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Epilogue

Tensions in the Right to Science Then and Now

Christine Mitchell

Until now, a universal human right to science has not received the attention it should have. In the past, other rights may have seemed more fundamental, more urgent, easier to claim, and, perhaps, more straightforward to ensure. Yet a right to science is increasingly critical. Life, and planet earth itself, is threatened by climate change, global pandemics, exhaustion of mineral resources, mass extinction of species, human overpopulation, inequitable resource distribution, non-sustainable agriculture, and the possibilities of nuclear warfare, hostile artificial intelligence, and cosmic threats. Scientists of every sort are needed from astrophysicists to epidemiologists and sociologists to zoologists. Equally important: the understanding and participation of a wider, diverse public is essential if science is to effectively address these problems in line with shared social values.

A right to science has been included in modern visions of human rights, beginning at least from the compilation of rights in the American Declaration on the Rights and Duties of Man in 1945[1] and continuing most notably through the Universal Declaration of Human Rights (UDHR) and the International Covenant on Economic, Social, and Cultural Rights (ICESCR)[2] accepted across the globe and ratified by 171 nation states.[3]

Then, when rights were being enumerated in the 1940s, science made possible the saving of millions of lives with penicillin, as well as the mass killing of humans and all living beings with atomic bombs. These put "Science" in the United Nations Educational Scientific and Cultural Organization (UNESCO([4] and undoubtedly helped to keep a right to science among the declared human rights as many marveled at the miracles of science while also worrying about "what the scientists will do to us next."[5]

[1] Cesare P. R. Romano, Chapter 2 in this Volume, p. 33.
[2] www.ohchr.org/EN/professionalinterest/pages/cescr.aspx.
[3] https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-3&chapter=4&clang=_en.
[4] Mikel Mancisidor, Chapter 1 in this Volume, p. 17.
[5] "Miss Ellen Wilkinson included in her statement at the Conference for the Establishment of an International Agency (London, 6 November 1945) the following passage: 'Though Science was not

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Now, seventy-five years later, we live in a frightful time of deaths from a global pandemic, widespread public protests about shocking social inequities, and international migration to escape political aggression in so many countries. Attention must focus on a universal right to science if we are to preserve human dignity, enable human flourishing, and address world problems. This chapter will consider what counts as science and examine two of the tensions (by no means all) built into the right to science as articulated in the UDHR and ICESCR.

What constitutes science itself has been described by Christensen[6] and authors herein, but must be noted, at least in summary, in order to see the tensions inherent in the way a right to science is understood. For, science may be, at times, (1) universally objective while also being culturally relative, and (2) practiced primarily by scientists, yet also open to the public in a variety of ways.

Science is different from the arts in that the source of its knowledge typically exists with or without human observation or intervention. Music, paintings, and novels require artists. The evolution of species, the birth and death of stars, and DNA replication happen whether or not scientists study these phenomena. As ten-year-olds are taught, "the scientific method" is applied to an already existing world. There is therefore a tendency to think of scientists as researching rather than creating. Although many scientists study existing phenomena, nevertheless, most also create. They routinely create conditions for research and new knowledge, as with e-brains,[7] or create applications of scientific knowledge, as with rocket science, or create new phenomena, such as altered genomes, or algorithms for machine learning.

In earlier times, science was understood as a quest for truths about the knowable world, often cited in western histories as starting with Aristotle[8] and including both theoretical and practical investigations aimed at discovering universal laws that apply at all times everywhere. The word "scientist" did not come into being until

included in the original title of the Organization, the British delegation will put forward a proposal that it be included, so that the title would run "Educational, Scientific and Cultural Organization." In these days, when we are all wondering, perhaps apprehensively, what the scientists will do to us next, it is important that they should be linked closely with the humanities and should feel that they have a responsibility to mankind for the result of-their labours. I do not believe that any scientists will have survived the world catastrophe, who will still say that they are utterly uninterested in the social implications of their discoveries.' And as this was in fact a concern was that felt by all delegates, at the third meeting of the Conference, on 6 November, science was included in the name of what would henceforth be known as the United Nations Educational, Scientific and Cultural Organization, and the 'S' was added to the abbreviation, which became UNESCO."

Fernando Valderrana Martinez, A History of UNESCO, (1995) pp. 21–23; see also Cinzia Caporale and Ilja Richard Pavone, *International Biolaw and Shared Ethical Principles: The Universal Declaration on Bioethics and Human Rights* (New York: Routledge, 2018).

6 Ivan Lind Christensen, Chapter 4 in this Volume.

7 EBRAINS is a digital brain research infrastructure being developed by the Human Brain Project, publicly funded (in part) by the European Commission and based in Brussels, Belgium. https://ebrains.eu/.

8 Aristotle, *Physics*.

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the nineteenth century,[9] however, when William Whewell patronizingly chided Mary Somerville (1780–1872)[10] about her writing *On the Connexion of the Physical Sciences* which had become a bestselling popular science book[11] in 1846. Whewell argued that the sciences were inevitably disintegrating into specialties such as astronomy, geology, physics and the like, and he offered as evidence the absence of a general name for those who study the material world in all its facets. He proposed the deliberately absurd neologism "scientists," which began to catch on after his death as industrialists and educators sought to separate science from literature, humanities, and the arts. In the year of Somerville's death, *The Popular Science Monthly* was founded by Edward Youmans "to disseminate scientific knowledge to the educated layman."[12] As Henry Cowles recounts in his new book on the history of the scientific method,[13] Youmans and the authors who wrote for his magazine, championed the actual study of things using a methodology they reified – the scientific method – and this way of thinking permeated American culture in the twentieth century. Thus, scientists observe, hypothesize, predict, experiment, analyze, conclude, and report their findings about the natural world.

Science is no longer so simple, nor singular. Taking an expansive view, the Committee on Economic, Social and Cultural Rights describes "the sciences" as "a complex of knowledge, fact and hypothesis, in which the theoretical element is capable of being validated in the short or long term, and to that extent includes the sciences concerned with social facts and phenomena." As such, science encompasses both natural and social sciences, and refers both to a process following a rigorous methodology ("doing science") and to results of that process in the form of scientific knowledge and its applications.[14] Thus, scientific "knowledge should be considered as science only if it is based on critical inquiry and is open to falsifiability and testability. Knowledge which is based solely on tradition, revelation or authority, without the possible contrast with reason and experience, or which is immune to any falsifiability or intersubjective verification, cannot be considered science."[15]

What, then, is this thing that scientists do? According to UNESCO, in 2017,

> the word "science" signifies the enterprise whereby humankind, acting individually or in small or large groups, makes an organized attempt, by means of the objective

[9] Jessica Riskin, "Just Use Your Thinking Pump," *The New York Review of Books*, July 2, 2020, 48–50.

[10] Elisabeth Strickland, !Mary Fairfax Somerville, Queen of Science, Notices of the AMS," September 2017, 929–931 www.ams.org/publications/journals/notices/201708/rnoti-p929.pdf.

[11] Richard Holmes, "In Retrospect: On the Connexion of the Physical Sciences," *Nature*, October 22, 2014, (514), 432–433.

[12] www.gutenberg.org/wiki/Popular_Science_Monthly_(Bookshelf).

[13] Henry M. Cowles, *The Scientific Method: An Evolution of Thinking from Darwin to Dewey* (Cambridge, MA: Harvard University Press,2020).

[14] General Comment No. 25 on Article 15 of ICESCR (1), (b), (2), (3), (4), April 30, 2020 (Section II. 4.) http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=4slQ6QSmlBEDzFEovLCuW1a0Szab00XTdImnsJZZVQdxONLLLJiul8wRmVtR5Kxx73i0Uz0k13FeZiqChAWHKFuBqp%2B4RaxfUzqSAfyZYAR%2Fq7sqC7AHRa48PPRRALHB.

[15] General Comment No. 25.

> study of observed phenomena and its validation through sharing of findings and data and through peer review, to discover and master the chain of causalities, relations or interactions; brings together in a coordinated form subsystems of knowledge by means of systematic reflection and conceptualization; and thereby furnishes itself with the opportunity of using, to its own advantage, understanding of the processes and phenomena occurring in nature and society.[16]

These descriptions of science hint at the tension between science as the acquisition and application of a specific sort of universal human knowledge, and science as a human enterprise that has its own practices, beliefs, and, we might add, its own customs, culture, and specialty tribes.

CULTURAL SCIENCE

Contrasting a historical understanding of science "then" with a more contemporary view of science "now," illuminates the tension created by a basic view of science that is not only universal, but true, objective, factual, perhaps seen by some as infallible, and, hence, the best way of settling arguments about the way the world is. Indeed, some scientific findings about fluid dynamics, magnetism, the structure of atoms, genes, and other phenomena may be absolute and universal across cultures, time, and place. Nevertheless, it is also the case that other things once thought to be scientifically established are not absolute. Rather, they are refined (as with Linnaeus' hierarchical taxonomy of living things), revised (as when Mendelian inheritance patterns were supplemented by genomic and proteomic science), revoked (as in the transition from Ptolemaic to Copernican cosmology), or rejected based on subsequent science, as when the theory of spontaneous generation of life from inorganic matter was replaced by an understanding of biogenesis.

Even empirically "proven" scientific findings, as well as theoretical science, are subject to incomplete, limited, culturally influenced perspectives and paradigm shifts.[17] There is more than ample evidence now, that scientific knowledge is incremental and often more relative than absolute. Mistakes even in laws of science believed to be universal can arise from incomplete knowledge, as in the transition from the Newtonian law of gravity to Einstein's theory of general relativity. What may be claimed as scientifically established can also be wrong in other ways, through error,[18] misconduct (as Roberto

[16] UNESCO, Recommendation on Science and Scientific Researchers, November 13, 2017, I.1.(a) (i). http://portal.unesco.org/en/ev.php-URL_ID=49455&URL_DO=DO_TOPIC&URL_SECTION=201.html.

[17] Thomas Kuhn, **The Structure of Scientific Revolutions**, Chicago: University of Chicago Press 1962, pp. 54.

[18] Andrew W. Brown, Kathryn A. Kaiser, and David B. Allison, "Issues with Data and Analyses: Errors, Underlying Themes, and Potential Solutions," *PNAS*, March 13, 2018, 115 (11) 2563–2570.

Andorno[19] describes in this book), and fraud,[20] but also, *relative* to its time and surrounding culture.

Culture, as used here, is a word for the way of life of a group of people, that is, the way they see the world and themselves in it – their values, beliefs, behaviors, and symbols, deeply assumed and accepted with little thought or question, and passed on by communication and imitation to members (acculturation) and new generations (enculturation).[21] Science can be "cultural" in two ways. First, science is part of culture – it is influenced by the culture in which it is situated, and it influences that culture as it did in the diffusion of "the scientific method" described earlier. In many modern societies, science plays a major role in shaping cultural beliefs, thinking patterns, and assumptions about the way the world is, as well as views of the people and other phenomena in it. Sometimes this occurs by gradual, unorchestrated diffusion of ideas from science into the culture. At other times, however, there is a conscious effort, by scientists and others, to use the authority of science to claim that scientific theories and evidence support a particular belief system or political goals. Secondly, science itself and the sciences have their own culture of beliefs about who may be a scientist, practices for doing science, and rituals marking scientific discoveries and achievements.

Although there are many examples of how science is cultural, perhaps one of the most unfavorable illustrations of its cultural boundedness is structural racism in academic sciences and the persistence of racist science. First, concerning structural racism, we note that the practice of science in many countries – especially who gets to do science – is, unfortunately, a mostly white endeavor.[22] Contemporary protests by scientists and their supporters[23] are bringing belated attention to longstanding systemic racism in science, and the ways institutional culture in the academy[24] and science itself privileges whiteness and Anglo-euro-centric worldviews and ways of knowing. Although Blacks comprise 12 percent of the US population, for example, they received just 1.8 percent of all Ph.D.s in science and engineering in the USA in 1987, and the number is declining.[25]

[19] Roberto Andorno, Chapter 5 in this Volume.

[20] Horace Freeland Judson, *The Great Betrayal: Fraud in Science*. (Orlando: Harcourt, 2004).; Daniele Fanelli, "How Many Scientists Fabricate and Falsify Research? A Systematic Review and Meta-Analysis of Survey Data," *PLOS ONE*, May 2009, 4 (5), PMID: 19478950, e5738.

[21] Interestingly, there is no formal definition of culture used by UNESCO nor described in the UDHR and ICESCR, as is acknowledged in in the Report of the independent expert in the field of cultural rights, Ms. Farida Shahed, to the Human Rights Council, fourteenth session, UN General assembly, March 22, 2010 (see II (A) (4), page 4 A/HRC/14/36).

[22] Sandra Harding (ed.), *The "Racial" Economy of Science: Toward a Democratic Future* (Bloomington: Indiana University Press, 1993).

[23] Leah Crane, "Scientists Around the World are Striking Against Racism in Academia," *New Scientist*, June 10, 2020 www.newscientist.com/article/2245743-scientists-around-the-world-are-striking-against-racism-in-academia/.

[24] Frances Henry and Carol Tator (eds.), *Racism in the Canadian University: Demanding Social Justice, Inclusion, and Equity* (Toronto: University of Toronto Press, 2009).

[25] Hugh McIntosh, "Special report: Where are Today's Black Scientists?" *The Scientist*, January 1989, www.the-scientist.com/news/special-report-where-are-todays-black-scientists-62328.

In the USA, for example, in 2018, the latest date for which data are available, Black residents were 12.3 percent of the U.S. population, but only 8.4 percent of bachelor's graduates, 8.3 percent of master's graduates and 5.5 percent of doctoral graduates.[26] As thirteen scientists, (not one of whom is Black) on the editorial board of Cell put it in 2020, "science has a racism problem."[27]

Still considering the cultural situatedness of science and widening the lens, it must be noted that three-quarters of the world's scientific publications came from Western Europe and North America. And more than 90 percent of the Nobel laureates in the natural sciences are from Western countries, despite the fact that these countries are home to only 10 percent of the world's population.[28]

The second and related example concerns racist science. Even as human rights were being discussed in many parts of the world and drafted into written documents in the twentieth century, the science of eugenics was flourishing in Nazi Germany, the USA, and elsewhere,[29] aimed at improving the quality of white "races" by denigrating and removing people deemed inferior. With the help of racial science experts, physicians, psychiatrists, anthropologists, and newly medically trained geneticists, Nazi Germany developed racial health policies that involved mass sterilization of "genetically diseased" persons resulting in approximately 400,000 forced sterilizations, over 275,000 euthanasia deaths, and the near annihilation of European Jewry.[30]

Drafters of the UDHR will have been acutely aware of medical science gone wrong through the Nuremberg Doctors Trials[31] in 1946–1947 which resulted in sixteen being found guilty and seven sentenced to death and executed on June 2, 1948. Nevertheless, Julian Huxley (1887–1975), the evolutionary biologist and Life Fellow of the (British) Eugenics Society, became the first Director-General of UNESCO and described his amended vision of "world evolutionary humanism,"[32] [33] even as the human rights

[26] Fred Guterl, "Diversity in Science: Where are the Data?," *Scientific American*, October 2014, 311 (4), 40–41.

[27] The Cell Editorial Team, "Science has a Racism Problem," *Cell*, June 25, 2020, 181, 1443–1444. www.cell.com/cell/pdf/S0092-8674(20)30740–6.pdf.

[28] Maurizio Iaccarino, "Science and Culture," *EMBO Reports*, March 2003, 4 (3): 220–223.

[29] In France, for example, the use of anthropometry and the claim of links between physiognomy and criminality, developed by Alphonse Bertillion and others, claimed to scientifically establish and predict criminality in the late 1800s, and was adopted and used by police departments in many countries before it was discredited. Similarly, theories of social Darwinism and "scientific" measurements were used during the eugenics movements in Germany, France, Brazil, and Russia. See Mark B. Adams (ed.), *The Wellborn Science: Eugenics in Germans, France, Brazil, and Russia* (New York: Oxford University Press, 1990).

[30] Francois Haas, "German Science and Black Racism – Roots of the Nazi Holocaust," *The FASEB Journal [Federation of American Societies of Experimental Biology]* 2008, 22:, 332–337; see also Unites States Holocaust Memorial Museum, www.ushmm.org/collections/bibliography/nazi-racial-science.

[31] Robert Jay Lifton, *The Nazi Doctors: Medical Killing and the Psychology of Genocide* (New York: Basic Books, Inc., 1986).

[32] Paul Weindling, "Julian Huxley and the Continuity of Eugenics in Twentieth-Century Britain," *J Mod Eur Hist*. November 1, 2012, 10 (4): 480–489. www.ncbi.nlm.nih.gov/pmc/articles/PMC4366572/.

[33] Julian Huxley, *UNESCO: Its Purpose and Philosophy, 1946* (London: Euston Grove Press, English facsimile edition, 2010) 144 pp.

revolution brought about the UN and International Court of Justice in 1945, UNESCO in 1946, the World Health Organization in April 1948, and the Universal Declaration of Human Rights in December 1948. Still today, the search continues by some scientists for measurable biological differences between "races," despite decades of studies yielding no supporting evidence, as science absorbs and reflects back the racism in societies in which it is situated.[34]

As science is part of culture, the right to take part in cultural life includes the right *of everyone* to take part in scientific life. Readers familiar with the field of human rights and those who have read the foregoing chapters will not be surprised, since the right to science is nested within cultural rights in both the UDHR and ICESCR. As Mylene Bidault[35] explained, the right to science, contained in the right to take part in cultural life (as these together comprise article 15 of the ICESCR), is primarily a right of access to participate in science. The right to science contains correlative duties to ensure the conservation, development, and diffusion of science, to respect the freedom indispensable for scientific research, and to encourage and develop international contacts and cooperation.

It is easy to acknowledge that excellence in science requires diversity and equity, but there is far to go in achieving a diversity of perspectives in the various sciences, not only those of persons of color, but also women and LGBTQ persons, those with disabilities,[36] and other members of the public. It is necessary, therefore, to examine the tension between science as done by professional, educated, expert, science specialists, and science in which the public may effectively participate. For while science provides knowledge about the way the world "is," society is necessary for deliberating together about the way things "ought" to be.

OPEN SCIENCE

A universal right to science is not merely about respecting the freedom necessary for science and protecting the interests of scientists – though it is that. It is also the right of *everyone* to participate in that aspect of cultural life that is named science.

Passively, as first expressed in the UDHR, the right to science is a right "to share in scientific advancement and its benefits" (Article 27 (1)), and, as expressed in the ICESCR, "the right of everyone to enjoy the benefits of scientific progress and its applications" (Article 15 (1) (b)). In a time when science ranges from experiments conducted in a hadron collider to constructing artificially intelligent robots and modifying the genome of embryos, one might automatically assume on first reading that only scientists have the education and expertise to contribute to scientific knowledge. Hence, a universal right to science might be expected to relegate the rest of humanity to patiently receiving the benefits of science, as indeed some

[34] Angela Saini, *Superior: The Return of Race Science* (Boston: Beacon Press, 2019).
[35] Mylene Bidault, Chapter 8 in this Volume.
[36] Valerie Bradley, Chapter 9 in this Volume.

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delegates argued during the drafting and discussion prior to approval of the UDHR by the General Assembly of the UN. At most, public participation would thus be primarily as consumers of science.

As Mikel Mancisidor[37] took care to explain, however, it is a misapprehension of the right to science to limit its scope to sharing in the benefits of science, such as the benefit of affordable medicine. Rather, as Mancisidor's historical hermeneutic shows, the word "share" entails action, agency, and active participation. He therefore proposes that "to share in" be considered synonymous with "to participate in" or "take part in." The right to science, he shows, "goes beyond 'benefit from' and advocates broader concepts of 'participation in'; a right which includes participation in scientific creation (citizen science, or "ordinary people doing science"[38]), the dissemination of scientific knowledge, and participation in scientific policy, among other things."[39]

A right to science that entails more robust public participation in science aligns with the original goals of the human rights drafters then, in the 1940s, and now, in the 2020s, as people in both eras aspire to enable human flourishing and peace throughout the world. Much has since been done to develop strategies for public engagement in science[40] and document the value of citizen science[41], though much remains to be done. Two examples may suffice.

When Sharon Terry's two children were diagnosed in 1994 with a rare progressive genetic disease (pseudoxanthoma elasticum PXE), she learned that neither their doctors nor scientists knew much about it. Terry[42] was a former college chaplain who had become a full-time mother, and her husband was a construction manager who had majored in drafting. Together they persuaded Harvard to let them use lab space at night and, with the informal help of generous postdoctoral students, they

[37] Mancisidor, Chapter 1 in this Volume, p. 17.

[38] E/c.12/GC/25 (10)

[39] Ibid. p. 9.

[40] Laura Trouille et al., "Citizen Science Frontiers: Efficiency, Engagement, and Serendipitous Discovery with Human-Machine Systems," *PNAS*, February 5, 2019, 116 (6): 1902–2909; see, for example, www.zooniverse.org/, a website for "people-powered research."

[41] Maria Aristeidou and Christothea Herodotou, "Online Citizen Science: A Systematic Review of Effects on Learning and Scientific Literacy," *Citizen Science: Theory and Practice*, 2030, 5(1): 1–12; Brandi Leach, et al. *Emerging Developments in Citizen Science: Reflecting on Areas of Innovation* (Rand Europe, 2020) web-only document number: RR-4401-THIS, https://doi.org/10.7249/RR4401; Committee on Designing Citizen Science to Support Science Learning, Rajul Pandya, Kenne Ann Dibner (eds.), *Learning Through Citizen Science: A Consensus Study Report of the National Academies of Sciences, Engineering, Medicine* (Washington, DC: The National Academies Press, 2018) http://nap.edu/25183.

[42] www.ted.com/speakers/sharon_terry; Terry's TED talk is entitled "Science didn't understand my kids' rare disease until I decided to study it." www.pcori.org/people/sharon-terry-ma; see a fuller description of their story in Karen Taussig, "The Molecular Revolution in Medicine," in Susan McKinnon and Sydel Silverman (eds.), *Complexities: Beyond Nature and Nurture* (Chicago: University of Chicago Press, 2005) pp. 239–241.

Also see Karen Taussig, *Ordinary Genomes: Science, Citizenship, and Genetic Identities* (Durham: Duke University Press, 2009).

learned about genes and eventually built a diagnostic test and posted data on an open online consortium, called Genetic Alliance, which Sharon Terry now runs. Genetic Alliance[43] offers tools to help other families, gives advice on how to do scientific research and how to become a political activist, and runs a participant owned and managed registry and biobank.[44]

The Terrys had to overcome numerous barriers to contribute as they did to science. The majority of science research is publicly funded through tax monies allocated through grants, by governmental agencies like the (US) National Institutes of Health and the European Commission, almost exclusively to science investigators selected by review committees of fellow scientists. Most science is done in academic and government settings or for-profit companies. Scientists who share their findings in scholarly articles, monographs, and books for the academic market are generally not paid to publish, and their data, findings, and publications are usually not freely available to the general public. Instead, scientists submit their work to journals and publishing corporations, such as Elsevier,[45] who handle scientific peer review and publication, and the information is privatized and put behind a paywall.[46] Libraries then pay an institutional fee for faculty to have access, or individuals may pay a fee per article. Sometimes authors pay publishing companies a fee as well, usually in the thousands of dollars, for their work to be freely available – typically labelled "open access"– in which case the for-profit publishing company collects fees from both the universities and authors.[47]

Given such boundaries around academic science in western countries, a second, less heartening example of opening access to science involves the young internet pioneer, Aaron Swartz,[48] whose best-known contribution is the one that also led to his death. In his teens, Schwartz was a wunderkind involved in developing RSS (which organizes web feeds), Markdown (a simple editing language for webpages),

[43] www.geneticalliance.org/about.

[44] http://geneticalliance.org/Registry_BioBank.

[45] Blair Fix, "The Legacy of Aaaron Swartz: The Fight for Open Access," December 23, 2019, https://capitalaspower.com/2019/12/the-legacy-of-aaron-swartz-the-fight-for-open-access/.

"In 2018, Elsevier's profit margin was 37%. Let's put this in perspective. Even during the peak of its profitability, Apple's profit margin never got above 27%."

[46] For information about the economics of academic publishing, see the 2018 free online documentary film *Paywall: The Business of Scholarship*, directed and produced by Jason Schmitt, which focuses on the need for open access to research and science. https://paywallthemovie.com/.

[47] Fix, note 45. "Author-funded open access has also led to the dubious practice of 'double dipping'. Companies like Elsevier give authors the option to publish their articles as open access – even in journals that are otherwise paywalled. Elsevier charges authors thousands of dollars for this privilege. But then Elsevier continues to charge universities the same subscription price for the rest of the paywalled articles. So universities effectively pay for access twice."

[48] Justin Peters, *Aaron Swartz and the Rise of Free Culture on the Internet* (New York: Scribner, 2018); See also Aaron Swartz, *Raw Thought Raw Nerve: Inside the Mind of Aaron Swartz* (New York: Discovery Publisher, 2014); see also Sean B. Palmer, *The Boy Who Could Change the World: The Writings of Aaron Swartz* (New York: The New Press, 2015); see also the documentary film "The Internet's Own Boy: The Story of Aaron Swartz" directed by Brian Knappenberger, www.youtube.com/watch?v=2MoGQww1GoY.

Reddit (now a massive news aggregation site), and Creative Commons (a nonprofit copyright-sharing system). In 2008, Swartz raised concerns about the tyranny of academic publishing in an online document entitled "Guerilla Open Access Manifesto."[49] He wrote, "The world's entire scientific and cultural heritage, published over centuries in books and journals, is increasingly being digitized and locked up by a handful of private corporations." He called for sharing information openly and freely with the whole world, not just scientists, elite universities, and citizens of the First World.

As a research fellow at Harvard, Swartz had free online library privileges. In late 2010 he hooked up his computer to the internet in an unlocked, unmarked closet at MIT, and wrote a program to download articles from behind the paywall operated by the journal storage company, JSTOR, to make them freely available around the world. He was arrested and charged with breaking and entering. Although JSTOR declined to press charges, US Federal prosecutors aggressively pursued the case, charging him with eleven violations of the computer fraud and abuse act, carrying a cumulative maximum penalty of $1 million in fines, thirty-five years in prison, asset forfeiture, restitution, and supervised release. He declined to plead guilty and plea-bargain. In 2013, Aaron Swartz hanged himself in his apartment.

The interests of scientists as authors, of science publishing companies, science communities, and the wider public, are obviously in tension even though they are contained together in the right to science articulated in Article 15 of the ICESCR. The current imbalance that prioritizes protection of the material interests of scientists could be addressed in part by applying the right to science in a manner that aligns with the order of priorities as they are listed in ICESCR. Article 15 not only recognizes the right of everyone "(c) to benefit from the protection of the moral and material interests resulting from any scientific, literary or artistic production of which he is the author," but *first* declares the right of everyone "(a) to take part in cultural life "and "(b) to enjoy the benefits of scientific progress and its applications . . . " As Aaron Swartz, we, and other human rights scholars realize, redressing and restricting the "unprecedented expansion of intellectual property regimes"[50] and profits from science applications and publishing will be necessary for science to be open and public participation in science to flourish.

One encouraging follow-up to the tragedy of Aaron Swartz's death is the formation of SciHub[51] "the first pirate website in the world to provide free public access to tens of millions of research papers,"[52] Library Genesis, Open Science, and internet

[49] https://archive.org/stream/GuerillaOpenAccessManifesto/Goamjuly2008_djvu.txt.

[50] Effy Vayena and John Tasioulas, "We the Scientists: A *Human Right to Citizen Science*," *Philosophy & Technology*, 2015 (28), 479–485.

[51] https://scihub.to/.

[52] Sci-Hub was developed by Alexandra Elbakyan when she was a student in Kazakhstan. "Elbakyan's university couldn't afford to pay subscription fees to many of the journals that she needed to read. So to do her research, she either had to buy access to each article (typically at $30 a piece) or find friends and colleagues who had access."

sites[53] that make science and other articles and books available to those who have access to computers and the internet. Access to science publications, however, is just the foundation for open science. Robust and diverse participation in open science includes not only the most widespread forms of engagement by educating the public about science, but also forms of participation that enable communities and individuals to actively participate in science and do science themselves.

The following are examples of public participation in the development and diffusion of science internationally, across cultures:

(1) Widespread science education both in public schools for children and adolescents, and other forums for adults to examine the latest science and its implications;
(2) Participating in human research as an informed, consenting, volunteer in studies;
(3) Donating data (e.g. Open Humans)[54] or being a subject in large public research projects (institutionally reviewed and approved) for which individual consent may be waived;
(4) Serving as a member of committees, commissions and the like with scientists and funders that shape selection of problems to be studied;
(5) Being a community member of an Institutional Review Board or other research ethics review committee or data safety monitoring board;
(6) Individual (or small group) consultant, collaborator, or public partner on specific science research regarding which the public member has special interest or historical commitment;
(7) Embedding in science labs and research projects increasingly done by bioethicists, moral philosophers, humanities scholars, journalists, and others to provide an "outsider" perspective, identify ethical concerns prior to problems, and keep the general public abreast of scientific discoveries and their implications;
(8) Being a "citizen scientist" as in collecting ecological data on birds and butterflies,[55] or mapping brain slices,[56] or conducting one's own science project in a do-it-yourself lab such as DIY Science.[57]

Although these may not constitute full realization of a universal human right to enjoy, access, and participate in science, they would constitute significant progress

[53] https://openscience.com/tag/library-genesis/.
[54] Bastian Greshake Tzovaras et al. "Open Humans: A Platform for Participant-Centered Research and Personal Data Exploration," *GigaScience*, 2019, 8 (6).
[55] James Wang Wei et al., "Citizen Science and the Urban Ecology of Birds and Butterflies – A Systematic Review," *PLOS ONE*, 10 June 10, 2016 https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0156425.
[56] Amy Robinson, "EyeWire, A Game to Crowdsources Brain Mapping, Citizenscience.gov," US General Services Administration www.citizenscience.gov/eyewire-brain-mapping/#.
[57] https://diybio.org/.

toward opening science to everyone. Further, the right to science explicitly includes the duty of "conservation, development and diffusion of science" (ICESCR 15 (2)) as well as "encouragement and development of international contacts and co-operation in the scientific and cultural fields" (ICESCR 15 (4)). This book, we hope, has contributed to meeting that part of the right to science.