ARESA

ADVANCING RESEARCH ETHICS
TRAINING IN SOUTHERN AFRICA

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Dear REC Members,

We are very pleased and honoured to circulate the latest ARESA Newsletter to you. In this issue, we highlight some of the important activities of the ARESA Program for the past year. Specifically, the newsletter highlights both the REASA Workshop and the ARESA Seminar, which were held at the Spier Conference Centre in Stellenbosch from 23rd to 25th May 2018.

This 2018 newsletter also features the 15th Anniversary Celebration of the Centre for Medical Ethics & Law (CMEL), the launch of an online Interactive Education Program on HIV cure research, achievements of our ARESA graduates, and an update on the ARESA Bioethics Leadership Program.

We are also pleased to inform you that the ARESA PhD students will organize the next ARESA Seminar to be held in May 2019 and we are in the planning process. We will send you more information in due course.

We wish you happy reading!
Best wishes,

Theresa Burgess, Francis Masiye & Shenuka Singh

Principal Investigator: Prof Keymanthri Moodley,
Centre for Medical Ethics and Law
Faculty of Health Sciences, University of Stellenbosch
Co-PI: Prof Stuart Rennie, Center for Bioethics,
University of North Carolina, Chapel Hill, United States

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HIGHLIGHTS FROM THE 7th ANNUAL ARESA RESEARCH ETHICS SEMINAR

24 & 25 MAY 2018

This year, 130 delegates from various Southern African Research Ethics Committees (RECs) attended our annual seminar, and we were delighted to welcome back ARESA Alumni. A wide range of stimulating talks on current and topical issues in research ethics were delivered by South African speakers (Ms Anita Kleinsmidt, Dr Gasnat Shaboodien, Ms Nakita Laing, Prof Himla Soodyall, Prof Marc Blockman, Prof Anne Pope, Dr Theresa Burgess, Prof Anton van Niekerk, Prof Ambroise Wonkam, and Prof Lesley Le Grange). International speakers were from the USA (Prof Stuart Rennie and Dr Kristen Sullivan) and Kenya (Prof Walter Jaoko).

Below, we present to you a flavour of the ARESA seminar proceedings through brief summaries of some of the presentations.

DAY 1: 24 May 2018

Genetics, genomics & the POPI Act of 2013

Ms Anita Kleinsmidt

A background to the POPI Act was provided. All service providers who deal with personal information will be subject to the Act. The purpose of the Act is to provide an overarching regulatory framework to protect personal information and regulate its use. The Act will also provide rights and remedies for misuse of personal data. Genetic research is significant in the context of the Act because the information from the research subject contains information about the DNA of the participant. DNA can tell us about inherited characteristics, ancestry, forensics and disease risks but there may also be incidental findings such as paternity, unknown adoption or consanguineous relations between the parents. Generally, in the Act, consent is required to process information and should be 'voluntary, specific and informed'. The purpose of use of data should be explicitly defined, lawful and specific. But biobanks, for example, by their very nature store samples for unknown future use. Therefore, it is essential that researchers carefully consider how informed consent will be constructed and obtained to align with the requirements of the POPI Act.

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UNIVERSITEIT STELLENBOSCH UNIVERSITY

UNC CENTER FOR BIOETHICS

The Information Regulators at ARESA

Most of the POPI Act is given over to the establishment of the Information Regulator. We were honoured to host Prof Tana Pistorius and Advocate Collen Weapond, information regulators, who attended the seminar and participated in a panel discussion following the first session. Prof Soraya Bardien-Kruger chaired the session.

CDH2: The final piece of the puzzle

Dr Gasnat Shaboodien & Ms Nakita Lang

The ground-breaking research journey of discovering CDH2 as the gene responsible for sudden death among young people and athletes was presented. The CDH2 gene causes Arrhythmogenic Right Ventricle Cardiomyopathy (ARVC), a genetic disorder that predisposes young people to cardiac arrest. From an ethics perspective, testing of at-risk relatives younger than age 18 years requires consideration of the potential risks and benefits. The principal arguments against such testing are that it removes the individual's choice to know or not know this information, it raises the possibility of stigmatisation within the family and in other social settings, and it could have educational and career implications.

In terms of potential benefits, early detection of the family-specific pathogenic variant may provide helpful insight to guide management of minors, particularly in the setting of known early-onset and/or aggressive disease.

It also allows for stringent surveillance for the onset of asymptomatic (but clinically detectable) HCM and earlier risk assessment for sudden death, an important consideration for asymptomatic at-risk young people interested in or involved in competitive sports. Decisions regarding genetic testing in adolescents are complex. Potential proponents for genetic testing include the potential harms associated with maintaining uncertainty & withholding information; testing may help in learning to cope with the information; the benefits associated with fostering autonomous decision making in adolescents; and the value in allowing parents and their children to decide. Potential opponents of genetic testing in adolescents cite violation of future autonomy; mature decision-making is variable during adolescence; the creation of feelings of distress and anxiety; potential harms to self-esteem (feelings of unworthiness); the distortion of family relationships; the interference in normal development of self-concept; and the right of the child not to know.

Genomic research in Africa – challenges and expectations

Prof Himla Soodyall

There is a strong need for further genomics research and translation in Africa. An example is seen in disparities in cancer research and treatment in high- versus low-resourced countries, particularly Africa. In developed countries, cancer treatments are profoundly informed by genomics. But many African nations have only a handful of cancer specialists, and limited capacity for diagnosis and treatment. Although breast-cancer rates, for example, are lower in parts of Africa than in developed countries, more Africans die from the disease and not just because of a lack of access to care; as standard treatments sometimes seem less efficacious in some African women. The Human Hereditary and Health in Africa (H3Africa) Initiative aims to develop a network of African laboratories that can conduct genomics and precision medicine research. However, challenges include cost of genomic technologies in Africa;

sharing of genomic data; physical and infrastructural challenges of large scale genomic studies in Africa; challenges to re-use of publicly available data; ethical challenges in sharing of genomic data; protection of participants; guidelines and requirements of different ethics boards; and skills development. There are also many ethical, legal and social issues associated with genomics research in Africa. International research may often be regarded as exploitative, due to issues associated with a lack of respect or reference to indigenous research; and consent processes that do not align or respect traditional practices or culture. The San Code of Research Ethics was highlighted, as it includes values of respect, honesty, justice and fairness and care. The Global Code of Conduct for Research in Resource-Poor Settings was also referenced, with key principles of fairness, respect, care and honesty.

Does academic freedom trump research ethics?

Prof Marc Blockman

Integrity, accountability and responsibility in conducting academic research form the cornerstone of any academic programme and violations of academic research standards represent serious offences to the entire academic community. They harm the credibility of an institution that professes to promote excellence in academic research. Academic integrity requires that academic research conforms to professional standards, including appropriate research design and frameworks, adheres to high levels of research ethics and abides by the requirements set out by professional and regulatory research guidance and research ethics frameworks issued in all appropriate areas. Individual researchers are constantly faced with new kinds of ethical dilemmas. Importantly, this may occur without the traditional supports of a strong collegial and participatory decision-making culture to help them frame and make the 'right' choices. It is here where research ethics committees must enforce the integrity of ethical research. Research ethics committees should encourage researchers to collaborate on ethical aspects of their research, where an assessment of the ethical dimensions of a research project are required. Importantly, RECs should act as a consultative body for any matter concerning research ethics and conduct and make recommendations to the institution in terms of any action required.

Researcher perspectives on building trust in relationships with the REC

Prof Walter Jaoko

This presentation looked at reasons for researchers' mistrust of RECs. The institution of RECs resulted from historical loss of trust in researchers due to the atrocities researchers inflicted on research participants in the name of scientific research. This loss of trust led to the establishment of rules & guidelines that regulate researchers today. In response, generally speaking, researchers view RECs with suspicion as they feel that RECs don't trust them. RECs remain quite mysterious to many researchers, compounding the lack of trust. Although RECs provide timelines for reviewing proposals they don't adhere to them. Where possible, a tracking system of review of research proposals should be installed to help researchers see the movement of their proposals from receipt, to review to secretariat to feedback to researchers etc. In addition, RECs should regularly self-assess themselves and review their timeline performance with the objective of making improvements where there are delays. Sometimes REC members themselves are researchers and viewed as competitors in the field of research. Researchers may feel RECs do not understand the research to be undertaken. Researchers tend to think that REC comments should be restricted to ethical issues and not touch on the scientific ones. To address the issue of perceived flawed review, RECs should co-opt reviewers for proposals that are too technical. In addition, RECs should invite researchers to committee meetings to present their studies and have Q and A sessions scheduled to help clarify any unclear issues. Researchers also view RECs as being too conservative and preferring to stick only to familiar ground.

This in the opinion of researchers, leads to delays in starting a study or makes it difficult to venture into new but vital areas of research, such as stem-cell research, use of monoclonal antibodies for therapy of HIV, and so on. Researchers also raise concerns that the fees are too high in some cases especially for review of clinical trials, making RECs appear to be mere moneymaking ventures. Lastly, researchers are concerned about the wide difference in how RECs adjudicate similar or identical research protocols which is a major cause of frustration among researchers especially in multi-site studies as it causes unnecessary delays in initiating the studies.

Exploring the nature of trust in biomedical research

Associate Prof Stuart Rennie

Research involves diverse stakeholders, including RECs, researchers, funders, commercial companies, hospitals, research participants, and communities. Each have different missions, interests, priorities, and levels of power. Relationships among and between stake-holder groups require trust to function. But what is trust? Trust is implicit in the vast majority of human interactions and practices. We are essentially trusting beings. Trust involves risk, vulnerability and dependency. To trust is to count on other persons or institutions to do something, where there is an inherent risk that it might not happen. Betrayal of trust leads to destructive consequences, including damaged relationships, loss of reputation, and loss of self-respect. Trust is unavoidable, important and may also be dangerous at times. Trust has a limited rational basis; but has instrumental and intrinsic value. Distrust can be a virtue. Potential ethical implications of trust were discussed, including what it means to 'build' or 'repair' trust. Will it foster trust if RECs have a more robust monitoring role over studies? And is consent based on trust morally inferior to consent based on information? Does trust undermine choice? There is a pervasiveness of trust in the consent process, to a greater or lesser degree. RECs should not consider that trust is in conflict with valid informed consent.

DAY 2: 24 May 2018

Ethical inclusion of pregnant women in biomedical research: focus on HIV

Dr Kristen Sullivan

There is limited research on treatment and prevention of HIV and co-morbidities in pregnant women. Drugs are rarely developed with pregnant women in mind. Research done on non-pregnant cannot simply be applied to pregnant women. The resulting harm of research exclusion in clinical trials includes lack of data on dosing and safety in pregnancy. Overall, exclusion of pregnant women from research does not ensure foetal safety. Other potential harms for research exclusion could include reticence to prescribe needed medication; exclusion from direct benefits of participation in research and possible delays and discrepancies in health policies and programmes. The PHASES study goal is to facilitate ethically responsible inclusion of pregnant women and their needs in HIV research. This qualitative study provides interesting insights into women's perspectives on reproductive control, health effects on the woman and their off-spring; and the burden of contraception placed on women in the study sites in the USA and Malawi. The study points out that women's views should inform efforts to advance a more inclusive and responsive research agenda. From a research perspective, there is need to balance the dynamics of power and trust between researchers and participants.

Impact of research on reproductive health in South Africa: tilting the risk-benefit ration in REC deliberations

Dr Theresa Burgess

The risk of a woman in a developing country dying from a maternal-related cause during her lifetime is about 33 times higher compared to a woman living in a developed country. HIV is the leading cause of death of women of reproductive age.

In sub-Saharan Africa, women are disproportionally affected, accounting for 59% of all infections. Globally, young women aged 15 to 24 years are most vulnerable to HIV with infection rates twice as high as in young men and accounting for approximately one quarter of all new HIV infections. Women living with HIV are more likely to experience violations of their sexual and reproductive rights, for example forced sterilization and may be victims of different levels of stigmatization and discrimination. Because of their lower economic & sociocultural status in many countries, women and girls are also disadvantaged when it comes to negotiating safe sex, and accessing HIV prevention services and information. Differences in gender norms, relations or roles may limit opportunities or resources needed to attain health, and thereby result in discrimination and inequalities that may have negative consequences on health. The critical question that was posed in this presentation was: how can RECs fulfil their ethical duty and responsibility to protect study participants and improve health if we do not recognise structural drivers of reproductive health; and make some attempt to ensure these are addressed in ethical reviews of reproductive health research? Research ethics committee deliberations should focus on both broad societal and individual ethical considerations. Broad societal considerations that may tilt the risk: benefit ratio include structural inequalities, social value, capacity development and community engagement. Individual research participant considerations include the individual physical risk: benefit ratio, relational risks, sociocultural risks (including stigma and discrimination) and risks to future reproductive health.

Ethics review considerations for research involving pregnant women

Prof Anne Pope

Why is research on pregnant women a controversial topic? Pregnancy is the ultimate 'off-label condition' because the only drugs registered for use during pregnancy relate to reducing labour pain. All other use of drugs is off label.

Is it because of reticence to treat and adherence to the precautionary principle due to unknown effects on the unborn child, or fear of liability? Are pregnant women really a vulnerable population? It is better to view this population as 'scientifically complex'. The challenges with treatment (safety and efficacy, pharmacokinetics and pharmacodynamics of drugs) should not be an excuse to avoid research involving pregnant women. The ethical challenges include complex risk/benefit assessments, conflation of risk levels and informed consent. The legal implications include the need for excellent data for risk/benefit assessment. In the foreseeable future we require baseline information that is separate from existing data on non-pregnant women.

Ethics review considerations are: the need for good, reliable data from research involving non-pregnant women; useful and appropriate data from animal studies; design of the trial (phased approach) and composition of the research team (appropriate skills and expertise).

Is decolonisation a legitimate and appropriate value in the research enterprise?

Prof Anton van Niekerk

'Decolonised' science and research refer to the indigenisation of the scientific and educational enterprise in a post-colonial context. Decolonisation is not a new concept and many activists, researchers and thinkers have worked on this for years. Decolonisation is desirable because of the atrocities of a particular form of exploitation. There is no such thing as a value-free science. The idea of decolonisation is not new; but the question arises whether the striving to decolonise is valid, given the nature of the research and education enterprise as it unfolds historically.

What then is the methodological justification of the effort to decolonise knowledge?

In accordance with the work of Jurgen Habermas, knowledge harboured on the basis of the 'technical interest' and the empirical-analytical sciences based on that interest bear little promise of decolonisation. In the empirical-analytical sciences, decolonisation is not applicable; the kinds of knowledge claims made in these sciences are testable for their validity irrespective of the 'social context' in which they are formulated. Social perspectives pertaining to decolonisation' therefore make no difference, as there is a standard way of determining technical knowledge.

The 'practical interest' on the other hand, is the interest we all have, based on continuous inter-subjective dialogue, to come to a mutual understanding or consensus about the kind of life that is worth our while and the values that ought to inform that life. Further, self-reflection is also determined by an alleged 'emancipatory cognitive interest'. Critically oriented social sciences share this interest with philosophy. Values regarding choices are wholly influenced by historical, political and social factors. The testing of social theories is only possible in terms of establishing the kind of practices these theories yield. For example, we ought to think in a post-colonial fashion about informed consent. A decolonised world requires an emancipated practice. Research and knowledge that are sought on the basis of the practical and emancipatory interests can be decolonised.

Decolonising biomedical curricula and research

Prof Ambroise Wonkam

For colonialists, biomedical sciences were among the 'generous offers' from the European empires to the colonial world. In some ways they allege that non-Europeans were intellectually inferior and needed to be colonised for their own good. Colonialism was driven by the extraction of raw materials from mines and plantations of many territories throughout the world and went hand-in hand with harvesting scientific information and specimens from exploited colonised people.

Despite the formal end of colonialism, when it comes to biomedical research, former imperial nations still project themselves as almost self-evidently superior to most of the once-colonised countries, thus perpetuating the science culture biases and disadvantages imposed by colonialism. The colonial legacies continue to shape trends in science today in terms of research topics, funding policies, international collaborations, and curricula development. There is enough evidence that long before the colonial invasions, scientific and biomedical expertise were developed from different ethnic groups and countries worldwide, specifically from old African civilisations. The author discussed the intended and unintended consequences of colonial sciences and provided some ideas to address these in modern biomedical sciences research and curricula, with a focus on Africa.

Decolonising research: research ethics and the (post)human condition

Prof Lesley le Grange

The recent student protest movements and associated period of decolonisation has opened up spaces for discussions and debates. It is a crucial and watershed moment in the history of South African higher education. We need to initially consider first generation colonisation, which was about colonising and occupying the land of people. Then the extraction of minerals and mineral wealth followed, and became tied in with the concept of capitalism. It also introduced the concept of land ownership. However, when land was taken away, it was traumatic as it was deeply entwined with notions of being. There was also an associated exploitation of people.

The second generation of colonialism occurred through education and controlling the minds of people. Colonialism was associated with an unequal sharing of knowledge and also an unequal sharing and decimations of knowledge, epistemicide. Much knowledge has been lost or denigrated. When there is a critique of western science, there is critique of the concept of Eurocentrism and that Europe becomes the universal standard against which the rest of the world is othered.

Its knowledge is considered as ‘science’, and that of the rest of the world is considered as ‘culture’. The posthuman condition is characterised by a predicament: namely on the one hand, the imperative of embracing all life and its connectedness so that life is sustained; but on the other, resisting the negative of the posthuman (the potential downside of robotics, drones, artificial intelligence, commodification of the human body, etc.). How do we engage with decoloniality with the predicament of the posthuman condition? Research informed by an immanent ethics opens up pathways for researchers to live, love the world and connect positively to everything in the cosmos. The idea of unlocking the power of life might seem romantic; however, there is a need to experiment theoretically with celebrating life and having empathy. Key concepts in this journey are interrelatedness and Ubuntu, ‘because we are, I am’. This expresses the ability to care for living beings.

Africa Day at ARESA

The second day of the ARESA seminar (25 May) was also Africa Day, the annual commemoration of the foundation of the Organisation of African Unity on 25 May 1963. The final session of ARESA was given over to discussion on the decolonising of scientific research. Prof Ambroise Wonkam was dressed in the resplendent traditional clothing of his birth country, Cameroon.

ARESA Bioethics Leadership Program

Three students have been awarded the ARESA bioethics leadership scholarship to pursue their PhD degrees in clinical and research ethics. They attended the PhD induction module in August 2017, the doctoral programme at the African Doctoral Academy in January 2018, Stellenbosch and a 3-week sabbatical at the Centre for Medical Ethics & Law in May 2018. In July, they set off for the University of North Carolina at Chapel Hill. Read more about them below.

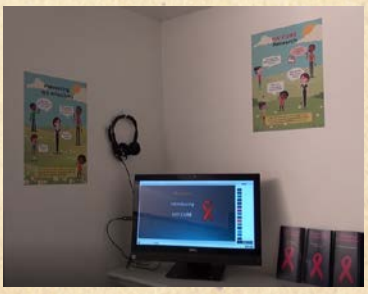
Mr Francis Masiye, B Phil (Urbaniana, Rome), MSc Med (UCT), PGDip (Johns Hopkins) and PG Cert (Georgetown). He is currently employed as a health research ethics administrator at the Stellenbosch University and is an honorary lecturer in bioethics at the University of Malawi. His PhD is titled 'Views of stakeholders on broad consent and future use of samples of data collected in Malawi and South Africa'.

Dr Theresa Burgess, M HSc (Toronto), BSc Physiotherapy (UCT), BSc Med Hons (UCT), PhD (UCT) is a senior lecturer in physiotherapy at UCT. Her PhD topic is 'Ethical and legal issues associated with female adolescent sexual and reproductive health research and ancillary care provision in South Africa'.

Associate Professor Shenuka Singh, B Oral Health (UDW), MSc Dentistry (UWC), PGDip (Stell), PhD (UWC). Her PhD will deal with 'Developing online educational modules on the ethical, legal and social issues related to biobanking—A resource for clinicians, researchers and research ethics committees in South Africa'.

CENTRE FOR MEDICAL ETHICS AND LAW (CMEL) LAUNCH OF THE INTERACTIVE HIV EDUCATIONAL PROGRAMME

On 18th May 2018, the Centre for Medical Ethics & Law (CMEL) launched the Interactive HIV Educational Programme at a Gala Dinner at the Cape Town Marriot Hotel, Crystal Towers. The event was attended by Stellenbosch University Leadership and staff members, key leaders and stakeholders from the Western Cape Department of Education, clinicians, educators, and ARESA Bioethics Leadership Program students. A/Prof Rennie provided background and context to the importance of the Interactive Educational Programme with a talk that highlighted the collaborative research with the CMEL on ethical and social issues in HIV cure research. Dr Farha Cassim and Ms Melany Hendricks then provided an overview of the process of developing and assessing the Interactive HIV Educational Programme. The key components of the Interactive HIV Educational Programme were described; as well as the receptiveness and enthusiasm of learners and educators when engaging with the programme. The CMEL has already been successful in having the Interactive HIV Educational Programme adopted as part of the online resources available to the Western Cape Department of Education.



REASA: A STORY OF DEVELOPMENT, EXPANSION AND INTROSPECTION

Introduction

The Research Ethics Association of South Africa (REASA) celebrated the first year of its existence by facilitating a half day a training workshop for its members entitled 'Research Ethics Leadership: An African perspective'. The workshop was held on the 23rd May 2018 at the Spier Conference Centre in Stellenbosch as a precursor to the ARESA Annual Seminar. REASA originated from the vision of the prolific collaboration between the founders of the ARESA program, Prof Keymanthri Moodley (Centre for Medical Ethics and Law) and Prof Stuart Rennie (University of North Carolina and Chapel Hill). Thirty-seven academics and REC members from various disciplines, including medicine, social work, physiotherapy, clinical psychology, law, business and economic sciences; and representing eight different higher learning institutions from across Southern Africa, including Kenya and Botswana, gave overwhelmingly positive feedback after their attendance of the workshop.

Ethics leadership in context

Shenuka Singh, an Associate Professor in the department of Dentistry at the University of KwaZulu-Natal, a member of the National Health Research Ethics Council (NHREC) and a doctoral candidate in research ethics as Centre for Medical Ethics and Law, started the workshop with an insightful introduction to ethics leadership in research. In her introduction, Prof Singh identified the complexities in the research environment, current debates in research ethics, critique faced by RECs as research oversight institutions and the multi-faceted role of the REC within higher learning institutions. Prof Singh emphasized the multiple layers and functions of RECs, which include driving policy development and implementing policy, and the complexities of leadership between these extremes.

Governance of ethics and ethics of governance

Dr Retha Visagie, integrity officer at UNISA, an internationally certified ethics educator, and the current Chairperson and dynamic force behind the success of REASA, continued to discuss the role of the REC as a 'strategically engaged partner' in the research process. In this conceptualization of the multi-layered role of the REC, the REC provides ethical leadership and functions according to internationally acceptable governance regulations. Dr Visagie distinguished these roles as the ethics of governance, which includes the developing of policy or 'steering norms' and the governance of ethics, referring to the role of the REC as the manager and facilitator of a visibly ethical research process.

Independence of RECs

Prof Walter Jaoko, an internationally renowned scientist, presented a personal account of ethics leadership in Africa. His talk, entitled 'Defending the independence of RECs in Africa' focused on the threats to the independence of RECs as a collective and on the individual members. Prof Jaoko identified funders, lack of resources and skills, institutional policies and culture as being amongst the things which threaten the independence of the REC. Prof Jaoko proposed that the independence of the institutions could be enhanced if the institutions provide adequate funding for RECs, increase training opportunities and have clear SOPs and regulations detailing the limitations of the relationships with the funders and other external sponsors and collaborators. In addition, a legal framework which prevents government interference and promotes transparency will further serve the independence of the RECs.

Prof Lizeth Roets, an expert in Adult Education, explored the literature to provide an account of legislation, governance and leadership in the protection of human participants in research. She found that operational practice is stated as a major concern, with some requiring up to one year to obtain ethics approval. While there are comprehensive regulations and legislation, the bureaucracy associated with it is experienced as stifling, and the lack of resources and funding brings into question the role of the REC as facilitators of research.

Conclusion

Prof Brenda Morrow, a REASA member, and National Health Research Committee member, provided a powerful conclusion to the session. The theme that cuts across all the presentations is that of reflection and self-reflection. To be an ethical leader, one must remain aware of one's own practices and roles as benchmarked against international and national standards. One must continuously reflect on one's prejudices so that internal processes of discrimination and weakness do not contaminate one's role as an ethical leader. The solutions offered above in conjunction with continued self-reflection and awareness will place the REC in the ideal situation to be effective facilitator of research rather than the perceived obstacle.

REASA STEERING COMMITTEE: STRENGTHS, OPPORTUNITIES, ASPIRATIONS AND RESULTS

Join us (and like us) on the REASA Facebook page!
For those with a Facebook account, search: 'REASA'.

For more information contact: secretary.reasa@gmail.com

REASA
RESEARCH ETHICS COMMITTEE ASSOCIATION OF SOUTHERN AFRICA
CONNECTING RECs IN SOUTHERN AFRICA

15TH ANNIVERSARY CELEBRATION OF THE CENTRE FOR MEDICAL ETHICS AND LAW (CMEL)

The 15th Anniversary of the Centre for Medical Ethics & Law (CMEL) was celebrated at a Gala Dinner on 25th May 2018, held as Spier Conference Centre. The celebration was attended by Stellenbosch University Leadership, CMEL staff and collaborators, ARESA Seminar speakers, ARESA alumni, current ARESA Bioethics Leadership Program students and supporters. Associate Professor Stuart Rennie, a longstanding collaborator and colleague of Prof Keymanthri Moodley, acted as MC for the celebration. Other speakers included Prof Jimmy Volmink (Dean of the Faculty of Medicine and Health Sciences), Prof MR Moosa (Executive Head, Department of Medicine) and Prof Anton van Niekerk (Distinguished Professor, Dept of Philosophy). All speakers spoke glowingly of Prof Keymanthri Moodley's exceptionally high work rate, and her energy, enthusiasm, drive, determination and unwavering commitment that have resulted in the massive growth and success of the CMEL. Indeed, it is rare to be in the presence of a visionary, who had the insight and passion to lead teaching, research and capacity development in clinical and research ethics in Southern Africa. Prof Moodley was recognised for her outstanding leadership and contributions to clinical and research ethics over the past 15 years. Congratulations to Prof Keymanthri Moodley and the amazing CMEL team on achieving this incredible milestone!

ARESA ALUMNI NEWS

Dr **Retha Visagie** received the 2018 Department of Technology/SARIMA award for Professional Excellence in Research Management for her role in research ethics leadership in Southern Africa. She also continues as a member of the UNISA Social and Ethics Committee of Council. She was invited as a panellist for the Globethics.net international conference in Geneva, Switzerland for a session on 'Managing and teaching ethics in higher institutions: resources, skills and content'.

Dr **Lemphi Moremi** embarked on a new position in May 2017, and is working as the senior consultant at the Institute of Development Management (IDM). IDM is a regional organisation in Botswana, Lesotho and Swaziland established to help these countries meet their management needs through training, research and consultancy. Responsibilities include teaching public health students Biostatistics, Epidemiology, Research and Research Ethics. Dr Moremi is also working towards establishing a Research Ethics Committee in this Institution.

Dr **Lillian Otieno-Omutoko** was recently appointed a member of the Research Advisory Board, University of Nairobi & reappointed as a member of the National Bioethics Committee, Kenya. She participated in development of a curriculum for training Institutional Research Ethics Committee members and Administrators which is to be offered by National Commission of Science Technology and Innovation whose mandate is to regulate research. She was also part of the team which developed a monitoring and evaluation tool which was pilot tested in six Institutional Ethics Review Committees.

THE TRUST PROJECT

http://trust-project.eu/

Many international groups and organisations are working on governance frameworks and standards to guide research activities. The TRUST project aims to unite disparate efforts and suggest a guiding vision for these activities.

In an interdisciplinary collaboration between multi-level ethics bodies, policy advisors/makers, civil society organisations, funding organisations,

industry and academic scholars from a range of disciplines, this project combines long-standing, highly respected efforts to build international governance structures with new exciting network opportunities in Europe, India, Sub-Saharan Africa, China and Russia.

TRUST's strategic output are three sets of tools based on participatory engagement covering all continents: (1) a global code of conduct for funders (2) a fair research contracting on-line tool and (3) a compliance and ethics follow-up tool, which takes limited resources into account. The goal of the TRUST Project is to catalyse a global collaborative effort to improve adherence to high ethical standards around the world.

The San Code of Research Ethics was developed under the auspices of TRUST. In May 2018, staff from the Centre for Medical Ethics & Law consulted with Mr Roger Chennells, a consultant to the San people and had a fruitful discussion on historical unethical practices, community engagement in research and the development of the San Code.

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UPCOMING CONFERENCES & EVENTS

6th International Conference on Ethics Education, 3-5 Oct 2018, Spier, Stellenbosch
https://www.iaee6.com/

Global Forum on Bioethics in Research, 13-14 Nov, Stellenbosch
http://www.gfbr.global/news/call-now-open-gfbr-2018/

International Association of Bioethics World Congress, 5-7 Dec, Bengaluru, India.
http://ijme.in/nbc-20140321/index.php/14th-wcb-india/index/pages/view/registration

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