

## INTRODUCTION: INTERNATIONAL RESEARCH ETHICS EDUCATION

JOSEPH MILLUM AND BARBARA SINA  
*National Institutes of Health*

**ABSTRACT:** NIH'S FOGARTY INTERNATIONAL Center has provided grants for the development of training programs in international research ethics for low- and middle-income (LMIC) professionals since 2000. Drawing on 12 years of research ethics training experience, a group of Fogarty grantees, trainees, and other ethics experts sought to map the current capacity and need for research ethics in LMICs, analyze the lessons learned about teaching bioethics, and chart a way forward for research ethics training in a rapidly changing health research landscape. This collection of papers is the result.

**KEY WORDS:** research ethics, education, Fogarty International Center

*Received: March 4, 2014; revised March 6, 2014*

**O**VER THE LAST COUPLE OF DECADES, THE amount of health research conducted in low- and middle-income countries (LMICs) has dramatically increased. In response to the corresponding need for research ethics expertise, the NIH's Fogarty International Center has provided grants for the development of training programs in international research ethics for LMIC professionals since 2000. Twenty programs have now graduated approximately 600 long-term trainees from 74 LMICs. The participants train others in research ethics, lead ethical review of research protocols, develop ethical guidance for research, and contribute to national and international debates on issues in research ethics.

Drawing on 12 years of research ethics training experience, a group of Fogarty grantees, trainees, and other ethics experts sought to map the current capacity and need for research ethics in LMICs, analyze the lessons learned about teaching bioethics, and chart a way forward for research ethics training in a rapidly changing health research landscape. This collection of papers—published in two special issues of *JERHRE*—is the result (Box 1).

### BOX 1. The Fogarty International Center Research Ethics Education Collection.

#### JERHRE 8.5

Joseph Millum, Christine Grady, Gerald Keusch, and Barbara Sina	Introduction: The Fogarty International Research Ethics Education and Curriculum Development Program in Historical Context
Sana Loue and Bebe Loff	Is There a Universal Understanding of Vulnerability? Experiences with Russian and Romanian Trainees in Research Ethics
Martin A. Strosberg, Eugenijus Gefenas, Sana Loue, and Sean Philpott	Building Research Ethics Capacity in Post-Communist Countries: Experience of Two Fogarty Training Programs
Henry Silverman, Hillary Edwards, Adil Shamoo, and Amal Matar	Enhancing Research Ethics Capacity in the Middle East: Experience and Challenges of a Fogarty-Sponsored Training Program
Sana Loue and Bebe Loff	Mentoring International Research Ethics Trainees: Identifying Best Practices
Henry Silverman, Martin Strosberg, Florencia Luna, Sean Philpott, and Cheryl A. Hemmerle	An Analysis of Online Courses in Research Ethics in the Fogarty-Sponsored Bioethics Training Programs
Jonathan Fix, Jere Odell, Barbara Sina, Eric M. Meslin, Ken Goodman, and Ross Upshur	A Bibliometric Analysis of an International Research Ethics Trainee Program

#### JERHRE 9.2

Martin A. Strosberg, Eugenijus Gefenas, and Andrei Famenka	Research Ethics Review: Identifying Public Policy and Program Gaps
Amal Matar, Sam Garner, Joseph Millum, Barbara Sina, and Henry Silverman	Curricular Aspects of the Fogarty Bioethics International Training Programs

(Continued)

**BOX 1. (Continued)**

Paul Ndebele, Douglas Wasenaar, Solomon Benatar, Theodore Fleischer, Mariana Kruger, Clement Adebamowo, Nancy Kass, Eric M. Meslin, and Adnan Hyder	Research Ethics Capacity Building in Sub-Saharan Africa: A Review of NIH Fogarty-Funded Programs 2000-2012
Joseph Ali, Nancy E. Kass, Nelson K. Sewankambo, Tara D. White, and Adnan A. Hyder	Evaluating International Research Ethics Capacity Development: An Empirical Approach
Bridget Pratt, Cassandra Van, Yali Cong, Harun Rashid, Nandini Kumar, Aasim Ahmad, Ross Upshur, and Bebe Loff	Fogarty Bioethics Training Programs in the Asia-Pacific: The Merging of Cultures
Bridget Pratt, Cassandra Van, Emily Trevorror, and Bebe Loff	Perspectives from South and East Asia on Clinical and Research Ethics: A Literature Review
Carla Saenz, Elizabeth Heitman, Florencia Luna, Sergio Litewka, Kenneth W. Goodman, and Ruth Macklin	Twelve Years of Fogarty-Funded Bioethics Training in Latin America and the Caribbean: Achievements and Challenges

In the present issue:

- Strosberg et al. describe a framework for identifying the policy and program gaps in research ethics systems, drawing on their work with trainees in the post-Soviet countries of Eastern Europe.
- Matar et al. survey the curricula content, trainee and faculty characteristics, and special challenges faced in designing culturally sensitive and contextually relevant research ethics education programs.
- Ndebele et al. describe the research ethics capacity built in Sub-Saharan Africa in the context of the challenges faced by the continent.
- Ali et al. present a tool developed to evaluate the impact of ethics training on African grantees that can readily be adapted to other contexts.
- Pratt et al. present a qualitative analysis of interviews describing the impact of research ethics education

and the challenges Asian trainees face incorporating research ethics into institutional practice.

- A second paper by Pratt et al. examines the research ethics literature from Bangladesh, China, India, and Pakistan, and explores how religious, social, and cultural norms affect the interpretation of research ethics and the application of international standards in these countries.
- Finally, Saenz et al. analyze the achievements and challenges faced by training programs in Latin America and the Caribbean.

These papers represent the emergence of a community of practice for international research ethics education. They present detailed local knowledge, lessons learned, novel tools, and needs analyses, which may inform others who work in research and research ethics in LMICs.

*Disclaimer:* The opinions expressed are the authors' own. They do not reflect any position or policy of the National Institutes of Health, US Public Health Service, or Department of Health and Human Services.

#### Author Note

Address correspondence to: Joseph Millum: joseph.millum@nih.gov, or Barbara Sina: sinab@mail.nih.gov.

#### Authors' Biographical Sketches

**Joseph Millum** serves as a liaison between the Clinical Center Department of Bioethics and the Division of International Science Policy, Planning, and Evaluation at the Fogarty International Center, where he provides ethics consultation and educational support. His current research focuses on the rights and responsibilities of parents, global justice and bioethics, priority setting for global health, and international research ethics.

**Barbara Sina** is the Program Officer for the International Research Ethics Education and Curriculum Development Program in the Division of International Training and Research, Fogarty International Center, National Institutes of Health.