

IN-DEPTH INTERVIEW GUIDE FOR RESEARCH ETHICS COMMITTEE MEMBERS

Study Title: Community Engagement in Genetics and Genomics Research: A Qualitative Analysis of Stakeholders' Experiences and Perspectives, in Central Uganda

Tool Title: Research Ethics Committee members' perspectives on Community Engagement in Genetics and Genomics Research in Uganda

Introduction: You have been identified to potentially participate in this study because you have been involved in the review and/or approval of, and/or oversight of genetics and genomics research (GGR), and therefore have knowledge and experience relevant to our topic of discussion.

Discussion Questions

General views on CE and genomics research

1. How would you describe genetics research, and genomics research? *(If the participant is not well versed with the concept, you go ahead to explain)*
2. What ethical issues that pertain to GGR are you aware of?
3. How do you understand the concept of community engagement (CE) in research? Explain. *(If the participant is not well versed with the concept, you go ahead to explain)*
4. CE is recognized on principle but the knowledge base on how it should be effectively conducted in GGR is limited. What is your view on that?

Oversight of CE for GGR

5. What aspects do/would you look out for on the community engagement plans for GGR protocols? *(Probe: stages involved, time scope, ethical considerations, cultural sensitivities, composition of CE team, budget, expertise, nature of genomics research)*
6. In your view, what challenges do/could researchers face when engaging communities in GGR? How would you as a research regulator advise the researcher on how to solve such challenges? *(Probe on funding, resources, the process, seeking help, guidance, complexity etc)*

Perspectives on CE in GGR

7. In order to ensure ethical community engagement in GGR, how would you go ahead to guide researchers?
8. CE requires joint decision making between researchers and communities. However, there is a challenge of researchers not truly considering in-put of community members. How do you think this would impact on GGR?
9. It is usually recommended that to be effective, CE should start from conception of the study to; planning, implementation, and reporting back of findings. How possible is this for GGR? Give a brief explanation.
10. CE is fundamentally about building relationships. Given that GGR may have implications to not only the research participants but to also their family, close relatives or even communities. How far should a researcher go in building such relationships?
11. As a measure of accountability, there should be feedback of GGR findings to the community and where possible, to the individual. In your opinion, how should GGR findings be handled? (*Probe: starting when, how to feedback, who to feedback, what to feedback whether: uncertain/inconclusive, incidental, individual/aggregate results*)
12. Genomics research findings take long or are never returned; because it takes time to derive validated results. How should researchers address this issue to communities given that participants are usually expecting to know their findings?
13. Is there anything else you would like to address in line with our discussion?

Okay, thank you very much for your time and very useful ideas.