



Biospecimen and Biobanking Practices in East Africa

Maseno University, York University, & Wayne State
University Collaborative Conference

SUMMARY

The collection of human tissue, or biospecimens materials, is a critical process in biomedical research in areas as diverse as cancer research to tropical medicine. However, the collection, storage (biobanking), and sharing practices of human samples or biospecimens (blood, semen, breastmilk, foreskins, vaginal secretions, tissue) have raised many concerns among scientists and communities, resulting in legal cases, new regulations, and policy changes (Van Assche, Gutwirth, Sterckx, 2013).

In Kenya, biospecimens continue to be collected and, too often, shipped abroad for storage in the Global North, raising concerns about how those biospecimens are being shared, used, and eventually disposed of. Many Western researchers argue that the region doesn't have the scientific infrastructure required for biobanking, yet this isn't accurate. It has some of the continent's leading infrastructure due to investment resulting from HIV/AIDS science in the region.

We propose a collaborative workshop to explore the racial, ethical, and cultural controversies, networks, and collaborations that would facilitate the advancement of human biobanking in East Africa. We ask: How might East African scientific infrastructure be strengthened to support biospecimen storage and its local regulation?

The purpose of our workshop is twofold: 1) To begin to document and understand the processes, practices, and ethical challenges among researchers for collecting, transporting, sharing, storing, and either disposing or repatriating human biological samples in global health clinical trials; and 2) to develop a new, multi-disciplinary international team of researchers with a commitment to further exploring the ethics of biobanking and questions about data sovereignty among East African communities socialized for scarcity.

WORKSHOP SCHEDULE

Day 1

Opening Remarks

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| 8:30 AM | Tea and mandazi to be served. |
| 9:00 AM | Welcome Dr. Patrick Mbullo Owuor, Assistant Professor, Wayne State University, Detroit, USA |
| 9:15 AM | Dr. Louisa Njeri Ndunyu, Chair, School of Public Health, Maseno University |



- 9:20 AM Dr. Pauline Andang'o, Dean, School of Public Health & Community Development
- 9:25 AM Professor Philip Okinda, Chair, Maseno University Scientific and Ethics Review Committee
- 9:30 AM Professor Joseph Chacha, Deputy Vice Chancellor Partnerships, Research and Innovations
- 9:35 AM Dr. Patrick Mbullo Owuor, Wayne State University and Dr. Denielle Elliott, York University

Theme 1: Policy and Ethics

9:45 – 10:10 (15-20 min per presentation, 5-8 min Q&A)

1. Dr. Bernard Guya, School of Public Health & Community Development, Maseno University

Presentation: Ethical Issues in Biobanking and Genomic Data Sharing: Possible strategies to navigate through the challenges

10:10 – 10:35

2. Dr. Jane Wathuta, National Bioethics Committee (NBC), Professor of Law at Strathmore University

Presentation: Regulation and Governance of Human Biobanking in Eastern Africa vis-a-vis the International practice: Are we at par?

10:35 – 11:00

3. Dr. Evelyn Chege, Head Technical Services for Kenya Tissue and Transplant Authority

Presentation: Policy, Legislative and Regulatory Framework in Cells, Tissue and Organ Banking for Transplantation

Q&A 11:00 – 11:15

Theme 2: Community Practices

11:15-12:40

4. Dr. Timothy Thomas, Physician Researcher, Alaska Native Tribal Health Consortium

Presentation: Indigenous models of regulation for data and biospecimens: Reflections from the US

11:40-12:05

5. Mr. Pascal Macharia, Program Manager, Health Options for Young Men on HIV/AIDS/STI (HOYMAS)



Presentation: The Critical Role of Target Communities in HIV Phylogenetic and Other Biomedical Research Design and Implementation.

12:05 – 12:30

6. Ms. Melba Katindi, KEMRI-SERU

Presentation: Emerging Trends in Community-Led Research in Kenya: Threat or Opportunity?

12:30 – 12:55

7. Ms. Sarah Karanja, Public Health, KEMRI

Presentation: Biopiracy and data sovereignty

12:55 – 1:15 Q&A

1:15 – 2:30 Lunch

Theme 3: Scientific Considerations

2:30 – 2:55

7. Leonard Kingwara, Head of Genomic and Molecular Surveillance Laboratory Unit at NHRL

Presentation: The biorepository of pathogens at the Kenya National Public Health Institute

2:55 – 3:20

8. Naomi Lucchi, Laboratory Director for the CDC Global Health Security programs

Presentation: Laboratory logistics of biospecimen storage and transfer.

3:20 -- 3:45

9. Martin Rono, Head of Biobank, KEMRI Wellcome Trust

Presentation: Biobanking in Africa: Lessons from KEMRI Kilifi Biobank

3:45 – 4:10

10. Albert Okumu, Laboratory Director, KEMRI, Kisumu

Presentation: Human biological samples, the Gem of Research

4:10 – 4:45 Q&A and final thoughts

Pre-registration is required for this conference. To register, please email Doreen at d.obondo@gmail.com



DAY 2 is limited to presenters and organizers

Day 2: Moving forward

This session will be opened only to workshop presenters and will focus on developing a new multi-disciplinary international team of researchers with a commitment to further exploring the ethics of biobanking and questions about data sovereignty. This session will specifically explore funding and opportunities, as well as training and capacity strengthening for researchers and students.

8:30 Tea and mandazi

9:00 Welcome and agenda – number of trials that have been carried out in Kenya, and how many of them export biological samples [PM]

9:20 Review of yesterday (concluding thoughts) [DE]

9:35 What did we miss the day before [PM]

10:30 Moving forward: [PM]

- a. White paper? Or peer-reviewed paper (suggestions of journals)
 - a. Process?
- b. Team grant to explore more (possibilities, leads, who wants to be involved, what they would need from the grant, funding for a grad student, second follow-up meeting, research question, methods, other possible collaborators, brainstorming).
 - a. Global Research Excellence (GRE) Seed Funding (York internal)
 - b. CIHR
 - c. NFRF
 - d. NIH
 - e. NSF
 - f. Other opportunities?
- c. Working group

12:30 Wrap up.