

REALIZING THE RIGHT TO SCIENCE

By Erica Lessem and Suraj Madoori

As science-based activists, the right of everyone “to share in scientific advancement and its benefits”¹—or more simply, the right to science—offers tremendous potential for our work. Yet this right has been underexplored and underutilized. Under the leadership of Mike Frick, now co-director of our TB project, TAG began framing our advocacy within a right to science lens in 2015, adding to the small but growing body of work to understand and apply the right.² Building off the body of work that has resulted over the past five years, we decided to dedicate an edition of *TAGline* to the right, in light of upcoming official detailed communications on what the right to science means ([The Right to Science Finally Comes into Sight](#)). We had no idea that by edition launch, we’d be in the throes of a pandemic, with the need to realize the right to science more important than ever.

The emergence of the SARS-CoV-2 virus, and the resultant pandemic of COVID-19 disease facilitated by many countries’ horrible mismanagement of it, are tragic demonstrations of why the right to science is so essential. Science underpins all the tools we need to combat a pandemic: evidence-driven epidemiology and public policy; sound information and public communications; and eventually, new diagnostics, therapeutics, and possibly vaccines. Only a science-based response will get us out of this with as minimal impact and lives lost as possible. Such a response requires strong political will and effectual governments to make adequate fiscal and policy investments to—in the language of the right to science—both develop and diffuse those advances to all who need them.

On the investment side, we see clearly from recent events that waiting until an emergency to make investments in research and development (R&D) means that high-quality, life-saving tools come far too late. While it can be hard, if not impossible, to predict what pathogen will explode as the next global health crisis, proactive and sustained investing in infectious disease research and product development helps support an infrastructure that can be readily deployed and adapted to respond to emerging threats. Instead, years of a free market-driven approach to R&D means that many companies have abandoned their infectious disease drug and

vaccine development units in favor of more lucrative, yet less essential therapeutic areas. Chronic underfunding of science directly threatens the rigor of biomedical research, with fewer resources to conduct and power randomized controlled trials to generate quality data.³ Underinvesting in research and accepting potentially biased or anecdotal evidence in place of randomized trials result in weak guidelines and challenge uptake of new interventions. Sustained and increased investments in public research institutions, such as the U.S. National Institutes of Health, are critical for building a basic science knowledge base to understand conditions and underpin product development, as well as providing funding opportunities to attract private sector endeavors. Investments also ensure that our best and brightest engage in advancing crucial research, while bringing promising, early-career researchers into the fields of emerging and neglected infectious diseases.

But developing the tools is only half of the battle. Making sure they equitably reach those affected is equally essential. With the COVID-19 pandemic, we are already seeing the breakdown of who benefits from science, including publicly-funded science, as we continue to see with the HIV, TB, and HCV epidemics. This inequity applies both within and across borders. For example, though the human right to science and its benefits is universal, the ability to obtain testing for COVID-19 hugely depends upon in which country one lives (compare early testing rates in South Korea versus the U.S., for example)³ as well as how resources and health care coverage are distributed within a country.⁴ A particularly egregious example of this breakdown is President Trump attempting to buy exclusive rights to a vaccine candidate from a German company, with an eye toward making it available only in the U.S.⁵ Or the case of U.S. Secretary of Health and Human Services Azar not committing to ensure that any vaccine developed would be affordable.⁶ In a time where rapid and unfettered access is vital, the policies lobbied by industry in the name of protecting innovation and intellectual property rights are barriers to meeting urgent health needs and limits the realization of the right to science for all. So while economic stimulus packages to incentivize private sector development may help produce

tools, they raise important questions about what safeguards are needed in terms of who will ultimately benefit from them, in order to ensure that human rights are respected, protected, and fulfilled. As you'll see in the following pages, the right to science offers us important insights to answer these questions.

Putting the Right to Science into Practice in U.S. Policy

In the U.S., as we enter the fiscal year 2021 appropriations season, there are clear opportunities to put the right to science into practice. Investments across the full spectrum of research and development—in the National Institutes of Health, the Center for Disease Control and Prevention, U.S. Agency for International Development, the Biomedical Advanced Research and Development Authority, and the Food and Drug Administration—are essential. And not just for COVID-19, but for longer-standing epidemics as well—we cannot rob Peter to pay Paul. We cannot leave unfinished the job of ending the HIV, HCV, and TB epidemics, which would be greatly facilitated by preventive vaccines, a cure for HIV, and shorter cures for HCV and TB. Such public investments should come with access guarantees and transparency, so taxpayers don't pay twice for developing and using an intervention. The government should not be afraid to exercise existing Bayh-Dole march-in rights to ensure affordability of tools when we need them most. Sustaining and increasing investments to strengthen disease response programs are also necessary: for example, as experts in addressing airborne infectious diseases, TB controllers are incredible front-line responders to COVID-19, and their expertise is being relied upon in this current crisis; however, years of chronic underfunding for TB mean limited capacity to respond to both challenges. These oft-neglected programs provide necessary infrastructure to smoothly implement new tools resulting from publicly funded research and to shift healthcare capacity to respond to emergencies; these programs need increased resources to flexibly respond to emerging and concurrent epidemics.

In this edition, we explore the right to science and its applications, moving from the theoretical to the practical. We begin with an interview with human rights expert Gisa Dang

([Opportunities for Activism with the Right to Science](#)) about the right to science, its interplay with other rights, and how it can inform and empower activists. Mike Frick ([The Right to Science Finally Comes into Sight](#))—who started TAG's work on right to science back in 2015—then explains the United Nations general comment process to provide authoritative legal interpretation of the right, and what we hope and need to see from it. Annette Gaudino and Bryn Gay then begin to move us into applications of the right to science, as they explore what the right means in the context of diagnostics development in interviews with developer BLINK Diagnostics and the Access Campaign of leading implementing organization Médecins Sans Frontières. David Branigan homes in even more concretely on implications of the right to science on development of and access to molecular diagnostics to better detect TB.

Whether fighting the oldest infectious disease known to humans, or this new pandemic, the right to science offers us an invaluable frame for our activism and for reframing government policy. A transnational emergency—with unprecedented political attention and investments in health and research—is also a unique opportunity for incorporating, advancing, and codifying the right to science in fiscal, healthcare, trade, and regulatory policies to benefit vulnerable communities. We need science more than ever. What greater benefit of science is there than saving lives?

Endnotes

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