

Genetics and Genomic Research in Uganda: Towards Context Specific Ethics Guidelines



The Goal: To develop culturally appropriate model ethics guidelines for conducting genetics and genomics research (GGR) in Uganda.

The Problem

GGR has been conducted in Uganda for more than 20 years, and the volume of GGR activity is expected to continue to increase because of its potential to advance targeted disease detection and interventions to address significant burdens of communicable and non-communicable diseases in the country. GGR presents unique challenges for ethical and regulatory oversight, especially in low-income countries such as Uganda. An in-depth understanding of these ethical, legal and social issues is essential to the process of developing meaningful ethics guidelines for GGR.

Project Strategy

1. Assess stakeholder awareness of GGR, and the nature of ethical and social concerns associated with GGR in Uganda.
2. Evaluate existing guidelines on the ethics and oversight of GGR for applicability to the Ugandan setting with a particular emphasis on guidelines developed by and for Africa.
3. Understand local needs and issues and provide robust data for later guideline development.
4. Develop and disseminate a model guideline for the ethics of GGR in Uganda.

Potential Impact

Through an interdisciplinary collaboration of Ugandan and international experts in bioethics, law, social science, philosophy, genetics and genomics research, and clinical science, this project will undertake a systematic process to document and analyze the ethical, legal, and social issues relevant to GGR in Uganda. The ultimate output of the project is context-specific model guidelines for the conduct of GGR in Uganda. These guidelines will improve the protection of the rights and special interest in Ugandans, as well as improve the population's chances of benefiting from GGR. The data derived from this study, its methods, and its products are likely to be of great utility to other countries in Africa.

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