South African Research Ethics Training Initiative

SARETI Newsletter 2002-2003

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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. 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 world class 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 newsletter provides an overview of the activities of our first year of activity, and is the first of what will become a series of more frequent updates and communications about SARETI.

1. SARETI SCHOLARS AND FELLOWS

- Between September and November 2002 we recruited our first SARETI scholars and fellows. We received 43 applications from 14 of 29 Anglophone African countries.
 - Of these, we accepted two MPH SARETI scholars (one from Zimbabwe, one from Tanzania). To date they have successfully completed all the coursework and examinations of the MPH, and are progressing well on their research dissertations.
 - We also accepted four non-degree SARETI fellows (one from Zimbabwe, two from Nigeria, one from South Africa) who have all successfully completed their coursework and examinations.
 - One partially self-funded fellow from Zimbabwe was enrolled and has completed the coursework and examinations and 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 2003 group comprised equal numbers of women and men. All our trainees were black. Selection was merit based.
 - Three self-funded applicants for PhD study in SARETI were received for 2003. We decided not to accept these due to the pressure of getting our core Masters programme up and running for 2003.
 - The 2003 selections were ratified by a meeting of the SARETI executive and the SARETI International Advisory Board, which was attended by Drs Cordier and Mwinzi. Apologies were received from the remaining International Advisory Board members.
- We have recruited and selected our trainees for 2004. We received 38 applications from 12 African countries.
 - Selection of four Masters scholars and four non-degree fellows for 2004 is complete. In addition, two of ten places for REC/IRB members have been filled for the REC/IRB short course. Recruitment is ongoing.
 - Our 2004 group is 60% women and 40% men. All but one of these are black.
 Again, selection was primarily merit based.

- Applications for the Ethics Review Committee Training Programme short Course are currently open.
- Collaborative writing projects between fellows, scholars and faculty have been initiated. One book chapter (Wassenaar & IJsselmuiden) has been submitted and several papers are in draft format.
- SARETI students attended and contributed to a number of meetings of RECs and IRBs in Pretoria and KwaZulu-Natal.
- The two SARETI Masters scholars attended the summer programmes in bioethics and international research ethics at Johns Hopkins and the Kennedy Institute of Ethics at Georgetown University, as part of the SARETI scholarship curriculum.
- Dr A Nyika was awarded the prize for the best research presentation at the School of Psychology Annual Postgraduate Research Conference.
- SARETI fellow Prof. K. S. Gamaniel of Nigeria has been invested by President
 Obasanjo of Nigeria as Officer of the Order of the Niger (OON) "In recognition of his
 remarkable contributions to the health sector of the nation and University medical
 scholarship in the field of pharmacology and medicine". SARETI was mentioned in
 President Obasanjo's citation. Professor Gamaniel has been instrumental in the
 establishment of the Nigerian National Ethics Review/Research Board.



Mr Owen Mapfumo - SARETI scholar, Zimbatwe: Dr Doug Wassenaar - SARETI Co-Director UNP; Dr Aceme Nyika - SARETI Fellow, Zimbatwe: Dr Ogenna Manafa - SARETI Fellow, Nigeria; Ms Melissa Stobie - SARETI lecturer, UNP; Prof Graham Lindegger - SARETI lecturer UNP; Prof Mariana Kruger - SARETI Co-Director, University of Pretoria; Ms Joyce Ikingura - SARETI Scholar, Tanzania Ms Deobie Marais - SARETI administrator, UNP; Ms Bronwyn Moffest - SARETI administrator, University of Pretoria.

2. SARETI PROGRAMME

- Version I of the SARETI website was set up late in 2002, has been updated regularly and is due to be revised soon - see http://shsph.up.ac.za/sareti/sareti.htm
- A multidisciplinary research ethics training workshop for REC/IRB members was held in Pretoria in November 2003 in collaboration with the HIV AIDS Vaccines Ethics Group (HAVEG). This was attended by over 40 REC/IRB members. Formal feedback was overwhelmingly positive.
- Dr Reidar Lie (University of Bergen and NIH Bioethics Centre) was brought to South Africa for a SARETI faculty training workshop. In addition, he delivered papers to REC's at the Universities of the Witwatersrand and Pretoria. His visit was cosponsored by HAVEG for whom he contributed to a working group revising the South African guidelines on health research involving children.
- An independent reviewer (Professor L J van Bogaert) was commissioned to conduct a review of the SARETI modules to advise on programme coherence and coverage, with a view to improving the programme for 2004. The reviewer's report has been received and many items are proposed for discussion and possible revision.

- Each SARETI module was evaluated quantitatively and qualitatively by our students.
 Feedback is available to all staff and adjustments are being made to modules where indicated.
- Mr Banson Barugahare, Senior Research Scientist and bioethics scholar at the Joint Clinical Research Centre, Kampala, Uganda, contributed to the SARETI module on International Collaborative Research with Prof IJsselmuiden. Mr Barugahare was also invited to comment on aspects of the SARETI programme, and made helpful suggestions.
- Dr J Singh, Head of the Bioethics Research Programme, Centre for the AIDS
 Programme of Research in South Africa (CAPRISA) was jointly hosted by HAVEG
 and SARETI to deliver a seminar in Pietermaritzburg entitled HIV/AIDS research at
 the Centre for the AIDS Programme of Research in South Africa: Current ethical,
 legal and social issues. Dr Singh is a fellow of Dr Peter Singer's Toronto Fogarty
 Bioethics programme. Informal discussions have taken place to include contributions
 from Dr Singh in SARETI's 2004 programme.
- SARETI staff are collaborating with Dr F Hirsch of the Institut National de la Santéet 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.
- SARETI has been approached by Professor T Quinlan of the University of Natal's Health Economics & HIV/AIDS Research Division (HEARD see http://www.und.ac.za/und/heard/index.html) with a view to SARETI scholars and fellows presenting background papers on selected ethical issues in HIV/AIDS research for HEARD (in relation to its Orphan Welfare project) in 2004. In this way SARETI's links and integration with active health research units will be developed further. Professor Kruger was a consultant to HEARD in 2003 on special issues related to health research with orphaned children.
- In 2004 we hope to develop modules or materials on the following areas which are not covered by the current SARETI modules:
 - Ethical issues in genetics and genomics
 - Ethical issues in the Pharmaceutical Industry: The industry perspective, GCP, GMP and related issues
 - o Ethical issues in research with animals
 - Nursing perspectives on ethics in health research
 - Research with psychiatric patients
 - Environmental Ethics
- SARETI contributed to bioethics book holdings in the libraries of both the universities
 of Pretoria and Natal.
- The University of Natal will formally merge with the University of Durban-Westville in January 2004 and become the largest university in South Africa. The merged university will be known as the **University of KwaZulu-Natal** (UKZN) from 2004.

3. SARETI EXECUTIVE AND LECTURING STAFF

- Professor Mariana Kruger has replaced Prof. Graham Howarth as a member of the SARETI executive. Dr Howarth accepted a senior ethics advisory position with the Medical Protection Society in the UK early in 2003.
- The SARETI executive met monthly throughout 2003 and met regularly with the group of scholars and fellows.

- SARETI academic staff contributed papers and presentations in 2002-2003 at several international and national congresses, including the Pan-African Bioethics Initiative (Addis Ababa); WHO-UNAIDS, the UNAIDS African AIDS Vaccines Programme (Addis Ababa; Nigeria and Kampala), the Fogarty IRENSA programme in Cape Town; the Fogarty Bioethics Programme at Aga Khan University in Pakistan; the Foundation for Research and Development in Sri Lanka; the Global Campaign for Microbicides Conference in Washington DC, and attended the International Association of Bioethics Congress in Brasilia.
- SARETI staff were invited to serve in advisory capacities to Bioethics Initiatives in Sri Lanka and at the University of Ibadan, Nigeria. Two members of the SARETI executive have been appointed to the advisory Board of the EU Sixth Framework multi-sectoral project to develop a Network for Ethics on Biomedical Research in Africa (NEBRA), which will focus on building bioethics capacity in West Africa and Francophone countries.
- SARETI staff have been invited to contribute research ethics inputs to a research training workshop funded by the Wellcome Trust planned for Nairobi in March 2004.
- A member of the SARETI executive has been an ethics reviewer for the Director-General of Research of the European Commission.
- SARETI fellows on return home have been active in improving health review systems and review in Nigeria and Zimbabwe to date.
- 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.
- The SARETI PI and Co-PI attended the NIH Fogarty Directors' meeting in Bethesda in October 2003 and reported on selected programme and training issues.
 Collaborations with other grant holders were fostered – Aga Khan, Albert Einstein/Argentina, Nigeria, Sri Lanka and Malawi. Ties with our partners at Johns Hopkins were also advanced further.
- Dr Donna Knapp van Bogaert, who teaches bioethics and research ethics at the Medical University of South Africa has replaced Dr M Painter-Morland as a member of the SARETI executive. Dr Painter-Morland continues to run and teach on the Introductory Philosophy module for SARETI. Dr Painter-Morland has been promoted to director of the Centre for Professional and Business Ethics at Pretoria – a major SARETI partner.
- Nhlanhla Mkhize has successfully completed his PhD on the topic *Cultural factors in moral and ethical decision-making: A dialogical approach* a topic which links directly to his SARETI module on culture and ethical issues in health research.
- Administrative staff one each in Pretoria and Pietermaritzburg were appointed for 2003. A replacement appointment for the Pretoria administrator for 2004 is complete. Ms Nasreen Khan (B. Comm.), who has worked as a researcher in research ethics will run the Pretoria office while Ms Debbie Marais (B.A. Hons.) has been promoted to senior SARETI administrator from the Pietermaritzburg office. We thank Bronwyn Moffett (B. A. Hons.) for her dedicated efforts in our start-up phase for setting up sound administrative and tracking systems, and we wish her well in her studies towards professional registration as a clinical psychologist.
- Finally, major news: Professor Carel IJsselmuiden has been appointed as Director of the Council on Health Research for Development (COHRED), Geneva as from January 1st 2004. He will remain an active member of the SARETI executive and will still teach his module on Ethical Issues in International Collaborative Research. Prof IJsselmuiden's vision and conceptualization of the SARETI programme will continue with the following changes. The SARETI executive has recommended to Fogarty/NIH that Dr Doug Wassenaar assume the role of PI from January 1st 2004, with Prof Mariana Kruger as SARETI Co-PI. Dr Donna Knapp van Bogaert and Prof Linda

Richter will serve as Deputy Co- Pl's for SARETI. The host institution will be the School of Psychology at the University of KwaZulu-Natal (formerly the University of Natal) and the subcontracting institution will be the School of Health Systems and Public Health at the University of Pretoria. This will involve a simple reversal of the roles of these institutions in hosting SARETI to date. The SARETI programme, its many affiliated partners and collaborating academic staff remain unchanged.

4. THANKS

- The SARETI executive thanks the following persons for their active contributions to and support of the SARETI programme:
- For KWAZULU-NATAL: Dr M Bennish, Prof K Durrheim, Prof G C Lindegger, Dr P McLaren, Ms J Manegold, Mr DJ Mansfield, Dr A Masemalo (NICD), Ms C Milford, Dr N J Mkhize, Prof J Moodley, Dr A Robinson, Ms C Slack, Mr V P Solomon, Ms M Stobie, Ms A Strode, Prof A Williamson (UCT)
- For PRETORIA: Ms K Barrett-Grant, Ms C Botha, Prof P Cleaton-Jones (Wits), Prof P Carstens, Prof S Kidson (UCT), Mr J Kruger, Prof M Painter-Morland, Prof P Rheeder, Prof J Snyman, Dr R Sommers, Dr P Tabensky, Dr W van Staden, Prof F Viljoen
- BALTIMORE: Dr Nancy Kass and staff of the Bloomberg School of Public Health and Bioethics Center, and faculty of the Kennedy Institute of Ethics at Georgetown University.
- EXTERNAL EXAMINER: Dr T Fleischer of the International Research Ethics Network of South Africa (IRENSA: Fogarty/NIH Funded), University of Cape Town.
- We also wish to thank the following collaborating institutions for ongoing support to our programme:

KWAZULU-NATAL:

- The HIV AIDS Vaccines Ethics Group
- Human Sciences Research Council
- The WHO-UNAIDS African AIDS Vaccines Programme working group on Ethics, Law and Human Rights
- The Nelson R Mandela Medical School Ethics Committee
- The Africa Centre, Mtubatuba
- The Unilever Ethics Centre

o PRETORIA:

- Committee for Research on Human Subjects (Medical), University of the Witwatersrand (Johannesburg)
- Department of Internal Medicine & Clinical Epidemiology Unit & Faculty of Health Sciences Ethics Review Committee, University of Pretoria
- Centre for Human Rights, Faculty of Law, University of Pretoria
- Centre for Professional and Business Ethics
- We also wish to thank members of the SARETI International Advisory Committee for support, inputs and comments during this first year:
 - Prof S Abdool Karim, Deputy Vice-Chancellor (Research & Development), University of Natal, Durban, South Africa, and Professor of Clinical Public Health, Columbia University, and Adjunct Professor of Medicine, Cornell University.
 - Prof G Tangwa, Department of Philosophy, University of Yaounde, Cameroon.
 - Dr L J Cordier, Administrator: European Commission, Research Directorate-General, Brussels, Belgium.

- Dr L Makubalo, Chief Directorate: Health Information and Epidemiology, Department of Health, Pretoria, South Africa.
- Dr U Mehta, Department of Pharmacology, and WHO Collaborating Centre for Drug Policy, University of Cape Town, Cape Town, South Africa.
- Dr T Mokoena, Head: Department of Surgery, Kalafong Hospital, University of Pretoria, and Chairman of the Board, South African Medical Research Council (MRC).
- Dr P Mwinzi, Kenya Medical Research Institute (KEMRI), Nairobi, Kenya.
- Finally, and most importantly, we wish our 2003 trainees well with the important work they face in the future. To facilitate networking, and with their consent, we list their names, countries and email addresses below:
 - MPH Group:

Ms Joyce Ikingura, Tanzania <u>jikingura@yahoo.com</u>
 Mr Owen Mapfumo, Zimbabwe <u>omapfumo@hotmail.com</u>

Non-Degree Fellows:

Prof Karniyus Gamaniel, Nigeria ksgama@yahoo.com

Prof Pauline Kuzwayo, South Africa <u>pkuzwayo@medunsa.ac.za</u>

■ Dr Ogenna Manafa, Nigeria <u>ogennam@hotmail.com</u>

or <u>ogennam@yahoo.com</u>

Dr Aceme Nyika, Zimbabwe nyikaa@yahoo.com

Externally funded Fellow:

■ Mr Paul Ndebele, Zimbabwe mrcz@blair.co.zw

or <u>pndex@hotmail.com</u>

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

We wish you a peaceful festive season and very best wishes for a prosperous and productive new year.

The 2003 SARETI EXECUTIVE:

Carel IJsselmuiden
Doug Wassenaar
Mariana Kruger
Donna Knapp van Bogaert
Linda Richter

Administrators:

Bronwyn Moffett (to Dec 2003)

Debbie Marais

Nasreen Khan (from Jan 2004)

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