

SPECIAL POINTS OF INTEREST:

- Update from
Pauline Osamor
- 2008 Trainee
Joins Institutional Review
Committee
- A Note to
FABTP Alumni

INSIDE THIS ISSUE:

- Report from the Field |
- From the Director |
- Report from the Field (Cont'd) 2
- From the Director (Cont'd) 2
- 2008 Trainee Joins IRB 3
- A Note to FABTP Alumni 3
- Publications, Events and Announcements 4

Report from the Field: Research Participation in Nigeria



Pauline Osamor

Why do people choose to participate in research studies? How do they make the decision to do so? When they sign informed consent forms, are they acting autonomously? Are women as autonomous as men when they make the decision to participate? These were the types of questions I often asked myself when I worked

as a study coordinator overseeing biomedical studies in the Institute of Child Health of the College of Medicine of the University of Ibadan. The Johns Hopkins-Fogarty African Bioethics Training Program gave me the opportunity to answer some of these questions. I designed my practicum to study the factors that motivate people to participate in research in a traditional Nigerian community, to assess the degree to which others influence the decision-making process, to examine issues of autonomy in decision making, and to identify existing male and female differences within each of these study areas.

My field site was Idikan, a poor, urban community in Ibadan, located in southwest Nigeria. Idikan is a traditional patriarchal African society, and as such offers an opportunity to study how people in this type of community make decisions, including the degree to which they involve others in their decisions about participating in research and whether this is impacted by the participant's gender.

My study results revealed that the primary reasons for participating in a research study were to learn more about an illness and to receive medical care. The findings also showed that the majority of participants discussed the enrollment
Continued on page 2

From the Director



Nancy Kass

Happy New Year to the many friends and alumni of the

FABTP! Our most important news to report in this newsletter is that our program was refunded by the Fogarty International Center. We are tremendously grateful to Fogarty for the continued confidence that they have placed in our program. It is a tribute to our extraordinary trainees, their accomplishments upon returning to Africa, and the impact they have made that

our program has received four years' additional funding to continue our work together. With this new award comes a request from our funder to concentrate our training with particular centers within Africa or with particular countries. We have accepted trainees for 2009 to Johns Hopkins, but we also will plan to spend time in the
Continued on page 2

Report from the Field: Research Participation in Nigeria (Cont'd)

ment decision with someone else, and 39% obtained permission from someone else (usually a spouse or family member) before participating in the study. Women were more than twice as likely as men to obtain permission from someone else before participating in a study, and nearly one-half of women said they received permission from their husbands, as compared to only 14% of men who said they received permission from their wives. However, most of those who obtained permission (men and women) said they would have participated even if they had not received permission, suggesting that this was not a limiting factor.

This field study presented an

opportunity for me to examine not only why people participate in a variety of different types of biomedical studies, but also how they made their decisions about participation. The resulting manuscript will soon be submitted for publication. The study also helped to demonstrate that further research is needed in a variety of contexts in order to expand our understanding of why people decide to participate in research studies and the process they go through in order to make that decision.

On a personal note, I am currently finalizing my PhD program at the University of Ibadan, Nigeria where I am specializing in Medical Sociology. On my return from Johns Hopkins, I

worked on implementing a grant on a Framework for Global Health targeted at training and research in non-communicable diseases. I also lectured briefly at the West African Bioethics Centre, where graduate-level students pursue a Masters course in Bioethics. I am currently a Lecturer at the department of Sociological Applications, Faculty of Social & Management Sciences, Bowen University, Iwo, Osun State, Nigeria.

Pauline Osamor

2007 JH-FABTP Trainee

From the Director (Cont'd)

next six months identifying the best approaches to accomplish this new strategy for partnering for the new cycle. We will be drawing on the guidance of our African faculty, of African colleagues associated with other Fogarty bioethics programs, and of other African leaders of bioethics and research as we focus our program goals for the coming four years.

I am also happy to report a "mini-reunion" I had with Martin and Solomon during the 2008 PRIMR meetings in Florida, USA. The PRIMR meetings are one of the preeminent meetings on the topic of research ethics in the world. While PRIMR used to

focus only on the ethics of research in the U.S., they have specifically expanded their attention to global research ethics and include many sessions on international research on their program. They grant a small number of scholarships to first-time attendees from resource-poor countries, and many of our FABTP trainees have secured these scholarships over the years. It was great to see Martin and Solomon again, to compare notes about our work, and to have them meet more people with shared interests.

We also send best wishes to Paulina who had a baby, to Paul who is starting a new bioethics

center in Botswana, to Pauline who starts a new faculty position, to Martin who joins a new IRB, and to Belien who starts a new position with USAID, getting her back into international work! Best wishes to all for a healthy and stimulating 2009. May be it be a year of peace throughout the world.

Nancy Kass

FABTP Director

2008 Trainee Joins Institutional Review Committee

Martin Anu Nkematabong, a 2008 FABTP trainee, has been elected as a non-scientific member of the Institutional Review Committee (IRC) of the University of Yaounde I Biotechnology Centre in Cameroon. Martin is a senior health journalist working for the national bilingual daily, *Cameroon Tribune*, and was also the first journalist to participate in the FABTP. He successfully completed the first part of his fellowship program in July 2008, and returned to Cameroon to work on his practicum project titled "Media Perception and Understanding of Biomedical Research and Research Ethics in Cameroon." When asked about becoming a member of the IRC, Martin responded with enthusiasm.

"I feel exceptionally honoured to be elected into the ethics committee of

our famous university," he said. "It is a great mark of confidence bestowed on me by the public health family in Cameroon. You may like to know how I felt after reviewing my first protocol as a committee member. It occurred to me that I now have something precious to offer to Cameroonians. This feeling was stirred by the numerous handshakes and hugs I received from fellow committee members for my active participation, but also by the respect they professed for the Berman Institute of Johns Hopkins University. My experiences at Johns Hopkins have informed my efforts to protect fellow citizens who volunteer for biomedical research studies. I hope to relentlessly see for the blind and speak for the voiceless in the world of research."

Martin is also a member of the Camer-

oon Bioethics Initiative (CAMBIN), as well as a member of the Association of Health Care Journalists (AHCJ).

Martin Nkematabong

2008 JH-FABTP Trainee



A Note to FABTP Alumni

Greetings to you all. I hope this new year brings joy and peace. I wanted to write a quick note to offer encouragement and assistance in facilitating your partnership efforts at home. You are now 26 strong, and growing. We know that many of you are working on similar projects, and managing to overcome similar obstacles in your bioethics work. Some of you have been working in the field of bioethics for many years now and you have developed your own professional networks that you consult in your work. Others are new to this field and are seeking the benefit of shared experiences and opportunities for collaborative work that will further develop acumen in bioethics and research ethics. It is our hope that you will continue to see each other as partners in your professional development. I offer myself as a resource in facilitating your interaction

and bringing your ideas to each other. A growing number of you now live in the same cities, countries or regions. I know that at times you may seek a particular resource, or need assistance with project work. It is always helpful to be reminded that you are part of a network of resourceful people with various types of experience. I was recently reminded of this when I found myself chatting with a 2009 trainee who happened to have enough expertise in media technology to help me overcome a hurdle in a project that involves research ethics videos.

You are dentists, doctors, journalists, philosophers, nurses, researchers, administrators, professors, consultants, and committee members, and yet you share a common interest and similar vocabulary. In such a network, it is a safe bet that one person's obstacle is

another's expertise. You truly are uniquely situated, and we hope that you take full advantage of this.

If you are developing a research proposal and need feedback, if you have a paper in the pipeline that could benefit from the added insight of a co-author, if you have reached what seems to be an impasse in a project, or if you are hoping to organize a workshop but the task just seems to daunting, please write to me and I will help facilitate your interaction and point you in the direction of any resources at our disposal. For those seeking "ethics work," please also write and I will do my best to align you with incoming opportunities. It is always great to hear from you, and we hope that you will bring each other great success in 2009!

Joe Ali

FABTP Coordinator

A NEWSLETTER FROM THE
JOHNS HOPKINS-FOGARTY
AFRICAN BIOETHICS
TRAINING PROGRAM

BIOETHICS Exchange

VOLUME 3, ISSUE 3

DECEMBER 2008

Executive Committee

Nancy E. Kass, ScD
Adnan A. Hyder, MD, MPH, PhD

Advisory Committee

Chris Beyrer, MD, MPH
Wen Kilama, PhD
Suzanne Maman, MHS, PhD
Maria Merritt, PhD
Paul Ndebele, PhD candidate, MSc
Paulina Tindana, MHSc

Affiliated Faculty

Hilary Bok, PhD
Jack Bryant, MD, MPH
Ezekiel Emanuel, MD, PhD
Ruth Faden, PhD, MPH
Reidar Lie, MD, PhD
Joseph Mfutso-Bengo, PhD, MA
Andrea Ruff, MD
Jeremy Sugarman, MD, MPH, MA
Godfrey Tangwa, PhD, MA
Holly Taylor, PhD, MPH

Recent Publications

- Ajuwon AJ**, Adegbite O. "Ethical and methodological challenges involved in research on sexual violence in Nigeria" *Research Ethics Review* (2008) Vol 4, No 1, 3-9.
- Faith E. Fletcher, **Paul Ndebele**, Maureen C. Kelley, "Infant feeding and HIV in Sub-Saharan Africa: What lies beneath the dilemma?" *Theor Med Bioeth* (2008) 29:307-330.
- Christine Grady, Jennifer Wagman, **Robert Ssekubugu**, et al, "Research Benefits for Hypothetical HIV Vaccine Trials: The Views of Ugandans in the Rakai District." *IRB: Ethics & Human Research* 30, no.2 (2008): 1-7.
- Masiye, F., Ssekubugu, R.** "Routine third party disclosure of HIV results to identifiable sexual partners in Sub-Saharan Africa," *Theor Med Bioeth*, Published Early Online, Dec 2, 2008.
- Paul Ndebele**, Joseph Mfutso-Bengo, **Francis Masiye**, "HIV/AIDS reduces the relevance of the principle of individual medical confidentiality among the Bantu people of Southern Africa" *Theor Med Bioeth*, Published Online, Dec 2, 2008.
- Rennie S, Norris Turner A, **Mupenda B**, et al. "Conducting Unlinked Anonymous HIV Surveillance in Developing Countries: Ethical, Epidemiological, and Public Health Concerns," *PLoS Medicine* 2009 6(1): e1000004. Doi 10.1371/journal.pmed.1000004.

Upcoming Events

South African AIDS Conference, April 1-4, 2009, Durban, South Africa

Announcements

Baby News!

We are thrilled to announce the birth of Raphael Alemwine Amenga-Etego, the son of Paulina Tindana (FABTP 2002), on September 29, 2008. We wish the very best to the new family.

New Appointments

- Martin Nkematabong (2008 JH-FABTP Trainee) was recently elected to the Institutional Review Committee (IRC) of the University of Yaounde.
- Pauline Osamor (2007 JH-FABTP Trainee) received a faculty position for Bowen University, located in Iwo, Nigeria, in the department of Sociological Applications.
- Belien Solomon (former FABTP Coordinator) joined USAID's Foreign Service Program in November.
- John Appiah-Poku was awarded the Deanship of the Faculty of Allied Health Sciences at Komfo Anokye Teaching Hospital in Kumasi, Ghana.

© 2008 Johns Hopkins University



Your comments about the current issue, and ideas for the next issue are what will keep the Bioethics Exchange an interesting and lively newsletter!!
Please send contributions and suggestions to nkass@jhsph.edu

JOHNS HOPKINS | BERMAN INSTITUTE
OF BIOETHICS



624 N. Broadway
Hampton House 344
Baltimore, MD 21205

Phone: 410-955-0310
Fax: 410-614-9567