

July 29, 2022

Dr. Roger Glass
Director
Fogarty International Center
31 Center Dr.
Bethesda, Maryland 20892

Dear Dr. Glass:

The Global Health Technologies Coalition (GHTC) is the premier advocacy organization focused on research and development (R&D) of global health technologies. GHTC is a coalition of 43 organizations based around the world focused on developing new drugs, vaccines, diagnostics, and other global health tools—many working in partnership with the National Institutes of Health (NIH).

GHTC hosts an Equity Working Group (EWG) for its members to collaborate on advancing diversity, equity, inclusion, decolonization, antiracism, and social justice in global health R&D. On behalf of GHTC and the EWG, we submit some identified gaps and recommendations below for improving equity in global health research.

Inequities and disparities in global health R&D are rooted in the current challenges and histories of racism, sexism, ableism, colonialism, and other forms of bias and oppression that intersect. Like other social injustices, these global health R&D inequities are harmful and will persist without acknowledgement and action by many stakeholders, including the Fogarty International Center (Fogarty) and other NIH institutes and centers (ICs).

We believe that Fogarty and other NIH ICs should be front and center in addressing these global health inequities. Fogarty's role in strengthening R&D capacity in low-resource settings gives it considerable influence over the evolution of the global health biomedical R&D ecosystem. Fogarty and the other NIH ICs should adjust their policies and procedures to address these challenges and create a future system that is more equitable, inclusive, and effective. These changes should be based on the “nothing about us, without us” principle that was popularized by the disability rights movement in South Africa and applies to global health R&D. This work is both the right thing to do and the smart thing to do if our nation is truly committed to a future in which there is continuous advancement in the health, well-being, and prosperity for all.

We recognize that NIH ICs, including Fogarty, have taken steps to both acknowledge global research inequities and disparities and to rectify them, such as by providing training to scientists and ensuring that NIH programs with a focus in other countries are led by researchers based in those countries. These are welcome steps in the right direction but are insufficient for the scale of the challenge. We ask NIH to go further and to uphold its place as a leader in the biomedical research ecosystem by taking ambitious actions for improving equity in global health research.

Below, we offer recommendations and the key challenges to global health equity they address:

Recommendations

- **Reimagine scientific capacity strengthening:** “Capacity building” is often used to describe US investments in the research ecosystems of other countries. GHTC asks Fogarty and other NIH ICs to recognize that many “capacity building” investments, however, lead to reciprocal innovation and mutual capacity strengthening, in which ideas, products, and people flow back to the United States and benefit the US biomedical research ecosystem. We recommend that:
 - NIH increases funding for programs for research exchange, mutual capacity strengthening, and reciprocal innovation.
 - NIH explicitly recognizes that history has produced a global scientific epistemology that is Western-based and biased against knowledge and discoveries produced by researchers in low- and middle-income countries (LMICs). To restructure this paradigm, NIH should acknowledge the expertise of those researchers and make greater investments in their leadership.
 - NIH grants for research in LMICs should intentionally require and include funding for sustainable investments in infrastructure (such as lab capacity, internet access, and electronic medical records) and for staff and researcher training that will strengthen their ability to apply for and administer future grants.
 - NIH increases LMIC partners’ access to journal subscriptions by providing funding or by working with journals directly.
 - NIH funding prioritizes the analysis of research specimens to be

conducted in the country in which they were collected.

- NIH continues to prioritize strengthening partnerships both between institutions based in LMICs and between institutions based in the United States and LMICs. In these partnerships, NIH should emphasize that scientists and institutions based in LMICs should be leading or co-leading the projects that are relevant to their communities.
- In addition to local training programs, Fogarty should support innovative approaches to staff and researcher training programs, such as e-learning modalities and remote mentorship.
- **Make training opportunities and conference attendance more accessible for researchers in LMICs:** Often technical training opportunities and conferences are hosted in high-income countries (HICs), which limits the ability for researchers from LMICs to attend. This limits opportunities for all researchers to learn, network, and share information. NIH should strengthen the capacity of LMIC institutions to host training opportunities and conferences locally that center health-related issues within the region.
- **Make it easier for scientists around the world to apply for NIH grants:** The US Agency for International Development (USAID), as part of its new administrator-led mandate for *inclusive development*, has committed to directing more of its funding to local partners in LMICs. To facilitate this process, USAID launched www.workwithusaid.org, a free, user-friendly website to train potential partners on how to work with USAID. We encourage Fogarty to create a similar portal or resource to better facilitate grant applications from researchers and institutions around the world. Fogarty could also provide trainings for research-support staff, such as administrative support teams, and human-subjects research standards, such as institutional review boards (IRBs).
- **Acknowledge diversity across and within countries:** NIH partners with institutions around the world and should recognize that equity challenges are dynamic and vary by geography depending on different power structures, local histories, and cultural contexts. NIH ICs should recognize that initiatives may need to be tailored to address context-specific global health equity challenges.
- **Center the voices of people in affected communities:** In the United States, patient advocacy movements have pushed the biomedical R&D ecosystem toward patient-focused medical product development—a paradigm that puts patients at the center of every phase of biomedical R&D. We encourage NIH to align with this movement and advance it in global health by prioritizing consultation, engagement, and the centering of affected individuals and

communities in global health-related research.

We recommend that NIH grants require and provide funding for collaboration and bidirectional feedback between researchers and local partners (such as through community advisory boards, which should reflect the demographics of the affected communities) to develop and guide research questions, conduct, and reporting. The outcomes of this research should ultimately address local priorities and public health challenges. One example of successful community engagement is the Microbicide Trials Network, which includes community participation in the development, conduct, and interpretation of research. AVAC and UNAIDS also provide [good participatory practice guidelines for HIV/AIDS research](#).

Part of this solution could be that most or nearly all grants provided by NIH for research in LMICs should include a requirement for joint funding by LMIC and HIC investigators.

- **Ensure research conducted in low-resource settings adds value to local communities:** “Parachute research”—when a researcher goes to a community to gather data and then leaves without any current or future benefit to the community—is a particular challenge in global health, where it is unfortunately still common for researchers from HICs to visit low-resource settings without reciprocating any long-term value to those communities. NIH could mitigate this trend by providing guidelines requiring demonstration of how the research will add value to local communities or requiring its grant recipients who are conducting research in low-resource communities in other countries to partner with, be advised by, or work under the supervision of local researchers, institutions, or community members.
- **Strive for more equitable scientific publication practices:** For academics, success is often determined by a positive feedback loop between publications produced and funding received. Many researchers based in LMICs, unfortunately, face an extra hurdle of overcoming explicit and implicit bias against them, their ideas, and their research contributions. NIH and Fogarty have taken steps to improve recognition of the work of scientists in LMICs, but inequities still exist—as evidenced, for instance, by researchers in HICs being disproportionately placed in the most respected authorship positions on publications. NIH should continue to tackle these inequities by working with scientific journals, incorporating grant provisions, and requiring open and clear communication between researchers describing the expectations and roles and responsibilities of all parties involved in research. NIH should also require

researchers to explicitly recognize the role of local stakeholders and non-scientists in their academic papers.

- **Prioritize underrepresented groups including women, pregnant and lactating individuals, and minorities in global health research:** The biomedical research sector has a history of excluding women, pregnant and lactating individuals, nonbinary individuals, and other underrepresented groups in research, both as researchers and as participants in clinical trials. The problem of inequitable gender representation in clinical trials has been recognized in legislation and in previous NIH research policies, which have helped drive some progress. Still, in 2019, only an estimated 29 percent of pharmacology studies included both male and female participants. The US Food and Drug Administration found that of 293,000 participants in clinical trials globally, more than three-quarters were white. The products produced through global health R&D often reflect these disparities, with many first-generation medical products for neglected diseases having been tested outside of the affected countries, not being suitable for the populations most at risk—such as pregnant and lactating individuals and children.

NIH must redouble its efforts to improve diversity across all clinical trials so that cohorts of trial participants better reflect the diversity of end users. This should include dedicated funding to fill knowledge gaps that exist as a result of ‘gender blindness’ in research; setting or elevating guidelines or policies to support the mainstreaming of sex and gender considerations in research, such as the [Sex and Gender Equity in Research guidelines](#); continuing and strengthening support for women and minority researchers, such as by including grant provisions that cover or require institutional maternity and paternity leave or child-care support; incorporating grant review mechanisms to account for career breaks taken by caregivers; and requiring the reporting of sex- and gender-disaggregated data, whenever possible.

- **Increase support for the Fogarty International Center’s budget:** Fogarty plays an outsized role within NIH for global health R&D leveraging less than 0.20 percent of the total base budget. With a substantial increase in funding to Fogarty, but modest relative to NIH, the center could have exponential impact in strengthening the global health R&D system. We urge NIH leadership as it develops its next congressional budget justification to recommend an increase in the base NIH budget that includes a significant increase to Fogarty’s baseline.
- **Continue to collaborate with external partners:** The GHTC Equity Working Group would welcome further collaboration with Fogarty and other ICs on

promoting promising practices, crafting evidence-informed policies, sharing ideas, and raising community awareness of how to improve equity in global health R&D.

Key Challenges

Infrastructure

- Lack of national or institutional support for maintaining the capacity of a research site after a research program concludes.
- Many researchers do not have administrative support for handling the finances of large grant programs.
- After a grant concludes, there often is not local funding available to sustain local research agendas.
- Many local sites do not have robust internet connectivity or computer processing power.
- Many institutions do not have electronic medical record systems or sustainable maintenance of those systems.
- Research programs often do not collect or share sex- and gender-disaggregated data.

Know-how

- Except for some well-funded existing partnerships with local institutions in LMICs, many sites have limited staff to support the work of their researchers.
- Local researchers may be unfamiliar with how to write proposals for NIH grant applications or other technical protocols, which could limit their ability to apply for funding.
- Local researchers may not have access to or consultation opportunities with statistics departments.
- Limited training or availability for IRBs or other human-subjects research standards can impede local applications for human-subjects research.
- Research capacity is often sustained through mentorship, which may not be as robust in many institutions in LMICs.

Improving equity in global health research is not only the right thing to do, but it also will lead to more impactful discoveries and health products in the future for all people. As the largest funder of research for global health, it is critical that Fogarty and other NIH

ICs use their influence to address the global health research inequities and disparities. We thank you for considering our recommendations toward this end.

Please do not hesitate to contact Jamie Bay Nishi at jnishi@ghtcoalition.org if you have any questions.

Sincerely,

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