

IN-DEPTH INTERVIEW GUIDE FOR RESEARCHERS IN GENETICS AND GENOMICS

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

Tool Title: Researchers' experience and perspectives on Community Engagement in Genetics and Genomics Research, in Uganda

Introduction: You have been identified to potentially participate in this study because you are a researcher in genetics or genomics, and so have knowledge and experience relevant to this topic of discussion.

Discussion Questions

Experience on community engagement (CE) for genetics and genomics research (GGR)

1. What was/is the nature of the genetics or genomics research you were/are involved in? What samples did/do you collect?
2. What ethical issues that pertain to genomics research are you aware of?
3. How would you explain the concept of community engagement (CE)? (*If not well versed then explain the concept*)
4. In carrying out your GGR, did you conduct community engagement? Why/why not? (*If not then proceed by asking in future tense*). What was your objective (s)? where you able to achieve your objective (s)? if yes, what measures enabled you to?
5. What was your target community? At what stage of your study did you involve the target community and why at that stage? How did you access your community? Which particular individuals/groups did you work with in the community and why?
6. How is/was the layout of your CE plan? (*Probe: stages, team composition, tools and resources, etc*).
7. What approach/method(s) do/did you use to engage with your community? What influenced that approach? What did you do to evaluate whether those approaches were/are effective or not?
8. You as an individual, what's your role in CE?

9. CE is not a one-way communication but an opportunity for co-learning between researchers and communities.
 - a) Did you identify any community expectations for your GGR? if yes, what were they? If no, did you try to identify them?
 - b) What aspects did you learn from your community that were relevant to your GGR?
(Probe: *cultural, social-economic, political, religious*)
 - c) Why are/were those aspects relevant?
10. Before engaging your community in GGR, did you anticipate any possible challenges (barriers/ ethical, legal or societal issues)? If yes, which ones and how did you avoid/address them?
11. Do/did you have a feedback of findings plan? What do/did you plan to feedback to the community?

Perspectives on CE in genomics research

12. 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?
13. In your view how should researchers effectively engage communities in GGR?
14. It is usually recommended that to be effective, CE should start from conception of the study, planning, implementation, and reporting back of findings. How possible is this for GGR? Give a brief explanation.
15. 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?
16. 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 results?

Evaluation

17. What benefits do/did you identify in conducting CE for your GGR?
18. What challenges did you encounter while engaging your community in GGR? What recommendations would you give to solve such challenges?

Recommendations

19. Do you have any questions, additions or concerns in line with our discussion?

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