

Brocher Workshop on the Human Right to Science with a focus on Health

28.11.2022 – 01.12.2022

GENEVA
SCIENCE & DIPLOMACY
ANTICIPATOR

Brocher Foundation

The mission of the Brocher Foundation is to be a dynamic exchange platform on the health challenges of the 21st century.

It focuses on the impact of new medical development on society. It is a bridge between the scientific world, OIGs, NGOs, and citizens.

The Brocher domain is located a few minutes from Geneva International in a splendid three-hectare park by the lake.

The Brocher Foundation is renowned for its promotion of pluridisciplinary research on the Ethical, Legal and Social Issues (ELSI) of new medical development and health policies.

The Brocher Foundation is a Swiss private law Foundation created by Mr and Mrs Brocher. According to the founder's will, its main aim is to welcome Researchers from all over the world to work and to hold meetings.

All these activities give rise to scientific publications. Scientific articles service namely as a basis for the development of national and international conventions and laws.

GESDA (Geneva Science and Diplomacy Anticipator)

The governments of Switzerland and Geneva founded GESDA in 2019 as an independent foundation to leverage the anticipative power of science with diplomacy organizations and citizens working in Geneva and around the world.

They created it based on the growing awareness

- That the world is experiencing breakthrough science and technological discoveries at an unprecedented speed;
- That these breakthroughs will reshape how we view ourselves as humans, how we relate to each other in society and how we care for our environment;
- That humanity, especially people living in less advanced or emerging countries, cannot afford to miss the potential of those science and technology advances for global well-being and inclusive development.

The Foundation aims, in favour of multilateralism, to leverage the International Geneva ecosystem to anticipate, accelerate and translate into concrete actions the use of emerging science-driven topics.

General Introduction

Technological change is intense, rapid and characterized by the convergence of the physical, digital and biological worlds. This “Fourth Industrial Revolution” has the potential to change not only society, but even human beings themselves, through genetic modification or human-machine interfaces.

Decisions concerning the development and use of these powerful technologies should be adopted within a human rights framework, and with a holistic and inclusive view. Using a human rights framework brings to the fore principles of transparency, accountability, non-discrimination, and an overarching concern for safeguarding human dignity. Adopting a human rights framework is a further invitation for collective reflection

beyond merely managing risks, culminating in the potential to responsibly realize the opportunities that scientific and technological development present. Of particular relevance in this context is the human right to “enjoy the benefits of scientific progress and its applications” (called henceforth the Human Right to Science (HRS)). The right has its origins in Article 27 of the 1948 *Universal Declaration of Human Rights* and in Article 15 of the 1966 *International Covenant on Economic, Social and Cultural Rights*. The existence of this right is important for both scientists and society. Yet, despite its potential for furthering science and human rights causes, the HRS had been hitherto largely neglected until UNESCO’s 2009 *Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications*. Now awoken, this former “sleeping beauty” of human rights nevertheless continues to raise more questions about its content, application, enforcement, institutional logic, and relationship to other human rights.

This expert workshop consists of four parts:

1. The HRS and the Anticipation of the Risks and Benefits of Science
2. The HRS in the Health Context
3. The HRS and the Child's Right to Health
4. General discussion regarding the workshop's findings.

Organizers

Samantha Besson (Collège de France, Paris & University of Fribourg; Member of GESDA’s Board of Directors) & **Bartha Maria Knoppers** (McGill University) & **Jean-Dominique Vassalli** (University of Geneva) & **Gérard Escher** (Senior Advisor to GESDA’s Board of Directors)

Program

Monday, November 28, 2022

Anytime Arrival of participants

19:00 Dinner: the Board of GESDA invites the workshop participants to a dinner, on site at the Brocher Foundation

Tuesday, November 29, 2022

Part 1: The Human Right to Science & The Anticipation of the Risks and Benefits of Science

Following the emergence of dual-use technologies, but also, more generally, of potentially beneficial scientific practices that may have an irreversible impact on human beings (incl. their health), the issue of the adequate (reasonable or diligent) anticipation not only of the risks (of harm) of science, but also of its (opportunities for) benefits has become more pressing.

One framework from which States and, arguably, other (domestic and international) (mostly public, but also arguably private) institutions derive duties (and/or responsibilities) to anticipate both (and at the same time) the so-called “risks” and “benefits” of science is the human right to enjoy the benefits of scientific progress and to participate in that progress (in short, the “human right to science” [HRS]; art. 15(1b) International Covenant on Economic, Social and Cultural Rights). Not only indeed does that right include everyone’s right to participate in the scientific enterprise and its organization (i) and to access to and enjoy the benefits of scientific progress (ii), but it also includes their right to be protected against the adverse effects of science (iii). The latter prong of the right has long remained controversial, but it has since been endorsed by most scholars and by various reports and statements (e.g. Report of the Special Rapporteur in the field of cultural rights on the Right to Enjoy the Benefits of Scientific Progress and its Applications (2012), at 9 ff; UNESCO, Venice Statement on the Right to Enjoy the Benefits of Scientific Progress and its Applications (2009), at 13(a)(b) and (c)). Interestingly, while some duties to anticipate grounded in the HRS are briefly mentioned, albeit not in those terms, in the recent UN Committee on Economic, Social and Cultural Rights’ General Comment 25 (2020) on Science and Economic, Social and Cultural Rights (at 56-7, 71 and 72-6), their specific content and bearers have not yet been addressed in depth by scholars and practitioners of the right. Nor have the tension and relationship between preventing the risks of science and promoting its benefits, created by their unique combination in the duties correlative to the HRS, been clarified to date. The notions of “(opportunities for) benefit” and “(risk of) harm”, but also, more generally, the “risks v. benefits” framework also need to be interpreted and assessed critically.

The aim of this first part/day of the workshop will be to specify the content, scope and bearers of the various duties and responsibilities to anticipate diligently (including, albeit

non-exclusively, “precaution” and “prevention” duties) the (risks of) harm caused by emerging technologies and other scientific innovations, but also to promote the latter when (potentially) beneficial to humanity. Our discussions will focus on the HRS, but comparisons with various anticipation duties and responsibilities arising under other human rights (e.g. other social and cultural rights) or under other international law regimes (e.g. international environmental law, international health law, international humanitarian law, international disaster law) will also be encouraged.

Given the focus on the Brocher Foundation and of the workshop in general on the human right to science in the health context, including child health issues, all speakers in the first part/day of the workshop are asked to consider (even if it is only by way of a side comment or conclusions) what their argument could imply with respect to health more specifically. A specific paper and intervention at the beginning of day 2 will be dedicated to the transition between the two parts/days of the workshop and of our reflections.

8.30-9.00	General introduction (Brocher & GESDA)
9.00-9.20	Introduction: Anticipation under the HRS, Concepts and Stakes (Besson)
9.20-10.00	Historical Considerations on Anticipation and the Risk/Benefit Nexus within the HRS (Schabas; Commentator: Porsdam)
10.00-10.40	Anticipation under the HRS and the Risk/Benefit Nexus at the Indigenous-Western Science Interface (Hill; Commentator: Perruso)
10.40-11.10	Break
11.10-11.50	Anticipation Duties and Responsibilities under the HRS (Donders & Plozza; Commentator: Müller)
11.50-12.30	Anticipation under the HRS and under Other Social and Cultural Rights (Perruso; Commentator: Donders)
12.30-13.10	Anticipation under the HRS and under Other Regimes of International Law (Yotova for IHL et al. & Hubert for IEL et al.; Commentators: Hubert & Yotova)
13.10-15.00	Lunch
15.00-15.40	Anticipation under the HRS and Participation/Citizen Science (Jasanoff; via Zoom; Commentator: Schabas)
15.40-16.20	Anticipation under the HRS and International Institutional Cooperation (Müller; Commentator: Besson)
16.20-16.50	Break
16.50-17.30	Anticipation under the HRS and “Science Diplomacy” (Porsdam & Porsdam Mann; Commentator: Hubert)
17.30-17.40	Final Words & Open Questions (Besson & Perruso)
19.30	Dinner

Wednesday, November 30, 2022

Part 2: The Human Right to Science in the Health Context

Human health is inextricably linked to science. Ensuring that all may benefit from scientific progress entails the adequate (reasonable or diligent) anticipation not only of the risks (of harm) of science, but also of its (opportunities for) benefits.

One framework from which States and, arguably, other (domestic and international) (mostly public, but also arguably private) institutions derive duties (and/or responsibilities) to anticipate both (and at the same time) the risks and the benefits of science is the human right to enjoy the benefits of scientific progress and to participate in that progress (in short, the so-called “human right to science” [HRS]; art. 15(1b) International Covenant on Economic, Social and Cultural Rights). In particular, the HRS is increasingly relevant in policymaking surrounding the determinants of human health, including the health of children.

No longer a “dormant right”, UN bodies such as UNESCO, the UN Committee on Economic, Social and Cultural Rights, and the UN Special Rapporteur in the field of cultural rights have in recent years begun to elucidate the content of the HRS, as well as its relationship to other human rights. Non-governmental organizations such as the American Association for the Advancement of Science (AAAS) and the Global Alliance for Genomics and Health (GA4GH) have also used the HRS as a catalyst for policymaking and advocacy. Still, however, the potential and limits of the HRS have yet to be anticipated and determined. Indeed, the emergence of new bioscientific advances, such as heritable human genome editing and artificial intelligence, pose specific issues that may help to better understand the HRS.

Whereas the aim of the first part/day of the workshop was to specify the content, scope, and bearers of duties to diligently anticipate the (risk of) harm and the (potential) benefits to human that scientific innovation engenders, this second part/day of the workshop seeks to explore the potential application of these duties to specific health-related contexts. The session addresses it at two levels. First, our discussions will centre around the intersection of the HRS, health, and other areas of law that play a key role in the production and translation of biomedical knowledge. Second, we will examine selected case studies where the HRS has either already contributed to policymaking or where emerging technologies in the health domain may further help delimit the HRS.

- 9.00-9.20** Introduction: The HRS and Re-Defining the Future “Human” (Knoppers)
- 9.20-10.00** Anticipation under the HRS in the Context of Health: A Critical Appraisal (Boggio; Commentator: Yotova)
- 10.00-10.40** The HRS, Health and Research Ethics Governance (Dove; Commentator: Beauvais)
- 10.40-11.10** Break

11.10-11.50	The HRS, Health, the Environment, and Future Generations (Gaillard; Commentator: Schabas)
11.50-12.30	The HRS, Health and the Role of Open Science (Kunz; Commentator: Dagron)
12.30-15.00	Lunch
15.00-15.30	Implementing the HRS, Health and Intellectual Property (TBD)
15.30-16.00	Implementing the HRS, Health and Data Governance (Molnár-Gábor)
16.00-16.20	Break
16.20-16.50	Implementing the HRS and AI in Health-Related Research and/or Clinical Care (Ho)
16.50-17.20	Implementing the HRS and Neuroscience (Greely)
17.20-17.50	Implementing the HRS and Heritable Human Genome Editing (van Beers)
17.50-18.00	Final Words & Open Questions (Beauvais)
19.30	Dinner

Thursday, December 1, 2022

Part 3: The Human Right to Science and Children with Rare Diseases

Like their adult counterparts, children are holders of international human rights. Children are further holders of rights under the 1989 *Convention on the Rights of the Child* (CRC). Children have a right under art. 24 to “the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health”. However, the CRC does not contain a child's right to science. Instead, children's claims to the HRS are under the same instrument as adults. The relationship between children's rights under the CRC and the HRS is underexplored, in particular, the child's right to health and in the special case of children with rare diseases.

This part of the workshop is dedicated to exploring the potential promises and limitations of the HRS and the child's right to health. It builds directly off the topics in Parts 1 and 2 of the workshop. One paper will be dedicated to exploring the HRS and the child's right to health. Implementing the HRS in the case of children and rare diseases will be the subject of the second paper. Children with rare diseases present a compelling case study through which to understand the HRS.

9.00-9.10	Introduction (Vassalli)
9.10-9.50	The HRS and the Child's Right to Health (Tobin; Commentator, TBD)
9.50-10.20	Implementing the HRS in the Case of Children and Rare Diseases (Dagron; Munnich, TBC)
10.20-10.40	Break

Part 4: General Conclusion

Parts 1-3 of the workshop will have explored some of the interlinkages between subject areas. Part 4's objective is to bring a focus onto the workshop as a whole. A 30-minute general conclusion will be given by a participant with a longer round table discussion. The discussion should highlight the breakthroughs of the workshop and synthesize the main messages, for academic researchers and for the wider world (policy makers and other stakeholders).

- 10.40-11.10** Concluding Remarks (Shaheed)
- 11.10-12.30** Round Table General Discussion (input from all; chairs: Besson; Escher; Knoppers)
- 12.30** Lunch and farewell

List of Participants

1. Michael Beauvais, University of Toronto
2. Britta van Beers, Free University of Amsterdam
3. Samantha Besson, Collège de France & University of Fribourg
4. Andrea Boggio, Bryant University
5. Stéphanie Dagron, University of Geneva
6. Yvonne Donders, University of Amsterdam
7. Edward Dove, University of Edinburgh
8. Gérard Escher, Geneva Science and Diplomacy Anticipator
9. Émilie Gaillard, Sciences Po Rennes
10. Henry T. Greely, Stanford University
11. Ro Hill, Commonwealth Scientific and Industrial Research Organisation
12. Calvin Ho, Hong Kong University
13. Anna-Maria Hubert, University of Calgary
14. Sheila Jasanoff, Harvard University
15. Bartha Maria Knoppers, McGill University
16. Raffaella Kunz, Max Planck Inst. for Comparative Public Law and International Law
17. Fruzsina Molnár-Gábor, Heidelberg University
18. Arnold Munnich, Hôpital Necker, Paris Descartes University
19. Amrei Müller, University College Dublin
20. Camila Perruso, University of Montpellier
21. Louise Philippoussian, University of Fribourg
22. Monika Plozza, University of Luzern
23. Helle Porsdam, University of Copenhagen
24. Sebastian Porsdam Mann, Harvard University & University of Copenhagen
25. William Schabas, University of Middlesex
26. Farida Shaheed, Shirkat Gah-Women's Resource Centre, Pakistan
27. John Tobin, University of Melbourne
28. Jean-Dominique Vassalli, University of Geneva
29. Rumiana Yotova, University of Cambridge