

## **A CONFERENCE SUMMARY REPORT**

**The 9<sup>th</sup> Annual National Research Ethics Conference (ANREC) 11th - 12th July 2017 at  
Kampala Serena Hotel, Uganda**

**Theme:** “Effective Collaboration in Research: Promoting Mutual & Equitable Partnerships”

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### **1.0 Introduction**

Collaborative research does not just happen when groups of people come together around a shared idea or research topic. Unless the focus on teamwork, collaboration, and managing the inevitable conflicts that arise is deliberate and thoughtful, both the process and outcomes may be superficial or even fraught with struggle and damage. Drawing from individual and combined experiences from stakeholders about this issue of collaboration, clear decision-making guidelines involving all levels need to be developed and documented to show how decisions are made at all levels within each organization since individuals share a stake in both processes and outcomes of the collaboration. Clear roles and policy guidelines should be developed to clearly understand each partner’s roles and responsibilities. Agreements on operating policies should be developed and documented so that each participating organization understands their role. Accountability standards where clear expectations of performance are established for each participating organization should be formulated as well. Similarly, means of managing conflict should be in existence to raise and address grievances in a constructive way. Conflicts should be managed effectively and channelled into finding useful solutions. All these issues surrounding collaboration in research were a subject of discussion at the 9<sup>th</sup> Annual National Research Ethics Conference (ANREC) that was held from 11th - 12th July 2017 in Kampala, Uganda

The 9<sup>th</sup> ANREC was successfully held with the theme, “Effective Collaboration in Research: “Promoting Mutual & Equitable Partnerships”. A total number of 549 participants attended the conference. Some of the participants came from Commission for Science and Technology in Tanzania, National Commission for Science, Technology of Kenya, and Medical Research Council, Zimbabwe. A number of other foreign nationals working and living in Uganda together with their Ugandan counterparts attended the conference.

ANREC is a platform for engagement and interaction among the various actors involved in human subjects’ protection in Uganda. It brings together researchers, regulators, policy

makers, members of research ethics committees, civil society groups and research communities. These stakeholders share experiences and discuss contemporary issues affecting the conduct of human subjects' research in Uganda and the region. ANREC has been consistently held every July by Uganda National Council for Science and Technology (UNCST) since 2009 in conjunction with partners, notably the National Drug Authority and the Uganda National Health Research Organisation.

The 9th ANREC established the evolution of collaborative research in Uganda and how various researchers or institutions work together to achieve a common mission. The objective was to equip researchers, policy makers, research ethics committees, community representatives and other stakeholders with knowledge and understanding of the digital age and the changing nature of collaboration in research, assessing if genomics and biobanking would reduce or enhance future collaboration in research, how research subjects and research institutions can get fair and equitable benefits from collaborations in research with respect to human materials and data. These issues were explored within the Uganda context but with perspectives from East Africa and around the world. It is hoped that the lessons learnt through the 9<sup>th</sup> ANREC will improve research collaboration in Uganda. The 9<sup>th</sup> ANREC featured distinguished local and international speakers.

## **2.0 High level participation at the opening and closing ceremonies**

The Chief Guest at the Opening Ceremony was the Rt. Hon Prime Minister, who was represented by Hon. Dr. Elioda Tumwesigye, Minister for Science, Technology and Innovation. Hon. Tumwesigye informed participants that the Ministry of Science, Technology and Innovation established a National Innovation Fund which will present an opportunity of implementing Uganda's own research agenda. Mr. David O.O. Obong the Permanent Secretary, of the Ministry of Science, Technology and Innovation closed the conference on 12<sup>th</sup> July with award of certificates to participants.

## **3.0 Appreciating our champions: The 2017 National Bioethics Award**

The 2017 National Bioethics Award was presented to Prof. Philippa Musoke of Makerere University - Johns Hopkins University Research Collaboration for distinguished leadership in institutionalizing compliance with ethical standards in collaborative research among vulnerable populations. Annually, UNCST recognises outstanding individual contribution of Ugandan men and women towards the protection of human research participants in Uganda and for the advancement of bioethics for national development. The award was given at a colourful opening ceremony of the 9<sup>th</sup> ANREC.

## **4.0 The main issues and recommendations**

- a. African researchers have lower negotiation power in collaborative research. Concern was raised over the feasibility of ensuring security for electronic data capture and storage, having realized that data sharing in collaborative research is complicated by the variations in governing laws. It was urged that publication authorship is almost impossible for African scientists because their most frequent role is providing samples and conducting fieldwork other than being involved in the project research design. All these were

presented as areas where current inequalities undermine equal partnerships and collaborations in research.

- b. Genomics and biobanking in research has introduced new ways of undertaking science, based on values of sharing and reuse of data and samples. Overall, in the rapidly changing landscape of science needs to be broad and flexible enough to accommodate changes. Key principles related to genomics and biobanking need to be incorporated in the research guidelines for greater openness, sharing of resources, collaboration between scientists from across the world, and re-use of samples and data for secondary research. These emerging technologies will require setting new ethical standards.
- c. Community engagement in research supports mutual respect of values, strategies, and actions for reliable partnership of people affiliated by a geographic location, shared interest, or similar circumstances to address issues affecting community wellbeing. It is a collaborative process between the researcher and community partner that creates and disseminates knowledge with the goal of contributing to the discipline and strengthening the well-being of the community. The process also identifies the assets of all stakeholders and incorporates them in the design and conduct of the different phases of the research process. It was therefore recommended that communities should be consulted at all levels of research since it promotes better research and translation of findings.
- d. There is need to establish a regional mechanism for joint review of research protocols especially clinical trials. It was noted that the review process of clinical trials in the country takes a long time considering that there are several levels of regulatory approvals. It was suggested that research regulators should consider having a joint review mechanism of clinical trials to avoid duplication of efforts and also save on the turnaround time for researchers. Revival of the East African regional research bodies such as the East African Health Research Commission should be optimized to implement our regional research and Science, Technology and Innovation agenda.
- e. To many, informed consent is mistakenly viewed as the same as getting a research participant's signature on the consent form. It is believed that obtaining a research participant's verbal or written informed consent is only part of the process. Informed consent involves providing a potential participant with: adequate information to allow for an informed decision about participation in the research investigation, facilitating the potential participant's understanding of the information, an appropriate amount of time to ask questions and to discuss with family and friends the research protocol on whether one should participate. The consent process is very crucial to clinical research, and should be strengthened by improving the content and readability of the consent forms especially those that involve storage, use and exportation of samples.
- f. Other issues discussed included the need for revision of the National Research guidelines for Research involving Humans as Research Participants to incorporate the evolving research issues and changes in international research laws and regulations, monitoring of

transferred research materials abroad is still difficult to enforce by regulators, there is therefore, need to develop mechanisms for acquiring periodic reports on materials from Principal Investigators. Host institutions were also encouraged to step up their financial support to RECs to enable them operate effectively.

#### **4.0 Thanks to our partners**

We acknowledge the support from our key partners for the 9th ANREC, who were: Organisations that sponsored their staff to participate in the 9th ANREC, National Drug Authority, Uganda National Health Research Organisation, International AIDS Vaccine initiative and Medical Research Council. Self-sponsored participants are similarly acknowledged.

Great thanks also go to the Advisory and Planning Committee members comprised of: Dr. Rhoda Wanyenze (Makerere University School of Public Health), who was the Conference Chair, Dr. Christine Nabiryo (Mildmay Uganda, REC), Dr. Francis Bajunirwe (Mbarara University of Science and Technology, REC), Dr. Masitula Nanfuka (The AIDS Support Organisation, REC), Dr. David Kyaddondo (Uganda Cancer Institute, REC), Dr. Sam Okware (Uganda National Health Research Organisation), Ms. Leah Nawegulo (African Field Epidemiology Network -AFENET), Dr. Julius Ecuru (Uganda National Council for Science and Technology). Ms. Winfred Badanga (Uganda National Council for Science and Technology) and last but not least, Ms. Hellen Opolot (Uganda National Council for Science and Technology).

#### **5.0 Next (10th) ANREC**

The 10th ANREC, will be held from 11<sup>th</sup> - 13<sup>th</sup> July 2018. The nominations for the 2018 National Bioethics Award is also open. Guidelines may be obtained from the UNCST website at [www.uncst.go.ug](http://www.uncst.go.ug).