

To the Committee on Economic, Social, and Cultural Rights:

The UN Committee on Economic, Social, and Cultural Rights has issued an important call for a discussion on the nature of the rights protected by Article 15 of the International Covenant on Economic, Social, and Cultural Rights (ICESCR) – specifically, the rights encompassed by the right to enjoy the benefits of scientific progress and its applications. With regard to scientific progress in biomedicine, it is now widely recognized that biomedical advances can indeed contribute to the advancement of numerous rights, including the right to health, especially when the benefits are distributed to all without regard to their economic, social, and cultural status. However, to ensure that these advances constitute true benefits for the persons that they reach, UNESCO’s experts have emphasized that Article 15 also “requires that individuals should be protected from the possible negative effects of scientific and technological progress on the enjoyment of human rights”.<sup>1</sup> As these experts have explained, scientific advancements in biomedicine should be tested to avoid possible damage to individuals and to prevent new technologies from putting other rights, such as the right to privacy, at risk.

This complex understanding of how the right to benefit from science requires safeguards is well recognized in the field of medical ethics, but the obligations of nation-states to ensure that scientific advances in biomedicine are not harmful are less clear under international law. As elaborated below, several soft-law international instruments recognize this right explicitly, including the Universal Declaration on Bioethics and Human Rights (2005), as well as specific instruments, such as the Universal Declaration on the Human Genome and Human Rights (1997) and the International Declaration on Human Genetic Data (2003). The norms embodied in these documents are also elaborated in greater detail in *the International Ethical Guidelines for Health-related Research Involving Humans* prepared by the Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO), as well as in the *Declaration of Helsinki* by the World Medical Association. In Europe, many of these same principles are enshrined in the Council of Europe’s Convention on Human Rights and Biomedicine and its Protocols. Nevertheless, only a bare majority of European nations have ratified the Convention on Human Rights and Biomedicine. While two UN Special Rapporteurs have emphasized the importance of protections for some groups of persons from biomedical interventions under Article 12 of the ICESCR and under the Convention Against Torture, a General Comment on Article 15 from the Committee on Economic, Social and Cultural Rights is very much needed explicitly to clarify the right to protections under Article 15.<sup>2</sup>

We, the undersigned, are scholars at Swedish universities with a broad range of expertise on matters of law, ethics, and biomedicine. We submit this comment to highlight special areas of

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<sup>1</sup> UNESCO, *The Right to Enjoy the Benefits of Scientific Progress and its Applications* (2009) p. 5.

<sup>2</sup> Report of the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health (A/64/272) (2009); Report of the Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment (A/HRC/22/53) (2013).

concern where protections in the field of scientific advances are necessary to ensure benefits to persons affected by them. We are particularly concerned that many rights of children in biomedicine are at risk from scientific advances and uncertainties from new biomedical interventions. We urge the Committee on Economic, Social, and Cultural Rights to explain the link between Article 15 and Article 12 of the ICESCR, as well as their links to Article 24 of the Convention on the Rights of the Child (CRC). We have keyed our responses to the questions raised in the Committee's Discussion Paper on Article 15.

***Rights in biomedicine generally – Discussion Paper Questions 7, 12, and 26.***

The UN has contributed significantly to the documentation of a global consensus on the need for protection from risks posed by scientific advances to health, as well as risks to individuals' rights. UNESCO's Declaration on Bioethics and Human Rights requires that the benefits of scientific knowledge are shared but also require protections to ensure that research is ethical and does not lead to harm to the intended recipients of those benefits. Article 4 provides that "in applying and advancing scientific knowledge, medical practice and associated technologies, direct and indirect benefits to patients, research participants, and other affected individuals should be maximized and any possible harm to such individuals should be minimized." It further provides that in advancing and applying scientific knowledge, medical practices, and associated technologies, human vulnerabilities should be taken into account, and individuals and groups with special vulnerabilities should be protected. Articles 5 through 6 provides that autonomy and the right to consent must be protected in both scientific research and preventive, diagnostic, and therapeutic medical interventions. Article 7 requires special protections for persons who cannot consent.

The Convention on Human Rights and Biomedicine, Declaration of Helsinki, and CIOMS/WHO Guidelines on research reflect these norms, too, but they also require protections to ensure that patients undergoing biomedical research do not receive care of inferior quality to what they would receive in standard health care. These protections include obligations for clinicians to protect patients from unnecessary risk in research design, to ensure that patients understand the difference between research and standard medical care, to monitor research and determine when it should be terminated, and to ensure that patients have access to quality care. The legal impact of these recommendations, however, has been limited. While many national laws may refer to the Declaration of Helsinki, the legal force of these references is often unclear.

Currently, only the Convention on Human Rights and Biomedicine and its protocols obligate Contracting States to ensure that these protections are legally established. When the Council of Europe inaugurated the Convention, it warned that biomedicine's expansion into clinical practices has had "new complexity and extensive ramifications" for patients' rights, placing burdens on national legal orders to ensure access to scientifically advanced care and to protect human rights and patient safety.<sup>3</sup> It also recognized that Member States have diverse standards of care, with a duty to undertake quality assurance and provide remedies for "undue damage", but without clear obligations to ensure that risks are assessed to ensure that treatment is safe.

For these reasons, we believe that the Committee on Economic, Social, and Cultural Rights is in a unique position to determine what responsibilities Contracting States to the ICESCR have to

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<sup>3</sup> Explanatory Report to the Convention on Human Rights and Biomedicine, paras 2-3 & 24-30.



ensure that science yields benefits on balance to all persons. Particularly, it would be helpful to understand what legal relationship, if any, Article 15 has with the declarations that UNESCO has steered, as well as what symmetries may exist between Article 15 and the ICESCR as a whole, as well as the Convention on Human Rights and Biomedicine and its protocols.

### ***Rights of children – Discussion paper Questions 7, 12, 25 & 26***

In 2016, the Committee on Bioethics for the Council of Europe commissioned three of the undersigned authors to study scientific advances and uncertainties in health care that may affect children's rights.<sup>4</sup> The Committee published its report in 2017 – entitled *The Rights of Children in Biomedicine* – to launch an ongoing project to determine potential gaps in international human rights law for the protection of children in biomedicine as a whole. As the authors noted, technological advances and scientific challenges may affect the rights of children from birth through adolescence in a variety of ways. Far too frequently, these concerns arise from lack of sound data regarding the safety and benefits of many biomedical interventions affecting children. Much of the medical literature concerning advances in pediatric care reflects candid acknowledgements that ongoing practices lack scientific support or that the causes of adverse effects on children from interventions are poorly understood. Given that even more severely negative outcomes are almost certainly not reported in the literature and that much of the reported data cannot be verified, any authority concerned for the rights of children should be concerned as much by what is *not* known as well as by what is known, especially as many known troubling practices have not been stopped in the wake of scientific skepticism and criticism.<sup>5</sup>

Biomedical interventions both inside and outside the clinical context may, for example, affect the *child's right to the highest attainable standard of health*, recognized in Article 24 of the CRC. Ensuring the highest attainable standard of health for each child requires an understanding of the risks that each child faces, which often vary at several stages of child development. Many of the risks to children noted in the report reflect a lack of caution in biomedical practices, with questionable interventions on neonates, infants, young children, and adolescents surfacing even in pediatric clinical practice. These challenges in relation to children's right to health overlap with other closely connected rights, such as their right to respect for human dignity and physical and psychological integrity and freedom from torture and degrading treatment – all recognized (indirectly) in the CRC in Articles 19 and 37 of the CRC. The presumption that parents and clinicians make decisions in the best interests of their children to promote their physical and psychological integrity may be challenged in cases where parents and clinicians' authorize invasive treatments with questionable benefits for children. Many interventions in the real world of biomedicine also intersect with both the *child's right to identity* and *right to private life*, such as in the protection of children's genetic information of children, as well as for protection of those children whose gender or sexuality has been targeted with invasive medical procedures.

With this in mind, we see the need for sustained oversight of scientific advances and uncertainties in biomedicine in order to safeguard children from possible negative effects that scientific and technological progress may have on the enjoyment of their human rights. Greater information is

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<sup>4</sup> Zillén, Garland, and Slokenberga, *The Rights of Children in Biomedicine: Challenges posed by scientific advances and uncertainties*, Council of Europe 2017. See <https://rm.coe.int/16806d8e2f>.

<sup>5</sup> For example, see the discussion of gender-conforming procedures in the aforementioned report, *ibid* pp. 40-45.

needed to determine when scientific progress in the field of medicine may challenge the rights of children and how these rights may be protected.

### *Dignity and “Permissible science?” – Discussion Question 26*

In an international context, as well as in European regulatory frameworks (at the regional and national level), human dignity has a considerable role and value in shaping regulatory responses and judicial solutions. It has also emerged in other regional legal orders, for example, the African Union, the Organization of American States, and the League of Arab States. In Europe, the importance of dignity as a framing device is reflected in the full name of the Convention on Human Rights and Biomedicine – more properly known as the Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine. This Convention seeks to protect dignity in regard to the application of biology and medicine through several prohibitions, highlighting practices that are considered incompatible with human dignity institutionally within the Council of Europe, as well as among the states that have chosen to bind themselves to the provisions enshrined in the Convention.

In the field of biomedicine, questions about the limits of permissible science constantly manifest in discussions of whether the law is prepared to accommodate future biomedical advances. Of a particular concern is the creation of embryos for research purposes,<sup>6</sup> as well as the permissibility of interventions on the human genome in light of optimistic projections and theoretical, academic discussions. The latter has been regulated within the EU in the clinical trials regulatory framework, whereas the rules relating to the former (notably, for human tissue and cells) are constructed to accommodate diverse national legal solutions in the EU framework.

We believe that the Committee on Economic, Social, and Cultural rights has a unique and important role to play on the question of how benefits of science can be more fully realized with regard to all of the rights of the ICESCR that relate in some way to human dignity and integrity. Before any sensitive questions can be fully answered, such as the creation of embryos for research or modification of human genome that affects descendants are revisited and bans are lifted or encouraged to be lifted, there needs to be a certain level of understanding and consensus that the conception of human dignity has evolved and deepened since the ICESCR was adopted. In this context, in our view, the right to science should be interpreted as including considerations on what science is legally permissible and ethically acceptable, allowing for accommodating solutions of varying degrees of dignity, as far as it is relevant and justifiable.

For these reasons, we believe it would be helpful for the Committee to elaborate on the relationship between Article 15 and the ICESCR as a whole, as well as other UN treaties that protect the dignity and integrity individuals. The current text of Article 15, without elaboration, is often misused in legal discourse to support a push for science, commercial interests, and technological imperatives, rather than promoting the careful deliberation that could enable law to respond to radical new technologies or approaches like germline gene editing in humans.

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<sup>6</sup> Sweden is among the states that have departed from this prohibition, which is among key purposes why the state has not proceeded with ratifying the Convention on Human Rights and Biomedicine.



*Final Comments – Including Comments to Questions 10, 21, and 22*

As an overarching matter, our concerns remain that the ICESCR is first and foremost a legal instrument. Article 15, therefore, must be read in light of the Covenant as a whole and the rights that might be affected by an expansive reading of the article without regard for the potential harms of science and need for governmental regulation.

These concerns relate to several of the questions put forward by ICESCR. In regard to *Question 10*, while we see the link between Article 15 of the ICESCR and 27 of the Universal Declaration of Human Rights, we would like to emphasize the importance of the current language used in ICESCR. In our view, changing “share in scientific advancement and its benefits” to “participate in scientific advancement and its benefits” could completely change how decisions are made in science with far-reaching implications on research agendas at the detriment of most vulnerable groups of the society. Moreover, we note that some countries, such as Latvia, have translated the mentioned provisions focusing on what can directly be translated as “using” scientific benefits. Question 10 is also closely related to *Question 21*. The concept of “citizen science” has a rather particular nature, as opposed to “participation” more generally, which, if interpreted broadly, may create tensions between the existing jurisprudence of the European Court of Human Rights and the ICESCR. Question 10 is also related to *Question 22*, where democratic participation is broadly suggested but without clear agendas or guidelines as how discussions should be framed and steered toward the protection of the rights encompassed by the ICESCR to ensure that benefits of scientific advances are not merely goods unto themselves but compatible with rights enshrined in all UN treaties.

We welcome the Committee’s input on the legal importance of Article 15.

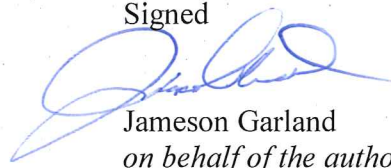
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