

# Bioethics Exchange

A newsletter from the  
Johns Hopkins-Fogarty African Bioethics Training Program



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## From the Directors



institution, we transitioned to a consortium model in 2012. All four institutions have joined together as the **African Bioethics Consortium (ABC)**. The ABC retains the goal of research ethics capacity development but leverages the strengths of each partner to work towards foci of excellence within each institution. Read about our work, our trainees and our collective activities in this exciting and updated newsletter.

### A big hello from Baltimore!

In this issue, we revive the Bioethics Exchange, our newsletter designed to provide information about the Johns Hopkins-Fogarty African Bioethics Training Program. Over the past 15 years, our program has changed in many ways, though its core mission remains a commitment to strengthening research ethics capacity in sub-Saharan Africa. The first nine years of our program were devoted to providing year-long training in research ethics for individual African scientists and researchers. In 2009, we began pursuing a new model of training by part-

nering with one African institution each year to help deepen research ethics capacity at the institutional level. Through this model we received applications from dozens of institutions and were fortunate to establish partnerships with the University of Botswana Office of Research and Development in 2010, Makerere University College of Health Sciences in 2011 and University of Zambia School of Medicine in 2012.

We are delighted to announce that inspired by similar goals and growing numbers of members trained in research ethics at each

Peace to all!

Adnan Hyder and Nancy Kass  
Directors, FABTP

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## Helping IRBs identify needs

This spring, African Bioethics Consortium members from the Johns Hopkins Berman Institute of Bioethics, along with FABTP alumni Paul Ndebele '01 Paulina Tindana '02, will pilot an IRB Needs Assessment tool with Consortium members at the University of Botswana and the University of Zambia. The tool is intended to provide a method to systematically assess the needs of IRBs to support quality assurance, operational efficiency and benchmarking, particularly those LMICs.

This IRB needs assessment pilot testing was made possible by supplemental funding from the NIH Fogarty International Center.



Tweets from FABTP Director  
Adnan Hyder @ahyder1

- Dr. Kutuyabami @makererechs announces #bioethics resource center in Kampala!
- IRB decentralizing at Uni of Botswana says Dr. Kasule @bermaninstitute
- Dr. Gershom @UNZA\_ZM says IRB chairs in Zambia need to meet & discuss #ethics issues

## What is the Fogarty African Bioethics Consortium?

In 2012, FABTP established the African Bioethics Consortium, a network devoted to enhancing bioethics capacities, resources, structures and strategies within African institutions. Consortium member-institutions currently include:

**Makerere University,**  
College of Health Sciences  
(Uganda)

**University of Botswana,**  
Office of Research and Development

**University of Zambia,**  
School of Medicine

**Johns Hopkins University,**  
Berman Institute of Bioethics and  
Bloomberg School of Public Health

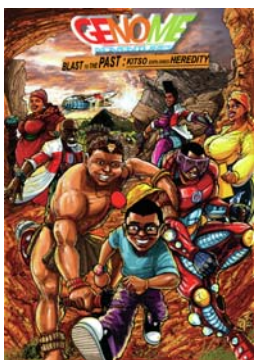


### Consortium activities include:

- ◆ **Strategic planning** to support the creation of academic Centers for Bioethics at member institutions.
- ◆ **Long- and short-term graduate-level training** in bioethics at Johns Hopkins for scholars, investigators, ethics committee members, or staff of member institutions.
- ◆ **Professional training workshops** in research ethics, held at consortium institutions, and co-taught by consortium faculty and trainees.
- ◆ **Short exchange of key personnel** across consortium institutions to support collaborative work on shared tasks.
- ◆ **Guidance and professional development** of all trainees who participate in the training programs.
- ◆ **Networking**, including consortium meetings, site visits, and scholarly publication and presentation

## Genomics Research Meeting at the University of Botswana

On Oct 14, 2015, UB hosted a *Human Genomics Research Plenary Meeting*, focusing on ethical and regulatory issues surrounding bio-banking and genomics research in Africa, attended by 70+ individuals. Our annual ABC meeting was



held the next two days, during which each institution provided updates on work plans and activities, trainees' practicum projects, and future goals. We also spent time discussing the future of the consortium. On Oct 17, UB hosted a consortium benchmarking activity around IRB best practices and resource sharing, with a focus on improving efficiency and quality of the IRBs.

## FABTP Alumni Updates

As in past years, many alumni pursue Master's or doctoral degrees after their FABTP training. In the last year, one PhD was successfully defended (**Musonda Simwinga '07**) and one alumna (**Dimpho Ralefala '10**) finished her coursework and is submitting her final report to complete her Master's degree in the SARETI program. Other alumni achievements during the past year include:

**Paul Ndebele ('01)** currently serves as an adjunct professor at Africa University, convening the Health Care and Research module and the Health Legislation model.

**Paulina Tindana ('02)** was appointed at chair of the H3 Africa Community Engagement Working Group and began serving as the chair of the Tamale Teaching Hospital IRB in Ghana in July 2015.

**Francis Masiye ('06)** is currently carrying out a funded empirical research project entitled "Ethical Challenges in Obtaining Informed Consent in a Genomic Study on Rheumatic Heart Disease (RHDGEN).

**Freddy Kitutu ('11)** secured a 2016 Brocher Foundation Residency for Visiting Researchers.

**Linda Kampata ('12)** received a PRIM&R Global Research Scholarship to attend the 2014 AER Conference in Baltimore, MD.

**Gershom Chongwe ('14)** is collaborating with colleagues on a manuscript entitled "Genomic Research in Zambia: Confronting the Ethics, Policy and Legal Frontiers in the 21<sup>st</sup> Century" and currently teaches a week-long bioethics course for MPH students at UNZA.

## Consortium Profile: Mary Kasule

Dr. Mary Kasule is currently the Assistant Director of Research Ethics at University of Botswana (UB) and since 2013 has served as UB leadership with-



in the Fogarty African Bioethics Consortium. Originally from Uganda, she completed her

PhD in Public Health in 2014 with a focus on research ethics and informed consent protocols from the University of Western Cape (South Africa).

Dr. Kasule has worked in Botswana to improve national capacity for ethical research through research and teaching. She has founded and served on IRBs in Botswana, supported Community Advisory Boards, and conducted training workshops and programs. While completing her PhD, Dr. Kasule was a Principal Research Officer at the Botswana Ministry of Health's Council on Health Research for Development (COHRED).

Dr. Kasule's ongoing research is firmly grounded in the goal of building capacity for upholding ethical research standards in African institutions. Recently, Dr. Kasule published "Silent voices: Current and future roles of African research ethics committee administrators," with Fogarty International Center grant awardee, Douglas Wassenaar of the South African Research Ethics Training Initiative. The article describes the findings of the first empirical study conducted specifically on the roles, responsibilities, and potential of administrators for African research ethics committees.

## Recent Publications

### Exploring Institutional Research Ethics Systems: A Case Study from Uganda

A. Hyder, J. Ali, K. Hallez, T. White, N.K. Sewankambo, N.E. Kass. *AJOB Empirical Bioethics* 2015;6(3):1-14.

### Ethical Guidelines for Military-Based Research: An unmet need in Africa?

J. Nwobegahay, J. Ali, D. Ter Goon, A. Hyder. *South African Journal of Bioethics & Law* 2015; 8(2): 11-16.

### Silent Voices: Current and Future Roles of African Research Ethics Committee Administrators

M. Kasule, D. R. Wassenaar, C. Ijsselmuiden, B. Mokgatla. *IRB Ethics and Human Research* 2016; 38(1): 13-19.

## 2016 FABTP trainees



Joseph Zulu, PhD  
University of Zambia



Dolly Ntseane, PhD  
University of Botswana



Imelda Namagembe, MPH,  
MMed  
Makerere University

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## Announcements

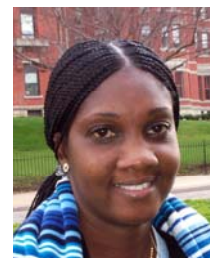
### Julius Nwobegahay '07

Julius Nwobegahay '07 was promoted to Lt. Colonel and appointed as Head of the Military Health Research Center (CRESAR), Yaounde, Cameroon.



### Pauline Osamor '07

Pauline Osamor was awarded a post-doctoral fellowship at the Clinical Center, Department of Bioethics, National Institute of Health, Bethesda, Maryland.



### Caroline Kithinji '06

Caroline Kithinji was accepted into the 2017 cohort of the Masters in Bioethics in the Centre of Biomedical Ethics and Culture in the Sindh Institute of Urology and Transplantation, in Karachi, Pakistan.



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## Our partners

