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Community engagement conduct for genetics and genomics research: a qualitative study of the experiences and perspectives of key stakeholders in Uganda

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Abstract

Background Community engagement (CE) is one of the key strategies to optimize ethical integrity in research. However, the knowledge base on how CE should be effectively and ethically conducted, particularly for genetics and genomics research (GGR), is limited. Lessons have not been drawn from the experiences of key stakeholders in GGR, on CE, in Uganda.

Aim To analyze the experiences and perspectives of the key stakeholders (GGR researchers, lay communities, and REC members) on engaging communities in GGR, to consequently inform how communities could be ethically engaged in such research, in Uganda.

Method A cross-sectional qualitative study was conducted at; Makerere University, Uganda Virus Research Institute, and Mulago National Referral Hospital. Twenty-five GGR researchers, twenty REC members, and thirty-eight community members, participated in this study. Data were collected using in-depth interviews guides, and Focus group discussions. Data was analyzed thematically, using NVivo version 12 Plus.

Study findings Thirteen of the twenty-five GGR researchers had conducted CE in their studies, seven REC members had ever reviewed GGR protocols, and all the community respondents had ever participated in GGR. The goal for CE was reported to depend on the type of GGR as either basic or applied. Planning for CE involved; defining the community and for GGR this includes individuals not directly involved in the research but share the study gene with participants; a bigger CE budget to cover extra costs in GGR. The conduct of CE was reported to mainly occur at sample collection stage, rarely at study conception, and had not occurred at the return of results stage. Implementation of CE involved; engaging leaders first to gain access and acceptance of the research in the community; having a genetic counsellor on the CE team to handle the social issues in GGR.

Conclusion This study provides challenges and facilitators on the conduct of CE in GGR in Uganda. Measures including the building of capacity especially knowledge in both GGR and CE for all the stakeholders, and using this

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study findings to inform policy, regulation, and further research will potentially contribute to ethical CE in GGR in Uganda and similar research contexts.

Keywords Community, Community engagement, Experiences, Genetics and genomics research, Perspectives, Researchers, Research ethics committee, Uganda

Background

Community engagement (CE) is one of the key strategies to optimize ethical integrity in research [1-3]. CE is recommended for all research that involves human participants, where procedures and results could affect communities' interests and the environment [4, 5]. The need for CE in research has been underscored and cited as one of the key ethical considerations in the Council for International Organizations of Medical Sciences (CIOMS) guidelines [1]. The guidelines emphasize that proactive and sustained engagement with the communities from which participants will be invited to participate is a way of showing respect for them and the traditions and norms that they share [1]. The UNESCO declaration on bioethics and human rights stresses the respect for both the community and individuals in research [6]. The National guidelines on Community engagement in Uganda emphasize the requirement for CE as a process for building transparent, meaningful, collaborative, and mutually beneficial relationships with interested or affected individuals, groups of individuals, or organizations, with the ultimate goal of shaping research collectively [7].

Genetics and genomics research (GGR) aids in understanding of genetic disease management by providing insight into the host's genetic factors that influence susceptibility to disease, disease progression, tolerance, resistance and treatment outcome [8]. Genomics for example, enables the identification of the genetic and environmental factors underlying the variations in genetic disease susceptibility, treatment, prevention, and diagnosis, among other things [9]. However, GGR also raises a number of ethical, legal and social issues including; those in the informed consent process, participant privacy as well as the collection, storage and sharing of genomic data [10], fears of exploitation, discrimination and stigmatization [11]. CE is one of the mechanisms through which most of the ethical, social and legal issues can be appropriately identified and addressed when conducting GGR [12–14]. CE creates the potential to build relationships, increase trust, improve the consent processes and empower the communities, among other things. This is so because CE provides opportunities for continuous sharing of information between researchers and the community throughout the life of the project. This enhances the understanding of the science and rationale of a specific GGR project, provides a platform for identifying and addressing any possible concerns and contributes to ethical integrity in the research process.

Despite recognizing the value of CE, the knowledge base on how it should be conducted for GGR in Uganda and a number of countries in Africa, is limited [15]. There is a dearth of literature on empirical studies demonstrating the conduct of CE in GGR [16]. The genetics and genomics projects that have reported empirical work on the conduct of CE in Africa are, mainly members of the H3Africa consortium [15, 17–19]. H3Africa was a consortium that facilitated fundamental research into diseases in the African continent while also developing infrastructure, resources, training, and ethical guidelines to support a sustainable African research enterprise led by African scientists, for the African people [20]. The consortium developed guidelines for CE to guide researchers in developing and conducting their CE activities [21]. The key elements for consideration in these guidelines included; defining the goal(s) of CE by highlighting why the engagement is important; defining 'the community' or 'the public' in the research with the recognition that there is no standard definition of community and what counts as 'community' in a research project is dependent on the nature of the research, the participants who will be enrolled, the social and political context and the goals of the engagement activity; identifying strategies, models and methods for CE while noting that there is no one size fits all strategy for CE but researchers can draw on a variety of communication tools and methods to tailor engagement strategies to fit research needs, goals of engagement, funding and research constraints; having a trained and dedicated CE personnel to carry out the project's engagement activities; discussing the roles and expectations for CE of both the research team and the community members; anticipating and addressing the challenges with CE [21].

Hanchard et al., (2022) highlight the approaches used for CE by H3Africa. These have their roots in long-established culture sensitive approaches to community consultation and participation. These approaches are applicable to engaging African community while respecting specific cultural ideals and concerns [22]. This approach nurtures the trust needed to establish long-term relationships that will meaningfully and equitably involve communities in research [23]. Since H3Africa is a consortium, comprising of genetics and genomics researchers (GGR) from different African countries, it is important to appreciate how CE approaches have been contextualized to different country settings. This is because, different settings have varying context in values, structures, priorities, social and legal settings, among other things. There is, scanty literature describing how CE in GGR in Uganda has been or is being conducted.

As the call to diversify genetics and genomics research intensifies, there is growing impetus to take seriously and apply the lessons learned elsewhere [22]. This includes articulating a substantive commitment to ensuring genuine CE. This involves a willingness to learn from the views and experiences of key stakeholders, and to adapt CE approaches to accommodate those experiences [22]. This would therefore inform on how ethically CE for GGR should be conducted. When the views of relevant stakeholders in a given research are assessed, it allows greater understanding of that research processes. This in turn aids the designing and implementation of efficient and effective research practices [24]. Lessons have not been well drawn from the experiences and perspectives of relevant stakeholders, on engaging communities in GGR in Uganda. This study, therefore, sought to analyze the experiences and perspectives of the key stakeholders (GGR researchers, research communities, and REC members) on engaging communities in GGR in Uganda. The findings of this study highlight some challenges and facilitators to engaging Ugandan communities in GGR. This information will potentially guide researchers on how to ethically plan and implement their CE activities for GGR. The findings can also provide evidence to inform policies relevant to GGR.

Methods

Study design

This was a cross-sectional qualitative study. Cross-sectional study design was appropriate because this study aimed to gather the perspectives and experiences of key stakeholders in GGR at a single point in time [25]. The qualitative approach helped to gain a deeper understanding of the stakeholders' experiences and perceptions of CE in GGR.

Study sites

This study targeted institutions and affiliated communities that were involved in GGR conduct or regulation in Central Uganda.

The study sites for genetics and genomics researchers were Makerere University and the Uganda Virus Research Institute (UVRI). These institutions were selected because they had projects that had conducted GGR.

Makerere University is a public university that was established in 1922. The University focuses on increasing its investment in research, recognizing that pertinent and applicable research is critical to the development needs of the country. The University is located on Makerere Hill, a suburb of Kampala the capital city of Uganda. GGR researchers were recruited from three colleges at the University; the College of Health Sciences (MakCHS), College of Veterinary Medicine, Animal resources and Bio-security (COVAB), and the College of Natural Sciences (CoNAS). These colleges were selected because they were centers for projects conducting human GGR.

The Uganda Virus Research Institute (UVRI) is a Medical Research Institute owned by the government of the republic of Uganda. It is located in Entebbe Municipality in Central Uganda. The focus of research at UVRI is on infectious viral and parasitic diseases [26].

The research ethics committee (REC) members were recruited from RECs that had reviewed, or were potential reviewers of GGR protocols. This was based on the institutions they were affiliated to, that is, institutions that were centers for a number of GGR projects. These institutions included; Makerere university, Mulago National Referral Hospital, and UVRI.

Mulago hospital is a national referral and teaching hospital for Makerere University. It is located within Kampala City, in the Central region of Uganda [27].

Communities were those that had ever participated in GGR projects at Makerere university and UVRI.

Data collection tools

The data collection tools included; an in-depth interview (IDI) guide for GGR researchers [see Additional file 1]; in-depth interview guide for REC members [see Additional file 2], and a focus group discussion (FDC) guide for the community members [see Additional file 3]. These data collection tools were developed for this study basing on; the aim of the study, scholarly views and guidance on good practices in CE in research and in GGR [28, 29]. The tools were then subjected to review by doctoral research committee, and subjected to pretesting among genomics and genetics researchers, REC members and lay community. This process helped introduce new themes in the guides and refine the phrasing of questions. During the interviews, some adjustments were made in the guides, informed by the participants' responses. The major questions in data collection related to; participant experiences and perspectives in CE in GGR. The focus group discussion guide was translated to Luganda, a local language spoken in the participants' communities. The translation was done by a qualified translator.

Sample size

Twenty-five GGR researchers, and twenty REC members participated in their respective in-depth interviews. Thirty-eight community members participated in four FGDs. These sample sizes were determined at the respective points of data saturation for each category of participants (stakeholders), that is, points at which no new ideas were being generated from additional interviews or discussions [30].

The sample sizes depended on a range of parameters of saturation, including the purpose of the study, study population, and types of codes [31].

The purpose of this study was to get stakeholders' perspectives on CE for GGR in Uganda, which was not a well understood phenomenon that needed getting a number of dimensions from participants to get meaning of the concepts involved.

The study populations for the in-depth interviews (for researchers and REC members) were diverse as each involved individuals of different positions, for example, REC members included the REC chair, community representative, social scientist (where available), GGR scientists (where available). GGR researchers included the GGR scientists, CE officers, nurses, and counselors. These diversities in each population influenced the purposive selection of participants basing on their respective positions, and this potentially contributed to the sample sizes of above twelve. For a homogeneous group, a sample of twelve would likely be sufficient [31, 32]. To allow saturation, this study assumed a certain degree of structure within interviews, that is, a similar set of questions were asked of all participants from each population. Otherwise, data saturation could never have been achieved as new responses would keep being given to newly introduced questions [32].

For community stakeholders, data saturation was attained at four FGDs. This is within the range reported by Guess et al. (2017) that by three to six FGDs, 90% of themes will have been discovered from the data [33]. Participants were similar with respect to experience in GGR as all were former participants in GGR in Uganda. More focus groups may be needed to reach saturation as the heterogeneity of the sample population increases [33] which was not the case for this study. Moreover, the FGD guide used for this study had open-ended questions that were asked verbatim in all FGDs and in the same order. For qualitative inquiry that doesn't employ a guide or scripted questions, saturation is likely to require more focus groups than in this study [33].

The sample sizes in this study also depended on both code and meaning saturation. For each category of participants, initial codes were deductively developed from topics in the respective data collection tools. To assess code saturation, transcripts were reviewed of every interview or discussion that was conducted and recorded. For each interview/discussion, we recorded new codes inductively developed, and code characteristics including the code name, code definition, any notes about the new code (e.g., clarity of the issue), and whether any previously developed codes were present in the interview. We also recorded any changes made to codes developed in previous interviews, including the nature of the change and the interview number at which each change occurred. This code development and iterative refinement of codes continued for each interview or discussion individually until no new codes emerged from the participants' responses.

Assessing saturation needed to go beyond code saturation (whereby codes are simply identified) toward meaning saturation (where codes are fully understood) [31]. Achieving meaning saturation also necessitated using an iterative process of sampling to monitor diversity, clarity, and depth of data, and to focus data collection on domains that were less understood. Meaning saturation was needed to capture all dimensions of an issue in CE in GGR in Uganda to fully understand it. It was at points where no new codes and meanings were emerging from interviews/discussions that data collection was stopped.

Sampling procedure

Purposive sampling technique was used in this study [34, 35].

Purposive sampling was used to identify individuals to participate in this study. Researchers in GGR were selected based on their role and experience in conducting GGR. The roles under consideration were; genetics/ genomics researcher, research coordinator, a member involved in sensitizing and consenting participants or in charge of planning and overseeing CE in the study. REC members selected were; the chair and/or vice chair, a community representative, and an expert in GGR or social science (where available).

The communities were recommended by researchers and were former participants in their respective GGR projects. Community lay members recruited were adults that had ever participated in GGR and could speak Luganda.

Data collection procedure

For one-on-one in-depth interviews (IDI), the potential participants were approached either in person, by telephone or via email. They were well briefed about the study and requested for a convenient appointment to participate in the IDI. Interviews were conducted physically for between 40 and 90 min at the participants' official working addresses. All interviews were conducted in English and audio recorded using a Sony Digital Voice Recorder (ICD-PX470) after obtaining participants' consent to record. Notes were recorded as back-up for the oral interviews and for coding the identities of study participants. Participants were recruited up to the point at which no new ideas were being generated from additional interviews.

The FGDs consisted 6-12 people and were led by an experienced moderator, following an FGD guide. The potential participants were contacted through phone calls by a specific genetics and genomics research team. This was after checking in their data set to identify those that; had participated in a genetics or genomics study, were adults, and could speak Luganda. These were invited to the health facility as potential participants in the study. The FGDs were conducted physically at sites allocated by the GGR coordinators, and discussions lasted between 90 and 120 min. Before recruitment, the potential participants were briefed on arrival about this research and allowed to ask questions to which the research team responded. Those who accepted to participate in the research were consented in writing, and invited to take part in the FGD. All discussions were conducted in Luganda, and audio recorded using a Sony Digital Voice Recorder (ICD-PX470), with consent from the participants. Notes taking was also done to capture some key issues as they arose during the discussion, and as back-up for the discussions. The audio records were then transcribed and translated from Luganda to English.

Data analysis

This study used thematic analysis method [36]. Data from each of the stakeholders (GGR researchers, REC members, or lay community) was analyzed independently. The interviews and focus group discussions were transcribed verbatim. The transcripts were then coded both manually and with Nvivo data analysis software [37]. Preliminary coding of the data was done manually using a deductive approach, based on the topics in the data collection tools. Further analysis was done inductively, and Nvivo aided in exploring and organizing of the data during the analysis.

The open codes which were generated were grouped into nodes/families. The generation of nodes was guided by the research questions for which the coded data served as part of the answer put forth for interpretation. Nvivo 12 [37] was also used to manage quotations. This was by way of identifying and marking sections from the transcripts that were to be quoted verbatim in the presentation of research findings. The identity of the respondents in the quotations was kept confidential by use of codes encompassing sex, role, and assigned individual numbers. (e.g. Male REC chair IDI_001). Data from the various key stakeholders (GGR researchers, REC members, and community members) was triangulated. This study used data source triangulation that involved the collection of the experiences and perspectives on CE in GGR from different categories of people (sources) including individuals and communities [38]. This approach was to increase the credibility and validity of the findings [39], and this was achieved when the different data collection sources yielded the same results (similar themes). At the analysis stage, data saturation was attained when no new themes were identified.

Ethical considerations

Ethical approval for this study was sought from the Higher Degrees Research and Ethics Committee of Makerere University School of Biomedical Sciences, Ref No: SBS2021-66. This was followed by obtaining ethical clearance from the Uganda National Council for Science and Technology (UNCST), Ref No: SS1172ES. Participation in the study was voluntary. A written informed consent was obtained from each participant. For FGDs, participants recruited had previous participated in a GGR project. In order to maintain their confidentiality, only the coordinators in the previous GGR study contacted them, explained the purpose and sought their participation in this study. Those who accepted to participate in this study were invited and introduced to our team by the coordinators. For anonymity, serial codes instead of participants' names were used to identify participants. All information material and the audio-recordings were kept confidential under lock and key until it is deemed that there is no further reference to them in regards to validation, then they will be destroyed. All the study participants were given a token cash compensation for their effort, time, and the costs incurred (especially transport) to participate in this study. COVID-19 Standard Operating Procedures as set by the Ugandan Ministry of Health [40] were followed.

Results

Participants' socio-demographics

Twenty-five GGR researchers participated in this study and sixteen were male. The mean age of all the researchers was 43 years (range 33–63 years). Twenty-four had attained at least a master's degree in formal education, (19/25) were genetic/genomics scientists, and (17/25) had at least five years of experience in aspects of GGR.

Twenty REC members participated in this study. Of these, 12 were male, and the mean age of all the participants was 50 years (range 32–72years). The average experience of respondents in the review of research was 8 years. Ten were from the field of health sciences.

Thirty-eight individuals from communities participated in four FGDs. Twenty-three were male, the mean age of the respondents was 36 years (age range 20–69) years, and 13/38 had attained at most primary level of education. The socio-demographics are summarized in Table 1.

Themes from the data

Four themes emerged from the data: need for CE conduct in GGR, planning for CE, stages of community involvement in the research, and considerations for CE implementation. The themes are detailed in Table 2.

 Table 1
 Socio-demographics of respondents

Category	Researchers	REC members	Community members
Number	25	20	38
Sex	Male: 16 Female: 9	Male REC members: 12 Female REC member: 8	Male: 23 Female: 15
Age	Mean age: 43 years, Age range: 33–63 years	Mean age: 50 years, Age range: 32–72years	Mean age: 36 years, Age range: 20–69 years
Education	≥ Master's: 24	≥ Master's: 14	≤ Primary: 13
Experience	GGR scientist: 19 Nurses: 3 CE officers: 2 Counselors: 1 ≥5years in GGR: 17	Average experience in review and regulation of research: 8years Ever reviewed GGR protocol: 7	Ever par- ticipated in GGR: 38

Table 2 Themes and sub-themes developed from the d	lata
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Theme	Sub-themes a. Reasons for conducting CE in GGR b. Reasons for not conducting CE in GGR c. Determine the stage of community involvement	
Need for CE conduct in GGR		
Planning for CE	a. Defining the research community b. Budgeting for CE in GGR	
Stages of community involvement in the research	a. Engaging the community at the research conception stage b. Engaging the community at data and sample collection stage c. Engaging the community at the return of genetic results stage	
Considerations for CE in GGR implementation	a. Engaging community leaders as entry to the community b. Methods of community engagement c. Community engagement team composition	

Need for CE conduct in GGR

In this section, reasons were given for why and why not, CE was conducted for GGR.

Reasons for conducting CE in GGR

Thirteen out of the twenty-five researchers conducted CE in GGR. One of their reasons was because of the nature of GGR. This involves the study of genes which are substances that are shared among relatives in families or even communities. This was said to necessitate the engagement of everyone that shared that gene as they could to be impacted by the research.

communities still share genes and so one finding may have implications on the entire community... (Male GGR research-IDI 12).

Researchers conducted CE in GGR because they considered CE as; a sign of respect for communities, a measure to realize and address community expectations about the research, and allay anxieties in the community in regards to the research. Nine of the thirteen GGR researchers in this study conducted CE for instrumental goals such as: to create awareness of GGR in the community, gain acceptance of the research in the community, receive community input and advice on research design and implementation. On the convention, as a reason for conducting CE, one of the participants stated that:

Community engagement.... is the modern way of doing research by engaging the community and getting their permission to be in the research. (Male GGR research-IDI-3)

Reasons for not conducting CE in GGR

Twelve out of the twenty-five researchers did not conduct CE in their GGR. Researchers reported having huge workload and conflicting activities and so did not give CE the required time. Their main focus for CE was to collect data and leave the community.

We don't get time, when you go you talk to them, get consent and move away to collect data. I think it is the nature of the way we conduct our studies that doesn't allow further engagement. (Male GGR researcher-IDI-1).

REC members also stated that researchers find CE cumbersome and requiring a lot of time so, they try to avoid it. REC members further, reported that researchers do not take effort to acquire CE skills including, communication skills.

Additionally, REC members reported that they demand GGR researchers to conduct CE as a pre-requisite for ethical approval. One REC member attested to this when he said that; "*The researchers only involve the community because they are actually forced by IRBs [RECs]. (Male REC chair IDI-21)*". This was echoed by three researchers when their reason for conducting CE was because it was a pre-requisite for getting ethical approval at the REC. While two researchers conducted CE because it was a requirement by the funders.

Another reason for not conducting CE was that GGR researchers did not expect communities to make valuable contribution to the research through the engagement. Researchers perceive communities to lack knowledge on genetics and so, cannot contribute to the science. This was evidenced when one REC chair stated that;

So, they are looking at them [community] as low people who don't know the science, who cannot contribute anything but it's them the scientists to come up with solutions to benefit those people, but they don't see the value of involving them. (Male Vice REC chair IDI-22)

Community respondent conceded to low understanding of GGR and, for thinking that all studies on genes are intended for paternity confirmation.

Most people do not know these things because they are just coming up. We have just started to hear of DNA testing.... Most people who know genes come in, in such cases where a parent is denying a child, then we should go for blood testing. But not these things of knowing that the family may have a disease in that, you can go and test to check the possibility of a child getting it. (FGD4-Male Respondent 2)

Some genetics and genomics research were said not to require CE. Mentioned among there were; research that did not require direct interface with the communities, such as, research in which archived samples were used; studies that had no potential to inform policy nor provide direct treatment to participants. One of the researchers had the following to say:

Of course, CE may not be feasible for certain studies; now if I get specimens and store them for future research, I may have research that may not have a community impact; I am not interfacing with the people who consented to give the samples and even the results that are going to come back especially laboratory which are what we call basic science studies. If it does not have a direct impact on policy, it doesn't have a direct impact on treatment of these patients and so on, of course there is no need to have CE because it is not really directly interfacing with the communities. (Male GGR researcher- IDI-5).

One researcher said he did not conduct CE because his research was too short to require a continuous relationship with the community/participants.

CE depends on the type of study. Unless it is a ten year or five-year longitudinal kind of study that is continuous, you're not going to tell someone who has studied for one year to keep engaging: in what! (Male GGR researcher- IDI-6)

Planning for CE

All the GGR researchers found it vital to plan for CE at the beginning (conception) of the study. Planning for CE involved defining the research community and budgeting for CE.

Defining the research community

During the reviewing of GGR protocols for ethical approval, REC members said they ask researchers how the research community was defined, and identified as appropriate for the study.

Researchers that participated in this study described their communities in two categorizes; disease-specific communities, and communities identified by geographic proximity. For disease-specific communities, the major diseases studied were; tuberculosis (TB) and HIV. Other diseases of study were; trypanosomiasis, schistosomiasis, cancer, and psychiatric disorders. In these diseasespecific communities, GGR researchers were basically investigating the genetic factors associated with those diseases. Two researchers reported conducting research in what they called "community genetics". This was described as the study of people's genes to identify the ethnic group they belonged to.

Basing on the nature of GGR, the community was reported to involve even individuals who may not directly be involved in the research. REC members said that researchers should explain whether they would involve the participant's relatives, as part of the community. The REC members reasoned that; the relatives may share the gene of study with the participants. Therefore, the researchers should consider engaging the participants without affecting the participant's relatives, or bleaching the participant's confidentiality.

When it comes to genomics, the risks might go beyond the individual to involve the family so, you might find that actually for certain studies you really need to go and get samples from the entire family. So, the thing is how best are you going to address that to participant's family without causing anxiety.... (Male REC chair- IDI-14)

Budgeting for CE in GGR

Budgeting for CE was considered a key consideration by four REC members when they echoed that, with an appropriate budget presented during ethical review of the CE plan, they (REC members) gain confidence that the engagement will be implemented. In that case, REC members require that GGR researchers have a budget plan for facilitating the CE team which covers; paying transport costs to the community members; facilitation of the community mobilisers in terms of food and refreshments; and transport refunds for community members during community involvement.

The CE budget for GGR was portrayed to cover unique budget items owing to the nature of this research. REC members illustrated that; the community in GGR may not be geographical but rather, a gene pool, and the members may be scattered. Tracing them therefore requires extra costs. Also, translation of GGR results into action was said to be costly. CE in GGR would need the training of the team involved in the CE if it is to acquire adequate knowledge in GGR, which needs resources.

The gene pool is not necessarily a geographical location, I may carry this gene but I live in Mbarara, so it is not necessarily like the other community studies where you are talking about a clearly defined geographical area.... So, the direct cost associated with engaging them may be hard. (Male REC community representative).

Translation of results into action is problematic, costly and even that translation is likely to take a long time... (Male REC chair-IDI4).

Determine the stage of community involvement

Another reason for planning for CE early was to enable the researchers determine at what stage they would engage (approach) their respective communities and to also realize key considerations. For example, in planning for CE, GGR researchers said they had to identify; the community, the language(s) used in the community, and the appropriate timing for engagement. They also considered factors like; community's social setup, and economic conditions of the community. There are broad factors, so planning any community engagement may need to plan for things like language issues, you may need to look at the social set up, the economic activities, and the most favorable time for you to engage them (male CE officer- IDI-8).

Stages of community involvement in the research

Researchers involved their communities at varying stages in the research from conception to data collection and then return of results.

Engaging the community at the research conception stage

Only two researchers had involved the communities at the conception stage of the study. Their reasons for engaging the community at conception were; to gain a safe stay in the community, to obtain community in-put, to identify community interests and considerations in regards to the research.

You engage the community before you start because you don't want to be beaten in the community. (Male GGR researcher- IDI-2)

Before you begin the project, proposals are written, there is that interaction to make sure that the communities have an input, there is always affirmative research done in understanding communities... as a researcher you must have some bearing from what the communities want and therefore you are researching (male CE officer- IDI-8).

In this study, involving the community at the conception stage was low (two researchers engaged at conception) and this was attributed to researchers undervaluing the community's contribution to the research at that stage.

Two REC members reported that GGR research has been approached from a paternalistic angle, that is, conceptualization of research projects has been left solely to the scientists (researchers). So, to researchers, engagement in terms of community input, comes in later as a form of damage control. This was said to lead to misaligned research.

Unfortunately, the scientists sit and think for the communities, they think that this is the problem in the community and they do not consult, they do not work entirely with the communities to find out: what is your problem, what is it that you want to have addressed, and it's a trend where research has been approached from a paternalistic angle. (Male Rec chair IDI-9).

Another reason researchers gave for not involving communities at conception was the lack of secured funding by that stage to involve the community. Availability of funds was said to determine whether research teams will conduct CE or not. As noted earlier by REC members; it is when researchers present the CE budget that they (REC members) have the confidence that it (CE) will be conducted.

Lack of funds for CE was said to be a major limitation to the practice of CE, noting that requirements like; facilitation for the engagement teams, refreshment and reimbursement for transport and time for participants, remain unmet.

There are costs attached to it (CE) You need for example, if you're meeting the leaders, to motivate them, compensate for their time... they need to be facilitated, give them something; some water, drink, refreshment, such that they listen to you (Researcher IDI-9).

However, it was feared that funded research sometimes does not incorporate in community input at the conception of the study, as one REC member stated;

At conception level, there are two challenges; sometimes the projects are internationally funded and they already have a given, I'll say objective or given study direction that they are supposed to take. So, engagement at conception becomes difficult ... (Female REC member-IDI-2).

Engaging the community at data and sample collection stage A majority (11/13) of the researchers that had conducted CE, approached the communities at the data and sample collection stage.

So, the time that I engaged with the participants was during the time of consenting and enrollment. (Female GGR researcher- IDI-15).

All the community members that had prior participated in GGR said that they got involved in the research at sample collection stage.

We came to this room and they gave us a paper in Luganda talking about genes and they gave us transport to go home but pass by the laboratory, so, when I went there, I was given a tin for urine. (FGD3-Female Respondent 3)

Two REC members supported researchers' involvement of the community from the stage of data collection. They opined that actually, GGR researchers can involve the participants with an already developed research protocol because communities would not provide valuable scientific contribution to protocol development. However, they said that in case researchers realize community values that require protocol adjustment, then they can apply for protocol amendment from the REC.

"For me I don't belong to the book of thought which says the idea should come from the community, the community may not come up with that genomics idea... but the researcher can come up with the idea then roll it out in the community." (FDD5-Female REC community representative 2).

Engaging the community at the return of genetic results

All the GGR researchers had not returned GGR results to communities. Conversely, community members (who had ever participated in GGR) had not received their GGR results, much as they were interested in receiving them.

They also approached me, we filled some forms but we have never received the results. (FGD1-Respondent 4).

Many times, actually the community is interested in receiving their results at the end of the day, that one they want to know, that is a major expectation from the community. (Male GGR researcher-IDI-12).

Reasons for not having returned (or delay, thereof) GGR results, were; researchers not having reached the return of results stage in their research timeline; results not being conclusive and so not of value to the participants. Some genetic samples needed to be shipped abroad for further analysis, and be compared with samples from other sites, which delayed the process. For blinded studies, it was not possible to refer the results to the owners since they (results) had been anonymized.

Ever since we started doing genomic studies, we haven't issued any results, it's now eight years, we haven't given out any results. (Male nurse-IDI 21).

You have to be very careful that whatever you're returning is valid then, the community can also advise but you may not reveal the specifics. (Male GGR researcher-IDI 12).

Failure to return GGR results was feared by researchers to have negative consequences, such as: communities sabotaging the research on knowing that their (community's) genetic results would not be returned. This fear was genuine because communities' acceptance of GGR was influenced by them (community) receiving their results.

I like that idea of studying our blood to know any disease susceptibility especially sickle cells... So, that is precisely why I would like to be in the study. (FGD1-Respondent 9)

Yes, I can give my sample reason being, I have to know my status as a person. (FGD2- Respondent 9)

Therefore, not returning GGR results was a major issue to community acceptance of GGR. This was more evidenced when some community respondents said they would not participate if they knew that their results would not be returned. Others said that by not returning their results, researchers lied to them, using them just for the sake of getting samples, to attain their academic degrees.

If you come to our community and find out that our results have not yet been returned, someone may say "They lied to us." (FGD3-Female Respondent 5)

To handle the non-return of GGR results, REC members opined that, researchers should inform the community that the results would not be returned soon and with a reason. In line with this, some community respondents (who had prior participated in GGR) stated that researchers had informed them that the results would not be returned because they would raise conflicts in families.

...They [researchers] informed us that they would not disclose to us the results because they did not want to raise conflicts in our family. (FGD2-Respondent 3)

Some [2] GGR researchers advised that other results (even if non-genetic) should be fed back, as communities wait for the delayed results. Five REC members suggested that there should be continued interface between the community and the researchers so that the community does not feel abandoned when results delay. Some (three) researchers were of a similar view that they (GGR researchers) should maintain a constant relationship with communities, as they wait to finally get conclusive results.

You can actually share the glucose levels when you know that, that one is right, then tell them the final results of this genomics study will take some time because we need to give validated results.... (Male GGR researcher- IDI-12) A few [2] researchers, however, reported difficulty in keeping such working relationship with study participants from the point of data collection to when results would be returned. This was said to be because, from data collection to the time genetic results are returned, the researchers do not have valuable information to discuss with the community. This was particular to researchers whose GGR results take long to be returned.

I think it is very difficult (to keep a working relationship) for example I go to the village here, collect my sample, report, and am busy working out all those things. So, for five or ten years I may not have any reason to go back. So, it is hard to just go and say 'hi people, how are you?' So, at least you have to have something to share with them (male GGR researcher-IDI-2).

Considerations for CE implementation

For considerations in the implementation of CE, three subthemes emerged from participants' responses: engaging community leaders as entry to the community, methods of community engagement, and community engagement team composition.

Engaging community leaders as entry to the community

GGR researchers reported to interacting with the community leaders first so as to obtain authorization to enter the community. Talking to the leaders was also for the researchers to present themselves as people with a genuine cause. The community leaders included; political leaders at village and district levels, religious leaders, prominent/influential people, and elders. Also engaged were security agencies like the police.

You can talk to the local leadership but then you have to talk to the higher leadership as well before you go down, and they can give you authorization to work in a particular community... With the Internal Security Organizations, anybody seen in the community can be seen as a wrong element so we want to make sure that right from the authorities up, they are aware... (Male CE officer-IDI-8).

This approach by the researchers of first talking to the leaders was supported by community respondents when they said that GGR research teams should respect community leadership since people would trust the research when mobilized by their leaders. The most recommended leaders were the Local Council (LC) chairmen. Community members said that they heed to the LC chairman and would accept the research when he spoke to them. They further remarked that they trust the LC chairman to have the community's interests at heart, that is, he wants them to get the research benefits [treatment].

Methods of community engagement

The interactions researchers said to have had with the communities were mainly through dialogue and small group meetings. Other interaction approaches included; community hall meetings, outreaches, attending clinic days, home visits, refresher courses and trainings, seminars/workshops, and routine engagement with study participants.

They usually have clinic days when they usually call them together ... you talk to them and tell them what you are going to do. (Male GGR researcher-IDI-2)

We have our home visitors who go out to the community to pursue this as well. (Female GGR researcher-IDI-3)

Community engagement team composition

Researchers reported forming CE teams composed of individuals of diverse expertise, who would contribute knowledge from their respective fields to the CE process. Mentioned among these were; genomics and genetics scientists, community engagement officers, doctors, counsellors, nurses, and peers.

In line with who the researchers should include in their CE team for GGR, REC members emphasized the need for social scientists, genomics/genetics scientist, community liaison personnel who had the skills in working with and within the community and guiding the researchers on how to approach the community. The GGR researchers also said that the CE team should have a communicator, and journalists given their expertise in relaying messages to communities in a way that they [communities] easily understand. Bioethicists were also suggested to help address the ethical issues involved in GGR. Genetic counsellors were suggested, to handle anxieties communities could possibly have that related to how their samples would be managed, and in handling the implications of their results. However, much as regulators highlighted the need for genetic counsellors, they reported that no such professionals are present in Uganda. One REC member further emphasized that the CE team should; have basic knowledge on GGR and CE to be able to educate the community and to create awareness about GGR; have communication skills and be able to communicate in a language people understand. It was also suggested that the CE team should be given those necessary facilitations in communication including visual aids, videos or posters.

Having dedicated team for CE to me may be something that may matter... (Male REC chair-IDI4).

I was wondering, in Uganda unless maybe I stand to be corrected, I don't know if we do have that specialized training to become a genetic counsellor. (Female REC member-IDI2)

Four GGR projects had their CE teams work with the Community Advisory Boards (CAB)s. CABs were considered links of researchers to communities who work closely with the researchers and also go out to the community to inform them about the research and also get their [community] views. Four REC members also suggested that the GGR teams should form CABs. One stated that;

Basically, what we look out for on the research team; do they have community representatives like CABs to advise the team and to link the team to the research participants.... How often are they [CABs] going to be engaged, what sort of input are they going to be able to contribute, what kind of plan are they going to link to the research participants? (Male Vice REC chair IDI-22)

Discussion

This study aimed to analyze the experiences and perspectives of the key stakeholders (GGR researchers, lay communities, and REC members) on CE in GGR, to consequently inform how communities could be ethically engaged in such research, in Uganda. The findings have indicated reasons as to why CE in GGR should be conducted and instances in which such conduct is not possible. Other findings have highlighted the planning for CE, stages of community involvement and why at those stages, and lessons have been drawn on the considerations for CE implementation in the local communities.

The reasons given by researchers, for conducting community engagement in GGR are in two categories; intrinsic and instrumental. Intrinsic reasons included respect for communities while instrumental goals included gaining community acceptance of the study. The reasons for engaging communities depend on the type of the health research between basic research or applied research [41]. It is suggested that applied health research places a greater emphasis on meaningful (collaborative) engagement with communities, that is, engagement that is co-designed, co-implemented and co-evaluated by the researchers and the community. The collaborative partnership thread of CE is less common in basic research, and instead, engagement with instrumental goals and approaches dominates [42]. In this study, a majority (9/13) of the researchers engaged their communities for instrumental reasons. This indicates that such studies were potentially basic GGR. This was portrayed when most of the GGR researchers aimed at basic understanding of participants' genetic factors that made them (participants) susceptible to diseases, with no clinical remedy with in those same GGR studies.

However, though basic research potentially seems less suited and/or inclined to adopt more structured forms of CE, this does not mean such forms of engagement are not ethically ideal. This is because of the social, ethical and legal sensitivities that such research could raise. This is coupled with the legal and regulatory entities that require that CE, regardless of whether it is conducted in basic or applied research, should be collaborative. Given the different reports on studies failing to achieve collaboration (of researchers with the communities) involved in basic science [43], there is a need to research further into the practicality of it, otherwise what is required to be CE for basic research may actually result into 'participation washing'. Participation washing is a situation, Birhane (2022) and Sloane (2022) describe as one where efforts mischaracterized under the banner of participation are weakly-executed or co-opt the voice of participants to achieve researchers' predetermined aims [43, 44].

REC members demanding (forcing) the GGR researchers to embrace CE implies that researchers did not appreciate the value of CE to their research, by not giving it the required time and skills. This likely results in sub-optimal community engagement that is potentially exploitative and disrespectful to communities (Moodley & Singh, 2016; Staunton, Tindana, Hendricks, & Moodley, 2018b).

Other researchers did not engage communities because they (communities) lacked technical genetic knowledge. However, this should be the very reason researchers engage communities to sensitize and empower them. Communities are composed of rational beings who have the ability to learn and comprehend information, and make informed contribution to the research. Not engaging them for presumed lack of technical knowledge in genetic science is a violation of their dignity. Disregarding the potential contribution of the community to the research also excludes the communities as partners in the research. The communities will therefore not be in position to offer the researchers collective effort aimed at achieving solidarity in the research. Without solidarity, there is no mutual respect, mutual understanding, and consensus in decisions making.

Not engaging the community because the research would neither inform policy, nor provide direct benefit to participants raises concerns of reciprocity in research participation. This demeans community members as rational beings who should not be used as mere means to another's end, but rather, as ends in themselves. Individuals and their communities should be informed beforehand on whether there will be no benefits and why, to enable them make informed decisions on whether to participate in the research or not.

Planning for CE involved defining the community to be engaged in the research. Since a community is comprised of members with a shared identity, then individuals with a shared gene of interest (for example defective gene for sickle cell) form a community. The very characteristic of CE requires the involvement of those affected or may be impacted by the research [45–47]. This means that researchers should involve the relatives to the participants in GGR since they [relatives] too, may be affected by the research.

In regards to the stage at which the community was involved in the research, majority engagement was at data collection stage, scantly at conception of the study and not at the return of results stage. Involving the community at the conception stage was low (2/25)researchers engaged at conception) because researchers undervalued the community's contribution to the research at that stage. Similar to this study, Nunn et al (2019) while reviewing public involvement in human genomics projects concluded that the stages of engagement with the lowest number of initiatives reporting involvement were "funding" (1/32), "identifying topics" and "prioritization" (4/32)". REC members in this study reported that GGR research has been approached from a paternalistic angle. This paternalistic stance compromises the very nature of CE in which the researchers and the community have to work as partners. GGR researchers should be made to bear much stronger obligations to ensure that the communities and research participants gain sufficient knowledge about the study. The community should know the various potential benefits and risks the research presents, to be able to comprehend and make informed decisions, and valuable contribution towards the research. This is important, especially considering that, sometimes when potential participants gain significant understanding of the GGR, they decide not to participate, as one GGR researcher noted; If people have understood very well, you expect some challenge like; I'm not ready for that (male GGR researcher-IDI-12).

Lack of funds for CE by the conception of the study was said to be a major limitation to the engagement at that stage. However, it was feared that funded research sometimes does not incorporate in community input. Most of the genomics studies conducted in Uganda and Africa at large, are funded and are done through international or intercontinental collaborations. This is mainly because harnessing African genomic complexity requires sustained commitment and equitable collaboration from the scientific community and funding agencies [48]. The community being part of the design and development of the research, instead of the research being directed by funders, is in observation of inclusivity, as a value in CE. Not involving the community in setting the research agenda excludes them as partners in the research and it denies them the right to contribute knowledge and be part of the decisionmaking process of the research. Additionally, if the funders set conditions that compromise the community values and priorities, then the research will not have respected the communities as ends in themselves. In respecting them, communities should be involved in problem identification, and measures should be in place to ensure that the community contributes valuable knowledge to the research.

It is indicative from the community respondents' description of how they were engaged, that, the process was more of recruitment for sample collection. The CE principles; of collaboration, mutuality, accountability, which also mirror as the aspects of moderate communitarianism, were given no consideration. These illustrations confirm the earlier reports that researchers do not give CE time, and also lack skills in executing it. This extent of CE is substantial, and as earlier marked, can be potentially exploitative and disrespectful to communities [49].

Reasons for delaying to return genetic results was because genetic samples needed to be shipped abroad for further analysis and be compared with samples from other sites, which delayed the process. Having to ship biological samples abroad for further analysis can be owed to the limited capacity of the local institutions to fully and expeditiously analyze and translate genomics data [50]. The process of shipping samples could get lengthy given the bureaucracy involved including processing the Material Transfer Agreements. This could contribute to the delay to return the genetic results to participants and their communities. Nevertheless, data sharing with other investigators for comparison is necessarily, but appropriate oversight measures should be in place to manage that. This would include regulation of data access to ensure that the data are used in ways that will minimize the risk of harm to the participants and their communities [51].

Failure to return genetic results due to anonymization could be owed to genetic information being considered sensitive and private, and the assumption that disclosure of this information could bring about harm. This is why researchers would opt to anonymize such data as a demonstration of respect for individuals' autonomy and community identity [51].

Not returning GGR results was presented as a major issue to community acceptance of GGR. One way of showcasing humanness to participants includes reciprocating research participation [52]. If communities have borne the burden of research in some way, part of treating them right/humanely could entail sharing research benefits and outcomes with them. Otherwise, the community will have been used as a mere means to the research. This was the perception by two community respondents who exclaimed that, by not returning their results, researchers are using them just for the sake of getting samples to achieve their academic degrees.

Contrary to the above perception, the main goal of research is to contribute generalizable knowledge (which is a common good). It is suggested that principles such as solidarity and equity that emphasize people's responsibility to engage in activities for the common good should be adopted as underlying moral principles for GGR acceptance [53–57]. This interest in solidarity, equity and benefits is seen as adopting a communitarian approach to GGR [58, 59].

Considerations for the implementation of CE included engaging the elders first in the community, using appropriate CE methods and forming a diverse CE team composition. GGR researchers engaged the community leaders first. Explaining to leaders first was also reported in a study by Olubumni and colleagues, and the reason given was that communities have trust in their leaders [60]. This implies that the research team should always respect the leadership structures in the communities. In Africa, religious and cultural leaders have notable influence on society [61]. A typical example is among the Buganda tribe in Uganda where the traditional leader encourages the tribe members to test for sickle cell disease before marriage [62]. This leader's advice is prone to being respected considering that formal Buganda traditional marriages are sealed by a certificate from the tribal administration. In such cases, the researchers should be cautious of the influence leaders have on community members. However, researchers should be keen to ensure that the trust communities have in their leaders does not cloud the right of the community members to understand on their own and make informed personal decisions about the research.

The methods of CE reported by researchers e.g. community hall meetings, agree with what has been suggested in literature [15]. Researchers reported forming CE teams composed of individuals of diverse expertise, who would contribute knowledge from their respective fields to the CE process. Genetic counsellors were suggested vital on GGR CE team to handle the psychosocial implications potential to this research. The requirement for genetic counsellors has been emphasized much in studies on people's genes [63–65]. These counsellors are considered to have the responsibility of talking to people to help them handle negative genetic results, prepare families on the social

implications of GGR, among other things [66]. That way, genetic counsellors aid in improving the wellbeing of the community members and also maintain social relationships and interactions. By explaining the cause of genetic conditions, they clear people's misconceptions of, for example, thinking others bewitched them, hence creating social harmony. This understanding also could encourage individuals to embrace others with genetic conditions and cater for them to ensure their wellbeing. However, in Uganda, just as in a majority of African countries, there are no qualified genetic counsellors [67, 68]. This is concerning because, considering the psychosocial implications of GGR, communities stand to be left in social disintegration. This further emphasizes the need for building such capacity or have provisions in place to substitute for genetic counselling in the due course.

Implication of the research

GGR and CE are emerging fields of research in Uganda and so their experience and perception by the key stakeholders is low. Effective CE in GGR requires gaining the experiences and perspectives of key stakeholders to realize any challenges or facilitators to CE. These inform what measures to put in place to ensure ethical CE in GGR. Findings in this study indicate the need to define the community appropriately considering that all those that share the gene under study comprise the community. There is need to understand the type of research in order to apply the appropriate goals for CE. Budgeting for CE is essential and for funded research, measures should be in place to ensure that funders' influence on the research does not violate community interest and values. The challenges to involving communities at all stages of the research need addressing and knowledge capacity should be boosted in communities to allow members make valuable contribution and decisions in the research. Capacity building should also include training people in genetic counselling since GGR presents psychosocial implications yet there are no genetic counsellors in Uganda. These findings can also inform policy and development of frameworks or guidelines to ensure ethical conduct of CE for GGR in Uganda.

Limitations

This research mainly targeted people that had experience in GGR, that is, GGR researchers, REC members and communities that had ever participated in GGR. This was intended to gain valuable input to inform the aim of this research. Research among individuals with no prior experience in GGR is recommended to compare with the findings of this study and potentially inform more on the challenges and facilitators to conducting CE for GGR in Uganda. This would contribute to an understanding on how to conduct ethical CE in GGR.

This study was conducted in central Uganda. There is need for similar research to be conducted in other study settings as a way of comparing and contrasting the findings with those of this study to inform further ethical CE for GGR.

The other limitation of the study was the missing questions addressing policy & regulatory gaps in GGR. However, related work addressing the regulation of CE in GGR in Uganda is currently ongoing by the same research team which we hope will enrich the available data.

Even though our study focused on CE, we understand that ethical GGR requires broader stakeholder engagement beyond study communities. Hence, we recommend innovative and more inclusive CE approaches/ models beyond only "research community" to include policy makers and Civil Society Organizations (CSOs) to fasttrack translation of findings into policy.

Conclusions

This study provides information on how CE in GGR has been conducted and the perceptions the different key stakeholders have on how ethically it should be conducted. Collaborative research is more suitable for applied GGR research, and less suitable for basic GGR research. Community in genetics and genomics research can include even individuals not directly involved in the research, but share genes with research participants. Engaging community leaders first aids researchers in getting access and acceptance to conduct their research in the community. The conduct of CE was mainly at sample collection and minimal at the study conception. Engagement at conception was low because GGR researchers underestimate the community's contribution to genetics/genomics science. Engagement for the return of findings had not happened for any of the GGR projects recruited. This was because of technical limitations, and clinically relevant results were not yet derived and validated. It was implicit that what most researchers recruited communities for, was sample collection, which was indicative of sub optimal CE. Measures including the building of capacity especially knowledge in both GGR and CE for all the stakeholders, and using this study findings to inform policy, conduct, regulation, and further research will potentially contribute to ethical CE in GGR in Uganda and similar research contexts. Ethical CE does not only provide a platform to identify and address a number of ethical, social and legal issues in GGR but also respects community values, practices and interests in the research.

Abbreviations

CAB	Community advisory board
CE	Community engagement
CAfgen	Collaborative African Genomics Network
DNA	Deoxyribonucleic Acid
FGD	Focus Group Discussion
GGR	Genetics and Genomics research
GPP	Good Participatory Practices
H3Africa	Human Heredity and Health in Africa
IDI	In-depth interview
REC	Research ethics committee
UNCST	Uganda National Council for Science and Technology
UVRI	Uganda Virus Research Institute

Supplementary Information

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Supplementary Material 1	
Supplementary Material 2	
Supplementary Material 3	
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Author contributions

HN, a PhD candidate drafted the manuscript under the supervision of EW, VPA, EM, and JB. Each of EW, VPA, EM JB provided conditional comments and suggestions to the manuscript which were addressed by HN and this was done two more times to produce the current version. All authors read and approved the final manuscript.

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Data availability

Data is provided within the manuscript or supplementary information files.

Declarations

Ethics approval and consent to participate

Ethical approval for this study was sought from the Makerere University School of Biomedical Sciences Higher Degrees Research and Ethics Committee, Ref No: SBS-2021-66. This was followed by obtaining ethical clearance from UNCST, Ref No: SS1172ES. Participation in the study was voluntary, and participants' written informed consent was sought. All the methods were carried out in accordance with relevant national and international guidelines and regulations.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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