

Topic: Community engagement for Genetics and Genomics research: a qualitative analysis of stakeholders' experiences and perspectives, in Central Uganda

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ABSTRACT

Community engagement (CE) in research is largely rooted in the recognition that health is socially determined and so, health initiatives including research, ought to involve community partners to provide their own perspectives to the initiative. Currently, there is scanty literature on how to engage Ugandan communities in genetics and genomics research (GGR). This study explored the perspectives and experiences of key stakeholders in GGR in order to develop an ethical framework for CE for GGR in Uganda. This was a cross-sectional, qualitative study, grounded on constructivism ontology. Participants were recruited from Makerere University, Uganda Virus Research Institute, Uganda National Council for Science and Technology, and communities in Central Uganda. Semi-structured interview guides were used to collect data which was analyzed thematically. This study premised on the theoretical lenses of Gyekye's African moderate communitarianism whose ethical aspects also guided in the analysis of the data.

The findings reported unique aspects pertaining to GGR that call for special consideration when engaging Ugandan communities in such research, including; 1) the genetic science being complex which makes its comprehension by the communities difficult. Sensitization of the communities was recommended to boost their genetic knowledge and enable informed decision making. 2) GGR was perceived to have social implications since it works on genes which are shared entities among individuals. This calls for the observation of communitarian values to ensure social wellbeing. 3) Communities were reported to have cultural myths in relation to genes which should be identified and addressed to allow harmonious conduct of GGR. 4) GGR researchers were reported to have limited CE skills, and there was lack of CE guidelines for them to follow, suggesting a need to develop such. The findings were discussed and combined to develop an ethical framework that will potentially guide the conduct of CE for GGR in central Uganda.