

# Serving East African Bioethics Information and Education Needs

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# Outline

**Objective:** To identify the challenges of supporting the information needs of students and researchers participating in an international research ethics education practicum between universities in Kenya and the United States.

- Background
- Information needs and skills
  - » Kenyan students visiting the U.S.
  - » Kenyan students returning to Kenya
- Unexpected Outcomes
- Lessons Learned



# Disclaimer

The lead author of this presentation has yet to visit Moi University (or any other place outside of North America).

# IU-Kenya

- 1917 – Eldoret “Cottage” Hospital
- 1984 - Moi University (Eldoret, Kenya)
- 1989 - IU-Kenya Partnership
- 1990 - Moi University Faculty of Health Sciences
- 1998 - Moi Teaching and Referral Hospital
- 2001 - AMPATH: Academic Model for Prevention and Treatment of HIV/AIDS

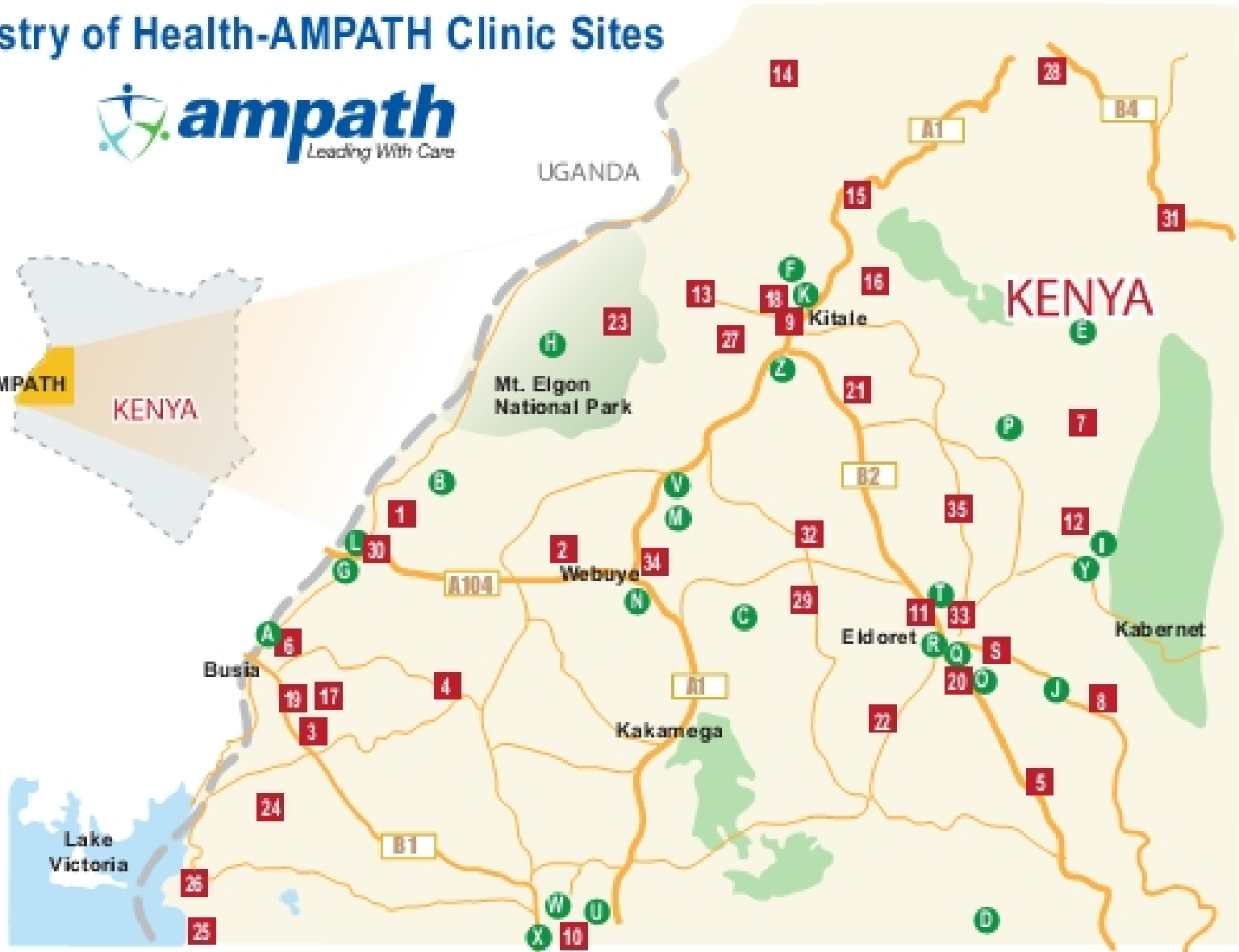
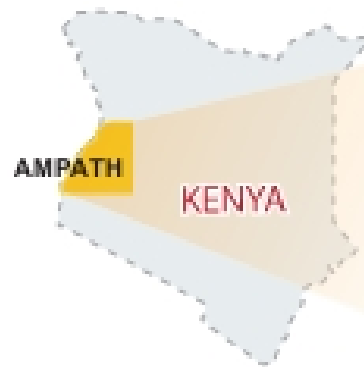


# AMPATH: Academic Model Providing Access to Healthcare (2008)

- "critical needs for primary healthcare, chronic disease care, and specialty care"
- 140,000 HIV-positive patients
- 10,000 Newborn deliveries
- 8,000 Oncology patients
- 3,000 Enrolled in diabetes outreach



# Ministry of Health-AMPATH Clinic Sites



# Global - Local

## Clinical research: global\*

- 15% annual growth in non-U.S. sites
- 78% of all subjects in clinical trials at non-U.S. sites in 2008
- The number of non-U.S., non-European human subjects doubled between the years 2004 and 2009.

\*<http://hdl.handle.net/1805/3296>

## Ethical issues: local

- Informed consent ?
- Vulnerable populations?
- Benefit sharing?
- Language, religion and cultural issues?
- Are different standards ... "lower" standards?
- What is "a person"?
- Privacy?
- Community?
- Justice?

# Indiana University-Moi University Academic Research Ethics Partnership (IU-Moi U AREP)



International Research Ethics Education and Curriculum  
Development Award (Bioethics): NIH Fogarty,  
<http://www.fic.nih.gov/Programs/Pages/bioethics.aspx>

## IU-Moi U AREP

Building local capacity to address  
international research ethics issues

- Co-PIs
- Dual Master's Degrees
- Overlapping Components
- Joint Advisory Committee
- Cross-cultural practicum experience





# The Practicum (U.S.)

- **Six students from Moi U**
- Six weeks at IUPUI (Fall)
- Work with local mentors
- Develop the groundwork for a capstone project
- Conduct a literature review
- Full access to library, computing, software, training
- Complete capstone in Kenya
  
- **Three librarians**



# IU Medical Library: Crash Course

- **2011** - 3 Sessions (Basics; Bioethics Information Resources; EndNote) + 18 individual consultations
- **2012** - 4 Sessions: (Basics; Bioethics Information Resources; EndNote; Zotero) + 16 individual consultations

## Basics

- Login to IU system & courseware
- Use the internet, find: campus IT support, key campus websites, library databases, PubMed, Google Scholar
- Campus map

## (Bioethics) Information Search Skills

- Find the call number for a specified book title
- Access the full text of an ethics article (in a specified journal)
- Find the "Bioethics" subject guide
- Use PubMed to find articles about ....

## Reference Management

- Install software/create account
- Create a record
- Import items
- Manage and edit collection
- Create a reference list
- Format a reference list
- Create an in-text citation
- Find help

# General Observations from Librarians

- **Wide range of information skills**--from “digital natives” with (U.S.) graduate degrees ... to ... new to the keyboard & mouse.
- **Quiet during group sessions** (reluctant to volunteer and share).
- **Oceans of literature:** Some students underestimated the typical number of articles published on any given bioethics topic.
- **Eager to try everything**, even if resource would not be available in Kenya, but ...
- **Looking for books.**



# Feedback from Students

- “Overall I would rate this session ...” - 4.47/5.0
- “This will save me a great deal of time ...”
- “I will have to download more information for my thesis ...”
- “This will enhance the outcome of my paper. Also I will be able to reference most of my papers.”
- **“Exposed me to resources I never imagined existed.”**



# “Slow down the pace.”



“The US has a much faster pace than Kenya. The situation was worsened by the fact that many of us were not conversant with basic computer skills

....

Asking us to follow maps to find our destinations around the campus was stressful. We rarely use maps in Kenya and yet the assumption was that we could all read maps. I know some of us who missed our appointments merely because we could not find our way to specified offices.”

# Unexpected Outcomes

## Practicum students in the U.S. = Educators in Kenya

“This was a turning point in my work, literature review and referencing. ... This is something I can share with my colleagues and students.”

The logo for Zotero, featuring the word "zotero" in a lowercase, sans-serif font. The letter "z" is red, and the remaining letters "otero" are black.

Home > MEDLINE/PubMed Resources

PubMed® Special Queries

Directory of Topic-Specific PubMed Queries

The logo for Globethics.net, featuring the text "Globethics.net" in a white, sans-serif font on a blue background. There are thin white curved lines above and below the text.

Dialogue, reflection and action

Library | Network | Research | Services

70'000

Participants registered

# Unexpected Outcomes

## Students = Advocates

### Open Access + Public Access

- “We have materials for references out here ... I hope I can access / get other literature for my papers.”
- “access is pertinent to research”
- “more knowledge available”
- “utmost importance”
- “HINARI is not enough”



# Unexpected Outcomes

## Moi University Bioethics Library

- Launched: February 3, 2012

**Purpose:** "in preparation for the establishment of the Moi University Centre for Bioethics"

**Goal:** "Be a resource centre for the greater Eastern Africa Region which includes Kenya, Tanzania, Uganda, Rwanda, Burundi , South Sudan, Ethiopia and Somalia."





# Unexpected Outcomes

## Moi University Bioethics Library

- Launched: February 3, 2012

### Current resources:

- 38 titles
- Space
- \$2,400 - Deputy Vice Chancellor in Charge of Research and Extension, Moi University
- Donations from individuals (from Moi U and IU)

### Needs:

- Books and materials - bioethics, research ethics, legal issues, international issues, social issues in public health and health research.
- Furniture - (shelves, desks, tables, chairs ...)
- Computers

# Unexpected Outcomes

## Moi University Bioethics Library

- Launched: February 3, 2012

“We, the pioneer class, wanted it created because we had a difficult time studying bioethics without basic resource materials . We wished that students coming after us would have an easier time. We were overwhelmed when we got to Indiana to find so many materials on human research ethics and it was difficult to read all these over our 6 weeks stay given our busy schedules. ... Each of the students in the pioneer class donated at least one book.”



# Lessons Learned

- **Slow down:** shorter sessions, more sessions.
- **Online skills:**
  - team-based learning = good (best in pairs);
  - classroom participation = not so good.
- **Accessible search tools:** PubMed, EthicShare, Globethics, GoogleScholar ...
- **Affordable Software:** Zotero, LibraryThing, Google Drive ...
- Schedule (plenty of) **one-to-one time** with a librarian.
- Students used: **Custom searches** (canned PubMed strings), pre-prepared bibliographies ...
- Students loved: **Print-based** resources and monographs
- **Teach the teachers:** Students have requested guides and tutorials to share with peers

# Lessons Learned



**“There is a sharp difference between instruction in the US and in Kenya.** Having taught in IU for a year, I noticed that the relationship between lecturers and students is much more relaxed (friendly) than back here in Kenya where we have a British kind of education. In a highly formal setting for instruction, students tend to shy away from commenting in front of their peers lest they are wrong and get embarrassed. Unless one is confident that his comment will be well taken by the lecturer as well as by fellow students, a student will not volunteer or respond to questions.”

# Lessons Learned

**Book Collections = Space = A Voice**

“There was barely one book on research ethics in the general Moi University library. ... Here we prefer print to electronic resources because many of us do not have access and competence in computer use let alone internet connectivity. ...

Our goal is to have a well stocked library as a prerequisite to the development of a Centre for Bioethics at Moi University.”



# Donations Encouraged

“Individuals are welcome to donate towards the Moi University Library for Bioethics by sending us books or funds to buy books or linking us to electronic libraries.”

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