



GILES

Genomics Inheritance Law Ethics & Society

Initiative for genomics, ethical, legal and societal issues
(ELSI) in bioresources and human genomics in Zimbabwe.

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Goal

To understand the current, emerging and persisting ethical, legal and societal issues (ELSI) related to bio- and data resources which involve biospecimen collection, storage and genomic analysis for use in research and healthcare in Zimbabwe



Background

- Small to large scale biorepositories exist in Zimbabwe
- Purposes range from disease surveillance, clinical trials to student research projects
- Few established specifically for genomics research but the existing ones have potential for being used in genomics
- These activities have been carried out with limited knowledge and expertise about (ELSI)
- Emerging trends in research and health which involves biobanking and genomics justifies the need for developing up-to-date ELSI structures

Specific aims

- Review **current status of ELSI's** for biobanking for human genomics in Zimbabwe.
- Establish **knowledge, attitudes and practices** of human biospecimen collection, storage and use in genomics research and healthcare applications.
- **Strengthen capacity** for ELSIs of bio- and data resources and human genomics in Zimbabwe

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**Document, desk review,
needs assessment**



Current status of ELSI related activities, gaps & needs in the education, review processes, legal & policy coverage.



**Reviews, analysis, synthesis, consolidation,
stakeholder workshop**



**Strengthen capacity in ELSIs of
biobanking and genomics**

**Assessment of knowledge,
attitude and practice (KAP)**



Understand attitudes & practices of public, research donor participants, health & research professionals



24 mo

30 mo

36 mo

Progress to date

- Formed teams to focus on each objective
- **Document review**
 - Developed data collection tools
 - Collecting and reviewing the documents
- **FGDs and IDIs**
 - Developed the guides
 - Reviewing the guides and training

Document review

- **Guidelines** and **policies** which regulate and govern for biobanking and genomics in Zimbabwe.
- **Questions** to be addressed
 - What are the documents and policies that regulate or guide health practice and research in Zimbabwe?
 - Are there any ELSI issues related to human health research mentioned/addressed by this document?
 - Are there any considerations of ELSI issues specifically related to specimen/data biobanking and genomics?

Current status of ELSIs

- **Application of ELSIs for biobanking and human genomics in Zimbabwe**
 - Questionnaire tool – data abstraction form
 - Applications made to the MRCZ over the last 5 years
- **Needs assessment for education** of ELSIs of biobanking and of human genomics for health research and clinical applications

Knowledge, attitudes and practices
of human biospecimen collection and
use in genomics research
and applications

-Focus Group Discussion
-In-depth Interviews

Context/Themes

Knowledge	Attitude/Perception	Practices	Ethical, Legal and Social issues
Biobanking			
Genomics			
Consent			

Focus Group Discussions

Group	Sub-group	No. Of participants	No. Of FGDs	Region
Professionals	Clinical and biomedical research scientists & social scientists	8-12	1	Harare
	Healthcare practitioners	8-12	2	Harare/Mutare
Participants	Research participants enrolled in research studies/clinical trials	8-12	4	Harare/Mutare
Influential community members	Religious and cultural leaders	8-12	1	Urban/peri-urban

In-Depth Interviews

- **Key Informants identified**
 - Ethics committee members, regulatory authorities and policymakers (10)
 - Research Leaders (8)
 - Managers of non-research based biospecimen collections (5)
 - Community representatives (CAB members) (5)
 - *Research participants (5)*
 - *Religious and traditionalists (5)*

Discussion and continuing work

- Complete review of documents
- FGDs and IDIs
- Data analysis

Future plans – strengthening capacity

- Collaborate with local IRBs and H3Africa Ethics Working Group – policies, guidelines
- **Stakeholder consultation** - Technical Committee for Genomics and Biobanking
- Engagement and educational activities
 - Seminars in academic institutions
 - Community engagement
 - Adaptation of development of educational materials/vignettes and translation into local languages

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