

LIVE
WEEKLY
WEBINAR

20
26

FRIDAY
8-9pm



Busoga
HEALTH FORUM
Always caring, Always here, because your life matters



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13th
FEBRUARY

PRESENTER



Dr. Frederick Nakwagala

Senior Consultant Physician,
Mulago National Referral Hospital and
Chair Accreditation Committee for RECS and
IACUCS at Uganda National Council for
Science & Technology (UNCST)

TOPIC:

Ethical Issues in Health Research in Uganda

Regulatory and ethical review processes, researcher
responsibilities, and practical ethical issues encountered
during research implementation in Uganda.

MODERATOR



Dr. Wilberforce M Kabweru

Senior Consultant Surgeon, Mulago National
Referral Hospital, Vice President, Uganda
Medical Association (UMA), CPD Chair,
Busoga Health Forum.

Register today



<https://shorturl.at/IVhBz>

A Healthy, Thriving Busoga



@BusogaHealth



Busoga Health Forum



www.busogahealthforum.org



BUSOGA HEALTH FORUM Official

What is Busoga Health Forum



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Busoga Health Forum (BHF) is an association of like-minded people and professionals stimulating community, Government and Partner actions for better Health of the people. We are a national, not-for-profit voluntary membership-based organization headquartered in the heart of Busoga-Jinja city.

BHF works in collaboration with the Ministry of Health, local governments, and Civil Society Organisations to coordinate health interventions through established technical working groups and technical/administrative structures including; District Health teams, and formal and non-formal community structures.

BHF is therefore a think tank, generating evidence to drive health policy action to improve the health and development of individuals in Busoga and beyond.



Ethical Issues In health Research in Uganda

DR NAKWAGALA FREDERICK NELSON

SENIOR CONSULTANT PHYSICIAN MULAGO NATIONAL REFERRAL HOSPITAL AND CHAIR
ACCREDITATION COMMITTEE OF RECS AND IACUCS OF THE UNCST

13/2/2026

Main focus of presentation



Regulatory and ethical
Review processes

Researcher and
Institutonal
responsibilities

Theoretical and
practical ethical issues
during research
implementation in
Uganda

MAIN DOMAINS

METAETHICAL

- PHILOSOPHICAL REFLECTIONS ON THE WHY OF RESEARCH
- CONCEPTUAL ISSUES ON NON PRIORITISATION OF FUNDING RESEARCH
- WHY RESEARCH IS NOT LOOKED AT FROM BUSINESS ASPECT

NORMATIVE

- DO WE HAVE ADEQUATE PRESCRIPTIONS ON HOW RESEARCH REGULATION SHOULD BE DONE IN UGANDA

DESCRIPTIVE

- TO WHAT EXTENT HAVE WE CONTEXUALISED OUR UNIQUE SETTINGS?
- HOW HAVE WE DONE IT?
- HAVE THE TRADE OFFS BEEN ETHICALLY JUSTIFIED

HISTORY OF RESEARCH IN HEALTH IN UGANDA



1901-1902 First clinical trial at Mengo Hospital by Dr Albert Cook on Trypanosomiasis. All study participants died!

There was a national Research Council at Office of the President

Mulago Hospital had first Institutional research ethics committee headed by the late Prof Odonga

Main guidance was Declaration of Helsinki.

Health research history in Uganda



Uganda was instrumental in discovery of prostaglandins and important tumours like Burkits Lymphoma.



UVRI established in 1936 with discovery of Zika Virus.



Unregulated and hidden use of Thalidomide in Church based Health Institutions in Western Uganda leading to Phocomelia



Uganda Trypanosomiasis Control Council established in 1992 used framework of One health to control illness by an Act of Parliament.



Uganda Industrial Research Institute In Ministry of Trade, Industry and Cooperatives.

AFTER 1986



- 1990 UNCST FORMED BY ACT OF PARLIAMENT
- 1993 NDA
- 2011 UNRHO

- JUMP IN RESEARCH DUE TO HIV/AIDS. OTHER FIELDS LIKE MALARIA, TUBERCULOSIS, TRYPANOSOMIASIS, COVID 19, OBSTETRICS AND PEDIATRICS, ONCOLOGY, SICKLE CELL, SOCIAL SCIENCE RESEARCH ETC.

- VARIOUS TRAINING INSTITUTIONS STARTED REQUIRING RESEARCH AND MODIFIED CURRICULAR TO ACCOMMODATE THIS, BUT SENIORS IGNORANT AND SUPERVISION AND / OR MENTORSHIP IS POOR

UNCST



HAS MADE GREAT STRIDES IN GUIDELINES DEVELOPMENT WITH EXPECTED REVISION PROVIDING FOR EMERGING ISSUES

ACCREDITATION OF RECS/IACUCs

CONDUCTS CONTINUING MONITORING

ESTABLISHED OFFICE OF RESEARCH INTEGRITY

REMAINS UNDERFUNDED

SPECIALISED COMMITTEES



RECS

IACUCS

NBC

IBC

National Accreditation Committee for RECs and IACUCs

AD HOC TASK FORCES LIKE AT JOINT REVIEW AND PEER REVIEW

UNCST HAS DELIBERATELY AVOIDED A NATIONAL REC

RECS IN UGANDA



Present in regions except Karamoja, Bunyoro and Kigezi subregions

They have significantly energized research regulation in Uganda.

Many still look at Science more than the ethics

Undergo accreditation and renewals of accreditation every

three years.

NDA



HAS REGULATIONS FOR CLINICAL TRIAL
CONDUCT

HAS ELABORATE MONITORING ACTIVITIES

IN UNDERGOING REVIEW OF ITS ACT TO
TRANSFORM INTO FOOD AND MEDICINE AGENCY

UNRHO

CONTINUES LAME DUCKING

GUIDELINES



- UGANDA HAS SPECIALISED IN WRITING GUIDELINES BUT IN RESEARCH AREA THESE ARE LARGELY FOLLOWED WITH FEW EXCEPTIONS
 - Delayed updates
 - Non accreditation of biobanks yet operational
 - Operationalisation of non accredited RECs by some institutions
 - Inappropriate or illegal transfer of data
 - Slowed response to emerging issues like digital migration and AI
 - Open flouting of existing guidelines with lack of concept of Research integrity at Institutional level.
 - Failure to implement Post Trial Access, benefit sharing and Intellectual properties

MAJOR CHANGES IN NATIONAL GUIDELINES



NEED FOR SITE INSPECTION BEFORE STUDY APPROVALS BY RECS

REMOVING CATEGORY OF MATURE AND EMANCIPATED MINORS

NEW GUIDANCES ON AI, RESEARCH INTEGRITY, COMPLEX STUDIES, GENE THERAPY, GENE EDITING OR THERAPY, CONTROLLED HUMAN INFECTION MODELS, POST TRIAL ACCESS DATA SHARING AND TRANSFER

OTHER CURRENT STRATEGIES



ONE HEALTH APPROACH

EMBRACING RESEARCH INTEGRITY

COLLABORATION WITH PUBLIC AND PRIVATE PLAYERS

INCREASED PUBLIC SECTOR SUPPORT AND FUNDING

PATHOGEN ECONOMY

IP AND PATENTS

COMMUNITY ENGAGEMENT

DIGITAL MIGRATION AND AI EMBRACING.

BIOETHICS TRAINING IN UGANDA



FORMALLY STARTED WITH FORGARTY NIH GRANTS IN 2001

LATER MAKERERE STARTED MASTERS IN BIOETHICS

MUST, UCU, UGANDA MARTYRS AND MAKERERE SCHOOL OF PUBLIC HEALTH PROVIDE BLENDED COURSES INCORPORATING ETHICS

MANY INSTITUTIONS PROVIDE SHORT COURSES LIKE GCP OR GCLP

UNCST COMPRISES TEAMS TO TRAIN IN HSP, GRRP, GCP.

TRUMP EFFECT



- The sudden withdrawal or termination of research grants under USAID and NIH mechanisms sent numerous reverberations across the world
- Some argue it will be overall positive as we learn self reliance and redirect funding mechanisms to alternatives

COVID 19 EFFECT



- The advent of Covid 19 shook many traditional foundations.
- UNCST developed specific guidelines for research conduct.
- Uganda was able to conduct clinical trials and other related research despite the pandemic.
- digital meetings and online regulation escalation
- Vaccine hesitancy
- Increased awareness of need for transparency
- Increased need for more assertive government regulation for public health disease control
- Need for expediting regulation of pandemics
- More commiitement by governments to improve local health delivery and research for home solutions due to lock down

ARE UGANDAN INSTITUTIONS PLAYING PIVOTAL ROLE



NO. NOT YET BUT MANY ARE IMPROVING

IMPOVERISHED BUDGETS

MISMATCH BETWEEN CLAIMS, MANDATES AND BUDGETARY COMMITMENTS

DEPENDENCY SYNDROME

OUTRIGHT FRAUD LIKE NOT PAYING SUPERVISORS THEIR FEES HENCE STUDENTS GO UNSUPERVISED

YET HUGE OPPORTUNITIES PREVAIL FOR GROWTH OF RESEARCH ENTERPRISE

NO POLICIES FOR ISSUES LIKE RESEARCH INTEGRITY, CONFLICT OF INTEREST

Investigators

- Are doing great work despite the challenges but:
 - Need to be further educated on ethics and human participant protection
 - Carry out unregulated research
 - Flout policies a lot
 - Receive tonnes of training but application remains low
 - Grudgingly pay participants compensation!
 - Are willing to be used by others
 - Do not pay attention to detail especially documentation

ROLE OF SUPERVISORS



Is largely ceremonial.



Scrutiny of the research process is wanting



Institutions had little conceptualisation of research



Many are ignorant of research regulation and ethics

CONTROVERSIES IN STANDARD OF CARE



DART AT IDI AND JCRC

TB PREVENTION STUDIES AT CWRU COLLABORATION

PROMISE AT MUJHU/MULAGO

COAST AT MULAGO

HIVNET 012 AT MULAGO

HIV VACCINE TRIALS AT JCRC

PARTICIPANT COMPENSATION



Historically was held as a taboo to offset undue inducement in limited resource settings.



Average Investigator uses this as scapegoat to offset budget shortfalls



Many students in training don't appreciate the justification for compensation.



Many cheat participants even after signing consent forms

CONCLUSION

UGANDA BOASTS OF A RICH HISTORY AND CULTURE OF RESEARCH
REGULATION SOMETIMES WOVEN IN CONTROVERSY AND FACED WITH
HUGE ETHICAL CHALLENGES BUT OBJECTIVELY TUNED TO ADAPTATION
TO SUIT EVOLVING TRENDS