



AMANET Health Research Ethics Capacity Building Project in Africa

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Background

- Increase in health research in Africa
 - Due to disease burden
 - Efforts to bridge the 10/90 gap
 - Efforts to meet the UN Millennium Development goals
- Exposure of African populations to possible intentional and/or unintentional harms
- Hence the need to strengthen HRE in Africa



Needs Assessment Survey across Africa

- AMANET conducted an extensive and comprehensive survey of Ethics Committees across Africa(2006-2007)
- Six Ethicists conducted the survey
- First questionnaire sent electronically to respondents, followed by face-to-face interviews by surveyors to ensure accuracy and clarity



AMANET Survey Instrument

- Questionnaire has 103 questions covering:
 - Legal frameworks
 - Composition, independency,
 - Training of members and training needs
 - Availability and sources of resources
 - Availability and quality of SOPs
 - Review procedures,
 - Data management and archiving systems
 - Etc

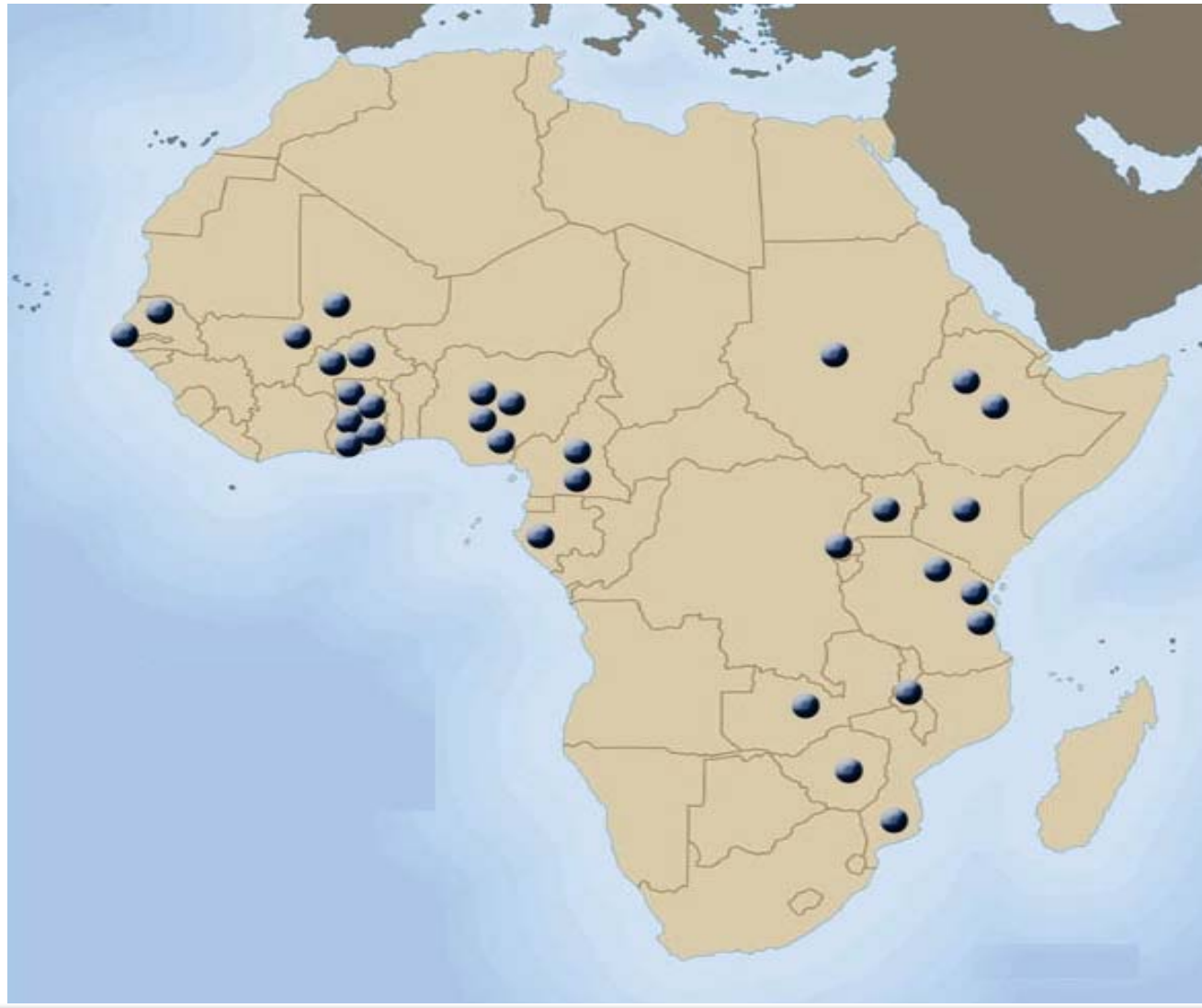


AMANET Survey Results: Overview

- 84% (31/37) response rate
- Ethics Committees in Anglophone and Francophone countries surveyed
- Traditional barriers broken
 - Francophone versus Anglophone
 - Central region of Africa accessed
- Results are covered in detail in two papers in press (JME and DWB)



AMANET Survey Results: Overview



Survey Results: Offices and equipment

- Inadequate / lack of committee office space
- Inadequate / lack of office equipment
 - Furniture, telephone, fax machines, photocopiers, computers, internet
- Reliance on cumbersome paper-based data management and archiving systems
 - All 31 surveyed committees
 - Compromises efficiency and frustrates the secretariat



Survey Results: Composition of ERCs

- Membership ranged from 3 to 21, with mean of 11 members per committee
- Challenges convening meetings
 - Busy work schedules of members
 - No sitting allowances to cover travel costs
- Lack of full time secretariat for committees
- Challenges getting members with specialized expertise
- Limited resources for consultations



Survey Results: Training needs

- Lack of (10/28) or inadequate training for members on joining
- Lack of (15/28) or inadequate continuing training of members
- Complex protocols
 - Clinical trials
 - Genomic epidemiological studies
 - Behavioural studies
 - Etc
 - Wrong decisions could compromise welfare of people
 - Approving unethical studies or rejecting ethical studies
- Increasing workload; more complex protocols for review
- Lack of (10/31) or outdated Standard Operating Procedures (SOPs)
 - Limited capability to develop/review SOPs



Survey Results: Inadequate oversight

- Lack of (16/30) or inadequate oversight of approved studies
 - Protocol deviations
 - Informed consent procedures
 - Views/concerns of participants
 - Helps to improve implementation of protocols
- Passive monitoring: reliance on reports from researchers
- Detection of potential harms compromised
 - Cumbersome paper-based data management and archiving systems (31/31) inefficient
 - If SAE reports may be 'lost' in disorganized offices follow-up and protection of participants may be compromised.



Players in HRE capacity building in Africa

- AMANET is implementing various capacity building activities in Africa
- There are other organizations involved in capacity building in Africa
 - Pan African Bioethics Initiative (PABIN)
 - South African Research Ethics Initiative (SARETI)
 - International Research Ethics Network for Southern Africa (IRENSA)
 - Training and Resources in Research Ethics Evaluation (TRREE)
 - JHU-Fogarty African Bioethics Training Program
- In light of the magnitude of the task of capacity building in Africa, complementary efforts are needed, and overlaps do not harm



Concluding remarks

- Needs assessment survey revealed challenges hindering operations of ERCs in Africa
 - Membership and attendance of meetings
 - Lack of or inadequate office space and equipment
 - Lack of or inadequate training of committee members
 - Lack of or outdated SOPs
 - Lack of or weak oversight of approved research
 - Cumbersome paper-based data management and archiving systems
- What is AMANET doing about the identified needs?



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