



# RESEARCH ETHICS COMMITTEE ASSOCIATION OF SOUTHERN AFRICA

CONNECTING RECs IN SOUTHERN AFRICA

## Newsletter

Issue 1/April 2018

# REASA

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Dear REASA member,

The REASA newsletter is one way in which the Executive Committee ensures that you get relevant insights into the most important activities conducted by the REASA Executive Committee, information about what we plan, and how our ongoing activities change to remain relevant in a dynamic research environment. Each newsletter addresses a focal point of high relevance for members of Research Ethics Committees (RECs) in Africa in general, and for Southern Africa in particular. The previous issue addressed the nexus between research ethics and research integrity (<http://www.reasa.africa/wp-content/uploads/2017/11/REASA-Newsletter-October-2017-V4.pdf>). This issue focuses on *Research Ethics Leadership in Africa*. To this end, Brenda Morrow, REASA's Deputy Chairperson, in her message to REASA members calls

*"... those who have benefitted from training and teaching programmes ... to step forward as leaders in their field – to*

*continue to learn themselves; and to share their knowledge and expertise with their peers, junior or emerging researchers, field workers, and general citizens alike".*

In 'A newbie's guide to leadership in ethics', Wayne Towers offers an interesting glimpse into his own experience as a "newbie" in the research ethics leadership domain. I found his lessons learnt refreshing and I hope you will too.

**Please do not miss the invite in this newsletter to attend the first REASA event, a workshop focusing on leadership for RECs in Africa, on 23 May 2018 at SPIER, Stellenbosch. For more information and access to the programme, visit the REASA website: <http://www.reasa.africa/wp-content/uploads/2017/10/Programme-REASA-Workshop-23-May-2018.pdf>.**

With warm regards,

*Retha Visagie*

Chairperson: Executive Committee, REASA

**BUILDING LEADERS TO DEVELOP  
RESEARCH ETHICS CAPACITY IN AFRICA**

*Message from REASA Deputy Chairperson,  
Prof Brenda Morrow*

*“Wealth, if you use it, comes to an end;  
learning, if you use it, increases” ~ Swahili  
proverb*

In the 21<sup>st</sup> century, there are sadly still considerable inequities in terms of health and health services delivery across the globe, with regions in Africa disproportionately burdened by poverty, inadequate access to health services, and serious endemic diseases (1-3). Many of these challenges and their solutions can and should be identified and addressed through well-designed research. Such research could include biomedical studies of epidemiology, diagnostics and therapeutics, as well as health-related studies aimed at addressing the complex inter-relationships amongst society, the environment, and human behaviour, including the social determinants of health.

Research is as an essential component in improving the health of the African people. However, many African societies are particularly vulnerable to exploitation and human rights abuses. Historical cases of unethical research practices in Africa include:

- Richard McGown, a British anaesthetist working in Zimbabwe, who conducted unauthorised clinical trials (without patient knowledge or consent), leading to a number of deaths (4);
- the well-known *Pfizer*-sponsored trial of trovafloxacin (*Trovan*) in Nigerian children with meningitis, which had not been ethically approved locally. Parental consent was inadequate, and the research was responsible for a number of participant deaths and brain injury (4);
- the case of Werner Bezwoda, who conducted unapproved breast cancer treatment research in South Africa and falsified his data, leading to a number of women with breast cancer undergoing unpleasant and ineffective treatments (high dose chemotherapy with bone marrow transplant) (4, 5); and

- the Ugandan Boehringer Ingelheim-sponsored trial of nevirapine in HIV treatment, which did not obtain participant consent for changes in experimental design and administered incorrect drug dosages (6).

Pharmaceutical company-sponsored trials are increasingly being conducted in low and middle income countries. Many of these countries have inherently weak health systems, the potential for fast and cheap recruitment of participants (the majority impoverished and with low educational levels), and in many cases, there is less stringent ethical, regulatory, and legal oversight of human research (7). Clinical trials have been, and are being conducted in Africa, which would never have been approved in well-developed countries owing to ethical concerns. For instance, some use placebo controls despite internationally accepted standard of care therapy, unavailable in the study region, and some do not offer post-trial access to the tested therapy. The question of whether these trials are purely exploitative, or regionally relevant remains debatable (6, 7). Although global health initiatives offer substantial potential benefits to healthcare in Africa, there is the continual threat of exploitation and power imbalance. The appropriateness of such research being conducted in African countries, therefore, requires stringent independent review and oversight by regional African research ethics committees (RECs), in order to ensure the research is appropriate in terms of the local context, customs, potential benefits and harms of the planned research.

The challenges of conducting health research in Africa have been recognised, and there has been appropriate attention to developing research ethics capacity throughout the continent over the last two decades. Many funded programmes are successfully training African researchers, strengthening existing RECs, developing research ethics training programmes at African institutions, and contributing to national ethics policies (8). Over thirty African countries now have established RECs. However, there are still challenges amongst these RECs in terms of membership profiles, training levels, capacity, efficiency, and quality/consistency of review

processes (9). Other African countries still do not have RECs in place at all. For RECs to be effective and consistent, there should be consideration of both international ethical norms and standards, as well as local customs, traditions, and laws (10). To continue the positive trajectory of growth and capacity development in research ethics in Africa, those who have benefitted from training and teaching programmes need to step forward as leaders in their field – to continue to learn themselves; and to share their knowledge and expertise with their peers, junior or emerging researchers, field workers, and general citizens alike.

A number of REASA Executive Committee members are privileged to have been beneficiaries of advanced research ethics training programmes, and others are already established in the field. As leaders in animal and human research ethics in Southern Africa, we recognise our responsibility to continue developing research ethics capacity throughout the region. This is enshrined in REASA’s mission, as stated in the constitution, to:

- a. seek out and establish mutually beneficial connections between RECs in Southern Africa;
- b. promote the philosophy and practice of ethical human and animal research in Southern Africa;
- c. provide information, support, and training to its membership, by (amongst other activities):
  - establishing local, national and international networks for the discussion of research ethics-related topics of mutual interest;
  - facilitating co-operation and communication amongst its membership;
  - developing regional policies on research ethics based on the collective view from the regions;
  - providing a mentoring, consultative and advocacy service for its members; and
  - providing capacity development courses and other interventions to build the capacity and capabilities of research ethics committees in Southern Africa.

This Newsletter speaks to several of the above aims, and we hope you, the member, benefit from the information shared in these pages. We also invite your feedback about potential ideas for future Newsletters, such as areas of particular interest, philosophical questions, or ethical concerns.

To achieve all the aims of REASA and, more importantly, to ensure adequate protection of the African people in research, we rely on research ethics leaders (current and future) to spread the word and work together to prioritise and develop local, relevant, African research ethics capacity.

(A complete list of the references is available on page 6.)

*“That which gains the attention of a leader will be solved” ~Ugandan Proverb*

### **REASA ACTIVITIES**

REASA is proud to announce that the association has officially moved into cyberspace with the publication of our own website. The website (which can be accessed at <http://www.reasa.africa/>) is freely accessible to all interested parties and provides an overview of the vision and drive behind the establishment of REASA, important information about the mission and history of REASA, and it offers access to various ethically relevant documents for members of RECs. It also acts as a central registration point for the training opportunities that REASA will make available to its members and the general public, both now and in the future (see the discussion of our upcoming workshop entitled, “Research Ethics Leadership: An African Perspective” below). In terms of member-specific functionality, we are currently in the process of developing a “member forum” page that will allow REASA members to communicate, share experiences and best practice in an easy and secure manner. It is hoped that the website will become a valued resource for all REASA members.

On your first visit to the site, you will also notice the new REASA logo, which is part of the

rebranding initiative of the new Executive Committee. The Baobab tree is representative of REASA's intention to grow into a far-reaching and robust association that deeply cares about the wellbeing of the research ethics community of Southern Africa. It also serves as a reminder to never forget our strong "roots" which were cultivated and nurtured by the ARESA programme (<https://www.sun.ac.za/english/faculty/healthsciences/aresa>), which gave us the opportunity to take seed and has allowed us to keep reaching skyward. The logo change and rebranding go hand-in-hand with the establishment of the new Executive Committee and our renewed commitment to supporting our members and promoting "sustainable networks between RECs in Southern Africa and the African continent".

As part of this mission, we would also like to invite all our members to the first training opportunity presented by REASA. The focus of this workshop ties in with the overarching theme of this newsletter, which is "*Research Ethics Leadership: an African Perspective*". The workshop will provide attendees with a framework of the necessary tools and skills that are required for us to become leaders in the field of research ethics. The workshop will consist of four presentations. First, an "Introduction to research ethics leadership" will set the scene. This will be followed by a session on "Leadership skills for running your REC" which will focus on the governance of ethics and how we can implement guidelines into practice. Next, "Leadership in Ethics review" will be examined with a clear focus on the role that ethics committee members play in improving the quality of research in institutions and ensuring sustainability and rigour in these processes. Finally, we will discuss "Defending the independence of the REC". We believe that this session will provide attendees with the tools required for steering their RECs through the choppy waters of academia and research, while being barraged by numerous undercurrents of resistance to change by researchers, the perceived negative impact on research outcomes, and the realities of the financial constraints placed on RECs due to the current academic milieu, not to mention surviving the tsunami of administration

associated with the correct functioning of RECs.

The workshop will be presented prior to the annual ARESA seminar and will be held on **23 May 2018** from **09:00 to 13:30** at the **Spier Conference Centre in Stellenbosch**. Interested parties are welcome to register for the workshop via the REASA website (by logging in at <http://www.reasa.africa/education/>).

## **A NEWBIE'S GUIDE TO LEADERSHIP IN ETHICS**

*A reflection by Prof Wayne Towers*

I recently made a massive career change. It completely caught me off guard, and I think many of my friends and colleagues as well. I had been an avowed laboratory-based human geneticist my entire life. However, three years ago I was given a wonderful opportunity to become an academic advisor within my faculty's Ethics Office. Thus began my incredible and challenging journey in the field of research ethics, which forced me into a world that I knew very little about, and which filled my little reductionist heart with dread, i.e. one wherein I had to deal with other people. What a challenge this seemed to me as a card-carrying introvert, whose longest conversation with others involved troubleshooting a pesky reaction that would not work. However, I soon realised what an enriching and exciting world it actually was, which has allowed me to grow not only as a scientist but also as a human being.

It has not been a simple process, though. I truly felt like the proverbial "fish out of water". I had to take the limited knowledge I had about ethics and, under the tutelage and leadership of my incredible supervisor, had to implement it into a workable system which would protect our research participants, our researchers, and the University itself. No mean task for an individual who had very little experience with the finer nuances of academic management and leadership. As any good adventurer knows, the first lesson I learnt was to "find the best and learn from them". I was thus extremely fortunate in finding an incredible mentor who truly took me under her wing and guided me through the numerous pitfalls, traps

and dead-ends in traversing the murky waters of implementing research ethics into an academic environment.

The second lesson I learnt from her was to “arm yourself with the weapon of knowledge”, because how can you possibly overcome the obstacles and challenges that arise if you do not have the necessary information to develop a solution? As such, I found myself enrolling at the ripe (old?) age of 35 years for a post-graduate diploma in health research ethics, which meant I was back to studying for exams like a first-year undergraduate student. All I can say is that a vista opened up for me when I realised a) the importance of ethics in our everyday lives and b) the sheer diversity of its application. I suddenly became a philosopher who had to implement subjective concepts such as “right” and “wrong” into, what I always assumed, was the objective world of science.

I had to start asking questions such as, “Is my research truly going to benefit my participants? Am I excluding those that are at greatest risk due to my own convenience? Am I sure that they understand the concepts that I am talking about when I know that my fourth-year students are struggling with the same concepts? Do my participants have a voice in the type of research I am asking them to take

part in?” These were questions that completely blew my mind as they forced me to re-evaluate my worldview as a researcher. I could not, in good faith, carry on with my paternalistic view that I was somehow the expert, who would sweep in and fix, what I thought were my participants’ problems. I had to realise that the fact that I was given the opportunity to become a researcher, as well as the privilege I was granted because of that, actually meant that I had a great responsibility to serve the community that made that opportunity available to me.

And so, I learnt my third lesson, which was, “don’t do it alone,” and this is, in fact, my call-to-arms, dear reader. It is too great a responsibility for just one person to carry and so I beg of you to be the change in your institutions, research entities, governmental departments, and communities. Be proponents of beneficence, autonomy, and justice. Undertake research that truly serves your communities. Appreciate the great gift we have received in the form of our education and how it should lead to a life of service and not one of power. Realise that the only way we can move forward is if we move together as one. It is only in this manner that we can change “being ethical” from something we do to being something we are.

### **UPCOMING EVENTS**

#### **REASA Workshop on Research Ethics Leadership on 23 May 2018**

For more information, go to <http://www.reasa.africa/education/>

#### **ARESA 7<sup>th</sup> Seminar in Health Research Ethics on 24-25 May 2018**

For more information, go to <https://www.sun.ac.za/english/faculty/healthsciences/aresa/Documents/7th%20ARESA%20Research%20Ethics%20Seminar%202018%20Flyer-final5.pdf>

#### **6<sup>th</sup> International Conference on Ethics Education during 3-5 October 2018**

For more information, go to <https://www.iaee6.com/>

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