

Developing Best Practices of Community Engagement for Genomics and Biobanking in Africa (CEBioGen)



The Goal: To investigate the role of community engagement in genomic research and biobanking in sub-Saharan Africa.

The Problem

Genomic research raises important ethical questions such as the appropriate consent models for the use of archived samples, data sharing, privacy and confidentiality, how communities should be engaged in the research process and how to communicate genetic results to research participants. Although these questions have received considerable attention through academic discourse and empirical research, very little attention is given to the question of what should count as the best ethical practice in communicating genomic research results particularly in Africa.

Project Strategy

1. To investigate the role of community engagement (CE) in genomic research and biobanking in sub-Saharan Africa by conducting collaborative research projects across four African countries: Ghana, Nigeria, South Africa, and Kenya.
2. Elicit key stakeholders' views on the value and purpose of CE in genomics.
3. Examine the key ways in which local communities should be involved in genomics and biobanking in Africa.
4. Identify core competencies that are required for best CE practices.
5. Serve as a training and resource center for ethics and CE to support the implementation of genomic research across sub-Saharan Africa.
6. Provide short and long-term training opportunities

Preliminary Outcomes

- Conducted empirical studies with key stakeholders across six research sites in West, East and South Africa
- Developed a short course on communicating genetics and genomics results to participants and communities
- Organised workshop on community engagement
- Training 3 PhDs and 2 Masters in Public Health and Ethics
- Developed a video clip on *Journey of my sample*

Project Leads

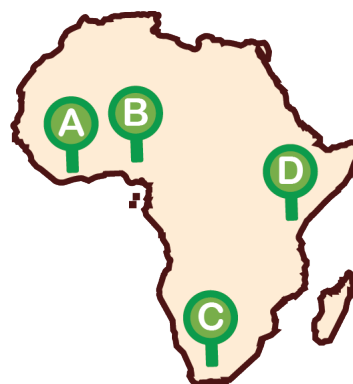


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Project Sites



A: Ghana
University of Ghana School of Public
Health, University of Ghana Medical
School, Navrongo Health Research Centre

B: Nigeria
University of Ibadan, University of Nigeria

C: Kenya
African Population and Health Research
Center

D: South Africa
Agincourt Health and Demographic
Sureveillance Site, University of
Witswatersrand

Non-African Collaborators:
University of Arizona

