ARESA

ADVANCING RESEARCH ETHICS TRAINING IN SOUTHERN AFRICA

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Editors: Prof. Stuart Rennie, Bioethics Center, University of North Carolina, Chapel Hill (USA) and Prof. **Keymanthri Moodley**, Centre for Medical Ethics & Law, Dept of Medicine, Faculty of Medicine and Health Sciences, Stellenbosch University, South Africa

Dear REC Members,

The ARESA project has entered its second year of operations since its beginning in October 2011. This is a research ethics and bioethics training program that targets mid-level health professionals in Southern Africa, where selected trainees complete a Postgraduate Diploma in Health Research Ethics (PGDip) at the University of Stellenbosch. The project is a collaboration between the Center for Medical Ethics and Law at the University of Stellenbosch and the University of North Carolina at Chapel Hill (USA), and is funded by the Fogarty International Center at the National Institutes of Health.

Our second set of trainees, who were introduced to you in the previous edition of the newsletter, have completed Modules 1 & 2 of the training program. They have completed the introduction to research ethics and the interrelationships between ethical review of research and the diverse methods of health research with human participants.

From September 9-20th, Module 3 of the ARESA program will take place, and the module sessions will concentrate on the theme of vulnerable populations. We will also be holding our second annual ARESA Research Ethics Seminar on September 19-20th, 2013. The Seminar in August 2012 attracted more than 120 delegates from around Southern Africa to discuss shared ethical concerns regarding health research involving human subjects, and we expect an equally stimulating and well-attended event this year. For more details, please visit the ARESA website (www.sun.ac.za/aresa) where you will also find ARESA faculty information, how to apply for the PGDip in Health Research Ethics, and much more.

Best wishes,
Stuart Rennie and Keymanthri Moodley

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UNIVERSITEIT STELLENBOSCH UNIVERSITY

UNC CENTER FOR BIOETHICS

REPORT: FOUR DAYS IN BRAZZAVILLE

Malcolm de Roubaix

I recently spent four days in Brazzaville, capital city of the Republic of Congo, co-facilitating the training of WHO staff and research ethics committee (REC) members from the Francophone region of Central-West-Africa, and the Cameroon Bioethics Initiative (CAMBIN). Congo-Brazzaville should not be confused with the Democratic Republic of Congo (DRC) with its capital Kinshasa just across the massive Congo River. For those interested in Trivial Pursuit: these are the two closest capital cities in the world, and the Congo is second only to the Amazon in terms of volume of flow (Amazon: average 219000m^3/second, maximal >300000; Congo: average 41000, maximal> 75000). At maximal flow, the Congo could fill all 500 of our national dams from empty within a week; the Amazon could do it within 34 hours! Visitors to Rwanda are shown a real watershed point; rivers to the north of this point, it is said, flow towards the Nile, and those to the south, towards the Congo. The Congo meanders north and south of the equator, thus benefiting from both rainy seasons.

My visit was at the invitation of the World Health Organization and its Africa Regional Office based in an immense walled and secured compound on the outskirts of Brazzaville, and was mediated through the Centre for Medical Ethics and Law (CMEL) of the University of Stellenbosch Faculty of Medicine and Health Sciences (FM&HS). The official languages were French (most of the country representatives are French speakers, some don't speak English at all, and few are fluent in English) and English with excellent simultaneous interpretation. Participants came from the host country, DRC, Central African Republic, Gabon, Cameroon and Angola; in total somewhere between 40-60 (decreasing as time wore on…).

My task was teaching (in as much as ethics can be "taught"!) and facilitating group case discussions, the preferred method of teaching the underlying principles and international guidelines of health research ethics It was clear to me that the organizers and participants were quite envious of our well-developed fundamentals: acts, regulations and guidelines which comprehensively regulate health research ethics; a government and National Health Minister who by and large understand the importance and contemporary pitfalls of health research; a structure running from the National Health Research Ethics Council down to individual ethics committees which are independent and self-sufficient and are recognized as such; an academic environment that appreciates, promotes and fosters the central role of RECs in health research and the training of REC members; academics who sacrifice time and effort to serve on RECs, and last, but certainly not least, an academic milieu that supports the necessity and central role of ethics review and oversight in research endeavours.

I was tasked with the keynote address which covered an introduction to the philosophical background to research ethics, and an overview of underlying principles and international guidelines. Those familiar with these guidelines will appreciate this as a mammoth task, but fortunately there was ample opportunity to embroider upon this introduction in ensuing sessions. On each ensuing day I addressed one particular topic (confidentiality, standard of care, protection of vulnerability) by means of a short introduction, followed by a group/plenary case discussion. Other facilitators covered themes such as informed consent, role of the REC in oversight, benefit/risk ratio, and regulatory oversight in clinical trials.

Invariably one learns as one teaches. The first thing that struck me was how fortunate we are in

the RSA to have a well-functioning ethics review system in place. Without trying to present instant fixes, being sensitive to the hazards of generalisation, and appreciating the limitations (but also the advantages) of outsider illumination, certain fundamental local (in the area) challenges were apparent. The first is the tendency towards centralization, probably secondary to the French connection (this is how research ethics is managed in France) and local politics. RECs therefore often comprise of ministerial representation rather that qualified reviewers, are regarded as power-wielding authorities, and can hardly be independent – the first requirement for reliable review. The audience were clearly figures of authority (which, granted, does not necessarily translate to ineffective review). Even where university or other RECs exist, there is a tendency to create national RECs; as one delegate put it: "to act as referral board in case of complaints". There is a glaring deficit in capacity to review, and few training opportunities such as this. Most RECs review far too few protocols to gain sufficient experience. Some meet on a quarterly or even ad hoc basis, and then review three or four applications. Some committees review between 12-20 applications per annum (each of the two US FM&HS committees does more per month!). There is little continued oversight and follow-up by, at least, annual progress reports. It is not clear that RECs have definite SOPs. Finally, there appears not to be national research agendas driving research. I fear that the above may lead to rubberstamping endeavours initiated by others, probably the worst form of contemporary paternalism. And there certainly was no equal gender representation!

But let me not be pessimistic. I thoroughly enjoyed the rich interaction with delegates, both during/after presentations and privately. Their passionate participation underlined that they, at least, understood the rules of the game. At times it was quite difficult to manage case discussions with delegates enthusiastically demanding to be heard, quite opposite to what I'm familiar with! Perhaps this indicates a crying need for a regional forum where discussions can take place on a more regular basis. During the discussion recurring themes included the age-old clash of community v individual, defining personhood and human rights in an African context, contextualising bioethics/research ethics in an African framework, and the applicability of traditional Western philosophical notions in the African context.

Interspersed among the delegates, one encountered exceptional talent and expertise. Several now teach or have taught at American or European (particularly German) universities. One had just submitted his second PhD thesis (on African diaspora – in German!) and promptly mailed me a copy!

WHO clearly has an agenda and strategy to build capacity in the region, and local endeavours to create an association of RECs of the region were taken a step further during a separate post-conference meeting.

These countries suffer a heavy burden of disease including malaria and HIV/AIDS. The changing political landscape and the new Winds of Change rustling through Africa may translate into hope that important humanitarian concerns like ensuring that research complies to ethical principles and standards become national priorities; I may have experienced some of this hope in Brazzaville.

The first African philosopher I had ever met was Godfrey Tangwa, professor of philosophy at Cameroon's Yaoundé University. More than a decade ago he taught in an MPhil programme in applied ethics at the University of Stellenbosch and to this day I recall his explanation of how colonialism had decimated historical local power/authority structures, brought in new rulers from the fringes of society (who could be controlled), and left them in power when they withdrew. For the first time I appreciated how fundamentally damaging this aspect of colonialism had been; its legacy is apparent all over Africa. Godfrey was a member of the Cameroon delegation and heads CAMBIN. During my last presentation – the last of the conference – I reminded Godfrey of his visit to Stellenbosch, adding that I found the completion of the circle – here I am teaching them, but one of them had

also taught me – poetic. Godfrey's response summed the growing appreciation (as they got to know me and my sense of humour) that I had felt emanating from the delegates: "O thank you, Malcolm!" Hard work, but worthwhile if appreciated!

P.S. Yes, I did see the Congo and it IS massive!

Dr. Malcolm de Roubaix is an anesthesiologist who developed an interest in ethics. He has served on the University of Stellenbosch health (formerly human) research ethics committee for five years, and has chaired HREC2 for the past four years. He is a Fellow of the US Department of Philosophy Center for Applied Ethics.

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BIOBANK GOVERNANCE AND INFORMED CONSENT IN AFRICA

Ciara Staunton

The decoding of the human genome has led to an emergence of genetic research which has necessitated the establishment of biobanks worldwide. Africa is no exception with a national biobank set up in the Gambia and other formal and informal biobanks emerging across the continent. The Human Heredity and Health in Africa (H3Africa) project was launched with the aim of identifying the genetic and environmental factors that contribute to common diseases in Africa. It is expected that this will ultimately improve the health of Africans, but key to its success is the establishment of biobanks across Africa.

Biobanks, however, force us to reassess our understanding of long held ethical principles such as informed consent. The principle of informed consent, enshrined in the Declaration of Helsinki, requires research participants to be informed of all risks associated with the research and that these risks are voluntarily accepted. The difficulty with biobanks is that the purpose of the research or future secondary uses of the sample may not be known at the time that the biological sample is obtained and stored. If the principle of informed consent is to be adhered to, the sample can only be used for research to which the donor of the biological sample consented. Should the sample be used for other research, each donor must be re-contacted and their re-consent obtained. This would not only impact upon the usefulness of biobanks, but it would also severely hinder genetic research. To respond to this issue, two alternative consenting models have been put forward: broad consent and tiered consent.

Under the broad consent model, donors can give consent to the use of their biological sample for future unspecified research. This negates the need to re-contact the donor and simplifies the consent process for the researcher. The problem is that broad consent cannot be considered to be informed consent. If the donor is not informed of the research for which their sample will be used, they cannot be aware of the risks associated with the research. The one exception would be if the risks across a number of studies are similar, but the broad consent model does not propose to limit it to these situations.

An alternative is tiered consent. Under this model, the donor is presented with a range of consent options from which they choose one: they may opt for broad consent, they may opt to be recontacted before their sample is used for secondary research not contained in the original consent document, or they may opt that REC approval is sought prior to any secondary use of their sample. While this consenting model does not eradicate the difficulties with the broad consent model or the difficulties with re-contacting all donors, this model does strike a balance between protecting the rights of the donor with the interests of progressing science.

Despite the clear need to reconsider informed consent in the context of biobaking, there has

been a lack of progress on this issue in Africa. To date, it appears that there have only been six studies examining the attitudes of research participants towards biobanking in Africa. While these have only been small studies, they do suggest that research participants are willing to look beyond the traditional informed consent model. However a recent study by Moodley et al signal that donors do not want RECs to consent on their behalf, thus putting some doubt on the suitability of the tiered consent model. A further problem is that legislation and research guidelines in Africa have not responding to the changing face of informed consent. A review of regulations relating to research in Africa illustrate that not only have most jurisdictions failed to enact regulations pertaining to biobanks and the use of stored biological samples, but where there has been legislative activity, there has been a failure to recognize that there are situations in which strict informed consent may be waived in favour of other models. For example, the South African National Health Act states that informed consent must be obtained prior to the storage of a biological for research but is silent as to whether re-consent is necessary for secondary uses. The Ethics in Health Research Guidelines do recommend each institution to draft guidelines concerning re-consent, but this raises the problem that different institutions may enact differing guidelines and ethical principles.

If it is possible for a difference in guidelines to exist between research institutions within South Africa, it is likely that biobanks across the African continent will have differing governance process. This will not only be limited to informed consent but may extend to process in place to protect the confidentiality of donors as well as guidance concerning the transfer of the biological samples between researchers. Differing ethical principles may hinder the transfer of samples as country A may require certain ethical principles to be followed which are not required in country B. This may negatively impact the possibility of country A from involving country B in their work which hinders collaboration, a key aim of H3Africa.

There is thus a need for the governance of biobanks to keep pace with the development of biobanks in Africa. Large studies investigating the views of research participants towards biobanks across Africa are necessary. These studies should access the concerns of participants in genetic studies and measures which can be put in place to address their concerns. Furthermore, regulations need to address the particular issues which biobanks raise and there should be some harmonization of regulations across Africa. While it is not realistic to suggest complete uniformity on all issues is possible, efforts must be made to ensure that any local differences in governance will not hinder collaboration between institutions across the continent. In this way, biobank governance will support biobank research and ensure the success of the H3Africa project.

In 2013, Clara Staunton worked as an intern at the Center for Medical Ethics and Law at the University of Stellenbosch. She is currently finalizing her Ph.D. (Law) thesis entitled 'The Regulation of Stem Cell Research in Ireland' at the National University of Ireland, Galway.

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ACTIVITIES AT THE UNIVERSITY OF NORTH CAROLINA BIOETHICS CENTER

Stuart Rennie

As you hopefully know, the ARESA program is a collaborative effort between the Center for Medical Ethics and Law at the University of Stellenbosch, and the Center for Bioethics at the University of the University of North Carolina-Chapel Hill. But I have noticed when presenting myself at ARESA sessions that trainees have

wondered what this unseen collaborating American institution is all about. In the following, let me try to dispel the mystery to some extent.

The University of North Carolina (UNC), established in 1789, is the oldest public university in the United States. UNC, in fact, has over the centuries evolved into a system of 17 university campuses spread throughout the state of North Carolina. UNC at Chapel Hill, however, is typically regarded (by us at least!) as the main or flagship campus within the system. North Carolina itself is a state in the American South, situated above South Carolina and Florida. As the old joke goes, the only thing Northern about North Carolina is its name.

Although UNC is old, UNC's Center for Bioethics is very new. There were precursors: a bioethics center at UNC-Chapel Hill was first proposed back in 1999 by Larry Churchhill (now at Vanderbilt University) and Dr. Laura Hanson, and a "Center for Health Ethics and Policy" existed from 2001 to 2004. In 2010, the UNC School of Medicine established the current UNC Center for Bioethics, under the leadership of Prof. Eric Juengst (Center Director, formerly of Case Western University) and Prof. Anne Lyerly (Associate Director, formerly of Duke University).

The UNC Center for Bioethics collaborates closely with the UNC Department of Social Medicine, as well as many other centers and institutes at UNC, in a large and diverse number of research and educational projects. Below I will briefly describe projects in five areas likely to be future sources of UNC-Stellenbosch bioethics collaborations, and which are hopefully of interest to the ARESA readership.

Ethics and genetics. UNC Center for Bioethics is involved with a new five-year research project conducted by the UNC Center for Genomics and Society. We have 20 UNC investigators, including bioethicists, social scientists, public health researchers, and clinical geneticists. The Center has one main research project. In consultation with community advisors, physicians, and policy makers, it will develop a framework based on multidisciplinary discussions to launch a pilot screening program. Much like newborn screening for adults, this program would offer testing for a limited number of genes that are related to serious medical conditions for which prevention or treatment is available. The first year's work of the Center will be to convene meetings to assess the implications of which genes are chosen, what populations are likely to be most affected, and how such a program should be implemented.

As a part of the larger Center for Genomics and Society's larger project to address issues in the public health uses of genomic screening, Prof. Eric Juengst is leading an effort to examine the ethics of opportunistic screening in public health settings. Opportunistic health screening -- testing patients for health problems different from their presenting complaints without their consent-- is usually justified in terms of controlling the spread of infectious diseases such as HIV to others. The question under consideration in this project is whether circumstances exist in which it would be justifiable to conduct opportunistic screening in adults for their own benefit without their permission.

As part of another research project on the clinical integration of genomic medicine, Prof. Juengst is also currently documenting the widespread recognition that genomic medicine involves assigning patients to stratified risk groups rather than "individualizing" their treatment to their personal genomes, and the implications of the resulting shift from "personalized" to "precision" medicine for population stratifications that reproduce socially engineered ethnic classifications.

Genetic and genomic research requires storage and sharing of biological samples, and the appropriate management of 'biobanks' has become an ethical concern worldwide. Prof. Gail Henderson and Dr. Jean Cadigan at UNC's Department of Social Medicine are currently working on two projects involving biobanking. The first, the U.S. Biobank Study (http://usbiobankstudy.web.unc.edu/), is an examination of the ethical implications of the policies and practices of biobanks in the United

States. They have conducted case studies of six biobanks and administered a survey to 456 biobank managers. They are currently analyzing data and publishing our results. The second is a study of the attitudes of patients with inflammatory bowel disease (IBD) towards banking their specimens for future genetic and microbiome studies. They are currently collecting data for this project through interviews and a survey.

Reproductive health ethics. In August 2013, Penguin Books will publish Prof. Anne Lyerly's *A Good Birth*. The book originated from Prof. Lyerly's frustration at the highly polarized dialogue around birth, which was characterized by the twin organizing principles of pathology (in which a good birth is presumed to be a birth with a good medical outcome) and technology (in which a good birth is one which is "natural" and done without medical intervention). The book draws on interviews with over 100 diverse women with diverse childbearing experiences, and aims to craft a view of the good birth that turns on the things that matter most to childbearing women themselves. In addition, Prof. Lyerly continues her work on the Second Wave Initiative, which aims at advancing responsible inclusion of pregnant women and their interests in biomedical research. The tendency to exclude, reflexively, pregnant women and women of childbearing potential from research in order to "protect" them has led to a dearth of information about how to treat women who face illness during pregnancy. Her group works to identify needs and challenges and aims to develop strategies to ethically move forward the knowledge base needed for evidence-based treatment during pregnancy. They are working toward securing funding to address these issues specifically as they relate to HIV and pregnancy.

Clinical care ethics. President Obama's health care reforms highlight a long-standing ethical tension within the American health care system: how to meet the health needs of the poor or underinsured and at the same time control health care costs. In the absence of overarching policy response to this tension, it falls into the hands of hospitals and their staffs to adjudicate on a case-by-case basis. Prof. Arlene Davis (UNC Bioethics Center) and Michelle Rivkin-Fish (UNC Department of Anthropology) are leading a study that examines the clinical ethical issues this default raises, and the practical strategies that clinicians develop to address them. Their goals are to describe the moral distress professionals experience in such cases, the strategies they develop in striving to resolve that distress, and the impacts of these ethical dilemmas and strategies on professionals, patients, and the health care system itself. Finally, they aim to devise recommendations for clinical ethics practice and hospital policy based on their findings.

More specifically, this study focuses on length of stay (LOS) monitoring and management, a form of knowledge and practice that involves both medical experts and a special unit of non-physician professionals, the Clinical Care Management (CCM) team. Cases of patients' extended LOS become a flashpoint for the ethical tension between cost control and uncompensated care when patients' socio-economic contingencies, rather than medical needs, prevent timely hospital discharge. These patients may have limited options for safe disposition due to poverty, social alienation, or immigration status and the need for continued complex care. Their prolonged hospital stays arouse staff distress and catalyze efforts to find solutions by tapping into hospital, family, community, and societal resources. This study hypothesizes that LOS monitoring and management reflect an emerging formation of ethical hospital practice in the U.S. that expands professional responsibility beyond providing technically competent medical care for the individual to include considerations of cost containment for the good of the hospital and larger society. While LOS per se is rarely categorized as an 'ethical dilemma,' and the strategies devised to reduce LOS are rarely the outcome of explicit ethical deliberation, these cases are characterized by pressing anxieties over fairness, entitlement, and duty. The study hypothesizes that the moral distress aroused by extended LOS reflects a growing dissonance, on

the one hand, between clinicians' implicit ideals of distributive justice as related to balancing individual and societal needs, and the logics driving resource allocation currently underway in the hospital and larger society, on the other.

Animal research ethics. Developing evidence-based health interventions for humans is an obviously valuable goal. Some of this research requires the involvement of non-human animals, and there are increasing concerns about the welfare of animals involved in 'human-centered' research. Prof. Rebecca Walker's (UNC Bioethics Center) work in animal ethics has focused on the moral implications of the U.S. regulatory structures for animal research as well as on a virtue ethics approach to animal ethics, following up on her previous publications, including her edited volume Working Virtue: Virtue Ethics and Contemporary Problems (Oxford Univerity Press, 2007). In the fall of 2013, she will be on research and study leave from the University of North Carolina, in order to work toward a book manuscript synthesizing these two interests in a virtue ethical approach to animal research. Does a researcher or lab technician who develops relationships with her animal subjects owe them a greater duty of care than one who does not? What is the moral significance of the positive or negative psychological effects on the researcher of doing animal research? Can, or should, a rhesus macaque monkey live a life that is a good one for its kind when it is housed in a research facility? What about a genetically modified mouse? These questions are of critical importance for a virtue-ethical assessment of animal research practices.

Ethics and global health. UNC is involved in many research and scholarship initiatives around the world. At the latest count, UNC leads or collaborates in research projects in 85 countries, is responsible for roughly 300 study abroad programs for graduate and undergraduate students, and has 325 international partnerships. Over the last decade, a number of UNC institutes have added the word 'global' to their name: UNC Center for Global Initiatives, UNC Global Research Institute, UNC Institute for Global Health and Infectious Diseases, and UNC Gillings School of Global Public Health, and so on. The recent outbreak of the concept 'global' gives rise to philosophical and ethical questions: what do we mean by 'global' anyway? Is it just a polite way of referring about vast health inequalities between countries, an indirect way of expressing the interconnectedness of health problems among world regions, or both? Why should health inequalities be a matter of moral concern anyway? What kinds of ethical problems are raised by initiatives to lessen health inequalities, via health research, public health programs or changes in clinical practice? What can reasonably be done to make such initiatives more ethical, and what do we mean by 'more ethical'? Are there special problems when these initiatives are led or funded by institutions in the world's more affluent nations? These are the sorts of questions that have occupied Prof. Stuart Rennie (UNC Bioethics Center) for the past decade, often inspired by his experiences in UNC's NIH-Fogarty bioethics project in Francophone Africa (2004-present), and often expressed in his Global Bioethics. Blog: http://globalbioethics.blogspot.com.

Suggestions for and questions about any of these projects from Southern African perspectives are welcome!

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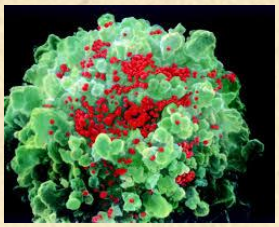

THE ETHICS OF HIV CURE RESEARCH

Stuart Rennie

The first time I heard about HIV cure research, my initial response was: "Excuse me? Did you say **cure**?" During its history, HIV has gradually changed its status, the changes often driven by scientific advances. Early on, living with HIV was synonymous with dying – sooner rather than

later -- from HIV/AIDS. HIV was in principle preventable, but not treatable or curable. It would take years before effective antiretroviral treatments would be discovered and refined, turning HIV into a serious but potentially manageable chronic disease – at least for those able to reliably access affordable treatment. Will HIV research change its profile again, from incurable to treatable to curable?

Recent scientific developments indicate that a biomedical cure for HIV is not unthinkable. Five years ago, Timothy Brown, a man with HIV infection and leukemia, received a stem-cell transplant that removed the virus from his body as far as modern research techniques can detect. He represented the first HIV cure. More recently, an HIV-positive child in Mississippi (USA) received aggressive antiretroviral treatment 30 hours after birth, and has continued to test negative for HIV two years later despite having stopped medications after 18 months. In France, a group of patients called the 'Visconti cohort' started taking antiretrovirals very soon after they became infected. After three years of medication, they stopped taking ARVs, which would usually result in the HIV-infection resurging. However, in this case they were able to stop taking the medication and yet remain with low levels of virus in their systems for an average of seven years. All of these examples indicate that, in the future, effective cures for HIV may be possible, and this has stimulated research initiatives in HIV cure research.

In May 2013, the Center for Bioethics at UNC-Chapel Hill and the Center for Medical Ethics and Law at the University of Stellenbosch were awarded a five-year grant (2013-2018) from the National Institutes of Health (NIH) to explore the ethical and social dimensions of HIV cure research and initial implementation of new cures. ARESA faculty Professor Keymanthri Moodley and Stuart Rennie are Principal Investigators in this project. The study will involve both conceptual and empirical research at three sites, in the United States, China and South Africa. It will address questions such as: what do we mean by 'cure'? What are the ethical challenges faced by research on HIV cure involving HIV-positive persons? What effects will successful cures likely have on HIV treatment and prevention initiatives? How will communities respond to HIV cure research, particularly in regions (such as Africa) where many alleged indigenous HIV cures have been proclaimed in the past? Some of these issues will be discussed at the second annual ARESA Seminar in September, but we will report ongoing findings when appropriate in this Newsletter.

Dr. Stuart Rennie is Associate Professor in Social Medicine and Core Faculty of the Bioethics Center at the University of North Carolina-Chapel Hill. He is head of the ethics program at UNC's Center for AIDS Research (CFAR) and is co-Principal Investigator in the ARESA program.

ARESA RESEARCH ETHICS SEMINAR SPOTLIGHT: MICHAEL IGBE

The Annual ARESA seminar in September 2013 is pleased to host Prof. Michael Igbe as visiting guest speaker. Michael was trained as a zoologist at the University of Jos, Nigeria, and later completed a master's degree in Applied Entomology and Parasitology at the same university. This specialization brought him into research and sparked a quest for ethics that led him into a career in bioethics and to complete a Masters degree in Bioethics at the University of Ibadan, Nigeria. He is a Programme Manager at the National Onchocerciasis/Lymphatic Filariasis Elimination Programme of the NTDs Division, Department of Public Health, Federal Ministry of Health, Abuja, Nigeria. He is the UNICEF focal

person for Onchocerciasis Elimination Programme, Nigeria. He holds many other positions such as Desk Officer-Leishmaniasis Control Programme; Entomology and Cytotaxonomy Desk Officer; Research Desk Officer and Advisor on Bioethics matters. Michael recently conducted studies to assess public knowledge and willingness to participate in biobank research in Nigeria and has a paper entitled "Qualitative study of knowledge and attitudes to biobanking among lay persons in Nigeria", and this being the first of such a study in Africa on biobanking, he has travelled widely to present papers in conferences and workshops.

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TRAINEE NEWS

Adri Labuschagne (ARESA Graduate, 2012) has written an article on the use of placebo in clinical trials on the Medical Research Council's AfroAIDS website. The piece can be found in the Policy section of the website, available at: http://www.afroaidsinfo.org/.

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ARESA SHORT COURSE III: Research and vulnerability (9 to 20 September 2013)

Module 3 will focus on the concept of vulnerability that has, for understandable reasons, 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 and mental health research, as well as vulnerability related to research on specific health conditions such as genetic and oncology research. 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 **08 August 2013.**

For more information, and If you are interested in applying for these short courses, please forward your curriculum vitae and a short motivation letter on why you would like to be considered to kelseyf@sun.ac.za or bioethics@sun.ac.za.

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ARESA 2014 Intake: Postgraduate Diploma in Health Research Ethics

Ten scholarships for the ARESA Postgraduate Diploma in Health Research Ethics are available for 2014. The deadline for applications is **30th August 2013.**

For more details, please visit the ARESA website www.sun.ac.za/aresa

For queries please contact:
Kelsey February – **kelseyf@sun.ac.za**

ARESA
ADVANCING RESEARCH ETHICS TRAINING IN SOUTHERN AFRICA

UPCOMING CONFERENCES AND EVENTS

2nd Annual ARESA Seminar in Health Research Ethics, Southern Sun Hotel, Newlands • 19 & 20 September 2013

Program:

- **HIV Research: from Prevention to Cure**
- **Interpreting the Investigator's Brochure: animal studies and early phase research**
- **Biobanking in Africa**
- **Research related injuries and Compensation**

International & national speakers • CPD accredited

Closing date for registration: **05 August 2013** (registration is sponsored by a generous grant from the National Institutes of Health).

Please email registration forms to:
kelseyf@sun.ac.za
Or fax to 021-9389731

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Public Responsibility in Medicine and Research (PRIMR), Advancing Ethical Research Conference, Boston (November 7-9, 2013)

This is the largest annual conference in the United States devoted to research ethics and regulatory issues for research involving human participants. The conference has an International Scholarship Program open to REC members, administrators and researchers in low- and middle-income countries. These scholarships may consist of full and partial fee waivers to the 2013 AER Conference, round trip coach airfare to Boston, hotel accommodations for the length of the meeting, and a stipend to cover meals not offered at the conference. The conference program can be downloaded here: http://www.primr.org/uploadedFiles/PRIMR_Site_Home/Microsite_Pages/2013_AER_Conference/2013AER_program.pdf.

UNESCO Chair in Bioethics, Ninth World Conference (November 19-21, 2013)

This year's theme for the UNESCO conference is: Bioethics, Medical Ethics and Law: Towards the 21st Century, and it will be held in Rome, Italy. Deadline for receipt of abstracts is September 15th, and more information about the conference can be found at: http://www.isas.co.il/bioethics2013/.

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