12th ANREC
ANNUAL NATIONAL RESEARCH ETHICS CONFERENCE

CONFERENCE PROCEEDINGS

UNCST
UGANDA NATIONAL COUNCIL FOR SCIENCE AND TECHNOLOGY

THE REPUBLIC OF UGANDA

12th ANREC

ANNUAL NATIONAL RESEARCH ETHICS CONFERENCE

21-22 October 2025

Hotel Africana
Kampala,Uganda

THEME

COMMUNITIES AS PARTNERS: STRENGTHENING COMMUNITY ENGAGEMENT IN RESEARCH

CONFERENCE PROCEEDINGS

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Conference Summary

Theme: **Communities as Partners: Strengthening Community Engagement in Research**

Duration: 21st – 22nd October 2025

Participants: 706 International and Regional Participants from Uganda, Kenya, Ethiopia,Tanzania and USA

Venue: Hotel Africana, Kampala Uganda.

Guest of Honor: Dr. Cosmas Mwikirize the superintendent Industrial Value Chains/Chief Scientist at the Science Technology and Innovations Secretariat- Office of the President (STI-OP) who represented the Hon Minister for Science Technology and Innovation

The Keynote Speakers: Dr. Jenestic Twikirize, Associate Professor of Social Work, Makerere University College of Humanities and Social Sciences Kampala and Dr. Flavia Matovu Kiweewa, Senior Research Scientist MUJHU Care Ltd.

Conference arrangement: The 2025 ANREC was arranged into Plenary sessions and Parallel sessions organised into Keynote Addresses, Case Study Presentations, Panel Discussions and a Networking cocktail, complemented by an engaging drama skit titled “Did you engage the community?”

Acronyms

ANREC	Annual National Research Ethics Conference
AVAREF	African Vaccine Regulatory Forum
ATDs	Adaptive Trial Designs
CAB	Community Advisory Board
CHIM	Controlled Human Infection Model
CONATHEPA	Natural Therapeutics Clinical Trials Program
FRECU	Forum for Research Ethics Committee Chairpersons in Uganda
IACUC	Institutional Animal Care and Use Committees
ILRI	International Livestock Research Institute
KWRP	Kenya Medical Research Institute-Welcome Research Program
MDAs	Ministries, Departments, and Agencies
MU-JHU	Makerere University – Johns Hopkins University Research Collaboration
MUST	Mbarara University of Science and Technology
NDA	National Drug Authority
NDP	National Development Plan
REC	Research Ethics Committee
PTA	Post Trial Access
PRR	Post Research Responsibility
TCAM	Traditional, Complementary and Alternative Medicine
UNCST	Uganda National Council for Science and Technology
UNHRO	Uganda National Health Research Organization
SOPs	Standard Operating Procedures
STI-OP	Science Technology and Innovation Secretariat – Office of the President
UVRI	Uganda Virus Research Institute

Acknowledgement

We, at the Uganda National Council for Science and Technology (UNCST), thank everyone who participated in the 12th Annual National Research Ethics Conference (ANREC).

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). Special thanks go to participants who sponsored themselves to participate in the 12th ANREC.

Great thanks also go to the Scientific and Planning Committee members comprised of: Dr. Joseph Kagaayi (Makerere University School of Public Health- REC) who was the Conference Chairperson, Dr. Grace Ndeezi (Joint Clinical Research Center -REC), Dr. Fred Bulamba (Mbale Regional Referral Hospital), Dr. Ashaba Scholastic (Mbarara University of Science and Technology), Dr. Noah Kiwanuka (Makerere University School of Public Health), Dr. Victoria Namuggala (Makerere University School of Social sciences REC), Dr. Slyvia Baluka Angubua (Makerere University, College of Veterinary Medicine, Animal Resources and Bio-security), Ms. Teopista Nakyanzi (MUJHU Research Collaboration), Dr. Sam Okech (Makerere University, College of Veterinary Medicine, Animal Resources and Bio-security), Dr. Yahaya Gavamukulya (Busitema University College of Health Sciences - REC), Dr. Julaina Obika (Gulu University - REC), Ms. Eva Magambo (Makerere University School of Health Sciences- REC), Dr. Helen Ndagije (National Drug Authority), Dr. Sam Okware (Uganda National Health Research Organization), Ms. Hellen Opolot (Uganda National Council for Science and Technology), Ms. Deborah Kasule (Uganda National Council for Science and Technology) and last but not least, Ms. Winfred Nazziwa (Uganda National Council for Science and Technology).

Introduction

Research involving humans as research participants and animal subjects 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.

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. These issues, 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.

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 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.

The ANREC is a platform for engagement and interaction among the various actors involved in human and animal subjects' research. It provides 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 Uganda National Council for Science and Technology (UNCST) since 2009 in conjunction with partners, notably the National Drug Authority (NDA) and the Uganda National Health Research Organization (UNHRO).

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.

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. (Additional information on these can be obtained at: *www.uncst.go.ug*).

Launch of National Guidelines for Research: The key highlight of the 12th ANREC was the launch of three major regulatory instruments intended to strengthen Uganda's research ethics landscape. The Chief Guest launched the following national guidelines during the opening ceremony.

The revised National Guidelines for Research Involving Humans as Research Participants, September 2025, which reinforce our national commitment to the protection of human subjects, ensuring informed consent, confidentiality, and the minimization of risks in line with both international best practices and Uganda's cultural and legal context.

National Guidelines for Joint Scientific and Ethical Review of Research, September 2025; These. facilitate and fast track the process of submission and review of research applications in preparation for the mandatory research oversight and clearance process in the country. The establish a coordinated process of reviewing a research application jointly at a convened

meeting by the NRAs (UNCST, UNHRO and NDA), Institutional Committees, persons with subject matter expertise and appropriate stakeholders in a given field.

National Guidelines for Community Engagement in Research, March 2022; These provide a structured framework for researchers to collaborate meaningfully with communities by promoting respect, transparency, and mutual benefit. They emphasize early engagement, cultural sensitivity, and shared decision-making throughout the research process.

Through presentations and interactive discussions, participants examined these guidelines, reflected on their implications, and discussed how they would shape future research practices in Uganda and the region.

Conference Breakdown

Day One: 21st October 2025

Plenary Session 1: Welcome and Opening Remarks

Session moderators: Dr. Joseph Kagaayi and Ms. Deborah Kasule

Welcome remarks from the Chairperson Scientific and Planning Committee (SCP) of the conference

Dr. Joseph Kagaayi warmly welcomed all participants to the 12th ANREC and expressed his delight at the impressive turnout. He noted that the high-level in-person attendance marked a significant and encouraging shift from the previous year's virtual conference, which, while necessary, had limited opportunities for interaction, networking, and collaborative learning. The strong physical presence this year, demonstrates the growing commitment within the research community to advance ethical research practices in Uganda and the region.

As the Chairperson of the Scientific Planning Committee, he noted that, *"I take immense pride in this gathering, which brings together researchers, regulators, policymakers, and community representatives to reflect on how to make research more ethical, inclusive, and responsive to the needs of the people it serves"*.

He noted that this year's theme underscores a fundamental truth that communities are not merely subjects of research but vital partners whose participation determines the relevance, quality, and social value of research. Noting that genuine community engagement transforms research from an activity done on communities to one conducted *with* and *for* them. Such collaboration ensures that research priorities reflect community needs, enhance public trust, and strengthen the ethical foundation of the entire research enterprise.

Dr. Kagaayi further noted that, the 12th ANREC convenes at a time of remarkable progress in the global and national research ethics landscape. The World Medical Association recently adopted the tenth revision of the ***Declaration of Helsinki***. In parallel, the Uganda National Council for Science and Technology (UNCST) has aligned the ***National Guidelines for Research Involving Humans as Research Participants*** with the revised ***Declaration of Helsinki*** and developed new ***National Guidelines for Community Engagement in Research***. It has also institutionalized the ***Joint Scientific and Ethical Review of Research*** to improve the effectiveness and efficiency of ethical oversight. These important milestones provide a timely backdrop for the reflections and discussions that will unfold during this conference.

A central focus of this year's deliberations is the evolving conversation on post-research responsibilities (PRR) issues that speak directly to fairness and justice in research, particularly in low- and middle-income settings. He highlighted that the conference would offer a platform to examine critical yet unresolved questions: Who is responsible for ensuring post-trial access? What constitutes a fair and reasonable plan? And how can researchers, sponsors, and regulators work together to ensure that participants and their communities share equitably in the benefits of research? Addressing these questions is essential to strengthening public trust and ensuring that research contributes tangibly to human welfare.

In his remarks, the SPC Chairperson highlighted the conference sub themes that would shape the deliberations over the two-day conference. These included, *(i)* The Changing Regulatory

Landscape for Research Ethics: Global and National Outlook, *(ii)* Community Engagement across the Research Life Cycle, *(iii)* Emerging Technologies and Research Ethics *(iv)* Ethics and Animal Welfare: Considerations for Animals in Research, *(v)* Ethical Issues in Disease Outbreaks and other Emergencies and *(vi)* Research Ethics and Traditional-Alternative Medicine Research. He noted that the sub themes are central to the evolving research landscape and require collective reflection and alignment among researchers, regulators, sponsors, and communities. These conversations will help shape practical strategies for embedding ethical principles into research design, implementation, and dissemination.

He underscored the foundational ethical principles of fairness, justice, respect, and collaboration, stressing that these values must guide all research efforts if communities are to meaningfully benefit from the studies conducted among them. Ethical conduct, he noted, is not merely a procedural requirement but the very basis upon which research gains credibility, public trust, and long-term social value. Without fairness in participant selection, transparency in communication, and equitable access to research outcomes, scientific advancements risk deepening existing inequities rather than addressing them.

Dr. Kagaayi extended his appreciation to the UNCST for its leadership in organizing the conference, as well as the Scientific Planning Committee for their strategic guidance in shaping the programme. He also acknowledged the distinguished speakers, panelists, facilitators, exhibitors, and all attendees whose expertise and active participation enrich the discourse each year.

He further commended the conference's diversity reflected in the variety of institutions, disciplines, countries, and community perspectives represented. This diversity, he noted, is essential for fostering innovative thinking, strengthening partnerships, and nurturing a research environment grounded in shared ethical commitments. As he concluded, he encouraged participants to take full advantage of the sessions, discussions, and networking opportunities to forge stronger collaborations and contribute to shaping the future of research in Uganda in ways that are both scientifically rigorous and ethically robust. He then wished all the participants fruitful deliberations and a memorable conference.

Welcome remarks

Director General Uganda National Health Research Organization (UNHRO)

Dr. Sam Okware began by welcoming all participants to the conference and proceeded to highlight the mandate and ongoing work of the UNHRO in addressing the country's evolving ethical challenges in health research. He explained that UNHRO, guided by the UNHRO Act of 2011, plays a central role in regulating research activities, developing national standards, coordinating health research institutions, and ensuring that all research protocols adhere to ethical and scientific requirements. This includes close alignment and collaboration with bodies such as the National Drug Authority (NDA) and the Uganda National Council for Science and Technology (UNCST) to strengthen coherence within the national research regulatory environment.

He emphasized that communities are not merely passive recipients of research but are key partners whose involvement is vital to the promotion, acceptance, and successful implementation of research activities. Drawing from ongoing initiatives, he highlighted the success of social labs- innovative platforms that bring community members and researchers together to co-create solutions, test ideas, and improve mutual understanding. These social labs, he noted, have significantly enhanced community engagement, improved the relevance of research questions, and increased the quality and trustworthiness of the data collected.

He also acknowledged that research does not occur in a vacuum. It interacts with deeply rooted cultural norms, beliefs, and social expectations, which can sometimes create tension or misunderstandings between researchers and communities. When not adequately addressed, such cultural conflicts can undermine research credibility, hinder participant recruitment, and compromise the protection of participants' rights and welfare.

To ensure that research remains ethical and community-centered, the speaker underscored the importance of adhering to core ethical principles such as transparency, integrity, inclusion, respect for diversity, confidentiality, and accountability. He stressed that communities must be represented meaningfully-through Community Advisory Boards (CABs), stakeholder dialogues, and participatory platforms that allow community members to critically engage with research processes, voice concerns, and jointly shape research priorities. He reiterated a powerful expectation commonly expressed by, *"Communities expect no harm, no compromise, no their basic rights, transparency, integrity and inclusion in research practices and narratives"*.

He then shifted focus to emerging ethical challenges introduced by the rapid growth of artificial intelligence, digital technologies, and social media. These tools, while offering new opportunities for research, also present substantial risks. For example, the speed and virality of social media can spread misinformation during disease outbreaks, potentially distorting public perceptions and undermining research credibility. AI-driven tools may inadvertently violate privacy, introduce algorithmic biases, or compromise data security if not properly regulated. Digital platforms can also enable unauthorized dissemination of confidential data, creating new vulnerabilities in research environments.

Given these challenges, Dr. Okware called for a collective effort to develop strategies that mitigate the risks associated with digital innovation. He encouraged conference participants to explore ways of strengthening ethical safeguards through effective science communication, responsible integration of social labs, and coordinated action across institutions. He emphasized that overcoming these challenges will depend on fostering a culture grounded in teamwork, inclusiveness, trust, group cohesion, and shared responsibility. In conclusion, he urged stakeholders to use the conference as an opportunity to reflect deeply on how Uganda can uphold the highest ethical standards while embracing innovation, ensuring that research continues to serve and protect the communities at its heart.

Welcome remarks

Acting Executive Uganda National Council for Science and technology (UNCST)

Dr. David Serukka added his voice in welcoming the participants, to the conference, offering special recognition to colleagues and partners from Kenya, Ethiopia, and Tanzania. He expressed sincere gratitude to all participants for the continued dedication and purposeful participation in the ANREC since its inception in 2009. Their consistent presence, he noted, is a testament to the shared commitment across the region to strengthen ethical research practices and promote scientific excellence that ultimately serves the health and development needs of the African people. He emphasized that the diversity of expertise present at the forum enriches the conversations and strengthens regional solidarity in addressing emerging ethical challenges.

He underscored that, UNCST has organized the 12th ANREC under the theme, ***"Communities as Partners: Strengthening Community Engagement in Research"***, and as you may all know. Dr. Serukka highlighted Uganda's strong position as one of the most active research hubs in Africa, pointing out that over 1,000 new research projects-conducted by both local and international researchers—are registered annually with the UNCST. This vibrant research environment has brought about an increase in multidisciplinary studies, the adoption of advanced technologies, and the formation of cross-border research collaborations. However, he cautioned that the growth in scientific activity, no matter how impressive, cannot achieve its intended impact if the very communities meant to benefit from it are not actively engaged or adequately involved.

He stressed that: *"When we engage communities as partners and not merely as participants, we build trust, hence making research more relevant, responsible, and responsive to the needs of the people."*

He elaborated that meaningful engagement transforms communities from passive subjects into equal contributors helping researchers understand local realities, enhance acceptability, and ensure that research outputs address genuine societal needs. Without community trust and participation, research risks becoming disconnected from the lived experiences of the populations it seeks to serve. Turning to the rapid evolution of science, he discussed the emergence of powerful new technologies such as biotechnology, data science, and artificial intelligence (AI). While these innovations offer immense potential for improving health, agriculture, and socio-economic development, they also introduce complex ethical challenges, particularly around data privacy, informed consent, potential misuse of data, and the broader societal implications of technologically driven decisions. He stressed that early and continuous engagement of communities throughout the research process is essential. Their perspectives, concerns, and values must shape how new technologies are introduced, regulated, and integrated into national policy frameworks.

Dr. Serukka reaffirmed UNCST's enduring commitment to fostering an ethical, transparent, and community-centered research ecosystem. He explained that UNCST will continue to develop and disseminate guidance documents, regulatory frameworks, and capacity-building tools that support meaningful community participation at every stage of the research cycle. Furthermore,

UNCST is committed to providing platforms such as ANREC, that bring together stakeholders to reflect, dialogue, and collaborate on strengthening responsible research conduct.

> "Our collective efforts in research must begin by engaging communities as partners, not merely as participants. This builds the trust necessary to make research relevant, responsible, and responsive to the people's needs, ultimately enabling us to harness the full potential of Science, Technology, and Innovation for National Development while safeguarding their rights and interests. **Dr. Serukka**"

He concluded by emphasizing that collective effort is key. Only through sustained collaboration among researchers, communities, regulators, policymakers, and regional partners can Uganda and the broader African region harness the full potential of Science, Technology, and Innovation (STI) for national and continental development. At the same time, he underscored the importance of safeguarding the rights, dignity, and interests of the people, noting that ethical research is the foundation upon which sustainable development is built.

Drama Skit: Did you engage the community?

The skit portrayed a picture of real-life scenario common among researchers when the study coordinator/principal investigator (in red on the right) was updating the Professor (sited center) about a research project that was disengaged from the community. It all came to light when the tea girl (on the left with a try) coincidentally happens to be among the community members (VHT) and shared with both that study was on community not with community as they often see the study team big cars cruising on their village collecting data without community engagement. The Prof promised to investigate and address.

Keynote Address 1: Communities as Partners in Research: What does research mean to be responsive to the needs and priorities of local communities. A Global Overview

Dr. Jenestic Twikirize, *Associate Professor of Social Work, Makerere University College of Humanities and Social Sciences*

Dr. Twikirize delivered the first keynote addressing the question: "What does it mean for research to be responsive to the needs and priorities of the local community?" She congratulated the organizers of the conference for this honorable cause. She noted 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 go beyond consultation; they create spaces where communities become active contributors to the generation of knowledge. By involving communities at every stage from conceptualization to dissemination researchers build trust, uphold ethical standards, democratize the production of knowledge, honor indigenous and local expertise, and significantly improve the quality, relevance, legitimacy, and long-term sustainability of research outcomes.

If research is to be relative to the community, it involves: **Shifting the focus:** from research on communities to research with communities. This involves moving from traditional research (which researchers do on their own, prioritize expert knowledge, community members are seen as source of information) to recognizing community members as partners in knowledge creation, share interpret and co-use knowledge as co-researchers, recognition, value and use of local knowledge systems and lived experiences.

Starting from bottom-up: By understanding local realities. "*We have to get used to appreciate that research begins from the bottom"* What if we started by listening to the communities? How would it determine the outcomes of research? This can be done through formative assessment and community dialogues to understand local authorities.

Community representation, voice and agency: Responsive research has to recognize assets and resources in research management, adopts mechanisms that promote representation of diverse community voices in decision making, that is, "paying attention to who is likely to be excluded". This is found by engaging community members before, during and after the study cycle during which they are more enthusiastic.

Accountable and reciprocal knowledge sharing: People must know why the research is going on and appreciate the purpose and of the research. Dissemination where community access results in accessible language formats and forums.

Building long-term partnerships: Once overreach projects are necessary but not always responsive. Responsiveness grows through trust.

Aiming for long-term partnerships: Are we just looking for data to feel good or are we looking to translate/ transform lives? Once communities have information, they are able to hold accountable those responsible.

Dr. Twikirize further highlighted that the UNCST guidelines articulate that community engagement is designed to; foster transparent and collaborative relationships between

researchers and communities; ensure that research is responsive to community needs, priorities, and lived realities; promote community acceptance, ownership, and shared responsibility for research activities and strengthen long-term trust and credibility in the research enterprise. In line with these principles, the shift from *"research on communities"* to *"research with communities"* signifies a profound transformation in research culture. It challenges traditional extractive models where communities serve merely as study sites or data sources, replacing them with participatory, partnership-centered approaches.

If research is to be responsive, it begins with recognizing the inherent value of community knowledge systems, aspirations, and worldviews. It prioritizes 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. This approach ensures inclusion particularly of traditionally marginalized groups such as women, youth, refugees, people with disabilities, rural populations, and minority ethnic groups whose perspectives often remain invisible in conventional research.

> "We should shift the focus of research on communities to research with communities. **Dr. Jeneste Twikirize**"

A key pillar of responsive research is accountable knowledge sharing, which emphasizes that communities should be involved throughout the research lifecycle. This includes 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.

Importantly, dissemination must 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.

Long-term, trust-based partnerships are essential to this model. They must deliver tangible benefits, including improved services, strengthened research literacy, leadership development, economic empowerment, or enhanced social cohesion. Such partnerships move beyond the project cycle and are built around principles of continuity, mutual respect, and collective responsibility.

Dr. Twikirize gave some examples that demonstrate the effectiveness of community rooted approaches:

- Rakai Health Sciences Programme (RHSP), which pioneered community-led HIV research and built a culture of trust and co-ownership that continues decades later.
- Farmer Field Schools (FFS) in agricultural research, where farmers co-produce knowledge with scientists and test innovations directly in their environments.
- Refugee-led research initiatives, where displaced persons define priorities and influence humanitarian programming.
- Makerere University community social labs, which bring together academics, policymakers, and community actors to co-design and test solutions to pressing social issues.
- Participatory Action Research (PAR) using community reference groups in conflict-affected settings to support trauma-informed and locally grounded peacebuilding efforts.

She highlighted some of the obstacles/barriers 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, often due to colonial legacies in global science systems; Funding limitations that fail to support long-term engagement or community capacity building; 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.

To address the above challenges, Dr. Twikirize proposed some reforms and pathways for Strengthening Community-Engaged Research. 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 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.

Concluding reflections: Constantly reflect on uncritical reliance on euro-western research, agendas and framework. Open up to other ways of research and evaluation practice. Strengthening policy framework and guidelines on community partnerships and responsive research Embedding responsive research in education as a norm. Accountable research partnerships. The ones we are engaged in, who owns the data, how will the community gain?

In conclusion, community engaged research is not simply an ethical requirement, it is a transformative approach that reshapes how knowledge is generated, shared, and used. When communities are recognized as co-creators of knowledge, research becomes more just, credible, and impactful, ultimately leading to better outcomes for society as a whole.

Official Opening and Launch of National Guidelines for Research

Remarks from Prof. John Muyonga - Vice Chairperson

Prior to inviting the Chief Guest to officially open the 12th ANREC Prof. John Muyonga the Vice Chairperson of the UNCST Council made some remarks. On behalf of the UNCST, he welcomed all participants to the 12th ANREC. He noted that the conference remains a very important platform for advancing dialogue, collaboration and action in the governance of research ethics in Uganda.

It brings together regulators, policy makers, members of the research ethics committees, civil society and research communities to share experiences, reflect on progress, and reflect on the future of ethical research in our nation. In a special way, he welcomed our partners from Ethiopia, Kenya, and Tanzania noting that their presence here reflects our shared commitment to advancing ethical research governance and strengthening regional collaboration in research ethics.

He reechoed that theme of the 12th ANREC "***Communities as Partners: Strengthening Community Engagement in Research,"*** resonates deeply with our collective mission to foster ethical, inclusive, and impactful research that serves society at large. It reminds us that research excellence cannot be achieved in isolation. It flourishes where science and society meet, where communities are active participants in the pursuit of knowledge that transforms lives. With

reference to the **UNCST, Act of 1990** and the **Presidential Directive of January 2022**, one of our core functions is to regulate and coordinate all aspects of Science, Technology, and Innovation (STI) in Uganda.

He noted that UNCST remains firmly committed to ensuring that research conducted across our nation adheres to the highest ethical standards, promotes societal well-being, and upholds the rights and dignity of our people. By integrating ethical research practices, community participation, and innovative STI policies, this conference contributes to the realization of Uganda's Vision 2040, which aspires to ten-fold economic growth and the translation of research into tangible social and economic benefits.

Dr. Muyonga reaffirmed that meaningful community engagement is not just an optional aspect of research but rather, it is its very foundation. When communities are actively involved as true partners, research becomes more trustworthy, culturally sensitive, and sustainable. Such engagement enhances the relevance, acceptance, and ethical integrity of scientific endeavors and ensures that research outcomes align with the priorities and realities of the people it seeks to serve.

"We gather today not only to discuss the importance of community participation but also to mark a significant milestone in our country's research oversight framework." He noted that during this conference, three key national research guidelines were to be launched which were designed to strengthen ethical practice, promote coordination and enhance the inclusiveness of Uganda's research ecosystem.

1. National Guidelines for Community Engagement in Research, February 2022
2. Revised National Guidelines for research Involving Humans as Research Participants, September 2025
3. National guidelines for Joint Scientific and Ethical Review Guidelines, September 2025

The above-mentioned national guidelines reinforce our national commitment to the protection of human participants and animal subjects in research and the minimization of risks in line with both international best practices and Uganda's cultural and legal context.

He also highlighted that these guidelines were carefully developed through extensive consultation with stakeholders who included community representatives, researchers, policymakers and regulatory bodies. They are not just technical documents, but they represent a national commitment to integrity, respect, and community partnership in all research activities conducted within our borders.

Dr. Muyonga concluded by commending all those researchers who adhere to good scientific and ethical conduct of research and to also call upon all of us as research stakeholders to promote good ethical practice that protects both human and animal research participants. He also thanked the Partners, the National Drug Authority and the Uganda National Health Research Organization as well as the Government of Uganda for the support to this great initiative. In addition, he thanked all participants for attending the 12th ANREC as well as organizing Committee for the conference and the UNCST staff for a job well done.

He then welcomed the Chief Guest to give his remarks, officially open the conference and launch the National guidelines for research.

Opening Remarks

Dr. Cosmas Mwikirize, the Chief Guest and Superintendent - Industrial Value Chains Development at the Science, Technology, and Innovation Secretariat - Office of the President (STI-OP)

The Chief Guest began by commending the UNCST, the partners NDA UNHRO, for sustaining the ANREC platform for dialogue and capacity-building since 2009. Your efforts have not only nurtured a culture of ethical reflection in research but have also strengthened Uganda's global standing as a leader in responsible scientific inquiry.

With this year's theme: ***"Communities as Partners: Strengthening Community Engagement in Research"*** challenges us to go beyond regulatory compliance and focus on inclusivity and fairness in research." He further noted that when communities are treated as equal partners, research becomes more ethical, relevant, and impactful. Engagement fosters trust, ownership, and social value, ensuring that science serves the people it is meant to benefit. In Uganda, where research increasingly involves complex technologies, from genomics to traditional medicine and One Health studies, meaningful community engagement is vital to uphold respect, equity, and cultural sensitivity. Further the theme for the conference highlights equity which ensures that communities and participants who contribute to research also share in its benefits. Ethical research must not end with data collection. It must ensure post-research responsibilities, access to proven interventions, follow-up care and feedback of results to communities. "When ethics is central in research, innovation becomes credible, reproducible, and scalable." Dr. Mwikirize

> "When ethics is central in research, innovation becomes credible, reproducible, and scalable. **Dr. Mwikirize**"

He noted that; Science, Technology, and Innovation are key drivers for national transformation in Uganda's Vision 2040 and the upcoming NDP-IV. Achieving progress requires not only infrastructure and funding but fundamentally depends on public trust, built through ethical research grounded in respect, justice, and beneficence. Innovation without ethics is short-lived, undermines confidence, and divides communities. Ethical research ensures empirical integrity, protects the vulnerable, and preserves the social contract between scientists and society. Uganda's growing capacity in the "pathogen economy" (diagnostics, therapeutics, and vaccines) underscores the need for unimpeachable public trust.

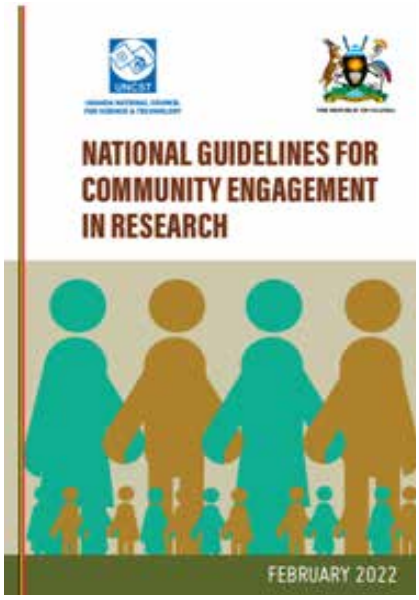
Dr. Mwikirize noted that Institutional Review Boards (IRBs) play a vital role as the first line of defense for the credibility of Uganda's science. As Uganda embraces the Fourth Industrial Revolution (4IR), research ethics must evolve to address data-driven science and Artificial Intelligence (AI), where issues like data sovereignty and algorithmic fairness arise. Stakeholders ought to address ethical questions concerning informed consent in emergencies, the protection of indigenous knowledge, and fairness in the era of AI. ethical research systems through empowered and well-resourced committees. He underscored the importance of community engagement in making research participatory, culturally relevant, and impactful.

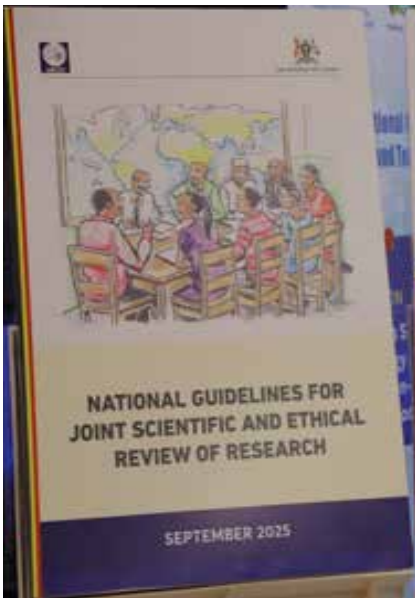
The Chief Guest re-affirmed the commitment of Government of Uganda through the STI-OP and the UNCST in promoting robust, ethical and innovation driven research sector. He further committed to strengthening regulatory frameworks and ensuring that research contributes directly to national development priorities under Vision 2040 and NDPIV.

Before concluding his remarks, the Chief Guest noted that as a country, we have made significant strides in building an ethical and enabling research environment which is reflected in the launch three key regulatory instruments that will guide and strengthen our national research ethics system.

1. The Revised National Guidelines for Research Involving Humans as Research Participants.
2. The National Guidelines for Community Engagement in Research
3. The National Guidelines for Joint Scientific and Ethical Review of Research.

He accentuated that the three instruments reflect Uganda's commitment to international best practices while maintaining alignment with our national context and development aspirations. Through these frameworks, we reaffirm that science must advance not only knowledge but humanity.





He concluded his remarks by thanking the UNCST for organizing the conference along with NDA and UNHRO. He acknowledged all the partners who include National Regulatory Agencies, academic institutions, local government authorities, Research Ethics Committees, health institutions and civil society organizations for their unwavering commitment. He called upon the stakeholders to continue collaborating, sharing knowledge, and upholding integrity as the cornerstone of science and innovation in Uganda. He then officially opened the 12th Annual National Research Ethics Conference and to launched the national research guidelines that will steer Uganda towards a future of ethical, inclusive and impactful research.

He led a team of dignitaries in launching and digital signing of the three new regulatory instruments designed to strengthen Uganda's research ethics ecosystem.

Digital signing of the of the launched national guidelines

Plenary Session 2: The Changing Regulatory Landscape for Research Ethics: Global and National Outlook

Session Moderators: Dr. Pauline Byakika- Kibwika and Dr. Victor Musiime

Presentation 1: Updates on the Declaration of Helsinki and Implication for research in Uganda and Region

Dr. Nakwagala Frederick, Senior Consultant Physician, Mulago National Referral Hospital

Dr. Nakwagala detailed the significance of the revisions to the Declaration of Helsinki, adopted at the 75th World Medical Association General Assembly in October 1964, and their implications for research ethics in Uganda and the Eastern Africa region. He stated that the Declaration of Helsinki, established by the World Medical Association (WMA) in 1964, remains the most influential global framework for ethical conduct in medical research involving human participants, as well as the collection and use of identifiable biological materials and data.

Over the past six decades, it has evolved in response to scientific advancements, emerging ethical dilemmas, and lessons learned from global research practice. The 2024 revision anticipated for adoption at the 75th WMA General Assembly represents one of the most comprehensive updates to date, reflecting contemporary challenges in clinical research, digital health, and public health emergencies.

A central feature of the Declaration is the reaffirmation of respect for participants not merely as research subjects, but as active stakeholders whose rights, welfare, and interests must guide every stage of the research process. This includes enhanced requirements for community engagement, recognition of local contexts, and responsiveness to cultural values. The updated Declaration also integrates emerging priorities, such as environmental sustainability and the ethical use of digital technologies, illustrating the need for research integrity even in resource limited or emergency settings where pressures to act quickly can compromise ethical standards. Uganda, which has historically woven the Declaration into its national ethics guidelines, stands among African countries that have consistently upheld these principles.

One of the most significant shifts in the 2024 revision is the expansion of ethical responsibility. Previously, the Declaration framed obligations primarily around physicians conducting research. The new version extends accountability to entire research teams, recognizing that today's research is multidisciplinary and involves investigators, data analysts, laboratory technologists, clinical officers, social scientists, sponsors, and implementing institutions. This ensures that ethical compliance is a shared duty, not a physician-centric obligation.

The updated Declaration also mandates meaningful community participation throughout the research lifecycle beyond consultation or basic community entry approvals. Communities should be involved in priority setting, co-design of protocols, consent processes, monitoring of study progress, and dissemination of findings. This aligns with global calls for research that is co-owned, socially responsive, and culturally aligned, particularly in African contexts where historical inequalities and extractive research practices have eroded trust.

Additionally, the revisions require ongoing evaluation of interventions, ensuring that safety, effectiveness, and accessibility are assessed continuously rather than only at pre-determined checkpoints. This supports adaptive trial designs and aligns with the need for long-term monitoring, particularly in low-resource settings where interventions may have different risk profiles.

A major ethical concern addressed in the 2024 revision is the inclusion of vulnerable populations. The Declaration clarifies that these groups such as children, refugees, persons with disabilities, and economically disadvantaged communities should be included when exclusion would lead to widened health inequities. This directly challenges the historical practice of over protection, which frequently deprived vulnerable populations of the benefits of scientific progress. The requirement for free and informed consent is strengthened as well, with tailored guidance for participants unable to consent and clear expectations for re-consent when new information arises.

As one Ugandan expert noted, *"The emphasis has shifted from patient health to 'Health and Wellbeing,'* recognizing broader issues like meals, compensation, and psychological wellbeing. The Ugandan regulatory systems are already enacting these changes." This signals an important conceptual shift from a narrow clinical focus to a holistic understanding of human wellbeing as central to ethical research.

Post-trial responsibilities, long debated in global ethics circles, are also significantly reinforced. Sponsors and researchers are now required to ensure that trial participants have access to beneficial interventions after the study ends. Any deviation from this obligation must be explicitly justified and approved by ethics committees. These responsibilities include planning for sustainability, affordability, and access pathways in advance preventing situations where successful interventions remain inaccessible to the very populations that contributed to the research.

Transparency in results dissemination is further emphasized. The revised Declaration insists on timely, complete, and publicly accessible reporting, addressing persistent global problems of delayed or selective publication. This is particularly critical in public health emergencies, where delayed information can cost lives. The revisions also provide guidance to minimize misuse of investigational products during outbreaks and align with Uganda's experience managing unproven interventions during Ebola and COVID-19 responses.

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 will require policy refinement, capacity building, training of ethics committees, and integration of new ethical expectations into institutional procedures.

With thoughtful implementation, Uganda is well positioned not only to comply with the updated Declaration but also to continue leading the region in advancing ethical, equitable, and community-responsive research.

Presentation 2: Overview of the revised national guidelines for research involving humans as Research Participants

Dr. Nelson Sewankambo, Prof. Emeritus, College of Health Sciences, Makerere University, Kampala

Dr. Nelson Sewankambo provided a detailed overview of the revised National Guidelines for Research Involving Human Participants, highlighting their expanded scope and ethical commitments.

The revised guidelines fundamentally emphasize protecting participants' rights and welfare, upholding informed consent and confidentiality, minimizing harm, preventing data fabrication, and ensuring robust community engagement. These updates significantly strengthen regulatory frameworks to support ethical research across a diverse range of fields, including medical, social sciences, public health emergencies, technology, forensics, medical tourism, and traditional medicine.

The revision process involved a thorough review of the 2014 guidelines, extensive consultation with international guidance, and robust stakeholder engagement. This process included Research Ethics Committees (RECs), Ministries, Departments, and Agencies (MDAs), researchers, and communities, coordinated through multidisciplinary task force meetings at UNCST.

The updated guidelines reflect evolving research ethics, aiming to maintain scientific integrity while successfully adapting to modern technologies and methodologies. The guidelines present seven completely new sections and a number of additions. They broaden the research governance framework and align with contemporary ethics while retaining the core principles from the 2014 edition: respect for persons, beneficence, non-maleficence and justice. The new and expanded sections including Emerging Research Areas, namely: research in emergency situations, advanced therapeutics and diagnostics, genetics and genomics, and the ethical use of AI (addressing algorithmic fairness, data privacy, integrity, and transparency). In regard to Infrastructure, it includes guidance on biobanks, research data management, partnerships, capacity building, research integrity, and post-study obligations and responsibilities.

Guidance for establishment of Data and Safety Monitoring Boards, National Biobank Certification Committees, Community Advisory Boards, and the National Bio-safety Committee, alongside defining enhanced REC functions and joint scientific and ethical reviews.

Also, specific guidance covering detailed informed consent processes (including for children and e-consent), reporting of adverse events, and researcher/institution responsibilities regarding human materials. Implementation of the updated guidelines will be supported through strategies including forums (Forum for Research Ethics Committee Chairpersons in Uganda - FRECU, ANREC, National Science Week), integration into regulatory Standard Operating Procedures (SOPs), UNCST training programs, and regional outreaches.

The resumption of ANREC, coinciding with the launch of the guidelines, addresses rising public skepticism towards science and highlights Uganda's commitment to strengthening research standards and ensuring ethical and scientifically robust human research in line with global best practices. The revised national guidelines for research involving humans as research participants 2025 represent the evolving landscape of research embedding stronger governance, consent, and data-protection mechanisms to address contemporary realities in the various emerging fields.

Presentation 3: National Health Research Priorities: The Essential National Health Research Agenda 2026 - 2030.

Dr. Sam Okware, Director General, Uganda National Health Research Organization (UNHRO)

Dr. Okware presented Uganda's strategic roadmap for health research, emphasizing its role in national development and outlining the top ten priorities for the 2026 – 2030 period.

He noted that national development is intrinsically linked to the health of the population. A healthy population is not only a moral imperative but also a critical driver of economic growth, productivity, and social well-being. Strengthening health-related skills and fostering a vibrant indigenous health industry that leverages local knowledge, resources, and expertise is therefore essential to meeting the population's health needs while promoting sustainable development.

Health research serves as the foundation for evidence-based decision-making. By identifying critical health challenges, informing resource allocation, and shaping public health strategies, research ensures that interventions are timely, effective, and responsive to the communities they are designed to serve. Moreover, robust health research fosters collaboration among stakeholders including government agencies, academic institutions, civil society, communities, and private-sector partners thereby enhancing the relevance, sustainability, and impact of health interventions.

The establishment of national health research priorities involved a systematic, consultative process that ensures inclusivity, transparency, and alignment with national health goals. The process typically encompassed. Planning: Identifying objectives, stakeholders, and scope, Situation Analysis: Reviewing current health trends, burden of disease, and gaps in knowledge, Priority Setting: Ranking research areas based on public health impact, feasibility, equity, and innovation potential, Validation: Consulting stakeholders, including communities, researchers, policymakers, and development partners, Dissemination: Communicating priorities widely to inform funding, policy, and programmatic decisions, Implementation: Integrating priorities into research agendas, funding mechanisms, and policy frameworks.

> "Uganda's health research priorities provide a strategic roadmap to address key challenges. A focus on maternal/child health, infectious, non-communicable diseases, mental health, and technological innovations is to ensure improved outcomes, efficient resource use, and sustainable public health impact. Community engagement, evidence-based policy, and innovative technologies remain essential for advancing population health and national development. **Dr. Sam Okware**"

Uganda's national health research priorities reflect the country's disease burden, development goals, and commitment to evidence-based interventions. The ten national health research priorities include:

1. **Maternal, Sexual and Reproductive Health:** Research aims to reduce maternal and neonatal morbidity and mortality by identifying risk factors, improving access to quality

care, promoting early intervention, and engaging communities in health education and preventive practices.

2. **Adolescent and Child Health:** Focused on nutritional status, immunization coverage, mental wellbeing and early identification of developmental disorders.
3. **Infectious and Communicable Diseases:** Research includes HIV/AIDS, malaria, tuberculosis, emerging and re-emerging diseases, and antimicrobial resistance (AMR). Priorities include understanding transmission dynamics, outbreak prediction, and designing targeted interventions.
4. **Health Systems Research:** Investigates optimal resource allocation, cost-effectiveness, sustainable financing, and evidence-based policy development to strengthen health service delivery.
5. **Non-Communicable Diseases (NCDs):** Focuses on diabetes, cardiovascular diseases, cancer, nutrition, and lifestyle-related conditions, emphasizing risk factor identification, preventive strategies, and improved treatment modalities.
6. **Environmental Health:** Addresses the impact of climate change, sanitation, water quality, and pollution on population health, guiding interventions for mitigation and adaptation.
7. **Mental Health and Behavioral Research:** Prioritizes understanding prevalence, risk factors, and interventions for mental health disorders, stress-related conditions, and substance use.
8. **Community Health, Regulations and Primary Care:** Promotes evidence-based health promotion strategies, vaccination programs, and implementation of regulatory frameworks to strengthen primary healthcare services.
9. **Traditional Medicine:** Explores the safe and effective use of herbal and traditional therapies, integration with conventional care, and preservation of indigenous knowledge.
10. **Innovations in Technology, Diagnostics, Vaccines and Biotechnology:** Supports development and deployment of novel diagnostics, personalized treatments, vaccines, and biotechnological solutions to address national and global health challenges.

Maternal and Child Health Research: Research in maternal and child health remains a top priority due to the high morbidity and mortality associated with pregnancy, childbirth, and early childhood. Interventions focus on: Early identification of maternal and neonatal risk factors, Community-based health promotion and education programs and Strengthening emergency obstetric and neonatal care services.

Infectious Disease research: Infectious diseases remain a significant public health challenge. Research priorities include Understanding pathogen transmission and epidemiology, Predicting and responding to outbreaks, Combatting antimicrobial resistance through stewardship and innovative treatment strategies.

Non-Communicable Diseases and Mental health: As Uganda faces a dual burden of disease, research on NCDs and mental health aims to: Identify and mitigate lifestyle-related risk factors, improve preventive and curative health services and integrate mental health care into primary health systems.

Health systems and community engagement: Effective health research and policy implementation depend on strong health systems and active community participation. Research informs: Resource allocation and priority-setting, Health promotion campaigns and Monitoring and evaluation of interventions for accountability and sustainability. Community engagement ensures interventions are culturally appropriate, socially acceptable, and aligned with local needs, thereby increasing uptake and impact.

Technological Innovations in Health research: Technological advancements are rapidly transforming health research and service delivery. Key areas include Digital Health and Telemedicine: Expand access to care, enable remote monitoring, and improve patient management. Artificial Intelligence (AI): Enhances diagnostic accuracy, treatment planning, workflow efficiency, and predictive modeling for disease outbreaks. Biotechnology and Genomics: Support innovative therapies, personalized medicine, vaccine development, and understanding of disease mechanisms. Integration of technology with community-centered approaches ensures interventions are equitable, accessible, and tailored to population needs.

In conclusion, Uganda's health research priorities provide a strategic roadmap to address the country's most pressing health challenges. By emphasizing maternal and child health, infectious and non-communicable diseases, mental health, health systems strengthening, traditional medicine, and technological innovations, Uganda can achieve improved health outcomes, more efficient use of resources, and sustainable public health impact.

As he concluded his talk, Dr. Okware highlighted some key enablers for success including strong community engagement at all stages of research, evidence-based policymaking and integration of research findings into health programs, Investment in technological and scientific innovations that complement local knowledge. Together, these priorities and strategies contribute not only to better health for Ugandans but also to broader national development goals, enhancing productivity, social equity, and economic growth.

Presentation 4: Looking beyond Community Advisory Boards: How to effectively engage a research community

Ms. Noni Mumba, Head of Engagement, Kenya Medical Research Institute-Welcome Research Program (KWRP)

Ms. Noni Mumba, presented the evolution and successful strategies of the KWRP's community engagement platform, emphasizing that meaningful community involvement is a continuous, institutionalized process crucial for ethical and successful research.

The KWRP, which began in Kilifi in 1989, established its formal community engagement platform in 2005, growing into a well-established operation by 2025. The program rapidly expanded its physical footprint from a simple building to a state-of-the-art campus with large clinical, microbiology, and immunology labs, expanding operations from Kilifi to Nairobi and Mbale.

The target population was initially primarily rural, characterized by low literacy levels and a poor understanding of research. This context led to constrained healthcare and the spread of rumors about the program. The KWRP experience aligns with the revised Helsinki Declaration's emphasis on meaningful participation and providing communities a chance to express their research interests.

KWRP's core community engagement philosophy is on respecting the rights, interests, and well-being of research participants to enhance processes like informed consent and fair distribution of benefits/payments. Scientists are required to comprehend the lived experiences of communities throughout the planning and execution of research.

To address these challenges, KWRP placed increasing emphasis on respecting participant rights, interests, and wellbeing, thereby enhancing processes such as informed consent, ethical payments or benefits, and transparent communication. Recognizing the importance of understanding the lived experiences of communities, KWRP has incorporated participant perspectives into all stages of research planning and execution.

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. KWRP's community engagement strategy exemplifies these principles in practice, translating ethical guidance into actionable programs.

Ms. Noni presented the KWRP Community Engagement Model that comprises of **Community Advisory Boards (CABs):** CABs are composed of local community members serving non-renewable three-year terms. They facilitate participation, organize open days to counter misinformation, and maintain transparency with local leaders, youth groups, women's groups, motorcycle taxi ("boda-boda") riders, and religious institutions. Laboratory and research teams use these events to address community inquiries, fostering trust and dialogue.

Researcher Contiguity: Scientists are expected to be present and engaged within communities. Engagement occurs through policy forums, social gatherings, and community meetings, allowing researchers to understand social contexts and community priorities. This integration ensures that researchers are seen not only as distant investigators but as active, approachable participants in community life.

Broader Public Engagement: KWRP extends its reach beyond Kilifi through theater performances, radio programs, social media campaigns, and exhibitions. This strategy disseminates research findings, builds public trust, and fosters awareness of the program's work on national and international levels.

Nurturing Future Scientists: Young people are leveraged as ambassadors to disseminate scientific knowledge to their communities. Initiatives include school attachments, media discussion shows, inspirational publications, and mentorship programs, aimed at encouraging youth to pursue careers in science and dispelling myths about the exclusivity of scientific research.

Institutionalization of Engagement: KWRP ensures community engagement is embedded within the program's structure. A dedicated community engagement team evaluates research protocols, methodologies, and ethical considerations, ensuring that engagement is a core component of research design rather than an afterthought.

From decades of experience, critical insights have emerged, she shared some of the best practices and key learnings. **Engagement is Continuous:** Community engagement is an ongoing process, not a one-off activity and building long-term trust requires repeated interactions, feedback loops, and responsiveness to community concerns.

Ethical Implementation: Engagement must be conducted ethically, respecting local norms, values, and participant rights and processes such as informed consent, transparency about benefits, and clear communication are central to ethical practice.

Resource Allocation: Effective engagement requires dedicated resources, including personnel, time, and budget lines for community activities. Engagement should not be treated as a checkbox but as a core component of research planning.

Balancing Research Timelines with Meaningful Engagement: Short-term research pressures must be balanced with the need for genuine community involvement. Leadership support is critical to prioritize engagement alongside scientific objectives.

Trust and Transparency: Addressing misinformation, rumors, and misconceptions is essential for sustaining long-term community partnerships. Engagement strategies should foster mutual accountability, allowing communities to see the tangible benefits of their participation.

The KWRP experience demonstrates that structured, ethical, and institutionalized community engagement is foundational to high-quality research. By combining local advisory boards, researcher integration, public outreach, youth mentorship, and institutional oversight, KWRP has built a sustainable model for engaging communities in research. This approach not only aligns with the Declaration of Helsinki and global best practices but also enhances research credibility, participant trust, and the social value of scientific endeavors. The lessons from Kilifi offer a replicable blueprint for other research programs aiming to embed meaningful community engagement as an ethical and operational cornerstone.

Presentation 5: Status of Community Engagement in Research in Uganda: A Regulatory Perspective

Ms. Hellen Opolot, Assistant Executive Secretary, Uganda National Council for Science and Technology (UNCST)

Ms. Opolot, outlined the regulatory landscape for Community Engagement in Uganda, emphasizing its role as a fundamental ethical requirement for ensuring research is respectful, transparent, and aligned with local needs.

She noted that Community engagement is recognized globally for enhancing accountability, social value, and trust in scientific inquiry. Meaningful community engagement is especially critical in Uganda for studies involving complex technologies, ensuring cultural sensitivity, equity, and ethical integrity.

The UNCST requires researchers to integrate community engagement throughout the research lifecycle, from project inception to post-research follow-up. Specifically: Research protocols submitted to Research Ethics Committees (RECs) must include a comprehensive CE plan. Protocols should identify key stakeholders, define feedback mechanisms, and outline dissemination strategies. RECs and UNCST are responsible for oversight and evaluation, while investigators are accountable for implementation and reporting. Community Advisory Boards (CABs) provide a structured platform for dialogue, enabling communities to: Express concerns and expectations. Provide input on research priorities. Monitor ongoing studies and ensure accountability. Strengthening trust and transparency between researchers and the community.

Key guidance documents supporting CE in Uganda include National Guidelines for Research Involving Humans (2025) emphasizing participant-centered practices, ethical oversight, and integration of CE into study design. National Drug Authority Regulations for Clinical Trials (2024) outline responsibilities of research sites in conducting CE, particularly in clinical research.

In order to plan and implement CE effectively, Researchers are encouraged to develop detailed Community Engagement Plans (CEPs), which include goals and objectives: clear purpose and expected outcomes of engagement activities, stakeholder mapping: identification of community leaders, vulnerable populations, youth groups, women's associations, and other relevant actors. engagement approaches: methods for dialogue include, participatory workshops, town hall meetings, school programs, and media outreach. Work Plans and Budgets: Annual activities with allocated resources for personnel, logistics, and materials. Communication Strategies:

accessible and culturally appropriate messaging using local languages and media. monitoring and evaluation: Metrics to assess effectiveness, participation, feedback incorporation, and long-term impact. Risk management and follow-Up: plans for addressing misinformation, adverse events, and sustained community involvement after research completion.

Well-designed CE provides multiple ethical and practical benefits, for instance: enhancing ethical integrity: CE ensures that research aligns with participants' values and rights. improving relevance and Feasibility: Engagement provides insights into local needs, cultural practices, and logistical challenges. strengthening consent processes: Continuous interaction improves understanding and informed decision-making. Promoting participant welfare and benefit-Sharing: CE ensures participants gain meaningful benefits and that outcomes are socially acceptable. Increasing Acceptance and Trust: Transparent communication reduces rumors, fear, and mistrust, facilitating smoother study implementation. Producing Culturally Sensitive and Sustainable Outcomes: Engagement fosters ownership, making results more likely to be applied and sustained.

She further highlighted some of the UNCST Public Engagement Campaigns conducted in 2024 indicating that UNCST led nationwide initiatives to raise awareness about participant rights, regulatory processes, and ethical research conduct. Key strategies included: Radio broadcasts in local languages, reaching rural and urban populations. Collaboration with district leadership, hospitals, and universities to disseminate accurate information. Workshops and community meetings to address misconceptions, clarify research benefits, and explain regulatory safeguards. Media campaigns emphasizing the importance of transparency, feedback mechanisms, and community involvement in advancing research. These initiatives have highlighted the critical role of information, collaboration, and dialogue in promoting ethical, participatory, and socially accountable research in Uganda.

In conclusion, Ms. Opolot noted that Community engagement is no longer optional, it is a central component of ethical research practice. By embedding CE throughout the research lifecycle, Uganda has strengthened: Participant protection and welfare, Transparency and trust in research and Relevance, feasibility, and social value of scientific studies. Sustained, well-resourced, and ethically guided engagement ensures that research is conducted with communities, not merely on them, fostering both scientific excellence and social accountability.

Plenary Session 3: Ethics and Animal Welfare: Considerations for Animal Research in Research

Session Moderators: Dr. Sylvia Angubua Baluka and Dr. Lawrence Mugisha

Presentation 1: Animal health and community engagement in research: Historical Perspectives on animal research in Uganda

Dr. John David Kabasa, Prof. Emeritus College of Veterinary Medicine Animal Resources and Biosecurity, Makerere University, Kampala

Dr. Kabasa, delivered a provocative address tracing the history of animal health research in Uganda. He sharply critiqued the current definition of "community" as a group separate from the researchers and in need of their help. He argued that there should be a radical shift in the definition, role, approach, and scope of community engagement to avoid positioning the researcher as superior to the communities they serve. Communities are not merely research subjects/ passive participants but co-creators of knowledge.

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. Also, they should not 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.

He further noted that there is a critical need to learn from the 100 years of evolution of veterinary medicine (from pre-colonial times to the present). This history holds rich lessons on how decades of modern practices, which pre-dominantly served the colonial agenda, negatively impacted local capacity and eroded community trust. **Pre - Colonial (Before 1900)**: Local communities practiced ethno-veterinary medicine, demonstrating a capacity for research and the creation of indigenous knowledge.

Colonial Era (1900 - 1960): Colonial actions, such as introducing rinderpest and the subsequent coercive administration of medicine, eroded community trust. Research was commissioned primarily to advance the colonial agenda, not community welfare, despite scientists recognizing the inter-connectedness of animal and human health (e.g., sleeping sickness).

Post - Independence (1960 - 1990): This period saw the rise and tragic collapse of veterinary infrastructure due to political and economic shocks, leading to the privatization of veterinary services and a severe service deficit.

Modern Resurgence (1990s - Present): Efforts to combat diseases like rinderpest and sleeping sickness eventually led to the mobilization of Community Animal Health Workers, illustrating the effectiveness of participatory approaches and the need for a One Health approach.

Dr. Kabasa noted that there is a need to 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. Diseases like rinderpest and sleeping sickness have created global industries,

but Africa has been victim to a "culture of research" rather than a system that fully harnesses these assets. Communities should be recognized as the stewards of bio-assets and therefore their role in research must move beyond mere consent to become that of co-producers of knowledge and knowledge products.

Ethical Mandates: Future research must institutionalize ethical safeguards around: risk-benefit fairness, data sovereignty, benefit sharing and acknowledgement, and cultural safety. Research must be purposeful and supportive of national development within a one-world, one-market, one-farm context. This means that research ethics must be contextually appropriate to secure sustainable harnessing of the country's bio-assets.

In conclusion, Dr. Kabasa's address called for a 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. He highlighted the enduring wisdom, agency, and stewardship of local communities. Noting that communities must be treated not as passive beneficiaries but as co-creators of knowledge and guardians of Africa's bio-assets, whose insights and rights are essential to ethical, equitable, and impactful research. Ultimately, he called for research frameworks grounded in shared power, cultural safety, knowledge justice, and sustainable benefit, ensuring that animal health research meaningfully contributes to both national development and a more just global scientific ecosystem.

PARALLEL SESSIONS

Track 1: Ethics and Animal Welfare: Considerations for Animals in Research

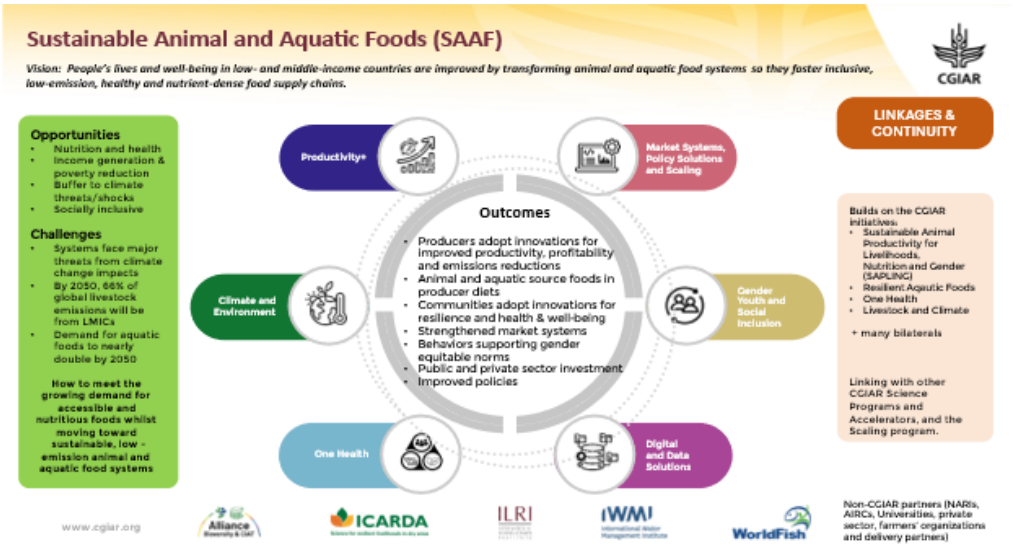
Moderators: Dr. Sylvia Angubua Baluka and Dr. Lawrence Mugisha

Presentation 1: Community Engagement and Animal Research: Engaging animal owners in research that involves animals as research subjects

Dr. Emily Ouma, Country Representative Uganda International Livestock Research Institute (ILRI)

"Animal research is at the core of what ILRI does", states Dr. Ouma in her opening remarks. She shared the vision of ILRI which is to ensure that people's lives and wellbeing in low- and middle-income countries are improved. Dr. Ouma further noted that ILRI does research to improve livelihoods of animal owners since they are at the core of animal research.

She noted that, there are different players in the productivity chain, but it is important to engage animal owners in research that involves animals. Because *(i)*animal owners have better understanding of their issues since they know what is acceptable and what is not. *(ii)*There is need to co-create solutions with the community and this will help increase adoptions of the solutions. *(iii)*Animal owners feel empowered when engaged and they own the solutions thereafter. *(iv)*They are part of ownership and *(v)*It safeguards ethics in animal research.



She further highlighted ways in which animal owners can be engaged; *(i)*Participatory processes: through local leadership and animal owners, treating them as equal partners, which is why it is critical to have them on board. *(ii)*Through healthy communication for clarity, and in the process agree on methodology and the risks involved in the research and the methodology to be used. *(iii)*Clarification of the different roles of each player in the research. *(iv)*Obtaining consent forms is critical prior to enrollment. The process should be voluntary without coercion. Ensuring animal owners comprehend the language used in the consent forms as well as stating the

elements to be covered in the consent forms. *(v)*Specification of the types of data and samples to be collected in the process and *(vi)*Indicating feedback modalities to animal owners.

Dr. Ouma gave an overview of ILRI's research compliance indicating that ILRI is committed and very reliant and has a research compliance Unit for oversight and coordination of research, ethics approval, biosafety and biosecurity related approval and application for research licenses and permissions for moving research materials. Some of the research compliance committees for review and approval of research activities include, Institution Research Ethics, Institution Animal care and use and Institution Biosafety Committee.

All research involving animals as research subjects requires comprehensive administrative, scientific, and ethical approvals, including oversight by authorities such as the National Institutional Animal Care and Use Committee (NIACUC). Ethical clarity, proper anesthesia, and careful animal management are essential, particularly to prevent zoonotic disease transmission to humans. Animal welfare is regulated by five freedoms, namely: freedoms from hunger, discomfort, pain, and distress, and the allowance of natural behaviors. Welfare principles apply broadly, extending to fish and some insects, and require that capture techniques minimize harm. All research in this area must adhere to welfare principles that benefit both humans and animals. Wildlife conservation remains critical, guiding protection efforts, especially for endangered species such as mountain gorillas.

Community engagement is crucial, especially given the rising demand for livestock like pigs, which necessitates effective management and research. ILRI's approach, through programs like Productivity Plus, involves multiple stakeholders across the livestock value chain. Engaging animal owners is essential because they possess in-depth knowledge of their animals and local practices. Co-creating solutions empowers the owners, promotes the adoption of findings, and ensures ethical safeguards are upheld for both animals and communities.

In conclusion Dr. Ouma's addressed the necessity of effectively engaging animal owners in research involving animals, emphasizing that ethical and successful outcomes depend on partnership, strict animal welfare adherence, and responsible use of technology. Advanced techniques, such as altering fertility in pigs to enhance livestock outcomes, must be carefully implemented. A holistic approach to ensure ethical research must be considered, paying keen attention to environmental risks and cultural sensitivities. Ethical practices, animal welfare, and active community engagement must be central throughout all research and intervention processes.

Presentation 2: Wildlife Animal Welfare: Navigating Research Oversight and Compliance

Dr. Margret Driciru, Head of Research Department, Uganda Wildlife Authority

Dr. Driciru outlined the regulatory framework and specific roles of key stakeholders in ensuring that welfare of free-ranging wildlife is used as research subjects. She emphasized compliance with established guidelines. She stated by defining Animal welfare which broadly refers to the well-being of animals in their natural habitat; ensuring they are healthy and free from disease. Animal welfare issues arise from

their us, occupation and nature which enhance human beings as companions.

She then highlighted the International Union for Conservation of Nature (IUCN) categorization of wildlife species as indicated below

Dr. Diriciru noted that it is only in Uganda, Rwanda and Congo where mountain gorrilas are still found. In all the status of wildlife in their categories: 109 are critically endangered, 70 endangered and 247 vulnerable. Thus, any action done by the Uganda Wildlife Authority (UWA) is towards their protection.

Special administrative clearance is required by researchers undertaking research in the under listed institutions before UNCST/IACUC; Uganda Wildlife Authority (UWA), National Forestry Authority (NFA), National Environmental Management Authority (NEMA), Uganda Wildlife Education Center (UWEC), National Animal Genetic Resources Centre and Data Bank (NAGRC&DB) for research involving genetic resources. The Procedure for research approvals include administrative clearance MAAIF, UWA, NFA, NEMA, NAGRC/DB ect, then Submit research protocol to IACUC for scientific, ethical review/approval and final clearance and research permit by UNCST.

She gave guidance for use of wildlife species in research and teaching, noting that the regulatory framework is guided by International Conventions and Treaties to which Uganda is a signatory. Such as:

- IUCN – International Union for Nature Conservation, enacted in 1948, Geneva, Switzerland
- CITES – Convention on International Trade in Endangered Species of Wild Fauna and Flora, enacted in 1963, Geneva, ratified by Uganda in July 1991
- CBD – Convention on Biological Diversity, 1992, Montreal, Quebac, ratified in Uganda, 1993
- Bonn Convention (1979), Convention on Conservation of Migratory Species of Wild Animals
- RAMSAR – Convention on Wetlands of International Importance for waterfowl conservation, 1971, ratified by Uganda in 1988
- World Heritage Convention for protection of world cultural and Natural Heritage sites, enacted in 1971, ratified in Uganda in 2017
- National laws eg Constitution of Uganda (1995), Prevention of Cruelty to Animals Act (1957), Uganda Wildlife Act 2019, and the National Drug Policy and Authority Act (2000), 30, 32

She highlighted the animal welfare principles noting that research aiming at animals is only aimed at improving human and animal welfare and the justification for animals selected should

be relevant. She further noted the five animal freedoms, Freedom from hunger and thirst, Freedom from discomfort, Freedom from pain, injury and disease, Freedom to express normal behavior, Freedom from distress. Capture techniques of animals should minimize injury and mortality, use chemical capture, use capture devices that are safe, avoid animal capture in bad terrain and consider seasonality.

Dr. Diciru highlighted ethical considerations for use of Wildlife species in research and teaching, noting that animal research plays vital role in many scientific and medical advances leading to better understanding of various disease processes, and subsequent development of new products, medicines and treatments. However, some procedures cause distress, suffering, pain, long-lasting harm, or death to animal research subjects. It is important to note that use of None-human primates in experimental studies is restricted and banned for endangered species like chimpanzees, except in biomedical areas essential for the benefit of humans and NHP where there are no alternatives. Noninvasive techniques, e.g., use of derivative specimens like fecal, urine are recommended. Use of highly qualified personnel is recommended. For clinical trials mostly used in species of list concern, like mice, bats, vervet monkeys during vaccine and drug testing research.

Additional guiding principles for instance scientific integrity, (very sound research techniques and protocols should be used, avoid wastefulness in research procedures that subject unnecessary number of animals to pain). Animal welfare: minimize pain and suffering to research animals. Holding facilities for research animals should be strong, safe, well aeriated, have food, water. Wildlife capture techniques should be safe and minimize stress and pain. Chemical capture with recommended anesthetics like opioids for herbivores, ketamine derivatives for primates and carnivores. Avoid medications, procedures, drug administration routes that cause intense pain & distress. In vaccine production studies, minimize the volume of blood collected to avoid shock. Define endpoint criteria in approved protocols to humanely euthanize research animals at the end of clinical trial studies.

Researchers need to be cognisant of the vulnerabilities in animal research and teaching such as Inherent vulnerability- feels pain, illness, disease and death. Researchers need therefore to identify and remedy harm to research animals. Special interest groups for protection include endangered wildlife species whose populations are low and at the verge of extinction. These are protected under international and National laws that restricts research and use in their products. Pregnant, lactating, young, and senile animals with compromised immunity and physiological state. It is important to consider animal specific behaviours for example, Giraffes are very sensitive to opioids, reverse with antidote immediately after recumbence. Immobilized elephants on sternal recumbence prone to respiratory failure and death. Some mitigation strategies, Professionals be used, train personnel in ethics and tech, sound protocols and Special permit, import, export permits required before approvals.

She ended by highlighting the key animal welfare principles such as rationale-procedures involving animals should be designed and performed with due consideration of their relevance to human or animal health, the advancement of knowledge, or the good of society. Justification: The animals selected for a procedure should be of an appropriate species and quality and the minimum number required to obtain valid results. Methods such as mathematical models, computer simulation, and in vitro biological systems should be considered. Minimize pain and distress; proper use of animals, including the avoidance or minimization of discomfort, distress, and pain when consistent with sound scientific practices, is imperative. Unless the

contrary is established, investigators should consider that procedures that cause pain or distress in human beings may cause pain or distress in other animals. Humane endpoints: Animals that would otherwise suffer severe or chronic pain or distress that cannot be relieved should be painlessly killed at the end of the procedure or, if appropriate, during the procedure. Training: Investigators and other personnel shall be appropriately qualified and experienced for conducting procedures on living animals. Adequate arrangements shall be made for their in-service training, including the proper and humane care and use of laboratory animals. Ethical Review: decisions should not rest with the investigators directly concerned but should be made by an appropriate review group such as an IACUC. Such exceptions should not be made solely for the purpose of teaching or demonstration.

In conclusion Driciru, retaliated that welfare issues arise from how animals are used as research subjects. Compliance with regulatory frameworks and established guidelines is essential to safeguard animal welfare.

Presentation 3: Agricultural Animals in Research: Ethical consideration related to the use of agricultural animals in biomedical research

Dr. Swadiq Mugerwa, Deputy Director General National Agricultural Research Institute (NARO)

Dr. Mugerwa highlighted the growing role of agricultural animals in biomedical translational and comparative research, emphasizing the necessity of robust ethical oversight and participatory engagement strategies to ensure integrity and animal welfare. He noted that there are two types of animals: those in agriculture, and those in protection. Examples of agricultural animals include cattle, goats, pigs among others. Some of the reasons he gave as to why agricultural animals are used in research, for instance; Animal physiology and organ systems are usually closer to humans than laboratory animals, Animals share diseases with humans and have appropriate sizes for surgical training.

He further noted that agricultural animals are increasingly vital in research, providing a better understanding of disease processes and contributing to the development of new medicines and treatments. Their roles span several areas of use including translational and pre-clinical research - Used in translational biomedical research and preclinical trials for new products, medicines, and treatments, comparative Medicine, observing and treating diseases across multiple species to gain valuable insights, Nutrition, physiology and metabolic studies, generic engineering and biotechnology and dietary manipulations.

Other considerations include use penetration, to ensure use of Anastasia, need to ensure ethical clarity, management of animals during trials should be catered for, Closeness with humans should be monitored to avoid transmitting diseases, Generic changes can be made in animals for us to change reduced fertility. For example, manipulation of genes engineering in pigs, some animals escape and go into the environment, genetic engineering of food animals may conflict with cultural religious norms, fish perceive pain so suffering and crowding should be minimized possibly with anesthesia, Evidence suggests some insects feel pain, many insects are pests and disease vectors if they escape and Welfare of animals should be considered in research.

Research involving animals as research subjects also requires research clearance and regulatory approval. This could be in form of administrative clearance (The Commissioner for Animal Health, and NAGRIC), Science, ethical review and approval (clearance from scientific committee, clearance from IACUC with numerous stages taken, clearance from institutional biosafety committees and clearance from the UNCST, registration of study and research permit. Dr. Mugerwa highlighted some of the ethical principles of that should be considered while conducting research that involves agricultural animals' research. Integrity, Competence, Beneficence, Privacy, Autonomy and Justice.

In conclusion, Dr. Mugerwa underscored the expanding importance of agricultural animals in biomedical translational and comparative research, demonstrating their unique physiological relevance to humans and their critical contributions to advancing medical knowledge and innovation. He emphasized that this growing reliance must be matched with rigorous ethical oversight, clear regulatory pathways, and strong welfare protections to ensure responsible scientific practice. Moreover, he highlighted 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. Together, these insights reinforce the imperative for ethically grounded, scientifically robust, and socially responsive engagement in the use of agricultural animals in research.

Presentation 4: Establishment of institutional animal care and use committees, roles and responsibilities, challenges

Dr. Halid Kirunda, Director of Research – National Agricultural Research Organization

Dr. Kirunda's presentation highlighted the necessity and function of Institutional Animal Care and Use Committees (IACUCs) as the primary ethical and oversight body for research involving animals. He noted that IACUCs should be established by any institution that owns or manages animals used in research or teaching.

The central purpose of the IACUC is to oversee all research activities involving animals, ensuring that their use is conducted humanely and upholds the highest ethical standards. They exist to co direct research, and their goal is to ensure humane care and responsible use of animals in research and teaching.

IACUCs operate under accreditation provided by the Accreditation Committee at the UNCST. Their overarching goal is to safeguard the welfare of animals throughout all research processes. Requirements for establishment of IACUC include a statement of principles for protecting the welfare and care of animals, List of members composition. It should have at least five members, each one being a vet, with varying backgrounds to ensure balanced views.

Best practices of IACUCs: No member shall participate in review where they're conflicted, each member should take a course relevant in committee, Invitation of members based on expertise, A person shall not serve as a member in more than two IACUCs concurrently and Members term of service is three years

Roles and responsibilities of IACUCs: To maintain ethical standards of practice, protect research animals and researchers from harm or exploitation, protect welfare and humane care of

research animals and assure the public of the welfare of research animals. Functions of IACUCs: To evaluate and approve that involves animal subjects', monitor care and use of animals in research, inspect any facilities where animals are kept and investigate suspected or reported non-compliance. Some of the basic considerations for IACUC approval include Methods used ought to be scientifically valid and practically feasible, Appropriate jurisdiction for use of animals, Protocol has scientific or educational merit and has potential benefit, and Protocol demonstrates value by adding new knowledge. He noted that IACUCs have authority to halt, suspend or terminate approved research permits.

He emphasized some of the responsibilities of the key stakeholder in research that involves animals as research subjects. Investigators: develop and own protocol, seek ethical and regulatory approvals, ensure competence of people involved in research, Training and capacity building of the researcher team members, ensure animal welfare and care, Veterinary oversight and monitoring, safety and adverse events, Quality assurance and data integrity, reporting feedback and communication and ethical accountability and presence. While sponsors are required to approve final study, Responsible for compensation in event of injuries, provide information about investigational product and cause the timely reporting and management. Research institutions establish support functional ethical oversight structure and ensure scientific professional research.

He noted some of the opportunities and challenges faced by IACUCs: Opportunities in establishments and use of IACUCs: Eligibility for major research funding, Clear governance and risk management of approved studies, better science and reproductivity, Stronger alignment with other health and international norms, public trust and institutional legitimacy, Operational improvements and investment cases and Capacity building and professional development.

Challenges, Ethics review can be a burden, Species multiplicity, Resource limitations, Delayed relay of information, Need for committed lay persons, Appropriate capacity of members, Conflict of interest, Disappearing integrity,

In conclusion, Dr. Kirunda emphasized that Institutional Animal Care and Use Committees (IACUCs) are indispensable to ensuring ethical, humane, and scientifically responsible use of animals in research and teaching. By outlining their establishment requirements, membership composition, responsibilities, and oversight powers, he highlighted how IACUCs safeguard animal welfare, protect researchers, uphold public trust, and strengthen institutional credibility. Despite challenges such as limited resources, species diversity, and the need for highly competent and impartial members, he noted that effective IACUCs create significant opportunities for improved research quality, increased funding eligibility, and stronger governance. Ultimately, his presentation reinforced the essential role of IACUCs in promoting ethical integrity, regulatory compliance, and high standards of animal care across research environments.

Track 2: Research Ethics and Traditional Alternative Medicine Research

Moderators: Dr. Yahaya Gavamukulya and Dr. Ahmed Kiswezi

Presentation 1: Research in traditional and alternative medicine: Ethics, Intellectual property and culture relevance.

Dr. Sekagya Yahaya Hills (Kagali III), Director Institute of Traditional Medicine, President PROMETRA Uganda

Dr. Sekagya began by saying that the theme of the 12th Annual National Research Ethics Conference; ***"Communities as Partners: Strengthening Community Engagement in Research"*** was both timely and necessary. He said that his presentation would focus on research in traditional and alternative medicine, particularly the ethical issues, intellectual property concerns, and the cultural significance surrounding these knowledge systems.

In his talk, Dr. Sekagya noted that the central problem is what he called a ***"Western lens"*** that dominates most research.

He explained that Western approaches often prioritize quantifiable data and standardized interventions, and he said that these methods frequently fail to capture the spiritual nuances, social contexts, and healer priorities that are essential to traditional medicine. He said that this disconnect can lead to misinterpretation, ethical compromises, and ultimately limited benefit for the communities involved.

He went on to say that to bridge this gap, we must understand what he described as the ***Galaxy Outlay*** a framework that acknowledges the spiritual dimension of illness. This framework encourages researchers to see the whole picture by considering spiritual, social, and cosmological forces. He emphasized that these forces are interconnected and that a holistic perspective must go beyond quantifiable data.

Galaxy outlay – Spiritual Dimension of illness

He also said that there is an important difference between illness and disease, noting that African or indigenous interpretations of illness often differ from biomedical definitions of disease. This illustrated a larger ontological challenge where differing worldviews must be respected. Researchers must avoid imposing one worldview onto another.

When addressing ethical concerns, he noted that the intellectual property rights of communities and practitioners must be protected. Ownership of data, equitable benefit-sharing, and avoidance of co-option or misrepresentation were essential responsibilities in ethical research. Adding that the guiding principles should be reciprocal responsibility and respectful representation. A new framework is needed one based on community co-creation. Research should prioritize qualitative approaches like ethnography, participatory action research, and narrative inquiry. Research questions should come from the community itself, and that knowledge should be co-created and jointly disseminated.

Dr. Sekagya indicated that African complex science is often hidden beneath what Western methodologies recognize, and that this has led to weaknesses in research. He said that elements such as divine or psychic connections, African medical symbolism, ancestral communication, sacrificial systems, and the diversity of African healing practices are often overlooked or dismissed instead of studied with respect.

He further said that Indigenous Knowledge holders must be included on ethics committees. He said they provide credible and culturally informed oversight, help mitigate risks, and ensure that traditional knowledge and its custodians are respected. Strengthening indigenous science and local healthcare systems is an act of reciprocity. He emphasized that communities should be empowered to protect their cultural heritage and that investment in indigenous science is essential for sustainable and culturally grounded health systems. Toward the end, he said that many questions remain about traditional medicine and the deeper medical traditions embedded in African cultures. These questions will only be answered through respectful engagement, curiosity, and culturally rooted research approaches.

Conclusion

He concluded by saying that moving forward requires a shared journey toward ethical and equitable research. He said that community engagement must remain at the center, that culturally sensitive methods are essential, and that respect and reciprocity must guide all efforts. He emphasized that protecting and honoring traditional knowledge is not only ethical but vital for meaningful and transformative research partnerships.

Presentation 2: Data ownership and knowledge in traditional and alternative medicine research: a case of Batwa indigenous people and local communities in Kisoro District, Uganda

Dr. Francis Omujal, Senior Scientist, National Chemotherapeutics research Institute

Dr. Omujal began by explaining that his presentation focused on data ownership and knowledge in Traditional and Alternative Medicine (TAM), specifically looking at the Batwa Indigenous People and local communities in Kisoro District, Uganda. He noted that TAM heavily depends on Indigenous Knowledge Systems, and that these community-held practices play a crucial role not only in biodiversity conservation but also in providing primary health care for both humans and animals.

He highlighted that in recent years, the question of who owns and controls traditional knowledge and data in TAM research has become increasingly important. He emphasized that

data ownership involves clarity on who holds the rights over documented knowledge and biological samples. Research activities such as documenting traditional medicine often bring questions about who collects information, how it is stored, and who ultimately benefits from commercialization. According to him, traditional health practitioners have frequently shared knowledge without sufficient recognition, compensation, or agreements regarding ownership, access, and benefit-sharing.

To frame the international context, Omujal referred to the Nagoya Protocol on Access to Genetic Resources, adopted in 2010. Mentioning how South Africa's Council for Scientific and Industrial Research (CSIR) helped the San community negotiate benefit-sharing agreements for products developed from Hoodia gordonii, Sceletium tortuosum (commercialized as Zembrin), and the Rooibos plant. These examples illustrated how Indigenous knowledge could be fairly recognized and protected.

Turning to the Ugandan context, he described the Batwa, an Indigenous group who historically lived in the forests of Bwindi and Mgahinga. After these areas were designated as national parks in 1992, the Batwa were evicted and became marginalized and landless. Despite this displacement, he stressed that the Batwa still hold valuable traditional medicinal knowledge. His project sought to bio prospect this knowledge ethically, with the intention of developing herbal products.

He explained that ethical engagement was a central component of the study. The research protocol received approval from Makerere University's School of Health Sciences Research Ethics Committee and the Uganda National Council for Science and Technology. Consent was sought individually, and communication took place in the local languages, Rukiga and Umufumbira. He emphasized that the Batwa were recognized as rights-holders and co-creators, and that researchers had an obligation to provide ongoing feedback.

When discussing Prior Informed Consent (PIC), he said that Uganda's national Access and Benefit-Sharing regulations guided how information and biological resources could be accessed. Under these regulations, the Batwa retained intellectual property rights over their traditional knowledge, including formulas and preparation methods. National Chemotherapeutics research Institute (NCRI's role, he clarified, was to act as the custodian of the dataset, ensuring proper storage and regulated access.

He elaborated on the development of community protocols, which outline how Batwa knowledge and resources can be accessed, used, and shared. This process involved community meetings, awareness activities, and discussions on benefits. He referenced the official community protocol created under Uganda's legal framework for accessing genetic resources and benefit-sharing. Dr. Omujal then explained the engagement process with Kisoro District local government leaders and the United Organization for Batwa Development in Uganda (UOBDU). He described the interactions carried out with Batwa communities, which preceded data collection. Data collection methods included ethnobotanical surveys, focus group discussions, and field observations.

He presented how different stakeholders interacted in the research process. The Batwa, as owners of traditional medicine knowledge, set conditions for access and storage through PIC. NCRI served as the collector, analyst, and custodian of data. Research funders such as the Global Environment Facility (GEF) supported the work, while government bodies like NEMA and the Kisoro District Local Government provided regulatory oversight. He further illustrated how biological resources were accessed and how communities were engaged regarding the herbal

products derived from their knowledge. Finally, he showcased examples of bio prospected herbal products developed with Batwa knowledge.

Conclusion

Francis concluded by reaffirming that while the Batwa Indigenous people retain ownership over their traditional medicinal knowledge, NCRI serves only as a custodian of the data under strict ethical and legal frameworks established by Uganda's Access and Benefit-Sharing regulations. He emphasized that the project ensured meaningful participation of the Batwa, with clear benefit-sharing arrangements that support their empowerment, protect their cultural heritage, and encourage sustainable use of their knowledge. He ended by expressing gratitude to all stakeholders involved

Presenter 3: Pathways to conventional clinical trial testing or traditional and alternative medicine research; Negative fears of intellectual property rights and loss. How to effectively engage communities in Traditional and alternative medicine

Dr. Pauline Byakika-Kibwika, Vice Chancelor Mbarara University of Science and Technology (MUST)

Professor Pauline Byakika-Kibwika opened her presentation by situating Traditional and Alternative Medicine (TAM) within global health realities. She explained that the World Health Organization defines traditional medicine as a cumulative body of knowledge, practice and belief often transmitted orally that communities apply in maintaining health and treating disease. She reminded the audience that this knowledge encompasses far more than herbal remedies: it also includes faith-based healing, mind-body interventions, massage, and a wide spectrum of natural therapeutics.

She emphasized that TAM remains indispensable across the developing world, where up to 80 percent of people rely primarily on natural medicines. The COVID-19 pandemic, she added, had magnified this trend globally as communities sought easily accessible plant-based therapies in the absence of quick pharmaceutical solutions. Yet many of these remedies continue to be used without systematic evaluation of their safety, efficacy, pharmacokinetics or interactions. This gap, she noted, is precisely what WHO's guidance on herbal medicine research seeks to address.

Turning to Uganda's context, she introduced the Clinical Trials of Natural Therapeutics of Uganda (CONAT) program, a government-funded initiative coordinated through the Makerere Lung Institute and supported by multiple national research institutions, including COVAB, NCRI, UVRI, DGAL and Mbarara University of Science and Technology (MUST). She explained that CONAT was designed to create a structured pathway for evaluating herbal products using conventional clinical trial methodologies ensuring that natural medicines undergo the same scientific scrutiny as pharmaceutical products.

She then outlined how WHO recommends that herbal products move toward clinical testing. According to her, the process begins with botanical verification before moving to in-vitro and in-vivo studies, especially when the remedy lacks a robust history of safe use. Where safety concerns exist or evidence is weak, additional toxicity studies including immunotoxicity or genotoxicity assessments become necessary. Efficacy evaluation, she noted, may draw from observational

studies, ethnographic documentation or single-case analyses, and only advances to clinical trials once a credible evidence base has been established. She reminded the audience that trial designs often need modification for herbal medicines due to strong tastes or distinctive characteristics that compromise blinding.

Professor Byakika-Kibwika described how CONAT operationalizes these steps: innovators are invited to submit products; laboratories perform phytochemical profiling and identify bioactive markers; UVRI conducts in-vitro testing; COVAB undertakes toxicity studies; and human trials at the Mulago Clinical Trials Unit examine safety, pharmacokinetics and preliminary efficacy. She noted that two natural therapeutic clinical trials have already been completed, and new trials targeting malaria prevention and diabetes control are in preparation.

However, she acknowledged that building this system was not without challenges. As she explained, Uganda's early phases of natural therapeutics research were marked by limited infrastructure, fragmented systems and significant mistrust, both within communities and among innovators. Many traditional healers feared that sharing their formulations would lead to intellectual property loss, misappropriation or biopiracy. On the institutional side, limited resources, lengthy regulatory reviews and conflicting expectations added further strain. She observed that these tensions often reflected deeper concerns about cultural erosion, misrepresentation of TAM practices, and the difficulty of fitting collective, orally transmitted knowledge into Western IP frameworks that prioritize novelty and individual ownership.

To address these barriers, Professor Byakika-Kibwika highlighted the central role of ethical, transparent and participatory engagement. She emphasized the importance of Access and Benefit-Sharing (ABS) agreements aligned with the Nagoya Protocol, which ensure that communities retain rights to their knowledge, are fully informed about intended research uses, and have well-articulated benefit-sharing arrangements. She argued that communities must be treated not as subjects but as equal research partners co-owners of the process and beneficiaries of its outcomes.

She explained that community engagement requires structured mechanisms such as Community Advisory Boards, participatory study designs, and community-based research approaches that honor cultural protocols. True engagement, she said, is less about consultation events and more about sustained co-creation, transparency, and respect for elders and knowledge custodians. She illustrated this with examples of community-level training led by scientists and herbalists, where mutual learning fosters trust and strengthen both scientific and traditional practices.

Professor Byakika-Kibwika then discussed institutional innovations at MUST designed to safeguard intellectual property while supporting TAM research. She traced a timeline of capacity-building efforts: the establishment of PHARMBIOTRAC in 2017, the Centre for Innovations and Technology Transfer (CITT) in 2018, the adoption of an institutional IP policy in 2021, and CITT's subsequent certification as a regional Technology and Innovation Support Centre by WIPO and URSB. These developments, she said, ensure that innovators in TAM benefit from structured IP protection mechanisms, non-disclosure agreements, professional mentorship, and systems that support commercialization without compromising cultural ownership.

Throughout the presentation, she repeatedly underscored that scientific rigor and cultural respect are not opposing forces. Instead, she described them as complementary pillars of a modern research ecosystem, one that recognizes community wisdom as legitimate data and sees trust as the most valuable currency in traditional medicine research.

Conclusion

Dr. Byakika-Kibwika concluded by observing that 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. She emphasized that Uganda's CONAT program and MUST's institutional frameworks demonstrate that it is possible to protect indigenous intellectual heritage while fostering scientific advancement. Ultimately, she argued, the future of TAM research lies in building authentic, respectful, and mutually beneficial relationships where communities are not only knowledge holders but active contributors to innovation, evaluation and therapeutic discovery.

Presenter 4: Intellectual property landscape in Uganda, Application to traditional and alternative medicine research: regulatory perspective.

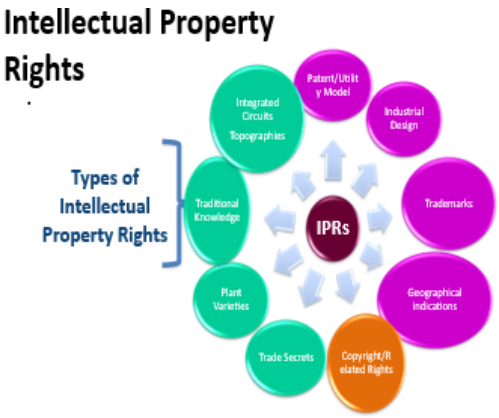
Mr. Marvin Alinaitwe, Intellectual Property Officer Uganda National Council for Science and Technology

Mr. Alinaitwe started by explaining that discussions about Intellectual Property (IP) are inseparable from contemporary developments in Traditional and Alternative Medicine (TAM). He noted that both WHO and global market trends highlight the growing importance of traditional medical knowledge not simply as a cultural resource, but as a major economic and innovation frontier. With TAM projected to become a trillion-dollar global enterprise within the next decade, he argued that the regulatory and IP landscapes must adapt to protect both national interests and the rights of traditional knowledge holders.

He framed TAM within two broad conceptual categories: traditional medicine rooted in indigenous cultural practices, and complementary and alternative medicine, which often coexists alongside conventional biomedical systems. While these definitions are well known, he emphasized that they matter greatly for legal interpretation because different knowledge systems map onto different IP instruments, and each carries its own vulnerabilities.

He then transitioned into the core of his talk: understanding intellectual property as the set of legal tools that protect creations of the mind, functioning almost like an invisible boundary that determines who may use, distribute or commercialize knowledge. He clarified that IP differs fundamentally from tangible property not only because it is intangible, but because its protection is limited in time, territorially bounded, and governed by specific legal instruments such as patents, trademarks, copyrights, geographical indications and trade secrets.

From this basis, he outlined Uganda's own IP ecosystem. He described it as multi-layered, involving global regimes such as the WTO and Convention on Biological Diversity, regional frameworks such as ARIPO and the African Continental Free Trade Area, and national regulators including UNCST, NDA, and STI-OP. He stressed that these layers do not always align cleanly, which explains why researchers and traditional practitioners often experience confusion or mistrust when engaging with IP processes.



Explaining how IP tools apply to TAM, he noted that patents protect technical inventions, though many herbal

innovations fail patent tests because they build on existing traditional knowledge. Design protection, he said, may apply to medical devices or specialized equipment. Trademarks allow herbal producers to differentiate their products in the market, while copyright protects datasets, manuals and scientific outputs derived from TAM research. Geographical indications, he suggested, offer particularly promising opportunities for communities because they tie product reputation to place and collective identity mirroring the structure of many traditional medicine practices. Trade secrets, meanwhile, remain a common mode of protection among healers, who often rely on secrecy to safeguard formulas that would otherwise be vulnerable under patent law.

He offered practical examples, such as China's protection of Schisandra under a geographical indication system, the commercial history of liquor ice root, and the centuries old Chartreuse formula maintained exclusively through trade secrecy. These examples, he remarked, illustrate why TAM requires a varied toolkit rather than a single IP pathway.

A major portion of his presentation addressed the tension between two global systems: the TRIPS Agreement under the WTO and the Convention on Biological Diversity/Nagoya Protocol. He highlighted how TRIPS privileges private, codified inventions, whereas the CBD recognizes collective rights over genetic resources and traditional knowledge. This mismatch, he explained, creates the conditions under which biopiracy occurs, because TRIPS does not require disclosure of origin nor proof of consent from knowledge holders. By contrast, the Nagoya Protocol mandates prior informed consent and benefit-sharing, giving countries legal grounds to demand accountability from foreign researchers and corporations.

The Hoodia Cactus

To illustrate this conflict, he revisited the well-known Hoodia case in Southern Africa, where traditional knowledge of the San people was patented by external actors without their consent. He emphasized that the eventual benefit-sharing agreement became a global precedent showing that traditional knowledge can generate significant commercial value, but only if legal safeguards and community participation are properly integrated from the outset.

Reflecting on the broader implications, he argued that conventional IP systems do not adequately protect collective ownership, cultural rights or orally transmitted knowledge. This creates vulnerabilities for communities and, at the same time, legal uncertainty for researchers working at the intersection of innovation and tradition. He emphasized that without community engagement and transparent governance systems, well-intentioned research can inadvertently contribute to exploitation.

In the final section of his talk, Alinaitwe outlined key recommendations for building a stronger, fairer IP ecosystem for TAM research in Uganda. He suggested establishing a dedicated sui generis law specifically designed to protect traditional knowledge and genetic resources, one that recognizes collective custodianship rather than individual inventorship. He recommended creating a national digital registry of TAM to catalogue prior art and prevent outsiders from patenting knowledge already known within communities. He also called for strengthening commercialization pathways so that TAM research can meaningfully contribute to national development, insisting that benefit-sharing mechanisms must ensure that knowledge holders receive both recognition and economic gains. Finally, he urged full compliance with Nagoya

Protocol provisions, noting that this is not just a legal obligation but a strategic tool for protecting national sovereignty over biological and cultural resources.

Conclusion

Mr. Alinaitwe closed by stressing that Uganda's TAM research ecosystem stands at a critical juncture. As global interest and commercial value accelerate, the country must 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. Ultimately, he argued, the true measure of progress will not be 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.

Question & Answer Session Track 2

Question 1

"How do we ensure that the Batwa and other indigenous communities retain ownership of their traditional knowledge while engaging in clinical trials?"

Presenters noted that ownership is maintained through Prior Informed Consent (PIC) and community protocols. The Batwa, remain the rights-holders of their knowledge, while institutions like NCRI act only as custodians of data. Co-creation, regular feedback, and benefit-sharing agreements are critical to ensure communities have decision-making power at every stage.

Also, clinical trials must integrate cultural consultation from the design stage. By involving communities as equal research partners and recognizing their intellectual contributions in publications and patents, researchers avoid appropriation while ensuring scientific rigor.

From a regulatory perspective, IP instruments alone are insufficient. Sui generis legal frameworks and ABS agreements under the Nagoya Protocol are essential to protect collective community ownership and prevent unauthorized commercialization.

Question 2

"What challenges arise when integrating traditional remedies into conventional clinical trials?"

Herbal products often have complex formulations, making blinding and placebo controls difficult. Trial designs must adapt to account for pharmacological uniqueness and prior traditional use. Observational studies and ethnographic research can complement trials to generate baseline efficacy data.

Community engagement is crucial. Without trust, participants may be reluctant to share accurate knowledge or follow trial protocols, compromising data integrity.

Question 3

"How can researchers address the fear of intellectual property loss among traditional knowledge holders?"

Intellectual property fears can be mitigated through NDAs, IP training, and transparent contracts. Open communication about rights, ownership, and benefit-sharing supported by national policies and TISC mechanisms is vital.

Participatory co-creation, early engagement, and shared leadership in research teams build trust and reduce perceived risk of exploitation.

Question 4

"What mechanisms exist to prevent biopiracy in TAM research?"

Uganda relies on ABS regulations, PIC requirements, and national digital registries of traditional knowledge to establish prior art. International frameworks, such as the Nagoya Protocol, require foreign users to obtain consent and share benefits.

Community protocols codify how knowledge can be accessed and used, ensuring that research and commercialization are consistent with community-defined rules.

Question 5

"Can observational or single-case studies suffice for efficacy evaluation in TAM?"

Minor conditions or traditional remedies with long-standing use, observational and single-case studies can provide valuable preliminary evidence. However, when safety and efficacy are uncertain, full clinical trials are necessary to meet international standards.

Also combining ethnobotanical surveys with such studies strengthens contextual understanding and ensures trials respect traditional knowledge.

Question 6

"How do global IP regimes like TRIPS conflict with the protection of traditional knowledge?"

The TRIPS emphasizes individual, codified inventions and does not account for collective ownership. Traditional knowledge often exists in the public domain under TRIPS, exposing it to appropriation. In contrast, the CBD/ Nagoya Protocol prioritizes community rights, requiring PIC and benefit-sharing.

The misalignment underscores the need for national sui generis systems that complement international IP regimes.

Question 7

"How can TAM research balance scientific rigor with cultural respect?"

Trust and co-creation are foundational. Clinical protocols must respect local hierarchies, knowledge-keeping traditions, and oral histories while adhering to ethical standards. Cultural humility allows researchers to design scientifically valid studies without undermining traditional practices.

Providing continuous feedback, acknowledging community contributions formally, and ensuring equitable benefits are essential to sustaining this balance.

Legal safeguards PIC, ABS agreements, and IP protection—as complementary tools to maintain cultural respect while enabling rigorous research.

Track 3: Ethics of Novel Innovation and Emerging Research Designs

Moderator: Dr. Fred Bulamba

Presentation 1: Ethical Conduct of Cell and Gene Therapy Research: Novel challenges and ethical considerations for researchers and regulators (REC, UNCST & NDA)

Dr. Cissy Kityo Mutuluuza, Executive Director, Joint Clinical Research Centre (JCRC)

Dr. Kityo detailed the transformative potential of Cell and Gene Therapy (CGT), the ethical challenges it presents, and the critical need for strengthened regulatory oversight in Africa. She noted that Gene therapy seeks to modify or manipulate the expression of a gene or to alter the biological properties of living cells for therapeutic use. Alterations can include Inactivation or deletion of disease-causing gene, replacement with a healthy copy of gene, Insertion of a new or modified gene, Somatic editing modifies non-reproductive cells.

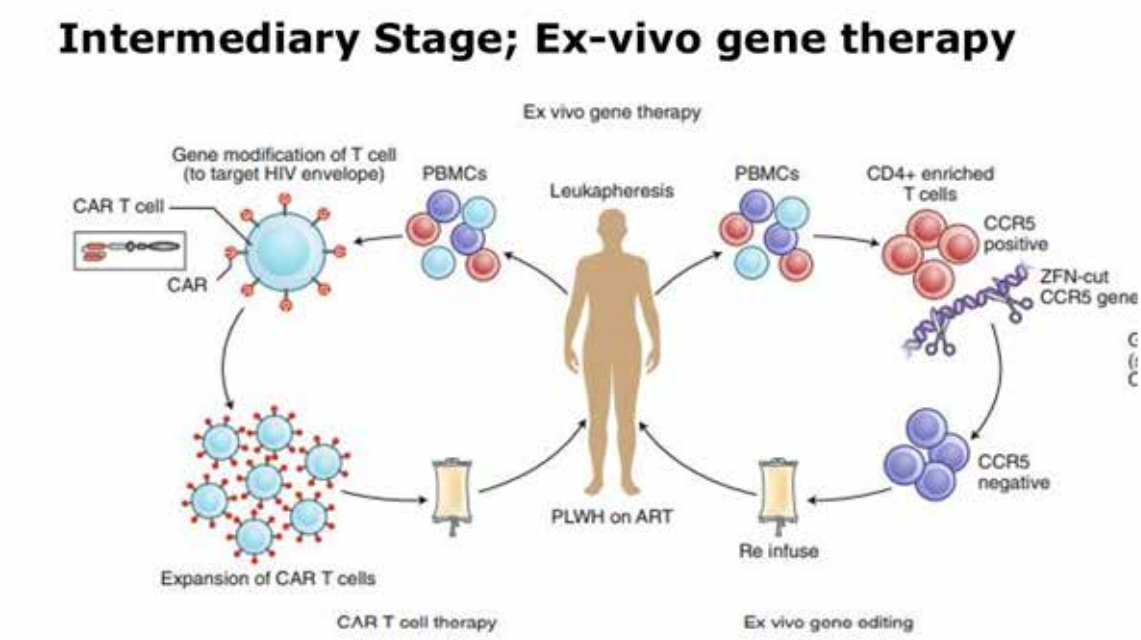
She further highlighted the potential of gene therapy noting that Genetic therapies focus on underlying disease biology, rather than symptom management. If genetics are known, there is no need to identify small molecules that can treat, gene therapy can immediately be developed for treatment or cure. Genetic therapies could be a one-time treatment with transformational and curative potential.

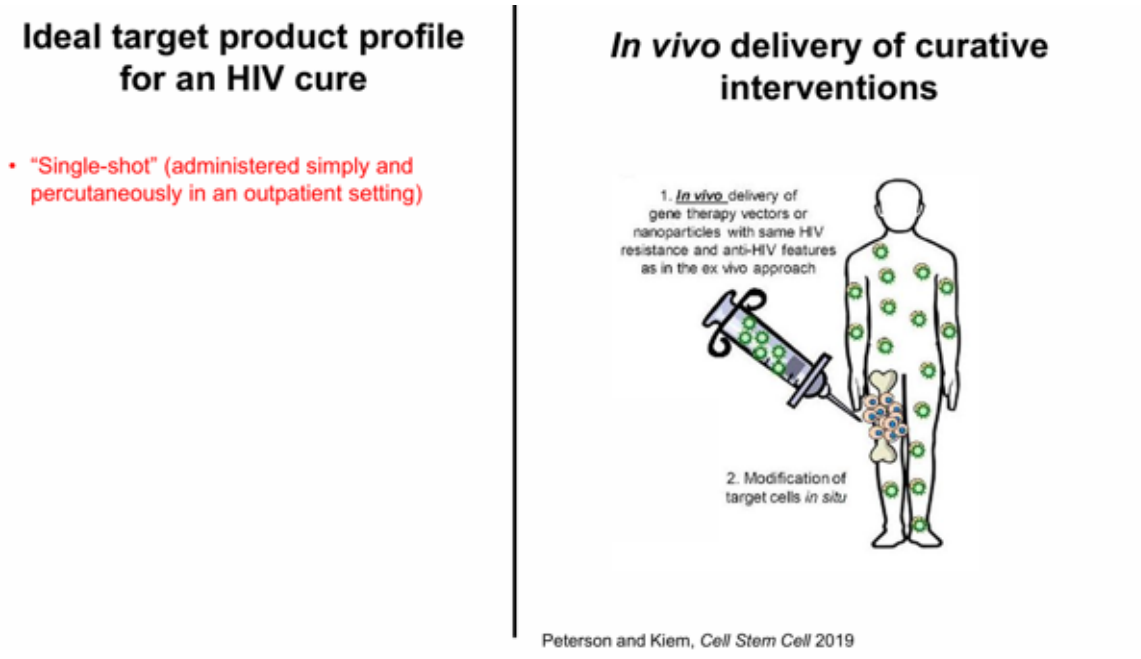
There are thirty-two (32) gene therapies that were first approved by the U.S. FDA and EMA. The FDA anticipates 10-20 new approvals per year by 2025. As of 2022, there were 1,221 active clinical trials of gene therapies which are designed to treat >100 different diseases worldwide. (Statista.com; Number of active trials for cell and gene therapies worldwide 2022 by trial phase, Published by Matej Mikulic , Nov 23, 2022)

Given its potential, Dr. Kityo noted that GT is a new Era in Medicine representing a paradigm shift in medicine moving from treating symptoms to curing diseases at their genetic root. It holds curative potential for previously incurable diseases (HIV, Sickle Cell Disease, Cancers). There are over 30 approved gene therapy products on the market. Cell and gene therapy is highly relevant in Africa due to the heavy burden of genetic and infectious diseases and a predominantly young population. For instance, over 300,000 babies born annually with SCD in Sub-Saharan Africa, Millions living with HIV/AIDS and rising rates of cancer and non-communicable diseases. Gene

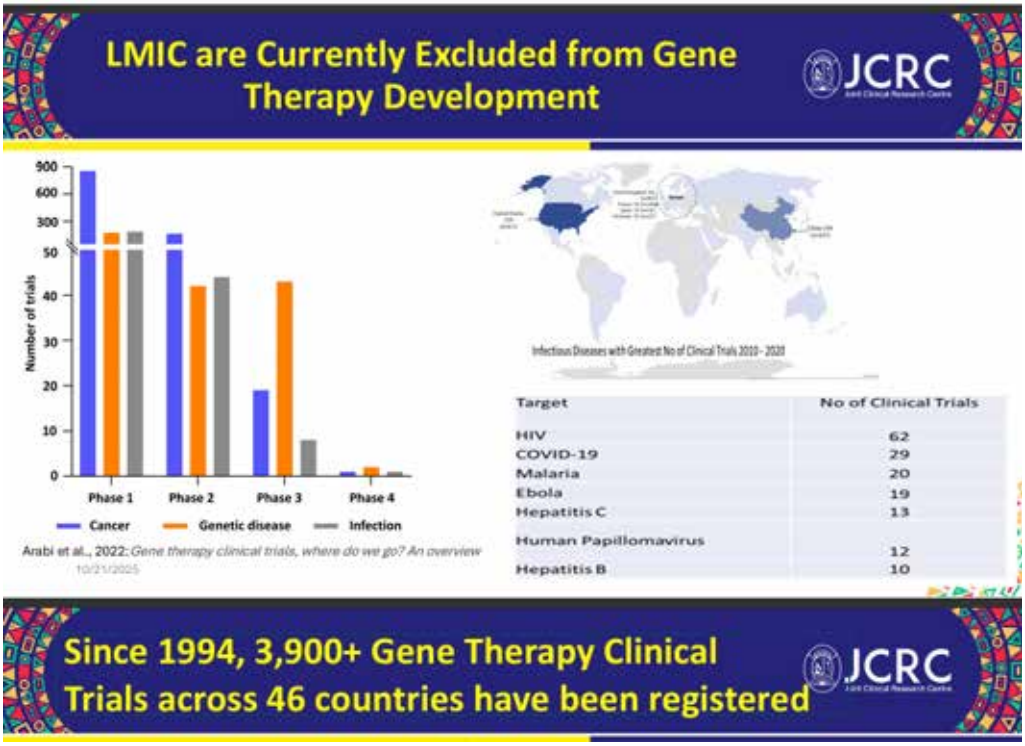
therapy offers hope for durable, cost-effective solutions that reduce long term healthcare costs and improve quality of life.

She explained that Cell and gene therapy uses two main approaches: ex vivo (modification outside the body) and in vivo (direct delivery). Ex vivo gene therapy takes cells from the body, administers the gene therapy to the cells in a laboratory, and then returns those cells to the body. In vivo gene therapy delivers genetic material directly to living cells inside the body.

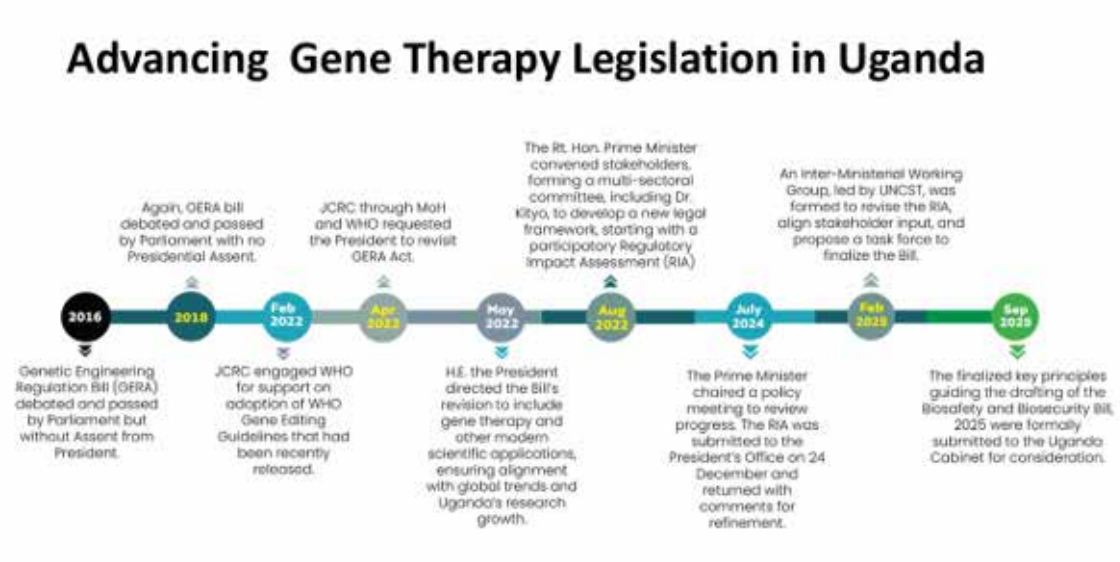




She noted that currently, most gene therapies are administered by adeno associated viruses (AAV) vectors or lentiviral vectors (LV). The first seven gene therapies approved globally include both in vivo and ex vivo approaches for cancer and inherited diseases. However, low- and middle-income countries remain underrepresented in CGT research.



Following the controversial 2018 genome-editing case in China, the World Health Organization (WHO) established a global framework emphasizing ethical principles, governance, and oversight to prevent premature or unsafe human genome editing. She further, highlighted the pathway for establishing legal framework for gene therapy in Uganda as indicated below.



Dr. Kityo highlighted the key novel ethical dilemmas and challenges in CGT research include: Informed consent - the complexity of genetic research makes it difficult for participants to fully grasp the long-term implications of treatment.

- Risk–Benefit analysis - first-in-human studies present highly uncertain outcomes, requiring extreme ethical caution.
- Equity and access - limited global availability and prohibitive cost raise serious fairness concerns regarding access in low and middle-income countries.

- Privacy - Protecting extremely sensitive genetic data from misuse or discrimination is paramount but extremely challenging.
- Capacity - limited regulatory capacity, complex consent documents, poor communication, and participant mistrust limit implementation capacity.

Uganda has a regulatory and institutional framework to support CGT. 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. To advance CGT safely in Uganda, policy updates, collaboration, and enhanced training are essential among Uganda's regulatory bodies:

Presentation 2: Ethics of Adaptive Trial Designs: What they are and what Research Ethics Committees (REC), Research regulators (UNCST, NDA) and research participants need to know

Dr. Victoria Nankabirwa, School of Public Health Makerere University, Kampala

Dr. Nankabirwa defined ethics of Adaptive Trial Designs (ATDs), outlined their advantages and disadvantages, categorized the types of adaptations, and detailed the crucial information needed by RECs, research regulators, and participants.

ATDs are clinical studies that allow for pre-planned modifications to one or more aspects of the trial while it is ongoing, based on data accumulating from the study. This approach aims to streamline the long and costly process of testing medicines, vaccines, and devices while maintaining scientific validity and integrity

ATDs offer flexibility, efficiency, and cost reduction by allowing investigators to adjust the study based on emerging data, leading to advantages such as earlier decisions, lower costs, and higher success rates; however, they introduce disadvantages like complexity, logistical challenges, and the need for specialized expertise and modified statistical requirements. Adaptations are categorized by when the modification is planned or implemented for instance,

1. Prospective Adaptations (Pre-planned): Modifications included in the initial protocol, such as adaptive randomization, early stopping for efficacy, futility or efficacy at interim analysis, dropping the losers (or inferior treatment groups) and sample size re-estimation.
2. Concurrent Adaptations (Unplanned): Modifications that arise during the trial based on emerging information, such as changes to inclusion/exclusion criteria, dosing, or study endpoints.
3. Retrospective Adaptations (Post-data): Adjustments made to the statistical analysis plan before the database lock or treatment unblinding.

She emphasized that in practice, prospective, ad hoc, and retrospective adaptations are implemented by study protocol, protocol amendments and regulatory reviewers' consensus. ATDs protocols must explicitly specify stopping rules for both efficacy and futility. If a trial is stopped early based on these rules and or as written in the protocol. The Principal Investigators must promptly notify RECs although no immediate protocol amendment would be required.

The protocols should be updated as soon as practicable after changes to study arms to simplify activities for sites. The Patient Information Sheets (PIS) ought to be updated immediately with removal of information that is no longer pertinent and sent to the ethics committee(s) for information and approval.

> "Adaptive trial designs are a valuable tool for improving clinical research efficiency, but their complexity necessitates careful planning, rigorous scientific justification, and heightened ethical oversight and regulatory approval at every stage to ensure validity, participant safety, and reliable outcomes."
>
> Dr. Victoria Nankabirwa

She noted that, since ATDs introduce unique review requirements, research regulators and RECs need to maintain participant safety and scientific integrity by ensuring that:

- Purpose of adaptation enhances the trial and NOT remedy inadequacies in planning.
- Area of adaptation, not all adaptations may be appropriate for every trial. Regulators need to carefully consider which aspects can be "adaptive"
- Justification of adaptations must be scientifically reasonable and as much as possible prospectively planned and based on analysis of unblinded data.
- Indicators of adaptation and focus areas should be clearly stated, including their implications on the trial outcomes/endpoints.
- Application of adaptive designs may result in a totally different trial that is unable to address the intended scientific questions/hypothesis due to major differences in the actual trial population versus the original target population. Trial power and hypotheses tested and associated confidence intervals and or p-values. Trial endpoints/outcomes and their ascertainment and analysis before and after the adaptation should be considered.
- The review assess the adaptation's effect on the study population, trial power, hypotheses, endpoints, sample size, and statistical confidence
- Study population post-adaptation, questions on whether the pre-adaptation study population in the remaining trial groups contribute to final analysis? Are the pre-adaptation study population in the dropped trial groups eligible for enrolment in the retained groups? Does the adaptation scientifically justify change in the study population?
- Study design, does the adaptation lead to a new design or new trial phase? If a new trial phase is needed, is the priori go-no-go criteria satisfied? (safety + intended effect)
- Study outcome: Is the primary outcome changing or getting modified? If yes, why and what is the impact on sample size, power and trial results?
- Sample size and power: the Original estimated SS & power; a priori interim analyses and their adjustments on SS & power; post-adaptation SS & power; final analysis SS & power
- REC approval for each adaptation, each adaptation should be preceded by a presentation to the REC and approval. No blanket approval of all adaptations without returning to the REC for individual adaptation approval.

In addition, she highlighted that research participants need clear, ongoing communication about the adaptive nature of the study, which must be clearly detailed in the Informed Consent process. They Must 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. And Ought to be informed of the stopping rules and be notified promptly

if the trial is terminated early for safety, efficacy, or futility. 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.

Presentation 3: Ethics of Social Behavioral Research and Community Engagement

Dr. Stella Neema, College of Humanities and Social Sciences, Makerere University

Dr. Neema's presentation highlighted that Socio-Behavioral Research (which investigates human attitudes, beliefs, and interactions using qualitative and quantitative methods must be ethically inseparable from effective community engagement to ensure validity, relevance, and impact.

Social behavioral research ethics ensures studies protect the rights, safety, and dignity of participants while upholding research integrity. The core principles guiding social behavioral research align with established ethics frameworks of respect for people, informed consent, justice, beneficence/non-maleficence, and confidentiality/privacy

Community engagement is a collaborative process that involves communities throughout the research lifecycle, fostering trust, transparency, and mutual respect. Ethical community engagement transforms social behavioural research into participatory research, guaranteeing relevance and culturally appropriate, actionable outcomes. Community engagement models include community advisory boards, community-based participatory action research, Capacity Building and Community-Led Initiatives.

> "Ethical SBR and effective CE are inseparable. The goal is to move from studying participants to partnering with communities, which enhances research validity and maximizes societal benefits. Building long-term, reciprocal partnerships is both a scientific and moral imperative for research in Uganda and globally."
>
> Dr. Stella Neema

Socio behavioral Research Ethics (SBRE) are principles and guidelines that ensure studies involving human participants are conducted responsibly. Protecting participants' rights, safety, and wellbeing. Key principles include obtaining informed consent, protecting confidentiality, avoiding harm, and ensuring justice and fairness in the research process. It is vital to focus on human participants and the special vulnerability in social contexts (e.g., power imbalances, reputational harm). Just like in biomedical sciences research, ethics is vital for the integrity, credibility, and validity of the research Aim: To protect participants and uphold the integrity of the research process.

The ethical conduct of SBR and community engagement face several challenges, notably: Power imbalances where researchers' institutional authority can overshadow community voices, alongside the risk of researchers acting as "data extractors" by taking data without returning results and continuous engagement. CE efforts are essential to reduce and counterbalance this inherent disparity actively. Obtaining consent at both the individual and community level (often requires engaging community leaders). Confidentiality vs. Context: In small or tightly knit communities, anonymity can be difficult to maintain, increasing the risk of identification.

Community Misrepresentation: Research findings could unintentionally stigmatize or inaccurately portray the community.

To address these issues, she highlighted promising practices for ethical CE in SBR, Preparing before, during and after phases, Implementing equitable measures to share power and resources between researchers and community partners, Engaging communities early and continuously in the research design, Establishing partnerships early and involving the community in defining the research questions and design- community-identified needs and priorities before solutions or research protocols are decided., Seeking informed consent and broader approval for research, Prioritizing reciprocity, mutual benefit and trust, transparency, and ongoing feedback throughout the project lifecycle.

In conclusion, Dr. Neema noted that while SBR and biomedical research differ in scope and methods, both are united by a common set of core ethical concerns. Ethical SBR is inseparable from good CE as the goal is to shift from studying participants to partnering with collaborators as a continuous process. She note that community engagement transforms research validity (making it more relevant) and impact (making it more actionable). Prioritize building long-term, continuous engagement over one-off data collection for meaningful outcomes. Effective and ethical conduct of SBR depends on robust and reciprocal community engagement beyond mere consultation. A committed partnership between researchers and the community is essential to ensure studies are culturally appropriate, ethically sound, and directly relevant to local needs. Therefor adopting participatory models not only enhances the scientific rigor and validity of the research but is also a moral imperative for respecting the autonomy, dignity, and privacy of participants, ultimately fostering trust and maximizing the positive impact of SBR on Ugandan society.

Presentation 4: Establishing a single sex Schistosoma mansoni Controlled Human Infection Model for Uganda

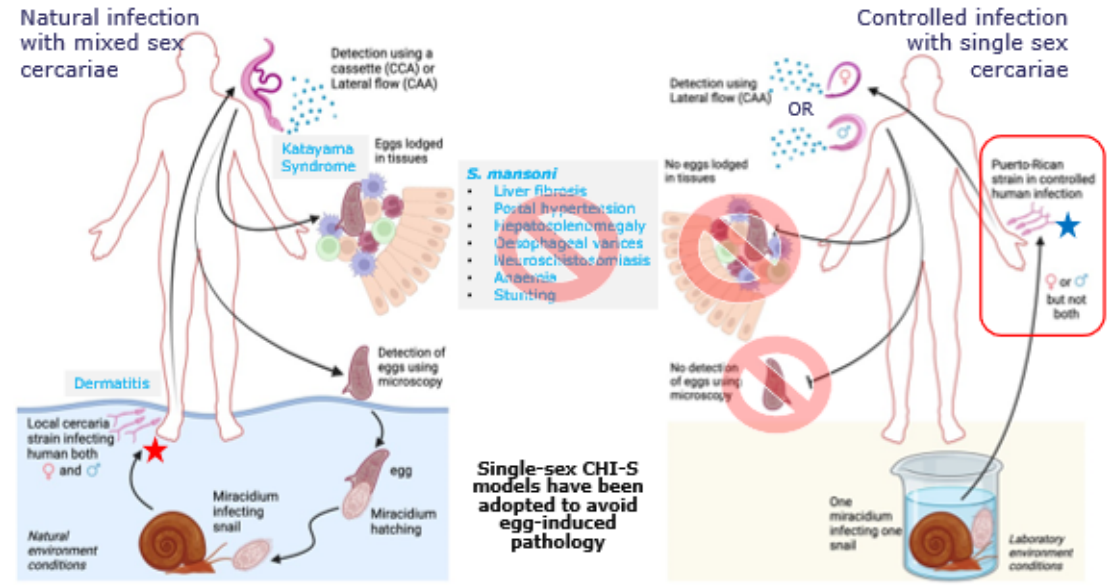
Dr. Moses Egessa, Senior Scientist - Uganda Virus Research Institute

Dr. Egessa presented the experiences and lessons learned from establishing the first single-sex Schistosoma Mansoni Controlled Human Infection model in Uganda. This initiative is vital given the country's high schistosomiasis prevalence (25.6%) and the challenges (of high

reinfection rates, concerns about drug resistance and limited long-term effectiveness) facing mass drug administration. He noted that the traditional phase 3 vaccine trials are slow and require immense resources, using Controlled Human Infection (CHI) studies a necessary and efficient pathway to accelerate the development of novel drugs, vaccines, and diagnostics.

> "The Uganda CHI-S study demonstrates a robust, structured approach that successfully navigated scientific, ethical, regulatory, and ecological considerations to advance schistosomiasis vaccine development, setting a crucial precedent for future controlled infection studies in high-burden, endemic settings. **Dr. Moses Egesa**"

The CHI model uses single-sex (male) S. mansoni cercariae to induce infection while avoiding egg-induced pathology (which causes severe morbidity) in participants. CHI studies conducted elsewhere have shown that infection is well tolerated, detectable via sensitive tests (like serum CAA), treatable with praziquantel, and undetectable one-year post-treatment.



The study was strategically placed in Uganda, where prior exposure to schistosomiasis and other environmental factors influences immune responses, and where the vaccine is most urgently needed. The primary objective of the study is to assess the safety, tolerability, and infectivity of the male S. mansoni cercariae in healthy adults (18–45 years) with varying levels of prior exposure to the parasite. It is designed as an open-label intervention with 66 participants recruited from two communities (minimal and intense prior exposure). The study used a dose escalation approach (10, 20, and 30 cercariae) subject to Data Safety Monitoring Board review. The key endpoints of the study include monitoring adverse events, the dose required for 100% detectable infection, time to positive serum CAA, and humoral/cellular immune responses.

The study required a rigorous implementation roadmap focusing on compliance, engagement, and safety. Ethical and regulatory approvals were obtained through a joint review process involving UNCST, UVRI-REC, National Drug Authority, Ministry of Health and National Environmental Management Authority. Communities were engaged in the development of educational materials and piloting of consent forms. Community feedback revealed that while participants were knowledgeable about schistosomiasis and vaccines, they were unfamiliar

with CHI. Participation willingness depended heavily on a clear understanding of procedures and social network influence.

A major lesson involved ecological risk. Local Ugandan snails resisted infection, leading to the consideration of importing non-indigenous *Biomphalaria glabrata* (used in Dutch studies). This necessity triggered an environmental impact assessment and required adjustments to the CHI roadmap to address potential ecological risks.

In preparation of the first volunteer infection, Dr. Egessa, noted that a number of activities were undertaken by the team such as staff retraining, community engagement sessions, TSC meeting, DSMB meetings, community Advisory Board meeting, site initiation visit and the first human infection of three participants happened on 25th September 2025. He concluded his talk by acknowledging the study participants, community leaders, University Authorities, ethics and scientific committees (UVRI-REC, LSHTM- ethics, National regulators/ authorities (NEMA, NDA, UNCST, MAAIF) and the research funders.

Questions & Answer Session Track 3

Question 1

"What strategies are you using to involve biosafety committees in your gene therapy plans?"

Gene therapy protocols for HIV have been shared with the National Council for Biosafety, which has reviewed them. Local biosafety committees are being established at Joint Clinical Research Centre and UVRI to ensure compliance and oversight.

Question 2

"How have you engaged communities in developing research questions, and how is this feasible given that current funding is focused on a single disease area?"

Through pretesting and iterative discussions, multi-level community engagement guarantees the relevance and acceptability of research, a crucial factor even when funding is restricted to a single disease entity.

Question 3

"Why is it necessary to treat both infected and non-infected subjects during the human infection and follow-up trial?"

Safety and participant care remain the highest priority, particularly during the 12-week monitoring period. Therefore, both infected and non-infected participants may receive treatment if infection is detected during follow-up.

Question 4

"How do you compensate the participants in the CHI studies?"

Compensation for volunteers in CHI studies is determined by agreements made with the community and reviewed by regulators to ensure fairness and ethical standards.

Track 4: Research Ethics in Disease Outbreaks and Other Emergencies.

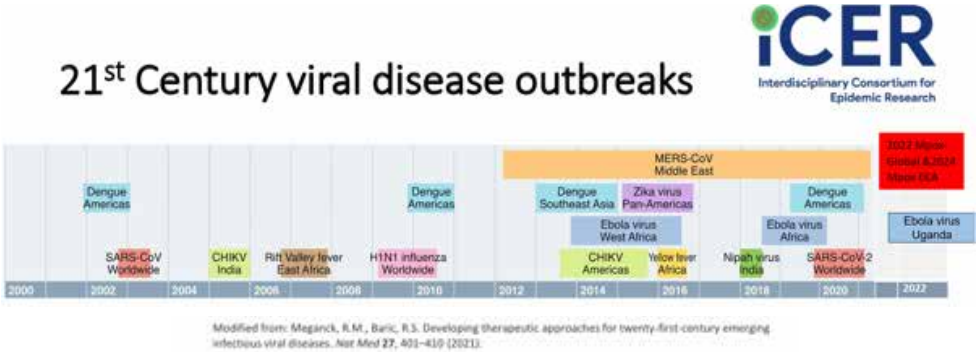
Moderators: Dr. Richard Katuramu and Dr. Kassim Sadik

This session established that research is no longer a "nice-to-have" activity but an integral component of any epidemic response, essential for developing vaccines and reducing mortality. The discussion moved beyond infectious diseases to address the unique ethical demands of climate-driven disasters. The session's central message was that ethics cannot be suspended in emergencies. Instead, crises must be seen as opportunities for learning and strengthening systems that embed research, ethics, and community partnership into the national response architecture.

Presentation 1: Research Ethics and Research in Emergency situations.

Dr. Bruce Kirenga, Principal College of Health Sciences, Makerere University

Dr. Kirenga's presentation focused on the critical ethical challenges and implications of conducting research during emergency situations, where the urgency of the crisis must be carefully balanced with the fundamental principles of informed consent and participant protection. He began by defining an epidemic as *"an increase, often sudden, in the number of cases of a disease above what is normally expected in that population in that area."* He noted that many conditions would therefore qualify as an epidemic, including both communicable and non-communicable diseases. In many cases epidemics are considered in the context of an infectious disease outbreak. Research brings evidence-based tools Such as diagnostics, treatments, vaccines, public health interventions e.g. lockdowns to prevent and control epidemics. However, epidemics occur and will continue to occur, tools get obsolete, develop resistance, or become ineffective calling for continued research to develop new ones. He highlighted some of the common viral disease outbreaks that have over the years since 2000 as indicated below.



Modified from: Meganck, R.M., Baric, R.S. Developing therapeutic approaches for twenty-first-century emerging infectious viral diseases. *Nat Med* **27**, 401–410 (2021).

He noted that epidemics, which are more prevalent in Africa are due to factors like conflict and displacement, the rich and preserved flora and fauna that foster wild-human life interactions, weak public health systems, poverty and limited access basic resources, limited indigenous medical counter measures and science, weak surveillance systems and climate and environment. All these pose crucial ethical challenges that require systematic resolution. In addition to ethical issues, research during epidemics is prone to a number of challenges, for instance,

- Partial understanding of the disease especially in the early stages of an epidemic. Where little may be known about the disease causing the outbreak. This can delay development of research protocols.
- The rapidly evolving situation: epidemics can spread quickly and change rapidly complicating research due to rapidly changing information about the disease. Also, the limited time for research, usually the epidemic could intermittent and not feasible to conduct research.
- Inadequate resources: Epidemic research often requires significant resources, yet research funding mechanisms of most funding organizations follows a pre specified process such as announcement/calls, review award. Epidemics do not fit in such framework.
- Ethical considerations: Epidemic research by nature is conducted in situations of heightened psychological and physical distress. It must be done fast, and it occurs in unusual settings such as community.
- Access to research evidence and data: Researchers may face challenges in accessing data on an outbreak particularly if the data is controlled by government agencies or private organizations.
- Communication challenges: Epidemic research often involves many stakeholders; government officials, healthcare providers, foreign officials, funders and the general public. Therefore, effective communication is crucial to ensure that research findings are accurately conveyed and understood by all parties involved.
- Access to investigational products intellectual property: R&D driven by profit-oriented pharma competition may disrupt and delay trials, yet the Interventions can only be tested clinically during an outbreak.
- Competition among academic and other public researchers particularly for funding and launch of many similar trials affecting accrual powered samples sizes. This may compromise privacy as well as lead to community misinformation.

To address some of the challenges, Dr. Kirenga suggested that *(i)* research must be designed as an integral component of the response itself, focused on transformation and resilience. *(ii)* Adaptive trial designs must be used to evaluate interventions rapidly and ethically. *(iii)* Issues of equity and post-trial access require Uganda to leverage its bargaining power (especially for endemic diseases like Ebola Sudan) to secure intellectual property rights and free access for participating communities, and Clinical trial liability demands that insurance be mandatory, with investigators budgeting for both clinical care and liability insurance, while regulatory agencies provide clarity on the distinction between the two.

He shared case study of impact of epidemic research on Ebola in Democratic Republic of Congo and Guinea. He compared the outbreaks in 2014/2016/ 2018 with the ebola outbreaks in 2021. Where there was a great reduction in the duration of outbreak as well as the number of deaths and cases. Which is mainly attributed to research/clinical trials, vaccine availability, experimental vaccines, multisectoral response team mechanisms, improved health system infrastructure and work force trained in surveillance and response.

DRC	GUINEA

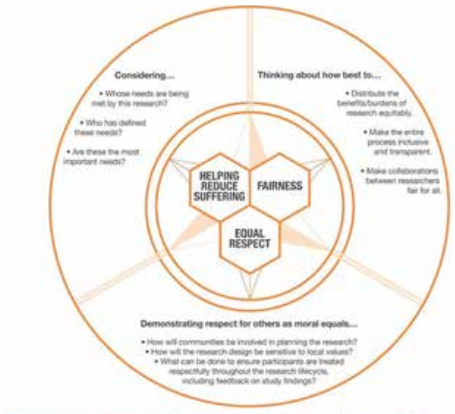
• 2018 – 2020 (702 Days)
  • 2280 EBV Zaire deaths & 3470 cases
  • Start: July 25, 2018
  • Detection: July 28, 2018
  • Verification: August 1, 2018
  • Control: June 25, 2020
• 2021 (103 Days)
  • 09 EBV Zaire deaths & 20 cases
  • Outbreak declared over in 3 months
  • Start: September 5, 2021
  • Detection: October 7, 2021
  • Verification: October 8, 2021
  • Control: December 16, 2021
• Attributed causes were vaccine availability, improved health systems infrastructure, and workforce trained in surveillance and response.
	• 2014-16 (889 Days)
	  • 11,310 EBV Zaire deaths & 28,616 cases
	  • Start: December 26, 2013
	  • Detected: March 10, 2014
	  • Verification: March 22, 2014
	  • Control: June 1, 2016
	• 2021 (153 Days)
	  • 12 EBV Zaire deaths & 23 cases
	  • Epidemic declared over in 6 months
	  • Start: January 18, 2021
	  • Detected: February 11, 2021
	  • Verification: February 13, 2021
	  • Control: June 19, 2021
	• Attributed causes were deployment of experimental vaccines, clinical trials, multisectoral response team mechanism in place, and strengthening of healthcare infrastructure, including detection.

Source: https://preventepidemics.org/epidemics-that-didn't-happen/ebola/

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. However, like all research, the need for regulation and participant protection is of paramount importance. There are several 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 the interventions quality and effectiveness given the speed at which they are developed and its impact of research on distressed communities.

In regard to the key ethical considerations on epidemic research, Dr. Kirenge posed some questions that participants needed to ponder on.

i. Do pandemics necessitate or justify deviations from ethical and scientific standards for research?
ii. Do pandemics raise novel ethical questions for research?
iii. How should research priorities be set during pandemics?
iv. How should research be conducted in the context of other response efforts?
v. How should pandemic research be governed and coordinated?



The Nuffield ethical compass to aid in the navigation of issues in pandemic research, by Jade Rawling. (Nuffield Council on Bioethics 2020)

He concluded his talk, Dr. Kirenga noted that research is not a value-neutral enterprise, yet epidemics are more frequent in vulnerable resource poor settings. Research, especially of medical countermeasures, is most speared by players from settings capable of developing these measures. This disconnect should be realized such set priorities take care of all stakeholders. The need, burden of disease, magnitude of benefits/equity, the needs of vulnerable and disadvantaged groups, cost-effectiveness of research, cost-effectiveness of proposed interventions and likelihood of research success should be considered.

Presentation 2: Ebola vaccine trials in Uganda: Community Engagement in emergency disease outbreaks: Lessons learned.

Dr. Betty Mwesigwa, Deputy Executive Director, Makerere University Walter Reed Project

Dr. Mwesigwa's presentation focused on the critical lessons learned regarding Community Engagement during the urgent deployment of Ebola vaccine trials in Uganda, highlighting the critical importance of CE for ethical research and effective outbreak response.

Dr. Mwesigwa started by giving an overview of the Ebola Virus Disease (EVD) as a severe, often fatal illness caused by viruses in the Filoviridae family. She noted that EVD has a case fatality rate ranging from 25% to 90%. Transmission is through direct contact with infected bodily fluids, contaminated surfaces, or infected animals (e.g., fruit bats, primates). Prevention and control rely mainly on community engagement to ensure IPC, case management, contact tracing, and vaccination and safe burials.

She further noted that some strains of EBV have no licensed vaccines. The Phase I and II trials have mainly been conducted in 'non outbreak' periods. Providing critical efficacy data under outbreak conditions impacts negatively on public health responses and optimize vaccine deployment.

Dr. Mwesigwa highlighted the importance of vaccine trials during outbreaks noting that rapid vaccine trials during outbreaks enable quick assessment of vaccine effectiveness to control disease spread. The Adaptive trial designs allow simultaneous evaluation of multiple vaccine candidates, accelerating results. In addition, pathogens evolve quickly allowing ongoing vaccine trials to determine if existing vaccines require modification for emerging variants. Vaccine trials during outbreaks enhance global collaboration /cooperation for vaccine development and distribution thus enabling data sharing and resource pooling. Also, real-time data from vaccine trials helps to build resilient health systems to respond to current and future outbreaks leveraging diverse expertise worldwide. Finally, vaccine trials during outbreaks can ensure equitable access to vaccines and interventions.

In emergency response, community engagement builds trust and resilience, enabling timely and culturally appropriate responses to health crises. It also facilitates teamwork and acceptance, involving communities in planning and implementation 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.

She mentioned some of the lessons learned from engaging communities during outbreaks. Trust being foundational, therefore building trust with communities before an outbreak is critical, MUWRP established the Community Led Ebola Action (CLEA) Approach *(communities take their own action, and their own analyses)*. This enabled faster behavior change and better compliance with health measures.

Two-way communication is critical with the involvement of the local leads: Engagement must be dialogic not just informing but listening. Real-time feedback mechanisms helped adapt

strategies during outbreaks empowering local leaders and community-based organizations foster ownership and sustainability of health interventions.

Cultural sensitivity: Understanding local customs and beliefs helps tailor interventions that are more acceptable and effective.

Dr. Mwesigwa then shared Uganda's experience with Ebola noting that, Uganda has faced eight (8) Ebola outbreaks since 2000, with the deadliest in Gulu (2000) which had 425 cases, 224 deaths. Five (5) of these outbreaks involved the Sudan strain, including the 2022 outbreak with 164 cases and 55 deaths. The most recent was declared this year (2025) with 14 cases (12 confirmed, 2 probable), 4 deaths, and 10 recoveries. Uganda has always had strong national response involving; contact tracing, quarantine, and community mobilization.

Photo Credit: *The Guardian - Health workers among dead in Ugandan Ebola outbreak*

She further noted that in 2009, MUWRP conducted Africa's first Ebola vaccine trial using a DNA vaccine (RV247). The trial showed safe and immunogenic responses in Ugandan volunteers. Subsequently MUWRP conducted Phase 1b trials of ChAd3 vaccines for Zaire and Sudan strains. The Phase II Ad26, MVA vectored vaccines in a prime boost regimen. MUWRP is currently completing follow up for Sabin 003, a Phase II Ebola Sudan Vaccine Trial. Also, the institution conducted long-term studies on Bundibugyo Ebola survivors (2007–08) which revealed persistent health issues like vision loss, memory problems, and joint pain.

In the recent Ebola Vaccine Research, Uganda launched a clinical safety and efficacy trial for the rVSV Sudan Ebola virus vaccine (IAVI) in February 2025. The Trial readiness was achieved in 4 days after outbreak confirmation. The research efforts were led by Makerere University Lung Institute, UVRI, and WHO. Ring vaccination strategy that targets contacts of confirmed cases was used.

She highlighted some of the lessons learned from the ebola vaccine research. First, the inter outbreak period which is an opportunity that allows for protocol development and regulatory approvals, staff training, which were completed before outbreak occurred. Secondly, the involvement of multi-disciplinary teams including community engagement experts in community engagement strategies for recruitment, retention and risk communication were clearly laid and implemented. Last, lessons from Sierra Leone and DRC- ring vaccination trial preparations and implementation were harnessed in which vaccines were prepositioned in the country.

Dr. Mwesigwa emphasized the Community Engagement pillars to outbreak response and vaccine research including stakeholder mapping & early involvement to build trust and ownership, Risk communication and social mobilization to address fears, misinformation and promote vaccine acceptance, Community Advisory Boards to provide feedback on Trial design, consent process and community concerns, Participatory dialogue and co-design to give contextual insights on trial recruitment, follow up and feedback mechanisms and leveraging the existing health infrastructure of the Village Health Teams (VHTs), local clinics to disseminate information and manage referrals.

Despite the success of vaccine trials during outbreaks are not void of ethical dilemmas, for instance;

- Experimental vaccines in crisis settings raise concerns about safety, urgency, and informed consent. Communities may feel like "test subjects", especially when vaccines are unlicensed and outcomes uncertain.
- The Use of placebos in double-blind trials during deadly outbreaks can be controversial with no proven treatment exists. Balancing scientific rigor with humanitarian urgency is ethically complex.
- Gaining true informed consent is difficult amid fear, misinformation, and low health literacy. Also, historical mistrust of medical research can hinder participation and fuel resistance.
- Concerns when trial communities lack access to vaccines after the end of the studies. Calls for fair benefit-sharing and regional vaccine manufacturing are growing louder
- Balancing autonomy and public safety, use of measures like quarantine and mandatory vaccination raise questions about individual rights versus collective health.
- Issues of resource allocation especially in deciding who gets limited resources (e.g. vaccines, hospital beds) involves ethical trade-offs, especially in underserved areas/communities.
- Transparency vs fear: Sharing information about risks ought to be balanced against the potential to cause panic or stigma
- Informed consent in research: Conducting clinical trials during outbreaks requires careful ethical oversight, especially when communities are vulnerable. Extra vigilance by RECs during protocol review required.

As she concluded her talk, Dr Mwesigwa shared her experience on what did not work in the conduct of conduct of vaccine trails during outbreaks. Top-down messaging: In several outbreaks, centralized communication failed to resonate with local communities, leading to mistrust and resistance. The lack of preparedness, whereby many regions lacked pre-established community engagement frameworks, delaying effective response Ignoring local knowledge. Dismissing traditional practices or community insights often alienated populations and hindered cooperation Insufficient monitoring, Real-time tracking of engagement efforts was limited, making it hard to adjust strategies quickly. The limited community understanding of Ebola and vaccines (exhumation of safely buried bodies due to mistrust), delays in vaccine development and diagnostics and under investment in outbreak research compared to COVID-19.

She recommended; 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.Training frontline workers: Equipping health workers with skills in cultural competence and community dialogue is essential. Global standards: Adopting minimum quality standards for community engagement to guide consistent, ethical practices across contexts. Establishing ethical frameworks for emergency trials by developing context-specific ethical guidelines for conducting research during outbreaks. Standardizing community engagement approaches (Learning from past experiences) 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.

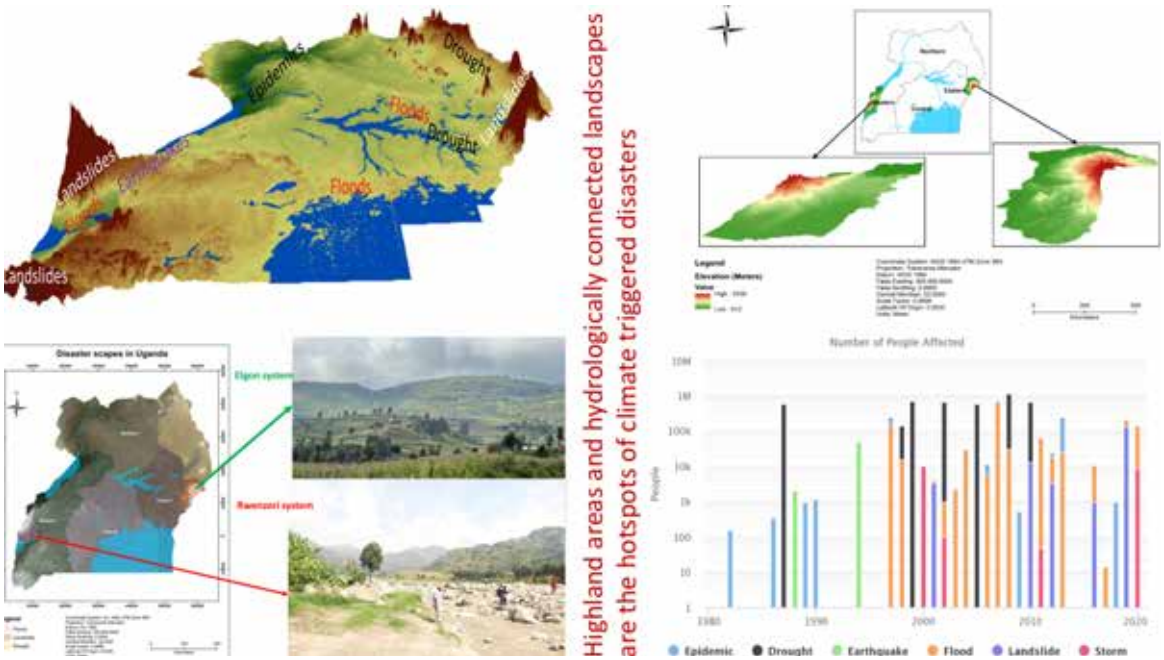
In Conclusion, Dr. Mwesigwa noted that Community engagement is not optional; it is essential. Uganda 's experience with the ebola outbreaks offers valuable lessons for the region and the world. And ethical, inclusive, and proactive approaches are key to future conduct of research during outbreaks.

Presentation 3: Community engagement and Research during Climate Driven Disasters: what are the Ethical Challenges?

Dr. Yazidhi Bamutaze, Deputy Principal College of Agricultural and Environmental Sciences, Makerere University, Kampala

Dr. Bamutaze noted that disasters globally have been increasing over the last 30 years in frequency and magnitude. In Uganda, it is indicated that there has been a steep rise from 1-9 disasters registered annually. A significant number of disasters are linked to climate change which is expected to heighten the numbers Increasing need to knowledge on disaster risk to help in cultivating solutions. He broadened the ethical scope to include climate-driven/ meteorological disasters which form over 70% of emergencies that Uganda deals with.

> "Disasters in Uganda are heavily linked to climatic conditions. Events of hydro-meteorological (70%) origin constitute the large majority of disasters in Uganda. They are likely to increase due to climate change especially in fragile and sensitive landscapes inhabited by vulnerable populations."
>
> Dr. Yazidhi Bamutaze



He further noted that disaster research is broader than infectious disease research (involving hazard, exposure, and vulnerability) 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" and must ensure ethics are centered across the entire research value chain Research must focus on the "build back better" principle, ensuring

it is fit for purpose in transforming society and building resilience against cyclic hazards.

With the increasing demand for knowledge, innovations and solutions to climate change disasters, a paradigm shift (transformative universities) oriented to address societal challenges is necessary. An education model that fosters innovation ecosystems, societal development, industrialization and societal transformation.

Meaningful engagement of the communities for research that is beneficial is necessary. Community engagement that recognizes local people as equal partners rather than mere recipients of aid. Leveraging on existing local knowledge and resources to foster trust and social change needed to address community vulnerabilities and build resilience *(effective disaster preparedness, response, recovery, and resilience building)*.

Disaster situations are dynamic and risks can change in unpredictable manners, raising complex ethical dilemmas. Research during a disaster situation imposes logistical and ethical challenges. Adapting procedures for emergency contexts is important. Also, disaster response activities must be ethically responsive, respecting the dignity, boundaries, and lived realities of affected populations. Disaster research should ideally contribute to building resilient societies and generating actionable knowledge in disaster prone contexts. Intentionally embedding community perspectives at all stages. Legitimacy and representation create co-ownership and translation into acceptable interventions.

Researchers need to be cognizant of the heightened vulnerability of research participants due to the destabilization and destruction following a disaster. The primacy of saving lives following a disaster should be at the forefront during disaster research and response. Immediate response through research protocols developed because of the need to respond quickly after a sudden onset event. Cross-cultural issues when international researchers conduct studies during a disaster that has occurred in another country.

He further highlighted Ethical issues in the disaster research value chain noting that; The research value chain is geared at having an impactful and transformative research. At each stage of the value chain, there are ethical issues to contend with. The responsibility for ensuring ethical research lies with the Research and Ethics Committees. RECs are charged with review and oversight to better understand and respond to the ethical dimensions of disaster research.

In the conduct of disaster research there are distinctive ethical considerations that require attention to ensure that participants are protected; *(i)* assessing the justification for conducting research, *(ii)* addressing pervasive vulnerability during the event, quite often you are dealing with vulnerable and traumatized persons *(iii)* promoting safety, confidentiality and data security in insecure or unstable environments; and *(iv)* Gauging the possibility for meaningful community engagement.

He further explained why ethical issues matter more in disaster contexts because disaster settings are characterized by urgency, scarcity, trauma, and social upheaval. Ethical issues are instilled to prevent exploitation or harm to survivors: Research benefits ought to outweigh harm to the community. Damage to community relationships and cooperation. Reduced effectiveness of aid and recovery efforts. Moral injury and distress among both participants and researchers lead to loss of credibility and trust in research outcomes.

The core ethical principles in disaster (respect for persons in disaster situations), research benefits have to outweigh the potential harm in the communities, Fair and equitable selection of participants -working collaboratively with affected communities. Results ultimately

communicated and disseminated to the researched communities (Accountability and transparency).

Beyond REC ethical review and oversight: 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). Ethical review and approval from committees (RECs). Avoiding re-traumatization of the communities during data collection. avoiding misrepresentation of finding during data analysis, respectful dissemination: Sharing findings with affected communities and relevant authorities.

As he concluded he stressed Issues of consideration for instance; context sensitivity and adaptability, ethical frameworks should be flexible and allow for rapid ethical assessment. Recognition of power imbalances between researchers and participants. Account for cultural and contextual norms of affected communities. Ethical competencies, developing context-specific ethical guidelines for medical and social science. Consideration of the possibility of including locals (communities) on the RECs, Community empowerment, disseminating findings that contribute to recovery and resilience building.

Questions and Answers Session Track 4

While addressing questions from the participants, panelists unanimously affirmed that ethical safeguards must be maintained even in emergencies.

Question 1

"How can post-trial access to interventions be managed equitably in emergency settings, especially for the communities that participated in their development?"

Uganda aims to secure intellectual property rights for endemic pandemic products (e.g., Ebola Sudan) to ensure free post-trial access for participating communities. This commitment was formalized in a draft "pandemic code," which ultimately failed to be adopted due to resistance from some stakeholders.

Question 2

"Regarding ethical standards and emergency interventions, how should research priorities be set, and how do we prepare for the next emergency?"

Uganda is actively updating its national sero-survey for Ebola, which provides vital, actionable information. The 2020 survey indicated that certain areas, despite never officially reporting an Ebola case, demonstrate the presence of Ebola antibodies in the population. This unexpected presence of antibodies in previously unaffected areas is crucial for prioritizing future research and response strategies, shifting the focus from reaction to proactive surveillance and identifying high-risk, though seemingly quiet, zones. Investing in research preparedness for endemic threats like Ebola Sudan, where Uganda has unique experience, makes logical sense for the country.

Question 3

"What are the ethical and financial considerations for investigators regarding clinical trial liability insurance during emergency infectious disease outbreaks?"

Clinical trial insurance is not equal to standard medical insurance. While the cost for trial participant coverage is included in the clinical care costs budget line, this coverage is typically restrictive, only covering illnesses or injuries directly related to the trial itself ("the trialists"). It does not provide comprehensive coverage of standard medical insurance. Key recommendations for ethics and funding:

Investigators ought to negotiate with funders to ensure a sufficient budget is allocated for potential medical costs that may fall outside the scope of the standard trial coverage.

Regulatory agencies must make an effort to educate all research stakeholders most critically, the study participants to ensure they clearly understand this distinction and the limits of the coverage provided.

Question 4

"Who is authorized to provide substitute informed consent for incapacitated participants in emergency research?"

The authorization for substitute consent for incapacitated participants in emergency research primarily rests with the legally authorized representative, following a specific hierarchy outlined in the approved research protocol and national law. In critical, time-sensitive situations, a protocol may be approved for deferred consent, often requiring consultation with the attending physician and an independent witness, with the condition that full consent be sought from the patient or legally authorized representative if the patient recovers capacity.

Day Two: 22nd October 2025

Plenary Session 1: Community Engagement Across the Research Life Cycle and Post Research Responsibilities

Session Moderator: Dr. Grace Ndeezi

Keynote address 2: Ethics of Post Research Responsibilities (PRR) and obligations

Dr. Flavia Matovu. Senior Research Scientistic MU-JHU Care Ltd

> "Post Research Responsibilities is the bridge between scientific discovery and social benefit, demanding partnership, justice, and sustainability. It ensures that participants and communities share equitably in research benefits, thereby building trust and securing lasting health impact."
>
> Dr. Flavia Matovu

Dr. Flavia Matovu began her keynote address defined Post-Research Responsibility (PRR) and outlined a path forward for Uganda and the region to ensure that research translates into sustained social benefit. She emphasized the ethical importance of post research responsibilities (PRR).

She explained that while the research community often celebrates scientific breakthroughs, such as advances in HIV treatment and PrEP, an enduring ethical question arises regarding the fate of participants and communities after trials end and sponsors depart. She noted that the success of research creates a moral debt that obliges investigators to ensure continued benefit beyond the study period.

She defined PRR as the duties owed to participants, communities, and health systems after the completion of formal study interventions and data collection. These responsibilities, she explained, are grounded in the ethical principles of beneficence, non-maleficence, and justice. PRR encompasses post-trial access to interventions, ancillary care, and sustainable capacity building, reflecting a social contract between researchers and host communities.

Dr. Matovu traced the historical evolution of PRR, highlighting that research was previously extractive, with participants and communities rarely benefiting from the outcomes. She pointed out that early ethical frameworks like the Nuremberg Code, Declaration of Helsinki, and Belmont Report primarily focused on participant protection. Over time, there has been a paradigm shift toward actively promoting sustained benefit, formalized in international guidelines. She referenced the Declaration of Helsinki and CIOMS/WHO guidelines, noting that current standards require clear provisions for post-trial access and sustainable community benefit, communicated to participants during informed consent.

2024 Declaration of Helsinki, article 18 eemphasizes post-trial access to proven interventions; ***"Every research should include provisions for post-trial access to interventions identified as beneficial in the study or access to other appropriate care. This provision should be made known to the participant during the informed consent process."***

She discussed areas of consensus, emphasizing that community engagement, transparency, capacity building, and equitable access to research benefits are universally recognized ethical obligations. At the same time, she acknowledged ongoing controversies, including the interpretation of *"reasonable access,"* the scope of obligations to individuals versus health systems, funding responsibilities for sustaining post-trial access, the duration of PRR obligations, ancillary care for unrelated conditions, and the stewardship of research data and biological specimens.

Regarding the Ugandan context, Dr. Matovu noted significant progress, including the work of regulatory bodies such as UNCST and NDA, the accreditation of research ethics committees, and the inclusion of PRR clauses in local guidelines. She highlighted the role of local research institutions as stewards of PRR, tasked with advocating for participants, building capacity, linking international partners with communities, and facilitating policy translation. She also emphasized regional collaboration, pointing to platforms like African Vaccine Regulatory Forum (AVAREF) under the WHO that enable joint ethical reviews for multi-country studies. She used the example of PrEP trials, including the fast-tracked introduction of twice-yearly injectable Lenacapavir, to illustrate how early and sustained community engagement, combined with dedicated funding for post-trial access, can ensure ethical obligations are met in practice.

Dr. Matovu concluded by outlining next steps for Uganda and the region, recommending 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. In her final concluding remarks, she argued that PRR is the bridge between scientific discovery and social benefit. She emphasized that ethical research should be measured not only by what is achieved during a study but also by the lasting impact on participants and communities. She called on researchers, institutions, and policymakers to ensure that no participant should leave a successful trial without access to the interventions they helped discover, framing PRR as an essential investment in trust, sustainability, and justice.

Presentation 1: Landscape of traditional and alternative medicine research in the region: Ethics, Challenges and Opportunities – Global Overview

Ogwang Patrick Engeu, PhD, Associate Professor of Pharmacy - Mbarara University of Science and Technology

Traditional medicine encompasses knowledge, skills, and practices rooted in indigenous cultures for maintaining health and treating illness. Alternative medicine is used in place of standard treatments, while complementary medicine supports mainstream healthcare. Integrative medicine combines evidence based conventional treatments with complementary therapies, addressing the whole person body, mind, and spirit.

The global TCAM market is projected to reach $359–$437 billion by 2032. Countries like China, India,

> "Regulation is important, but it should NOT stifle progress."

and Ghana have integrated TCAM into national healthcare systems, including medical training for practitioners. In Uganda, pharmacy and some nursing schools include TCAM in their curricula, though focus has historically been on products rather than practices. Regulation is advancing through the Traditional and Complementary Medicine Act 2019 and ongoing updates to the National Drug and Health Products Authority bill.

Research Landscape: Globally, TCAM research has focused on ethnobotanical surveys and lead compound discovery, with countries like China, India, South Korea, the EU, and the USA also studying traditional practices and integrating modern science. In Uganda, academic research has largely concentrated on ethnopharmacology, but few drug molecules have been developed, as most research compounds are exported. Recently, clinicians and pharmaceutical experts in Uganda have begun conducting clinical trials and product development in herbal and phytopharmaceuticals, enhancing evidence generation and translational potential.

Advances and Opportunities: Modern techniques such as ultrasonic-assisted extraction, supercritical fluid extraction, nanotechnology-based encapsulation, plant cell and hairy root cultures, metabolic engineering, and artificial intelligence are improving yield, stability, efficacy, and safety of herbal products. Standardized production, contamination control, regulatory frameworks, and scientific validation are increasingly emphasized to bridge traditional practices with evidence-based methods. Clinical applications are expanding, and efforts are underway to integrate traditional healing with contemporary healthcare for broader accessibility and effectiveness.

Ethics and Challenges: Key concerns include ownership and publication of ethnobotanical data, commercialization of community-originated formulas, and use of unapproved or unvalidated products. Research ethics require REC approvals for clinical trials to protect participants, while preclinical stage approvals are debated due to intellectual property risks. Accreditation of preclinical facilities is recommended, aligning with practices in countries like China, India, and the USA.

Presentation 2: Engaging communities in identifying community needs and protocol development (Researchers' perspective and experiences): Case study of Uganda.

Dr. Clemensia Nakabiito, MU-JHU Care Ltd

In her talk, **Dr. Nakabiito** described how communities were engaged in the research processes and the study outcome of the MTN-042. She began by giving a summary of the MTN-042 (DELIVER) study that evaluated the safety, adherence, and acceptability of two HIV prevention methods, monthly Dapivirine Vaginal Ring (DVR) and daily oral Truvada among HIV-uninfected pregnant women in Malawi, South Africa, Uganda, and Zimbabwe.

Participants included male partners, mothers/mothers-in-law, community leaders, and healthcare providers. The study used a stepwise cohort approach based on gestational age: Cohort 1 (36–37 weeks), Cohort 2 (30–35 weeks), and Cohort 3 (12–29 weeks).

Community engagement was central to the study, involving Community Advisory Boards (CABs) and formal groups of local stakeholders provided input on study design, acceptability, recruitment strategies, and implementation. Potential and enrolled participants' communities who included women of reproductive age and their families in the catchment areas where MTN-042 was conducted. The Local health care providers and clinic staff of Mulago National Referral Hospital & Kawempe National Referral Hospital. Community leaders and local stakeholders eg, District health officers, traditional and religious leaders, women's group representatives, and staff from Community Based Organizations, Community-based health-care providers from Kampala Capital City Authority Health centers, Village Health Teams (VHTs), Traditional Birth Attendants (TBAs). Other stakeholders included Policy Makers (WHO, MoH, UNAIDS), Regulatory Authorities (RECs, UNCST, NDA & UNHRO), Civil Society Organizations (AVAC, White Ribbon Alliance, ICWEA, UNASO, RHU & Community Based Organizations), Media (reporters, social media).

Research explored attitudes toward DVR and oral PrEP, revealing high HIV risk in pregnant women and the influence of healthcare provider support, male partners, and family members on uptake. A regional consultation in Johannesburg (April 2018) involving 35 experts from participating countries informed protocol design, highlighting the need for safety data on oral PrEP and the Dapivirine ring in pregnancy. Recommendations included infant follow-up up to one-year, standardized definitions for pregnancy complications, provision of oral PrEP postpartum, and inclusion of African experts in interim safety reviews.

Pre-study activities included sensitization meetings with hospital staff, health centers, and community stakeholders. Rollout strategies involved re-engaging communities, male partner involvement, sensitizing private health workers and traditional birth attendants (TBAs), and displaying study education videos in antenatal clinics. Findings were disseminated through community forums, posters, and accessible formats to reach participants and broader communities.

Community engagement contributed to high recruitment and retention rates (up to 98%), strengthened ethical integrity, cultural relevance, and community ownership. Feedback shaped study design, consent processes, messaging, and informed national HIV prevention guidelines for pregnant women. Challenges included unrealistic community expectations, resource limitations, cultural sensitivities, and regulatory delays, while opportunities included fostering trust, budgeting for engagement, empowering women as advocates, and joint ethical reviews.

Lessons Learned: Active stakeholder involvement ensures comprehensive protocols, smooth research review, advocacy, and community ownership. Early consultations, consultation should not be confused with updates, inclusion of diverse voices and the right people, equal participation, commitment to continuous engagement, and culturally appropriate communication are critical for successful research and community trust.

Presentation 3: Ethics of controlled Human Infection studies in low-resource settings, Is the region ready?

Dr. Primus Che Chi, Ms. Maureen Njue & Mr. Enoch Kebenei – Kenya Medical Research Institute (KEMRI), Welcome Trust Research Programme (KWTRP)

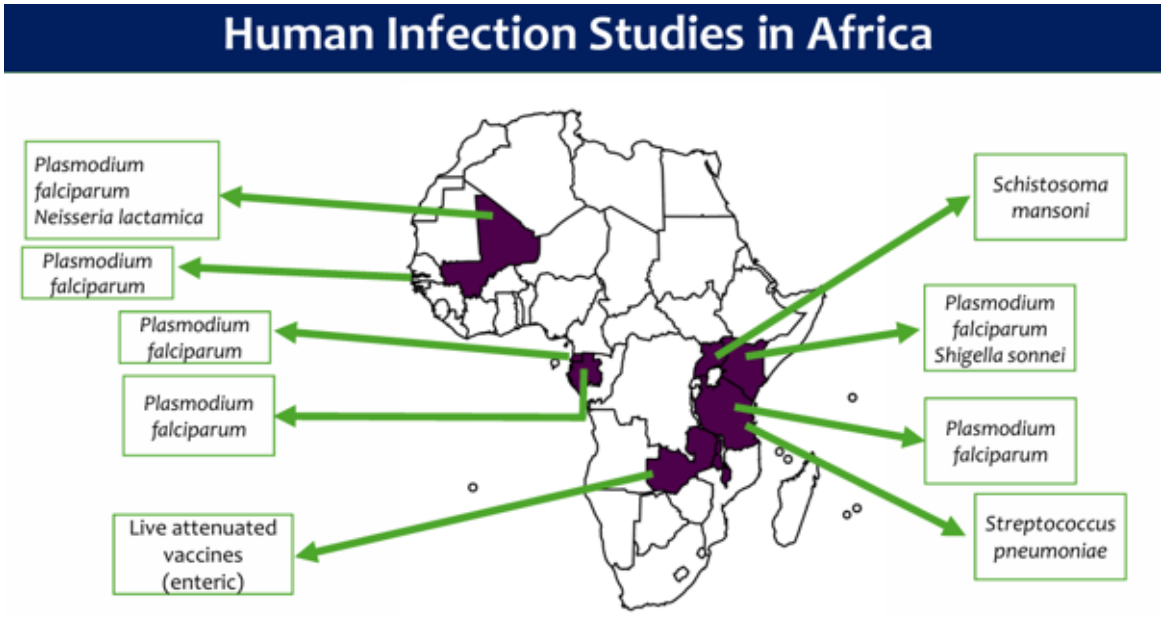
Controlled Human Infection (CHIM) studies deliberately infect healthy volunteers with disease causing pathogens under controlled conditions to generate knowledge about host-pathogen interactions and to test vaccines and therapeutics.

Globally, over 22,000 volunteers have participated in CHIM studies by 2015, but few have been conducted in low- and middle-income countries (LMICs), despite high burdens of vaccine-preventable diseases. Challenges in LMICs include limited infrastructure, expertise, unfamiliarity with regulatory and ethics systems, and socio-cultural concerns

In Africa, CHIM studies are increasingly conducted in countries like Kenya, Uganda, Tanzania, Malawi, Gabon, and Zambia, focusing on pathogens such as malaria, Shigella, schistosomiasis, and pneumonia. These studies accelerate vaccine and drug development but raise ethical, regulatory, and practical issues. Ethical considerations include deliberate infection versus the principle of *"do no harm,"* informed consent, compensation, limited withdrawal rights, and risk of third-party infections. Social science research is crucial to understanding community perceptions, acceptability, motivations, and the benefits and burdens of participation.

Frameworks for establishing and ethical review of CHIM Studies in LMICs include; scientific justification of the CHIM study, In LMIC, emphasis should be on diseases relevant to the context where the study is conducted, CHIM Studies design in LMICs should be of *"equivalent International standards"*, Safety of CHIM model should be demonstrated from prior studies, Quality Assurance of the chosen challenge strain (local vs imported), Promotion of capacity building (technical, infrastructural , regulatory), Development of localized and relevant regulatory frameworks suited for the context, Centrality of community engagement and appropriate informed consent processes.

Progress has been made on conduct of CHIM studies in Africa, with, focus on pathogens relevant to the African populations there is increase in CHIM studies being conducted in Africa; wider scope of pathogens relevant to endemic settings, Testing of vaccines in CHIM studies e.g., Malaria vaccines. There are also potential studies to develop locally relevant strains of pathogens for CHI models e.g., local Malaria strains. Increased infrastructural capacity to carry out 'international standard' CHIM studies (laboratory facilities, improved clinical facilities, personnel). Building a critical mass of technical expertise within the continent to establish and manage CHIM studies and expansion of African scientists leading collaborative CHIM studies.



Regarding governance, regulation and ethical review of CHIM studies on the African continent, there is improved regulatory and ethical capacity to review CHIM studies that has helped to balance between social value and participant protection. Individual countries continue to develop locally relevant guidelines for CHIM studies. E.g. Pharmacy and Poisons Board (PPB)-Kenya, Development of guidelines at the continental level provide guidance to countries conducting CHIM studies e.g., The African Vaccine Regulatory Forum (AVAREF). The cross learning/peer learning opportunities between researchers, regulators and ethics committees. Capacity building of ethics committees and regulatory bodies on CHIM studies.

At the Kenya Medical Research Institute (KEMRI), the Scientific and Ethics Review Unit (SERU) oversees CHIM studies, providing ethical oversight, active monitoring, and continuous ethics education. Key ethical concerns addressed include disease burden, risk/benefit assessment, appropriate compensation, infection control, dosing, site selection, and biological sample handling. Post-trial considerations include reversibility, pathogen shedding, medical insurance, counseling, and community acceptance to mitigate stigma.

Engagement and social science research play a critical role in ethical acceptability of CHIMs, especially in settings unfamiliar with CHIM studies. Dr. Chi noted that at the KWTRP, social science studies have been embedded since 2017 to date Malaria and Shigella. The involvement of a wide range of stakeholders: former and current participants, their families, community members, research staff, regulatory bodies, ethics committees. Studies have given insight into the social and ethical issues of conducting CHIM studies in the Kenyan context. The issues explored include participant experiences, levels of compensation, participant benefits and burdens, potential risks and harms.

Best practices at KEMRI and the Kilifi site include robust community engagement, staggered compensation for participants, inclusivity of participants regardless of literacy, demonstration tools for specific volume of blood drawn as part of the informed consent process, incorporating the 'uncovered' benefits & burdens in the IC process. National and international guidance frameworks informing CHIM practices include PPB Kenya, WHO ethics guidance, VolREthics Charter, and AVAREF recommendations. Capacity building in infrastructure, technical expertise, and regulatory and ethical oversight ensures locally led CHIM studies aligned with international standards while addressing LMIC-specific challenges.

Question and Answer Sessions

Question 1: "How does Uganda's TCAM research landscape compare globally, and what are the main opportunities?"

Uganda has historically focused on ethnopharmacology, mainly cataloging plants and exporting compounds, unlike countries like China, India, and South Korea, which integrate TCAM into national health systems and medical curricula. Opportunities now include clinical trials, translational research, and modern techniques such as nanotechnology, metabolic engineering, and AI to enhance efficacy, safety, and standardization. This creates potential for locally developed evidence-based herbal products.

Question 2: "What are the key ethical considerations in TCAM research?"

Panelists highlighted issues including ownership of ethnobotanical data, commercialization of community-originated formulas, and use of unvalidated products. Ethical research requires REC approvals for clinical trials, community engagement, and respect for traditional knowledge. Preclinical approvals remain debated due to intellectual property risks, but accreditation of laboratories is recommended to align with international best practices.

Question 3: "How does community engagement influence study outcomes, as demonstrated in the MTN-042 study?"

The panelist referenced the MTN-042 (DELIVER) study, noting that active involvement of CABs, local healthcare providers, and stakeholders led to high recruitment and retention (up to 98%). Community feedback shaped protocol design, consent processes, and messaging, ensuring cultural relevance, ethical integrity, and ownership. Early and continuous engagement also informed national HIV prevention guidelines.

Question 4: "Are LMICs ready for Controlled Human Infection Models (CHIM), and what are the ethical challenges?"

Dr. Chi and Dr. Njue observed that CHIM studies are increasingly feasible in Africa due to capacity building and regulatory frameworks, but challenges remain, including risk to volunteers, informed consent complexity, compensation, infection control, and societal acceptance. Social science research is critical to understanding motivations, perceptions, and minimizing stigma. Rigorous oversight by ethics committees and scientific units ensures ethical alignment.

Question5: "What are the main challenges in integrating TCAM research into health systems in Uganda?"

The panelist noted that challenges include regulatory delays, limited funding for clinical trials, lack of standardized production, and historical focus on products rather than practices. Ethical challenges such as IP rights, benefit sharing, and community consent also persist. However, opportunities exist through harmonized regulation, capacity building, translational research, and collaboration with international partners to advance safe and evidence-based integration.

Plenary Session 4: Panel Discussion: Community Engagement Across the Research Life Cycle!!

Moderator: Dr. Philippa Musoke and Dr. Julaina Obiika

Presentation 1: Gains achieved through Pathogen Economy community engagement

Ms. Brenda Nakazibwe – Science Technology and Innovation in the Office of the President

Ms. Nakazibwe highlighted the role of science, technology and innovation in community engagement. To support community at all levels from national to family level to solve problems of under development. With the mission of making Uganda the best technologically advanced and most innovative nation in the region.

She further noted that the Pathogen economy is making, saving and encouraging use of goods and services related to the prevention, control and treatment of damage due to pathogens. For the Pathogen control consideration is on vaccines, currently the country has candidate vaccines for humans and animals. As well as diagnostics and therapeutics. These have been achieved through community engagement and at different levels of collaboration.

She noted that the priority value chains that the country is driving at under science and technology relate to the pathogen economy, which includes health; aeronautics and space science, mobility, infrastructure innovations, but particularly for the pathogen economy emphasis is on vaccines, therapeutics, diagnostics and all the way. In terms of therapeutics, the country has registered a reduction in importation of medicines from the grants. For example, Jena herbals received a grant to take COVIDEX through clinical trials and to construct a GME facility in Soroti industrial park. Over seven pre-clinical trials on therapeutic products basis is on products from natural sources. During Tarehe sita celebrations at Kyotera, the President disseminated products from Kazire herbals and Busitema University Faculty of Health Sciences. These were mainly for acute respiratory infections trials.

At the moment the STI-OP in collaboration with scientists is handling malaria, Analgesics and diabetes products for clinical trial for which already have protocols approved. In addition, over 50,000 samples for research have been obtained from within and outside Africa, COVID-19 samples from the bio repository Makerere University and at the Uganda cancer institute with support by STI-OP. Over 2,000 samples have been archived. The STI-OP secretariat with partners has so far worked on five human vaccines that are now getting into clinical trials. She noted that these are the first nascent vaccines for the country and COVID19 opened the door. Other infectious disease conditions being considered are rift valley fever, MPOX.

Regarding diagnostics, through partnerships and collaborations with some scientists in Uganda, COVID-19 kits were developed and are on the market currently. With that, the country saves UGX 135.8 billion on importation of kits, which is a return on investment. With the establishment of the STI-OP in March 2022, some returns on investment such as on the PCR kits have been registered. These were through the grants and investment from the government of Uganda.

In addition, the team supports twenty-six (26) countries to develop proficiency panels for their diagnostics. From Jenna herbals, Diva Pharma, the country/government has an offtake of over 20 drugs, this has facilitated import substitution. Also, STI-OP is supporting the Microheam Scientifics limited, to obtain WHO pre-qualification this in way facilitates an off-take with government for sickle cell anemia, HIV and malaria RDTs.

The central laboratory animal research facility (CLARF) is currently working on pathogen free mice with some transgenic mice being bred. She further noted that a team is to be sent to the USA for capacity strengthening on transgenic models. A Biosafety Level III laboratory has been set up at COVAB to handle similar works. In addition, STI-OP has established a clinical trials platform of natural therapeutics led by prominent scientists in the country.

She further noted that with community engagement, the STI-OP secretariate operates at the macro, mid-level but also the communities. The secretariat has engaged the communities in a number of ways. First by understanding the community. She noted that at the start, it was important to know who is doing what? This was through eyeballing at some point and then engaging. For instance, the secretariat identified scientists who were already working on some products. Jointly, the team has worked on a saliva diagnostic kit for COVID-19 which is currently into validation now.

The indigenous scientists (herbalist) form part of our community. She noted that at the STI-OP secretariat herbalists are referred to as indigenous scientists. These hold the indigenous knowledge. At national level, one of the main things in National Development Plan IV is for the pathogen economy to engage with the indigenous scientists at the national level. The Secretariat has recently engaged scientists from 22 districts at Busitema University.

Also, the STI-OP has initiated international engagements, national-level engagements, inter-ministerial engagements and high-level engagements with HE the president of Republic of Uganda who has promised to support scientists. The STI-OP has received strategic guidance from HE the president of Republic of Uganda, to work with communities, specifically indigenous scientists. She noted that most indigenous scientists are not in labs, many have not heard about a research ethics committee or clinical trials, but the STI-OP secretariat is trying to bridge that gap. Every Wednesday for 2 hours, we sit and discuss their products and see how to organize them through the RECs, UNCST, NDA such that they are able to go through clinical trials process.

The STI-OP works with the identified eco-system in all stages from ideation, innovation, protocol development, research, dissemination and product commercialization. Engagements are done with academic institutions (universities), research institutions and other relevant government agencies. The secretariat has engaged scientists (students are invited) at the first science summit, where some scientists were celebrated. This is now an annual event during National Science Week.

Presentation 2: Clinical trials insurance Are we enriching or making insurance companies Wealthier, serious adverse events and compensation for research related injury. Roles of the different players

Ms: Diana Nakitto Kesi, Manager Clinical Trials Unit – National Drug Authority

Clinical trials involve human participants in the drug development process, with participant safety as a cornerstone of ethical research. Clinical trial (CT) insurance serves as a safety net, providing medical and financial support if harm occurs due to the study.

Trials may test new drugs, dosages, or formulations, and pre-clinical data may not fully capture safety risks, necessitating ongoing monitoring.

Serious adverse events (SAEs) in trials can include death, hospitalization, life-threatening conditions, or disability. Regulatory frameworks and national guidelines mandate timely reporting of SAEs typically within 7–14 days to the sponsors and regulators. Due to the presence of risk in any given CT which could be anticipated (that you prepare for) or unanticipated (that you do not prepare for) clinical trial insurance is necessary. Clinical trial insurance ensures participants' rights are safeguarded, supporting both ethical conduct and trust in research.

"Protecting participants = Protecting Science"

Ms. Nakitto cited some challenges with securing compensation from insurance companies; unclear procedure for determining causation requiring compensation by study team, Lack of awareness about this provision by study participants. Defining the types of harm /injury in the insurance policy that are eligible for compensation is confusing for both the researcher and the regulator and defining the role of the different players in supporting this process following approval of the clinical trial is complicated. Challenges like delays in reporting SAEs/quality of reports, disputes around causality assessments and lack of dedicated persons to review the SAEs and ensure claims are in practice.

However, at the moment, reviewing available guidance to define procedures for compensation and who shall be in charge at institutional level, defining types of compensation harm, defining types of compensation to ensure fair treatment and defining a compensation process at institutional, regulatory and insurance levels of oversight are changing.

She highlighted the various roles of the parties concerned, the **Principal Investigator (PI)** ought to ensure valid insurance before trial initiation. This serves as first contact for SAE reporting, communicates transparently with participants and families, informs participants about compensation procedures, reports SAEs accurately and on time, and engages an independent medical monitor to assess compensable events. Files a claim if harm is related to the clinical trial.

The **regulator (NDA)** requires proof of insurance policy and certificate before approving trials from a local insurance provider. The insurance policy should be sufficient for the clinical trial. The approved insurance providers are available on the Insurance Regulatory Authority (IRA) website; Goldstar, Britam, ICEA, Jubilee, UAP Old Mutual, MUA Insurance (Uganda) Limited. The regulator also provides insurance guidelines and oversight, liaises with the RECs following safety evaluation to ensure monitoring and compensation for the affected study participants,

monitors all adverse events related to the clinical trial and ensures participants are informed about compensation procedures.

The **insurance provider** reviews and assesses claims promptly, supports team training on compensation processes, and provides the financial/medical coverage for harm related to the trial. The participants benefit from guaranteed medical treatment if harmed, financial compensation for disability or death, fairness and transparency in protection, and greater confidence in volunteering for trials.

Moving forward, Ms. Nakitto recommended strengthening regulatory frameworks on insurance, improving participant awareness on their rights, ensuring transparent and timely compensation/ utilizing the complaints bureau at the IRA and harmonizing guidelines on clinical trial insurance. She concluded by noting that Clinical trial insurance is essential for ethical research, protects participants, builds trust, ensures compliance, and requires collaboration between regulator, PI, sponsor and insurer. And protecting research participant is equivalent to protecting Science.

Presentation 3: Changing paradigms electronic research methods and consenting: Ethical and legal issues and how to engage research communities

Dr. Adrian Jjuuko, Makerere University, School of Law

Dr. Jjuuko started by highlighting the changing times -changing paradigms, noting that we live in the computer age, the age of the internet, the age of Artificial Intelligence (AI) and the Age of the internet of things. Computers are now handheld and mobile enabling people to communicate from anywhere on the globe. He also, noted that the Pandemics like COVID-19 led to an exponential rise in the use of the internet and indeed in many countries the internet and digital technologies remained the only legal ways of engagement.

The internet and electronic transactions are generally faster, cheaper and 'cooler.' These developments cannot affect every other facet of our lives without affecting research. Researchers have adopted electronic research methods. However, these challenge research ethics as we know it and pose a number of ethical issues.

He defined electronic research methods as the 'emerging range of methods which use the internet to support the creation of primary research data' as per Claire Hewson 'Ethics Issues in Digital Methods Research' in Snee, H., Hine, C., Morey, Y., Roberts, S. & Watson, H. (2015). According to Digital Methods for Social Science: An Interdisciplinary Guide to Research Innovation. Palgrave, Macmillan, 206. Electronic research methods are variously referred to as online research methods, web-based research methods, digital research methods, e-research, and internet-mediated research (IMR). They refer to two distinct research practices the collection of internet-based data using algorithms (including now – AI) which may not involve seeking informed consent, and the conversion of offline research methods to online research methods, which usually obtains seeking informed consent. He noted that a study can also have both online and offline engagements. For example, some people may be interviewed online and others physically or some data collected online and others physically.

Regarding the legality of electronic research methods Dr. Jjuuko noted that Ugandan law does not prohibit electronic research and *what the law does not prohibit, it allows*. Article 29(1)(b) of

the Constitution of the Republic of Uganda, 1995 protects *'freedom of thought, conscience and belief which shall include academic freedom in institutions of learning.'* Therefore, research is covered under this right including electronic research. The Electronic Transactions Act Cap 99 has one of its objects at to *'enable and facilitate electronic communication and transactions.'* This clearly indicates that Ugandan law recognizes electronic transactions. The legality of electronic research methods, under section 2 of the electronic transactions are defined to mean *'the exchange of information or data, the sale or purchase of goods or services, between businesses, households, individuals, governments, and other public or private organizations, conducted over computer mediated networks.'* Clearly includes electronic research. The UNCST in its National Guidelines for Conduct of Research During Coronavirus Disease 2019 (COVID-19) Pandemic, 2020, authorized the use of *'electronic methods for seeking, confirming and documenting informed consent in research studies.'*

Dr. Jjuuko highlighted the some key ethical concerns that arise from the use of electronic research methods for instance *(i)* how to distinguish between public and private data, *(ii)* Informed consent related issues such as; identifying the person who has actually consented and who has not since the other party is not there physically, how to ensure that there is no third party alteration of data during transmission, ensuring the identity of the person presumed to be consenting in the age of AI and deepfakes. *(iii)* How to protect confidentiality of participants during electronic research and computer misuse issues, *(iv)* Access to computers/internet as an inclusion/exclusion criterion, *(v)* Compensation of research participants using digital means and *(vi)* How to undertake community engagement online especially with communities that have no or limited access to internet/mobile phones.

Regarding the private vs public data, Section 11(1) of the Data Protection and Privacy Act requires that a person collects personal data directly from the data subject. "Personal data" is defined as information about a person from which the person can be identified, that is recorded in any form and includes data that relates to the nationality, age or marital status of the person; the educational level, or occupation of the person; an identification number, symbol or other particulars assigned to a person; identity data; or other information which is in the possession of, or is likely to come into the possession of the controller and includes an expression of opinion about the individual. Which implies that one should not obtain a person's personal data from third parties. However, under section 11(2), personal data can be collected from third party sources in certain circumstances, the ones which are relevant to online research being - where the data is contained in a public record and this includes the internet; or where the data subject has deliberately made the data public; or where the data subject has consented to the collection of the information from another source.

He noted that the law makes a distinction between private personal data and public personal data indicating that collection of 'private' personal data over the internet requires consent while 'public' private data that is already available on the internet does not. However, even in the case of public personal data, care must still be taken to ensure that accuracy of the data and this may sometimes require seeking the clarification of the data subject.

The informed consent process in electronic research; In terms of the law, Article 41 of the Constitution of the Republic of Uganda, 1995 (as amended) provides for the right of access to information held by the state or its organs. This, however, means that no one has a right to access information that belongs to private individuals or companies or organizations. Article 27(2) of the Constitution protects the privacy of persons including research participants. The

Data Protection and Privacy Act Cap 97 regulates the collection and processing of personal data. Section 7(1) provides that *"a person shall not collect or process personal data without the prior consent of the data subject."* The law uses the term 'consent' and not 'informed consent.' This means that the guidance on what constitutes consent is regulated by the specific discipline. Ethical standards on informed consent such as Guideline 5.2 of the National Guidelines for Research involving Humans as Research Participants, 2014 adopted by the UNCST provides that, *'Except as provided elsewhere in these guidelines, no researcher shall involve an individual person as a research participant unless the researcher has obtained informed consent of the individual or the individual's authorized representative.'*

Despite it being a cornerstone of research ethics, as it serves to fulfil the research principles of respect, beneficence and justice, the limits of informed consent are not clearly defined. Ethical standards on informed consent under Article 1 of the Nuremberg Code, 1947 informed consent is explained as meaning that *'the person involved should have legal capacity to give consent;* should be so situated as to be able to exercise free power of choice, without the intervention of any element of force, fraud, deceit, duress, overreaching, or other ulterior form of constraint or coercion; and should have sufficient knowledge and comprehension of the elements of the subject matter involved as to enable him to make an understanding and enlightened decision.' The Belmont Report, 1979 provides that *'Respect for persons requires that subjects, to the degree that they are capable, be given the opportunity to choose what shall or shall not happen to them*. This opportunity is provided when adequate standards for informed consent are satisfied.' It underscores three aspects of informed consent: Information, Comprehension, and Voluntariness.

For Information to be provided during the informed consent process, the laws of Uganda and the UNSCT Guidelines apply to both traditional field research and electronic research (Guideline 5.2). Guideline 5.3 provides for the information to be included in the informed consent form. Under Guideline 5.1 *'informed consent is not just a form or a signature/mark/thumbprint but a process of information exchange between the researcher and research participants on the whole research process.'* This implies that whatever is applicable to traditional field research should also apply to electronic research.

Regarding Electronic and digital signatures, Section 6 of the Electronic Transactions Act Cap 99 provides that *'Where a law requires a signature or provides for consequences where a document is not signed, the requirement is fulfilled if an electronic signature is used.'* An electronic signature is defined as 'data in electronic form affixed to or logically associated with a data message, which may be used to identify the signatory in relation to the data message and indicates the signatory's approval of the information contained in the data message; and includes an advanced electronic signature as well as secure signature.' Meaning that once one signs electronically and the data can be linked to them, they are bound.

One can therefore sign by simply clicking a box without reading as commonly seen in software agreements etc. However, how to prove informed consent in electronic research is still a challenge. The Electronic Signatures Act Cap 99 provides for electronic signatures and digital signatures; digital signatures are a type of electronic signatures where the identity of the person signing can be determined using private and public keys. However, whether it is a digital signature of another type of electronic signature, this clearly does not satisfy the requirement of informed consent as understood in research ethics, although it satisfies the evidential burden of the law. As such the focus is not on the signature and its validity but rather on whether the person understood the basics of the research and validly consented.

Dr. Jjuuko highlighted the court case of Mukoda alias Naigaga v International Aids Vaccine Initiative & 11 Ors Human Rights Petition No. 305 of 2017 decided in 2020. The High Court

emphasized the importance of informed consent and went beyond the signature to ascertain whether the researchers fulfilled their obligations under the Helsinki Declaration. Third party alterations of electronic data. Third party interventions in transmission of electronic data is a common concern. The concern is whether the very message sent is the very message that has actually reached the other person. Third party alterations can be in the form of man-in-the-middle attacks. This highlights the importance of data security.

Identity of the person consenting in the era of AI and deepfake is still an issue. An important consideration in the validity of informed consent in electronic research is whether the person presumed to consenting is actually the one doing so. With AI and deepfake, one can never be sure even if there is video evidence. Deepfake technology enables the manipulation of images, videos, audio, and even text to generate highly realistic synthetic content, including written material intended to mimic an individual's communication style, often without their consent. T. Kirchengast Deepfakes and image manipulation: Criminalization and control Information and Communications Technology Law, 29 (3) (2020), pp. 308-323. Consequently, the issue is how to prove that the person you spoke to is the person you intended to speak to. AI is very crucial in research as its tools can be used to analyses large datasets, and automate tasks, but they should be used as tools to augment human expertise, not replace it. However, one must beware falsification of data issues and fake references.

Dr. Jjuuko highlighted the laws that speak to the protection of confidentiality during electronic research, The Computer Misuse Act Cap 96 criminalizes a number of things if done through a computer, and the relevant ones to researchers are: Section 11(1)(a) criminalizes unauthorized access to another person's data or information, Section 11(1)(b) criminalizes unauthorized voice or video recording of another person. Section 11(1)(c) criminalizes unauthorized sharing information about or that relates to another person without authorization commits an offence. Under section 11(7), the punishment is a fine not exceeding 15 million shillings or imprisonment for ten years or both. Section 23 unauthorized sharing of information about children – without parental consent etc commits an offence punishable by a fine of 15million or imprisonment of seven years or both Confidentiality during electronic research.

These laws show the importance of obtaining informed consent during electronic research but also of ensuring confidentiality of research data. It is now criminal offence if data confidentiality is breached. Electronic processes are however almost inherently vulnerable to internet attacks including unauthorized access to databases, man-in-the-middle attacks, networking sniffing on unencrypted connections and third and by exploiting vulnerabilities in third-party vendors which all can occur during transfer of data. There is therefore need for more data security so that researchers avoid going afoul of the law and ethical principles.

The access to computers/internet as an inclusion / exclusion criterion, Including internet access as an inclusion criterion in research is necessary for studies that rely on online data, platforms, or communication. However, this creates a digital divide by excluding participants with limited access. This is a serious issue with countries with low internet penetration such as Uganda. Most importantly, it goes to the validity of the research findings as well as generalizability. It may also go to community engagement to what extent the researcher has involved less technologically advantaged community members.

Digital compensation of participants, Compensation of participants is an important issue in research ethics. With the adoption of mobile money technologies, mobile banking platforms, paying money is much easier than ever. Issues would arise when there is no easy access to such technologies by participants. Questions on How study participants will get compensated remain.

Regarding community engagement in electronic research, Community engagement is a very important concept in research. Guideline 12.1 of the UNCST HSP Guidelines provide that *'Researchers shall make reasonable effort to involve community stakeholders in the research process, where appropriate, right from the inception of research to post research period.'* · The UNCST's 'National Guidelines for Community Engagement in Research' 2022 indicate that community engagement is an opportunity for communities to participate in the design and conduct of research and enhances the relevance, ownership, and applicability of research findings.

Since electronic research does not involve physical field visits and community engagements, the question of how community engagement will be done becomes important. Most communities in Uganda are rural based and do not have access to the internet. Thus, how does one genuinely and meaningfully engage them electronically? Community engagement in electronic research. The Guidelines envisage using digital media like internet and mobile telephones (phone text) as well as Internet media e.g., social media, emails, websites, Facebook, X, WhatsApp as one of the ways of undertaking community engagement. However, the Guidelines envisage these to be used when reaching out to a broader community where a study is not under one geographical area or to a particular group of individuals. How about when the participants are a smaller group and in one area? Researchers employing electronic research methods should use technology to involve communities in the research process, from design to dissemination. This can range from researchers leading a study with community input to full community partnership where the community drives the research agenda. Using electronic research methods does not preclude physical engagements more especially at the design stage so that the research get to understand the community more and therefore determine the best technology to use – not the technology that is convenient to them, but that that is convenient to the communities.

In conclusion, Dr. Jjuuko noted that the rapid developments in technology have made research much easier. They have also similarly created major challenges in research. Such challenges affect both the legal framework and the ethical framework. The law does not prohibit electronic research and indeed clearly regulates it through laws such as the DPPA, and the Computer Misuse Act. The issues affecting informed consent, privileging the views of those with access to computers, as well as the need to ensure confidentiality and data security online all becoming important. He cautioned that researchers need to be aware of the technological developments, the ethical challenges that arise from the use of technologies as well as the legal developments, and how all these issues enhance or diminish community engagement and work to ameliorate them.

Presentation 4: Social Behavioural research engagement and post research responsibilities.

Dr, David Mafigiri, Makerere University College of Humanities and Social Sciences

Post research responsibilities – how do we conceptualize harm? Who are we responsible for?

As a way of introduction, Dr. Mafigiri highlighted the goal of social behavioral research it helps to fill the gaps in existing knowledge about our social world, supporting critical and normative reflection (evidence-based decision making). He noted that research must be disseminated widely in order to fulfil these goals. No research is complete unless it results in dissemination. Investigators have a responsibility to engage in activities that nurture an informed public. An informed society is better placed to reflect on matters of public concern, make informed decisions and innovations to help respond to changes (crises).

Looking at the history of harm to research participants, biomedical sciences have a long history of abuse (trials, physical pain, death), psychological harm (stress, upset). Human stakes of social sciences are lower than biomedical sciences but should not be degraded. Forms of Social harm are real and may be unavoidable for instance to explore (and oppose) social and economic injustices often impacts influential/powerful, may have detrimental effects on reputation of individuals, corporations, institutions.

Conceptualize the nature of relationship between the social behavioral researcher, the research being undertaken and the society they speak about/ speak to. Social behavioral research uses normative principles 'borrowed' from biomedical sciences that point to a participant protection, such as risks of participating in study, protection of the rights of the participant above all other parties in the study and researcher duties and obligations underpinning ethical regulation of social sciences

Considering the nature of relationship between social behavioral researchers and participants it is less asymmetrical power relations. Often the participant has more power *(more knowledgeable, authority, prestige)* – hence the researcher is more vulnerable. The aim of social behavioral research is to explore/expose inequality/seek to redress injustice in the society they speak about and speak to. If the aim is to criticise the status quo or suggest better alternatives where even the participants are stakeholders, may not support the research aims. Research participants are not disinterested objects as in biomedical sciences, not vulnerable individuals seeking the help of researchers. At times data not gathered willingly or freely offered through consent but through deception, duplicitousness, recourse to legal and coercive means (Freedom of Information Act).

Conceptualize the nature of social harm in social research, unlike biomedical sciences Social behavioral research has (less trials, physical pain, death), More likely to cause psychological harm (stress, upset) or potential harm to participant interests (reputation, finances, career). Social science research harms private interests of individuals indirectly, often has inescapable ramifications e.g. detrimental effects on reputation of individuals, corporations, institutions. Therefore, is prioritising individual rights and avoidance of harm inappropriate?

Dissemination and Post research responsibilities are similarly important in social behaviour

research. Researchers generate plenty of information and knowledge which must be shared with peers, colleagues and other scientists, Policy makers and the general community (community engagement as iterative process). Withholding information and knowledge is a disservice and may be deemed unethical. Dissemination includes research reports, abstracts & presentations, scientific manuscripts, policy briefs, public engagement.

However, there are concerns or healthy debates in social sciences on ethics and politics of social research; Is it appropriate to import/impose regulation from biomedical into the social sciences? Could the principles underpinning researcher-participant relationship (underpinning ethical regulation) hinder successful execution of social science researcher obligations? Is it necessarily unethical to pretend to be sympathetic to a form political extremism to be able to interview members of a political group? Is information acquired through deception voluntary? Informing participants of study aims may radically alter results they give.

In conclusion, Dr. Mafigira noted that realities of social science research may call for careful consideration of conceptualization of harm. The principles underpinning researcher-participant relationship (underpinning ethical regulation) also pose obligations during and post research. The principles of post research obligation to the individual and society are similar for the most part to those of biomedical research. There is need for a framework which recognizes that some ethical considerations pertaining to social sciences are not always the same as those for biomedical sciences.

Questions and Answer session

Question 1: "What is the role of clinical trial insurance, and does it protect participants effectively?"

Insurance is crucial for safeguarding participants against harm, including medical expenses or disability. Challenges include unclear causation procedures, participant awareness, and timely claims processing. Collaborative roles between the PI, regulator, and insurer are necessary to ensure transparency, trust, and ethical compliance. Strengthening frameworks and participant education are ongoing priorities.

Question 2: "Who is eligible for insurance. If I get an accident while coming from the research site, how am I compensated?

As long as there is a relationship between insurance product and the cause/event - the compensation should happen, what is considered is the causal relationship.

Question 3: "In light of protecting rights of participants under the insurance compensation; elaborate on the scope of compensation. a case a participant sustains a SAE how does insurance do this?"

Compensation in case of disability, the current guidelines require coverage within one year claim for one year.

Professional Indemnity and insurance – protect the investigator; insurance protects the participant.

Question 4: "Foreign insurance coverage. Whereas NDA and UNCST emphasize local providers. The provision that allows foreign providers creates inconsistencies – grey areas. Can you eliminate that. Could you help us appreciate why you have to consider that provision considering the challenges in due diligence in pursuing compensation?"

Foreign policy – studies are sponsored. Locally we require that there is a relationship with a local provider for clinical trials.

Question 5: "Compensation and insurance. We have been talking about compensation for harm SAE but have not identified or defined the harm and risks. One area which I need clear definition about and compensation is when there is death in clinical trials associated with or directly emanating from the trial. Do we have national provisions apart from international ones?"

Death – relationship between the product and the cause – which must be confirmed that it was because of the research. In the new guidelines harm is defined.

Question 6: "Protection of vulnerable people against potential harm in AI research which involves labelling data, annotations and exposing people to traumatizing content. What is our country doing since regulation may not be applicable in our country"

The legal systems have provisions for protection of research participants in online spaces. Law and private information – deep fakes – there are provisions in the computer misuse act.

Question 7: "Data is running ahead of us same as technology. Today, someone tells you their phone eats first. Children can change information and create or fabricate information about people can we prevent data sharing from individuals who have not consented. "

Balancing research and protection of participants – deception is illegal under the law, people must know.

Question 10: "Government collects a lot of data, under which law do we get protected that this data is not misused?"

Government collecting data in hospitals – learn to say no.

Question 11: "How do I obtain Informed consent my participants ae insects and snails how do I go about informed consent?"

For Research involving animals as research subjects, there are clear national guidelines for research involving animals as research subjects with a section on informed consent from animal owners.

Question 12: "We are faced with challenging Waiver of consent, situation are there provisions for waiver of consent where participants are unable to consent?

The national guidelines for research involving humans as research participants provide guidance on waiver of informed consent.

Questions: "Are there frameworks or how research institutions are ensuring that data is open enough to further research but private enough to protect participants."

Question: "How can you engage communities and strike a balance between confidentiality and community engagement?"

Balancing confidentiality and engagement, as an investigator the need to know – you are a researcher not a journalist, policy or doctor. Determine when it is ethical to share certain information.

Question 8: "I was very stunned coming across the issue of deception in research. What guidance do you give to RECS to handle deceptions when we have the issue of justice and protection of participants in the face of impending litigation and violation of the rights of individuals."

As a REC, protocols should be considered case by case. If you think deception is necessary, do not disclose it to participants. However, there is need to balancing research and protection of participants – deception is illegal under the law, people ought to know.

Question 9: "Serious reflection is required on risks from social science research. Th nature of harm in social sciences is economic, reputational, psychological etc it seems more complex than in biomedical sciences there is need for a framework to guide this".

One universal guideline – we need the principles as universal, but implementation should be cognizant of the context. You can't study corruption, child abuse, accountability… without causing harm. Some studies are purposefully opposed to the status quo.

Question 10: "How do you help scholars doing anthropological studies and the community if you want to delineate this harm, is there a framework?"

Protecting people who immerse themselves in a setting – google the term – going native social science research, anthropology etc. it can be a double-edged sword. In old times it was seen as completely terrible they try to be objective. It can be positive or negative

Plenary Session 4: Panel Discussion: Stakeholders' Perspective Community Engagement

Session moderators: Dr. Frederick Nakwagala & Dr. Victoria Namuggala

Not Just Optional: Why do Community Voices matter in Public Health Emergencies?

Panelists

1. Dr. Martin Ongol, Deputy Executive Secretary, UNCST
2. Dr. Ponsiano Kaleebu, Executive Director, UVRI
3. Dr. Alfred Driwale Commissioner of Health Services, Ministry of Health
4. Ms. Carol Nakimera, Community Advisory Board member, MUHJU Research collaboration
5. Dr. Kyadondo David, Senior Lecturer, Makerere University, College of Humanities and Social Sciences
6. Ms. Susan Namayega Community Advisory Board member, Nakiwogo Fishing Village

The panel discussion focused on five key areas: the scope of Public Health Emergencies (PHEs), the challenges faced by research regulators in PHE, how to balance public health and civic liberties during PHE, ethics of handling isolation centers/quarantine (guidelines and laws), and how to make community a meaningful partner handling PHE (the role of community engagement in PHE).

Scope of Public Health Emergencies in Uganda

Dr. Alfred Driwale highlighted Uganda's common PHEs, including infectious diseases like sleeping sickness, measles, Viral Infections: yellow fever, viral hemorrhagic fever, Meningitis meningitis, Ebola, COVID-19, bacterial Infections: dysentery and cholera, as well as non-infectious events such as road traffic accidents and rising non-communicable diseases (diabetes, hypertension, cancers). He noted that the Ministry of Health maintains a robust disease surveillance system with weekly reporting from health facilities to monitor trends.

In addition, Ponsiano Kaleebu noted that PHEs now include non-traditional threats like bioterrorism, requiring active surveillance, institutional preparedness, and rapid deployment of interventions. Upholding ethical standards to protect research participants is essential, and

swift, joint protocol reviews by RECs and other research regulatory bodies can prevent response delays. Effective emergency response demands a multi-pronged approach with strong national, regional, and international collaboration.

Challenges and Regulatory Mechanisms in PHE

Dr. Martin Ongol, reported on institutional efforts to ensure research safety and quality during PHEs, highlighting collaboration among regulatory bodies (NDA, UNHRO, UNCST, MOH) through the MOH PHE Task Force. Key initiatives include joint scientific and ethical review Mechanisms, the National Research Information Management System with rapid ethical review, and science diplomacy to acquire advanced sampling equipment. Core regulatory challenges include managing fluctuating participant numbers, balancing rapid scientific validation with participant protection, lack of dedicated emergency research funding, and combating widespread misinformation during emergencies.

Dr. David Kyadondo addressed the critical issue of balancing rights during PHEs, specifically the necessary trade-off between public safety measures (such as lockdowns and movement restrictions) and the inevitable curtailment of civil liberties (including freedoms of movement, speech, and interaction). He stressed the importance of simultaneously considering and mitigating the negative implications of these restrictions, citing the potential for increased poverty as a key area of concern that must be addressed alongside public health policy.

Dr. Frederick Nakwagala underscored the severe ethical compromise of conducting research in haste during a PHE, illustrating this with two powerful anecdotes from the Mulago COVID-19 treatment unit. The first involved a patient in desperate need of an ICU bed hoping for another's death to gain access. The second concerned a lawyer who signed a broad consent form detailing 15 experimental drugs while "gasping for breath," later complaining of being "over-experimented on." This emphasized the profound difficulty of obtaining true informed consent when individuals are facing a life-threatening emergency and may prioritize immediate care (like oxygen access) over fully comprehending the research details.

Community Experiences and Engagement Strategies

Ms. Carol Nakimera highlighted the severe social and economic impacts of COVID-19 lockdowns in her community, including rises in domestic violence, family breakdowns, job losses, and teenage pregnancies. She noted that abrupt lockdowns often separated fathers from families, leaving mothers solely responsible for care. She called for early warning systems and creative strategies for future pandemics, allowing families time to reunite before restrictions are enforced.

Ms. Susan Namayenga stressed the community's right to report concerns and side effects after mass vaccination campaigns. She highlighted a trust gap during the COVID-19 vaccine rollout, where communities lacked proper orientation and follow-up on adverse effects, undermining confidence in vaccine safety. She urged researchers to return to the community to provide feedback on vaccine efficacy and research results.

Dr. David Kyadondo emphasized the critical need for inclusivity and a multi-stakeholder approach in emergency management, tailored to the specific type and context of the emergency. Highlighting that communities are diverse, he stressed understanding local nuances and building on existing resilience strategies. Effective, localized communication remains a key challenge, and he advocated leveraging trusted local structures, such as women's groups and Village Health Teams (VHTs), to enhance community engagement.

Discussion /Questions and Answers

The panel addressed technical questions and further ethical considerations, particularly regarding vaccine development and research governance.

Question: How does the rapid development and regulatory context of COVID-19 vaccines, along with their efficacy, inform the historical timelines and long-term feasibility of developing an effective HIV vaccine?

The COVID-19 vaccines were developed rapidly due to mRNA technology, whereas standard vaccines like those for malaria or tuberculosis typically take over a decade. COVID-19 vaccines distributed underwent full approval and were deemed safe. Developing an HIV vaccine is especially challenging because no natural immunity exists to guide design. While no fully effective HIV vaccine is available, research has advanced understanding and therapeutics. Vaccines are not 100% effective and mainly aim to prevent severe disease rather than infection.

Question: How can multi-sectoral public health strategies effectively address road traffic accidents, ensure equitable distribution of essential resources like mosquito nets, and promote accurate, responsible media reporting at the community level?

Road traffic accidents are increasingly recognized as a major public health issue, worsened by poor road design, construction on roads, and unsafe driving behaviors. Addressing these challenges requires multi-sectoral collaboration, investment in road safety, and clearly defined roles for stakeholders. Communities are central to public health efforts, contributing to disease detection, safety awareness, and proper referrals. The media also plays a critical role, as seen during COVID-19, highlighting the need to train journalists to effectively communicate accurate public health messages.

Question: How are research findings communicated and applied to benefit grassroots communities, and what mechanisms ensure they are informed of the outcomes and any resulting products?

Feedback and dissemination of research findings is a gap within the research community. Researchers need to be intentional about providing feedback (positive or negative) to the participating community.

Question: What are the key strategies CAB members use to maintain community trust and prevent the perception that they are aligned with researchers instead of their community?

Elected by the community, CAB members serve voluntarily, earning trust through established relationships and local work. They clearly delineate their role to community mobilization, deferring technical aspects to scientists. Crucially, openly demonstrating that they do not benefit financially from the research reinforces their legitimacy and community standing.

Plenary Session 5: Closing Session

Session moderators: Dr. Joseph Kagaayi and Dr. Martin Ongol Appreciation remarks

Dr. Martin Ongol, the Deputy Executive Secretary, UNCST expressed profound appreciation for the successful 2-day event, highlighting the valuable presentations, learning, and experience sharing. He specifically thanked the different national task forces for the rigorous work in supporting the drafting of three national guidelines that were launched on day 1 (National Guidelines for Research Involving Humans as Human Participants; National Guidelines for Joint Scientific and Ethical Review of Research and National Guidelines for Community Engagement in Research). He affirmed that these documents will be extremely useful to the research community in ensuring safe and ethical research processes. Dr. Ongol also extended gratitude to the STI-OP, the event chairpersons, the Scientific planning committee, participants and all stakeholders that were involved in making conference a success.

Summary of the proceedings Dr. Joseph Kagaayi Chairperson Scientific & Planning Committee 12th ANREC

Dr. Kagaayi gave the brief overview of the conference arrangement for the two days and some key highlights from the 2025 ANREC Event.

He noted that the over-arching take home message from the conference is that ethical research is no longer just about scientific rigor it must be participatory, responsive, and community centered.

Some of the key messages from the conference include: the need to treat communities are co-creators of knowledge, not merely research subjects, institutionalizing continuous community engagement, mandatory budgeting for CE during research planning, the shift from research on communities to research with communities, reconceptualize the concept of harm to include unique aspects of social and behavioral research, national regulatory alignment with updates to the 2024 Helsinki Declaration, strengthening ethical frameworks, embedding community input and accountability, Community partnerships, improving access to clinical trial insurance coverage for participants, 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; Uganda ought to adopt IP frameworks that protect traditional knowledge, empower communities and enable responsible innovation, institutionalize community engagement training, embedding community representation in ethics committees, promoting downward accountability, and recognizing indigenous knowledge as scientific knowledge, disseminate research findings promptly and appropriately, post research responsibilities; the need for 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. In closing Dr. Kagayi noted that there is need to reflect on the feedback we have received so that research is not just scientifically sound, is social responsive and community centered.

Vote of thanks

Participant representative, **Mr. Joseph Sserunjogi**, Chairperson Community Advisory Board MUJHU/CARE, a community representative for Uganda Heart Institute REC.

He noted that the This opportunity to give a vote of thanks on behalf of the conference participants is part of the efforts to strengthen community engagement in research. It justifies/ confirms that we are no longer research participants but partners. Mr. Sserunjogi thanked the CAB members, government representatives, research institutions, and researchers in different capacities who fully participated. He also thanked the UNCST and partners for making the conference possible. He also appreciated the conference moderators, speakers and presenters from different professions particularly from the community, all the service providers as well as participants from other countries especially Kenya who shared their experiences.

He also appreciated the formulators of the guidelines that were launched and committed that these will be read and applied in research activities. He further noted that the community is a broader aspect, it is not just us as CAB members and the people we represent but it is all inclusive. One of the takeaways was the importance of engaging communities at the earliest stage. He noted that several messages on the meaning and application of community engagement have been raised during the two-day conference. the need to enhance post-research responsibilities. All the recommendations are very welcome given that they are geared towards better science/ research as well as protection of the research participants and communities.

Closing remarks

Dr. David Serukka, Executive Secretary UNCST

Before giving the closing remarks, Dr. Serukka awarded the scientific planning committee for the 12th ANREC, keynote speakers, foreign participants from Kenya, Ethiopia and Tanzania with gifts as tokens of appreciation for their contribution towards success of the conference.

In his closing remarks, Dr. Serukka noted the conference has provided a dynamic platform for reflection, dialogue and learning. It has helped us to see how to strengthen ethical research and meaningful community engagement in Uganda and the region at large. The arrangement was great and thanked everyone who was involved in organizing the 2025 ANREC event. Over the past 2 days, we have witnessed robust discussions on multi-ethical issues on community engagement. These conversations have re-affirmed that community engagement is not an accessory to research, but it is a foundation of ethical and impactful science.

Dr. Serukka further noted that UNCST remains committed to ensuring that research conducted in Uganda upholds the highest ethical, scientific and regulatory standards through the newly launched three national research guidelines. These will help to strengthen the national framework for ethical research and oversight. These tools will guide our shared mission to make research responsive to community needs, protect participants and promote trust between scientists and the community and society at large. He also extended his heartfelt appreciations to the 12th ANREC Scientific planning committee for a job well done. The UNCST staff, session chairs, presenters and participants for their valuable contributions. Also, he thanked the collaborative institutions and regulatory agencies, district leadership and international partners who have continued to support ethical research and excellence. To all conference participants, he noted that their engagements, questions asked and the insights shared have enriched the conference and provided fresh ideas for advancing ethical research, governance

and community involvement. He also thanked the exhibitors for displaying materials that added to the conference experience of our partners in the oversight regulatory role. Lastly, he appreciated the conference partners UNHRO, NDA and STI-OP for their contribution towards a successful event.

He called upon all stakeholder to take forward the spirit of partnership that has been built during the conference and to apply the lessons learned to strengthen our institutional ethics systems and to ensure that every research activity contributes to Uganda's national development and global scientific progress. He also highlighted the need to continue championing ethics in action where community engagement is not just practiced but it becomes a culture within our research eco-system. Finally, he encouraged stakeholders to include budget lines for community engagement when planning for research. He then thanked everyone for their participation, dedication and collaboration and declared the 12th ANREC conference closed.

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 and the Uganda National Health Research organization. Self-sponsored participants are similarly acknowledged.

Great thanks also go to the Scientific and Planning Committee members comprised of: Dr. Joseph Kagaayi (Makerere University School of Public Health- REC) who was the Conference Chairperson, Dr. Grace Ndeezi (Joint Clinical Research Center -REC), Dr. Fred Bulamba (Mbale Regional Referral Hospital), Dr. Ashaba Scholastic (Mbarara University of Science and Technology), Dr. Noah Kiwanuka (Makerere University School of Public Health), Dr. Victoria Namuggala (Makerere University School of Social sciences REC), Dr. Sylvia Baluka Angubua (Makerere University, College of Veterinary Medicine, Animal Resources and Bio-security), Ms. Teopista Nakyanzi (MUJHU Research Collaboration), Dr. Sam Okech (Makerere University, College of Veterinary Medicine, Animal Resources and Bio-security), Dr. Yahaya Gavamukulya (Busitema University College of Health Sciences -REC), Dr. Julaina Obika (Gulu University- REC), Ms. Eva Magambo (Makerere University School of Health Sciences- REC), Dr. Helen Ndagije (National Drug Authority), Dr. Sam Okware (Uganda National Health Research Organization),Ms. Hellen Opolot (Uganda National Council for Science and Technology), Ms. Deborah Kasule (Uganda National Council for Science and Technology) and last but not least, Ms. Winfred Nazziwa (Uganda National Council for Science and Technology).

Scientific Planning Committee 12th ANREC

Some of the UNCST staff



12th ANREC


12th ANREC

12th ANREC

12th ANREC

12th ANREC

12th ANREC



NATIONAL GUIDELINES FOR JOINT SCIENTIFIC AND ETHICAL REVIEW OF RESEARCH
12th ANREC
ANREC

Conference Program

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

21-22 October 2025 | Hotel Africana Kampala,Uganda

CONFERENCE PROGRAMME

Monday 20th October 2025

TIME	ACTIVITY
9:00am - 1:00pm	Chair: **Dr. GRACE NDEEZI** Forum for REC/IACUC Chairpersons in Uganda **(for Research Ethics Committees/ Institutional Animal Care and Use Committees Chairpersons ONLY)**

Tuesday 21st October 2025

TIME	ACTIVITY
8:00 - 8:30am	Registration of participants – **UNCST Secretariat**
8:30 - 10:50am	**PLENARY SESSION 1:** Moderator/Chair: **Dr. Joseph Kagaayi & Ms. Deborah Kasule**
8:30 - 9:00am	Welcome remarks: a. Chair Organizing Committee b. Secretary to the Authority NDA c. Director General UNHRO d. Executive Secretary UNCST
9:00 - 9:15am	Drama Skit: "Did you engage the community?"
9:15 - 10:00am	**Keynote address 1:** Communities as partners in Research: What does it mean for research to be responsive to the needs and priorities of local community? A global overview **Dr. Janestic Twikirize College of Humanities and Social Sciences, Makerere University (CHUSS)**
10:00 - 10:30am	Official opening: **a. Dr. Rhoda Wanyenze**, Chairperson, UNCST Council **b. Hon Dr. Monica Musenero,** Hon Minister of Science Technology and Innovation Launch of • Revised National guidelines for research involving Humans as Research participants • Guidelines for Community Engagement in Research • Guidelines for Joint Scientific and Ethical Review of research
10:30 - 10:35am	Group photograph
10:35 - 11:00am	HEALTH BREAK
11:00am - 1:15am	**PLENARY SESSION 2: The Changing Regulatory Landscape for Research Ethics: Global and National Outlook** Chair & Co-Chair: **Dr. Pauline Byakika-Kibwika & Dr. Victor Musiime**
11:00 - 11:25am	a. Updates to the Declaration of Helsinki and potential impact for Research in Uganda and the Region - **Dr. Frederick Nakwagala, Mulago National Referral Hospital**
11:25 - 11:45am	b. Overview of the revised National Guidelines for Research Involving Humans as Research Participants - **Dr. Nelson Sewankambo, Prof. Emeritus College of Health Science (CHS), Makerere University**

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TIME	ACTIVITY
11:45 - 12:10pm	c. National Health Research Priorities: The Essential National Health Research Agenda 2026 - 2030 **Dr. Sam Okware, Director General Uganda National Health Research Organization (UNHRO)**
12:10 - 12:40pm	d. Looking Beyond Community Advisory Boards!! How to effectively engage a research community. **Ms. Noni Mumba, Kenya Medical Research Institute-Wellcome Research Programme (KWRP), Kenya**
12:40 - 1:00pm	e. Status of Community engagement in Research in Uganda: Regulatory perspective **Ms. Hellen Opolot, Assistant Executive Secretary, Uganda National Council for Science & Technology**
1:00 - 1:15pm	Panel discussion (Q& A session)
1:15 - 2:00pm	LUNCH BREAK
	PLENARY SESSION 3: Ethics and Animal Welfare: Considerations for animals in research Chair & Co-Chair: **Dr. Sylvia Angubua Baluka & Dr. Lawrence Mugisha**
2:00pm - 2:30pm	Animal health and Community Engagement in Research: Historical perspectives on Conduct of Animal Research in Uganda **Dr. John David Kabasa, Prof. Emeritus College of Veterinary Medicine Animal Resources & Biosecurity (COVAB), Makerere University**
2:35 - 5:00pm	PARALLEL SESSIONS
	TRACK 1: Ethics and Animal Welfare: Considerations for animals in research Chair & Co-Chair: **Dr. Sylvia Angubua Baluka & Dr. Lawrence Mugisha**
	Presentation 1: Community engagement & Animal research: How to effectively engage animal owners in research that involves animals as research subjects. **Dr. Emily Ouma, Country Representative Uganda International Livestock Research Institute (ILRI)**
	Presentation 2: Wildlife animal and welfare: Navigating the world of research oversight and compliance with free-range species (Role of the Principal Investigators, attending veterinarians, Uganda Wildlife Authority and Institutional Animal Care and Use Committee). **Dr. Margret Driciru, Head Research Department, Uganda Wildlife Authority (UWA)**
	Presentation 3: Agricultural animals in research: Special issues and ethical consideration related to the use of agricultural animals in biomedical research. **Dr. Swadiq Mugerwa, Deputy Director General National Agricultural Research Institute (NARO)**
	Presentation 4: Establishment of Institutional Animal Care and Use Committees (IACUC) and Roles & Responsibilities of the IACUC, Host institutions, Investigators, Sponsors: Challenges and Opportunities. **Dr. Halid Kirunda, Director Research National Agricultural Research Organization (NARO)**
	TRACK 2: Research Ethics and Traditional-Alternative Medicine Research Chair & Co-Chair: **Dr. Yahaya Gavamukulya & Dr. Ahmed Kiswezi**
	Presentation 1: Research in Traditional and Alternative Medicine: Ethics, intellectual property & Cultural Relevance. **Dr. Sekagya Yahaya Hills (Kagali III), Director Institute of Traditional Medicine, President PROMETRA Uganda (NGO)**
	Presentation 2: Data Ownership and Knowledge in Traditional and Alternative Medicine Research: Case of Batwa Indigenous People and Local Communities in Kisoro District, Uganda **Dr. Francis Omujal, Senior Research Officer, Natural Chemotherapeutics Research Institute (NCRI)**
	Presentation 3: Pathways to conventional clinical trial testing of Traditional and Alternative Medicine research: Navigating fears of intellectual property rights & loss. How to effectively engage communities in Traditional and Alternative Medicine (TAM) research? **Dr. Pauline Byakika-Kibwika, Vice Chancelor Mbarara University of Science and Technology (MUST)**
	Presentation 4: Intellectual property landscape in Uganda, Application to Traditional and Alternative Medicine research: Regulatory Perspective **Mr. Marvin Alinaitwe, Intellectual Property Officer, Uganda National Council for Science & Technology (UNCST)**

TIME	ACTIVITY
2:35 - 5:00pm	**PARALLEL SESSIONS**
	TRACK 3: Ethics of Novel Innovations and Emerging Research Designs **Chair & Co Chair: Dr. Fred Bulamba & Dr. Jane Nakibuka**
	Presentation 1: The ethical conduct of cell and gene therapy research: Novel challenges and ethical considerations for researchers and regulators (REC, UNCST & NDA) **Dr. Cissy Kityo, Executive Director Joint Clinical Research Center (JCRC)**
	Presentation 2: Ethics of Adaptive trial designs: What are they and what do Research Ethics Committees (REC), research regulators and research participants need to know? **Dr. Victoria Nankabirwa, College of Health Science, School of Public Health Makerere University**
	Presentation 3: Ethics of Social Behavioral Research and Community Engagement **Dr. Stella Neema College of Humanities and Social Sciences (CHUSS), Makerere University**
	Presentation 4: Establishing a single sex Schistosoma mansoni Controlled Human Infection Model for Uganda: Experiences and Lessons Learned **Dr. Moses Egessa- Uganda Virus Research Institute/Medical Research Council- London School of Hygiene & Tropical Medicine (UVRI/MRC-LSHTM)**
	TRACK 4: Research Ethics in Disease Outbreaks and other Emergencies **Chair & Co-Chair Dr. Richard Katuramu & Dr. Kassim Sadik**
	Presentation 1: Research Ethics and Research in Emergency situations: Balancing Urgency with Informed Consent and Participant Protection. What are the ethical implications? **Dr. Bruce Kirenga, Principal College of Health Sciences (CHS), Makerere University**
	Presentation 2: Emergency Research Prioritization: Who is researched on? Who benefits? Who decides? **Dr. Alex Riolexus Ario, Uganda National Institute of Public Health, Ministry of Health**
	Presentation 3: Ebola vaccine trials in Uganda: Community Engagement in emergency disease outbreaks: lessons learned. **Dr. Betty Mwesigwa, Deputy Executive Director, Makerere University Walter Reed Project (MUWRP)**
	Presentation 4: Community engagement and Research during Climate Driven Disasters: What are the ethical Challenges? **Dr. Yazidhi Bamutaze, Deputy Principal College of Agricultural and Environmental Sciences (CAES), Makerere University**
4:40 - 5:00pm	Panel discussions in the Tracks (Q & A session)

****** END OF DAY 1 ******

Wednesday 22nd October 2025

TIME	ACTIVITY
8:00 - 8:30am	Registration of participants – UNCST Secretariat
8:30 - 10:40am	**PLENARY SESSION 1: Community Engagement Across the Research Life Cycle and Post Research Responsibilities** Chair: **Dr. Grace Ndeezi & Dr. Ian Clarke**
8:30 - 9:10am	**Keynote address 2**: Ethics of Post Research Responsibilities (PRR) and obligations: The Past and Present, Areas of Agreement and Controversies; Next steps for Uganda and the Region. **Dr. Flavia Matovu, Senior Research Scientist MU-JHU Care Ltd**
9:10 - 9:35am	a. Landscape of Traditional and Alternative Medicine Research in the region: Ethics, Challenges and Opportunities - Global overview **Dr. Patrick Ogwang Engeu, Associate Professor of Pharmacy, Mbarara University of Science and Technology**
9:35 - 10:00am	b. Engaging communities in identifying community needs and protocol development (Researchers' perspective and experiences): Case study of Uganda: **Dr. Clemensia Nakabiito, Clinical Research Site (CRS) Leader MU-JHU Care Ltd**

TIME	ACTIVITY
10:00 - 10:25am	c. Ethics of Controlled Human Infection Studies in low resources Settings, Is Region Ready? **Dr. Primus Che Chi & Dr. Maureen Njue, Kenya Medical Research Institute (KEMRI) - Wellcome Trust Research Programme (KWTRP)**
10:25 - 10:40am	Panel Discussion (Q& A session)
10:40 - 11:00pm	HEALTH BREAK
11:00am - 1:00pm	**PLENARY SESSION 2: - Community Engagement Across the Research Life Cycle!!** **Chair & Co-Chair Dr. Phillipa Musoke & Dr. Julaina Obika**
11:00 - 11:25am	a. Community Engagement in a Pathogen Economy **Ms. Brenda Nakazibwe- Pathogen Economy Team Lead Science Technology and Innovation - Secretariat (STI-OP)**
11:25 - 11:50am	b. Clinical Trials Insurance, are we enriching or making insurance companies wealthier: Serious Adverse Events and compensations for research related injury (Role of the Research Ethics Committee, Principal investigator and National Regulators (UNCST & NDA). Who is responsible for what? **Ms. Diana Kesi Nakitto, Manager Clinical Trials Unit National Drug Authority**
11:50am - 12:15pm	c. Changing paradigms, electronic research methods and consenting: Ethical and legal Issues and how to engage the research communities. **Dr. Adrian Jjuuko, School of Law, Makerere University**
12:15 - 12:40pm	d. Social and Behavioral Research: Engagement and Post Research Responsibilities **Dr. David Mafigiri, College of Humanities and Social Sciences, Makerere University**
12:40 - 1:00pm	Panel Discussion (Q& A session)
1:00 - 2:00pm	HEALTH BREAK- LUNCH
2:00 - 4:00pm	**PLENARY SESSIONS**
2:00 - 3:00pm	**PLENARY SESSION 4 - PANEL DISCUSSION:** **Stakeholder Perspective - Community Engagement** Session Chair & Co Chair: **Dr. Frederick Nakwagala & Dr. Victoria Namuggala**
	Not Just Optional: Why do Community Voices matter in public health emergencies? Shared experiences in community.
3:00 - 4:00pm	**PLENARY SESSION 5 - CLOSING SESSION** Session Chair & Co Chair: **Dr. Joseph Kagaayi & Dr. Martin Ongol**
	Summary of Proceedings, Chairperson Scientific & Planning Committee 12th ANREC
	Vote of thanks, Participant representative
	Official Closing **Dr. Rhoda Wanyenze**, Chairperson UNCST Council
4:00pm	COCKTAIL AND DEPARTURE

PARTNERS

NATIONAL DRUG AUTHORITY

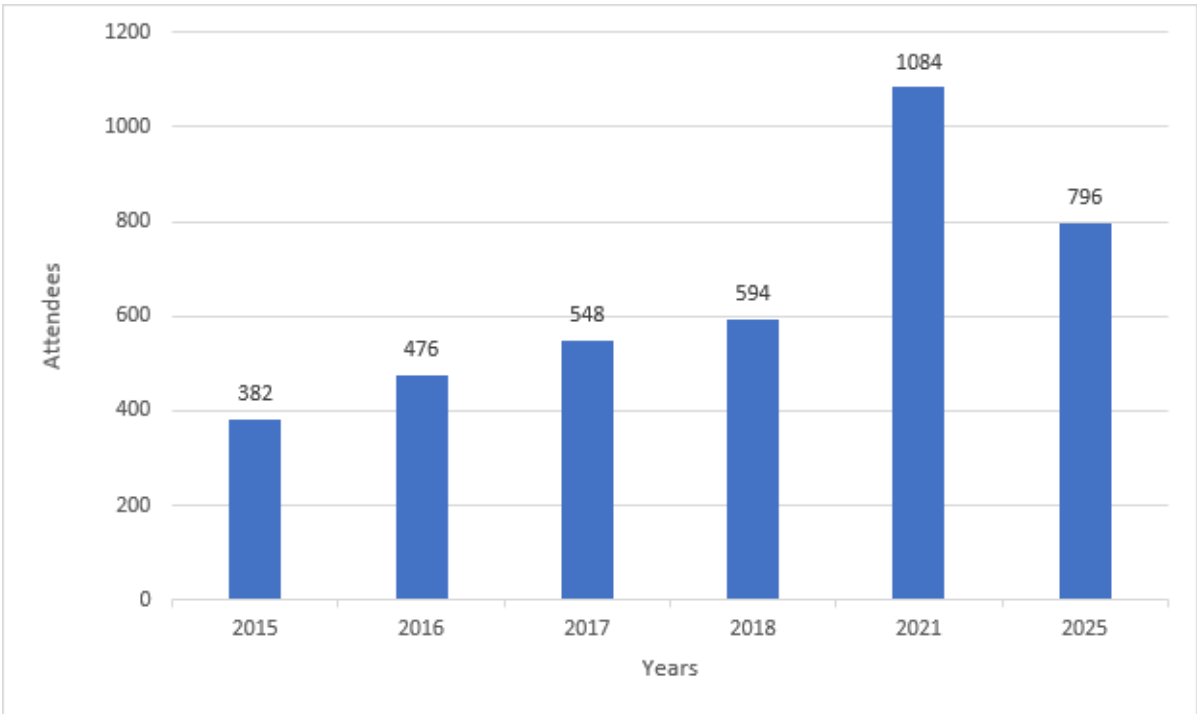
UNHRO Uganda National Health Research Organisation

MAKING UGANDA THE BEST

Participants Evaluation of the Conference

	Percentage of Participant's Evaluation					
	Excellent	Very Good	Good	Fair	Poor	Total
Choice of Presenters	45.4%	47.2%	7.4%	0.0%	0.0%	216
Quality of Presentations	30.6%	57.9%	11.1%	0.5%	0.0%	216
Relevance of Presentations	45.8%	44.4%	9.7%	0.0%	0.0%	216
Time allocated for discussions	9.7%	27.8%	36.6%	21.3%	4.6%	216
Time Management	5.1%	15.7%	33.8%	34.3%	11.1%	216
Choice venue	35.2%	31.5%	21.8%	10.2%	1.4%	216
Extent to which expectations were met	19.9%	54.2%	23.1%	2.8%	0.0%	216
Overall rating of conference	25.9%	53.7%	19.0%	1.4%	0.0%	216

Attendance Trends 2015 to 2025



Gender Participation Overview

Gender	Number	Percentage
Females	396	49.7%
Males	400	50.3%
Total	**796**	**100%**

Age Composition of Conference delegates

Age bracket	Number	Percentage
18 - 35	143	18.0%
36 - 55	339	42.5%
56 & Above	77	9.6%
Unconfirmed	237	29.8%
Total	**796**	**100%**

Frequency of Attendance

First Time Attendee	Number	Percentage
Yes	329	41.3%
No	230	29.9%
Unconfirmed	237	29.8%
Total	**796**	**100.0%**

Nature of the Participants.

Student Attendee	Number	Percentage
Yes	25	3.14%
No	539	67.7%
Unconfirmed	237	29.9%
Total	**796**	**100.0%**

Institutions of Affiliation

Organisations	Number of Participants
Makerere University	106
Mbarara University of Science and Technology of Science and Technology	65
Uganda National Council for Science and Technology	56
Makerere University –Johns Hopkins University Research Collaboration	38
Uganda Virus Research Institute	30
Uganda Cancer Institute	28

Organisations	Number of Participants
Uganda Heart Institute	21
The Aids Support Organisation	18
Baylor Foundation Uganda	17
Kyambogo University	16
Mulago National Referral Hospital	15
Uganda Management Institute	15
Joint Clinical Research Centre	14
Busitema University	13
MRC/UVRI & LSHTM Uganda Research Unit	13
Mbale Regional Referral Hospital	13
Kampala International University	13
St. Marys Hospital Lacor	12
Infectious Diseases Institute	11
National Drug Authority	11
St. Francis Hospital Nsambya	10
Gulu University	8
Global Health Uganda	8
Uganda Christian University	8
Uganda National Health Laboratory Services	8
Lira University	8
Kabale University	7
Researcher	7
Hospice Africa Uganda	6
Epicentre MSF	5
FILMERA	5
Mildmay Uganda	5
Bishop Stuart University	5
	5
National Agricultural Research Organisation	5
Epicentre MSF	4
Uganda Martyrs University	4
Ibanda University	4
Soar Research Foundation	4
Clarke International University	4
Vector Control Division	4
Kenya Medical Research Institute	4

Organisations	Number of Participants
Institute Of Disease Research Centre	4
Bugema University	3
Afya Na Haki	3
DVI	3
IDU	3
Nkumba University	3
Researcher /Investigator	3
Africa Renewal University	3
Ministry of Science, Technology and Innovation	3
Kawempe National Referral Hospital	3
Jinja Regional Referral Hospital	3
Africa Medical and Behavioral Sciences Organization	3
Visual Extreme	3
THRIVE Gulu	3
Mengo Hospital	3
Venue Services	2
All Saints University Lango	2
Lubaga Hospital	2
Ernest Cook University	2
Uganda Virus Research Institute – International AIDS Vaccine Initiative HIV Vaccine Program	2
Adara Development Uganda	2
Islamic University	2
Kyabirwa Surgical Center	2
Busia	2
International Livestock Research Institute	2
UVRI Plague Program	2
African Field Epidemiology Network	2
Soroti University	2
Radio 1	2
Victoria University	2
Rakai Health Sciences Program	2
Kabwohe Clinical Research Center	2
Mbarara	2
Deputy Resident City Commissioner	1
UPU	1

Organisations	Number of Participants
Uganda Industrial Research System	1
Makerere University Business School	1
International Livestock Research Institute	1
Jimma University	1
Uganda Broadcasting Corporation Television	1
Jinja City	1
WALIMU	1
Nakawa Blessed Sacco	1
Medical Research Council / Uganda Virus Research Institute	1
Nakawa Division	1
Ernest Cook University	1
Engineering Development and Innovation Centre	1
Livestock Research Institute	1
Ethiopian Food and Drug Authority	1
Driver – Resident City Commissioner, Jinja City	1
Natural Chemotherapeutic	1
Bukedde	1
Natural Chemotherapeutics Research Institute	1
Uganda National Health Research Organisation	1
New Uganda Securiko	1
Institute of Traditional Medicine	1
New Vision	1
UVRI-IAVI HIV Vaccine Program	1
National Institute for Medical Research	1
IQVIA Holdings Inc.	1
Jinja City	1
Daily Monitor	1
Not aplication	1
Team University	1
Program for Appropriate Technology in Health	1
DMI	1
POMU	1
Ministry of Agriculture, Animal Industry and Fisheries	1
Kampala Central Women	1
Masaka City	1
Radio Sanyu	1

Organisations	Number of Participants
Mbale City	1
African Population and Health Research Center	1
Uganda National Association of Community and Occupational Health	1
Resident City Commissioner	1
Womens Council	1
Refuge and Hope International	1
UNIPAH	1
Research Ethics	1
Medical Research Council	1
Research Ethics Manager	1
UVRI Plague Project	1
Capital Fm	1
Mulago Hospital Research Ethics Committee	1
Kiruddu Hospital	1
Uganda Wildlife Authority	1
Self-Employed	1
Ministry of Health	1
St. Francis Hospital Nsambya Research and Ethics Committee	1
ISBAT University	1
Cavendish University Uganda	1
Assistant Resident City Commissioner – Masaka City	1
(blank)	1
MC & IT	1
Grand Total	796

List of Participants

NAME	ORGANISATION
Aanyu C Harriet	The Aids Support Organisation
Achom Irene	Mulago National Referral Hospital
Aciro Joyce	Thrive Gulu
Adeodata Kekitiimwa	Baylor Foundation Uganda
Adia Nakuti	Uganda Broadcasting Corporation Television
Adokorach Gladys	St.Marys Hospital Lacor
Adrian Jjuuko	Makerere University
Adron C. Nsibambi	Kyambogo University
Afizi Kibuuka	Jinja Regional Referral Hospital
Agatha Mukanza	Makerere University
Agnes M. Mugagga	Makerere University–Johns Hopkins University Care Limited
Agnes Nakalema	Self-Employed
Agnes Lwanga	Lubaga Hospital
Agnes Nalubiri	Mbale Regional Referral Hospital
Ahairwe Ulian	Mbarara University of Science and Technology
Ahmed Kiswezi	Kampala International University
Ahumuza Eliva	Joint Clinical Research Centre
Aida Nakawunde	Makerere University
Aidah Nanvuma	Makerere University
Ajok Florence	Infectious Diseases Institute
Akandinda Mildred	Kampala International University
Akidi Hellen	St.Marys Hospital Lacor
Akim Twinamatsiko	Mbarara
Akullu Winnie	Uganda Cancer Institute
Alen Musisi	Ernest Cook University
Alex Erejo	Hospice Africa Uganda
Alex Thomas Ijjo	Cavendish University Uganda
Alexander P. Isiko	Kyambogo University
Alfred Driwale	Uganda National Council For Science And Technology
Alfred Nuwagaba	Uganda Management Institute
Ali Kalulu	Uganda Heart Institute
Ali Ssetaala	Uganda Virus Research Institute – International AIDS Vaccine Initiative
Asseta Ejamo	Ethiopian Food and Drug Authority

Allen Kekibiina	Mbarara University of Science and Technology
Alex A. Riolexus	Uganda National Institute of Public Health and Allied Health Sciences
Ayugi Joyce	National Drug Authority
Allen Kabagenyi	Makerere University
Allen Kiconco	Mbarara University of Science and Technology
Allen Nambooze	Makerere University
Allen Naamala	Uganda Cancer Institute
Alison Elliott	Medical Research Council/Uganda Virus Research Institute and London School of Hygiene & Tropical Medicine Uganda Research Unit
Alliyah Nakato	Uganda Virus Research Institute
Amongi Lydia	Lira University
Amuge Salome	Thrive Gulu
Andrew Ojok Mijumbi	The Aids Support Organisation
Andrew Okello	Makerere University
Angela Tushabe	Mbarara University of Science and Technology
Angella Mpooya	Uganda Virus Research Institute
Angella Mirembe	Uganda Cancer Institute
Angucia Bridget Sharon	Uganda Cancer Institute
Annah Atuhaire	Bishop Stuart University
Anne Kapaata	The Aids Support Organisation
Anne Ruth Akello	Lira University
Anne Nganda	Lubaga Hospital
Anne Mary Nakyajja	Makerere University–Johns Hopkins University Care Limited
Anne Ampaire Musika	Makerere University
Anne Kapaata	The Aids Support Organisation
Annet Kutesa	Makerere University
Annet Beatrice	Makerere University
Annet Aketoko	Makerere University
Annet Kembabazi	Mbarara University of Science and Technology
Annet Kutesa	Makerere University
Anthony Mpairwe	Bishop Stuart University
Anyango Judith	St. Francis Hospital Nsambya
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