101 and 103–106; [A/HRC/28/57](#), paras. 94–98 and 104; and [A/HRC/20/26](#), para. 74 (o)–(q).

²¹ See “Refusal to waive IP rights for COVID-19 vaccines violates human rights: experts”, available at <https://news.un.org/en/story/2023/08/1140262>; and contribution from Maat for Peace, Development and Human Rights Association, p. 4.

²² [A/HRC/20/26](#), para. 20.

B. Right to participate in cultural life includes the right to participate in science

20. Considering science as an element of culture leads to anchoring the right to access to and participation in science in cultural rights. The Committee on Economic, Social and Cultural Rights has therefore observed that the right of everyone to take part in cultural life includes the right of every person to take part in scientific progress and in decisions concerning its direction.²³

21. That does not mean that everyone should be recognized as a high-level scientific researcher and their views received with the same attention. People might do research in their own fields and in relation to their own concerns and aspirations, using knowledge and refining it for their own personal development. There are many ways in which people can participate in science without undermining the expertise of scientific professionals, complementing it in many ways and demanding that science respond to their needs and those of the wider society. Farmers, for example, are not mere performers implementing guidelines and instruction manuals but are full participants, observing, being creative and practising science, adapting it and improving it. Science is not performed only by professionals. It is hence not only professionals who have the right to participate in science.²⁴

C. Avoiding exclusionary processes through the definition of science

1. Defining science

22. Science is defined in the Recommendation on Science and Scientific Researchers of UNESCO as the enterprise whereby humankind, acting individually or in small or large groups, makes an organized attempt, by means of the objective study of observed phenomena and its validation through sharing of findings and data and through peer review, to discover and master the chain of causalities, relations or interactions; brings together in a coordinated form subsystems of knowledge by means of systematic reflection and conceptualization; and thereby furnishes itself with the opportunity of using, to its own advantage, understanding of the processes and phenomena occurring in nature and society (para. 1 (a) (i)). In addition, the term “the sciences” signifies a complex of knowledge, fact and hypothesis, in which the theoretical element is capable of being validated in the short or long term, and to that extent includes the sciences concerned with social facts and phenomena (para. 1 (a) (ii)). Therefore, science does not include only the physical or natural sciences but any discipline, practice or activity that includes the above elements.

23. The Committee on Economic, Social and Cultural Rights, while resorting to the UNESCO definition, has added to the definition of science by stating that knowledge should be considered as science only if it is based on critical inquiry and is open to falsifiability and testability.²⁵ Importantly, both of those definitions distinguish science from belief or faith but also protect it as a common good from ideological, political or commercial interference and from misinformation and disinformation.

24. Responses to the questionnaire show that, in many countries, defining science does not seem to be a problem. Some respondents reported a reliance on the UNESCO definition, although sometimes unofficially. Others adopted an approach based not on defining science by describing methods but rather by describing its purpose, for example as a serious, planned attempt to determine the truth,²⁶ to create objectivity based on verifiable facts and coherent arguments²⁷ or by obtaining and applying new knowledge.²⁸

²³ General comment No. 25 (2020), para. 10.

²⁴ Ibid.

²⁵ General comment No. 25 (2020), paras. 4 and 5.

²⁶ See contribution from Lutz Möller, German Commission for UNESCO.

²⁷ See contribution from Patrice Meyer-Bisch, Observatoire de la diversité et des droits culturels.

²⁸ See contribution from the Russian Federation (in Russian).

2. Avoiding exclusionary processes

25. The definition of science, while including its distinction from both faith or belief and disinformation and misinformation, must not exclude from scientific discussions reliable knowledge production anchored within predominant narratives. The criteria of “validation” (Recommendation on Science and Scientific Researchers) and “falsifiability” and “verification” (Committee on Economic, Social and Cultural Rights, general comment No. 25 (2020), para. 5) must be interpreted in an open and inclusive manner so that their application does not lead to the prevalence of one specific methodology or limit science to a particular historical context. Science may also include traditional knowledge, Indigenous science and other community, public or alternative science, as long as they satisfy broadly the above criteria. Ongoing reflection on such criteria is important to capture the nuances of an evolving concept. As one contribution underlined, science should not be used as an instrument of cultural imposition.²⁹

26. The Special Rapporteur stresses the importance of open science, namely the extended collaboration between scientists and societal actors beyond the scientific community, by opening up practices and tools that are part of the research cycle and by making the scientific process more inclusive and accessible to the broader inquiring society based on new forms of collaboration and work.³⁰ Open science provides the basis for individual and community involvement in the generation of knowledge and the basis for an enhanced dialogue between scientists, policymakers, practitioners, entrepreneurs and community members, giving all stakeholders a voice in developing research that is compatible with their concerns, needs and aspirations. Citizen science (or better called public science) and citizens’ participation have developed as models of scientific research conducted by non-professional scientists, following scientifically valid methodologies and frequently carried out in association with formal, scientific programmes or with professional scientists with web-based platforms and social media, as well as open source hardware and software as important agents of interaction.³¹

27. Efforts are still needed, however, to make such inclusive understanding of science a reality, as many groups are still excluded. In particular, many Indigenous Peoples call for the recognition of Indigenous sciences as science per se, contesting false hierarchies, prejudices and discrimination against their specific knowledge and highlighting their specific methodologies and tools. Other Indigenous Peoples favour the use of so-called knowledge systems when their systems cut across science, belief and cultural practices and are therefore not universalizable or replicable outside the community. The decision of which concept of the two is used relies on the Indigenous Peoples in question as part of their recognized right to self-determination.

28. Of utmost importance is the eradication of perceptions of Indigenous knowledge “as primitive, inferior, unscientific, superstitious or even dangerous” and the acknowledgment that it can be “a sophisticated set of understandings of no less value than the other kinds of knowledge that often form the foundation of ‘western’ science”.³² While some level of recognition of Indigenous traditional knowledge and science has been achieved, in particular by means of article 31 of the United Nations Declaration on the Rights of Indigenous Peoples and new initiatives³³ or agreements,³⁴ as well as the practice of human rights mechanisms³⁵ and States,³⁶ many areas of disrespect remain unchallenged. Efforts must be made to devise

²⁹ See contribution from the Center for Reproductive Rights, p. 18.

³⁰ Recommendation on Open Science, para. 10.

³¹ Ibid.

³² A/HRC/51/28, para. 8.

³³ See contribution from the International Federation of Library Associations and Institutions. See also https://www.wipo.int/meetings/en/details.jsp?meeting_id=81190.

³⁴ See, for example, the Kunming-Montreal Global Biodiversity Framework, sect. C, para. 7 (a) and (l); sect. G, goal C; sect. H, targets 13, 21 and 22; and sect. K, para. 22 (a).

³⁵ Committee on the Elimination of Discrimination Against Women, general recommendation No. 39 (2022) on the rights of Indigenous women and girls, paras. 48 and 52; and Committee on Economic, Social and Cultural Rights, general comment No. 25 (2020), para. 39.

³⁶ See contributions from Ecuador (in Spanish); Guatemala (in Spanish); and Defensoría del Pueblo de la Nación, República Argentina (in Spanish).

direct mechanisms so that Indigenous sciences are included in the formulation of public policy,³⁷ always acknowledging their contribution and allowing for benefit-sharing.³⁸

29. Minority communities are in a similar situation. International human rights law requires States to guarantee that members of minority communities participate effectively in cultural, religious, social, economic and public life and in matters that affect them at the national and regional levels. Yet, that is not the case. For example, reports suggest that, in China, Uyghur science is recognized as constituting religion or cultural heritage and is excluded from the definition of science and seen both as politically sensitive and as an obstacle to “real” science.³⁹

3. Recognizing scientific diversity

30. Due consideration should be given to scientific diversity, acknowledging that scientific knowledge is produced by communities that are historically and culturally situated. That means understanding sciences in the plural form, from various traditions and cultural backgrounds, in various languages and following diverse ways of researching and carried by a variety of scientific or epistemic communities, from very local ones to cross-cultural ones.⁴⁰

31. The Special Rapporteur fully agrees with the inclusive approach adopted in the Recommendation on Science and Scientific Researchers, in which the term “sciences” is used in addition to “science”. Although the use of both terms is welcome, the Special Rapporteur favours continuing the use of the wider term “science”, as used in international texts, so that the term continues to evolve and is interpreted in a dynamic way, promoting an inclusive understanding. Similarly, the terms “the right to participate in science”, “the right to participate in sciences” and “the right to participate in scientific progress” can all be used interchangeably. Although the Special Rapporteur recognizes the strengths of the use of one term over another, she maintains the more generic phrase “the right to participate in science” in order to allow the widest possible scope and also to continue the dynamic and inclusive interpretation and application of the term, always consistent with evolving concepts and understandings.

32. A harsh distinction between sciences and traditions lacks the desired nuance and undermines the immense diversity of knowledge around the world. Science is also a tradition. It is a body of knowledge that develops over time within an epistemic community, with its internal modes of communication, its own ways of selection and authentication of knowledge and authorities and its external modes of communication with the societies in which and for which it develops. Its objective is to find, develop and share meaning.⁴¹ Traditional medicine in Togo and other African countries offer such examples.⁴²

IV. Defining participation in science

A. Access and participation: two interdependent concepts

33. Access and participation in science are interdependent dimensions. There can be no meaningful participation in science if individuals do not have access to knowledge, data, technology and applications. In addition, individuals must be able to rely on strong public institutions that guarantee access to unbiased scientific information and genuine democratic debate, which can serve as guidance for them in their own choices. Inequalities in access to science and applications translate into growing inequalities in participation in all dimensions of social life.⁴³

³⁷ See contribution from Ecuador.

³⁸ See contribution from One Ocean Hub.

³⁹ See contribution from Minority Rights Group in relation to Uyghur science in China.

⁴⁰ See contribution from Michela Massimi.

⁴¹ See contribution from Patrice Meyer-Bisch, Observatoire de la diversité et des droits culturels.

⁴² See contribution from Togo (in French).

⁴³ See contributions from Malaysia and the International Federation of Library Associations and Institutions.

34. Participation also enables access. It makes science familiar rather than hostile and foreign and brings people closer to it. It is a prerequisite for access to the benefits of scientific progress, ensuring that it is applicable and relevant to specific groups of people. The lack of recognition, for example, of Indigenous ancestral knowledge makes Indigenous women sceptical of non-Indigenous health systems and contributes to their poor access to culturally appropriate sexual and reproductive health services.⁴⁴ Another example is the participation of pregnant women, children and people with disabilities or living with HIV in research, guaranteeing their access to specific medical treatment. Without fostering participation, States cannot live up to the duty of ensuring non-discrimination in access to science and its benefits.⁴⁵

B. Who participates?

35. Participation should be understood to include the activities of professional scientists and the meaningful involvement of non-scientists or non-professionals. The Committee on Economic, Social and Cultural Rights has criticized the rigid distinction between the scientist who produces science and the general population, entitled only to enjoy the benefits derived from research conducted by scientists.⁴⁶ The right to participate in science as a human right means that all individuals, without discrimination, are rights holders, however with varying modalities of participation. Science is certainly a field in which expertise should prevail and experts must be guaranteed participation and space to make their opinions heard. The circle of experts who have enhanced participation, however, is not as exclusive as it used to be and experts are not the only ones with the right to participate in science.

36. In global health research, the most common term used to refer to the participation of non-scientists is “affected communities”. The rich tradition of community participation in global health research evident today dates back to the start of the movement to combat HIV/AIDS, when people living with HIV and dying of AIDS fought for equal footing in HIV/AIDS research.⁴⁷ The right of people affected by a disease to participate in all decisions concerning their lives has been a core tenet of global health research since the formulation of the Denver Principles in 1983. Rejecting the passivity of labels such as “victims”, “patients” and “subjects”, a vision of self-determination, autonomy and empowerment reshaped the ways in which global health research was organized and conducted.⁴⁸

37. Other actors and stakeholders also have different roles to play in science: researchers, scientists and scholars, leaders at research institutions, educators, academia, members of professional societies, students and young researcher organizations, information specialists, librarians, museum professionals, users and the public at large, including communities, Indigenous knowledge holders and civil society organizations, computer scientists, software developers, coders, creatives, innovators, engineers, citizen scientists, legal scholars, legislators, magistrates and civil servants, publishers, editors, technical staff, research funders and philanthropists, policymakers, learned societies, practitioners from professional fields and representatives of the science, technology and innovation-related private sector.⁴⁹

38. Their participation must be guaranteed regardless of nationality, ethnicity, gender, language, age, discipline, socioeconomic background, funding basis and career stage or any other grounds and particular attention should be paid to those suffering from structural discrimination, including Indigenous Peoples and minorities, migrants, persons living in poverty, persons with disabilities or living with illness and women.⁵⁰ For example, Mexico is the only country in which 30 per cent of scientific projects are led by women.⁵¹ Even when

⁴⁴ See contribution from the Center for Reproductive Rights.

⁴⁵ See contribution from the Treatment Action Group.

⁴⁶ General comment No. 25 (2020), para. 9.

⁴⁷ See contribution from the Treatment Action Group.

⁴⁸ *Ibid.*, para. 7. See also Advisory Committee of the People with AIDS, the Denver Principles (1983).

⁴⁹ Recommendation on Open Science, para. 12.

⁵⁰ See contribution from Coming Out.

⁵¹ See contribution from Mexico (in Spanish).

women are not excluded, their scientific contributions can remain invisible or diminished and their position not recognized.

39. In addition, participation in scientific endeavours should not be affected by geographical considerations. In a globalized scientific landscape, participation is restricted at times for non-Western researchers, who experience prejudice and for whom barriers to access to scientific publications have been replaced by barriers to publishing. Furthermore, much research is conducted in English.⁵²

40. The term “citizen science” should not be restricted to nationals. It is an open concept encompassing all relevant people and communities, including non-citizens and across countries. That is why such terms as public, community and participatory science may be preferable.

41. The collective element of the right to participate in science must be recognized. Each individual participates and collectively shapes scientific process and shares in its benefits and applications. Scientific endeavour as a collective endeavour includes setting priorities, conditions and possible limits for the use of science as a common good.

42. That collective dimension must be distinguished from the collective right to participate in science that Indigenous Peoples must enjoy as part of their right to self-determination, with full respect for their right to free, prior and informed consent.

C. Various layers of participation

43. The right to participate in science includes many dimensions, including, for example, the right to scientific literacy, the right to access to the scientific professions, the right to contribute to scientific progress and the right to participate in policy decisions relating to science.⁵³ The Special Rapporteur recalls, in that respect, that diverse provisions of international law, particularly articles 19 and 25 of the International Covenant on Civil and Political Rights and articles 13 and 15 of the International Covenant on Economic, Social and Cultural Rights, including article 15 (3) on respecting the freedom indispensable for scientific research and creative activity, ground such participation.

1. Participation in scientific endeavour

44. Modalities of participation may differ for different types of participants in different scientific fields.

45. For example, communities affected by a particular disease or condition have a right to participate in research as more than just clinical trial participants or passive beneficiaries of medical advancements. They have the right to be involved at every level of decision-making, to be given equal credibility in forums as other participants and to receive full explanations of all medical procedures and risks, to choose or refuse their treatment modalities, to refuse to participate in research without jeopardizing their treatment and to make informed decisions about their lives. People living with a disease must have an equal voice, if they so choose, at each stage of the research process, from setting the overall scientific agenda, to shaping the questions studied in key trials, to overseeing how people are treated in research, to informing the translation of research results into policy, to finally ensuring that people in need could benefit from new diagnostic, therapeutic and prevention tools. Such elements are now included in scientific guidelines,⁵⁴ which should be prioritized and be made widely available.

⁵² See contribution from the International Federation of Library Associations and Institutions.

⁵³ “The right to participate in scientific progress”, in Cesare Romano and Andrea Boggio, *The Human Right to Science. History, Development, and Normative Content* (Oxford University Press, 2024) (forthcoming).

⁵⁴ See contribution from the Treatment Action Group. See also the Denver Principles and the guidelines for tuberculosis and HIV research included in the suite of “Good participatory practice guidelines”, available at <https://avac.org/project/good-participatory-practice>.

46. The specific example of community advisory boards by means of which affected communities participate in medical research can be set as a model. Composed of people living with and affected by tuberculosis, HIV/AIDS or other diseases, they act in an advisory capacity to scientists, funders and pharmaceutical companies conducting clinical trials or public health studies. Beyond facilitating the exchange of information between scientists and communities, they actively intervene in the research itself. They can propose studies, object to the exclusion of certain populations from studies, question the utility of specific procedures and offer views on whether the overall research agenda is moving in a direction that will meet the needs of people.⁵⁵

47. There are many examples of public, community or participatory science in many fields, for instance using reverse engineering to ensure access to knowledge and developing capacities to repair or build machines or providing access to and creating data to defend rights.⁵⁶ It also can take the form of public participation in the scientific research process. Involvement can include helping to define research questions, gathering or contributing data and validating findings. It contributes to democratizing knowledge, fighting misinformation and disinformation, addressing existing systemic inequalities and enclosures of wealth, knowledge and power and guiding scientific work towards solving problems of social importance, acting as a powerful accountability tool to address State inaction or non-transparency, as reported, for example, in China and the United States.⁵⁷

48. The Special Rapporteur welcomes the information on the promotion of public, community or participatory science by States, for example in Argentina,⁵⁸ Germany⁵⁹ and Malaysia.⁶⁰ In Africa, “citizen science” is developing and generating knowledge that responds to societal needs and informs policymakers on such issues as air pollution, malaria prevention and biodiversity protection and management.⁶¹

2. Participation in decision-making

49. Participation in the scientific endeavour and in decision-making overlap, as shown in examples in the previous section. As mentioned in the guidelines for States on the effective implementation of the right to participate in public affairs, participation may occur through various modalities. The guidelines should be taken fully into consideration, keeping in mind specific elements pertaining to scientific issues.

50. In particular, in its general comment No. 25 (2020), the Committee on Economic, Social and Cultural Rights recognized the right of every person to take part in decisions concerning the direction of scientific progress.⁶² It specified that, with due respect to scientific freedom, some decisions concerning the orientation of scientific research or the adoption of certain technical advancements should be subjected to public scrutiny and citizen participation. As far as possible, scientific or technological policies should be established through participatory and transparent processes and should be implemented with accompanying transparency and accountability mechanisms.⁶³

51. The Committee also considered that States should endeavour to align their policies with the best scientific evidence available,⁶⁴ pointing out the right to scientifically based decision-making and to socially responsible science. The Recommendation on Science and

⁵⁵ See contribution from the Treatment Action Group.

⁵⁶ See Paul-Olivier Dehaye, co-founder of PersonalData.IO, “Citizen science, open science and open innovation; the right to participate in science; the right to seek, receive and impart information”, presentation at the Social Forum 2023, Geneva, 3 November 2023, video, 00:43:00, available at <https://media.un.org/en/asset/k15/k154t3ap8w?kalturaStartTime=3929>.

⁵⁷ See contribution from the Treatment Action Group.

⁵⁸ See contribution from the Grupo de Estudios sobre Derechos Culturales de Argentina (in Spanish).

⁵⁹ See contribution from Lutz Möller, German Commission for UNESCO.

⁶⁰ See contribution from Malaysia.

⁶¹ See contribution from Maat for Peace, Development and Human Rights Association.

⁶² General comment No. 25 (2020), para. 10.

⁶³ *Ibid.*, para. 55.

⁶⁴ *Ibid.*, para. 54.

Scientific Researchers contains the recommendation, in paragraph 7, that States use scientific and technological knowledge in decision-making and policies for international relations.

52. “Alignment” or “use” does not mean the automatic adoption of advice from scientists or some scientists. It refers to a process whereby science, taking into consideration scientific diversity, informs the law but leaves space for other considerations and allows for decisions that balance different rights and people’s aspirations. Importantly, considering that scientific diversity also refers to the diversity of scientific disciplines, such sciences as, for example, sociology, psychology and history must also be used and interact with natural sciences to provide evidence and inform political decisions, including by opening up and untangling issues of ethical considerations in more depth⁶⁵ and deconstructing “techno-solutionism”. The recent past has shown that difficult ways forward need to be based on science, in all its diversity but must also inform people of their basis and be open to their questioning and critical enquiry. In that respect, education in science is of paramount importance.

53. Scientific experts are often called upon to contribute to public discussions as part of their social responsibility. At times, they are pushed to the front of what should be political decisions. Within the context of a shrinking civic space, the search for scientific consensus to legitimize political decisions and convince the general public of their suitability, even done with the best intentions, diminishes the space for further understanding of all parameters and for real discussion. The more that science is presented as prescribing clear-cut ways forward in very challenging matters that go beyond scientific considerations, the more that scientists are asked to oversimplify science and science is presented as dogma, a process that shuts down dialogue and disagreement. Tensions then occur and the distrust and resentment are erroneously pointed towards scientific experts. Their expertise is doubted and some have been threatened, detained, undermined or ridiculed. Meanwhile, unscientific suggestions and populist, oversimplified explanations and uncritical suggestions become dominant in the public sphere, often through social media.

54. The right to participate in science per se should not hinder the right to the best applications of science. The unlimited participation of non-experts can lead to erroneous conclusions and claims. The reality is that we do not all have equal epistemic capacity. The difference between certified expertise and experiential expertise cannot be neglected. In applying a system of human rights in striving towards equality, States must also take measures to restrict epistemic applications that are not of high quality and high scientific calibre. Although the right to expression is an important consideration, the voices of certified scientists cannot be allowed to be drowned out by the voices of amateur scientists, as that creates confusion and a false balance in the mind of the public.

55. Science-policy interfaces are important ways to ensure participation in decision-making, by engaging all relevant stakeholders, particularly scientific researchers from all relevant disciplines, securing opportunities for the informed participation of the public and ensuring that, where science is unable to offer sufficient evidence, policies are developed in accordance with the precautionary principle.⁶⁶

56. Such science-policy interfaces must fulfil the elements suggested in the above-mentioned guidelines to ensure the appropriate participation of scientific stakeholders in the decision-making of public authorities and must also go beyond. Multiple interfaces must exist in the State to ensure a variety of voices and to diminish the fear of a reliance on dominant narratives and all such interfaces should have real, not nominal, power. As highlighted by several contributors, science policy interfaces may include public institutions especially designed for such purposes but not be limited to those, including universities, research institutes, ethics committees, national academies of science in addition to such institutions as museums and libraries. As mentioned in the contribution from Spain, there is an emerging albeit still fragile ecosystem of scientific and technical advice that is rich and diverse, in which numerous interconnected actors participate.⁶⁷ In addition, several key conditions need to be met, including respect for scientific and academic freedom and for

⁶⁵ See contribution from Maat for Peace, Development and Human Rights Association.

⁶⁶ A/HRC/48/61, para. 50.

⁶⁷ See contribution from Spain (in Spanish).

scientific diversity, real inclusivity of all stakeholders, including Indigenous Peoples and civil society organizations, transparency in debates and outcomes and the prohibition of conflicts of interest.⁶⁸ Effective communication that bridges the gap among the language and priorities of scientists, policymakers and the general population is of paramount importance. In that function, journalists have a crucial role to play and should be guaranteed access, information and freedom of speech.

3. Participation in benefits and in preventing harms

57. In paragraph 56 of its general comment No. 25 (2020), the Committee stressed that participation included the right to information and participation in controlling the risks involved in scientific processes and their applications. In view of the unequal distribution of benefits and risks within and among societies, the Special Rapporteur underscores that participation must entail a conversation on both benefits and risks and whom they affect. In particular, focusing on the participation modalities of vulnerable and marginalized groups, including Indigenous Peoples, peasants and those located in remote areas, is essential.

58. The recognition of communities or knowledge previously excluded, such as Indigenous science and traditional knowledge, and benefit-sharing are key elements of participation. Participation can facilitate a collaborative and inclusive approach that enables the responsible exploration of the opportunities to benefit scientific progress and its applications, checked against specific risks for specific communities. Benefit-sharing includes sharing in the material benefits or products of scientific advancements and access to scientific knowledge and education and developing one's critical mind and faculties associated with doing science.⁶⁹ All of those achievements must be shared with everyone in all parts of the world without discrimination and without restrictions based on commercial interests. The only caveat that the Special Rapporteur would raise relates to the right of Indigenous Peoples, deriving from their right to self-determination and the recognition of historical injustices committed against them, to decide on the level to which they open up their traditional knowledge to the world.

59. The right to participation in science also includes the right to participate in anticipating the harms resulting from science, in accordance with States' obligation to prevent harm and the precautionary and the due diligence principles (see sect. V). In that respect, it is important to be wary of the self-validation of science by means of impact assessments, as their technical nature does not fully address questions of wider human rights and dignity. Participation in decision models, rather than mere impact assessments, can offer better ways of predicting and preventing harms.

4. Right not to participate in science

60. An important aspect of the right to participate in science is the right not to participate. The issue of consent is an important one and must always be taken into consideration, based in particular on article 7 of the International Covenant on Civil and Political Rights, providing that no one shall be subjected without one's free consent to medical or scientific experimentation. Guaranteeing informed consent is also a fundamental dimension of the right to health and requires adopting policies, practices and protocols that are respectful of autonomy, self-determination and human dignity.⁷⁰

61. More widely, the right not to participate derives from considering the right to access to and participation in science as a cultural right. As has always been stressed under the mandate, people always enjoy their right to participate or not to participate in one or several communities, to freely develop their multiple identities, to access their cultural heritage as well as that of others and to contribute to the creation of culture, including through the contestation of dominant norms and values within the communities they choose to belong to as well as those of other communities.⁷¹

⁶⁸ See, for example, contribution from Hungary.

⁶⁹ General comment No. 25 (2020), para. 10.

⁷⁰ [A/64/272](#), para. 93.

⁷¹ See, for example, [A/HRC/14/36](#), para. 10.

62. Those rights were confirmed by the Committee on Economic, Social and Cultural Rights, which stressed that the decision by a person whether or not to exercise the right to take part in cultural life individually, or in association with others, was a cultural choice and, as such, should be recognized, respected and protected on the basis of equality. The Committee noted the crucial importance of that aspect for Indigenous Peoples,⁷² who could refuse to participate in collective testing or any other scientific endeavour.

63. The possibility for people to refuse to give data or to undergo a specific medical treatment or vaccines, or to submit themselves to any specific scientific innovation labelled as “progress” is crucial. Of particular importance is one’s right to refuse to participate in research without jeopardizing one’s medical treatment.⁷³ The cases in which consent is not required are very rare and should be interpreted in the most restrictive manner.

V. Limits of the right to access to and participation in science

64. The right to access to and participation in science is not absolute and may need to be balanced with other rights, such as the rights to privacy and bodily integrity, or with public interests, such as the general welfare in a democratic society, as stated in article 4 of the International Covenant on Economic, Social and Cultural Rights. Such balance also needs to be considered within the various dimensions of the right to access to and participation in science. Importantly, both elements of that right, namely, the duty to promote the beneficial aspects of science and the duty to protect against its adverse effects,⁷⁴ must be addressed. Hence, the right to science must not be used to justify the development of approaches that would potentially hinder ecosystems and fundamental rights across the globe,⁷⁵ nor can it be used to attack or to enable attacks against science as a common good.

65. The legality, necessity and proportionality test serves well in balancing the right to science with other principles and rights. While States have an obligation to fully respect, protect and fulfil the right to access to and participation in science, they also have the obligation to prevent harm, in particular under their obligation to respect and protect all human rights, and to ensure the implementation of the precautionary and due diligence principles.

66. As mentioned by the Committee on Economic, Social and Cultural Rights, the precautionary principle requires taking measures to avoid or minimize risks of serious and irreversible harm, where scientific evidence is uncertain.⁷⁶ As the risk for harm becomes more tangible and more certain, States must move from precautionary measures to prevention measures. The standard of due diligence becomes important then, as States should use their best efforts to prevent or mitigate harm in specific circumstances. Equity towards future generations should also be taken into consideration.⁷⁷

67. In that context, States must hold companies that operate within their territory accountable for harm resulting from scientific research and their products by implementing national legislation. Furthermore, States must extraterritorially protect the right not to be harmed by science and scientific products by preventing companies that have their main offices within their territory from violating that right abroad.⁷⁸ States are under the obligation to take reasonable steps to prevent harm resulting from the scientific endeavours and products of their companies beyond their territory.⁷⁹ Appropriate monitoring and accountability

⁷² General comment No. 21 (2009), para. 7.

⁷³ Advisory Committee of the People with AIDS, the Denver Principles.

⁷⁴ Samantha Besson, “The ‘human right to science’ *qua* right to participate in science”, *The International Journal of Human Rights*, 6 September 2023.

⁷⁵ See contribution from the Center for International Environmental Law.

⁷⁶ General comment No. 25 (2020), para. 56.

⁷⁷ See contribution from Monika Plozza. See also Monika Plozza, “The science lens: the human right to science” (2023), available at <https://radar.gesda.global/introduction/2023-highlights-deep-dives/the-science-lens-the-human-right-to-science>.

⁷⁸ E/C.12/2011/1, paras. 5 and 6. See also Committee on Economic, Social and Cultural Rights, general comment No. 19 (2007), para. 54; and general comment No. 14 (2000), para. 39.

⁷⁹ Committee on Economic, Social and Cultural Rights, general comment No. 24 (2017), para. 33.

procedures must be put in place to ensure effective prevention and enforcement.⁸⁰ Those include remedies, including judicial remedies, for victims of such harm.

68. The same human rights approach is required by States when acting as members of international organizations. They cannot ignore their human rights obligations⁸¹ but must actively ensure that the effective participation of civil society is guaranteed in discussions with international organizations that relate to the benefits and harms of scientific products. That is currently not the case. More space must be ensured for civil society and for more consideration of alternative scientific understandings beyond the prevailing ones in decision-making by such organizations. For example, the Special Rapporteur was disappointed to hear that Indigenous scientific evidence is ignored in UNESCO discussions on designating world heritage status for territories in which Indigenous Peoples live. She also notes the presentation of the International Indigenous Forum on Biodiversity at a recent meeting on the Convention on Biological Diversity regarding the lack of robust indicators of traditional knowledge in the monitoring mechanism for the Kunming-Montreal Global Biodiversity Framework.⁸² It is reported that the continuing failure to agree on a robust monitoring mechanism is due to the resistance of several member States.⁸³

69. Finally, scientific freedom, protected under articles 13 and 15 the International Covenant on Economic, Social and Cultural Rights and article 19 of the International Covenant on Civil and Political Rights, also comes with scientific responsibility, which includes the duty to conduct and apply science with integrity, in the interest of humanity, in a spirit of stewardship for the environment, and with respect for human rights.⁸⁴ Paragraph 16 of the Recommendation on Science and Scientific Researchers contains a long provision on the civic and ethical aspects of scientific research.

VI. Obstacles and challenges to participation in science

A. Attacks against scientific and academic freedoms

70. Academic and scientific freedom are two overlapping rights that can apply at the same time, protecting academics and scientific researchers, whether professionals or not, but also those adjacent to scientific endeavours who play a crucial role in ensuring access to and participation in science, such as journalists, educators and judges.

71. As previously described by other Special Rapporteurs,⁸⁵ attacks against scientific and academic freedoms are numerous across the world, with a chilling effect on the broad academic and scientific community.⁸⁶ Such attacks target those participating in science, professionals or not, including science journalists. They take various forms, such as harassment, arrest and detention, threats and loss of positions or jobs and interference in research and publication, including by means of defunding and impediments to publication. In other cases, specific credible directions in science attract no funds and are looked upon with enough suspicion and even contempt that the scientists finally change direction. The critical enquiry of science may also be considered to clash with faith or religion. For example, blasphemy laws are used to arrest and detain those advocating scientific and rational thinking and to push back against specific progress.

⁸⁰ Ibid.

⁸¹ General comment No. 25 (2020), paras. 83 and 84.

⁸² See https://www.cbd.int/doc/interventions/6551e213e1b990410aada718/Final.IIFB.statement.WG8j.agenda.item.7_13NOV2023.pdf.

⁸³ Avaaz, "It's a tough game out there: Avaaz comments on SBSTTA-25 of the Convention on Biological Diversity, 15–19 October 2023, Nairobi, Kenya", p. 3, available at <https://avaazimages.avaaz.org/Avaaz-SBSTTA-25-Final.comments.pdf>.

⁸⁴ See American Association for the Advancement of Science, "Statement on scientific freedom & responsibility". See also International Science Council, "A contemporary perspective on the free and responsible practice of science in the 21st century", discussion paper, December 2021.

⁸⁵ [A/HRC/48/61](#), para. 84; and [A/75/261](#).

⁸⁶ See contribution from Humanists International.

72. The lack of progress towards open access and open science in all countries also poses a threat to scientific and academic freedoms, as not all researchers may benefit from access to the full range of existing knowledge when carrying out their own research.⁸⁷

73. All such practices seriously undermine the right to science, lead to the weakening of public institutions and the dysfunction of science-policy interfaces, open wider the door to misinformation and disinformation and impede the adoption of science-based solutions for the well-being of societies.

B. Structural underfunding and imbalance in access

74. Access ensures participation. The poor financing of universities and budget cuts in public research funding, sometimes as a result of austerity measures, is at odds with States' commitments under article 2 of the International Covenant on Economic, Social and Cultural Rights. In paragraph 24 of its general comment No. 25 (2020), the Committee on Economic, Social and Cultural Rights stated that there was a strong presumption that retrogressive measures taken in relation to the right to participate in and to enjoy the benefits of scientific progress and its applications were not permissible. The Committee noted that examples of such measures included the removal of programmes or policies necessary for the conservation, the development and the diffusion of science and the adoption of legal and policy changes that reduced the extent of international collaboration on science. In rare circumstances when such measures were inevitable, they must be necessary and proportionate and should remain in place only insofar as they were necessary. States must mitigate inequalities that could grow in times of crisis and ensure that the rights of disadvantaged and marginalized individuals and groups were not disproportionately affected and guaranteed the minimum core obligations.

75. Disparities in funding between the global North and the global South are enormous, leading to important brain drain from the South to the North. That creates a vicious circle, resulting, in the South, in the continued lack of infrastructure, the diminution of opportunities, weakened science education and the loss of specialist staff.⁸⁸

76. Information housed in the global North does not flow to countries of the global South.⁸⁹ Scientific priorities and modalities tend to be determined by donors and researchers from the global North, overlooking the needs and priorities of the global South and extracting data with the help of researchers from the global South without fully enabling their equal contribution. In ocean science, in particular deep-sea science, only 10 countries in the world appear to benefit from research. The Special Rapporteur is concerned by reports that States with modern nautical charts, “‘actively prevent the release of data’ (and restrict marine scientists’ mobility and access because of ‘the link between obtaining improved knowledge of the ocean and [States’] growing interest in exploring offshore natural resources and technological advances that might be relevant to naval security’”.⁹⁰

77. On that basis, there has been a call to set specific policies on the transfer of knowledge and technology to the academic field and the productive sector,⁹¹ and to ensure capacity-building and technology development opportunities for the global South. That can be done by means of research collaborations, mutual capacity-building between Governments of the global North and global South and various other actors to ensure effective and appropriate benefits to local contexts and the co-development of technologies.⁹²

⁸⁷ Contributions from Togo, response to question 4; and the International Federation of Library Associations and Institutions, response to question 2.

⁸⁸ See contributions from the Observatorio de Derechos Humanos de la Universidad de Los Andes, Venezuela, and Curating Tomorrow.

⁸⁹ See contribution from Curating Tomorrow.

⁹⁰ See contribution from One Ocean Hub (quoting Robert Wilson, “Surveying the sea” and Anna-Maria Hubert, “Marine scientific research and the protection of the seas and oceans”).

⁹¹ See contribution from Defensoría del Pueblo de la Nación, República Argentina.

⁹² See contribution from One Ocean Hub.

C. Restrictions resulting from the privatization of science

78. Although the influx of private funds in science allows for major achievements in all fields, enabling scientists to work in their chosen fields unhindered by budgets or political pressure, States must protect science, understood as a common good, and the right to access to and participation in science from powerful commercial and private interests. The primary quest of commercial actors for profit rather than social justice means that they must be guided by clear limits and strong public bodies to ensure an overall inclusive approach to science. The well-meaning attempts of public bodies to collaborate with the private sector must not result in the dilution of scientific freedom and the overlooking of public needs.⁹³ Intellectual property rights, the overpublicization of science to attract more so-called clients or funding and the commodification of knowledge must be counterbalanced by States with clear priorities and policies based on human rights. On the one hand, the State must not be allowed to asphyxiate any scientific expression, while on the other, unregulated private greed must not be allowed to limit science to the few. The balance is difficult but absolutely necessary to ensure that the multilayered right to science is materialized.

D. Instrumentalization of science

79. Science, even though historically and culturally situated, is not to be ideologically and politically loaded or manipulated.⁹⁴ Care is required to ensure that specific actors do not circumvent or contaminate scientific discourse or use scientific or pseudoscientific discourse in a manipulative way for particular ends. For example, reports indicate that climate change deniers and fossil fuel companies have, for decades, actively undermined climate action by the manipulation of public opinion through the selective presentation and active suppression of information or have manipulated public opinion through providing funding to science museums and exhibitions.⁹⁵ Private organizations and lobbying groups, through the multiplication of so-called scientific publications, aim to foment doubt regarding scientific results and delay policy decisions that may run against their interests. Furthermore, misinformation and disinformation cast doubt on scientific results and smear credible processes and scientists.

E. Restrictions based on morality

80. In some States, there is a clear reluctance to take into consideration scientific advancements to inform policy developments and decision-making based on uncritical principles of morality.

81. For example, comprehensive sexual education is being restricted in States even though it is underlined in the *International Technical Guidance on Sexuality Education: An Evidence-Informed Approach*⁹⁶ that such education is scientifically accurate, with substantive content that improves attitudes relating to sexual and reproductive health and behaviours, promotes knowledge of one's body, fosters well-being and promotes gender equality. Yet, continuous narratives spread misplaced fears of teaching that do not stand to clear scientific evidence.

82. Women are particularly targeted by pseudoscience put forward by those who want to maintain control over them. Attempts to restrict access to medication abortion are made with

⁹³ Canadian Association of University Teachers, *Open For Business: On What Terms?* (Ottawa, 2013).

⁹⁴ See contribution from the Observatorio de Derechos Humanos de la Universidad de Los Andes, Venezuela.

⁹⁵ See contribution from Curating Tomorrow.

⁹⁶ UNESCO, Joint United Nations Programme on HIV/AIDS, United Nations Population Fund, United Nations Children's Fund, United Nations Entity for Gender Equality and the Empowerment of Women (UN-Women) and World Health Organization, *International Technical Guidance on Sexuality Education: An Evidence-Informed Approach* (Paris, 2018).

disregard to public opinion and scientific evidence;⁹⁷ even more so, they completely violate the right of women to participate in science. They certainly run counter to the view of the Committee on Economic, Social and Cultural rights set out in paragraph 33 of its general comment No. 25 (2020), in which the Committee explicitly noted that a gender-sensitive approach was of particular relevance to the right to sexual and reproductive health and that States parties must ensure access to up-to-date scientific technologies necessary for women in relation to this right. The Committee also stated that, in particular, States parties should ensure access to modern and safe forms of contraception, including emergency contraception, medication for abortion, assisted reproductive technologies, and other sexual and reproductive goods and services, on the basis of non-discrimination and equality, as outlined in general comment No. 22 (2016) on the right to sexual and reproductive health and that special attention should be given to the protection of women's free, prior and informed consent in treatments or scientific research on sexual and reproductive health. The Committee's comment is also pertinent to the current misinformation and pseudoscientific evidence on the participation of trans women in sporting events.

F. Using science without considering its human rights implications: the example of digital technologies

83. The use of digital science, which brings many benefits, should be regulated to ensure that human rights are respected. In medicine, digital advancements allow for the medical history of the patient to become known in any emergency, saving lives. However, that ability also redefines the doctor-patient relationship and has an impact on the rights of patients, caregivers, families and practitioners.

84. In migration, the use of science and technology currently being explored by the European Union to predict and manage migration is being developed with little consideration to the human rights of migrants and refugees, who are seen mainly through a security lens. Scientific research emphasizes that flow prediction tools can lead to serious human rights violations, as data are unreliable and biased.⁹⁸

85. In education, digital technology has allowed distance learning. However, as stressed by the Special Rapporteur on the right to education and UNESCO, while digital technologies in education can bring important benefits, they cannot, on their own, solve the many issues faced by education systems and carry many risks that can be detrimental to the right to education and other human rights within education systems.⁹⁹

G. Bypassing democracy and the rule of law

86. Emergencies, real or inflated, have been used to bypass democratic control in scientific use. There is a need to use law, including human rights law, in implementing science, and to reinforce the legal, regulatory and policy framework to allow for democratic control over the scientific enterprise. Democratic control does not equate with state control. States must allow a variety of voices rather than ensuring its monopoly in decision-making regarding scientific matters.

⁹⁷ See joint contribution from IPAS and the Expanding Medication Abortion Access Project. See also contribution from the Center for Reproductive Rights.

⁹⁸ Mengia Tschalaer, Alexandra Xanthaki and Ermioni Xanthopoulou, "Migration flows prediction tools and asylum policy commitments in alignment with human rights", IT Flows, Policy Brief No. 5 (2023), available at <https://www.itflows.eu/wp-content/uploads/2022/06/ITFLOWS-Policy-Brief-5-D8.1.pdf>.

⁹⁹ A/HRC/50/32, para. 94; and Mark West, *An Ed-Tech Tragedy? Education Technologies and School Closures in the Time of COVID-19* (Paris, UNESCO, 2023).

VII. Conclusions and recommendations

87. There is a pressing need for States, international organizations and private actors to adopt a human rights approach in all matters relating to science.

88. States and other stakeholders should fully recognize, respect, protect and promote the right of everyone, not only professionals, to participate in science as a human right to varying modalities, without discrimination.

89. A wide, inclusive and decolonized understanding of science is an important way to fulfil the right to participate in science. States must revisit their policies to eradicate any exclusionary processes in defining and applying science.

90. Participation in science requires education in science for all. Special measures must be taken to improve the educational opportunities for vulnerable and marginalized groups.

91. The participation of multiple scientific societies adds to the scientific matrix of society and ensures representation and the advancement of comprehensive solutions to current challenges.

92. States must:

(a) Devise public science programmes that involve individuals of all sectors of the population, not only in the collection of information, but in all aspects of research, including design, development, the analysis of results and the preparation of reports;

(b) Remove the specific obstacles that prevent women from participating effectively in science, including stereotypes and biases;

(c) Take specific and special measures to ensure the effective participation of marginalized and vulnerable sectors of the population, including minorities, migrants, individuals in rural and remote areas and those living in poverty and socioeconomically deprived situations;

(d) Ensure the free, prior and informed consent of Indigenous Peoples in all matters relating to science that concern them. Their sciences and traditional knowledge must be recognized and used, including in matters that affect them, to the degree that they so decide. Their participation in the benefits of scientific endeavours must also be guaranteed;

(e) Ensure that alternative science models and their contributions are included in education and discussed in public spaces.

93. States should establish and support multiple science-policy interfaces, engaging all relevant stakeholders, including affected communities and scientific researchers from all relevant disciplines, with due respect for scientific diversity, to participate in decision-making on science matters. Such interfaces should also provide opportunities for the informed participation of the public. They should ensure that policies are developed based on the best scientific evidence available and in accordance with the precautionary and due diligence principles and the obligation to prevent harm.

94. States and other stakeholders, particularly private research institutions and business enterprises, should fully respect, protect and promote the right to academic and scientific freedom, in accordance with articles 13 and 15 (3) of the International Covenant on Economic, Social and Cultural Rights, with due attention paid to general comments No. 13 (1999) and No. 25 (2020) of the Committee on Economic, Social and Cultural Rights, article 19 of the International Covenant on Civil and Political Rights and the Recommendation on Science and Scientific Researchers.

95. Particular attention should be paid:

(a) To protecting scientists from attacks;

(b) To refraining from instrumentalizing scientists;

(c) **To identifying and avoid conflicts of interest by scientists and ensuring whistle-blower protections;**

(d) **To effectively addressing the disinformation economy, in particular in the science-policy interface.**

96. **States and other stakeholders should consider science as a public and common good.**

97. **The United Nations must:**

(a) **Request all United Nations bodies and satellite agencies to review their regulatory frameworks in line with a human rights approach to science and the right to participation in science, including the sharing of the benefits of scientific progress and emerging technology;**

(b) **Strengthen, through its monitoring processes, the implementation of the right to participate in science, including through core indicators and guiding questions.**

98. **Explore a proposal for a new special rapporteur on the right to science and technology, fully understood as a cultural right.**
