'Sleeping Beauty': The Right to Science as a Global Ethical Discourse

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"Sleeping Beauty": The Right to Science as a Global Ethical Discourse[1]

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"[Everyone has the right] to enjoy the benefits of scientific progress and its applications."[2]

"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."[3]

ABSTRACT

Everyone has a human right to science (RtS), as enshrined in the Universal Declaration of Human Rights and the International Covenant on Economic, Social and Cultural Rights. Despite its significance for scientists and society, this right has not received the attention it deserves. To remedy this, the

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1. This chapter is a longer and much more elaborate version of S. Porsdam Mann, Y. Donders, C. Mitchell, V. J. Bradley, M. F. Chou, M. Mann, G. Church, & H. Porsdam, *Opinion: Advocating for Science Progress as a Human Right,* 115 PNAS 10820 (23 Oct. 2018), https://doi.org/10.1073/pnas.1816320115. The methods used in the literature review that forms an important part of this chapter and a detailed elaboration of the results found is available in an Appendix of Supporting Material in the PNAS opinion piece. The authors thank C. Mitchell, V. J. Bradley, M. F. Chou, M. Mann, and G. Church for allowing us to base this chapter on the PNAS Opinion Piece.
2. Universal Declaration of Human Rights, *adopted* 10 Dec. 1948, G.A. Res. 217A (III), U.N. GAOR, 3d Sess, art. 27, U.N. Doc. A/RES/3/217A (1948).
3. International Covenant on Economic, Social and Cultural Rights, *adopted* 16 Dec. 1966, G.A. Res. 2200 (XXI), U.N. GAOR, 21st Sess., art. 15(1)(b), U.N. Doc. A/6316 (1966), 993 U.N.T.S. 3 (*entered into force* 3 Jan. 1976) [hereinafter ICESCR].

United Nations called for input from academic and scientific communities in 2009. Its Committee on Economic, Social and Cultural Rights is currently drafting a General Comment—a document of authoritative guidance to state parties on the normative contents of the RtS. The scientific community is therefore in a unique position to influence how this right is elucidated within a human rights context. Informed by a systematic review of the relevant literature, we first explore the history, importance, and content of the RtS. We then examine a few important topics that fall within the remit of the RtS but were absent or inadequately addressed in the extant literature, and conclude by discussing the implications of the RtS for science policy.

I. INTRODUCTION

Is there a human right to science (RtS)?[4] According to Article 27 of the Universal Declaration of Human Rights (UDHR) from 1948, everyone has the right "to share in scientific advancement and its benefits." Likewise, the 1966 International Covenant of Economic, Social and Cultural Rights (ICESCR) recognizes the right of everyone "to enjoy the benefits of scientific progress and its applications" in Article 15(1)(b).[5] So yes, there is a human RtS—a right that has remained a "sleeping beauty" for many years, as William A. Schabas puts it.[6]

We argue that there is great potential in the RtS. Interacting in all sorts of ways with economic, political, social, and military interests, scientific research is more global than ever today. Taking this particular right seriously gives us a forum and a global ethical discourse in which to tackle urgent and difficult issues. Sustainable development and climate change constitute global challenges, for example, that involve science in various ways and that can only be addressed through a global discourse.

> Science, its methodologies, its processes, and the truths it can reveal, are vital to human rights. . . . [A]s the world grows more complex and globally connected, science becomes more essential to the basic processes of democracy. The right to vote and the right to participate in public life have little meaning if citizens

4. Realizing that the formulation of this right in international law is different, we prefer to use the right to science (in analogy with the right to health which is formulated as the right to the highest attainable standard of health). *See also* Mikel Mancisidor, *Is There Such a Thing as a Human Right to Science in International Law?,* 4 Eur. Soc'y Int'l L. Reflections (7 Apr. 2015), https://esil-sedi.eu/post_name-132/.
5. The UDHR is not legally binding. The two instruments that made the rights outlined in the UDHR legally binding are the International Covenant on Civil and Political Rights, *adopted* 16 Dec. 1966, G.A. Res. 2200 (XXI), U.N. GAOR, 21st Sess., U.N. Doc. A/6316 (1966), 999 U.N.T.S. 171 (*entered into force* 23 Mar. 1976) [hereinafter ICCPR]; ICESCR, *supra* note 3, respectively. Both Covenants were ready for ratification in 1966. Together with the UDHR, the two Covenants are called the International Bill of Human Rights.
6. William. A. Schabas, *Looking Back: How the Founders Considered Science and Progress in Their Relation to Human Rights,* 4 Eur. J. Hum. Rts. 504 (2015).

cannot evaluate policies and proposed interventions in light of scientifically rigorous assessments of both risks and opportunities.[7]

As the Marches for Science that have taken place in a number of cities and towns around the world since 2017 have shown, a number of people both within and outside the scientific community perceive the value of scientific inquiry to be under siege. The stated goals of the Marches are to affirm science as a crucial part of a strong democracy and to highlight the value of evidence-based inquiry and policy-making. Public trust in science has suffered as a result of "fake news," the deliberate presentation of falsehood as fact motivated by political influence or financial return. Fact-based knowledge and evidence no longer exert the rational pull they once did. In the United States, creationism and other religious theories challenge widely held scientific explanations about the origin of the universe. Creationism also seems to play an expanding role in public debates about science policy and school curricula in Europe.[8] And in parts of the Arab world, the schism between science and Islam seems to widen with time, making the philosophical implications of e.g. relativity, chaos theory, or stem cells unacceptable.[9]

In 2009, as a result of two years of discussion aimed at clarifying the content of the RtS, UNESCO published the "Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications."[10] Importantly, this statement calls for the input of "academic and scientific communities" to help clarify this right. Since the UN is currently drafting authoritative guidance, in the form of a General Comment,[11] on the RtS, the call for input means that academic and scientific communities are in a unique and time-limited position to influence its content and, by extension, what will later become international law on their domain.[12] We hope to raise awareness of

7. Jessica M. Wyndham & Margaret W. Vitullo, *Why the Right to Science Matters for Everyone* (2017), https://www.opendemocracy.net/en/openglobalrights-openpage/why-right-to-science-matters-for-everyone/.
8. Creationism in Europe (Stefaan Blancke, Hans Henrik Hjermitslev & Peter C. Kjærgaard eds., 2014).
9. Pervez Hoodbhoy, *Islam and Science—Unhappy Bedfellows*, Global Agenda (2006), http://eacpe.org/content/uploads/2014/02/Islam-and-Science-unhappy-bedfellows.pdf; Pervez Hoodbhoy, Islam and Science: Religious Orthodoxy and the Battle for Rationality (1991).
10. *Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications*, UNESCO, 16–17 July 2009, https://www.aaas.org/sites/default/files/VeniceStatement_July2009.pdf.
11. Each of the treaty bodies publishes its interpretation of the provisions of its respective human rights treaty in the form of "general comments" or "general recommendations". General Comments are not, strictly speaking, legally binding, but they are considered to be the most authoritative we have in explicating rights mentioned in a specific human rights treaty and providing general guidance on the information that should be submitted in state reports relating to specific articles of the treaties.
12. Press Release, *Committee on Economic, Social and Cultural Rights Holds Day of General Discussion on the Right to Enjoy the Benefits of Scientific Progress*, U.N. CESCR (2018), https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=23714&LangID=E.

this opportunity to help ensure that the voices of academics and scientists ring loud in the drafting of legal documents that will affect them intimately.

Our chapter is divided into three parts. We start, in part one, by looking at how the RtS was developed—that is, at the relevant drafting history. We then analyze, in part two, what the RtS is, legally and conceptually speaking. Our analysis is followed by an exploration, in part three, of some of the most contentious issues relating to the RtS. This exploration takes the shape of a presentation of the results of a systematic review, carried out across legal and scientific databases. Collecting and summarizing all empirical evidence that fits our pre-specified eligibility criteria, this review informs our discussion on the state of scholarship on the RtS and how the RtS can be used to inform and advance difficult questions within science and science policy. We conclude by pointing to promising areas of further investigation.

II. HOW WAS THE RIGHT TO SCIENCE DEVELOPED? DRAFTING HISTORY

In both UDHR Article 27 and ICESCR Article 15, the RtS is mentioned together with the rights to participate in cultural life and enjoy the arts. Both relate to the pursuit of knowledge and understanding as well as to human creativity. Just like the right to participate in cultural life enables people to be creative and to contribute to society's "cultural meanings and manifestations," so the RtS gives people the freedom to engage in critical thinking and to "investigate and contribute new knowledge" in the field of science.[13]

In her thematic report on the right to enjoy the benefits of scientific progress and its applications, Farida Shaheed, the first UN Special Rapporteur in the field of cultural rights, relates the link between culture and science to the need to protect academic research and academic standards.[14] It is interesting in this context to recall how the word 'scientist' was first coined. It happened in 1833 when the poet Samuel Taylor Coleridge complained during the third meeting of the British Association for the Advancement of Science that the phrase "natural philosophers" had by now become a misnomer. Far from being philosophers who took the time to think about things, modern scientists were, Coleridge argued, practical men who experimented with electricity or spent their time digging for fossils. In response, the host of the meeting, William Whewell, invented the phrase 'scientist' by anal-

13. Special Rapporteur, *The Right to Enjoy the Benefits of Scientific Progress and its Applications*, U.N. ESCOR, Comm'n on Hum. Rts., ¶ 18, U.N. Doc. A/HRC/20/26 (2012) [hereinafter *Report on Right to Science*]. The following paragraphs on the drafting history of the RtS are based on Helle Porsdam, The Transforming Power of Cultural Rights: A Promising Law and Humanities Approach 126–54 (2019).

14. *Report on Right to Science*, *supra* note 13.

ogy to 'artist.' Just like the average artist is more interested in doing art than in philosophizing about what art is or ought to be, so the modern scientist conducts experiments and does not necessarily speculate about the more philosophical aspects of those experiments.[15]

The framers of the UDHR saw the right to participate in culture and science as crucial to "the full development of one's personality." Originating in a draft submitted by the American Federation of Labor, this phrase "was seen by most delegates as a way of summarizing all the social, economic, and cultural rights in the Declaration."[16] They counted it among the most fundamental of all human rights, and the rights listed in Articles 23 through 27 in fact "aim at the realization of the right to the full development of one's person."[17] The right to freely participate in cultural life and to share in scientific advancement and its benefits therefore seems to have enjoyed more or less universal support.

There was a difference of opinion among the founders of the UDHR as to what the notion of participation meant for culture and for science. Whereas there was no disagreement about cultural life being open to the participation of everyone, the Cuban delegate noted that, "not everyone was sufficiently gifted to play a part in scientific advancement" and proposed that the text say that everyone has the right "to share in the benefits that result from scientific advancement."[18] This proposal was well received. French delegate René Cassin agreed that "even if all persons could not play an equal part in scientific progress, they should indisputably be able to participate in the benefits derived from it." Several delegates stressed everyone's ability for aesthetic enjoyment, but did not appear to think that active participation in science could be expected from everyone.[19]

A second difference of opinion arose over the framing and definition of the nature of science itself. UDHR Article 26(2) specifically says that education must be directed, first and foremost, to the full development of the human personality and to the strengthening of respect for human rights and fundamental freedoms. Secondly, it must promote understanding, tolerance, and friendship among all nations, racial, or religious groups, just as it must further the activities of the UN for the maintenance of peace. The UDHR does not, however, mention anything about the purposes of

15. Laura J. Snyder, The Philosophical Breakfast Club: Four Remarkable Friends Who Transformed Science and Changed the World 3 (2011).
16. Johannes Morsink, The Universal Declaration of Human Rights: Origins, Drafting, and Intent 210 (1999).
17. *Id.* at 212.
18. *Id.* at 219.
19. *Id.* The same was true during the negotiations that led to the ICESCR—see Hans Morten Haugen, *Human Rights and Technology—A Conflictual Relationship? Assessing Private Research and the Right to Adequate Food,* 7 J. Hum. Rts. 224 (2008).

scientific research.[20] The Soviet delegation found this odd and submitted various formal proposals, including one saying that "[t]he development of science must serve the interests of progress and democracy and the cause of international peace and co-operation."[21] Though various other delegations found the idea behind the Soviet proposals important, these proposals were solidly defeated as many were afraid of placing science at the service of a particular political ideology.

This fear was not entirely unfounded as the Soviet delegation more or less aggressively hinted at science being subservient to militaristic goals and weapons in parts of the West, especially the United States. Early cold war concerns were obvious, and the sad result was a missed opportunity of anchoring science and scientific research squarely within the normative provisions of the UDHR. As Schabas sees it, however, "there is considerable authority for the view that a notion analogous to the text in UDHR Article 26, concerning education, should also apply with respect to science."[22] He bases his argument on the fact that "the only reference to science in the International Covenant on Civil and Political Rights (ICCPR) occurs in the provision concerning torture, ICCPR Article 7: 'In particular, no one shall be subjected without his free consent to medical or scientific experimentation.'" The adoption of Article 7 was driven by a wish never again to experience anything similar to "the abuse of scientific research conducted by Nazi doctors in extermination camps such as Auschwitz."[23]

The fiercest debates among the founders of the UDHR seem to have taken place with relation to the inclusion of the protection of the moral and material interests of authors and scholars in Article 27.[24] At the first session of the Commission on Human Rights of the United Nations in New York City in early 1947, the Chilean delegation presented a text that attempted to balance the duty of the state to encourage the development of culture and science with its duty to "see to it that laws for the protection of trademarks, patents, and copyrights are not used to the establishment of monopolies which might prevent all persons from sharing in the benefits of science."[25] This wording was removed from the final version of UDHR Article 27—another missed opportunity to address from the very beginning an issue that has since given rise to considerable discussion worldwide.

It is in the area of intellectual property (IP) that some of the most intense cultural and scientific fights are currently going on. Initiatives such as open access (OA), access to knowledge (A2K), and open source software (OOS) all

20. Schabas, *supra* note 6.
21. *Id.* at 511.
22. *Id.* at 516.
23. *Id.*
24. Morsink, *supra* note 16.
25. Schabas, *supra* note 6, at 507.

share the wish to fight what they see as powerful forces favoring increased IP rights and corporate control over knowledge. With both patents and copyright, (a lot of) money is at stake, moreover. Heavily patented pharmaceutical products are very expensive and therefore out of reach for many people in developing countries. Also, in their search for new bioresources, researchers and pharmaceutical companies sometimes draw on local peoples' traditional knowledge about the properties of a particular plant, animal or chemical compound. Sometimes, they use such traditional knowledge without permission, or they exploit the cultures it comes from for commercial gain. This is referred to as biopiracy.[26] Over the past few years, in an attempt to prevent such biopiracy, some indigenous peoples and other minorities have begun to invoke IP rights in their fight for the distinctive rights to their traditional knowledge and intangible cultural heritage.

Several factors were at play for the founders of the UDHR. These include the contemporary revision of the *Berne Convention for the Protection of Literary and Artistic Works* (first accepted in 1886 and usually known as the *Berne Convention*) which made the concept of authors' moral rights part of international law. The French delegation thought that UDHR Article 17 on property rights did not adequately protect moral rights relating to the integrity of the author and his/her creation and therefore proposed that language on the protection of authors' moral and material interests be included in the UDHR. A number of Latin American delegations supported the French proposal due, at least in part, to the fact that a provision of authors' rights was included in the contemporary drafting of the *American Declaration of the Rights and Duties of Man*. Both the US and the UK delegations were opposed, arguing that copyright and related rights are not fundamental human rights.[27]

During the drafting of ICESCR Article 15 in the 1950s, which repeated more or less verbatim the wording of UDHR Article 27, the question of the protection of authors' rights again came up. As was the case during the debate on Article 27 in the UDHR, there was no major disagreement on the provision on enjoying the benefits of scientific progress. With regard to the authors' rights provision, however, the cold war context was noticeable. Views on private property and the role of government in culture, art and science differed widely, and the right to the protection of moral and material interests of authors was only adopted at the last minute. It was strongly opposed by socialist countries who argued that this provision would be protecting an individual author's rights at the cost of the rights of the community. The political overtones of the debate were quite explicit, the subtext to the entire discussion being the issue of government control over science

26. *See* Porsdam, *supra* note 13, at 155–84, 213–32.
27. Morsink, *supra* note 16.

and art, and scientists and artists. The provision on authors' rights became associated with protection for authors' freedom from state intervention.[28]

Maria Green notes that "by raising both the right to 'benefit from the advances of science' and the right to 'material and moral interests' resulting from one's work to the level of human rights, the drafters set up a tension that must be resolved if [A]rticle 15 is to be made effective."[29] This tension especially has to do with the contrast between culture and science as public goods, and intellectual property (IP) as private property.[30] In the context of the RtS, patents are very important—especially when the rights to health and food or climate change are involved. A good deal of research is available on the right to health, but climate change and the right to food are also receiving more attention.[31] Patented medicine for illnesses suffered especially by people in developing countries such as HIV/AIDS or malaria is often prohibitively expensive.[32] A human rights perspective changes the focus of analysis. It reframes legal discourses in such a way that they no longer automatically protect IP over individual rights and social values. It also provides mechanisms to hold governments accountable that do not provide minimal levels of health care, just as it "emphasizes the need to restructure incentives for medical research and innovation toward the treatment of neglected diseases and the health needs of the world's poor."[33]

III. WHAT IS THE RIGHT TO SCIENCE?

In addition to the UDHR and the ICESCR, the RtS is referred to in a number of other international instruments. The implication is that, just as governments are expected to adopt measures to respect the rights to, say, freedom of speech and due process, so they must also uphold the right to the benefits

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28. Maria Green, *Drafting History of the Article 15(1)(c) of the International Covenant on Economic, Social and Cultural Rights*, U.N. Doc. E/C.12/2000/15 (2000), http://www.unhchr.ch/tbs/doc.nsf/0/872a8f7775c9823cc1256999005c3088/$FILE/G0044899.pdf.
29. *Id.* at 13–14.
30. Lea Shaver & Caterina Sganga, *The Right to Take Part in Cultural Life: Copyright and Human Rights*, *Faculty Scholarship Series* 23 (2009), http://digitalcommons.law.yale.edu/fss_papers/23.
31. Yvonne Donders, *Exploring the Cultural Dimensions of the Right to the Highest Attainable Standard of Health*, 18 Potchefstroom Electronic L. J. /Potchefstroomse Elektroniese Regsblad (PELJ/PER) 180 (2015), http://www.saflii.org/za/journals/PER/2015/16.pdf.
32. Lawrence R. Helfer & Graeme W. Austin, Human Rights and Intellectual Property: Mapping the Global Interface (2011) In *id.* at 90–170, Helfer and Austin talk about the "global drug gap":

    > a phrase coined to emphasize the fact that most new drugs remain beyond the financial reach of most of the world's population, and that private research and development largely ignore the many diseases (such as tuberculosis, malaria, and Dengue fever) prevalent in poor developing countries.

    Id. at 92.
33. *Id.* at 144.

of scientific progress. To date, however, as the American Association of 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."[34]

A. Interpreting the Right to Science

What does the right to enjoy the benefits of the progress of science and its applications entail? Guidelines on the legal interpretation of treaty provisions can be found in the Vienna Convention on the Law of Treaties. According to Articles 31 and 32 of this treaty, provisions of international treaties should be interpreted according to the ordinary meaning of the wording of the provisions, in their context and in light of their object and purpose. Context, object, and purpose can be determined on the basis of subsequent international legal instruments, state practice, as well as the work of international bodies supervising the treaties. Supplementary means of interpretation include the preparatory work and drafting history of the treaty. However, it is broadly recognized that human rights treaties are dynamic instruments that should be interpreted in present day conditions. This allows the human rights treaties to be adapted to current times through interpretation without having to modify the text.

The most authoritative source of guidance stems from UN treaty bodies such as the Human Rights Committee and the Committee on Economic, Social and Cultural Rights (CESCR) in the form of so-called 'General Comments.' Various General Comments have pointed out the importance of the RtS, for example, for "older individuals (General Comment 6), vocational education (General Comment 13), equal access of men and women to scientific participation (General Comment 16), and protection of moral and material interests arising from scientific production (General Comment 17)."[35] A Draft General Comment on Science was published by the CESCR in January 2020 and is currently being discussed.[36]

While the UDHR was originally a non-binding statement, most of its provisions are currently recognized as international customary law which is binding upon all states. The ICESCR, on the other hand, is a treaty that is only legally binding upon states if they have ratified it. At present, 170

34. *Right to Science*, American Association for the Advancement of Science (n.d.), https://www.aaas.org/article15.
35. Brian Gran, Margaret Waltz & Holly Renzhofer, *A Child's Right to Enjoy Benefits of Scientific Progress and its Applications*, 21 Int'l J. Children's Rts 323, 328 (2013), http://booksandjournals.brillonline.com/content/journals/10.1163/15718182–02102002.
36. *Supra* note 12.

states from all regions of the world are parties to the ICESCR, one notable exception being the United States. By ratifying a human rights treaty, states assume the legal obligation to implement the rights recognized in that treaty in their domestic legal order through legislation and other measures. The creation of human rights treaties also implies that human rights no longer merely belong to the domestic spheres of states, but may be subjected to international supervision and accountability.[37]

The RtS largely depends on cultural, economic, social, and political development. According to ICESCR Articles 2 and 3, state parties must ensure protections of all rights under the ICESCR equally and without discrimination, just as they must take "deliberate, concrete and targeted" steps toward the full realization of these rights. This principle of progressive realization is one that distinguishes the ICESCR from the other major Covenant, the ICCPR. Article 2(1) of the ICCPR provides that each state party undertake to respect and ensure the rights recognized in ICCPR, whereas Article 2 of the ICESCR provides that the state party will take steps to use its maximum available resources gradually to realize the rights of the Covenant. The two Articles of these Covenants thus impose different types of obligations, those under ICESCR being more conduct-oriented and contextual in nature. This has, in the past, made many argue that the ICESCR is of lesser importance than the ICCPR.

In General Comment No. 3 from 1990, the CESCR has given an interpretation of the meaning of progressive realization.[38] This concept was included in the ICESCR to acknowledge the fact that states parties are in different economic, social, and political positions. Limited resources are also relevant to the implementation of the RtS since science and technology may be costly. Moreover, in terms of priorities, states may argue that science is not on the top of their list of human needs, but they are still legally obliged to invest, to the maximum possible, in scientific and technological advancement and the sharing of benefits. Furthermore, states parties should start the implementation immediately and should move as expeditiously and effectively as possible towards total realization.[39]

Progressive realization and moving as speedily as possible toward full realization imply that, in principle, the level of protection should not decrease after a certain level has been reached. So-called retrogressive measures are allowed only in exceptional cases. Like most other human rights in international law, the RtS is not absolute. Under certain circumstances,

37. Christian Tomuschat, *Human Rights: Between Idealism and Realism* 1–3 (3d ed. 2014); Sir Nigel Rodley, *International Human Rights Law, in* International Law 783, 785–86, 820 (Malcolm D. Evans ed., 2003).
38. CESCR General Comment No. 3: The Nature of States Parties' Obligations (art. 2, ¶ 1, of the Covenant), U.N. Doc. E/1991/23 (14 Dec. 1990), http://www.refworld.org/docid/4538838e10.html.
39. ICESCR, *supra* note 3, ¶ ¶ 1, 2.

states may limit the enjoyment of human rights. Most human rights treaties contain limitations clauses, sometimes as general clauses and sometimes as sub-paragraphs of particular provisions. Limitation clauses reflect the idea that sometimes the enjoyment of rights needs to be restricted for the common good or to protect the rights of others.

The ICESCR contains a general limitations clause in Article 4. Limitations of the rights in the ICESCR should be "determined by law and only in so far as this may be compatible with the nature of these rights and solely for the purpose of promoting the general welfare in a democratic society." Accordingly, states have to adopt national laws that incorporate the scope of the limitation. There should further be a legitimate aim, for example the protection of public order or security, or the protection of the rights and freedoms of others, and the limitation should be proportionate and appropriate to serve this aim. With respect to the RtS, states may adopt specific measures to limit the conduct of science or the dissemination of scientific results in order to prevent harm or disrespect for other human rights.[40]

Core obligations of the RtS could include: respect for the freedoms indispensable for scientific research; promotion of access to the benefits of science and its applications on a non-discriminatory basis; prevention of harmful effects of science and technology; and strengthen international cooperation, including respect for collaboration of scientists across borders.[41]

B. Underlying Values: Dignity, Universality, Access, and Participation

The preambles of the International Bill of Human Rights state that the rights in these instruments "derive from the inherent dignity of the human person."[42] In addition to dignity, equality, and non-discrimination, there are also crosscutting principles of international human rights law. Human rights should be respected and ensured to all individuals "without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion, national or social origin, property, birth or other status."[43] Human dignity and the equal value or worth of humans form the basis, that is, for the recognition of equal rights. When it comes to the global norms governing biomedical issues and to the international policy documents of the last twenty years relating to bioethics, moreover, the concept of human dignity seems to play an increasingly prominent role.[44]

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40. Yvonne Donders, *Balancing Interests: Limitations to the Right to Enjoy the Benefits of Scientific Progress and Its Applications*, 4 Eur. J. Hum. Rts. 486, 492 (2015).
41. Yvonne Donders, *The Right to Enjoy the Benefits of Scientific Progress: in Search of State Obligations in Relation to Health*, 14 Med. Health Care & Phil. 371, 373 (2011).
42. UDHR, *supra* note 2.
43. ICCPR, *supra* note 5, art. 1.
44. Roberto Andorno, *Human Dignity and Human Rights, in* Handbook of Global Bioethics 45, 45–46 (Henk A.M.J. ten Have & Bert Gordijn eds., 2014).

The emphasis in international human rights instruments on dignity, equality, and non-discrimination means that the subject or rights holder of the RtS is "everyone," that is, literally every human. Most human rights instruments contain individual rights, but collective dimensions of human rights are also recognized. This is especially true for cultural rights.[45] The term "everyone," moreover, encompasses both those participating in science and generating new technologies and those who are the end users: beneficiaries, communities, and ordinary citizens, but also individuals who rely on the results of scientific endeavors, including those who may be negatively impacted by the conduct of science.

Groups relevant to collective rights in this context include indigenous peoples, cultural, linguistic, and ethnic minorities, people with physical and intellectual disabilities, people with mental health issues, women, children, and those living in poverty. While there are some overarching principles that should govern recognition of the needs of sub-groups of end users, there are also differences in their concerns and needs. In order to ensure that the conduct of science recognizes the specific human rights and well-being of these groups, involvement of end users in the scientific project is paramount. It is also important to understand the critical and life-altering role that science plays for end users including the ability to live independently, to hold a job, to participate in cultural life, and to thrive into adulthood.

In order that everyone, individually and/or collectively, may participate in the advancement and share in the benefits of human knowledge recognized and protected by the RtS, the notion of access is crucial: "The right to enjoy the benefits of scientific progress is related to how the direct and indirect results of science are made available to everyone. [. . .] This right naturally applies to everyone, and there is no requirement that one has actually contributed to this progress."[46] Notions of citizen science or crowd-sourced science are interesting in this context. Whereas the framers of the UDHR did not necessarily perceive active participation in science as something that could be expected from everyone, as we saw, an increasing number of people today wish to contribute directly to scientific research. In her report on the RtS, Shaheed accordingly notes that the rights to science and culture should be read "together and in conjunction with, in particular, the right of all peoples to self-determination and the right of everyone to take part in the conduct of public affairs."[47] For Shaheed, the normative content of the right to benefit from scientific progress and its applications directly concerns access and the opportunity for all to participate in decision-making.[48]

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45. General Comment No. 21, *Right of Everyone to Take Part in Cultural Life* (art. 15, ¶ 1 (a), of the International Covenant on Economic, Social and Cultural Rights), U.N. Doc. E/C.12/GC/21 (2009), https://www.refworld.org/docid/4ed35bae2.html.
46. Haugen, *supra* note 19, at 232.
47. *Report on Right to Science*, *supra* note 13, ¶ 7.
48. Helle Porsdam & Matthias Mann, *The Right to Enjoy the Benefits of Scientific Progress and its Applications, in* Nego tiating Cultural Rights: Issues at Stake, Challenges and Recommendations 79 (Lucky Belder & Helle Porsdam eds., 2017).

The diffusion of science is a precondition for public participation in decision-making. Today, this primarily involves the digital media—making public digital versions of new research by means, for example, of open-access journals and repositories and mandatory open-access policies that enable publicly funded research to be shared across the world. Ensuring access to information to communication technologies and the internet is therefore a crucial obligation for states. Significant digital divides exist today; not everyone around the world can afford (quality) access to the internet, and when it comes to the use of digital media, gender and age still seem to be a major factor. Furthermore, intellectual property constitutes a barrier to digital access.[49]

From a human rights perspective, participation must ensure input into decision-making and public consultations on scientific advances and their implications. All persons, not least marginalized populations such as indigenous peoples, must be protected from "the negative consequences of scientific testing or applications on, in particular, their food security, health or environment."[50] Scientific research cannot be completely free, but must be conducted in a socially and ethically responsible manner.[51] Ensuring the participation of individuals and communities in decision-making is important, furthermore, for the promotion of appropriate research that can address vital societal needs, e.g. in the areas of public health and the environment.[52] "Major decisions regarding funding and research priorities, science policies, emerging areas of research, and new technological applications should entail a participatory process," writes Shaheed, referring by example to the ways in which some states have initiated consensus conferences, dialogues, and other consultative mechanisms with the participation of the general public.[53]

IV. WHAT ARE SOME OF THE CONTENTIOUS ISSUES?

Though long a neglected right (along with other cultural rights), the RtS is currently "[having] its dust blown off."[54] Directly or indirectly, this right is involved in a number of controversies. In order to ascertain which topics are currently considered the most relevant and/or contentious, we conducted a systematic review of the extant literature on the RtS.[55] This information has not previously been synthesized. This method, frequently employed in

49. *Id.*
50. *Report on Right to Science, supra* note 13, ¶ 43.
51. *Id.* ¶ 52.
52. *Id.* ¶ 33.
53. *Id.* ¶ 43.
54. Donders, *The Right to Enjoy the Benefits of Scientific Progress, supra* note 41.
55. We thank Pascal Braak for his extensive help in conducting the literature search and Max Schmid for his extensive help in editing the manuscript.

medical research, uses a comprehensively described and reproducible search strategy to identify all studies relevant to a particular area of research. Potentially relevant studies are screened according to pre-determined criteria. In our case, reports published in English, referring to the RtS as instantiated in UDHR Article 27 or ICESCR Article 15, and not referred to more fully elsewhere, were included (see below).

A. Methods and Results

> *"Breaking down the right to science into separate, but interlinked, components is a helpful step towards a more systematic discussion of its content"* (Elisa Morgera).[56]

The methodology for the systematic review has been published online and is available on: https://www.pnas.org/content/115/43/10820/tab-figures-data under the heading "Supporting Information." In preparation for this article, we conducted an update of the 2018 systematic review using the same search protocol.[57] This yielded eighteen studies in addition to the fifty-two we identified in our previous review.

In total, seventy studies met our inclusion criteria. We identified fifteen themes in the included studies (please see supporting material). Many of these were umbrella categories subsuming several further themes. For example, the category 'equality and non-discrimination' included issues relating to gender, poverty, international relations, children, persons suffering from disabilities, race, and sexuality.

B. Access

> *"Meaningful access may consist of something quite different depending on the social role of the person seeking access, be that scientist, student, educator, patient, subject of a clinical trial, a person with a disability, farmer, policymaker, or some other type of rights holder"* (AAAS Science and Human Rights Coalition).[58]

Access was, together with the need for balancing with other rights, the only theme universally (96 percent) touched upon in the included studies. This is no wonder, access being, as we saw, among the fundamental, crosscutting principles of international human rights law.

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56. Elisa Morgera, *Fair and Equitable Benefit-Sharing at the Cross-Roads of the Human Right to Science and International Biodiversity Law*, 4 Laws 803 (2015), http://www.mdpi.com/2075–471X/4/4/803.
57. Systematic Review, https://www.pnas.org/content/115/43/10820/tab-figures-data. We would like to thank Bo Søgaard Jensen for his extensive help in conducting the updated systematic review.
58. *Defining the Right to Enjoy the Benefits of Scientific Progress and its Applications: American Scientists' Perspectives*, AAAS Science and Human Rights Coalition (2013), https://www.aaas.org/sites/default/files/content_files/UNReportAAAS.pdf.

As rightly pointed out in qualitative work conducted by the American Association of the Advancement of Science (AAAS), different types of access are relevant in various contexts relating to the RtS.[59] For example, access to scientific information is essential for researchers, yet access to innovations like information communication technologies (ICT) may be of greater importance for people living in low- and middle-income countries (LMIC).[60] Based on analyses of focus groups conducted with 145 American scientists from various disciplines, the AAAS working group identified five types of access. They depicted these on a continuum stretching from the interests of the general public to those of scientists.[61]

Issues of access have been explored in the related human rights contexts of health, education, and protection of moral and material interests resulting from scientific, literary of artistic production of which one is the author.[62] These rights have been analyzed through the so-called 4A-scheme. For example, to fulfill its educational human rights obligations, a state must ensure that education is *available* in sufficient quantities, *accessible* economically and physically, without discrimination, of *acceptable* quality and relevance, and sufficiently *adaptable* to respond to changing needs of students.[63] The General Comment on the right to health follows the same scheme, though it emphasizes *quality* in place of *adaptability*; whereas the General Comment on protection of moral and material interests of authors focuses on the availability and accessibility of the legislative, procedural and policy infrastructure necessary for such protection.[64]

Similarly, scientific information, education, literature, and applications should be made available in sufficient quantities, be accessible without discrimination both economically and physically, and be of acceptable quality. In addition, the policy, legislative, and educational infrastructure supporting the development, conservation, and diffusion of science should be accessible by and available to all without discrimination and be of sufficient quality to support scientific activity. Given scarcity of resources and competing goals, priority should go to the infrastructure, information, and applications necessary for the realization of human rights generally.

Shaheed, then the UN Special Rapporteur for Cultural Rights, noted that access to innovations "essential for a life with dignity" is of great priority.[65] Similarly, access to technologies necessary to realize other fundamental

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59. *Id.*
60. *Report on Right to Science*, *supra* note 13.
61. AAAS Science and Human Rights Coalition, *supra* note 58.
62. Donders, *The Right to Enjoy the Benefits of Scientific Progress*, *supra* note 41.
63. General Comment No. 13, *The Right to Education*, U.N. ESCOR, Comm. on Econ., Soc. & Cult. Rts., 21st Sess., U.N. Doc. E/C.12/1999/10 (1999).
64. Donders, *The Right to Enjoy the Benefits of Scientific Progress*, *supra* note 41.
65. *Report on Right to Science*, *supra* note 13, ¶ 29; AAAS Science and Human Rights Coalition, *supra* note 58.

human rights principles, such as equality and freedom, are likewise of high priority.[66] Examples of these in the included studies are electricity, essential medicines, ICT, sanitation, water purification, and vaccines.[67]

For the same reason, facilitating access to scientific information relevant to these principles is of great importance. Information concerning the equality of genders and races, the causes, incidences and treatments of illness and disabilities, and the natural variation in sexual preferences all fit in this category.[68] Facilitating access to educational information and materials more broadly furthermore assumes urgency when considered under a human rights-based approach.

C. Intellectual Property Protection

> "[*The* RtS*] may create tensions with the intellectual property regime, which is a temporary monopoly with a valuable social function that should be managed in accordance with a common responsibility to prevent the unacceptable prioritization of profit for some over benefit for all"* (Venice statement).
>
> *"He who receives an idea from me, receives instruction himself without lessening mine; as he who lights his taper at mine, receives light without darkening me"* (Thomas Jefferson, quoted in Stiglitz 1999).[69]

ICESCR Article 15(1)(c) and UDHR Article 27(2) recognize the right of everyone "to benefit from the protection of the moral and material interests resulting" from scientific production of which he or she is the author. The moral and material interest referred to should be understood as 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 a way prejudicial to one's reputation or interests. Both scholarly sources and official documents took pains to emphasize that IP protection as currently instantiated is not a human right.[70] As we saw above, this is an issue that was much debated by the founders of both the UDHR and the ICESCR.

The tension between IP protection and access to technology and information was noted by all save sixteen of the included studies. As described

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66. Aurora Plomer, Patents, Human Rights and Access to Science (2015).
67. *Report on Right to Science*, *supra* note 13, ¶ 29; Plomer, *supra* note 66; Lea Shaver, *The Right to Science and Culture*, 1 Wisc. L. Rev. 121 (2010), https://ssrn.com/abstract=1354788.
68. Maya Sabatello, *Advancing Transgender Family Rights Through Science: A Proposal for an Alternative Framework*, 33 Hum. Rts. Q. 43 (2011).
69. Thomas Jefferson, *quoted in* Joseph. E. Stiglitz, *Knowledge as a Global Public Good, in* Global Public Goods: International Cooperation in the 21st Century 308 (Inge Kaul, Isabelle Grunberg & Marc A. Stern eds., 1999), http://s1.downloadmienphi.net/file/downloadfile6/151/1384343.pdf#page=346.
70. Shaver, *supra* note 67; *Report on Right to Science*, *supra* note 13.

by Jefferson and later Stiglitz, knowledge is non-rivalrous—the use of knowledge by one individual does not detract from that of another.[71] Once disseminated, it is also hard to exclude others from making use of knowledge. These features—non-rivalry and non-excludability—are the hallmarks of public goods. Twenty-four of the included studies explicitly referred to the public good aspect of knowledge.

The non-excludability of knowledge is a hurdle for those seeking to gain from knowledge production or dissemination, as others can copy knowledge products without remuneration or acknowledgement. IP protection, especially copyright and patent systems, reduce the likelihood of this happening by making knowledge more excludable. As a result, it becomes more difficult to access knowledge when protected by IP legislation. Where such knowledge is necessary to respect, protect, or fulfill human rights obligations, a balance must be struck between the interests of authors, inventors, and the rest of humanity. Examples mentioned in surveyed studies included educational material, medical and public health technologies and substances, ICT, electricity, books and journal articles, genes and other biological material, seeds and agricultural technology, nanotechnology, and technology enabling development.[72]

Sources also called into question the efficacy of IP protection in incentivizing innovation.[73] Only one paper argued that current levels of IP protections are adequately balanced and fulfill their incentivizing purpose.[74] Notably, this paper referred to only four others, none of which provided evidence sufficient to support this position.

Several papers noted that levels of IP protection have been rising 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.[75] 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 forty-three studies. In addition, the participatory aspect of RtS is threatened when the needs and interests of the less wealthy are not included when research priorities are set.

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71. Stiglitz, *supra* note 69.
72. Thomas A. Faunce, *Global Artificial Photosynthesis: Challenges for Bioethics and the Human Right to Enjoy the Benefit of Scientific Progress* (2013), https://papers.ssrn.com/sol3/papers.cfm?abstract_id=2235984.; Plomer, *supra* note 66; Olivier De Schutter, *The Right of Everyone to Enjoy the Benefits of Scientific Progress and the Right to Food: From Conflict to Complementarity*, 33 Hum. Rts. Q. 304 (2011).
73. *Report on Right to Science*, *supra* note 13; Shaver, *supra* note 67.
74. Jens Bammel, *The Impact of Copyright on the Enjoyment of Right to Science and Culture*, 30 Publishing Res. Q. 335 (2014), doi: 10.1007/s12109–014–9382–3.
75. Shaver, *supra* note 67.

D. Participation

> *"[Everyone] has the right to be heard and to shape the decisions that affect their lives and communities"* (United Nations).[76]

Participation is a key element of the RtS and was touched upon by forty-five included studies. States have an immediate legal obligation to ensure that citizens can enter the scientific profession without discrimination, as already noted. In addition, participation by non-scientists is crucial to ensure that the needs and viewpoints of all, and especially the most vulnerable, members of society are included in discussions concerning scientific advances that affect their lives.[77]

The human rights principles of inclusion and equality require states to take special consideration of the factors that prevent members of disadvantaged groups from participating in science. Gender and racial disparities in scientific professions are of special concern. States should provide the infrastructure and resources necessary for marginalized citizens to develop the capabilities required to participate in science. States should also ensure that the benefits of science can be accessed by disadvantaged members and groups of society.[78] Fifty-one of the surveyed studies stressed the fundamental importance of equality and non-discrimination.

There are large disparities between states in their abilities to provide the necessary resources and infrastructure for scientific participation. Therefore, international cooperation between states is critical for implementation of the RtS, a fact picked up on by forty-five studies. Article 15(4) ICESCR recognizes "the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields."[79] Without cooperation, the benefits of science will be one-sided.[80]

Noting this point in relation to IP protection, the Government of Pakistan told the United Nations Commission on Human Rights in 2001 that "it is painfully evident that [at least in the] short and medium term, the costs being borne by the developing countries are higher than the gains, and that the balance between the rights holder (mostly from the developed countries) and the user of intellectual property has shifted dramatically in favour of the former."[81] The right of citizens to engage in science should not be unduly

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76. *On Human Rights Day, UN Officials Highlight how Every Voice Counts*, UN News (2012), http://www.un.org/apps/news/story.asp?NewsID=43722#.WYRddsaZOqB.
77. *Report on Right to Science*, *supra* note 13.
78. Amrei Müller, *Remarks on the Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications (Article 15(1)(b) ICESCR)*, 10 Hum. Rts. L. Rev. 765 (2010).
79. *International Covenant on Economic, Social and Cultural Rights (art. 15(4))*, *adopted* 16 Dec. 1966.
80. Plomer, *supra* note 66.
81. *Id.*

burdened by IP protection.[82] Participation in science by citizens domestically and internationally is not possible where access to necessary resources and infrastructure is prohibitively expensive or unavailable.[83] In addition, scientific participation can increase critical thinking skills by promoting the use of the scientific method, which helps empower citizens to realize other rights and the rights of others.[84]

As the Special Rapporteur's report noted, public participation is necessary to help determine what should count as "scientific progress" and "benefits."[85] The institutional, legal, and policy framework implemented by states to meet their RtS obligations should be regularly reviewed in a transparent and participatory manner.[86] In addition, an important aspect of the RtS "relates to the opportunities given to individuals and peoples to make informed decisions after considering both the possible improvements offered by scientific advances and their potential side effects or dangerous usages."[87]

E. Dual Use

> *"The concern is to avoid harm resulting from the use of scientific and technical progress that adversely affects the enjoyment of human rights, irrespective of whether private actors or States are involved"* (Hans Morten Haugen).[88]

The RtS can be subject to limitations, notably to protect from potentially harmful effects resulting from misuse of science and technology, as outlined above.[89] The possibility of limiting the RtS reflects the dual nature of some technologies and discoveries. Nuclear energy, for example, can be used as a source of energy, but also as an instrument of warfare or oppression. More recent technologies such as CRISPR/Cas-9 gene editing can likewise be used in ways respectful of or contrary to human rights principles. The potential for dual use of science and technology was touched upon by thirty-five of the surveyed studies.

Scientific and academic freedom, including the related freedoms of expression, information and association, was mentioned by forty-four studies. The freedom of scientists to conduct and disseminate research and to associate with other scientists can only legitimately be limited under the conditions mentioned above. That science is concerned foremost with the

82. Effy Vayena & John Tasioulas, *"We the Scientists": A Human Right to Citizen Science*, 28 Phil. & Tech. 479 (2015), http://link.springer.com/article/10.1007/s13347–015–0204–0.
83. *Id.*
84. AAAS Science and Human Rights Coalition, *supra* note 58.
85. *Report on Right to Science*, *supra* note 13, ¶ 22.
86. Müller, *supra* note 78.
87. *Report on Right to Science*, *supra* note 13, ¶ 22.
88. Haugen, *supra* note 19, at 233.
89. *Report on Right to Science*, *supra* note 13, ¶ 50.

advancement of knowledge in general, and not necessarily with practically useful knowledge, is recognized in official sources.[90] Nevertheless, there is no doubt that scientific priorities informed by both scientific and human rights interests will differ from those derived from purely commercial interests.[91]

States have an obligation to ensure that advances and technologies with dual use potential are not used to violate human rights. Similarly, they must ensure that the process and conduct of science proceeds in a manner consistent with the human rights of subjects. For example, persons have a right to be informed about research conducted on their genetic information, and human subject research should not be conducted without the informed consent of participants.[92] If such consent is not possible to obtain, for example in the case of minors, the incapacitated, and some types of records-based research, the research should be carried out only for the health benefits of the subjects or others (and not for commercial purposes).[93] In addition, scientists themselves have special responsibilities of intellectual integrity, meticulousness, and caution.[94]

F. Balancing Rights

> *"In conformity with the principles of universality, indivisibility, interdependence and interrelatedness, this right is relevant to the realization of other civil, cultural, economic, political and social rights"* (Venice statement).

A common theme (96 percent) of included studies is the need to recognize that the RtS is inextricably linked to other rights. Studies highlighted connections between the RtS and the rights to food, health, education, development, a clean environment, social security, water, information, and labor rights, amongst others.[95] It was recognized that science has both intrinsic and instrumental value.[96] The instrumental value of science includes its usefulness in promoting other human rights as well as its potential to inform and empower citizens, as noted above.[97] Noticing the interconnections between the RtS and other rights is of utmost importance for attempts to balance the interests of various right holders, especially in the cases of IP protection and international cooperation.[98]

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90. Müller, *supra* note 78.
91. *Id.*
92. Donders, *The Right to Enjoy the Benefits of Scientific Progress*, *supra* note 41.
93. *Id.*
94. *Id.*
95. *Id.*; Gran et al., *supra* note 35.
96. Shaver, *supra* note 67.
97. AAAS Science and Human Rights Coalition, *supra* note 58.
98. Donders, *Balancing Interests*, *supra* note 40.

Finally, many of the studies surveyed stressed the importance of balancing such conflicting interests in accordance with human rights principles, especially equality, freedom, participation, and an emphasis on the needs of the most disadvantaged. These principles provide a set of criteria that ought to be used in discussions relating to funding, dissemination, inclusion, cooperation, goals, and priority-setting in science.

G. What's Missing?

> *"[Commentators have not considered], however, whether states bear a responsibility to accept or adopt the results of scientific inquiry"* (AAAS Science and Human Rights Coalition).

We noticed that a number of important topics falling within the remit of the RtS were absent or inadequately addressed in the extant literature. These topics, briefly outlined here, are fruitful areas for further investigation. The RtS seems to include the right of citizens to benefit from the application of scientific progress in policy-making. Many policies affecting the human rights and interests of citizens are not based on scientific evidence. Some have never been tested empirically. For example, in the European Union and developed countries generally, "the number of large-scale evaluations of education projects remains limited, and the vast majority of empirical evidence available in education today derives from non-experimental evaluations."[99] Similarly, there is sometimes a lack of evidence on the impact of policies on health care, public health, development, housing, and many other areas important for human rights. In addition, the evidence that is available is often not used in policy-making. An interesting question for future research is the extent to which such negligence is a violation of the RtS.

The potential of citizen participation in scientific endeavors, though mentioned by many, was the explicit focus of only one included paper.[100] Increased participation in science by citizens provides several opportunities for the advancement of science. Potentially enormous amounts of subjects, data, and funds can be crowdsourced by citizen-scientists. To leverage this potential, however, citizens, scientists, and states need to explore appropriate frameworks for citizen science which enable and make best use of these benefits while also protecting the rights and interests of participants. In addition, the roles, responsibilities, and human rights obligations of non-state actors in general have received insufficient attention.

Control over scientific progress is increasingly vested in corporations and private actors, whose interests are often driven by commercial concerns.

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99. Adrien Bouguen & Marc Gurgand, *Randomized Controlled Experiments in Education* 24 (2012), http://www.eenee.de/dms/EENEE/Analytical_Reports/EENEE_AR11.pdf.
100. Vayena & Tasioulas, *supra* note 82.

Since their actions affect the rights and well-being of others, it is important that their duties and roles in relation to the RtS be clarified.

Such a process of clarification is also necessary in relation to the duties and responsibilities of state and international actors. The focus of surveyed studies was almost exclusively on rights rather than correlative duties, although the importance of correlative duties was noted in the majority (fifty-seven of seventy) of studies. In the absence of clarity on this point, we risk multiplying rights without sufficient regard for who is meant to bring about their protection and fulfillment and how they are meant to do so. The lack of legal implementation is likely to lead to disappointment and detract from the respect necessary to take the RtS seriously.

IP protection of traditional knowledge was scarcely addressed (twenty-three of seventy) in the extant literature. This is an important but difficult topic, to a clarification of which a RtS perspective may well contribute. Similarly, the capabilities approach as developed by Sen and Nussbaum was referred to in a handful of studies only. The development of the capabilities necessary to enjoy a life with dignity can be greatly aided, as we saw above, by making science and technology available to everyone. The 'fit' between the current international system for IP protection and the protection of traditional knowledge systems is an uneasy one, to put it mildly.[101] The former has developed in line with the needs of technologically advanced societies in the West. Traditional knowledge, on the other hand, is a living body of knowledge that is often informal and oral and is developed and passed on from generation to generation within a community, forming part of the cultural or spiritual identity of this community. Hard to define and communal in nature, it is not easily protected by the current intellectual property system, which typically grants protection for a limited period to inventions and original works by named individuals or companies.[102]

Finally, though the topic of dignity itself was mentioned in nearly half (thirty of seventy) of the included studies, 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 upon the types of innovations and actions that are compatible 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 especially frequently invoked in discussions of biomedical advances and associated bioethical issues, such as the use of stem cells in developmental biology and

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101. *See* Fons Coomans, *A Dual Perspective on the Right to Enjoy the Benefits of Scientific Progress, in* Critical Indigenous Rights Studies 89 (Giselle Corradi, Koen De Feyter, Ellen Desmet & Katrijn VanHees eds., 2019).

102. *Traditional Knowledge and Intellectual Property—Background Brief*, World Intellectual Property Organization (WIPO) (2019), http://www.wipo.int/pressroom/en/briefs/tk_ip.html.

potential therapies, germline editing of human embryos, and the development of novel lifeforms. These and other areas of scientific research risk being shut down wholesale as contrary to dignity if the concept is not clarified in relation to the RtS. In addition, some religious and cultural objections to aspects of science, though relevant in their own right, may be rhetorically framed as concerns for human dignity. This risks obscuring the fundamental and universal qualities of dignity as a human rights principle. As a consequence, the criteria for limitations based on human dignity should be thoroughly laid out in policy and be consistent with human rights principles.

V. CONCLUDING REMARKS

The RtS provides a human rights-based framework to examine contentious issues relating to the development of science and technology. By emphasizing the human rights principles of inclusion, participation, equality, and balancing of rights and respect for human rights norms, scientists and policymakers can advance science while ensuring that everyone benefits from its progress and its applications.

The wording of UDHR Article 27 and ICESCR Article 15(1)(b) reflects a positive view of both science and its applications. It identifies state obligations to make available not merely the latest scientific research, but also information as to how this research can be applied in practice.[103] With scientific and technological innovations such as the atomic bomb which changed human existence in ways that were previously inconceivable, however, the very notion of 'scientific progress' began to be seriously challenged. Indeed, even the understanding of science "as knowledge that is testable and refutable, including revisiting and refuting existing theorems and understandings" began to be questioned.[104]

While progress in science and technology can be abused and can lead to violations of human rights, scientific research can play a role in preserving human rights if directed toward solving problems that are relevant to human rights.[105] In his seminal *Science in the Service of Human Rights,* Claude showed how scientists have helped address problems relating to biomedical ethics and information technology.[106] Discussing the fight against bioterrorism in the US mail in 2001, social media—such as Twitter—as a tool in the Arab Spring uprisings, and high-resolution satellite images and spatial

103. Haugen, *supra* note 19, at 232.
104. *Report on Right to Science, supra* note 13, ¶ 18.
105. Jeffrey H. Toney, Hank Kaplowitz, Rongsun Pu, Feng Qi & George Chang, *Science and Human Rights: A Bridge Towards Benefiting Humanity,* 32 Hum. Rts. Q. 1008 (2010).
106. Richard Pierre Claude, Science in the Service of Human Rights (2002).

analysis providing evidence of mass atrocities and severe humanitarian crises, Toney and colleagues demonstrate how biologists, computer scientists, and geologists can use their respective disciplines to further human rights causes.[107] Likewise, a letter published in *Science* in 2017 asked young scientists how their scientific work can support human rights. Examples given in response 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 understanding the neural underpinnings of variations in empathic response to members of different races or ethnicities.[108]

We should also not forget that the link between science and culture can enable people to think of a better future for themselves, to hope for improvements in their socio-economic situations, but beyond that also for a life with self-realization, dignity, and meaningful participation in the community. Access to science and culture can be a major, transformative tool for realizing and making dreams come true.[109] In his 2006 article, "The Right to Research," social-cultural anthropologist Arjun Appadurai famously links the capacity to do research with the cultural capacity to 'aspire:' "Without aspiration, there is no pressure to know more. And without systematic tools for gaining relevant new knowledge, aspiration degenerates into fantasy or despair. Thus, asserting the relevance of the right to research, as a human right, is not a metaphor. It is an argument for how we might revive an old idea, namely, that taking part in democratic society requires one to be informed."[110]

In conclusion, a more fully worked out RtS would be of great relevance to several current debates and issues. By not properly meeting the conditions of limitation set out in ICESCR Article 4, decreases in public funding for science could be said to constitute a retrogressive measure and thus a violation of the duty of progressive realization. The same is true for restriction of scientists' freedom of movement if these are based on discriminatory grounds such as ethnicity or nationality. Political claims denying climate change or policies on controlled substances that manifestly deny available scientific evidence may furthermore be said to violate citizens' RtS. Similarly, the failure to implement social programs of demonstrated worth and cost-effectiveness and to test their counterparts in actual use arguably amounts to a violation of the RtS. And finally, the use of scientifically incorrect state-

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107. Toney et al., *supra* note 105.
108. Lauren Segal et al., *Promoting Human Rights Through Science*, 358 Science 34 (2017).
109. A good example is the Hole-in-the-Wall Education Project, http://www.hole-in-the-wall.com/.
110. Arjun Appadurai, *The Right to Research*, 4 Globalisation, Societies & Educ. 167 (2006).

ments by industry representatives in political lobbies, as witnessed in the controversies over climate change, vaccination, and the health effects of cigarettes, red meat, and dairy, also threaten citizens' RtS.

These debates and issues concern us all around the world. The RtS gives us a global ethical discourse with which to raise and negotiate conflicting interests and come to balanced solutions.