**Comments of Knowledge Ecology International (KEI) on the Draft General Comment: Science and economic, social and cultural rights Art. 15: 15.1b, 15.2, 15.3 and 15.4 | 2 January 2020 draft.**

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**To: Committee on Economic Social and Cultural Rights, cescr@ohchr.org.**

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**Paragraph 10.**

Currently reads:

The term “benefits” refers first to the material results of scientific research, such as medicines, vaccination, fertilizers, technological instruments and so on.

The 2019 debate at the World Health Organization on transparency included discussions of how to define health technologies. Among the issues were the status of new cell and gene therapies, which can be described as procedures or services rather than drugs or products.

WHA72.8, was titled: “Improving the transparency of markets for medicines, vaccines, and other health products.” Footnote 1 of that resolution stated: “For the purposes of this resolution, health products include medicines, vaccines, medical devices, diagnostics, assistive products, cell- and gene-based therapies, and other health technologies.”

It should be clear that “medical devices, diagnostics, assistive products, cell- and gene-based therapies, and other health technologies” are included, particularly since cell and gene therapies are now much less equal in terms of access than are drugs or vaccines.

Another category of benefits, that might be worth mentioning, are those related to safety in automobiles, since new, life-saving innovations such as blind side protection, automatic stopping, etc, are often now an expensive add-on, unlike, for example, mandatory seatbelts or airbags.

***Paragraph 17.***

As regards the “material interests resulting from any scientific, literary or artistic production of which he or she is the author,” it is useful and important to distinguish between “material interests” and “intellectual property.” Many inventions and many copyrighted works are produced under work for hire contracts that eliminate future rights in data for the relevant inventor, author or performer. Simply having a patent or copyright regime does not solve this problem. Also, there are many people who work collaboratively and inventions or works that are based upon efforts by teams should be considered apart from works or inventions by persons working individually or in very small collaborations.

When inventions or copyrighted works are considered, material interests can be addressed through means other than the grant of exclusive rights in inventions or copyrighted works.

***Paragraph 18.***

The grant of exclusive rights in inventions reduces the freedom to engage in research and in the development of innovations that build upon earlier inventions. Since science is mostly about building upon the knowledge and innovations of others, this creates conflicts, some of which can be resolved by rewarding innovation through mechanisms that do not involve exclusive rights.

One area of particular interest, as regards medical inventions, is the possibility that market entry rewards (sometimes referred to as innovation inducement prize funds) could replace exclusive rights to sell patented medical technologies, thus delinking R&D incentives from prices, and making access to medical technologies more equal, while providing robust material rewards for innovators. Undertaking feasibility studies of such reforms in business models is quite important, and also, unfortunately, controversial, having been blocked in the 2018 World Health Assembly as regards cancer drugs.

**Paragraph 31.**

The mechanisms to enforce the progressive realization of human rights are currently weak.

One effort to make more concrete the obligations to work toward the realization of human rights was explored in 2009, in the context of the right to development. This involved obligations to search for new arrangements, including global norms or business models, that are more consistent with equal access to the benefits of science, including new medical technologies

A 2009 evaluation of “The Global Fund to Fight AIDS, Tuberculosis and Malaria, the Special Programme for Research and Training in Tropical Diseases (TDR), and the right to development,” for the Human Right Council, Working Group on the Right to Development ([A/HRC/12/WG.2/TF/CRP.4/Rev.1](https://www.keionline.org/wp-content/uploads/A-HRC-12-WG2-TF-CRP4-Rev1.pdf), 18 June 2009), looked at the nature of the obligation to progressively realize human rights. In Table 3 of that report, these were among the proposed obligations:

* Has the institution made reasonable medium and long-term projections regarding the resources necessary to accomplish its objectives?
* Has the institution secured sustainable funding sufficient to accomplish its objectives?
* If access to knowledge goods (including new medicines, vaccines, diagnostics, compound libraries, data, research tools, etc) is important for success, is there a feasible strategy to obtain sustainable access at affordable prices, consistent with resource constraints?
* Are policies regarding intellectual property rights transparent and consistent with human rights?
* If current business models fail to promote development and undermine human rights, does the institution encourage and support efforts to evaluate or promote new business models that are better for development and human rights?

The notion that one has to search for feasible and better paths to achieving human rights outcomes, and not just settle for small incremental changes, is important.

**Paragraphs 41-42.**

In relation to persons with disabilities who have suffered deep discrimination in the enjoyment of the right to participate in scientific progress, the draft general comment should refer to the rights and obligations of state parties to implement the Marrakesh Treaty to Facilitate Access to Published Works for Persons Who Are Blind, Visually Impaired, or Otherwise Print Disabled.

**Paragraph 44.**

The only way the governments can eliminate unequal access to medical technologies is to delink R&D incentives from prices. All other reforms will fall short of equal access.

**Paragraph 57.**

The issues of transparency and participation are quite important.

Trade negotiations are often conducted with asymmetric access to information. Corporate lobbies are often briefed on the details of norms for intellectual property rights or other provisions, on the grounds that they have special rights as stakeholders, while the public is left in the dark, even though the agreements can have life or death consequences.

High prices for medical technologies are justified by narratives about research and development costs which involve exaggerations, and inaccurate and deliberately misleading estimates.

Policies by governments that block the transparency of research and development costs, such as the costs of conducting human subject clinical trials in the development of drug, vaccine, cell and gene therapies, are, in our view, violations of human rights. In the case of a lack of transparency or excessive secrecy of R&D costs, the predictable outcome is to permit drug companies to lie and mislead the public in order to justify high prices and unequal access. Another consequence is that it far more difficult to explore new arrangements including new business models that delink incentives from prices, when the actual costs of R&D are shrouded with mystery and inaccurate information.

**Paragraph 65.**

The CESCR, in collaboration with WHO, should conduct a feasibility study to examine models of different possible means of de-linking research and development costs from product prices, in the context of states seeking to achieve universal health coverage, and more equal global access to new technologies.

**Paragraph 66.**

Intellectual property rights can be implemented without exclusive rights, either as part of a liability rule regime, which preserves the freedom to use inventions, data and works, subject to economic remuneration of some type, or where incentives are completely delinked from prices, such as with market entry rewards for new drugs, vaccines, cell and gene therapies.