UNCST
UGANDA NATIONAL COUNCIL
FOR SCIENCE AND TECHNOLOGY

THE REPUBLIC OF UGANDA

12th ANREC
ANNUAL NATIONAL RESEARCH ETHICS CONFERENCE

THEME
COMMUNITIES AS PARTNERS: STRENGTHENING COMMUNITY ENGAGEMENT IN RESEARCH

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Hotel Africana
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SUMMARY REPORT

by
Nazziwa Winfred

1.0 Introduction

Research generally is important for human progress, knowledge generated provides the basis for decision making on matters which directly affect the health and wellbeing of people and their communities. Research involving humans as research participants ought to be conducted in accordance with the basic principles of research ethics. The premise of research ethics is to ensure that research participants and or animal subjects are treated with dignity, and their rights, values, interests and welfare are respected during research. Respect for, and protection of communities and research participants in the process of research is an ethical obligation for researchers. In principle, if research is to be responsive to the needs and priorities of communities, then communities should be involved in the entire research process right from the identification of the research problem to implementation of the findings.

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Community engagement is a process of working collaboratively with and through individuals and or groups of people linked by geographical location, special interest, similar situations or other identities, to address issues affecting their interests. In the context of research, community engagement involves a range of activities and interaction between researchers, members of the research community and other stakeholders that are affected by or can affect the success of the research. Such collaborations and engagements are fundamental, in any research process.

Conducting research in low-income countries raises concerns of fairness when it comes to post research responsibilities (PRR) and obligations specifically Post Trial Access (PTA). Yet the principle of justice holds that particular individuals, groups or communities should neither bear unfair share of the direct burdens of participating in research, nor should they be unfairly excluded from the potential benefits of research participation. In principle participants and their communities ought to receive fair benefits from participating in research. Issues related to PRR are complex, with number of gaps and challenges in its implementation.

The existing guidelines, both international and national are inconsistent and ambiguous, making PRR one of the major unresolved issues in international research ethics. Including, who is responsible for what in regard to PRR? Who should provide PTA? What counts as a reasonable plan or effort? What is the appropriate duration of provision? The role of the Research Ethics Committee (REC) and other regulators. Pre-trial/study planning for responsiveness; Negotiations with relevant stakeholders for infrastructure improvements and reasonable availability and transitional responsibilities. These issues and questions, among others, were the subject of intense discussions at the 12th Annual National Research Ethics Conference (ANREC) that was held from 21st – 22nd October 2025 in Kampala, Uganda.

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2.0 Participation and Attendance

The 12th ANREC Event was successfully held with the theme, **"Communities as Partners: Strengthening Community Engagement in Research".** A total of 706 participants attended the conference including the secretariat, speakers, moderators, delegates, media, and service providers. Attendance was consistently high across both days, with 694 participants on Day 1 plenary sessions and strong engagement in breakaway tracks, while Day 2 recorded 628 in the morning and 595 in the afternoon. The conference achieved near gender parity (51% male, 49% female), drew representation from 74 institutions, and reflected a healthy generational mix dominated by mid career professionals. While student participation was low (4%), the event demonstrated strong national ownership with 95% Ugandan participants, alongside regional and international delegates. Importantly, 62% of respondents were first time attendees, underscoring ANREC's expanding reach. Some of the participants came from the National Medical Research Institute in Tanzania, The KEMRI WellCome Trust, Kenya, the Food and Drug Authority Ethiopia, Jimma University Ethiopia. A number of other foreign nationals working and living in Uganda together with their Ugandan counterparts attended the conference.

The Uganda National Council for Science and Technology (UNCST) adopted the concept of the ANREC in 2009 to provide a platform for sharing experiences, discussing contemporary issues relevant for human and animal research, building capacities, sensitizing the public and identifying options for addressing ethical dilemmas experienced in the conduct of research. The ANREC brings together researchers, regulators, policy makers, members of research ethics committees and Institutional animal care and use committees, civil society groups, institutional officials and research communities. These stakeholders share experiences and discuss contemporary issues affecting the conduct of human participants and animal subjects research in Uganda and the region. The ANREC has been organized by UNCST in conjunction with partners, notably the National Drug Authority and the Uganda National Health Research Organization.

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The 12th ANREC demonstrated various ways through which research stakeholders can effectively engage research communities in the entire research process and what it means for research to be responsive to the needs of the communities. In addition, the 2025 ANREC event examined issues related to PRR, obligations and PTA particularly the un-settled areas. While other issues were examined, the main focus was on how to foster community engagement and equity in research. These issues were explored within the Uganda context but with perspectives from East Africa and around the world. It is hoped that the lessons learned through the 12th ANREC will improve research conduct in Uganda. The 12th ANREC featured distinguished local and international speakers.

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3.0 High Level Participation at the Opening/Closing Ceremonies and launch of Research Guidelines

The Chief Guest at the Opening Ceremony was the Hon Minister for Science Technology and Innovation who was represented by **Dr. Cosmas Mwikirize** the superintendent Industrial Value Chains/Chief Scientist at the Science Technology and Innovations Secretariat- Office of the President (STI-OP). The Vice Chairperson of the UNCST Council **Prof. John Muyonga** was the co-host. The Chief Guest also launched the revised national guidelines for research involving humans as research participants, National Guidelines for Community Engagement in Research and National Guidelines for Joint scientific and ethical review of research. **Dr. David Serukka**, the Acting Executive Secretary UNCST closed the conference on 22nd October 2025 with recognition of the Scientific Planning Committee of the ANREC and regional participants.

4.0 The Main Issues and Recommendations

The conference highlighted several action areas and key issues for regulators, policymakers, community representatives, researchers, and other stakeholders, as outlined below.

Community partnerships: Recognizing that community partnerships are fundamental to developing adaptive, inclusive, and innovative engagement strategies that ensure even the most disadvantaged, marginalized, or disconnected populations are meaningfully included in research processes. Such partnerships should go beyond consultation; to create spaces where communities become active contributors to the generation of knowledge. Involving communities at every stage from conceptualization to dissemination builds trust, upholds ethical standards, democratizes the production of knowledge, honors indigenous and local expertise, and significantly improves the quality, relevance, legitimacy, and long-term sustainability of research outcomes.

Advocacy for community engagement: The need for advocacy for CE in the entire research process including dissemination of study findings was re-echoed. The same effort shown as researchers seek to engage participants in research activities should be the same effort used to disseminate research findings to the research participants and communities and not only the elite who rarely participate in research. Advocacy to seek the communities' input into the study protocols and not just fly in protocols from the West.

Institutionalizing continuous community engagement: Engagement must be implemented in an ethical manner. Balancing research timelines with meaningful engagement. Involvement and support from institutional heads/ leadership is crucial for successful engagement. CE requires resource allocation including budget for staff and activities. Researchers should deliberately plan and budget for meaningful and sustained community engagement throughout the research lifecycle (not as a one-off event).

Transformation in research culture: Recommendation to have a shift from "research on communities" to "research with communities" which signifies a profound transformation in the research culture. Although this challenges traditional extractive models where communities serve merely as study sites or data sources, replacing them with participatory, partnership-centered approaches.

Participatory Assessments: Prioritization of participatory assessments, co-learning sessions, and open dialogues, allowing communities to identify pressing issues, shape research questions, and interpret findings in ways that align with local priorities. If research is to be responsive, it begins with recognizing the inherent value of community knowledge systems, aspirations, and worldviews.

A key pillar of responsive research is accountable knowledge sharing, which emphasizes that communities should be involved throughout the research lifecycle. Including participation in data governance and stewardship; negotiation for intellectual property and benefit-sharing arrangements; interpretation of results and co-creation of dissemination tools and messages.

Reforms and pathways for strengthening community-engaged research include; strengthening national and institutional policy frameworks that require and monitor community engagement, embedding responsive research principles into university curricula, ethics training, and research mentorship, ensuring authentic and diverse community representation, particularly from marginalized/vulnerable groups, promoting local control and leadership in research governance, agenda-setting, and resource allocation, enhancing downward accountability mechanisms, where researchers and institutions answer directly to communities as key stakeholders and developing inclusive models of research evaluation that value community impact, social relevance, and equity.

Extractive model of research: Researchers should shift from the extractive model of doing research from communities with fly-in protocols to doing research with communities based on shared power, accountability, and mutual respect. Researchers ought to recognize and leverage indigenous knowledge as valid scientific knowledge and address knowledge justice. Not only focus on merely scientific rigor and pre-trial consent but must be participatory, responsive and community centered across the research cycle from design through to post-trial responsibilities.

Capacity strengthening for media professionals: The media was acknowledged as a key stakeholder in research; it was recommended to proactively strengthen capacity for the media professionals to become a better vehicle to relay research messages.

Social behavioral Research (SBR), Although SBR and biomedical research differ in scope and methods, both are united by a common set of core ethical concerns. It is important to reconceptualize the concept of harm to include unique aspects of social and behavioral research, such as social, psychological, economic harm, which may not be adequately addressed by traditional biomedical ethics. Also, ethical SBR is inseparable from good CE as the goal is to shift from studying participants to partnering with communities as a continuous process.

Disaster research is broader than infectious disease research and raises the stakes, necessitating different ethical considerations than non-crisis research. Researchers must find ways to enter communities without being viewed as "disaster tourists". Ethical issues should be embedded across the entire research value chain through problem identification that prioritizes community needs and avoiding disaster tourism, engaging communities in risky areas to define research questions (co-creation and co-design).

Avoiding re-traumatization of the communities during data collection, misrepresentation of finding during data analysis, respectful dissemination and sharing findings with affected communities and relevant authorities. Research should focus on the "build back better" principle, ensuring that research is fit for purpose in transforming society and building resilience against cyclic hazards.

Disease outbreaks: Institutionalizing engagement whereby community engagement is embedded in national preparedness plans, not treated as an afterthought. There is need to invest in community engagement as a core pillar of outbreak response. The use of digital tools for feedback leveraging mobile platforms and social media to enhance real-time communication and data collection. Equipping health workers with skills in cultural competence and community dialogue is essential.

Ethics in emergency planning: While rapid decision-making is necessary during outbreaks, there is a need for pre-planned ethical review frameworks to enable speed without suspending ethics. Transparency and community engagement remain essential, even in a crisis.

Research in emergency situations, outbreaks, epidemics and pandemics is no longer a just nice to have activity but an integral component of the epidemic response, the need for regulation and participant protection is of paramount importance. However, there are concerns about epidemic research e.g distraction from epidemic response including taking away resources from the response, ethical standards may not be upheld, doubts about quality of the interventions and effectiveness given the speed at which they are developed and its impact of research on distressed communities.

During emergency response community engagement helps to build trust and resilience, enabling timely and culturally appropriate responses to health crises. It facilitates teamwork and acceptance, improves uptake of public health measures and reduces misinformation. Two-way communication with local leadership is essential for effective surveillance, safe practices, and sustained emergency preparedness which may translate into ownership of interventions.

Establishing ethical frameworks for emergency trials by developing context-specific ethical guidelines for conducting research during outbreaks. Standardizing community engagement approaches, laying strategies that ensure trial participants and affected communities have priority access to vaccines and therapeutics once proven effective.Training multidisciplinary rapid response teams with expertise in epidemiology, social science, ethics, logistics, and communication.

Review for novel and uncommon research designs like adaptive clinical trials demand flexible yet robust ethical review frameworks that allow the dynamic evolution of informed consent and community communication as protocols change. The complexity of adaptive trials must be communicated in a clear, understandable manner to ensure consent is truly informed and to avoid the therapeutic misconception. Research participants need clear, ongoing communication about the adaptive nature of the study, which must be clearly detailed in the informed consent process. Participants should understand that the trial design is flexible and that aspects like dosage, study population, or the chance of being randomized to a specific arm may change based on accumulating data.

Dissemination of research findings ought to be done promptly to address the pervasive weakness of poor dissemination by ensuring timely and thorough feedback (positive or negative) to communities, which is crucial for building trust and demonstrating research benefit. Importantly, dissemination should be conducted using accessible, culturally appropriate formats such as community dialogues, storytelling, radio programs, visual summaries, or participatory exhibitions that empower communities to use the findings for self-advocacy, planning, and improving their own wellbeing.

Post research responsibilities: successful implementation of post research activities /responsibilities requires pre-trial agreements with ring-fenced funding, strengthened regulatory enforcement, rapid translation of research findings into policy, sustainable capacity building within local institutions, and ongoing investment in trust and equitable partnerships with communities and global sponsors. Similarly, regulators should plan and budget for post-research responsibilities to ensure continuous ethical oversight.

Strengthening ethical frameworks: These frameworks must address emerging issues such as social harms in behavioral research, uphold international standards like the Helsinki Declaration, and adapt to evolving research designs, including Adaptive Clinical Trials. During public health emergencies, rapid decision-making must still be transparent and community centered. The ethical landscape (policy and practice) must make the necessary shifts to fully reflect the commitments of the Helsinki Declaration, particularly concerning the protection of human participants, free/voluntary informed consent, and community engagement.

Participant Protection and Insurance; Improve access to clinical trial insurance coverage for participants. clarify compensation rights, create clear awareness among participants about their right to insurance and clarify procedures for eligibility for compensation for Serious Adverse Events to improve protection and ethical treatment.

To advance gene therapy research safely in Uganda, policy updates, collaboration, and enhanced training are essential among Uganda's regulatory bodies. Uganda has a regulatory and institutional framework to support cell gene therapy. Key institutions include RECs (review protocols to protect participants and ensure adherence to standards); UNCST (provides policy guidance and overarching regulatory oversight); and National Drug Authority) regulates biological and advanced therapy products and pharmaceuticals.

The journey toward **integrating traditional and natural medicines** into conventional clinical trial pathways demands more than laboratory capacity or regulatory reform. It requires addressing historical fears of intellectual property loss, acknowledging the collective nature of traditional knowledge, and creating equitable partnerships between researchers and communities.

Traditional alternative medicine research ecosystem, Uganda ought to adopt IP frameworks that protect traditional knowledge, empower communities and enable responsible innovation. This requires reconciling international trade rules with biodiversity and cultural rights, strengthening national regulatory systems and adopting legal approaches tailored to collective knowledge systems. The true measure of progress is not the number of herbal patents filed, but the extent to which Uganda ensures that its traditional healers, communities and indigenous knowledge custodians retain control over their heritage while benefiting equitably from future scientific and commercial advances.

Acknowledge Africa's bio assets: Recognize strategic importance of Africa's bio-assets and promote the community's role in preserving indigenous knowledge to preserve and harness them. Bio-assets (plants and animals) are the essence of life and wealth that have historically been neglected. Communities should be recognized as the stewards of bio-assets and therefore their role in research must move beyond mere consent, passive beneficiaries to become co-producers of knowledge and knowledge products. Future research ought to institutionalize ethical safeguards around risk-benefit fairness, data sovereignty, benefit sharing and acknowledgement, and cultural safety. It must be purposeful and supportive of national development within a "one-world, one-market, one-farm" context.

The importance of agricultural animals in biomedical translational and comparative research demonstrates their unique physiological relevance to humans and their critical contributions to advancing medical knowledge and innovation. The growing reliance must be matched with rigorous ethical oversight, clear regulatory pathways, and strong welfare protections to ensure responsible scientific practice. The need for careful management of risks from disease transmission to genetic engineering concerns and for research approaches that respect cultural norms, uphold ethical principles, and prioritize humane treatment.

The necessity of effectively engaging animal owners in research involving animals emphasizes that ethical and successful outcomes depend on partnership, strict animal welfare adherence, and responsible use of technology. Advanced techniques, such as altering fertility in animals to enhance livestock outcomes, should be carefully implemented. A holistic approach to ensure ethical research must be considered, paying keen attention to environmental risks and cultural sensitivity.

Animal Health Research: Profound reimagining of how animal health research is conceived and practiced in Uganda, urging a move away from extractive, colonial legacies toward genuinely collaborative, community-centered science. By tracing the evolution of veterinary practice from indigenous ethno-veterinary knowledge through the disruptions of colonialism, the collapse of veterinary systems, and the recent resurgence of participatory approaches.

The 2024 revisions to the Declaration of Helsinki underscore meaningful participation and the need to give community members, particularly prospective participants a voice in shaping research agendas. Overall, the 2024 revisions represent a strengthening of global ethical expectations. They reinforce participant protection, advance community centered research, expand post-trial obligations, and enhance scientific accountability.

While Uganda's regulatory framework through UNCST, RECs, and institutional guidelines already embodies many of these principles, the new Declaration invites further alignment. This requires policy refinement, capacity strengthening, training of ethics committees, and integration of new ethical expectations into institutional procedures.

Finally, **recognize the obstacles** that limit the full realization of equitable community- engaged research such as, power imbalances between academics and communities, where researchers retain decision-making authority, donor-driven priorities that may overshadow local needs or silence local voices, devaluation of indigenous and experiential knowledge, funding limitations that fail to support long-term engagement or community capacity strengthening, rigid academic reward systems that prioritize publications over community impact, language, literacy, and educational barriers that restrict meaningful participation and structural inequities in governance and resource allocation.

5.0 Thanks to our partners

We acknowledge the support from our key partners for the 12th ANREC, who were: Organizations that sponsored their staff and community members to participate in the 12th ANREC, the UNCST, the National Drug Authority, Uganda National Health Research organization and the Science Technology Innovation-Office of the President secretariat (STI-OP) . Self-sponsored participants are similarly acknowledged.

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6.0 Next 13th ANREC

The next, 13th ANREC,
will be held from
22nd – 23rd October 2026.

FOR MORE INFORMATION PLEASE, CONTACT:

Ms. NAZZIWA WINFRED

TEL: **+256 414 705 500/414 705 526,**
0705 860 522

EMAIL: **winnfry@gmail.com**
w.badanga@uncst.go.ug
info@uncst.go.ug