



University of Pretoria

SARETI Newsletter: First Semester 2004



SARETI - the South African Research Ethics Training Initiative is a research ethics training programme funded by a grant from the Fogarty International Center and the US National Institutes of Health (<http://www.fic.nih.gov>) SARETI provides Masters-level training in research ethics and non-degree training for members of African Research Ethics Committees, researchers and other stakeholders. The SARETI curriculum is multidisciplinary, combining skills and resources from the University of Pretoria and the University of KwaZulu-Natal. SARETI aims to provide advanced training in research ethics relevant to the health and research needs of the African continent, and hopes to promote and foster African scholarship in research ethics.

This, our second newsletter, provides an overview of the activities of our second year of activity, and continues as part of a series of regular updates and communications about SARETI.

1. SARETI SCHOLARS AND FELLOWS

- Between September and November 2003 we recruited our second group of SARETI scholars and fellows. We received 38 applications from 12 African countries.
- Of these, we accepted four MPH SARETI scholars (two from Zimbabwe, one from Nigeria, and one from Mali). To date they have successfully completed half of the MPH coursework and are progressing well on their research dissertations. They have also just returned from a spell of coursework at Johns Hopkins University (<http://www.hopkinsmedicine.org/bioethics/research/ire/fogarty.html>) and the Kennedy Institute of Ethics at Georgetown University (<http://www.georgetown.edu/research/kie>).
 - Our scholars are:
 - Ms Awa Keita (Mali)
 - Dr Ogenna Manafa (Nigeria)
 - Dr Aceme Nyika (Zimbabwe)
 - Ms Rosemary Musesengwa (Zimbabwe)
 - We also accepted three non-degree SARETI fellows (one from Ethiopia, one from Burkina-Faso, and one from Kenya) who have all successfully completed their coursework and returned to their home countries.
 - Our fellows are:
 - Dr Hama Diallo (Burkina Faso)
 - Dr Wellington Oyibo (Ethiopia)
 - Dr Moses Limo (Kenya)

South African Research Ethics Training Initiative SARETI

<http://shsph.up.ac.za/sareti.htm>

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- Our partially self-funded fellow from Zimbabwe has provisionally enrolled for a PhD on the Pietermaritzburg campus. SARETI matched in kind his funding from Scholars at Risk (see <http://scholarsatrisk.nyu.edu/>)
- Our 2004 group comprises 3 women and 4 men. Selection was merit based.
- SARETI also enrolled and trained 9 members of South African Research Ethics Committees for the intensive 3-week course for members of Research Ethics Committees. The following departments and their respective ethics committees were represented: the Department of Paediatrics & Child Health, MEDUNSA; the Department of Nursing, University of the Western Cape; the Gauteng Department of Health; the Polokwane Mankweng Hospital Complex (PMHC); Pharma-Ethics; The Women's Leadership & Training Programme; and the Ekurhuleni Metropolitan Municipality.
- Collaborative writing projects between fellows, scholars and faculty are ongoing.
- SARETI students continue to attend and contribute to a number of meetings of RECs and IRBs in Pretoria and will do so in KwaZulu-Natal in the second semester of 2004.
- SARETI scholars and fellows on return home have been active in improving health review systems and review in Nigeria, Tanzania, and Zimbabwe to date:
 - Mrs Joyce Ikingura participates regularly in discussions and gives advice on ethical issues in research proposals at Research Ethics Committee meetings held monthly at the NIMR in Tanzania.
 - Since returning to Zimbabwe at the end of last year, 2003 scholar, Mr Owen Mapfumo has been involved in reviewing research proposals submitted to the MRC of Zimbabwe for ethical and scientific soundness. He has also been a co-facilitator at workshops on ethical issues in PPTCT, and on introductions to research ethics at the University of Zimbabwe Medical School.
 - Professor Pauline Kuzwayo, representing SARETI and the MEDUNSA Research Ethics Committee coordinated a two-day workshop in ethical issues in medical research in June 2004. This included presentations by a number of key ethicists from around South Africa.
 - Upon returning home, Dr Hama Diallo, our 2004 fellow from Burkina Faso, drafted a proposal for training and is currently working on collaborations with NEBRA for ongoing development and training in health research where needed.
 - Dr Ogenna Manafa was sponsored by SARETI to attend the 5th Global Bioethics Forum in Paris in April 2004. She also continues to consult on her local and national ethics committees in Nigeria, and was involved in the drafting of the standard operating procedure guidelines for the local and national ethics committees.
 - At the invitation of 2003 SARETI fellow Professor Karniyus Gamaniel, SARETI Executive member Dr Carel IJsselmuiden will present a paper at the meeting of the West African Network of Natural Product Research Scientists (WANNPRES) in Nigeria in August 2004.
 - Prof Gamaniel was also the keynote address speaker at the Federation of Indian Chambers of Commerce and Industry (FICCI), Voluntary Health Education and Rural Development Society (VHERDS) and Times Foundation India, where he delivered a lecture on the ethics and procedural issues involved in herbal medicine development.
 - Prof Gamaniel has also been involved in developing draft standards of procedure for the Gede AIDS and Infectious Diseases Research Institute (GAIDRI).

2. SARETI PROGRAMME

- The ratification of the University of KwaZulu-Natal as the grantholding institution for SARETI has been confirmed by Fogarty International Centre and the NIH as from January 1st 2004. The University of Pretoria remains an integral partner to this programme.
- The SARETI website has been revised and updated - see <http://shsph.up.ac.za/sareti.htm>
- SARETI staff are collaborating with Dr F Hirsch of the Institut National de la Santé et de la Recherche Médicale (INSERM) in Paris to assist in developing research ethics training for Francophone African countries which cannot access SARETI training, which is in the English medium. One 2004 trainee is from Mali and another from Burkina Faso.
- Mr Doug Mansfield has begun work on a module on research ethics for animal research to supplement the other SARETI modules.
- The Informed Consent module has been shortened as components have been assigned to new modules. Ms Nicola Barsdorf, an MHS graduate fellow of the Johns Hopkins Bioethics Programme has been appointed to convene the Informed Consent module for 2004.
- The new module "Children and Health Research" will be offered in 2004, convened by Professor Mariana Kruger.
- SARETI has continued to contribute to bioethics book and journal holdings in the libraries of both the universities of Pretoria and KwaZulu-Natal.
- The University of Natal formally merged with the University of Durban-Westville in January 2004 and became the largest university in South Africa. The merged university is now known as the University of KwaZulu-Natal (UKZN) see <http://www.ukzn.ac.za/> .

3. SARETI EXECUTIVE AND LECTURING STAFF

- **The SARETI Executive for 2004 is:**
- **Dr Doug Wassenaar: Principal Investigator**
- **Professor Mariana Kruger: Co-Principal Investigator (Pta)**
- **Dr Nhlanhla Mkhize: Co-Principal Investigator (KZN)**
- **Dr Theresa Rossouw: Deputy Co-Principal Investigator (Pta)**
- **Professor Linda Richter: Deputy Co-Principal Investigator (KZN)**
- **Professor Carel IJsselmuiden: Senior Executive Member**
- **Nasreen Khan: Administrator (Pta)**
- **Debbie Marais: Administrator (KZN)**

- We warmly welcome Drs Nhlanhla Mkhize (UKZN) and Theresa Rossouw (UP) to the SARETI Executive as from March 2004.
- Dr Donna Knapp van Bogaert resigned from the SARETI Executive for personal reasons. Fortunately Dr van Bogaert will still teach on SARETI modules and remain the coordinator on the Introduction to Bioethics module. We thank Donna for her support to the SARETI Executive and students.
- The SARETI Executive has met monthly throughout 2004 and met regularly with the group of scholars and fellows.

- SARETI academic staff have contributed papers and presentations in 2004 at several international and national meetings and congresses,
 - **Dr Nhlanhla Mkhize:**
 - Mkhize, N. (2004). "Social Reality, Clinical Reality and Culture: Implications for Moral and Ethical Decision-making in health-related research" Paper presented at the Annual Meeting of the Wellcome Trust/KEMRI Research Unit, Kilifi, Kenya (March 9-12, 2004)
 - Mkhize, N. (2004) "African perspectives of autonomy and their implications for IRBs." Paper presented at the workshop titled "Partnership for Enhancing Human Research Protection", held in Blantyre, Malawi (31 May to 4 June 2004)
 - Mkhize, N. (2004). "Methodological considerations in health-related social science research." Paper presented at the workshop titled "Partnership for Enhancing Human Research Protection", held in Blantyre, Malawi (31 May to 4 June 2004)
 - 5th Global Forum on Bioethics in Research. Paris, France, April 22-23, 2004 (attended and chaired a session).
 - He has also been appointed to serve on the UKZN REC and on the REC of the Nelson R Mandela School of Medicine Research Ethics Committee from July 2004.
 - Dr Mkhize has been invited to present a paper at the PRIM&R (Public Responsibility in Medicine and Research) 2004 Annual IRB Conference. San Diego, CA. (29-30 October, 2004). His paper will focus on "Indigenous conceptions of personhood, health and illness: Implications for IRBs."
 - Dr Mkhize's paper on "Indigenous Selves and Ethical Decision-making: Towards Dialogue between Universalism and Communalism in Ethics", has been accepted for presentation at the 7th World Congress of Bioethics, University of New South Wales, Sydney, Australia (9-12 December, 2004).
 - Presentation to medical staff and postgraduate students, Faculty of Health Sciences, University of Pretoria.
 - **Professor Mariana Kruger**
 - Attendance and participation by invitation: Nuffield Council on Bioethics (<http://www.nuffieldbioethics.org/home>): Workshop on the ethics of research related to healthcare in developing countries: 12 - 14 February 2004, Cape Town.
 - Invited Lecture: "Informed Consent in clinical drug trials": Annual Congress of the Neurological Association of South Africa: 10-13 March 2004: MEDUNSA: The MEDUNSA Research Ethics Committee: Workshop in Research Bioethics Medunsa June 3 - 4 2004: Ethics in Vaccine Trials.
 - HEARD – UKZN (<http://www.ukzn.ac.za/heard>): Invited to this workshop as participant: HIV/AIDS Orphan Researcher Workshop: 31 May 2 June 2004, Durban.
 - HAVEG (see <http://www.saavi.org.za/haveg.htm>): Invited workshop participant: Ethical Issues in HIV vaccine trials: Children and Adolescents.
 - **Dr Theresa Rossouw**

Lectures given:

 - The Ethics of Nutrition: Obesity in Children. 01/06/2004. Nutrition and Paediatric Congress, University of Pretoria: Feeding for Optimal Child Health. Nestle Nutrition Institute Africa
 - Female Genital Mutilation and Human Rights. 03/06/2004. O&G Private Practice Association.

Lectures attended:

 - Prof. RJ Levine. 28/06/2004. Historical Perspective on Biomedical Ethics. University of Pretoria
 - Prof. Norman Daniels on Justice approaches to fair distribution of ARV treatment in developing countries. Africa Centre, Hlabisa, see <http://www.africacentre.ac.za/> .

Meetings attended:

 - Private meeting with Prof RJ Levine to discuss SARETI. 30/06/2004. On the strength of this meeting Professor Levine has expressed interest in contributing to the SARETI programme in future.

- **Dr Doug Wassenaar**
 - Kenya: KEMRI/Wellcome Trust: Wassenaar, D.R. (2004). Issues in the ethical review of health research in developing countries. Paper presented at Annual research conference, Kenyan Institute for Medical research (KEMRI)/Wellcome Trust, Kilifi, Kenya.
 - Kenya: KEMRI/Wellcome Trust: Wassenaar, D.R. (2004). What makes research ethical? Paper presented at Annual research conference, Kenyan Institute for Medical research (KEMRI)/Wellcome Trust, Kilifi, Kenya.
 - HSRC Annual research Conference, Johannesburg, July. – Wassenaar, D.R. Costs, risks and benefits: Issues in the ethical review of social science research. Invited Plenary Lecture. (Co – panelists: Chair: Dr P Cleaton-Jones, Dr J Singh (CAPRISA), Prof. U Schuklenk (Wits), Dr R Southall, (HSRC)).
 - Attended presentations by Dr E Emanuel, (NIH Bioethics Centre) – Access to Treatment in developing Country Research; Elements of a successful bioethics research centre.
 - Co-facilitated with Dr N Mkhize the HAVEG consultative forum on the ethical-legal framework for enrollment of children and adolescents in HIV Vaccine trials in South Africa, July 2004, see <http://www.saavi.org.za/haveg.htm>
- **Dr Carel IJsselmuiden**
 - Attended the Global Forum for Bioethics in Research (Forum 5) in Paris in April 2004. Besides issues related to the conference, discussions focused on the Council on Health Research for Development's (COHRED: see <http://www.cohred.ch>) hosting of the Secretariat for the GFBR, which was agreed subject to funding being procured.
 - Invited to attend and address a meeting in Ghana in August on ethical aspects in traditional medicine research, together with his former SARETI student, Karniyus Gamaniel.
- Mr Doug Mansfield has assisted the SA MRC with the revision of their ethical guidelines on the use of animals in research.
- SARETI co-funded Professor Tiaan de Jager to attend the Research Skills for Health Professionals course at Oxford University from 10 – 20 May 2004, to contribute to his coordination and teaching of the SARETI module on “Evaluating Research Designs”. The course focused on research designs and research skills for health professionals with some experience in the field. It addressed important issues and gave the candidates the necessary tools to do proper research. Valuable information was also gathered to improve current courses in research methodology, research designs and ethics.
- SARETI staff have continued to make contributions to the development of Health Research Ethics infrastructure nationally, and continue to serve on a number of key national, regional and university REC's and IRBs, and contribute research ethics inputs to other major research institutes (e.g. the UNAIDS African AIDS Vaccine Programme, the HIV AIDS Vaccines Ethics Group (HAVEG), the Africa Centre, Mtubatuba, and the Human Sciences Research Council.
- Ms Debbie Marais (B.A. Hons.) has been promoted to senior SARETI administrator for the Pietermaritzburg office. Ms Nasreen Khan has taken over the Pretoria SARETI administration.
- Drs Theresa Rossouw and Doug Wassenaar attended a presentation by Dr Norman Daniels of Columbia University held at the Africa Centre, Mtubatuba. Melissa Stobie and Nicola Barsdorf also attended.
- Dr Theresa Rossouw attended a presentation by Dr R J Levine of Yale University and also had an opportunity to discuss SARETI with Dr Levine. Dr Levine expressed interest in contributing to the SARETI programme.
- Dr Doug Wassenaar has been invited to serve on the steering committee of the Bioethics Strategic Research Initiative at the University of KwaZulu-Natal 2004.

- SARETI and HAVEG at UKZN co-hosted a visit by Dr Zeke Emanuel (NIH Bioethics), kindly sponsored by the Nelson Mandela School of Medicine REC (c/o Professor Ames Dhai) and the South African MRC. Dr Emanuel gave a talk on “An approach to the Standard of Care debate in research in developing countries”.

4. THANKS

- The SARETI Executive thanks the following persons for their active contributions to and support of the SARETI programme:

Professor Kuku Voyi, Head of the School of Health Systems and Public Health, University of Pretoria.

Shaun Schoeman, Finance Officer at the School of Health Systems and Public Health, University of Pretoria.

Members of the SARETI International Advisory Board for support and contributions on various matters.

We welcome your comments on this newsletter and any other aspect of the SARETI programme. Please direct these to maraisd@ukzn.ac.za

The 2004 SARETI EXECUTIVE:

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Mariana Kruger

Nhlanhla Mkhize

Theresa Rossouw

Linda Richter

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Administrators:

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