# Defining the Right to Enjoy the Benefits of Scientific Progress and Its Applications: American Scientists' Perspectives


ADVANCING SCIENCE, SERVING SOCIETY

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# Acknowledgements

This report was prepared by Dr. Margaret Weigers Vitullo (American Sociological Association) and Jessica Wyndham (American Association for the Advancement of Science (AAAS)) on behalf of the Service to the STEM Community Working Group of the AAAS Science and Human Rights Coalition.

We want to acknowledge the members of the Working Group, the Coalition Steering Committee and Coalition Council who provided comments on a draft of the report. Specific thanks are due to Dr. Juan Gallardo, Dr. Susan Hinkins, Dr. David Proctor, Dr. Janet Stocks and Dr. Jeffrey Toney. In addition Dr. David Brunsma, Dr. Cliff Duke, Dr. Bruce Friesen, Dr. Brian Gran and Alyson Reed each provided helpful feedback on earlier versions of the report.

Thanks must also be extended to Dr. Mark Frankel, Director of the AAAS Scientific Responsibility, Human Rights and Law Program and Theresa Harris, AAAS Senior Program Associate, for their feedback on the report, as well as members of the AAAS Committee on Scientific Freedom and Responsibility for their initial comments on the focus group findings.

Special thanks go to Dr. Audrey Chapman for her advice in drafting the focus group protocol and to AAAS interns Michael Bueno, Elizabeth Ingianni, Kate Saylor, Kristina Thorsell and Celestine Warren for their work in coding the focus group comment sheets and transcripts. Additional special thanks are due to the American Sociological Association.

We also want to thank the scientific, engineering and health associations that hosted focus groups and the staff and members with whom we worked in organizing them.

Cite as: 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/srhrl.aaa0028

# Defining the Right to Enjoy the Benefits of Scientific Progress and Its Applications: American Scientists' Perspectives

## 1. Introduction

The Universal Declaration of Human Rights recognizes the right of everyone to "share in scientific advancement and its benefits" (Article 27(2)). This right became the basis for Article 15 (1)(b) of the International Covenant on Economic, Social and Cultural Rights (1966).

> **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.

The Committee on Economic, Social and Cultural Rights (CESCR) has not adopted a general comment on the right to enjoy the benefits of scientific progress though it has adopted general comments on Article 15(1)(a) and (c). In 2007, UNESCO launched a process intended to inform the development of a general comment, culminating in 2009 with the development of the *Venice Statement* which provides a preliminary assessment of the meaning and content of the right. Among the next steps identified, the *Venice Statement* called for the participation of "the scientific and academic communities" in elucidating the meaning of the right, raising awareness about the right, its implementation and the monitoring of its realization.

In April 2010, the Board of Directors of the American Association for the Advancement of Science (AAAS) adopted a statement on the right to enjoy the benefits of scientific progress and its applications, undertaking to engage the scientific community in defining the content of the right and determining its application to a diverse range of scientific disciplines and to contribute these findings to the UN process of defining the right (Statement: Appendix A). The AAAS Science and Human Rights Coalition led the initiative that forms the basis for this report.

Over the course of 18 months, the Coalition conducted 17 focus groups, involving 145 participants from a diversity of scientific and engineering disciplines (Protocol: Appendix C). The objective of the focus groups was to learn the perspectives of U.S. based scientists, engineers and health professionals as to the meaning, application and barriers to implementation of Articles 15 1(b), (2-4) and is the first effort of its sort. This report starts from the basis of the current understanding of the right and reveals how the focus group participants perceive the right in ways consistent with or contrary to the existing literature. In the discussion that follows, the term scientist is used broadly to include all the focus group participants, including engineers and health

professionals. The results of the current qualitative study cannot be generalized to all scientists in the United States, much less all scientists globally, however the results do provide insights, nuance and practical examples that can inform future discussions regarding the meaning of Article 15.

Although the focus group protocol followed a structure designed to elicit participant discussion, this report reflects the structure of a general comment (Protocol: Appendix C) to enhance the translation of the focus group findings for a human rights audience and to help facilitate the preparation of a general comment by the CESCR.

## How Do Scientists Define the Benefits of Science and Its Applications?

Do scientists make a distinction between the benefits of science and the benefits of technology? Do scientists see the benefits of science as primarily material or are the benefits of science also conceptual, methodological, and cultural?

Focus group participants were first asked to identify three specific benefits of their discipline to society. Each of the benefits listed in Table 1 was identified by a broad range of focus group participants, pointing to a set of shared perspectives regarding the benefits of science independent of disciplinary background. Due to the space constraints of the current report, the discussion below focuses on only the first 5 benefits.

**Table 1: Ten Most Frequently Mentioned Benefits of Science**

| Rank | Code |
|---|---|
| 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 (not health) |
| 8 | Advancing methods and technology for science |
| 9 | Influence on/of culture |
| 10 | Economic impact |

Benefit #1: Health. Health was mentioned as a benefit of scientific progress and its application in all but two of the focus groups. In their discussions, participants from a wide array of disciplines described ways that science and engineering have increased our understanding of the fundamental nature of health and illness, from "mapping disease outbreaks and understanding sources and solutions" (geography cc:1383-1444)[1], to "defining psychopathology as a disease… not a personality issue or a moral issue" (psychology tc:2362-2758), to "the potential to understand and explain how the interactions of physical and biological processes affect the health and abundance of all organisms – including humans" (ecology cc:234-399).

They also discussed health as a result of technologies, for example, the refrigeration of medicines (mechanical engineering tc:20963-21399) and the complementary roles of diverse scientific approaches, for example, the development of vaccines and drugs (tropical medicine and hygiene tc:33009-3352X) and the psychology behind the adoption of vaccines (social psychology tc:15261-15939).

[1] Data notations list scientific or engineering discipline followed by 'tc' or 'cc' indicating transcript character or comment sheet character and end with the numeric range of characters in the cited data.

Benefit #2: Advancing Knowledge. Focus group participants emphasized the power of the scientific method for revealing new truths about everything from the vastness of the galaxies, to the vibrations of atoms within solid structures, to the impact of germs and the complexities of humans interacting within social systems. In addition, knowledge was discussed as necessary for planning and predicting the future, particularly environmental changes, and, therefore, for ensuring survival.

> What I consider even more important than the specifics that you might learn in the class, is the process of science and the process of thinking so that you can produce citizens who know to question … and to look for evidence rather than just political statements.
> (chemistry tc:2323-2609)

Scientific knowledge was also discussed as fundamental to effective citizenship. Focus group participants described how knowledge of the scientific method increases critical thinking and analytic reasoning skills, which in turn empower individual actors to effectively use information within their social milieu.

Benefit #3: Ecological/ Environmental/ Wildlife. Focus group participants saw science and technology as essential tools for mitigating and preventing destruction of the natural environment, and for responding to the changing conditions of a world with a rapidly growing population and increasingly limited natural resources. The dynamic tension between energy production and environmental protection, and the contributions of science to both sides of that equation were also discussed. As one participant pointed out "It has been said that the challenge of our generation is the environment" (social psychology tc:17806-17929).

Benefit #4: Education and Training. Focus group participants saw the contributions of science to the educational process as a key benefit. "Social psychology theory and intervention strategies are applied to school settings to enhance educational processes and promote skills for productive social interaction in students of all ages," said one focus group participant (social psychology cc:3161-3356). The participants also discussed the ways that science education produces curious, critical thinkers and problem solvers. One participant explained that students of science gain a "focus on logical thinking tested against facts and observation as a general method for approaching problems" (physics cc:1651-1759). Finally, the following quote illuminates the strong connection between education and training and the fifth most frequently mentioned benefit, providing an empirical basis for governmental decision making. "Inadequate education of the population can lead to [government] representatives that can't make sound decisions about scientific issues" (tropical medicine and hygiene cc:6041-6141).

Benefit #5: Empirical basis for laws/policies/programs. Science was seen among participants as a basis for gaining reliable information about the status quo in order to generate public policies based on sound information and rational, objective thinking. Participants also saw science as instrumental in establishing enforceable regulations (mechanical engineering cc:9612-9679) and contributing to the evidence necessary for just and fair prosecutions (forensics cc:562-688). Finally, focus group participants discussed the power of the scientific method to evaluate the effectiveness of existing laws, policies, and programs.

## 2. Normative Content of Article 15 – Components of the Right

**Science.** 'Science' has not been defined for the purposes of human rights and the need to do so was articulated in the *Venice Statement* (11.7). A frequent starting point is the UNESCO *Recommendation on the Status of Scientific Researchers* (1974), according to which, 'science' is:

> the enterprise whereby mankind, acting individually or in small or large groups, makes an organized attempt, by means of the objective study of observed phenomena, to discover and master the chain of causalities; bring together in a coordinated form the resultant sub-systems of knowledge by means of systematic reflection and conceptualization, often largely expressed in the symbols of mathematics; and thereby furnishes itself with the opportunity of using, to its own advantage, understanding of the processes and phenomena occurring in nature and society.

The *Venice Statement* and the 2012 report to the Human Rights Council by Farida Shaheed, Special Rapporteur in the field of cultural rights, reflect a shared understanding of 'science' as knowledge [UNESCO 2009, Section III.8; Shaheed 2012, paras 17,18]. In addition, the Special Rapporteur states that science includes life, physical, behavioral and physical sciences, as well as the social sciences [Shaheed 2012, para 24]. The *travaux préparatoires*, recording the negotiations that lead to the adoption of Article 15, indicate that 'science' *per se* should not be ascribed a social or other specific goal beyond the continued development of science. At the same time, the *Venice Statement* emphasizes that science "is not only about advancing knowledge" but also "enhancing the conditions for further scientific and cultural activity" [UNESCO 2009, Section III.8].

Among the focus group participants, science was discussed as an iterative, logical and empirically based process. Consistent with the *Venice Statement* and the report of the Special Rapporteur, they also discussed science as the body of specialized knowledge that is accumulated through that process. However, focus group participants added an additional level of specification, describing rigorous peer review and ethics as essential elements of science itself, not additions to it, which guide the investigative process and appraise the resulting knowledge.

**Benefits of Science.** According to the *travaux préparatoires*, the 'benefits' of science include not only material benefits. Mr. Havet, the UNESCO representative at the drafting of the International Covenant on Economic, Social and Cultural Rights, referred to the dissemination of scientific knowledge as having the potential to "contribute largely to the removal of certain prejudices, for example racial prejudices, which constituted a direct threat to the whole edifice of human rights" [Commission on Human Rights 1951, 11]. The Special Rapporteur identifies several other non-material benefits of science including 'participation'. She adds "the 'benefits' of science encompass not only scientific results and outcomes but also the scientific process, its methodologies and tools [Shaheed 2012, paras 22, 24]. Focus group participants also described the benefits of science as including both material and non-material elements, as outlined above.

**Conservation, Development, and Diffusion.** While some attention has been paid to defining 'science' for the purposes of understanding Article 15, much less attention has been given to defining clearly "conservation," "development" and "diffusion" as laid out in Article 15(2). The Special Rapporteur defines these terms as follows:

- "conservation requires the identification and safeguarding of scientific knowledge, products and tools, including literature, databases, specimens and equipment";
- "development demands an explicit commitment to the development of science and technology for human benefit";

- "diffusion encompasses the dissemination of scientific knowledge and applications both within the scientific community and in society at large." [Shaheed 2012, paras 46-48]

Richard Pierre Claude's interpretation in his article, "Scientists' Rights and the Human Rights to the Benefits of Science," is generally consistent with that of the Special Rapporteur. Where his interpretation appears to diverge, however, is in relation to the term 'conservation' which he interprets as the requirement to safeguard "the integrity of the scientific enterprise" [Claude 2002, 259].

Focus group participants were asked what they saw as the necessary governmental actions to ensure the conservation, development and diffusion of their scientific disciplines. Their discussions suggest that the **conservation of science** should be defined as the continuous maintenance of the processes used to conduct scientific inquiry, the values and norms that guide those processes, and the resultant scientific knowledge. Conservation of science includes retaining scientific discoveries as well as the data behind them, which must be preserved in a form that allows replication of those discoveries. It requires both technology and standards for storage and retrieval, but also a scientifically educated population that is capable of understanding and using the materials that are conserved.

According to focus group participants, the **development of science** depends upon the free and open interchange of ideas and people as well as adequate and consistent funding, robust science education and recognition of the need for knowledge-based decision making and the contributions of science.

> "I don't really see how you can separate… diffusion, development, conservation. I think you need the same for all three. I think you need basic STEM education support. You need a recognition that this is an important field. You need knowledge-based decisions… [and] what I call purposeful investment…" (geology tc:28037-28422).

Focus group participants saw the **diffusion of science** as a communication process between social groups, including communication between basic and applied scientists, the scientific and engineering communities and the lay public and policy makers, developed and less developed nations, and between dominant groups and underserved, under-represented groups. Diffusion was discussed as a moral obligation with strong social justice elements. Scientific literacy and the free circulation of people and ideas, including international collaboration, were seen as critical elements in successful diffusion. Funding was mentioned often as the necessary pre-condition, in this case, for diffusion.

Common elements are found in the focus group discussions of these three terms, suggesting that while distinct definitions of conservation, development and diffusion may be established, they need to be seen as an inter-related and inter-dependent system.

### Elements of the Right

Few commentators have explicitly addressed the elements of the right to enjoy the benefits of scientific progress and its applications, which include availability, accessibility, acceptability and quality. In the following discussion we focus on the element of accessibility because of the tremendous complexities of considering universal access in light of the range of scientific knowledge and applications on the one hand, and the fact that meaningful access may consist of something quite different depending on the social role of the person seeking access, be that scientist, student, educator, patient, subject of a clinical trial, a person with a disability, farmer, policymaker, or some other type of rights holder.

According to the Special Rapporteur, Article 15 connotes access to science as a whole, not only to specific scientific outcomes or applications. She specifically addresses access to (1) scientific knowledge; (2) scientific information; and (3) scientific advances. She adds, "At the juncture of the right to education and the right to information, it implies a right to science education" including being "informed about main scientific discoveries and their applications," "instilling a spirit of scientific inquiry," and popularizing science outside formal educational institutions. While access to scientific knowledge is conceived as a right of all people, access to scientific information is interpreted as being most relevant to researchers. Recognizing the many scientific advances that exist and the need to prioritize, the Special Rapporteur identifies as "one core principle" the right of everyone, in particular marginalized populations, to "innovations essential for a life with dignity" [Shaheed 2012, paras 26-29]. In the examples she provides, the Special Rapporteur emphasizes access to computers, the Internet and information communication technologies [Shaheed 2012, paras 36-37].

With regard to the other elements of the right, the Special Rapporteur says that "States should ensure that the benefits of science are physically available and economically affordable on a non-discriminatory basis" [Shaheed 2012, para 30]. She adds that "affordability is crucial and may require delinking research and development costs for product prices" [Shaheed 2012, para 34]. No further specific guidance is provided in the literature with regard to these additional elements of the right.

The existing literature leaves many unanswered questions. For example, what does it mean to have access to science "as a whole" in contrast to specific applications? Does meaningful access to science connote something different depending on the social role of the person seeking access? Where does scientific knowledge stop and information begin? What are the conditions necessary for people to access the opportunities to create as well as consume science?

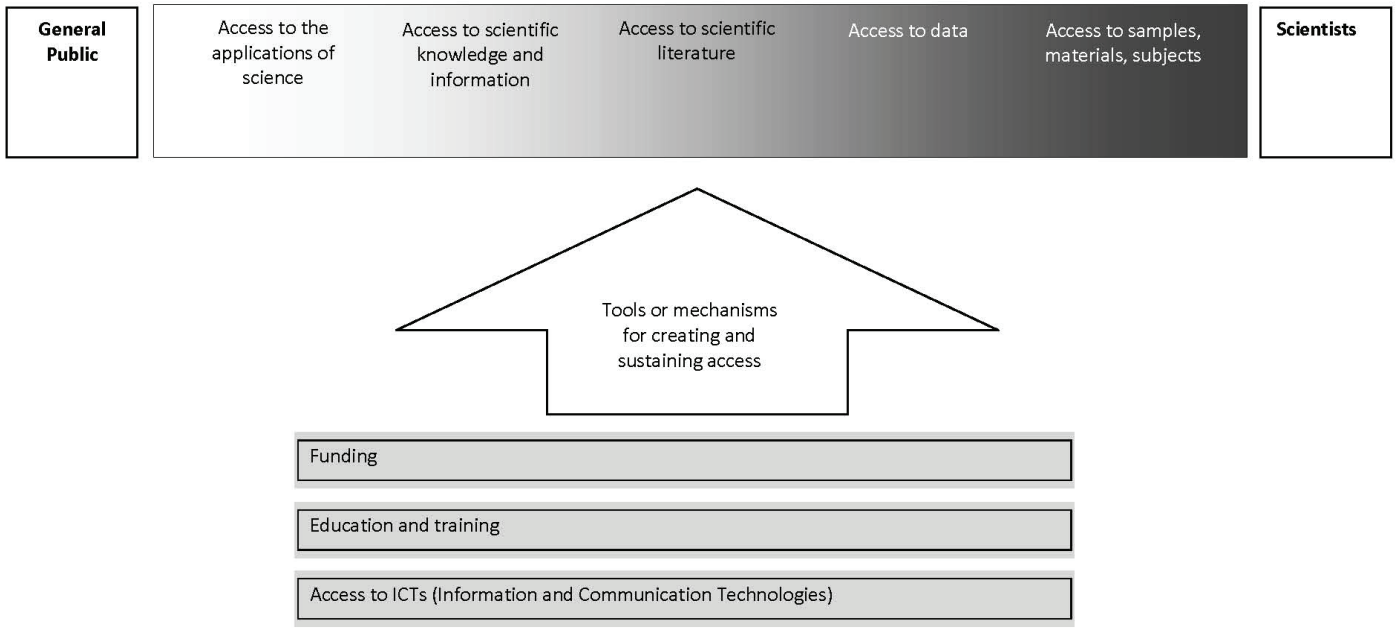
### Continuum of Access

Data from the focus groups sheds considerable light on these questions, suggesting a conceptual framework for considering the meaning of access as it applies to Article 15. Through a close analysis of the focus group discussions, two themes emerged: the first theme defines a fluid and bi-directional continuum of access, defined on one end as "access for general public" and on the other as "access for scientists"; the second theme addresses essential "tools or mechanisms for creating access" that have relevance at each point along the continuum. A person's position on this continuum can change over time, depending on his/her social context, interests, ability, and training. These two themes and the relationships between them are represented in Diagram 1: "Continuum of Access." The discussion below is framed within the conceptual map represented by this diagram.

> Scientific societies gain most of their support through their publications. If you take away the revenue stream, they will disappear and they are the place that nurtures the future scientists in fields and generates both the publications and the meetings where people can distribute scientific information
> (geology tc:32318-33078)

Access to the Applications of Science: When considering access to science for the general public, many of the focus group discussions centered on the applications of science – the treatments, technology, and applied knowledge that improves health, living standards, and policy outcomes – and the factors that would tend to limit access, including economic barriers. Forensic scientists discussed disparities in spending allocations for forensic analysis between the defense and the prosecution, increasing the risk of poor defendants being wrongly convicted. Geographers discussed cost barriers for humanitarian organizations purchasing GIS software licenses that could help them identify areas of greatest need and thus make better decisions about resource allocations.

## Diagram 1: Continuum of Access




Access to Scientific Knowledge/Information: Focus group participants saw providing access to scientific knowledge and information as a responsibility of both the scientific community and governments (forensics tc:81431-81577). They discussed the need for scientists to engage in translational work to address the fact that technical journal articles are often not written to be understood by scientists in other specialty areas, much less the general public. But they also saw a crucial role for the government: in protecting and promoting peer review, in helping regular citizens ascertain the validity and reliability of the enormous amount of information (and misinformation) that is available on the internet, and by supporting science journalism (chemistry tc:47115-48114).

Access to Scientific Literature: Scientific literature consists mainly of the peer-reviewed professional journals in which scientists publish their research findings. While the audiences for scientific journals are predominantly scientists, the focus group participants stressed that access to scientific journals should be wide spread and that scientists as well as interested members of the public across the globe should have access. To this end, the responsibility of governments to subsidize the cost of journals in public libraries was widely discussed.

Across all focus groups there was strong support for the potential of open access to scientific journals to diffuse scientific information. Discussions regarding the challenges of diffusing scientific information centered on how to make scientific journals as widely available as possible, generally in digital form with open access on the internet, while protecting the revenue stream necessary to support the scientific organizations and publishers that facilitate double-blind peer review, a process essential to scientific progress. In this context, it is useful to distinguish between providing electronic access to journals, which simply changes the delivery system, and

providing open access, which transfers the cost of production from the end users and their institutions to an alternative source, most commonly either advertisers or authors. In the short run, participants were clear that digital delivery alone had many limitations, particularly for people without reliable electricity and access to computers. Their comments point to the need for input from scientists in developing countries regarding effective mechanisms for assuring access to scientific literature.

Access to data: The centrality and importance of access to data for meaningful implementation of Article 15 was strongly affirmed in the focus groups. Three issues associated with data access were discussed: data generation; data storage; and data dissemination. Focus group participants affirmed that data collection processes should be open and transparent, and not guided by political interests, but rather by scientific standards and peer review (statistics tc:58250-59899; physics cc:12283; geology tc:26947-27189). Once generated, archiving data and making it accessible to researchers is important for (1) on-going research potential; (2) reproduction of results for validation; (3) longitudinal comparisons; (4) training and education of the next generation of scientists; and (5) historic value. Access to data requires increased capacity for data storage, international agreements on how to store data so it can easily be accessed, and wide dissemination – to scientists, policy makers, and to the public, both nationally and internationally.

The focus group participants acknowledged the complexity of responsibly providing access, particularly in the context of national security concerns and the potential misuse of science, and the need for consideration of privacy and confidentiality (physics tc:20142-20555). However, they felt that the default position should be for data to be openly available and accessible. Limiting access to data or discoveries that have dual-use or national security implications was seen as less likely to deter misuse and terrorism than to thwart positive scientific development (chemistry tc:18501-18908).

Access to samples, materials and subjects: In each case, these require specialized handling in order to protect and preserve them and to assure their ethical use, including humane handling of animals and respecting the terms of informed consent and confidentiality of human subjects. In keeping with this, the focus group participants generally seemed to assume that the individuals who would be accessing sensitive samples and materials, or who might be interacting with the people volunteering as human subjects in research studies, would be individuals specially trained or otherwise designated as scientific professionals or working under the supervision of scientific professionals.

**Samples** = scientifically gathered portions of the objects of study (e.g., a tissue or geological sample)
**Materials** = objects of scientific interest that have not yet been extrapolated to the abstract, consistent form often referred to as data (e.g., historical documents or videos, animals used as model systems)
**Research subjects** = legally and ethically distinct category of human beings who participate in a research study.

Tools or mechanisms for creating and sustaining access: The lower half of Diagram 1 shows three elements that emerged in the focus group discussions as central tools or mechanisms for creating and sustaining access that have relevance at each point along the continuum: funding, education and training, and access to basic information communication technologies.

Funding: The focus group participants understood that unlimited funding for science and engineering is neither a realistic nor advisable social goal. However, they were deeply concerned with how priorities are established in determining the level of available funding—including relative allocations to military funding and science funding--and how decisions are made for the distribution of those funds. Across all of the discussions of funding, three core issues emerged: funding should be steady, it should reflect the value of basic research as well as applied and commercially relevant investigations, and it should be based on peer review that is free of political influence.

Education and training: At each point along the continuum, access to science is created and enhanced by education and nearly every focus group participant identified education, especially childhood education, as a key element for assuring access to science. Education—both formal and informal and appropriate to the local context--was described as a gateway through which access to science was gained for the general public, as a prerequisite for giving lay persons the option of accessing science at the increasing levels of complexity represented as one moves along the continuum, and for making informed personal choices about the use, or not, of the applications of science (mechanical engineering tc:67132-67431).

A more sophisticated level of training and education is required to be able to understand and use data and to safely and ethically manage the use of samples, materials and subjects (chemistry tc:55947-56370). To this end, focus group participants were equally as united in calling for funding and support for graduate education--including fellowships and post-doctoral training--as they were for early childhood, grade school, and secondary education.

Access to ICTs (Information and Communication Technologies): Computers, networks, and the Internet are essential for accessing science at every level, from primary education to the exchange of ideas and data among scientists at the cutting edge of discovery. At the first instance, access to these technologies is itself an example of having "access to the applications of science." Computers, networks and the Internet also facilitate the ability to access the aspects of science represented by each of the subsequent points along the continuum.

> Besides education, which is the surest route to long-term [scientific] development, the next is information infrastructure. And money for fundamental research (physics cc:11341-11488).

**Limitations to the Right**

The *travaux préparatoires* include lengthy discussions of the potential limitations on the right to enjoy the benefits of scientific progress. One potential limitation to the right that was firmly rejected was the suggestion that the purposes of scientific research and technological development should be circumscribed, for example, to contribute to international peace and security. Concerns were also raised that the term "indispensable" in Article 15(3) could be used to limit the scope of measures to protect "scientific freedom." That interpretation was also rejected. However, certain limitations of the right have been acknowledged.

Though Article 15 focuses on the "benefits" of science and "progress" in science, it is recognized by commentators in the field that the process and outcomes of science may not always be positive and may not always be consistent with human rights. For that reason, the *Venice Statement* recognizes that measures should be taken to prevent abuse and the adverse effects of science and its applications (UNESCO 2009, 12.f, 13.c, 14.d). One significant implication of this, as Audrey Chapman points out in her formative article on Article 15, is that "scientific freedom is not absolute" (Chapman 2009:17) With scientific freedom, explicitly recognized in Article 15(3), comes scientific responsibility. Among the responsibilities of scientists is to comply with "legitimate regulation" established for national security reasons (Claude 2002:266).

> We have become so risk-averse in terms of national security that we compromise civil rights and scientific rights with regulation (acoustics tc:56296-56724).

Finally, a practical and historical, if not normative, limitation on the right arises as a result of the tension between the right to benefit from scientific progress and the "moral and material interests" clause elaborated in Article 15(c). Though this tension was not discussed during the drafting of Article 27 of the UDHR (Shaver 2010:149) and is not considered inherent within Article 15, it is

recognized that such a tension may now exist (UNESCO 2009, III.10). The importance of addressing the relationship of Articles 15(1)(b) and (1)(c) is emphasized by the Special Rapporteur, who says, "the potential of intellectual property regimes to obstruct new technological solutions to critical human problems such as food, water, health, chemical safety, energy and climate change requires attention (Shaheed 2012, para 50). As an approach to reconciling the two rights, the Special Rapporteur proposes "the adoption of a public good approach to knowledge innovation and diffusion."

The focus group participants' discussions of the limitations of the right often centered on the freedom and responsibility nexus. They recognized that there are circumstances which legitimately require regulation, including: protection of data and privacy for the general public as well as human subjects; protection against dual-use/misuse of scientific advances; and to protect national security (chemistry cc:3684-3761; geography 10043-10128; tropical medicine tc:56516-57248; mechanical engineering cc:10284-10386; sociology tc:13431-14670). At the same time, participants expressed concern when the regulatory environment created conditions that were stifling to scientific freedom. According to the participants, when required, regulations and laws that impinge upon scientific freedom should be limited, unified, consistent, processed expeditiously, and externally reviewed and updated based on efficacy and value (tropical medicine cc:11436-11493; acoustics cc:8480-8582; statistics tc:22189-22865).

Regulations were discussed as a necessary but far from sufficient response to the limitations of the right. "That's with any technology, with any science. You either use it for the benefit of humanity and the world in which we live, or you abuse it" (chemistry tc:16881-17022). Governments as well as scientific communities and professional associations were seen as having a role in nurturing scientific responsibility and ethics. Broadly acknowledged responsibility across multiple social sectors was seen as the best and most effective way to reduce the chances that the discoveries of science would be used for nefarious ends (mechanical engineering: 41548-42001).

The tension between the right to benefit from science and intellectual property was not the focus of much discussion among participants. To the extent that any comments were made on the issue, participants recognized the existence of intellectual property protections while suggesting they should be "less restrictive" to increase dissemination, exchange and accessibility of scientific knowledge and products (chemistry tc:39554-40286; geology cc:9613-9689; mechanical engineering cc:17107-17255).

### Persons and Communities Requiring Special Protection

Among the specific populations identified in the literature as requiring special protection are: people living in poverty; persons with disabilities; the elderly; women and children; indigenous populations; racial ethnic and linguistic minorities; and rural residents. The Special Rapporteur specifically mentions the increased risks faced by these groups when they serve as human research subjects in scientific research (Shaheed 2012, para 52). However, few details have been provided concerning the measures that should be taken to protect these populations. An analysis of the UN Declaration on the Rights of Indigenous Peoples within the specific context of Article 15 would be helpful, but is not found in the current literature.

> The absence of the voice of poor women, for the most part, in theorizing, data collection, data analysis, and implementation [of science] in regard to issues related to gender, children, sexuality, reproductive issues, etc. So the concern I have is that… in large measure [science as it is generally practiced]… doesn't include the lived experience of poor women (sociology tc:16826-17233).

In her report, the Special Rapporteur states that "specific measures encompass eliciting the priority needs of such

[vulnerable and marginalized] populations through a consultative process and facilitating targeted research by both public and private sector institutions" (Shaheed 2012, para 31). Chapman gives particular emphasis to the steps that should be taken to ensure implementation of the right among women, including measures to redress existing gender imbalances in science and technology education and training, as well as professional advancement.

Chapman adds that a gender-based approach requires "the identification of priorities for investments in scientific research and development attempt to meet girls' and women's particular needs" (Chapman 2009:13).

> Sometimes governments… are not invested in recognizing anything about minority groups and they're afraid that [linguistic] narratives, for instance, will point to [a justification for] a homeland for these groups and they don't want to have that made public (linguistics tc:42598-42928).

Beyond the measures necessary to ensure marginalized and vulnerable populations receive quality science education, the focus group participants recognized the need for the inclusion and consideration of marginalized and vulnerable populations at each stage of the scientific process, including the framing of research questions, the placement of research sites, and the dissemination of findings (geography tc:56276-57034; sociology tc:16826-17233; astronomy tc:50848-52051; tropical medicine tc:66439-67338). At the methodological level, inclusion and consideration of marginalized populations was discussed in terms of assuring the validity of samples by not assuming the homogeneity of a population or subpopulation. Another issue that was raised was the need to avoid the introduction of social biases in analysis (linguistics tc:6152-7994), including the misattribution of causality in correlational data (statistics tc:57925-5823), which can have a particularly profound impact, for example, on vulnerable populations caught up in the criminal justice system (forensics cc:7954-8140).

# 3. States Parties' Obligations

### Specific Legal Obligations (respect, protect, fulfill)

There has been rich discussion among commentators concerning the responsibilities of States Parties to respect, protect and fulfill the right to enjoy the benefits of scientific progress and its applications. The Special Rapporteur, in her report, identifies four general obligations: "access to the benefits of science by everyone, without discrimination; opportunities for all to contribute to the scientific enterprise and freedom indispensable for scientific research; participation of individuals and communities in decision-making; and an enabling environment fostering the conservation, development and diffusion of science and technology." This list is not intended to be exhaustive (Shaheed 2012, para 25).

The data from the focus groups include extensive empirical evidence that reinforces and confirms much of the current discussion of States Party obligations. It also moves beyond the commentators in several regards. The sections that follow summarize the current literature on states obligations and then describe the extensions to the existing commentary found in the focus group data.

#### *Respect*

According to the *Venice Statement*, States must respect: the freedoms indispensable for scientific research (e.g., freedoms of thought, to hold opinions, and to seek, receive and impart information); the right of scientists

to form and join professional societies; and the freedom of scientists to collaborate within and across borders. States also have the duty to prevent the use of science and technology in a manner "that could limit or interfere with the enjoyment of human rights" (UNESCO 2009, IV.14.a-d).

The Special Rapporteur recognizes the above and adds that states should respect "the autonomy of higher education institutions and the freedom of faculty and students to, *inter alia*, express opinions about the institution or system in which they work, and to fulfill their functions without discrimination or fear of repression" (Shaheed 2009, para 40). Chapman adds the freedom of scientists to undertake research and to report their results. Neither Chapman nor other commentators, however, consider whether states bear a responsibility to accept or adopt the results of scientific inquiry.

> I was trying to think of… access to the scientific results for those parts of the world that may not have [the science] themselves. We run into technology transfer restrictions… for much of our astronomical work, even though in fact it's not really defense-based (astronomy tc:43972-44362).

Focus group participants supported and reinforced the foregoing assessment, giving particular emphasis to the duty of States Parties to facilitate international scientific cooperation and exchange through clear, flexible and reasonable regulation. They also asserted that States Parties should establish legal frameworks that institutionalize scientific peer review as the primary basis for decision making regarding scientific priorities, processes, and funding, and implement strong whistle blower laws to protect scientists and engineers from retribution when they bring situations of potential risk or misconduct to public attention (astronomy cc:11046-11071).

***Protect***

The private sector plays an increasing role in scientific research, development and funding. It is within that context that the *Venice Statement* articulates the following duties on States Parties: to ensure that all relevant interests are balanced in the advancement of scientific progress and in accordance with human rights; to take measures to prevent and preclude the use by third parties of science and technology to the detriment of human rights; and to ensure the protection of the human rights of people subject to research activities. (See also, UN Declaration on the Use of Scientific and Technological Progress in the Interests of Peace and for the Benefit of Mankind (Articles 2, 6, 8) and UNESCO Universal Declaration on Bioethics and Human Rights (Articles 4, 8)).

The Special Rapporteur called for greater attention to companies that "undertake research that would be illegal in one country but which, owing to a lack of legal protections, are possible in another" (Shaheed 2012, para 55). Chapman adds an additional nuance, addressing how the "precautionary principle" may be applied to the development of new technologies in such a way as to protect populations from the harmful impacts of science and technology. (The *Venice Statement* explains the precautionary principle as follows: "in the absence of scientific consensus, caution and the avoidance of steps are required in case an action or policy might cause severe or irreversible harm to the public or the environment.")

Two specific mechanisms central to protection were discussed at length by the focus group participants: establishment and enforcement of appropriate regulations to protect human subjects, and the need for conflict of interest regulations. The protection of human subjects in research requires international standards, as well as appropriate training protocols that would apply to both public and private actors (geography cc:10144-10409; tropical medicine tc56516-57248; acoustics cc:17443-17541). Within those standards, focus group participants believed that governments "should provide resources for citizens to have access to information and [a mechanism to] present complaints if necessary" (social psychology cc:9224-9510). Conflict of interest regulations were seen as necessary to protect against scientific processes being biased by parties that have a

stake in specific research outcomes (acoustics tc:46170-46401), for example, when monitoring and evaluation is conducted internally and not verified by an external body.

Finally, the issue arose of how to encourage private actors to work towards public goals. One focus group participant advocated efforts to "encourage global consciousness when developing standards or technologies" through a mechanism to "incentivize corporations to think about other markets rather than just the US market when they're trying to come up with new health technologies or whatever it may be" (mechanical engineering tc:42167-42702).

### *Fulfill*

The literature includes a wealth of suggestions for the responsibilities of States Parties to fulfill the right to enjoy the benefits of scientific progress. The responsibilities particularly emphasized are the dissemination of scientific information to the public that increases their capacity to make decisions about the applications of science that are personally significant; to provide quality science education; to create opportunities for meaningful public participation in decision-making related to science; and to facilitate international cooperation and assistance in science (Chapman 2009:24-25; UNESCO 2009, s. IV.15; Shaheed 2012, para 15).

Another responsibility identified by several recent commentators concerns the need to set priorities for science funding and research that reflect societal needs, and particularly the needs of marginalized and vulnerable populations (Chapman 2009:25; Shaheed, para 31). The Special Rapporteur adds that public, as well as private, funding for scientific research and development is important (para 71).

The *Venice Statement* incorporates the above responsibilities together with additional responsibilities: to adopt a legal and policy framework and to establish institutions to promote the development and diffusion of science; to promote access to the benefits of science on a non-discrimination basis; and to monitor, respond to and inform the public of the potential harmful effects of science and technology.

Whether in monitoring existing laws, policies or programs or developing new ones, focus group participants emphasized the central role of science in providing a rational empirical basis for government action (acoustics cc:15473-15594; physics tc:29638-30670). The same rigorous scientific approach should be applied, it was argued, in determining funding priorities. Indeed, the emphasis given to funding concerns by focus group participants suggests that funding for science is a primary prerequisite for the realization of the right to enjoy the benefits of scientific progress and its related rights. Participants addressed funding for infrastructure, for education, research, peer review, and publically-accessible scientific information.

Finally, the continuum of access and corresponding tools and mechanisms for creating and sustaining access provide an organizing framework for considering the States Parties responsibilities for the fulfillment of Article 15 outlined above. In addition, it highlights the responsibility of States Parties to establish structures and institutions that encourage and reflect increasing levels of technical literacy and active engagement in the scientific enterprise.

## Core Obligations

In few instances have commentators on the meaning of the right to enjoy the benefits of scientific progress identified which state obligations, from among the many suggested, should be considered minimum core obligations. However, from the *Venice Statement*, the Special Rapporteur's report, and the writings of Chapman, Claude and Yvonne Donders, it is possible to distill a summary of key obligations around which there appears to be consensus and which are consistent with the approach taken by the CESCR when identifying the core content of other economic, social and cultural rights. These obligations are to:

(a) Take legislative and any other necessary steps to guarantee non-discrimination and gender equality in the enactment of the right to enjoy the benefits of scientific progress and its applications, both individually and collectively;
(b) Take legislative and any other necessary steps to prohibit OR prevent the violation of human rights by scientific progress and its applications;
(c) Adopt the measures necessary to protect and address the needs of marginalized and vulnerable populations, including with regard to funding, determining research priorities and the conduct of science;
(d) Create a participatory environment for the conservation, development and diffusion of science and technology, including equal access and participation for all, as well as capacity-building and education;
(e) Take steps to protect scientific freedom, including freedom of expression and opinion, freedom of association, freedom of movement, and freedom from economic, religious and other influences;
(f) Eliminate barriers or obstacles to international cooperation in science and adopt measures to facilitate international scientific exchange and technology transfer.

Based on the foregoing analysis of the focus group materials at least two additional core obligations can be identified. The first obligation is to take steps to integrate scientists and scientific data, analysis and findings into government functions, including law, policy and program development, monitoring and evaluation. The second obligation is to develop and implement mechanisms for ensuring adequate funding for scientific research and development and/or technology adaptation and adoption based on available resources and without inappropriate political or other interference.

**International Obligations**

During the drafting of the ICESCR, Mr. Chaudhuri (Pakistan) said, "great efforts" should be made nationally and internationally "in order that countries where science had made little progress might attain the goals set forth in the proposed provision." Mr. D'Souza of India reiterated this view (A/C.3/SR.796, paras 13, 20). The recognition of science as a global good underlies Article 15(4), which specifically recognizes the obligation of States Party to encourage international contacts and cooperation in science.

According to the Special Rapporteur, for "industrialized States" Article 15(4) translates into an obligation to provide "direct aid, financial and material, as well as the development of international collaborative models of research and development for the benefit of developing countries and their populations (Shaheed 2012, para 68). Chapman elaborates further, suggesting an international collaborative model would include full and open availability of scientific data, open publication of results; the free circulation of scientists; the provision of international assistance on the part of developed countries; and access to essential knowledge and technologies." Chapman recognizes that "what that assistance should entail and what those products should be … needs to be specified" (Chapman 2009:28-30).

> [Governments should provide support to] strengthen ethical research training in developing countries, and to have strong partners in those countries that are ethics experts that can provide… expertise to build guidelines, to build properties, to build review systems

Beyond the provision of aid or international assistance, the focus group participants saw international exchange of ideas and collaboration as fundamental to scientific knowledge production in a global age. They called for removing barriers to international travel and information exchange, including allowing national funding agencies to support international partnerships on scientific projects.

# 4. Violations

Limited explicit attention has been given in the literature to the actions or inactions that would constitute a violation of the right to enjoy the benefits of scientific progress. Claude provides the broadest analysis of violations that he illustrates through specific case examples. He notes that violations of the obligation to *respect* include: dismissal of professors for publicly espousing principles of academic freedom and, in another case, to prevent disclosure and criticism of environmental practices in the context of trade negotiations; travel restrictions imposed on scientists; and censorship of information regarding the consequences of a nuclear accident.

Violations of the obligation to *protect* include: low representation of women among science faculty; failure to prosecute a private sector company that caused a major environmental disaster leading to death, damage and injury; weak regulatory framework to prevent sale and use of fraudulent medicines; patenting naturally occurring genetic material; and bio-prospecting.

Finally, Claude identifies the following violations of the obligation to *fulfill*: transferring the risk and cost of nuclear energy to resource-poor countries; unethical clinical trials that do not meet requisite standards or benefit the individuals or communities involved; suppression of an epidemiological report; neglect of women's reproductive rights; and provision of medical information to prospective employers that may lead to discriminatory hiring decisions.

The focus group participants' comments regarding violations of Article 15 can be grouped into four categories. First, participants spoke at length about the ways over-regulation can have the cumulative effect of stifling the freedom indispensable for scientific research and creative activity (geology tc:15007-15214; tropical medicine cc:11436-11493; forensics cc:3385-3593; acoustics tc:56296-56724; mechanical engineering 7031-7089). While regulations individually may or may not be reasonable responses to concerns about national security, trade, or violations of intellectual property rights, an accretion of overlapping, vague and contradictory regulations can smother the scientific enterprise (ecology tc:29168-32993).

The second category stands in tension with the first, addressing situations in which the government fails to establish necessary regulations to protect against the negative effects of science or its misuse (acoustics cc:17334-17439; mechanical engineering cc:11643-11821).

The third category addressed politically motivated governmental actions that restrict scientific freedom. This included political persecution of scientists themselves for their ideas or the results of their studies (geography cc:17149-17238; history cc:4235-4275; linguistics tc:42555-43428; statistics tc:7146-7550), and political tests for access to science or the tools and mechanisms necessary for creating and sustaining access (history tc:32229-23216).

The final category of violations discussed centered on the misuse of science by the government or third parties that leads to violations of human rights, including the right to privacy (physics 26222-27044; forensics cc:5324-5406; psychology cc:4092-4142; geography tc:35223-36102).

## 5. Obligations of Actors other than States

With respect to the right to enjoy the benefits of scientific progress, three actors are identified as being key: States, the private sector/commercial enterprise, and the scientific community (UNESCO 2009, III.9). In addition, the Special Rapporteur identifies in the conclusion and recommendations of her report, several international organizations whose work is closely tied to the right, including UNESCO, the World Intellectual Property Organization, and the World Trade Organization.

Greatest attention has been paid in the literature to the role of the private sector. As the Special Rapporteur notes, "the diminishing role played by the State in research and development and the concomitant extensive increase in the involvement of the private sector are reducing the ability of Governments to identify priority research areas, conduct research and disseminate resultant products" (Shaheed 2012, para 70). Yet, as the *Venice Statement* explicitly acknowledges, "it is not inconsistent with the economic objectives of the private sector for enterprises to act in ways that advance this right" (UNESCO 2009, V.27). Examples provided by the Special Rapporteur include socially responsible licensing, innovation prizes and patent pooling.

Suggestions for how the scientific and engineering communities can contribute to the realization of the right are less well-developed, focusing principally on the role of scientific and engineering societies. In particular, Chapman and the Special Rapporteur both mention the role of professional societies in developing standards and codes of ethical scientific research and practice. As Chapman acknowledges, however, these codes are primarily concerned with the ethics of individual conduct and do not place the scientific enterprise in a broad social context (Chapman, 2012:17). Indeed, as the Special Rapporteur notes, few such codes of ethics are explicitly based on or refer to human rights (Shaheed 2012, para 53).

> Scientific societies should be taking a leadership position in terms of making sure that there is international cooperation, international dissemination of scientific information… (geology tc:36993-37311)

Like Chapman and the Special Rapporteur, the focus group participants saw an important role for professional associations in the fulfillment of Article 15. They spoke of the key role of scientific associations in guiding the development of curriculum (sociology tc:38812-39496), nurturing future scientists and promoting information exchange and discussion by disseminating scientific information through both peer-reviewed journal publication and hosting scientific meetings (geology tc:32318-33078; chemistry tc:28779-29295; sociology cc:6093-6226). They also saw professional associations as having a key role in the international development of science (geology tc:36635-36987).

Participants also saw a protective role for professional associations. While non-governmental actors like professional associations cannot legislate responsibility, directly prevent misuse, or impose legal sanctions, establishing codes of ethics and including human rights provisions within them was discussed as a mechanism for nurturing cultures of scientific responsibility and increasing awareness of the human rights implications of science—both positive and negative (social psychology tc:32694-33296; mechanical engineering tc:39817-41536; geography tc:899-1305).

# 6. Summary of Key Findings and Next Steps

### Key Findings

This study solicited the views of scientists, engineers and health professionals as to the meaning of the right to enjoy the benefits of scientific progress and its applications. The study was intended and designed to inform the ongoing UN process of defining the right.

The key findings of this study are:

i. The benefits of science and the benefits of technology are interconnected and they include material benefits as well as conceptual, methodological, and cultural benefits;
ii. 'Science' is both an iterative, logical and empirically-based process and the body of specialized knowledge accumulated through that process. Rigorous peer review and ethics are essential elements of science itself;
iii. While distinct definitions of "conservation," "development" and "diffusion" may be established, they are closely inter-related and inter-dependent;
iv. Among the core obligations of States are the obligations to:
    a. take steps to integrate scientists and peer-reviewed scientific data, analysis and findings into government functions, including law, policy and program development, monitoring and evaluation; and
    b. develop and implement mechanisms for ensuring adequate funding for scientific research and development and/or technology adaptation and adoption, given available resources and with scientific peer review as the primary basis for decision making;
v. Access to the benefits of scientific progress and its applications exists along a fluid and bi-directional continuum. A person's position on this continuum can change over time, depending on their social context, interests, ability and training;
vi. Scientific freedom is not absolute, but centers on the nexus of freedom and responsibility. When necessary, laws and regulations limiting scientific freedom should be narrowly defined, unified, consistent, processed expeditiously, and subject to on-going evaluation for effectiveness and continued need;
vii. Persons and communities requiring special protections should be included at each stage of the scientific process, including the framing of research questions and the placement of research sites;
viii. Strong whistle blower laws should be implemented to protect scientists and engineers from retribution when they bring situations of potential risk or misconduct to public attention.
ix. Human subjects protections are central to the realization of Article 15. They should be enforced consistently across countries and expertise in international human subjects protocols and ethics fostered through training;
x. Scientific, engineering and health associations have several important roles, including:
    a. Promoting information exchange and discussion by disseminating scientific information through peer-reviewed journals, scientific meetings and public engagement;
    b. Promoting international development of science; and
    c. Nurturing cultures of scientific responsibility and increasing awareness of the human rights implications of science and technology.

## Next Steps

Several questions remain to be addressed concerning the meaning and implementation of the right to enjoy the benefits of scientific progress and its applications. The further engagement of the scientific, engineering and health communities, together with human rights experts and others are required to be able to address these issues, which include:

i. What do members of the general public, key beneficiaries of the right, believe the right to enjoy the benefits of scientific progress and its applications means?
ii. How can traditionally marginalized voices be incorporated into the process of defining this right, including women in rural areas, ethno-religions minorities and lesbian, gay, bi-sexual and transgender persons?
iii. What is the influence of non-state actors on states and their compliance with this right?
iv. To what extent is science inevitably politicized, both within countries and between them, and how might that impact realization of the right to enjoy the benefits of scientific progress?

The findings presented in this report reflect the views of the participants of the focus groups who represented a diversity of disciplines and some demographic variability. However, the findings cannot be extrapolated to the scientific community as a whole, and were clearly geographically proscribed to participants based in the United States.

The central question of this study was to explore how scientists themselves would define the right to enjoy the benefits of scientific progress. The strength of the type of grounded analysis of small samples of carefully collected qualitative data used in this study is its ability to generate theories of meaning and motivation that are open to subsequent testing with larger samples and quantitative data (Hafner-Burton and Ron 2009). As the UN process of defining the right to enjoy the benefits of scientific progress and its applications continues, it is our hope to be able to extend the focus group process. To that end, the next steps in this effort will include:

i. conducting a global study involving both quantitative and qualitative components;
ii. broadening the scope of inquiry to address issues of particular significance among marginalized and vulnerable populations;
iii. recruiting, as study participants and research partners, scientists, engineers and health professionals in developing countries.

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### Human Rights Instruments and Statements


*Declaration on the Rights of Indigenous Peoples* (2007), G.A. Res. 61/295, U.N. Doc. A/RES/47/1.

*International Covenant on Economic, Social and Cultural Rights* (1966), G.A. res. 2200A (XXI), 21 U.N.GAOR Supp. (No. 16) at 49, U.N. Doc. A/6316, 993 U.N.T.S. 3, *entered into force* Jan. 3, 1976.

*Recommendation on the Status of Scientific Researchers* (1974), UNESCO Gen. Conf. Res. 18 C/Res.40, 18th Sess.

*Universal Declaration of Human Rights* (1948), G.A. res. 217A (III), U.N. Doc A/810 at 71.

*Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and Its Applications (2009), UNESCO* Experts' Meeting on the Right to Enjoy the Benefits of Scientific Progress and its Applications, 3rd Meeting, Venice, Italy, 16-17 July 2009.

*Universal Declaration on Human Rights and Bioethics* (2005), UNESCO Gen. Conf. Res. 36, 33rd Sess.

# Appendix A: AAAS Board of Directors – Statement


***AAAS Statement***

***On the human right to the benefits of scientific progress***

The human right to enjoy the benefits of scientific progress and its applications was first internationally recognized in the 1948 Universal Declaration of Human Rights. Basic tenets of the right include: ensuring equitable access to the benefits of scientific progress, with particular focus on vulnerable and marginalized groups; investing in R&D and creating incentives for innovation to address forms of suffering experienced by these groups; ensuring the freedom of scientists to engage in scientific inquiry while also conducting their work responsibly; and fostering international cooperation in science.

An international process is currently underway that will take into account different perspectives and diverse interests in defining with greater clarity the meaning of the right and in determining how best to implement the right in practice. Recognizing that this right lies at the heart of the AAAS mission and the social responsibilities of scientists, AAAS will pursue opportunities to collaborate with the global scientific community so that the voice, interests and concerns of scientists can be brought to this process.

Building on AAAS's strength as the world's largest multi-disciplinary scientific society and its unique contributions in bringing science and scientists to human rights work, AAAS will:

- bring to the attention of its affiliates and members the importance of engaging in discussions concerning the human right to benefit from scientific progress and its applications;
- engage the domestic and global scientific communities in defining the content of the right and determining its application to a diverse range of scientific disciplines and issues of concern to the scientific community;
- coordinate the efforts of the AAAS Science and Human Rights Coalition to conceptualize the right and pursue strategies for integrating this right into the work of Coalition members; and
- building on these activities, engage the US government and other key actors in dialogue on the right to benefit from science and its implications for relevant policies and programs.

[*Adopted by the AAAS Board of Directors, 16 April 2010.*]

## Appendix B: Methodology

While scientists, engineers and medical professionals have deep scientific knowledge, that knowledge is at considerable distance from the legal and philosophical framework of human rights. How could scientists and engineers be asked about the meaning of Article 15 in a way that would create a bridge between their distinct areas of expertise and accustomed epistemological approaches and the international legal concepts and ontological basis of human rights?

After considering a variety of approaches, the Coalition decided to conduct a series of focus group interviews in which scientists would be asked to reflect on their views regarding the meaning of Article 15. In this methodology, a small group of individuals who share a personal characteristic, body of knowledge, or lived experience related to a specific research question are invited to participate in a structured group discussion. The focus group participants are asked a series of questions designed to illicit a conversation centered on the research topic. The interaction between the participants is one of the strengths of focus groups as a data collection mechanism because it can uncover shared understandings and values that might not be apparent in one-on-one interviews with the same individuals (Krueger and Casey 2000).

In this study, the participants in each focus group shared a common scientific disciplinary background and, with the exception of the focus group involving chemists, each of the focus groups was sponsored by a scientific or engineering society. During the focus groups, participants were asked to respond to a set of 10 open-ended questions about the benefits of scientific progress and its applications in terms of their own discipline, and the corresponding responsibilities of governments related to scientific freedom, international contacts and co-operation, and the conservation, development and diffusion of their discipline. Before the full conversation regarding each pre-established question began, focus group participants were invited to gather their thoughts for a few minutes and write their ideas on a comment sheet. After the focus group was over, the comment sheets were collected from each participant. This allowed us to get a sense of the full range of opinions and ideas expressed by the participants in order to compensate for the fact that in any group discussion, some individuals will be more vocal and others less so. This also made it possible to discern if an actively-discussed topic in a focus group was already salient for participants prior to the discussion, or emerged as a result of the focus group interaction.

This report includes data from 16 focus group interviews conducted with a total of 145 participants.[2] The disciplines represented in the present analysis include five social and behavioral sciences, five physical and chemical sciences, three biological and medical sciences, one discipline within the category of the history and philosophy of science, and one discipline within the area of engineering and technology.

All the focus group discussions were audio recorded and transcribed verbatim. These transcripts, as well as the written comments provided by participants during the focus groups, were analyzed using a systematic qualitative coding process reflective of the grounded theory approach first developed by Glaser and Strauss (1967) and increasingly recognized as a systematic and rigorous methodological tool across numerous disciplines (Bradley et al 2007; Charmaz 2006; Bitsch 2005; Glazer 2004). Two rounds of inductive open coding were conducted, involving a line-by-line process of constant comparison to identify themes and issues in the data (Strauss and Corbin 1990). In this way a coding frame was developed and refined, and then systematically applied across the interviews in a third round of coding. Finally, a fourth round of coding occurred for topic-specific portions of the data that were identified in the previous coding processes, once again employing the method of constant comparison (continuously asking questions and making comparisons between words,

[2] An additional focus group was conducted with philosophers of science, and while their insights were important and useful to the larger project, the data from that focus group is not included in the analysis of focus groups presented here.

phrases, and sentences) in order to develop an explanatory theory. In total there were 700 pages of textual data (including the verbatim transcripts and participant comment sheets) to which 148 codes were inductively produced and deductively applied across 3,770 excerpts resulting in approximately 11,800 code applications.

**Disciplines Represented in Focus Groups**

**Table A1: Five Categories of Scientific Disciplines and Their Representation in Focus Groups**

| Social and Behavioral Sciences | Biological and Medical Sciences | Physical and Chemical Sciences | Engineering and Technology | History and Philosophy of Science |
|---|---|---|---|---|
| Geography | Ecology | Acoustics | Mechanical engineering | History |
| Linguistics | Forensics | Astronomy | Statistics | Philosophy* |
| Psychology | Tropical medicine and hygiene | Chemistry | | |
| Social psychology | | Geology | | |
| Sociology | | Physics | | |

*Data from the focus group with philosophers is not included in this analysis

**Table A2: Demographics of Focus Group Participants**

| | | Percent |
|---|---|---|
| Gender | | |
| | Female | 39 |
| | Male | 61 |
| Age | | |
| | 20-39 years | 24 |
| | 40-59 years | 44 |
| | 60-79 years | 32 |
| Race* | White | 86 |
| | Racial/ethnic minority | 16 |
| Employment sector* | | |
| | Education | 56 |
| | Government | 21 |
| | Non-profit | 15 |
| | Private | 7 |
| | Independent practice | 8 |

*Percents total to more than 100% because respondents could choose more than one category

# Appendix C: Focus Group Protocol

**Focus Group Protocol**

[insert association/society title]

**Perspectives on the Human Right to**

**the Benefits of Scientific Progress and Its Applications**

[insert date]

[insert city, state]

## Welcomes and Introductions

[Welcome]

[2-3 minutes: [insert name] will welcome the participants and provide context regarding the organization's participation in this focus group process.]

[Introductions of staff facilitators]

## Script begins

Before we ask you to introduce yourselves, I will give you a quick overview of our plan for the group and give you the chance to opt out. Then, we will ask those who choose to stay to introduce yourselves to one another. Next we will provide some basic information about the subject of our focus group—the human right to enjoy the benefits of scientific progress and its applications, Article 15 of the International Covenant on Economic, Social, and Cultural Rights. Then, with that shared background, we will ask you to respond to a series of questions.

Before I continue, I hope that you have all completed the demographic information on the sheet in front of you. If you have not, please do so now. Just note, we are not asking for your name.

The focus group is expected to take two hours. We will be asking you a series of questions and soliciting two or three responses. If you have any additional information you would like to note about a question you may do so on the paper provided. We are recording the session in order to help us gather the full range of comments made during the focus group. Your name will not be associated with the content of this discussion; and we will not identify anywhere the participants in the focus group, except in general terms using the demographic questions we have asked you to answer.

Is anyone unwilling to participate while being recorded? Will everyone be able to stay until the end?

[If anyone chooses not to stay, then thank them and proceed as they leave the room.]

Thank you all very much for being willing to participate.

Now, please introduce yourselves by telling us your name, your specialty area, and any connection you may have had with the topic of human rights.

Thanks. Now [insert name] will give us a short background presentation on Article 15.

[Presentation. Stop on "Questions"]

[Facilitator begins]

Now we are ready to begin the focus group discussion.

Under Article 15, governments are committed to recognize the right of everyone to enjoy the benefits of scientific progress and its applications.

1. Please turn over the sheet you just filled out and write down on the flip side three benefits of scientific progress and its applications in [your discipline]. Emphasize benefits that you consider *essential* for individual and/or societal well-being.
   [Pause before reading the example]

For example, engineering provides the knowledge necessary to purify water, ensuring proper hydration for living beings.

[Wait 3-10 minutes.]

Will someone give us one benefit?

[Pause as a participant explains their example/s]

Now will someone give us a different benefit?

[Probe, if needed, to ensure that participants are thinking both about benefits to society and about benefits to individuals.]

2. Let's take the benefits you have identified above. What government action or inaction stands in the way of people accessing these benefits?

   [Pause before reading the example]

For example, inadequate and poorly enforced government construction standards may endanger the lives of individuals using basic infrastructure, including buildings, roads and bridges.

[Pause before continuing]

Who wants to share their example?

[Pause as a participant explains their example/s]

Who wants to share a different example?

[Continue eliciting examples and discussion for 10 minutes]

Though Article 15 does not specifically address scientific responsibility, for the purposes of developing a comprehensive approach to Article 15, it will be important to understand the ways in which the conduct of science and/or its applications may give rise to violations of human rights.

3. What are two current areas of research or practice in [your discipline] that have, or may have, social justice and human rights implications?
   [Pause before reading the example]

For example, patient-driven online medical communities are not peer-reviewed or otherwise professionally moderated and may lead to the dissemination of scientifically unproven or unsound advice that, in turn, may have severe consequences.

[Ask for examples.]

Please remember that you may write down on your piece of paper any ideas that you have that have not been recorded.

4. What measures can or should government put in place to monitor or prevent the potential dangers arising from research in [your discipline] or misuses of the application of [your discipline]?

[Pause before reading the example]

For example, government should adopt the measures necessary to monitor the potential harmful effects of science and technology, to effectively react to the findings and inform the public in a transparent way.

[Ask for examples.]

Turning now to our rights as scientists Article 15 requires states to respect the freedom indispensable for scientific research.

5. Do any actions or inactions by government create a barrier to research in [your discipline]? Please give two examples.
[Pause before reading the example]

For example, export controls limit interactions between scientists and in some cases inhibit industry development. By deeming a large and overly broad list of scientific areas as militarily-sensitive, collaboration is unnecessarily difficult and sometimes impossible.

[Ask for examples. Probe, as needed, for challenges related to the topic or content of research, to the method, or to dissemination; encourage specific examples, when possible.]

Under Article 15 governments have committed to recognize the benefits to be derived from the encouragement and development of international contacts and cooperation in science.

6. What does and/or should the government do to encourage or support the development of international contacts and cooperation in [your discipline]?
[Pause before reading the example]

For example, the government should support the development of web-based platforms for sharing information and facilitating collaboration.

[Ask for examples.]

In order to fully realize the right to enjoy the benefits of scientific progress and its applications, Article 15 requires governments to take the steps necessary for the conservation, development, and diffusion of science. In the next series of questions, we're going to first ask you to tell what you think the key words "conservation," "development," and "diffusion" mean for [your discipline]. Then we'll ask you to identify the steps that governments must take to achieve conservation, development, and diffusion.

Let's take them in reverse order and remember that we are focused on areas of government influence.

7. What steps must government take to ensure the <u>diffusion</u> of [your discipline]?

[Pause before reading the example]

For example, government must provide support, through legal, financial and other measures, for the dissemination of scientific literature and findings including online and in schools.

[Ask for examples. If a definition of diffusion is asked for: Diffusion may mean the dissemination of information about [your discipline], as well as the spread of the practice of [your discipline].]

8. What about the development of [your discipline]. What steps must government take to ensure the development of [your discipline]?
[Pause before reading the example]

For example, government support is required for basic STEM education at all levels of learning, including minimum core requirements to be taught at primary and secondary levels.

[Ask for examples. If a definition of development is asked for: Development may mean the growth or expansion of [your discipline] as a field of research and area of practice.]

Please remember that you may write down on your piece of paper any ideas that you have that have not been recorded.

9. And now, conservation. What steps must government take for the conservation of [your discipline]?

[Pause before reading the example]

For example, Governments should maintain an online and freely accessible repository of biochemical data for use by researchers (e.g., Protein Data Bank)

[Ask for examples. If a definition of conservation is asked for: conservation means "a careful preservation and protection of the discipline." If needed, use the following probe: For example, is there specific knowledge, or are their specific products or tools of [your discipline] that must be conserved?]

Other Issues Not Covered Yet

10. Is there any other issue that you think we should consider and discuss?

That completes the focus group interview. Thank you for your participation.