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Research participants and stakeholders' views on feedback of genetic research findings: a qualitative study of the H3Africa Kidney Disease Research Network in Ghana

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Abstract

Background There is evidence that variants of the Apolipoprotein L1 gene in Africans and people of African descent increase the risk of developing chronic kidney disease (CKD). A study conducted by the H3Africa Kidney Disease Research Network showed that 28.2% of the Ghanaian study population carried 2 *APOL1* high-risk variants. Relatives of patients with CKD may be at increased risk of developing CKD. Researchers of this project are faced with an ethical dilemma of whether, study participants and their relatives should be informed about their risk of developing CKD. The aim of this study was to investigate perspectives of research participants and other research stakeholders on returning individual genetic findings and aggregate results related to the kidney disease research at the Korle Bu Teaching Hospital in the Greater Accra Region of Ghana.

Methods This study was conducted under the auspices of the H3Africa Community Engagement and Biobanking in Genomics collaborative project. An exploratory qualitative approach was employed utilising in-depth interviews, focus group discussions and deliberative workshops. Participants included genomic researchers, research participants, family members and members of the research ethics committee affiliated with the Korle-Bu Teaching Hospital and the Ghana Health Service in Accra, Ghana. Thematic analysis was performed using NVivo qualitative analysis software (version 12) to examine perspectives on what results to return, who should receive these results and how they should be communicated.

Results There was consensus among the key stakeholders interviewed that both validated individual genetic results and aggregate results from the kidney disease research should be communicated to research participants and their relatives, as well as aggregate research results to communities. Most research participants expressed a preference for receiving individual genetic results through direct communication from a medical doctor or research scientist. Participants also suggested the use of traditional media to communicate aggregate results to broader communities.

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Conclusion The study concludes that there are compelling reasons for communicating both individual and aggregate genetic research results related to kidney disease research with participants, their relatives and communities. More efforts should be invested in educating research participants, families and communities about the risks associated with the *APOL1* risk variants prior to returning these results. Additionally, research teams should explore innovative communication strategies to support the feedback process and to promote public engagement in genetic and genomic research.

Trial registration Not applicable.

Keywords Genomic research, Genetic research, Biobanking, Feedback of findings, Kidney disease, Ghana

Introduction

Chronic kidney disease (CKD) affects an estimated 14% of adults in sub-Saharan Africa [1]. Emerging genetic research has demonstrated compelling evidence regarding the role of Apolipoprotein L1 (*APOL1*) gene variants in Africans and people of African descent, which substantially contribute to CKD pathogenesis and progression [2–4]. Although *APOL1* renal risk variants are common in most sub-Saharan African populations, they are most frequent in West African populations, but with lower frequency in East Africa.

The H3Africa Kidney Disease Research Network (H3A-KDRN) is a collaborative multinational consortium comprising 15 African university teaching hospitals and medical schools in three countries; Ghana, Nigeria and Tanzania, and supported by nine (9) North American and Israeli universities/biomedical research institutions. This network seeks to develop a pan-African case-control study to investigate the genetic contribution to CKD [5–7].

The H3A-KDRN has been investigating the genetic causes of CKD for over a decade and recent data have revealed that 28.2% of the study population carried two *APOL1* high-risk variants (unpublished data). This finding has profound implications for understanding the genetic susceptibility to kidney disease. It is also known that relatives of research participants with CKD may be at increased risk of developing CKD [8].

The original consent for the H3A-KDRN study did not include returning significant genetic findings to participants, yet the health implications of these findings on participants and their families, raise an important ethical dilemma for researchers regarding whether, to feedback these findings to research participants. In addition to the ethical quandary surrounding the decision to provide feedback, there are still uncertainties regarding which research findings should be shared and which individuals should be included in the feedback process.

Much of the literature on reporting individual genetic research results to research participants are mainly from data in high-income countries (HICs) [9–13] and suggest that researchers have some obligation to return individual genetic research findings to research participants.

Recent literature indicates some efforts on the African continent in the area of feedback [14–17], however, there is limited empirical evidence regarding the attitudes and preferences of research participants and other research stakeholders in Ghana.

The H3Africa Consortium developed a policy on feedback of genetic findings within the context of Africa [18], and recommended that, the decision to feedback individual genetic research findings should be made by the research participants through the informed consent process and with approval from relevant ethics review committees. A decision tree which was developed as part of the policy framework recommended key considerations that should inform the feedback process. Based on key principles, including participant volition, utility and validity, the decision tree provides a step-by-step approach to guide researchers and research teams [18].

Although there is a growing literature on community engagement in the context of genomics and biobanking [19–21], none of these studies have addressed the question of how community engagement could facilitate the return of genetic and genomic research results, including individual genetic research findings and aggregate genomic results. While earlier studies explored ways in which community's views could help inform the development of policies on feedback of individual genetic findings [22, 23], these studies did not specifically address questions related to methods that could facilitate the return of genetic research results to research participants and aggregate findings to communities. In recent years, several projects within the H3Africa Consortium have conducted empirical studies to explore the perspectives of genomic researchers and research participants on feedback of individual genetic findings [24–26], but there is limited data on the views of family members of research participants and members of research ethics committees in sub-Saharan Africa on feeding back aggregate genomic results.

This study involved Ghanaian participants from the kidney disease research network, specifically those affiliated with the Korle Bu Teaching Hospital, and their relatives, regarding feeding back genetic research findings of

the H3A-KDRN to research participants, families, and communities.

Methods

Study design

The research employed an exploratory qualitative study design that involved individual interviews and focus group discussions to explore the views and beliefs of purposively selected research participants. This design was deemed appropriate for addressing the key objectives of this study because it enabled the research participants to share their rich insights on the research topic based on their lived experiences [27]. The theoretical underpinning of this research is interpretivism, which emphasizes the importance of understanding the subjective meanings and experiences of individuals within their social context [27].

Participants were recruited from the KDRN project in Ghana and focused on the personal and societal meanings that research participants attached to research findings, which was made possible using qualitative research methods. Given that this study design provides for some flexibility, the research team also incorporated some innovation by taking a deliberative approach to the focus group discussions and workshops with the members of the research ethics committees. As a result, the team was able to understand what would count as best ethical practice in feeding back research findings by combining the collection and analysis of empirical data with critical analysis of the key ethical issues.

Study setting

This study was conducted at the Renal Unit of the Korle Bu Teaching Hospital, which is the largest tertiary hospital in the Greater Accra Region of Southern Ghana. The unit is a subspecialty under the Department of Medicine and currently offers haemodialysis and kidney transplantation as modalities of kidney replacement therapy to patients who have end-stage kidney disease. During the period of this study, there were about 220 patients receiving chronic haemodialysis, with the majority receiving dialysis at least twice a week. The unit provides outpatient services to more than three thousand patients annually including general nephrology cases, dialysis, and transplant patients, and those with glomerular disease. The unit currently has three nephrologists, twelve trainees, fifty-nine renal nurses, a clinical pharmacologist, a dietician, and two dialysis technicians, along with a research administrator, coordinators, and assistants.

The University of Ghana's College of Health Sciences' Ethical and Protocol Review Committee (EPRC) examines applications from academics, staff, and outside organizations. The committee is interdisciplinary and diverse, comprising experts in scientific and medical ethics, a

legal professional, and a reverend minister. The officers of the EPRC consist of the chair, vice chair, and administrator, with a secretariat providing support. The research protocol of the KDRN was also reviewed and approved by the Ghana Health Service Ethics Review Committee and thus the perspectives of members of this committee were also sought during the deliberative workshops.

Sampling of study participants

A purposive sampling framework was employed to select all the researchers conducting genomic and genetic studies on kidney disease, sickle cell, haematology, and virology at the Korle-Bu Teaching Hospital. Additionally, individuals who participated in the kidney disease research, specifically those associated with the Korle Bu Teaching Hospital in Accra, Ghana, as well as their relatives, who expressed their willingness to participate, were included. Members of two Institutional Review Boards who were involved in the review of the Kidney Disease Research protocol were also invited to participate in the deliberative workshops. Sampling ceased when we reached data saturation, which is recognized as an acceptable methodological principle in qualitative research.

Ethical considerations

A generic study protocol developed by the Community Engagement in Biobanking and Genomics (CEBioGen) project was tailored to the context of the Kidney Disease Research Network and submitted to the College of Health Sciences Ethics and Protocol Review Committee for ethical clearance (*approval no: CHS-Et/M9-4.1/2018–2019*).

Participants were taken through the informed consent process, using a participant information sheet and consent form, before the in-depth interviews (IDIs), focus group discussions (FGDs) and deliberative workshops were conducted. They were assured of the confidentiality of their personal data and given unique identifiers to protect their identity. This is reflected in the quotes that were used to support the key findings of the study.

Data collection

Data were collected from three main sources: Individual interviews (IDs) with researchers and research participants, focus group discussions (FGDs) with families of research participants, and deliberative workshops with members of research ethics committees. Interview guides were developed based on the key objectives of the study and covered questions on participants' general understanding of genomics, their perspectives on feedback of general research findings, aggregate results, individual genetic results, methods for feeding back as well as challenges to anticipate in the feedback process. The

individual interviews had an average duration of 45 minutes while the workshops lasted for two and half hours.

The deliberative workshops were informed by a growing body of literature on the importance of deliberative approaches to research on complex topics such as genomics and biobanking research [17, 23, 24]. This approach involved a series of formal presentations on basic genetics, an overview of the genetics of kidney disease and implications as well as the key ethical considerations in genetics, genomics and biobanking. These presentations provided participants of the workshop with information to support the deliberative process. The presentations were followed by questions and answers to clarify any issues or concerns on the topics discussed before the actual interviews were conducted.

Data analysis

All the IDIs and FGDs were conducted in English, audio-recorded and transcribed. The transcripts were uploaded onto the NVivo 12 qualitative analysis software [28], to aid coding and analysis. To facilitate the analysis process, a codebook was developed, informed by the study objectives and included codes and their definition that were discussed among the study team. Initial coding was conducted by the first author (GG) with the results discussed at team meetings. This process involved reading each transcript line by line and labelling segments of text to identify common patterns. This was followed by another round of coding by the fourth author (STC), a qualitative research expert who was not originally part of the research team. The analysis was both deductive, guided by the study objectives and inductive, paying attention to emerging themes from the data.

Reflexivity and rigour

Reflexivity is a continuous process in which the researcher reflects on his or her values, preconceptions and behaviours, which could affect the research process and interpretation of data [29]. Prior to the conception of the research idea, study design, sampling, data collection and analysis procedures, the research team did not have any preconceived ideas and interest concerning the findings.

The study team employed an objective sampling method to ensure that participants met the established inclusion and exclusion criteria. During the data collection phase, participants were also informed of the need to reflect objectively on the issues being studied and to provide responses based on their own experiences to address the research questions. The data were interpreted, and the results presented based on the responses and perspectives shared by participants, devoid of any preconceived notions from the study team. This approach has

Table 1 Stakeholder groups interviewed in accra, Ghana

Category	Interview type	Number conducted	Number of participants involved
Genomic researchers	In-depth interview	9	9
Institutional Review Board members	Deliberative workshops	2	7 in both workshops
Kidney Disease Research Participants	In-depth Interview	20	20
Family members of Research Participants	Focus Group Discussions	2	9 (4 in Group 1 and 5 in group 2)
Total number of participants			45

contributed to mitigating any potential biases that could negatively affect the findings of the study.

Results

A total of forty-five individuals above the age of 18 years participated in in-depth interviews (IDIs), focus group discussions (FGDs) and deliberative workshops. Table 1 outlines the category of participants and number of interviews conducted.

Views on returning general research findings

Research participants and researchers were asked to share their opinions on whether researchers have an ethical obligation to return general research findings to research participants. From the discussions, majority of research participants in the IDIs were in support of sharing research findings with those who participated in the research. According to them, sharing research findings would help individuals take necessary precautions to improve their health. Some were of the view that research participants had the right to know the outcome of their participation in the research.

The results must be returned so that the participant will know his or her health status, whether there is improvement or deterioration. (IDI-M 72 year Participant-008)

I think it will be good to return results because participants have the right to know their results. (IDI-24 year M Participant-011)

Views expressed by researchers on feedback of genetic results, were in line with opinions shared by research participants. Most researchers who were interviewed thought research results should be returned to participants to enable them to take the necessary steps to reduce risk, and thus improve their health.

It is very important and must be in every consent form, because the participants have the right to know the results. Some results must be returned at once for patients to receive treatment or take measures to minimize risk of a disease. (IDI-M research team member-007)

Some participants in the in-depth interviews (IDIs) expressed the view that withholding study findings from participants may potentially serve as a deterrent to their involvement in future research projects.

Yea, you should return the results because, it's about me, it is my blood and urine. If you don't give the results, it could discourage people from doing it.... (IDI-32 year F Participant-020)

If research teams take samples from participants without feedback, with time they will not be willing to partake in any research activity. (IDI-M research team member-004)

However, one participant had a different opinion. It did not matter to him if his results were not returned. According to this participant, his motivation for participating was to advance scientific knowledge.

In research, you don't expect results to be given to you because they are meant to bring improvement in a particular field, so if it doesn't come back to me, no problem. Also, I cannot process the results given to me, so I am not concerned about getting the results but for the researchers to use it for the purpose of research, I am okay. (IDI-67 year M Participant-016)

Views on returning individual genetic results to research participants

Participants were asked directly if individual genetic research findings should be shared with study participants. These are results that relate to the health status of the individual participants and are often anticipatable. Most research participants believed it would be helpful for study participants to receive their individual genetic results since this would help them to understand their genetic makeup in order to assist relatives to understand their risks and prevent certain heritable diseases.

It will be good to know what is happening to me as an individual and the community around me, so I think it will be good to return genetic results to everyone involved. (IDI-79 year M Participant-001)

Yes, return everything because I believe that the

moment you draw blood out of my body, I am entitled to know everything. If it comes, it will help me to know the health problems in my family and look out for signals in my children which will help me take extra care of them. (IDI-32 year F Participant-020)

One participant felt that research participants should be given sufficient explanation of the findings.

I do not know anything about genetics, so I think it should be given with explanation. (IDI-25 year M Participant-007)

While research participants expressed a desire to be informed of all research findings, some researchers held the view that genetic results which do not add any value to research participants should not be disclosed to them.

Some genetic results might not be of value to participants, so such results should not be returned to them. (IDI-M research team member-003)

Although members of the research ethics committees were in favour of returning validated genetic results to participants, they advised researchers to use caution while doing so.

Participants should be informed about the findings. And this information should not pose as a threat to the participants but as a sort of awareness and education to benefit the participants. Researchers should ask other scientists to review and validate the research findings before feedback to participants. (FGD-IRB members-01)

Some relatives of research participants who took part in the focus group discussions also shared similar views as research participants. They suggested that genetic results should be returned for participants' benefits.

Yes, this is important because knowing that an individual has a risk will help the person ask questions and manage his or her lifestyle not to trigger getting kidney disease. (FGD In-law, Family-02)

However, other relatives had mixed opinions about feeding back genetic research findings to participants. While they supported the idea of feeding back, they believed that feeding back genetic research findings without any accompanying remedies could lead to increased anxiety.

I will like you to share but sharing results that do not have remedy might result in anxiety depend-

ing on how the information is received. However, it is important for them to know so that they can plan their life. (FGD-Auntie, Family-01)

The issue is that when you are walking around without knowing you have a condition you are free, but immediately you are told you have a condition, hypertension begins to set in, which might lead to other conditions. My general thought is, it is difficult to decide because immediately I am told I have a condition, I begin to think of how long I have to live on earth. (FGD-In-law, Family-02)

Views on sharing genetic results to families

Relatives and ethics review committee members were asked to share their views on returning genetic research results to families of research participants, who bear the target risk variants of kidney disease. Most relatives felt they should be informed about the findings because that will make them test as well.

I think the immediate family should know, that will help them test as well. We don't know much about it, but if relatives know, they will be helpful in managing a relative with kidney problem. (FGD-Sister, Family-02)

However, members of ethics review committees believed that it was wise to leave that decision solely to the research participants.

It would be best to leave that to the research participants to decide whether they want the findings to be extended to their families. By families we included parents, offspring, and siblings. It is better to just leave it as it is and educate the participants about the possibility that their immediate families may be at risk of developing kidney disease due to their genetic relations. (FGD-IRB members-01)

What results to feedback?

Participants' perspectives were requested on the type of genetic research outcomes to feedback, including individual, aggregate, or incidental findings. Researchers were of the view that personal, incidental findings and aggregate results may be communicated to research participants depending on the value of the findings.

I think individual and summary of aggregate results are both important to feedback. Aggregate results normally reflect the disease risk of a group of people, so feeding back such findings to those groups will help them to take steps to reduce their risk of the dis-

ease. Individual results need to be returned to participants because it is important for them to know. (IDI-M research team member-006)

We must feedback individual research results, incidental findings and aggregate results to the individuals and community, especially if it is of clinical importance. (IDI-M research team member-007)

Individual genetic research results

Although majority of research participants did not mind receiving aggregate results, they indicated that they would prefer individual genetic results.

I would want to know my personal results because if I have the APOL1 gene and the chances of my kids having the disease is high, I will probably not have kids. I wouldn't want my kids go through my experience with the disease. I wouldn't mind receiving aggregate results as well. (IDI-25 year M Participant-007)

I would prefer my personal results because that will help me to know how I am doing in terms of my health. It will also help my family to take measures to minimize getting the disease. I used to take in a lot of sugary foods, everyday, which I think might have caused me to have diabetes. If I had known, I would have taken precaution and so, if my family members know they are predisposed to kidney disease, they will take precaution. Aggregate result is good, but personal results will help improve my life, which is more important to me. (IDI-M 72 year Participant-008)

Some relatives expressed similar sentiments to those of the research participants. To them, sharing individual genetic results could be more beneficial to participants compared to the aggregate results.

Before the participant agrees to be part of the study, I believe he or she might be going through some difficulties already. So, if there is an underlying condition, which is life threatening, there should be a nice way of breaking the news to the participant. (FGD-Wife, Family-02)

However, a researcher was of the view that returning certain individual genetics results could lead to psychological issues.

Returning individual genetic results to a participant, not knowing when he/she may have the disease is a

bit difficult. This is because feeding back such results may put the person in a certain psychological frame of mind. It may even lead to stigmatization. (IDI-F research team member-002)

Views on sharing aggregate results

Participants were asked to share their views on sharing aggregate findings of the H3Africa kidney disease research with the community. Research participants, researchers, relatives and ethics review committee members were of the view that aggregate findings could be shared with the larger community. They perceived that would increase public awareness, help citizens take precaution, demystify beliefs surrounding kidney disease and also influence government policies.

Aggregate results must be shared with the community because kidney disease is affecting so many young people now, but we don't know what is causing it. So, we need to know so that we will take good care of ourselves. (IDI-39 year F Participant-018)

Since no one's name will be mentioned, I think it should be shared for all to know. This will help demystify the superstitious beliefs surrounding the disease. (FGD-Wife, Family-01)

Feeding back these findings to the community will also help policymakers to make policies to benefit people. (IDI-M research team member-006)

How to feed back individual genetic results

Most of the research participants, preferred to receive their genetic results from a doctor or researcher either at the health facility, through e-mail or phone call.

I will appreciate to be informed in person or through phone communication by my doctor, so I will have the opportunity to ask questions. Email will not be a bad idea either. (IDI-32 year F-Participant-003)

While some participants preferred the presence of a counsellor, others said they did not need a counsellor.

Either the doctor or researcher can give it to me because the researcher conducted the research. I wouldn't mind a genetic counsellor being around to counsel me on what to do. (IDI-68 year M Participant-019)

I would like my results to be given to me personally by my doctor. I don't think I would need a counsellor to calm me down. (IDI-44 year M Participant-006)

Whereas some participants preferred their results to be given to them in the presence of family members, others preferred to receive their results without any family member being present.

I wouldn't mind my parents being around because I had my genes from them. (IDI-32 year F-Participant-003)

I wouldn't like any family member to be present, it is my cross, I will carry it. (IDI-48 year F Participant-010)

The researchers shared the same view as the research participants on the subject.

Depending on the kind of results, the research team, medical personnel or a genetic counsellor could feedback both to individual participants and the community. (IDI-M research team member-008)

The principal investigators and the research team together with clinicians because they can explain it well. (IDI-M research team member-007)

Sharing aggregate results at community level

The research participants suggested varied ways to feedback aggregate results to the research community. Methods included television and radio broadcast, community durbars and social media platforms.

You can use the media, that is, the television, radio and social media platforms for a broader community. You can also use durbars for an in-depth discussion at the community level. (IDI-32 year F-Participant-003)

Banners, newspapers, posters and articles were also mentioned as appropriate channels that could be used to return aggregate genomic research results to community members.

Aggregate results can be communicated to the community through newspapers, you can write an article and publish for people to read. (IDI-48 year F Participant-010)

You can reach the general Ghanaians through social media, writings, banners, and posters. (IDI-24 year M Participant-011)

Methods such as conferences, community durbars, churches, mosque, and clinic-based gatherings were

highly recommended by researchers to return genetic results to community members.

Depending on the type of research, we can organize community durbars, conferences or clinic-based gatherings. (IDI-M research team member-007)

I recommend community durbars, gathering at churches and mosque to present aggregate results through role play, power point presentation and leaflets. (IDI-M research team member-003)

Communication methods may include acting, dancing, fliers, radio discussions and phone in. Some community studies have used games such as snake ladder to depict the effect of some organisms in the body, which is innovative. Those in the urban areas will however appreciate a small report with explanation and some discussions. (IDI-F research team member-002)

One research participant was of the view that the best way to return aggregate results to community members was through the activities of the Ghana National Commission on Civic Education (NCCE) as illustrated in the quote below.

You can return aggregate results to communities through the National Commission on Civil Education. (IDI-M 72 year Participant-008)

Relatives of research participants shared similar views as the research participants and researchers.

Apart from creating awareness on world kidney day, you can constantly go to the schools, churches and mosques to educate people. (FGD-Daughter, Family-01)

Engagement such as what we are having now can be the first method to communicate to a particular family. (FGD-Wife, Family-02)

Challenges to anticipate with feedback of findings

Challenges are inevitable in research; thus, researchers were asked to share their perspectives on some anticipatable challenges the kidney disease research network would face in their attempt to communicate genetic study findings to research participants and community. Researchers who were interviewed mentioned several challenges including difficulty in communicating genetic results, particularly in the local languages of research

participants and funding. These perspectives are indicated in the extracts below:

I think the major challenge is how to explain genetic results to the understanding of community members, especially in their native language. Returning genetic results without proper set up for counselling will also be a major challenge. (IDI-F research team member-002)

I think explaining the genetic terms to participants in a language they understand will be a challenge. Cultural values and practices might also affect the way participants will react to these findings. Anxiety and psychological challenges might also set in, which must be handled with care. (IDI-M research team member-006)

Funding could be a problem because we must refresh people during durbars, or per-diem if there is going to be conference. (IDI-M research team member-007)

Researchers did not only throw light on anticipated challenges but also offered some solutions to address them. These strategies included training genetic counsellors to communicate individual genetic findings and involving opinion leaders in the feedback of aggregate results.

Training genetic counsellors is key to enable them to communicate genetic issues to participants and community members where these studies are conducted. Also, there is need to train people to conduct tests locally and set up laboratories here in Ghana to reduce cost. (IDI-M research team member-004)

We need to train more people, including genetic counsellors to provide counselling services to people. We also have to encourage health personnel to sensitize patients on genetics to minimize the spiritualization of genetic disorders. (IDI-M research team member-005)

I recommend genetic scientists to get a dictionary of genomic terms in our local languages, especially in communities where such research is conducted. (IDI-F research team member-002)

Involve the opinion leaders and policy makers both at community and national level in genetic research processes. (IDI-M research team member-006)

We need to engage our institutions to develop infrastructures that will support competitive genetic

research in Africa. (IDI-M research team member-009)

The researchers also shared their views on ethical principles pertaining to the return of research findings to participants. According to them, feedback must be done with respect and confidentiality, not causing harm to the participants, families or community.

This should be done with respect and confidentiality. Individuals or families should not be mentioned or discussed in a community-based discussion. (IDI-F research team member-002)

Good ethical practice is fulfilling your promise and follow exactly what the participant consented to and as stated in the protocol. (IDI-M research team member-005)

A good ethical practice will be to engage stakeholders and returning results that will be of benefit to the participant without causing any harm. (IDI-M research team member-009)

Discussion

The question of what and how genetic and genomic research findings should be communicated with research participants in genomic research remains a contentious issue. This study sought to establish if genetic research findings should be communicated with participants in the renal disease study through the perspectives of researchers, research participants and their family members as well as members of research ethics committees.

Generally, participants agreed that returning study results could enable research participants to receive information about their health status. Most people usually participate in research with the aim of getting information about their health status and feel they have the right to know the outcome, resonating with findings by *Ralefala et al., 2023* on the importance of promoting solidarity and reciprocity [30], and findings by *Wilkins et al., 2019* on what participants want [31]. If samples of such people are taken for research and results are not returned to them, it could demotivate them from taking part in future studies. Similarly, apart from returning general research findings, research participants, relatives, researchers, and ethics review committee members thought researchers have an obligation to feedback genetic research findings to those who give their samples for such studies. Genetic and genomic findings, whether intended or incidental, according to research participants, must be returned to them. The researchers, who supported the research participants' views believed that

the intention to feed back genetic and genomic research findings with participants should be stated in every consent form, agreeing with previous studies by *Tindana et al. 2020*, *Kisangani et al., 2021* and *Mwaka et al., 2022* [17, 24–26].

In addition to feeding back genetic research results to participants, the families who were interviewed were strongly of the view that genetic findings of the kidney disease research should be returned to relatives of research participants. They perceived that this could create awareness within families about the risk of kidney disease and help them appropriately manage their health, supporting the findings from a study by *Fox et al., 2018* on returning results to family members [32]. However, though most of the kidney research participants supported the idea of feeding back to families, a few of them were not in favour. Hence the ethics review committee advised researchers to leave the decision regarding whether or not to inform family members, solely to individual research participants.

Similar to findings from the study in Kenya by *Kisangani et al., [24]*, researchers, ethics review committee members, relatives and most participants in this study were in support of feedback of aggregate genetic research results to the community to create awareness of the genetics of kidney disease, educate them on healthy lifestyles and influence government policies.

While the majority of study participants agreed that it was important to feedback individual and aggregate genetic results of the kidney disease research, some researchers and family members felt differently about returning individual genetic results to study participants. They believed that receiving positive genetic results could have psychological repercussions, particularly when the findings are not medically actionable. Apart from the psychological effect, which resonates with the findings of *Hallowell et al., 2013* [33], individuals and families could be stigmatized by society. Moreover, it is generally well established from a scientific point of view that an individual's genotype establishes a baseline probability for a phenotypic effect and the ultimate phenotype produced is highly variable. Therefore, the fact that an individual carries one or two copies of the *APOLI* risk variants does not mean that individual will develop kidney disease. Rather it increases an individual's risk of developing kidney disease depending on other genetic and environmental factors [2]. It is therefore important to proceed with caution and make provisions for proper counselling services to participants before returning their genetic research results, as pointed out by participants in this study and supporting the H3Africa feedback of findings policy recommendations [18].

Researchers could explore several methods to feedback genetic research results. The kidney disease research

participants in this study suggested that physicians, researchers, and genetic counsellors should handle the process of informing research participants about their unique genetic results. They believe these are the best individuals to appropriately evaluate the findings, provide information, and assist in managing any potential psychological stress. Depending on the target audience, as indicated by this current study and related studies, aggregate results can be communicated with the community through social media platforms, media houses, community durbars, and social and religious gatherings in addition to papers and presentations at conferences [24].

Apart from the lack of funding, one of the challenges facing researchers as they prepare to share the results of their genetic study with individuals, families, and communities is the challenge of explaining genomic terms to the understanding of individuals, especially indigenous communities. Participants in this study suggested that the H3Africa kidney research network should either hire or train genetic counsellors to assist with the feedback process.

In any event, if the individual genetic results from the Kidney Research project are to be returned to research participants and their families, as suggested by this study, key ethical considerations, including respect for participants' rights and confidentiality of their data should be addressed. As recommended by the H3Africa feedback policy [18], researchers should also validate findings before sharing the information with participants and other community members to ensure accuracy of information shared.

Limitations of the study

The main limitations of this study are its qualitative design and the fact that it was conducted in a single health facility. However, the insights shared by the research participants are likely to align with findings from similar contexts.

Conclusion

The study concludes that research participants and their families want to receive individual genetic research results and aggregate results related to the Kidney Research for varied reasons. It is important to note that having one or two copies of the *APOL1* risk variants does not directly cause kidney disease but rather increases an individual's risk of developing the condition depending on other genetic and environmental factors. Therefore, the H3Africa Kidney Disease Research Network should educate participants, families and communities on the concept of risks associated with the *APOL1* risk variants. This education should occur prior to returning individual genetics results to participants and their families as well as sharing aggregate findings with the community.

Research teams should also explore innovative communication strategies to support the feedback process and promote public engagement in genetic and genomic research.

Key recommendations

Feedback on genetic results related to kidney disease has the potential to raise awareness, educate, and influence policy. However, it may also lead to psychological repercussions. In line with the H3Africa feedback of findings policy, we recommend that the Kidney Disease Research Network validate participants' genetic research results prior to providing individual feedback to participants and their relatives. It is also important that the team trains genetic counsellors and explores innovative strategies to support the feedback process. Finally, we recommend that researchers should allow research participants to decide whether to extend feedback of their genetic results to their families during the informed consent process.

Abbreviations

H3A-KDRN	Human Heredity and Health in Africa Kidney Disease Research Network
CKD	Chronic kidney disease
FGD	Focus Group Discussion
IDI	In-depth Interviews

Acknowledgements

We are grateful to all research participants, researchers and members of the Ghana Health Service and the College of Health Sciences ethics review committees for sharing their views on the research topic with the research team.

Author contributions

PT, DA and AG conceptualised the study; GLG and PT conducted the interviews and analysed the data; SC analysed the data; GLG wrote the first draft; All authors reviewed the manuscript, provided substantial feedback and approved the final version for submission.

Funding

The study was funded by the National Institutes of Health (NIH) – (USA) – under the Human Heredity and Health in Africa (H3A) Initiative, Grant No. 5U54HG010275. NIH-USA had no role in the study design, data collection, analysis, and decision to publish or preparation of the manuscript.

Data availability

The datasets generated and analysed during the current study are purely qualitative and are available from the corresponding author on reasonable request.

Declarations

Ethics approval and consent to participate

Ethics approval was obtained from the College of Health Sciences Ethics and Protocol Review Committee for ethical clearance (*approval no: CHS-Et/ M9-4.1/2018–2019*). The research was conducted in line with the Declaration of Helsinki. All individuals who were willing to participate were taken through an informed consent process for their consent.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Received: 27 March 2024 / Accepted: 30 June 2025

Published online: 08 July 2025

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