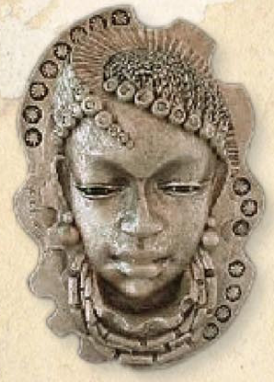

ARESA

ADVANCING RESEARCH ETHICS
TRAINING IN SOUTHERN AFRICA

Vol. 1 No 1 **November 2011**

Editors: Prof Keymanthri Moodley & Dr A le Roux-Kemp, Centre for Medical Ethics & Law, Dept of Medicine, Faculty of Health Sciences, Stellenbosch University, South Africa
Prof Stuart Rennie, Bioethics Center, University of North Carolina, Chapel Hill, USA

Dear REC Members

In June 2011 the Centre for Medical Ethics and Law, Stellenbosch University and the Center for Bioethics, University of North Carolina were awarded a grant from the Fogarty International Centre of the National Institutes of Health (NIH) to develop and present the ARESA (Advancing Research Ethics training in Southern Africa) program. The program comprises a Postgraduate Diploma in Health Research Ethics (PGDip), a REC Network and a new ARESA Newsletter.

It gives me great pleasure to launch the new ARESA Newsletter in 2011. Many of you have previously received and contributed to the SAREC Newsletter and we hope that you will continue to support and contribute to the ARESA Newsletter. This issue contains contributions from some of our trainees.

Our first module on the PGDip was successfully concluded in October 2011 and we use this introductory issue of the ARESA Newsletter as an opportunity to introduce our ARESA trainees to you. We invite you to visit our new website: www.sun.ac.za/aresa and to start interacting with us and each other via our new ARESA REC Network. We also invite you to join us at our ARESA Seminar in August 2012.

With best wishes for a peaceful and blessed festive season.

Keymanthri Moodley and Stuart Rennie

ARESA Newsletters will be made available at www.sun.ac.za/aresa

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

ARESA

ADVANCING RESEARCH ETHICS
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2012 ARESA TRAINEES

The ARESA Postgraduate Diploma in Health Research Ethics was advertised with Research Ethics Committees, academic institutions and other health institutions in South Africa and on the NIH listserve in July 2011. Approximately 40 high quality applications were received and the ARESA Advisory Committee selected ten ARESA trainees for the 2011/2012 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 2012 ARESA trainees.

Dr Beyene Ademe is a medical practitioner and microbiologist by profession. He is currently working for Jimma University, Health Colleges, Ethiopia as a lecturer and coordinator of the Health Sciences Research and Postgraduate School. He is specifically interested in ethics, bioethics and human rights in clinical and health research. He would like to contribute towards the strengthening of research ethics undertakings in his country (Ethiopia) as a whole and Jimma University in particular.

Ms Margaret Ellis lives in Pretoria and works as an SMO manager and SSC at Scion Clinical Research, an organisation that is involved in phase 1-4 clinical trials. She has a background in Nursing Science and is interested in Health Research Ethics in general. She has a specific interest in the guidance and standards for GCP in South Africa, as well as in the design, conduct, recording and reporting of clinical trials. Ms Margaret Ellis would like to pursue a doctoral degree in Research Ethics after completing the ARESA Postgraduate Diploma in Health Research Ethics.

Dr Prem Govender is the Deputy Director of Research (Faculty of Health Sciences) at the Medunsa Campus of the University of Limpopo in Ga-rankuwa, South Africa. He has a PhD in Entomology and has worked at several South African universities (Kwazulu-Natal, Pretoria and Limpopo) and research institutions since 1980. He has been involved in undergraduate and postgraduate teaching and international research initiatives, with interests in Applied Entomology and the development of integrated Pest and Diseases Management Programmes. Dr Govender has been tasked with providing strategic management and leadership in terms of cutting edge research and associated activities, facilitating and enhancing the quality of research and implementing research strategy within the different Schools of the Faculty of Health Sciences. This also includes the management of the Medunsa Research Ethics Committee (MREC).

Dr Ronell Leech joined the Department of Nursing Science, University of Pretoria in 2007 as a senior lecturer. She teaches research methodology (post registration undergraduate level and postgraduate level), community nursing science (postgraduate level) and nursing management (post registration undergraduate level). While teaching research methodology she realised that ethical research is essential for the nursing profession as it allows for the generation of sound evidence-based practice for nursing. She consequently volunteered to serve on the research ethics committee to assist students in her department to become competent in observing sound standards of ethics and to act in their participants' best interests. Dr Leech was accepted as a member of the student research ethics committee, Faculty of Health Sciences, University of Pretoria in January 2011.

Mrs Sabina Mubanga Luputa has over 10 years work experience in administrative management in NGOs. She has worked extensively with NGOs dealing with vulnerable women and children and became involved with caring for the vulnerable. She is furthermore fully conversant in all areas of Marketing, Strategic Operations, Project and Business Development. Mrs Luputa has been working as Director - Business Management at ERES Converge (privately owned IRB in Zambia) for the past three years, and has been actively involved in reviewing research protocols. She holds a Bachelor's Degree in Business Administration and is currently finalising a Master of Science Degree in Project Management at Cavendish University Zambia.

Adv Jamwell Maswanganyi holds the following qualifications: B.Proc, LLB, LLM and a Higher Diploma in Company Law. He is currently teaching law at the Tshwane University of Technology, where he is also the head of the Department of Law. Within the University, he serves on both the Faculty Research Ethics Committee (Humanities), and the Research Ethics Committee (Institutional) as their legal representative.

Mr Thabo Molebatsi obtained a Master of Public Health (MPH) degree from the University of Limpopo Medunsa Campus in 2010. He also holds a Bachelor of Social Sciences Population Studies and a Bachelor of Administration& Economics from the University of Northwest. His MPH thesis dealt with the regulation of health research ethics systems in South Africa. Mr Molebatsi joined the Department of Health as Deputy Director for Health Research in 2007. His duties include providing secretariat and technical support to the National Health Research Ethics Council (NHREC), Health Data Advisory Coordination Committee (HDACC) and sometimes the National Health Research Committees (NHRC). He also provides technical support as a member of the Steering Committee for the South African National TB Prevalence Survey 2010 - 2012. His other responsibilities involve coordination of health research in the Department and other stakeholders such as academic institutions, research councils and non-government organisations. He also participates in the development of research policies and guidelines, coordinates research projects commissioned to stakeholders such as Human Sciences Research Council (HSRC), Medical Research Council (MRC) and Health Systems Trust (HST).

Ms Jane Nabbuto is currently employed as the Research Compliance expert at Uganda National Council for Science and Technology (UNCST), an organisation in charge of research coordination and oversight in Uganda. She is a graduate of Biomedical Laboratory Technology from Makerere University. She has studied Population and Reproductive Health at Makerere University and her current research focuses on "Factors influencing male participation in family planning and antenatal care in Uganda". For the past seven years, Ms Nabbuto completed courses in research ethics and has been instrumental in building a coherent national framework for human and animal research protection in Uganda, especially through her contribution to the establishment and accreditation of research ethics committees, assisting in the development of research ethics curricula for training of IRB members and scientists in research ethics and coordinating activities of the Network of IRB Chairs in Uganda. Over the past few years, Ms Nabbuto has greatly contributed to monitoring of research projects to ensure compliance with the National Guidelines for Research Involving Humans as Research Participants. She is also a member of the Uganda Society for Health Scientists' Bioethics Working Group an umbrella body which brings together all ethicists in Uganda.

Dr Blanche Pretorius holds the position of Director in the Department of Research Capacity Development at the NelsonMandela Metropolitan University (NMMU). She graduated with the degree Bachelor of Social Science (Social Work) from the former University of Natal, Durban. She later pursued Honours, Master's (Clinical Social Work) and Doctoral studies at the former University of Port Elizabeth (now NMMU). She has practised as a registered social worker in a variety of non-governmental organisations from 1979 to 1998. She then joined the former University of Port Elizabeth (UPE) in 1998. Positions held at UPE were as lecturer and student counsellor, later as senior lecturer and Head of Department and Programme Leader for Social Work until she joined the Department of Research Capacity Development (RCD) in 2009. Her current involvement in the area of research ethics is on a number of levels: as chairperson of the NMMU's Research Ethics Committee (Human) since 2008, as RCD responsible for the administrative oversight of research ethics at NMMU and research supervision of doctoral candidates in Social Work and Nursing Science.

Dr Geremew T Tsegaye is from Ethiopia and he is a medical doctor with a masters' degree in public health and bioethics. He graduated from the Ethiopia Medical School with an MD and obtained an MPH at the Free University of Brussels, Belgium. He also attended the European Masters of Bioethics in the Erasmus Mundus Program. He has worked as a medical practitioner and a medical director in public hospitals, and as a lecturer in the public health department at Mekelle University in Ethiopia. He is currently employed as a Project manager of HIV/AIDS Training Center of Excellence in All Africa Leprosy, TB & Rehabilitation Training Center (ALERT). The centre has 3 main divisions: Research (Armauer Hansen Research Institute-AHRI), Hospital Services and Training divisions involved in an infectious disease programs including Leprosy, TB, HIV and tropical dermatology. He coordinates the training division in particular and is responsible for the design, coordination and implementation of national and international training activities. He is also responsible for health research ethics training in his country.

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ARESA SHORT COURSES

Module 1 of the ARESA Postgraduate Diploma in Health Research Ethics was held in October 2011 and served as an introduction to health research ethics. The module was presented as part of the PG Dip but also as a short course. Similarly modules 2 and 3 will be offered as short courses registered with Stellenbosch University and accredited for CPD points**.**

ARESA SHORT COURSE II: Dual Review of Research as an Ethical Imperative (13-24 February 2012)

Research ethics committees in Southern Africa are charged with the task of dual review of research. Scientific review of research remains a challenge in most research ethics environments in Southern Africa. Module 2 will focus on the scientific review of both health science and social science research. Trainees will be introduced to a broad range of research methodologies and designs that can give rise to significant ethical problems. The goals of this module/short course will be to examine the dual responsibility of research ethics committees to conduct both scientific and ethical review; to provide a critical overview of major research designs and methods; and to examine issues regarding scientific integrity and publication ethics.

The deadline for short course applications for this module is **6 Dec 2011.**

ARESA SHORT COURSE III: Research and vulnerability (21 to 31 August 2012)

Module 3 will focus on the concept of vulnerability that has, for understandable reasons, become an important concept in regulations and ethical discussions in regard to the ethics of conducting research with human participants in developing countries. The goals of this module are to better understand what is meant by 'vulnerability' and how the various kinds of vulnerability should be taken into account in evaluating the ethics of research studies. Attention will be devoted to vulnerability connected to special populations, such as research with children and mental health research, as well as vulnerability related to research on specific health conditions such as genetic and oncology research. Since the concept of vulnerability is applicable at individual and community levels, attention will also be devoted to ethical issues regarding infectious disease control and associated principles of public health ethics.

The deadline for short course applications for this module is **29 June 2012.**

For more information please contact aresa@sun.ac.za or visit www.sun.ac.za/aresa

NHREC – current status

By Thabo Molebatsi and Prof D du Toit (NHREC Chairperson)

The health research ethics environment in South Africa is constantly advancing. The promulgation of the South African Constitution (Act No. 108 of 1996) was an important development in the history of South Africa. Enshrined in it, is section 12(2) which gives citizens the right not to be subjected to medical or scientific experiments without their informed consent. The promulgation of the National Health Act (Act No. 61 of 2003) in which chapter 9 deals with research was an important development even though some sections of the chapter have not yet been signed into law. The publication of the guidelines for health research ethics (blue book) and good clinical practice in clinical trials (red book) in 2004 and 2006 respectively was a good resource for researchers and RECs alike. The National Health Research Ethics Council (NHREC) was established in 2006, to oversee health research activities in the country. In 2010, the Department of Health published regulation number R 839 which operationalises the functioning of the NHREC.

The NHREC is currently in the second term of office which runs from 2010 to 2013. Six Council members were retained from the previous term

of office and eight new members were appointed for the current term. During the 2010/2011 financial year, the NHREC has evolved from operating with seven to four working groups and three committees. Below is a list of NHREC committees and working groups: NHREC Executive Committee (EXCO); Registration and Auditing Committee; Complaints and Disciplinary Committee; Training Committee; Human Subjects and Vulnerable Populations working group; Health Research Involving animals working group; Material Transfer and Biological Specimens working group, Ethics in Health Research: Principles Structures and Process working group. The latter two working groups are newly established based on the current need and scope of work of the NHREC. It is envisaged that the NHREC committees will remain in existence longer than the working groups in order to address the Council's core and long term functions.

During 2010/2011 the NHREC assessed 33 Research Ethics Committees (RECs) in preparation for the independent audit. While preparing for the audit of the 33 RECs, the NHREC is also gearing to assess 10 Animal Research Ethics Committees (ARECs). The assessment will allow the ARECs to prepare for auditing during 2012.

Finally the NHREC website has been updated

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Research priority identification at Jimma University, Ethiopia

By Dr Beyene Ademe, Public Health & Medical Sciences Research and Postgraduate Office, Jimma University, Ethiopia

The need to identify priority areas for research is especially pivotal at Jimma University, Ethiopia due to the various challenges that this country's health system faces, and the limited resources available for health research in general. It is therefore important that health research is focussed on improving health indicators and social justice for all Ethiopians, by linking national health priorities with specific health research priorities.

The practical feasibility, the availability of various resources and capacity, as well as the sustainability of the proposed health research must therefore be goal orientated and informed by national health indicators, the burden of disease in Ethiopia and relevant developmental needs. In addressing priorities in health research, equality and access to health care should also be taken into consideration. Health research should therefore be informed by common underlying values that address these specific needs.

Currently, the major health concerns in Ethiopia include the following: communicable diseases like HIV, TB, STDs, zoonotic diseases, vector-borne diseases, intestinal parasitoses and other epidemic diseases; food insecurity and nutritional problems focusing on vulnerable groups like children and pregnant women; maternal and new born health problems and assessment of related interventions like immunisation; child specific health problems and non-communicable diseases like hypertension, diabetes mellitus, common cancers and mental health problems.

These concerns should be addressed through, *inter alia*, the evaluation of Ethiopia's health extension program, as well as an evaluation of the functionality and effectiveness of the current tier system of health care delivery (private and public health care systems). This should be considered in terms of the resources available for specific health priorities and needs.

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Incentives and retention gifts in clinical trials

By Ms Margaret Ellis, SCION Clinical Research, South Africa

Offering incentives for research participation remains a contentious issue. Some argue that health research should not be treated as a commodity that can be bought and sold and participants should not be remunerated. Others argue that patient autonomy emphasises the rights of patients to make a voluntary decision about their participation in clinical research

based on risks and benefits and that they should be remunerated for this.

Payment to clinical research participants is a fairly common and long standing practice. Yet, little consensus exists about why, when, how or how much patients should be paid. Minimal guidance exists to help determine whether or how much participants should be paid. In this regard, the ethical guidelines merely state that the possibility of coercion and undue influence should be minimised. Participants in South Africa are not paid to participate in research but are remunerated for expenses sustained in participating in research on scheduled visits.

Recruiting the most suitable participants in sufficient numbers for clinical trial research is a worldwide challenge. Even more challenging, however, is motivating the participants to remain in the research project until completion. High dropout rates can endanger the statistical validity of the clinical trial data and have a severe cost implication for the research site and project.

Finding the right balance for encouraging but not coercing the participants is key. The provision of incentives should therefore be commensurate with the effort and time required from participants. Careful consideration is furthermore needed with fair selection criteria for the study population as well as with regard to the incentive or gift to be provided. When deciding to offer a retention gift or completion bonus, the following should be taken into consideration: the nature of the study, particular participant contributions and vulnerabilities, institutional and organisational guidelines regarding participant remuneration, as well as local societal and cultural norms. Incentives are unduly influential if the offer is so attractive that the participant finds it too irresistible to decline.

No guidance for retention gifts is available. What type of gift represents an undue inducement in clinical trials, especially long term trials? A study done by Tread Research at Tygerberg Hospital, Western Cape indicated that 64.3% of participants in the study showed that the receipt of a gift did not influence them to continue with the study and 69% said that the quality of the gift did not affect their participation. The results furthermore indicated that retention gifts are a useful motivational tool for studies of long duration and study participants generally appreciated the gifts. (Burgess & Sulzer 2011)

The approval and implementation of retention gifts in the correct settings can be useful to motivate participants to continue with studies and minimize drop-outs to ensure statistical validity and applicability of study results. Incentive or retention gifts in research represent a strategy to encourage participation, increase continued participation and compensate the participant for potential burdens such as time, inconvenience, travel. However, it is important that all gifts to participants are approved by a REC.

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National Research Integrity Symposium 15 November 2011

Keymanthri Moodley

The Research Integrity Symposium was convened by the National Research Foundation to consider the principles and the responsibilities outlined in the Singapore Statement on Research Integrity, and to discuss their appropriateness to the South African context. Sixty delegates working in the research, research ethics and academic

environments from around South Africa were invited. The document was discussed at length. While there was general agreement that the document is important and applicable to all research and academic environments implementation of its principles in practice was critical. Clearly research integrity policies are implemented in a variable manner throughout institutions of higher education in SA with some institutions having an Office of Research Integrity and others having no structures/policies and processes in place. All institutions were encouraged to find ways to practically implement the principles enshrined in the Singapore Statement.

Singapore Statement on Research Integrity

The Singapore Statement on Research Integrity was developed as part of the 2nd World Conference on Research Integrity, 21-24 July 2010, in Singapore, as a global guide to the responsible conduct of research. It is not a regulatory document and does not represent the official policies of the countries and organizations that funded and/or participated in the Conference. For official policies, guidance, and regulations relating to research integrity, appropriate national bodies and organizations should be consulted.

www.singaporestatement.org

Preamble

The value and benefits of research are vitally dependent on the integrity of research. While there can be and are national and disciplinary differences in the way research is organized and conducted, there are also principles and professional responsibilities that are fundamental to the integrity of research wherever it is undertaken.

Principles

- *Honesty* in all aspects of research
- *Accountability* in the conduct of research
- *Professional courtesy and fairness* in working with others
- *Good stewardship* of research on behalf of others

Responsibilities

1. Integrity: Researchers should take responsibility for the trustworthiness of their research.

2. Adherence to Regulations: Researchers should be aware of and adhere to regulations and policies related to research.

3. Research Methods: Researchers should employ appropriate research methods, base conclusions on critical analysis of the evidence and report findings and interpretations fully and objectively.

4. Research Records: Researchers should keep clear, accurate records of all research in ways that will allow verification and replication of their work by others.

5. Research Findings: Researchers should share data and findings openly and promptly, as soon as they have had an opportunity to establish priority and ownership claims.

6. Authorship: Researchers should take responsibility for their contributions to all publications, funding applications, reports and other representations of their research. Lists of authors should include all those and only those who meet applicable authorship criteria.

7. Publication Acknowledgement: Researchers should acknowledge in publications the names and roles of those who made significant contributions to the research, including writers, funders, sponsors, and others, but do not meet authorship criteria.

8. Peer Review: Researchers should provide fair, prompt and rigorous evaluations and respect confidentiality when reviewing others' work.

9. Conflict of Interest: Researchers should disclose financial and other conflicts of interest that could compromise the trustworthiness of their work in research proposals, publications and public communications as well as in all review activities.

10. Public Communication: Researchers should limit professional comments to their recognized expertise when engaged in public discussions about the application and importance of research findings and clearly distinguish professional comments from opinions based on personal views.

11. Reporting Irresponsible Research Practices: Researchers should report to the appropriate authorities any suspected research misconduct, including fabrication, falsification or plagiarism, and other irresponsible research practices that undermine the trustworthiness of research, such as carelessness, improperly listing authors, failing to report conflicting data, or the use of misleading analytical methods.

12. Responding to Irresponsible Research Practices: Research institutions, as well as journals, professional organizations and agencies that have commitments to research, should have procedures for responding to allegations of misconduct and other irresponsible research practices and for protecting those who report such behavior in good faith. When misconduct or other irresponsible research practice is confirmed, appropriate actions should be taken promptly, including correcting the research record.

13. Research Environments: Research institutions should create and sustain environments that encourage integrity through education, clear policies, and reasonable standards for advancement, while fostering work environments that support research integrity.

14. Societal Considerations: Researchers and research institutions should recognize that they have an ethical obligation to weigh societal benefits against risks inherent in their work.

Changes to the US Common Rule: implications for Southern Africa

By Prof Stuart Rennie, Department of Social Medicine, University of North Carolina

For decades, Institutional Review Boards (IRBs) in the United States, charged with protecting the rights and welfare of human participants in scientific research, have been criticized for having regulations and procedures that are inappropriate, cumbersome, bureaucratic, and inconsistently applied. These criticisms led the US Federal government to convene a working group that has issued what is called an 'Advance Notice of Proposed Rulemaking' (ANPRM). The ANPRM proposes a number of substantive changes to the US Common Rule, and includes some 74 questions for public comment. Over the last months, research institutions all over the United States have been submitting their remarks, criticisms and concerns about the proposed changes. Due to the fact that US government-funded research increasingly takes place all over the world, whatever changes are made to the Common Rule are bound to have a significant global impact. What proposed changes should those involved with biomedical research in Southern Africa keep their eye on?

One noteworthy proposal concerns consent for the use of biomedical specimens. Currently, the US Common Rule permits the use of biospecimens (from clinics or prior research) without obtaining consent as long as all identifiers have been removed. The change being considered would require written consent for the use of biospecimens even if the identifiers were removed. Researchers would use a standard, brief, open-ended consent for most research uses of a variety of biospecimens (such as all clinical specimens that might be collected at a particular hospital). Why the change? The answer seems to be: in the not-too distant future, genetic analysis of DNA will render any biospecimen identifiable and confidentiality cannot be guaranteed. This proposal has already raised many objections. For example, even if one analyzes the DNA of a biospecimen such that it will be known to belong to only one individual, how will it be known to belong to a specific person, unless we have other

data from that person to match it with? Some studies will involve the collection of thousands of biospecimens: is there to be a separate consent process for them all and how would this be accomplished, particularly in low-resource settings? Won't it turn rapidly into a meaningless ritual? Is an 'open-ended' consent for use of biospecimens really an *informed* consent, when the research participant has not details about the uses to be made of the tissues or blood they give? Is this consent just a waiver of the participant's rights in relation to what uses will be made with the biospecimens, potentially including the development of lucrative drugs or other interventions? The latter issue should be of particular interest in Southern Africa, since African biospecimens are commonly exported, analyzed and stored in the United States.

After the US federal authorities assimilate the comments generated from the ANPRM, they will issue a Notice of Proposed Rulemaking (NPRM) that will be open to further public comment. Those outside the United States involved in biomedical research should also let their voices be heard, since in the past they often found themselves required to follow foreign regulations that they had no opportunity to determine.

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ADVANCING RESEARCH ETHICS TRAINING IN SOUTHERN AFRICA

ARESA Annual Seminar

30 – 31 August 2012

Cape Town, South Africa

Upcoming Conferences & Events

• **Advancing Ethical Research Conference**
PRIM&R Public Responsibility in Medicine and Research
National Harbour, Maryland USA
2-4 December 2011

• **14th edition of the advanced European Bioethics course 'Suffering, Death and Palliative Care'**
14 – 17 February 2012
Nijmegen, the Netherlands

•**Translational Science 2012 Meeting: Improving Health through Research & Training**
Society for Clinical and Translational Science
18 – 20 April 2012
Washington DC, USA

PLAN AHEAD

• **World Conference on Research Integrity**
5 - 8 May 2013
Montreal, Canada

• **11th World Congress of Bioethics: Bioethics for the future. The future of Bioethics: Challenges, Changes, Concepts**.
Erasmus Medical Centre, Rotterdam
26 - 29 June
Rotterdam, the Netherlands

NOTES

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ADVANCING RESEARCH ETHICS TRAINING IN SOUTHERN AFRICA

On a lighter note....

By Dr Beyene Ademe

"I Do, I Do, I Do, I Do, I Do – the informed consent song"

<u>Things you would **not** say during an informed consent conversation</u>

"Now, this is the bit that all the other patients objected to..."

"You're free to leave the study at any time....if you don't mind being called a quitter."

"We'll publish the results....or they'll come out in the courts, whichever is sooner."

"It is an experimental treatment: we don't know how much better it is than the alternatives."

"No, I didn't understand that bit either...."

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