



# ARESA

ADVANCING RESEARCH ETHICS  
TRAINING IN SOUTHERN AFRICA

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Dear REC Members,

It is amazing how quickly time flies. Roughly five years ago, the ARESA program was first conceived, and since then much has been achieved: modules offered, trainees trained, conferences held, and papers published. It has been particularly rewarding to see our ARESA alumni take positions of responsibility and influence in regard to bioethics and research ethics throughout the southern African region. Given that our project is funded for five years, this is also a time for reflection and thinking about the future: should we seek renewed funding for our initiative, and if so, what form should "ARESA 2.0" take to help meet the research ethics challenges in southern Africa in the coming years?

In the meantime, of course, we are still actively preparing for Module 3 of the ARESA program with our 2015 cohort, including our short-course participants, and we are gearing up for our annual ARESA seminar on 17-18 September in Cape Town. As we have done in the last years, Module 3 will be discussing with our trainees the ethics of health research with vulnerable populations – with special focus on African contexts. The ARESA seminar, which regularly attracts more than 120 delegates each year, will be tackling the subjects of, community engagement, governance in biobanking, ebola research and updates of health research ethics guidelines. The seminar is also a great opportunity to network with others in southern Africa working in research involving human participants, ethics education in medicine, or who are on research ethics committees. For more details on all ARESA activities, please visit our website here:

[http://sun025.sun.ac.za/portal/page/portal/Health\\_Sciences/English/Centres%20and%20Institutions/Bioethics1/ARESA](http://sun025.sun.ac.za/portal/page/portal/Health_Sciences/English/Centres%20and%20Institutions/Bioethics1/ARESA)

Best wishes, Stuart Rennie and Keymanthri Moodley

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## REPORT: WHO DESIGNATION OF THE CENTRE FOR MEDICAL ETHICS AND LAW



Collaborating Centres (CCs) in Bioethics represent an extension of the capacity of the World Health Organisation to implement its ethics mandate. In April 2015, the Centre for Medical Ethics and Law officially joined the global network of 6 existing centres at the universities of Toronto, Zurich, Miami, Singapore, Monash and Columbia University in New York. It is the first CC on the African continent. The designation is based on a long-term working relationship with the WHO on various projects including immunisation during humanitarian crises and Ebola vaccine trials. Future working relationships have been established in HIV research and ethics, governance in biobanking, neuroethics and health research ethics. A common ethics project in which all centres are currently involved relates to public health surveillance. The global network is poised to conduct collaborative research on various areas of mutual interest in bioethics. We are grateful for the opportunity to be part of this network and for the confidence expressed by the WHO in our Centre.

### NEW VISITING ARESA FACULTY

We were pleased to welcome and host **Dr Adam Gilbertson** for Module 2 from UNC Chapel Hill. During Module 2, Adam taught Social Science research ethics, Social Science methods and ethics: Ethnography, Social Science methods and ethics: Focus groups and Social Science methods



and ethics: qualitative interviews. Adam has a DPhil in Anthropology and an MSc in Medical Anthropology from the University of Oxford. He is a Postdoctoral Research Fellow in the Institute for

Global Health and Infectious Diseases and the Center for Bioethics, Department of Social Medicine at the University of North Carolina at Chapel Hill, USA. In his doctoral research, Adam focused on experiences of household food insecurity and intimate partner violence within the largest informal settlement in Mombasa, Kenya. Presently, Adam is working with Dr. Joe Tucker and Prof. Stuart Rennie on the *searchHIV* project. Funded by a US National Institutes of Health (NIH) R01 grant, this project seeks to elucidate the intended and unintended social and ethical implications of curing HIV. This project has field sites in Chapel Hill, USA; Cape Town, South Africa; and Guangzhou, China.

### ARESA ALUMNI AT PUBLIC RESPONSIBILITY IN MEDICINE AND RESEARCH (PRIM&R) 2014

#### Dr Alwyn Mwinga



I was privileged to attend the 2014 Public Responsibility in Medicine and Research conference with partial support from ARESA. The conference was held in Baltimore, Maryland from 5 – 7 December

2014. One of the pre-conference meetings was a symposium on 'Critical Ethical Issues for Health Research in Africa' held at the John Hopkins Bloomberg School of Public Health. In attendance were participants from across the globe who had benefitted from the Fogarty

training in Bioethics. The preconference program included several training opportunities in various aspects of research ethics. The PRIM&R conference had 2500 participants representing all 50 US states, including Puerto Rico, as well as participants from 30 other countries. This year's conference marked the 40<sup>th</sup> Anniversary of the PRIM&R conference. The conference provided many opportunities for networking with the conference participants, though the availability of networking tables during the lunch break, during the tea break and the poster viewing sessions. One of the very interesting sessions was a 'Living Room conversation' with 5 of Henrietta Lacs' descendants, including her grand-daughter, discussing the impact of the issues surrounding the use of HeLa cells. Though the initial response of the family was one of lack of trust, including them in the committee overseeing data requests has helped them to feel that had some control over Henrietta Lac's legacy.

The opening and closing ceremonies were unique in that, in addition to the welcome speeches and key note presentations, entertainment was provided in the form of singing groups. What was interesting about these groups is that they consisted of staff from PRIM&R, and more interesting was that they adapted the words of popular songs to an ethics theme. In the closing ceremony the song that was sung was to the tune of "Pretty Woman, walk on by", however the words were changed to "Human Subject walk on by".

## **ARESA SHORT COURSES**

### **ARESA SHORT COURSE III: Research and vulnerability (7 to 18 September 2015)**

Module 3 will focus on the concept of vulnerability that has become an important concept in regulations and ethical discussions in regard to the ethics of conducting research with human participants in developing countries.

The goals of this module are to better understand what is meant by 'vulnerability' and how the various kinds of vulnerability should be taken into account in evaluating the ethics of research studies. Attention will be devoted to vulnerability connected to special populations, such as research with children, adolescents and mental health research, genomic research as well as vulnerability related to research on specific health conditions such as genetic diseases and cancer. A number of sessions will combine theoretical presentations with more hands-on case study work. Since the concept of vulnerability is applicable at individual and community levels, attention will also be devoted to ethical issues regarding infectious disease control and associated principles of public health ethics.

The deadline for short course applications for this module is **21 August 2015**.

## **ANNUAL ARESA SEMINAR**

The Annual ARESA Seminar will take place at the Southern Sun Hotel in Newlands, Cape Town, 17-18 September 2015. This year the seminar will discuss four topics, namely: community engagement, governance in biobanking, ebola research and health research ethics guidelines update. The seminar will include national and international speakers, and the registration fee is R300 per person. Closing date for registration is 21 August, 2015.

Please email registration forms to: [kelseyf@sun.ac.za](mailto:kelseyf@sun.ac.za).

## TRAINEE NEWS



**Anna-Marie Wium** has been promoted to Associate Professor. She presented a paper on the “Ethical issues in Ototoxicity management” based on her research assignment at the ototoxicity symposium at Sefako Makgatho Health Sciences University in June 2015.



**Shenuka Singh** has been appointed Chair of the Council for Scientific and Industrial Research (CSIR) Research Ethics Committee for a 3 year period.

## ARESA ALUMNI NEWS



**Ashley Ross** has been promoted to Deputy Dean, Faculty of Health Sciences, Durban University of Technology. He has been appointed to the position for a 4 year term and is hoping to make a significant contribution to the progress of the Faculty, with specific reference, inter alia, to the research portfolio (he will also be chairing the Faculty Research and Higher Degrees Committee). He will also be assisting with the training in Ethics within the University and facilitated a 2-day workshop on Research Ethics in the Faculty of Management Sciences at DUT on 10-11 June.



**Alwyn Mwinga** has accepted a position as patient representative on the Board of Directors for the Drugs for Neglected Diseases initiative (DNDi) that is based in Geneva.



**Christine Wasunna** participated in the 7th European and Developing Countries Clinical Trials Partnership (EDCTP) Forum in Berlin, where she made a presentation entitled ‘Establishment of an integrated clinical trials register in Kenya: a hub for knowledge sharing and exchange across two institutions’.



**Lillian Otieno-Omutoko** was recently appointed as a member of The National Bioethics Committee that operates under the auspices of National Commission of Science, Technology and Innovation, Kenya. The mandate of the committee includes oversight of ERCs, ensuring high ethical standards and advising Government on scientific and technological requirements.



**Blanche Pretorius** has received an Honorary Associate Professorship from the Faculty of Health Sciences at the Nelson Mandela Metropolitan University where she is currently engaged in supervision of postgraduate students.



**Minrie Greeff** presented a talk entitled “Phronesis: beyond the research ethics committee. A critical ethical decision making skill for health researchers during community research”, at the South African Academy for Science and Arts Conference, September 2014, Pretoria.



**Joyce Tsoka-Gwegweni** is now chair of the University of KwaZulu-Natal Research Ethics Committee.

