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The Right to Benefit from Science and Its Implications for Genomic Data Sharing

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Abstract

The right to benefit from science and its applications is one of the least studied, discussed and applied human rights. In the current time of globalization, characterized by the rapid advancement of science and its technological applications, as well as by increased flows of scientific data, there is a growing need to fully awaken the right of everyone to enjoy the benefits of science. This would enable science to better serve the humanitarian purposes of the law as well as foster scientific and technological development through data sharing. This article contributes to the awakening of the right by exploring it doctrinally with the aim of ascertaining its normative content by reference to the preparatory works of Article 15 of the International Covenant on Economic, Social and Cultural Rights and, especially, the subsequent state practice in its application. Based on the evidence, it will be argued that, today, the right to benefit from science has two aspects – first, the right to access scientific knowledge and information and, second, the right to benefit from scientific applications. It will be shown that the first aspect of the right is increasingly reflected in the practice of states and international organizations and has important implications for the regulation and sharing of big genomic data.

1 Introduction

The right to enjoy the benefits of scientific progress and its applications (in short, 'the right to benefit from science') is one of the least studied, discussed and applied human rights. It was set out as early as 1948 in the Universal Declaration on Human Rights (UDHR)[1] and, later, incorporated in the widely ratified International Covenant on Economic, Social and Cultural Rights (ICESCR).[2] Accordingly, it is no surprise that

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1 GA Res. 217A (III), 10 December 1948 (UDHR).

2 1966, 993 UNTS 3 (ICESCR).

scholars have dubbed it the 'sleeping beauty' of human rights.[3] Indeed, the states parties to the ICESCR scarcely provided information about its implementation in their early reports. Recently, however, there have been discernable signs that the right is awakening, with a growing number of states reporting that measures have been taken to realize it in practice. In the last decade, the United Nations Educational, Scientific and Cultural Organization (UNESCO)[4] and the United Nations (UN) Special Rapporteur in the Field of Cultural Rights[5] have also started turning their attention to this 'underdeveloped'[6] right, and the Committee on Economic, Social and Cultural Rights (CESCR) recently issued a general comment on it.[7]

In the current period of globalization, which has been characterized by the rapid advancement of science and its technological applications, as well as by increased flows of scientific data, there is a growing need to fully awaken the right of everyone to enjoy the benefits of science. This would enable science to better serve the humanitarian purposes of the law, as well as to foster scientific and technological development through data sharing. This article contributes to the awakening of this right by exploring it doctrinally with the aim of ascertaining its normative content by reference to the preparatory works of Article 15 of the ICESCR and, especially, the subsequent state practice in its application. Based on the evidence, it will be argued that, today, the right to benefit from science has two aspects – first, the right to access scientific knowledge and information and, second, the right to benefit from scientific applications. The second aspect of the right is still largely unsettled and subject to widely varying interpretations by states. Therefore, it is difficult to ascertain its normative status and content in the practice of states and, more broadly, in general international law.

The first aspect of the right, however, is increasingly reflected in the practice of states and international organizations. It has important implications for the regulation and sharing of big genomic data, which is understood as human genetic data in electronic format that is large in volume, diverse in variety and moving with high velocity, thus requiring high-speed data processing.[8] Given its importance for the development of modern science, as well as its direct technological applications in medicine, big genomic data will be used as a case study for the implications of the right to benefit from science.

[3] Schabas, 'Looking Back: How the Founders Considered Science and Progress in Their Relation to Human Rights', 4 *European Journal of Human Rights* (2015) 1, at 1.

[4] United Nations Educational, Scientific and Cultural Organization (UNESCO), Report of the Experts' Meeting on The Right to Enjoy the Benefits of Scientific Progress and Its Applications (2007); UNESCO Recommendation on Science and Scientific Researchers (2017); Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and Its Applications (2009); see also Y. Donders and V. Volodin, *Human Rights in Education, Science and Culture: Legal Developments and Challenges* (2007).

[5] Report of the Special Rapporteur in the Field of Cultural Rights, Farida Shaheed, The Right to Enjoy the Benefits of Scientific Progress and Its Applications, Doc. A/HRC/20/26, 14 May 2012.

[6] *Ibid.*, at 1, para. 3.

[7] General Comment no. 25 (2020) on science and economic, social and cultural rights, ESC, E/C.12/GC/25.

[8] Laney, '3D Data Management: Controlling Data Volume, Velocity, and Variety', 6 February 2001, available at https://blogs.gartner.com/doug-laney/files/2012/01/ad949-3D-Data-Management-Controlling-Data-Volume-Velocity-and-Variety.pdf.

Recent state practice reinforces the need to ascertain the implications of human rights for genetic data sharing and vice versa. In 2018, a number of states, including the United Kingdom (UK), Australia, Finland, Switzerland and France, announced nation-wide genome projects aiming to sequence millions of genomes.[9] In the same year, the European Union (EU) opened for signature a declaration that encourages member states to give cross-border access to their genomic and other health data in order to advance knowledge and improve health.[10] Big genomic data itself has important implications for the realization of the right to benefit from science. The digitalization of large-scale genomic data is catalysing scientific research by helping to understand the genetic associations causing diseases. The analysis of genomic data is also becoming cheap enough to be used in healthcare for more effective treatment and prevention,[11] thus enabling the second aspect of the right – namely, the right to benefit from scientific applications. The right to access scientific knowledge when applied to big genomic data creates a fundamental precondition not only for the development of science itself but also for the exercise of other important social and cultural rights, including the right to health, education and the freedom of research. This aspect of the right can help bridge the gap between developing and developed states in its realization by promoting equality of access.

The methodology adopted in the present study interprets the right to benefit from science by reference to the subsequent state practice in the application of the ICESCR as evidence of the attitude of the parties towards its interpretation under Article 31(3)(b) of the 1969 Vienna Convention on the Law of Treaties (VCLT)[12], as well as by reference to the preparatory works of Article 15 of the ICESCR as a supplementary means of interpretation under Article 32 of the VCLT. We have identified 123 reports from the 169 states parties to the ICESCR that give specific information on the implementation of the right. These are used to ascertain which aspects of the interpretation of the broadly worded right have attracted general agreement and which ones remain to be normatively established, as well as the trends in the evolution of the right. While most scholars search for the meaning of the right to benefit from science in its history and the preparatory works of the instruments that incorporate it,[13] this article will demonstrate that the drafters left the right open intentionally for future development.

[9] See announcements at the Sixth Plenary Meeting of the Global Alliance for Genomics and Health, 3–5 October 2018, available at www.ga4gh.org/event/ga4gh-6th-plenary/#3a.

[10] See also EU Declaration of Cooperation towards Access to at Least 1 Million Sequenced Genomes in the EU by 2022, available at https://ec.europa.eu/digital-single-market/en/news/eu-countries-will-cooperate-linking-genomic-databases-across-borders. It has now been signed by 21 member states and Norway.

[11] *Ibid.*, at 3–4.

[12] 1969, 1155 UNTS 331 (VCLT).

[13] See Haugen, 'The Right to Food, the Right to Benefit from Science and the TRIPS Agreement', in W.B. Eide and U. Kracht (eds), *Food and Human Rights in Development* (2005), vol. 1; Schabas, 'Study of the Right to Enjoy the Benefits of Scientific and Technological Progress and Its Applications', in Donders and Volodin, *supra* note 4, 16; Boggio and Romano, 'Freedom of Research and the Right to Science: From Theory to Advocacy', in S. Giordano, J. Harris and L. Piccirillo (eds), *The Freedom of Scientific Research: An Anthology* (2018) 162.

Accordingly, the key to understanding the right lies mainly in the present and future, not in the past. The awakening of the right is evidenced not only in the increasing number of domestic measures taken to fulfil it but also in the growing willingness of domestic and international courts to enforce it. International organizations too are taking initiatives to flesh out aspects of the right in their soft law instruments guiding state practice. The broader normative question that underpins this study is whether a human rights approach is sufficient to address the challenges posed by the rapid advancement of science and technology, including the growing gap between developed and developing states in this context, or whether an alternative or a hybrid regulatory framework should be explored.

It should be noted that this article merely observes the trends in state practice on the right to benefit from science reported by states under the ICESCR and makes no claims about the correlation, let alone the causation between the provision and the practice, which would require a thorough empirical investigation. It is acknowledged that state practice can be motivated by a number of factors other than human rights obligations. In addition to describing the content of the right, the article will also make normative suggestions for its future development based on the identified good practices. Conclusions will be drawn not only in regard to the potential, but also to the limits of the right in addressing the scientific and technological challenges posed by big genomic data in the future. Most of the literature on the right to benefit from science focuses on its relationship with intellectual property law. This falls outside of the scope of the present study. It is fully acknowledged that genomic data sharing could only work with the proper attribution and recognition of all authors and with full respect for medical law, including privacy, security and the right of patients to give informed consent. These considerations should be borne in mind as relevant in shaping state practice on the right to benefit from science, but they fall outside the scope of the present study.

2 Formulations of the Right

The right to benefit from science was set out for the first time in a general international instrument in the Universal Declaration of Human Rights, of which Article 27 provides that '[e]veryone has the right freely … to share in scientific advancement and its benefits'. [14] This formula set out the paradigm for all of the subsequent expressions of the right, and it merits a few observations. First, the right to science is set out together with cultural rights – a systemic place, which has been replicated in all other instruments and has implications as to the characterization of the right as a cultural one. Second, the right to science is always followed by a provision on the protection of the moral and material interests of the authors of scientific products, raising the question of the relationship between the two. Finally, even though the provision refers to 'the right' to share in scientific advancement, its formulation is more akin to that of a freedom not to be prevented from doing something by the state rather than a positive right imposing an obligation on the sovereign to enable it.

[14] UDHR, *supra* note 1.

The right was later included in the 1966 ICESCR with a different formulation emphasizing its positive normative aspects: 'The States Parties to the present Covenant recognize the right of everyone to enjoy the benefits of scientific progress and its applications.'[15] For the purposes of the present study, the ICESCR and the subsequent state practice in its implementation will be the key focus, given the general character of the Covenant, its nearly universal ratification and the absence of any reservations to the right to benefit from science.[16] Furthermore, Article 15(1)(b) of the Covenant has served as a model for most of the later regional treaties incorporating the right.[17] Most importantly, the ICESCR sets out the specific obligations incumbent upon states in relation to the right to benefit from science in greatest detail compared to other instruments, 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 co-operation in the scientific' field.[18] The obligations on states with regard to the development and the diffusion of science form the core of the right and arguably have the most important implications for big genomic data.

The inclusion of the right to benefit from science in the ICESCR is significant for both conceptualizing and contextualizing it. This is because the Covenant includes human rights that are subject not to immediate application but, rather, to progressive realization, including through the adoption of legislative measures, and subject to the available economic resources of each state party.[19] As observed by Canada during the negotiations of the covenant, economic, social and cultural rights are 'responsibilities of the state in the field of economic policy and social welfare which usually require for their effective implementation detailed social legislation and the creation of appropriate administrative machinery'.[20] The Economic and Social Council (ESC), being the treaty body overseeing the compliance with the ICESCR,[21] also opined that the rights set out in Article 15 have a non-self-executing character, requiring states to take legislative and other measures to ensure their application.[22] Recent judicial practice, however, challenges this assumption by making the right actionable. Another important aspect of economic, social and cultural rights is the emphasis on equality

[15] ICESCR, *supra* note 2, Art. 15(1)(b).

[16] The ICESCR has 171 states parties. See https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-3&chapter=4&clang=_en.

[17] See notes 26–29 below.

[18] ICESCR, *supra* note 2, Art. 15(2)–(4).

[19] *Ibid.*, Art. 2(1).

[20] Compilation of the Observations of Governments of Member States on the Draft International Covenant on Human Rights and Measures of Implementation, as Drafted at the Sixth Session of the Commission on Human Rights: Memorandum by the Secretary-General, Doc. E/CN.4/552, 24 April 1951; see also Report Submitted by the Director-General of UNESCO on Regulations Concerning Economic and Social Rights in the International Covenant on Human Rights, Doc. E/1752 (1950).

[21] ICESCR, *supra* note 2, Arts 16–22.

[22] Economic and Social Council (ESC), General Discussion on the Right to Take Part in Cultural Life as Recognized in Article 15 of the ICESCR, Doc. E/C.12/1992/2 (1992), at 59, para. 216.

of access. Indeed, the reference to 'everyone' was intended to emphasize that these rights are recognized for every individual without any distinction.[23] Due to these specific characteristics and their relative novelty on the international plane, scholars have expressed doubts as to the effectiveness of economic, social and cultural rights. For example, Hersch Lauterpacht pointed out in 1952 that these 'lie at the vanishing point of human rights' and, even less optimistically, that the right to benefit from science 'lies at the vanishing point of economic, social and cultural rights'.[24] This right is very much dependent upon the level of economic and technological development of each state. It is in relation to this right where the gap between developed and developing states is the widest, as evidenced in the soft wording of Article 15(4) of the ICESCR that recognizes the benefits from international scientific cooperation without mandating it.

The right to benefit from science can be found in varying formulations in most regional human rights instruments.[25] For example, the Charter of the Organization of American States defines the right as an interstate right rather than as an individual one, requiring that states 'extend among themselves the benefits of science and technology'.[26] The Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights adopts an individual human rights approach instead, recognizing the right of everyone 'to enjoy the benefits of scientific and technological progress'.[27] The Association of Southeast Asian Nations' (ASEAN) Human Rights Declaration defines the right to benefit from science both as an individual and a collective one.[28] Interestingly, the right to benefit from science is absent from African human rights instruments.

Notably, the European approach towards science defines it as a freedom rather than as a positive right. This freedom can be traced back to the constitutional traditions of European states, such as the 1867 Austrian Constitution.[29] The EU Charter of Fundamental Rights construes it as freedom of scientific research that belongs to the scientific community,[30] which significantly limits the beneficiaries of the provision to the collective of scientists.

[23] UNGA Tenth Session, 3rd Committee, 658th Meeting, Doc. A/C.3/SR.658, 9 November 1955, para. 32.

[24] Lauterpacht, 'The Problem of the Revision of the Law of War', 39 *British Yearbook of International Law* (1952) 139.

[25] The only formulation substantially identical to the ICESCR is that in Art. 42 of the Arab Charter on Human Rights, 22 May 2004, reprinted in 12 *International Human Rights Reports* (2005) 893. The African Charter on Human and People's Rights 1981, 1520 UNTS 217, contains only a general reference to cultural development but not to science. See also Art. 12(2) of the Protocol to the African Charter on Human and Peoples' Rights on the Rights of Women in Africa 2003, 2nd Ordinary Session of the Assembly, AU requiring states to promote the education of women particularly in the fields of science and technology.

[26] Charter of Organization of American States 1948, 119 UNTS 3, Art. 38.

[27] Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights 1988 18th session of the GA, OAS Art. 14 on the Right to the Benefits of Culture.

[28] Association of Southeast Asian Nations (ASEAN) Human Rights Declaration 2012, Art. 32, available at https://asean.org/asean-human-rights-declaration/.

[29] Fundamental Law Concerning the General Rights of Citizens, 1867, Art. 17 available at https://ecommons.cornell.edu/bitstream/handle/1813/1443/Austr_Const_1867.pdf?sequence=1&isAllowed=y, which provides that 'Science and its teaching shall be free'.

[30] Charter of Fundamental Rights of the European Union, OJ 2012 C 326/02, Art. 13.

The commentary to the charter clarifies that the provision is based on the freedom of expression set out in the European Convention on Human Rights (ECHR) and the relevant case law of the European Court on Human Rights.[31] Notably, the ECHR itself does not contain a provision on the right to science.[32] The same is true for the European Social Charter.[33] Accordingly, in Europe, with its many scientifically and technologically developed states, the right to benefit from science is understood as a form of collective freedom of expression rather than as a positive right. This approach entails that the obligations of the state are negative and limited to not interfering with the freedom rather than requiring a proactive realization of the right. Nonetheless, the EU has developed soft law initiatives to promote access to science, including 'Open Science' and the Commission's 'Open Research Publishing Platform', which mandates the open access publication of the results of research funded by the EU's Horizon 2020 programme,[34] as well as the EU's declaration on cooperation towards access to at least 1 million sequenced genomes.[35] Notably, the open access movement was initiated from the bottom up by research organizations and professional societies in Europe with the 2003 Berlin Declaration on Open Access to Knowledge in the Sciences and Humanities.[36]

Overall, the key conceptual differences in formulating the right to benefit from science are, first, that some instruments define it as a positive human right, while other regional instruments treat it as a mere freedom. Second, some instruments treat this freedom as belonging collectively to the scientific community, thus excluding everyone else from the benefits of science. This division of approaches between developed and developing states, and, especially, the comparatively passive *laissez-faire* stance of Europe, which is otherwise at the forefront of the protection of human rights, is arguably partly responsible for the dormancy of the right. What is required to fully awaken it is a shift of paradigm in the practice of developed states.

3 Interpretation of the Right

A *Ordinary Meaning*

One of the main difficulties with conceptualizing and implementing the right to benefit from science stems from its broad formulation, including the general and vague language used in its definitions, as well as the dynamic character of the underpinning concepts. As observed by the ESC, cultural, economic and social rights are underdeveloped 'largely because of a lack of clarity in respect of their legal nature and content'.[37] Accordingly, the interpretation of the right is key to understanding its content and to

[31] Commentary of the Charter of Fundamental Rights of the EU, EU Network of Independent Experts on Fundamental Rights (2006), at 134–138.

[32] 1950, 213 UNTS 221.

[33] 1996, 2151 UNTS 277.

[34] Horizon 2020, available at https://ec.europa.eu/research/openscience/index.cfm.

[35] See *supra* note 10.

[36] Berlin Declaration on Open Access to Knowledge in the Sciences and Humanities, available at https://openaccess.mpg.de/Berlin-Declaration.

[37] ESC, *supra* note 22, at 57, para. 204.

giving it effect in practice. A starting point could be the definition of the right to benefit from science in the ICESCR, interpreted 'in good faith in accordance with the ordinary meaning to be given to the terms of the treaty in their context and in light of its object and purpose'.[38]

The formula that states 'recognize the right of *everyone*' was intended to emphasize the requirement of equal access to the right for every individual without discrimination.[39] However, it could also be understood as indicating that the right to benefit from science is both an individual and a collective one. This is because the scope of the potential beneficiaries of science and its applications not only includes individuals but also different groups of people within a society, such as the vulnerable, disabled or marginalized people, as well as the members of the scientific community, including researchers, medical professionals and academics. This approach is reinforced by systemic interpretation by reference to the other paragraphs of Article 15, given that the development of science, freedom of research and international cooperation in the scientific field strongly imply the involvement of the scientific community. UNESCO's Venice Statement, the *Report of the Special Rapporteur in the Field of Cultural Rights* as well as ASEAN's Human Rights Declaration define the right to benefit from science as being simultaneously an individual and a collective right.[40]

While not legally binding, these interpretations coming from the UN and regional bodies with expertise in the area of science carry authoritative weight. The collective character of the right could have specific implications for big genomic data by promoting access for the communities of scientists, researchers, academics, medical practitioners, indigenous people and patients affected by a specific genetic defect. The individual character, on the other side, implies that any person can rely on the right *vis-à-vis* the obligation holder – the state. The reference to 'everyone' could also be read as intending for it to cross state borders in an aspiration for truly universal application. Such an interpretation is reinforced by the emphasis on international scientific cooperation in Article 15(4) of the ICESCR. While it is possible to interpret the right as a collective one, it is important to emphasize its individual character in order to guarantee equality of access to science to everyone, not just those belonging to the scientific collective.

The second term that needs clarification is 'science', which could either be interpreted broadly as including all sciences or narrowly as encompassing only natural science. The former approach is preferable in light of the discussions during the drafting of the ICESCR, where the chair of the ESC clarified that the term 'science' 'was to be understood broadly and was meant to apply to social sciences too and to every possible branch of scientific research'.[41] Such a broad interpretation is also in line with UNESCO's approach to the definition of 'science'.[42] It should be stressed, however, that

38 VCLT, *supra* note 12, Art. 31(1).

39 Compilation of the Observations, *supra* note 20 (emphasis added).

40 Venice Statement, *supra* note 4, para. 7; Report on Cultural Rights, *supra* note 5, at 1; ASEAN Human Rights Declaration, *supra* note 28, Art. 32, stating that '[e]very person has the right, individually or in association with others…to enjoy…the benefits of scientific progress and its applications'.

41 ESC, 293rd Meeting, Doc. E/CN.4/SR.293, 27 May 1952.

42 See UNESCO Recommendation, *supra* note 4, Art. 1(a)(i).

the term 'science' is not defined in the ICESCR itself, probably for the better, given the dynamic character of the concept. Accordingly, the term is left open to development.

The ordinary meaning of 'benefit' entails the receiving of an advantage or profit.[43] The legal definition of the term is also twofold,[44] with the second aspect being strongly economically focused and meaning 'profit or gain'.[45] Interpreted in the context of science and its applications, the concept of benefiting is far from clear. Does it include economic benefits or merely non-economic ones? If it means the former, does everyone have the right to benefit freely, openly or equitably? And, finally, how does this individual and/or collective right to benefit from science and especially its applications fit with the rights of authors to benefit from the protection of their moral and material interests? These questions are left open by Article 15 of the ICESCR. Arguably, there is also a significant difference between being able to benefit from science, on the one hand, and benefiting from its applications, on the other. While the former can be achieved by having access to scientific information, the latter can take varying forms depending on the specific character of the scientific application and creates more tension with intellectual property rights over technological inventions.

According to the Special Rapporteur in the Field of Cultural Rights, the term 'benefit' should be interpreted broadly as conveying 'the idea of a positive impact on the well-being of people and the realization of their human rights' and, furthermore, as 'encompass[ing] not only scientific results and outcomes but also the scientific process, its methodologies and tools'.[46] The right to benefit from scientific processes, tools and methodologies is particularly relevant and beneficial to the sharing of big genomic data given the complexities in processing it. Furthermore, the emphasis on the positive impact of science underlying the term 'benefit' excludes, *a contrario*, the possible negative aspects of science from the scope of Article 15, such as the use of unsafe medicines or technologies. This choice of wording could be interpreted as imposing a positive obligation on states to protect everyone from the negative effects of science and technology, as suggested by the special rapporteur and by the Committee on Economic, Social and Cultural Rights in its General Comment no. 17 on Article 15(1)(c) of the ICESCR,[47] by the ESC,[48] as well as in the Guidelines on Treaty-Specific Documents, which require states to provide specific information on the 'measures taken to prevent the use of scientific and technical progress for purposes which are contrary to the enjoyment of human dignity and human rights'.[49] One implication of this aspect of the right for genomic data sharing would be the obligation on states to ensure this happens with due respect for privacy and with the informed consent of those whose genetic information is being shared.

[43] *Oxford English Dictionary*, available at https://en.oxforddictionaries.com/definition/benefit.

[44] B Garner *et al.* (eds), *Black's Law Dictionary* (10th edn, 2014), at 188.

[45] *Oxford English Dictionary*, *supra* note 43.

[46] Report on Cultural Rights, *supra* note 5, para. 24.

[47] *Ibid.*, para. 43; Committee on Economic, Social and Cultural Rights (CESCR), General Comment no. 17, Doc. E/C.12/GC/1712 (2005), para. 35.

[48] ESC, *supra* note 22, at 57, para. 207.

[49] ESC, Guidelines on Treaty-Specific Documents to Be Submitted by States Parties under Articles 16 and 17 of the ICESCR, Doc. E/C.12/2008/2 (2008), para. 70(b).

The interpretation of the term 'progress' seems straightforward and can be done by reference to its ordinary meaning, which is 'development towards an improved or more advanced condition'.[50] A question arises as to the meaning of the 'applications' of science. As noted above, some regional human rights treaties equate these with technological applications. Such an approach, however, may be unduly restrictive. For instance, 'technology' was defined by UNESCO as 'knowledge as it relates directly to the production or improvement of goods or services'.[51] It is unclear whether the outcomes of scientific research in the form of academic writings would necessarily fall under this definition as they do not always relate directly to the production or improvement of goods and services. Yet the right to benefit from them is arguably an important part of, if not a precondition for, the right to benefit from science. As stressed by UNESCO, 'open communication of the results, hypotheses and opinions … lies at the very heart of the scientific process, and provides the strongest guarantee of accuracy and objectivity of scientific results'.[52] Accordingly, it is preferable to interpret the applications of science broadly as including, but not limited to, technological, academic and other applications. When it comes to genomic data, the right to benefit from the applications of science could imply a right to benefit from academic writings analysing or describing the data as well as from applications of genomic technologies.

Finally, it should be underlined that, according to the discussions of the right to benefit from science in the Third Committee of the UN General Assembly, a number of the concepts and notions in Article 15 were still in the process of evolution at the time of its adoption.[53] This is a strong indication that the drafters intended to leave the provision open for future development and that evolutionary interpretation should play an important part in assessing the meaning of Article 15 and the content of the right in light of the significant advances in science and its applications in the decades following the adoption of the ICESCR. This method of treaty interpretation was defined by the International Court of Justice as entailing that an international instrument has to be interpreted and applied by reference to legal developments[54] and to modern-day conditions.[55]

B *Preparatory Works*

As seen in the previous section, although applying the general rule of Article 31 of the VCLT leaves the meaning of Article 15(1)(b) of the ICESCR ambiguous, resort can be had to the supplementary means of interpretation in accordance with Article 32

[50] *Ibid.*

[51] See UNESCO Recommendation, *supra* note 4, Art. 1(b).

[52] *Ibid.*, preamble, para. 5(c).

[53] United Nations General Assembly (UNGA), Report of the Third Committee, Doc. A/3764, 5 December 1957, para. 74.

[54] *Legal Consequences for States of the Continued Presence of South Africa in Namibia (South West Africa) Notwithstanding Security Council Resolution 276 (1970)*, Advisory Opinion, 21 June 1971, ICJ Reports (1971) 16, at 31, para. 53.

[55] *Dispute Regarding Navigational and Related Rights (Costa Rica v. Nicaragua)*, Judgment, 13 July 2009, ICJ Reports (2009) 213, at 243–244, paras 66–71.

of the VCLT – in particular, the preparatory works of the treaty. The terms that need disambiguation include 'everyone', 'benefit' and 'applications'. More generally, the resort to the general rule of interpretation fails to clarify the normative content of the right to benefit from science, as well as the specific obligations it imposes on states. Indeed, the main difficulty during the drafting of Article 15(1)(b) lay in the differing understandings of the character, content and implications of the right. Turning to the character of the right, a provision on science was incorporated at the initiative of the Soviet Union, which was formulated not as an individual right but, rather, as an obligation incumbent on the state to ensure the development of science and education in the interest of progress, democracy, international peace and cooperation.[56] It was later agreed that science is not only a public policy objective but also an individual right. This generated a controversy regarding the characterization of the right as a positive one or merely as a freedom. Most developed states, including the USA, France and the UK, conceptualized the right to benefit from science as a freedom to be exercised without interference by the state rather than as a positive right imposing an obligation to extend resources to ensure it.[57] Therefore, the preparatory works do not shed much light on the character of the right, and the differing approaches of states in this respect persist to date.

While the provision on the right to benefit from science attracted broad general agreement in principle, opinions were divided with respect to the actual content of the right. The USA thought that the right to benefit from science was 'simply the right to enjoy the results of scientific research', but 'what was really required was to ensure conditions in which [scientific] research could be freely conducted'.[58] The UK's understanding of the right was even more limited and boiled down to making the benefits of science available to all 'within the limits and by use of the machinery which already existed'.[59] According to UNESCO, the content of the right to benefit from science was twofold: on the one hand, 'the right to full access to the enjoyment of the technical and cultural achievements of civilization'[60] and, on the other, guaranteeing scientists the fullest freedom and security.[61] The divide between the approaches of developed and developing states towards the right to benefit from science persisted throughout the drafting and is evidenced in the subsequent domestic implementation of the right. Nonetheless, the right to access scientific achievements as part of the core content of the right to benefit from science is gaining increasing support in the practice of states, and the protection of scientific freedom is now well established.

The drafters' interpretations as to the specific legal obligations entailed by the right differed significantly too. A number of states, including Belgium, Denmark, the UK,

[56] Commission on Human Rights (CHR), Report of the 6th Session, 27 March–19 May 1950, at 27.

[57] CHR, 292nd Meeting, Doc. E/CN.4/SR.292, 27 May 1952, statements by Mrs Roosevelt and Mr Hoare; see also by Mr Azkoul (Lebanon).

[58] *Ibid.*, Mrs Roosevelt.

[59] *Ibid.*, Mr. Hoare.

[60] UNESCO, The Grounds of an International Declaration of Human Rights, Doc. Phil/10, 31 July 1974.

[61] Report Submitted by the Director-General of UNESCO on Regulations Concerning Economic and Social Rights in the International Covenant on Human Rights, Doc. E/1752, 11 July 1950, para. 34.

France, India, Syria, Iraq, India and Liberia, criticized the provision on the right to benefit from science in the ICESCR for 'the lack of clarity or ambition as to the obligations [it] entailed for the State'.[62] UNESCO opined that a more complete solution required the adoption of various subsequent regulations.[63] Others, however, were content with the ambiguity of the provision. Jordan thought it preferable to restrict the provision to a statement of principle, given that the notions in the subject were not yet clearly defined.[64] According to Norway, at that stage in the development of human rights, it was undesirable to specify the rights and obligations in too much detail but better to lay the foundations to enable future progress.[65] With respect to the varying understandings of the legal obligations entailed by the right to benefit from science, at one extreme end of the spectrum was France, which thought that the undertaking to provide conditions for the practical attainment of the right to science 'would in no sense bind States to modify their legislation in a rigid way if they did not wish to do so'.[66] Guatemala and Chile were at the other end of the spectrum, arguing that all provisions of the ICESCR should impose a positive obligation on states 'to use all available means to ensure the enjoyment of the rights'.[67] The developing states focused on the international dimensions of the right. Pakistan stressed the importance of greater international efforts,[68] and Egypt argued that, while scientific property ought to be protected domestically, all states should have free access to the achievements of other states on the international plane.[69] Overall, the preparatory works indicate that there was little common ground with respect to the specific legal obligations that the right to benefit from science imposed on states and that these were intentionally left open for development in future practice.

With respect to the beneficiaries of the right expressed with the term 'everyone', both the USA and the Soviet Union stressed the intended universality of the sharing in the benefits from scientific discoveries. Yet the specific understanding of who 'everyone' was differed. For example, the Soviet Union, supported by India, declared the benefits of science to be 'the heritage of mankind', including future generations in the understanding of 'everyone'.[70] Similarly, while the understanding of the term 'benefit' was agreed in principle, the USA and the Soviet Union had a diametrically opposed understanding of its implications in practice. The Soviet Union understood it to impose an obligation to reveal the patents for scientific discoveries, whereas the USA

62 CHR, 8th Session, Provisions Concerning Economic, Social and Cultural Rights: Memorandum by the Secretary-General, Doc. E/CN.4/650, 10 March 1952, para. 11; see also UNGA, 3rd Committee, 796th Meeting, Doc. A/C.3/SR.796, 31 October 1957, para. 18.

63 UNESCO, *supra* note 60, para. 34.

64 UNGA, 3rd Committee, 798th Meeting, Doc. A/C.3/SR.798, 1 November 1957, para. 4.

65 UNGA, 3rd Committee, 799th Meeting, Doc. A/C.3/SR.799, 4 November 1957, para. 7.

66 CHR, 7th Session, Summary Record of Meeting, Doc. E/CN.4/SR.229, 7 May 1951, at 13.

67 UNGA, Third Committee, 6th Session, 5 December 1951, para. 27; CHR, 292nd Meeting, *supra* note 57, Mr Valenzuela.

68 UNGA, 796th Meeting, *supra* note 62, para. 13.

69 CHR, 292nd Meeting, *supra* note 57, Mr Azmi Bey.

70 UNGA, 796th Meeting, *supra* note 63, para. 18.

thought that it did not.[71] Overall, the negotiating states generally agreed that the right to benefit from science was an important and necessary right, adopting the provision by 71 votes to none, with one abstention.[72] It was recognized, however, that certain concepts and notions that it contains were still in the process of evolution.[73] Having failed to agree on the precise character, content and legal implications of the right to benefit from science during the drafting of the ICESCR, the states parties left it to be fleshed out in the future. Therefore, the preparatory works of Article 15(1)(b) do not contribute significantly to its interpretation but, rather, reinforce the underlying ambiguities purposefully built into the provision.

4 State Practice on the Right to Benefit from Science

Given the high level of generality used in the formulation of the right to benefit from science, the evolutionary terms built into it and the absence of a clear consensus as to its normative content during the negotiations of Article 15 of the ICESCR, agreement on the interpretation of the right could be sought in the subsequent practice of states applying the covenant in accordance with Article 31(2)(b) of the VCLT and as evidence of whether and which aspects of the right to benefit from science have crystallized as a matter of law. Even where not sufficiently general, the practice of states is relevant as a supplementary means of treaty interpretation under Article 32 of the VCLT. For the former point, special consideration ought to be given to the scientifically and technologically developed states, as they constitute specially affected states whose practice is especially relevant in assessing the status of the right.[74]

The International Law Commission (ILC) clarified in its report on subsequent agreements and subsequent practice in relation to the interpretation of treaties that such practice is an authentic means of interpretation, being objective evidence of the parties' understanding of the meaning of treaties by narrowing, widening or otherwise determining the range of possible interpretations.[75] Where the subsequent practice falls short of establishing the agreement of all parties as to the interpretation of the treaty, it can still be used as a supplementary means of interpretation under Article 32 of the VCLT to confirm the meaning ascertained through the application of the general rule in Article 31.[76] Subsequent practice is particularly relevant where the parties have left a provision open for evolutionary interpretation by using generic terms

71 CHR, Summary Record 9th Meeting, Doc. E/CN.4/AC.2/SR.9, 10 December 1947, at 3.

72 Draft International Covenant on Human Rights, Report of the 3rd Committee of the GA, Doc. A/3764, 5 December 1957, para. 82(h). Czechoslovakia abstained due to concerns that the protection intellectual property rights did not belong in an article dealing with science and culture.

73 *Ibid.*, para. 74.

74 *North Sea Continental Shelf Cases (Federal Republic of Germany v. Denmark and The Netherlands)*, Judgment, 20 February 1969, ICJ Reports (1969) 3, para. 73.

75 International Law Commission (ILC), Report of the 68th Session, GAOR, Doc. A/71/10 (2016), at 120, Draft Conclusion 3; at 121–122, Draft Conclusion 6.

76 *Ibid.*, at 129.

capable of evolving over time.[77] This study adopts the ILC's approach to evaluating state practice by looking for practice that is a 'broad-based, settled and qualified form of collective practice',[78] while bearing in mind the discretion left to states in progressively implementing the ICESCR subject to their available resources.

Pursuant to Articles 16 and 17 of the ICESCR, the states parties are required to submit reports to the ESC on the measures they have adopted to give effect to the rights in the Covenant. These reports are arguably the most directly relevant, but they are also the most accessible evidence of subsequent state practice given their status as official communications arising under the ICESCR.[79] Also relevant are the responses of the UN members who replied to the questionnaire of the Independent Expert on cultural rights, Farida Shaheed, on the right to enjoy the benefits of scientific progress and its applications. These responses will be assessed together with a view to ascertaining whether there is an agreement emerging as to the interpretation and the content of the right. It is acknowledged that this approach has limitations as it presents only a partial picture of the evidence of state practice and does not show to what extent the human right to benefit from science actually shaped it. The latter would necessitate a different empirical methodology. During the evaluation, due consideration was given to the scope of discretion left to states in the realization of economic, social and cultural rights, which allowed adopting slightly different approaches towards their implementation without necessarily detracting from the general agreement as to their core normative content.

The guidelines on the form and content of the reports under the ICESCR issued by the ESC should be borne in mind when evaluating the state practice, given the high likelihood that they influenced, if not shaped, the reports of states on the right. This is because, following the 'inadequate in scope and insufficient in detail' initial reports on the implementation of the right in the initial reports of states parties, the ESC revised the guidelines in 1991 to require states to report on detailed aspects of the right.[80] These included the diffusion of information on scientific progress, the measures taken to ensure the application of scientific progress for the benefit of everyone and the measures taken to prevent the use of scientific progress in a manner contrary to human rights.[81] On the requirement to protect and respect scientific freedom, the ESC also asked states to report on the 'measures taken to guarantee the freedom of exchange of scientific [and] technical information'.[82] The revised 2008 guidelines require states to report on '[t]he measures taken to ensure *affordable* access to the benefits of scientific progress and its application for everyone, including disadvantaged and

[77] *Ibid.*, at 184–186, quoting *Dispute Regarding Navigational and Related Rights (Costa Rica v. Nicaragua)*, Judgment, 13 July 2009, ICJ Reports (2009) 213, paras 64–68.

[78] *Ibid.*, at 189–190.

[79] ILC, *supra* note 75, at 142.

[80] ESC, Revised General Guidelines Regarding the Form and Contents of Reports to be Submitted by States Parties under Articles 16 and 17 of the ICESCR, Doc. E/C.12/1991/1 (1991), at 1, para. 2.

[81] *Ibid.*, at 20, para. 2.

[82] *Ibid.*, at 21, para. 5.

marginalised individuals and groups'.[83] These detailed reporting requirements have the potential to indirectly influence the actual practice of states in the implementation of the right. The guidelines are also indicative of the interpretation of the right to benefit from science by the ESC, being the treaty-monitoring body responsible for monitoring and ensuring compliance with the ICESCR. While not legally binding on states, the ESC's interpretation has authoritative value. Overall, the guidelines emphasize the importance that the ESC attaches to state action aimed at ensuring that scientific progress is accessible and applied in a way that benefits everyone. According to the ESC, accessibility as a key aspect of the content of the right entails free access to scientific information and affordable access to scientific applications.

The question is whether states accept and give effect to these interpretations in their practice under the ICESCR. Of the 170 states parties to the ICESCR, 139 have submitted reports pursuant to Article 16 and 17 of the Covenant.[84] Around 90 per cent of these – 123 states – have reported taking specific measures to implement the right to benefit from science. Thus, only 10 per cent of the states parties to ICESCR submitted reports containing no information about taking measures to give effect to the right to benefit from science. The majority of these silent states are developing states, with Italy being the only developed state that failed to report on the right. The fact that the very large majority of states parties to the ICESCR have taken positive measures to implement the right to benefit from science is evidence of the general acceptance of the right as a positive rule of international law, as well as of the fact that it is interpreted in the subsequent practice of the states parties as having its own normative content separate from the right to take part in cultural life.

In terms of the interpretation of the actual content of the right, state practice is less clear-cut as the ICESCR parties have reported adopting varying combinations of measures to give it effect. The variation of approaches is broadly in line with the scope of discretion left to states in choosing how best to implement the right. Just over half of the states that reported taking measures to give effect to the right to benefit from science – 76 in total – adopted express legislative provisions to incorporate it domestically.[85] These states represent a good mix of developed and developing states, although there are some notable exceptions from the scientifically developed states.[86] The large

[83] Guidelines on Treaty-Specific Documents, *supra* note 50, at 15, para. 70(a) (emphasis added).

[84] See ICESCR, available at https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-3& chapter=4&clang=_en.

[85] Algeria, Angola, Burkina Faso, Burundi, Cape Verde, Democratic Republic of Congo (DRC), Egypt, Libya, Madagascar, Mauritania, Mauritius, Argentina, Brazil, Chile, Colombia, Costa Rica, Dominican Republic, Ecuador, El Salvador, Guatemala, Honduras, Mexico, Paraguay, Peru, Uruguay, Afghanistan, China, Indonesia, Iran, Iraq, Japan, Jordan, Kazakhstan, Republic of Korea, Kuwait, Kyrgyzstan, Mongolia, Sri Lanka, Syria, Tajikistan, Thailand, Turkmenistan, Uzbekistan, Vietnam, Yemen, Albania, Armenia, Austria, Azerbaijan, Belarus, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, France, Germany, Hungary, Iceland, Latvia, Liechtenstein, Lithuania, Macedonia, Moldova, Montenegro, Poland, Portugal, Russian Federation, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Turkey and Ukraine.

[86] That is, Australia, Belgium, Canada, Finland, India, Israel, Italy, The Netherlands, New Zealand, Norway and the United Kingdom (UK).

majority of the domestic legislative provisions are of constitutional character,[87] showing the importance that many states attach to the right. However, domestic laws display variations in the formulation of the right to benefit from science: 41 formulate it as right to the freedom of scientific research rather than as a positive right.[88] In half of these instances, however, the formulae are accompanied by a positive obligation on the state to support the development of science.[89] Overall, the right to benefit from science is interpreted as imposing a direct obligation on the state to promote, support or encourage the development of science in 39 of the domestic laws of states parties to the ICESCR,[90] making this the second most agreed-upon aspect of the content of the right to benefit from science after the freedom of scientific research. This indicates that there might be a growing common understanding that, in addition to the negative obligations, Article 15 also imposes an obligation to take positive action.

Notably, the right to benefit from science is transposed *eo nomine* into the domestic laws of only 17 states, including only three scientifically and technologically developed states.[91] This is symptomatic of the uncertainties arising out of the broad formulation of the right and, arguably, of the perceived significant burden that it can impose on developed states to give everyone equal access to their advancements in science and technology. A number of developed states do not include the right to benefit from science in their legislation at all. The UK purports to justify that stating that '[n]o legislation or other government measures have been taken, or are considered necessary, to guarantee that right'.[92] This indicates that domestic law silences do not necessarily imply negation of the right. It should be borne in mind that a number of domestic legal systems incorporate customary international law automatically, including, arguably, the right to benefit from science, and thus do not require express legislation to give it effect. [93] It can be hoped, however, that the UN initiative to clarify

[87] Algeria, Burkina Faso, Burundi, Cape Verde, DRC, Egypt, Madagascar, Mauritania, Mauritius, Argentina, Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Honduras, Paraguay, Peru, Afghanistan, China, Indonesia, Iran, Iraq, Japan, Kazakhstan, Republic of Korea, Kuwait, Kyrgyzstan, Mongolia, Tajikistan, Thailand, Uzbekistan, Vietnam, Yemen, Armenia, Austria, Azerbaijan, Belarus, Bulgaria, Croatia, Denmark, Germany, Hungary, Liechtenstein, Lithuania, Macedonia, Moldova, Portugal, Russian Federation, Serbia, Slovakia, Spain, Switzerland, Turkey and Ukraine.

[88] Algeria, Angola, Burkina Faso, Cape Verde, DRC, Egypt, Madagascar, Mauritania, Mauritius, Argentina, China, Iran, Japan, Kazakhstan, Kyrgyzstan, Turkmenistan, Uzbekistan, Vietnam, Austria, Azerbaijan, Belarus, Bulgaria, Croatia, Czech Republic, Estonia, Germany, Hungary, Latvia, Liechtenstein, Moldova, Montenegro, Poland, Portugal, Russian Federation, San Marino, Serbia, Slovakia, Sweden, Switzerland, Turkey and Ukraine.

[89] Angola, Egypt, Madagascar, Mauritania, Argentina, China, Iran, Turkmenistan, Uzbekistan, Azerbaijan, Belarus, Croatia, Czech Republic, Latvia, Lithuania, Moldova, Portugal, Serbia, Slovenia and Switzerland.

[90] ICESCR, available at https://treaties.un.org/Pages/ViewDetails.aspx?src=IND&mtdsg_no=IV-3&chapter=4&clang=_en. See also Brazil, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Guatemala, Honduras, Paraguay, Peru, Afghanistan, Jordan, Republic of Korea, Kuwait, Sri Lanka, Syria, Thailand, Macedonia and Spain.

[91] DRC, Libya, Madagascar, Dominican Republic, Mexico, Afghanistan, Iraq, Jordan, Tajikistan, Yemen, Albania, Armenia, Denmark, France, Spain, Burkina Faso and Indonesia.

[92] UK, First Periodic Report, Doc. E/1990/7/Add.16, 24 November 1993, para. 62.

[93] For the incorporation of custom in the UK, see J. Crawford, *Brownlie's Principles of International Law* (9th edn, 2019), ch. 3; see also German Constitution (1949), Art. 25, stating that general rules of international law are an integral part of federal law, enjoy primacy over it and directly create individual rights and duties.

the content of the right to benefit from science in a general comment will both help incentivize more states to incorporate it domestically and elucidate which aspects of it are self-executing, thus facilitating the actionability of the right in domestic courts.

Interestingly, a number of domestic laws go beyond the actual wording of Article 15 of the ICESCR to flesh out more specific understandings as to how the right can be fulfilled in practice. For instance, some developing and a few developed states interpret the right as entailing an obligation on the state to encourage and support those applications of scientific progress that are for the benefit of everyone, notably in the areas of health and information.[94] Another detectable and growing trend is defining the right to benefit from science as a right to access science. Some developing states define the right broadly as a right of everyone to access the benefits from scientific progress.[95] Brazil even specifies in its Constitution that the state is responsible for providing the means required for accessing science.[96] Notably, a growing number of developed and developing states define the right to benefit from science as an obligation on the state to give access to everyone to scientific information and to disseminate science.[97] A few states specify that the access to scientific information ought to be free.[98] Others provide for access to scientific knowledge on an equitable basis.[99] More importantly, however, since the 2000s, there have been a growing number of developed and developing states that provide that state-funded research ought to be open access.[100] The growing consensus that the core content of the right to benefit from science now includes an

[94] Denmark, Libya, Ecuador, Jordan, Slovenia, Spain and Indonesia.

[95] Madagascar, Mexico, Tajikistan, Yemen, Albania and Armenia.

[96] Brazil, Initial Reports, Doc. E/1990/5/Add.53, 20 November 2001, para. 856.

[97] Colombia, Third Reports, Doc. E/1994/104/Add.2, 15 August 1994, para. 745 (d); Dominican Republic, Third Reports, Doc. E/C.12/DOM/3, 30 June 2009, para. 40; Honduras, Initial Reports, Doc. E/1990/5/Add.40, 23 July 1998, para. 389; Paraguay, Initial Reports, Doc. E/1990/5/Add.23, 24 January 1995, para. 401; Afghanistan, Initial Reports, Doc. E/1990/5/Add.8, 9 August 1991, para. 40; Yemen, Initial Reports, E/1990/5/Add.54, 17 May 2002, para. 596; Denmark, Third Periodic Reports, Doc. E/1994/104/Add.15, 30 September 1996, para. 380; Spain, Fourth Periodic Report, E/C.12/4/Add.11, 14 January 2003, para. 498; Lithuania, Initial Reports, Doc. E/1990/5/Add.55, 9 December 2002, paras 642, 651; Moldova, Second Periodic Reports, Doc. E/C.12/MDA/2, 27 January 2009, para. 916.

[98] Azerbaijan, Initial Reports, Doc. E/1990/5/Add.30, 17 June 1996, para. 428; Czech Republic, Initial Reports, Doc. E/1990/5/Add.47, 25 May 2001, para. 642; Ukraine, Third Periodic Reports, Doc. E/1994/104/Add.4, 17 October 1994, paras 253–254.

[99] See, e.g., Sudan, Initial Reports, Doc. E/1990/5/Add.41, 29 October 1998, para. 131.

[100] Chile, Third Periodic Reports, Doc. E/1994/104/Add.26, 14 July 2003, para. 873; Colombia, Fifth Periodic Reports, Doc. E/C.12/COL/5, 9 January 2009, para. 947; China, Second Periodic Reports, Doc. E/C.12/CHN/2, 6 July 2012, para. 76; New Zealand, Third Periodic Reports, Doc. E/C.12/NZL/3, 17 January 2011, para. 740, for open access to research findings funded by the Health Research Council; Croatia, Initial Reports, Doc. E/1990/5/Add.46, 21 August 2000, para. 426; Czech Republic, Initial Reports, Doc. E/1990/5/Add.47, 25 May 2001, para. 709; Denmark, Fourth Periodic Reports, Doc. E/C.12/4/Add.12, 28 April 2003, para. 501; Estonia, Initial Reports, Doc. E/1990/5/Add.51, 2 October 2001, para. 249; Norway, Fifth Periodic Reports, Doc. E/C.12/NOR/5, 29 October 2012, para. 494; Slovenia, Initial Reports, Doc. E/1990/5/Add.62, 26 May 2004, para. 886; Spain Submission to Independent Expert on Cultural Rights' Questionnaire, 24 March 2017, at 7; Sweden, Sixth Periodic Reports, Doc. E/C.12/SWE/6, 16 March 2015, para. 616; Canada Submission to Independent Expert on Cultural Rights' Questionnaire, 28 November 2011, at 6.

obligation on the state to enable access to scientific information is supported not only by legislative but also by a number of policy and other measures taken by the states parties to the ICESCR with respect to the diffusion of science. Half of all of the ICESCR parties – 83 states – reported taking concrete measures to promote the dissemination of science, indicating a growing agreement that the diffusion of science is part of the core content of the right.[101] Indeed, this number is greater than that of states that have implemented the right in their domestic laws and is the most commonly reported type of measure taken by states to give effect to the right.

The specific measures taken to give access to science include obliging national science institutes funded by the state to publish their research studies and results;[102] improving technological infrastructure and digitalizing information to allow citizens online access to science,[103] the setting up of state scientific document repositories, data banks and data bases being the most commonly adopted measure;[104] establishing data-exchange scientific networks between research institutions;[105] subsidizing researchers to publish their work;[106] imposing an open access requirement for state-funded research, as discussed above,[107] and providing for a right to freedom of (scientific) information.[108] A handful of states interpret the right to benefit from science as meaning exclusively a right to access digital information and technology.[109] Notably, the removing of restrictions on the freedom of information, including on the Internet, in order to enable everyone to benefit from science is one of the recurring lines of questions posed by the ESC in response to the state parties' reports on the right to benefit from science.[110]

With respect to the interpretation of the right as one to access the applications of science, there is a clear split in the approaches of developed and developing states:

[101] Algeria, Benin, Burkina Faso, Burundi, Cameroon, DRC, Egypt, Ethiopia, Gabon, Gambia, Libya, Madagascar, Mauritania, Mauritius, Niger, Senegal, Sudan, Togo, Tunisia, Bolivia, Brazil, Canada, Chile, Colombia, Costa Rica, Dominican Republic, El Salvador, Guatemala, Mexico, Nicaragua, Peru, Trinidad and Tobago, Uruguay, Venezuela, Bangladesh, China, India, Indonesia, Iran, Iraq, Israel, Japan, Jordan, Republic of Korea, Democratic People's Republic of Korea, Kuwait, Kyrgyzstan, Philippines, Sri Lanka, Tajikistan, Uzbekistan, Australia, New Zealand, Albania, Austria, Azerbaijan, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Iceland, Kosovo, Latvia, Lithuania, Macedonia, Moldova, Monaco, The Netherlands, Norway, Poland, Portugal, Russia, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland, Ukraine and the UK.

[102] Algeria, Benin, Mauritania, Denmark and Sweden.

[103] Chile, Mexico, Uruguay, China, Poland, Sweden and Niger.

[104] Senegal, Canada, El Salvador, Mexico, China, India, Iran, Japan, Jordan, Korea, Uzbekistan, Austria, Azerbaijan, Czech Republic, Denmark, Latvia (reporting the establishment of a single genome database of the population), Macedonia, Moldova, The Netherlands, Portugal, Russian Federation, Slovenia, Sweden, Ethiopia and Bangladesh.

[105] New Zealand, Belgium, Croatia and Yugoslavia.

[106] Tunisia, Japan, Slovenia and Switzerland.

[107] See *supra* note 102.

[108] Republic of Korea, Tajikistan, Albania, Azerbaijan, Macedonia, Moldova, The Netherlands and Ukraine.

[109] Burkina Faso, Gabon, Gambia and Indonesia.

[110] See, e.g., CESCR, Report 1992, Doc. E/C.12/1992/2 (1992), at 25, para. 73 (Belarus); at 35, para. 121 (Poland); at 41, para. 147 (Hungary); CESCR Report 2006, p. 34, para. 197 (China); *ibid*, p. 78, para. 607 (Libya).

according to some, the right entails access via the transfer of technology, with developed states emphasizing the domestic aspect – from academia to industry[111] – and developing states focusing on attracting the international transfer of technology.[112] There are other examples of interpretations of this aspect of the right to access scientific applications: Brazil adopted a policy to widen access to drugs by setting up a state institution regulating the market by establishing prices and incentivizing more research by domestic laboratories.[113] Canada sees its competition law and policy in relation to pharmaceuticals as a guarantee for the right of everyone to benefit from scientific applications.[114] Germany interprets the right as imposing an obligation on the state to make the benefits of medical research quickly available to patients via the healthcare system.[115]

Only 37 of the states parties to the ICESCR have reported taking specific legal or policy measures to protect people within their jurisdiction from the negative effects of science, with some notable exceptions from scientifically and technologically developed states. The measures taken are aimed at the possible infringements by science and technology on human rights and privacy, especially in the fields of biomedical or clinical research involving human beings.[116] Nonetheless, the requirement to exercise the right in a manner respectful of other human rights is implicit in its systematic position in a human rights treaty and could be interpreted as part of the content of the right under the general rule of treaty interpretation, including the principle of good faith. In addition to the adoption of legislative and diffusion measures, states have also reported taking numerous institutional measures to give effect to the right,[117] as well as adopting domestic policies on the promotion of science and technology.[118] A significant number of the 76 developed and developing states reported adopting financial

[111] Canada, Australia, New Zealand and the UK. But see also Venezuela and Moldova.

[112] Egypt, El Salvador, Brazil, Costa Rica, the UK and Hong Kong.

[113] Brazil, Second Periodic Reports, Doc. E/C.12/BRA/2, 28 January 2008, para. 552.

[114] Canada, Third Reports of States Parties to the ICESCR, Doc. E/1994/104/Add.17, 20 January 1998, para. 78.

[115] 'The right to enjoy the benefits of scientific progress (REBSP) – Implementation in Germany (Overview)', report to UNESCO, available at https://studylib.net/doc/17702592/, at 3.

[116] Burkina Faso, DRC, Egypt, Ethiopia, Libya, Madagascar, Mauritius, Niger, Tunisia, Bolivia, Brazil, Canada, Mexico, Hong Kong, Jordan, Lebanon, Sri Lanka, New Zealand, Albania, Bulgaria, Croatia, Czech Republic, Denmark, Germany, Iceland, Lithuania, Macedonia, Malta, Moldova, Montenegro, Norway, Poland, Russia, San Marino, Serbia, Slovakia, Slovenia, Spain, Sweden, Switzerland and the UK.

[117] Algeria, Benin, Burkina Faso, Burundi, Cameroon, DRC, Egypt, Ethiopia, Kenya, Libya, Madagascar, Mauritania, Mauritius, Morocco, Senegal, Tanzania, Tunisia, Zambia, Bolivia, Brazil, Canada, Chile, Colombia, Costa Rica, Dominican Republic, El Salvador, Guyana, Mexico, Panama, Trinidad and Tobago, Uruguay, Venezuela, Bangladesh, India, Israel, Jordan, Republic of Korea, Kuwait, Lebanon, Nepal, Philippines, Sri Lanka, Uzbekistan, Australia, New Zealand, Azerbaijan, Bulgaria, Croatia, Denmark, Greece, Iceland, Ireland, Kosovo, Lithuania, Luxembourg, Macedonia, Malta, Moldova, The Netherlands, Norway, Poland, Portugal, Russian Federation, Slovenia, Turkey and the UK.

[118] Burkina Faso, Ethiopia, Tanzania, Tunisia, Zambia, Bolivia, Canada, Colombia, Costa Rica, El Salvador, Mexico, Uruguay, Bangladesh, China, India, Japan, Lebanon, Mongolia, Tajikistan, Thailand, Turkmenistan, Uzbekistan, Vietnam, Yemen, New Zealand, Azerbaijan, Croatia, Czech Republic, Denmark, Finland, Georgia, Ireland, Lithuania, Macedonia, Malta, The Netherlands, Norway, Russian Federation, Serbia, Slovenia, Switzerland and Turkey.

measures to foster the development of science, including awarding prizes and subsidies for scientific research, funding research institutes and private business enterprises, supporting scientists to take part in international conferences or study abroad, financing research considered to be of benefit to society, offering publication subsidies, as well as providing tax incentives.[119] Notably, states also indicated that most of the funding for the development of science and technology comes from the private sector.

Finally, there is relevant domestic and international case law offering judicial insight into the right. So far, few individuals have relied on the right to benefit from science before domestic courts to obtain equitable access to scientific applications. The available state practice in response to such claims, even if limited, seems to support that this aspect of the right is actionable before domestic and international courts. The Supreme Court of Venezuela decided a case brought by a group of HIV-positive patients against the Venezuelan Institute for Social Security (IVSS) requesting that the IVSS ensure a regular and consistent supply of HIV drugs and cover the expenses for all relevant medical tests.[120] The Supreme Court held that the failure of the IVSS constituted, *inter alia*, a violation of the right to enjoy the benefits of scientific progress.[121] In a similar vein, the Inter-American Court of Human Rights upheld a challenge against Costa Rica's blanket ban on *in vitro* fertilization, reasoning:

> The right to have access to scientific progress in order to exercise reproductive autonomy and the possibility to found a family gives rise to the right to have access to the best health care services in assisted reproduction techniques, and, consequently, the prohibition of disproportionate and unnecessary restrictions, *de iure* or *de facto*, to exercise the reproductive decisions that correspond to each individual.[122]

In his concurring opinion, Judge Diego García-Sayán acknowledged that the available health services and programmes will vary depending on the developmental level of the state party, but he emphasized that access to healthcare services ought to be economically accessible – that is, affordable for all, particularly for those who do not have the financial resources to access them otherwise.[123]

Based on the state practice under the ICESCR, it can be observed that the normative content of the right to benefit from science and its applications is crystalizing in international law. The subsequent practice of states under Article 15 of the ICESCR

[119] Algeria, Benin, Burundi, Cameroon, Cape Verde, DRC, Egypt, Ethiopia, Kenya, Madagascar, Senegal, Tunisia, Bolivia, Brazil, Canada, Chile, Colombia, Costa Rica, Ecuador, El Salvador, Mexico, Peru, Uruguay, Venezuela, Bangladesh, China, India, Israel, Japan, Jordan, Republic of Korea, Democratic People's Republic of Korea, Kuwait, Lebanon, Mongolia, Philippines, Sri Lanka, Syria, Tajikistan, Uzbekistan, Vietnam, Yemen, Australia, New Zealand, Albania, Austria, Azerbaijan, Belgium, Bulgaria, Croatia, Cyprus, Czech Republic, Denmark, Estonia, Finland, France, Georgia, Hungary, Iceland, Ireland, Lithuania, Macedonia, Moldova, Montenegro, The Netherlands, Norway, Poland, Portugal, Russia, San Marino, Serbia, Slovenia, Spain, Switzerland, Turkey and the UK.

[120] Supreme Court of Venezuela, *López, Glenda y otros c. Instituto Venezolano de los Seguros Sociales*, Sentencia no. 487 (2001).

[121] *Ibid.*

[122] IACtHR, *Artavia Murillo v. Costa Rica*, Judgment (Preliminary Objections, Merits, Reparations, and Costs), 28 November 2012, at 159, para. 150.

[123] *Ibid.*, para. 10, Concurring Opinion of Judge Diego García-Sayán.

indicates a broad agreement that the right's core content should be interpreted as including freedom of scientific research, and an obligation on the state to enable access to scientific information and to support the development of science. Other aspects of the right are still in the process of development, especially the right to benefit from the applications of science and its proper balance with the moral rights of authors. The key challenge to the realization of the right to benefit from science is that, as indicated by the reports of the states parties, most scientific research and the generated data are privately funded. This makes it much more difficult for states to enable access to it, given that human rights do not impose obligations directly on private parties absent explicit domestic regulation to this effect and that such measures are scarce in state practice so far. However, domestic courts have shown readiness to step in and strike the balance between the right, the economic interests at hand and the obligations of state to enable it. Furthermore, in its latest Recommendation on Science and Scientific Researchers, UNESCO stressed that '[s]o as to ensure the human right to share in scientific advancement and its benefits, Member States should establish and facilitate mechanisms for collaborative open science and facilitate sharing of scientific knowledge'.[124]

5 Implications of the Right to Benefit from Science for Genomic Data

The history and analysis of the integration of the right of everyone 'to enjoy the benefits of science and its applications' indicate that the core content of this right now includes freedom of research and the diffusion of, and access to, scientific information. This data-oriented interpretation chronologically coincided with the emergence of the Internet. Even more recently, there is no doubt that the influence of the push towards the 'Open Science Cloud' by, for example, the European Commission,[125] and towards data sharing by funders and open publications by journals, undergirds this interpretation of the right to benefit from science, propelling it into more concrete 'actionability'. Accordingly, the potential of big data and the cloud, together with the power to combine data across borders, populations and patients, while promising, requires clear ethical framing and international legal regulation. In particular, deeper understanding of the ethical and legal framing of data-sharing issues, using genomic data as an example, may help to elucidate the challenges for the realization of the right in the domain of science.

As highlighted above, the human rights framework for the governance of science and genomic data has inherent limitations, especially in a transborder context and given the significant contribution to the field by non-state actors. In order to address these gaps, an argument could be made for complementing the human rights

[124] UNESCO Recommendation, *supra* note 4, para. 21.

[125] European Commission, Realizing the European Open Science Cloud: First Report and Recommendations of the Commission High Level Expert Group on the European Open Science Could (2016).

framework with a global public goods approach. This argument is threefold: first, scholars,[126] scientific, political and research organizations,[127] as well as UNESCO[128] have called for science and knowledge to be viewed as a global public good in order to provide access to it for the benefit of the international community as a whole. Second, the human genome itself and genomic data have been conceptualized as the 'common heritage of mankind' by states and the UN during the negotiations that resulted in the 1997 Declaration on the Human Genome and Human Rights.[129] This expression was used to denote the underlying principle of solidarity in the sharing of knowledge derived from scientific research.[130] It was emphasized that ensuring access to scientific knowledge concerning the human genome was part of the concept of the common heritage of humanity[131] and that 'the notion of heritage covers the knowledge accumulated by men and women about themselves as a source of potential for the progress of humankind'.[132] Finally, from a normative standpoint, a global public goods or common heritage approach to the governance of science and genomic data, if adopted by states, would help bridge the gap in this field between developing and developed states, as well as fostering the development of science by promoting data sharing between state and non-state actors.

Bottom-up initiatives led by scientists in the field of genetics support the framing of genomic data as a global public good. One of the first attempts to address the ethical and legal issues of data-intensive science originated in the 1990s in the work of the Human Genome Organization (HUGO) – an association of scientists – as part of its support of the international Human Genome Project (HGP). For over a decade between 1993 and 2004, its Ethics Committee issued a series of guiding statements whose preambular principles affirmed that the human genome at the level of the species should be considered as the 'common heritage of humanity', a concept that is a

[126] See, in general, K. Strandburg, M. Madison and B. Frischmann (eds), *Knowledge Commons* (2014); Skre and Eide, 'The Human Right to Benefit from Advances in Science and Promotion of Openly Accessible Publications', 31(3) *Nordic Journal of Human Rights* (2013) 427, at 453; see also Contreras and Knoppers, 'The Genomic Commons', 19(1) *Annual Review of Genomics and Human Genetics* (2018) 1.

[127] See the 2002 Budapest Declaration on Open Access, available at www.budapestopenaccessinitiative.org, which was signed by 976 organizations and over 6,000 individuals; the 2003 Bethesda Statement on Open Access Publishing; and the 2003 Berlin Declaration on Open Access to Knowledge in the Sciences and Humanities, available at https://openaccess.mpg.de/319790/Signatories, which was signed by 626 organizations, including universities, research institutes and political organizations.

[128] UNESCO Recommendation, *supra* note 4, para. 36.

[129] UNESCO, Universal Declaration on the Human Genome and Human Rights, 11 November 1997, Art. 1. The declaration was endorsed by consensus by the UN General Assembly in GA Res. 53/152, 9 December 1998.

[130] UNESCO, Birth of the Universal Declaration on the Human Genome and Human Rights (1999); International Bioethics Committee (IBC), First Meeting of the Legal Commission of the IBC, 7 April 1994, at 30; UNESCO, Methodology for the Preparation of an International Instrument for the Protection of the Human Genome, 2 June 1994, at 35.

[131] UNESCO, Methodology, *supra* note 130; International Consultation on the Outline of a UNESCO Declaration on the Human Genome, 5 April 1996, at 77.

[132] International Consultation, *supra* note 131; IBC, Fourth Meeting of the Legal Commission of the IBC, 22 April 1994, at 56.

close corollary to that of a public good.[133] Indeed, HUGO spearheaded this humanistic vision of data-intensive science in its 1996 Bermuda Principles.[134] These principles required that all DNA sequences generated by the HGP be released to the public 24 hours after their generation – that is, an approach of rapid prepublication data release. Thus, it was not surprising that its 2002 Statement on Human Genomic Databases recommended that human genomic databases be considered as 'global public goods'.[135] This pivotal 2002 statement maintained that '[k]nowledge useful to human health belongs to humanity' and that '[a]ll humans should share in and have access to the benefits of databases as a public resource'. The Ethics Committee defined global public goods as 'those whose scope extends worldwide, are enjoyable by all with no groups excluded, and, when consumed by one individual are not depleted for others'. In a similar vein, the World Medical Association's 2016 Declaration of Taipei on Ethical Considerations Regarding Health Databases and Biobanks considers health research to represent 'a common good that is in the interest of individual patients, as well as the population and the society'.[136]

Together, the concepts of the 'common heritage of humanity' and the 'global public goods' have furthered the emergence of collaborative genomic science focusing on international data sharing to build what has been termed the 'genome commons'.[137] These genome commons have sought the establishment of 'a global knowledge resource for the advancement of science', where 'all human genomic sequence information, generated by centres funded for large-scale human sequencing, should be freely available and in the public domain in order to encourage research and development and to maximize its benefit to society'.[138] Today, this same commons concept reinforces the appeal of the right to benefit from science. This dormant right, examined above in the context of international human rights law, may well constitute the new foundation for finally realizing global genomic data sharing (to say nothing of sharing within jurisdictions and between institutions). The soft law instruments and voluntary private initiatives examined in this part help complement the existing interstate human rights framework and pave the way for its future development. Indications of such development can already be seen at the domestic policy level.

[133] Human Genome Organization (HUGO) Ethics Committee, Statement on the Principled Conduct of Genetics Research (1995); HUGO Ethics Committee, Statement on DNA Sampling: Control and Access (1998); HUGO Ethics Committee, Statement on Cloning (1999); HUGO Ethics Committee, Statement on Benefit Sharing (2000); HUGO Ethics Committee, Statement on Gene Therapy Research (2001); HUGO Ethics Committee, Statement on Human Genomic Databases (2002).

[134] HUGO, Principles Agreed at the First International Strategy Meeting on Human Genome Sequencing (1996).

[135] Statement on Human Genomic Databases, *supra* note 133, at 1.

[136] World Medical Association, Declaration of Taipei on Ethical Considerations Regarding Health Databases and Biobanks, (2017), Art. 5, available at: www.wma.net/policies-post/wma-declaration-of-taipei-on-ethical-considerations-regarding-health-databases-and-biobanks/.

[137] Contreras, 'Bermuda's Legacy: Policy, Patents and the Design of the Genome Commons', 12 *Minnesota Journal of Law, Science and Technology* (2011) 61, at 63–123.

[138] Statement on the Principled Conduct of Genetics Research, *supra* note 133.

State practice also offers increasing support for adopting a global public goods approach to genomic data sharing. In 2003, the US National Institutes of Health (NIH) issued a policy requiring NIH-supported studies to release data into its Data Base of Genotypes and Phenotypes[139] and the UK's Medical Research Council and other research councils did likewise for the European Genome-Phenome Archive.[140] Moreover, international consortia such as HapMap, the 1000 Genome Project and the International Cancer Genome Consortium put such data-sharing ideals into practice. The 2015 NIH Genomic Data Sharing Policy expects NIH-designated repositories to offer controlled access and, in 2017, to ensure the secure use of cloud-computing services for the storage and analysis of such controlled-access data.[141] As noted above, the EU issued a declaration in 2018 promoting access to genomic data among its member states. In the short period since the opening for signature of the EU's Declaration, two thirds of the member states, including Sweden, Italy and Spain, have signed it,[142] committing to ensure authorized and secure access to national and regional banks of genetic and other relevant data for the advancement of science and innovation.[143]

Since 2009, scholars have also recognized this emerging duty to share and to provide access to data, particularly in the field of genomic research.[144] Today, data sharing is considered critical for realizing 'the promise of Big Data'.[145] Indeed, scholars have argued that governments should 'force companies to share their data' in order to spur innovation.[146] Nowhere is the need for the operationalization of the right to benefit from science more evident (or, perhaps, already 'in action') than in the world of big genomic data.[147] Most beneficial applications of big genomic data are expected in the area of biomedical research, particularly for public health.[148] Some would even argue that researchers have an ethical duty to share prepublication data.[149] The 2014

[139] US National Institutes of Health (NIH), Final NIH Statement on Sharing Research Data (2003), available at https://grants.nih.gov/grants/guide/notice-files/NOT-OD-03-032.html.

[140] Lappalainen *et al.*, 'The European Genome-Phenome Archive of Human Data Consented for Biomedical Research', 47(7) *Nature Genetics* (2015) 692.

[141] Contreras, 'NIH's Genomic Data Sharing Policy: Timing and Tradeoffs', 31(2) *Trends in Genetics* (2015) 55.

[142] See 'EU Countries Will Cooperate in Linking Genomic Databases across Borders', *European Commission*, available at https://ec.europa.eu/digital-single-market/en/news/eu-countries-will-cooperate-linking- genomic-databases-across-borders.

[143] EU Declaration, *supra* note 10, at 4.

[144] Kaye and Hawkins, 'Data Sharing Policy Design for Consortia: Challenges for Sustainability', 6(1) *Genome Medicine* (2014) 4.

[145] Kosseim *et al.*, 'Building a Data Sharing Model for Global Genomic Research', 15(8) *Genome Biology* (2014) 430.

[146] Mayer-Schoenberger and Ramge, 'A Big Choice for Big Tech: Share Data or Suffer the Consequences', *Foreign Affairs* (September/October 2018).

[147] Contreras and Knoppers, 'The Genomic Commons', 19(1) *Annual Review of Genomics and Human Genetics* (2018).

[148] Auffray *et al.*, 'Making Sense of Big Data in Health Research: Towards an EU Action Plan', 8(1) *Genome Medicine* (2014) 71.

[149] Schickhardt, Nelson and Winkler, 'Researchers' Duty to Share Pre-Publication Data: From the Prima Facie Duty to Practice', in B.D. Mittelstadt and L. Floridi (eds), *The Ethics of Biomedical Big Data* (2016), vol. 29, 309.

[150] *Ibid.*

Framework of the Global Alliance for Genomics and Health catapulted the right to benefit from science as undergirding data sharing, channelling the efforts of private actors towards promoting the realization of the right, including by advocating its direct applicability to non-state actors.[150] The Framework for Responsible Sharing of Genomic and Health-Related Data:

> interprets the right of all people to share in the benefits of scientific progress and its applications as being a duty of data producers and users to engage in responsible scientific inquiry and to access and share genomic and health-related data across the translation continuum, from basic research through practical applications.[151]

The next more concrete step in developing the human rights approach and extending it to private actors could be realized via the EU's 2016 General Data Protection Regulation (GDPR), which foresees the possibility of organizations, institutions and sectors developing codes of conduct.[152] If approved by the European Data Protection Board, such codes would allow for transborder data sharing by those promising to adhere thereto. Adherence to an approved code of conduct would be one way of demonstrating compliance with the Regulation's security mechanisms. Codes of conduct can establish legally binding professional standards based on bottom-up approaches, creating practical benchmarks for standards tailored to a particular sector. These decision-making guidelines can form their own context and can be established in a way that ensures compliance with ethics and human rights, allowing decision-making frameworks to become part of an independent regime of norms.[153] The Council of Europe has also recognized the importance of genomic data governance via codes of conduct, which further the principles that undergird privacy and data protection regulation while securing data sharing that is essential to genomic and other areas of health research.[154] The recognition of a sector-specific approach to genomic data governance allows organizations such as international health research consortia to continue to approach privacy and data protection through the lens of facilitating data sharing and collaboration, which in turn promotes science as a common good. The Biobanking and BioMolecular Resources Research Infrastructure – European Research Infrastructure Consortium, a pan-European network devoted to the harmonization of biomedical research procedures, has undertaken the drafting of a code of conduct that would facilitate compliance with the GDPR while serving the needs of furthering health research.[155]

[151] Knoppers, 'Framework for Responsible Sharing of Genomic and Health-Related Data', 8(1) *HUGO Journal* (2014) 3.

[152] General Data Protection Regulation, Reg. 2016/679 (2016), Art. 40; see also Recital 113.

[153] Phillips *et al.*, 'Concretizing the Cloud', *Nature* (2019) (under review).

[154] Committee of Ministers to Member States on the Protection of Health-related Data, Doc. CM/Rec (2019) 2 (2019), preamble.

[155] Biobanking and BioMolecular Resources Research Infrastructure: European Research Infrastructure Consortium, available at http://code-of-conduct-for-health-research.eu/.

International organizations too are calling for genomic data sharing between states. The 2017 Organisation for Economic Co-operation and Development's Recommendation on Health Data Governance specifically mentions 'that governments support transborder cooperation in the processing of personal health data for health system management, research, statistics and other health-related purposes that serve the public interest subject to safeguards: … identify and remove barriers to effective cross-border cooperation [and] facilitate the compatibility or interoperability of health data governance frameworks'.[156] The World Health Organization's first call for data sharing was with respect to public health emergencies,[157] but, in 2018, it introduced a policy on the use and sharing of data collected in member states outside the context of a public health emergency.[158] Most recently, in the 30 January 2020 report of the Emergency Committee established under the International Health Regulations (2005), the WHO actively encouraged rapid data sharing regarding COVID-19, including pre-publication peer-reviewed articles but also online datasets and full viral genome sequences through a public access platform. One professional society has gone so far as to recommend that clinical data should be captured and available in the public domain. In a rebuke to 23andMe,[159] it held that 'improved interpretation of such tests will be served by broad sharing of data, not by establishing proprietary databases that are not accessible by all'.[160] These examples demonstrate that the framing of science as a global public good encourages actors from across the spectrum of governmental and non-governmental entities – public and private – to examine the ways in which scientific advancement is sustained and to promote genomic data sharing. Notably, we see non-governmental actors appealing to the right to benefit from science and even accepting it as directly binding upon them.

6 Conclusion

Overall, there is a growing agreement in the international community that the right to benefit from science includes, in its core content, a right to access scientific information, including data and scientific publications, to be enabled by states. The precise character of this access is interpreted differently, for some being free and for others being open or equitable or, indeed, limited to state-funded research. These interpretations are well within the margin of appreciation left to states in the field of economic, social and cultural rights, and they take into account the difference between developed

[156] Organisation for Economic Co-operation and Development (OECD), Recommendation on Health Data Governance (2017), Recommendation IV, available at www.oecd.org/health/health-systems/Recommendation-of-OECD-Council-on-Health-Data-Governance-Booklet.pdf.

[157] World Health Organization (WHO), Policy Statement on Data Sharing in the Context of Public Health Emergencies, 13 April 2016, available at www.who.int/ihr/procedures/SPG_data_sharing.pdf.

[158] WHO, available at www.who.int/publishing/datapolicy/en/.

[159] 23andMe is a US-based biotech corporation providing direct genetic testing to consumers, including DNA sequencing and analysis.

[160] Addison, 'ACMG Is Not on Board with 23andMe's FDA Approval', *Front Line Genomics* (10 April 2017), available at www.frontlinegenomics.com/news/11105/acmg-responds-23andmes-fda-approval/.

and developing states. The interpretation of the right to benefit from scientific applications as a right to (affordable) access to technology is at present not generally accepted due to the resistance of the specially affected technologically developed states. An example of good practice in this respect is the taking of positive steps by states, including financial incentives and funding, to support and promote those scientific applications that are most beneficial to society and humankind at large.

The human rights approach to the benefits of science and its applications has inherent limitations. First and foremost, human rights are primarily aimed at protecting the individual, so in the event of a conflict the individual interest would prevail over that of society. Second, human rights bind the state *vis-à-vis* the individual but do not apply horizontally as between individuals and corporations. This is a significant limitation given that in modern times it is the private industry that provides the majority of funding for science and technology and, accordingly, has the ability to provide access to it. Finally, the human rights approach does not really answer the question about the transboundary implications of the right to benefit from science and the proper cooperation between developed and developing states. Accordingly, a global public goods approach to scientific knowledge and information could be needed to ensure the effective realization of the right and, even more importantly, the equal access to it. Such an approach has been advocated by scholars,[161] by the Special Rapporteur in the Field of Cultural Rights,[162] as well as in soft law instruments and private initiatives in the area of big genomic data. Indeed, in its most recent recommendation on science, UNESCO recognized 'the significant value of science as a common good'.[163] It remains to be seen, however, whether states would adopt it as a matter of law. In any event, it can be hoped that states would do more to ensure access to scientific data, including genomic data, irrespective of whether it comes from public or private sources.

[161] Benvenisti, 'Ensuring Access to Information: International Law's Contribution to Global Justice', Cambridge Legal Studies Research Paper Series no. 17/2018 (2018), at 19; Rosenbaum, 'Data Governance and Stewardship: Designing Data Stewardship Entities and Advancing Data Access', 45 *Health Services Research* (2010) 1442, at 1452.

[162] Report on Cultural Rights, *supra* note 5, para. 65.

[163] See, e.g., UNESCO Recommendation, *supra* note 4, preambular para. 5(a).