THE RIGHT TO SCIENCE AS A GAME-CHANGER AGAINST PANDEMICS: TOWARDS AN INTERNATIONAL INSTRUMENT AGAINST GLOBAL HEALTH EMERGENCIES

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IN PARTNERSHIP WITH

TAGTreatment Action Group

SCIENCE FOR DEMOCRACY







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EXECUTIVE SUMMARY

Background

On 1 December 2021, the World Health Organization (WHO) reached consensus to initiate a negotiating process towards the adoption of an international instrument to strengthen pandemic prevention, preparedness and response; to this purpose, the Intergovernmental Negotiating Body (INB) was established¹. In May 2022, a group of human rights experts urged States to ensure that ongoing multilateral negotiations on said instrument are grounded in human rights.² Among these, the right to science is particularly relevant.

The Report "The Right to Science as a Game-Changer against Pandemics: towards an International Instrument against Global Health Emergencies" aims at recommending the explicit inclusion of the right to science – as enshrined in Art. 15 of the International Covenant on Economic, Social and Cultural Rights and Art. 27 of the Universal Declaration of Human Rights – in the upcoming instrument. To this end, and building on CESCR General Comment No. 25 on Science and economic, social and cultural rights (GC25), the Report provides a detailed analysis of the beneficial contribution of the right to each phase of pandemic management.

The study was conducted by a Team of five students involved in the Strategic Litigation: International Human Rights Legal Clinic of the University of Turin (UniTo), supervised by Professor Andrea Spagnolo and Ms Giulia Perrone, in partnership with Treatment Action Group and Science for Democracy.

Content overview

Based on the framework proposed by the WHO in its Decision SSA2(5), the Report devotes its focus on the role of the right to science in each phase of pandemic management, namely: prevention, preparedness and response. In addition, it suggests the inclusion of a fourth phase: recovery.

The analysis is conducted in light of the so-called 'AAAQ framework' (Availability, Accessibility, Acceptability and Quality) which sets out a behavioral threshold to be met by States in the implementation of the right. The main implications of the inclusion of the right to science in pandemic

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¹ World Health Organization, The World Together: Establishment of an intergovernmental negotiating body to strengthen pandemic prevention, preparedness and response, UN Doc. SSA2(5), 1 December 2021, available at The World Together: Establishment of an intergovernmental negotiating body to strengthen pandemic prevention. preparedness and response (all links were last accessed on 22 September 2022).

² United Nations Special Procedures, Negotiations for international instrument on pandemic preparedness must be guided by human rights: UN experts, 20 May 2022.







management can be summarized as follows. To ensure maximum clarity of the arguments presented, the report also examines a few instances where States' behavior reflected the framework of said right, at least partially, during health emergencies.

I. Prevention

Prevention involves all those processes that ensure that problems are foreseen before they occur, for instance: public health guidance on the avoidance of risky behavior or protection from dangerous exposures, the responsible use of antibiotics, or the transportation of toxic products in appropriately reinforced containers, as was the case for masks and medical waste during the Covid-19 pandemic. The inclusion of the right to science in the upcoming instrument would require States to enforce said measures in compliance with the AAAQ framework.

II. Preparedness

Preparedness means ensuring that all countries have the capability to manage any type of health emergency, including through international and transnational assistance and cooperation in the scientific field. As provided by Art. 15(2), the realization of the right to science would require steps for the conservation, the development and the diffusion of science. To this end, States' investment in the development of science would be key for their preparedness to health emergencies – starting with public funding for basic science which, in the case of COVID-19, laid the basis for the creation of mRNA vaccines. Indeed, State investments in HIV research created a clinical trial infrastructure and decades of experience on everything from developing oral antiviral treatment to engaging communities in research to devising novel vaccine platforms that benefitted COVID-19 innovation.

III. Response

Upon the outbreak of a health emergency, the right to science finds its application in the decision-making process. This guarantees that States ground their normative action on scientific evidence and data. From the right to science perspective, States should distribute medicines and vaccines in an equal, non-discriminatory manner all over their territory, with particular attention to those regions where the pandemic is particularly burdensome, to lowest-income areas, and to the most remote parts of the country. Moreover, the right to science would require States to adopt measures that align with scientific evidence, hence policymakers would conform their choices to data-based evidence and constantly revise the limitations of other human rights previously implemented in order to persistently amend them based on the most updated science available.







IV. Recovery ("the missing phase")

Post-outbreak activities are crucial for community-level healing and remedying human rights violations suffered during the peak. In this scenario, the right to science would require States to make a final transparent assessment of the efficacy of their virus-containing measures. They would be demanded to provide proper redress for the injustices which took place during the pandemic. The right to science would ensure guarantees to medical and scientific personnel, who would be granted rest periods and recovery tools, and it would secure psychological and medical assistance to all citizens in order to ensure community-level healing. This would include, among others, healthcare for harm caused by the lack of timely medication or from vaccine side effects; omission of care of other illnesses than the pandemic-causing one; absence of care due to overextended hospital capacity; mental health aid; and finally, judicial redress and economic reparations for all these injustices.

Conclusions

This report directs attention to a topic which can no longer go unnoticed: the right to science and its undeniable significance in managing pandemics. Its main purpose is to recommend the inclusion of an explicit reference to Art. 15 ICESCR and Art. 27 UDHR in the WHO instrument being drafted and negotiated. As recent history has taught us, viral pathogens and other infectious diseases spread untrammeled until global forces cooperate to provide citizens with reliable information, effective measures and reliable medical appliances. As these fundamental principles are all encompassed in the right to science, our report reflects the need to include this right in the upcoming international instrument, to ensure its effectiveness and value and the opportunity for all the countries to advance in the rights-based management of health emergencies.







ACKNOWLEDGMENTS

This Report was drafted between February and June 2022 by a Team of five students involved in the *Strategic Litigation: International Human Rights Legal Clinic* of the University of Turin (UniTo), supervised by Professor Andrea Spagnolo, Associate Professor of International Law (UniTo), and Giulia Perrone, PhD candidate in International Law (UniTo). The project was carried out in partnership with Treatment Action Group (TAG) and Science for Democracy (SfD). Indeed, the report is the result of fruitful cooperation between the students participating in the clinic, TAG and SfD. The Clinic Team and Advisors are grateful to TAG and SfD for their extremely valuable support during the project.

The Clinic programme involved a number of Guest Lectures that allowed for active interaction between students, scholars and other professionals working in the field of science and human rights. Among them: Marco Perduca (co-Founder and Coordinator of Science for Democracy), Mikel Mancisidor (Member of the UN Committee on Economic, Social and Cultural Rights, Rapporteur of the General Comment no. 25 on Science, Professor of International Human Rights Law at the Universidad de Deusto, the American University and the René Cassin Human Rights Institute), Mark Harrington (co-Founder of Treatment Action Group, former Member of ACTUP/New York's Treatment + Data Committee), Mike Frick (MPH, TB Project Co-Director, Treatment Action Group), Gisa Dang (Health and Human Rights Consultant, Treatment Action Group), Konstantinos Tararas (Program specialist, public policies and capacity-building section, UNESCO), Theresa Harris (interim Program Director of the Scientific Responsibility, Human Rights and Law Program at AAAS), Nathaniel Weisenberg (Associate of the Scientific Responsibility, Human Rights and Law Program at AAAS).

Their contribution has been incredibly helpful for the successful outcome of the project. The Clinic Team wishes to thank them for their insightful presentations, inputs and suggestions. The content of this Report does not necessarily reflect their personal views on the matter.







INTRODUCTION

On 1 December 2021, the 194 Members of the World Health Organization (WHO) reached consensus to initiate a drafting and negotiating process towards the adoption of "a convention, agreement or other international instrument under the Constitution of the World Health Organization to strengthen pandemic prevention, preparedness and response". To this end, an Intergovernmental Negotiating Body (INB) was established to facilitate the entire process, including the participation of "Observers, representatives of non-State actors in official relations with WHO, and of other relevant stakeholders" as to recognize "the importance of broad engagement to ensure a successful outcome".4

In line with the need to maximize civil society engagement in international law-making, and based on the urgency of promoting fruitful public debate over the prevention, preparedness, response to and recovery from pandemics, the present report primarily recommends the inclusion of an explicit reference to the right to participate and enjoy the benefits of scientific progress and its applications (hereinafter, the "right to science"), as enshrined in Art. 15 of the International covenant on economic, social and cultural rights (ICESCR) and Art. 27 of the Universal declaration on human rights (UDHR), in the upcoming WHO instrument.

To justify and support the main recommendation, the present report provides detailed guidance on how States should maximize the effectiveness of pandemic management by illustrating the specific standards set by the right to science, which are pivotal in the enactment and implementation of successful public health measures.

The first section of this study provides an overview of the right to science, from its legal interpretation – as provided by General Comment No. 25⁵, adopted by the United Nations Committee on Economic, Social and Cultural Rights (2020) - to the key relevance of its essential elements for the management of the current and future pandemics. The second

⁴ Ibid. 1, §2.

³ Ibid. 1.

⁵ CESCR, General Comment n. 25 (2020) on science and economic, social and cultural rights (article 15 (1) (b), (2), (3) and (4) of the International Covenant on Economic, Social and Cultural Rights), ((E/C.12/GC/25), available at: OHCHR | General comment No. 25 (2020) on article 15: science and economic, social and cultural rights.







section addresses the role of the right to science in each phase of health emergency management, as identified by WHO: the prevention, preparedness, and response phases. Here, the analysis sheds light on a "missing phase" – namely, the "recovery" phase – and suggests including it in the WHO framework.

The third section provides some practical examples of pandemics management. This involves the analysis of case studies wherein States have in fact implemented the right to science, even without mentioning it in their reports or public statements.

The fourth section concludes the report with final observations and the recommendation to include an explicit reference to Art. 15 ICESCR and Art. 27 UDHR in the WHO instrument. Here, the recommendation is supported by a detailed description of the positive implications that such a reference would have in each phase of pandemic management.







Section 1 – The Right To Science as a Key Factor Against Pandemics

The human right to participate and enjoy the benefits of scientific progress and its applications (hereinafter "right to science") is primarily recognized by Art. 15 (1) (b), (2), (3) and (4) ICESCR. Moreover, it is enshrined in regional instruments, national constitutions and Art. 27 UDHR⁶. CESCR General Comment No. 25 on Science and Economic, Social and Cultural Rights (hereinafter "GC25") provides the authoritative interpretation of Art. 15 ICESCR, thus allowing for a better understanding of its scope and implementation. Indeed, it clarifies that the right to science includes the "right of every person to take part in scientific progress and in decisions concerning its direction",⁷ it explains that the definition of "benefits" is not limited to the material outcomes of scientific research, but goes beyond tangible applications of science to include "the scientific knowledge and information directly deriving from scientific activity",⁸ and it describes the role of science in forming "critical and responsible citizens".⁹ Moreover, GC25 further examines the obligations of States to conserve, develop and diffuse science (Art. 15 (2)), protect scientific research (Art. 15 (3)), and promote international cooperation (Art. 15 (4)).

GC25 also provides the interpretation of the "essential elements" of the right to science – the so-called AAAQ framework, already applicable to the right to health¹⁰ – which sets out a minimum behavioral threshold to be followed by States in the implementation of the right. They are:¹¹

⁶ A recent study shows that a large majority of world constitutions contains one or more of the four components of the right to science: i) the enjoyment of the benefits of scientific progress, ii) the freedom of scientific research; iii) the protection from adverse effects of science, and iv) the duty to foster scientific and technological progress. In particular, 141 of the 202 constitutions currently in force mention some of the mentioned components and 27 even include the language used in Article 15.1.b of the Covenant. See C. P.R. Romano, A. Boggio, The Right to Benefit from Progress in Science and Technology in World Constitutions (June 3, 2020). An entry in Max Planck Encyclopedia of Comparative Constitutional Law (forthcoming), Loyola Law School, Los Angeles Legal Studies Research Paper No. 2020-17, available at: www.ssrn.com/abstract=3618685.

⁷ Ibid. 5, § 10.

⁸ Ibid. 5, § 8.

⁹ Ibid.

¹⁰ Ibid. 5, § 12.

¹¹ Ibid. 5, §§ 16-20.







- I. Availability, which implies that States shall provide appropriate instruments and infrastructures for the conservation, development, and diffusion of science. This entails that States' resources should be managed in a way as to ensure that scientific progress concretely takes place, and that its outcomes and benefits are made available to everyone, especially to vulnerable and marginalized groups.
- II. Accessibility, entailing that States must ensure access without discrimination to scientific knowledge and its applications. States Parties shall remove all barriers in order to guarantee equal access to both a) the applications of science, b) adequate information regarding the risks and benefits of scientific and technological innovations and c) and the opportunity to participate in scientific progress.
- III. Quality, which requires States to ground their decision-making on the most updated, generally accepted, and verifiable science available. This can only be achieved through a constant dialogue with the scientific community, aimed at ensuring that public access to scientific innovations is regulated and certified on the basis of widely accepted scientific knowledge.
- IV. Acceptability, requiring States to explain and disseminate science and its applications in a way that facilitates acceptance by everyone, taking different cultural and social contexts into adequate account. This element implies the incorporation of ethical standards and the respect for human dignity, cultural diversity, and pluralism.

Given these elements, the right to science becomes a powerful tool which States can take advantage of in their prevention of and response to global health emergencies. To this purpose, this report focuses on the crucial contribution of the right to science to each phase of a pandemic management, showing how an explicit reference to Art. 15 ICESCR and Art. 27 UDHC would greatly enhance the effectiveness of the WHO instrument against pandemics.







Section 2 – The Right to Science in Pandemic Management

PREVENTION

Prevention of pandemics cannot be overlooked by national governments in their strategic planning of emergency operations. The right to science, if incorporated within the new instrument,, will provide States with the right tools to strategically face future global health emergencies. Ever since the influenza crisis, the WHO has grouped the pandemic phases and recommendations in the five components of preparedness and response, which transpire as substantial and are as follows: planning and coordination; situation monitoring and assessment; reducing the spread of disease; continuity of health care provision; and communications. These address the fact that many health emergencies can be prevented or quelled before they cause extreme damage: however, in order for this to happen, governments must understand the relevance of a comprehensive program of pandemic prevention, which is best achieved through the prerogatives of the right to science.

The WHO has been working with partners to prevent events such as disease outbreaks because any failure of prevention can be deadly. Prevention involves all those processes that ensure that problems are foreseen before they occur, for instance: public health guidance on the avoidance of risky behavior or protection from dangerous exposures, the responsible use of antibiotics, or the transportation of toxic products in appropriately reinforced containers, as was the case for masks and medical waste during the Covid-19 pandemic. The inclusion of the right to science in the upcoming instrument, under the framework established by the General Comment No. 25, would result in States' obligation to properly enforce said measures.

¹² See: World Health Organization, Pandemic Influenza Preparedness and Response: A WHO Guidance Document, Geneva, 2009, available at www.apps.who.int/iris/handle/10665/44123.

¹³ See: WHO launches first ever global report on infection prevention and control, Reveals that good IPC programmes can reduce health care infections by 70%, 6 may 2022, www.who.int/news/item/06-05-2022-who-launches-first-ever-global-report-on-infection-prevention-and-control.







In the scope of the WHO framework for prevention, there are sets of main actions that are meant to develop, exercise, and revise national actions for national prevention and response plans.

This is to be achieved through a complete, transparent, and updated communication strategy. implemented by governments. 14 Institutional communication should be based on data and information shared by researchers and health care professionals, thanks to initiatives of datasharing activities between different systems, in order to assess the presence of a real or potential risk of pandemic breakouts. This would greatly benefit emergency control as it would promote an agile participation of society to the new measures introduced by States, whenever those are based on scientific evidence, then shared and disseminated to citizens¹⁵. Important to mention in this case are the activities of research and development (R&D) and surveillance (includina surveillance of disease new pathogens at the human/animal/environmental nexus) and investments in public health system and workforce i.e., the routine business of public health and primary healthcare.

One example is that of tuberculosis (TB), which is managed as a public health disease in most countries. In the early days of COVID-19, TB clinics became COVID-19 clinics and TB doctors and nurses were some of the first to respond to COVID-19 in many countries because they knew how to handle an airborne, respiratory, highly contagious disease¹⁶. Of course, activities such as these would greatly benefit from rapid exchanges of information, resources and assistance between States, "in the context of the maximum of [their] available resources, [both] individually and through international assistance and cooperation"¹⁷.

¹⁴ Based on the WHO Constitution, each Member State is required to report annually to the Organization on the "action

taken and progress achieved in improving the health of its people", (Constitution of the World Health Organization, art. 61).

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¹⁵ Ibid. 5, §§ 45-50.

¹⁶ T. Dlangalala, A. Musekiwa, A. Brits, K. Maluleke, Z.N. Jaya, K. Kgarosi, T. Mashamba-Thompson, Evidence of TB Services at Primary Healthcare Level during COVID-19: A Scoping Review, in *Diagnostics*, 11(12), 2221, 27 November 2021, available at: www.pubmed.ncbi.nlm.nih.gov/34943458/.

¹⁷ Ibid. 5, §51.







PREPAREDNESS

Preparedness means ensuring that all countries have the capabilities to manage any type of health emergency, including through international and transnational assistance and cooperation in the scientific field. Strategic risk assessments must be undertaken before a pandemic occurs and used to guide risk-informed programming to catalyze action to prevent, prepare for and reduce risks associated with a specific health threat of pandemic potential. The adoption of a national plan of action for the development and dissemination of scientific advancements is crucial for the effective management of pandemics through the maximum use of States' available resources. 18 both budgetary and participatory. 19 This involves the necessary identification and priority-setting of the resources available to each State,²⁰ whereby the term 'resources' goes beyond pure financial resources. Rather, it involves other types of resources relevant for the realization of economic, social and cultural rights²¹, including human resources. For scientists themselves, it is important that states ensure access to the means, methods, and materials necessary for scientists to conduct research, interpret data, share findings, and exchange information with their peers. An explicit reference to the right to science would help to ensure speedy access to the tools necessary to handle pandemics.²² Not only would it enhance State preparedness, but it would also reinforce the strategic approach of the government whenever facing a pandemic outbreak. This would influence the level of credibility and foster trustworthiness of the state vis-à-vis its population, since the transparency and concerted action provided would reassure and ensure a swift response by National Health Systems. Indeed, the latter would be prepared to quickly assess risks and prioritize hazards, therefore limiting the impact of a disease outbreak on the State's economy and strategic planning...

¹⁸ World Health Organization, International Health Regulations, 2005, art. 44.

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¹⁹ Ibid. 5, §§ 23, 46.

²⁰ Ibid. 5, § 87.

²¹ This can be inferred, among others, from some pronouncements of the Committee on the Rights of the Child, which has expanded the meaning of resources to include human, technical, organizational, natural and information resources. See, for example: See, for example, CRC/C/KHM/2-3, CRC/C/SDN/CO/3-4, CRC/C/15/ Add.216, and CRC/C/15/Add.205.

²² Ibid. 5, § 17.







The right to science requires States to respect transparency when communicating about risks and any ad hoc measures or responses. Governments should not approach these issues alone, but together with other institutions, such as Universities, research hubs and technical laboratories, also ensuring "enhanced" cooperation and assistance between high-, middleand low-income countries.²⁴ The right to science would foster this approach through the cooperation of those bodies not only with each other, but with citizens as well, so that nobody is left behind.²⁵ Transparent communication promotes not only beneficial behaviors in individuals for self-protection, but it also comprises equitable access to pharmaceuticals and vaccines, which would be strengthened with the observance of the right to science, especially in light of the enjoyment of the benefits derived by an approach that treats knowledge and its applications as a common, shared, public good.²⁶ This is in line with the work of the WHO, which supports the goal of clear communication before and during a pandemic, which encompasses the duty to provide and exchange relevant information with the public, partners and stakeholders to allow them to make well informed decisions and take appropriate actions to protect health and safety, as well as their response, a fundamental part of effective risk management.²⁷

This phase would also be crucial for the enforcement of Art. 15 (2), namely, the States' duty to foster the conservation, development, and diffusion of science and its benefits. Public funding must be devoted to scientific research not only to tackle ongoing pandemics, but also to prevent future ones. Part of the preparedness phase encompasses States' investment in the development of science – starting with public funding for basic science, which in the case of COVID-19, laid the basis for the creation of mRNA vaccines. Indeed, State investments in HIV research created a clinical trial infrastructure and decades of experience on everything

²⁴ Ibid. 5, §§ 25-27.

²³ Ibid. 5, § 82.

²⁵ Ibid. 5, §§ 47-49.

²⁶ Ibid. 5, §§ 8-14.

²⁷ World Health Organization Outbreak Communication Planning Guide, 2008.







from developing oral antiviral treatment to engaging communities in research to devising novel vaccine platforms that benefitted COVID-19 innovation.²⁸

The examination of public investments can yield insights on the innovation ecosystem as it relates to the development of diagnostics, medicines, and vaccines and downstream access to such material benefits of science. This includes prices that are asked for the administration of vaccines to end users and the analyses of whether there has been an efficient return on public-sector investment in the development of health technologies²⁹. To reference the AAAQ framework: state investments in development are also related to availability of funds – the tools needed to respond to certain health conditions at those times are unavailable because states have not properly invested in research and development.

RESPONSE

During the response phase, policies implemented by governments and international organizations shift from preparedness to actual management of the pandemic. The ultimate goal of these actions shall be to effectively lessen the impact of the virus on society, to ensure access to scientific benefits such as medicines, vaccines and diagnostics to all, and to keep citizens properly advised about the progress of the pandemic and necessary behavioral norms and risk mitigation measures.

In this context, the right to science will not only represent a guarantee to the freedom of research and information; rather, it will shift toward its most policy-oriented features, translating into actual measures what was previously achieved in terms of data collection and communication.

During the response phase, States would be committed under the right to science framework to promptly and effectively grant healthcare to their citizens through correct and quick application of scientific progress. They shall distribute medicines and vaccines in an equal,

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²⁸Allen, For Billion-Dollar COVID Vaccines, Basic Government-Funded Science Laid the Groundwork; Much of the pioneering work on mRNA vaccines was done with government money, though drugmakers could walk away with big profits, in Kaiser Health News, 18 November 2020, available at: www.scientificamerican.com/article/for-billion-dollar-covid-vaccines-basic-government-funded-science-laid-the-groundwork/.

²⁹ D. Gotham, L. McKenna, S. Deborggraeve, S. Madoori, D. Branigan, Public investments in the development of GeneXpert molecular diagnostic technology, Plos One, 31 August 2021, available at: www.journals.plos.org/plosone/article?id=10.1371/journal.pone.0256883.







non-discriminatory manner all over their territory, with particular attention to those regions where the pandemic is particularly burdensome, to lowest-income areas, and to the most remote parts of the country. Distribution of medicines shall follow the standards set by General Comment 25, the AAAQ framework.³⁰ In particular, in this phase, the right to science regime would secure the highest degree of quality medicine and infrastructure available to States in providing to citizens the most updated science, which would imply the most reliable diagnostic, therapeutic and preventive applications of science, fully efficient medical support and, overall, an efficient response to the pandemic. Moreover, the right to science would require States to adopt measures that align with scientific evidence,³¹ hence policymakers would conform their choices to data-based evidence: citizens would be subject to restrictions only where strictly required by the infection rates, without suffering from unduly extensive limitations on their private lives.

The right to science also ensures the application of scientific progress whenever this is crucial to the enjoyment of other human rights. To these purposes, States would constantly revise the limitations of other human rights previously implemented in order to persistently amend them based on the most updated science available. This also mirrors what was recommended by the WHO at the outbreak of the COVID-19 pandemic and in compliance with Art. 15 of the 2005 International Health Regulation. Indeed, the WHO suggested that States periodically adjust their measures according to the epidemiological situation and take their health system capacity into consideration.³²

Last, including the right to science in the upcoming international instrument would allow States to benefit from the mutual observance of said right. Concerning inter-State relations, international cooperation would be reinforced under this framework: this implies that States in the response phase are required to provide mutual assistance in the scientific field to one

³⁰ Ibid. 5, § 15.

³¹ Ibid. 5, § 52.

³² See: World Health Organization, Statement on the tenth meeting of the International Health Regulations (2005) Emergency Committee regarding the coronavirus disease (COVID-19) pandemic, 19 January 2022, available at: <a href="https://www.who.int/news/item/19-01-2022-statement-on-the-tenth-meeting-of-the-international-health-regulations-(2005)-emergency-committee-regarding-the-coronavirus-disease-(covid-19)-pandemic.







another, both in sharing scientific discoveries and relevant infrastructure, so that the pandemic can come to a close globally more quickly (Art. 15(4)).

In conclusion, States' obligation to implement the right to science when responding to pandemics would result in a general commitment to respect a minimum standard: the one suggested by GC25.

THE MISSING PHASE: RECOVERY

One striking absence from Resolution WHA 74.7, decision WHA 74(16) and WHA SSA2(5) is a mention of the recovery phase from a pandemic³³. Indeed, the importance of post-peak activities must not be understated: States must evaluate their own actions during the outbreak and redress any act or omission that might have caused injustice in their pandemic management.

In the recovery phase, States shall carry on their vaccination plans and keep ensuring medicine availability and quality. Because through the right to science there shall be no public hindrance to access to scientific data, States shall provide to citizens transparent, comprehensive and disaggregated data on the course of the pandemic and on the effectiveness of the measures implemented. Not only would this allow individuals to personally assess the success of governmental action, but their right to be informed of their own rights and of the availability of avenues for redress for any injuries suffered during the pandemic would also be ensured by this scenario.

Further on the latter issue, States would be bound to provide proper redress for the injustices which took place during the pandemic. The right to science would ensure guarantees to medical and scientific personnel, who would be granted rest periods and recovery tools, and it would secure psychological and medical assistance to all citizens in order to ensure community-level healing. This would include, among others, healthcare for harm caused by the lack of timely medication or from vaccine side effects; omission of care of other illnesses

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³³ The present report was completed before the INB reached agreement on the Working draft, presented on the basis of progress achieved, for the consideration of the Intergovernmental Negotiating Body at its second meeting (A/INB/2/3), which contains references to the recovery phase. The Working draft is not immune from criticisms with specific regard to the way in which it refers to the recovery phase. However, the analysis of the Working draft falls outside the scope of this study. The Working Draft can be accessed at: www.apps.who.int/gb/inb/pdf_files/inb2/A_INB2_3-en.pdf.







than the pandemic-causing one; absence of care due to overextended hospital capacity; mental health aid; and finally, judicial redress and economic reparations for all these injustices. Such medical, psychological, monetary, and legal care is the fundamental core of the recovery phase. Moreover, States shall ensure that research efforts that suffered setbacks due to the pandemic are resumed and that investments are directed towards progress lost on other diseases during the outbreak; for instance, by helping TB programs to recover from COVID-19 related disruptions.

In conclusion, ignoring the momentousness of a recovery phase, and of the need for the right to science in such a phase, would imply insufficient State action, and a missed opportunity for further providing information guarantees and adequate policies to the civil society. Specifically, even the most well-performed response phase would prove insufficient if not followed by the recovery stage, where citizens can heal from the emergency and find redress for their needs at the public level.







SECTION 3 - BEST PRACTICES

Though it has been rarely explicitly mentioned by States, the right to science framework has been successfully applied in different cases in previous pandemics. Section 3 examines a few instances where States' behavior reflected that framework, at least partially, during health emergencies. As for the previous Sections, the analysis will be structured in four distinct phases.³⁴

PREVENTION

To prevent pandemics, it is imperative to foster development of the following three key areas: surveillance, manufacturing, and coordinated research and development (R&D).

In order to ensure surveillance of pathogens, it is necessary to continuously analyze samples of pathogens of concern or pandemic potential, including any genetic mutations which may make known pathogens more transmissible or deadly. As prescribed by the right to science, these processes must be carried out via the most updated technology available and through highly qualified personnel and equipment. International cooperation and the sharing of pathogens and data on genomic sequencing has already proved critical for COVID-19 and is also being used to counter the spread of the Monkeypox viral infection³⁵. This high-level technology has been successfully employed by the United Kingdom, which was able to analyze a great quantity of virus samples daily³⁶ and was able to identify early on the Alpha variant of the Coronavirus. Furthermore, as recommended by the right to science, a high degree of coordination is necessary to ensure the reception of all samples, so to gather all data required for processing scientific evidence as quickly as possible in order for it to be reported daily to public health agencies and the Department of Health and Social Care. Great

³⁴ Section 3 provides an assessment of measures and policies adopted by States from a right to science perspective only. It follows that the analysis does not involve an all-encompassing assessment of States' behavior. ³⁵World Health Organization, Multi-country monkeypox outbreak in non-endemic countries, 21 May 2022, available at: www.who.int/emergencies/disease-outbreak-news/item/2022-DON385.

³⁶ See S. Gonçalves, An expert explains how to track coronavirus variants, Sonia Gonçalves, 16 April 2021, available at www.wellcome.org/news/track-coronavirus-variants-genomic-surveillance.







examples of this practice are the South Africa and Botswana cases, identifying the Omicron variant through their routine sequencing systems and sharing their findings³⁷.

As far as both manufacturing and R&D are concerned, often enough, health technology innovation is left to the pharmaceutical industry, which is driven by profit and motivated by market incentives. The right to science offers a counterweight to for profit innovation by reorienting research toward the creation of public goods through the purposive, needs-driven development of health technologies. The right to science prescribes the adoption of people-centered approaches to research and innovation and sustainable policies that deliver health democratically. A great example was the smallpox eradication, the first human infectious disease to be declared eradicated in 1979, as its vaccine was the first to be deployed widely and to be distributed systematically.³⁸ Another example is the creation of the polio vaccine, which was famously never patented by its inventor, Jonas Salk.

Public support of the R&D sector forms an integral part of pandemic prevention. When States invest in research and development, it is important that they do so in ways that uphold each dimension of the AAAQ standard at the heart of the right to science. Conditionalities placed on public funding to ensure the availability and accessibility (affordability) of medicines, diagnostics, and vaccines; opportunities for public participation in research to inform acceptability; and the regulation of ethical scientific conduct to promote quality. The right to science enshrines States' duty to invest in the scientific sector and to ensure that the public can realize returns on such an investment. Where public funding is given without conditionalities, access is often limited or inequitable. One illustrative example is the new TB drug bedaquiline: although government investments in the research and development of bedaquiline exceeded spending by the originator company (Johnson & Johnson) by a factor of 3–5 times, Johnson & Johnson retained a monopoly on the drug and has priced it too high for most public health systems to afford.³⁹

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³⁷ R. Viana et al., Rapid epidemic expansion of the SARS-CoV-2 Omicron variant in South Africa, in Nature, 603, pp. 679-686, 07 January 2022, available at: www.nature.com/articles/s41586-022-04411-y#citeas.

³⁸ Brian Greenwood, The contribution of vaccination to global health: past, present and future, Philos Trans R Soc Lond B Biol Sci., 369, 1645, 19 June 2014, available at: www.ncbi.nlm.nih.gov/pmc/articles/PMC4024226/.

³⁹ D. Gotham, L. McKenna, M. Frick, E. Lessem, Public investments in the clinical development of bedaquiline, Plos One, 18 September 2020, available at: www.journals.plos.org/plosone/article?id=10.1371/journal.pone.0239118#sec017.







PREPAREDNESS

Pandemic preparedness encompasses buttressing the healthcare sector, also making sure that health goods and services remain affordable for all without discrimination. A balance must be reached between economic interests and the full enjoyment of economic, social and cultural rights, especially those affected by the outbreak of a pandemic, such as the right to science and the right to health. . Countries which managed to find such a balance during the COVID-19 pandemic, such as Japan and Germany, eventually showed a much lower fatality rate than non-prepared countries.⁴⁰

Public-private partnership would therefore enhance preparedness to health emergencies. Said partnership should be provided for by a national emergency plan, regularly updated to constantly reflect current scientific knowledge and applications. Moreover, the preparedness phase would highly benefit from the periodic evaluation of national emergency management, which should be carried out as part of the recovery from each pandemic.

Indeed, those States that carried out an assessment of the measures adopted during past health emergencies – such as SARS and H5N1 – proved more prepared for COVID 19 than those who did not. Vietnam is a case in point as it managed to crystallized its learned lessons from past emergencies into current legislation during COVID 19⁴¹. Though the COVID 19 pandemic is still ongoing, it is nevertheless possible to identify successful cases of structured emergency plans, such as the one drafted by, respectively, South Korea and New Zealand. 42

RESPONSE

During the response phase, States opting for a whole-of-government approach as recommended by the right to science were able to combat the spread of the virus efficiently.⁴³

 40 S. Orešković, S. Porsdam Mann, Science in the Times of SARS-CoV-2, in H. Porsdam, S. S. Porsdam Mann, The

right to science, 2020, available at: https://www.cambridge.org/core/books/right-to-science/science-in-the-times-

of-sarscov2/FF9327A30EA2EE9A0A2D51B117FF9EAA, p. 188.

⁴² I. Bremmer, The Best Global Responses to the COVID-19 Pandemic, 1 Year Later, Time, in Time, 23 February 2021, available at: https://time.com/5851633/best-global-responses-covid-19/.

⁴³ M.G. Baker, A. Kvalsvig, A.J. Verrall, New Zealand's COVID-19 elimination strategy, in Med J Aust., 213(5), 2020, pp. 198-200.







Such a plan entailed the coordination of healthcare professionals, policymakers, scholars, and Ministries of Health. This would ensure that policies are based on scientific evidence and that they undergo proper democratic supervision. One aspect that should be noted is that coordinating a multi-stakeholder action does not necessarily require a highly funded healthcare system: States like Lebanon and Syria, whose health governance is otherwise scattered, were able to set up task forces grouping together NGOs, local medical personnel, and international organizations which proved successful in managing the outbreak.⁴⁴

Furthermore, joint action shall also be furthered between public and private actors: this synergy has previously proven effective in accelerating the discovery and distribution of new health-related technologies, which was key in the management of the AIDS pandemic.⁴⁵ Private-public coordination has also proven effective in Singapore, where data sharing frameworks were established so that governmental agencies and the private sector were facilitated in exchanging accurate information on the pandemic.⁴⁶

Furthermore, once a State is well-prepared for tackling a health emergency and has put in place wide-ranging plans of action based on science and data, it should also take into account the importance of transparent and efficient communication, as required by the right to science. Indeed, an efficient policy response to pandemics requires States to keep all people within its borders informed about the development of the emergency and the efficacy of its response.⁴⁷ During the COVID 19 pandemic, public authorities who were able to engage individuals in their decision-making process, such as by explaining to them the scientific reasons behind every restriction, have seen their leadership strengthened and recognized at the international level post-peak. It is the case of New Zealand⁴⁸ and Vietnam,⁴⁹ where

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⁴⁴ Practical lessons for recovery from the COVID-19 pandemic: principles for recovery, in International Recovery Platform, 2020, p. 11, available at: https://recovery.preventionweb.net/publication/practical-lessons-recovery-covid-19-pandemic-principles-recovery.

⁴⁵ Report of the UN Secretary General's High Level Panel on Access to Medicines, September 2016, p. 14.

⁴⁶ Ibid. 44, p. 13.

⁴⁷ Ibid. 5, §§ 8-14.

⁴⁸ E. Hunt, Words Matter: How New Zealand's Clear Messaging Helped Beat Covid, in The Guardian, 26 February 2021, available at: www.theguardian.com/world/2021/feb/26/words-matter-how-new-zealands-clear-messaging-helped-beat-covid.

⁴⁹ World Health Organization, No Road Too Bumpy: Viet Nam Brings COVID-19 Information to Remote Areas, 21 February 2022, available at: <a href="https://www.who.int/vietnam/news/detail/21-02-2022-no-road-bumpy-enough-viet-nam-pws/detail/21-02-2022-no-road-bumpy-enough-viet-nam







governmental leaders credibly instructed people on data and science anytime new policies were implemented: this led to a stronger, more credible leadership and to educated individuals, as already foreseen by the General Comment 25.50 This credibility stemmed not only from scientific education, but also from a careful communication strategy whereby every speech and explanation was backed up by solid logic and scientific evidence supporting the government's choices.

RECOVERY

In the aftermath of the pandemic, the framework set by the right to science would commit States to ensure community-level healing. This was successfully carried out by New Zealand, which employed a Psychosocial and Mental Wellbeing Recovery Plan coordinating various governmental agencies toward restoring citizens' psychological health.⁵¹ New Zealand also implemented a feedback mechanism whereby individuals could submit complaints and recommendations in order to ameliorate the government's interventions.

On a more general note, the right to science requests States to endeavor to ensure the highest level available of social protection during health emergencies. Such guarantees must also be kept in place in the post-surge phase, as States which enforced strict welfare systems and solid social safety nets were able to restore their citizens' physical and mental health quickly and effectively.⁵² This includes not only social and economic policies, but also structural changes in infrastructure and city management: this was successfully carried out, for

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<u>brings-covid-19-information-to-remote-areas</u>; T. Pollack et al, Emerging COVID-19 Success Story: Vietnam's Commitment to Containment', in Our World in Data, 05 March 2021, available at: <u>www.ourworldindata.org/covid-exemplar-vietnam</u>.

⁵⁰ Ibid. 5, §§ 53, 82.

⁵¹ Ibid 44, p. 20; see also: Kia Kaha, Kia Māia, Kia Ora Aotearoa: COVID-19 Psychosocial and Mental Wellbeing Recovery Plan, 15 May 2020, available at: https://www.health.govt.nz/system/files/documents/publications/covid-19-psychosocial-mental-wellbeing-recovery-plan-15may2020.pdf.

⁵²C. Bodewidgstéphane Hallegatte, Building back better after COVID-19: How social protection can help countries prepare for the impacts of climate change, in Wolrd Bank Blogs, 14 July 2020, available at: https://blogs.worldbank.org/climatechange/building-back-better-after-covid-19-how-social-protection-can-help-countries-prepare.







instance, in Italy and Lithuania, where public spaces were rethought and redesigned to fit the community's post-pandemic needs at best. 53

⁵³ Ibid 44, p. 20.







CONCLUSIONS

This report directs attention to a topic which can no longer go unnoticed: the right to science and its undeniable significance in managing pandemics. Its main purpose is to recommend the inclusion of an explicit reference to Art. 15 ICESCR and Art. 27 UDHR in the WHO instrument being drafted and negotiated. As previous experience has shown, States have successfully coped with health emergencies through the non-explicit, and thus partial, application of the right to science. Its explicit inclusion would have several implications for pandemic prevention, preparedness, response, and recovery.

Firstly, the so-called AAAQ framework must be respected in its entirety. Availability, Accessibility, Acceptability and Quality of scientific knowledge and applications must be understood as the minimum standards for a State to manage health emergencies. Such thresholds include the existence of appropriate instruments and infrastructures, the possibility to access the most updated scientific knowledge and its applications, a constant dialogue with the scientific community, while considering the different cultural and social contexts in the dissemination of science. The protection of this framework must be monitored at all times during the management of a pandemic, taking into account its applicability to all stages as mentioned above in Section 2.

Finally, the Report has highlighted how some States have carried out an effective response to past pandemics through the application of the elements of the right to science, even unknowingly. If the right to science were enshrined in the WHO international instrument, States would greatly benefit in terms of strategic organization, health care management, social and economic consequences.

• [Prevention] Proper investments in disease surveillance (including surveillance of new pathogens at the human/animal/environmental nexus) and public health system and workforce would enhance the possibility to anticipate and avoid the outbreak of a health emergency. Also, by setting up a complete, transparent, and up-to-date communication strategy and a system of information-sharing States would diminish







the possibility of false risk assessments. This includes the involvement of both the general public and the scientific community. Indeed, on the one hand, States must give proper public health advice on risky and unsafe behavior. On the other hand, researchers and experts must be given the rightful tools to communicate among themselves and with national governments, to ensure there is no discrepancy between the latest research results and national policies.

- [Preparedness] National resources must be identified and prioritized, alongside a national plan of action for the promotion and dissemination of scientific advancement. Such resources should be interpreted in terms of financial means as public funding must be devoted to scientific research in order to both tackle ongoing pandemics and to prevent future ones as well as other relevant resources, i.e. human resources including scientists able to access the means, methods, and materials of scientific discovery and interpretation. The right to science fosters a system of cooperation between States, institutions and citizens, where information is provided and exchanged in respect of the principles of transparency and reliability.
- [Response] Upon the outbreak of a health emergency, the response of governments shall necessarily follow the requirements of the right to science. This is of fundamental importance during the decision-making process, as it will guarantee the apt and effective management of healthcare issues of any kind, avoiding discrimination and balancing the response to help regions particularly harmed by the emergency. Under the right to science, States would benefit from the reinforcement of international cooperation as they would be called to its mutual observance, providing mutual assistance in the scientific field to one another. Moreover, according to the AAAQ framework, the policies adopted during a pandemic must be taken according to data-based evidence. This is pivotal to safeguard the protection of other human rights, avoiding burdensome and unnecessary restrictions.
- [Recovery] An efficient emergency response is incomplete without the consideration of this phase, as it addresses the possibility of further waves of pandemics and the possible existence of any omissions or errors made previously. The mentioned international instrument will represent an effective and powerful tool to provide







individuals proper redress for the injustices which took place during previous pandemics, ensuring community-level healing through psychological, financial and medical assistance to all citizens, both in the short and the long term.

As recent history has taught us, viral pathogens and other infectious diseases spread untrammeled until global forces cooperate to provide citizens with reliable information, effective measures and reliable medical appliances. As these fundamental principles are all encompassed in the right to science, our report reflects the need to include this right in the upcoming international instrument, to ensure its effectiveness and value and the opportunity for all the countries to advance in the rights-based management of health emergencies.