# **Reviving the Human Right to Science**

#### Abstract

The notion that everyone has a right to benefit from scientific progress is enshrined in the United Nations' 1948 Universal Declaration of Human Rights. (UDHR), adopted under the guidance of Eleanor Roosevelt, who chaired the drafting committee, and in the UN's 1966 International Covenant on Economic. Social and Cultural Rights (ICESCR) and other international and regional treaties. It is far from clear, however, exactly what freedoms and responsibilities derive from this established right of all people to "share in scientific advancement and its benefits", as the UN declared, and for most of its history, governments have largely allowed this right to remain dormant and neglected. As science and technology take an ever-greater role in our lives, now might be the time to bring this right back to life. An important first step would be to specify just what exactly is meant by the right to science. Proposals for reviving this right include a collective commitment to open science and inclusivity, new forums for data-sharing and the establishment of a deliberative body to ensure the latest scientific evidence is taken into account in policymaking.

- What freedoms and responsibilities does the "right to science" entail?
- How can the right to science be used to benefit humanity?
- How can we make this a "living human right" that is taken seriously by policymakers, and how can we encourage signatories to the UDHR to renew their commitment to the right to science?

### **Participants**

Moderated by:

Samira Kiani, CEO and Founder, GenexGen; Director, Tomorrow.Life Initiative; Associate Professor, Liver Research Center, Department of Pathology, School of Medicine, University of Pittsburgh; Member, GESDA Academic Forum, USA

With

**Michelle Bachelet**, UN High Commissioner for Human Rights (OHCHR); Former President of Chile; Member, GESDA Diplomacy Forum, Chile *(remotely)* 

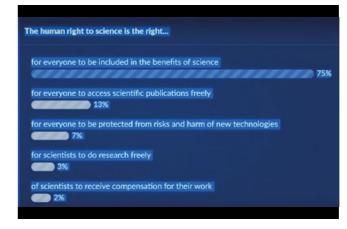
**Yvonne Donders**, Head, Department of International and European Public Law; Commissioner, Netherlands Human Rights Institute, University of Amsterdam, The Netherlands

**Kamila Markram**, neuroscientist, cofounder and CEO of Frontiers, Germany

**Peter Maurer**, President, International Committee of the Red Cross; Member, GESDA Diplomacy Forum, Switzerland

## **Highlights**

In the wake of World War II, leaders saw the need to connect science with human rights, and enshrined this in the Universal Declaration of Human Rights (1948) which states in Article 27 that "everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits". The war's outcome was shaped by rapid science and technological advances like the atomic bomb, cavity magnetron-enhanced radar, faster computers, and large-scale production of penicillin. Each brought benefits but also risks. In 1966, the United Nations adopted two important treaties, the International Covenant on Civil and Political Rights (CCPR) and the International Covenant on Economic, Social and Cultural Rights (CESCR), which has been joined by 170 nations that voluntary assume it as a legal obligation. A poll of the plenary audience found 75% believe this right means science must benefit everyone. Another 13% said it means free access to science publications; 7% defined it as a protection from harm; 3% said it means unhindered research; and 2% called it an assurance that scientific work is compensated. No one chose a sixth option: a belief that it ensures all traditional knowledge must be kept alive.



Vote by the audience on the meaning of the Human Right to Science, at the start of the conference.

Note the predominant view that this right is about inclusiveness; it should be invoked to remove barriers to access of the benefits of science.

UN human rights chief Michelle Bachelet said the human right to science is more than just access to knowledge. It is also a tool to facilitate other rights to basic needs and services such as food, water, housing, education, and health. "Sadly, it is still far from being a reality for everyone," she said. "Nowhere is this more visible now than with the case of vaccine injustice, which restricts people's rights to life and health, to development and to the benefits of scientific progress." Despite the unprecedented speed and deployment of COVID-19 vaccines during the pandemic, four-fifths of the doses administered

globally went to high- and upper-middle income nations even though they account for less than half of the world's population. Bachelet, a medical doctor who was the first female president of Chile, said the vaccine gap between rich and poor is "a stark example of the severity of inequalities we should never grow accustomed to" but that once again a big segment of the world has been left behind. "As in every right, the right to science must be accessible by all and benefit for everyone's participation, without discrimination," she said. "In addition, it mandates that scientific innovations benefit people, rather than harm them. But here too, there is often a gap between what should happen and what actually happens." Part of the problem, she added, is that the human right to science is not widely known.



Because science affects so many areas of our lives, the human right to science has many implications for diplomacy. Even if it does not prevent abuses, it does offer valuable principles that express what societies care about. Science also offers solutions grounded in facts that are key to solving global problems like the pandemic, climate change and major humanitarian crises, said Peter Maurer, a veteran Swiss diplomat who served as ambassador to the UN and a top official in the Swiss foreign ministry before taking the helm of the ICRC. Emerging questions over massively disruptive technologies like autonomous weapons systems and social media-inflamed disinformation and hate speech all illustrate the need for scientists to help frame our responses, he said. "When you see the relationship between multilateral policy and science, you become aware how important it is to have evidence-based policymaking," said Maurer. "The confrontation with the humanitarian challenges and issues today at the ICRC made me such a strong advocate of evidence-based policymaking, which is another word for being an advocate of the human right to science - for having societies take advantage of scientific research in order to solve problems."

There is no lack of published scientific research (including three million articles a year published just in English-language journals), but the question of who has access to this research affects the

human right to science. Legacy publishers kept their old business models in place, so universities and businesses today spend more than \$10 billion a year to access science journals that remain behind paywalls. Two-fifths of that revenue goes to US publishers, and the rest is split about evenly between publishers in the EMEA and Asia-Pacific regions. Ironically, scientists created the Internet decades ago partly to reach a wider audience. In the face of these paywalls, an open-source movement has sprang up to unlock millions of science articles.



"When you restrict access to science, the only thing that actually happens is that we slow down our global innovation cycle. Science today is really underpinning every single aspect of our lives," said Kamila Markram, who co-founded a leading open-access academic publisher and social network for researchers. And since no one can afford to subscribe to all of the paid journals, she said, "the consequence is that researchers don't have full access even within their own research fields to the latest science". The same goes for policymakers, medical doctors, patients, innovators, and journalists, and whoever else might benefit from all of this research. By region, access breaks down even further; people living in Eastern Europe, Africa, and South America are more often excluded from the benefits of science, said Markram, the CEO of a large open science enterprise, Frontiers. "On the other hand, what happens when you open up this vast knowledge of science?" she asked, before answering her own question. "Last year, when the pandemic hit us, something happened that none of us had achieved in 20 years of trying. It basically opened up the scientific literature overnight, almost."



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What happened was that Chinese scientists sequenced the genetic makeup of the novel coronavirus, then made it publicly available at the start of 2020. That triggered a race for vaccines in research labs worldwide. Most scientific journals made COVID-19 research papers freely available; also in March 2020, the White House mandated that all COVID-19 papers must be available through open-access publications; as of December 2021, 500,000 papers were stored in the COVID-19 Open Research Dataset Challenge (CORD-19) and made accessible to all. "Only because all of this science was made open, were scientists able to collaborate now far more effectively and they delivered. They delivered solutions at a speed that we have never seen before in human history," Markram said. "It was the absolutely right policy decision to do that, but I think that policymakers actually need to learn from this experience, because it's not the only emergency we're in." Beyond providing more access to all of this original research, people need more help understanding it all. That puts the onus on scientists to better translate their work. Al and machine learning tools are also needed to sift through the research, which is far more than any one person can digest. "What we need are proper tools - how to make sense out of all of this research," she said. "In COVID, this is what has been happening."



One of the major challenges to this human right is that the private sector produces a significant amount of science. When the UDHR was drafted, experts said, the institutions around science were more homogenous, in large part because of a lack of diversity. International legal instruments were not equipped to deal with private institutions; they were designed to address how governments implement science. Framing science as a human right can help illuminate the core issues of how to balance competing interests, provide access to scientific information and protect vulnerable people. It also should help clarify society's values and principles, even if lawyers alone cannot resolve the way forward. GESDA's decision to highlight the human right to science signals that something important is happening, according to Yvonne Donders, a prominent international and human rights law expert. "Ten years ago, nobody would have a session

on the human right to science in these kinds of summits," said Donders. "The fact is that nothing really happened with it" in the decades since the right was established, she said, because countries and academics "have not paid a lot of attention" to it until recently. "That has changed over the last years. More academic research is done on this right. There are a lot of legal developments going on in courts."

#### **Takeaway Messages**

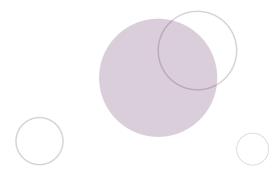
Reviving the human right to science is a timely and important initiative. **GESDA** can serve as an appropriate forum to encourage this conversation.

The existing international legal framework does not appropriately reflect the economic, cultural and social aspects of today's science enterprise.

Open and free access to scientific data and publications should be a consequence of this right.

This human right is violated when low-income countries cannot benefit from scientific breakthroughs (like the COVID-19 vaccines).

This right mandates evidencebased policymaking – having society take advantage of scientific research in order to solve problems.



#### **Additional content**

Introductory remarks by Michelle Bachelet, UN High Commissioner for Human Rights (OHCHR); Former President of Chile, Chile

I am delighted to be part of this important discussion.

Every day, I feel in awe with scientific and technological progress. Not that long ago, I remember waiting for the morning newspaper, to receive news of the day before.

Now, everything is reported in real time and through ever evolving communications methods and channels.

Today, we share information easily and we even have robots to assist in many spheres of life. With cameras, we can visit anyone, anywhere in the world, and many of us are forever grateful for that, in the recent times away from family and friends during lockdown, but also everyday.

As a medical doctor, I have seen so many advances in medical science – enough to amaze me for the rest of my life.

As they should everyone. It is within our right.

So, what is the human right to science exactly?

You have already shown Article 27 of the Universal Declaration of Human Rights, which states the right of everyone to share in scientific advancement and its benefits. That it reinforced by Article 15 of the International Covenant on Economic, Social, and Cultural Rights (CESCR) which, as of July 2020, had 170 States Parties voluntarily assuming this article as a legal obligation.

As you correctly said, the human right to science is more than access to knowledge. It is also a tool for the realization of other human rights and fundamental freedoms, such as food, water, housing, education, and health.

But, sadly, it is still far from being a reality for everyone.

Nowhere is this more visible now than with the case of vaccine injustice – which restricts people's rights to life and health, to development and to the benefits of scientific progress.

The pace at which we gained scientific knowledge has been extraordinary, and countless lives have been saved. By August 2021, almost five billion vaccine doses had been administered. But the vaccine gap between rich and poor is a stark example of the severity of inequalities we should never grow accustomed to. More than 80% of the doses administered globally had gone to high- and upper-middle income countries, even though they account for less than half of the world's population.

The lack of access to vaccines and medicines puts millions of lives in developing countries in immediate danger. It also poses a threat to people everywhere, as mutating forms of the virus may emerge among largely unvaccinated populations.

The pandemic also has demonstrated that access to digital technology and the internet plays an essential role in disseminating public health information, ensuring incomes during lockdowns and enabling that children to continue their education. But once again, a huge part of the population has been left behind.

As in every right, the right to science must be accessible by all and benefit for everyone's participation, without discrimination.

In addition, it mandates that scientific innovations benefit people, rather than harm them. But here too, there is often a gap between what should happen and what actually happens.

For example, while artificial intelligence can help improve productivity, monitor epidemics, or support economic growth, it can also have built-in discriminatory effects. Openness and transparency in the development of Al algorithms can help prevent people from being discriminated against, based on characteristics such as their race, age, sex or disability.

It is also important to see that science is developed while respecting human rights. The improvement of public policy and governance through science-policy interface can be undermined if scientists are harassed for speaking out about their findings or been denied fundamental freedoms to carry out their work

The Right to Science is not widely known and all of us can help change that. Because respecting human rights is essential to creating the world we all want to live in".



More information

Session recording on YouTube

Related interviews: Samira Kiani, Peter Maurer

Tweets related to the session

Michelle Bachelet's remarks