

# Placing Equity at the Core of Global Health Research: Time for an Expanded Ethical Framework?

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## Opinion statement

It is generally accepted that the fundamental goal of global health research is to improve health and achieve equity in health for all people. Global health research has made valuable and important contributions toward achieving this, through clinical progress resulting from scientific discovery as well as enhancements in local research capacity and academic development. However, notable challenges remain. There are difficulties with the research itself, including obtaining authentic informed consent, effective safety monitoring, and overly cumbersome, often inapplicable regulations. Significant ethical tensions are also present, such as harmonizing research priorities with local health needs, addressing disparities in academic recognition between local and international researchers, and clarifying the ethical responsibilities of researchers after the completion of a study. We propose a revised ethical framework for global health research that calls for a renewed focus on equity. We put forward key elements of this framework and provide some examples of how these can be put into practice.

## Introduction

The issue of equity in global health was a disquieting shadow when two of us were involved in coaching a MicroResearch group in Uganda

about 8 months ago and spent some time in the clinical pediatric wards at two large, public hospitals.

The clinical environment was all too familiar and bore similar characteristics to many resource-poor environments where we had worked before. Dark and damaged concrete walls with barred windows, rooms filled with steel bed frames, many with no mattresses, where 2–3 children shared a bed and their caregivers (most often, mothers) lying on the dusty floor. There was no running water in the main rooms, a paucity of clean IV needles, and hardly any light. There were 2 nurses for every 25 patients. Children were dying from vaccine preventable diseases and rheumatic heart disease when inexpensive antibiotics and vaccines could have prevented death and disability. It was difficult to reconcile that these were not remote health centers but provincial pediatric referral centers.

Juxtaposed to this was our knowledge that within these walls, many prominent academic institutions from North America and Europe have run some of the most important, well-funded research trials in history; that many academics have established successful careers working on projects involving these patients; and that in these wards, countless medical trainees have done clinical and research electives.

Our point here is not to be unduly critical of these specific hospitals or overly cynical toward the academic global health community. Indeed, much more research is needed to address the multitude of questions related to healthcare in resource-poor areas of the world. The global health milieu is a complex dance involving political, institutional, economic, and health systems factors. However, as academics involved in global health research, it behooves us to attempt to address the following questions:

Is or should the fundamental goal of global health research be to improve health equity (i.e., lessen the disparity in health outcomes between rich and poor)? Do researchers and the institutions that support them have an ethical imperative to improve not only the health but also the delivery of and access to health care for the populations they study? Should this imperative exist beyond the lifespan of the study? Furthermore, do they have a responsibility to advocate directly for the populations they study and should this role be formalized in the research protocol and involve deliverables? Do international researchers have an inherent responsibility to build or ameliorate research capacity so that local experts can initiate and conduct future research in the region?

None of these questions are new, but their relevance is now higher than ever. Inequity in access to and

delivery of health care as well as in health outcomes worldwide are growing. Children in low-income countries are now nearly 18 times more likely to die before the age of 5 years versus in high-income countries, whereas in 1990, they were 14 times [1]. Global health has not only emerged as an academic discipline in its own right, but in the context of an increasingly connected and yet inequitable world, it is now a centerpiece for ensuring human survival.

The unfolding Ebola crisis in West Africa this year is a stark reminder of how disease is caused, affected by, and propagated by poverty and health inequity [2]. It compels those of us involved in global health research to move into a new era of accountability. Our purpose is to put forward and discuss some of the complexities of conducting global health research in the current ethical paradigm, examine some of the pitfalls of this approach, and consider a re-envisioning of the global health research framework that puts equity at the core.

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### Issues of inequity

We firmly believe that global health research is necessary, valuable, and beneficial. A widely accepted definition of global health argues that global health is a field for study, research, and practice that places its fundamental priority on improving health and achieving equity in health for all people [3–5]. If we accept that the achievement of health equity is the central goal of global health research, it is unarguable that it is necessary, given the current disparities in health status worldwide. The life expectancy at birth, for example, varies over 50 % depending on the country of birth. The average life expectancy is 80 years or more in Canada, whereas in Afghanistan and Sierra Leone, it is about 40 years [6]. Furthermore, the lifetime risk of a Canadian woman dying from pregnancy complications or childbirth is 1 in 11,000. In Niger, the risk is 1 in 7 [6]. Clearly, further global health research is needed to reduce disease burdens and increase access to health care in low- and middle-income countries using safe and effective strategies [7].

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### Benefits

Global health research has yielded valuable and beneficial outcomes, both in the discovery of medical interventions that have improved the clinical care of patients and in its contributions to the enhancement of local research infrastructure. Regarding the former, there are countless examples of global health research that have resulted in the advancement of knowledge related to

HIV/AIDS care, maternal and child health, tropical diseases, vaccinations, chronic diseases, and injury prevention, to name a few [8]. As to the latter, global health literature has more recently focused on a number of endeavors that aim to enhance local research capacity and infrastructure [9, 10]. Moreover, it is now commonplace for global health funding agencies to require research proposals to contain elements of sustainable capacity-building (<http://www.gatesfoundation.org/How-We-Work/General-Information/Grant-Opportunities>, <https://www.clintonfoundation.org/about>). The World Health Organization reports that there has been a nearly 200 % increase in research output in the last 5 years in resource-limited countries [11]. Furthermore, there has been a substantial increase in the number of researchers in developing countries and in the number of high-level research centers in the African continent as well [12, 13].

### Practical challenges

Notwithstanding the benefits, global health research is a complex endeavor. Researchers face a unique set of challenges. Most global health research is conducted in vulnerable populations where local clinical, academic, research, and public health capacity is limited. It has been noted elsewhere that, in contrast to clinical trials in wealthy nations, trials in developing countries frequently have severe endpoints (i.e., serious morbidity and mortality), they more often involve children, and they are more often sponsored by not-for-profit organizations as opposed to industry [10]. The physical, political, and social environments are also often rudimentary and/or unstable. Given these differences, there are challenges in achieving effective safety monitoring and follow-up, and in obtaining authentic informed consent [14–16].

In addition, the guidelines regulating these trials, most of which are geared toward research in wealthier nations, may be irrelevant, inapplicable, and/or ineffective. As a result, the regulations are often cumbersome, unnecessarily complicated, and/or obstructive to the research [10, 17, 18]. This can lead researchers to abandon important research projects, discourages local researchers from initiating and conducting studies and in the worst case, results in some researchers circumventing regulations altogether [10, 15]. Clearly, regulations are necessary and are needed to protect research subjects and enforce ethical standards. However, we and others are suggesting that a collaborative, developing-country specific approach to the application of these regulations would increase their effectiveness and efficiency [10, 19, 20].

### Ethical challenges

In addition to the challenges, inherent ethical tensions exist with research in resource-limited settings. Firstly, it is often difficult to achieve harmonization between the acute clinical priorities and the research agenda. This may result in research that is academically interesting, but unresponsive to local needs and thus, non-contributory to increasing health equity. Part of the problem is that the research agenda is often established by external sponsors, donors, or public-private partnerships, with little understanding of the local context and limited to no local representation. This has resulted in the concern of “scientific imperialism” and risks increasing the power inequities [21].

Another aspect to this problem is the unbalanced distribution of research grants, which favor research that focuses on understanding the biology of disease or finding effective treatments over research about the effective delivery of the treatments [22]. In many developing countries, the pressing need is for improvement in access to and delivery of existing therapies. In this vein, Leroy [23] demonstrated that 97 % of grants were targeted at the development of new technologies, which reduces child mortality by 22 %. Research on how to utilize and deliver existing technologies, however, reduces child mortality by up to 66 %. In its worst form, this problem results in the diversion of precious clinical resources (i.e., health care personnel, medical equipment, clinical space, medicines, etc.) away from the acute, clinical needs and toward the research, thus exacerbating health inequity.

Another ethical tension is the disparity in academic recognition (i.e., publications, career advancement, financial gain, etc.) between local and “international” researchers. It is difficult, if not impossible in many cases, for local researchers to initiate, conduct, and lead significant trials due to resource and capacity limitations. A growing amount of global health academic research occurs in the form of collaborations between local and international researchers. Although this has resulted in an increase in global health research overall, there is an ongoing concern that local researchers have not been adequately supported to gain representation in the first or last author category in publications. Moreover, despite the marked rise in research being run in low- and middle-income countries, particularly India, China, South Korea, Brazil, Iran, and South Africa, there is some question about the comparable quality of this research to those produced by high-income countries as well as the continued discrepancy in representation in high-impact publications. The Royal Society published a

report in 2011 in which they measured the number of times a research paper had been cited by other scientists in the years after publication as a proxy of quality [24]. Research emerging from US scientists remained in the lead with about one-third of all the citations, followed in second place by UK scientists. King [25] similarly showed that only 31 nations, out of a total of 191, contribute 98 % of the volume of citations to scientific research. Only three of these nations were developing countries—China, India, and Iran. This disparity is also highlighted by the fact that 90 % of important scientific research is published in 10 % of journals and while developing countries comprise 80 % of the world's population, only 2 % of indexed scientific publications come from these countries [26].

Finally, there is the question of whether and to what extent global health researchers have an ethical responsibility to help improve the overall health of the populations they research, both during and after the study. The principle behind this question relates, in part, to a paragraph of the revised Declaration of Helsinki (paragraph 20), which asserts that “Medical research with a vulnerable group is only justified if the research is responsive to the health needs or priorities of this group and the research cannot be carried out in a non-vulnerable group. In addition, this group should stand to benefit from the knowledge, practices, or interventions that result from the research.” [27] Macklin [15] has discussed the inherent subjectivity and consequent disputes that this provision contains. She notes that the criteria for determining “likelihood” is unclear, as is how much likelihood is necessary. Even beyond this provision, however, is the argument that populations should benefit not only from the results of the specific research project but also that there should be elements included in the research funding application and protocol that serve to improve the general health of the region in which the study is occurring (i.e., ameliorate public health infrastructure, advance local clinical capacity, improve medical education, etc.). While initiatives like this are admirable, in that they attempt to mitigate the exploitation of vulnerable populations and ultimately improve health outcomes in a broad and sustainable way, their realistic application remains unclear and controversial.

### The way forward

An ever-increasing sense of global connectedness underscores the need for global health as a foundation for security. Over the past several decades, massive interest and advances in global health research have produced

unprecedented benefits. But serious challenges and ethical tensions exist, arising primarily from the underlying power disparity between external sponsors and researchers, local researchers, and the vulnerable communities, where much of this work takes place [28, 29]. A fundamental tension has emerged between the imperative to reap the benefits while at the same time ensuring that increasing equity between all of these partners remains the core goal of this work.

The global health research community can exert a significant impact on mitigating and overcoming some of these issues. Global health researchers have unique opportunities to reach and engage vulnerable communities, help develop local capacity, and, ultimately, find sustainable solutions to pressing health challenges worldwide. A better approach to global health research requires collective vision and action, as well as a cohesive research governance structure with the ability to establish and enforce priorities that align with local needs. Leaders in global health can help refocus the academic community by promoting an expanded ethical framework for global health research that conceptualizes global health not just as a field of study, but as a vehicle for delivering equity. This expanded framework would mean that potential studies are more rigorously evaluated for parameters such as:

- (a) How the research aligns with local disease burden and health priorities for that region.
- (b) How the research improves local capacity to initiate and conduct future research endeavors in that area.
- (c) How academic recognition and reward will be equitably distributed between local and international contributors.
- (d) How the research will improve the health of individuals in that region beyond the lifespan of the study.
- (e) How the research will improve the delivery of and access to health care for the population they study during and following the study.

There are a growing number of global health research initiatives that demonstrate how giving priority to these types of questions might work in practice. MicroResearch initiatives aim to foster local research capacity through coaching and collaboration. Following a brief training period, local researchers carry out research projects that arise from questions they pose about sustainable solutions to their local problems [30]. The

projects are usually small in scope and relevant to local needs and challenges. Moreover, local researchers initiate, lead, and carry out the studies. For the project and protocol design phase, international global health researchers collaborate with the local researchers, but the project is envisioned and driven by the local team. The local researchers also lead and own the academic product of the research (<http://www.microresearch.ca>).

Other authors have described the potential usefulness of using adaptive trial design in developing countries [19]. Adaptive trial design is a new approach to clinical studies where the design allows modification to the trial and/or statistical procedures without compromising its validity and integrity, resulting in improved flexibility and efficiency, and minimizing patient exposure to research interventions.

Whyte [31] has recently demonstrated that for many study participants in low-income countries, clinical and

research functions are often indistinguishable and they would like to be informed about the results of the clinical investigations in which they are involved. This prompts us to consider whether research protocols should include a description of how the study results will be shared with the participants.

At an institutional level, some funding agencies and academic institutions are using a more diverse approach to evaluate global health research protocols, but this is not widespread. In few cases is there any formal mechanism in the academic environment for recognizing significant local capacity building efforts or support for local authorship in peer-reviewed publications. Where institutional ethics review considers the relative benefits and harms of a global health project, a deeper review would help ensure that benefits will be shared among international and local researchers/institutions, and in the ideal case, designed to improve local systems in a durable way.

## Conclusion

The tragedy of the Ebola crisis has renewed the global commitment to addressing issues of health equity. This is a time of opportunity in global health research. We need to be thoughtful about how we confront this new reality. Expansion of the ethical discourse will result in better research, healthier populations, and the ability to respond to future health crises more effectively.

## Compliance with Ethics Guidelines

### Conflict of Interest

Kristopher T. Kang, Niranjana Kissoon, and Ashley Roberts declare that they have no conflict of interest.

### Human and Animal Rights and Informed Consent

This article does not contain any studies with human or animal subjects performed by any of the authors.

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