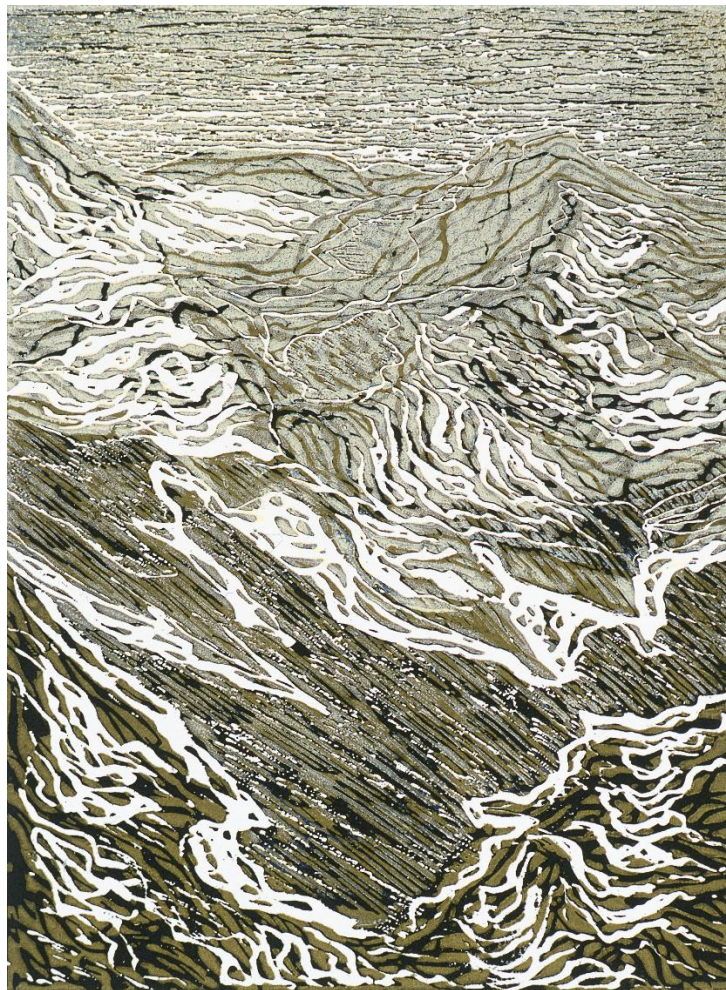


Is Science a Human Right?

Implementing the Principle of Participatory, Equitable, and Universally Accessible Science



Prepared for the Canadian Commission for UNESCO
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Suggested reference texts and further reading:

Canadian Commission for UNESCO:

[The Status of Science, The UNESCO Recommendation on Science and Scientific Researchers: Issues, Challenges and Opportunities](#) (2018) by Michèle Stanton-Jean.

[An introduction to UNESCO's Updated Recommendation on Science and Scientific Researchers](#) (2018) by the Canadian Commission for UNESCO and the Netherlands National Commission for UNESCO.

[The Non-Linear Paths of Women in STEM: The Barriers in the Current System of Professional Training](#) (2018) by Liette Vasseur.

UNESCO:

[Declaration on the Responsibilities of Present Generations Towards Future Generations](#) (1997).

[Declaration on Science and the Use of Scientific Knowledge](#) (1999).

[Universal Declaration on Bioethics and Human Rights](#) (2005).

[Recommendation on Science and Scientific Researchers](#) (2017).

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Introduction

“It is our responsibility to ensure that science and its applications are in harmony with the full set of universal standards. A human-rights approach to science must be at the heart of what we want to be a sustainable future. Key steps are to define its normative content, to elucidate the related state obligations and also to consider what are the necessary conditions for its implementation.” - Nada Al-Nashif, Assistant Director-General for Human and Social Sciences, UNESCO

The right of every human being to have access to scientific knowledge and participate in its development (also called “the right to science”) is enshrined in Article 27.1 of the *Universal Declaration of Human Rights*, adopted by the United Nations General Assembly on December 10, 1948. This article stipulates that:

“Everyone has the right freely to participate in the cultural life of the community, to enjoy the arts and to share in scientific advancement and its benefits.”

In 1966, the right to science was included in Article 15 of the *International Covenant on Economic, Social and Cultural Rights*, which called on the States Parties to “recognize the right of everyone to enjoy the benefits of scientific progress and its applications” and take the necessary steps for “the conservation, the development and the diffusion of science.”

Despite these normative foundations, the right to science has long remained a “Cinderella right.”¹ In fact, this right has rarely been actualized by states, even though they are major actors in its implementation and deployment.² Furthermore, the right to science is often considered as a right to access a material good (for example, access to medications), whereas this right is more broadly a universal cultural right to participate in building democratic societies.³ By virtue of this right, individuals should not only benefit from the products of science but also be able to adopt scientific concepts, theories, and methods in order to become more independent and capable of conducting their personal lives and participating in their community.⁴ For the member states themselves, implementation of the right to science is essential to the full achievement of the potential inherent in the UN’s Sustainable Development Goals (SDGs).⁵ When freely and responsibly generated, scientific knowledge is a means for informing political decisions, and for basing those decisions on human, social, economic, and environmental priorities. Alongside – and in conjunction with – other fundamental rights (to education, non-discrimination, and so on), the right to science constitutes a cornerstone of the progress of contemporary societies towards prosperity, social justice, and respect for the planet.⁶ However, the question of how this fundamental right can be mobilized and implemented still remains a subject for debate and discussion.

Given that 2018 marked the 70th anniversary of the Universal Declaration of Human Rights – and the very first statement of the right to science, various events to celebrate the anniversary and stimulate reflection about science as a human right were organized, in partnership with the Canadian Commission for UNESCO (CCUNESCO), at four Canadian universities (Brock University, the University of Prince Edward Island, the University of Montreal, and the University of Ottawa) and at the Science and Technology Awareness Network (STAN)⁷ Conference.

These meetings were also held in conjunction with the publication of UNESCO's new [*Recommendation on Science and Scientific Researchers*](#),⁸ unanimously adopted by its member states in November 2017. This Recommendation, which replaces the 1974 *Recommendation on the Status of Scientific Researchers*,⁹ incorporates new ideas about the right to science in the context of contemporary transformations such as the internationalization of research, the expansion of the open-access movement, and the increasing incorporation of scientific research in new commercial and financial applications, often supported by national policies on science and innovation. In the face of these transformations, the Recommendation underlines the need to strengthen the links between science and society by ensuring universal access to the benefits of scientific activity. The Recommendation not only underlines the rights but also the ethical responsibilities of researchers as generators of the kind of knowledge that can have major impacts on future generations.

In this discussion paper, we build on these principles in order to explore the issues raised by the implementation of a social right to science. Drawing on recent research and ideas of researchers who attended the meetings, we begin by describing the challenges entailed in universal access to scientific knowledge and then present some thoughts on how to construct equitable and participatory science that could engage a growing number of citizens, while preserving the relevance and integrity of scientific knowledge.

1. Science: A common good at risk of confinement

1.1 Barriers that restrict access to scientific knowledge

In the preamble to the Recommendation on Science and Scientific Researchers, UNESCO recognizes that science is an essential human activity and its products constitute a common good. This means that scientific knowledge, insofar as it is locally produced by particular individuals or groups, nonetheless constitutes a collective good that every human should benefit from in complete freedom. The knowledge derived from the sciences, moreover, forms the basis of the “capabilities” of individuals¹⁰ to make free and independent decisions to ensure their personal well-being (such as feeding oneself, taking care of oneself, housing oneself, and working). Access to scientific knowledge thus remains, first and foremost, a prerequisite of citizenship. Mobilization of scientific knowledge is also essential in allowing individuals, communities, organizations, and societies to adapt to major contemporary challenges such as climate change, conflict resolution, and violence prevention, or even recent transformations in the world of work.

However, many barriers currently restrict the universal dissemination of scientific knowledge and the equitable distribution of the benefits of this knowledge among all members of society. These barriers are deployed at the level of systems, organizations, and individuals.

While many thinkers have hailed the advent of a “knowledge economy,”¹¹ driven by information technologies and the digitization of knowledge, much of the world’s population still remains excluded from this digital revolution. These people – an estimated 3.5 billion – are victims of the “digital divide.”¹² Mostly living in low-income countries where access to knowledge via traditional media (books, magazines, radio, and television) is already limited, they are subject to the cumulative impact of inequality in its various forms – social, economic, ethnic, geographic, and, more recently, digital.¹³ They also suffer from the fact that they speak and live in a linguistic universe where less scientific knowledge is produced and disseminated, primarily due to the low rate of translation of scientific texts into their own languages.¹⁴ Digital exclusion, combined with linguistic isolation, thus limits the ability of individuals to take part in not only social, economic, and scientific activities, but also in political discussions that concern their future as citizens. Mindful of the transformative potential of digital tools, governments can decide to use them for good or ill by, for example, creating new platforms for disseminating scientific knowledge in their own countries and in their own languages or, conversely, by censoring, for partisan purposes, information available on the Internet and the results of scientific research.

Depending on how they are used, digital tools can also play opposing roles in the scientific training of populations. Social networks, for example, constitute places where new communities for learning and sharing scientific knowledge are emerging, particularly for younger generations.¹⁵ At the same time, these networks can sometimes be used to disseminate pseudo-scientific or quite simply erroneous information that can harm the scientific literacy of populations and create major public health issues.¹⁶ For example, the World Health Organization considers that the mistrust of vaccines, fuelled by many social networks, is one of the 10 threats to global health to be addressed in 2019.¹⁷

Discussion: The still-distant links between science and society

Several of the researchers during the talks and panel discussions co-organized by CCUNESCO, four Canadian universities, and STAN pinpointed the main restrictions on the dissemination of scientific knowledge and its appropriation by the general public.

The researchers taking part in the Brock University meeting highlighted some of the intrinsic defects in the process of creating scientific knowledge – defects that further broaden the gap between the producers of science and its potential beneficiaries. In practice, new scientific knowledge is sometimes expressed in terms that remain opaque and even unintelligible for most people, even in the case of the humanities and social sciences (HSS). Furthermore, scientific knowledge is usually transmitted through traditional channels (such as academic publishing houses), which necessitates many months and even many years to make the new knowledge accessible.

Apart from these problems of how scientific knowledge is produced and disseminated, other issues revolve around the appropriation of this knowledge by the general public. As pointed out by several STAN participants, the issue of digital literacy is central to understanding the barriers that limit access to scientific knowledge. Not only can people find it difficult to grasp new knowledge (largely due to the digital divide), but they also lack the necessary critical tools to question this knowledge (in terms of source and content) and assess its reliability. Therefore, both formal and informal educational institutions now have a central role to play in the scientific training of citizens and in teaching about the strict standards that govern how science is produced and disseminated in society.

1.2 Making science truly accessible

According to the Organization for Economic Cooperation and Development (OECD), scientific culture (also called “scientific literacy”) can be defined in terms of three competencies – the respective abilities to:

1. **Explain** phenomena scientifically;
2. **Evaluate and design** scientific enquiry;
3. **Interpret** data and evidence scientifically.¹⁸

In Canada, teachers have access to a wide range of educational resources to instruct students about the processes of scientific research and the fundamental theories of science.¹⁹ From the primary grades on, young students are given the opportunity to participate in various scientific activities to gain practical experiences of the sciences.²⁰ Unfortunately, teachers do not always have the wherewithal to adequately carry out these activities due to either a lack of time or because of workload pressures (to finish programs, help students in difficulty, and so on).²¹ As a result, students can leave school without having acquired all the tools they need for developing critical thinking and being able to interpret and question scientific results. However, the development of scientific literacy can continue beyond elementary and high school through various learning activities, such as reading popular science books, visiting exhibitions about scientific discoveries, or meeting scientists who do research in science and technology. These multiple methods of science education were highlighted by participants at both the Brock University gathering and the STAN Conference, who stressed the importance of developing new learning platforms for supporting the acquisition of scientific knowledge by as many people as possible. In fact, lifelong learning constitutes one of the enabling factors for achieving SDG 4 in the sense that continuous education can enable everyone who was unable to benefit from quality education in elementary or high school to acquire the key tools for finding innovative solutions to the problems they encounter in their lives.

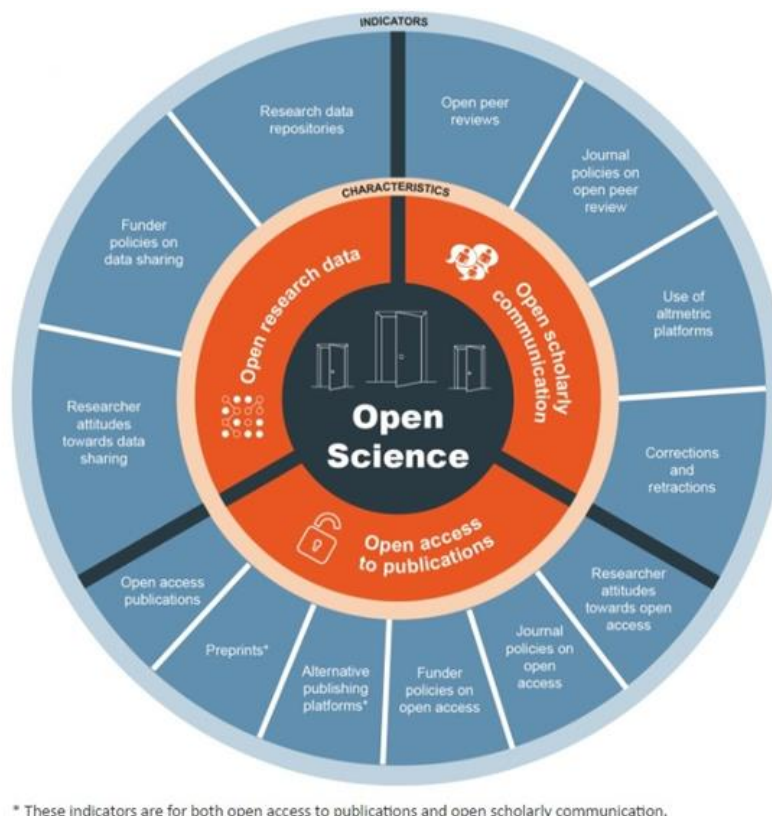
A variety of methods for teaching scientific knowledge is therefore useful to help people become scientifically literate. However, this knowledge needs to be expressed in different languages so that most of the world’s population can understand and acquire it. Despite the progress made in translation efficiency (primarily through the development of automated translation tools), multilingualism in science is still limited. English remains the relatively dominant language in most disciplines, especially in

the natural sciences.²² It is therefore necessary to develop new multilingual models and platforms to support the production of scientific research, as well as its appropriation and dissemination, in accordance with criteria that reflect the diversity of cultural spaces.²³

The imperative to broadly disseminate scientific knowledge is often communicated to scientific researchers. For several years, many authors have appealed to the research community to contribute to the “open science” movement (Figure 1).²⁴ In addition to freely disseminating their data, methods, and results, researchers are being called on to engage more in society and reach out to actors in the communities of practice (industries, media, civil society organizations, and so on).²⁵ This does not mean “popularizing” science but rather presenting its results in a way that connects powerfully with the public. In his books,²⁶ Randy Olson argues that the scientific community needs to use narratives to communicate scientific discoveries intelligibly and stimulate the interest of the general population. As laudable as such an argument might be, it must be coupled with a few caveats because we need to prevent the “publish or perish” that scientists face resulting from an evaluation of knowledge based solely on its social utility. According to Prof. Martin W. Bauer, a fervent critic of the utilitarian approach, many initiatives by scientific researchers subsequently revealed the extent to which the scientific world was infiltrated by commercial agendas²⁷ – for example transformation of some scientific events into professional trade fairs for sponsors or the increase in the number of marketing and public relations projects in research labs.

The increased importance assigned to “useful science” must therefore be carefully conceptualized to protect scientific integrity and honesty. It is also necessary for researchers to acquire the communication skills to effectively explain the value of their work. In this regard, Laurentian University in Canada is offering a complete master’s program in scientific communication.²⁸ It would be beneficial if such a program were extended across the country to help both researchers – and students who aspire to become researchers – to develop the essential tools for “translating” their scientific activities and results into comprehensible language for as many people as possible.²⁹

Figure 1: Open science characteristics and their various indicators³⁰



1.3 Example: The problem of open access

In recognizing the importance of digital tools in disseminating knowledge, the new UNESCO Recommendation on Science and Scientific Researchers now emphasizes sharing scientific data, while also addressing consequential issues. It calls upon its member states to make sure that scientific researchers are “balancing between protection of intellectual property rights and the open access and sharing of knowledge, as well as ensuring the protection of sources and products of traditional knowledge” (Recommendation, Section IV.18. (d)). As a result, despite the benefits that the open-access revolution has created by giving the general public access to scientific knowledge, it still generates many concerns, particularly for HSS researchers.³¹ In general, a considerable gap still remains between the wish of citizens to access scientific content and their actual ability to obtain and appropriate it.³²

As described by Prof. Vincent Larivière at the University of Montreal gathering, open access is now a public policy objective endorsed by many organizations that fund scientific research (such as the National Institutes of Health in the United States and various research councils and institutes in Canada). In order to publish a scientific article in open-access mode, researchers have two options: “gold open

access” and “green open access.”³³ Under “gold open access,” the article becomes directly available on the website of either an open-access journal or a subscription-model journal that makes some articles freely accessible. In this model, publication costs, when they exist, are no longer the financial responsibility of readers (via subscriptions), but rather that of the research authors, whose costs are generally covered by either the academic institution or research institute with which they are affiliated or by the organization that funds the research in question. Under “green open access,” the researcher submits the published article into either an open archive operated by the subscription-model journal or into an institutional repository. In some cases, open access to the article is subject to an embargo period at the publisher’s request so the journal can keep its subscribers.

The open-access system was originally introduced to break the hold of major scientific journal publishers over knowledge users. In response to the increasing costs of paid subscriptions for university libraries, a revolt in the United States in the mid-1990s aimed to restore scientific dissemination channels to researchers by freeing them from the constraints imposed by publishers.³⁴ However, during the massive promotion of open access, little attention was paid to the structural differences among the various academic disciplines and their respective modes of scientific communication. In the case of the HSS, the free and systematic online posting of all publications (following a short embargo) imperilled a whole swath of small, often national, publishers that support genuine cultural pluralism in the scientific world.³⁵ In practice, low-cost HSS journals are still generally read by non-academic readers, unlike most journals in the exact fields of science, technology, engineering, and mathematics (STEM). Since then, the problem of access to the HSS has not been due to the high cost of their dissemination, but rather to the small size of the community that it is targeting.

Today, some open access journals – the so-called “megajournals” such as PLOS ONE and Scientific Reports – publish articles that are selected using scientific validity criteria that differ from those of traditional journals. For example, PLOS ONE allows authors to submit studies that replicate or are very similar to previous work (“replication studies”).³⁶ Moreover, the logic of commercialization that pervades knowledge diffusion may lead some open access journals, as well as traditional journals, to lower their scientific validity criteria due to pressure faced by editors to accept a growing number of manuscripts. As shown by a cause célèbre in 2015,³⁷ the associate editors of *Frontiers In Public Health* have few resources at their disposal to reject a paper directly submitted to them by its authors. In fact, this weakness has led to the publication of controversial research that, in one instance, suggested that the HIV virus is not responsible for AIDS.³⁸ This type of controversy finally convinced some researchers to label *Frontiers* as a publisher of “predatory journals.”³⁹ This term refers to fraudulent journals that send out mass electronic mailings that offer to publish researchers in open-access mode for a fee.⁴⁰ These commercially-driven journals can compromise the integrity of scientific research insofar as the content is not verified at all (hence, the risk of plagiarism), nor even scientifically validated (no peer review).⁴¹ Since they are difficult to identify as such, these predatory journals may mislead young researchers who are sometimes induced to submit their manuscripts to them out of an eagerness to be published in order to build their academic careers.⁴²

Lastly, despite the promises made by the open-access movement, we seem to have returned to the initial, central question of how to facilitate the effective dissemination of scientific knowledge while preserving its integrity. If making the products of science more available to the general public seems a necessity, dissemination mechanisms must be envisaged that are adaptable to the various ways in which scientists express themselves, and thereby facilitate genuine appropriation of information resources by citizens.

1.4 Possible solutions

In the STEM sphere, digital data-sharing platforms now play a central role in the emergence of new scientific partnerships conducive to advancing research and spreading innovation. For example, the [Global Alliance for Genomics and Health](#) (GA4GH), co-founded by Prof. Bartha Maria Knoppers, one of the speakers at the University of Montreal gathering, is currently creating a global ecosystem to promote (as stated on its website) “responsible genomic data sharing for the benefit of human health.” The Global Alliance, which comprises 500 organizations and 2,000 members from 71 countries, is preparing a set of multilingual manuals designed to guide researchers from the entire world on how to disseminate scientific results. Open access to data therefore implies new responsibilities for researchers, particularly in terms of monitoring the quality of the information they put online (for integrity and interoperability) and adhering to the applicable ethical norms and standards applicable in using this information (such as ensuring that personal data are anonymous and non-attributable). In addition, the large-scale dissemination of scientific data requires the development of new methods of collaboration among researchers, political decision-makers and ordinary citizens in order to ensure the responsible governance of science.

In the HSS context, the new digital infrastructures for publishing and sharing information must adapt to the very specific nature of the scientific product. This is because, unlike STEM where access to raw research data is crucial for reproducing results, there can often be little value for the HSS in sharing all their information. For example, how would one react to a historian who, in connection with the publication of their academic paper, made available all their plans and ideas in bulk form, as well as many versions of their bibliography?⁴³ Such a possibly useless proliferation of largely irrelevant documentary resources would clearly not advance scientific knowledge in any significant way.

In reality, the issue for countries that wish to give value to the knowledge produced by the HSS is to establish mechanisms to balance the dissemination of scientific knowledge with the preservation of editorial and linguistic diversity. In both Europe and North America, such mechanisms already exist and are often cited as models. For more than 20 years, the [Érudit](#) online platform has offered centralized access to more than 150 HSS journals, most notably academic and cultural publications, such as books, proceedings, dissertations, theses, and various research documents and data sets. In Europe, the interdisciplinary portal [Cairn.info](#) is a joint initiative of four HSS publishers and provides access to 420 research journals: article abstracts and outlines are available in open access and complete articles are available for a fee or at the expiry of an embargo period.

Although these initiatives are promising, they are not sufficient to guarantee the appropriation of scientific knowledge beyond academic circles. Science, even when completely accessible, can only truly have transformative potential when it is the result of collective work, and not the product of a cloistered community. The descriptions of initiatives below exemplify the participatory and equitable generation of scientific knowledge.

2. Towards participatory and equitable science

2.1 Expanding the boundaries of the scientific community

The new UNESCO Recommendation on Science and Scientific Researchers proposes an extensive, precise, and perhaps exhaustive definition of the types of discrimination that people can experience in their attempts to participate in science (Section III.13.(a)). The Recommendation therefore underlines that UNESCO member states must combat all forms of discrimination in order to foster the creation of a body of scientific researchers that reflects the social makeup of their countries. These forms include gender discrimination, which, despite being included in international conventions for many years, still remains highly problematic. Thus, although gender equality constitutes the basic thrust of SDG 5, girls and women continue to suffer different forms of discrimination, particularly in their access to quality education and good jobs. As noted by Prof. Isabelle Duplessis at the University of Montreal conference, only 17 women since Marie Curie have been awarded a Nobel Prize in physics, chemistry, or medicine, as opposed to 579 men.⁴⁴ Similarly, women represent less than 29% of all scientific researchers in the world.⁴⁵

These disparities are not due to chance or a stronger attraction by males in general towards scientific or technical disciplines. In reality, a slew of cultural and socioeconomic factors limit access by females and members of the LGBTQ2+ community to scientific professions and impede their careers, even in well-off countries where anti-discrimination policies have been in force for many years. A recent study by Canadian researchers demonstrates the existence of a sexist bias in the awarding of scientific career grants by the Canadian Institutes of Health Research.⁴⁶ This type of discrimination has major repercussions on the entire careers of those who are subject to discrimination: “Getting funding can lead to more publications which can make it easier to attract good scientists to your lab, which in turn can help you do more good science and get more funding” (Jennifer Raymond, a neuroscientist who wrote a commentary on the study).⁴⁷

These systemic obstacles are in addition to more explicit types of discrimination. This is the conclusion of a 2017 study by the Pew Research Center, which demonstrates that in the United States 50% of the women working in the fields of science, technology, engineering, and mathematics (STEM) – i.e. fields in which men are overrepresented – say that they have been subject to discriminatory practices.⁴⁸ Initial composition of the workplace is thus a determining factor in understanding the systemic character of various types of discrimination. Furthermore, this finding is not new insofar as studies investigating the impact of organizational structure (male/female ratio) on work dynamics were conducted as far back as

the 1970s (particularly through the work of Rosabeth Moss Kanter⁴⁹). More recent analyses also show how a combination of sociodemographic factors (being a woman and being black, for example) can severely limit access to scientific careers.⁵⁰

It is therefore urgent to expand the boundaries of the scientific community to ensure that it more accurately reflects the pluralistic composition of society. Other than strengthening mechanisms to combat discrimination, steps must be taken to ensure more participation by different social groups in generating new scientific knowledge.

Discussion: Generating science that is grounded in society

The researchers participating in the conferences organized by CCUNESCO, the four Canadian universities, and STAN, presented many possible solutions for grounding science more firmly in society.

At the University of Ottawa, Brock University, and STAN conferences, participants highlighted the importance of considering Indigenous knowledge as integral to the conversation about “science, a human right,” pointing out that diverse forms of scientific knowledge exist and are applied differently depending on sociocultural context. Although ancestral knowledge is all too often relegated to the status of non-scientific knowledge and therefore deemed irrelevant as a result of the “colonization” of science by modes of Western thinking, Indigenous knowledge should be assigned greater value in terms of making us more aware of existential problems for humanity, such as global warming. This point was demonstrated by Dr. Heather Morrison (University of Ottawa) during her presentation, in which she noted how First Nations perspectives, based on preserving present resources for future generations, could greatly enhance what we do to protect the planet.

Along the same lines, participants at the Brock University gathering recommended inserting scientific research and activity more fully into societal debates. Researchers therefore must question not only the scientific relevance, but also the social implications of their investigations, by engaging in dialogue with their peers and the general population. This ultimately raises the question of research equity: what questions do researchers ask in the first place? And are the answers for researchers or society as a whole? Several initiatives are now being pursued by the scientific community to respond to such questions. In the health field, for example, the involvement of patients as research *partners* is strongly encouraged by the Canadian Institutes of Health Research to build collaboration towards developing more sustainable, accessible, and equitable healthcare systems.⁵¹

In the final analysis, the challenge is how to open up the world of science to new actors to enhance the legitimacy of scientific knowledge in society. As noted by participants at the University of Prince Edward Island conference – and as clearly shown by the Global Climate Strike for the Future by school students around the world on March 15, 2019 – younger generations today are motivated by a wish to contribute to scientific debates. The same motivation was behind the initiative of some young people to take legal action against the American government because of its lack of action to combat climate change.⁵² These initiatives are definitely a sign that civil society, including its youngest members, can exercise decision-

making power in science by orienting the nature of conversations to ultimately lead to new public policies. In addition, the media have a central role to play in this context by responsibly and proactively communicating scientific results and verifying their sources. This point was emphasized by many participants at the STAN conference, who debated the importance of the scientific literacy of journalists and other communicators.

2.2 Fostering ethical, honest, and responsible research practices

Although highly desirable, the participation of more people in developing science must not lead to the erosion of the values that govern the scientific community. Scientific research is based on a set of ethical principles designed to ensure that research is beneficial and not harmful for human subjects or the environment.⁵³ For example, the recent scandal around the use of the CRISPR-Cas 9 (“DNA scissors”) technique in China to modify the genomes of twin babies clearly illustrates the potential risks of disconnecting science from ethics.⁵⁴

As the new UNESCO Recommendation on Science and Scientific Researchers stresses, scientific activity comes with many responsibilities that underpin the development of reliable, fair, and equitable science (IV. 16.). These responsibilities include:

- Minimizing harm to each living subject of research and to the environment;
- Facilitating access to research findings and the sharing of scientific data;
- Disclosing actual or presumed conflicts of interest;
- Obtaining the consent of each human subject of research and consulting the communities whose members could be affected by research work;
- Ensuring that knowledge stemming from traditional, national, or local sources is correctly attributed, acknowledged, and compensated, and that the resulting knowledge is then communicated back to its sources.⁵⁵

Scientific researchers are invited to be mindful in terms of regularly questioning their practices in order to discharge these responsibilities not only out of a wish to adhere to rules, but also out of an awareness of the societal impact of their research. This is because scientific activity cannot do without an ethical framework and its associated mechanisms. This was the message from several researchers, from both Brock University and the University of Ottawa, when they mentioned the integral role played by the HSS (law and philosophy, for example) in developing normative tools to guide scientific practice in accordance with a humanist perspective dedicated to the common good.

Today, however, many commercial agendas operate in the various research milieux and threaten to undermine the trustworthiness of scientific knowledge. In the biomedical field, for example, more than 60% of the clinical research conducted in the United States between 2003 and 2008 was funded by private corporations.⁵⁶ This funding can introduce bias into scientific output, as has been shown by many studies analysing the impact of conflicts of interest on research results.⁵⁷ For example, the research funded by the pharmaceutical or agri-food industries produces results that are favourable to those

industries much more frequently than the results from research funded by other sources.⁵⁸ Moreover, the influence of funders is often exerted in a relatively subtle and discreet way since, in some cases, it is research methods that are affected and not the research results directly.⁵⁹ These commercial agendas also influence the editorial choices of scientific journals. Again, in the case of biomedicine, the scientific journals in this field sometimes receive considerable funding from industry (in advertising purchases, for example), which can alter the thrust of both the editorial line and the published research.⁶⁰ Furthermore, journal editors are not always obliged to disclose these types of financial partnership.

Transparency therefore becomes imperative in both the production and dissemination of research. In fact, it is necessary to implement effective mechanisms to prevent failings of responsible scientific behaviour. This is because even when scientists are required to be transparent (in terms of conflicts of interest, for example), they sometimes fail to do so because they are not always aware of how modes of funding impact their research.⁶¹ It is thus necessary to raise awareness and train researchers, early in their careers, about the importance of scientific ethics by explaining, for example, the consequences of some of their other activities (such as consultancy, shareholdings, and parallel private-sector employment) on their research. Given that science progresses rapidly, such training should also be offered throughout researchers' careers.

In this regard, the Fonds de recherche du Québec (FRQ) followed up the publication of its [*Policy for the Responsible Conduct of Research*](#) in 2014 by launching a series of initiatives to engage institutions in promoting ethical research practices. Apart from the obligation to comply with the provisions of the *Policy* to receive funding, institutions were required to designate someone in authority primarily to train the scientific community on the importance of responsible conduct. Initiatives by funding agencies therefore play a determining role in protecting the credibility and reliability of scientific results. According to Mylène Deschênes, the FRQ's Director of Ethical and Legal Affairs, who intervened during the University of Montreal conference, the *Policy for the Responsible Conduct of Research* would be further improved by aligning itself with the concept of human rights expressed in the *Universal Declaration of Human Rights*. Failings of responsible conduct in research could then be presented as practices directly affecting human rights by harming each person's ability to access valid and potentially transformative scientific knowledge.

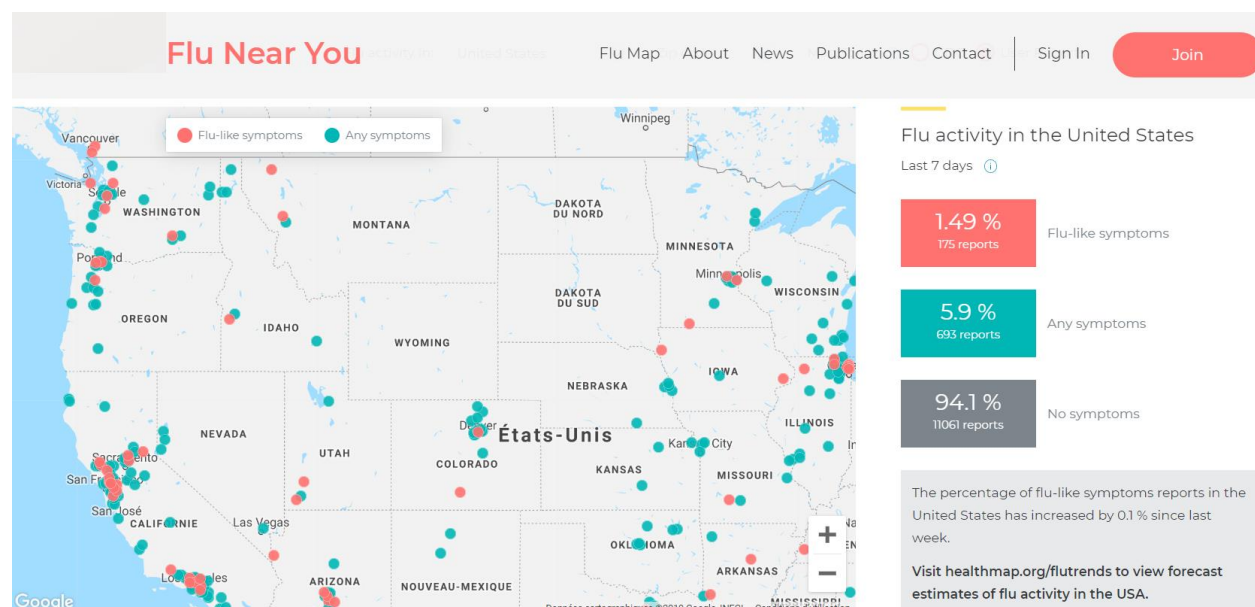
Through these initiatives, it is ultimately the question of people's trust in scientific research that is at stake. Strengthening the connections between science and society means guaranteeing the integrity of scientific knowledge, while continuing to involve more people in how scientific knowledge is produced and disseminated.

2.3 Example: The development of citizen science

Since the 1980s, scientific initiatives involving researchers and ordinary citizens from many countries have been undertaken in the wake of the upsurge in new information technologies. Grouped under the banner of "citizen science"⁶² (also called participatory or collaborative science), these initiatives offer innovative ways of producing and disseminating scientific knowledge, based on the active participation

of people of every age in scientific activity (collecting and analysing data, communicating results, etc.). In Canada, many citizen science projects are currently underway, usually with federal government support.⁶³ In the health field, the [Flu Near You](#) program enables all the residents in a given region to share their flu symptoms with the public health system and thereby establish the extent of the flu epidemic in their locality (see Figure 2). These data are used to generate maps in real time and make predictions that can target prevention measures more effectively. Since 1996, [EcoSpark](#), an environmental charity in Ontario, has involved more than 80,000 people in its training programs to learn about and protect the environment. Students and professionals from all fields are encouraged to explore the natural spaces in their communities in order to scientifically analyse their resources and develop concrete steps to protect them from the impacts of urbanization.

Figure 2: Visualizing the extent of a flu epidemic thanks to the Flu Near You programme⁶⁴



Citizen-science initiatives have advantages for the advancement of research and its applications. Indeed, since citizen-researchers are volunteers, the costs of data collection are considerably reduced. In addition, the massive participation of individuals located in multiple parts of the world considerably accelerates data collection and analysis processes. Finally, the integration of citizens into research projects contributes to the development of scientific literacy by democratizing research methods and scientific knowledge through new channels of dissemination. In a way, citizen science makes it possible to "demystify" scientific activity and encourages the development of new vocations.⁶⁵

Despite the benefits of these new scientific practices, they do raise some concerns among researchers. In March 2019, the open-access journal *Citizen Science: Theory and Practice* devoted a special issue to the ethical issues associated with citizen-science research.⁶⁶

In practice, these new forms of investigation raise a number of questions such as: When citizens are asked to share personal data for research, are they always informed about how their data will be used?

Can citizen-researchers, if they wish, become integral participants in the research – not only in collecting and analysing data but also in contributing to the publication of results? To address such questions, several guides on ethical practices in citizen science have been produced in recent years. In September 2015, for example, the European Association of Citizen Science published 10 guiding principles to foster responsible practices in collaborative research programs.⁶⁷ According to these principles, citizen science projects should engage participants as research contributors, collaborators, or leaders at all stages that interest them (from the setting of the research question, through the collection and analysis of the data, to the publication and communication of the results, etc.). Furthermore, citizen science initiatives should benefit all participants in the same capacity as professional researchers (in terms of training possibilities, publishing scientific articles, etc.).

2.4 Possible solutions

We now need to promote a new paradigm of scientific research to ensure that all scientific activities, including those associated with “citizen” participatory and collaborative science, are founded on values of inclusion, respect, and social justice. The task of ensuring that everyone can have the same opportunities to participate in scientific progress and take advantage of the benefits of science implies repositioning the concept of **equity** at the core of producing and disseminating scientific knowledge. Equity in science is based on three central principles:

Opening up the scientific community.

Remove the obstacles that currently prevent excluded or discriminated groups from participating in the production of new scientific knowledge. The participation of the populations concerned by the research (both individuals and organizations) should occur at all phases of the scientific investigation – from the definition of research protocols to the concrete application of science in society. The principle of transparency would thereby apply at each phase of the research and not only beforehand (evaluation by an ethics committee) and afterwards (free access to the results).⁶⁸

Orienting research towards social and environmental outcomes.

Maximize the positive and transformative effects of this research in society so it is no longer a question of solely reducing the risks incurred. Although social utility should not become a central evaluation criterion of research, researchers would be encouraged to envisage the consequences (both positive and negative) of their work, of whatever kind, on the most vulnerable populations in society. The primary objective would be to ensure that the results of the scientific activity would equitably benefit all the populations concerned.

Creating egalitarian relationships among scientific communities.

Bridge the gap between researchers and citizens in the countries of the north and south by using new modes of producing and disseminating scientific knowledge. In northern countries, establish mechanisms to make scientific knowledge more accessible to all research communities (for example, by systematically awarding research grants conditional on the mandatory publication of the research results in open-access mode and investing in the translation of the knowledge into multiple languages).

In addition, develop new international research partnerships to mobilize scientific knowledge towards more rapid achievement of the SDGs globally.

The perspective proposed in this paper makes equity a fundamental principle of scientific activity – from the stage of producing knowledge to the stages of disseminating and applying it in society. In this context, science and ethics are no longer envisaged as two separate elements that need to be reconciled to avoid shortchanging or harming populations. Rather, equity as a guiding principle of science would constitute a supreme responsibility for researchers and other knowledge-producers. Based on this responsibility, new commitments could be defined to guarantee that scientific knowledge cannot only become the fruit of an inclusive and collaborative process, but can also be appropriated by most members of society.

The implementation of new research practices consistent with the principle of equity constitutes a genuine challenge for the scientific community, industry players, and political decision-makers. It requires striking the right balance between including new populations in scientific activity and applying scientific standards that guarantee the integrity of the knowledge produced and academic freedom. The ultimate challenge is to guarantee a wide dissemination of transformative knowledge in society by ensuring the communication and dissemination of research do not take precedence over the essential processes of validating scientific knowledge.

In conclusion, the importance of formulating science in terms of human rights is essential to support and direct the efforts of the actors engaged in developing and sharing scientific knowledge, whether as public decision-makers, funding organizations, universities, research institutes, researchers, and so on. Indeed, this formulation, which could subsequently be made more precise in other normative tools — as shown by the UNESCO Recommendation — would make a major contribution to defining scientific standards of practice that could be established by these actors and by civil society as a whole. Notably, these norms could, in certain circumstances, be integrated into national legal systems in various countries (through their courts and legislation, for example⁶⁹) and help create public expectations of accountability with respect to achieving the goals inherent in these norms.

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