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**South  
African  
Research  
Ethics  
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Initiative**

# SARETI

Newsletter • 2013–2014 • [sareti.ukzn.ac.za](http://sareti.ukzn.ac.za)

**DEVELOPING RESEARCH ETHICS IN AFRICA**

# SARETI

South African Research Ethics Training Initiative

Newsletter

2013-2014

sareti.ukzn.ac.za

## CONDOLENCES

### Dr Lizette Schoeman

The death of Dr Lizette Schoeman is a great loss to the research ethics world. Her colleagues and students at SARETI express their deep sadness at the passing of this inspirational teacher, trainer, colleague and friend. Many of them have posted their condolences on the SARETI website at this link: <http://sareti.ukzn.ac.za/Condolences.aspx>.

May her gentle soul rest in peace.



4 Nov 1959 - 3 Nov 2014

## Editorial



Mariana Kruger, MD PhD, SARETI Co-PI

It is with great pleasure that I introduce you to our next newsletter for the activity period 2013-2014. As explained in our previous edition, our funding situation currently allows us to present some of our 'old but exciting' news. This editorial is written on behalf of my colleagues in the SARETI Executive Committee, Professors Doug Wassenaar, Nhlanhla Mkhize and Carel IJsselmuiden.

This newsletter shares with you the activities of our SARETI III funding period, which covers the second and third years of our third competitive renewal by the Fogarty International Center of the US National Institutes of Health. This period was very productive with numerous scholarly ethics publications by students and staff, including a research ethics guidebook, *Research Ethics in Africa, a resource for research ethics committees*, edited and written by SARETI staff and students – a truly great experience to

work together as a team for the greater good of Africa's research participants.

By the end of 2014, SARETI-funded graduates numbered 23 (in addition to our one PhD graduate, 9 scholars in training, 22 fellows and 180 short-term trainees that have benefitted or are benefitting from SARETI's research ethics training). These colleagues are now active in ensuring the protection of research participants on the African continent, serving in research ethics committees, developing and teaching research ethics in various African institutions and advising national health departments on research ethics issues. It is a wonderful experience to share in the success of our students and to note the leadership positions they eventually fill after graduating.

In addition to thanking the Fogarty International Center of the US NIH for generous support, we must also thank the following SARETI staff members for their committed and excellent adult education activities for SARETI during the past two years:

- Dr Nicola Barsdorf
- Dr Zaynab Essack
- Dr Janet Frohlich
- Dr Lyn Horn
- Prof Graham Lindegger
- Dr Nicole Mamotte
- Dr Surita Roux
- Dr Lizette Schoeman (who passed away in November 2014)
- Dr Catherine Slack
- Mr Vernon Solomon
- Dr Ann Strode

A complex and active programme like SARETI requires someone to attend to programme management and we especially wish to thank Ms Carla Pettit for her excellent and committed management of SARETI, as well as the UKZN School of Applied Human Sciences for hosting SARETI's MSocSc (Health Research Ethics) programme. Please share with us any comments or news items: [pettitc@ukzn.ac.za](mailto:pettitc@ukzn.ac.za).

Mariana Kruger, MD PhD





## SARETI graduate returns to Zimbabwe as Director of MRCZ

In 2013, after several years abroad, Dr Paul Ndebele, a University of KwaZulu-Natal (UKZN) PhD graduate who received specialised training in Research Ethics at UKZN through the SARETI Masters programme, was appointed Director of the Medical Research Council of Zimbabwe (MRCZ).

Dr Ndebele attained his BSc Honours degree in Sociology and his MSc in Population Studies from the University of Zimbabwe in Harare. He received specialised training in Research Ethics at Johns Hopkins University in the United States, through the NIH/Fogarty African Bioethics Programme (FABTP), and at UKZN through the NIH/Fogarty SARETI Masters Programme.

Dr Ndebele completed his PhD in 2011 in the School of Applied Human Sciences (UKZN) focusing on understanding of randomisation, placebos and double-blinding in HIV prevention microbicide trials.

Dr Ndebele was a visiting scholar at various academic institutions, including

Padova University in Italy and the Ethox Centre at Oxford University in England.

Dr Ndebele previously worked for the MRCZ as the Liaison Officer and Head of Secretariat from 1999 to 2005.

He then left Zimbabwe to take up a dual appointment from 2005 to 2008 as visiting Professor at Michigan State University, and Deputy Director of the Centre for Bioethics at the College of Medicine, University of Malawi.

He joined the University of Botswana in 2008, working as Assistant Director for Research Ethics in the Office of Research and Development. During his time in Botswana, he also served as a member of the Human Resource Development

Council (HRDC) in the Botswana Ministry of Health.

He joins the MRCZ from the Division of AIDS (DAIDS), at the National Institutes of Health (NIH) in the USA, where he was serving as a Contractor Bioethicist at the Henry Jackson Foundation for the Advancement of Military Medicine.

In his role as a bioethicist, Dr Ndebele's main role was to provide specialist advice and support on DAIDS-funded studies on matters pertaining to the well-being of research participants. In this role, he provided guidance on various HIV/AIDS and TB studies conducted in various countries.

Dr Ndebele's main function will be to strengthen the role of the MRCZ in promoting and co-ordinating health research in Zimbabwe. He will work closely with the Ministry of Health and Child Welfare in ensuring that the MRCZ executes its mandate. ■



# Ghana and Research Ethics: Developments

## Pamela Emefa Selormey

SARETI MSocSc Research  
Ethics graduate and member  
of the Ghana Association of  
Administrators of Research Ethics  
Committees (GHAAREC)

A two-day conference on research ethics took place in Accra, Ghana: 'Moving towards a holistic protection of human participants: the voice of research participants', the first research ethics conference held in Ghana.

The conference sought to

- Offer opportunities for RECs, research ethicists and researchers to share their experiences on good research ethics practice.
- Identify the various ethical dilemmas in research with human participants; and so to uplift standards of health research in Ghana.
- Inform research scientists, REC members, and the general public of challenges encountered by scientists when applying ethical principles in practice.



Pamela Emefa Selormey

A meeting was convened to review, identify and address challenges confronting research ethics in Ghana. Challenges identified included:

- Lack of financing for RECs in Ghana: RECs are not adequately funded by their institutions, which leads to fees being charged for the submission of research protocols for ethical approval.
- Ethics shopping, or 'REC shopping', as many RECs have been established, giving scientists the opportunity

to shop around when protocols are rejected by some RECs;

- The lack of a national body to regulate ethics activities nation-wide, to serve as a common front for the RECs and to monitor the various RECs.

Addressing the issue of RECs charging fees was a priority. Some felt RECs should charge fees. The issue of proper monitoring, abuse of the fees, and the negative impact of fee charging were considered, and no firm decision was taken.

A meeting was held to discuss the development of a National Ethics Committee in Ghana. A national ethics guidelines document has already been drafted, and some of the authors were present at the meeting. Earlier attempts to set up an NEC failed, as scientists ran into difficulties when trying to define a mechanism to get the Government of Ghana and Parliament to buy into the notion. A communication plan was developed to enhance effective dissemination of information to stakeholders. ■

## Francis Kombe joins new Pwani University Ethics and Review Committee

Mr Francis Kombe, a researcher with a keen interest in community engagement issues, was awarded a 3-week SARETI fellowship in 2011 to attend 3 health research ethics modules and is a 2016 SARETI Masters student.

As part of on-going collaboration with Pwani University, Mr Kombe, a staff member from Kenya Medical Research Institute (KEMRI)/Wellcome Trust Research Programme (KWTRP), has been appointed to the Pwani University Ethics and Review Committee (PU ERC), pending confirmation from the National

Commission for Science, Technology and Innovation (NACOSTI).

Mr Kombe is a member of the Communication and Consent Committee (CCC) that works with all protocols coming through KWTRP for consent information and community engagement plans. His appointment comes as PU is re-establishing its ERC, after the expiration of the previous committee's tenure. Mr Kombe joins 16 other members in reviewing proposals from undergraduate, masters and doctorate students from a wide range of disciplines. His appointment



enhances collaboration between the two institutions and the quality of reviews and ethical standards of the research emanating from Pwani University. ■

# HISTORY OF SARETI

**The South African Research Ethics Training Initiative (SARETI) is the oldest Africa-based Masters programme in health research ethics.**

Based at the University of KwaZulu-Natal, the programme equips African public health professionals with the theoretical and practical experience needed to provide sound ethics review of the numerous and complex health studies taking place in Africa. SARETI aims to build African capacity for the ethical review of health research and to strengthen Africa's institutional training capacity to achieve and sustain this aim.

SARETI is a comprehensive, multi-disciplinary, Africa-based degree programme in health research ethics and offers training and support programmes to achieve these goals.

SARETI started in 2003, and by 2014 had graduated 1 PhD, 29 Masters and 22 non-degree fellows. SARETI offered modular courses to 164 self-funded students from 17 African countries.

UKZN will benefit from a third competitive funding award (2012-2017) from the Fogarty International Center of the US National Institutes of Health which supports advanced research ethics training at institutions in low- and middle-income countries around the world.

The successful five-year grant, worth US\$1.25 million, has been awarded to the discipline of Psychology in UKZN's School of Applied Human Sciences to continue offering its highly successful interdisciplinary, Africa-based Masters programme in health research ethics.

The funding allows SARETI to provide scholarships to a small number of Masters students who match the required selection criteria.

SARETI collaborates with Johns Hopkins University and other leading research ethics centres, and has multidisciplinary leadership and academic staff drawn from several leading South African and international universities and research centres. ■

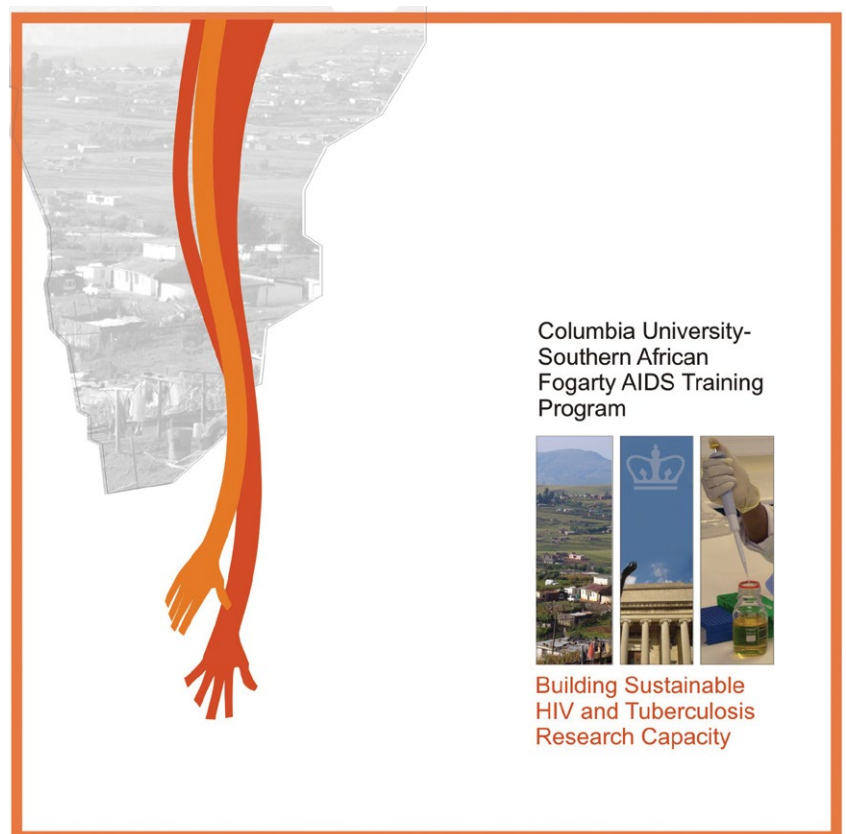
<http://sareti.ukzn.ac.za/Homepage.aspx>

## Collaboration between SARETI and CU-SA: Fogarty AIDS International Training Program, 2013-2014

Towards the end of 2012, an agreement was entered into between Professor Q Abdool Karim of Columbia University-Southern African (CU-SA) Fogarty AIDS International Training and Research Program (AITRP) and Professor Doug Wassenaar of SARETI to co-sponsor two fellows per year to study at SARETI, starting in 2013. This collaboration between SARETI and the CU-SA Fogarty AIDS International Training and Research Program (AITRP) was made possible as a result of funding through the Fogarty International Center, National Institutes of Health (FIC/NIH) (grant # D43TW000231).

A requirement of the SARETI Masters programme in Health Research Ethics is that all CU-SA students work on their own research projects.

In 2013 SARETI/CUSA trained Dr Joseph Alimasunya from Nigeria and Ms Samantha Chareka from Zimbabwe; and in 2014 SARETI trained Dr Omran El-Koha from Libya, now resident in South Africa and Dr Elizabeth Lutge from South Africa. ■



# THEORY INTO PRACTICE:

## SARETI students visit CAPRISA



Five SARETI students from five different African countries visited the Centre for the AIDS Programme of Research in South Africa (CAPRISA), at the Doris Duke Medical Research Institute (DDMRI) of UKZN's College of Health Sciences. Their guides were Ms Marian Swart and Dr Ayesha Kharsany, CAPRISA training coordinators.

The students were

- Dr Erisa Mwaka from Uganda;
- Ms Florence Mutevedzi from Zimbabwe;
- Dr Omran El-Koha from Libya, resident in South Africa;
- Ms Irene Honam Tsey from Ghana; and
- Ms Cebisile Ncube from South Africa.

The students were given an introductory presentation by Marian Swart on the activities of the research institute and its tremendous impact on the HIV pandemic. They then watched the plenary presentation by Prof S S Abdoel Karim,

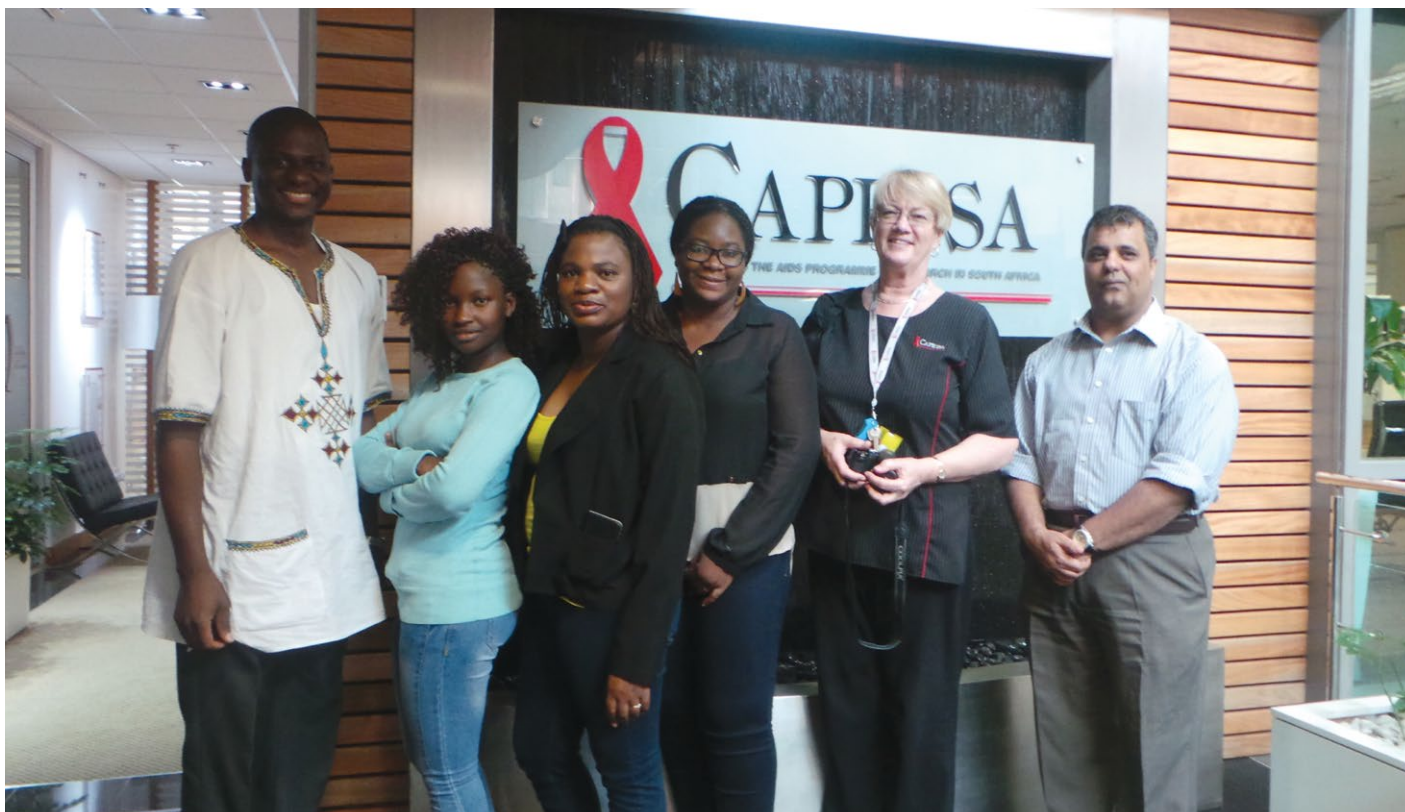
the director of CAPRISA, at the World AIDS Conference in Melbourne.

Discussions were held on the fact that HIV prevalence among the youth (18-25 age group) was on the increase, with a HIV prevalence rate of 40% for those attending antenatal clinics, and the fact that behavioural factors could be a key contributor. There were discussions on the issues of stigma and mainstream media, microbicide gel and ring research; and some aspects of cancer in HIV. Different country perspectives added depth to the discussion, and drew attention to the fact that many prevention programmes target females because they are not

in a position to negotiate for safer sex. There is a need for an holistic approach, to encompass both males and females in the fight against HIV.

Students then visited the eThekweni Clinical Research Site (CRS) on a tour of the Prince Cyril Zulu Communicable Diseases Centre (PCZCDC), the CAPRISA Treatment Clinic and the CAPRISA Prevention Clinic. They met with Dr Kogieleum Naidoo: head of treatment programme and Dr Lulu Nair: the project director, HIV prevention study.

The students found the tour an emotional experience, as it made real the theoretical learning they had, and showed what actually happens on the ground. They were given instruction on how and why the treatment centre came into existence and the on-going study projects at the centre. They were taken on a tour of all departments with extra precautions at the TB centre to prevent infection. They learnt that there was a high prevalence



Five SARETI students from five different African countries visited CAPRISA.



of TB infection in KZN, with 70% of TB sufferers likely to be HIV positive. Both HIV and TB treatment are free of charge and the clinic is strategically located at a taxi rank in downtown Durban. Staff members have an ethical obligation to make sure the patients complete their treatment, and have a mechanism for following 'lost to follow-up' patients.

They were shown the administrative logistics involved in patient consent and participant enrolment and visited the data management office where they were shown the E-link system used to ensure participants do not enrol in more than one study at a time.

The researchers expressed the desire for the UKZN Biomedical Research Ethics Committee (BREC) to initiate a monitoring visit. This would help BREC to understand some of the real issues on the ground and enhance the review process. The students proposed the Improved Quality Improvement Philosophy, which is an approach whereby monitoring is done based on the investigators' request to be monitored. This type of monitoring focuses on actual research conduct and investigators and other parties receive feedback on how to improve the research process.

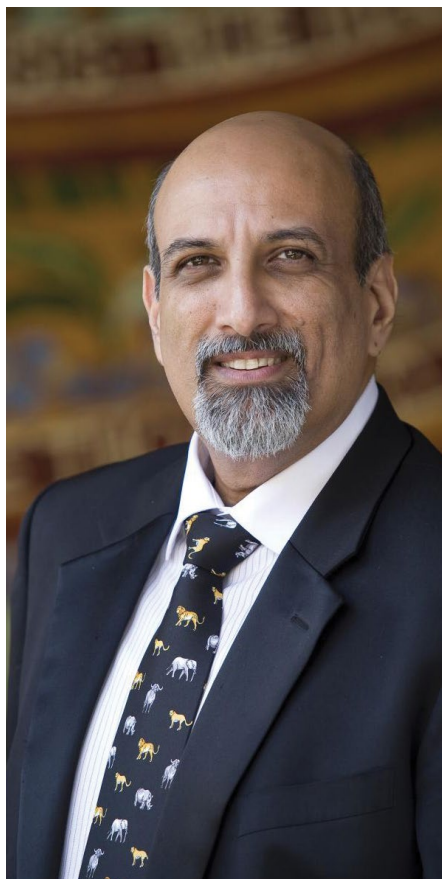
Students were shown the HIV prevention clinic and the pharmacy. Dr Nair demonstrated the application of the microbicide vaginal ring. Students were then given a tour of CAPRISA (DDMRI) facilities and shown the well-equipped lab and the HR and Administration section where they met with the data management team. In the data management office, it was demonstrated how research questionnaires are scanned from the research sites and linked to a data base in CAPRISA DDMRI - [caprisa.org/](http://caprisa.org/)

## Challenges/Observations

1. There is high risk of exposure to TB for staff members.
2. Prevention programmes in their HIV studies mainly target females.
3. There is a high rate of loss to follow-up due to migration of participants and patients.
4. The issue of blood sample collection - they indicated that participants sometimes exaggerate the quantity of blood to be drawn.

## Recommendations

If possible, future SARETI students should visit more research sites and participate practically in the informed consent procedure so that they can appreciate the entire process and any challenges arising. ■



Prof Salim Abdool Karim - Director of CAPRISA

# Research Ethics Publications 2013–2014

## Publications by SARETI Students

(SARETI students indicated by bold type)

### 2013

- Kamuya, D.M., Marsh, V., **Kombe, F.K.**, Geissler, P.W., & Molyneux, S.C. (2013). Engaging communities to strengthen research ethics in low-income settings: selection and perceptions of members of a network of representatives in Coastal Kenya. *Developing World Bioethics*, 13(1), 10–20. doi:10.1111/dewb.12014
- Marsh, V., **Kombe, F.**, Fitzpatrick, R., Williams, T.N., Parker, M., & Molyneux, S. (2013). Consulting communities on feedback of genetic findings in international health research: sharing sickle cell disease and carrier information in coastal Kenya. *BMC Medical Ethics*, 2013 14:41. doi:10.1186/1472-6939-14-41. Accessible at: <http://www.biomedcentral.com/1472-6939/14/41>
- Marsh, V., Mocamah, G., Mabibo, E., **Kombe, F.**, & Williams, T.N. (2013). The “Difficult Patient” Conundrum in Sickle Cell Disease in Kenya: Complex Sociopolitical Problems Need Wide Multidimensional Solutions. *The American Journal of Bioethics*, 13:4, 20–22. Accessible at: <http://dx.doi.org/10.1080/15265161.2013.767960>
- Ndebele, P.** (2013). The Declaration of Helsinki, 50 Years Later. *JAMA*. 2013 Nov 27;310(20):2145–6
- Sikweyiya, Y.**, Jewkes, R., & Dartnall, E. (2013). Men’s perspectives on participating in violence against women perpetration research. *Agenda*, 2013, 27(1), 40–48
- Sikweyiya, Y.**, & Jewkes, R. (2013). Potential Motivations For and Perceived Risks In Research Participation: Ethics in Health Research. *Qualitative Health Research*, 2013, 23(7), 999–1009
- Umeora, O.U.J.**, & **Chukwuneke, F.N.** (2013). Ethical dilemma and management of infertility in HIV seropositive discordant couples: A case study in Nigeria. *Ann Med Health Sci Res*. 2013 Jan;3(1):99–101. doi:10.4103/2141-9248.109460. PMID:23634339 [PubMed]
- Umeora, O.U.J.**, & **Okonta, P.I.** et al (2013). Is there a place for mandatory HPV vaccination in Nigeria? Public health, human rights and ethical considerations. *Nigerian Journal of Clinical and Biomedical Research* 2012;6(1):5–11
- Uzoma Manafa, O.**, Lindegger, G., Ijsselmuiden, C. (2013). Informed consent in a clinical trial: participants’ satisfaction of the consent process and voluntariness

of participation. *Online Journal of Health Ethics*, 2013, 3 Volume 1 (Retrieved from: <http://www.aquila.usm.edu/ojhe/vol3/iss1/6>) (based on 2006 SARETI work assignment at UKZN)

### 2014

- Chukwuneke, F.N.**, **Umeora, O.U.J.**, Maduabuchi, J.U., & Egbunike, N. (2014). Global bioethics and culture in a pluralistic world: How does culture influence bioethics in Africa? *Annals of Medical & Health Sciences Research* 2014;4:672–5.
- Dal-Ré, R., **Ndebele, P.**, Higgs, E., Sewankambo, N., & Wendler, D. (2014). Protections for clinical trials in low and middle income countries need strengthening not weakening. *BMJ* 2014;349:g4254. doi:10.1136/bmj.g4254
- Kombe, F.**, **Anunobi, E.N.**, **Tshifuluga, N.P.**, Wassenaar, D.R., **Njadingwe, D.**, **Mwalukore, S.**, **Chinyama, J.**, **Randrianasolo, B.**, **Akindeh, P.**, **Dlamini, P.S.**, **Ramiandrisoa, F.N.**, & **Ranaivo, N.** (2014). Promoting research integrity in Africa: an African voice of concern on research misconduct and the way forward. *Developing World Bioethics*, 14(3), 158–166. ISSN 1471-8731 (print); 1471-8847 (online)
- Munalula-Nkandu, E., **Ndebele, P.**, Siziya, S., & Munthali, J.C. (2014). To What Did They Consent? Understanding Consent Among Low Literacy Participants In A Microbicide Feasibility Study In Mazabuka, Zambia. *Developing World Bioethics*. doi:10.1111/dewb.12069
- Mutenherwa, F.**, & Wassenaar, D. (2014). Ethics review of social and behavioural research in an African context. In M. Kruger, **P. Ndebele** & L. Horn (Eds.), *Research Ethics in Africa: A Resource for Research Ethics Committees*: SUN MeDIA Stellenbosch; Stellenbosch
- Ndebele, P.**, Blanchard-Horan, C., Shahkolahi, A., & Sanne, I. (2014). Regulatory Challenges Associated With Conducting Multicountry Clinical Trials in Resource-Limited Settings. *Journal of Acquired Immune Deficiency Syndromes*. 2014; 65: S29
- Ndebele, P.**, & **Musesengwa, R.** (2012). View Point: Ethical dilemmas in malaria vector research in Africa: Making the difficult choice between mosquito, science and humans. *Malawi Medical Journal*; 24 (3):65–68 September 2012
- Ndebele, P.**, **Ruzariri, S.** & **Gutsire-Zinyama, R.** (2013). Interpreting and dismissing the relevance of the “wait and wive” finding from the circumcision studies conducted in Africa. *Malawi Medical Journal*, 2013
- Ndebele, P.**, Wassenaar, D., Masiye, F., & Munalula, E. (2014). Trial participants’ understanding of randomization, double-blinding and placebo use in low literacy populations: Findings from a study conducted within a microbicide trial in Malawi. *Journal of Empirical Research on Human Research Ethics*, Vol. 9, No. 2. doi: 10.1177/1556264614540592
- Ndebele, P.**, Wassenaar, D., Benatar, S., Fleischer, T., Kruger, M., Adebamowo, C., Kass, N., Meslin, E., & Hyder, A. (2014). Research ethics capacity building in Sub-Saharan Africa: A review of NIH Fogarty-funded programs 2000–2012, *Journal of Empirical Research on Human Research Ethics*, Vol. 9, No. 2, pp. 24–40
- Ndebele, P.**, Wassenaar, D.R., Munalula, E., & Masiye, F. (2012). Improving understanding of clinical trial procedures among low literacy populations: an intervention within a microbicide trial in Malawi. *BMC Medical Ethics* 2012, 13:29
- Njue, M., **Kombe, F.**, **Mwalukore, S.**, **Molyneux, S.**, & **Marsh, V.** (2014). What Are Fair Study Benefits in International Health Research? Consulting Community Members in Kenya. *PLoS ONE* 9(12): e113112. doi:10.1371/journal.pone.0113112
- Okonta, P.I.** (2014). Ethics of clinical trials in Nigeria. *Nigerian Medical Journal*, 2014;55(3):188–194
- Okonta, P.I.**, & **Rossouw, T.** (2014). Misconduct in research: A descriptive survey of attitudes, perceptions and associated factors in a developing country. *BMC Medical Ethics*. 2014 Mar 25;15(1):25–28
- Omondi Aduda, D.S.**, & **Mkhize, N.J.** (2014). Ethical issues evolving from patients’ perspectives on compulsory screening for syphilis and voluntary screening for cervical cancer in Kenya. *BMC Medical Ethics* 2014, 15:27 doi:10.1186/1472-6939-15-27
- Umeora, O.U.J.**, **Umeora, M.C.**, Emma-Echiegu, N.B., & **Chukwuneke, F.N.** (2014). Surrogacy in Nigeria: Legal, ethical, socio cultural, psychological and religious musings. *African Journal of Medical and Health Sciences*, 2014;13:105–9

### Books:

Research Ethics in Africa. A Resource for Research Ethics Committees. Editors: M Kruger, **P Ndebele**, L Horn, Sun MeDIA Publishers, June 2014



# Research Ethics Publications 2013–2014

## Chapters in books:

Christine Wasunna, Jemee Tegli, **Paul**

**Ndebele.** (2014). *Informed consent in an African context (Chapter 9)* In Kruger, M., Ndebele, P., & L. Horn (Eds), 2014. *Research Ethics in Africa: A Resource for Research Ethics Committees*. Sun MeDIA Stellenbosch; Stellenbosch

Khama Mita, & **Paul Ndebele.** (2014). *Payment of research participants (Chapter 18)* In Kruger, M., Ndebele, P., & L. Horn (Eds), 2014. *Research Ethics in Africa: A Resource for Research Ethics Committees*. SUN MeDIA Stellenbosch; Stellenbosch

Lyn Horn, Hany Sleem, **Paul Ndebele.** (2014). *Research vulnerability (Chapter 12)* In Kruger, M., Ndebele, P., & L. Horn (Eds), 2014. *Research Ethics in Africa: A Resource for Research Ethics Committees*. SUN MeDIA Stellenbosch; Stellenbosch

Okwere Boateng, **Paul Ndebele** & Dan Mwesiga-Kayongo. (2014). On-going monitoring of research post REC approval. In Kruger, M., Ndebele, P., & L. Horn (Eds), 2014. *Research Ethics in Africa: A Resource for Research Ethics Committees*. SUN MeDIA Stellenbosch; Stellenbosch

**Paul Ndebele**, Gabriel Mwaluko, Mariana Kruger, Odile Ouwe Missi Oukem-Boyer, Moses Zimba. (2014). *History of research ethics review in Africa; (Chapter 2)* In Kruger, M., Ndebele, P., & L. Horn (Eds), 2014. *Research Ethics in Africa: A Resource for Research Ethics Committees*. SUN MeDIA Stellenbosch; Stellenbosch

## Publications by SARETI Staff

(SARETI staff indicated by bold type)

## 2013

**Mamotte, N., Wassenaar, D.R., & Singh, N.** (2013). Compensation for research-related injury in NIH sponsored HIV clinical trials in Africa. *Journal of Empirical Research on Human Research Ethics*, 8, 45-54

**Strode, A., & Slack, C.** (2013). Child privacy rights: A 'Cinderella' issue in HIV prevention research. *Southern African Journal of HIV Medicine*, 14(3), 108-110

**Strode, A., Toohey, J., Slack, C., & Bhamjee, S.** (2013). Reporting underage consensual sex after the Teddy Bear case: A different perspective. *South African Journal of Bioethics and Law*, 6(2), 45-47

**Uzoma Manafa, O., Lindegger, G., Ijsselmuiden, C.** (2013). Informed consent in a clinical trial: participants' satisfaction of the consent process and voluntariness of participation. *Online Journal of Health*

*Ethics*, 2013, 3 Volume 1 (Retrieved from: <http://www.aquila.usm.edu/ojhe/vol3/iss1/6>) (based on 2006 SARETI work assignment at UKZN)

**Williams, J, Kruger, M., et al.** (2013). Consensus Standards for Introductory e-Learning Courses in Human Participants Research Ethics (medethics-2013-101572). *Journal of Medical Ethics* – published online on 19 August 2013

## 2014

**Bekker, L.G., Slack, C., Lee, S., Shah, S., & Kapogiannis, B.** (2014). Ethical Issues in Adolescent HIV Research in resource-limited countries. *Journal of Acquired Immune Deficiency Syndromes*, 65(1) s24-s28

**Essack, Z.** (2014). Ensuring access to HIV prevention services in South African HIV vaccine trials: Correspondence between guidelines and practices. *Public Health Ethics*, 7(2), 195-206

**Kombe, F., Anunobi, E.N., Tshifuluga, N.P., Wassenaar, D.R., Njadingwe, D., Mwalukore, S., Chinyama, J., Randrianasolo, B., Akindeh, P., Dlamini, P.S., Ramiandrisoa, F.N., & Ranaivo, N.** (2014). Promoting research integrity in Africa: an African voice of concern on research misconduct and the way forward. *Developing World Bioethics*, 14(3), 158-166. ISSN 1471-8731 (print); 1471-8847 (online)

**Laloo, U., Bobat, R., Pillay, S., & Wassenaar, D.R.** (2014). A strategy for developing future academic leaders for South Africa in a resource constrained environment. *Academic Medicine*, 89(8) S55-S59

**Littler, K., Millum, J., & Wassenaar, D.R.** (2014). The Global Forum for Bioethics in Research: Past, present and future. *South African Journal of Bioethics and Law*, 7(1), 5-8. doi: 10.7196/SAJBL.312

**Mokgatla-Moipolai, B., Ijsselmuiden, C., & Wassenaar, D.R.** (2014). MARC (Mapping African Research Ethics review) project. In M. Kruger, P. Ndebele & L. Horn (Eds.) *Research Ethics in Africa: A Resource for Research Ethics Committees* (pp. 11-20). SUN MeDIA Stellenbosch; Stellenbosch

**Moorhouse, R., Slack, C., Quayle, M., Essack, Z., & Lindegger, G.** (2014). Stakeholder views of ethical guidance regarding prevention and care in HIV vaccine trials. *Biomedical Central (BMC): Medical Ethics*, 15(51), 1-11

**Mutenherwa, F., & Wassenaar, D.R.** (2014). Ethical review of social and behavioural

research in an African context. In **M. Kruger**, P. Ndebele & **L. Horn** (Eds.) *Research Ethics in Africa: A Resource for Research Ethics Committees*, (pp. 117-124). SUN MeDIA Stellenbosch; Stellenbosch

**Ndebele, P., Wassenaar, D.R., Benatar, S., Fleischer, T., Kruger, M., Adebamowo, C., Kass, N., Meslin, E., & Hyder, A.,** (2014). Research Ethics capacity building in Sub-Saharan Africa: A review of NIH Fogarty funded programs 2000-2012. *Journal of Empirical Research on Human Research Ethics*, 9(2), 24-40

**Ndebele, P., Wassenaar, D.R., Masiye, F., & Munalula, E.** (2014). Trial participants' understanding of randomization, double-blinding and placebo use in low literacy populations: Findings from a study conducted within a microbicide trial in Malawi. *Journal of Empirical Research on Human Research Ethics*, 9(10) 2-10

**Shah, S.K., Persaud, D., Wendler, D.S., Taylor, H.A., Gay, H., Kruger, M., Grady, C.** (2014). Research into a functional cure for HIV in neonates: the need for ethical foresight. *Lancet Infectious Diseases* 2014; doi: 10.1016/S1473-3099(14)70766-2

**Singh, N., & Wassenaar, D.R.** (2014). Development of an online research ethics training resource specific to South African Health law and guidance: A UKZN-MEPI funded project. In S. Zvacek, M.T Restivo, J. Uhomibhi, & M.C. Heifert (Eds.), *Proceedings of CSEDU 2014, 6th International conference on Computer Supported Education* (pp. 24-30). Barcelona: Scitepress

**Slack, C.** (2014). Ancillary care in South African HIV vaccine trials: Addressing needs, drafting protocols and engaging community. *Journal of Empirical Research on Human Research Ethics*, 9(1), 83-95

**Tsoka-Gwegweni, J., & Wassenaar, D.R.** (2014). Using the Emanuel framework to examine ethical issues raised by a biomedical research ethics committee in South Africa. *Journal of Empirical Research on Human Research Ethics* 9(5), 36-45. doi: 10.1171/1556264614553172

## Books:

Research Ethics in Africa. A Resource for Research Ethics Committees. Editors: **M Kruger**, P Ndebele, **L Horn**, Sun MeDIA Publishers, June 2014. ■

# SARETI Footprint : Trainees : 2002 - 2014

COUNTRY	STUDENTS
1 Botswana (2)	Mrs Boitumelo Mokgatlha-Moipolai Ms Dimpho Njadingwe
2 Burkina-Faso (1)	Dr Abdoulaye Diallo
3 Cameroon (2)	Mr Primus Chi Mrs Perpetua Akindeh
4 Ethiopia (1)	Dr Wellington Oyibo
5 Ghana (4)	Ms Evelyn Anane-Sarpong Ms Hannah Frimpong Ms Pamela Selormey Ms Irene Tsey
6 Kenya (4)	Ms Caroline Gikonyo Dr Moses Limo Mr Dickens Aduda Omondi Mr Francis Kombe
7 Libya (1)	Dr Omran El-Koha (CUSA)
8 Malawi (2)	Ms Janelisa Musaya Mr Abdallah Chilungo
9 Mali (1)	Juriste Awa Keita
10 Nigeria (13)	Dr Olubayo Fasola Dr Olawunmi Fatusi Prof Karniyus Gamaniel Dr David Irabor Dr Ogenna Manafa Dr Benjamin Olley Dr Kolawole Oyediji Dr Felix Chukwuneke Dr Odidika Umeora Dr Babatunde Adewale Dr Patrick Okonta Dr Eucharika Anunobi Dr Joseph Alimasunya (CUSA)
11 South Africa (4)	Prof Pauline Kuzwayo Ms Matsie Ratsaka-Mothokoa Mr Yandisa Sikweyiya Dr Elizabeth Lutge (CUSA)
12 Tanzania (5)	Prof Muhsin Aboud Mr Cuthbert Kabero Butendeli Mrs Joyce Ikingura Dr Asungushe Kayombo Dr Lumuli Mbonile
13 Uganda (2)	Dr Elizabeth Kwagala Dr Erisa Mwaka
14 Zambia (3)	Mr Bornwell Sikateyo Ms Nancy Soko Mr Jonathan Chinyama
15 Zimbabwe (9)	Mr Owen Mapfumo Mrs Rosemary Musesengwa Mr Paul Ndebele Dr Aceme Nyika Ms Sithembile Ruzairi Mr Farirai Mutenherwa Mr Claudius Madanhire Ms Samantha Chareka (CUSA) Ms Florence Mutevedzi

## SARETI-trained research ethics staff in Africa



SARETI GRADUANDS : 2013  
Mr Farirai Mutenherwa & Ms Sithembile Ruzairi (Zimbabwe)

Total number of  
SARETI-funded  
trainees:  
64

Total number  
of countries:  
15



SARETI GRADUANDS : 2014  
Dr Lumuli Mbonile (Tanzania)



## SARETI FACULTY MEMBERS and MODULE PRESENTERS 2013–2014

The following staff lectured during this period:

1. *Introduction to Bioethics:*  
Dr L Schoeman
2. *Professional Ethics in Health Research:*  
Professor Doug Wassenaar
3. *Culture, Morality and Comparative Ethics:*  
Professor Nhlanhla Mkhize
4. *Critical Issues in Informed Consent:*  
Dr Zaynab Essack  
Professor Graham Lindegger  
Dr Nicole Mamotte  
Professor Nhlanhla Mkhize  
Dr Pam McLaren  
Dr Ann Strode  
Ms Chitra Singh
5. *Ethical Issues in Community-Based Research:*  
Mr Vernon Solomon
6. *Ethical Issues in HIV Vaccine Trials:*  
Dr Cathy Slack  
Professor Graham Lindegger  
Dr Ann Strode  
Dr Zaynab Essack  
Dr Surita Roux  
Dr Janet Frolich
7. *Institutionalising Ethical Review of Health Research:*  
Professor Mariana Kruger  
Dr Lyn Horn  
Dr Nicola Barsdorf
8. *Ethical Issues in International Collaborative Health Research:* Professor Carel Ijsselmuiden

## SARETI EXECUTIVE MEMBERS

**Professor Doug Wassenaar**, PI

**Professor Mariana Kruger**, Co-PI

**Professor Nhlanhla Mkhize**, Deputy Co-PI

**Professor Carel Ijsselmuiden**, Senior Executive Member

## SARETI ADMINISTRATION

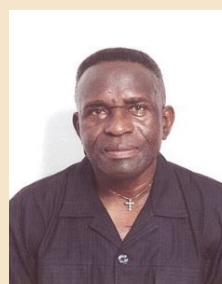
**Ms Carla Pettit**, Project Manager

## SARETI INTERNATIONAL ADVISORY BOARD MEMBERS 2012–2017



**Dr Nancy Kass** (ScD) is from the USA. Dr Kass is the Phoebe R. Berman Professor of Bioethics and Public Health in the Department of Health Policy and Management, Johns Hopkins Bloomberg School of Public Health, and Deputy Director for Public Health in the Berman Institute of Bioethics. Dr Kass is also the director of the Johns Hopkins Fogarty African Bioethics Training Program.

<http://www.jhsph.edu/faculty/directory/profile/362/nancy-kass>; [https://www.researchgate.net/profile/Nancy\\_Kass](https://www.researchgate.net/profile/Nancy_Kass)



**Prof Godfrey Tangwa** (PhD) is from Cameroon. Professor Tangwa is Professor of Philosophy and former Head of the Department of Philosophy at the University of Yaounde 1, Cameroon, and his teaching and research interests include African philosophy and Bioethics.

<http://www.fabtp.com/dr-godfrey-tangwa-cameroon/>; [https://www.researchgate.net/profile/Godfrey\\_Tangwa](https://www.researchgate.net/profile/Godfrey_Tangwa)



**Prof Catherine (Sassy) Molyneux** (PhD) is from Kenya. Dr Molyneux is an Associate Professor at Oxford University, based at the KEMRI-Wellcome Trust Research Programme in Kilifi, Kenya, since 1994. She has a PhD in behavioural studies, and is currently the chair of the Social Science and Ethics in Public Health theme in Kilifi.

<http://kemri-wellcome.org/author/sassy>; [https://www.researchgate.net/profile/Sassy\\_Molyneux](https://www.researchgate.net/profile/Sassy_Molyneux)



**Dr Aceme Nyika** (PhD, MPH) is from Tanzania. Dr Nyika is the Executive Director of Public Health Projects in Africa (PHPAfrica), and a former SARETI Masters class of 2004 student. Dr Nyika is currently a Faculty Research Co-ordinator, Health Sciences Research Office, University of the Witwatersrand.

<https://www.wits.ac.za/health/research/contact-us/>



**Prof Dominique Sprumont** is from Switzerland. Professor Sprumont is Professor of Health Law at the Law Faculty of the University of Neuchâtel (Switzerland) and Founder and Deputy Director of the Institute of Health Law of the University of Neuchâtel, one of the five academic centres of the World Medical Association.

<http://www2.unine.ch/dominique.sprumont>; [https://www.researchgate.net/profile/Dominique\\_Sprumont](https://www.researchgate.net/profile/Dominique_Sprumont)

# SARETI students and staff make significant contributions to a new book for RECs

**Research Ethics in Africa: A Resource for Research Ethics Committees**  
edited by Mariana Kruger, Paul Ndebele and Lyn Horn

In 2011 the European and Developing Countries Clinical Trials Partnership (EDCTP) funded a research ethics capacity development project that was a little different. The aim of this particular project was to bring together those that had benefited from EDCTP and Fogarty research ethics capacity building training programmes over the previous ten years, and were now actively working in the field of research ethics, to write a book on research ethics from a uniquely African perspective.

The primary aim of this book is to provide research ethics committee members in Africa with a practical guide intended to build capacity in Research Ethics governance in Africa. It will also be useful to researchers and to those working in related entities such as medicine regulatory authorities.

All the authors are currently active in various aspects of research ethics in Africa. The majority have been trained in bioethics training programmes sponsored by the European and Developing Countries Clinical Trial Partnership (EDCTP), or the Fogarty International Center of the NIH.

The book was initiated with an intensive workshop held in 2011, where the participants presented research ethics issues they felt were most relevant to the circumstances that obtain on the African continent, and these were debated.

The result was a consensus on the important topics dealing with research ethics from an African perspective. Chapters were then allocated to authors. After the workshop, additional authors were invited due to their particular expertise in specific research ethics topics.

This is potentially the first book dedicated to research ethics from an African

perspective. It has five parts.

Part I introduces the book, provides a history of research ethics in Africa and discusses the MARC project (the Mapping of Research Ethics Committees throughout Africa).

Part II, titled 'The Research Ethics Committee' (REC) comprises five chapters and covers the operation of an REC including running a meeting, developing standard operating procedures, etc.

Part III covers specific topics, for example, traditional medicine research, public health research, vulnerable participants, and risk benefit assessment.

Part IV is a section with valuable resources such as a chapter on educational resources.

Part V contains some useful templates.

*This book is available as a paper copy, and as an ebook free of charge to anyone residing in Africa.*

**Research Ethics in Africa: A Resource for Research Ethics Committees**  
Mariana Kruger, Paul Ndebele, Lyn Horn.  
2014 SUN MeDIA ISBN 978-1920689-30-8  
is available for download here:

<http://www.sun.ac.za/english/faculty/healthsciences/paediatrics-and-child-health/research-ethics-in-africa> ■



Editors of 'Research Ethics in Africa', **Dr Lyn Horn** and **Professor Mariana Kruger**, hope to build greater awareness of research ethics issues in Africa.



**Dr Paul Ndebele**, a University of KwaZulu-Natal (UKZN) PhD graduate who received specialised training in Research Ethics at UKZN through the SARETI Masters programme.