ARESA

ADVANCING RESEARCH ETHICS TRAINING IN SOUTHERN AFRICA

Vol. 4 No 2 **December 2014**

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Prof Stuart Rennie, Bioethics Center, University of North Carolina, Chapel Hill, USA

Dear REC Members

It gives me great pleasure to announce the successful completion of another year on the ARESA Postgraduate Diploma (Health Research Ethics) program. Seven trainees graduated in December 2014 (three cum laude: Prof Brenda Morrow, Prof Walter Jaoko and Prof Minrie Greeff) and two will graduate in March 2015.

Module 3 of the program including the 3rd Annual ARESA Research Ethics Seminar was held in September this year and it was a huge success. Approximately 100 delegates from South Africa and other African Countries attended and participated actively in vibrant discussion sessions. The highlight this year was the addition of a trainee based session focussing on the ethics of conducting research during the Ebola outbreak in West Africa.

With best wishes for a peaceful and joyous festive season.

Keymanthri Moodley and Stuart Rennie

Previous issues of the ARESA Newsletters are available at www.sun.ac.za/aresa

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2015 ARESA TRAINEES

The ARESA Postgraduate Diploma in Health Research Ethics was widely advertised at health science institutions in Southern Africa in 2014. Approximately 33 high quality applications were received and the ARESA Advisory Committee selected eleven ARESA trainees on scholarship and two on a self-funded basis for the 2015 academic year. The Diploma programme consists of three modules and a short research assignment. For more information on the Diploma programme visit www.sun.ac.za/aresa.

See below a short biosketch on each of the 2015 ARESA trainees.

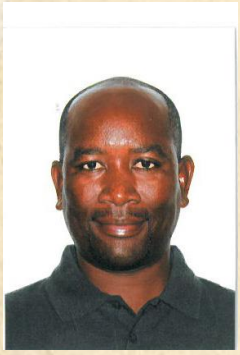
Dr. Dudu Jankie is a senior lecturer in the Department of Languages & Social Sciences Education, Faculty of Education at the University of **Botswana.** She completed her PhD at the University of Wisconsin – Madison in 2001. Dr Jankie has been a member of the University of Botswana Institutional Review Board (UB-IRB) since October 4, 2011.

Dr Retha Visagie is the Manager: of Research Integrity at the University of South Africa **(UNISA)**. She obtained her DCur degree from the University of Johannesburg in 2010. She is a UNESCO trained ethics educator. Her research niche area is the capacity development of researchers in Higher Education Institutions with a special interest in research integrity and ethics. She has authored a book, peer-reviewed articles and presented numerous papers at national and international conferences.

Dr Gordon Wayne Towers is a population geneticist and is employed as a Senior Lecturer within the Centre of Excellence for Nutrition (CEN) at North-West University (Potchefstroom Campus), South Africa. The main research focus of his laboratory is investigating the interface between nutrition and genetics and how this results in the increased epidemic of non-communicable disease (NCD) currently occurring in developing countries. Dr Towers is also vice-chairperson of the Health Research Ethics Committee (HREC) of the Faculty of Health Sciences at the North-West University (Potchefstroom Campus). He trained in the field of molecular human genetics and received his PhD in 2005 and completed a postdoctoral fellowship at the Centre for Genome Research, North-West University in 2008.

Dr Shenuka Singh is a Senior Lecturer and Academic Leader (Head) of the Discipline of Dentistry in the School of Health Sciences, UKZN. She has a primary degree in Oral Health, a masters degree in Dental Sciences and a doctoral degree in Dentistry (in the field of Dental Public Health). She is the Chair of the Humanities and Social Sciences Research Ethics Committee at UKZN (2014-2016), the Co-Chair of the School Research and Higher Degrees Committee and a member of the Biomedical Research Ethics Committee (BREC) at UKZN. She presented a paper on Informed Consent for Community Based Oral Health Research at the IDEALS Conference in Cape Town in September 2014.

Mr Lemphi Mayoyo Moremi is the Principal Research Officer in the Ministry of Health, Botswana and an active member of the Health Research and Development Committee (HRDC) and University of Botswana Research Ethics Committee (UB IRB). He completed his tertiary education at the University of Botswana in 2002 where he majored in Statistics for his Bachelor of Arts degree in Social Sciences. In 2008, he pursued a Master of Science degree in Epidemiology and Biostatistics at the University of Witwatersrand in South Africa. He is now employed as the Principal Research Officer at the Ministry.



Mr Nyanyukweni Pandeni Tshifugula holds a diploma in nursing and a degree in nursing education and community health from the University of Namibia. He worked as a registered nurse in the Namibian Ministry of Health and Social Services from 1998 to 2003. In 2002 Mr Tshifugula obtained a Post-Graduate Diploma in Public Health from MEDUNSA, and a Master's degree in Public Health from the same institution in 2004. He obtained a degree of Master of Bioethics with a Magna Cum Laude from Katholieke Universiteit Leuven (Belgium), Radboud Universiteit Nijmegen (Netherlands), and Universita Degli Studi Di Padova (Italy) in 2013. Since 2000 he is a lecturer in the Health Sciences Faculty at the University of Namibia where he teaches nursing ethics to nursing students.

Ms Babazile Shongwe holds a diploma in General Nursing and Midwifery and an Advanced Degree in Nursing from the University of the Free State. She has been involved with the health sector for 14 years, having worked for Good Shepherd mission hospital as a Nurse, the Mbabane Government Hospital as a Senior Nurse Clinician and the Mbabane Public Health Unit as a Community Nurse. She is currently working as Research Officer in the Ministry of Health within the Research Unit. She currently serves as Secretary of the Swaziland Ethic Committee. She has also led the process of developing the National Health Research Policy, National Health Research Strategic Plan and National guidelines for researchers as well as participating in development of the National Health Sector strategic Plan (NHSSP)

Ms Melody Shana currently serves as a Compliance/Research Officer within the Medical Research Council of Zimbabwe Secretariat for the past six years. Melody is mainly responsible for servicing the National REC hosted by MRCZ. She also assists in running Research Ethics and GCP courses offered by the MRCZ. Melody holds a BSc degree from the University of Zimbabwe and a Diploma in Clinical Trial Monitoring and Research Site Coordination obtained from the Kriger Research Centre-KRC International (Canada). Melody has successfully completed an online Internship as a CRA with the Clinproxy Research Services (Canada).

Ms. Imot Stella is currently an IRB Administrator for the Makerere University School of Health Sciences Research and Ethics Committee in Uganda. In 2011, Ms. Imot attained a post graduate diploma in Leadership and Management from Kenyatta University Nairobi Kenya and a Bachelor's Degree in Social Work and Social Administration from Uganda Christian University in 2006. She was awarded a scholarship to pursue training and internship at the NIH Department of Bioethics, Bethesda, Washington DC, in July 2012. She has also

attended the Research Ethics and Institutional Review Board operation training held in Cape Town, South Africa from the 24th to 25th October 2014 organized by FHI360. Stella is keen to build her capacity in research ethics such that she may be part of the human resource available to develop and strengthen research ethics systems in Uganda and the region.

Prof Francis Rakotsoane is from Lesotho and holds a Bachelor of Philosophy degree from the Urbaniana University, Master of Social Sciences degree and a PhD from the University of Cape Town. He has served as a Tutor, Interim Head of the School of Arts and Humanities, Head of the Department of Theology & Religious Studies and Dean of the Faculty of Humanities. He is currently the Acting Pro-Vice Chancellor of the National University of Lesotho. His research interests cover areas such as education in general, Basotho religious thought, African rites of passage, philosophy of culture; religion and society, African traditional worldviews, African philosophy, environmental ethics, global warming, moral issues and HIV & AIDS.

Dr Beatrice Amugune is a Senior Lecturer in the Department of Pharmaceutical Chemistry, School of Pharmacy of the University of Nairobi. She is a trained pharmacist specialized in Pharmaceutical analysis and holds a doctorate in Pharmaceutical Chemistry from the University of Nairobi. She has been a member of the Kenyatta National Hospital–University of Nairobi Ethics Review Committee (KNH/UON ERC) since 2005. Beatrice completed the Collaborative Institutional Training Initiative (CITI) in Human Subjects' research and NIH online course on Protecting Human Research Participants. She is currently a Co-investigator in a multidisciplinary NIH Mental Health grant involving staff from the University of Nairobi and the University of Washington. Previously, Beatrice has worked as a backup Consultant Pharmacist at Kenya AIDS Vaccine Initiative Institute of Clinical Research.

Ms Pamela Claassen has a MSc. Degree. She is an Environmental Sociologist at the University of Namibia's Research and Publications Office. Her interest in research ethics stemmed from frustration during the course of her research activities as a social scientist, believing research is constrained by university research governance structures and regulators of ethical practices that seemed to be mismatched between her own ongoing ethical research practices and the process of obtaining ethical clearance. Her pursuit for answers to the perceived ethical review mismatch, prompted her inclusion in the university's Interim Ethics Committee in 2009.

Ms Mercy Mbewe is the Coordinator of Health Management programmes at the National Institute of Public Administration and Chairperson of the University of Zambia Biomedical REC. She holds a Master of Education degree and BSc in Nursing degree from University of Manchester and University of Zambia respectively. In conjunction with colleagues she has developed and implemented short courses in research ethics to build capacity among health workers. She was awarded the Olaf Palme scholarship for teaching exchange at Karolina Instituted (2004), recognition award for outstanding contribution to ECSACON (2001) and award for outstanding contribution to Nursing Education and Clinical practice (2006).

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ARESA SHORT COURSES

Module 1 of the ARESA Postgraduate Diploma in Health Research Ethics will be held on 16-27 February 2015 and serves as an introduction to health research ethics. The module is presented as part of the PG Dip but also as a short course. Similarly modules 2 and 3 will be offered as short courses. Some of the topics that will be discussed include:

Module 1: Week 1 (16 – 27 February 2015)

- historical perspectives on the ethics of biomedical & behavioural research
- ethical challenges in human subjects research
- international and domestic codes & guidelines
- operational challenges of research ethics committees
- participant vulnerability in research

Module 1: Week 2 (23 –27 February 2015)

- the philosophical approach to ethics
- major ethical theories and principles
- African philosophy and research
- the ethics of recruitment
- confidentiality in research
- assessing risks and benefits in research
- legal aspects of health research

If you are interested in applying for these short courses please forward your curriculum vitae and a short motivation letter outlining your interest. Please indicate if you would like to do week 1, week 2 or both weeks.

Cost:
R3500 per week

All short course applications must be submitted by 19 January 2015.

Contact: Kelsey February at kelseyf@sun.ac.za

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HIGHLIGHTS FROM THE 3rd ANNUAL ARESA RESEARCH ETHICS SEMINAR

18 & 19 September 2014

100 delegates attended this annual seminar from various South African RECs as well as from Malawi, Kenya, Uganda, Botswana and Zimbabwe. A wide range of stimulating talks was delivered by South African speakers (Prof Himla Soodyall, Ms Ann Strode, Dr Laila Asmal, Dr Stefan Du Plessis, Prof Moodley, Dr Tina Malan and Dr Blanche Pretorius). International speakers hailed from the University of North Carolina (Prof Arlene Davis, Prof Dan Nelson, Prof Stuart Rennie), Uganda National Council for Science and Technology, Uganda (Dr Julius Ecuru), Kenya (Prof Walter Jaoko) and Ireland (Dr Ciara Staunton). Prof Sharon Kling, Dr Lesley Henley, Prof Jacquie Greenberg and Dr Theresa Rossouw contributed to lively panel discussions.

Day 1 of the session focused on children and research and Dr Blanche Pretorius, an ARESA graduate (2012) presented the findings of her research assignment. The afternoon of day 1 saw the conversation shift to genetic research where Prof Walter Jaoko of the 2014 ARESA programme presented.

The discussion during day 2 began with debates on biobanking, covering experiences from the US, Uganda and community engagement. In the afternoon, the session focused on a new and exciting topic of neuroethics where ARESA graduate of 2013, Dr Tina Malan presented.

Entering a new phase in the regulation of child health research

Ms Ann Strode, School of Law and the HIV AIDS Vaccines Ethics Group (HAVEG), University of KwaZulu-Natal.

1 Developments in the legal framework for child research

In the post-apartheid era the regulation of research has become institutionalised and subject to distinct legal norms contained with the

National Health Act of 2003. In particular, the National Health Act now sets out when and how children can participate in health research. Despite the Act having been passed by parliament more than a decade ago, the regulation of child health research has been in a state of flux largely due to the phased way in which the Act was implemented. This has led to uncertainty for both researchers and members of Research Ethics Committees (RECs). However, in September 2014 the framework for child health research became become fully operational with the publication of the Regulations relating to Research with Human Participants. This has introduced a new era in the regulation of child health research which there is certainty on some issues and new forms of uncertainty on others.

2 Implications for researchers and RECs

Child researchers, and reviewers of child health research, must now be aware that norms in section 71 of the National Health Act of 2003 are now in effect and are binding on all stakeholders. Some of these norms are restrictive, especially those regarding consent for child research, and conflict with ethical principles, and will introduce ethical-legal dilemmas.

The section below summarises the norm in s71 (in italics) and sets out brief implications for stakeholders.

Health research with minors[1] *can only be conducted if the consent of a parent or legal guardian is obtained. The Act does not allow independent consent or consent by care-givers*. This is contrary to the approach taken in the national ethical guidelines (Department of Health, 2004) and many international guidelines.

Minors who demonstrate 'understanding' will consent alongside the person providing proxy consent and not merely assent to the study. This suggests that attention will have to be paid to the threshold of understanding represented by 'consent' versus 'assent'.

Research must be divided into either therapeutic or non-therapeutic research. The Regulations define therapeutic research as being research that 'holds out the prospect of direct benefit to the participant' (Government Gazette, 2014). Whilst non-therapeutic research is 'research that does not hold out the prospect of direct benefit to the participant but holds out the prospect of generalizable knowledge' (Government Gazette, 2014). This approach has been criticized because all research comprises a mix of components that do and do not hold out the prospect of direct benefit (Stobie, Strode and Slack, 2005) however this approach means that applicants and reviewers will have to consider which category of research best accommodates the presenting protocol.

Ministerial consent must be obtained for non-therapeutic research with minors. Regulation 7 provides that an application must be made on a standard form (Form A) and submitted to an REC with an application for ethical approval (*Government Gazette*, 2014). The Minister of Health has delegated the authority to provide 'ministerial consent' to RECs. This means that applicants and reviewers will have to become familiar with the criteria used on Form A and show how these criteria will be fulfilled in the child NTR protocol. This should not be too burdensome as the criteria are familiar formulations used in research ethics.

Therapeutic research must be shown to be in the best interests of the minor. 'Best interests' is defined in the regulations as 'significant decisions affecting a minor's life should aim to promote, amongst others, the minor's physical, mental, moral, emotional and social welfare' (*Government Gazette*, 2014). This suggests that reviewers will have to consider the degree to which TR facilitates the welfare of the child participants.

3 Conclusions

In this era, there will be more certainty about some norms introduced by s71 such as Ministerial Consent. However, there will be less certainty regarding other norms such as mandatory parental consent – given the stark contrast in approach between the law and

[1] **The National Health Act uses the term /minors rather than children.**

national guidelines. The former adopts a rigid protectionist stance (Strode et al., 2014) and the latter balances child protection with research facilitation. Research stakeholders will be faced with complying with the law or ethical guidelines. The chief operational consequence may be that applicants and reviewers will have to deliberate on, defend, and document much more carefully the consent approach to be adopted in child research. Overall, this tension will remind research stakeholders about dilemmas presented by the rigid legal reporting requirements for underage sex versus a more nuanced ethical approach (Strode & Slack, 2009). Research stakeholders should get involved in advocacy for law reform – as discussed by the National Health Research Ethics Council at their public meeting with RECs – because ultimately an ethical-legal framework in which legal and ethical principles are discordant is neither desirable nor sustainable.

References on request.

Research in Neuroethics- a quick review

Dr Tina Malan, Department of Psychiatry, University of Stellenbosch

In August 2013 President Barak Obama called together a commission to design a set of ethical guidelines accompanying the large scale, multimillion BRAIN (Brain Research through Advancing Innovative Neurotechnologies) project in the United States. They are to draw up guidelines similar to the ELSI (Ethical, Legal and Societal Implication) programme accompanying the Human Genome project. Another large scale project is currently being conducted in Europe, the HBP (Human Brain Project), with their own "Ethics and Society Programme". In the Asia-Pacific region the UNESCO Bioethics Committee has started discussing neuroethics and the Japan Association for Bioethics is interacting closely with neuroscientists to consider neuroethics.

We are privileged to have the first 3 Tesla MRI Scanner in Africa based at the Stellenbosch University's Health Science Campus in Cape Town, South Africa. This scanner is based in CUBIC (Cape Universities Brain Imaging Centre) and is dedicated to brain research since 2007 in collaboration with different universities and disciplines in Cape Town. There are currently approximately 20 different neuroimaging studies conducted at this centre. One of these studies is a flagship project of the South African Medical Research Council in collaboration with the University of Stellenbosch's Psychiatry Department under Prof Soraya Seedat, the Shared Roots study. This study will be doing neuroimaging, amongst other investigations on a sample of 600 participants with different Psychiatric conditions.

Global neuroscience research is fast outgrowing our knowledge and strategies on how to handle findings, specifically incidental findings. There are a number of other neuroethics research issues in this field: vulnerable participants, informed consent and the public communication of findings. "Responsible science communication and dissemination of findings is critical to ensure public support of and trust in neuroscience research" (Judy Illes, a leader in the field of Neuroethics, University of British Columbia in Canada).

Divulging incidental findings on neuroimaging research is ethically daunting. A multicentre meta –analysis in 2009 showed an overall prevalence of incidental findings on a Brain MRI study of 2,7% , that incidental findings increase with age and that 135 of approximately 19,559 participants had cancerous brain lesions. Recommendations from this study were that research volunteers should receive information on incidental findings and that a procedure dealing with incidental findings should be in place as part of the protocol.

From global research it seems we need more research in this field on African populations and can benefit from forming commissions or collaborations drawing up neuroethics guidelines for research in our unique circumstances. We also need more trained bioethicists on Research Ethics Committees as strongly advised by Amy

Guttman, a political scientist and philosopher from the University of Pennsylvania. The time has come for African neuroscientists and ethicists to take hands and venture this new territory together safely.

"For all that scientists have studied, the brain remains the most complex and mysterious human organ" – Carey 2009

REC Review of Bio-banking Protocols: Experience from Uganda

Dr Julius Ecuru Uganda National Council for Science and Technology

Scientists have always relied on human materials (HM) like hair, tissue, blood and other body fluids to understand human biology and disease, and discover novel preventative and treatment solutions. HM are even more valuable today because rapid advances in molecular biology make working with HM easier, cheaper and faster. Consequently, we see demand for HM rising, usually collected as left over samples from human studies or in some instances, as donations to bio-banks. The idea is that what we cannot do today may be possible do in future as science advances. Another thing is that storing HM preserves valuable biological information. The practice also saves time and resources, and lessens the burden of returning to people for fresh samples. Therefore, the value of HM cannot be overemphasised. The concern, however, is that HM are collected from resource-limited communities and stored in more advanced facilities abroad for use in future presently unknown studies. This is happening in Uganda for a number of reasons, one being weak or inadequate in country scientific capacity (human and physical, e.g. less equipped laboratories, unreliable electricity supply, and need for better safety measures). Sometimes, multi-country studies use reference laboratories abroad for quality assurance. Students also carry HM with them for their studies abroad. Furthermore, it is cheaper to work with HM in more advanced facilities abroad, which have more experienced personnel. International ethics guidelines such as Declaration of Helsinki[2] and CIOMS[3] limit their guidance on HM to informed consent issues. The Declaration, for example, states that: "For medical research using identifiable human material or data, such as research on material or data contained in bio-banks or similar repositories, physicians must seek informed consent for its collection, storage and/or reuse. There may be exceptional situations where consent would be impossible or impracticable to obtain for such research. In such situations the research may be done only after consideration and approval of a research ethics committee". CIOMS, while it also focuses on informed consent, goes a little further to require specific information on use of samples, potential commercial benefit and details about storage to be given to study participants prior to consent.
The question bio-ethicists and researchers are trying to address is whether study participants should provide broad, blanket or specific consent for storage and future use of HM. But concerns of people who provide HM appear to be much broader than consent issues. People fear losing control of HM and data stored or bio-banked abroad. We see this in the questions they ask, like: where are the HM and data stored? Who owns them? How will they be used, for what purpose and by whom? How shall we benefit from results or products developed using our HM? Will our research partners ever come back now that they have our HM? These questions attracted debate in Uganda on whether to prevent transfer of HM and data for bio-banking abroad, or allow transfer but under certain terms and conditions.

Concerns over HM storage and future use can be complex and difficult to address, but a broader perspective on the issue may be essential. First, good equipment and well trained personnel are needed to maintain viability of HM during collection, transportation and storage. Second, study participants should consent and be assured

[2] Section 32 of Declaration of Helsinki (2013)
[3] Guideline 5 of Council for International Organizations of Medical Sciences (CIOMS) in collaboration with the World Health Organization (WHO), 2002, Geneva

of privacy and confidentiality and responsible use of HM. Third, ownership and benefit sharing should be negotiated at the beginning and commitments or arrangement made for this to happen.

Research Ethics Committees (RECs) and regulatory agencies in Uganda presently uses a trusteeship model where HM are held in trust on behalf of study participants by the organization where the researcher is affiliated. The organization is responsible for transfer or exchange of HM under certain terms and conditions. The organization holding the HM negotiates appropriate benefit sharing through use of material transfer agreements (MTA). A separate informed consent process is used, which is broad to allow or not storage and future use of HM, but recognises rights of study participants to withdraw their HM when necessary at any time[4]. Furthermore, RECs review all future studies involving storage of HM regardless of where they are conducted. Such a study should include a Ugandan scientist as co-investigator. Transfer of HM for research purposes is approved by Uganda National Council for Science and Technology, which is a government agency overseeing research.

Uganda's experience with HM and bio-banking research underscores the need for researchers to build trust[5] in research collaborations. According to Beauchamp and Childress (1994)[6], "trust is a confident belief in and reliance upon the ability of and moral character of another person". African, and not least, Ugandan researchers, also need knowledge and skills to negotiate for sharing in intellectual property and longer term research programs involving HM. Signing research agreements and using MTAs are important trust building undertakings, which foster strong research partnerships. In conclusion, demand for HM will continue to rise because advances in molecular science, enables scientists to define genetic predisposing factors to disease and focus targets for drug development. It also enables us to develop better genetic counseling strategies. Therefore, RECs, researchers and all stakeholders should continually articulate HM and bio-banking issues in a broader scientific, ethical, legal, social and economic context. Long term benefits of HM use and how such benefits can be fairly and equitably shared with communities where HM are collected should be incorporated in reviews of bio-banking research.

[4] See UNCST (2014) National Guidelines for Research involving Humans as Research Participants.
[5] See also, Emerson, *et al*: Access and use of human tissues from the developing world: ethical challenges and the way forward using a tissue trust. *BMC Medical Ethics*, 2011, 12:2
[6] Beauchamp, T. L and Childress, F.J (1994) Principles of Biomedical Ethics, 4th Edition

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Southern African Human Genome Project (SAHGP): Ethics, Legal & Social Issues

The SAHGP was launched in 2011 with seed funding from the Department of Science and Technology (DST). The objective is primarily to develop capacity for genomic research in Southern Africa. The project was established with the intention of promoting a spirit of collegiality, data sharing, prioritisation of projects, respect for and protection of indigenous populations. Community and public engagement are strongly supported. The ELSI seminar hosted on 19 November by Prof Himla Soodyall and Prof Michael Pepper focussed on ethics, social and legal issues related to the human genome project in Southern Africa. There was an outstanding talk by a member of the San community, Mr Mogodu. One of our ARESA trainees, **Dr Tyson Welzel** (pictured above with Prof Melanie Slabbert)

delivered an insightful talk on **data sharing in genomic research.**

In Memory of Lizette Schoeman

4 Nov 1959 - 3 Nov 2014

Dr Lizette Schoeman was well known in research ethics circles in South Africa. Her untimely demise on 3 November 2014 was a shock to everyone, and is a loss to academia, colleagues, friends and family. This is a short tribute to her life and work.

Training

Lizette was born in Bloemfontein and matriculated at the Hoër Meisieskool Helpmekaar in Johannesburg. She was a Registered Pharmacist, having obtained a BPharm degree at the University of the North-West. This was followed by a BA Hons in Psychology at the University of Pretoria, and in 2001 she completed her a PhD in Medical Psychology at the University of KwaZulu-Natal under the mentorship of Prof Lourens Schlebusch. Her thesis, titled *The role of informed consent in the treatment of patients with oesophageal cancer: as related to perception of illness, locus of control, stress and coping*, explored the psychological benefit of the ethical principle of informed consent. Furthering her interest in research ethics, Lizette completed the International Diploma in Research Ethics at UCT in 2004 after being awarded an NIH scholarship. In 2007 she received a Wellcome Trust scholarship to attend the Biomedical Ethics Summer School at the University of Leicester, UK, and she attended an intensive course in bioethics at Georgetown University, Washington DC, USA.

Research ethics activities

Lizette served on various Research Ethics Committees, including the MRC Ethics Committee since 2008, the REC of the Faculty of Health Sciences, University of Pretoria, of which she was the vice-chairperson, and PharmaEthics. She was also chairperson of the Research Ethics Forum at the University of Pretoria's Faculty of Health Sciences, and lectured ethics to students in the School of Medicine, School of Dentistry, School of Health Systems and Public Health and as well as the School of Health Care Sciences in the Faculty of Health Sciences, University of Pretoria. She attended all three ARESA annual seminars, and other ethics workshops where she often acted as presenter.

Research interests

Lizette was employed in the Department of Internal Medicine at the University of Pretoria, Pretoria Academic and Kalafong Hospitals. She was involved as Principal Investigator in both quantitative and qualitative research projects related to life-style diseases with specific interest in HIV and diabetes mellitus. She was involved in clinical research in the Department of Medical Oncology for the past 20 years, and was involved as investigator of the Symptom Management Consortium of the Eastern Cooperative Oncology Group in the USA. Since 1994 she collaborated with the Centre on Outcomes, Research, and Education (CORE), Evanston Northwestern Healthcare, Evanston, Illinois, USA, on quality of life questionnaire development, translation and testing. Lizette also acted as external examiner on postgraduate theses. Lizette was part of an interdisciplinary team of the University of Pretoria's Department of Internal Medicine at Kalafong Hospital that in 2013 commenced a study to evaluate the impact of a lifestyle intervention on diabetic patients. The study aimed to promote a healthy lifestyle among diabetic patients who are already receiving treatment, and to reach out to others in the community who are affected by this chronic condition.

Compassion

Lizette was never impressed by so-called celebrities, she believed that the real heroes were the people living their everyday lives in the face of adversity, such as disease and other hardship. She also believed that there is good in everybody. The cancer patients she worked with over the years profoundly touched her heart. This innate compassion always made her insist at every Ethics Committee meeting that research participants should be treated fairly. Lizette's colleagues on the MRC Ethics Committee experienced her contributions as knowledgeable, insightful, wise, invaluable and a source of learning. They felt that her smile, friendliness and warm relationship made a lasting impression; they mourn the great loss of our beloved Lizette.

A personal note

Lizette was a very interesting person, who looked at life from a different angle. We recently discussed the possibility of marketing face masks to travellers, to have the masks made of bright and colourful material, or with prints of painting on it, as a fashion statement. She loved the arts. She studied piano and sang in the Ad Libitum Choir for a number of years. She believed in supporting different art forms and would attend musical recitals and art exhibitions when possible. She was also a regular at Philosophy and other events at the Café Riche in Pretoria. Lizette loved to travel. International conferences offered her the opportunity to experience new places and cultures. Her free spirit thrived on exploring new horizons.

Farewell

Lizette fell ill in September and was admitted to hospital in mid-October. After a period in intensive care, she succumbed to the complications of her condition on Monday 3 November 2014. Lizette's passing fills us with great sadness. We will deeply miss her kind, friendly and caring nature. She made everyone feel special. We convey our sincere condolences to her family and loved ones. Rest in peace, Lizette. We will never forget you.

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What have our ARESA Trainees been up to?

In May, **Dr Christine Wasunna** was appointed to the International Scientific Advisory Board for the Phylogentics and Networks for Generalised HIV Epidemics in Africa (PANGEA-HIV) project which seeks to provide new insights into HIV transmission dynamics in epidemics in Africa and also provide a different approach for the evaluation of HIV transmission interventions. The lead partners in the PANGEA-HIV project are the Division of Infection and Immunity at the University College London (UCL) and the Wellcome Trust Africa Centre for Health and Population Sciences at UKZN, South Africa.

Since completing the ARESA programme in 2012, **Ms Jane Nabbuto** enrolled for a HIV/AIDS fellowship under the continuous quality improvement track with the Makerere University College of Health Sciences School of Public Health. Uganda National Council for Science and Technology had a problem with delays in providing feedback to research sites after field inspection. This led to a delay in responding to concerns provided by the auditors hence leading to violation or deviation from the approved protocols by the investigators hence violating the rights of research participants. As part of the fellowship program, she designed and implemented a project to improve turnaround time for providing feedback to research sites after field inspections conducted by UNCST. She analyzed the root causes of the problem and put measures in place which helped to improve turnaround time from 3 weeks to 4days.

Mrs Tanya Coetzee presented an oral paper at the IAEE in Ankara Turkey during 22-24 May 2014 on the work she completed during the ARESA programme. She is currently preparing a project with Dr Hoffman and Prof Nortje to continue developing her ARESA project.

Prof Joyce Tsoka-Gwegweni recently published the work she completed during the ARESA programme under the supervision of Prof Eric Juengst and Prof Doug Wassenaar. Entitled 'Assessing the Emanuel et al Framework to Assess Ethical Issues Raised by a Biomedical Research Ethics Committee in South Africa' it was published in the *Journal of Empirical Research on Human Research Ethics*.

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ARESA Faculty Updates

We are pleased to announce that **Keymanthri Moodley** has recently been promoted to full professor effective 1 January 2015. She has been appointed to the SAGE WHO Working Group on Ebola Vaccines and Vaccinations and the International Scientific WG of the International AIDS Society (IAS).

Stuart Rennie (University of North Carolina-Chapel Hill) successfully obtained a research (R01) grant from the US Institutes of Health (NIH) to study the responsible conduct of HIV research involving adolescents in Kenya. This project is a collaboration between UNC, the Pacific Institute of Research and Evaluation (PIRE) and KEMRI, and will commence in December 2014.

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Conferences & Events

4th Annual ARESA Research Ethics Seminar
17 & 18 September 2015
Cape Town (venue tbc)

UNESCO 10th World Congress
6-8 January 2015
Crowne Plaza Hotel, Jerusalem, Israel