

FOCUS GROUP DISCUSSION (FGD) GUIDE FOR RESEARCH COMMUNITIES

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

Tool Title: Research communities' experience and perspectives on Community Engagement in Genetics and Genomics Research

Introductions: You have been identified to potentially participate in this study because you are an adult resident in this community, and have ever participated in a study about your genes.

I have already introduced myself to you and now I will give everybody a chance to introduce themselves. I propose that each one introduces themselves by name and your position in this community. Each one will be assigned a code and after this, every time each person gets an opportunity to speak, they will only repeat their code and **NOT** their name.

Questions

Experience in CE in genetics and genomics research (GGR)

1. How do you understand the following;
 - Genomics
 - Genetics
 - DNA testing?
2. Have you ever participated in a study where you had to provide specimens to test your genes or DNA? What steps did you go through as participant?
3. At what point did you and your community get involved in the study.
4. At what point did your involvement in the study end?
5. What was your motivation for accepting GGR in your community?
6. Did you anticipate any risks (to you as; an individual, family or community) for participating in GGR? What measures would you recommend for avoiding such risks?

Perspectives on community participation in genomics research

7. In your culture, norms and religion, do you have any practices similar or in contrast to genetics, DNA testing or genomics? Which are those? Would you prefer to maintain such practices or you prefer the scientific ways of working on genes/DNA?
8. What opportunities that exist in your community do you think researchers should capitalize on in order to successfully engage your community in studies about genes? (Probe: life style, exposure, socio-economic, political, infrastructural etc.)
9. What challenges do you think GGR researchers would face in conducting research in your community? What advice would you give them in order to successfully conduct their GGR in your community?
10. What do you think would be the most effective way of maintaining an ongoing communication between you and the genomics researchers? Your choice can be anything; phone calls, email communication, in-person consultation hours, what do you think would work best?

Other ideas

11. In view of what we have discussed, what other concerns do you have, if any, about conducting GGR in your community?
12. Do you have any questions as regards to this topic?

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