Panel: Challenges and Opportunities in the Bioethics Research Workforce Infrastructure and for Ensuring Diversity

Latin America and the Caribbean: Achievements and Pending Challenges

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The landscape has changed significantly but some challenges persist

TWELVE YEARS OF FOGARTY-FUNDED BIOETHICS TRAINING IN LATIN AMERICA AND THE CARIBBEAN: ACHIEVEMENTS AND CHALLENGES

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RUTH MACKLIN Albert Einstein College of Medicine (USA) participants coexists with a negative public perception of research as inherently exploitative. The proliferation of ethics review committees and research ethics education activities has occurred amid limited and inconsistent governance of human subjects research. Despite the remarkable growth in research ethics education across the region, the participation of Latin America and the Caribbean in global discussions on research ethics is scarce overall. Four bioethics training programs funded by the Fogarty International Center (FIC) over the past 12 years have contributed significantly to the development of research ethics in the region. The complexity of the regional landscape warrants assessment of their achievements, along with reflection on the challenges

- Production is almost entirely descriptive.

Program on

- Main challenge: development of analytic skills to produce conceptual work.





In-depth training is needed

Opinion

VIEWPOINT

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International Research Ethics Education

Nearly 20 years ago, a series of trials evaluating short-course zidovudine for the prevention of mother-to-child transmission of human immunodeficiency virus (HIV) provoked global controversy when the sponsors were accused of ethical double standards—conducting research on vulnerable developing country populations that would not be permitted in high-income countries. Following this controversy, and responding to underrepresentation of developing countries in these debates, the Fogarty International Center at the National Institutes of Health (NIH) launched a grants program to support masters-level, socioculturally relevant training in research ethics in low- and middle-income

of awards (18/48, or 37.5%) and 40% of program funding focused on sub-Saharan Africa, which was thought to have the least research ethics capacity in 2000. Among the 60 grants funded through 2011, 26 awards (43%) were awarded directly to LMIC institutions.

Some additional sources of support for research ethics activities in LMICs are now available. These include the Society and Ethics program of the Wellcome Trust, the ethics and regulatory projects of the European and Developing Countries Clinical Trials Partnership, and the Human Heredity and Health in Africa Ethical, Legal, and Societal Issues Research Program of NIH (H3Africa ELSI). However, support for founda-

Highest level of training needed to produce knowledge on bioethics: conceptual research, guidance development, global dialogue.

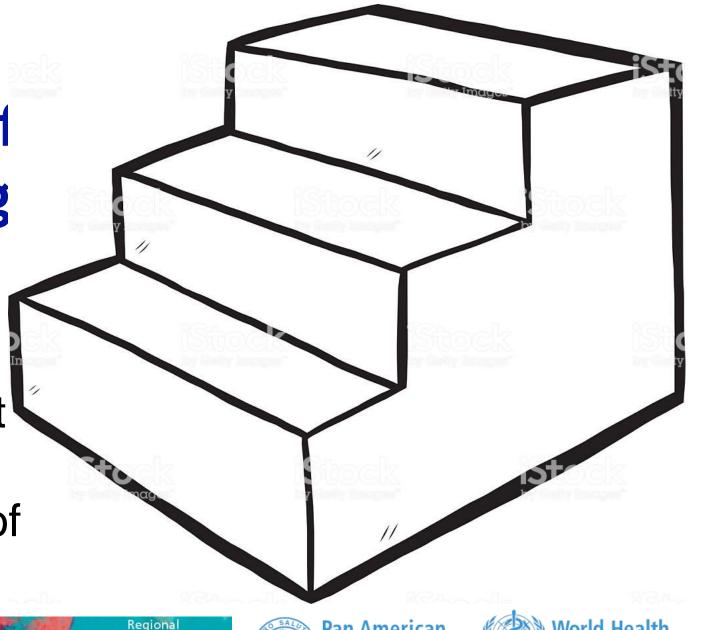






Three levels of training

We need to take the last step: our own cadre of experts.









What is stopping us?

- It's hard to train to develop practical skills.
 - Bioethics = activity, not just knowledge.
 - Very time consuming, handful of very busy experts
- Even harder to teach tricks to an old dog.
 - Mid-career and part-time approach.
 - Often no prior conceptual background.
- We speak a different "language":
 - Limited consumption of international bioethics literature → limited production of bioethics literature that meets international standards.





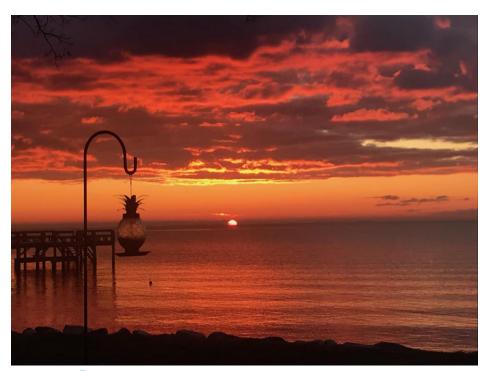


But we're making progress

Honest, critical assessments and collaborations among training programs:

- From step 2 to 3
- Focus on our needs
- Push from PAHO:
 Mandate from
 Countries in the
 Americas

New generations!



www.paho.org/bioethics





