

Giving Meaning to the Right to Science: A Global and Multidisciplinary Approach

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Giving Meaning to the Right to Science: A Global and Multidisciplinary Approach

Executive Summary

For the past decade, the American Association for the Advancement of Science (AAAS) Science and Human Rights Coalition has been eliciting the perspectives of scientists, engineers, and health professionals as to the meaning of the right to “enjoy the benefits of scientific progress and its applications” and the associated governmental obligations as elaborated in Article 15 of the International Covenant on Economic, Social and Cultural Rights (ICESCR). An initial focus group study that engaged U.S.-based scientists added clarity regarding the broad benefits of scientific progress relevant to the right. The scientists saw these benefits as going beyond the material to include the scientific process itself and the value of scientific evidence as the basis for laws and policies. In addition, the focus group study gave rise to a new conceptual framework for considering ‘access to science’ in the context of Article 15.

Building on this prior research, AAAS received funding from the Open Society Foundation to support (1) development, dissemination and analysis of a preliminary global questionnaire to elicit the views of scientists, engineers and health professionals as to the meaning of the right; and (2) organization of a briefing for the United Nations Committee on Economic, Social and Cultural Rights to inform its development of a General Comment on the right. Two additional research efforts were undertaken: a series of interviews with health advocates around the world on how the right to science might apply to and help advance their work; and a project to create data visualizations of the ‘right to science’ references contained in periodic reports of States Party to the ICESCR.

Preliminary Global Questionnaire

The global questionnaire was distributed electronically across AAAS social media outlets and listservs, generating a convenience sample of 3,462 usable responses, including 2,115 open-ended responses. The following are highlights from the results:

- The two most frequently selected benefits of science overall—improving health and advancing knowledge—were also the most frequently mentioned benefits in the prior focus group study.
- Like the focus group participants, the questionnaire respondents viewed the benefits of science as far broader than just its material applications.
- When comparing the most frequently selected benefits of science by respondents from different disciplinary groups, significant differences were found for each of the thirteen benefits examined.
- Much less variation was found across global regions, suggesting that scientific discipline may be a stronger determinant of respondents’ views on the benefits of science than regional location.
- Respondents in the global south were the most likely to select economic development as among the top three benefits of science.

- The top five government actions that respondents indicated would support the advancement of their work were: increase funding for scientific infrastructure and research; provide adequate science education to the general public; promote a positive view of science and scientists among the public; ensure open access to scientific information; promote and protect academic freedom.
- For those in the industry/commercial sector, reforming intellectual property laws and promoting technology transfer were of higher priority than for scientists in other sectors.
- Respondents in the global south were the most likely to select technology transfer as an action required by government to support their work.

Because the global questionnaire relied on convenience sampling, the findings cannot be generalized. Nevertheless, the results do suggest patterns of variation and convergence in scientists' views on the meaning of the right to science across specific demographic and geographic characteristics that could be tested with a larger study employing randomized sampling.

Data Visualization and Quantitative Analysis

The data used for this analysis included: (a) countries' ratification of ICESCR and reporting on the right to science, and (b) country characteristics (i.e., Gross Domestic Product (GDP), scientific and technical journals published), and (c) public health indicators. The first category enabled initial exploration of the status of global reporting on the right to science, while the second category allowed exploration of the relationship between state reports and public health characteristics of those states. Analysis revealed:

- The right to science has been reported on by many, but not all, States Party and there has been considerable variation in what States Party have reported. Reporting increased over time. No geographic pattern was found.
- Country GDP was positively correlated with state reporting. The number of scientific and technical journal articles published in a state was positively associated with the number of references to the right to science. No significant association was found between public health indicators and state reporting.

Interviews with Public Health Advocates

In order to examine the implication and applications of a right to science within a specific context, five public health advocates were interviewed. Key themes emerging from the interviews were:

- Universality makes human rights a potentially useful frame for discussing public health globally.
- Article 15 highlights the unacceptability of denying individuals access to products of scientific knowledge that are essential for lives of dignity. However, the right to science is not limited to the products of science; it encompasses the right to access scientific knowledge itself; for public health this is essential for spurring innovation and protecting public safety.

- Government obligations under Article 15 could lead to policy reforms that would promote realization of Article 15 in the realm of access to medicine.
- Article 15 highlights the current paradoxical system in which discoveries based on public investment in biomedical research lead to economic benefits for private corporations.
- The potential of Article 15 for advancing public health and access to medicines is limited by the often contentious relationship between governments and human rights activists, and the lack of enforcement mechanisms for human rights treaties.

Briefing for the United Nations Committee on Economic, Social and Cultural Rights

After a presentation of the preliminary findings from all components of this study, members of the U.N. Committee were invited to pose questions. Key themes from among their questions included:

- How should funding for basic and applied science be conceived of within the framework of Article 15?
- What are the tensions between conceptions of science as the product of technical, formal training and traditional knowledge?
- How can Article 15 be used to assess/address potentially harmful impacts of scientific developments?
- How can the role of the commercial sector in developing medicines and other products be reconciled with the government funding that underpins the research on which such products are based?
- How does Article 15 support everyone's right to participate in, contribute to, and benefit from scientific progress and its applications?
- How did the low response to the global questionnaire from scientists in the global south impact findings?

I. Introduction

For the past decade, the American Association for the Advancement of Science (AAAS), together with the AAAS Science and Human Rights Coalition, has been exploring and elucidating the meaning of the right to “enjoy the benefits of scientific progress and its applications” and the associated governmental obligations as elaborated in Article 15 of the International Covenant on Economic, Social and Cultural Rights (ICESCR).

The medium-term goal of this effort has been to contribute to the deliberations ongoing within the United Nations (UN) as to the meaning of the right and how it can best be applied in practice. The locus of that discussion currently is the UN Committee on Economic, Social and Cultural Rights which has begun the development of a General Comment on the right; that is, a definitive statement of the meaning of the right that is intended to guide the actions of the governments that are a party to the treaty. The longer-term goal is to contribute to the implementation of the right, particularly through raising awareness and engagement among scientists, engineers, and health professionals about the existence of the right, and its meaning and relevance to their work.

Prior work

Beginning in 2012, the AAAS Science and Human Rights Coalition’s work centered on a series of discipline-specific focus groups involving U.S.-based scientists, engineers and health professionals. Up until that time, Article 15 had received relatively little attention in either academic or public spheres and no one had systematically explored scientists’ views on the meaning of the right. The focus group process created an opportunity for participating scientists to consider the meaning of the right to science and its implications, articulate their ideas, and hone them through a conversation with disciplinary peers. The findings of the focus group process were presented to a meeting at the United Nations in 2013, and formed the basis of a

Article 15, International Covenant on Economic, Social and Cultural Rights

1. The States Parties to the present Covenant recognize the right of everyone:
 - (a) To take part in cultural life;
 - (b) To enjoy the benefits of scientific progress and its applications;
 - (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.
2. Shall take the steps necessary for the conservation, the development and the diffusion of science and culture.
3. Undertake to respect the freedom indispensable for scientific research and creative activity.
4. Recognize the benefits to be derived from the encouragement and development of international contacts and co-operation in the scientific and cultural fields.

report titled “Defining the Right to Enjoy the Benefits of Scientific Progress and Its Application: American Scientists’ Perspectives.”¹

Two core findings from this early effort have been widely viewed as contributing substantially to the evolving understanding of the meaning of the right to science: the first concerns the meaning of ‘benefits’ in the context of the language of the right; and the second concerns the notion of ‘access’ in the context of the right to science.

Benefits

A statement that everyone has the right to enjoy the benefits of scientific progress and its applications begs the question--what are the benefits of scientific progress? Are they primarily material goods? Are they so numerous that fulfillment of the right becomes impossible? Across the disciplinary focus groups, a core set of ten benefits were mentioned repeatedly. The focus group participants saw the benefits of science as extending far beyond the material realm, including the benefits of the scientific method itself as a system of rational thought. Health was the single most frequently mentioned benefit.

Table 1: Ten Most Frequently Mentioned Benefits of Science
(Focus Group Data)

Rank	Benefit
1	Health (including diagnosis/treatment/applications)
2	Advancing knowledge
3	Ecological, environmental, wildlife
4	Education and training
5	Empirical basis for laws/policies/programs
6	Technological/infrastructure applications
7	Understanding of personal behaviors
8	Advancing methods and technology for science
9	Influence on/of culture
10	Economic impact

Access

The focus group study examined in some detail the meaning of access in the context of Article 15(1)(b). Farida Shaheed, Special Rapporteur in the field of cultural rights, wrote in a 2012 report that access should

¹ AAAS Science and Human Rights Coalition, “Defining the Right to Enjoy the Benefits of Scientific Progress and Its Applications: American Scientists’ Perspectives” (Report prepared by Margaret Weigers Vitullo and Jessica Wyndham), October 2013. DOI: 10.1126/srhl.aaaao28

be to “science as a whole,” not only to particular scientific outcomes or applications.² She specifically stated that people have a right to access scientific knowledge, scientific information, and scientific advances. She also suggested that there is a natural nexus between the right to education and the right to information that coalesces in the right to science education in order to be “informed about main scientific discoveries and their applications” and to “[instill] a spirit of scientific inquiry.” Scientific education is particularly vital if all people are to have the right to create as well as consume science. Finally, the report suggested that the nature of access may be contextually dependent. For example, in her report scientific knowledge is framed as a right of all people, while scientific information was discussed as most relevant to researchers.

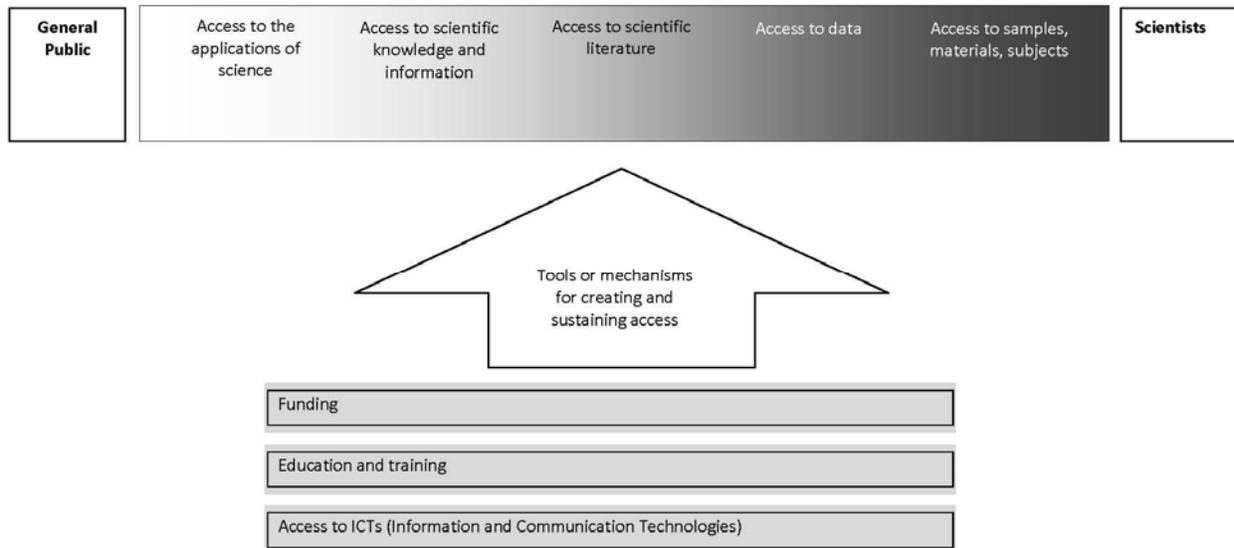
The results from the focus group discussions helped draw out the specific meaning of having access to “science as a whole,” and how all people can have a right to enjoy the benefits of scientific progress and its applications, while simultaneously taking into account context and the right of individuals to be protected from the misuse of science. Moreover, having access to science as a whole also implies a right to participate in science, not merely benefit from it. These results are summarized in Diagram 1 below, which includes a bi-directional continuum of scientific access that ranges between access for the general public to access for scientists as well as a set of tools and mechanisms that are essential for creating and sustaining access.

The tools and mechanisms in the diagram—funding, education and training, and access to information and communication technologies—are essential to ensure access at each point along the continuum. When the essential tools and mechanisms are in place, then having access to “science as a whole” (i.e., at each point along the continuum) becomes possible. A person’s place on the continuum depends on their needs, motivation, training, and knowledge—which are fluid and changeable. A scientist becomes a member of the general public when functioning outside his sphere of influence, moving from the right side of the continuum toward the left. When a physicist needs open-heart surgery, she becomes more like the general public. When a student goes to graduate school, or a climate activist decides to become immersed in the literature, or even to re-analyze the data on which a study is based, that person moves to the right on the continuum. The data from the focus groups made clear, that whenever possible, governments should not be involved in determining levels of access.³

² Shaheed, Farida (2012), “The right to enjoy the benefits of scientific progress and its applications,” 14 May 2012 (A/HRC/20/26,HRC, Geneva).

³ For a full discussion of the Continuum see “Defining the Right to Enjoy the Benefits of Scientific Progress and Its Applications: American Scientists’ Perspectives,” 2013:6-9.

Diagram 1: Continuum of Access
(Focus Group Data)



Current effort

Building on this prior research, AAAS received funding from the Open Society Foundation to support (1) development, dissemination and analysis of a preliminary global questionnaire to elicit the views of scientists, engineers and health professionals as to the meaning of Article 15; and (2) organization of a briefing for the United Nations Committee on Economic, Social and Cultural Rights to inform its development of a General Comment on the right. Two additional research efforts were undertaken: a series of interviews with health advocates around the world on how the right to science might apply to and help advance their work; and a project to create data visualizations of the ‘right to science’ references contained in the periodic reports of States Party to the ICESCR.

Building on the groundwork established through the U.S. based focus group study, as well as the existing literature on the right to science, the current effort addressed the following questions:

- 1) To what extent do discipline and global region impact the views of scientists, engineers and health professionals with regard to (a) the benefits of the right and (b) the government actions required to support the right?

- 2) To what extent does the right to science provide a useful framework for advocacy within a specific context? In particular, what are the implications and applications of a right to science for public health and access to medicines?
- 3) How do States Party interpret the right, as revealed in their periodic reports to the UN Committee on Economic Social and Cultural Rights?
- 4) What has the Committee said in its concluding observations with regard to the right? How do these comments compare with the views of scientists?

II. Global Questionnaire

A variety of factors were taken into account when designing the questionnaire. First, that the respondents would come from widely diverse backgrounds within science, engineering and the health professions, including both basic and applied researchers, as well as practitioners, educators, and students, all working within diverse socio-economic and cultural contexts. Second, that it was essential for the questionnaire to be written with unambiguous terminology and conducive to translation in Spanish, French and English, given the goal of reaching a global audience. Third, that the work had to be completed within strict resource constraints (both human and financial), which limited the length of the questionnaire overall and the number of open-ended items.

The questionnaire consisted of three core sections addressing: (i) respondent demographics; (ii) the benefits of science; and (iii) government actions needed to support science. In addition, a single open-ended item invited respondents to explain “in your own words, how is the right to enjoy the benefits of scientific progress and its applications relevant to your work?” The questionnaire was administered through SurveyGizmo, an online survey design program for which AAAS holds an institutional account.⁴ The strategy for disseminating the questionnaire reflected the goal of reaching as many scientists, engineers, and health professionals globally as possible without the resources necessary to construct a random sample. Beginning in December 2016, the questionnaire was disseminated through: (1) social media, principally generated by AAAS; (2) AAAS institutional listservs aimed at target audiences, including individuals interested specifically in the intersection of science and human rights; (3) the AAAS Science and Human Rights Coalition member organizations and, in turn, to their members; (4) AAAS members, with special efforts made to disseminate the questionnaire to members outside the United States; and (5) international non-profit and multilateral organizations. Dissemination of the questionnaire was exclusively online.

In total, we received 4,036 responses. We discarded 209 responses from individuals who either did not provide a scientific discipline, or who indicated they were not scientists, engineers or health professionals. A further 365 responses were discarded because the respondent did not answer any of the substantive questions or the open-ended question. In total, the results described in this report reflect 3,462 responses.

⁴ <https://www.surveygizmo.com/>

Those responses included 2,115 answers to the open-ended question. Because global questionnaire relied on convenience sampling, the findings cannot be generalized. Nevertheless, the results do suggest patterns of variation and convergence in scientists’ views on the meaning of the right to science across specific demographic and geographic characteristics that could be tested with a larger study employing randomized sampling.

Questionnaire Results

Demographics

Discipline. Respondents were asked to choose their scientific field from a list of six options. The options were created based on the National Science Foundation (NSF) Federal Support Survey Fields of Science and Engineering Codes and Definitions, modified only to remove the separate field of ‘psychology’ and to create the field of ‘social and behavioral sciences’. In addition, the question provided an option for respondents to indicate that they were not a scientist, engineer, or health professional, in which case they were taken to the end of the questionnaire and were not able to complete any further questions.

Table 2: Breakdown of disciplines

(Global Questionnaire Data)

Discipline	Example Sub-Disciplines Provided	% of total	Total number
Life sciences	Agricultural sciences, biology, botany, environmental biology, medicine, nutrition	41.0%	1419
Social and Behavioral sciences	Anthropology, economics, linguistics, political science, psychology, sociology	20.9%	722
Physical sciences	Astronomy, chemistry, physics	14.5%	502
Environmental sciences	Atmospheric sciences, geological sciences, oceanography, paleontology	8.4%	289
Engineering	Chemical, mechanical, civil or electrical engineering; bioengineering; and metallurgy	7.8%	270
Computer sciences and Mathematics	Logic, statistics, systems analysis	7.5%	260

The preponderance of responses from individuals in the life sciences is consistent with both the overall membership of AAAS (though the questionnaire was distributed well beyond AAAS members) and may also reflect the deliberate outreach to non-government organizations working in health-related fields.

Sector. The majority of respondents came from the university or college sector (54.8%). Those in the industry/commercial sector constituted 14.5% of responses, and government employees constituted 9.5%.

Respondents from the remaining sectors each constituted less than 8% of responses: non-profit (7.4%), research institution (7.4%), primary/secondary school education (1.2%), and other (5%). 0.3% of respondents left this question blank.

There were some disciplinary differences with regard to the sectors in which respondents worked. In the industry/commercial sector, more respondents came from engineering (43.3%) and computer sciences and mathematics disciplines (33.5%) compared with the university or college sector, where the most respondents came from the life sciences (42.3%), and social and behavioral sciences (27.6%). Additionally, it may be worth noting that in the industry/commercial sector, 83.0% of respondents identified as male.

Age and Gender. Of the total respondents who indicated their age group, 25.3% were over 69, of whom 76.3% indicated that they were retired. Also potentially of note was that among respondents under 30, 55.6% were female. Among those who were students, 52.2% identified as female. Asia is the only region in which there were more respondents in the lower age brackets (Under 30 – 49) than in the higher age brackets (50 – Over 69).

In the question concerning gender, the response option ‘a different identity’ was created in recognition that gender is a non-binary concern. Overall, 65.3% of respondents identified as male, 33.7% identified as female, and 0.4% identified as a different identity. This question was left blank by 0.6% of respondents. The greatest gender disparity existed with engineering (85.6% male), the physical sciences (82.1% male), and the computer sciences and mathematics (71.5% male).

Region. In order to safeguard confidentiality respondents were only asked to identify their region, rather than a specific country. The list of regions was drawn from the United Nations definitions, with the addition of the Middle East and North Africa, as defined by the World Bank. Despite the efforts made to reach a global audience of scientists, engineers, and health professionals, 79.5% of respondents resided in North America, including Canada, Mexico, and the United States of America. The region with the second largest number of respondents was Europe (9.8%). Respondents from the remaining regions each constituted less than 5% of responses: Africa (0.9%), Asia (3.5%), Latin America and the Caribbean (3.1%), Middle East and North Africa (0.4%), and Oceania (1.9%). Overall, 1.0% of respondents left this question blank. Due to the small number of responses outside of North America, Europe, and Asia, the remaining regions were collapsed into the category “global south.”

Analysis - Benefits

Respondents to the global questionnaire were asked: “How does (or will) your work in science, engineering, or the health professions benefit society?” They were then presented with a list of 13 potential benefits (plus an ‘other’ category) and asked to select up to three benefits. The list of benefits for this closed-ended item were drawn from the themes that emerged in the focus groups, building on that prior work and

providing an opportunity to compare the views of U.S. based scientists with those from a broader international sample.

The results from the focus group data (as seen in Table 1 above) and the questionnaire data (as seen in Table 3 below) reveal that the overall ranking of the benefits was similar across both studies. For example, among both groups, health and advancing knowledge were among the top ranked benefits.⁵ There were some important exceptions to this pattern. First, in the focus group data with U.S.-based scientists the economic benefits of science were ranked tenth; in the global questionnaire data economic development ranked fifth overall. When respondents from North America were excluded from the analysis of the global questionnaire data, economic development became the third most frequently mentioned benefit of science. Furthermore, when the results from the questionnaire were broken down by scientific field, significant differences were found for every benefit measured. In other words, scientists from different scientific fields viewed the potential benefits of their scientific endeavors quite differently.

Table 3: Benefits of Scientific Endeavors by Field
(Global Questionnaire Data)

Rank	How does your current work benefit society?	In which of the following fields do you work?						Total	Sig Diff
		Computer science and mathematics	Engineering	Environmental sciences	Life sciences	Physical sciences	Social and behavioral sciences		
1	Advances scientific knowledge	46.9%	36.3%	47.4%	57.1%	70.1%	32.3%	50.6%	*
2	Promotes health	27.3%	21.5%	6.9%	63.4%	16.9%	17.2%	36.3%	*
3	Advances knowledge of general public	32.7%	17.8%	39.8%	30.4%	31.3%	27.3%	29.9%	*
4	Protects environment	9.6%	28.9%	74.7%	29.0%	23.3%	6.5%	25.8%	*
5	Economic development	35.0%	52.2%	22.5%	16.3%	32.9%	9.6%	22.0%	*
6	Provides empirical basis for policy/law	17.3%	12.2%	32.5%	15.7%	9.4%	28.4%	18.7%	*
7	Explains social patterns, attitudes behaviors	12.3%	3.3%	3.5%	5.4%	2.0%	57.3%	15.9%	*

⁵ Forty-one percent of the respondents to the global questionnaire worked in the life sciences. Future analysis will explore whether the uneven distribution of respondents across scientific fields impacted the ranking of benefits, including health.

8	Overcome national/cultural divides	8.5%	5.2%	5.5%	6.4%	17.9%	37.8%	14.6%	*
9	Combats inequality/discrimination	7.7%	3.7%	3.8%	7.0%	5.2%	41.6%	13.5%	*
10	Contributes to national security	15.8%	23.7%	6.6%	3.7%	16.1%	4.6%	8.4%	*
11	Assures safe/effective infrastructure	14.2%	23.7%	10.4%	2.1%	8.4%	1.0%	6.1%	*
12	Strengthens justice system	2.3%	1.1%	1.0%	1.4%	1.8%	4.2%	2.1%	*
13	Current work does not benefit society	5.0%	4.1%	0.7%	0.8%	1.8%	1.0%	1.6%	*
	*Cramer's V ≤ .05								

Much less variation was found across global regions. Scientists in each of the four regions compared (North America, Europe, Asia and the Global South)⁶ saw the benefits of their work in similar ways, with five exceptions. Scientists in Asia were more likely to see their work as advancing scientific knowledge and explaining social patterns, when compared to the other regions. Scientists in North America were more likely to see their work as promoting health and contributing to national security. Scientists in the Global South were the most likely to see their work as promoting economic development (see Table 4 below).⁷ These preliminary findings suggest that scientific discipline may be a stronger determinate of respondents' views on the benefits of science than regional location. In other words, it may be that a similar pattern of disciplinary variation in scientists' views regarding the benefits of science exists across the globe, which could provide a foundation for a shared understanding of the right to enjoy the benefits of scientific progress and its applications.

⁶ For the purposes of analysis and trying to identify any variations by region, we combined the responses from respondents in Africa, Latin America and the Caribbean, and the Middle East and North Africa Oceania under the heading 'Global South.' We recognize that this analytical tool is not wholly adequate, including given that most of the responses from Oceania came from Australia and New Zealand.

⁷ There were no significant differences in the proportion of scientists working in each of the scientific fields by region.

Table 4: Benefits of Science by Region
(Global Questionnaire Data)

Rank	How does your current work benefit society?	North America	Europe	Asia	Global South	Total	Sig Diff
1	Advances scientific knowledge	49.7%	55.5%	63.3%	49.1%	50.6%	*
2	Promotes health	37.4%	34.8%	29.2%	28.4%	36.3%	*
3	Advances knowledge of general public	29.9%	26.0%	29.2%	34.9%	29.9%	
4	Protects environment	26.0%	23.9%	20.8%	31.7%	25.8%	
5	Economic development	21.2%	23.3%	20.8%	29.8%	22.0%	*
6	Provides empirical basis for policy/law	19.2%	18.0%	13.3%	18.8%	18.7%	
7	Explains social patterns, attitudes behaviors	15.0%	18.6%	25.8%	17.4%	15.9%	*
8	Overcome national/cultural divides	14.5%	16.5%	10.0%	14.7%	14.6%	
9	Combats inequality/discrimination	13.8%	10.6%	15.0%	12.4%	13.5%	
10	Contributes to national security	9.5%	3.8%	6.7%	2.3%	8.4%	*
11	Assures safe/effective infrastructure	6.5%	5.3%	3.3%	2.8%	6.1%	
12	Strengthens justice system	1.9%	2.4%	1.7%	3.7%	2.1%	
13	Current work does not benefit society	1.5%	2.4%	0.8%	0.9%	1.6%	
	*Cramer's V ≤ .05						

Analysis - Government actions

Article 15 includes several broad statements regarding government obligations pertaining to the right to science, including taking “the steps necessary for the conservation, the development and the diffusion of science,” “undertaking to respect the freedom indispensable for scientific research,” and recognizing “the benefits to be derived from the encouragement and development of international contacts and cooperation.” The global questionnaire included an item designed to explore how scientists related a range of specific government actions to these broad statements. It asked respondents to consider a list of 12 government actions and select up to three that they believed would most support advancement of their

current professional work. The response categories were generated based on the results of the prior focus group study.

The five government actions most frequently selected by respondents overall were:

- (1) Increase funding for scientific infrastructure and research
- (2) Provide adequate science education to the general public
- (3) Promote a positive view of science and scientists among the public
- (4) Ensure open access to scientific information
- (5) Promote and protect academic freedom

The level of agreement about the importance of these obligations is quite high across all geographic regions (see Table 5). Although the rank order varies slightly by region, these five government actions are the most frequently selected in North America, Europe and Asia. In the Global South, “promote technology transfer” was the fifth most frequently selected government action. A divergence in priority exists across different employment sectors (table not shown). Perhaps unsurprisingly, for those in industry/commercial sector reforming intellectual property laws and promoting technology transfer are of higher priority than for scientists in other sectors.

Table 5: Government Actions by Region
(Global Questionnaire Data)

Rank	What government actions would support the advancement of your work?	North America	Europe	Asia	Global South	Total	Sig Diff
1	Increase scientific funding	58.2%	60.5%	54.2%	62.8%	58.5%	
2	Provide science education	59.6%	48.1%	45.0%	49.5%	57.3%	*
3	Promote science to public	45.0%	41.3%	32.5%	35.8%	43.6%	*
4	Ensure open access to science info	36.9%	38.9%	39.2%	35.3%	37.0%	
5	Promote/protect academic freedom	25.4%	33.6%	31.7%	19.3%	26.1%	*
6	Ensure reasonable costs for products	15.5%	11.5%	17.5%	17.4%	15.3%	
7	Respect freedom of speech	12.4%	13.3%	12.5%	9.2%	12.3%	
8	Promote technology transfer	10.2%	13.0%	14.2%	23.9%	11.5%	*
9	Separate science and religion	11.5%	5.3%	6.7%	10.1%	10.6%	*
10	Reform Intellectual Property law	4.9%	7.4%	3.3%	6.4%	5.2%	
11	Respect freedom to travel	3.6%	6.8%	7.5%	2.3%	4.0%	*
12	Respect freedom of association	3.3%	3.5%	6.7%	4.6%	3.6%	
13	None of the above would help my work	1.1%	2.1%	0.8%	2.3%	1.3%	
	*Cramer's V \leq .05						

Analysis – Open-ended question

In addition to the closed-ended items discussed above, the respondents were given the opportunity to answer the question “In your own words, how is the right to enjoy the benefits of scientific progress and its applications relevant to your work?” Of the total 3,462 responses that serve as the basis for the study, we received 2,115 answers to the open-ended question (61% of the total responses). Respondents in each demographic group generally answered the open-ended question in the same proportion to the questionnaire overall.

The responses to the open-ended question were analyzed using Dedoose, a web-based application designed for qualitative and mixed method analysis of qualitative data. A three-step coding process was

used. First, a set of deductively generated codes corresponding to the close-ended question response categories was applied. Then, an inductive coding approach was used to identify themes not well reflected within the close-ended responses. In the third step the final combined coding framework was applied across all responses, resulting in 8,889 tags.

The “benefits of scientific progress”: 1,192 respondents (56% of total respondents to the open-ended question) addressed specific benefits of scientific progress. Consistent with the high proportion of life scientists among the respondents, precisely one-third of these respondents (388) discussed science as promoting health. A further quarter of respondents (258) addressed science as underpinning public knowledge to inform individual decision-making. Science as benefitting environmental protection and serving as the basis for further scientific inquiry were also frequently mentioned (218 and 186 respondents, respectively).

Of all respondents to the open-ended question, 117 (5.5% of total respondents to the open-ended question) addressed the ways in which science is a general benefit to society and the different temporal and philosophical frames in which the notion of science as a ‘benefit’ can be considered. That scientific pursuits should benefit society was a point of agreement among all these respondents, how they differed was in the nature of the benefits they identified. While some respondents stated that science “must be related to the solution of societal real problems” (R:3868), many other respondents’ comments reflected an understanding of the benefits of science that include both theoretical, and practical elements, from “understanding the nature of things” (R:2961), to drug development and healthcare.

Those pursuing basic research expressed regret that the public does not understand how science (especially basic science) works. Their comments indicated that because it can take more time for basic science to achieve any tangible benefit, it is less valued, less fundable, and its benefits less obvious. Yet, basic science, they argued, is the necessary foundation for applied research, it “is the foundation to all other discoveries” (517), allowing scientists to “invest in two generations ahead” (R:3389). Even absent further applied relevance, basic research is “a benefit for the mind” (R:3920).

Empirical Basis for Law: 181 respondents (8.5% of total respondents to the open-ended question) addressed science as an empirical basis for law. The respondents saw science as an essential tool providing an evidentiary basis for regulations, policies, and laws. Respondents described the many ways that scientific advancements shape governmental policy on the local, state, national, and international levels, from the “understanding of birth defects and the effects of environmental impacts ... for developing population and environmental policies” (R:2794), to “researching the ecological impacts of climate change... providing a foundation for environmental policy and land management decisions” (R:73), to “identifying drugs of abuse... to inform policy as well as law enforcement” (R:1448). Finally, respondents stressed the importance of policymakers having access to current and reliable scientific knowledge in order to make informed policy decisions.

In a distinct subset to the benefit of science providing an empirical basis for law, 91 respondents specifically described the responsibility governments have to enact policy based on current and reliable scientific information. Respondents described the work scientists and experts put into research, disseminating findings, and developing policy suggestions based on scientific evidence. Respondents explained that when scientists fulfill their duty to disseminate scientific findings, policymakers have a corresponding obligation to use those findings to make informed decisions. Many respondents emphasized the importance of expanding science advisory teams in government offices with “experts capable of interpreting published articles to ensure a rational and logical debate and applied to national political issues” (R:2616). Of the respondents who addressed the government’s responsibility in promoting science-based policies, 18.7% came from individuals working in environmental sciences. As such, policies not based on empirical findings were seen among respondents as having potentially detrimental effects on humans and the environment, with examples provided from climate change, clean energy usage, air quality monitoring, and clean water supply.

Continuum of Access: An analysis of the responses as they relate to the points along the continuum of access gives rise to some potentially interesting findings that could be further explored. Respondents from Europe were almost twice as likely to address issues related to Access to Scientific Literature as respondents from North America

(8.17% and 4.48% respectively). More respondents from Latin America and the Caribbean addressed Access to the Applications of Science than Access to Scientific Knowledge and Information, and Access to Scientific Literature. The opposite was the case for respondents from North America and Europe.

Respondents from the environmental sciences (6.56%) and computer and mathematics (4.37%) were more than twice as likely as respondents from other fields to address Access to Data; and engineers were least likely to address funding (1.69%) as compared to all other respondents (4.37%-7.27%).



“Government policy makers make daily decisions that directly affect the lives of every citizen. My work provides factual information to support their decision making process increasing the probability that their decisions are informed and based on sound science rather than purely ideologically driven and that the resulting policies will have their intended effects benefiting each and every citizen.” (R:630)

Access to science and inequality: Respondents saw a binary relationship between science and inequality. At the same time as scientific research can uncover the causes of inequality and provide technological advancements that can lift populations out of poverty, unequal access to the fruits of science and technology and unequal exposure to unintended negative side effects can exacerbate inequality. One respondent noted, “I am a chemist, and I struggle with the unintended consequences of chemicals in society, especially the disproportionate exposure to hazardous chemicals based on gender, race, and socioeconomic status” (R:118). Respondents cited access to clean water, sanitation, health care, and pharmaceuticals as major scientific advancements that are frequently inaccessible to minority groups. Respondents discussed how unjust distribution and access to advances in science and technology can

create “vast inequalities that undermine societal stability and function” (R:873), exemplified through the way current “water supply security and wastewater treatment infrastructure separate the haves from the have nots” (R:3736). Government regulation was suggested by one respondent as a way to alleviate inequality, “science has the capacity to unlock a lot of good for a lot of people, but only if we have measures in place to ensure people actually have access to those advances” (R:2669).

Funding: 157 respondents (7.4% of total respondents to the open-ended question) discussed funding, particularly the responsibilities and impacts of government/public funding. “The public funds my work, they are absolutely entitled to a ‘return’ on that investment,” (R:1186) said one respondent. “Publicly-funded research findings MUST be available freely to the public. Government research findings should almost never be patented,” (R:1635) said another. Along a similar line, “My organization is funded by taxpayers, so it is appropriate that any of its products available to the public should be free or no more expensive than require to recoup production costs” (R:3676).

Several respondents discussed the research/funder-public relationship in terms of responsibilities. “My responsibility as a leader of a major U.S. government-funded research institution is to ensure we deliver exceptional value for the taxpayer funds received by the Laboratory in terms of outstanding science, innovation, and engineering relevant to national missions” (R:2665). Directly linked to the question of public funding for science were comments from a small number of respondents (21, 1% of total respondents to the open-ended question) emphasizing that funding for science depends on the public either benefiting from science or understanding science. Thus, one respondent argued, “I think it is our responsibility as federal civilians to dedicate a small portion of our time and efforts to educate the public on the work we do and why it’s so important” (R:2385).

Separation of Religion/Culture/Political/Economic: Religion and culture were both discussed as external biasing influences on the scientific process by U.S. based focus group participants. The respondents to the global questionnaire identified a broader range of potentially problematic external influences, including religion and culture, but also political and economic interests. Policies based on religion were seen among respondents as a hindrance to science, with contextual examples from evolution education, reproductive health, stem cell and gene editing research. Cultural attitudes towards vaccines and guns were cited among respondents as examples of the ways in which societal beliefs and values impede scientific research and successful dissemination to the public. Many respondents addressed the impact political bias or coercion has on scientists’ ability to conduct and disseminate accurate and reliable scientific research. Finally, respondents described the demand to create short-term economic impact by political figures, special interest groups, and large corporations as an obstruction of scientific progress because it increased the risk of biasing research in order to increase financial gains.

Truth and Bias: – 85 respondents (4% of total respondents to the open-ended question) addressed current trends towards what many described as, ‘fake news,’ or ‘false science’ claiming to be scientific fact, and

'anti-science rhetoric.' These impassioned responses often discussed in length the need to "eradicate scientific misinformation, confusion, or outright denial" of scientific evidence among the public (R:1205). Denials of evolution and climate change were examples provided frequently in the responses. Respondents often discussed religion, culture, politics, and economics as factors that drive misinformation within the public. Respondents described the need to apply critical thinking skills to differentiate between credible sources of scientific information and sources instilled with outside bias. One respondent emphasized that the current trend of keeping scientific journal articles behind paywalls "keeps science away from non-scientists who then get their information from industry rhetoric, politicians with an agenda, and their favorite fake "news" outlets" (R:146).

Scientists' Responsibilities: 114 respondents (5.3% of respondents to the open-ended questions) commented on the corresponding responsibilities that the right to science engenders for scientists. The responsibilities discussed included ensuring transparency, reliability, and validity of published research, disseminating results to a wide audience, and engaging with the public in an accessible manner. Respondents discussed how scientists' findings "should be presented to the general public in an accessible, digestible, and understandable form such that high school educated individuals can comprehend the information" (R:2742). Others discussed the importance of engaging the public beyond written publications, including forums such as galleries, lectures, and educational workshops.

The nature of the scientific endeavor--Building on the work of others: 96 respondents (4.5% of total respondents to the open-ended question) reflected on the relevance of the right to science to their work in the context of how they understood the scientific endeavor in general. Several respondents specifically quoted Isaac Newton, "If I have seen further, it is by standing on the shoulders of giants." These respondents expressed their view of science as not occurring in a vacuum but rather building on the work of others, whether those scientists who have gone before, or the knowledge generated by other relevant disciplines. Science, they said, "is a cooperate enterprise" (R:1024), "collaboration is extraordinarily important" (R:1230), "it enables me to learn from other fields outside of my own to see the world through other disciplines" (R:1230). To those ends, respondents linked the notion of building on former research and cooperation to the infrastructure necessary to support such collaboration, including "journals, conferences, personal exchanges, professional associations, and so on" (R:1024).

International collaboration: an important form of cooperation addressed by 69 respondents (3% of total respondents to the open-ended question) was international collaboration, including communicating and networking with international colleagues, working in international laboratories, conducting work internationally, and sharing specimens,

All of the major problems facing the planet have a science and technology component, and all will require international cooperation. The best thing we can do is promote scientific research and collaboration if we hope to come close to solving any of them" (R:2805)

materials, and data. Such collaboration was expressed as being vital to the progress of science but also because pressing global concerns “are not limited by borders” (R:1320).

Not relevant: Finally, it is worth noting that 59 respondents (2.7% of total respondents to the open-ended question) responded to the question “how is the right to enjoy the benefits of scientific progress and its applications relevant to your work?” with the answer that it was not relevant (engineers, and computer scientists and mathematicians were more than twice as likely as respondents from other fields to provide this response). While the number of ‘not relevant’ responses and their ilk is extremely small, some of the reasons given may be instructive when considering the messaging that is required to communicate the existence, meaning and significance of Article 15. While about half of the respondents who considered the right not relevant to them gave that answer because they are retired, others took issue with the suggestion that there is a “right” to science at all. “I think this ‘right’ is more of a ‘privilege’ allowed by a stable society” said one respondent (R:2292); “This fabricated ‘right’ is based on nothing more than the desire to steal the fruits of someone else’s intellectual labor” said another (R:2048). Others considered the right not relevant for reasons including that their work was classified and therefore not broadly available, and because their research “does not have immediate applications” (R:3122).

III. Periodic Reports of States Party

The States party to the International Covenant on Economic, Social and Cultural Rights are required to submit to periodic reports to the UN Committee on Economic, Social and Cultural Rights. Under articles 16 and 17 of the Covenant, periodic reports to the Committee must be submitted within two years of the entry into force of the Covenant for a particular State party, and thereafter once every five years. Since 2007, AAAS has been engaged in an effort to review all periodic reports to the Committee with the purpose of identifying any and all references to the right to science.

The objective of this component of the research was to use the tools of geospatial information systems to organize the information extracted from state reports and produce a comprehensive dataset that would lead to new insights about how states report their obligations regarding the right to science. A related goal was to create a spatial-temporal visualization of found patterns and relationships. This approach was chosen in order to explore the possibility that reporting patterns might vary by geographic regions.

The specific research questions addressed were:

1. How do countries understand their responsibility to promote the right to benefit from science?
2. Is there variation (in density of reporting, type of reporting) in reporting on the right to benefit from science across countries? Across regions?
3. Is the understanding of the right to benefit from science by states dependent on location?

4. Is there a significant association between understanding of the right to benefit from science and quality of life indicators?
5. Is there a significant association between state reporting and maternal and child health indicators?
6. Is a significant association between state reporting and country background characteristics (e.g., GDP, number of scientific publications)?

This component of the research was led by Drs. Patricia Carbajales and Natallia Sianko (both of Clemson University). With support and guidance of AAAS and the American Sociological Association, Carbajales and Sianko launched the project as part of a small, advanced-level undergraduate course titled “GIS for Public Health” in Fall 2016. During the semester the four students in the course worked with their primary advisor (Carbajales) and visiting instructor (Sianko) to meet project objectives. To streamline project activities, two teams were established with two students per team. Of note, given the public health focus of the course, both teams incorporated global indicators of public health into their primary analyses.

Methods

Overall, the data used for this part of the analysis belongs to two broad categories: (a) data pertaining to country ratification of ICESCR and reporting on the right to science; and (b) country background characteristics and public health indicators. The first category enabled initial exploration of the status of global reporting on the right to science, while the second category allowed exploration of the relationship between state reports on the right and public health characteristics of those states. (See Appendix C for sources of data.)

Data Preparation and Transformation. Excerpts pertaining to the right to science were extracted from state reports submitted to the Committee on Economic, Social and Cultural Right between 1992 to 2013 and pulled together into a single database. Of note, the analysis only includes states whose territorial boundaries and sovereignty were intact during 1992-2013. Any reports from states that did not fit that definition (e.g., transitioning states) were excluded but are available for separate analyses. Geographical background and country indicators were added to the database. The first step of data preparation involved transforming of the right to science excerpts to a tabular database, with numeric values assigned to the textual information. The tabular data was then joined to the GIS data which contained all of the countries of the world projected globally. The International Standard ISO 3166 was used to ascribe country codes.

Descriptive and Analytic Procedures. Descriptive and analytic steps included data exploration and visualization. Specifically, spatial distributions, numeric distributions, and trend analyses were conducted to explore data and identify initial patterns and relationships. Spatial distributions of the datasets were explored through the creation of choropleth maps created for each individual indicator. Further, numeric

distributions were visualized with the help of histograms. Finally, a trend analysis was carried out on each indicator in order to explore geographic trends (north to south or east to west) in the data on a global scale.

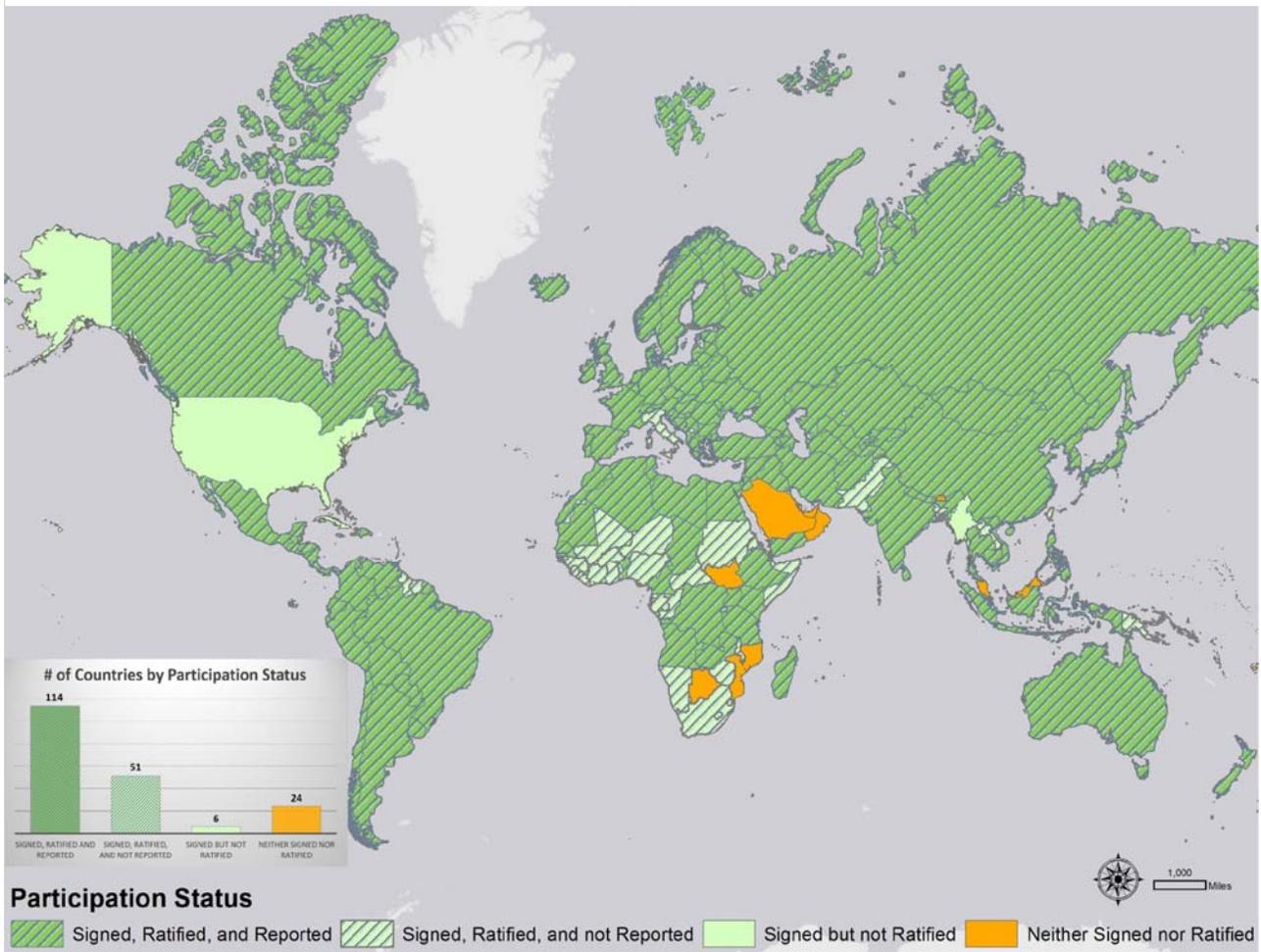
Additionally, a number of regression analyses were carried out to examine whether country characteristics could explain variation in state reporting. Country characteristics included: Gross Domestic Product; number of scientific and technical journal articles (including scientific and engineering articles published in the following fields: physics, biology, chemistry, mathematics, clinical medicine, biomedical research, engineering and technology, and earth and space sciences); and public health indicators (life expectancy, fertility rate, maternal mortality, and other).

Results

The Right to Science is Reported on but not Universally

In the period from 1992 to 2013, 114 states that are party to the Covenant reported on the measures they had taken to implement the right to science. In the same period, 51 states that are party to the Covenant did not report on any measures taken to advance the right to science. Map 1 outlines the global status of Article 15 reporting.

Map 1: Global Status of Right to Science Reporting
(Periodic Reports Data)



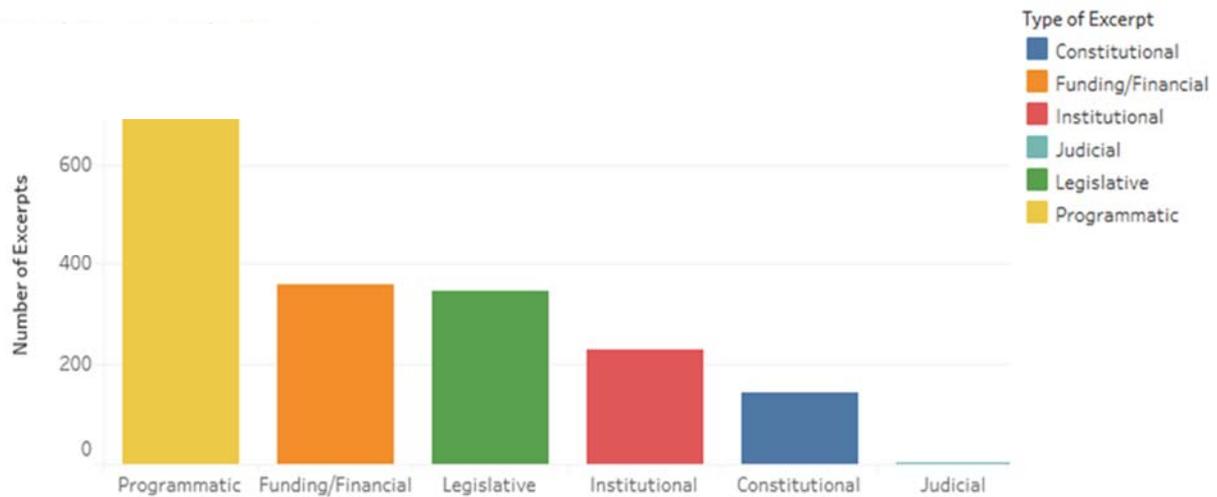
Diversity in State Reports on the Right to Science

The diversity in states’ interpretation of the right to science became evident early on. From a quantitative perspective, such diversity is evident in the frequency with which the right to science was mentioned. Some states reported as many as 45 government actions related to the right, while others (the majority of state parties thus far) only mentioned one or two specific measures adopted to implement the right. There was additional variation in what types of actions were mentioned.

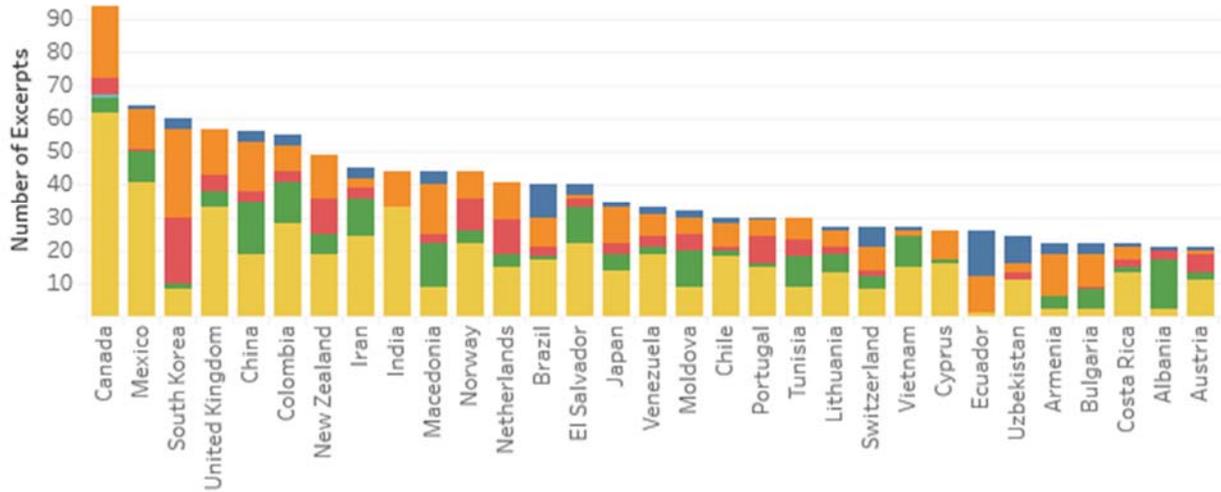
All Article 15-related government actions mentioned in state reports were grouped into six broad categories: constitutional, judicial, financial, institutional, judicial, legislative and programmatic. As can be seen in Graph 1, the most frequently reported actions (n = 745) were programmatic steps taken by states

with regard to implementation of the right. The second and third most frequently reported government activities were establishing or strengthening financial provisions for science (n = 358) and legislative activities to support science (n = 344). State reports less frequently provided information on institutional, constitutional and judicial actions to secure the right. Graph 2 includes countries that reported 20 or more government actions in response to Article 15. Of note, the majority of states (n = 60) mentioned ten or fewer activities with regard to right to science.

Graph 1: Total Excerpts by Type
(Periodic Reports Data)



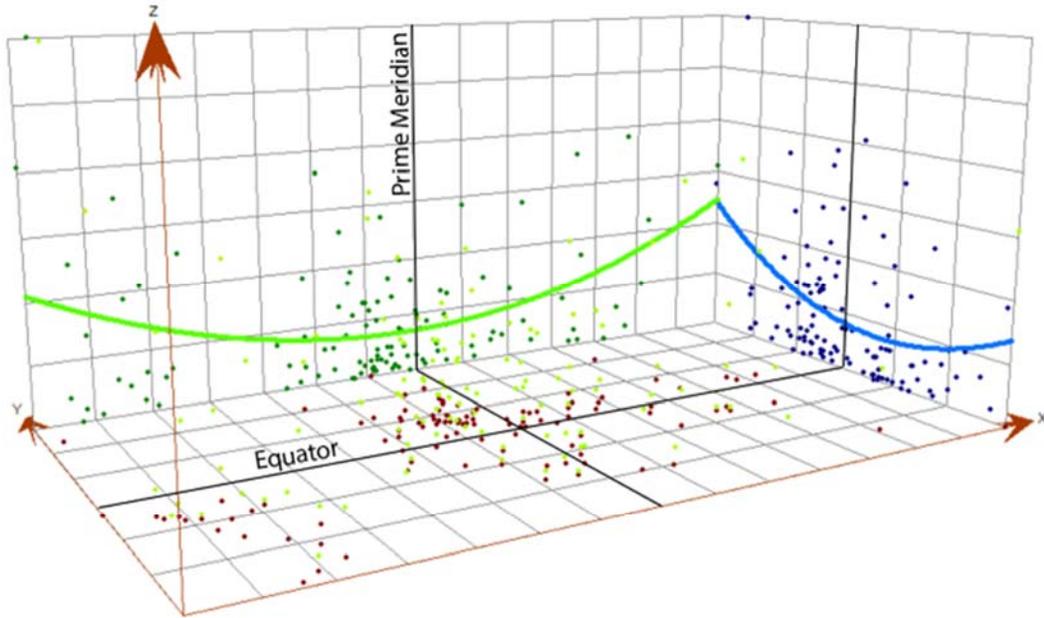
Graph 2: Number and Type of Excerpts by Country
 (Periodic Reports Data)



No Easily Discernable Geographic Patterns

Contrary to our expectations, application of quantitative assessments to state reporting on the right to science did not yield a clear pattern of geographic variation in states’ reports on their efforts to implement the right to science. Variation in the frequency of reporting was not explained by region or other geographic characteristics of the states. The ten states that reported the most measures to implement the right were in diverse regions. An exception was the trend analysis that revealed the number of excerpts decreased approaching the prime meridian and decreased approaching the equator (see Figure 1 below). It is clear, based on the data, that the low frequency of references to Article 15 in the reports of most Western European states and many African states accounted for the “dip” in the projected lines. However, what accounts for the low reporting in these countries is beyond the scope of this analysis.

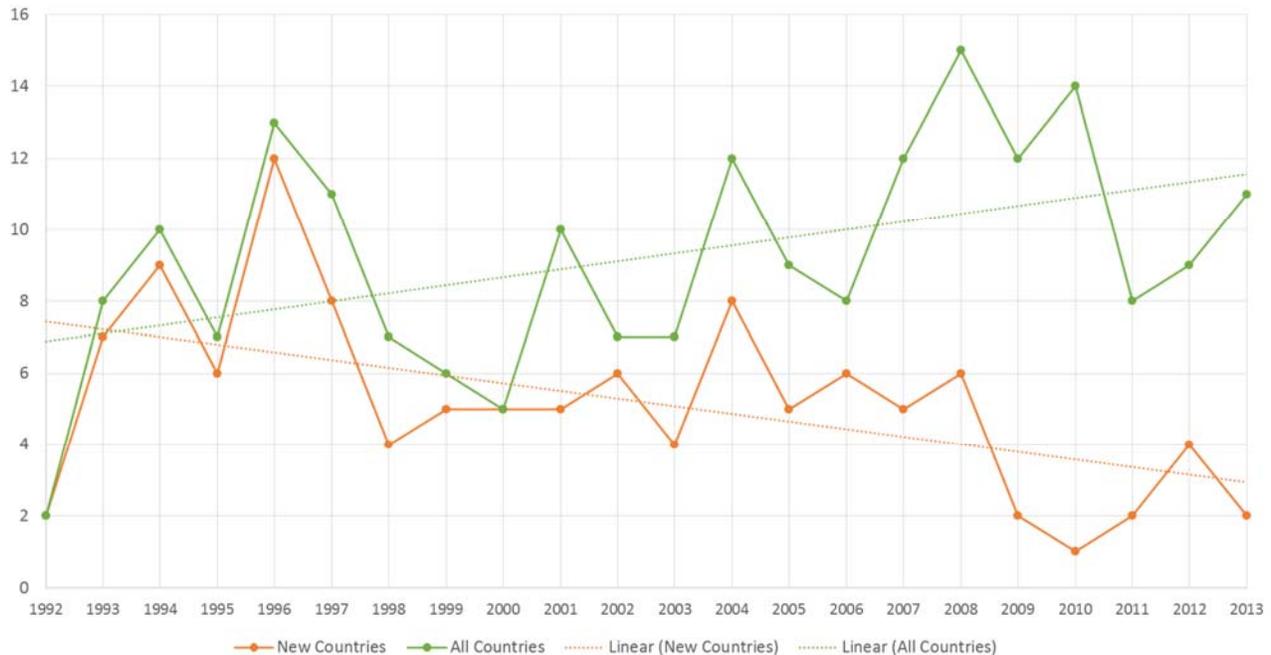
Figure 1: Frequency of references to the right in state reports
(Reports Data)



Changes in Reporting over Time

There has been an increase in the reporting on the right to science over time, with a decrease in the number of countries reporting on the right for the first time (Graph 3 below).

Graph 3: First-time reporting vs subsequent reporting - Countries
(Periodic Reports Data)



State Reporting and Country Characteristics

Two sets of country characteristics were analyzed with the goal of identifying similarities and differences among countries that displayed similar reporting activities. They were: (a) general country indicators (GDP; scientific and technical journal articles) and (b) public health indicators (maternal mortality rate, infant mortality rate, fertility rate, life expectancy at birth, undernourished % population). In the first category, country GDP was correlated with state reporting (the correlation was approximately .34). Similarly, the number of scientific and technical journal articles was positively associated with the number of references to right to science in state reports ($r = .32$). Surprisingly, no significant associations were found between public health indicators and state reporting.

Limitations and Directions for Future Research

Several limitations are worth noting. Operationalization of states’ commitment to the advancement of the right to science could be considered a limitation. As demonstrated in the results, data from states’ reports were primarily used to create count variables representing the frequency with which states reported on specific actions in relation to the right to science. Considerations regarding the varying social or scientific significance of specific state actions were not reflected. This approach resulted in a variable that could

potentially be biased, depending on how states initially reported and organized the reported information. A related limitation deals with categorization of excerpts. While useful for a general snapshot of state reporting activities, a more thorough analysis was not within the scope of the current effort. As noted in the Results, the Programmatic category was the most popular measure reported by states. Given the high frequency of this measure, a more nuanced categorization of programmatic aspects of implementing the right to science would be beneficial.

Additionally, the impact of reporting periods was not considered to a full extent. For example, some countries submitted one report, while other have done so two or more times. For the purpose of this analysis, all information from multiple reporting periods was pulled together. Future reviews of state reporting would usefully take into account the number of reports submitted by states. The approach to the multivariate analysis also presents some limitations. As described, a number of simple linear regressions were chosen to examine associations between state reports and country characteristics. Given the nature of the state reporting variable, a different approach to analyzing these data might be more suitable.

Furthermore, country indicators and reporting years were not matched for this analysis. Where possible, the most recent data with country characteristics were used. However, the possibility of a discrepancy between reporting cycles and country characteristics may have introduced additional bias. Therefore, results should be interpreted with caution.

Several directions for future efforts are suggested. First, there is a need for an alternative way to organize and process information from state reports. The present format of reports (PDF or Word copies) prevents conducting even basic quantitative assessments and requires much effort to transform the information into formats that would allow some quantitative exploration. Although the narrative nature of reports remains critical for monitoring efforts, it would be beneficial to explore options to design a database or data repository that would contain quantitative aspects of state reporting, such as year of reporting, number of efforts reported, amount of resources dedicated to selected or all efforts, who participated or benefited from those efforts, and other facts. Such a repository would complement the primary reports from states and NGOs while also allowing a more efficient quantitative analysis.

Second, efforts should be aimed at exploring options for creating an index measure of the right to benefit from science. For example, an index can be created by combining information from different aspects of the right.

Finally, consideration of reporting periods and cycles and especially changes that might have taken place between different reporting periods in the same states is critical. Efforts should be made to capture and clearly identify the information that builds on previous reports. Where possible, it is important to

acknowledge, as part of state implementation efforts, whether feedback from Committee from previous reporting cycles has been incorporated in subsequent state reports.

IV. Interviews with Public Health Advocates

For the right to science to have practical significance, it must provide a useful framework for policy development and analysis, advocacy, monitoring, and evaluation. To determine the extent to which the right would provide this type of framework within a specific context, we conducted five interviews with public health advocates. Specifically, we were interested to understand the implications and applications of Article 15 for public health and access to medicines. The five interviewees were Peter Maybarduk (Public Citizen), Judit Rius Sanjuan (Médecins Sans Frontières - MSF), Yannis Natsis (the European Public Health Alliance – EPHA), M.R. Rajagopal (Pallium India), and E. James Packard Love (Knowledge Ecology International - KEI). Interviewees were chosen from among grantees of the Open Society Foundation, with a focus on individuals and organizations working in public health and access to medicines. The interviews lasted approximately one hour, were conducted over the phone, and were recorded. Each participant gave explicit consent to be recorded, and for their name and organization to be recognized publicly for their participation in this project. See Appendix D for biographical details of the interviewees.

Common and Divergent Themes

A. The Usefulness of a Human Rights Framework

Interviewees were divided as to whether framing access to medicines and treatment as a human rights issue was helpful in their work. Yannis Natsis (EPHA) equated the innovation crisis in the European Union to a social justice and human rights issue. “It is a question of inequities within society. It is a question of human rights at the end of the day because national governments are unable to serve the needs and rights of their own citizens. When they impose very severe and restrictive policies in order to safeguard the sustainability of their public health care systems, this is unacceptable. You know there is a cure and you know the cure is sitting on the shelf but you cannot afford it. So, we do emphasize the human rights/social justice dimension.” He went on to say that this frame was useful because of its universality. It demonstrates that these are far reaching issues which gets many stakeholders on board.



“It is a question of human rights at the end of the day because national governments are unable to serve the needs and rights of their own citizens. When they impose very severe and restrictive policies in order to safeguard the sustainability of their public health care systems, this is unacceptable. You know there is a cure and you know the cure is sitting on the shelf but you cannot afford it. So we do emphasize the human rights/social justice dimension.”

Yannis Natsis (EPHA)

Dr. Rajagopal (Pallium India) sees access to pain relieving medications as a human right. He echoed the theme of universality, citing its appeal to all people equally. In his view, human rights also establish credibility for claims that barriers to access are wrong. “We grow the poppy, we sell opium to the rest of the world, and deny it to our own people who are writhing in pain. And what appealed to me most about you educating me about Article 15 is that that makes it so obvious. The scientific knowledge is there, the materials are there, it is simply not applied.”

Judit Rius (MSF) explained that MSF is quite familiar with the humanitarian legal framework. She hopes that governments will use the human rights framework and norms to inform their decisions, and increase policy coherence so it is better aligned with the human right to health. Here, human rights may have a place. If a notification goes out from the federal to state governments saying that access to pain relief is a human right, the lack of which violates people’s right to dignity, and their right to access existing scientific and medical knowledge, then states will have the clear obligation to make this essential medicine accessible both by providing it and by empowering medical professionals to provide it.

In many cases the same interviewees who found some positive aspects of a human rights framework, also expressed challenges to using the framework in their field. For Dr. Rajagopal, his concern was less with the framework itself and more with the fractious relationship that many human rights activists and organizations have with national governments. Other concerns about the human rights frame included the lack of recourse for responding to violations of human rights. Peter Maybarduk (Public Citizen) pointed out that there will always be efforts to create binding trade agreements that may or may not conflict with human rights. Trade agreements are binding and they include dispute resolution mechanisms. Human rights may have the same level of agreement, but no mechanism for enforcement. If pharmaceutical companies have a complaint, they have specific mechanisms for airing their grievances and taking legal action. This is not the case with human rights. Ideally, these agreements would both hold equal weight and have the same types of legal mechanisms to encourage compliance. James Love (KEI) also sees lack of enforcement as a major limitation of the human rights framework. In his evaluation, the current system of scientific innovation and intellectual property has produced massive global health inequalities that will not be addressed through a human rights framework that lacks enforcement.

B. Areas of Advocacy Focus Relevant to the Right to Science

B.1. Emphasis on development over research

Natsis noted that the way that the current system for medical innovation emphasizes the financial rewards of development over the benefits of research. “We see that most big pharmaceutical companies are not even doing R&D, they are only doing development. They are going around scouting and scanning the horizon to buy different companies... mergers and acquisitions is a big thing in pharma right now. It is the new business trend; to buy small labs and startups.” One example he gave was that of Sovaldi, a treatment for Hepatitis C, which costs \$1,000 per pill. Gilead, he said, bought a start-up that had developed the drug

with public funds. Gilead did not have to invest in the research underlying this product, yet it has brought the company USD \$35 billion in two years. Indeed, as Natsis noted, the price of the drug may not have anything to do with how much money it cost to create. Love also cited the imbalance between development and research in the pharmaceutical industry. He noted that large pharmaceutical companies grow not through the discovery of new drugs, but through acquisitions and manufacturing. Individual entrepreneurs (i.e., start-ups) and universities do not have the capacity to perform such large scale manufacturing, so they sell their research to larger companies.

B.2. Public Funds, Private Products

One of the biggest contradictions noted by Natsis, Love, and Rius is of public funding provided for drug research benefitting private entities. Natsis described it as a paradoxical system where “public money is going to private pockets”. To him, Article 15 has to do with society being able to reap the benefits of scientific research for which it has paid. Universities, start-ups, and public institutions pay for research, pharmaceuticals buy the innovation and patent it, and then the public pays again to get the medication. Rius related this concept to governments and citizens fully benefitting from the moral and material interests of public investments – the National Institute of Health (NIH) is one of the biggest funders of scientific research in the world. The private sector plays an important role, but so do other entities. It is important to respect all of their material interests.

Love gave an example of work that his organization is doing to drive down the price of a prostate cancer drug which costs \$130,000 in the U.S., and about \$40,000 in other countries. The drug was developed at the University of California Los Angeles (UCLA) with federal grants from the U.S. Army. Love’s strategy and that of KEI’s allies includes petitioning the federal government to take actions to exercise its "march-in" rights and license the patent to other companies, thereby, disrupting a lucrative monopoly. KEI is also working to prevent the Army from granting an exclusive license to patent a new vaccine for the Zika virus, largely because all the research and development for it has been funded by the U.S. government. Love noted that it is inappropriate for taxpayers to fund R&D and then buy the product at high costs so as to again incentivize the research and development.

B.3. Neglected diseases

Rius argued that monopolies and high prices have spurred some important innovation, but not the general enjoyment of the benefits of scientific progress. This is because when the expectation is that a market will not withstand high prices or lead to high profits, there is less incentive to innovate and produce. This is evidenced by the lack of research into many neglected diseases that disproportionately affect the poor, as well as the lack of research on new antibiotics. Because they should only be used sparingly in order to avoid decreases in effectiveness, companies have no expectation of widespread or chronic use and thus have little incentive to develop new antibiotics even though they are much needed. Love echoed this sentiment,

noting that Africa shares only 1% of the total pharmaceutical market. Why would a company invest resources into developing drugs for a market that guarantees such low potential for returns?

Natsis also raised the concern about unexplored biomedical areas because of the lack of financial incentive. There are many drugs for cholesterol, and impotence, and lifestyle diseases because these provide easy, predictable revenue and large profits to pharmaceutical companies. Similarly, disproportionate investment goes into treatments for the terminal stages of cancer based purely on financial reasoning.

B.4. Non-traditional incentive structures

Rius suggested that other motivating factors, beyond profit, do exist for drug and treatment development and can be mobilized with appropriate policies. Profit is one incentive, but there is also the motivation to save lives and help people. There are ways to reward people besides granting a monopoly, which has the undesirable outcome of greatly limiting access as well as follow up innovations. Indeed, she noted that other areas of science do not rely on monopolies to drive scientific progress and innovation. Offering prize funds and grants with access conditions can delink the costs and rewards for innovation from the price of products developed. She argued if these approaches were applied to biomedical innovation it would greatly increase the production and availability of affordable treatments, diagnostics and vaccines to meet global public health needs. She clarified that in her view there is nothing wrong with making money, but it is not the only thing that drives people to do the work they are doing and there are other ways to ensure that innovators are appropriately and generously compensated financially. Her research suggests that eradicating monopolies and their corresponding high product prices need not have a large cooling effect on the industry and can still provide mechanisms for recouping the costs and risks of innovation.

C. *Limitations on the Right*

C.1. Access to Knowledge

According to Natsis, subparagraph 1(b) of Article 15 that states that everyone has the right “to enjoy the benefits of scientific progress and its applications” is not only about access to medicines (or other applications) – it is also about access to knowledge. It is about sharing the wealth of scientific research that is produced, and immediately privatized by publishers who place it behind paywalls. This restriction on access to scientific knowledge inhibits innovation in his view, and contributes to siloing in the realm of biomedical knowledge because of the “tremendous shroud of secrecy” that covers each research institution’s work. Natsis’ seeing institutions as including both companies and universities. This dynamic inhibits exchange of information and knowledge, which in turn restricts innovation. He explained that this was why the goal at the European Public Health Alliance is less about giving everyone medication and more about restructuring the entire system to be more open and innovative, which will lead to better public health.

Maybarduk's take was similar. He noted that one way the language of Article 15 could be understood is it to mean that people should have the right to share and use clinical research data in a timely fashion. Having the complete record of the results of clinical trials is crucial to public safety. This would also do a lot for innovation -- research information can be pooled to help develop new product lines -- and help protect people from unsafe products (i.e., the companies know a lot more than the regulatory agencies do). However, rather than arguing for access alone as a principle, Maybarduk said that we should be thinking about bringing better products to markets. Sharing inputs -- the research -- benefits innovation and safety, while sharing outputs -- the products -- benefits access.

C.2. Access to treatment and medicine

Access to treatment and medicines is inhibited by high costs, which in most cases are created by monopolies. Dr. Rajagopal is primarily concerned with the availability of scientific knowledge and the material products created based on that knowledge. Essential pain medicines could be made available to three-fourths of the Indian population (they are currently available to >1%) with the existing knowledge available. Cost is one of the biggest barriers. Intellectual property laws and the restrictions they impose do not concern him so much in this context because these medicines and knowledge are not new or under patent. "Most of the pain burden can be alleviated with locally available inexpensive medicines. This is what we want. And we have the tool. The only thing is that we need to learn to use that tool effectively."

"Most of the pain burden can be alleviated with locally available inexpensive medicines. This is what we want. And we have the tool. The only thing is that we need to learn to use that tool effectively."

Dr. Rajagopal (Pallium India)

High cost as it relates to patenting was discussed by other interviewees. Love spoke about this issue, but more specifically as it relates to intellectual property: "Intellectual property rights are restrictions on freedom to make, sell, and distribute drugs. So if the U.S. puts pressure on another country to grant patents and not issue compulsory licenses, it is not just a question of there not being enough money to go around - we are deliberately making something more expensive than it has to be. We are taking away the freedom of people to make a drug that can save their life." Natsis said these restrictions are generating large scale political will in Europe to redress the problem. Several EU members have strict health care rationing systems, making low cost crucial for treatment to be approved.

Maybarduk also noted the difference between benefitting materially and having a monopoly. "It should be understood that 'material interests' is not an unlimited concept. To benefit materially does not necessarily mean you should have total freedom to charge whatever you want for an aspect of culture or science... We don't want 'c' [protection of moral and material interests] at the expense of 'b' [enjoyment of the benefits of scientific progress and its applications]." To him, it is important for scientists and artists to be motivated

to pursue what they are passionate about, but this is different than getting rich or having total control over something vital like life changing technologies.

Rius also addressed this point, noting that the “author” who should benefit materially from their discoveries, under Article 15, is the researcher. Yet, individuals sign their rights over to a corporation, which stands to benefit from the individual researchers’/scientists’ work. Because we are discussing ownership and authorship in the context of human rights, Rius thinks that the focus should be on ensuring the rights of individual researchers are respected. Currently, the legal frameworks for conducting research and achieving scientific advancement are generally designed by and for corporations, largely to their benefit.

D. The Role of National Governments

Interviewees were unanimous in asserting that governments play an important role in ensuring access to medicines and treatment. As Love puts it, “states have a responsibility to ensure that medicines are available to everybody, regardless of their income.” Rius also noted the significant role governments play. “Governments have created the current innovation system. Governments create norms and incentives to promote innovation; governments pay for research and for the outcomes of these research. And at the end of the day all stakeholders, be they public or private innovators or companies or researchers, everybody behaves or reacts to a policy environment that the government has created.” She went on to note that even free markets are created by governments (i.e., if the government decides not to regulate, that is still a governmental decision).

D.1. Policy Solutions

Suggestions for governmental reform varied by interviewee. For Dr. Rajagopal, advocacy and legislative solutions are crucial. Pallium India was instrumental in the Indian national government’s adoption of the National Program for Palliative Care (2012) and a 2014 Amendment to the Narcotics and Psychotropic Substances Act. This Act classified pain management drugs as “essential” medicines. The next step is for the 29 state governments to implement this policy. Dr. Rajagopal provides free medicines to patients through his organization, but thinks that if he expects this from the government it would be a major argument against the provision of palliative care. He, therefore, advocated for the government to class pain medications as essential. “All it will take is the political will to make this a priority. But in most of our countries that doesn’t happen because unless you have experienced pain, you don’t really see it as a problem.”

“Governments have created the current innovation system. Governments create norms and incentives to promote innovation, governments pay for research and for the outcomes of this research. And at the end of the day all stakeholders, be they public or private innovators or companies or researchers, everybody behaves or reacts to a policy environment that the government has created.”

Judit Rius (MSF)

Other interviewees argued for more systemic policy change focused on the incentive structure for research and development. Love is a proponent of government provided cash prizes to incentivize research, as opposed to monopolies and high product prices. KEI is proposing a new system where the government would provide these large cash prizes to whoever can develop an effective treatment or medicine, and the drug would remain generic. Love argues that this approach would incentivize competition and spur innovation, while ensuring equal access to a medicine or treatment. The money would no longer come from the patient; it would be built into the budget of the health care system.

Rius also spoke of open innovation models as the next steps in policy reform. To her, the resolution that respects the conservation, development, and diffusion of medicines, diagnostics, and vaccines is an open innovation model where innovators are rewarded through upfront investments in research and development rather than monopolies and high prices charged to patients in need of access to life-saving treatments. Such a model, she argued, would be achieved by delinking the initial investment of research and development from the resulting product's price. She said that the money could come from both public and private funds, as it does now, and that the public would still need to pay to sustainably fund future innovation. The difference is that prices would remain affordable because a monopoly would not be the main way to fund research. "We need to make a system where needs-driven innovation and affordable prices are not so delayed because of the prohibition of competition."

Another commonly suggested policy reform was to require the reinvestment of profits back into research and development. Love noted that pharmaceutical companies currently only reinvest between 10%-15% of their profits to fund future research. To him, states have the capacity to reinvest a much larger portion of the profits into research and development. Natsis also asserted that there should be conditions attached to funds that are provided for the public interest (i.e., by government agencies funded by taxes). These conditions would require those receiving funds to reinvest a large percentage of profits back into research, and require that any resulting drug be sold at an affordable price. He further noted that transparency legislation, including Sunshine Acts, pertaining to pharmaceutical companies are an important part of reform, and should also be part of the conditions attached to public funds. This would work to eliminate the shroud of secrecy under which pharmaceutical companies currently operate, and would ensure that public funds are used to the public's benefit. Natsis also suggested that states should start this process by investing more public money into research and development, so that they have a say in the price of the product. Love also made this suggestion, arguing that the NIH specifically should expand the types of research that they fund.

E. The Need for International Collaboration

Natsis was enthusiastic about the ability of international cooperation to balance the power dynamic in the European Union between individual states and multinational pharmaceutical companies. Pharmaceutical companies have vast amounts of information about all of the countries in which they operate, but the

respective countries know little about each other. This gives companies significant power and leverage. Thanks to efforts of his organization, “countries are now sitting at the same side of the table with the pharmaceutical companies on the other. This is a game changer.” According to Natsis, over the last two years EU member states have come out of their comfort zones to work together, trading information that traditionally would have been concealed. EPHA and EU states are working to combat the trend of “sky is the limit” drug pricing through such collaborations.

Dr. Rajagopal also saw international cooperation as an important approach, especially between and among organizations. He has worked for 20 years with a pain studies group in Madison, Wisconsin, for example, analyzing policies conducive to accessible pain medication. He has also worked extensively with Human Rights Watch (HRW). In 2008, HRW came out with a report recommending the International Narcotics Control Board (INCB) visit India, which started a discussion about pain relief. The INCB has repeatedly recommended to the Indian government that it improve access to and standards of pain relief within the country by making opioids available. This pressure has supported Dr. Rajagopal’s work. According to Rajagopal, this is part of the reason why Article 15 is beneficial to Pallium India. If the UN treaty-monitoring body were to make note of the fact that the Indian government is not using existing scientific knowledge to make essential medicines available to their citizens, this would hold some authority. Then, if the central government makes changes based on this pressure, then states must respect these changes as well. For example, if the Medical Council of India makes a change to their curriculum then all other medical universities must also legally make this change. He noted that a single collaboration does not change things overnight, but consistent international efforts can start to change attitudes and priorities of governments. He also cited funding organizations, like OSF, and international media as being crucial to upholding human rights and promoting change.

Love spoke of an overhaul of the current international trade system, similar to that which he suggested for national governments. He proposed that countries sign on to an international agreement and use funds from their health care budget to eliminate the monopolies on drugs, especially those for cancer treatments. This agreement would then obligate states to set aside a part of their health care budgets for future research and development. Ideas for systems like this are not new; iterations have been put before the World Health Organization since 2002. He pointed out that this system still respects authorship rights and benefits those who discover a medicine or treatment, but ensures at the international level that drugs remain affordable. In other words, the goal shifts from maximizing profit to maximizing access. Such international trade agreements, he argued, would counter those currently in place, which largely exist to ensure high prices of a drug rather than to fund future research and development.

Maybarduk’s work at Public Citizen initially focused on overcoming patent barriers to access to medicines. One example of this is the use of the compulsory licensing mechanism provided under the World Trade Organization’s Doha Declaration, which permits countries to import or manufacture a patented drug for reasons of public health in exchange for royalty payments to the patent holder, under the terms of the

Trade-Related aspects of Intellectual Property Rights (TRIPS) agreement. Small countries often have little expertise in international laws and need foreign law experts to navigate the agreements and their provisions. Even with technical assistance, governments must contend with pharmaceutical companies that vigorously defend the restrictive rules. Governments are hesitant to exercise their rights under more flexible provisions because of political opposition and repercussions and, according to Maybarduk, the World Intellectual Property Organization (WIPO) is biased towards implementing the tougher rules that favor license holders.

For Rius, the current innovation system directly contradicts subparagraph 4 of Article 15, which states that States Parties must recognize the benefits to be derived from international contacts and cooperation, because it is fundamentally centered on non-cooperation and keeping scientific progress secret. She mentioned proposals being made at the World Health Organization to start negotiating a global treaty to empower governments to better shape their health R&D agendas and increase the efficacy of the innovation system.

Finally, one of the most consistent messages from interviewees was that the seemingly tension-filled relationship between subparagraph 1(b) and 1(c) of Article 15 was not inevitable or inherent. In the system under which medicine and treatment is currently allocated, it seems that protecting material interests and allowing access would be at odds. But four of the five participants who worked in this area agreed that there are clear, logical steps to be taken to reconcile the goals underlying each provision, but that first what is required is a redrawing of the current relationship between publicly funded research and private development.

V. Briefing of the UN Committee on Economic, Social and Cultural Rights

On February 22, 2017, Margaret Weigers Vitullo and Jessica Wyndham led a briefing of the UN Committee on Economic, Social and Cultural Rights on the subject of 'The Right to Science.' The briefing was co-hosted by Mikel Mancisidor, who is the Vice-Chair of the Committee and the person responsible for preparing a draft General Comment on Article 15 for consideration by the Committee. The briefing was attended by the majority of the Committee members, in addition to staff of the Committee Secretariat, Office of the High Commissioner for Human Rights, and an observer from the Associazione Luca Coscioni.

Vitullo and Wyndham presented their research on the meaning of the right to science as reflected in this report. The discussion after the formal focused on areas for further in-depth research, as well as the challenging conceptual questions with which the Committee is grappling as it works towards adoption of a General Comment.

Areas for further research

- Comparative differences in the conception of this right, including the perceived benefits of science, in the developed and developing worlds;
- Good practices in integrating science in policy making;
- Protections needed to ensure freedom of science;
- Support structures needed to encourage and facilitate scientific research.

Challenging conceptual questions

- What are the tensions between conceptions of science as requiring technical, formal training and traditional knowledge and practices?
- How can the right be used to assess and address potentially harmful impacts of technological developments? What legitimate restrictions can be placed on science to prevent harm in the doing of science and the application of scientific knowledge?
- How can the role of the commercial sector in developing medicines and other products be reconciled with the government funding that underpins the research on which such products are based?
- Should the right be conceived of as a right to contribute to science and/or a right to benefit from science? What does it mean in practice for the right to be conceived of one way or the other?
- What does ‘science’ mean as a right when science encompasses basic and applied sciences, “hard sciences and ‘other’ sciences”?

VI. Conclusions and Next Steps

The findings reported here represent the most recent contributions of the AAAS Science and Human Rights Coalition toward informing the United Nations process of defining the right to enjoy the benefits of scientific progress. The report builds on earlier research to bring insights of the scientific, engineering, and health communities globally to the ongoing deliberations about the meaning of the right, its significance as a human right, and its value as a tool for supporting the scientific endeavor and promoting equitable access to the fruits of scientific research and technological development. To the best of our knowledge, the present report is also the first effort to organize and analyze from a quantitative perspective the information contained in State periodic reports to the UN that specifically reference the right to science and the efforts states party are reporting as indications of their actions in compliance with and interpretation of the right to science.

This project reinforced the value of the earlier focus group effort undertaken by the AAAS Science and Human Rights Coalition, particularly the relevance and usefulness of the ‘continuum of access’ as a

conceptual tool for understanding the right to science in practice. The results from the global questionnaire revealed that discipline of the scientist was the demographic variable most greatly associated with differences in opinion about the benefits of science. While the questionnaire did reveal some differences in perception about the relative benefits of science and the importance of certain government actions required to fulfill the right, overall, scientists across regions converged in their views. The analysis of the state reports, similarly, did not reveal regional trends. Rather, GDP and the number of scientific and technical journal articles were most strongly correlated with the level of reporting on the right to science.

The practical value of the right to science as having the potential to influence national and international policies and practices, specifically with regard to public health, was recognized by some public health advocates and not by others. The prevailing systems of drug development and health service provision are not oriented toward universal public access in most instances, even when public funding supported the underlying research. Those with a primarily national focus saw strategic value in the existence of the right to science as a framework for recommending policy and programmatic reforms and interventions. However, those with a more global and multilateral perspective expressed skepticism about potential for the right to science to be used to advance public health and access to medicines.

The UN Committee on Economic, Social and Cultural Rights continues in its efforts to develop an authoritative statement on the meaning of the right to science, while countries that are a party to the relevant treaty are increasingly reporting on their actions to implement the right, as they interpret it. Questions of interpretation remain, as identified by the Committee in the briefing held in February 2017. Those questions go to the core of what science is and, therefore, what should be promoted and protected through the right to science. Those questions also recognize that science must be conducted responsibly and, if not, may violate human rights. For these questions to be answered and the right to have meaning and impact in the lives of individuals and communities, the continued contributions and engagement of scientists, engineers, health professionals are vital.

Next steps

The results of the project will be disseminated at the July 2017 meeting of the AAAS Science and Human Rights Coalition which will focus on Article 15, bringing diverse scientists together to further explore the implications of these findings. A webinar for health advocates is also planned in the coming months that will provide an overview of Article 15 and these findings, as well as a discussion of the potential of Article 15 as a frame for advancing public health and access to medicines.

This project gives rise to three further lines of inquiry:

- (1) Development of a robust global survey instrument allowing validation of the findings of the questionnaire, particularly with regard to the unique perspectives of scientists in developing countries, and scientists in industry as compared to those in the public sector.

- (2) Exploration of the challenging conceptual questions that have arisen in the course of this project, including the specific questions with which the U.N. Committee is grappling.
- (3) Identification of scientists' views on the relationship between Article 15 1(b) – the right to enjoy the benefits of scientific progress and its applications—and Article 15 1(c) the right to benefit from the moral and material interests resulting from any scientific production, specifically, reward, recognition and incentive systems in science and how these can complement and support the right to science.

VII: Appendices

Appendix A: Questionnaire

1. In which of the following fields do you work?
 - Computer sciences and mathematics (e.g., logic, statistics, systems analysis)
 - Engineering (e.g., chemical, mechanical, civil or electrical engineering; bioengineering; and metallurgy)
 - Environmental sciences (e.g., atmospheric sciences, geological sciences, oceanography, paleontology)
 - Life sciences (e.g., agricultural sciences, biology, botany, environmental biology, medicine, nutrition)
 - Physical sciences (e.g., astronomy, chemistry, physics)
 - Social and behavioral sciences (e.g., anthropology, economics, linguistics, political science, psychology, sociology)
 - I am not a scientist, engineer or health professional

2. What is your current employment status?
 - Full time
 - Part time
 - Unemployed
 - Student
 - Retired

3. In what sector do you mainly work?
 - University or college
 - Primary/secondary school education
 - Government
 - Industry/commercial
 - Non-profit organization
 - Research institution
 - None of the above

4. Gender:
 - female/woman
 - male/man
 - A different identity (please specify) [*with text box*]

5. Age:
 - Under 30
 - 30-39
 - 40-49

- 50-59
- 60-69
- Over 69

6. In what region do you currently reside?

- Africa
- Asia
- Europe
- Latin America and the Caribbean
- Middle East and North Africa
- North America
- Oceania

7. How does (or will) your work in science, engineering, or the health professions benefit society? Please select up to three benefits from the list below.

[randomize response categories in survey; set maximum number of selections to 3]

- Contributes to economic development
- Promotes health (including illness prevention, treatments for mental and/or physical conditions)
- Protects the environment (including ecology and climate)
- Assures safety/effectiveness of the built infrastructure
- Provides a way to transcend national/cultural divides
- Contributes to national security
- Strengthens the justice system
- Provides an understanding of social patterns including attitudes, behaviors, preferences
- Combats social inequality and discrimination
- Provides an empirical basis for laws, programs, policies
- Advances knowledge of scientists and their capacity to advance science
- Advances knowledge of the general public to inform individual decision making
- My current professional work does not benefit society
- Other: please specify *[open ended text box, should always come last]*

8. Listed below are a variety of things that governments can do to support the advancement of science, engineering and the health professions. If you could persuade the government of the country where you currently reside to do up to three of these things, which three would most support the advancement of your current professional work?

[randomize response categories in survey; set maximum number of selections to 3]

- Ensure open access to scientific information
- Reform intellectual property law
- Provide adequate science education to the general public
- Increase funding for scientific infrastructure and research
- Ensure reasonable costs for treatments/products that arise from scientific findings

- Establish a separation between the scientific enterprise and religious/cultural institutions
 - Promote a positive view of science and scientists among the public
 - Protect freedom of travel
 - Protect freedom of speech
 - Protect freedom of association
 - Promote technology transfer
 - Promote and protect academic freedom
 - None of the actions listed above are needed in order to advance my current work.
9. In your own words, how is the right to enjoy the benefits of scientific progress and its applications relevant to your work? [*limit 500 characters*]

Thank you for completing this survey.

Appendix B: Questionnaire responses, demographic tables

	Count	Percent
Gender		
female/woman	1167	33.9
male/man	2262	65.7
A different identity	12	0.3
Age		
Under 30	405	11.8
30-39	486	14.1
40-49	391	11.4
50-59	533	15.5
60-69	749	21.8
Over 69	876	25.5
Employment status		
Full time	1954	56.6
Part time	262	7.6
Unemployed	64	1.9
Student	381	11.0
Retired	793	23.0
Sector		
University of college	1896	54.9
Primary/secondary school	42	1.2
Government	330	9.6
Industry/commercial	501	14.5

	Non-profit institution	255	7.4
	Research institution	255	7.4
	None of the above	173	5.0
Field			
	Computer science & math	260	7.5
	Engineering	270	7.8
	Environmental sciences	289	8.3
	Life sciences	1419	41.0
	Physical sciences	502	14.5
	Social & behavioral sciences	722	20.9
Region			
	North America	2751	80.3
	Europe	339	9.9
	Asia	120	3.5
	Global South	218	6.4

Appendix C: Data visualization, select data sources

Article 15 Excerpts. Provided by AAAS and originally retrieved from

http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=9&DocTypeID=29

Country GDP. Retrieved from the World Bank Open Data

<http://data.worldbank.org/indicator/NY.GDP.MKTP.CD>

Fertility Rates. Retrieved from the World Bank

http://data.worldbank.org/indicator/SP.DYN.TFRT.IN?end=2014&name_desc=false&start=2014&view=map&year=1992

Food Security. Retrieved from Food and Agriculture Organization of the United Nations

<http://www.arcgis.com/home/item.html?id=e99bc959b19641f58d45213a6a7f7055>

<http://data.worldbank.org/data-catalog/world-development-indicators>

Geographical Boundaries. Mapping Sources. Retrieved from

<http://www.naturalearthdata.com/downloads/10m-cultural-vectors/>

Infant, Neonatal, and under Five Mortality Rates. Retrieved from the World Health Organization

<http://apps.who.int/gho/data/node.main.525?lang=en>

Life Expectancy. Retrieved from the World Bank

http://data.worldbank.org/indicator/SP.DYN.LE00.IN?end=2014&name_desc=false&start=2014&view=map&year=1992

Scientific and Technical Journal Articles. Retrieved from

<http://data.worldbank.org/indicator/IP.JRN.ARTC.SC>

World Development Indicators. Retrieved from the World Bank Open Data

Appendix D: Interviewees

A. Peter Maybarduk of Public Citizen

Maybarduk is the Director of Public Citizen's Access to Medicines group. The organization covers a range of topics from climate to trade to government reform. One of their focus areas is the knowledge economy and the diffusion of science and culture. This can mean access to medicines but also copyright and internet freedom. The Access to Medicines group specifically seeks to lower the cost of pharmaceuticals. Their primary area of work is in the promotion of generics to increase competition. Maybarduk was part of a consultation with Special Rapporteur Farida Shaheed and is an intellectual property expert and lawyer.

B. Judit Rius Sanjuan of Médecins Sans Frontières (MSF)

Rius is the US manager and legal policy adviser of the MSF Access Campaign. The organization was founded on humanitarian principles and works in over 60 countries providing medical assistance. MSF does not accept funds from the US government or pharmaceutical companies so as to remain financially neutral and independent. They provide medical care to populations in need, primarily those affected by epidemics, armed conflict, natural disasters, exclusion from healthcare, etc., and speak out on behalf of the needs and challenges they witness where necessary. The Access Campaign was launched in 1999 to address lack of access and innovation for treatments, diagnostics and vaccines needed in MSF projects and beyond .

C. Yannis Natsis of The European Public Health Alliance (EPHA)

EPHA is a public health stakeholder in Brussels that lobbies national governments in the European Union (EU) and focuses on EU legislation on affordability and accessibility to medicines exclusively in Europe. They have 90 members and work in national ministries, associations, director generals, and with members of parliament on health and pharmaceutical issues. Natsis does a lot of public speaking in attempts to balance the influence of pharmaceutical companies in the EU parliament.

D. M. R. Rajagopal of Pallium India

Dr. Rajagopal started Pallium India to provide basic pain relief for those in need, often with untreatable terminal illnesses like cancer, and to integrate palliative care into the Indian healthcare system. Pallium India focuses on three primary areas to increase the accessibility of pain management medicines in India: the development of palliative care resources and the empowerment of healthcare professionals to use them; advocacy and legal solutions; and education about pain management to government officials, citizens, and other organizations. Over the last 12 years the organization has increased its focus on advocacy, and used international human rights frameworks as an international baseline from which to work.

E. James Packard Love of Knowledge Ecology International (KEI)

KEI aims to find better outcomes for and solutions to the management of knowledge resources. They are interested in access to information, what type of information is and is not produced, and the political structures that produce outcomes that do not adequately address social needs. One of their most critical issues is the topic of ownership over ideas and intellectual property. Love's projects focus principally on access to medicines and intellectual property/ patents, especially those that were developed with government funds.