#### African Health Research Ethics Symposium (AHRES)

Umhlanga Rocks, South Africa 29 September – 1 October 2010



South African Research Ethics Training Initiative SARETI http://www.up.ac.za/sareti/sareti.htm

http://www.up.ac.za/sareti/sareti.htm earty International Center, National Institutes of Healt Grant Number 2 R25 TW01599-10



supplementary funding from:







#### SOUTH AFRICAN RESEARCH ETHICS TRAINING INITIATIVE (SARETI) **AHRES II PROGRAMME**

#### Durban, September 29th - October 1st 2010

# Wednesday 29 September Morning: Session 1: Ethical Issues in Clinical Trials

Session chairs: Paul Ndebele and Elizabeth Kwagala

•	0850-0900:	Welcome and opening remarks:
		Doug Wassenaar
•	0900-0920	Olawunmi Fatusi
		Legitimising economic benefits from clinical trial participation (M Ukpong & O Fatusi).
•	0920-0940	Francis Jaji
		Perceptions of women participating in a clinical trial in Chitungwiza,
		Zimbabwe.
•	0940-1000	Mariana Kruger
		Paediatric clinical trials in developing countries – Ethical issues.
•	1000-1020	Farirai Mutenherwa
		A case study to assess participants' perceptions on voluntariness and
		motivations for participating in a clinical trial in Zimbabwe.
•	1020-1030	Discussion
•	1030-1100	TEA BREAK

#### **Wednesday 29 September Morning:**

Session 2: Oversight of Research Ethics Committees

Session Chairs: Mariana Kruger and Dickens Aduda Omondi

• 1100-1120	Rekha Kumar
	Research misconduct and research intensification: Some ethical
	dilemmas. The case of University of Botswana.
<ul><li>1120-1140</li></ul>	Patrick Okonta
	Perception of research misconduct among obstetricians and
	gynaecologists in Nigeria.
<ul><li>1140-1200</li></ul>	Moses Limo
	Biosafety regulatory systems in Kenya: challenges and opportunities.
<ul><li>1200–1220</li></ul>	Boitumelo Mokgatla-Moipolai
	Ethics of HIV/AIDS Research: Botswana challenges.
<ul><li>1220–1240</li></ul>	Discussion
<ul><li>1240–1345</li></ul>	LUNCH

## **Wednesday 29 September Afternoon:**

#### Session 3: Education & Capacity Strengthening in Research Ethics

Session chairs: Odidika Umeora and Evelyn Anane-Sarpong

•	1345-1405	Derrick Elemu
		Ethics training in medical and health sciences education in Zambia.
•	1405-1425	Janelisa Musaya
		The ethics of health and medical research reporting in the Malawian
		press.
•	1425-1445	Azza Radwan
		Regional Documentation and Information Center for Bioethics and
		Ethics of Science and Technology (RDIC-BEST).
•	1445-1505	Doug Wassenaar
		Review of SARETI I and SARETI II – where to from here?
•	1505-1515	Discussion
•	1515-1545	TEA BREAK

### Wednesday 29 September Afternoon: Session 4: Diverse Topics in Research Ethics

Session chairs: Primus Chi and Boitumelo Mokgatla-Moipolai

•	1545-1605	Elizabeth Kwagala
		Social-cultural sensitivities and value system challenges to counselling
_	1605-1625	in Uganda.
•	1005-1025	Benjamin Olley
		From Vilnius to Aro: An investigation of the mentally ill patient's
		awareness of their rights in treatments.
•	1625-1645	Dickens Aduda Omondi
		Ethical issues in screening populations for disease: frameworks for
		policy decisions and clients' perspectives in Kenya.
•	1645-1705	Yandisa Sikweyiya
		Disclosure of child murder: A case study of ethical dilemmas in
		research.
•	1705-1725	Evelyn Anane-Sarpong
		Stakeholder perceptions of the ethics of qualitative health research in
		Ghana.
•	1725-1745	Discussion
•	1800	DRINKS

## **Thursday 30 September Morning:**

#### Session 5: Research Ethics Committees 1

Session chairs: Janelisa Musaya and Patrick Okonta

•	0830-0845	Housekeeping & announcements
•	0845-0905	Kolawole Oyedeji
		Resources and needs of health research ethics committees in
		Southwestern Nigeria.
•	0905-0925	Lumuli Mbonile
		Behind closed doors: Research ethics committees and ethics of research involving marginalised groups in Africa.
•	0925-0945	Nancy Soko
		Legal, policy and institutional frameworks regarding ethics review committees in Zambia.
•	0945-1005	Odidika Umeora
		Organisational structure, operations and training needs of research ethics committees in Southeast Nigeria.
•	1005-1025	Primus Chi
	1000 1020	Profile of ethics committees in Cameroon.
•	1025-1045	Discussion
•	1045-1100	TEA BREAK

#### **Thursday 30 September Morning:**

1300-1400

#### Session 6: Research Ethics Committees 2

LUNCH

Session Chairs: Sithembile Ruzariro and Farirai Mutenherwa

• 1100-1120	Asungushe Kayombo Participants' voluntariness and understanding of a feasibility study to assess potential cohort suitability for future microbicide trials in North Western Tanzania.
• 1120-1140	Mary Kasule
	HIV clinical trial consent forms: Readability and understandability.
<ul><li>1140-1200</li></ul>	Caroline Kithinji
	The ethics review process in KEMRI.
<ul><li>1200–1220</li></ul>	Onochie Okoye
	Random musings on "Ten questions Institutional Review Boards should ask when reviewing international clinical research protocols" – The Nigerian scenario.
<ul><li>1220–1240</li></ul>	Azza Radwan
	Implementation of Egyptian Network of Research Ethics Committees (ENREC).
• 1240-1300	Discussion

#### Thursday 30 September Afternoon: Session 7: Issues in Informed Consent

Session chairs: Asungushe Kayombo and Nancy Soko

• 1400–1420	Babatunde Adewale
	Assessing participants' understanding and voluntariness of informed
	consent in a clinical trial in Nigeria.
<ul><li>1420–1440</li></ul>	Lizette Schoeman
	Informed Consent – a new look.
<ul><li>1440–1500</li></ul>	Theresa Rossouw
	To be or not to be a person: Implications for autonomy.
<ul><li>1500-1520</li></ul>	Discussion
<ul><li>1520–1545</li></ul>	TEA BREAK
<ul><li>1545–1605</li></ul>	Paul Ndebele
	Improving microbicide trial participants' understanding of
	randomisation, double-blinding and placebo use: A pilot intervention in
	Malawi.
<ul><li>1605–1625</li></ul>	Nhlanhla Mkhize
	Community members' conceptions of research and research
	collaboration (with Nondumiso Zukelwa).
<ul><li>1625–1645</li></ul>	Discussion
• 1645-1800	SARETI Masters students and Fellows: Business meeting with SARETI
	Executive and Academic Staff.
• 1830	SARETI DINNER: Kashmir Restaurant

#### **Friday 1 October Morning:**

### **Session 8: Ethical Issues in HIV Research**

Session Chairs Yandisa Sikweyiya and Rekha Kumar

0000 0050	
<ul><li>0830-0850</li></ul>	Housekeeping & Announcements
<ul> <li>0850-0910</li> </ul>	Sithembile Ruzariro
	The role of the Medical Research Council of Zimbabwe (MRCZ) in
	empowering communities in Zimbabwe in HIV/AIDS Prevention
	Studies.
<ul><li>0910-0920</li></ul>	Zaynab Essack
	HIV prevention in prophylactic HIV vaccine trials in South Africa: A
	normative and empirical exploration of decision-making.
<ul><li>0920-0940</li></ul>	Nicole Mamotte
	The ethical engagement of injection drug users in HIV research in Africa.
<ul> <li>0940–1010</li> </ul>	Closing Keynote Address:
	<b>Carel IJsselmuiden:</b> Creating interactive health research ethics review
	in Africa – the MARC Project (with Boitumelo Mokgatla-Moipolai and
	Doug Wassenaar).
<ul> <li>1010–1030</li> </ul>	Discussion
<ul><li>1030–1045</li></ul>	TEA BREAK
• 1045-1100	Award for best presentation, thanks and closing remarks

#### • 1200 LUNCH

SARETI is sponsored by a competitive grant no. 5 R25 TW001599-10 from the US National Institutes of Heath Fogarty International Center. SARETI is a collaborative programme based at the School of Psychology, University of KwaZulu-Natal and the School of Medicine, University of Pretoria.

Additional delegates were funded by a generous grant from the UK Wellcome Trust grant no.  $\,$  WT093495MA  $\,$ 

## **AHRES 2010 PARTICIPANTS**

Curnomo	Nama		Email	ABSTRACT TITLE
Surname	Name	Country	Eilidii	
Adewale (Dr)	Babatunde	Nigeria	Tundeb2005@yahoo.com	Assessing participants' understanding and voluntariness of informed consent in a clinial trial in Nigeria.
Adudo (Mr)	Dickens	Konyo	amondiada@yahaa aam	Ethical issues in screening populations for disease: frameworks for policy decisions and clients' perspectives in Kenya.
Aduda (Mr)	Dickens	Kenya	omondisda@yahoo.com	clients perspectives in Kenya.
Anane-Sarpong (Ms)	Evelyn	Ghana	evelynanane@yahoo.com	Stakeholder perceptions of the ethics of qualitative health research in Ghana.
Chi (Mr)	Primus	Cameroon	chi_primus@yahoo.com	Profile of ethics committees in Cameroon.
Chukwuneke (Dr)	Felix	Nigeria	ichiefn2002@yahoo.com	Good clinical practice, ethics and clinical trials in Nigeria: the journey so far.
Diallo (Dr)	Abdoulaye	Burkina Faso	diallohama@hotmail.com / hamadial@yahoo.fr	Teaching bioethics to doctors: experience from the Bobo-Dioulasso University School of Medicine, Burkina Faso.
Elemu (Mr)	Derrick	Zambia	delemu@yahoo.com	Ethics training in medical and health sciences education in Zambia.
Essack (Ms)	Zaynab	South Africa	essack@ukzn.ac.za	HIV prevention in prophylactic HIV vaccine trials in South Africa: A normative and empirical exploration of decision-making.
Fatusi (Dr)	Olawumni	Nigeria	ofatusi@yahoo.com	Legitimising economic benefits from clinical trial participation (M Ukpong & O Fatusi).
IJsselmuiden (Prof)	Carel	Switzerland	carel@cohred.org	Creating interactive health research ethics review in Africa - The MARC Project.
Jaji (Mr)	Francis	Zimbabwe	francis@uz-ucsf.co.zw_	Perceptions of women participating in a clinical trial in Chitungwiza, Zimbabwe
Kachedwa (Mr)	Mike	Malawi	kachedwa@msu.edu / kachedwa@ncst.mw	Observer
Kasule (Ms)	Mary	Botswana	mkasule@gmail.com	HIV clinical trial consent forms: Readability and understandability
Kayombo (Dr)	Asungushe	Tanzania	asungushe@yahoo.com	Participants' voluntariness and understanding of a feasibility study to assess potential cohort suitability for future microbicide trials in North Western Tanzania.
Kithinji (Ms)	Caroline	Kenya	rckithinji@gmail.com	The ethics review process in KEMRI.
Kruger (Prof)	Mariana	South Africa	marianakruger@sun.ac.za	Ethical Issues in clinical trials in the developing world
Kumar (Dr)	Rekha	Botswana	kumar@mopipi.ub.bw	Research misconduct and research intensification: some ethical dilemmas. The case of University of Botswana.
Kwagala (Dr)	Elizabeth	Uganda	elkwagala@yahoo.com	Social-cultural sensitivities and value system challenges to counselling in Uganda.
Limo (Dr)	Moses	Kenya	mklimoh@yahoo.com	Biosafety regulatory systems in Kenya: challenges and opportunities.

Surname	Name	Country	Email	ABSTRACT TITLE
Mamotte (Ms)	Nicole	South Africa	mamotten@ukzn.ac.za	The ethical engagement of Injection Drug Users in HIV research in Africa.
Mbonile (Dr)	Lumuli	Tanzania	Imbonile@gmail.com	Behind closed doors: Research ethics committees and ethics of research involving marginalised groups in Africa.
Mkhize (Prof)	Nhlanhla	South Africa	mkhize@ukzn.ac.za	Community members' conceptions of research and reseach collaboration (with Nondumiso Zukelwa)
Mokgatla-Moipolai (Mrs)	Boitumelo	Botswana	mokgatla@cohred.org	Ethics of HIV/AIDS Research: Botswana challenges.
Musaya (Ms)	Janelisa	Malawi	jmusaya@yahoo.com	The ethics of health and medical research reporting in the Malawian press.
Mutenherwa (Mr)	Farirai	Zimbabwe	fmutenherwa@brti.co.zw	A case study to assess participants' perceptions on voluntariness and motivations for participating in a clinical trial in Zimbabwe.
Ndebele (Mr)	Paul	Zimbabwe	pndexas@yahoo.com	Improving microbicide trial participants' understanding of randomisation, double-blinding and placebo use: a pilot intervention in Malawi.
Njadingwe (Ms)	Dimpho	Botswana	dnjadingwe@yahoo.com	Observer
Okonta (Dr)	Patrick	Nigeria	patrickokonta@yahoo.com	Perception of research misconduct among obstetricians and gynaecologists in Nigeria.
Okoye (Dr)	Onochie Ikechukwu Chiedozie	Nigeria	onochie@westafricanbioethics.net	Random musings on "Ten questions Institutional Review Boards should ask when reviewing international clinical research protocols" - The Nigerian scenario.
Olley (Dr)	Benjamin	Nigeria	Olley28@yahoo.com	From Vilnius to Aro: an investigation of the mentally ill patients' awareness of their rights in treatments.
Oyedeji (Dr)	Kolawole	Nigeria	kolaremi95@yahoo.com	Resources & needs of health research ethics committees in Southwestern Nigeria.
Radwan (Dr)	Azza	Egypt	azzasaleh@hotmail.com	Implementation of Egyptian network of research ethics committees (ENREC).
Rossouw (Prof)	Theresa	South Africa	ducati999@mweb.co.za	To be or not to be a person - implications for autonomy.
Ruzariro (Ms)	Sithembile	Zimbabwe	sithembileruzario@yahoo.co.uk	The role of the Medical Research Council of Zimbabwe (MRCZ) in empowering communities in Zimbabwe in HIV/AIDS prevention studies.
Schoeman (Dr)	Lizette	South Africa	lizette.schoeman@up.ac.za	Informed Consent – a new look.
Sikweyiya (Mr)	Yandisa	South Africa	yandisa.sikweyiya@mrc.ac.za	Disclosure of child murder: a case study of ethical dilemmas in research.
Soko (Ms)	Nancy	Zambia	nancysoko2005@yahoo.co.uk	Legal, policy and institutional frameworks regarding ethics review committees in Zambia.
Umeora (Dr)	Odidika	Nigeria	oujair@yahoo.com	Organisational structure, operations and training needs of research ethics committees in Southeast Nigeria.
Wassenaar (Prof)	Doug	South Africa	wassenaar@ukzn.ac.za	Review of SARETI I and SARETI II - where to from here?

#### SECOND AFRICAN HEALTH RESEARCH ETHICS SYMPOSIUM



Delegates at the African Health Research Ethics Symposium (AHRES II).

The South African Research Ethics Training Initiative (SARETI), a project funded by the US NIH Fogarty International Center, based at the UKZN School of Psychology on the Pietermaritzburg campus, in collaboration with the School of Medicine, University of Pretoria, directed by Professor Doug Wassenaar, hosted the second African Health Research Ethics Symposium (AHRES II) in Umhlanga Rocks, from September 29 to October 1.

The Symposium was attended by 39 delegates from 12 African countries, including the Director of the Council on Health Research for Development (COHRED), Professor Carel IJsselmuiden, who is based in Geneva, Switzerland and the Dean of Humanities at UKZN, Professor Nhlanhla J Mkhize.

This event, which is held every four years, aims to bring together all graduates of the SARETI programme, the SARETI Executive, and African scholars in research ethics. It is a forum for SARETI graduates to present their research work in the field of health research ethics and demonstrate how they have implemented their SARETI training in their home countries. This forum also allows SARETI trainees to build a collective identity and to network with trainees from similar programmes and with African experts in this area in general.

The Symposium was also attended by other interested parties thanks to a supplementary grant from the UK Wellcome Trust.