

# Advocating for science progress as a human right

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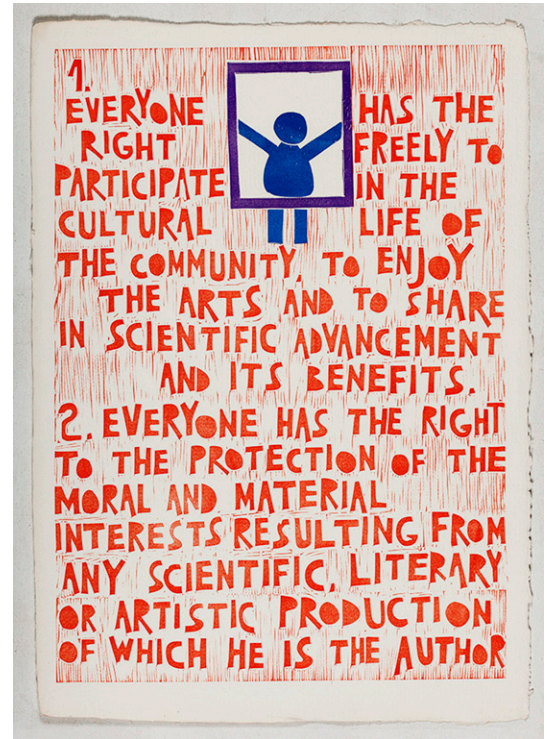
*"[Everyone has] the right to enjoy the benefits of scientific progress and its applications."*

*Article 15(1)(b), International Covenant on Economic, Social and Cultural Rights (1)*

We all have a human right to enjoy the benefits of scientific progress (the Right to Science [RtS]).\* The right has its origins in Article 27 of the United Nation's (UN's) 1948 Universal Declaration of Human Rights, which was adopted in the wake of World War II (2).<sup>†</sup> In 1966, the UN turned these commitments into binding obligations under international law. The implication is that, just as governments are expected to respect the rights to, say, freedom of speech and due process, so they must also adopt measures to respect and ensure the RtS (Fig. 1).

The existence of this right is important for researchers and society. It adds a legal and moral dimension to a range of fundamental issues, including scientific freedom, funding, and policy, as well as access to data, materials, and knowledge. Yet, despite its potential for furthering science and human rights causes, the RtS has not received the attention it deserves. As the American Association for the Advancement of Science (AAAS) notes, "governments have largely ignored their Article 15 obligations and neither the human rights nor the scientific communities have brought their skills and influential voices to bear on the promotion and application of this right in practice" (3).

We argue that the scientific community should be aware of this right—and make others aware, as well. The historical neglect of the RtS has, in part, been because of the difficulty in interpreting its implications, both normative and practical. We try to unpack these complexities here in hopes of not only explicating the



**Fig. 1.** The United Nations "Right to Science" adds a legal and moral dimension to a range of fundamental issues, including scientific freedom, funding, and policy, as well as access to data, materials, and knowledge. Image courtesy of Otávio Roth ([www.otavioroth.com](http://www.otavioroth.com)).

RtS but also demonstrating why the scientific community should act to enrich it.

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\*We use the term Right to Science because we believe it captures the normative content of the right.

<sup>†</sup>As a declaration, rather than a treaty or covenant, the Universal Declaration of Human Rights originally bore no force of law but rather expressed an ideal standard held in common with and by nations around the world. Today, it is generally considered to reflect international customary law, which is binding upon all states.

## Human Rights and Science

A recent letter published in *Science* asked young researchers how their scientific work can support human rights (4). Responses included the fortification of foods to prevent malnutrition, longer-lasting vaccines, wearable personal health trackers, genetically modified crops capable of resisting harsh climates, forensic anthropology to identify victims of genocide, ecological research to sustain our earthly habitat, and neural underpinnings of variations in empathic responses to members of different races or ethnicities (4).

Conversely, human rights can enhance science. Scientific research depends on the ability to examine, verify, and apply the findings of others. Increasing protections of intellectual property (IP) and data privacy threaten the scientific freedom to access the information necessary for research, especially in low and middle-income countries and among disadvantaged populations of high-income countries. The lack and underutilization of scientific evidence for some areas of policy making prevent many from enjoying the benefits of scientific progress. A human rights approach to scientific research can counter such trends and help further human rights principles of equality, participation, and dignity (5).

Much can be achieved, the AAAS Science and Human Rights Coalition notes, “when the science, engineering and health communities embrace human rights as an area suitable for and deserving of robust inquiry, and become an influential voice in the defense of human rights.” (6) In this regard, the Coalition’s own efforts over the past decade to elicit the perspectives of researchers and health professionals are instructive (7).

## An International Obligation

In Article 27 of the Universal Declaration of Human Rights (UDHR) and in Article 15 of the International Covenant on Economic, Social and Cultural Rights (ICESCR), the RtS is mentioned together with the right to participate in cultural life and enjoy the arts. Both are cultural rights relating to the pursuit of knowledge and understanding as well as human creativity. Along with Eleanor Roosevelt and the other framers of the UDHR,<sup>‡</sup> the delegates to the UN General Assembly met in Paris in 1948 to adopt the UDHR and saw the right to participate in culture and science as crucial to “the full development of one’s personality” and “as a way of summarizing all the social, economic, and cultural rights in the Declaration.” (8)

By ratifying a human rights treaty, States assume legal obligations to implement the rights recognized in that treaty in their domestic legislation and policies—and these rights can be subjected to international accountability and supervision (9, 10). With respect to the RtS,

minimal obligations of States could include respect for the freedoms indispensable for scientific research, promotion of access to the benefits of science and its applications on a nondiscriminatory basis, prevention of harmful effects of science and technology, and strengthening international cooperation, including respect for collaboration of researchers across borders (11).

The United States signed the ICESCR in 1977 but has not yet ratified it. Still, a State that has signed but not ratified a treaty is obliged to refrain from acts that would defeat the object and purpose of the treaty (Article 19, Vienna Convention on the Law of Treaties).

## Rights in Review

Directly or indirectly, the RtS has an impact on a number of controversies. To ascertain which topics are currently considered the most relevant or contentious, we conducted a systematic review of the extant literature on the RtS. Fifty-two studies met our inclusion criteria (see supporting information for methodology).

Access was the only theme that appeared universally. Articles discussed the importance of access to all parts of science, from the necessary education all the way to the data, knowledge, and applications that arise from scientific inquiry. Access interests range from those of the general public to those of researchers. They have also been explored in the literature related to the human rights to health, education, and protection of authors’ moral and material interests (5, 12).

The first UN Special Rapporteur in the field of cultural rights, Farida Shaheed, emphasized the importance of access to innovations “essential for a life with dignity” (5). Many scientific innovations are protected by IP rights, a tension noted by 42 of the 52 studies surveyed. Copyright and patents may complicate access to knowledge by taking useful information and innovations out of the public domain. A balance must, therefore, be struck among the interests of authors, inventors, and everyone else. Examples included educational material, medical and public health technologies and substances, information and communication technologies, electricity, books and journal articles, genes and other biological material, seeds and agricultural technology, nanotechnology, and technology enabling development (5, 12–15).

Thirty-five studies discussed participation. The human rights principles of inclusion and equality require States to take special consideration of factors preventing members of disadvantaged groups from participating in science, notably gender and racial disparities in scientific professions (5).

The potential for the dual use of science and technology was mentioned in 23 of the studies surveyed. Technologies such as CRISPR/Cas-9 gene editing can be used in ways respectful of, or contrary to, human rights principles. Thus, the RtS may relate in different ways to various applications of the same technology. All but one of the reviewed studies recognized that the RtS is inextricably linked to other rights related to food, health, education, development, a clean environment, social security, water, information, and labor rights. Finally, some studies recognized that science has both intrinsic and instrumental value. The latter includes its usefulness

<sup>‡</sup>Chaired by Eleanor Roosevelt, First Lady of the United States from 1933 to 1945, the United Nations Committee that drafted the Universal Declaration of Human Rights consisted of representatives of Australia, Chile, China, France, Lebanon, the Soviet Union, and the United Kingdom, in addition to the United States. Of the then 58 members of the United Nations, 48 voted in favor of the historic document on December 10, 1948, none voted against, 8 abstained, and 2 did not vote.

in promoting other human rights, as well as its potential to inform and empower citizens (13).

### Research Relevance

The RtS is relevant to current scientific research. For instance, health research, our own line of study, often requires citizen participation. The resulting data are potentially useful both to individuals and to society at large, but controversies persist over who may legitimately access an individual's medical data.

From an RtS perspective, data relevant to one's own health constitute a benefit of science. Hence, the starting point is that people have a right to access their own data. Like all other human rights, though, the RtS is not absolute; it may be restricted to protect human rights principles or the rights and/or well-being of others. Such limitations must be "strictly necessary to further the general welfare in a democratic society" and should always be "appropriate and proportionate" (Article 4, ICESCR). The RtS, therefore, places a burden of proof on those who would limit access. According to the RtS, to limit individuals' access to their own medical data requires that the Article 4 criteria—prevention of harm, appropriateness, proportionality, and strict necessity for general welfare—have been met.

There are, of course, complex cases with important tradeoffs to consider. For instance, to further medical progress, individuals have an interest not only in their own health data, but others' as well. In the future, more "omics" data sets (e.g., genomics, proteomics, and metabolomics) will be generated and combined with multidimensional dynamic data sets on individuals stemming from mobile devices, wearable devices, and nontraditional medical and wellness monitoring sources.

But although access to these omics data constitutes a benefit of science, several of the criteria for limitations seem to apply. Unlike cases concerning access to only one's own personal data, using others' data may expose them to harm (the first criterion) in the form of privacy breaches. We argue that keeping some personal medical information private is also necessary for the general welfare, given the potential for discrimination or other abuse of sensitive information (second criterion). Thus, from an RtS perspective, sensitive medical data should be kept confidential and not used without consent, as long as laws and policies to this effect are also appropriate (third criterion) and proportionate (fourth criterion).

It follows that studies should be designed with both the individual and society in mind. By way of example, in 2005, one of the authors (G.C.) created a comprehensive study that gathered medical and genomics data from research participants, with their consent and using a fully open-access protocol. Now approved in several countries, this project provides data for the benefit of both individuals and society ([www.personalgenomes.org](http://www.personalgenomes.org) and [www.openhumans.org](http://www.openhumans.org)). Despite the existence of such projects, many emerging medical research projects still recruit participants with disingenuous claims including that (i) data will be kept strictly confidential, (ii) data cannot be re-identified, and (iii) data cannot be returned to participants. The research

silos that result can unnecessarily prevent the democratization of science and frustrate both patient advocacy groups and citizen-researchers.

Over time, it will be even more important to be mindful of the RtS as trends toward institutional and commercial benefits and away from individual access complicate the clear understanding of knowledge ownership and provenance. In contrast, a generation of extensive, detailed personal data clouds for individuals is expected to empower and democratize the use of modern medical information (16). The RtS framework and the Article 4 limitation criteria offer a way to test future policies on the use of omics and personal data for research purposes.

### Future Directions

Although policy cannot ensure a full and robust adherence to the RtS, it can be formulated to anticipate and ameliorate conflicts. For instance, some objections to aspects of science may be rhetorically framed as concerns for human dignity. This risks both obscuring the fundamental and universal qualities of dignity as a human rights principle and may, if used in a frivolous or careless manner, obstruct important research.

Several studies we surveyed mentioned the concept of dignity. None attempted to define its meaning and importance in relation to the RtS. Human dignity is a foundational value in international human rights law, serving variously as the grounds from which human rights are derived or as a constraint on the types of innovations and actions that are incompatible with a human rights-based approach. Indeed, international human rights law expressly forbids any action or invention contrary to human dignity.

The concept has been frequently invoked in discussions of biomedical advances and associated bioethical issues, such as the development of novel lifeforms, stem cell therapies, and germline editing of human embryos. These and other areas of scientific research risk being labeled contrary to dignity if their intent is not clarified and balanced in relation to the RtS. The criteria for limitations based on human dignity should, therefore, be thoroughly laid out in policy and consistent with other rights and human rights principles.

Those who support the RtS should also be mindful of overly restrictive IP requirements, reducing transparency of public data and information, and diminishing public input into the development of scientific priorities. Articles 15 (1)(c) ICESCR and 27 (2) UDHR recognize the right of everyone "to benefit from the protection of the moral and material interests resulting" from their scientific production. This includes the right to be recognized as the author of one's work, to make an adequate living from it, and not to have it distorted in ways prejudicial to one's reputation or interests. Both scholarly sources and official documents surveyed in our study took pains to emphasize that IP protection as currently instantiated is not a human right (5, 17).

Several articles in our review noted that levels of IP protection have been increasing in recent decades. As a consequence, commercial interests now play a much larger role in science funding and priority setting than when the ICESCR was drafted and

discussed (17). This conflicts with the emphasis on equality in international human rights law to the extent that the commercialization of science diverts research from issues faced by those less able to pay, a point noted in 36 studies. In addition, the participatory aspect of RtS is threatened if the needs and interests of the less wealthy are not accounted for when determining research priorities.

The UN's independent body monitoring the ICESCR is currently drafting a document to help governments and courts understand the duties imposed on states by the RtS. Known as a General Comment, it will heavily influence how international law, in areas relevant to science and scientists, will be developed and interpreted—its main author has encouraged input from interested scientists.<sup>5</sup> General Comments also help devise a means for practical implementation and criteria for evaluating progress. If

the priorities and principles that underlie the RtS are to become an integral part of the interpretation of this right, input from the scientific community is sorely needed. Researchers can raise awareness of the RtS and its potential violations through human rights and scientific organizations such as the AAAS. Beyond providing input to the immediate General Comment, researchers could disseminate information on the RtS at scientific meetings, refer to it in research articles, and invite conversations on the right in research labs, whether private or academic.

At present, the RtS is too often an academic exercise or the province of UN and human rights scholars. In fact, the RtS is a basic human right with clear implications for the dignity, well-being, health, and education of all the world's citizens. The RtS adds an important legal and moral dimension to fundamentally important issues in science and policy. Let us make every effort to make it robust and responsible.

<sup>5</sup>Mikel Mancisidor de la Fuente, member of the Committee on Economic, Social and Cultural Rights and the author of the new General Comment, may be reached at mikel.mancisidor@deusto.es. His email address is listed here by his own permission.

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