

# **Advancing Global Bioethics**

Volume 15

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Kiarash Aramesh

# An Ethical Framework for Global Governance for Health Research

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*Dedicated to  
All the women and men who took part in  
Women's March on January 21, 2017,  
And chanted:  
"Love, not hate  
Makes us great!"*

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# Introduction

There is almost nobody on Earth who has not yet felt the winds of globalization blowing through the windows of technology and changing nearly every aspect of our public and private lives. In the realms of health care and health sciences, no single item remained unaffected. Science, no doubt, is a global enterprise, so is (in many aspects and dimensions) health care. A scientific development in one corner of our world affects people in all other areas. Problems also do not remain confined to the national borders. If you ignore an outbreak of an infectious disease in the farthest small village you have never heard from, you will likely find that disease in your hometown after a short time. Patients in developing countries and communities demand access to the expensive but lifesaving medications manufactured in the wealthiest countries. If you ignore this demand, you will see them dying from a curable disease or emigrating from their home countries.

Health care and health sciences are globalized entities. These globalized entities, in the absence of a global government, need—and have—global governance (GG), which has been named Global Health Governance (GHG).

Many scholarly works have already been published about GHG addressing many crucial aspects of health in a globalized world, such as the surveillance of infectious diseases, the control of pandemics, and fair access to medications. However, it seems that the global governance for health research enterprise has not been addressed enough, and there is a gap in this area. This book is an attempt to fill parts of this gap.

Chapter 1 provides a conceptual analysis of the key concepts involved in and related to Global Governance for Health Research (GGHR), including governance, GG, GHG, and other key concepts such as institution, organization, and state. These key-related concepts are involved in shaping the main conceptual framework that encompasses all the discussions and arguments. This chapter breaks down these ideas and discusses how they contribute to GGHR. The first chapter also depicts a brief history of the main ethical and theoretical development in the health research enterprise, especially after the 1940s, when the modern health research enterprise (adopting double-blind, randomized clinical trials as the gold standard) experienced exponential growth and created numerous ethical concerns that necessitate ethical frameworks to deal with.

Chapter 2 depicts a detailed picture of the various role-players involved in GGHR. The best way to understand GGHR and how it works is knowing and analyzing the various categories of its role-players, their compositions, functions, and dynamics. These role-players together shape a network that is in charge of GGHR. In other words, the second chapter explores the existing situation and portrays the map of GGHR in the contemporary world.

Chapter 3 discusses the main existing challenges of GGHR, as follows: exploitation and helicopter research, the problem of double standards, ethical imperialism and colonialism, bilateralism vs. multilateralism, biopolitics vs. bioethics, and problems associated with data sharing, big data, and international collaborations. By discussing these challenges, this chapter shows that power relation is a crucial element in all such challenges. Among the above challenges, the first four ones are mostly relevant to research collaborations (and power relations) between developed and developing countries. The fifth one, however, is more relevant to the collaborations (and power relations) among researchers from developed countries, although it can also be relevant to the partnerships between developed and developing countries and even the collaborations among developing countries. It goes without saying that all these challenges have essential and integrated ethical components; therefore, dealing with them needs an ethical framework. The third chapter also uses a model created by Thomas Weiss, titled the “frameworks of gaps,” for shedding more light on the characteristics of these challenges in the context of the current theories of GG. This model formulates the elements of the above challenges within a fivefold set of gaps that exist in the following arenas: (1) knowledge, (2) norms, (3) policies, (4) institutions, and (5) compliance.

Chapter 4 is specified to a number of case studies to portray the challenges of GHG and GGHR in the real-world through historical cases. The fourth chapter begins with a broader scope. In the first case, Zika pandemic, it shows how GHG uses previous experiences to deal with newly emerged pandemics. Research integrity in Iran discusses how local practices on research integrity are important at the global scale and should be addressed by GGHR. HIV/AIDS research in LMICs describes a paradigm case of exploitation in research that contributed to a significant shift in the history of clinical research. Sending biological specimens abroad discusses biopiracy as a topic within GGHR. Also, it shows how international collaborations may be seen from the weaker sides. Research on pre-implantation human embryo portrays how different religious and secular perspectives collectively take part in shaping the ethical grounds for GGHR. The final case study in this chapter, traditional medicines, science–pseudoscience debate, and biopiracy, addresses the globalized aspects of the science–pseudoscience debate and biopiracy by discussing traditional medicines as a paradigm example. By exploring such spectrum of real-world cases, the fourth chapter portrays the existing need of GHG and GGHR for a comprehensive ethical framework. It also shows how particular challenges or ethical principles are more relevant to each case.

Chapter 5 answers the central question of this book. The fifth chapter starts with providing a review of the existing approaches. Afterward, it presents the suggested ethical framework for GGHR. This ethical framework has three main elements:



first, a background of personal and subjective virtues that are the merging points of the traditional masculine and modern feminist accounts of virtue ethics; second, a core of principles mainly from the UNESCO Universal Declaration of Bioethics and Human Rights combined with the systematic framework that is named the NIH framework; and third, a place for situation ethics embodied in the crucial role of Research Ethics Committees and Institutional Review Boards.

Chapter 6 provides a conclusive picture of the suggested ethical framework for GGHR. The final chapter of this book examines the trends and possible developments in the future, along with the existing and potential threats and promises in the realm of GGHR. The sixth chapter also includes some suggestions for future research.

A number of abbreviations have been used in this book. A list of them is provided in Appendix 1. Besides, since the ethical framework that is developed and presented in this book is, in a large degree, based on the UNESCO Declaration of Bioethics and Human Rights, the full text of this important instrument is also included as the second appendix of this book.

This book is a step toward filling the theoretical gap in the realm of GGHR. It is not complete, but it needs to be followed by other scholarly works. The ethical framework provided in this book is not reductionist. It does not appeal to a single ethical theory or approach. Instead, it aspires to be comprehensive and inclusive. This can be considered an advantage and strength for this framework.

The fast-paced developments and trends in the health research enterprise keep producing new achievements, along with new challenges and issues. To address these challenges, updated and revised versions of ethical frameworks will always be needed. The best frameworks are the ones that are comprehensive, based on the common intellectual heritage of mankind, and culturally sensitive. Such frameworks may be accused of being influenced by ethical colonialism and imperialism. However, the fact is that such accusations are mostly rooted in various accounts of bio-politics that try to get rid of common-sense ethical standards and moral requirements. At the same time, however, scholarly criticism should always be appreciated because only by the help of the reviewers and critics, it may be possible to improve and update the ethical frameworks. The author of this book always welcomes and appreciates any feedback, criticism, and comment from the audience and regards them as valuable sources for scholarly growth and refining his thoughts and ideas.

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